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The value of self-report methods in neuropsychological diagnostics of patients after brain injury

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Summary

Self-report methods are commonly applied in medicine and psychology. However, their diagnostic value in assessment of patients with acquired brain damage can be limited due to a number of various difficulties encountered by these patients, including cognitive disorders, fatigue, similarity of psychopathological and somatic symptoms, psychological reaction to the disease and limited or lack of insight (anosognosia).

In our article we highlight the most important limitations of application of popular frequently used questionnaires in evaluation of brain-injured patients. We also discuss possible ways of adjusting self-report techniques to requirements of diagnostic process in this clinical population. Proposed modifications refer to, among others, specific construction of diagnostic tools (appropriate content and number of questions, methods of measuring responses), collecting information from relatives, using questionnaires along with more objective measures, and controlling conditions in which the assessment is carried out. Although relying only on self-report methods can be misleading, for an aware clinician it is still an important source of data on patient's subjective opinion and on the way they experience their symptoms.

Key words: brain injury, questionnaire, self-awareness

Introduction

The popularity of psychological self-report methods in various clinical disciplines continues to increase. Apart from their long use in psychiatry, these types of diagnostic tools have been developing dynamically for decades in other medical disciplines, e.g. for the assessment of somatic symptoms with psychological and social variables in internal medicine, cardiology and oncology [1]. Self-report methods are also used more often in neurology to evaluate cognitive and executive deficits, emotional and affective states, rehabilitation outcomes and quality of life [2].

In this paper we do not analyze the formal features of individual diagnostic tools (which are usually discussed in handbooks for relevant methods) or diagnostic process in psychology. Instead, we refer to some practical aspects associated with the type of measurement tool chosen intentionally by a clinician who will interpret results in the categories of a specific behavioural dysfunction.

Patients with brain damage, because of presenting specific symptoms, constitute a special group that requires a suitable method for the assessment of psychological variables. Unfortunately in practice patients are frequently assessed with methods that are inadequate for the clinical problem. Among many reasons there is limited access in Poland to many tests used internationally and general lack of new tools based on modern neuropsychological theories and measuring variables which are often theoretical constructs only recently introduced in psychology (e.g. executive functions). In many cases methods used in diagnostic process have not been primarily designed for the studied population of patients but for healthy subjects or patients with mental diseases.

Effects of structural brain damage symptoms on self-report

a) Cognitive and executive deficits

Strokes are the model case of acquired structural brain damage, and as a consequence of this condition up to about 80% of patients (depending on the adopted criteria and tool sensitivity, as well as recovery phase) present with some type of cognitive/executive disorder (e.g. affecting perception, memory, language, praxis, planning and self-control) [3]. It is estimated that about 60% of patients with traumatic brain injury present with cognitive disorders of various types and severity. Even in cases of minor head injuries 43% of analyzed patients had certain deficits in this area. Apart from focal injuries, cognitive deterioration is a component of the clinical image in many degenerative neurological, inflammatory, metabolic and neoplastic diseases. In non-progressive diseases these symptoms may gradually subside (particularly in 3-6 months after falling ill) as a result of spontaneous self-repair processes and specific training. Although in many patients deficits are relatively permanent despite the professional rehabilitation received.

Depending on the nature of cognitive dysfunctions, they have various effects on the reliability of the patient's self-report. Many patients find it difficult to understand precisely the language used in the measurement tool (questionnaire, scale etc.). About one third of patients with cerebral stroke [3], at least for some time, experiences aphasia, i.e. disorders in the formation and understanding of language, both spoken and written. Even mild dysfunctions of this type can lead to misunderstanding of questions, especially longer ones with a complex grammatical and logic structure. Difficulty of reading questions may arise from the primary disorders in visual perception (visual agnosia) or perceptual deficits, which are secondary to attention disturbance, including visuo-spatial attention manifests itself as unilateral neglect syndrome. Written answers in a questionnaire might be malformed due to impulsive reactions, perseveration and disorders in cause-and-effect reasoning. The last of symptoms is frequently revealed by patients with damage to anterior (prefrontal) brain structures. Giving certain information, e.g. on experienced emotions and affective states (sometimes in a specified time interval) is inseparable from its memorization, the ability to differentiate present and past situations, and the ability to imagine these states by the patient. Some difficulties

are expected in self-report in a group of patients with amnesia and with deficits in abstract thinking.

