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The impact of narcolepsy on psychological health and role behaviours: negative effects and comparisons with other illness groups.

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ABSTRACT

Adjustment to an illness can be conceptualised in terms of people's ability to adequately function in their life roles (eg worker, spouse, parent and friend). The PAIS-SR questionnaire assesses psychosocial adjustment across seven domains and was investigated in a sample of people with narcolepsy in relation to age, gender, the disruptive effects of symptoms and medication status. Participants (n=129) were recruited via the Australian narcolepsy support group and questionnaires were distributed and received by post. Males were found to be more vulnerable than females in terms of adjustment, and younger narcoleptics may have particular problems in the vocational environment. Those patients taking no medication for narcolepsy were least inclined to participate in social and leisure activities. The level of disruption reported due to symptoms was strongly associated with both psychological distress and overall psychosocial adjustment and was most notable in those taking both stimulants and tricyclic antidepressants. Narcoleptics reported more adjustment problems in comparison to three other illness groups (cardiac, mixed cancer and diabetes), with particular differences in health care orientation and psychological distress. A table of normative PAIS-SR values for narcolepsy was developed from this sample. The high levels of psychological distress found in this study are of particular concern, suggesting there is an urgent need for health professionals to provide support for adjustment problems experienced in narcolepsy across a variety of life roles. The need for action in several areas is discussed.

Key words: narcolepsy, psychosocial adjustment, medication, psychological health.

INTRODUCTION

There is a growing body of literature on how the main symptoms of narcolepsy, especially chronic excessive daytime sleepiness, impact on a person's life. The first major questionnaire study in this area, using patients across three continents [1], reported very significant detrimental effects in virtually all areas of functioning including job performance, education, household /occupational /driving accidents, interpersonal interactions, mood, leisure activities and memory. These findings have been replicated and expanded upon in a range of subsequent studies [eg 2,3]

While the detrimental effects of narcolepsy are consistently reported, the global terms used to describe research in this area have been various and sometimes used interchangeably; for example quality of life, life effects, coping, psychosocial impact and psychosocial adjustment. The instruments used to assess functioning have often been created specifically for the narcolepsy patient group, although some generic tools have been used to assess more specific psychological components such as self-esteem [4], social distance[5], metamemory[6], and depression [7]. Studies using the former, specifically constructed tools, have been important for describing illness specific effects as perceived by the narcoleptic but have methodologies which limit the comparison of studies within the narcolepsy population and across different illness groups, and unknown psychometric properties [8].

An important, well recognised way of conceptualising illness impact relates to patients' abilities to adequately fulfil their salient role behaviours, such as their vocational role as a worker, their domestic role as a spouse and/or parent and their roles in social and leisure activities [9]. The lack of supportive social relationships is increasingly recognised as a major risk factor for health [10]. Thus in assessing how a person is adjusting to a serious, chronic, lifelong disorder such as narcolepsy, it is most pertinent to assess his/her adjustment within their immediate daily environment. The Psychosocial Adjustment to Illness Scale - Self

Report (PAIS-SR) [9] was developed to assess response to illness via a patient's self-report of illness impact with a focus on key role behaviours. The tool assesses adjustment within seven domains: Health Care Orientation, Vocational Environment, Domestic Environment, Sexual Relationships, Extended Family Relationships, Social Environment and Psychological Distress. It has been widely used over the last decade with a variety of illness cohorts and has established reliability, construct validity, convergent validity, predictive validity and published norms for a variety of specific illness groups [9,11].

An assessment using such an approach has not previously been published with respect to narcolepsy. The advantages of using a standardised tool with established psychometric properties for various illnesses is that it facilitates quantitative comparisons with other variables and enables ready comparison with values reported by other illness groups. Once PAIS-SR norms for narcolepsy are established, the adjustment of particular patients can be compared with group values and comparisons for research purposes facilitated.

The aim of the present study was to use patient self-reports to assess psychosocial adjustment, (as yielded by the PAIS-SR in terms of a total score and within the seven domains), disruption due to symptoms, and medication problems. How these dependent variables changed with gender, age and medication status was investigated as well as the interrelationships between the dependent variables. The scores on the PAIS-SR for the narcolepsy sample were also compared with the scores from three other illness groups across the seven domains of psychosocial functioning and a table of normative values for a narcolepsy sample was created.

