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A path analysis of factors influencing life satisfaction among patients with narcolepsy in Japan

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Abstract: Narcolepsy is a sleep disorder characterized by excessive daytime sleepiness, impaired psychosomatic functioning, and a reduced quality of life. We identified several factors influencing life satisfaction and suggested ways to improve it in patients with narcolepsy. To the best of our knowledge, this is the first study to measure life satisfaction in patients with narcolepsy and to examine the interdependence of various factors related to life satisfaction using path analysis. A questionnaire was administered to 87 individuals diagnosed with narcolepsy. A hypothetical model was tested to determine its effect on life satisfaction. The results of the path analysis were $\chi^2 = 11.94$ ($p = 0.53$), GFI = 0.96, AGFI = 0.92, CFI = 1.00, and RMSEA = 0.00. The overall effects were impact on activities (β = 0.41), self-acceptance (β = 0.36), adaptive attitude (β = 0.36), excessive daytime sleepiness (β = 0.13), mental disorder (β = 0.10) and attention-deficit/hyperactivity disorder (β = 0.08). The results indicate that medical conditions such as sleepiness do not impair life satisfaction. This study suggests that life satisfaction can be increased through self-understanding and engaging in adaptive cognition.

***Keywords*:** narcolepsy, life satisfaction, adaptation, self-perception, mental-health

Introduction

Narcolepsy is an autoimmune disease that targets hypocretin/orexin-producing neurons within the hypothalamus (*1*). It is characterized by difficulty staying awake during the day. Some individuals with narcolepsy experience a sudden loss of muscle tone triggered by strong emotions, referred to as cataplexy (*2*). The worldwide prevalence is approximately 1 in 2,000, while in Japan, it is approximately 1 in 600 (*3*). The average age of onset in Japan is 17.8 years (SD 8.8) (*4*).

The most significant impact of narcolepsy is role limitations (*5*), affecting activities such as performing housework, attending school, and working. Depression and anxiety tendencies are higher in patients than in the general population (*6*). Recently, it has been reported that the hyperactivity/impulsivity and inattention symptoms observed in individuals with attention-deficit/hyperactivity disorder (ADHD) are genetically related to narcolepsy (*7,8*). People with ADHD experience a decline in executive function and impairment of social functions such as academics and employment. Studies have reported that the quality of life (QOL) of patients with narcolepsy is low. In addition to sleepiness, co-occurring disorders such as depression, other mental disorders, and ADHD may lead to a reduced QOL.

QOL is a comprehensive assessment of diverse aspects of life, including health, economic conditions, the environment, education, social relationships, and psychological state. It includes objective living conditions (*e.g.*, quality of housing, income, and education level) and subjective assessments (*e.g.*, well-being and stress levels). In contrast, life satisfaction is a subjective assessment of an individual's life satisfaction. It considers the totality of past experiences, current circumstances, and prospects, heavily depending on the individual's feelings and values. Even if QOL is low, life satisfaction may remain high depending on individual values and adaptability. Even with treatment, the QOL of patients with narcolepsy does not recover to general population levels (*9*), and it is challenging to improve comorbid disorders such as ADHD. We decided to focus on life satisfaction from the perspective of patients, which leads to well-being.

Research explicitly focusing on life satisfaction in patients with narcolepsy is limited. A PubMed® search until 2018 revealed only one review article with either life satisfaction or well-being in the title. That study

(*10*) suggested that children with narcolepsy are at a significant risk of cognitive impairment and emotional problems such as depression, anxiety, and low self-esteem. Currently, no studies have examined approaches to improve life satisfaction in patients with narcolepsy.

It is assumed that the life satisfaction of patients with narcolepsy is related to their medical conditions, comorbid disorders, and cognitive and health problem-related daily activities. Clarifying these associations will contribute to improving life satisfaction. Therefore, this study aimed to identify factors that influence life satisfaction in patients with narcolepsy.

Assessment

Participants were asked to provide basic demographic information and medical history (narcolepsy symptoms, disease duration, frequency of cataplexy, and presence of ADHD or mental disorders). Narcolepsy, mental disorders, and ADHD were diagnosed based on the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), which are based on a questionnaire survey and a history of upbringing conducted by a health care provider. However, this point was self-reported.

