

What do patients want from doctors?

Content analysis of written patient agendas for the consultation

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SUMMARY

Background. Although much has been written about what patients want when they contact their general practitioner (GP), there are no published data from large cohort studies of what patients expect.

Aim. To describe the expectations of a large group of patients who consulted with their GPs.

Method. A GP and a social sciences graduate carried out a content analysis of written agenda forms completed by 819 patients who consulted 46 randomly selected GPs. Inter- and intra-rater reliabilities were confirmed.

Results. A total of 756 (92%) agenda forms were returned. Inter-rater reliability was satisfactory ($\kappa > 0.6$ for all but two main themes). Almost all patients had requests they wished to make of their doctor, 60% had their own ideas about what was wrong, and 38% had considered explanations about why they were unwell. Forty-two per cent and 24% of patients had consulted because they had reached the limit of their anxiety or tolerance respectively. Seven per cent, 4%, and 2% had comments, which were usually negative, to make about previous management, communication with doctors, or time in the consultation.

Conclusion. These data demonstrate that most patients come to the consultation with a particular agenda. Failure to address this agenda is likely to adversely affect the outcome of many consultations.

Keywords: patient satisfaction; patient expectation; general practitioners.

Introduction

A key task of any consultation is for the doctor to discover why the patient has consulted, what the patient wants, and to elicit the patient's ideas and reasoning; in short, the identification of the patient's agenda. All four tasks of the consultation identified by Stott and Davies¹ are, arguably, dependent on its successful identification.^{2,3} Unfortunately, this is often not accomplished.^{4,5} Explicit recognition of the patient's agenda can theoretically be improved by enhancing the doctor's skills in eliciting it or by facilitating the patient in communicating it. Education of the doctor may require an increase in the doctor's understanding of the agenda or skills in eliciting it.

We have recently completed a randomized controlled trial of the effect of training doctors to identify the patient's agenda, and of patients writing down their agenda before the consultation and

giving it to the doctor. We used a patient agenda form (Figure 1),⁶ developed by JFM from previous work,⁶⁻⁸ which uses closed questions to collect information about particular actions requested of the doctor, but three-quarters of the space is allocated to open questions to encourage patients to express questions, ideas, and concerns. The completed agenda forms represent a cross-sectional sample of the agendas of patients who sought the help of their general practitioners (GPs), and thus present an opportunity to increase our understanding of the patient's agenda. In this paper, we report a content analysis of the agenda forms to describe the nature of the patient's agenda and the prevalence of the common themes.

Method

All GPs in Leicestershire and Nottinghamshire were invited to take part in the randomized controlled trial (RCT). Of the 103 who expressed an interest, 46 were selected at random. The design of the RCT in which these data were collected required that three consultation sessions were studied for each of 15 doctors in the education control arm and two for each of 31 doctors in the education intervention arm. Each randomly chosen consultation session had 16 appointments; half were randomly allocated to asking the patient who was given the appointment to complete an agenda form. Hence, a maximum of 856 agenda forms would be available for analysis. Receptionists were unaware of whether a consultation appointment was a control or intervention appointment until after it had been allocated to a patient. Those allocated to intervention appointments were asked to think of their list of concerns, to bring spectacles or an interpreter if needed, and to come five minutes early for their appointment so that they could complete the agenda form. They were instructed to hand the form to the doctor on entry to the consulting room and were aware that the doctor would refer to it during the consultation.

Ethics and consent

The RCT was approved by the Local Research Ethics Committee. Receptionists explained the study to all patients who had requested or were assigned an appointment during a study consultation session. This explanation was repeated and reinforced by a written information leaflet when the patients attended for their appointments. Patients were able to withhold or withdraw their consent at all stages between requesting an appointment and seeing their doctor.

Outcome measures and analysis

Quantitative. The frequency of responses to all questions and the number of items on each form were counted.

Qualitative. Everything patients wrote in response to the open questions on the patient agenda form was used in the content analysis. The initial analytic framework was developed from previous work by JFM³ and Stuart *et al.*⁹ This was further developed during the analysis of data from pilot studies and in an analysis of a random selection of 100 agenda forms from the study. At this stage no new broad categories emerged, although further

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Submitted: 21 August 1998; final acceptance: 12 April 1999.

