Time perception and illness acceptance among remitting-relapsing multiple sclerosis patients under treatment

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Summary

Aim. The aim of the study was to determine temporal orientation in patients diagnosed with RR-MS as compared with that of healthy individuals; to analyse self-evaluated acceptance levels in terms of physical and psychological condition and self-reliance; an attempt to identify factors of illness acceptance in patients with RR-MS including temporal perspective.

Method. Acceptance of Illness Scale (AIS, adapted into Polish by Z. Juczyński), Zimbardo Time Perspective Inventory (ZTPI, adapted into Polish by M. Mażewski), and original interview aimed to assess socio-demographic data and self-evaluated physical as well as psychological condition and self-reliance of patients with MS (referred to the neurological
testing according to the EDSS).

Results. Patients with RR-MS focus on fatalistic and hedonistic present more than healthy individuals. They also tend to reflect on their negative past experience. Acceptance of illness correlated positively with subjective assessment of physical and psychological condition as well as self-reliance, and negatively with objective disability score (measured with the use of EDSS) and a factor considering time of disease duration.

Conclusions. Avoiding contemplation of negative past and concentrating on hedonistic future constitute significant predictors of illness acceptance. These results may be of importance in terms of holistic approach to treatment of RR-MS patients. In the initial stage of the disease progression, patients might benefit from psychological support due to change in temporal orientation.

Keywords: multiple sclerosis, acceptance of illness, temporal perspective

Introduction

Multiple Sclerosis (MS, sclerosis multiplex) is a chronic, incurable and progressive inflammatory neurodegenerative disease of the central nervous system (CNS). According to recent statistics by Multiple Sclerosis International Federation, it is thought to affect approximately 2.3 million people, predominantly in the age between 20–40. [1]. The number of people diagnosed with MS in Poland is estimated to be over 40,000 [2]. The most common disease course of MS is remitting-relapsing, which is characterised by defined relapses followed by periods of remission. During such relapses, new neurological symptoms can occur suddenly and unexpectedly, or previously experienced deficits resulting from MS can exacerbate [3].

MS is a lifelong diagnosis and the aetiology of this autoimmune disease is still unknown despite extensive scientific research [4]. Neurological symptoms such as impaired motor coordination, chronic fatigue, disturbed sensation and muscle weakness, as well as speech and memory impairment [5] are just a few of the most commonly reported complaints. Neurological dysfunction was determined with the use of Expanded Disability Status Scale (EDSS).

Together with physical changes, the patient experiences changes in psychological orientation, particularly concerning the personal influence on one's life and perception of its quality [6]. Faced with psychophysical changes, patients diagnosed with MS struggle with new and difficult life experience and have to find a way to cope with it. However, the strategies adopted by such patients are not always successful. According to research, patients diagnosed with MS are highly susceptible to depression, and one out of two patients is likely to experience mental disorders related to depressed mood [5].

Therapeutic strategies of RR-MS rely heavily on immunomodulatory drugs which allow for suppression of symptoms. Public reimbursement treatment programs include drugs administered by subcutaneous or intramuscular injections in the form of commercially prepared pre-filled syringes which are designed to deliver a fixed dose of the drug. Apart from the inconvenience resulting from the regimen of self-administered injections, significant number of patients experience some adverse effects – the most common being influenza-like symptoms related to drug-induced stimulation of the immune system [7].

From a psychological, psychiatric and medical point of view, illness acceptance is a primary issue in terms of treatment, which in case of patients diagnosed with MS is particularly challenging as the patients are at high risk for depression. According to scarce empirical research, the ability to accept the illness is one of the most significant factors in better adaptation to illness and issues resulting from it. Illness acceptance translates into active attitude towards the condition rather than passive withdrawal from one's life [4].

