Archives of Psychiatry and Psychotherapy, 2010; 3 : 63–68

Self perception among patients with multiple sclerosis

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Summary

Aim. The aim of this study was to describe self perception among patients with multiple sclerosis and asses if it correlates with the degree of disability.

Method. 63 patients took part in this study – all fulfilled McDonald criteria of multiple sclerosis. Disability was quantified using the Expanded Disability Status Scale (EDSS) by Kurtzke. Self perception was estimated by Adjective Check List (ACL, Gough and Heilbrunn), which was divided into two parts: actual self perception and self perception before developing SM.

Result. The population of patients with Multiple Sclerosis is characterised by low self-esteem, decreased self-acceptance, resignation, despair and apprehension. These people tend to restrict or withdraw from interpersonal relationships, stop creating new challenges and aims and as a result their life slowly starts to concentrate mostly on observing symptoms of the illness. Another trend observed in this group is looking for support, protection and attention – which is connected with coming into dependency from other people.

Multiple Sclerosis / self perception / ACL / disability

INTRODUCTION

Multiple Sclerosis (MS) is a neurological degenerative illness of unknown aetiology, occurring mostly between the age of 20 and 40 years [1]. The clinical picture of the disease consists of demyelination areas located in white matter of central nervous system with inflammation and oedema of the axons. There are three main courses of MS: primary progressive, secondary progressive and relapsing and remitting one; the last one of which carries the best prognosis.

It is obvious, that neurological symptoms are not the only ones developing in patients with multiple sclerosis. Several studies focused on estimating mood disturbances, cognitive problems, psychotic episodes in the course of MS or the quality of life in patients suffering from the disease. However, there are only a few research studies concentrated on the self-picture of people suffering from MS.

Self perception is a set of features, which one identifies with. Such a self-picture is created and modified throughout the lifetime. It consists of convictions about one's general appearance, physical and intellectual condition, abilities, activity, social position, attractiveness, individual needs, moral regulations, etc. The most important activity of self perception is conducting activities aiming to protect, keeping and developing one's ego. Proper functioning of this system is available when three basic psychological needs are guaranteed: the need of keeping one's identity, self esteem and control over the surroundings.

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This research has not been aided by any grant.

Serious disabling disease and its consequences are such a strong stress, that changes in self perception are very sudden and not compatible with how it developed so far. In this context the illness might be compared to a cataclysm which changes everything. The ill person stops receiving feedback information which previously confirmed his identity, self esteem and control. A lack of this information is perceived as a threat for ego and leads to over-concentration on one's complaints and to distress. A sick person becomes a specific reference standard for him- or herself – this behaviour is called an egocentric type of regulation [2].

The aim of this study was to describe the self perception among patients with multiple sclerosis and asses if it correlates with the degree of disability.

METHODS AND MATERIALS

The sample consisted of 63 patients, recruited from the multiple sclerosis out-patient clinic. There were 27 men and 36 women and the mean age of the patients was 42.97 years, and the mean age at onset of SM – 31.13 years. All the patients fulfilled the McDonald criteria of multiple sclerosis [3]. Disability was quantified using the Expanded Disability Status Scale (EDSS) by Kurtzke [4] and the course of multiple sclerosis was also assessed. Self perception was estimated by the Adjective Check List (ACL, Gough and Heilbrunn), which was divided into two parts: actual self perception and self perception before developing SM [5]. ACL is a self-administered questionnaire, composed of 37 adjective scales.

The exclusion affected patients, who:

- were treated with steroids, β-interferon, anti-depressive or neuroleptic drugs during the last four weeks;
- fulfilled criteria of: dementia, affective and/or anxiety disorders of moderate or severe degree – in the past; psychoactive substance addiction;
- were suffering from any systemic diseases which might have disturbed the natural course of SM.

The statistic analysis methods used in the present study consisted of Kołmogorow-Smirnow test, variation analysis test (ANOVA), and t-student test. The assessment of relation between non-continuous variables was performed by Spearman's rank correlation and Pearson's correlation. The results were presented with the use of correlation factor – r, and probability – p.