METHOD

Subjects and Procedure

The questionnaire package was posted to 213 people who had (a) contacted the Australian narcolepsy support group (NODSS), (b) self-reported they had diagnosed narcolepsy and (c) indicated a willingness to be involved in research. One follow up phone call was made to recipients who had not returned the package within three weeks. Of the 147 returns received (69% response rate), 18 were eliminated because the responses regarding clinical history of narcolepsy did not indicate a history of cataplexy (from minor to severe), or the person had not been diagnosed by a medical specialist. The final sample consisted of 57 males and 72 females (total =129). The mean age was 52.8 years (SD = 13.8), with an age range of 18 to 81 years. The vast majority (78%) had been diagnosed with narcolepsy for at least five years. Of the respondents, 84 were married, 19 separated or divorced, 17 never married and eight widowed (and one unknown). In terms of educational attainment, 69 left school before year 11, 45 had completed a technical, trade or university course, 14 had completed year 12 and one was currently studying.

Questionnaires

The questionnaire package consisted of two parts.

Part 1: This included questions about demographics, clinical and diagnostic history, health status, medication intake, Epworth Sleepiness Scale (ESS) and a series of questions that yielded several dependent variables. These latter variables were created by averaging a series of related questions which referred to the last two weeks and all required a rating from 1 (not at all or never) to 5 (completely or always). All symptoms were carefully described in detail within the question as relevant.

- ◆ *Day Disruption* consisted of three questions on the extent to which daytime sleepiness/cataplexy/automatic behaviours reduced ability to carry out daily activities, plus one

question on frequency of hallucinations while awake. Questions related to the last two weeks and subjects were told that medication intake was irrelevant in making their assessments.

- ◆ *Night Disruption* comprised three questions on impact of nocturnal sleep disturbance/sleep paralysis/ nightmares. Again, questions related to the last two weeks and subjects were told that medication intake was irrelevant.
- ◆ *Stimulant Medication Problems* consisted of two questions about stimulant effectiveness in controlling daytime sleepiness and the extent of unpleasant side effects.
- ◆ *Tricyclic Antidepressant Medication Problems* consisted of two questions about the effectiveness of this medication in controlling cataplexy/sleep paralysis/hallucinations and the extent of unpleasant side effects.

As all the questions within the above variables were averaged, the score on each varied from one to five with five indicating more severe problems (some scoring was reversed to achieve this).

Part 2: The second part consisted of the PAIS-SR, a 46-item questionnaire [11], divided into seven sections (each being a domain as described below). Each item was in the form of a four choice multiple-choice question such as " How much has your illness interfered with your work and duties around the house?" with choices varying from "not at all" to "severe difficulties with household duties". The domains covered the following issues:

- ◆ *Health Care Orientation* questions related to patient's attitude to health care in general, perceptions of health care professionals, quality of health care information and the nature of the patient's expectations about the disorder and its treatment.
- ◆ *Vocational Environment* (indicates work, school, home as most appropriate) evaluated perceived quality of vocational performance, vocational satisfaction, lost time, vocational interest and issues associated with the quality of adjustment in the work sphere.
- ◆ *Domestic Environment* questions covered adaptation problems by patient and family in response to the illness, aspects of family living, financial aspects of the illness, quality of relationships, family communications and effects of physical disabilities.
- ◆ *Sexual Relationships* assessed quality of interpersonal relationships, sexual interest, frequency, quality of performance, level of satisfaction.
- ◆ *Extended Family Relationships* used the framework of typical interactions with extended family to assess any negative impact of the illness upon communication, quality of relationships, interest in interacting with the family and help expected/needed and received.
- ◆ *Social Environment* asked about current interests and actual participation in social and leisure activities including individual, family and social categories and an assessment of constrictions due to illness.
- ◆ *Psychological Distress* focused on recent dysphoric thoughts and feelings including evaluations of anxiety, depression, irritability, worry over illness, self-esteem, body image and inappropriate guilt.

