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Social disability and social functioning measurement in Polish psychiatric research

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Summary: This article is an attempt to add to the discussion on the actual state of art in the field of psychiatric social functioning and social disability measurement concerning research tools in Poland. Proceedings in Polish psychometric research in psychiatry with such instruments as Medical Outcomes Study SF-36, tools related to the International Classification of Impairments, Disabilities and Handicaps and its revisions (GSDSII) and Health Related Quality of Life (WHO-DASII) are included in the paper. The need for assessment of practical utilization in the broader health care system context is underscored. Therefore the demand for further intensive studies in Poland still remains valid.

Key words: social functioning, social disability, psychometric scales

A considerable increase in the number of the disabled has been observed in Poland during the last two decades. This trend constitutes a serious social, medical and economic problem. It is therefore essential to continue work on the detailed definition of disability and to develop new disability qualification-classification methods (evaluation of the degree of invalidity) [1]. In addition, on the international level the authors underscore that the presence of a disease or disorder is no longer perceived as an accurate predictor of receipt of disability benefits, work performance, return to work potential, or likelihood of social integration. Strong emphasis has been put on the need for disability assessment to predict health service needs, length of hospitalization, level of care required, to evaluate effectiveness of interventions and other indicators relevant to health policy and health system quality control and cost effectiveness [2]. Effectiveness of the multi-component interventions urges for establishing scientific basis (European Union projects, interregional cooperation), which provide for the integration of standardized health data, expanded data coverage for health services, medical interventions, health determinants and the costs of services, data exchange and connectivity, and increased analytic expertise and the dissemination of results. The Polish situation concerning prevalence of depression and anxiety disorders as well as disability pensions and benefits indicates the demand for comprehensive tools for disability evaluation. There is also a growing need for establishing not only supportive but also standardized instruments suitable for more precise evaluation of disability at

the level of health care institutions and the insurance system. Consequently, there is a growing need for cross-culturally comparable research tools with established psychometric properties of both the original and Polish versions.

In Poland there are several measures in scientific use related to disability. The simple tools such as work disability days are applied for assessment of the work absenteeism [3]. Disability Adjusted Life Years (DALY's) have been used by Polish researchers to evaluate burden of the disease. DALY is a combination of two dimensions: YLL - number of years lost due to premature mortality; YLD - loss of healthy years due to disability caused by disease [4]. However, the scope of domains in situations given is too narrow for research on disability to be placed in a broader psychosocial context. It may also refer to the instruments used in psychogeriatric studies, based on Instrumental Activities of Daily Living. They focus mainly on household activities, mobility, communication and some socializing, without taking into account "hobbies" and some important interpersonal relations [5].

Some instruments, having broad coverage, include many items referring to social outcomes. The Medical Outcome Study (MOS) SF-36 developed by Ware and Sherbourne [6] is such a comprehensive instrument, consisting of 36 items, with only one subscale measuring social outcomes in narrow sense [7]. It is used to assess several domains of functional impairment including physical functioning, role functioning, energy, emotional well-being, social functioning, pain, general health and health change. Polish validation of SF-36 was performed recently in a group of 1000 randomly chosen patients of family doctors in the city of Giżycko [8]. Some questionnaires containing social functioning items, although having good psychometric properties, are too physically-oriented for social disability measurement, as the Brief Disability Questionnaire constructed partly on the basis of SF-36 [9].

Research associated with social functioning in the population of schizophrenic patients is mostly focused on rehabilitation studies and assessment of quality of life. Quality of Life Scale (QLS, Heinrichs et al. 1984) and Self-Report Quality of Life Measure for People with Schizophrenia (SQLS, Wilkinson et al. 2000) were used by Czernikiewicz and Górecka [10]. The first scale contains factors referring to social disability: social functioning and functioning in roles, the second tool covers some aspects of social functioning (everyday activities, interpersonal relationships). Polish adaptation of quality of life Mercier and Tempier's scale includes a broad range of psychosocial disability areas (neighbourhood, appearance, friends, relations, free time activities, financial situation) [11].

The Birchwood Social Functioning Scale is an instrument used mostly in rehabilitation research and for family intervention studies in the population of patients suffering from schizophrenia. The tool includes areas concerning making contacts and relationships, interpersonal communication, recreation, work, socializing, independence and self-care. Its psychometric properties were verified by Załuska [12]. As to the content of the SFS dimensions it may be difficult to discern between the ability to perform skills (independence competence) and the performance of the skills (independence performance).

Scales of global functioning based on the DSM-IV classification system (the Global Assessment of Functioning Scale - GAF, the Global Assessment of Relational Functioning Scale - GARF, and the Social and Occupational Functioning Assessment Scale - SOFAS) were evaluated in Poland for the reliability and validity by Wciórka et al. [13]. However, Hilsenroth et al. [14] reported that in terms of validity, GAF was more connected to psychopathology and GARF more to personality disorders, SOFAS coming as the most appropriate tool for social functioning measurement.

In the area of affective disorders Nowicka-Sauer [15] studied psychosocial functioning in patients suffering from depression with focus on the willingness to communicate and self-presentation using the Polish adaptation of Willingness to Communicate Scale (WTCS) JC McCroskeya. Research on sexual functioning in chronically depressive patients was performed by Zięba et al. [16], based on a Polish version of the Mell-Krat scale.

