SEEKING CONSENT

Providing information

Patients have a right to understand their condition and the options available to them, and that includes the details of the treatment[1]. NCEPOD advisors expressed disquiet regarding the extent and quality of information that some patients may have received before entering the endoscopy room. This was particularly so in cases where the decision for a PEG insertion was made by non-medical staff, e.g. speech and language therapists, nutritionists or nursing staff without reference to medical staff.

Informing decision

Patients have a right to know the prognosis if the condition is left untreated. In an attempt to quantify concerns about consent NCEPOD asked its advisors to decide whether the procedure was appropriate and, if not, why not (Table 13). In 14% (230/1,625) of cases the advisors thought the procedure inappropriate and in a further 92 cases they had some doubt.

Table 13. Reasons why the procedure was inappropriate (answers may be multiple)

Reason	Total *n = 230*
A different endoscopic procedure was indicated	8
Surgery in the first instance would have been more appropriate	1
No endoscopic procedure was indicated	55
Futile procedure	145
Other	41
Total	**250**

The high numbers of procedures considered futile and where no endoscopic procedure was indicated are of particular concern. Futile procedures were those in which death was considered inevitable with or without the endoscopic procedure. Those where no endoscopic procedure was indicated were mostly patients with disseminated carcinoma, or some other condition where the procedure could not reasonably offer improved quality of life. Were these patients provided information on the risks and benefits of the procedure they were to undergo? Of course, it is easier to determine futility with the benefit of hindsight and a further study to look at this issue in more detail may be called for.

Real dilemmas for the endoscopist arise when the clinician encounters unforeseen findings. What is the sensible way to proceed?

Case Study

A patient was undergoing a diagnostic OGD when the endoscopist saw blood in the base of a peptic ulcer. There was no history of haematemesis or melaena and the patient had a Hb of 11.5gm/dl. The ulcer was injected with adrenaline, and the patient subsequently suffered a perforation.

Respecting autonomy

A patient who is of sound mind has the right to withhold consent, irrespective of the medical advice. There were several cases in which patients withheld consent until coerced into a procedure, particularly for insertion of a PEG after a stroke. Clearly this is not acceptable; it reflects the clinician's view of what is in the best interest for the patient, not the patient's view. However, dilemmas on respecting autonomy such as the following case are less clear-cut.

Case Study

A patient was admitted from a residential home where they had been in respite care. In the early hours of the morning the patient was found to be less responsive and had passed a melaena stool. Later that day a diagnostic upper GI endoscopy revealed oesophagitis, a discrete oesophageal ulcer, a large amount of blood in the stomach and a 1 cm acute duodenal ulcer. Two days later, after 3 units of blood and with a Hb of 9.9gm/dl, the patient was refusing further medical treatment and refusing to return to respite care. Three days later the patient collapsed with melaena and was given a blood transfusion. Later that day, and without written consent, an experienced SpR performed an oesophagogastroscopy, during which the duodenal ulcer was injected with adrenaline. The bleeding could not be stopped and the case was discussed with the surgeon who, in view of the patient's age, frailty and previously expressed wishes, thought surgery not indicated.

It is evident that in the patient's collapsed state they were unable to provide consent for the second gastroscopy. Was it appropriate to proceed given the patient's express wishes after the first endoscopy?

The circumstances above make the decision to proceed difficult. However, the GMC states that the expressed wishes of the patient must take precedent. *"Any valid advance refusal of treatment - one made when the patient was competent and on the basis of adequate information about his/her choice - is legally binding and must be respected where it is clearly applicable to the patient's present circumstances and where there is no reason to believe that the patient had changed his/her mind"*[4]. In the case above, was the advance directive of this patient valid?

Capacity to consent

16% (290/1,818) of patients were suffering from dementia or acute confusion. Those patients that were reported to be suffering from dementia or acute confusion who provided written consent are presented in Table 14.

Table 14. Written consent for those with dementia and/or acute confusion

Written consent obtained	Total	*(%)*
Yes	134	*(66)*
No	70	*(34)*
Sub-total	**204**	
Not answered	86	*(30)*
Total	290	

We were surprised to find that in these patients written consent was obtained in 66% (134/204). This is of concern given the guidance now available from the Department of Health on consent and patients without the medical capacity to consent to medical treatment. From the casenote review it was difficult to judge the extent of dementia or confusion for many of the patients. Nevertheless, with this diagnosis their capacity to consent must be questioned. An adult is presumed to have the capacity to consent if they can comprehend and retain treatment information, believe it and weigh it up to arrive at a choice[5]. If a patient has a diagnosis of dementia then the capacity to retain treatment information should be tested.

The advisor's opinion from case review was that often the process of obtaining consent was not transparent and in 18% (322/1,818) of cases the benefits of the procedure were doubtful. Since April 2002, new consent forms stating the risks of a procedure have been available and since April 2003, the closure of data collection for this study, the Department of Health has directed that they be used. Included is a form to be signed by the clinician that makes a decision on behalf of a patient without the capacity to consent to medical treatment[3]. Use of these consent forms should provide greater clarity around issues of consent and decisions made on behalf of patients, including those with dementia. The evidence from this chapter suggests that local audit based on issues surrounding consent is indicated.