Enhancing dysphonia clinic consultations through a focus on patients' expectations: Streamlining and validation of a new tool (ACaPELa-R)

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Abstract

Background

The Assessing and Caring for Patients Expectations in Laryngology (ACaPELa) questionnaire was developed to guide laryngology clinic consultations. This study aimed to audit its use, revise it depending on outcomes, and validate it.

Methods

The ACaPELa was completed by all new patients attending a laryngology clinic over one year. The questionnaire was refined (ACaPELa-R) and validated in a new cohort of patients over a 6-month period.

Results

37/242 (15.3%) patients incorrectly gave the same ranking to more than one question. Questions with similar content were collapsed to broader themes, and an outcome question added, resulting in the 5 question ACaPELa-R. Using ACaPELa-R there was a significant reduction in the number of same-ranking responders (4.4% vs 15.3%; p=0.003) and a high post-consultation patients' satisfaction (95.7%).

Conclusions

The ACaPELa-R makes patients' rank ordering easier. It can be used to inform how different topics should be approached during the consultation and for clinician self-audit.

Key words:

Laryngology, Questionnaires, Patient satisfaction, Feedback

Introduction

In the last decade there has been a shift to a patient-centred approach when evaluating outcomes of health care interventions. This is in an attempt to understand patients' perception of clinical effectiveness, which can differ from clinical-based outcomes. A plethora of quality of life questionnaires have been described in the ENT literature to assess the value of an intervention from the patients' perspective and measure satisfaction.[1-2] Quality-adjusted life-years questionnaires and stated preference methods have more recently been introduced in an attempt to not only identify a perceived improvement after an intervention, but also quantify the outcome based on patients' preferences.[2,3] The latter focuses on both health and non-health outcomes to understand patients' choices and satisfaction. [4]

The majority of research in this field focuses on subjective patient-centred outcomes after the completion of a given clinical intervention. [5] However, management is generally based on the clinician's presumptions of what is wrong with the patient and what their concerns are. These can be surprisingly different from what patients want, and are expecting to receive. [6-7] This suggests that patient-centered care models could be improved further by considering patients' concerns from the outset rather than solely measuring satisfaction levels post-management.

Understanding patients' expectations is particularly important in Otolaryngology, a specialty where a significant part of the clinical workload is focused on providing quality of life interventions. [1] Some attempts have been made to explore this aspect, but the focus has turned more towards clinical factors such as seniority of doctors in the outpatient clinic or theatre, waiting times and timing of consent rather than understanding what clinical questions the patient wants answered from the clinical encounter. [8-9] Whilst this has not yet been explored in detail in the ENT literature, research from other medical fields has highlighted areas of mismatch between patients' expectations and current models of care. In the field of geriatrics, for example, disclosure of dementia is not a routine practice in general practice and varies significantly in specialist clinics. Yet a study of patients' expectations prior to attending a dementia clinic showed that most patients and carers want to be informed of their diagnosis in order to plan for the future, receive treatment and learn coping strategies. More than half of the patients were concerned that they may have signs of early dementia prior to being seen in the clinic. [10]

Routinely, ENT clinicians use the GP referral letter when determining the patient's reason for clinic attendance and to prepare the setting prior to assessing the patient. Nevertheless, studies have shown that GPs' reason for referral and provisional diagnosis can contradict patients' expectations. [11-12]

In order to address the above points, and better understand patients' thoughts and concerns, we devised an open structured questionnaire that led to fourteen leading questions which patients wanted answered during a laryngology clinic consultation. These questions were further tested for internal reliability and removal of non-informative questions produced the 8-options - Assessing and Caring for patient expectations in Laryngology (ACaPELa) questionnaire.[11]

Since its initial development 2 years ago, it has become common practice to ask all patients attending our dedicated voice clinic to complete the ACaPELa questionnaire prior to their consultation. This involves the selection and rank ordering, in order of importance, of the questions they want answered. The responses are then reviewed by the clinicians at the beginning of the consultation to guide the discussion with patients, following completion of a focused ENT history and examination.

