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Main Article

What are the illness perceptions of people with dysphonia: a pilot study

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Abstract

Background: Patients do not respond to treatment in a predictable manner. Individual preconceptions determine help seeking, compliance and treatment outcome, yet clinicians rarely explore these issues. The illness perception approach sees the patient as an active participant in the healthcare process.

Aims: The aim of this study was to investigate the illness perceptions of people with dysphonia. The subsidiary aims were to correlate the Illness Perception Questionnaire with any psychological distress identified and a self-report measure of dysphonia, and to consider any potential implications for patient management.

Design: Prospective, cross-sectional observation.

Setting: Primary and secondary care, two general and four community hospitals.

Participants: Fifty adult patients with dysphonia due to benign disease completed three self-administered questionnaires, which investigated their illness perceptions, psychological distress and perceptions of the impact of the presenting 'illness'.

Measures: The dysphonia was categorised as being due to functional ($n = 40$) or organic ($n = 10$) causes. All the voices were rated by an expert listener according to the GRBAS (grade, roughness, breathiness, aesthenia, strain) scale. Participants completed the Illness Perception Questionnaire, the Vocal Performance Questionnaire and the Hospital Anxiety and Depression scale.

Results: Patients showed a wide variation in perception of causation. They had no strong perceptions about the causes, consequences or duration of the presenting dysphonia. Functional dysphonics reported greater consequences, lower perceived control and increased anxiety when compared to patients with organic dysphonia. In terms of cure/control, all patients expected treatment to be helpful but this expectancy reduced as time increased. Anxiety was more associated with functional dysphonia, however, only 17 per cent of the subjects in this group showed clinically significant levels of signs of psychological distress.

Conclusions: Lay illness representations often diverge from the clinician's understanding of the presenting problem and strongly influence treatment behaviour. Early exploration of illness perceptions may enhance health behaviour and maximise the impact of intervention.

Key words: Dysphonia; Functional Aphonia; Severity of Illness Index; Psychological Tests

Introduction

For many years, health psychologists have explored determinants of health behaviour. 'Help seeking' and use of medical services have been investigated together with compliance and motivation in both medical and therapeutic interventions.[1] In the 1980s, Howard Leventhal called for a dynamic model to explore individuals' responses to illness. He examined how individuals evaluate health threats by constructing their own representations or perceptions, which then influence coping patterns.[2] Leventhal proposed a 'self-regulatory' theory where people explore external information, integrating it with internal cognitive and emotional frameworks in order to understand and manage symptoms.[2] Illness representations constantly evolve through dynamic review of self-regulatory stages. In cancer screening, for example, compliance is determined by perceptions about control, consequences and treatability and shaped by anxiety and distress.[3]

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People do not merely react to symptoms[1] but construct meaning and explanations for them by relating them to, for example, 'pre-existing' internal knowledge frameworks (i.e. previous illnesses). People believe that health, illness and recovery are influenced by a wide variety of factors. They understand minor and more serious disease[4] according to well organised, stable cognitive representations, which in turn have important implications and covert influence on the treatment process.[1]

Development of the Illness Perception Questionnaire[5]

Following work in hypertension and oncology,[3] Leventhal identified the four key components of illness representations, by which seriously ill individuals cope with their condition: identity, cause, time-line and consequences. Each section of the Illness Perception Questionnaire is defined as follows:[5]

1 Identity – ideas about the 'label'/nature of their condition i.e. associated symptoms and the links between them.
2 Cause – ideas about the potential causes of the condition.
3 Time-line – perception of the likely duration of the 'illness'.
4 Consequences – perceptions about illness severity and the likely impact on physical, social and psychological functioning.
5 Cure/control – the extent to which the patient believes the condition or illness is amenable to control or cure.

Lau *et al.*[6] studied relatively healthy patients and identified a fifth component, that of cure. The original Illness Perception Questionnaire[5] was devised to explore health behaviour using these components or illness perceptions. Although widely used in clinical research, the Illness Perception Questionnaire has never been applied to a dysphonic population to the best of our knowledge.