Data analysis

(1) Reliability

As the PAIS-SR has not previously been used in a narcolepsy sample the internal consistency of the questionnaire (across all seven domains) was checked for this illness group using Cronbach's alpha and a high degree of reliability was found (0.863).

(2) Dependent variables

The dependent variables were initially grouped as follows:

- (a) SYMPTOMS: Epworth Sleepiness Scale (ESS); Day Disruption; Night Disruption
- (b) MEDICATION PROBLEMS: Stimulant Problems; Tricyclic Antidepressant Medication Problems
- (c) PAIS-SR VARIABLES: seven PAIS-SR domains as described above

A series of Pearson correlations were performed within each variable grouping to check that the variables correlated and hence should be grouped for subsequent MANOVA analyses. All variables within a group correlated at $p < .05$ except for the ESS which was consequently removed from the first group. The PAIS-SR Total was not included in the third group as it was not independent of the other PAIS-SR domains.

(2) Comparisons of variable mean values

The research question being pursued with the following analyses was whether the variables listed above changed as a function of gender, age and medication status. Each of the three variable groupings was analysed using a number of MANOVAs (Hotelling's t) where the independent variables were gender, age and medication status. Age was operationalised to form two groups: one aged under forty years of age ($n=20$) and one for those forty and over ($n=109$). Medication status was grouped in terms of medication taken for narcolepsy symptoms only: No medication currently taken ($n=24$); Stimulant medication only currently taken ($n=51$); Stimulant + tricyclic antidepressants currently taken ($n=46$). The eight subjects taking tricyclics only were not included in the medication status analyses. For inferential statistics an alpha of .05 was set.

(3) PAIS-SR Total Score

The PAIS-SR Total was calculated by summing the domain raw scores and this total was considered in relation to categories of good, fair and poor psychosocial adjustment as developed previously [12,13]. PAIS-SR Total scores were analysed using one-way ANOVAs where it was of interest to see how the scores differed with gender, age and medication status.

(4) Correlations

Another question of interest was whether important relationships existed between the PAIS-SR variables and the Symptom and/or Medication variables described above. To ascertain this a series of Pearson correlations were performed between the Symptom and Medication Problems variables against all the PAIS variables. For these analyses alpha was set at .01.

(5) Comparisons across illness groups and norms

The PAIS-SR scores obtained by the current sample were compared to scores obtained by three other illness groups published in the PAIS-SR manual [11]. For the narcolepsy sample, mean summated scores on each of the seven PAIS-SR domains were compared with raw scores obtained where the T-score equalled 50 in the tables of norms of four other illness groups [11]. As T-score conversions for the PAIS Total score were not available for the other illness groups, a different method was used to obtain an overall mean value, with the seven PAIS-SR domain scores within each illness group being averaged.

Key details of each illness group are set out below (for further details see 11).

Cardiac: 170 patients, mostly married white males, suffering from coronary artery disease, pre-operative for coronary bypass surgery. Duration of illness ranged from 2 to 156 months with a median of 12 months. Mean age was 53.6 years (9.6).

Mixed Cancer: 114 patients with a diagnosis of a variety of cancers, typically being treated with surgery or chemotherapy. Two-thirds of the sample were female, most were married and almost all white. Mean age was 53.1 years (13.4).

Diabetes: 99 individuals suffering juvenile onset, insulin dependent diabetes. Patients were participating in a national trial of an innovative glyceimic control regimen. Sixty four percent were female, almost all white, and the mean age was 32.5 years with little variation.

The table of normative PAIS-SR values for the current narcolepsy sample contains McCall's T scores obtained using linear transformation.

RESULTS

All means and standard deviations of variables where significant differences between means were found are displayed in Table 1.

Table 1. Mean values (and standard deviations) of selected symptom variables and all PAIS-SR domains as a function of gender and medication status.

