

**Do flexible goal adjustment and acceptance help preserve quality of life in patients with  
Multiple Sclerosis?**

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*Compliance with ethical standards*

The authors declare that they have no conflict of interest.

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

## **Abstract**

### *Purpose*

Acceptance and flexible goal adjustment are believed to be protective factors in chronic illness whereas tenacious goal pursuit is considered maladaptive. The present study aimed to investigate the role of these factors in quality of life of patients with Multiple Sclerosis (MS).

### *Methods*

A sample of 117 patients with MS was recruited. They completed questionnaires measuring quality of life (physical functioning, psychological functioning, psychological distress), acceptance, flexible goal adjustment, and tenacious goal pursuit.

### *Results*

Acceptance significantly accounted for variance in all three indexes of quality of life, beyond the effects of demographic and illness characteristics. The role of goal regulation style was less clear. Flexible goal adjustment significantly accounted for psychological wellbeing only. Surprisingly, tenacious goal pursuit predicted better psychological functioning and less psychological distress. No support was found for the hypothesis that acceptance and flexible goal adjustment would moderate the relation between illness severity and quality of life.

### *Conclusions*

The findings suggest the potential importance of acceptance in understanding MS patients' quality of life, although its hypothesized protective function could not be confirmed. Further conceptual work on acceptance and goal regulation style is needed, as well as prospective work investigating their causal status.

**Keywords:** Multiple Sclerosis; Quality of Life; Acceptance; Goal regulation; Coping; Chronic Illness

## **Introduction**

Multiple sclerosis (MS) is the most common neurologic disease among young adults [1]. Because of the wide range of aversive symptoms, the incurable and unpredictable character, and the difficult treatment regimens with side effects, MS is a particularly stressful disease with a severe impact on patients' quality of life (QOL) [2,3]. As the onset of MS is typically at a relatively young age, MS is a threat to the personal development of patients, often interfering with the construal and pursuit of personal goals in a variety of life domains including employment, relationships, social activity, and leisure activities [4,5]. Patients are thus continuously faced with adversity and uncertainty about the future, and hence, as a result, mood disorders like depression and anxiety are very common in MS [6,7]. Nevertheless, there are large individual differences in how MS affects patients' quality of life, and it is striking that objective illness factors such as extent of neurological disability, symptom severity, and illness duration, are often only modest predictors of quality of life [8,9]. More important might be how successful these patients are in coping with their MS and in adjusting to constraints in life goals resulting from it [10-13].

The dual-process model of coping has been proposed to describe two ways in which individuals typically deal with goals that have become blocked: assimilation and accommodation [14,15]. Assimilative coping refers to tenacious goal pursuit by attempting to adjust life circumstances to personal preferences. Accommodative coping implies flexible adjustment of personal goals to given situational constraints. The dual-process model was originally conceived to explain why elderly people still show high levels of life satisfaction despite reduced physical capacity and increased experiences of blocked goals as a result of ageing [16]. It has been argued that having an assimilative coping style is problematic when control over what blocks a goal is low or when the goal has become unrealistic, because coping efforts will consume scarce resources and will lead to repeated failure experiences

and frustration [17]. Evidence is accumulating that the ability to adjust unattainable goals to changing situations and life events may protect against the adverse effects of goal failure, and that people who are better able to abandon unattainable goals and to reengage in other meaningful activities experience greater subjective well-being and better physical health [18-21]. It has been proposed that these coping styles may have similar effects on adaptation to health problems and chronic illness [17,22]. In other words, one may expect that higher flexible goal adjustment and lower tenacious goal pursuit would be associated with better quality of life, and that the negative impact of severe illness on quality of life would be reduced in those who are capable of flexible goal adjustment. While the dual process model has been applied to chronic pain [23-25], it remains unexplored in MS.

One essential ingredient of flexible goal adjustment in the context of chronic illness is acceptance [22]. Acceptance may be defined as recognizing the need to adapt to a chronic illness while being willing to tolerate the unpredictable, uncontrollable nature of the disease [26]. In addition, acceptance has been specifically framed within the dual-process model of coping as a specific instantiation of flexible adjustment of goals that are blocked as a result of chronic illness [22,27]. Acceptance has been identified as a potentially adaptive way to cope with chronic illness. Research has shown the beneficial effects of acceptance on various measures of wellbeing in a variety of chronic diseases, including chronic pain [28,29] (e.g., McCracken & Eccleston, 2005; Viane et al., 2003), chronic fatigue syndrome [30,31] (e.g., Brooks et al., 2011; Van Damme et al., 2006), and cystic fibrosis [32] (e.g., Casier et al., 2008). Studies in patients with MS suggest similar associations between acceptance (or acceptance-related concepts such as sense giving) and life satisfaction, distress, mood, disability, and physical health [5,12,26,33,34,35,36,37]. However, its potentially dampening effect upon the impact of MS severity on quality of life remains untested.