In our initial publication on ACaPELa, [11] we reported on the process of arriving at the 8 item from the original open-structured questionnaire. No clinical validation of ACaPELa had been performed at that stage, and there are currently no other reports in the literature on the usability of ACaPELa. However, informal feedback received from our patients indicated that the questionnaire was proving difficult to rank order with patients finding some of the options very similar in content. We therefore felt that a formal audit of clinical applicability of the questionnaire was warranted. In addition, it also seemed appropriate to ask if the patients' ranked questions had been addressed or not and so these were added to the revised questionnaire. The aim of this study was to (1) audit the clinical applicability of the ACaPELa tool, (2) revise the tool if necessary, (3) introduce an outcome set of questions, and (3) validate the revised version in a new cohort of patients.

Materials and Methods

This study comprised a two-cycle audit conducted at the ENT department of Glasgow Royal Infirmary. In the first cycle we retrospectively audited patients' responses to the original 8 question version of the ACaPELa tool to investigate what kind of changes might be necessary. All new patients seen in the dedicated laryngology clinic between September 2016 and September 2017 were included in this analysis. All patients had completed the ACaPELa questionnaire prior to their clinic consultation.

Following cycle, the questionnaire was revised by reducing the question set. The new tool was then validated by prospectively collecting patients' responses between February and July 2018. During this second cycle, patients were also asked to comment on whether their questions were answered during the consultation, by replying yes or no next to the ranking of the revised ACaPELa questions. To ensure unbiased responses, this was performed after

the patient had left the consulting room. Patients' answers were checked by the clinic nurse and fed back to the consultant.

All questionnaire replies and satisfaction responses were transferred to an excel file and stored in an NHS computer. Caldicott approval had been obtained to run the study as a clinical effectiveness audit. The responses were anonymised, therefore ethics committee approval was not required.

The chi-square/Fisher's exact and analysis of variance test was performed for comparison of categorical data and continuous with categorical data respectively. The Friedman test with post-hoc pairwise comparisons was used to identify redundant questions in the ACaPELa appropriate for merging and collapse of the questionnaire to broader themes. The level of significance was set at 0.05. The IBM SPSS 20.0 statistical software was used for data analysis.

Results and analysis

A total of 242 patients completed the questionnaire during the first cycle. The population was female predominant with a ratio of 1.7 :1 (62.4% females) and a mean age of 52.8 years (SD 17.8). Patients' baseline characteristics were comparable with the study population used to develop ACaPELa (**table I**). Thirty-seven patients (15.3%) did not complete the ranking as instructed, giving the same ranking to more than one question, highlighting that there may have been similar options available in the questionnaire. These responses were not included in the subsequent pairwise rank ordering comparison analysis.

The ACaPELa results are shown in **table II**. The expectation that was most commonly ranked first was Question 1 (I want to know what is wrong with my voice), followed by Question 2 (I want to know what is wrong with my throat) and Question 3 (I want to know what is wrong/diagnosis). These along with question 6 (Tell me what I can do to make my throat problem better) were the most common expectations with the latter being rank ordered first less frequently. Despite the fact that only 8 patients (3.3%) were referred to the clinic urgently with a suspicion of cancer, 65.3% of patients (n=158) wanted to know if they had cancer, with 41 (16.9%) ranking this expectation first. There was no correlation between GP reasons for referral and patients' ranked expectations (p>0.05). Order of ranking was not associated with patients' age or gender (p>0.05 for each 8-level question respectively).

Pairwise comparisons of the ranked questions across our sample identified redundant questions within ACaPELa. These are questions with no detectable differences in patients' rank ordering (post-hoc Friedman test p>0.05). Question 3 was consistently given similar ranking to Question 1 and 2 (p=0.637 and p=0.895 on pairwise comparisons respectively)

hence can be incorporated within the first two questions. The same applied for question 4 and 5 (p=0.615). Similarly, Question 8 had closely related ranking to questions 6 or 7 (p=0.179 and p=0.983 respectively). On this basis, questions with non-detectable differences on ranking where collapsed to broader themes, resulting in a revised ACaPELa questionnaire (ACaPELa-R). **Table III** shows the modified question set.

