Informed consent: what do patients want to know?

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Summary

Informed consent is an important aspect of surgery, yet there has been little inquiry as to what patients want to know before their operation. This study has questioned 50 patients within 3 months of an ENT (ear, nose and throat) operation. We found that most were happy to allow doctors to determine their treatment but they wanted to know about their condition, the treatment, and the important side effects. Fifty per cent of patients admitted worrying about some aspect of their recent surgery. More than two-thirds thought signing a consent form primarily signified agreement to undergo treatment and that it was a legal document; 54% thought there was an important medico-legal aspect. Over half thought information sheets would be reassuring, one-third thought they would provoke anxiety and 8% thought they would frighten them from having surgery.

Closer examination of the answers to our questions showed that those who were most worried about aspects of their surgery had a higher mean anxiety score, as did those who thought an information sheet would be either frightening or anxiety provoking. However, a higher anxiety score was not associated with a desire to know less about the proposed treatment.

Introduction

Although informed consent is a patient's basic right it is often taken for granted that most patients are happy to do as their physician advises. It is also commonly said that telling patients about their treatment only serves to increase their anxiety and may even dissuade them from undergoing treatment. Little has been done to determine either what patients want to know or what they think about informed consent. A recent survey performed by *Which Magazine*[1] indicates that patients want more information about their illness and treatment. This study was designed to determine what patients want to know when surgery is advised and to assess their attitudes towards informed consent.

Method

We interviewed 50 patients attending the ENT outpatient clinic at Freeman Hospital. All were over 16 years of age and had undergone ENT surgery under a general anaesthetic within the previous 3 months. All agreed to answer the questionnaire. They were interviewed by a number of the nursing staff after their consultation. The questions asked are shown in Figure 1. The assessment of pre-operative anxiety was made using a linear analogue scale. The scale was 100 mm long and its extremes were marked 'Not anxious at all' and 'Most anxious possible'.

Chi-squared test and one-way analysis of variance were used to assess differences amongst the patients, and any difference considered significant when $P<0.05$.

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Results

There were 50 patients. The mean age was 41 years. Forty per cent had not had any other surgery, 60% had had previous surgery, 26% having had a previous ENT procedure. Fifty-four per cent had not taken any school examinations, 30% had taken CSE or O Level exams, 6% had taken A levels and 10% had undergone higher education.

The results of the questionnaire are shown at the right hand side of Figure 1, the numbers are percentages. We also looked at particular variables and compared them with answers to other questions.

Anxiety score

Different age groups, previous surgery and how many complications a patient wanted to know did not affect preoperative anxiety. However, admitting to worrying about different aspects of the proposed surgery was related to preoperative anxiety ($P<0.005$, F-Test, 49 df). Those with no worries having a lower mean anxiety score than those with one or two worries, who in turn had a lower mean anxiety score than those with three or four worries (Table 1).

Attitudes towards an information sheet

We found that patients who thought an information sheet would frighten them from having an operation had a higher mean anxiety score ($P<0.025$, F-Test, 47 df). There was also a greater mean number of preoperative worries amongst those patients who thought an information sheet would be anxiety provoking or frightening ($P<0.05$, F-Test, 48 df). Patients personal opinion about informed consent was not related to their attitude towards information sheets (Table 2).

Education level

The educational level attained was not related to differing anxiety scores, differing numbers of preoperative worries, the sort of complications patients wanted to be told about and their attitudes towards an information sheet (Table 3).

Age

There were no differences in answers to questions 2-7, 10 and 11 between different age groups.