Dysphonia

It is estimated that 3 to 9 per cent of adults and 20 per cent of professional voice users have a dysphonia,[7] which is due to inefficient vocal function without pathology[8,9] in approximately 60 per cent of instances.[10] Described as a prototype for functional disorders[11] or medically unexplained symptoms, dysphonia is subject to and indicative of psychological status.[12] Higher neuroticism, distress, psychiatric disturbance[13] and medically unexplained symptom scores[12,9] have been demonstrated in patients with dysphonia. Personality,[14] emotional well being and psychological status[15] are cited as contributors to dysphonia[14] in addition to physical factors such as voice misuse,[8] smoking and reflux.[16] Other findings have shown that dysphonic patients have no excess psychological disorder or previous medically unexplained symptoms when compared to general ENT out-patients.[17,18]

Clinically, there has been little or no exploration into how dysphonic patients interpret symptoms, perceive their 'illness', regulate coping and anticipate recovery. Using the Illness Perception Questionnaire as a framework to investigate their illness perceptions may provide insight into their cognitive and emotional strategies when faced with symptoms. A good understanding by health professionals of dysphonics' illness perceptions would be beneficial to current treatments such as speech therapy which often involves cognitive approaches and/or counselling.

Method

Fifty adult patients with a principal complaint of dysphonia caused by non-malignant laryngeal disease were recruited from the new referrals to the speech and language therapy departments of two general and four community hospitals over seven months. All patients had undergone fibre-optic nasendoscopy before being seen by speech and language therapy and then classified as follows. Those with a lesion on the vocal fold/s on nasendoscopy were categorised as organic (this included patients with vocal fold palsies, nodules, cysts, papilloma and Reinkes oedema). Those with no discernable physical change on nasendoscopy were considered to have a functional dysphonia. Ethical approval was obtained from the local Research Ethics Committee and informed consent was gained from each participant. All participants completed three questionnaires before initial speech and language therapy assessment.

The Illness Perception Questionnaire[5]

Patients completed an adapted version of the Illness Perception Questionnaire (Appendix I). The Illness Perception Questionnaire comprises 26 statements, rated by the respondent on a 5-point scale from (1) strongly agree to (5) strongly disagree. The questionnaire is divided into five sections: identity, cause, time-line, consequences and cure.

The Illness Perception Questionnaire allows for local modification to accommodate different patient groups. The modified list of twelve non-specific symptoms associated with dysphonia[11] is shown with the questionnaire in Appendix I.

The Vocal Performance Questionnaire[19]

This questionnaire enables patients to consider aspects of their vocal performance and rate severity in relation to normal voice usage. The Voice Perception Questionnaire has twelve questions with a choice of five statements for each. The statements are scored, from (1) 'never' up to (5) 'all the time'. The baseline score is 12 out of 60. In this study, 11 of the 12 items were used.

The Hospital Anxiety and Depression scale[20]

The Hospital Anxiety and Depression scale is a commonly used measure of emotional distress. It is a 14-item questionnaire and gives scores for both anxiety and depression. Subjects rate how they have been feeling over the last two weeks. A Hospital

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Anxiety and Depression scale score of 8–10 for either anxiety or depression is considered borderline.

The GRBAS score[21]

Each subject's voice was recorded as part of standard assessment and the GRBAS score noted by a trained speech and language therapist. It is made up of five parameters of voice quality (G = grade, R = roughness, B = breathiness, A = aesthenia and S = strain) each rated on a four-point subjective scale where 0 is normal and 3 represents severe abnormality.

Analysis

Data were collated on Excel® and Pearson's correlation co-efficient calculated as required.

Results

Fifty-one patients were recruited to the study (40 female, 11 male) of whom one withdrew. Mean age was 52 years (range 22–80, standard deviation [SD] = 17 years). The dysphonia had lasted for at least two months with a mean duration of three years. Forty patients had been diagnosed with a functional dysphonia and 10 with an organic dysphonia.

Illness Perception Questionnaire data

The mean scores for the modified Illness Perception Questionnaire are summarised in Table I with significant correlations shown in Table II.

Causes. Patients showed no strong perceptions about potential causes of their dysphonia. They attributed the dysphonia to a wide variety of causes, choosing items across all three categories – external, chance or internal causes.

Time-line. There were no strong perceptions about the duration of the dysphonia. As duration increased however, patients perceived the dysphonia was likely to be a long-term problem.