Although the general capability to flexibly adjust unattainable goals and the specific ability to accept the limitations imposed by illness seem conceptually related, to the best of our knowledge, no studies have investigated their interrelation and their relative contributions to quality of life in patients with MS. In the present study, therefore, self-report measures of both constructs were included, along with indicators of quality of life. Based upon previous research showing positive effects of acceptance on quality of life in MS [26], as well as studies documenting the benefits of flexible goal adjustment and the costs of tenacious goal pursuit in adaptation to negative life events [19], we hypothesized that flexible goal adjustment and acceptance would be significant positive predictors of quality of life beyond the effects of demographic and illness characteristics (hypothesis 1), whereas tenacious goal pursuit would negatively predict quality of life (hypothesis 2). We also examined the idea that flexible goal adjustment and acceptance work as protective factors against adversity [17]. In that case, one would expect that flexible goal adjustment and acceptance would moderate (reduce) the relation between illness severity and quality of life (hypothesis 3).

## **Method**

### *Sample*

Recruitment of patients for this study took place in the Department of Neurology of the Ghent University Hospital (Belgium). Inclusion criteria were: having a clinically confirmed diagnosis of definitive MS, being aged between 18 and 65 years, and being able to understand the Dutch language. Patients with Clinically Isolated Syndrome (CIS) were excluded. Also patients who were having an MS relapse at the time of attendance were excluded. Patients suffering from other neurological disorders and psychiatric disorders were excluded. The sample consisted of 117 patients (42 men, 75 women; mean age: 41 years [SD= 12]). Almost half of the patients (41%) received higher education. Mean time since first

symptoms was 9.83 years (SD= 7.73). Most patients (77%) were diagnosed with RRMS (Relapsing Remitting MS). The remaining patients were either diagnosed with SPMS (Secondary Progressive MS; 18%) or PPMS (Primary Progressive MS; 5%). The study protocol was approved by the Medical Ethical Committee of Ghent University. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients for being included in the study.

### *Procedure*

Eligible patients were informed about the study by the treating neurologist during routine clinic visits. Patients who agreed to participate were immediately after the consultation accompanied to a separate room where they were received a research assistant. They were explained in detail the purpose of the study, and an informed consent was obtained. Next, patients filled out a battery of questionnaires including measures of quality of life, acceptance and flexible goal adjustment. Patients asking assistance with completing the questionnaires were helped by the research assistant.

### *Measures*

Disease severity was derived from the Expanded Disability Status Scale (EDSS [38]). This instrument is widely used by neurologists and investigators in MS to measure the disease progression. It concerns a 20-step ordinal scale, which ranges from 0 (normal) to 10 (death due to MS). It is graded according to the findings of a standard neurologic examination. This results in eight Functional Systems: pyramidal, cerebellar, sensory, brainstem, bowel and bladder, visual, cerebral and other. We used the total score across the 8 domains. The EDSS was retrieved from patients' records.

Anxiety and depressive symptoms were assessed using the Dutch version of the Hospital Anxiety and Depression Scale (HADS [39-41]). The HADS consists of 14 items to be rated on a 4-point likert scale, according to the degree to which they have been experienced over the last week. It is divided into a depression subscale (seven items, e.g. “do you take as much interest in things as you used to?”), and an anxiety subscale (seven items, e.g. “do you feel tense and wound up?”). Higher scores indicate greater levels of depression and anxiety. The HADS is developed to identify anxiety disorders and depression among patients with a general medical condition. The validity of the HADS was also confirmed in the MS population [42]. Reliability in this study was satisfactory (Cronbach’s  $\alpha = 0.75$ ).

Health-related quality of life was assessed by the Dutch version of the Short Form 36 (SF36 [43]). The SF-36 consists of 36 items divided into 8 subscales (physical functioning, role limitations due to physical problems, bodily pain, general health perceptions, vitality, social functioning, role limitations due to emotional problems, and mental health). Two summary scores are typically used as indicators of physical wellbeing and mental wellbeing. The SF-36 is considered to be the gold standard generic measure of health status as experienced by patients. Reliability in this study was good for both the physical wellbeing component (Cronbach’s  $\alpha = 0.86$ ) and the mental wellbeing component (Cronbach’s  $\alpha = 0.91$ ).