However, it should be noted that the concept of illness acceptance is defined in literature of the subject in various ways. According to Dembo et al. [8], acceptance within the context of illness and disability is defined as accepting the loss understood as redefining self. Similarly, Zauszniewski et al. [9] defined acceptance as psychological acknowledgement and adjustment to potential limitations leading to integration of chronic illness into lifestyle. More specific definition was put forward by Davidson [10] who claimed that acceptance of illness primarily refers to redefining the way in

which patients comprehend the changes taking place in their life. McCracken in turn [11], defines acceptance in patients who suffer from chronic pain as readiness to pain, without the need of decreasing or avoiding it. Additionally, Hayes et al. [12] describe acceptance as active and aware embrace of personal experience without unnecessary attempts to change their frequency or form.

In terms of illness acceptance among patients with MS, time perception is a rarely researched issue [13, 14]. The indications mentioned above, as well lack of literature concerning illness acceptance and time perception among remitting-relapsing multiple sclerosis patients, inspired us to conduct the research to determine whether there are any differences in time perception among patients with MS and healthy people, and if so, to determine the extent of such differences. The present study also aims to determine to what extent the acceptance of illness relates to subjective assessment of one's physical as well psychological condition, self-reliance and objective stage of the disease progression.

The adopted hypotheses assume that: there are differences in time perception between people diagnosed with a chronic disease and healthy individuals (hypothesis 1); acceptance is connected with subjective and objective assessment of one's condition (hypothesis 2); the fact that a person is diagnosed with chronic disease induces changes in attitude towards the past, present and future (hypothesis 3). The last hypothesis assumes that negative past experiences can constitute a determinant factor in the lack of acceptance, as focusing one's attention on suffering encourages reminiscence of past negative experiences which in turn can be detrimental to the perception of the present as well as the future. In the research it was assumed that two dimensions of the present, Present-Hedonistic and Present-Fatalistic, can constitute a positive factor in illness acceptance. As far as hedonistic perspective is concerned, the patients strive to maximise life experience and feel pleasure in the here-and-now. Patients who manifest fatalistic orientation are driven by the need to experience novelty in order to compensate for unsatisfactory life events [15, 16]. Furthermore, the present research does not take into account the predictive relationship between illness acceptance and Past-Positive orientation as well as future perspective, due to the fact that MS, as a chronic and incurable illness, can limit positive attitude towards the things that happened in the past, as well as to what is yet to happen in the future.

Material

The study group comprised of 54 patients diagnosed with remitting-relapsing multiple sclerosis (RR-MS), undergoing immunomodulatory treatment (interferon beta, glatiramer acetate) as a part of therapeutic programme of the National Health Fund (NFZ), at the Neurology Clinic of Autonomous Public Clinical Hospital No. 1 in Szczecin. The age of the patients varied from 19 to 54 years (M = 35.44 years; SD = 7.7). The average age of onset in the study group was 29.8. The shortest period of treatment was 1 year (16 patients), followed by 2 year-long treatment (19 patients), 3 year-long (10 patients), 4 year-long (8 patients), and 5 year-long treatment (1 patient). Women constituted 66.7% of the study group. A significant majority of the patients – 85.5% lived in cities. Out of all the patients in the study group 46.3% held a university degree,

42.6% completed secondary education, and 11.1% completed vocational education. 60% of the patients in the study group declared that they were professionally active, 62% declared that they were in a relationship and 60% had children. Disability associated with MS was measured with the use of EDSS scale, and in 83% of patients the score was within the range of 0–2.5 points. The control group comprised of 44 patients selected in terms of age and sex (M = 36.2 years, women constituted 65.9% of the control group). The results presented in this paper are a part of a broad-range study which additionally includes neuroradiological analyses of patients on the basis of magnetic resonance imaging of the brain (NMR).

The research was approved by the Bioethical Committee of the Institute of Psychology at University of Szczecin (KB 2/2014). Some results were presented in the form of posters at the Conference of the Polish Neurological Society (Szczecin, September, 2014).

Method

According to previously described aims and adopted hypotheses, two questionnaires were selected for the present research: Acceptance of Illness Scale (AIS; B. J. Felton, T. A. Revenson and G. A. Hinrichsen, Polish adaptation by Z. Juczyński), The Zimbardo Time Perspective Inventory (ZTPI, Polish adaptation by M. Mażewski). Additionally, a structured interview was conducted in order to collect sociodemographic data and information concerning self-evaluated physical and psychological condition, as well as self-reliance of patients. Neurological condition of patients was evaluated with the use of EDSS scale.