RESULTS

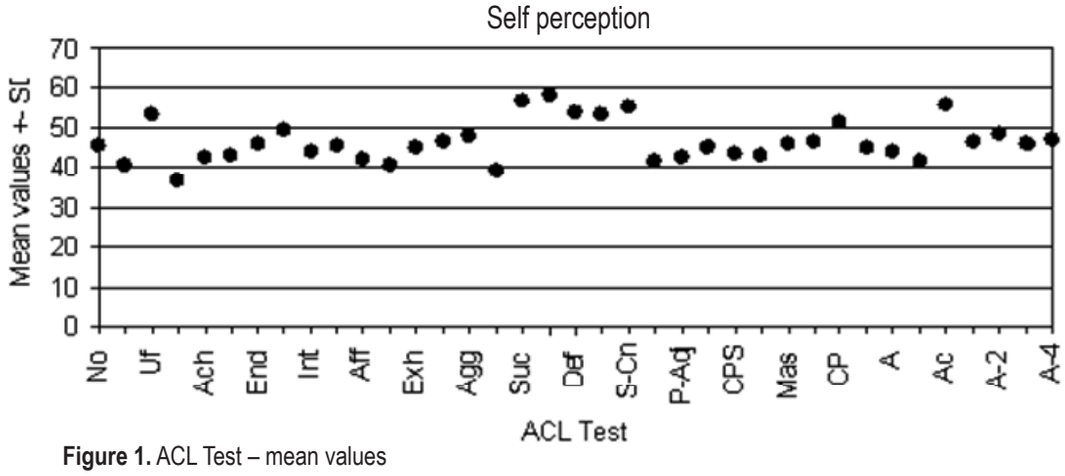

Figure 1. ACL Test – mean values

Patients with MS achieved the lowest scores in the following scales: Fav – Number of favourable adjectives, Com – Communality, Cha – Change and Het – Heterosexuality. The scores in scales: Ach – Achievement, Aff– Affiliation, S-Cf – Self-confidence , P-Adj – Personal Adjustment and Fc – Free child scale significantly decreased, whereas higher scores were reached in scales: Suc – Succorance, Aba – Abasement, Def – Deference, Crs – Counselling Readiness, S-Cn – Self-control and Ac – Adapted child.

Table 1. The relation between self picture and disability degree, controlling gender and age

2 factor analysis of variation, concomitant variable – age							
			2-factor				
	1-factor		EDSS	Interaction	Regression score		
Variable		p level	p level	p level	variable	r	p level
No	Gender	0.93387	0.32781	0.57188	Age	-0.02	0.87294
Fav	Gender	0.38427	0.38053	0.44559	Age	-0.23	0.08687
Uf	Gender	0.18848	0.18352	0.49703	Age	0.10	0.46471
Com	Gender	0.22674	0.38079	0.55838	Age	-0.03	0.82376
Ach	Gender	0.02770	0.56723	0.86673	Age	-0.11	0.39609
Dom	Gender	0.23866	0.37154	0.41205	Age	-0.22	0.09207
End	Gender	0.05363	0.75764	0.56246	Age	-0.09	0.51651
Ord	Gender	0.00711	0.22461	0.11979	Age	-0.10	0.44729
Int	Gender	0.48330	0.69443	0.53240	Age	-0.09	0.51417
Nur	Gender	0.50058	0.94217	0.43880	Age	-0.07	0.62036
Aff	Gender	0.26972	0.69804	0.30654	Age	-0.28	0.03593
Het	Gender	0.42890	0.50090	0.44907	Age	-0.38	0.00352
Exh	Gender	0.73976	0.72215	0.42943	Age	-0.33	0.01271
Aut	Gender	0.83352	0.74108	0.89756	Age	-0.11	0.39663
Agg	Gender	0.87232	0.89713	0.81111	Age	-0.14	0.31077
Cha	Gender	0.35072	0.02610	0.24695	Age	-0.14	0.30558
Suc	Gender	0.21618	0.05600	0.57812	Age	0.23	0.08791
Aba	Gender	0.28722	0.04185	0.15722	Age	0.27	0.03929
Def	Gender	0.93005	0.85504	0.65530	Age	0.18	0.17166
Crs	Gender	0.00069	0.20820	0.49987	Age	0.28	0.03476
S-Cn	Gender	0.21222	0.85983	0.91276	Age	0.19	0.16044
S-Cf	Gender	0.24373	0.29032	0.63112	Age	-0.26	0.05068
P-Adj	Gender	0.75345	0.26259	0.87011	Age	-0.21	0.11279
Iss	Gender	0.10244	0.16635	0.29584	Age	-0.17	0.19917
Cps	Gender	0.51310	0.09213	0.87799	Age	-0.27	0.04186
Mls	Gender	0.19055	0.51981	0.79874	Age	-0.10	0.44844
Mas	Gender	0.30497	0.81622	0.21743	Age	-0.05	0.68579
Fem	Gender	0.47735	0.86161	0.72009	Age	-0.18	0.18178
CP	Gender	0.41431	0.40859	0.64319	Age	0.01	0.95079
NP	Gender	0.96936	0.53203	0.16466	Age	-0.13	0.33206
A	Gender	0.28679	0.97633	0.22138	Age	-0.02	0.89782
Fc	Gender	0.96056	0.13633	0.80631	Age	-0.34	0.00897
Ac	Gender	0.14443	0.48104	0.36973	Age	0.17	0.20738
AA-1	Gender	0.16480	0.72430	0.34953	Age	-0.07	0.60414
AA-2	Gender	0.18458	0.63828	0.94551	Age	-0.02	0.87967
AA-3	Gender	0.14344	0.64960	0.36992	Age	-0.08	0.56127
AA-4	Gender	0.08554	0.94255	0.53722	Age	-0.06	0.66066

The degree of disability is related to the need of change, the need of abasement and the need of succorance.

