A question sheet to encourage written consultation questions

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Abstract

Problem

- Interviews with parents and children attending a hospital paediatric neurology clinic indicated they had difficulties in asking questions during consultations.

Aim

- To set up a process to enable parents and children to get the information they wanted.

Background and setting

- Two paediatric neurology clinics in separate hospitals in Greater Manchester, UK with a similar client group run by one consultant.

Design

- Various styles of question sheets were evaluated. The one that was chosen asked patients to write down questions and hand these to the doctor at the beginning of the consultation. Question sheets were given to all patients attending one clinic over a 13 week period.

 Strategies for change

- Use of sheets: number of patients taking or refusing a sheet, with reasons for refusal, were recorded. Doctors noted those who handed questions sheets to them
- Satisfaction with sheets: patients completed a short feedback form after the consultation
- Effect on consultations: evaluated through interviews with the doctors.

Effects of change

- In total, 66 (41%) of the 162 patients offered the sheet declined: 14 had already prepared questions; eight being seen for the first time felt they did not know what to ask. Seventeen had used the sheet on a previous visit and did not need it again; 19 gave no reason; the rest said they had no questions. Seventy six (84%) liked it and 61 (80%) found it useful. Fifty two (68%) wished to use it at future consultations. The doctors reported that through questions articulated on the sheets many issues, fears, and misunderstandings emerged which otherwise would not have been identified. Concerns about increasing consultation time and clinical disruption did not materialise. In contrast, doctors reported patients to be taking more initiative and control, particularly on subsequent visits. None of these changes was noted in the comparison clinic.

Lessons learnt

- An attractive, clear question sheet proved a simple but effective intervention in the consultation. Parents felt empowered to take control. The approach may have wider applicability, but implementation requires staff training and support to ensure its continuing use; this ensures medical staff adjust to a new consultation format, and that clinic nurses see the value of the sheets and continue to provide them.

Background

Patients often are reluctant to take the initiative and ask questions,1–3 and doctors fail to give patients the opportunity to ask questions.4 Yet more accurate recall of information has been found with patients who ask more questions.5 Patients’ questions help doctors to assess understanding and the need for further information.6 Doctors largely control and usually set the consultation agenda. Many patients do want to participate more in the decisions about their care but have difficulty overcoming “the inherent power structure of medical practice” and “time pressures within the consultation”.8 Studies of pre-consultation sessions with patients have found that this empowers patients to ask more questions9–11, but this is expensive. Pre-selected question lists are often inappropriate because people with knowledge may implicitly be dissuaded from establishing their own agenda. Providing patients with pre-consultation written information, for example leaflets and question prompt sheets that list potential questions, results in more active par-
A question sheet to encourage written consultation questions

...and there was no evidence of increased satisfaction, but the opposite can occur. Clearly, quality is more important than quantity and is better achieved when patients can communicate their agenda clearly and when doctors respond appropriately.

The studies report that question asking varies with patient variables (age, sex, and social class), the reason for the consultation (check up, diagnosis, and prognosis), and the context (for example, first visit with new doctor). Setting

Two paediatric neurology clinics (A and B) run by one consultant in Greater Manchester, UK looking after children who have long term neurological disability or recurrent paroxysmal disorders such as migraine and epilepsy. Families attending the clinics do so for initial diagnosis, a second opinion, to be given the news of disability, or long term follow up. Each clinic has a training role and two or three specialist registrars (and a senior registrar at the time of the study) are in attendance. Their work is supervised by the consultant in charge (RWN) whose practice is to see all families at the end of the consultation where a trainee has led. There is an active policy of encouraging parents to write down questions and bring them to the next consultation. Half the children have epilepsy, and a specialist epilepsy nurse supports work with these families. An auxiliary nurse also supports the clinics with access to a trained nurse.

Clinic support staff identified through informal discussion that it was common experience that consultations were not providing parents and children with the information they needed. This is not a new problem and is well documented. Parents had often not raised the issue concerning them most. Reasons cited were that they were conscious of time pressure on the doctor, or they thought their question was "silly". Children often had little knowledge about their condition or treatment plan.

It was decided to develop a question sheet to encourage parents to raise the points that were most worrying to them. This required some staff training. Nursing staff needed to see the potential value as part of a quality improvement programme. Trainee medical staff needed guidance on how to incorporate the sheet effectively into the consultation. In both clinics before the study started there was an active policy to encourage parents to bring their written questions along to the next consultation. It was planned to introduce the question sheet only into clinic A, allowing comparison with the standing policy which continued in clinic B.

