Psychological aspects of adductor spasmodic dysphonia: a prospective population controlled questionnaire study

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Objective: To examine psychosocial concomitants, illness perceptions, and treatment perceptions in patients with adductor spasmodic dysphonia.

Design: Prospective controlled cohort study.

Setting: A tertiary care facility.

Participants: Forty-nine out-patients (38 women, 11 men; average age of 52 years) with adductor spasmodic dysphonia completed a battery of reliable and validated psychometric assessment instruments. Control patients' data were derived from scores in questionnaires by samples in the formal Manuals of the questionnaires used.

Main outcome measures: Psychosocial functioning, illness perceptions, and treatment perceptions.

Results: Scores on psychosocial measures were elevated in male patients especially, indicating levels of psychological morbidity significantly above those seen in the general population. Assessments of illness perceptions and treatment perceptions indicated that patients perceive that they have a very low degree of control over the disorder, and experience a high emotional impact from it. Voice Handicap Index scores illustrated substantial degrees of perceived handicap.

Conclusions: Adductor spasmodic dysphonia is associated with significant negative psychosocial concomitants, coupled with low perceived control over the condition. Future research should elucidate the implications of illness perceptions and treatment perceptions for the biopsychosocial care of persons with adductor spasmodic dysphonia in order to improve self-management and enhance quality of life.

Adductor spasmodic dysphonia (AdSD) is a voice disorder, which expresses itself as sounds when speaking that are perceived as 'strain and strangle' sensations, by patients, their social environment and by physicians. Uncontrollable and abnormal contractions of involved muscles or muscle groups within the larynx are thought to be involved, as suggested by Pearson and Sapienza.[1] The voice quality of AdSD-patients varies over time. Medical treatment uses pharmacological treatment, where injections with botulinum toxin are the major approach. Patients with adductor spasmodic dysphonia represent a fascinating group in medicine. Their complaints vary, within and between patients, and over time; so do their responses to treatment, within and between patients, and over time. As is often the case in disorders where biomedical pathogenesis is incompletely understood, a number of psychiatric and psychological theories have emerged in an attempt to explain aspects of the causes and consequences of the condition, with much early theorising serving to stigmatise AdSD patients.[1] In modern medicine it is generally acknowledged that behavioural and cognitive factors are associated with any medical disorder, especially with regard to the way patients perceive symptoms, request medical help, and respond to treatment. As such, psychological factors can greatly influence the outcomes of medical management, such as quality of life (QOL).[2] Clinicians recognise how patients with identical 'objective' severity manifest a fascinating variety of subjective responses to illness.

Much previous research on such responses in AdSD has focused on generic psychological consequences, such the impact on self-reported QOL. In a qualitative study, Baylor et al.[3] found that AdSD patients cited personal, social, and physiological factors as affecting their QOL. Taking a more quantitative approach, Paniello et al.[4] and Rubin et al.[5] reported conflicting findings as to whether or not botulinum toxin injections contributed to enhanced QOL in AdSD patients. In general, the research to date has concentrated on outlining general psychological

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consequences both of AdSD, rather than considering more specific consequences relating to psychological or psychiatric morbidity. This results in the *first* aim of our study: to investigate whether specific negative psychological concomitants are associated with AdSD.

Another context in which psychological variables can be important in AdSD relates more to causal and moderating factors than to outcomes. In this regard, a recent subject of research has been to study patients' perceptions of their symptoms and of how their voice complaints are treated[6]. In such research, patients are seen as active problem-solvers who construct a set of cognitions and emotions about their disorder; these cognitions and emotions then guide coping behaviour, and thereby help determine treatment outcome. Whether patients' assessments are accurate and their cognitions and emotions 'medically correct' is largely irrelevant: the overriding influence on patients' responses is their perception of their situation.[2,7] 'Illness perceptions' has become the formal term used to denote the cognitive and emotional responses of persons trying to make sense of perceived symptoms. This paradigm has produced the 'Common Sense Model', a rather fruitful theory which was developed to offer clinicians and researchers a framework in which to understand and change illness perceptions, thereby improving both medical outcomes and quality of life.[2] In a similar vein, the term 'treatment perceptions' is used to refer to the idiosyncratic beliefs patients hold about treatment (medical, pharmacological, or psychological).[8,9] Further, intervening to modify illness perceptions and treatment perceptions has been shown to impact positively on outcomes in many medical conditions.[10] Our *second* aim, therefore, is to describe illness perceptions and treatment perceptions in our AdSD sample.