© British Journal of General Practice, 1999, 49, 796-800.

To help your doctor:-

1. Please make a list of all the points you wish to raise:

2. Do you have any thoughts about these points (for example, the cause of your problem)?:

3. Do you have any questions?:

4. What would you like the doctor to do? (Please answer yes or no):

i. Prescribe	Yes	No
ii. Explain	Yes	No
iii. Investigate	Yes	No
iv. Write note	Yes	No
v. (Other – please say what it is)		

Figure 1. Patient's agenda form.

subcategories were identified. Definitions of each category and subcategory were prepared, and a further sample of agenda forms was analysed by a social science graduate. The forms were analysed by JFM, who repeated the analysis after six months to assess intra-rater reliability. The number of separate presenting problems and symptoms on each form were counted.

Results

Of the 46 doctors, 33 (72%) were male, 29 (63%) held the MRCGP diploma, 43 (93%) were United Kingdom graduates, and 31 (67%) worked in urban practices. Of the 856 consultations in which patients were asked to complete agenda forms, data from eight were lost in the post and 37 (4.4%) patients did not attend. Agenda forms were received for 756 of the 811 consultations but seven were blank. Therefore, completed forms were received for 92% of available consultations. Eight (1.1%) forms were written for the patient by a member of staff and one patient also brought a list. Patients responded to a median of two (range = 0–3) open questions; 722 (96%) responded to question 1 ('Please make a list of all the points you wish to raise'), while 447 (60%) responded to question 2 ('Do you have any thoughts about these points?'). A total of 46% responded to question 3 ('Do you have any questions?').

We identified an average of 1.6 (median = 1, standard deviation = 1.0, range = 0–11) problems on each agenda form and 1.7 (median = 1, standard deviation = 1, range = 0–10) symptoms on each form. Patients had a total of 1452 direct requests they wished to make of their doctor, with the provision of an explanation (69%) or a prescription (55%) being the most common (Table 1).

Content analysis

Table 2 shows the frequency of each theme identified in the qualitative analysis and the kappa values for the inter-rater and intra-rater comparisons in the subsample on which they were checked. Kappa values of greater than 0.2 ('fair' agreement¹⁰) were achieved for all categories and subcategories. Intra-rater kappa values of greater than 0.6 ('good' or 'very good' agree-

ment¹⁰) were achieved for all main categories, except 'Anxiety limit' and 'Tolerance limit', and 2 subcategories ('comment; management' and 'questions; treatment').

Almost all forms contained a theme expressing a request of the doctor. Two-thirds of patients wanted an explanation:

'...headaches ... I do not know what could be causing the problem that why I have come to see the doctor. Hoping that the doctor will be able to explain or try to help me find the problem as I can not understand while I keep get my problem...' (Patient 12408)

'I have been to hospital, and want Doctor to explain what is going to happen ... explain things to my wife ... what after-care I will need.' (Patient 10116)

Over 55% of patients requested treatment, not always reflecting expressed realistic expectations, and 44% requested investigations that sometimes may not have been appropriate:

'I would like treatment for a verucca on my right foot please... Treat on the spot.' (Patient 13113)

'Want to know if I can go for X-ray on my ankles and knees. They are very painful and have started to swell.' (Patient 12306)

Approximately 60% of patients expressed underlying ideas that were offered as explanations for problems or issues to be presented in the consultation:

'...I believe that there is something wrong with my neck and it either creates other symptoms or is a by product of something else...' (Patient 13105)

Approximately 30% of patients expressed themes concerning 'reasoning' when they either explained the rationale for their ideas or wanted the doctor to explain his or her thinking:

'...spots... Possibly viral or stress related because it is recurring and worsening... What in your opinion is the cause ... and why do you think that?' (Patient 11104)

Almost 40% of patients offered opinions about what they believed to be wrong and, at times, offered complex ideas about causation, some of which may have assisted with making a diagnosis:

'...three days off school, not picking up, headache, diarrhoea, aching especially around lungs — front and back, coughing with phlegm... Virus or beginnings of pneumonia...' (Patient 24103)

'Problems with legs, is it related to mental health problem? I think it is the same as I had in the 70s.' (Patient 10213)

Almost half of patients had specific questions they wished to ask of their doctor. Most commonly, these concerned treatment (approximately one-fifth of patients), either to clarify whether it was appropriate or reflecting concern about side-effects or lack of effect:

'... indigestion ... I told the doctor at the hospital about this ... and he gave me the name of a medicine that can be prescribed, it began with G but I can't remember the name...'