b) Disorders of self-awareness

Self-report methods require subjects to have insight into their own functioning, including the ability to identify their own disease-related deficits and preserved skills, introspection in an individual and social aspects. In neuropsychology these functions are regarded as metacognitive. The cortical and subcortical neuronal organization of these processes is exceptionally complex and still not fully recognized. They could be disturbed both because of neurophysiological and structural brain pathology, focal or diffuse. Self-awareness deficits are relatively most frequently associated with prefrontal brain injury, but are also found in patients with lesions of association cortex in the posterior parietal and temporal lobe of both hemispheres [5]. Depending on the location and size of the brain damage, self-awareness deficits may be more or less severe, and concern one or more selected domains of functioning. In the most intriguing cases (anosognosia), they can be manifested as denial of such spectacular symptoms as hemiparesis, cortical blindness (Anton's syndrome), sensory aphasia or amnesia [6]. The underestimation of generalized cognitive deterioration, emotional, affective and executive dysfunctions by patients is a problem frequently observed in clinical practice [7]. For instance, Prigatano and Altman [8] found that patients with bilateral frontal brain injury clearly overestimated their competences in interpersonal relationships. In the study by Seniów et al. [9] patients with the neurological type of Wilson's disease in the Hopkins Symptoms Check List (HSCL) described themselves as less aggressive and hypersensitive in interpersonal relationships than healthy controls, although patient's relatives usually emphasized their increased irritability and conflictive nature. Alderman et al. [10] also underlined the fact that the general trend to underestimate or deny disease symptoms by patients with brain injury can affect not only the opinion of actual functioning but also a subjective assessment of rehabilitation outcome.

c) Emotional and affective disorders

Research and clinical observations confirm the influence of emotional and affective factors on the measurement of different behavioural variables. For example, there is a positive correlation between the severity of experienced anxiety and the number of reported ailments. The study by Sumpter and McMillan [11] reveals that subjects with brain damage might not only underestimate actual problems, but also aggravate them. Nolin et al. [12] examined 34 patients who suffered severe traumatic brain injuries using a questionnaire on posttraumatic stress disorder (PTSD) and found, based on the obtained scores, that 59% of patients met clinical criteria for PTSD. However, a structured and problem-specific clinical interview confirmed PTSD criteria only in 3% of the same examined subjects. According to authors, the hypothetical causes for this inconsistency in scores can be attributed, for example, to attention deficit and concre-

tistic thinking of subjects, which most likely affected the answers to the questionnaire. Patients might also underestimate difficulties in functioning that they already had when in good health (before falling ill), attributing all their current problems to the acquired brain damage [12]. As a result, the image of disorders caused by falling ill is sometimes aggravated. Apart from that, some symptoms of structural brain pathology might be similar to psychogenic dysfunctions (emotional response to the circumstances associated with falling ill, e.g. car accident, physical assault, etc.). Therefore, the primary cause, particularly of non-specific symptoms (e.g. sleep disorders, irritability, increased fatigability, mood swings), is often difficult to establish (direct effect of structural brain pathology vs. psychogenic symptoms, or their overlapping). The identification of the primary and secondary causes of dysfunction requires a detailed differential diagnosis, which cannot be based solely on self-report methods.

d) Specific nature of brain damage symptoms

Many typical diagnostic questions in inventories concerning mental state refer to symptoms which in patients with brain injury result directly from the acquired pathology (e.g. tremor, sensory disorders, adynamia, pain of various location), but are not primary psychopathological symptoms. Some neurological deficits can falsely suggest depression, e.g. hypomimia, apathy, or other disorders of drive and motivation. Disorders in emotional expression, without actual disorders in their feeling (e.g. involuntary laughing and crying) sometimes called 'pseudoemotions' (or 'pseudodepression' in the case of crying) [13] are additional elements that can distort the reliable assessment of emotional and affective states.