The AIS scale consists of statements which describe negative consequences of undesirable health status, and measures the level of acceptance of limitations due to illness, as well as feeling of dependence. The participants are asked to mark each statement on a scale from 1 to 5 – 1 denotes 'strongly agree', and 5 'strongly disagree'. The acceptance of illness is measured against the total number of points the participants obtained (8–40 points). The lower the score, the less a patient accepts the illness. Patients with low levels of illness acceptance also have low self-esteem and high level of negative emotions due to illness and treatment [17]. Reliability measured using Cronbach's alpha coefficient was high – 0.87, which demonstrates good psychometric properties of the tool.

The ZTPI questionnaire consists of 56 statements based on five subscales (time factors), and allows to determine the patient's time perspective. Past-Positive and Past-Negative time orientations refer to the attitude towards the past. People scoring high in these time frames particularly value the old-and-known and are naturally cautious. Present-Hedonistic and Present-Fatalistic dimensions embody the construction of the present, and people scoring high in these time frames focus on the here-and-now, that is the immediate and accessible present. Orientation towards the future refers to anticipation of future events and their consequences. The participants were asked to rate the statements on a 5-point scale in terms of how much they agree with them [18,

19]. Reliability of Polish adaptation of the scale, measured using Cronbach's alpha coefficient was 0.71, which shows satisfactory consistency of the tool.

The EDSS scores from 0 to 10 denote in detail the limitations or disability resulting from damage to the central nervous system. Score 0 refers to the absence of clinical signs and full motor capability, score 1.0 refers to discrete symptoms of damage to the nervous system. The highest score reflects the greatest level of disability.

Statistical analysis was performed using IBM SPSS Statistics Software, version 20. Due to normal distribution of the analysed variables, parametric tests were used – Student's t – test for independent samples, Pearson's r correlation test, and regression analysis.

Results

In accordance with the aims of the study, in the first stage of the analysis temporal orientation of patients with MS was compared to that of healthy individuals. The results of the comparison, i.e. arithmetic mean (M), standard deviation (SD) for each dimension of temporal orientation, Student's t-test values, and significance levels p are presented in Table 1. The results indicate that patients with MS tend to focus on the present, both in terms of fatalistic (p = 0.001) as well as hedonistic dimension (p = 0.039), more than healthy people. The significance at the level of p = 0.112 also demonstrates that in patients diagnosed with MS, temporal orientation towards Past-Negative is stronger than in healthy individuals.

Table 1. **Results of the ZTPI scale for patients with MS (N = 54) and healthy people (N = 44)**

Temporal orientation	patients with MS		healthy individuals		t	p
	M	SD	M	SD		
Past-Negative	2.66	0.73	2.42	0.72	1.60	0.112
Past-Positive	3.60	0.46	3.54	0.45	0.68	0.498
Present-Hedonistic	3.45	0.51	3.22	0.52	2.09	0.039*
Present-Fatalistic	2.90	0.52	2.37	0.66	4.38	0.001**
Future	3.57	0.53	3.68	0.53	-1.05	0.296

M – mean; SD – standard deviation; t – Student's t-test value; p – significance

In the following stage of the research, the statistical relationship between acceptance of illness and physical as well as psychological condition, self-reliance, disease progression and duration were verified with the use of Pearson's correlation. The results presented in Table 2 show that there is a strong positive correlation between illness acceptance and self-evaluated physical condition. The correlation between acceptance of illness and self-evaluated psychological condition together with self-reliance, proved to be moderately positive. There was a moderately negative correlation between acceptance of illness and disease progression. Acceptance of illness correlated negatively with disease duration (p = 0.055). None of the analysed sociodemographic factors was connected with acceptance of illness.

