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Narcolepsy and the Sickness Impact Profile: A general health status measure

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ABSTRACT

Objective: We characterized functional impact of narcolepsy on patients using a general health status measure, the Sickness Impact Profile (SIP). It has 136 items grouped into 12 categories and 2 dimensions.

Methods: We ascertained patients with physician-diagnosed narcolepsy in King County, Washington using multiple overlapping methods over four years starting July 2001. We recruited 226 patients (mean age 48 years, 65% female) who underwent in-person interviews and completed: Epworth Sleepiness Scale (ESS), Ullanlinna Narcolepsy Scale (UNS), and SIP. Linear regression was used to assess correlations between measures.

Results: Mean percent of total dysfunction was higher for psychosocial dimension (13.2) and independent categories (13.4) than physical dimension (5.0). Mean percent of total dysfunction in descending order for categories was: Sleep and Rest (23.6), Alertness Behavior (22.6), and Recreation and Pastimes (20.6). Ten items were endorsed by at least a third of all patients but only two of them concerned sleep. Unexpectedly, among the top ten items were, "My sexual activity is decreased," and "I forget a lot, for example, things that happened recently, where I put things, appointments." Percent of overall dysfunction on SIP (mean 10.3) was significantly correlated with ESS ($r=0.36$, $p<0.001$) and UNS ($r=0.47$, $p<0.001$). In this population-based sample, mean percent of total dysfunction on SIP in patients with narcolepsy (10.3) was higher than previously reported in the general population (3.6) and similar to that in other chronic disabling conditions.

Discussion: The SIP correlated with ESS and UNS, and captured unique aspects of the impact of narcolepsy on patients.

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1. Introduction

Scales that measure symptoms of narcolepsy emphasize rating clinical features of the disease such as excessive daytime sleepiness and cataplexy [1,2], but they may fail to capture the full functional impact of narcolepsy or its treatments. The Medical Outcomes Study Short Form-36 (SF-36) [3] has been used in patients with narcolepsy to characterize more fully the effect of the disease on physical and psychosocial spheres [4,5]. Another general health status measure, the Sickness Impact Profile (SIP) [6,7] has the potential to expand further our understanding of dysfunction in narcolepsy patients.

The SIP was designed to assess functional status of patients with any chronic disease [6,7]. Its reliability and validity have been extensively studied in neurologic [8,9] and non-neurologic diseases [7,10], but not in patients with narcolepsy, to our knowledge. The SIP contains 136 items grouped in 12 categories and requires about 30 min to complete. Each item describes a specific behavioral dysfunction, rather than a subjective self-evaluation. Patients are instructed to endorse only those items describing dysfunction due to their disease. Each item has a weight reflecting the relative severity of the dysfunction compared to other items [11]. The 12 category scores, expressed as percents, are the sum of the weighted scores for all the endorsed items in a particular category divided by the maximum score, which represents total dysfunction for that category. Some categories contribute to a physical dimension; some, to a psychosocial dimension; and some independent categories, to neither of these dimensions.

Our goals were to examine the performance of the SIP in a population-based study of patients with physician-diagnosed narcolepsy in King County, Washington. We wanted to compare the information obtained from the SIP to that from two measures used in patients with narcolepsy. We also wanted to generate a profile for patients with narcolepsy and see how this profile differed for various definitions of the disease.

2. Materials and methods

In the parent study, we attempted to identify all prevalent cases of physician-diagnosed narcolepsy who were 18 years and older and residing in King County, Washington as of July 1, 2001 [12]. Cases were recruited through multiple overlapping methods. For providers, we focused on clinicians working in sleep disorders centers but also contacted neurologists, family medicine physicians, psychiatrists, and community clinics where patients without financial resources often receive care. For patients, presentations were made at support groups and other regional meetings. Pharmacists in King County agreed to include an information sheet about the study with all prescriptions relevant to narcolepsy. Multimedia advertisements and public service announcements were also used and linked to telephone and online contact information.

Patients identified were contacted and asked to participate in an epidemiologic study. For those who provided written

informed consent, trained professionals administered a structured interview. Consent to provide buccal specimens and to obtain medical records was also requested from each participant. A total of 425 patients were entered into the narcolepsy registry. Of these, 78 cases could not be located, 10 could not be interviewed due to language barriers or psychiatric illnesses, and 55 refused. Interviews were arranged for 282 cases, 279 of whom completed the interview and provided buccal specimens for deoxyribonucleic acid (DNA), which was tested for *human leukocyte antigen* (HLA) DQB1*0602 as detailed elsewhere [13]. The University of Washington Human Subjects Committee reviewed and approved the study.

3. Data collection

Trained professionals administered in-person interviews to patients using a standardized questionnaire that included demographic information, the Epworth Sleepiness Scale (ESS) [1], and the Ullanlinna Narcolepsy Scale (UNS) [2]. We defined cataplexy as present if indicated by medical record review, self-reported cataplexy, or an affirmative response to questions about experiencing muscle weakness when telling or hearing a joke, or when laughing [14]. After the interview, the SIP was explained to the patient, who was given the choice of completing the SIP while the interviewer waited or to complete it at a later date and return it by mail. Of the 279 patients who participated in the study, the 226 (81%) who completed the SIP, the ESS, and the UNS are the focus of this report.

4. Analysis

Percentages were calculated for the SIP's 12 categories, two dimensions, independent categories not included in the two dimensions, and overall score. Results were examined for all patients with a physician diagnosis of narcolepsy, the subgroups with and without cataplexy, and the subgroups with and without HLA DQB1*0602 positivity. We conducted a two-way analysis of variance (ANOVA) to assess the difference in mean dysfunction scores according to cataplexy and HLA DQB1*0602. Linear regression was also used to assess the association between the SIP scores and cataplexy status and HLA status while controlling for age and sex. Associations between the SIP and the ESS and UNS were assessed with partial correlation coefficients from linear regression models of the entire sample, which included age, sex, and HLA DQB1*0602 status. Findings with *p*-values less than 0.05 were considered significant, and all testing was two-tailed. All analyses were conducted in Stata (version 10.0 for Macintosh, StataCorp, College Station, TX).

5. Results

Considering the 226 patients included in these analyses, the mean and median age was 48 years old with a range from 18 to 92 with 47% over 50 years old and 65% women. Of the 226

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