The problem of similarity between primarily organic symptoms and psychogenic diseases was addressed by Lezak et al. [14], who gave the example of the Beck Depression Inventory. As many as one third of the questions in this popular self-report inventory refer directly to somatic symptoms (e.g. bodyweight loss, fatigability) which may sometimes cause misinterpretation of results, particularly in subjects with medical conditions associated with such complaints, but not meeting the medical criteria for depression. Gordon et al. [14], in their study carried out in patients who suffered cerebral stroke, demonstrated that the items in this measurement tool referring to somatic symptoms have a lower degree of correlation with the score of the entire scale than the other items. Therefore, they have low diagnostic value in mood evaluation in a group of patients with acquired brain injury.

Another striking example is the popular Minnesota Multiphasic Personality Inventory (MMPI, Hathaway and McKinley, 1951), in which a number of questions about somatic symptoms are interpreted in terms of psychopathology (e.g. confirmation of muscle cramps, tremors or lack of energy increases scores of hypochondria (Hs) and schizophrenia (Sc) scales; walking imbalance - both of these scales as well as hysteria (Hy). Elevated scales Hs and Hy in the classical interpretation of the scores suggest conversion (ie psychogenic background), which in the case of neurological patients can lead to completely wrong conclusions. Also the eleviation of the so-called neurotic triad (scales Hs, D and Hy; typically high in patients with multiple sclerosis) can be misle-

ading. After removing the questions relating to neurologic symptoms, MMPI profiles obtained by MS patients were typically within normal limits [14]. Those patients, who are more aware of their cognitive deficits can confirm the number of items belonging to the scale Sc, (associated with impaired cognitive functioning). Affirmative answers to questions about.disorders of memory will also increase the scales of depression (D) and psychaesthenia (Pt) - but the scores are not consistent with the interpretation of these scales in terms of psychiatric symptomatology.

Methods for limiting the effect of symptoms resulting directly from brain damage on the results of self-report methods

When designing questionnaires (scales, structured interviews, etc.) much attention is paid to the form and content of individual items to express them in clear, simple and unambiguous language. For patients with brain damage this requirement is particularly vital. It seems that more valid answers are given to questions presented in a descriptive format, referring to concrete life circumstances, without statements that are overly generalized, non-specific or require making indirect conclusions [15]. For instance, Sander et al. [16] in their study demonstrated high consistency between the self-report given by patients and reports by their relatives when using the Community Integration Questionnaire (CIQ). CIQ is a tool containing very precise statements referring to everyday activities, thus minimizing the effect of difficulties with abstract thinking, working memory or language processing, which are frequent deficits in patients with brain injuries.

Because of the specific image of disease in the discussed population, other factors also need to be considered, such as potential deficits of vigilance, divided and sustained attention, as well as pathological fatigability. For these reasons the questionnaires/inventories should be short and include not more than few dozen of items, if necessary, to be answered over several sessions.

If patients fill in the questionnaire/inventory on their own, factors to consider include potential visual perception disorders (e.g. impaired visual acuity, hemianopsia, diplopia, visual agnosia) and spatial attention deficits (unilateral neglect) which affect the ability to read the text. Sometimes, it is sufficient to move the test sheet and place it within the functional part of the visual field. In other cases, the first-choice method relies on the oral presentation of questions by the examining person and writing down the patient's answers.

Because the anosognosia is one of the most serious factors reducing the reliability of results in self-report methods [6, 17], partial control of this symptom can be achieved by comparing the status described by the patient with reports given by his/her relatives. A practical example of this rule is the Dysexecutive Questionnaire (DEX), in which the self-awareness of the patient in a certain tested area is assessed through the comparison of the patient's own description of a given trait with the information obtained from the caregiver. DEX is one of the first standardized self-report tool testing executive functions that have been designed specifically for patients with brain damage [18]. Particular attention should be paid to the choice of the patient's assessor [18]. Fleming et al. [19] indicate many factors that affect the perception of patients by

their relatives, e.g. stress level impacting on the respondent giving answers (frequently higher in relatives than in patients), time that has elapsed from the moment of falling ill (adaptation to difficult circumstances), psychological traits of the informant (personality, cognitive skills, etc.).