		Results (%)
Q1	Were you satisfied with the information you were given about your operation?	
	No - Too much information	0
	Yes - Just the right amount	88
	No - Too little information	10
	Don't know	2
Q2	Do you think an information sheet describing your operation, the important potential complications and how you would feel afterwards would be:	
	(a) Reassuring	57
	(b) Anxiety provoking	33
	(c) Frighten you from having the operation	8
	(d) Don't know	2
Q3	Is the consent form a legal document?	
	Yes	80
	Don't know	10
	No	10
Q4	Which statement best reflects your opinion?	
	(a) I will do what the doctor recommends	24
	(b) I want to know what my treatment involves but will have it anyway as doctor knows best	46
	(c) The treament I have should be agreed after discussion of the pros and cons of the treatment and any alternatives	24
	(d) I should make the final decision about my treatment	6
Q5	Which of the following statements best reflects your attitude when signing the consent form?	
	(a) It is a formality	0
	(b) It is to protect the Doctor against being sued	14
	(c) It confirms that the operation and its effects have been explained to me	16
	(d) It shows I have agreed to have the operation	70
Q6	How anxious were you before your operation	
		Mean Score 36 (95% Confidence Interval) (27.7-44.3)
Q7	Which of the following things would you want to be told before you have another operation?	
	(a) The nature of your 'illness'	92
	(b) The reason for the operation	98
	(c) What will be done during the operation (in general terms)	80
	(d) How you will feel after the operation	70
	(e) The IMPORTANT POTENTIAL complications	44
	(f) All complications	38
	(g) No complications	18
	(h) How long you should be off work	86
	(i) The chances of a successful result of the operation	88
	(j) Any special precautions you should take afterwards	92
Q8	Did you think you had to sign the consent form?	
	Yes	90
	No	8
	Don't know	2
Q9	Would you have an operation if there was risk of serious complication?	
	Yes	14
	Depends on level of risk and need for operation	84
	No	2
Q10	Before your operation were you worried about any of these things?	
	The anaesthetic	28
	Complications of the operation	16
	The operation being successful	52
	Not waking up	24
Q11	Do you think you can change your mind once you have signed the consent forms?	
	Yes	83
	Don't know	6
	No	11
Q12	Do you think the preoperative interview and signing the consent form is important because:	
	(a) It gives me information	84
	(b) It helps me make my mind up	36
	(c) It protects the doctor medico-legally	54
	(d) It is not important. I will do as the doctor says	56
	(e) It is not important because I have decided to have the operation	46

Figure 1. Attitudes to consent questionnaire

Discussion

Most patients were satisfied with the amount of information they were given. This agrees with the findings of other studies which asked patients about their attitudes to informed consent some time after they had signed a consent form[2-3]. It may be said that if this is the case then why give more information. However, the patients had not necessarily experienced fuller disclosure of information and could not compare what they were told with what they could have been told. Denny *et al.*[4] compared two groups of patients undergoing surgery, one group had been given an information booklet. Ninety per cent of both groups said that they had been given enough information.

Table 1. Factors related to anxiety

Different age groups		*Previous surgery*		*How much do you want to know about complications?*		*What did you worry about? (Anaes/complic/success/death?)*	
Age (years)	*MAS*	*Previous surgery*	*MAS*	*Complications*	*MAS*	*No. of worries*	*MAS*
16-25	36.7	None	43.2	All	38.6	0	14.4*
26-35	38.3						
36-45	38.8	Yes	28.9	Important ones	32.1	1	40.5
46-55	25.3					2	41.8
56-65	30.7	ENT	35.9	None	32.0	3/4	71.6
>65	48.3						

*$P<0.005$; F-Test, 49 df
MAS=Mean anxiety score; anaes=anaesthetic; complic=complications; ENT=ear, nose and throat operation

Table 2. Attitudes towards an information sheet

Attitude towards information sheets	*Mean no. of preoperative worries*	*Mean anxiety score*	*Opinion about treatment decision (Question 4)*			
			a	*b*	*c*	*d*
Reassuring	0.86	31.77	5	13	8	2
Anxiety provoking	1.46	33.9	5	5	3	0
Frighten me from having operation	1.75 *	59 †	3	4	1	1

*$P<0.05$, F-Test, 48 df
†$P<0.025$; F-Test, 47 df

Alfidi[5] used information sheets for angiography and 89% of his patients were satisfied with the information given and although 27% were less comfortable about having the angiogram only 2% refused the investigation.

Most of our patients wanted to know about their proposed surgery and its effects. Most wanted to know about the important complications of their surgery; it is difficult to know if the 38% who said they wanted to be told all complications understood what this would involve. In some respects this is a hypothetical question as they probably had no such experience and for some procedures the majority of the patients we studied would have had difficulty comprehending all complications. Perhaps we should infer from this response that these people want to know more about the potential problems of their surgery than they thought they were told.