The need of abasement tends to decrease according to the progress of illness and the increasing degree of disability. The same is observed for

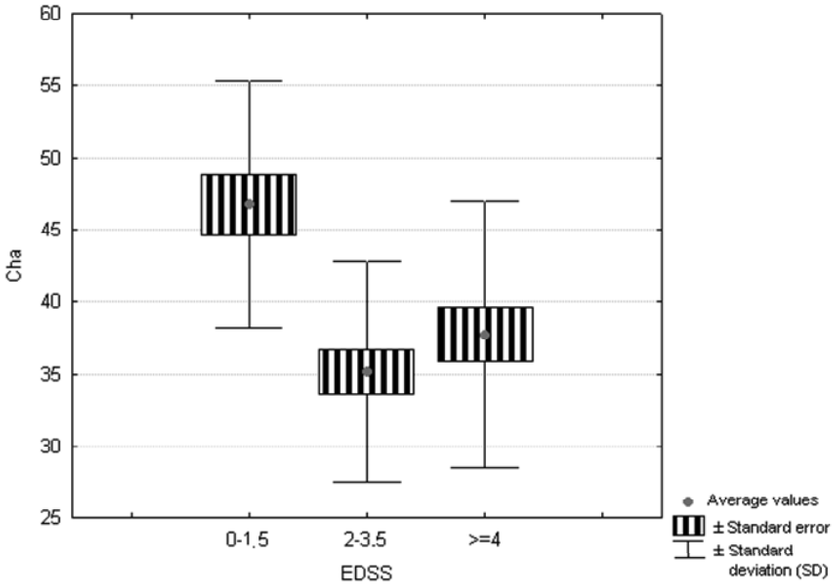

Figure 2. The relation between need of change (Cha) and disability degree

In the group of patients with MS, a small disability (EDSS: 0 – 1.5) causes an increase in the need of change. As the disease progresses, the need of change decreases up to EDSS=4; then it rises slowly again.