We assessed acceptance by the Illness Cognition Questionnaire (ICQ [26]), which measures illness cognitions in patients with chronic diseases. The ICQ consists of 18 items, measuring three types of illness cognitions, which reflect different ways of dealing with a chronic disease: (1) helplessness (6 items, e.g., “My illness controls my life”), (2) acceptance (6 items: “I can handle the problems related to my illness”, “I have learned to live with my illness”, “I have learned to accept the limitations imposed by my illness”, “I can accept my illness well”, “I think I can handle the problems related to my illness, even if the illness gets

worse”, and “I can cope effectively with my illness”), and (3) perceived benefits (6 items, e.g., “Dealing with my illness has made me a stronger person”). Psychometric research indicates that the ICQ is a reliable and valid instrument in various chronic illness populations including MS [26,44]. In this study, only the Acceptance scale was analyzed, which had high reliability (Cronbach’s  $\alpha = 0.87$ ).

Flexible goal adjustment and tenacious goal pursuit styles were assessed by means of the Tenacious Goal Pursuit and Flexible Goal Adjustment questionnaire (TENFLEX [18]). In this questionnaire, 2 distinct modes of coping with goal disruption are assessed: tenacious goal pursuit (TGP; e.g. ‘The harder a goal is to achieve, the more desirable it often appears to me’) and flexible goal adjustment (FGA; e.g., ‘In general, I am not upset very long about an opportunity passed up’). The scales each contain of 15 items. Respondents rate the degree to which they agree with each statement on a five-point Likert scale ranging from ‘fully disagree’ to ‘fully agree’. Reliability in this study was good for both the FGA subscale (Cronbach’s  $\alpha = 0.87$ ) and the TGP subscale (Cronbach’s  $\alpha = 0.83$ ).

#### *Data-analysis*

In order to detect associations between relevant variables, Pearson correlations were calculated. In order to test the specific hypotheses, 3 sets of hierarchical multiple regression analyses were performed, one on each of the dependent variables, i.e., physical functioning (SF-Phys), psychological functioning (SF-Psycho), and psychological distress (HADS). In the first step, sociodemographic variables (sex, age, SES) were entered. In step 2 objective illness factors (MS severity and duration) were entered. In the third step, we entered TGP and FGA. In step 4, acceptance was added. Finally, in the fifth step the interaction terms between illness severity and TGP, FGA, and acceptance were included. All predictors were centered.

## Results

### *Correlations*

Table 1 presents an overview of all correlations between independent and dependent variables. All indicators of quality of life were significantly interrelated, and were significantly associated with severity (but not duration) of MS. Higher scores on FGA as well as TGP were associated with better psychological functioning. In addition, tenacious goal pursuit was also related to better physical functioning. Higher acceptance was associated with better quality of life (all 3 indicators). Interestingly, acceptance was positively related to FGA but not to TGP.

INSERT TABLE 1

### *Regression analyses*

The results of the regression analyses are shown in Table 2. In all three regression analyses, step 3 (TGP, FGA) and step 4 (acceptance) significantly added to the explained variance, whereas step 5 (interaction terms) never did. Significant predictors of physical functioning were MS severity and acceptance, indicating that higher severity was associated with worse physical functioning, and higher acceptance was associated with better physical functioning. For psychological functioning, TGP and acceptance were significant predictors, showing that higher TGP and higher acceptance were associated with better psychological functioning. Psychological distress was significantly accounted for by TGP, FGA, and acceptance. More specific, higher scores on all three of these variables were associated with less psychological distress.

INSERT TABLE 2

## Discussion

The aim of the present study was to investigate the role of goal regulation style (tenacious goal pursuit and flexible goal adjustment) and acceptance in the quality of life of patients with MS. The main findings can be summarized as follows. First, in support of our first hypothesis, we found that both flexible goal adjustment and acceptance were overall positively associated with quality of life. Acceptance emerged as the best predictor. Second, tenacious goal pursuit was a positive predictor of the mental components of quality of life, which is opposite to what was expected. Third, the hypothesis that flexible goal adjustment and acceptance would moderate the association between illness severity and quality of life could not be confirmed.

