Effective instructions for patients

Abstract—Information designed for patients aims to educate them. This means that the written word must be both read and understood. In whatever format patient information is presented it must influence patient behaviour and favourably affect compliance and morbidity if it is to be of value. The production of patient information should take account of the needs of the audience as well as the aims of the educators. Prototypes should be field tested to ensure that they are effective and that the material can be revised before general use. Patient information and its effect on the understanding of disease processes and management can be assessed by various standard techniques. Their effectiveness must ultimately be validated in randomised controlled trials.

During the last decade there has been a proliferation of information leaflets for patients with chronic disorders. This has been encouraged by the concepts of patient empowerment, the Patients Charter, shorter hospital stays and greater health awareness. Consumerism and the emergence of self-help groups have also contributed. These developments run contrary to the medical tradition of Hippocrates, in which telling patients the whole truth about illness was not considered to be in their best interests [1]. In recent times, opposition to patient education has been based on the idea that such an approach will increase anxiety levels, raise consultation rates and prolong their duration. Indeed, the trembling patient who asks an arrogant doctor for more information has not yet completely disappeared from the clinical scene. However, government directives now demand that patients be given comprehensive information about their disease, its management and complications. Consent to procedures must be informed and risks acknowledged. Patients are being encouraged to get the best out of consultations by arriving with prepared lists of questions [2].

Patient education services should enable both patients and their families to make informed decisions about their health, to manage their illness and implement follow-up care at home. Such an approach has been an essential component of nursing since the time of Florence Nightingale and it is usually nurses who provide the information.

Written information provides a permanent record which is available for later consultation. To be effective, it must be noticed, read, understood, believed and remembered [3]. There has been surprisingly little effort to ensure that patients understand what they are given and few attempts at evaluation. In diabetes and asthma the need to understand the disease so that one can effectively share in its management is critical to successful treatment. Without this need the drive to produce effective high quality information and education programmes has been restricted to enthusiastic amateurs. As more and more medication becomes available over the counter, commercial interests promote new treatments directly to patients accompanied by ‘package inserts’ on the drug and its side effects. Clinicians must be involved in the process to ensure that the information is accurate and interpretation balanced [4,5].

Unfortunately the sophistication of today’s society is not always accompanied by an equivalent reading ability. Literary skills do not correlate with years of schooling or an individual’s intelligence [6,7]. There is often a significant educational gap between the providers of health education and the patients for whom it is designed [8–10]. There is virtually no evidence relating to the literacy factor that determines whether health-related information is noticed or read. In addition, patients frequently fail to understand their doctor because of cultural and ethnic differences [8]. Such differences can block any form of communication, yet in the worlds of marketing and education there have been considerable efforts to improve methods of teaching and information. Attractive material can be made available through audio tapes and videos as well as booklets, but their scientific evaluation has been less rigorous, although media professionals monitor audiences to assess their response [11]. Where evaluation has taken place, long term gain in knowledge has been limited. There appears to be good correlation between learning by listening and by reading, although individuals may show a strong preference for one or the other; audio tapes can be particularly useful for the visually impaired, for those for whom English is a second language or for people who have poor literacy skills [12]. Videos would seem to have a specific place in skill building where they can begin the process through demonstration.

Evidence-based treatment depends on the critical evaluation of information and educational resources, therefore randomised control trials of their efficacy are just as important as any other therapeutic trials.

Patient information

The success of educational packages for patients depends upon the demonstration that the information influences delivery and utilisation of care. Although
some people still believe that the main purpose of patient education is greater compliance, Rankin and Stallings [13] have underlined the fact that education allows patients to make informed choices, which can include non-compliance. They prefer the terms adherence, concurrence and cooperation. Although it may be thought unlikely that patient education will reduce mortality, there is hope that it will improve adherence to treatment and cooperation with surveillance programmes and that a greater awareness of side effects will reduce morbidity [14]. Fordham [15] found that written information led to cleaner colons in those attending for barium enema Xrays, and Mullen et al [16] presented evidence that patients instructed were significantly more adherent than patients receiving no education.

Patients should be involved in all the processes—from the identification of needs through to evaluation which should include tests of readability, comprehension and recall; of particular importance to patients will be the effects of educational material on anxiety levels and confidence in their own skills when performing procedures. Another outcome that can be evaluated is a patient’s ability to consult the doctor at the most propitious time for early diagnosis and treatment [17]. Before educational packages are marketed, they should be tested on representative groups of patients and their effect on outcomes assessed through randomised controlled trials. Once proven beneficial, such packages will be cheap to provide and should be seen as an adjunct to drug therapy or surgery.

