

Sleep disorder symptoms are common and unspoken in Canadian general practice

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Bailes S, Baltzan M, Rizzo D, Fichten CS, Grad R, Wolkove N, Creti L, Amsel R and Libman E. Sleep disorder symptoms are common and unspoken in Canadian general practice. *Family Practice* 2009; **26**: 294–300.

Objective. Primary care patients were surveyed for what sleep disorder symptoms they discussed with their physicians. Their responses were compared with those of new Sleep clinic patients. The goal was to discover what symptom presentation leads to a successful referral to a sleep clinic.

Methods. We recruited two samples: 191 older Primary care patients and 138 Sleep clinic patients. Participants completed the Sleep Symptom Checklist (SSC). This consists of 21 symptoms in four domains: insomnia, sleep disorder, daytime symptoms and psychological distress. All respondents indicated which symptoms had been discussed with their physician in the past year. Primary care subjects were designated as Decliners (completed SSC, refused further evaluation), Dropouts [completed some evaluation steps, but not polysomnography (PSG)] and Completers (completed PSG).

Results. Primary care participants frequently had symptoms but relatively few had discussed them with their doctor. Sleep clinic participants discussed significantly more symptoms with their referring physician than did Primary care Dropouts or Decliners in all categories except psychological distress. Primary care Completers, 88.5% of whom were ultimately diagnosed with sleep apnoea/hypopnoea syndrome and/or periodic limb movement disorder, also discussed their sleep disorder symptoms less frequently than did Sleep clinic patients but tended to give more prominence to symptoms of insomnia and impaired daytime function.

Conclusions. The findings suggest that Primary care patients often have symptoms they do not discuss, even when a primary sleep disorder exists. The brief SSC checklist, developed in our laboratory, has potential to improve the referral rates of older primary care patients who have sleep disorder.

Keywords. Primary care, referral, sleep clinic, sleep disorders, symptom reporting.

Introduction

Sleep apnoea/hypopnoea syndrome (SAHS) appears causally related to hypertension, insulin resistance and cardiovascular events.¹ It is also highly correlated with obesity and may be an associated risk factor in stroke² and atrial fibrillation.³ Treating apnoea with continuous positive airway pressure (CPAP) has a broadly beneficial outcome on daytime functioning and perceived quality of life.^{4–6} Recent studies dramatically

demonstrate changes in the structure and function of the heart that are caused by sleep apnoea^{7,8} and the reversal of these consequences by CPAP therapy.¹ Long-term use (7.5 years) of CPAP therapy was found to reduce mortality from cardiovascular disease compared to patients with apnoea who were non-adherent to treatment.⁹

Although the presence of diagnosed SAHS in the older population is high (prevalence is estimated in the 20–60% range^{10–13}), referral rates from primary

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care significantly under-represent the estimated population prevalence rates. Two reports on the prevalence of sleep disorder symptoms in the adult primary care population^{14,15} found high rates of sleep disorder symptoms [insomnia (32%), sleep apnoea (24%) and restless legs syndrome (29%)] and apnoea risk factors (obesity, hypertension, snoring and breathing pauses). However, in neither of the primary care surveys were the patients referred for further screening, so there is no information about how many patients actually had a diagnosable sleep disorder.

Given the important health risks associated with SAHS, identification and treatment of those with the disorder is a critical issue in primary care. Routine screening does not yet exist for SAHS as it does for diabetes, hypertension or cardiopulmonary diseases. Yet, physicians must be able to select and refer those at most risk. This process is hampered by the minimal time sleep medicine is taught in medical schools¹⁶ and in continuing medical education, resulting in primary care doctors being rather under-informed about sleep apnoea.^{17,18} In addition, clinical presentation of SAHS is variable and not always obviously related to the condition.^{19,20} Patients are usually unaware of disordered breathing during their sleep and are likely to report on poor-quality sleep, daytime sleepiness or fatigue or even psychological malaise. These symptoms may be reported in the context of other complaints, and the primary care practitioner needs to evaluate a wide range of physical systems. In fact, little is known about the process by which patients with possible sleep disorders are identified by their physicians and referred for polysomnography (PSG) screening. There is need for clear practice guidelines to identify patients who are likely to have SAHS as well as other sleep problems.^{21–23}