the need of succorance – which is presented [in the Fig.4] *next page.*

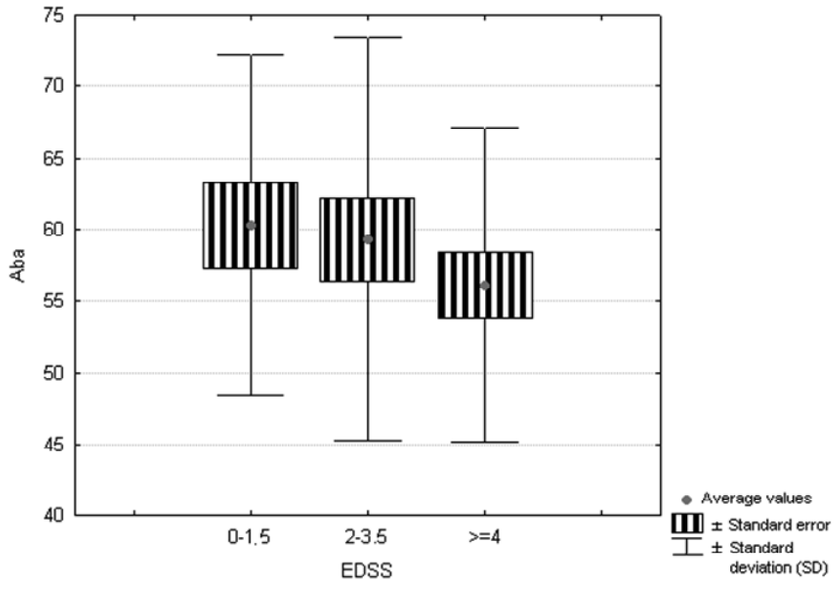

Figure 3. The relation between need of abasement (Aba) and disability degree

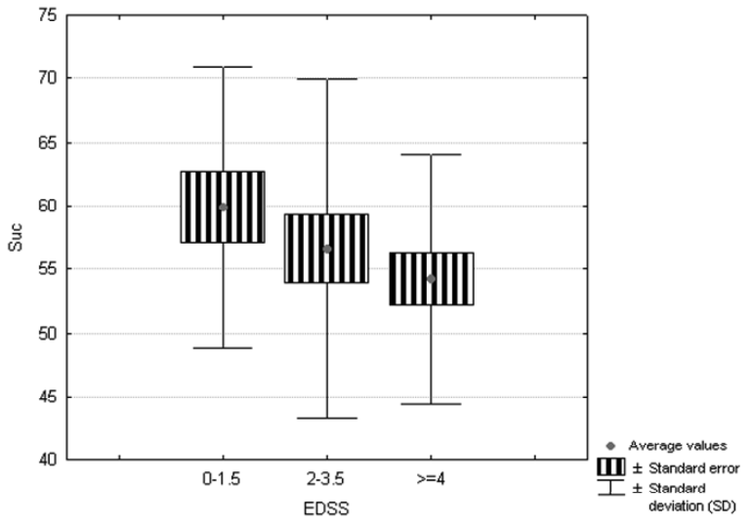

Figure 4. The relation between need of succorance (Suc) and disability degree.

DISCUSSION

A small amount of positive adjectives and – what is more important – the majority of negative adjectives, represent the low self-esteem of patients with multiple sclerosis, decreased self-acceptance, resignation, despair and apprehension. This population is lacking in self-trust – which is expressed by low scores in the self-confidence scale. MS patients tend to restrict or withdraw from interpersonal relationships – which is manifested by decreased scores in communality, affiliation and heterosexuality scale. Reduced scores in achievement and change scales illustrate patients' deficiency in motivation to implement plans for life, their shortage of verve and fantasy. They stop to create new challenges and aims and turn to be more passive and less enterprising. Slowly their life starts to focus on observing symptoms of the illness, which in consequence increases the level of fear and threat. High scores in:

Succorance, Deference, Counselling Readiness, Self-control and Adapted child scales mean a distinct trend of looking for support, protection and attention. There is also an observed evident difficulty in fulfilling their obligations or social roles, which is connected with coming into dependency from other people. Patients with MS feel unable to overcome stress, they have an inclination to indulge in fantasies – often connected with consciousness of guilt and helplessness. A significantly increased score on Abasement scale should be treated as a manifestation of self depreciation.

Very similar results were obtained by Papuć and Pawłowska, who have examined a group of 42 patients with Multiple Sclerosis. Apart from the features mentioned above, they focused on significantly decreased scores on the Creative Personality scale – which represent restriction of creativity and disinterest in how their lives are actively created [6].

Definitely an unlike population of patients is a group of patients with cardiac transplantation, investigated by Nasiłowska-Barud. These patients have achieved an average level of a need for achievement (Ach), a need for domination (Dom), not resigning from a leading role and a need of endurance (End) in grappling with life difficulties. Their social needs also remain moderate, which is manifested by average scores on scales of affiliation, Heterosexuality and Exhibitionist. A decrease was observed only with regard to the need for Autonomy and making Changes, which – similarly to patients with MS – means a decreased need for acting autonomously and lack of initiative in creating new plans or even making any decisions [7].

The fact of changes in self-perception concerns most patients with chronic diseases. The low self-confidence – as a characteristic feature – was described by MJ Fischer in a group of patients with chronic pulmonary diseases [8]. A similar observation was made by R Ziechen in a group of patients with diabetes mellitus and

chronic hepatitis [9] and by I Fuhrmann and R Krause with regard to patients with chronic kidney disease [10].

A lack of sense of autonomy was mentioned by Simon, while characterising a group of 67 patients suffering from phenylketonuria [11].

Deficiency in sense of security, resulting in disability of verbalising negative emotions (especially anger), was noticed by many authors dealing with cancer problems, particularly among patients with breast cancer [12, 13].

The disease activity has an irrefutable influence on self-perception among patients suffering from multiple sclerosis. The level of disability was related to the need of change, abasement and succorance.

In our group of 63 patients with MS, a low degree of disability is connected with an increased need of change. As the illness progresses, the need for change decreases – until an advanced phase of the disease, when it rises again. We might infer that the beginning of multiple sclerosis is a stage of fighting against the illness and trying to find one's place in a new reality, which is connected with the necessity of creating new solutions. The next phase is the phase of resignation, looking for stabilisation and tendency to avoid risk. The last stage of the disease appears when a patient is adapted to his new role of an ill person and his or her sense of control increases.

The beginning of the disease, regardless of how low the disability degree is, induces an increase of the need of abasement. A conclusion might be drawn that the fact of becoming ill causes such depreciation of self esteem. As the patient gets accustomed to illness, his or her self esteem slowly rebuilds. When considering the need of succorance – a very similar process takes place.

The changes described above clearly indicate that strategies of dealing with the illness which are used by SM patients are not effective enough. This result underlines an obvious need for specialist care – both psychiatric and psychological [14]. This care would help patients to accept their disease and create strategies of dealing with the illness – mostly through learning how to control the pain, disability and situation.

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