TABLE I

MEAN SCORES AND (SD) OF THE MODIFIED ILLNESS PERCEPTION QUESTIONNAIRE

	All patients $n = 50$ (SD)
Causes – External*	3.7 (0.5)
Causes – Chance*	3.6 (0.7)
Causes – Internal*	3.5 (0.8)
Time-line Ω Perceived duration	3.1 (0.7)
Consequences Δ Perceived impact	3.0 (0.8)
Cure/control ◇ Perceived lack of control	2.5 (0.6)

Scores range from 1–5, except consequences which scores 1–7; *lowest score = most likely to perceive as cause; Ω lowest score = perceived short duration; Δ lowest score = perceived fewest consequences; ◇ lowest score = perceived most control; SD = standard deviation

Consequences. Patients had variable but no strong perceptions about the impact of the dysphonia. There was no significant difference between the two groups in terms of impact or consequences but there was a trend for the group with organic dysphonia to report less impact or fewer consequences.

Cure/control. The figures in this section reveal no strong perceptions about treatment benefit or control although patients felt they played a role in recovery. They perceived that recovery was likely to be helped by treatment rather than not or being left to chance. As a group, the patients tended to perceive that the dysphonia could be controlled or cured with treatment but the strength of this association reduced with increased duration.

Significant correlations for the whole group are shown in Table II. The main observations are shown below:

1 Across the participants there was a perception that as duration increased the dysphonia would persist in duration with an associated increase in the impact or consequences.
2 Where therapists rated the overall quality of the voice more severely (increasing 'G' of GRBAS), this was associated with perceptions of greater consequences in the functional group.
3 Within the group, there was an association between anxiety and increased consequence reporting. However, anxiety was only found in the patients with a functional diagnosis. These patients with anxiety also tended to have perceptions that the problems would be of longer duration.
4 It appears that where patients perceive the dysphonia to have been caused by internal or chance causes, there is less associated anxiety.
5 There was a significant correlation between the Voice Perception Questionnaire and the Illness Perception Questionnaire consequences section for all patients. Figure 1 shows that where there is an increased perception of consequences, it is reflected in the Voice Perception Questionnaire scoring.
6 The patients with functional dysphonia did not have strong perceptions about the causes of their dysphonia whereas the organic group attributed causes across all three categories. There was a trend towards stronger causal beliefs than in the functional group and these beliefs were associated with stronger perceptions of cure/control.
7 Despite the small organic cohort, a number of possible trends appear to emerge within the organic group. These patients tended to perceive greater control over their dysphonia regardless of the cause. They perceived a shorter duration to the dysphonia despite higher GRBAS scores as rated by the therapists and this was associated with lower disease impact reporting.

GRBAS

The mean scores of the Voice Perception Questionnaire and the 'G' of GRBAS are summarised in

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TABLE II

SIGNIFICANT CORRELATIONS OF THE ILLNESS PERCEPTION QUESTIONNAIRE, VOICE PERCEPTION QUESTIONNAIRE, DURATION AND GRBAS, FOR **ALL PATIENTS** ($n = 50$)

	Chance	Internal	Time-line	Consequences	Cure/control
Onset		*−0.31*	**0.48** *0.55* 0.65	**0.40** *0.44*	
External			0.72		**0.77** 0.77
Chance			**−0.31** 0.66		**0.77** 0.69
Internal			0.81		**0.69** 0.85
Severity				*0.32*	
Time-line					0.86
Consequences					0.64
VPQ			−0.66	**0.58** *0.52* 0.69	
G				*0.41*	
Anxiety	*−0.35*	*−0.33*	*0.39*	**0.36** 0.33	

All patients ($n = 50$ is all the patients in the study) in **bold**; ($n = 40$ is the functional dysphonics) in *italic*; ($n = 10$ is the organic dysphonics) in roman; VPQ = Voice Perception Questionnaire; G = 'G' of GRBAS

Table III. External raters using GRBAS, tended to rate the voices of those subjects with an organic dysphonia more severely although the subjects themselves reported less impact using the self-report measure (Voice Perception Questionnaire).