	Males	Females	No medication	Stimulants only	Stimulants + Tricyclics
n ¹	57	72	24	51	46 ²
ESS /24	17.91 (5.3)	17.33 (4.4)	17.63 (5.4)	17.27 (4.7)	17.34 (5.5)
Day disruption /5	3.77 (2.4)	3.59 (2.5)	3.39 (2.2)	2.85 (2.1)*	4.45 (2.2)*
Night disruption /5	3.45 (3.2)	3.42 (2.7)	3.08 (2.2)	2.42 (3.0)*	4.34 (2.8)*
Health care orientation	10.61 (4.3)*	8.81 (3.7)*	11.42 (4.4)	9.0 (3.6)	9.7 (4.2)
Vocational environment	5.23 (4.1)	3.95 (4.8)	4.84 (2.9)	4.08 (5.1)	4.90 (4.6)
Domestic environment	7.25 (4.9)	5.56 (4.8)	6.95 (3.3)	5.64 (5.68)	7.04 (4.6)
Sexual relationships	6.04 (4.8)*	3.16 (4.7)*	4.16 (5.3)	3.88 (4.4)	5.57 (5.4)
Extended family rel.	2.67 (3.2)	1.71 (2.3)	2.0 (2.6)	2.51 (3.2)	2.04 (2.5)
Social environment	6.44 (5.4)	6.03 (5.5)	8.36 (6.2)*	4.77 (5.2) *	6.71 (5.2)*
Psychological distress	7.36 (5.0)	7.58 (5.4)	6.89 (4.7)	7.86 (5.2)	7.80 (5.5)
PAIS Total	45.32 (23.6)#	37.19 (22.8)#	43.45 (21.3)	38.19 (24.9)	44.11 (23.6)

* p<.05 # p<.10 (see text)

¹ Numbers may vary in different analyses owing to some missing data.

² Those 8 subjects taking auxiliary medication only were not included in these analyses.

Gender

Analyses involving all the PAIS-SR domains yielded a significant difference between males and females (MANOVA $F(7,104)=3.36, p=.003$). Univariate analyses showed that males reported more problems with Health Care Orientation ($p=.019$) and more difficulties with Sexual Relationships ($p=.002$) than females. There was a trend for the PAIS-SR Total score to indicate more adjustment problems for males than females ($F(1,114)=3.5, p=.06$).

There were no significant differences between male and female scores for Day and Night Disruption or for Medication Problems.

Age

There were no significant differences between the under and over 40 year age groups in terms of Day and Night Disruption, Medication Problems or PAIS-SR scores. A Pearson correlation showed a moderate correlation between age and the Vocational Environment PAIS-SR domain, whereby younger narcoleptics had more vocational adjustment problems. ($r=.30, p=.01$).

Medication Status

A significant difference was found between the three medication status groups (No Medication, Stimulants only, Stimulants + Tricyclics) across the seven PAIS-SR domains (MANOVA $F(14,196)=2.38, p=.004$). Univariate analyses found that only the Social Environment scores differed significantly with medication status ($p=.042$). Post-hoc tests showed that the Stimulant medication group had lower (better adjusted) Social Environment scores than the other two groups (Stimulants versus No Medication, $p=.038$; Stimulants versus Stimulants +Tricyclics, $p=.047$). PAIS-SR Total did not differ significantly with medication status.

An overall significance between the three medication status groups on the Day and Night Disruption variables (MANOVA $F(4,226)=3.892, p=.004$) was found. Univariate tests showed both Day Disruption ($p=.002$) and Night Disruption ($p=.005$) differed with medication status. Post-hoc analyses showed that the Stimulants group differed significantly from the Stimulants +Tricyclics group ($p=.002$) on both disruption variables with the Stimulants group reporting less disruption.

PAIS-SR Total Score

For the entire sample a mean PAIS-SR Total score of 40.90 (standard deviation of 23.48) was found. Previous studies [12,13] have used descriptive categories wherein a score of 0-35 indicates '*good*' adjustment, 36-51 '*fair*' adjustment and a score of over 52 being described as showing '*poor*' psychosocial adjustment. Using these categories it was found that 31.9% of the narcoleptics fell within *poor* adjustment and 19.8% *fair*. Less than half (48.3%) scored within the *good* category.