We previously developed the Sleep Symptom Checklist (SSC), which was intended as a symptom survey for use in primary care.²⁴ We have found it a useful survey of a broad range of symptoms that are both directly and indirectly related to sleep disorders. Substantial numbers of older, Primary care patients (both men and women) indicated that they experienced symptoms within the past month. Those who volunteered and completed an extensive sleep evaluation, including PSG, were found to have the most severe symptoms related to insomnia, daytime functioning and sleep disorder.²⁴

To study communication and referral patterns, in the present study, we examine what symptom or constellation of symptoms primary care patients discuss with their physicians and compare these with equivalent reports by patients already referred to a sleep clinic. The goal was to discover what constellation of symptoms discussed between patient and physician tends to lead to a 'successful' referral for evaluation in the sleep clinic. Our study explores possible

differences in presentation between those at risk patients who are successfully identified and appropriately referred and those, equally at risk, who remain unrecognized. Our hypothesis is that those patients who are successfully identified as at risk for sleep apnoea, as represented by the Sleep clinic sample, present their symptoms in some uniquely salient manner, compared to those in the Primary care sample.

Methods

Design

The present study is descriptive in nature. It has both retrospective (participants are asked about past patient/physician discussions) and prospective components (data are collected prior to PSG and diagnosis).

Participants

Primary care sample. Participants were recruited for an assessment study from the waiting areas of three family practice centres in Montreal. Inclusion criteria were as follows: age ≥ 50 , community resident, volunteer, sufficient cognitive and language skills to complete measures in English or French. All potential subjects were invited to participate in a study that offered a comprehensive evaluation of their sleep through interview, extensive sleep questionnaire battery, medical assessment and PSG. Exclusion criteria to further participation included current acute major medical or psychiatric illness or a previously diagnosed sleep disorder.

Sleep clinic sample. Consecutive new patients referred for evaluation of possible sleep disorder at two Montreal hospital-based sleep clinics. Inclusion and exclusion criteria were the same as for the Primary care sample, except that age was 18 years and older.

Measures

Sleep Symptom Checklist. The SSC is a survey of a broad range of sleep disorders symptoms. This instrument consists of 21 items relating to direct and indirect signs and symptoms of sleep disorder, including snoring, breathing interruption in sleep, insomnia, daytime fatigue, sleepiness, psychological distress, etc. The items are included in Figure 1. Participants first rate each symptom for its severity from 0 (not at all) to 3 (very severe) based on the previous month, then indicate if the symptom was discussed with their physician at the current appointment or within the past year. In an open-ended format, they report what, if anything, their doctor recommended in terms of referral or treatment. The Sleep Clinic version of the SSC also asks participants to rate each symptom based on the previous month and asks the