Anxiety and Depression

Results from the Hospital Anxiety and Depression scale scores are shown in Figure 2. Overall, on the depression scale, 90 per cent of the patients were rated as normal; 8 per cent were borderline and

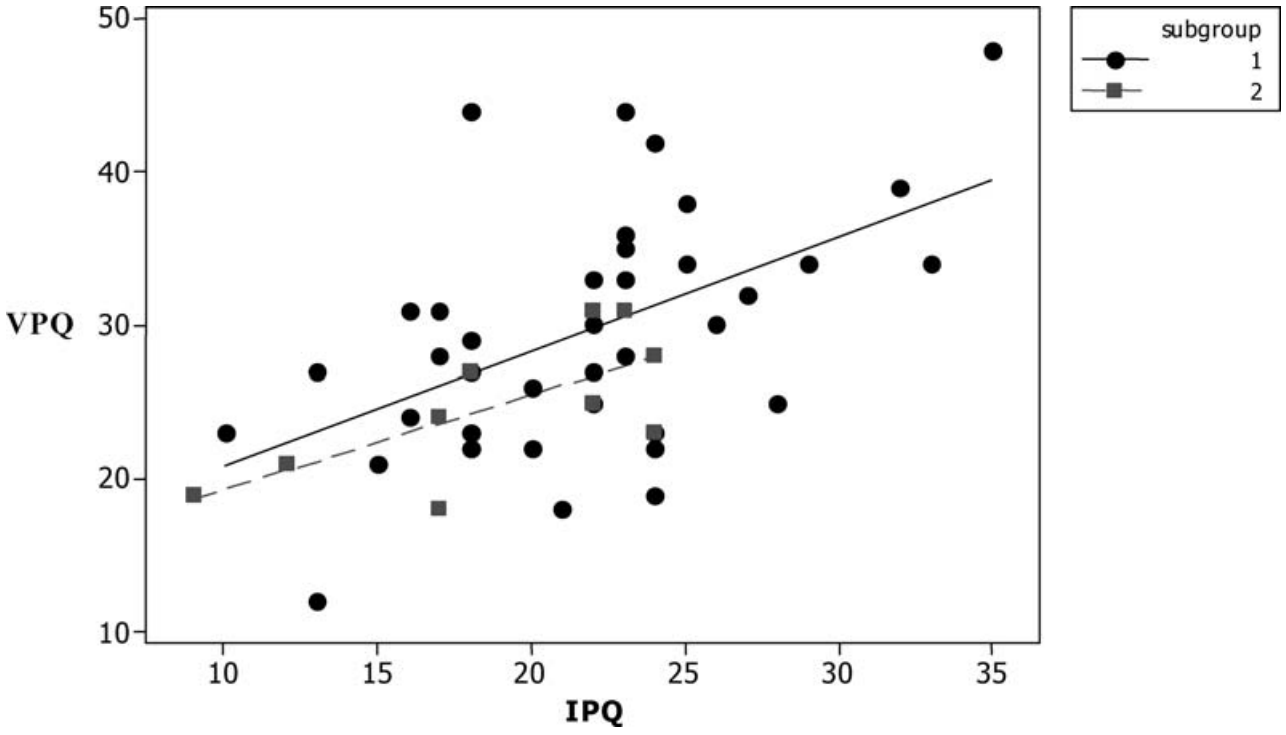

FIG. 1

Scatter plot of Voice Perception Questionnaire *vs* Illness Perception Questionnaire. VPQ = Voice Perception Questionnaire; IPQ = Illness Perception Questionnaire

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TABLE III

MEAN SCORES AND (SD) OF THE VOICE PERCEPTION QUESTIONNAIRE AND 'G' OF GRBAS

	Score range	All patients $n = 50$	FD $n = 40$	OD $n = 10$
Voice Perception Questionnaire	11–55	29 (7.4)	30 (7.8)	25 (4.6)
'G' of GRBAS	0–3	1.6 (0.8)	1.4 (0.8)	2 (0.5)

FD = functional dysphonic; OD = organic dysphonic; SD = standard deviation

2 per cent showed clinical levels of psychological distress. On the anxiety scale, 66 per cent of the patients were rated as normal; 20 per cent borderline and 14 per cent of patients showed psychological distress. Higher rates of anxiety were associated with the subjects with functional dysphonia when compared to those with organic dysphonia. However, even within the functional group, only 17 per cent of patients showed a clinical anxiety and 2 per cent a clinical depression. No patient in the organic group was classified as anxious or depressed using the Hospital Anxiety and Depression scale.