Materials and methods

Ethical considerations

The study was exempted from institutional review board approval because the questionnaires were administered as part of standard clinical care to assist treatment planning. The Research on Human Subjects Act in the Netherlands stipulates that 'completing a questionnaire does not generally bring a study within the scope of the Act' [http://www.ccmo-online.nl, accessed 8 July 2009].

Patients. From the outpatient clinic of the Department of Ear, Nose, and Throat Medicine (Leiden University Medical Centre), 49 consecutive patients with AdSD participated. All patients had received at least one injection with botulinum toxin before participating in the study. The

average age of the sample was 52 years (range 21–85 years); 38 patients were female, and 11 were male. The average period that patients had been receiving botulinum toxin injections for AdSD was 70 months (minimum 3, maximum 164 months). The average interval between the injections was 4 months (2 minimum, maximum 13 months). The main analyses of the present study required the comparison of means from our sample of 49 patients with previously published norms for samples ranging in size from 78 to 1074. As such, the present sample was sufficiently large to provide between 86% and 95% power to detect medium-sized between group differences.[11]

Measures. Psychological/psychiatric morbidity was measured using the Symptom Check List-90 (SCL-90).[12] This questionnaire is a self-report psychometric instrument, widely used in studies on patients in a medical setting to evaluate psychological problems and symptoms. It contains 90 items each of which requires the respondent to rate the rate of occurrence of a particular symptom over the previous 7 days on a five-point Likert scale (ranging from 'none' to 'extreme'). Items are distributed across nine primary symptom domains (somatisation; obsessive–compulsive; interpersonal sensitivity; depression; anxiety; hostility; phobic anxiety; paranoid ideation and psychoticism), with total ratings averaged to produce a 'global severity index'. Overall, the SCL-90 takes less than 20 min to complete. It is extremely widely used and has been thoroughly validated, with extensive population norms documented internationally.

Illness perceptions were assessed using the Brief Illness Perception Questionnaire (Brief IPQ), a nine-item instrument used to assess dimensions of perceptions about illness, which is designed to articulate with the Common Sense Model.[13] Treatment perceptions were assessed using the Beliefs about Medicines Questionnaire (BMQ), an instrument made up of 18 items designed to assess four categories of treatment perceptions.[8] Two categories pertain to perceptions specific to a given treatment, with the other two pertain pertaining to perceptions of treatments in general, as follows: specific-necessity (five items; e.g. 'My life would be impossible without my medicines'); specific-concerns (five items; e.g. 'I sometimes worry about long-term effects of my medicines'); general-overuse (four items; e.g. 'If doctors had more time with patients they would prescribe fewer medicines'); and general-harm (four items; e.g. 'All medicines are poisons').

Severity of AdSD was assessed with the validated Dutch version of the Voice Handicap Index (VHI), based on reports by the patient of handicap due to voice problems.[14] The VHI has 30 items, comprising three subscales

(emotional, functional, and physical). Items are scored from zero (never) to four (always), and result in a maximum score of 120 reflecting the poorest voice-related quality-of-life, and minimum score zero, reflecting maximum voice-related quality-of-life. A score of 10 or lower is considered normal.

Patients were also asked to provide a rating that described the quality of their voice at three moments in time (i.e. 'best ever', 'worst ever', and 'now, on the day of injection') based on a 10-point scale (1 = worst, 10 = best). Patients were also asked to rating voice quality at time of injection by clinician during the visit at the out-patient department (10-point scale, 1 = worst ever, 10 = best ever).