Correlations: Psychosocial Adjustment, Disruption and Medication Problems

Table 2 shows that the Day Disruption scores correlated positively and highly significantly, with a medium effect size ($r>.3$), with the majority of the PAIS-SR domains, while the correlations with the Psychological Distress and PAIS-SR Total variables approached a large effect size ($r>.5$). The Night Disruption scores correlated more selectively with the PAIS-SR domains and most correlations, while highly significant, were in the medium range. In addition, highly significant correlations were noted between reported medication problems and several PAIS-SR domains and the PAIS-SR Total. The PAIS domains of Domestic

Environment, Extended Family Relationships and Psychological Distress were noteworthy in the consistency of their correlations with the disruption and medication problem variables. It was found that ESS was not significantly correlated with any other variable assessed in this study.

Table 2. Significant Pearson correlation r values between PAIS-SR domains and symptom and medication problem variables (n=129)

PAIS Domains	ESS	Day Disruption	Night Disruption	Stimulant Medication Problems	Tricyclic Medication Problems
Health care orientation		.25 **	.29 ***		.33 **
Vocational environment		.32 ***			
Domestic environment		.44 ***	.38 ***	.30 **	.43 ***
Sexual relationships		.29 ***		.31 **	.35 **
Extended family rel.		.24 **	.31 ***	.33 ***	.39 **
Social environment		.37 ***	.32 ***	.24 **	
Psychological distress		.49 ***	.40 ***	.26 **	.41 ***
PAIS Total		.48 ***	.42 ***	.32 ***	.43 ***

** p<.01, ***p<.001

Comparisons of adjustment in different illnesses

Comparisons of PAIS-SR norms across four illness groups are shown in Figure 1. The narcolepsy group had a higher 'mean' total psychosocial adjustment score than the cardiac, mixed cancer or diabetes groups. Within the seven PAIS-SR domains the main comparative findings are that narcolepsy patients had much higher negative Health Care Orientation scores, more Psychological Distress and more Extended Family Relationship problems than all the other illness groups. Narcoleptics were more poorly adjusted than Mixed Cancer or Diabetes patients in all seven domains but had less problems than cardiac patients in Vocational Orientation, Domestic Environment and Sexual Relationships.

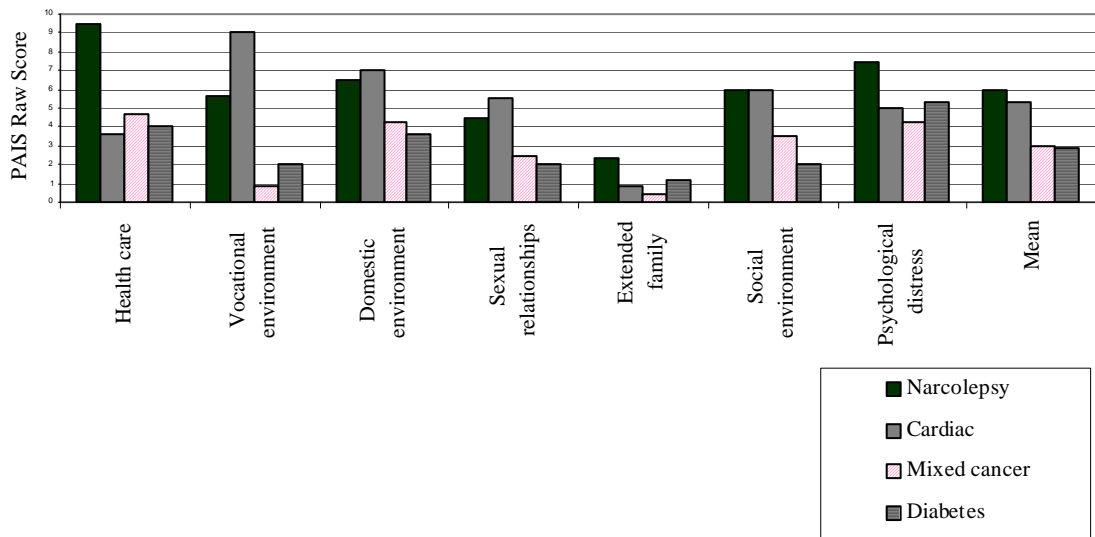


Figure 1: Comparison of normative values for P AIS-SR domains across four illness groups. Higher raw scores indicate poorer adjustment.