Discussion

This is the first study to explore the illness perceptions of people with dysphonia. When considered as a hetereogenous group, these patients had no dominant perceptions about the nature, duration, consequences or management of their dysphonia. Although all perceived that treatment was likely to help, they believed that the dysphonia would be less amenable to recovery as time went on. Potential causes were attributed widely by the patients with no perceived links to control. As time went on, they expected that the dysphonia would be of longer duration and with increasing consequences.

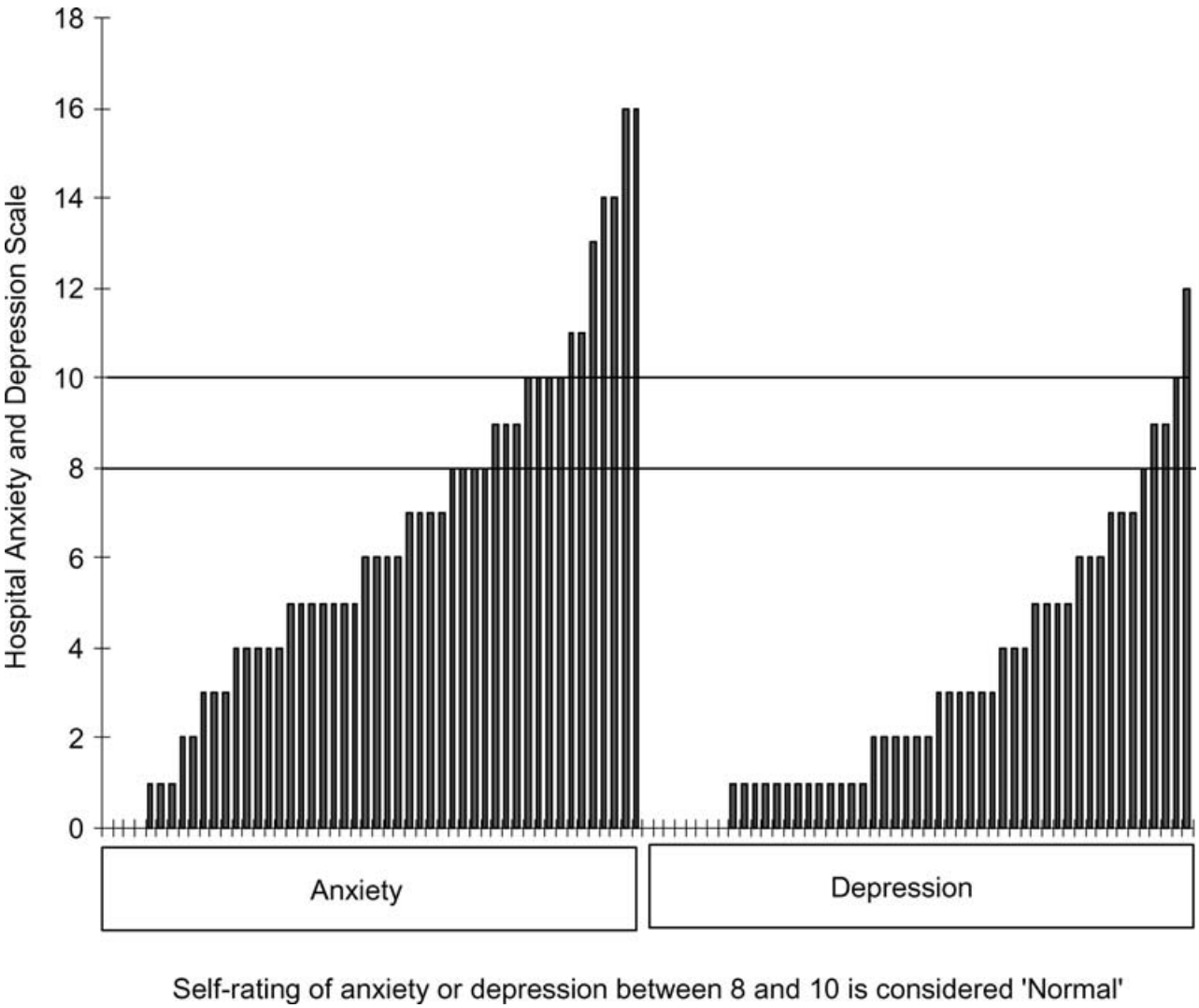

FIG. 2
Self-rated levels of anxiety and depression; all patients.

