

# Evaluation of Self-Efficacy and Health-Related Quality of Life in Pediatric-Onset Multiple Sclerosis Patients

## Çocukluk Çağı Başlangıçlı Multipl Skleroz Hastalarında Öz Yeterlilik ve Sağlıkla İlişkili Yaşam Kalitesinin Değerlendirilmesi

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### ABSTRACT

**Objective:** To assess the self-efficacy level and health-related quality of life in pediatric-onset multiple sclerosis (POMS) patients.

**Material and Methods:** A cross-sectional study was conducted between January-April 2022 at Hacettepe University Department of Pediatric Neurology using The Pediatric Rating of Chronic Illness Self-Efficacy (PRCISE) Scale and Pediatric Quality of Life Inventory (PedsQL).

**Results:** Twenty-nine POMS patients with a median age of 16.4 years (F/M: 20/9) were included in the study. The mean PRCISE Scale score was 101.8±22.4 and the mean PedsQL score was 66.5±16.2. Both scores were lower than previously reported in the literature.

**Conclusion:** Lower self-efficacy and HRQoL levels might be attributed to fatigue which is common in POMS. The impact of the COVID-19 pandemic on mental health and quality of life should be addressed in patients with POMS.

**Key Words:** Childhood, Health-related quality of life, Multiple sclerosis, Self-efficacy

### ÖZ

**Amaç:** Bu çalışma ile çocukluk çağı başlangıçlı multipl skleroz (çMS) hastalarının öz yeterlilik ve sağlıkla ilişkili yaşam kalitesi düzeylerinin değerlendirilmesi amaçlanmıştır.

**Gereç ve Yöntemler:** Ocak 2022 – Nisan 2022 tarihleri arasında kesitsel olarak gerçekleştirilen bu çalışmada çMS tanılı hastalar Pediatrik Kronik Hastalık İçin Öz Yeterlilik Ölçeği (PKHÖYÖ) ve Çocuk Çağı Yaşam Kalitesi Ölçekleri (ÇÇYKÖ) ile değerlendirilmiştir.

**Bulgular:** Ortalama yaşları 16.4 yıl olan 29 çMS hastası (K/E:20/9) çalışmaya katılmıştır. PKHÖYÖ ortalaması 101.8±22.4 puan elde edilmiş olup, ÇÇYKÖ skorlamasında ortalama 66.5±16.2 puan elde edilmiştir. Her iki değer literatürde daha önceki yapılmış olan çalışmalardan düşük olduğu görülmüştür.



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**Ethics Committee Approval / Etik Kurul Onayı:** This study was conducted in accordance with the Helsinki Declaration Principles. Ethical approval was obtained from Hacettepe University Clinical Research Ethics Committee (2022/01-07).

**Contribution of the Authors / Yazarların katkısı: ONCEL IH:** Constructing the hypothesis or idea of research and/or article, Planning methodology to reach the Conclusions, Organizing, supervising the course of progress and taking the responsibility of the research/study, Taking responsibility in patient follow-up, collection of relevant biological materials, data management and reporting, execution of the experiments, Taking responsibility in logical interpretation and conclusion of the results, Taking responsibility in necessary literature review for the study, Taking responsibility in the writing of the whole or important parts of the study, Reviewing the article before submission scientifically besides spelling and grammar. **SOLMAZ I:** Constructing the hypothesis or idea of research and/or article, Planning methodology to reach the Conclusions, Organizing, supervising the course of progress and taking the responsibility of the research/study, Taking responsibility in patient follow-up, collection of relevant biological materials, data management and reporting, execution of the experiments, Taking responsibility in logical interpretation and conclusion of the results, Taking responsibility in necessary literature review for the study, Taking responsibility in the writing of the whole or important parts of the study, Reviewing the article before submission scientifically besides spelling and grammar.

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**Sonuç:** Pediatrik Kronik Hastalık İçin Öz Yeterlilik Ölçeği ve ÇÇYKÖ ortalama skorlarının düşük olması çMS hastalarında yaygın görülen kronik yorgunlukla ilişkili olabilir. Ayrıca COVID-19 pandemisinin çMS hastalarında mental sağlık ve yaşam kalitesi üzerindeki etkisi de bu sonuçlar yorunmlanırken göz önünde bulundurulmalıdır.