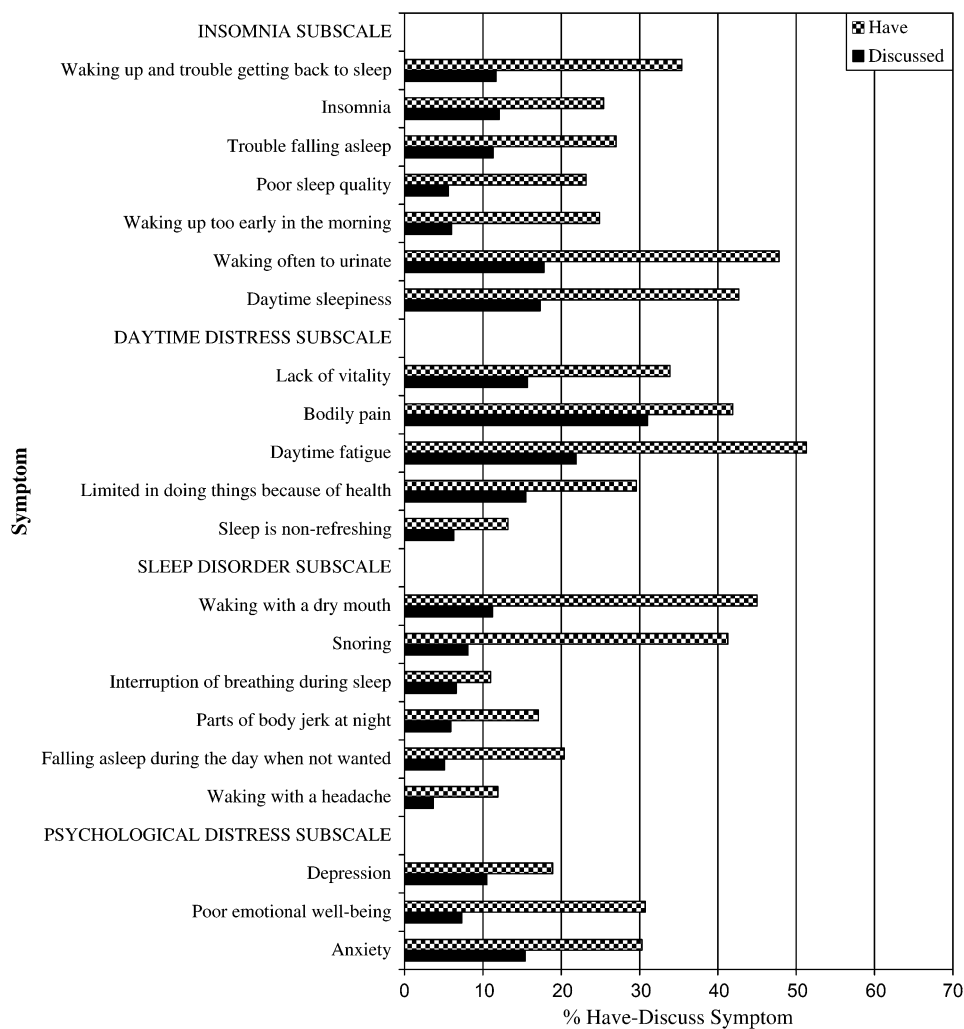


FIGURE 1 Per cent of participants (Primary care sample, $n = 196$) who indicated which symptoms they have (checked bars, ordered by subscale) and which they discussed with their primary care doctor (black bars)

participant about symptoms that had been discussed with the physician who had referred them to the sleep clinic. Temporal stability of the severity ratings was found to be acceptable (total score $r = 0.79$, $P < 0.01$). Cronbach's alpha was 0.74. Factor analysis yielded four distinct subscales: insomnia, daytime distress, sleep disorder and psychological distress.²⁴

PSG assessment. Participants were monitored in a supervised sleep laboratory from 10 p.m. to 7 a.m. Monitoring included three leads electroencephalogram (EEG), electrooculogram, bilateral anterior tibialis and chin electromyogram, electrocardiogram, pulse oximetry, nasal and oral airflow with nasal pressure cannulae (a thermistor for backup if technical difficulties were detected during recording) and respitrace bands for measurement of respiratory effort.²⁵ All signals were acquired on a digital data management system (Sandman, Nellcor-Puritan Bennett & Tyco, Ottawa, Canada). One certified PSG

technologist with 10 years of experience manually scored the studies blind to the results of symptom assessments. Sleep stages were first scored in 30-second epochs according to standard criteria.²⁶ Next, EEG arousals were scored according to standard current consensus criteria.²⁷ An apnoea event is scored when there was a cessation of breathing for ≥ 10 seconds. An hypopnoea was defined a priori as an event lasting at least 10 seconds with a decrease of $>50\%$ from a baseline in the amplitude compared to the mean of the largest three breaths over the previous four epochs or a lesser reduction in airflow signal amplitude accompanied by either at least a 3% desaturation or an EEG arousal.²⁸ Leg movements, apnoea events and associated arousals were scored manually according to the scoring rules established by the Atlas Task Force of the American Sleep Disorders Association.²⁹ The cut-off criterion for defining a case with significant apnoea/hypopnoea as well as periodic limb movements was ≥ 10 events per hour of EEG sleep.