Table 3 contains the normative values (McCall's T-scores) for the narcolepsy sample with a score of 50 representing the mean.

Table 3. P AIS-SR Domain T-Scores for narcolepsy patients (n=129)

Domain	Raw Scores	Health Care	Vocational Environ	Domestic Environ	Sexual Relations	Extended Family	Social Environ	Psychological Distress
1	29	37	38	42	46	40	38	
2	31	40	40	45	45	42	40	
3	34	43	43	47	53	44	42	
4	36	46	45	45	57	46	44	
5	39	49	47	51	60	48	45	
6	41	52	41	53	64	50	47	
7	44	55	51	55	68	52	49	
8	46	58	54	57	71	54	51	
9	49	61	56	59	75	56	53	
10	51	64	58	61	79	57	55	
11	53	67	60	63	82	59	57	
12	56	70	62	65	86	61	59	
13	58	72	65	67	89	63	61	

14	61	75	67	70	93	65	63
15	63	78	69	72	97	67	65
16	66		71	74		69	67
17	68		73	76		71	69
18	71		76	78		73	71
19	73		78				
20	76		80				
21	78		82				
22			84				

DISCUSSION

This study found a clear trend for males with narcolepsy to report more overall psychosocial adjustment problems than females (PAIS-SR-Total score). In addition, males reported significantly more problems in the domains of Health Care Orientation and Sexual Relationships than females. Reports of gender differences in the life effects of narcolepsy are rare with no differences being reported, for example, in self-esteem [4], depression [14], a range of psychological indices [15] or life effects [16]. In the present sample males were clearly more dissatisfied with their health care than females. The main focus in this domain is their views on the quality of their health care, access to information and the availability of effective treatment.

With regard to the quality of sexual relationships, male erectile problems in narcolepsy are well documented [17] and are usually attributed to the side effects of antidepressant medication. However, previous questionnaire studies have been inconclusive about gender differences in sexual relationship problems. Kales and colleagues [15] reported that more females (36%) than males (14%) reported sexual difficulties in their sample of 50, while a study involving 180 patients [16] found no gender differences in reports of sex drive changes. Over a third of the respondents in a later study reported that narcolepsy had negative effects on their sex life with impotence in males being the most widely reported problem [2]. The current finding of clear gender differences in the reported quality of sexual relationships may arise from the comprehensive nature of the six questions in this domain. Alternatively it may be related to the apparent older age of the current sample than in previous questionnaire studies, wherein perhaps gender differences in sexual difficulties manifest themselves more with age.

The problems that narcolepsy symptoms can cause in the work sphere have been well documented [1,2], as have their higher unemployment rates [3] but this is the first study to show that younger narcoleptics have more vocational adjustment problems than older patients (moderate correlation). The question arises as to whether this is related to symptom severity or older patients finding / creating a vocational environment that is more accommodating to their symptoms. Although there were no indications that symptom severity may decrease with age across the group in the current study, there is some indication in the literature that this may be the case [2] and this is consistent with anecdotal evidence obtained by the author from some

people with narcolepsy. Whatever the reason for the association between age and vocational adjustment, clinicians should be aware that younger narcolepsy patients might have particular difficulties adjusting to their work environments. Because of the importance of role perceptions [9], vocational maladjustment carries a substantial risk of concurrent psychological problems. Indeed Merritt [14] found that younger narcoleptics were more prone to depression than older patients.

Medication status (as relates to medication for narcolepsy) was important in self-reported adjustment within the Social Environment domain. The No Medication group were less likely to be interested in, and participate in, leisure and social activities since the onset of their illness than the two groups on medication. The group taking stimulants only reported higher levels of social adjustment than the group taking both stimulants and tricyclics (likely to have more severe symptoms) or the unmedicated patients. While the data suggests that the No Medication group is less inclined to social/leisure activities, there is no evidence that they are more psychologically distressed or maladjusted. Perhaps such patients find that, while being unmedicated limits their social activities, this is not an important issue for them.