**Anahtar Sözcükler:** Çocukluk Çağı, Sağlıkla İlişkili Yaşam Kalitesi, Multipl Sklerosis, Öz Yeterlilik

## INTRODUCTION

Pediatric-onset multiple sclerosis (POMS) defines multiple sclerosis manifesting before age 18 years. Approximately 90% of POMS cases present during adolescence, an age group where autonomy, individuation, self-efficacy, and self-reliance are in development (1, 2). Self-efficacy refers to an individual's confidence in their own ability for a specific behaviour or achievement. In terms of health conditions, self-efficacy comprises the belief in one's ability to manage the requirements of a disease adequately (3). The perception of self-efficacy is an important predictor of health-related behaviour and adherence to treatment in chronic diseases (4).

The multi-dimensional impact of a health condition and its treatments on the individual's physical, mental, emotional, and social well-being is defined as health-related quality of life (HRQOL) (5). Adolescents' and young adults' mental and emotional health and quality of life affect their education and career choices, their parents, and their use of the health care system. Therefore, the management of their disease often extends beyond the physical effects of medical treatment. The aim of this study was to evaluate self-efficacy and HRQOL in patients with POMS.

## MATERIALS and METHODS

We conducted a cross-sectional study between January and April 2022 with patients who had been diagnosed with POMS in Hacettepe University Faculty of Medicine, Department of Pediatric Neurology. Patients with POMS lasting more than three months and were able to read and complete the Turkish version of The Pediatric Rating of Chronic Illness Self-Efficacy Scale (PRCISE) and Pediatric Quality of Life Inventory (PedsQL) were included in the study. After informed consent from patients or parents to participate in the study, patients were asked to fill out the PRCISE and PedsQL during their routine clinical visit. Demographic and clinical data included age, gender, duration of disease, treatments, and last available expanded disability status scale (EDSS) scores were recorded from hospital registry. Ethical approval was obtained from Hacettepe University Clinical Research Ethics Committee (2022/01-07).

### Statistical analyses:

Statistical analyses were performed using a package program called SPSS (IBM SPSS Statistics 24). The data of the patients were classified by various parameters. Frequency tables and descriptive statistics were used to interpret the findings.

### Outcome measures:

Self-efficacy levels were measured with the PRCISE. The scale was developed by Emerson et al (6). It comprises 15 items and 6 sub-dimensions: exercise (1 item), obtain help from family, friends and doctors (4 items), illness management (3 items), chores, hobbies and recreation (3 items), symptoms (3 items) and mood (1 item). All items are answered on a Likert scale from 0 to 10 ranging from 0 for "not at all sure" to 10 for "very sure". A total PRCISE score ranges from 0 to 150, the maximum total score of 150 indicating the highest self-efficacy level. The Turkish version of the PRCISE Scale was adapted from the original scale by Gürcan et al (7) with acceptable validity and reliability for Turkish children.

Health Related Quality of Life (HRQoL) was measured using the Turkish version of PedsQL. Version 4.0 for 13 -18 years old. The PedsQL was developed to evaluate child perceptions of HRQOL in children with various health problems. This 23-item scale based on child/adolescent self-report consists of four domains: Physical Functioning (8 items), Emotional Functioning (5 items), Social Functioning (5 items), and School Functioning (5 items). PedsQL assesses the frequency of problems that occurred in the last one month. All items are answered on a Likert scale from 0 to 5 ranging from 0 for "never a problem" to 5 for "almost always a problem". All the items are then reverse scored and transformed into a 0-to-100-point scale (0=100; 1=75; 2=50; 3=25; 4=0), where a higher total score of PedsQL 4.0 indicates a better HRQoL. The validity and reliability of the Turkish version of PedsQL 4.0 Version for 13-18 Years Old were proven by Memik et al (8).