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In previous studies, patients perceiving fewer consequences and greater 'disease' control reported increased quality of life, greater acceptance of the illness and fewer symptoms. Those with strong illness identity, belief in psychological causes, long duration and low control reported greater consequences or disease impact. Findings in a comparable study into irritable bowel syndrome disease[22] showed that perceptions of consequences and cure/control had a direct influence on outcome. In rheumatoid arthritis,[23] low control beliefs were associated with increased hospital admissions and out-patient appointments. In primary care, patients with poor comprehension of symptoms and disease aetiology attended more, less frequent attendees tended to deliberate and attribute causes of the illness to factors under their control.[24] Where patients were unable to identify cause, there was greater dysfunction; increased consequences were linked to increased out-patient utilisation.[8] Rutter[22] concluded that illness outcome beliefs were more important than symptoms in predicting recovery. The Illness Perception Questionnaire could be very important because such findings may determine attendance rates, hospital admission and be a stronger determinant of clinical outcome than symptom severity.

Although the Illness Perception Questionnaire has previously facilitated clinical research, it focuses exclusively on exploring cognitive representations.[25] However, the cognitive and emotional components involved in illness perception cannot easily be separated[26] and it is becoming clear that behaviour in response to 'illness' may be a powerful determinant of outcome.

The recently amended Illness Perception Questionnaire has expanded the cure/control and timeline sections. The authors added four sections to increase internal reliability. Aiming to be a stronger psychometric tool, the Illness Perception Questionnaire-R[25] also incorporates an emotional perception section. Since voice is influenced by emotional well being[13] as well as physical factors, the new version may be a more effective tool to apply to this population. The Voice Perception Questionnaire is commonly used in voice assessment.[27] In this study, there was a strong correlation with the Illness Perception Questionnaire consequences section, which supports the validity of the Voice Perception Questionnaire in assessing the impact of dysphonia. It is essential that clinicians are able to assess the effectiveness of treatment and the Voice Perception Questionnaire is a useful tool in measuring patients' perceptions of the consequences of dysphonia.

It is often claimed that psychological distress accompanies dysphonia,[28] and is increased in patients with functional dysphonia.[9,29,30] In this study psychological distress was not identified in 66 per cent of participants. Those participants showing greater anxiety were however, more likely to attribute the cause of their dysphonia to internal/chance factors, i.e. self-blame, and to anticipate increased 'illness' duration and greater consequence reporting as is noted in other disease states.[7,8,31]

Recently, modification of the Hospital Anxiety and Depression scale scoring has been proposed.[32] After application of the questionnaire to a non-clinical population, the authors concluded the 'borderline' cut offs were arbitrary and should be extended. Their reported mean scores for anxiety (6.14) and depression (3.68) amongst 'normal' participants were comparable to the findings in this study which indicate that the emphasis of psychological distress in dysphonia may be unjustified. This supports previous work, which has shown that these patients are no more likely to have psychological distress than other out-patient populations.[15,17] Some patients however, were identified as either anxious or depressed and early referral to psychological services may be indicated if the Hospital Anxiety and Depression scale[9,17] was used routinely.

The provision of adequate information is important to help patients feel in control of their 'illness'.[24] Clinicians should ensure that all dysphonic patients are supplied with appropriate information in order to help them understand and manage the presenting problem.

Originally developed from the self-regulatory theory, the Illness Perception Questionnaire is a tool that has evolved from within the social cognitive model. Within the model, individuals are perceived as 'rational, deliberative decision makers',[33] systematically evaluating available information to manage health. This view has been challenged. Modern theories suggest that behaviour is more spontaneous and competes with other salient demands in the individual's life. Work in the last 20 years has suggested that cognition varies more dynamically than previously perceived.[33] The concept of 'self efficacy' and the relative strength of competing actions[34] are driving future research which should attempt a prospective, longitudinal study aiming to predict health behaviour using the Illness Perception Questionnaire-R, through treatment to discharge. Once illness perceptions (IP) are identified their amenability to change should be explored in order to optimise and promote rehabilitation.