Problem

QUESTION 1: WHAT WERE WE TRYING TO ACCOMPLISH?

In 1996, as part of a project to define the information needs of children with epilepsy an exploratory project was undertaken to elicit families' views of medical services. We became aware that users of our service were likely to want and need more information about the relevant condition than we were providing. To explore this assumption CC interviewed, using semi-structured interviews, a convenience sample of 15 parents and children from six clinics. They were asked about things they felt might be improved, if they were receiving relevant information, whether they still had unanswered questions, and in particular if the child's worries and needs were being addressed. Although there was a high level of satisfaction with the service, many did express difficulties with obtaining relevant information and felt that questions were often unanswered. For example, one child who has attended the clinic for some years asked, "what is epilepsy?"

We asked parents if they wrote down their questions before going to consultations and, if so, did they find it useful and if not, why not? Although all felt this approach to getting information "was useful", 10 had never written down their questions and only two had shown written questions to the doctor. Several felt that doctors would not like to be shown written questions and one parent, referring to a magazine article, expressed the view that if she did the doctor would consider her neurotic. Others indicated they would provide written questions if this were usual practice.

Yet, despite our policy of encouraging parents to bring questions to the next consultation we estimated that less than 15% of patients had done so in the previous six weeks. This led us to develop a question sheet to be given to families on arrival and handed to the doctor at the beginning of the consultation.

Designing a question sheet

The initial objective was to develop a more effective way to encourage parents and children to bring their queries into the consultation. Thus we did not wish to produce a sheet with lists of potential questions or strategies. Four question sheets were designed that varied in the amount of explanation that was included. These were presented to a convenience sample of 62 people—parents and patients attending the clinic, students, secretaries, and acquaintances—during a two week period. Ten of the sample were healthcare workers; all had been patients at some stage. They were asked what they thought about the idea and which format would most likely encourage people to write down their questions. All said they would probably use the sheet if it were offered when visiting a doctor: “Just being offered the sheet would make me feel they were interested.” Most preferred informal sheets with minimal explanation. Comments from these groups were used to produce the final version (fig1).

Key measures for improvement

QUESTION 2: HOW WILL WE KNOW THAT A CHANGE IS AN IMPROVEMENT?

Is the question sheet effective?

We focused on answering two main questions: (1) will parents use the question sheet? And (2)
how will it affect the nature of the consultation? We were also keen to find out which parents would not use it and why, to determine any problems with implementation, and to find out how doctors would feel about parents using it. Our interest was whether doctors would allow parents to be more in control, using the question sheet as a prompt, whether the sheet would complement rather than hamper consultation dynamics, and whether the consultation would be prolonged.

**Procedure**

The question sheets were used in one clinic (A) and data about the use of question sheets were collected from 13 consecutive weekly clinics. At the other clinic (B) during the same 13 weeks the consultant (RWN) noted the number of patients who arrived with questions as part of the usual policy.

Nurses in intervention clinic A explained to parents that they were “trying out a new idea to help improve the service” and offered each a question sheet. The number given out and reasons for refusal to take a question sheet were noted but in an unstructured way. Parents were asked to hand the sheet to the doctor at the beginning of the consultation. At the end of the consultation, doctors in clinic A asked if they could place the sheets in the patient’s notes for future reference. Parents who took a sheet were also given an anonymous feedback slip and asked to complete this and post it in a clearly labelled box in the waiting area. The consultant in clinic A had informal discussions with the three other doctors (one senior registrar and two registrars working in this clinic at this time). Notes from these discussions were used to structure an interview with the doctors.

A total of 182 children with one or both parents (in two cases, another close relative) attended the 13 clinics (fig 2). In total, 162 (89%) were offered the question sheet. Thirteen of the 20 parents not offered the sheet went into the consultation before being offered a sheet. The nursing staff did not feel it appropriate to offer a sheet to seven parents—of these seven, five did not speak English.

Ninety six (59%) parents accepted a sheet. Fourteen stated they would take it home for the next visit as they had not got their glasses. The nurses felt some may have had literacy problems and preferred to take the question sheet home. Thus, 82 (51%) of the parents offered a question sheet accepted it for the current consultation and 76 (47%) wrote questions on the sheet that were discussed during the consultation.

Sixty six (41%) parents declined to take a question sheet. No reason was given for 19. Sixteen stated that they had no questions; for eight it was their first visit and they felt they did not know what to ask until they had seen the doctor; two were not parents of the child; six considered the visit to the clinic to be “just a check up visit”. All parents were offered question sheets, but as the study progressed 31 parents were offered a question sheet a second time on a follow up visit. Seventeen who had used a question sheet on a previous visit felt they did not need/want one a second time. Four parents refused a sheet as they had already prepared a list of questions, and 10 said they knew what to ask.