To ensure reliable data collection and international comparability the World Health Organization developed a complete classification - (WHO) International Classification of Functioning, Disability and Health (ICF or ICIDH-2) [17], revision of proper International Classification of Impairments, Disabilities and Handicaps (ICIDH). The ICF now serves as the WHO's framework for health and disability; it is the conceptual basis for the definition, measurement, and policy formulations for all aspects of disability. Putting the stress on health and levels of functioning ICF presents a conception of disability as a continuum, relevant to the lives of all people to different degrees and at different times in their lives functioning in three dimensions (the person, the activity, and the environment in which the activity takes place). The ICF is the key to valid and reliable data on functional status. It is suitable as the basis for coding and data collection in population health surveys and other self-report questionnaires. The two important instruments conceptually linked to these classifications were constructed: the Groningen Social Disabilities Schedule – GSDS (now in use - GSDSII) and WHO Disability Assessment Schedule (now in use - WHO-DASII).

GSDSII and WHO-DASII have important common features. Disability in social functioning starts in roles that are enacted in a broad social context, like work functioning and participation in society. As disability in social functioning increases, more personal and private roles and functions are affected until ultimately, the attention to self-care can diminish. The instruments allow comparisons of general disability and domain-specific disability across both physical and mental disorders. They assess functioning and disability at the individual level instead of the disorder-specific level, co-morbid conditions (e.g. depression and diabetes).

Groningen Social Disabilities Schedule (GSDS) [18, 19] is a semi-structured interview, constructed according to the social role theory. It enables evaluation of the social disability, which is a combination of disability resulting from individual health-related impairment and psychosocial consequences. Developed on the basis of the WHO Psychiatric Disability Assessment Schedule [18] it took into account several sources of information, freedom of action, investigator based assessment (on a 4 point scale) of eight social roles in the area of self care, household role, family role, partner role, parental role, social role, citizen role and occupational role. The semi-structured

instruments demand some degree of experience of the users adjusted and familiar with cultural norms and expectations which may be disadvantageous for epidemiological field studies, but is very useful for scientific and sociomedical studies. The psychometric properties of GSDS in national and international trials proved satisfactory [19, 20]. GSDS assesses disabilities in social functioning while allowing for variance in culture-specific expectations in various populations of psychiatric patients (community, primary-care, inpatient and outpatient settings) [21, 22]. Epidemiologic studies have also documented moderate, but clinically significant, cross-sectional and longitudinal associations of psychiatric symptom severity with disability assessed with GSDS.

Inter-rater reliability of GSDS has been tested in a European multi-site randomized controlled trial on the effectiveness of acute psychiatric day hospitals (EDEN) [23]. In this cross-cultural research sample GSDSII was also perceived as a tool, which measures the overall social disability fairly reliably. However, in terms of role and dimensions rating, it demands taking into account the socio-cultural background, particularly for the citizen and occupational role [24].

The WHO Disability Assessment Schedule II (WHO DAS II) is a structured interview based on the concepts integral to the ICIDH-2 (ICF) framework. While the ICIDH-2 is used by clinicians, the WHO DAS II is a questionnaire developed to assess the nature of disability directly from the patient's responses. Therefore it penetrates areas related to body functions, activity limitations and participation in society. The WHO DAS II reflects six domains of functioning in daily life designed to reflect a hierarchy of disability. Global functioning, functioning in general behavioural domains, and functioning in special roles (work, household, and marriage) are measured. Hierarchy of subscales is especially useful for clinical purposes and for outcome research. In other health status instruments (SF-36), summary scores efficiently describe general changes in health-related quality of life, but may not capture important changes limited to a single domain or subscale. A profile of subscale scores may be of limited usefulness when effects vary across domains or subscales, and the summary scores may be difficult to interpret. In the WHO Collaborative Study, the WHO-DAS underwent psychometric testing on the Assessment and Reduction of Psychiatric Disability and in psychiatric patients. The 36-item interviewer version was found to be a reliable and valid tool for the assessment and cross-cultural comparison of psychiatric disability [25, 26]. In a demanding population such as in patients treated for long-term psychotic disorders WHODAS II may be sometimes experienced as relatively complex and at times difficult to administer with full cooperation. It may also come to underestimation of impairments in mental functions and activity limitations than that reported by clinicians [27]. The version of WHO-DASII mentioned, have been translated into Polish with the permission of WHO for research purposes.

Such a complex and multilevel area as social functioning brings some difficulties concerning their psychometric properties. The question under discussion is whether research tools which have not proven their sufficient psychometric values in international studies should be introduced in Poland. The WHO Short Disability Assessment Schedule (WHO-DAS-S) is an example. It is a semi-structured instrument intended for a clinician assessment of the following four specific areas of functioning in patients with mental disorders: personal care, occupation, functioning in relation to family and household members, and functioning in a broader social context, including participation

in leisure and other social activities. Janca et al. [28] analyzed the inter-rater reliability of the instrument tested in the context of two international world field trials of the ICD-10 multiaxial system and received poor outcomes. Another reason for cautiousness in the adaptation of research tools is a lack of validation studies. This is the case with the Sheehan Disability Scale, a brief scale evaluated in clinical trials of patients with anxiety disorders [29]. However, the only psychometric evaluation of that instrument in subjects with affective disorders was conducted in a primary care setting.

There is a discussion on the assessment of social functioning in the context of the research tool feasibility, practicability and its utilization in the context of health care monitoring and insurance system. The call for such a universal instrument covering social assessment of functioning in a broader range of mental disorders has been underscored by Rymaszewska [30] in the comparative study on the occupational and social functioning of the psychiatric patients in five European centres. Research tools demand further verification and psychometric studies if planned for such essential evaluation of disability criteria. This could fulfill the expectations of patients and professionals in the area of the psychosocial disability.

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