Goal setting for cerebral palsy children in context therapy: improve reliability when linking to ICF

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Abstract. The linking process of information to ICF is a common task in different strategies used in rehabilitation practise but is a time consuming process mainly due to reliability issues. This work aims to developed additional rules to those already published in order to improve reliability of the linking process to ICF. The results are encouraging and these work could help to develop information technologies tools for facilitate this process.

Keywords. ICF, Linking Process, Reliability

1. Introduction

Cerebral Palsy (CP) is a complex health condition, consequence of a brain lesion that causes movement and posture impairments [1] with a prevalence in Portugal of $1,78^{0}/_{00}$ live births [2]. CP children often require a multidisciplinary approach and different conceptual frameworks are used for configure rehabilitation intervention [3]. Despite this, establishing goals for intervention is a core practice in rehabilitation although there is a lack of evidence behind this process [4].

The World Health Organization suggests that International Classification of Functioning, Disability and Health (ICF) [5] could be used to improve the comparisons between policies, services and interventions in the health field, including the prescription of assistive technologies. As examples of strategies for implementation in current practice is possible to find in scientific literature the establishment of 'Core Set's' [6] and comparative analysis of assessment instruments [7].

For implement both strategies, the literature described that the mapping process is carried out independently by two professionals following the published rules and disagreements are resolved by consensus, involving sometimes a third professional [8]. In addition to the consumption of time that this exercise involves, the degree of agreement among professionals varies depending on the knowledge of the ICF, the length of professional experience and the type of information to link [9]. For this reasons information

technologies (IT) tools could help to facilitate this process with gains in reliability and validity.

This article aims to describe and analyze the reliability of the additional rules used to linking to ICF defined goals by rehabilitation professionals in a context therapy intervention with CP children.

2. Methods

2.1. Study Design

This study is part of a larger project that intends to assess the intervention in children with cerebral palsy through the use of environmental factors, measuring the effectiveness of the intervention compared to conventional intervention. The authors submitted the study to an Ethical Commission and it was asked permission to use the interventional records to the Cerebral Palsy Institutions involved.

2.2. Subjects

For this study were collected records from children between 12 months and 8 years old, with cerebral palsy and related neurological conditions.

2.3. Procedures

After the submission to an Ethical Commission, was asked permission to use the interventional records to the Cerebral Palsy Institutions involved. All identification of the participants was removed, ensuring anonymity and privacy of children.

The data analysed and linked to ICF was extracted from patients' records, namely records related to the definition of children routines and the rehabilitation goals (RG) defined by the multidisciplinary team with the collaboration of the family, namely the parents. The RG is composed by two types of records: the definition of RG and the corresponding strategies to achieve the RG defined. The RG is intended to be the main activity that children must achieve, in order to improve their functionality. The strategies are instructions to the caregiver (parents or health professionals) that support the RG achievement.

The ICF-Children and Youth version was used for the linking process.

The first phase consisted in link to ICF a sample of six records randomly obtained from the participants in the context therapy project in order to obtain a 'gold standard'. All records were linked to the ICF according to established rules, defined by Cieza et al. [10]. This process was done by two investigators with experience in ICF: the first step was the identification of meaningful concepts (MC) present in the records then, in the second step, each investigator linked every identified MC to an ICF category, the most specific category possible. All rules defined by Cieza were respect: one MC could be linked to more than one category, if needed; the codes created were respected, for example nd (not definable), nc (not covered) or pf (personal factors); the examples used in patients' records were also linked; or the impossibility to register frequency or periods of time through ICF. The linkers discuss incongruence and agreement was obtained by consensus. The second phase

included the linking process described above, by other two experienced investigators in using ICF and the comparison with the established 'gold standard'. These two phases were then repeated with a new random sample of records from three children but using the additional rules defined by a group of therapists and investigators with experience in using ICF. Proportion of corrected answers and inter-raters agreement statistics were calculated for both phases.

3. Results

Additional guidelines for the ICF linking process are presented in order to facilitate the linking process. The objective was to codify activities and participation and environmental factors that were referred in the records. The clinical information analyzed has to be correctly linked to ICF, in order to guarantee that all meaningful concepts are codified. These guidelines do not pretend to replace the rules defined by Cieza et al. [10], but be a complement to those.

Followed are listed the additional guidelines for ICF linking process:

- Guideline1 - The linking process of a RG involves the identification of the activity and the complements that restrict or cover the activity's execution. The Table 1 presents the codification of the RG *Explore one toy with two hands, during 5 minutes, without take it to the mouth, with an adult orientation.* The MC *Explore one toy (without take it to the mouth)* is the activity and the remaining MC define the complements that restrict or cover its execution.
- Guideline 2 - If the records related to strategies adopted don't have enough information about the activity, the coder can introduce additional information of the records related to the RG. For example, in the RG, *At floor, behind the child, the mother facilitates the position* related to the objective *Maintaining a sitting position, during 3 minutes, with weight bearing in one hand, with adult support*. The activity of the RG is *Maintaining a sitting position*.
- Guideline 3 - In RG the definition where the activities must be executed may have some importance to achieve them. In ICF is not possible to identify specific spaces, like bedroom, kitchen or floor, so the coder must identify the MC and codify with "nc";
- Guideline 4 - It is necessary to distinguish the activity agent, ie, who is involved in activities' execution: the patient or the one that gives support to the patient For example, to the RG *Use mainly big toys to promote the use of two hands* were codified the followed MC (Table 1):
- Guideline 5 – When a MC can be codify in more than one activity of an ICF chapter, the linking must identify if the categories are consecutive or non-consecutive (Table 2).
- Guideline 6 – When the MC is related to a meal it must be considered a full meal that includes the activities of eating (d550) and drinking (d560).
- Guideline 7 – When a RG is related to an advice, this must be codifying as an action. For example, in RG *Use mainly big toys to promote the use of two hands*, *Use mainly* is a MC that must be codify (see Table 1).
- Guideline 8 – If the activity involves awareness of the activity execution it should be identified as a MC, if not, then the category involve action of consciousness

should not be recorded. For example in RG *It has a quiet and continuous sleep with independent decubitus changes*, MC are presented in Table 1. It should not be considered independent decubitus changes (d4106 Shifting the body's center of gravity), because this category involves voluntary movement.

- Guideline 9 - When the MC are related to environmental factors (EF) it must be identify the activity, considering that an EF is a facilitator or a barrier to the execution of an activity. The Table 1 presents the linking to the RG *Use the transport chair and makes travel by private car.* This guideline is applied also when the RG is related to a body function.
- Guideline 10 – The physical characteristic are not codify in the ICF linking process. For example in RG presented in Table 1 the MC is toy and the characteristic of being big is defined as additional information.
- Guideline 11 – The codification of EF must consider its contribution to the activity's execution. For example in RG *To eat must be watching a movie on the tablet* the MC *Watching a movie* can't be codify as d110 Watching, because this MC is a support to the main activity Eating (table 1).

Table 1 – Additional Guidelines

Guideline	MC	ICF Linking	Additional Information
Guideline 1	Explore one toy (without take it to the mouth)	d1201, d1310	With two hands
	Toy	e1400	
	Adult orientation	e310:e350; e355:e360	
	during 5 minutes	Nc	
Guideline 4	Use	e310:e350; e355:e360	Mainly
	Toys	e1400	Big
	The use	d1201	
	Hands	s7302	Two
Guideline 8	Quiet sleep	b1343	
	Continuous sleep	b1341	
	Independent decubitus changes	Nc	
Guideline 9	Transport chair	e1201	
	Travel	d4701	By car
	Private car	d1651	
Guideline 11	Eat	d550, d560	
	Watching	d9202	movie
	Tablet	e1400	

Table 2 – Guideline 5

Consecutive	d4100:d4107
Non-consecutive	e310:e345;e355:e360

The proportion of corrected answers between gold standard and rater 1 was 0.49 (CI=[0.41-0.59]) and for rater 2 was 0.51 (CI=[0.43-0.61]) in the first linking process. Table 7 present the results for the second linking process. For the rater 1, the proportion of corrected answer was 0.83 (IC=[0.75-0.89]) z=-5.53, p<0.001) and for rater 2 was 0.76 (IC=[0.68-0.83], z=-3.57, p<0.001). As a measure of inter-rater agreement for the corrected answers of both raters, the proportion was 0.65 (IC=[0.56-0.73]).

4. Impact and Contributions to the Field

ICF linking is a complex process that needs objective guidelines to guarantee the correct translation of the RG data into ICF language. It seems more difficult to link interventions records, which are written in free text, than assessment scales that already are a standard. This may occur because the professional that creates the RG can have different backgrounds and different educational or professional training. This means that similar goals can be recorded differently. The additional guidelines purposed in these work are an approach to improve the linking process defined by Cieza et al. [10]. The results derived from the reliability analysis shown an increase in the value of the proportion of agreement.

The use of ICF as a tool for analyze the rehabilitation process is increasing and several countries adopt it for clinical practice and in research [11]. Different examples of strategies for implementing ICF use are being proposed but linking information is common to most of them. This process needs to be accurate and less time consuming, tasks and objectives. The results of this work can be used to categorize the RG data, in order to improve the records of RG leading professional on what information must be recorded. Is also can be used develop instruments that can contribute to automatize this process. These instruments must be tested concerning to their feasibility, usability and efficacy where this work could be used.

The merge of methodologies from the health field and IT field as consequence of the increase complexity of conceptual models used in rehabilitation is a desirable route to develop, that could lead to an improvement of the outcomes of care for patients.

5. Conclusion and Planned Activities

This work reflects a small part of the task analysis that could be developed based in the data gathered. It would be possible to analyze what kind of rehabilitation strategies, based on 'environmental factors', leads to an improvement in goal achievement and measure the impact on the children day to day routines, including the ones that require assistive technologies.

The results of this work can be used to categorize the information used in the definition of RG and develop IT instruments that can improve the RG records. It is intended to contribute with the development of indicators, based on the guidelines defined, to guide rehabilitation strategies and extend activities within the IT field for implement tools of linking information to ICF in a user friendly way.

As future work it seems necessary, before the system development, the validation of the categories defined to create RG.

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