In order to validate and evaluate the usability of ACaPELa-R, we audited a further 115 patients' responses to the revised questionnaire. Of these, 68.7% were females (n=79) and the mean age was 50.4 (SD 18.8). The ACaPELa-R results are shown in **table IV**. There was a statistically significant drop in the number of patients who completed the questionnaire incorrectly by giving the same ranking to more than one question from 15.3% (n=37/242) to 4.4% (n=5/115), (p=0.003). In response to the follow-up question whether their queries or concerns had been addressed, 95.7% (n=110) indicated that this was the case for the full set of questions ranked. Five patients (4.4%) noted in their responses that between one and all of their questions had not been answered satisfactorily. In three of these cases, this result was inevitable, i.e. in the first case, no diagnosis could be given to the patient, as further investigations were required. In the second case, the patient felt he had been provided insufficient advice on how he could improve his voice, as this aspect formed part of his future management with speech and language therapy services rather than something that could be provided during the consultation. The third patient had not understood the follow-up question and therefore indicated incorrectly that his questions had not been answered. This left two patients who were actually dissatisfied with the outcome (1.7%). Both patients had ranked the question about cancer exclusion as their 5th, i.e. lowest ranking priority, but felt that this issue had not been covered sufficiently during the consultation, highlighting that it is important to address all of the patient's concerns, even if they are not indicated as high priority.

Discussion

This study set out to validate a tool developed in our laryngology clinic to capture patient expectations and concerns, and in this process to refine the tool and establish its clinical applicability. During this process, we evaluated the tool both as a means to guide the consultation process, as well as a measure of patient satisfaction for quality control purposes.

Our results showed that in its original form (ACaPELa), the questionnaire contained too many options, some of which were similar to each other, creating difficulties for patients with the ranking process. By narrowing down the questions from eight to five in ACaPELa-R, we were able to reduce the number of incorrectly completed questionnaires to an acceptable

level (4.4%), considering for some patients certain aspects might have equal priority, irrespective of the number of choices offered.

We also identified a mismatch between GP letters and patients' expectations in our cohort. Looking particularly at the mismatch in expectations about excluding malignancy, this possibly reflects the fact that GPs base their referral on the current Head and Neck suspected cancer referral recommendations for hoarseness rather than patients' concerns and expectations. [13] Irrespective of the reasons for the mismatch, our results highlight the importance of exploring patients' concerns before the specialist consultation in order to address these effectively. The ACaPELa questionnaire is one way of bridging this gap.

The ACaPELa questionnaire has now been modified to make it easier for completion by the patients and interpretation by the clinician. In our opinion, it is a useful clinical tool and can be used in laryngology clinics as an additional source of information alongside the GP referral letter and the clinical findings to inform the clinical encounter.

In its latest form, the questionnaire also offers the option of a post-consultation feedback function. Patients can now answer "yes" or "no" next to each of their ranked questions as an assessment of their satisfaction at the end of the clinic consultation. Despite similar questionnaires being used and discussed in the ENT literature [8-9,14] the ACaPELa-R proposed feedback function has the uniqueness of assessing how well the patients' own concerns were addressed. Hence, the ACaPELa-R can be used to audit consultation performance as part of a clinical self-audit process. It can be also used as an immediate re-consultation and correction mechanism, where patients complete the post-consultation feedback, a clinic nurse checks the answers and informs the clinician of the patients with unsatisfactory responses. The clinician can then briefly see the patient again to address the concerns that remain unanswered. This could further improve patients' overall clinic satisfaction and result in a more patient-centred health care system.

We acknowledge that the latter process will incur additional clinic time to potentially see patients again after their consultation. This process will therefore not be suitable for all ENT clinics or hospitals, particularly taking into account that the majority of ENT clinics across the country are currently overbooked to meet demand, despite the ENT-UK recommendations for the maximum patient number per clinic. [15] The negative feedback rate was low in our cohort (4.4%) which allowed us sufficient time to see patients back at the end of the consultation to address any remaining unanswered questions. Nevertheless, this might prove challenging if high negative feedback rates are present.

Alternative ways of ACaPELa-R administration could be considered, such as the questionnaire being sent out to patients with their appointment letter or handed out at the

reception desk, and them handing the questionnaire directly to the clinician at the start of their consultation. The effectiveness of such alternative approaches would have to be evaluated to arrive at the best model to ensure the relevant information is available during the consultation.