Fifty four parents attended clinic B during a four week period. All were asked if they had prepared questions. None had prepared written questions; six (11%) had verbal questions prepared before the visit; 35 (65%) stated they thought up questions while waiting; and 14 (26%) had no questions.

**What parents felt about question sheets**

Seventy three feedback forms were returned. This represented 76% of the 96 accepting a form and 45% of the 162 offered a form. The form asked three questions (fig 2) the first and last rated on a three point scale and the second on a five point scale. The first set of figures are based on the 73 people returning the forms and the second set—in italics—includes the 23 who did not return the form and assumes they would have given an unfavourable response.

**Did you like the question sheet?**—Sixty four (88%) (67%) liked the sheet. Seven (9%) rated it as neutral and two (3%) (27%) disliked it.

**How useful did you find it?**—This was scored on an analogue scale: 1 = useful to 5 = not useful.

Forty three (52%) scored it as 5, and 18 (24%) as 4. Thus 61 parents (89%) (63%) were positive; nine (12%) scored it as 3, and 3 (5%) (28%) as 1 or 2—that is, not useful. Three parents who rated it 3 or 2 (that is useful or neutral) wrote that they had no questions this time but would like a question sheet for future visits. Of the three who rated it not useful, one offered a sheet on a return visit stated the doctor “had not even looked at the sheet and it was all a waste of time”.

**Would you like the question sheet at each visit?**—Fifty two (71%) (54%) replied yes; 18 (25%) (19%) said maybe; and 3 (4%) (27%) said no.

Of those parents who completed a feedback form, two (less than 5%) expressed some form of negative response. The majority—64 of the
QUESTIONS FOR THE DOCTOR STUDY

RESULTS:

Number of clinics .................................. 13
Attendance........................................... 182

Patients offered form.............................. 162 (89%)
Not offered because of language problem, (n = 5), distressed (n = 1),
aggressive (n = 1), went in to see doctor immediately (n = 13);
Refused form ........................................ 66 (41%)
Reason given:
Not recorded/given.................................. 19
Have written down already....................... 4
Know what to ask.................................... 10
Did it last time-no need............................ 17 – First 8 clinics ...... 6
Last 5 clinics ...... 11
Next time ............................................... 8
1st. visit don't know what to ask ............. 8

Took form............................................. 96 (59%)
Feedback form returned ......................... 73 (45% of those offered form)
(76% of those who took form)

14 said they would take it home for next visit.

FEEDBACK RESPONSES:

1. Did you like the form?
3 (yes) .......... 88%  67%  6%
2 .................. 9%  6%
1 (no) ............ 3%  27%

2. How useful did you find it?
5 (very) ........ 59%  63%
4 .................. 24%  63%
3 .................. 12%  63%
2 .................. 1%  28%
1 .................. 4%  28%

3. Would you like a form at each visit?
3 (yes) .......... 71%  54%
2 (maybe) ........ 25%  19%
1 (no) .......... 4%  27%

Figure 2  Responses from the study.

73 (88%)—had a positive response. Even if the
23 who did not return a form are considered to
have been negative, at least two thirds of the
respondents were positive.

Overall, 52 (43%) of the original 162 parents
offered a form took one, used it, and returned
their feedback slip with positive comments.

Doctors’ views about the question sheets
The three trainee doctors were asked a series of
questions by RWN at the end of study period:
- How often did they forget to ask for the form
  at the beginning of the consultation?
- To what extent did they use it to set the con-
  sultation agenda—did it alter their usual
  format for consultation?
- How often did questions arise which dif-
  fered from those expected and were there
  any that they would never have predicted,
  even knowing the parents?
- What were their perceptions of the parents’
  feelings about the question sheets?
- Would they like to continue to use the
  sheets?

As with any change in practice, the medical
team found it difficult to incorporate written
questions into the consultation. Each forgot
at least once to ask parents for the sheet and par-
ents did not always produce the question sheet
spontaneously. RWN and the registrars inter-
preted this as a sign of some parents being
reluctant to be assertive in the the consultation
and equally the professional inclination to
follow the path previously established and to
remain in control. After only two or three clin-
ics all doctors found that the question sheet
was useful and wanted the process to continue.

The main benefit identified by doctors was that
with written questions unpredictable issues
emerged along with things which the doctors
thought had been dealt with previously.

Doctors became aware just how often they
assumed explanations had been understood,
when clearly they had not.