The Day and Night Disruption variables asked about the extent to which a variety of symptoms reduced their day activities or the achievement of a good night's sleep over the previous two weeks. Medication intake was irrelevant in answering these questions, with evaluations of typical functioning being sought. It was found that the reported severity of disruption due to symptoms was related to their medication status with the Stimulants + Tricyclics group reporting significantly more problems than the Stimulants only group. (The values for the No Medication group fell between the two medication groups). Thus those with auxiliary symptoms requiring management with tricyclic medication reported more disruption to their normal day and night activities and, clearly, their medication was limited in its effectiveness. This is consistent with other reports of those with cataplexy having more problems [18] and medication limitations [19]. One study [2] noted that nearly half of the sample of 100 tolerated some symptoms because they did not want to increase the medication side effects, while a large number reported minimal or no improvement with drug therapy.

The reported level of disruption of day activities due to symptoms was strongly associated with Psychological Distress and the PAIS-SR Total Score. Night Disruption was also related to these two PAIS-SR variables at a more moderate level. As Psychological Distress assesses negative affect, these results are consistent with reports of symptom severity being associated with higher depression scores [14] and reduced self-esteem [4]. Many moderate level correlations were found between the variables associated with psychosocial adjustment and disruptions due to narcolepsy symptoms or medication problems. Psychological Distress and PAIS-SR Total were the main psychosocial variables to show such associations, while the domains of Domestic Environment and Extended Family Relationships were also important. The latter indicates that patients whose activities were more disrupted by symptoms and/or experienced problems with their medication were more likely to be dissatisfied in areas including relationships in the immediate and extended family, family support and their fulfilment of household duties. The ESS score (subjective sleep propensity) did not correlate significantly with any PAIS-SR variable (or indeed with the Day and Night Disruption scores). The mean ESS value was almost identical to the value obtained by Johns [20] on a small group of narcoleptics and within the range reported on 183 narcoleptics [19].

The self-report nature of all the variables in this study means that there was no objective measure of symptom severity. It is possible a patient who was having difficulties adopted a

'response set' that resulted in many life problems being attributed to symptoms and this may not be consistent with an objective measure of symptom severity. The objective assessment of narcolepsy severity is problematic, wherein the Multiple Sleep Latency Test (MSLT) is insufficiently sensitive to severity variations [21] and the Maintenance of Wakefulness Test (MWT), while being potentially more useful, is inconsistent in evaluating treatment effects [22]. Actigraphy may be valuable [23] but requires more extensive evaluation. Given the lack of correlations of the Day and Night Disruption scores with the ESS in the present study, and the recent report that the ESS does not measure the same parameter of sleepiness as the MWT in narcolepsy [24], perhaps the three different assessment approaches; subjective propensity to fall asleep (ESS), objective ability to maintain wakefulness (MWT) and subjective assessments of life disruptions due to symptoms are unrelated. If so to what extent are factors such as patient personality, self efficacy, locus of control and 'resilience' factors of greater importance than objective symptom severity in determining illness impact? Further narcolepsy research that adopts the methods of health psychology is required to answer such questions.

In comparison to the three other illness groups for which PAIS-SR values were available, narcoleptics reported more psychosocial adjustment problems. The diabetes and mixed cancer groups Total PAIS-SR score fell into the *good* category of adjustment, while the cardiac group was borderline between *good* and *fair* (extrapolating from the mean values in Figure 1). For the narcoleptics, however, the mean Total PAIS-SR score and single largest number of respondents (31.9%) fell into the *poor* psychosocial adjustment group. There is only one published study that compares the life effects of having narcolepsy with another disorder, wherein it was found that narcolepsy had a greater overall psychosocial impact than matched patients with epilepsy [25]. The present pattern of results suggests that Health Care Orientation clearly has significant room for improvement with this group of narcoleptics. As noted earlier this domain focuses on health care quality, illness information and availability of effective treatments. The dissatisfaction found might be a particularly Australian phenomenon and, as awareness of neurologically based sleep disorders grows among the medical profession and community, these problems may diminish. Both the Health Care domain scores and the Medication Problem scores highlight the need for practitioners to engage in detailed discussions and monitoring of treatments with narcolepsy patients and reinforces the desirability of a choice of affordable and efficacious narcolepsy treatments on the local market. The other domain that was particularly high for narcoleptics was Psychological Distress. Affective problems in narcolepsy have been documented for two decades [14, 18, 26] with an early study [15] suggesting that the psychopathology that may coexist with narcolepsy is an effect of the disorder, not a cause. Consistent with this, the current data shows that reported disruption due to symptoms is highly significantly correlated with psychosocial adjustment across all domains.