Table 2. **Correlation between acceptance of MS and physical as well as psychological condition, self-reliance and disease duration**

Variable	AKC	SFIZ	SPSY	SAM	EDSS	CTC
Acceptance (AKC)	1	0.668**	0.463**	0.462**	-0.405**	-0.265
Physical condition (SFIZ)	0.668**	1	0.508**	0.643**	-0.598**	-0.292*
Psychological condition (SPSY)	0.463**	0.508**	1	0.605**	-0.352**	-0.194
Self-reliance (SAM)	0.462**	0.643**	0.605**	1	-0.562**	-0.125
Disease progression (EDSS)	-0.405**	-0.598**	-0.352**	-0.562**	1	0.405**
Disease duration (CTC)	-0.265	-0.292*	-0.194	-0.125	0.405**	1

* correlation at the level of significance (two-tailed) 0.05; ** correlation at the level of significance 0.01

In the next stage of the research, temporal predictors of illness acceptance in patients diagnosed with MS were analysed – the results are presented in Table 3. Multiple linear regression method (MCR) was used in this analysis. The β-indices of regression analysis conducted for the entire group of participants demonstrate that two out of five factors proved to be determinants of acceptance: Past-Negative (-0.486; $p < 0.000$), and Present-Hedonistic (0.277; $p < 0.023$). The value of determination coefficient $cR^2 = 0.289$ indicates that the aforementioned variables can account for almost 29% of the variance in acceptance of illness. The correlation between the predictors and acceptance of illness can be considered significant, with $R = 0.563$.

Table 3. **The effect of Past-Negative and Present-Hedonistic time perspectives on acceptance of illness in patients with MS**

DEPENDENT VARIABLES → ↓ INDEPENDENT VARIABLES				Acceptance of illness			
Variable		M	SD	β	SE β	t(51)	p
Past-Negative		2.66	0.73	-0.486	1.19	-4.115	0.000
Present-Hedonistic		3.45	0.51	0.277	1.63	2.349	0.023
Characteristics of the equation:							
R	cR²	SE		F(2.51)	p		
0.563	0.289	5.94		11.38	0.000		

M – mean; SD – standard deviation; β – β coefficient; SE β – standard error of β coefficient t – Student's t-test value; p – significance; R – coefficient of determination; cR² – level of variance; SE – standard error; F – F-test

The results of the regression analysis suggest that levels of acceptance of illness may be higher in patients who do not exhibit negative past orientation (↓), and express the need for pleasure and living life to the fullest [20].

Furthermore, side-effects of the treatment and the possible influence they may have on the results obtained from the questionnaire were investigated. No significant relationships between side-effects and illness acceptance as well as temporal orientation were found during the research. In addition, continuous neurological care and

monitoring of the psychological condition of patients with particular attention paid to possible mood disorders provides a basis for ruling out coexisting depression.

Discussion

The results of the research indicate that patients with RR-MS exhibit different temporal orientation than healthy individuals – they focus more on the present, both in terms of fatalistic as well as hedonistic dimension. However, the results can be analysed from different perspectives. From an evolutionary point of view, people who live in an uncertain environment undertake short-term behavioural strategies, as opposed to people who live in a stable and non-threatening environment [21]. In cognitive psychology, such an attitude can be termed as presentism – a view that only the present exists and the past is nonexistent and therefore should be ignored, and the future is not significant [19, 22]. However, Hermans and Herman-Janses [23] claim that focus on the present can result from neuroticism and serve as a defensive mechanism which allows for separation from the negative past or fear of the future. When the present is difficult to endure due to admittedly incurable illness such as MS, and people diagnosed with it are afraid to think about the future which in their opinion is precarious and risky [24]. In such a situation the temporal horizon is narrowed and the person is stuck in the present, which can signal emotional dysregulation and lack of control [25].