Procedure

Primary care sample. A research assistant, stationed in the waiting room of each of three primary care settings, approached all individuals from the appropriate age group. The study was described to potential participants and they were asked to read and sign consent. Patients who were willing to complete a brief checklist (<10 minutes completion time) were administered the SSC immediately after they left their doctor's office. All patients were informed about the remaining aspects of the study and invited to participate. Participants who agreed to continue underwent a medical examination by a sleep medicine specialist and an overnight PSG.

All participants were offered a modest honorarium and were reimbursed for their parking expenses. Physicians were not asked to influence either the patients' decision to participate in the study or to pursue the PSG assessment.

Sleep clinic sample. Recruitment was carried out at two hospital-based sleep clinics in Montreal. A research assistant, stationed in the waiting room of the two sleep clinics, approached all first-time patients referred for suspected sleep disorder. The study was described to potential participants and they were asked to read and sign consent. Willing participants completed the Sleep Clinic version of the SSC prior to their appointment with the sleep physician and gave permission for the researchers to obtain diagnostic data after the full assessment was completed.

In addition to the assurance of confidentiality, patients in all recruitment settings were advised that they were free to withdraw their participation at any stage of the protocol without affecting their medical care.

Analyses

Data were treated using both the individual SSC items as well as the four SSC subscales. Chi-square tests were applied to assess differences in frequency of individual SSC items. Multivariate analysis of variance (MANOVA) was used to test hypotheses related to group differences. Age differences between samples were treated using analysis of covariance (ANCOVA).

Results

Sample sizes for the Primary care and the Sleep clinic settings as well as some sample characteristics are presented in Table 1. We categorized Primary care patients into three groups, depending on whether they accepted further sleep assessment after completing the SSC, as follows.

- Decliners: those who completed the SSC but declined further participation ($n = 150$).
- Dropouts: those continuers who dropped out before completing the PSG and who participated in the questionnaire/interview stage or in the clinical evaluation by a sleep specialist ($n = 20$).
- Completers: those continuers who completed overnight PSG ($n = 26$).

While the ratio of women to men was equal for the Primary care completers, a majority of men characterized the Sleep clinic sample. The Sleep clinic sample was significantly younger than any of the subgroups of the Primary care sample [$F(3, 315) = 65.5, P < 0.0001$]. The Sleep clinic sample reported having a significantly higher number of symptoms, overall, than the Primary care completers who, in turn, admitted to a significantly higher number of symptoms than either Primary care Dropouts or Decliners who did not differ from each other [$F(3, 327) = 82.05, P < 0.0001$]. Sleep clinic patients had discussed significantly more symptoms with their physicians than the Primary care participants [$F(3, 327) = 18.97, P < 0.0001$]. Sleep clinic participants reported that they had experienced their reported symptoms for an average of 9.1 (1.0) years. Most of the Sleep clinic sample (67%) had been referred by a primary care physician. There were 106 different referring physicians in the present sample, 17 of whom had referred two or more patients.