Whilst the wider use of ACaPELa-R in other institutions remains to be explored, we believe that the value this input provides to the health care provision of our patients, outweighs the costs of implementing this process. We suggest that other ENT subspecialties instigate similar processes that help clinicians to appreciate why patients are attending clinics and allow them to be appropriately prepared to meet their expectations. This could be of particular importance in vertigo, tinnitus and rhinology clinics where frequently there can be many, varied and challenging aspects to patients' symptoms.

Conclusions

This paper proposes a novel way of integrating patient expectations into clinical consultations in the ENT clinic setting, resulting in more patient focused health care provision. We have revised and evaluated our questionnaire to the degree where it is easy for patients to complete, and provides sufficient information for the clinician to guide their consultation to address patient's individual needs. In addition, the questionnaire can be used as a performance outcome measure for self-audit purposes.

Summary

- The ACaPELa questionnaire was developed to understand patients' expectations from a laryngology clinic and guide clinical consultation.
- Our audit showed that the ACaPELa contained options with similar content, making rank ordering difficult.
- The questionnaire was revised to broader themes, resulting in the 5 question ACaPELa-R and a post-consultation feedback function was integrated within the questionnaire.
- ACaPELa-R performed well on validation with low rate of same-rank questions and high post-consultation patients' satisfaction.
- It can be used to understand why patients are attending clinics and allow clinicians to be appropriately prepared to meet patients' expectations.

Table I.

Patients baselines characteristics from our current and previous voice clinic cohort

		Historic cohort	ACaPELa cohort
Total patients		455	242
Gender	Females	288 (63.3%)	151 (62.4%)
	Males	167 (36.7%)	91 (37.6%)
	Ratio	1.7:1	1.7:1
Age	Mean (years)	52.3	52.8
	Range	14-100	17-87
	SD	18.8	17.8
Most common diagnosis		Functional dysphonia*	Functional dysphonia n=96 (39.6%)
		Laryngitis*	Chronic laryngitis n=33 (14.4%)
Cancer		5 (1.1%)	4 (1.7%)

*% not recorded

Table II.

ACaPELa patients' questionnaire responses

Question	Ranked first *	Ranked last *	Total Responses	Not ranked
1. I want to know what is wrong with my voice	81 (33.5%)	11 (4.5%)	201 (83.1%)	41 (16.9%)
2. I want to know what is wrong with my throat	79 (32.6%)	5 (2.1%)	206 (85.1%)	36 (14.9%)
3. I want to know what is wrong/diagnosis	59 (24.4%)	4 1.7%)	199 (82.2%)	43 (17.8%)
4. I want to know if I have cancer	41 (16.9%)	45 (18.6%)	158 (65.3%)	84 (34.7%)
5. I want to know if have something seriously wrong	34 (14.1%)	31 (12.8%)	187 (77.3%)	55 (22.7%)
6. Tell me what I can do to make my throat problem better	30 (12.4%)	8 (3.3%)	190 (78.5%)	52 (21.5)
7. Tell me how I can improve my voice/I want my voice to improve	21 (8.7%)	33 (13.6%)	173 (71.5%)	69 (28.5%)
8. I want to know what the ENT team can do to make me better	26 (10.7%)	21 (8.7%)	183 (75.6%)	59 (24.4%)

*37 patients (15.3%) gave same ranking to more than one question

Table III.

Modified ACaPELa questionnaire (ACaPELa-R)

Modified ACaPELa questionnaire
1. I want to know what is wrong with my voice
2. I want to know what is wrong with my throat
3. Tell me how I can improve my voice
4. Tell me what I can do to make my throat problem better
5. I want to know if I have cancer

Table IV.

ACaPELa-R patients' questionnaire responses

Question	Ranked first *	Ranked last *	Total Responses	Not ranked
1. I want to know what is wrong with my voice	34 (29.6%)	11 (9.6%)	106 (92.2%)	9 (7.8%)
2. I want to know what is wrong with my throat	47 (40.9%)	3 (2.6%)	112 (97.4%)	3 (2.6%)
3. Tell me how I can improve my voice	11 (9.6%)	23 (20%)	104 (90.4%)	11 (9.6%)
4. Tell me what I can do to make my throat problem better	6 (5.2%)	11 (9.6%)	108 (93.9%)	7 (6.1%)
5. I want to know if I have cancer	26 (22.6%)	42 (36.5%)	104 (90.4%)	11 (9.6%)

*5 patients (4.4%) gave same ranking to more than one question

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