

MEASURING PARTICIPATION OF PERSONS SUFFERING FROM SCHIZOPHRENIA OR BRAIN INJURY:**Development of an ICF-based Assessment Instrument**

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Abstract Against the current lack of adequate instruments to assess the participation of persons suffering from schizophrenia or traumatic brain injury, the study aims at developing an ICF-based assessment instrument. The aim is threefold: (1) to meet more adequately these patients' needs in terms of health care and social support for independent living and participation; (2) to carry out a multi-centric validation of the tool; (3) to assess the appropriateness of current health care provided to these patients.

**Introduction**

Scientific literature dealing with psychic and cognitive disabilities shows the development of different theoretical models of disability and their impact on the evolution of legal provisions.

In the fields of schizophrenia as well as in that of traumatic brain injury significant improvements have been made regarding activity limitations assessment tools. But assessing the participation restrictions experienced by these patients progresses more slowly. Available data and tools do not allow to determine whether cognitive disabilities have the same consequences in terms of participation restrictions as psychic disabilities. Persons may experience same participation restrictions –such as not being able to go to the movies when they want– but for different qualitative reasons: some because they cannot plan the necessary actions, others because they cannot afford it, for instance.

This research aims at developing an assessment scale of daily life activities and participation of persons with psychic or cognitive disabilities: the *Cognitive Psychic Participation Rating Scale (CPPRS)*.

Using ICF's structure, this tool should allow a thorough description of participation restrictions in two populations facing psychic and cognitive disabilities: schizophrenic and brain injured patients.

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Methods & Materials**1. Designing the Assessment Tool**

Weekly meetings of the research team composed of an OT, PMR physician, psychiatrist, psychologist, neurologist, social workers and users' and families' organisations members are conducted:

- to clarify the concepts of psychic and cognitive disability on the basis of:
 - the ICF framework
 - the analysis of ecological examples of patients' participation restrictions;

- to build the assessment tool (cf. template) by selecting items that address most accurately participation in every day activities (« real-world functioning ») on the basis of clinical and family observations, then gathered according to the ICF sections; while paying special attention to how to deal with environmental factors that can be both obstacles and facilitators. Environmental factors include: Life conditions, Social support, Attitudes and Systems, Policy and legal context.

2. Data collection

- Data will be collected through face-to-face semi-structured interviews, real-life observations, video recordings, family members' and/or professionals' opinions

- Rating : each item of the scale will be rated with a 5 point Lickert scale.

3. First prototype trials and preliminary validation (in progress)

5 patients with schizophrenia and 5 patients with traumatic brain injury are currently assessed with the *Cognitive Psychic Participation Rating Scale (CPPRS)* for face validity and analysis of the psychometric quality of the tool.

4. Validation protocol

The validation protocol will consider sensitivity, internal consistency, construct validity on a bigger population sample, correlation with

Results

ICF section	Item	activity	participation	Life context	Social support	Attitudes	Systems, policies
Personal care	Caring for one's health						
	Grooming						
	Feeding						
Domestic life	Clothes						
	Householding						
	Budget						
	Outings						
Relationships	Shopping						
	Parents						
	Couple						
	Sexuality						
	Friends						
Productivity	Knows						
	Unknowns						
	School, formation						
	Looking for a job						
Leisure	Work						
	Indoor, outdoor						
	Unpaid activity						
Community	Clubs						
	Spirituality						
	Affairs						
	Voting						
Resources							

other standardised tools measuring same construct, intergroup reliability, interrater reliability, test-retest reliability.

Once validated a manual for professional use of the scale should be developed .

Conclusions

Clinicians as well as policy makers need more accurate measures of participation of persons with mental health disorders and cognitive disabilities, namely schizophrenic and brain injured patients. Based on ICF, the development and validation of the « Cognitive Psychic Participation Rating Scale » is meant to meet this need. Currently in its experimental phase, this scale should be available by the end of 2010.

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