- **This study aims to investigate the illness perceptions of people with dysphonia, using an illness perception questionnaire**
- **Fifty adult patients with dysphonia due to benign disease were studied**
- **Functional dysphonics reported greater consequences, lower perceived control and increased anxiety when compared to patients with organic dysphonia**
- **Although anxiety is more associated with functional dysphonia only a minority (17 per cent) of patients in this group showed clinically significant levels of signs of psychological distress**

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Conclusions

This study has demonstrated that patients have no strong perceptions associated with their 'illness' or dysphonia when considered as a group. However, there were significant findings in relation to their perceptions of the effectiveness of treatment, the impact of the dysphonia and the effect of psychological distress, which were influenced by the diagnosis. The results help to illustrate that patients with dysphonia may benefit from clear explanations of their disorder, symptoms and the potential causes tailored individually to their 'illness' perceptions before shared treatment planning can be successful. Illness perceptions are 'important predictors of outcome'.[22] Using the Illness Perception Questionnaire has revealed patterns of perceptions, which are likely to affect response to treatment and overall compliance. Patient choice and collaboration is at the centre of modern healthcare planning[35] but are patients ready and empowered to participate? If dysphonic patients are passive, shared decision making in treatment will be difficult to achieve. People play a vital role in their health management and the modernisation of assessment tools will allow more thorough exploration of health behaviour.

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APPENDIX I

ILLNESS PERCEPTION QUESTIONNAIRE FOR VOICE PROBLEMS

Voice problem Identity (Core symptom list)

Please indicate how frequently you now experience the following symptoms as part of your Voice problem

Rated: all of the time, frequently, occasionally, never

Hoarseness/huskiness.....	Reduced volume.....
Dry throat.....	Discomfort in neck/shoulders.....
Discomfort in throat.....	Lump in throat feeling.....
Shortness of breath.....	Sudden voice quality changes.....
Vocal fatigue.....	Loss of energy in voice .....
Ache in throat.....	Coughing and throat clearing.....

We are interested in your own personal views of how you now see your Voice problem.
Please indicate how much you agree or disagree with the following statements about your Voice problem.

Rated:	**Strongly agree**	**Agree**	**Neither agree nor disagree**	**Disagree**	**Strongly disagree**
	1	**2**	**3**	**4**	**5**

Cause

A germ or virus caused my Voice problem	1	2	3	4	5
Diet played a major role in causing my Voice problem	1	2	3	4	5
Pollution of the environment caused my Voice problem	1	2	3	4	5
My Voice problem is hereditary - it runs in my family	1	2	3	4	5
It was just a chance that I became ill	1	2	3	4	5
Stress was a major factor in causing my Voice problem	1	2	3	4	5
My Voice problem is largely due to my own behaviour	1	2	3	4	5
Other people played a large role in causing my Voice problem	1	2	3	4	5
My Voice problem was caused by poor medical care in the past	1	2	3	4	5
My state of mind played a major part in causing my Voice problem	1	2	3	4	5

Reference Number

Rated:	**Strongly agree**	**Agree**	**Neither agree nor disagree**	**Disagree**	**Strongly disagree**
	1	**2**	**3**	**4**	**5**

Time-line

My Voice problem will last a short time	1	2	3	4	5
My Voice problem is likely to be permanent rather than temporary	1	2	3	4	5
My Voice problem will last for a long time	1	2	3	4	5

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APPENDIX I Continued

Consequences

My Voice problem is a serious condition	1	2	3	4	5
My Voice problem has had major consequences on my life	1	2	3	4	5
My Voice problem has become easier to live with	1	2	3	4	5
My Voice problem has not had much effect on my life	1	2	3	4	5
My Voice problem has strongly affected the way others see me	1	2	3	4	5
My Voice problem has serious economic and financial consequences	1	2	3	4	5
My Voice problem has strongly affected the way I see myself as a person	1	2	3	4	5

Control/Cure

My Voice problem will improve in time	1	2	3	4	5
There is a lot which I can do to control my symptoms	1	2	3	4	5
There is very little that can be done to improve my Voice problem	1	2	3	4	5
My treatment will be effective in curing my Voice problem	1	2	3	4	5
Recovery from my Voice problem is largely dependent on chance or fate	1	2	3	4	5
What I do can determine whether my Voice problem gets better or worse	1	2	3	4	5

J. Weinman *et al.*[5]

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