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Quality of life and its correlates in adolescent multiple sclerosis patients

Slavica Ostojic [a], Dejan Stevanovic [b], Jasna Jancic [b,c,*]

[a] Institute for Mother and Child Healthcare of Serbia, University of Belgrade, Belgrade, Serbia
[b] Clinic of Neurology and Psychiatry for Children and Youth, University of Belgrade, Belgrade, Serbia
[c] Medical faculty, University of Belgrade, Belgrade, Serbia

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ABSTRACT

Introduction: Measures of health-related quality of life (HRQOL) are considered to be more comprehensive in health outcome assessments than scales assessing only the degree of neurological deficit.
Objective: The aim of the study was to evaluate HRQOL and its correlates among adolescents with multiple sclerosis (MS) in Serbia.
Methods: Demographic, clinical, and patient-reported outcome data were collected for 21 adolescents with MS, aged 14–18 years. The KIDSCREEN measure was used for HRQOL assessment. Anxiety and depressive symptoms were identified by the Revised Child Anxiety and Depression Scale (RCADS), while fatigue was assessed by the Paediatric - Functional Assessment of Chronic Illness Therapy-Fatigue (PedsFACIT-F).
Results: Compared to the national data for healthy adolescents, the scores for a domain assessing physical well-being were significantly lower among adolescents with MS. Five (23.8%) adolescents had the RCADS scores within the clinical range. The age of the disease onset significantly correlated with the social and school domain. Neurological impairment correlated negatively with self-perception, school environment, and social acceptance domain. Fatigue significantly correlated with physical and psychological domains. The RCADS scores and the disease duration correlated negatively with the majority of the KIDSCREEN scores.
Conclusion: In adolescents with MS physical HRQOL domain is most likely to be compromised, whilst functioning and well-being in other domains are relatively preserved. Severity of the disease, its duration, and fatigue, with increased anxiety and depressive symptoms, are significant HRQOL correlates.

1. Introduction

Paediatric multiple sclerosis (MS) has been largely recognised worldwide, representing 3–5% cases in adults with this disease (Huppke and Gärtner, 2010). Incidence and prevalence of acquired demyelinating syndromes (ADS) of the central nervous system (CNS) in children varies from as low as 0.66 to as high as 1.9 per 100 000 (Ketelslegers et al., 2012; Banwell et al., 2009; Langer-Gould et al., 2011). The vast majority of paediatric patients (> 95%) have a relapsing-remitting course of the disease, with progression to permanent disability, although progressing more slowly than in adult patients (Huppke and Gärtner, 2010; Ghezzi, 2004).

Health status outcomes of patients with MS based on physical or neuroradiological data possibly underestimate the difficulties they face in daily activities (Solari, 2005). Measuring health related - quality of life (HRQOL), as evaluation of MS effects and its treatment regimens on various aspects of everyday functioning and well-being, has been recognised as an indispensable step in the complete outcome assessment of MS patients (Solari, 2005), including paediatric cases (Lanzillo et al., 2016). HRQOL outcome may provide estimates about the course of the disorder and levels of disability from a child's perspective, additional treatment outcome data with patients` preferences, and data for estimating treatment costs.

MacAllister and colleagues were among the first to investigate HRQOL systematically in paediatric MS (MacAllister et al., 2009). Compared to the healthy population, children and adolescents with MS have more difficulties with physical and emotional functioning, as well as with fatigue, sleep, cognition, and academic functioning (MacAllister et al., 2009; Mowry et al., 2010). Fatigue was found to be particularly associated with a lower HRQOL

Abbreviations: MS, Multiple sclerosis; HRQOL, Health-related quality of life; RCADS, Revised Child Anxiety and Depression Scale; PedsFACIT-F, Paediatric - Functional Assessment of Chronic Illness Therapy-Fatigue; EDSS, Expanded Disability Status Scale

* Correspondence to: Dr Subotica 6a Street, 11000 Belgrade, Serbia.
E-mail address: jasna.jancic.npk@gmail.com (J. Jancic).

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(MacAllister et al., 2009), which confirmed that fatigue was a significant problem for children with MS, as it was for adult patients (Solari, 2005). Recently, higher levels of HRQOL were reported in patients with paediatric than in juvenile MS onset (Lanzillo et al., 2016).

Considering the fact that paediatric MS is a rare disorder, with a relatively small number of patients available for research, more epidemiological data are needed, including findings from more homogeneous samples regarding age, due to significant differences in HRQOL characteristics between children and adolescents (Frisén, 2007), and from different regions, so as to suggest models for multimodal assessment and treatment of paediatric MS, which includes valid HRQOL data.

The aim of the study was to evaluate HRQOL and its correlates among adolescents with MS in Serbia. In addition to various demographic and clinical characteristics of MS, fatigue and levels of anxiety and depressive symptoms were evaluated, based on self- and parent-ratings, as possible HRQOL correlates.

2. Materials and methods

2.1. Participants

This is a cross-sectional study including adolescents with MS referred to two paediatric university clinics in Belgrade: The Clinic of Neurology and Psychiatry for Children and Youth and The Institute of Mother and Child Healthcare of Serbia "Dr Vukan Cupic". The participants were identified retrospectively. Confirmed diagnosis of MS, as assessed by the revised McDonald criteria with patients up to 18 years of age, was the general study inclusion criteria (Polman et al., 2011).