Patients with diagnosed MS tend to have higher level of orientation towards negative past. According to Zimbardo and Boyd, Past-Negative orientation exhibits a positive correlation with high level of distress and aggravation of depression symptoms, and therefore constitutes a predictor of lack of health. A Past-Negative orientation is connected with timidity, aggression, subjective low self-esteem [26] and rumination. In the last case, being immersed in negative emotions and contemplating issues connected with unfortunate life events negatively affect one's mood and may indicate problems with coping with illness [27]. According to Trempała [28], the concept of time takes on a new meaning in terms of the course of life events, particularly if the patient is aware of the irreversible nature of the changes occurring in their life. In the case of MS patients negative emotions and thoughts concerning unpleasant live experiences decrease their mood, and may indicate problems with coping with the illness. Such patients often ask themselves why it happened to them.

Porter et al. [13] state that illnesses connected with severe stress can cause changes in time perception. This process results from experienced stress caused by pain or fear of death, which can in turn cause shortening of future time perspective and bring about negative emotions. Additionally, the results of study of renal replacement therapy patients by Zawadzka and Byrczek [14] show that the formation of a temporal perspective is an important aspect of adaptation to disease and treatment.

The second issue under analysis was verification of possible correlation between acceptance of illness and self-evaluated physical and psychological condition, self-reliance, objective disease progression and duration. The results show a positive correlation of acceptance of illness with physical as well as psychological condition and self-reliance, and a negative correlation with disability measured with EDSS and disease duration.

The positive correlations obtained in this study are in line with the results obtained in other studies [29]. According to the authors, increase in the level of disability, or in complaints about one's physical condition and depressed mood, coincide with the decrease of acceptance of illness. On the other hand, active coping with problems, self-reliance, positive mood and optimistic attitude lead to an increase in acceptance of illness. The results of the research conducted in Japan [30] reveal that EDSS score had a negative effect on, among others, acceptance, self-esteem, satisfaction and self-efficacy and general contentment. Negative correlation between duration and acceptance of illness may indicate that such patients have not accepted the illness, nor have they developed adequate repertoire of coping mechanisms to deal with the illness. This is evidenced by the statistically significant, negative correlation between disease duration and self-evaluated physical and psychological condition as well as self-reliance and, additionally, by the positive correlation between disease duration and disability (EDSS) (Table 2). The identified correlations point to the fact that the longer the disease lasts, the worse is the self-evaluated functionality of the patient, therefore the patient is less likely to accept the illness. It has been noted in the literature on the subject [31] that increase in acceptance of illness may take place with a significant time lag, provided that patients embrace various preventive strategies of managing and solving problems they are experiencing. The results obtained in the research may indicate that the patients in question require help in terms of coping with difficulties connected with MS.

According to the results, Past-Negative and Past-hedonistic dimensions were the requested factors, which suggests that patients diagnosed with MS exhibit higher level of acceptance when they do not focus on their negative past and are hedonistically-oriented. The significance of both factors in the process of acceptance of illness is well documented in the research to date. For example, remembrance of negative past can be treated as a short-term adaptation behaviour, yet in most cases it is distinguished as a significant predictor of suicidal intent in young people and depressive mood among people who suffer from chronic diseases such as diabetes and cancer [32]. In such cases, negative perception of one's past is indicative of both poor psychological condition manifested as neurotic tendencies [18], as well as lack of acceptance of current health condition. Moreover, negative past orientation can translate into small number of people with whom the patient forms meaningful relationships, and higher level of negative social interactions [33]. However, according to other authors [34], hedonistic orientation can be characteristic of people who feel that they do not control their own future. As far as patients with MS are concerned, illness can limit or deprive them of sense of agency. Therefore, it is worthwhile to work with the patients in order to help them redefine their life goals, assist in rediscovering positive past experiences and promote active attitude towards life in general.

Conclusions

1. Sense of agency and the increase in the level of subjective assessment of one's influence on the course of the disease as well as on effects of treatment should be fostered in patients.

2. Patients should be advised to focus more on their positive past and its elements, and through this behaviour adopt preventive measures against re-experiencing negative aspects of their past. Such an attitude can help patients to redefine their memories and establish hope for the future.

3. It seems significant to foster the Present-Hedonistic orientation in patients as it allows them to enjoy the present moment and can serve as defensive mechanism.

4. Acceptance of illness among MS patients can be positively influenced by active psychological support directed at developing adequate coping mechanisms to deal with medical problems.

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