Table 1. Frequency of responses to questions on the patient agenda forms.

Question	Number (%) n = 749
Q1. Please make a list of all the points you wish to raise	722 (95.5)
Q2. Do you have any thoughts about these points?	447 (59.1)
Q3. Do you have any questions?	351 (46.4)
Q4. What would you like the doctor to do?	733 (97.0)
i. Explain	524 (69.3)
ii. Prescribe	413 (54.6)
iii. Investigate	335 (44.3)
iv. Write certificate or letter	110 (14.6)
v. Other	70 (9.3)

Table 2. Frequency of themes not related to symptoms or presenting problems on the patient agenda forms and inter- and intra-rater comparisons on a sample of 100 forms.

Categories	Full data set		Sample of data set	
	Percentage n = 749	n = 100	Inter-rater comparison n = 100 (kappa value)	Intra-rater comparison n = 100 (kappa value)
Request	95	99	95 (0.92)	94 (0.90)
Explanation	68	67	63 (0.88)	64 (0.92)
Treatment	57	64	54 (0.68)	55 (0.72)
Investigation	42	45	43 (0.92)	41 (0.82)
Test result	7	6	5 (0.66)	7 (0.72)
Ideas underlying	61	61	64 (0.90)	63 (0.94)
Reasoning	29	30	24 (0.60)	28 (0.86)
Offering opinion	38	34	35 (0.94)	34 (1.0)
Questions	49	59	48 (0.62)	55 (0.86)
Treatment	22	25	24 (0.92)	33 (0.52)
Limit of anxiety	42	10	14 (0.42)	13 (0.54)
Limit of tolerance	24	10	9 (0.80)	7 (0.40)
Reporting	27	18	16 (0.60)	16 (0.78)
Own situation	22	12	8 (0.34)	11 (0.84)
Raising issues	19	19	18 (0.90)	15 (0.66)
Comment on				
System	15	11	12 (0.84)	11 (1.0)
Management	7	3	2 (0.34)	2 (0.34)
Communication	4	4	5 (0.60)	5 (0.60)
Time	2	3	3 (1.0)	3 (1.0)
Administrative	14	14	13 (0.86)	14 (1.0)

Kappa values: 0.21–0.40 = fair agreement; 0.41–0.60 = moderate agreement; 0.61–0.80 = good agreement; 0.81–1.0 = very good agreement.¹⁰

Do you think maybe I need to go back on the bicarb tablets that I used to be on before?’ (Patient 10809)

‘Why was it when I started to take the Paramax they work and now they don’t.’ (Patient 20407)

Many patients had reached a limit that had prompted them to consult. Forty-two per cent of patients could no longer cope with the anxiety associated with their problem and almost one-quarter could no longer cope with their physical symptoms:

‘I have got a mole. It is getting bigger. Is it bad?’ (Patient 21612)

‘My left eye is giving me immense pain! ...if you spend enough time thinking about it (especially when its at its worst) the term “migraine” disappears and darker scarier alternatives suggest themselves. What is it? Tell me anything and everything it could be! (so I can worry properly!’ (Patient 13603)

About one-quarter wished to report issues that concerned

them; the most common issue (one-fifth of patients) being to make sure doctors understood how they were affected by their problems:

‘Want to emphasize the seriousness of my phobia. ...not typical of my personality. ...have extreme reactions which are beginning to affect my life.’ (Patient 22702)

Another one-fifth wished to discuss specific issues concerning their health. This was almost always the current oral contraceptive pill ‘scare’, although third parties and attendances at hospitals were also included. One in eight patients either commented about previous management (usually to complain), difficulties in communicating with doctors, or the time pressures in the consultation:

‘Knowing the trouble and being so near, why he didn’t come out the first time we rang.’ (Patient 23915)

‘When you try to explain your simums [sic.], it’s very difficult to get a doctor to understand. I think they need to spend more time listening.’ (Patient 34306)

'Different doctors who do not understand me give out some strange diagnoses.' (Patient 21011)

'There is not enough time to talk to your doctor, many of physical pains are caused by mental problems.' (Patient 22308)

Discussion

These data provide a unique insight into the ideas, concerns, and expectations of a large number of people who had consulted their GPs. They complement much previous work on patients' expectations of the consultation,¹¹⁻¹⁷ folk and health belief models,^{5,18-27} and consultation theory.^{1,2,4,28-30} They demonstrate that the consultation is, at many levels, a meeting between experts,⁵ both of whom can learn from the interaction. Patients' ideas about causation may be different from those of doctors,¹⁸ but are useful to the latter in improving their understanding of the patient's presentation and sometimes in making the diagnosis (Patient 10213). Nevertheless, doctors often interrupt patients' accounts prematurely (Patient 34306) and, perhaps as a result, their actions may be unrelated to the patients' underlying concerns⁵ (Patient 21011 and 22308). These data also demonstrate the wide variety of motivations for requesting a consultation:^{16,22,24-26} a limit may have been reached (Patient 13603 and 21602), or information, advice, or understanding desired (Patient 12408). These data also illustrate the tensions that may arise between the patient's beliefs and expectations and those of the doctor, for example, about the efficacy of investigation and treatment (Patient 13113 and 12306) or the patient's desire to know and the ability of medicine to explain (Patient 20407).

These data also complement existing research on the consultation by demonstrating that most patients come to the consultation with a particular agenda. Failure to identify this agenda is likely to affect the outcome of many, rather than a few, consultations. Identification of the patient's agenda lies at the very core of the consultation, it is not an 'optional extra'. For example, 40% of patients had consulted because they had become concerned about their symptoms, and 60% had ideas about why they had developed their problems. Not addressing or discussing these issues could undermine the outcome of consultation, especially if they were at variance with the reasoning of the doctor. This, coupled with the finding that two-thirds of people specifically want an explanation of their problem when perhaps no satisfactory explanation exists, demonstrates the importance of discovering what the patient wants. Failure to explain, even if only to explain that no explanation is possible, will diminish the patient's perception of the worth of the consultation.

A significant minority of patients have comments that may reflect adversely on the care that they have received. Whether these adverse comments could be avoided by careful attention to the patient's agenda in the first instance is unknown but would be a fruitful area of research for the future.

We believe these data to be unique in offering a breadth of understanding of the patient's agenda, together with an estimate of the prevalence of the themes among random general practice attenders. Nevertheless, the dataset does have its limitations. The depth of the data from each patient has been curtailed by patient literacy, space on the form, and the time required for its completion. Patients may also have been inhibited by the knowledge that their doctors would read the forms, which may have reduced the frequency of adverse comments. It is likely, therefore, that we have underestimated the prevalence of each theme in the community. We have taken care to ensure the validity of the

themes that have been identified by basing the initial analytical framework on existing research and further developing it by using both medical and social science perspectives. We also took care to ensure that the analysis was reliable by checking the inter- and intra-rater reliabilities. Therefore, although the methodology falls short of the 'gold standard' of in-depth interviews with a non-medical interviewer who could assure patients of complete confidentiality, this approach offers other advantages, particularly quantification of the high prevalence of the themes among randomly selected general practice attenders. We have no feedback from either doctors or patients on their perceptions of using the patient agenda form but we are preparing to publish the results of the RCT comparing the outcome of consultations in which patients were or were not asked to complete an agenda form and to share it with their doctor.

Conclusion

This work demonstrates that many patients have well formed ideas about what is wrong, why it has happened and what they want from their doctors. It is imperative that doctors make themselves aware of the agendas that patients bring to consultations. Failure to do so is likely to adversely affect the outcome of many consultations.

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Acknowledgements

We would like to acknowledge the cooperation of the GPs and patients who took part in the study, Dr Francine Cheater for advice, and Dr Mary Horton-Salway for her invaluable assistance with the analysis.

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