Another importing fact is that the limited insight into deficits caused by the disease may vary in terms of its degree in various domains of functioning [15], e.g. patients after severe brain damage assess more accurately motor and somatic ailments than cognitive and emotional disturbances [8]. It has been assumed that the choice of a suitable measurement tool increases the sensitivity of a diagnostic process specifically focused on selected area of functioning.

Since the 1980s new self-report scales have been designed for the assessment of self-awareness regarding deficit disorders for subjects who have suffered brain damage. Patient self-report is mostly compared to independent rater assessment (relative or clinician), who evaluates the patient on the same scale. Examples of such methods are the Awareness Questionnaire (AQ) and the Patient's Competency Rating Scale (PCRS) [2]. These tools should be used at the first stage of the diagnostic process to enable the interpretation of results from other tests in the context of potential anosognosia symptoms. A wide range of questionnaire-based tools, scales and other self-report methods specifically designed for patients with acquired brain damage are presented in a comprehensive compendium by Tate [2].

One of the ways to compensate for the effect of anosognosia on the reliability of self-report methods is to refer its results to other standardized neuropsychological tests [20, 21]. Allen and Ruff [20] studied a group of 56 subjects who had suffered brain injury (one group of patients with severe injuries and another group with minor or moderate injuries). The self-report of functioning provided by the patients was compared to the results of cognitive neuropsychological tests and was found to be less valid in subjects who had suffered severe injury and who were in the early stages of the disease. Lannoo et al. [21] used standardized neuropsychological tests and a symptoms checklist to study a group of 85 patients with moderate or severe brain damage. The tests focused on somatic, cognitive, emotional and behavioural aspects. The study did not demonstrate any significant correlation between the subjective opinions given by patients and the results of standardized neuropsychological tests. Researchers trying to explain this discrepancy pointed out the effect of the time that had elapsed from the moment of falling ill and rehabilitation procedures on the adequate perception of health problems by the patients. Patients in the early period of recovery (up to one year) and those who did not receive specialistic therapy provide less adequate assessments of their own disorders than those who are at a later stage and are undergoing rehabilitation procedures [21]. These findings suggest that it is well justified to use more objective measurement tools in the early period after the brain injury and to combine data from questionnaires/scales with the results of standardized tests, particularly those with unambiguous prognostic estimates (offering ecological validity). Such tests, by principle, contain tasks simulating real-life situations, and their results are strongly correlated with the patient's behaviour in everyday life [22]. Examples of such tools are the Behavioural Assessment of Dysexecutive Syndrome [18], Behavioural Inattention

Test [23], Test of Everyday Attention [24], Rivermead Behavioural Memory Test [25], which so far are not available in a Polish language version.

Conclusions

Psychological measurement based on the subjective self-report of a patient's functioning is a significant issue in neuropsychological clinical practice and theory. It has unquestionable value if used appropriately and chosen adequately for the clinical problem. Diagnostic process reveals the limitations when based solely on tests [26]. In fact, there are certain aspects of behaviour for which a subjective report from the examined patient has the highest value (e.g. in the assessment of mood, experienced distress, or planning the future). However, in some patients with brain damage it may be of very low diagnostic value, and even provide misleading information. It should be supplemented and analyzed in the context of clinical observation of the patient's behaviour, information obtained from interviews, and the results of non-standardized clinical tasks and standardized tests, particularly those with high prognostic validity [27]. It can be reasonably argued that the most reliable and accurate results can be obtained through the use of diversified diagnostic methods, strictly focused on the analyzed clinical problem, and interpretation based on the knowledge of brain-behaviour relation and a broader, psychological background.

Neuropsychologists often in diagnostic practice use accurate and reliable methods but not for the purpose that was intended by the authors. Popular diagnostic methods, which are used in clinical practice, have been designed for populations other than patients with acquired brain damage. The problems highlighted in this paper should focus the attention of clinicians on the potential diagnostic pitfalls associated with the use of such methods.

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