Procedure and analysis. Patients were seen by a physician who examined the patient, assessed the patient's voice, and recorded the patients' responses to the question on perceived voice quality. They also handed out a booklet containing the various study questionnaires. Patients completed the booklet after the examination and before the injection, and then returned it to the physician. Data were analysed using simple comparison of means (i.e. Student's *t*-tests) for comparisons with published norms; effect sizes were also calculated.[11] Some standard deviations in SCL-90 subscores appear large in comparison to their relevant means, raising the question as to whether alternative methods of analysis could be employed to corroborate the present findings. However, given that the previously published norms are presented in terms of means and standard deviations, neither full transformation of distributions nor comparisons using non-parametric tests is possible. Visual inspection of histograms suggested that while a number of sub-scores were skewed to some extent, in no cases did there appear to be any more than three outliers. Further, it can be noted that the standard deviations for each subscore in the present study sample appear similar in magnitude to those for the comparison group sample. It is well established that the *t*-test is very robust for validity against non-normality, and that related problems are minimal when skewness is similar in both groups.[15]

Results

Sociodemographic and clinical background of the 49 patients that were included in the study are given in Table 1.

The first research question pertained to the psychological characteristics of the patients. On the various SCL-90 dimensions, the male patients scored significantly higher on the dimensions 'interpersonal sensitivity', 'phobic anxiety', and the 'global severity index'. The female patients scored within ranges of normal severity.[12] Table 2 presents the SCL-90 scores found in our sample alongside previously published healthy population norms. Sample-to-population comparisons are presented in clinical terms, with statistically significant deviations from the healthy population and effects sizes also highlighted.

The second research question concerned cognitive and emotional representations of voice problems. Scores on the Brief IPQ are given in Table 3, alongside norms from comparison groups of patients with diabetes mellitus and asthma.[13] Compared to patients with diabetes or asthma, patients with AdSD returned higher scores for perceptions relating to the consequences of illness, their emotional responses to illness, and their control over treatment, and returned lower scores for perceptions relating to illness identity, and personal understanding of illness. Importantly, despite reporting greater control over their treatment (presumably insofar as they are free to opt in or out of treatment), AdSD patients reported less personal control over their *illness* than did patients with diabetes or asthma. In summary, the clinical picture that AdSD patients paint of themselves is one characterised by low personal control over their condition and correspondingly high emotional consequences. The Brief IPQ includes an open-ended question asking patients to state what they feel is the most important causes of their illness. In the present sample, the AdSD patients' responses reflect the clinical picture summarised above, with a diverse range of perceived causes reported as follows: neurological cause, 'brain–vocal cord connection error', heredity ($n = 10$); stress/worry ($n = 6$); wrong/too intensive use of voice/ENT-cause ($n = 5$); introversion ($n = 3$); life event ($n = 2$); other cause ($n = 6$); don't know ($n = 17$).

This second research question is also addressed in Table 4, which depicts results relating to treatment perceptions as solicited using the BMQ. These scores reflect the attitudes of patients toward botulinum toxin injections, a subject which has not previously been addressed in the research literature on AdSD. AdSD patients appear to have generally similar BMQ scores to those reported for patients with diabetes and asthma.[8] Compared with asthma patients, AdSD patients appear to score lower on concerns about their own medication ('specific-concerns'), but report less concern about medical treatments in general ('general-harm'). Compared with patients with diabetes the AdSD patients report lower scores on 'specific-necessity' and somewhat higher scores on 'general harm'.

The mean score on the VHI at the day of injection was 49.84 (SD = 20; minimum–maximum = 9–94),

Table 1. Demographic and clinical characteristics

Sex (n, %)	
Male	11 (20.4)
Female	38 (79.6)
Age (years, mean ± SD)	54 ± 15
min–max	21–85
Number of injections in past (mean ± SD)	18 ± 14
min–max	1–50
Number of months on injections	70
min–max	3–164
Injection frequency (every … months)	4 ± 2
min–max	2–13

reflecting a quite substantial degree of perceived handicap. Patients' mean ratings of their voice quality at different times were as follows: 'best ever' = 8.47 (SD = 1.06, minimum–maximum = 5.50–10.00); 'worst ever' = 3.30 (SD = 1.69, minimum–maximum = 0.00–6.00); 'at time of injection' = 5.95 (SD = 1.54, minimum–maximum = 3.00–10.00). Clinicians' mean rating for 'voice at injection' was 6.14 (SD = 1.40, minimum–maximum = 2.00–8.00).