It is intended that the table of PAIS-SR normative values for narcolepsy be used for comparative research purposes, including longitudinal studies and also by health professionals wishing to evaluate the adjustment of individual patients in comparison with the group data documented here.

The patients who elected to participate in this study were self-selected in two important ways. Firstly, they were all people who had contacted the Australian narcolepsy support group and secondly, they were sufficiently motivated to complete and return a lengthy questionnaire (a task that is not easy for some with severe symptoms). Contacting the support group may result in being more knowledgeable about the disorder which may have beneficial effects in terms of one's ability to cope, or, alternatively, may mean that those patients with more problematic

adjustment problems and a greater need for support are the ones to make contact. Demographic details regarding ethnicity were not collected but anecdotal evidence suggests that non-Anglo ethnic groups are under-represented among the people who contact the Australian narcolepsy support group, compared to their representation in the community. (Indigenous people and immigrants from Greece, Italy and Vietnam are major ethnic groupings within Australia.) It should also be noted that in the current sample older narcoleptics are over-represented with only 15% being under 40 years of age. The ability to generalise results from this sample to a wider population of narcoleptics may be limited by the above factors.

In conclusion, the current study clearly indicates that narcolepsy can have a deleterious impact on psychological health and adjustment in salient role behaviours. Narcolepsy was associated with psychosocial adjustment problems of greater magnitude than that found in three other illness groups. The findings suggest a need for action in several areas. Firstly, the high level of reported psychological distress suggests a need for access to counselling services and Goswami [27] argues the case well for an integrative socio-medical model of counselling to be readily available for people diagnosed with narcolepsy. This is best achieved via a multidisciplinary support team that caters for medical, psychological and socio-environmental aspects of care. The overall health care needs of this group were not being well catered for, with the participants expressing dissatisfaction with the quality of care provided, access to information and treatments not meeting expectations. Hopefully, this finding will become dated as the practice of sleep medicine grows in Australia. In this regard it is encouraging that a national system of accreditation of sleep disorder specialists has been implemented in 1999, after this data was collected. It is also important that the typical location of sleep clinics within Departments of Respiratory Medicine in Australia does not mean that the expertise of specialists with knowledge of neurological sleep disorders is unavailable to those with narcolepsy. Not only do sleep specialists need to be well trained, they need to take extra time to discuss key issues with their patients, especially where they are newly diagnosed or having difficulties with their treatment. Awareness of potential treatment side effects such as sexual dysfunction and mood swings can be important for promoting positive marital and family relationships [26]. The patient needs to have realistic expectations about how well the disorder may be managed and be made aware of all the available options, including behavioural techniques of management [29]. As many general practitioners may have only one or two narcoleptics within their practice they are unlikely to be well informed about the disorder and may not be in the best position to meet the ongoing needs of the patient. Narcolepsy support groups can play an important role in providing information to patients and links between these groups and health professionals should be encouraged. A second area for action is the pursuit of opportunities to increase the level of awareness in the community about sleep disorders in general so that daytime sleepiness is not trivialised. A high level of ignorance and a dismissive community attitude towards sleep and sleepiness as a potential problem not only leads to significant delays in diagnosis, but can create an unsympathetic environment within the extended family, workplace, school and the general community. Clearly, this will impact negatively on a patient's psychological health and psychosocial adjustment.

Narcolepsy is an 'invisible' illness. The patient does not look sick or have a physical problem that is obvious or can be easily physiologically explained. Their illness does not have a high profile, there are no big community awareness campaigns about narcolepsy (despite it being more prevalent than multiple sclerosis or autism). People with narcolepsy look healthy but engage in what is a normal behaviour- sleeping- inappropriately and abnormally. This study, with its comparison of narcolepsy with three other serious illness groups, suggests that these

patients need extra efforts to facilitate optimum adjustment to living with the consequences of their disorder.

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