All adolescents participated in the study with at least one parent. The questionnaires were answered after the parents and adolescents had signed the informed consent. The adolescents answered the questionnaires themselves, whereas their parents completed the parent-reports. The study protocol was in accordance with the tenets of the Declaration of Helsinki and its later amendments. The study was approved by the Ethics Committee of the Medical School, University of Belgrade, Serbia.

2.2. Assessments

The Expanded Disability Status Scale (EDSS) was collected as a common measure of the MS neurologic impairment (Kurtzke, 1983). The EDSS rates a patient's level of neurologic impairment according to the effects of the disease on functional systems. The scale ranges from 0 to 10, where 0 indicates no neurologic impairment, and 10 indicates death as a result of MS. The age of the disease onset, time elapsed from symptom onset to evaluation, number of relapses in the previous year, and current medications have also been recorded.

The KIDSCREEN-52 was used for HRQOL assessments (Ravens-Sieberer and the European KIDSCREEN Group, 2006). The KIDSCREEN-52 is a HRQOL questionnaire that has 52 items in ten dimensions (scales): Physical Well-Being (5 items), Psychological Well-Being (6 items), Moods and Emotions (7 items), Self-Perception (5 items), Autonomy (5 items), Relations with Parents and Home Life (6 items), Social Support and Peers (6 items), School Environment (6 items), Social Acceptance (3 items), and Financial Resources (3 items). Rasch scores were computed for each dimension and transformed into *T*-values with a mean of 50 and a standard deviation of 10. Higher scores indicate better HRQOL. Details how the scores are computed were given in the manual. In the study, the Serbian self- and parent-report version were used (Ravens-Sieberer and the European KIDSCREEN Group, 2006; Stevanovic et al., 2013).

Fatigue was assessed by the Paediatric - Functional Assessment of Chronic Illness Therapy-Fatigue (PedsFACIT-F). The PedsFACIT-F is a self-reported measure for fatigue-related symptoms with 13 items (Lai et al., 2007). Eleven items belong to the Tiredness scale, whereas another two items belong to the Energy scale. Total score is the sum of all answered items in the two scales (possible score range is 0–52). The higher the PedsFACIT-F score, the less likely is for fatigue to be present. In the study, only self-report was used.

Depressive and anxiety symptoms were assessed by the Revised Child Anxiety and Depression Scale (RCADS, Chorpita et al., 2000). The RCADS is a 47-item self-and parent-report questionnaire and respondents indicate how often depressive and anxiety symptoms are present. The sum of all answered items was calculated to obtain the RCADS depression score (possible range 0–20) and RCADS anxiety score (possible range 0–74), where a higher score indicates more symptoms present. T-scores were calculated (a mean of 50 and a standard deviation of 10) for both symptoms scores and only T-scores ≥ 70 were considered indicative of significant anxiety or depressive symptoms. In the study, Serbian self- and parent-report versions were used, which were culturally translated and adapted (Stevanovic et al., personal communication).

2.3. Data analysis

Mean (M) and standard deviation (SD) were calculated for all KIDSCREEN-52, PedsFACIT-F, and RCADS scores. Published national data for KIDSCREEN questionnaire for healthy adolescents aged 14–18 (median 16) were used (Stevanovic et al., 2013). Differences in the KIDSCREEN scores between healthy adolescents and adolescents with MS were assessed using *t*-test. Cohen's d effect size was calculated and its values should be interpreted as: small ≤ 0.2, moderate 0.5, and large ≥ 0.8 (Cohen, 1988). The levels of agreement between adolescents and parents in reporting KIDSCREEN scores were assessed using intraclass correlation coefficient (ICC), which was interpreted as follows: < 0.4, poor to fair; 0.41–0.6, moderate; and > 0.61, good to excellent (Stevanovic et al., 2013). Adolescents with significant anxiety and/or depressive symptoms (the RCADS T-scores ≥ 70) were also identified (Chorpita et al., 2000). Pearson's correlation coefficient (r) was calculated in order to study correlations between KIDSCREEN scores and demographic as well as clinical variables (i.e. current age, age of the disease onset, disease duration, number of relapses in the previous year, current EDSS, RCADS Anxiety and Depression score, and PedsFACIT-F Total score). Correlation coefficients ranging 0.1–0.3 were considered low, those 0.31–0.5 moderate, and those exceeding 0.5 high (Cohen, 1988). All p values ≤ 0.05 were considered statistically significant.

3. Results

The study included 21 adolescents with MS (15 (71.4%) females), aged 14–18. Basic demographic and clinical data are presented in Table 1. All included adolescents had mild neurologic impairment, with current EDSS scores ranging from 0 to 3.5. They were all treated with corticosteroids in the relapsing phase of the disease, except for one adolescent, who was also treated with plasmapheresis. During the study conduction, 10 (47.6%) participants were on interferon treatment (INFβ1-a or INFβ1-b).

3.1. HRQOL, anxiety and depressive symptoms

Compared to the national data for healthy adolescents, scores of the Physical Well-being domain were significantly lower among