Discussion

Synopsis of key findings

Our prospective controlled questionnaire study on psychosocial concomitants of patients with AdSD generates two major findings. First, in our sample we observed quite a high level of psychosocial problems, accounted for by above-average scores among male patients, as assessed using reliable and valid psychometric diagnostic instruments. Second, these patients hold cognitive and emotional representations of AdSD that suggest a high degree of emotional bewilderment and a feeling of low control over the condition. The patients appear to be convinced of the necessity of their treatment and do not overly worry about the injections.

Strength of the study

Our sample is relatively large, compared to the literature. Our measures are established psychometric questionnaires which allow comparisons with samples from other illness categories.

Comparison with other studies

Our findings extend those of other studies on psychosocial aspects of patients with AdSD. In their qualitative study, Baylor et al. found botulinum toxin injections to have led to a variety of psychosocial implications, with respondents reporting quite outspoken idiosyncratic representations of spasmodic dysphonia.[3] Our data suggest that the psychosocial consequences reported by Baylor et al. reflect levels of psychological and psychiatric morbidity that can be measured using standardised symptom assessment instruments such as the SCL-90, and benchmarked against population norms. Our findings suggest that these phenomena are primarily salient for male patients. Our findings also corroborate the important work by Buck et al., who reported high levels of emotional consequences and low levels of personal control in a pilot study of patients with dysphonia caused by non-malignant laryngeal disease.[6] The present study also confirms findings by Hogikyan and colleagues, who reported high levels of perceived voice handicap in AdSD patients.[16]

One possible interpretation of our results pertains to the idea that AdSD patients adjust to their predicament, given the relatively effective biomedical treatment, albeit to a relatively short-lived extent. The treatment of their disorder may induce a certain degree of passivity, which reflects itself in scores on psychological questionnaires that, although indicating some degree of impact (primarily among males), for the most part demonstrate resilience (it can be noted that the majority of AdSD patients are women, who in the present sample reported normal-range SCL-90 scores). This is also reflected in the higher impact of the condition in male versus female patients: males may be more susceptible to the image of AdSD, which is associated with 'psychosomatic, psychiatric morbidity'.[1]

Possible limitations of our study pertain to diagnostic uncertainties and selection bias. Our study site is a major national referral outpatient clinic for AdSD patients in the Netherlands. As such, referral patterns may generate study samples that contain more difficult-to-treat cases, in that several patients will have been referred to the clinic only after other (more local) treatment options have proved ineffective. In this context, the personal stress experienced by such patients may generate a greater degree of psychopathology than would be typical of other sites, and so findings relating to psychological and psychiatric symptoms, such as anxiety, may not be typical of the AdSD population as a whole. Secondly, all patients were recruited to the present study after having previously received botulinum toxin treatment. Prior positive or negative experiences with such treatment may have influenced patients' scores on the various questionnaires, especially those relating to illness and treatment perceptions.

Table 2. Psychological characteristics of AdSD patients (11 males, 37 females), as revealed by the SCL-90, compared with healthy population