For the Primary care sample, the number of symptoms experienced during the past month was tabulated, as was the number of these symptoms discussed with the doctor during the current visit or during any visit within the past year. Figure 1 shows that a high percentage of participants experienced symptoms but that fewer than half discussed these symptoms with

TABLE 1 Participant characteristics, sleep disorder symptoms and symptoms discussed with a doctor

	<i>n</i>	Age Mean (SD)	Female to male Ratio	Total symptoms (of 21) Mean (SD)	Total symptoms discussed Mean (SD)
Sleep clinic	138	52.9 (11.9)	0.6:1	13.1 (4.5)	5.1 (4.6)
Primary care					
Completers	26	67.1 (10.6)	1.0:1	10.6 (4.9)	3.9 (5.0)
Dropouts	20	70.8 (11.7)	0.8:1	4.8 (3.8)	1.2 (2.4)
Decliners	150	70.4 (9.9)	2.2:1	5.4 (4.2)	1.9 (2.8)

their doctor. Chi-square tests on the Have and Discussed data for each symptom showed that these were all significantly different (Chi-square values ranged from 17.0–58.4, $P < 0.0001$). Examination of responses to an open-ended question showed that none of the 196 participants were referred for further sleep evaluation by their doctor.

Figure 2 shows the mean number of symptoms discussed with the primary care physician by Primary care Decliners, Dropouts and Completers, as well as the mean number discussed by Sleep clinic patients with their referring physician. Sleep clinic participants had discussed significantly more symptoms with their referring physician than had Primary care Dropouts or Decliners on all subscales with the exception of psychological distress [$F(12, 978) = 9.71, P < 0.0001$]. Primary care Completers did not differ from Sleep clinic patients on the number of insomnia symptoms discussed. However, Primary care completers discussed significantly fewer symptoms than Sleep clinic subjects on the Sleep disorder subscale. Because there was a significant age difference between the Primary care and the Sleep clinic samples, we repeated the analyses to account for this: ANCOVA, with age as the covariate, did not change the overall pattern of findings nor did repeating the ANOVAs, selecting only participants aged 55 and older from the Sleep clinic sample.

Finally, we compared the body mass index (BMI) and PSG respiratory distress index (RDI) results for the Primary care Completers (BMI = 28.5, RDI = 31) and for Sleep clinic participants (BMI = 30.1, RDI = 21.7). Primary care Completers and Sleep clinic samples did not differ significantly on these variables, though the 10-point spread on RDI suggests that the Primary care completers have a clinically more severe apnoea index. Similarly, on completion of the PSG,

80% of the Sleep clinic sample and 88.5% of the Primary care Completers have PSG findings exceeding the diagnostic cut-offs for SAHS and/or periodic limb movement disorder.

Discussion

Substantial numbers of older men and women patients in our Primary care sample reported having a wide range of sleep disorder-related symptoms; relatively, few had discussed these symptoms with their doctor within the prior year. The hallmark SAHS symptoms, daytime sleepiness and snoring, were well represented in this sample but were discussed by fewer than half of these patients during the previous year. We identified a small subset of patients (Completers), who were not only willing to spend a night in the sleep lab but also who were subsequently found to have high rates of SAHS. These patients endorsed more symptoms (and more sleep disorder symptoms) than the rest of the Primary care sample. They had also reported discussing more symptoms with their doctors yet did not get referred for further sleep disorder evaluation. So, what distinguishes the Primary care patients from the sample of Sleep clinic patients who were referred by their doctors?

The Sleep clinic patients appear to get to the point more effectively. Though overall, they reportedly both experienced and discussed more symptoms with their referring physician, they also presented more specifically sleep disorder-related symptoms than did the Primary care Completers. The two groups were similar in the number of symptoms reported in the Insomnia and Daytime distress categories. Our findings suggest that some Primary care patients who have significant SAHS complain of insomnia and daytime complaints rather than of the more recognizable sleep disorder signs.

Our study offers insight into why some patients with sleep disorder risk are recognized in primary care while others are missed. However, it must also be taken into account that the clinical context in the typical patient visit to his or her family physician is complex. One must also consider that the present data are based on retrospective self-reports and that these are only from the patient's perspective.