Excessive daytime sleepiness (EDS) was assessed using the Japanese Epworth Sleepiness Scale (JESS), a self-reported questionnaire. This subjective measure of daytime sleepiness was developed by Johns in 1991 (*11*). The JESS uses eight questions to assess the likelihood of falling asleep and encompassing daily situations. Respondents were asked to rate the items on a 4-point scale (0-3). A JESS score of 16 or higher was defined as EDS in this study, as a JESS score of 16 or higher is strong enough sleepiness to cause a traffic accident while driving (*12*). Impact of the activities, such as how their health problems affected productivity in regular unpaid activities or school life using a 0 to 10 Visual Analogue Scale (VAS). We asked subjects to respond to the statement of self-acceptance using a 5-point Likert scale, ranging from 1 = strongly disagree to 5 = strongly agree. Adaptive attitude was measured using a scale developed by Suganuma *et al.* (*13*). This scale measures adaptive attitudes, a positive attitude that accepts the negative aspects of the self and the situation as they are but does not dwell on them. Higher scores indicate a more accepting attitude toward the self and the situation while resigning oneself to it.

We used the Life Satisfaction Scale (SWLS) to measure how the subjects evaluated their lives. The SWLS, developed by Diener *et al.* in 1985, is self-administrated and is a short, 5-item instrument that uses 7-point Likert scale responses (*14*). The higher the score, the greater one's satisfaction with life. The Japanese version of SWLS was used in this study.

This study was approved by the ethics committee of Saitama Prefectural University (No. 19122) and administered by the Japanese Ministry of Health, Labor, and Welfare Ethical Guidelines for Medical and Health Research involving Human Subjects.

The data was analyzed with descriptive statistics. Path analysis was used to explore the variables' interrelations and verify the associations between the variables and the SWLS score. Path analysis used variables significantly different in the Mann-Whitney *U* test, correlation analysis, and EDS, as they are symptoms specific to narcolepsy. Standardized regression weights were used to represent the path coefficients between variables with $p < 0.05$.

Overview of the subjects

The study included 87 patients (62.1% female). The mean age of the patients was 35.0 (SD 10.0) years, and 64 patients (73.6%) had narcolepsy with affective cataplexy. Among the participants, 89.7% were currently undergoing evaluation treatment. Participants with EDS were 50 (57.5%), and 12 (13.8%) of the cases had a mental disorder, while eight (9.2%) had ADHD. Disease duration was less than five years in 1.1%, more than five years in 80.5%, and 5 to 10 years in 18.4% of participants.

Level of life satisfaction

The average SWLS score was 19.1 (SD 7.8) for men and 17.5 (SD 6.9) for women. This value was significantly lower than that for workers over 20 years of age doing desk work in Japan (mean 21.1, $p < 0.01$) (*15*).

What is related, and how does it affect life satisfaction?

Mental disorders, ADHD, and their impact on activities, self-acceptance, and adaptive attitudes were associated with life satisfaction. However, the impact on daily activities, self-acceptance, and adaptive attitudes had independent effects on life satisfaction.

The Mann-Whitney *U* test showed a significant difference between mental disorders ($p = 0.04$) and ADHD ($p = 0.02$). There were no significant associations between SWLS and sex ($p = 0.45$), cataplexy at least once per week ($p = 0.68$), disease duration ($p = 0.68$), or EDS ($p = 0.08$). Spearman's Correlation analysis showed that impact on activities ($\gamma = 0.43$; $p < 0.01$), self-acceptance ($\gamma = 0.53$; $p < 0.01$), and adaptive attitude ($\gamma = 0.49$; $p < 0.01$) were significant correlations. Age was not significantly correlated with SWLS ($\gamma = 0.04$; $p = 0.71$).

In this hypothetical model, $\chi^2 = 11.94$ ($p = 0.53$), GFI = 0.96, AGFI = 0.92, CFI = 1.00, and RMSEA = 0.00; thus, the model met all the criteria for this adoption (Figure 1). The estimated magnitudes of the standardized direct, indirect, and total effects were based on the path coefficients in Table 1. The direct effects were adaptive attitude ($\beta = 0.36$, $p < 0.01$), impact on activities ($\beta =$