The positive association between acceptance and all assessed indexes of quality of life further adds to a growing body of evidence in patients with MS [5,12,26,33-37] and in other chronic health conditions such as chronic pain [28,29], chronic fatigue syndrome [30,31], and cystic fibrosis [32]. Apparently acceptance is an important predictor in wellbeing in a broad range of chronic health problems, and MS is no exception. Based upon this finding, implementation of acceptance interventions in clinical practice may be recommended. Indeed, cognitive-behavioral interventions specifically aimed at helping patients deal with disability and increasing acceptance may be a useful addition to the treatment of patients with MS [45]. While there is preliminary support for the utility of acceptance-based treatments in MS [46], there is an urgent need for large high-quality clinical trials. Furthermore, given the broad range of processes covered by the acceptance construct [27] one may wonder what precisely is it that underlies its positive effect, and what are facilitating or hindering factors in attaining acceptance. Flexible goal adjustment may be an important factor in both ways.

On the one hand, flexible goal adjustment was positively associated with mental wellbeing and negatively associated with negative mood. Interestingly, it was also positively correlated with acceptance, suggesting that those patients with a higher ability to flexibly adjust unattainable goals are better in accepting their illness. This is not that surprising, given that there is some conceptual overlap between both constructs [20,24,26]. Nevertheless, the overlap is far from complete, and acceptance uniquely explained QOL on top of goal regulation styles. It could be speculated that having a flexible goal adjustment style may facilitate acceptance. On the other hand, it is possible that achieving acceptance of illness is a prerequisite to be willing to flexibly adjust goals, or that flexible goal adjustment is an important underlying process of the effects of acceptance. However, these ideas cannot be tested in the present study, because flexible goal adjustment was assessed as a general disposition, i.e., how patients usually deal with situations in which they experience goal disturbance, irrespective of the reason for this disturbance. It is thus unclear if patients' responses reflect how they cope with goal disturbance specifically resulting from MS. Therefore it could be recommended that future studies start investigating the role of illness-specific goal adjustment, i.e., how patients regulate goals that are affected by their illness. For this purpose, development of an illness-specific version of the TENFLEX would be helpful. Alternatively, the application of methods allowing a more detailed view on patients' goal construal and how they deal with goal disturbances as a result of their illness, for example by means of diary assessment or Personal Project Analysis [47], may be helpful.

While focusing on acceptance and flexible adjustment of unattainable goals in clinical practice of MS may seem sensible from our findings, we should be cautious before providing definitive recommendations, and this for several reasons. First, we need to know more about how flexible goal adjustment works. It is believed that flexible goal adjustment consist of two components, namely goal disengagement and goal reengagement [21]. In one study

specifically investigating the role of goal disengagement and reengagement in the context of MS, Neter and colleagues [48] found that neither disengagement from unattainable goals or re-engagement in new goals had a positive influence on wellbeing, although they found a complex interaction pattern suggesting that those patients high in goal disengagement and low goal reengagement were more likely to report higher levels of depression. This definitely deserves further examination in future studies.

Second, our hypothesis that tenacious goal pursuit would be negatively associated with quality of life was not supported. This contradicts previous research, typically showing that flexible goal adjustment, but not tenacious goal pursuit, is associated with psychological adjustment [49-51]. On the contrary, higher scores on tenacious goal pursuit were associated with better quality of life, and tenacious goal pursuit uniquely accounted for variance in both mental wellbeing and psychological distress. Apparently, tenacious goal pursuit is a more adaptive process in MS than originally thought. One possible explanation is that the instrument that was used to assess tenacious goal pursuit, namely TENFLEX, may have not really captured its presumed maladaptive perseverative character in this population, instead measuring a more adaptive tendency to hang on to valued goals despite illness. This is an interesting topic for future research, as some level of goal persistence and living according to one's values may be adaptive, and is also promoted in interventions such as Acceptance and Commitment Therapy [46]. The fact that in our data both goal regulation styles were not negatively correlated suggests that they are not opposites on one spectrum, but instead may represent different dimensions. It is definitely interesting to look further into how flexible goal adjustment and tenacious goal pursuit may work together in preserving wellbeing in patients with MS or other chronic diseases.