SCL-90 subscale [minimum–maximum]	AdSD group					Comparison of AdSD group with normative group[12]								
	Males (N = 11)	Females (N = 37)	AdSD gender comparison			Comparison with normative males (N = 1,044)			Comparison with normative females (N = 1,074)			Classification of AdSD patients as compared to healthy population		
	M ± SD	M ± SD	P	Effect size, d		M ± SD	P	Effect size, d	M ± SD	P	Effect size, d	Males	Females	
Somatisation [12–23]	17.1 ± 3.7	20.6 ± 7.5	0.14	0.59		16.6 ± 5.7	0.77	0.10	18.7 ± 7.1	0.38	0.26	Average	Average	
Anxiety [10–31]	15.9 ± 5.7	15.3 ± 6.7	0.79	0.10		13.0 ± 4.3	0.03	0.57	14.6 ± 5.7	0.69	0.11	Above average	Average	
Depression [16–45]	23.6 ± 7.8	24.9 ± 10.5	0.71	0.14		20.7 ± 6.3	0.13	0.41	23.8 ± 8.6	0.67	0.11	Average	Average	
Interpersonal sensitivity [21–55]	31.1 ± 10.1	24.9 ± 7.8	0.04	0.69		24.6 ± 6.8	0.002	0.75	26.3 ± 8.8	0.60	0.17	High	Average	
Obsessive–compulsive [9–25]	15.6 ± 5.3	15.5 ± 6.7	0.96	0.02		13.2 ± 4.6	0.09	0.48	14.1 ± 5.1	0.37	0.24	Average	Average	
Hostility [6–12]	8.0 ± 2.0	7.3 ± 1.8	0.28	0.37		7.5 ± 2.5	0.51	0.22	7.6 ± 2.4	0.68	0.14	Average	Average	
Phobic Anxiety [7–24]	9.4 ± 5.0	9.4 ± 5.2	1.0	0.00		7.9 ± 2.1	0.02	0.39	8.7 ± 3.4	0.50	0.16	Above average	Average	
Sleeping problems [3–11]	5.6 ± 2.7	5.2 ± 2.9	0.69	0.14		4.6 ± 2.4	0.17	0.39	5.2 ± 2.8	1.0	0.00	Average	Average	
Global severity index [98–256]	140.1 ± 44.5	134.7 ± 45.7	0.73	0.12		117.2 ± 27.3	0.006	0.62	128.9 ± 36.4	0.60	0.14	High	Average	

Table 3. Scores on brief illness perception questionnaire (Brief IPQ) of AdSD patients, compared to patients with diabetes and asthma

Brief illness perception questionnaire (Brief IPQ) (minimum–maximum)	AdSD group (N = 49) M ± SD	Comparison group: diabetes[13] (N = 119) M ± SD	P	Effect size, d	Comparison group: asthma[13] (N = 309) M ± SD	P	Effect size, d
Identity (0–8)	3.6 ± 2.9	4.6 ± 2.8*	0.039	0.35	4.5 ± 2.3*	0.015	0.34
Consequences (0–10)	5.6 ± 2.9	4.7 ± 2.9	0.069	0.31	3.5 ± 2.3***	<0.001	0.80
Timeline (5–10)	9.3 ± 1.4	9.2 ± 1.9	0.740	0.06	8.8 ± 2.2	0.124	0.27
Personal control (0–8)	2.2 ± 2.6	6.7 ± 2.3***	<0.001	1.83	6.7 ± 2.4***	<0.001	1.80
Treatment control (5–10)	8.7 ± 1.4	8.0 ± 2.3*	0.049	0.37	7.9 ± 2.0**	0.007	0.46
Concern (0–10)	4.2 ± 3.1	7.0 ± 3.1***	<0.001	0.90	4.6 ± 2.8	0.361	0.14
Understanding (0–10)	5.5 ± 3.5	7.9 ± 2.3***	<0.001	0.81	6.5 ± 2.6*	0.018	0.32
Emotional response (0–10)	5.0 ± 3.0	4.3 ± 3.3	0.202	0.22	3.3 ± 2.9***	<0.001	0.58

*Different from AdSD patients significant at $P < 0.05$ level.
**Different from AdSD patients at $P < 0.01$ level.
***Different from AdSD patients at $P < 0.001$ level.
Conventional cut-offs for d are as follows (Cohen 1992): small effect when $d \leq 0.2$, medium effect when $d \approx 0.5$, large effect when $d \geq 0.8$.

Table 4. Scores of AdSD patients on beliefs about medication questionnaire (BMQ) compared with those of other groups

BMQ dimension	AdSD group (N = 49) M ± SD	Comparison group: diabetes[8] (N = 99) M ± SD	P	Effect size, d	Comparison group: asthma[8] (N = 78) M ± SD	P	Effect size, d
Specific-necessity	18.25 ± 4.59	21.26 ± 2.98***	<0.001	0.78	19.67 ± 3.23*	0.043	0.36
Specific-concern	12.91 ± 3.86	12.91 ± 3.38	1.0	0.00	15.76 ± 4.09***	<0.001	0.72
General-harm	10.50 ± 2.59	9.29 ± 2.43**	0.006	0.48	10.24 ± 2.30	0.556	0.11
General-overuse	11.52 ± 3.05	11.43 ± 2.77	0.858	0.03	11.64 ± 2.59	0.813	0.04

*Different from AdSD patients significant at $P < 0.05$ level.
**Different from AdSD patients at $P < 0.01$ level.
***Different from AdSD patients at $P < 0.001$ level.
Conventional cut-offs for d are as follows (Cohen 1992): small effect when $d \leq 0.2$, medium effect when $d \approx 0.5$, large effect when $d \geq 0.8$.