Recent literature has suggested that the primary care setting falls short in recognizing sleep disorder, citing the insufficient emphasis on sleep medicine in medical schools or in continuing education,^{16–18} resulting in under-referral. At the same time, Canadian hospital-based sleep clinics (i.e. publicly funded), as noted for similar clinical settings in Europe,³⁰ tend to have very long wait times. It is notable that about 2/3 of patients we sampled from the sleep clinic had been referred by their family physician; the rest coming from other medical specialties. The referring family doctors in this sample are doing their part to keep

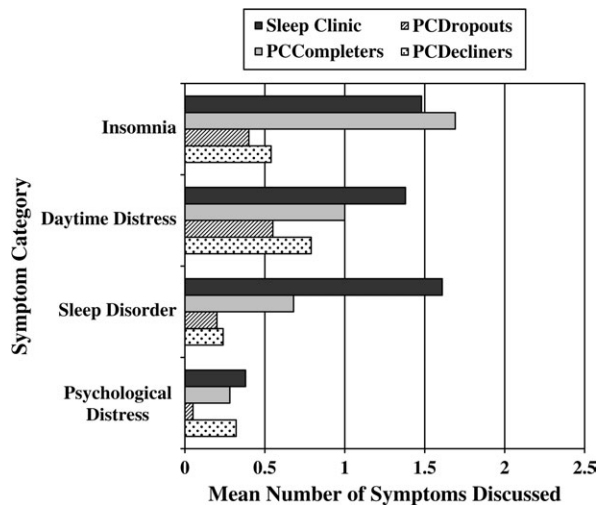


FIGURE 2 Mean subscale score of symptoms discussed with the Primary care or referring physician for Primary care Decliners, Dropouts and Completers and Sleep clinic patients

sleep clinics busy, with an impressive 80% hit rate for SAHS and/or periodic limb movement disorder diagnosis. However, the Primary care sample results suggest that there are possibly many more patients in need of referral and that sleep clinics need to become even busier, in spite of the cost of a lower hit rate for sleep disorder diagnosis.

Limitations of the study include the fact that the final number of Completers in the Primary care sample was low and represented only 13% of the total sample. Without PSG assessment, it is impossible to know what rate of sleep disorders exist in the Decliners subgroup who generally reported lower rates of symptoms. It is possible that, because physicians were not involved in recruitment process, patients with a less severe symptom profile may have been reluctant to pursue what may seem a time consuming and inconvenient assessment. We are currently evaluating this possibility in a study that is presently underway involving the participation of physicians in the recruitment process.

Wilson and Jungner³¹ have proposed 10 criteria to assess the justification for disease screening programmes. Accordingly, sleep apnoea screening is justified since it is a widespread and significant health problem, with an effective and recognized treatment and well-developed protocols for treatment decisions. The burden to the health care system of untreated sleep apnoea, with its pernicious risk factors, outweighs the costs of evaluation and treatment for any individual patient. However, a widely applied screening programme involving older patients, for example, who have a high likelihood (up to 60%) of sleep disorder, would be impossible to accommodate in the Canadian public health care system because of the cost of the overnight PSG procedure and the limited sleep laboratory facilities that exist at present. The brief SSC, while at present neither a screening nor a diagnostic instrument, appears to have potential to identify some patients with sleep disorders risk, who could be guided towards appropriate screening. Of particular interest is the finding that there was almost a one-to-one ratio between women and men among the high-risk Primary care Completers versus the 0.6–1 found for the Sleep clinic sample. This suggests that the SSC can help identify more women who have unrecognized sleep disorders. We are presently modifying the SSC for use as a clinical instrument that will highlight relevant symptoms, promote discussion between doctor and patient and, ultimately, increase appropriate referral for further sleep disorder evaluation.

Declaration

Funding: Canadian Institutes of Health Research (MOP-77816).

Ethical approval: The protocol for the study was reviewed and approved by the Research Ethics Committees of both McGill University and the Mount Sinai Hospital of Montreal.

Conflict of interest: none.

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