The majority of patients are happy to do as their doctor recommends though nearly half say they want an explanation of their treatment. A further quarter expect to discuss the pros and cons of their treatment before agreeing to it. These findings are similar to the USA report of the President's Commission for the Study of Ethical Problems in Medicine[2]. That study found that 94% of Americans want to be told everything about their diagnosis and treatment. Forty per cent of patients who had undergone an inpatient surgical procedure trusted their doctor to decide their treatment. Thirty-one per cent wanted to decide after discussion with their doctor and 21% said they should make the final decision. Cassileth *et al.*[3] found that 75% of their patients thought that consent explanations helped them decide about the proposed treatment. The higher proportion of patients actively involved in decision making in these two studies probably relates to the larger number of high school and college educated subjects compared with our group who predominantly had not taken any school examinations. The President's Commission found that college graduates were most likely to actively participate in treatment decisions.

Table 3. Questions compared with educational level

Education level	*Mean anxiety score*	*Complications desired*			*Preoperative worries*				*Attitude to information sheet*		
		All	*Imp*	*None*	*Anaes*	*Complic*	*Success*	*Death*	*Reassuring*	*Anxiety Provoking*	*Frightening*
Nil	36.1	8	15	4	7	3	10	8	16	5	6
CSE/O	32.8	8	2	5	5	2	9	3	6	7	2
A	39.7	1	2	0	0	1	1	1	3	0	0
Higher	42.8	2	3	0	2	2	4	1	3	1	1

Imp=Important; Anaes=anaesthetic; Comp=complications

Information sheets improve patients knowledge about their condition, treatment and potential side effects[4-6] without necessarily increasing pre-operative anxiety[4,7]. More than half of our patients thought an information sheet would be reassuring, another third thought it would make them anxious and 16% thought it would frighten them from surgery. In comparison, 65% of American patients agreed that written consent forms helped doctor-patient communication[2]. Also despite 27% of Alfidi's patients, who were given information sheets being less happy during their angiography, most still thought their information should have been given to them[5].

Over two-thirds of our group thought that signing the consent form primarily signified agreement to have their operation. Smaller proportions thought they were either confirming that an explanation had been given or that the form primarily provided medico-legal protection for the doctor; however, half the group thought there was a medico-legal element to informed consent. Most patients thought the consent form was a legal document and they had to sign it, although most recognized that they could change their mind. The President's Commission[2] had similar findings with 8% of patients considering that their signature on a consent form established agreement to treatment. They considered the consent form to be an official document. About 80% of the Cassileth *et al.*[3] group thought consent forms were necessary and more than 75% thought they were 'legal documents to protect physicians' rights'.

We used a linear analogue scale when asking patients to assess their preoperative anxiety. This is an easily understood method of measuring anxiety and has been shown to correlate well with state anxiety scores[8]. Our patients assessed their preoperative anxiety to a linear analogue score of 36. This is similar to the 'post consent' preoperative anxiety scores (29.8 and 30.9) recorded by Dawes *et al.*[7] in another study. Over half of our group admitted worrying about the operation being successful. We examined the relationship between the anxiety score and worrying about different aspects of the operation. Patients who admitted worrying about more aspects of their surgery had a higher mean anxiety score. They were also more likely to think that an information sheet would be anxiety provoking or frightening. Similarly, those who thought information sheets would be frightening had a higher mean anxiety score. All these associations reflect unease about treatment but none of these variables influenced the amount or type of information patients said they wanted before an operation. Furthermore, 20% said they would not want to know what an operation involved and 18% would not want to be told any complications. These individuals were neither more anxious nor more worried about particular aspects of their operation. They still wanted to know why they were having treatment and how it would affect them.

The doctrine of informed consent underlines a patient's right to determine what is done to their body. Doctors are required to give an explanation that allows the patient to decide if they will have the proposed treatment. It is recognized that full disclosure of all aspects of the illness, its proposed treatment, the alternatives and the associated risks is a formidable task that would confuse and possibly terrify patients, making them refuse treatment. In fact, most patients are happy to let doctors decide their treatment, but once this is done it is easy to give little information either to prevent making patients more anxious or because there is little time available in a busy outpatient clinic.

However, it must be recognized that most patients want to know what their treatment involves. In any population there will be a spread of anxiety with some, more anxious than others. Just because somebody is anxious it does not mean they do not want any information. It is well recognized that information helps some people cope better with their anxieties. It can reduce their anxiety and enable them to comply better with the post treatment constraints and to recognize and act appropriately should there be any complications[9,10]. Of course, there are those whose anxiety is aggravated when given information, but these individuals should be identifiable during the consultation and often admit their fears and ask to be told as little as possible.

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