As the Brief IPQ is a relatively new assessment tool, reference populations for comparisons between AdSD samples and other groups is quite limited. As such, our data will be instrumental in future research in this area. In this regard, our use of widely employed and rigorously validated assessment tools offers important benchmarking data for the validation of the Brief IPQ itself. Both the SCL-90 and the BMQ have been applied to standardisation samples in several countries and in different languages. The Brief IPQ is derived from previous instruments that have also been extensively tested (see http://www.uib.no/ipq/ for additional information on languages used in Brief IPQ research and additional psychometric information).

Clinical implications of the study

The implications of the present findings and limitations translate into a number of research suggestions and clinical suggestions. Given that patients need time to develop illness perceptions about their condition, the selection of patients who suffer from AdSD for a considerable time would enhance future research, as would the use of longitudinal designs. Furthermore, incorporating demographic and clinical variables in subgroup analyses in future work, with (much) larger samples and a longitudinal design would be instrumental in furthering knowledge in this field.

It can be noted that such results are liable to be influenced by medical and/or experiential variables, such as frequency of treatment, age, time since onset of condition, etc. For example, patients at an early stage of treatment may be influenced by a degree of hopefulness that is not present in other patients. Similarly, patients who have more experience of having received treatment may be influenced directly by their experiences. Given that such aspects impinge directly upon perceptions of illness,

it is recommended that future research examine more closely the impact of treatment on cognition. AdSD patients up to now are forced to adhere to a hospital-driven regime of a fixed injection interval. A patient-driven injection interval may be much more helpful for patients, and may increase their sense of control over their condition and treatment. Further, given that patients have low feelings of personal control over their illness and understanding of it (despite believing their treatment to be effective), it may be that interventions which seek to enhance patients' sense of control and understanding might be important in helping to reduce their distress.

In addition, future research would benefit from the development of condition-specific measures to assess psychosocial adaptation and coping in AdSD patients. Such an approach would be consistent with recommendations for the incorporation of behavioural elements into the medical management of such disorders. In a Cochrane review on botulinum toxin treatment for AdSD, Watts et al.[17] suggest that 'behavioral treatment combined with pharmacological therapy … may assist in improving voice quality and prolonging the benefit of pharmacological effects.' (p. 2). Findings from illness and treatment perception research suggest that such behavioural approaches may be most effective if they systematically incorporate patients' views in the diagnostic and therapeutic strategies used by physicians in AdSD patients. Addressing illness perceptions and treatment perceptions may be as helpful as carefully maneuvering a fine needle into a person's throat.[17] In research terms, a prospective randomised controlled trial of interventions that combine botulinum toxin injections with patient support groups focusing on the discussion of illness perceptions, would offer new knowledge on whether a behavioural medicine approach would be of use in a condition that many physicians still consider 'enigmatic'.[18] Including additional categories of patients would strengthen the research design of such work.[19] Further, the potential interrelationships of psychological morbidity, treatment, illness perceptions, and self-perceived voice quality could be considered as a future research topic. In addition, research that examines self-management options for this condition may be worthwhile, given the positive findings of pertinent studies in related medical conditions.[20]

Conclusions

In our sample of patients with AdSD in a tertiary care facility, levels of psychosocial morbidity were higher than in healthy reference groups, reflecting higher degrees of emotional insecurity, and a significantly higher degree of emotional and cognitive bewilderment about AdSD and its treatment. Self-management programmes that aim at addressing maladaptive emotional and cognitive responses to AdSD may be helpful in improving quality of life in AdSD patients.

Conflict of interest

None to declare.

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