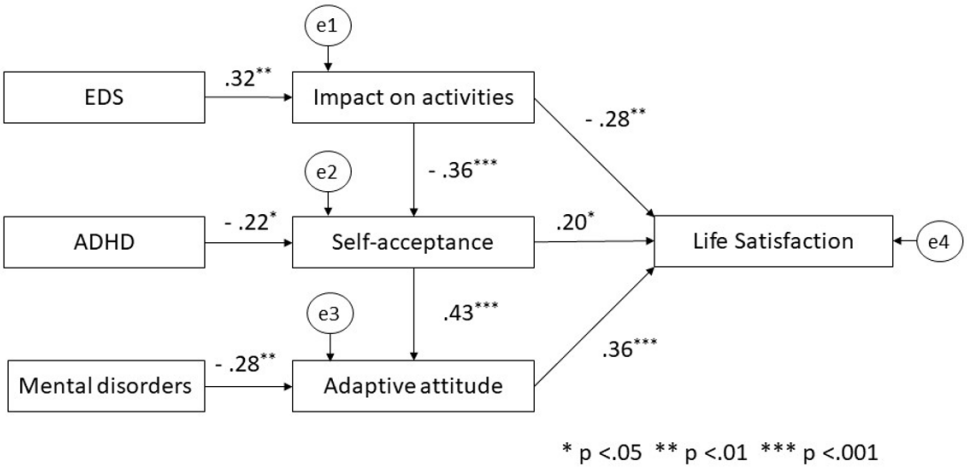

Figure 1. Path model of life satisfaction in patients with narcolepsy. The effects on the life satisfaction of patients with narcolepsy were analyzed: EDS increased the impact on activities, ADHD decreased self-acceptance, and mental disorders decreased adaptive attitudes. The impact on activities reduced life satisfaction, whereas self-acceptance and adaptive attitude contributed to increased life satisfaction.

0.28, $p < 0.01$), and self-acceptance (β = 0.28, $p = 0.04$). In contrast, indirect effects had an impact on activities (β = 0.13), self-acceptance (β = 0.16), mental disorder (β = 0.10), and ADHD (β = 0.08). The overall effects were impact on activities (β = 0.41), self-acceptance (β = 0.36), adaptive attitude (β = 0.36), EDS (β = 0.13), mental disorders (β = 0.10), and ADHD (β = 0.08).

Table 1. Summary of the direct, indirect, and total effects on life satisfaction

Variables	Effects		
	Direct	Indirect	Total
Mental disorder		-0.10	-0.10
ADHD		-0.08	-0.08
EDS		-0.13	-0.13
Impact of activities	-0.28	-0.13	-0.41
Self-acceptance	0.20	0.16	0.36
Adaptive attitude	0.36		0.36

The direct, indirect, and total effects of each variable on life satisfaction in the path analysis are described. The strongest overall effect on life satisfaction was the impact on activities at -0.41, with self-acceptance and adaptive attitudes at similar levels at 0.36.

How can life satisfaction be increased?

Reducing the impact of health problems on daily activities and enhancing adaptive cognition are essential for improving life satisfaction. Some patients with chronic diseases rate their condition as healthy (*16*), and individuals with disabilities have reported a high quality of life after coming to terms with their disability (*17*). Considering this, it is expected that addressing the limitations in daily activities, occasionally accepting them, and fostering psychological receptiveness can lead to improved life satisfaction.

A challenge of this study is that it failed to identify measures to reduce impact of daily activity-related factors on life satisfaction. Dodel *et al.* noted that sleepiness was not significantly associated with health function or quality of life as measured by the 36-item Short Form Health Survey (SF-36) (*18*). Similarly, this study found that the effect of sleepiness on life satisfaction was limited (β = 0.13). While the sleepiness inherent in narcolepsy can affect daily life, it may not be a major issue in a broader context. Therefore, it is necessary to focus on factors other than sleepiness. However, this study did not examine effects on activities beyond sleepiness and cataplexy. Future research should also consider other factors that may influence patient activity.

In conclusion, we conducted a path analysis to examine factors associated with life satisfaction in Japanese patients with narcolepsy. Our study gives hope that patients can achieve high life satisfaction, regardless of their medical condition. Excessive daytime sleepiness affects daily life activities, although its effect on life satisfaction is low. Adaptive attitude and self-acceptance played essential roles in life satisfaction. Reducing the impact on activities is critical to improving life satisfaction; however, what content influences activities at this stage is unclear. They are expected to achieve high levels of life satisfaction by accepting themselves and changes in their lives regardless of sleepiness. In the future, it is necessary to propose specific approaches to increase the flexibility of patients with narcolepsy and to identify factors that influence their daily life activities.

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