Patients’ issues generally centred on the irra-
tional fears (from the doctor’s point of view) of
parents based on misunderstandings or a belief
system that the doctor could not have pre-
dicted. This was usually because the parent’s
fear had been biologically implausible. This
was an issue identified in earlier research by
RWN.19  The trainee doctors expressed their
surprise at this and agreed with the inference
that such fears and beliefs would seldom
emerge in consultations where the doctor led
the agenda.

Consultation dialogue was re-ordered. Ini-
tially, doctors would note the written questions
at the onset and return to them at the end of
the consultation. For the first six weeks they
found that consultations were taking about five
minutes longer than usual, the written ques-
tions being dealt with at the end. Subsequently,
it became easier to blend the structured items
of the purely medical with the parental agenda.
There was often an overlap between the two. At
times an irrational fear could be discounted at
the start of a consultation leaving parents more
relaxed and more receptive to the subsequent
content. The written questions and their
answers were dealt with in letters to the family
practitioner and the question sheet stored in
the case notes. Several older children also
brought written questions and became more
involved in consultations during the study
period.

As parents returned who had previously used
the question sheet, many consultations became
more focused and shorter. Parents began to set
the agenda, even without the question sheet.
For example, some parents came to the clinic
with one or two specific questions, related rel-
levant points of information, and requested let-
ters of information when needed. Doctors
noted too that some parents felt able to end the
consultation—clearly satisfied—but leaving the
doctor feeling under used and certainly not in
total control. As one registrar said early on in
the trial, “I was not in charge, which I probably
should be”. No such observations about the
process of the consultation were observed in
the comparison clinic.

Thus, although the doctors initially experi-
enced problems incorporating the question
sheets into the consultation process their initial concerns were not supported: the sheets did alter the nature of the doctor-patient dialogue and resulted in more satisfactory and efficient consultations.

Implementing and maintaining the service

QUESTION 3: WHAT CHANGES CAN WE MAKE THAT WILL RESULT IN CONTINUING EFFECTIVE USE OF THE QUESTION SHEET?

Two problems emerged with implementation. Firstly, not all parents in the study period were offered a question sheet and secondly, doctors forgot to ask parents for them at the beginning of a consultation. Once parents had used question sheets they tended to state that they did not need one for subsequent consultations and nurses felt uncomfortable offering the question sheets. So, to embed this into routine practice the question sheets were sent to parents with appointment cards. The doctors involved in the study found the question sheets useful and felt that they enhanced the consultation and thus became used to asking for them. To engage new staff and trainees (who rotate to another service every six months) a report of the work is given on arrival; the consultant discusses the theoretical background with them and explains how to use the question sheet to plan the consultation agenda.

This approach to enabling parents (and older children) to articulate questions and queries has now run for more than a year in the clinic without difficulty. Our observations confirm that it does alter the nature of the consultation and the ethos of the clinic. Many more parents now arrive at consultations with a prepared agenda—often with the question sheet—and expect to be asked to state their points first and engage in the consultation. The ability of all family members, including children, to formulate their ideas for the consultation setting improves with time.

Conclusions

QUESTION 4: WHAT LESSONS HAVE BEEN LEARNED AND WHAT ARE THE NEXT STEPS?

Our question sheet has brought benefit to the consultation process and we have been able to introduce it into our routine practice. A sizeable minority of families (43%) used the question sheet and wanted it to continue to be available: we conclude that it allowed them to raise their own agenda more easily. Clinic staff at first found it difficult to adapt practice and attitudes, but the demonstration of benefit and the lack of any negative effect helped them to change.

Doctors need confidence and training to change from controlling the format of the consultation to sharing this role with families. Some parents responded by taking responsibility for subsequent consultations. More parents and children now come with a prepared agenda and an expectation and willingness to be actively involved.

This approach did not suit all parents. Some already had prepared questions and were confident in their dealings with doctors. We want to find ways of helping those who attend for the first time, as several stated that they did not know what to ask until after the first consultation. Some did not want to use the question sheets at all, and a few disliked them. It would help to be able to identify these parents as some may benefit from other approaches.

Thus the question sheet offers an easy procedure for enabling this group of families to get more out of the consultation and to establish more active patient participation. This may have a much wider applicability.

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Key messages

- Patients leave consultations with important information needs and concerns unresolved, even when encouraged to ask questions
- Patients’ worries are often biologically implausible and cannot be foreseen by doctors
- An invitation on which questions can be written overcomes the reticence of many to ask what is most worrying them
- Use of a question sheet probably has widespread applicability; staff need training to use it effectively

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