Third, it should be noted that our data did not support the hypothesis that flexible goal adjustment and acceptance would reduce the negative association between illness severity and

quality of life. This finding differs from what has been previously reported. In the aging literature, for example, Brandtstadter and Renner [14] found that flexible goal adjustment has a buffering effect on the impact of perceived developmental deficits on dissatisfaction with personal development. Wrosch and colleagues [21] found that goal disengagement and goal re-engagement tendencies compensate for the distress associated with the occurrence of unattainable goals. In the chronic pain literature, Schmitz and colleagues [24] found a buffering effect of flexible goal adjustment on the correlation between both pain intensity and disability, and depression. We have no direct explanation for the failure to observe any of the hypothesized moderation effects in this sample of MS patients. More research is clearly needed to confirm this in other samples. The fact that we found substantial associations between both acceptance and flexible goal adjustment, and indicators of quality of life, but that this did not translate into a protective effect against increasing illness severity, puts the causality of the observed association into question. Indeed, it is not unlikely that patients score higher on acceptance because of a better wellbeing. Longitudinal studies are urgently needed to clear this out. It is also possible that the hypothesized buffering effects of acceptance and flexible goal adjustment are especially prominent shortly after illness onset. As the illness duration of the patients in the present study sample was quite long, it may well be that the protective effects of acceptance and flexible goal adjustment could not be detected anymore. Prospective studies are recommended in which patients' acceptance and goal regulation strategies are assessed shortly after diagnosis.

To conclude, given the potential role of acceptance in MS patients' quality of life identified in our and others' studies, interventions aimed at increasing acceptance and focusing on valued goals may be a useful addition to the treatment of patients with MS. Caution is, nevertheless, required, as most of the available studies (including the present one) present cross-sectional data, allowing no causal relations. Prospective studies are needed to

demonstrate that acceptance actually predicts future quality of life, rather than being an epiphenomenon of better wellbeing.

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### **Compliance with ethical standards**

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Table 1. Means (*M*), standard deviations (*SD*), and Pearson correlations

	<i>M</i> ( <i>SD</i> )	1	2	3	4	5	6	7
1. SF-Phys	51.72 (11.85)							
2. SF-Psycho	49.25 (10.05)	.62 <sup>c</sup>						
3. HADS	10.86 (6.15)	-.50 <sup>c</sup>	-.69 <sup>c</sup>					
4. Severity	2.38 (2.15)	-.66 <sup>c</sup>	-.33 <sup>c</sup>	.20 <sup>a</sup>				
5. Duration	9.83 (7.73)	-.17	-.10	-.02	.35 <sup>c</sup>			
6. TGP	33.03 (7.28)	.23 <sup>a</sup>	.29 <sup>b</sup>	-.27 <sup>b</sup>	-.02	-.18		
7. FGA	40.14 (9.09)	.16	.33 <sup>c</sup>	-.42 <sup>c</sup>	.03	.12	.12	
8. ICQ-A	16.25 (4.08)	.39 <sup>c</sup>	.50 <sup>c</sup>	-.55 <sup>c</sup>	-.26 <sup>b</sup>	.01	.11	.43 <sup>c</sup>

<sup>a</sup>  $p < .05$ ; <sup>b</sup>  $p < .01$ ; <sup>c</sup>  $p < .001$

Table 2. Hierarchical linear regressions on physical functioning (SF-Phys), psychological functioning (SF-Psycho), and psychological distress (HADS). All  $\beta$  values are standardized and taken from the final model.

Predictors	SF-Phys		SF-Psycho		HADS	
	$\Delta R^2$	$\beta$	$\Delta R^2$	$\beta$	$\Delta R^2$	$\beta$
1. <i>Socio-demographic variables</i>	.17 <sup>c</sup>		.07 <sup>a</sup>		.10 <sup>a</sup>	
- Sex		-.02		-.08		.03
- Age		-.18		-.02		.08
- SES	.28 <sup>c</sup>	-.05	.08 <sup>a</sup>	-.01	.02	-.13
2. <i>Illness variables</i>		-.60 <sup>c</sup>		-.23		.09
- Severity		.13		-.02		-.06
- Duration	.03 <sup>a</sup>		.10 <sup>b</sup>		.17 <sup>c</sup>	
3. <i>Coping styles</i>		.12		.19 <sup>a</sup>		-.19 <sup>a</sup>
- TGP		.06		.12		-.21 <sup>a</sup>
- FGA	.03 <sup>a</sup>		.09 <sup>b</sup>		.11 <sup>c</sup>	
4. <i>Acceptance</i>		.20 <sup>a</sup>		.35 <sup>c</sup>		-.38 <sup>c</sup>
- ICQ-ACCEPT	.02		.03		.02	
5. <i>Interaction terms</i>		-.14		-.14		.11
- Severity x TGP		-.07		-.11		-.03
- Severity x FGA		.01		.08		.12
- Severity x Acceptance						
<i>Total R<sup>2</sup></i>	.48 <sup>c</sup>		.30 <sup>c</sup>		.35 <sup>c</sup>	

<sup>a</sup>  $p < .05$ ; <sup>b</sup>  $p < .01$ ; <sup>c</sup>  $p < .001$