## RESULTS

Total 29 POMS patients, median age 16.4 years (range: 13.4-17.7), female/male 20/9, were enrolled in the study. All patients had been on a disease modifying therapy for more than 3 months. All had an

**Table I: Demographic and clinical characteristics of POMS patients.**

F/M n (%)	20/9 (69/31)
Age (years) median (25-75%)	16.4 (13.4-17.7)
Disease duration	26 months (5-64 months)
Treatments (n)	
Interferons	11
Teriflunomide	9
Dimethyl fumarate	7
Ocrelizumab	1
Fingolimod	1

**POMS:** Pediatric Onset Multiple Sclerosis, **F:** Female, **M:** Male

Expanded Disability Status Scale (EDSS) score of 0 indicating no neurological disability, and none had a comorbid disease (Table I).

The mean PRCISE Scale score was  $101.8 \pm 22.4$  (median 103, 101.62 for girls and 102.12 for boys). The mean PedsQL score was  $66.5 \pm 16.2$  (median 66, 66.7 for girls and 66.2 for boys).

## DISCUSSIONS

Self-efficacy measurement is a standardized and practical way to evaluate a patient's self-management ability and identify patients at risk for medical nonadherence. It has been recommended as a part of chronic care and management (9). In our study we found the mean PRCISE score of  $101.8 \pm 22.4$  out of 150. In a previous validation and reliability study of PRCISE Scale on Turkish adolescents with different chronic illnesses, the mean PRCISE score was determined as  $106 \pm 17.9$  and no significant relation was found between self-efficacy level and age, sex and disease duration (7). The mean PRCISE score of the subgroup including patients with neurological disease was  $104.9 \pm 22$ . In the original study of PRCISE scale conducted by Emerson et al. (6) the mean PRCISE score was  $114 \pm 31.7$  in 7- 20-year-old patients with various chronic diseases, and the subgroup comprising patients with neurological diseases had a mean PRCISE score of  $113.5 \pm 32.7$ . The self-efficacy level of our patients was lower than those reported.

Self-efficacy is affected by type of illness, multimorbidity and functional disability (10). In our study, none of the patients had a chronic comorbid condition and neurological disability. Nevertheless, the lower self-efficacy level in our patients may be attributed to several reasons. One is fatigue, the feeling of exhaustion and tiredness known as one of the most common and disabling symptoms MS and affecting 9-76% of children and adolescents with POMS (11). In a recent study of adult MS patients from Turkey, the frequency of fatigue was reported as 68.2% (12). However, no available data was found regarding the prevalence of fatigue in Turkish POMS patients, and fatigue was not questioned in our study either. MS-related fatigue may impact physical functioning even in the absence of obvious neurological disability. An inverse association exists between fatigue and self-efficacy (13).

Both self-efficacy and fatigue have been found to be the major determinants of quality of life in adult patients with MS, along with neurological disability (14). The HRQoL evaluated in our study showed the mean score of  $66.5 \pm 16.2$ . In the validation and reliability study of Turkish PedsQL for adolescents aged 13 to 18 years, the mean PedsQL score of patients with chronic diseases was 74.82 and a recent systematic review and meta-analysis in POMS patients using PedsQL, reported mean HRQoL scores as 67.3-82.4 (15). The mean PedsQL score of our POMS patients was in the lower range of those reported in this meta-analysis. One possible reason of this result is the COVID-19 pandemic. Social distancing, self-isolation, and various restrictions that people faced

in all around the world during the last 2.5 years affected mental health of people, particularly those in younger age (16). Recent studies have shown that both self-efficacy and quality of life declined significantly in individuals due to COVID-19 pandemic (17, 18). Moreover, our study was conducted in a time frame where the highest COVID-19 cases were reported in Turkey (19). Therefore, the probable adverse impact of the pandemic on our results cannot be ignored.

The small number of patients, the inability to apply the scales according to the treatment subgroups, and the absence of a control group are the limitations of our study. Besides that, we did not evaluate our patients for psychiatric and behavioral problems, including depression or adjustment disorders, which may affect our results. Further studies with larger cohorts are required to address these limitations. The fact that PRCISE and PedsQL can be applied in chronic diseases such as POMS with a low incidence and prevalence is one of the strengths of our study.

We found both the self-efficacy and HRQoL levels were lower in POMS patients. These two variables interact in their effect on the patients' and parents' life. Developing strategies to support the self-management and strengthen the self-efficacy in POMS patients may help these adolescents to cope with MS and bring a higher quality of life.

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