Production

The production of attractive and robust educational material (Table 1) has to be based on a disciplined evaluation of patients’ needs [18] and the identification of those critical messages which clinicians wish to convey. To maximise the benefits for partially literate people the purpose of the material must be explained, its message should be logical and should relate to personal experience rather than express generalisations [19]. Illustrations and cartoons can significantly improve comprehension although this is not always the case [20-25]. The role of illustrated material in patient education programmes will inevitably change with the growth of videos and multimedia resources. The gap between the literate and illiterate may become narrower and discrepancies between various studies in the use of illustrations will be resolved.

Evaluation

Reading still remains the key to information for literate people, and those who cannot read operate at present on a more restricted information base [26]. The scientific evaluation of patient information must therefore include tests of both readability and comprehension [27] as well as the long term effects of the material.

Tests of readability

Readability encompasses the ease with which a piece of writing may be read. While there are many formulae for doing this [28-34] they fail to take account of the interest and background of the reader. For example, a patient with inflammatory bowel disease will know much of the technical vocabulary associated with that illness, so these formulae can sometimes over-estimate the difficulty of understanding written information [35,36]. Readability formulae also fail to take account of the reader’s motivation and the meanings that may be derived from the context of well-written material.

Despite these reservations, readability measures are often used by health educators to ensure their products can be understood by a wide cross-section of patients [37]. An adequate score is not a sufficient indicator of good writing—good readability scores can be obtained by documents written in appalling style or with poorly chosen content. Using both shorter words and shorter sentences is likely to increase comprehension provided the change in readability is large [38].

Tests of comprehension

Comprehension can be systematically scored by the Cloze technique in which readers are asked to replace exact words which have been omitted from a text they have previously read [39-42]. It is probably the best method of assessing a document’s value in patient education programmes but has seldom been used in clinical studies. Possible reasons include the feeling that the test is similar to an examination which one may pass or fail.

For people who can understand things better by listening than by reading it is more sensible to read

| Table 1. Effective writing for patients |
|---------------------------------------|
| • Write in a conversational style;    |
| • Use short words and short sentences;|
| • Use direct questions;               |
| • Be consistent with use of words;    |
| • Limit each paragraph to a single message; |
| • Use headers to alert readers to what is coming; |
| • Minimise information unrelated to the central concepts in the text; |
| • Use affirmative sentences most of the time; |
| • Use negative sentences to emphasise avoiding an action; |
| • Place the most important information first or last; |
| • Ask patients to read your script and make suggestions. |
the text out loud or give them an audio tape. However, there is no universally recognised technique for measuring comprehension after listening.

Effectiveness of written information

About 70% of patients claim to have read information given to them. Some people will keep leaflets for future reference. However, in 1964 Mohammed [43] showed that 33% of her sample of 220 patients drawn from 300 diabetics were unable either to read or comprehend printed health information written at the most basic level, and this has been repeatedly confirmed [44]. A further 10% were unable to see the information to read it, although this is likely to reflect the nature of diabetic eye disease rather than be true for the population at large. Such studies suggest that a patient's reading ability should be formally checked before handing out printed information.

Effectiveness of video information

Rigorous scientific assessment of the educational value of videos for patients is uncommon [11,45,46]. The extensive use of video technology in endoscopy and laparoscopy provides an opportunity for the production of instant, personalised colour movies. In 1980 Parker [47] used such films to help patients understand the procedures they were about to undergo and subsequently to show them precisely what had been done and why they should follow discharge instructions even though they did not feel well. However, Levy et al [48] did not find that this reduced anxiety prior to the procedure. Nowadays videos can be produced cheaply and tailor-made for a given patient population. They can ensure a standard level of teaching and are particularly useful when there is a high rate of illiteracy.

Measuring the long-term effects of patient education

The aims of patient education include better adherence to treatment and greater cooperation with surveillance programmes. Learning can be measured by:

- Direct observation of behaviour,
- Rating scales and checklists,
- Oral questioning,
- Written assessment.

A further important aspect of assessing the long-term consequences of educational material is the need to measure persistence of new knowledge.

Direct observation of behaviour

This is the most accurate method because it is well recognised that there is a clear difference between what people say they will do and what they actually do [49]. This technique is commonly used when assessing the acquisition of new skills, such as self injection techniques. However, it is hard to quantify.

Rating scales and check lists

Rating scales which describe behaviour patterns in words can be constructed to assess the effect of patient education programmes. Wording must be precise and the scale should include all pertinent points.

A check list is closely related to rating scales. In such a list crucial steps in behaviour are chosen and during its use each element of this behaviour is recorded as present or absent. It overcomes some of the difficulties in quantifying direct observation of behaviour.

Both rating scales and check lists are best used for assessing activities such as self administration of injections, rather than the understanding of diseases and why patients do not adhere to treatment.

Questionnaire tests of knowledge

The effects of educational programmes can be assessed by testing patients' knowledge. Tests may be constructed in a true/false or a multiple choice format. They should present problems in a sequence from simple to complex and be appropriate for the patient's literary level. They need to be comprehensive and evaluate all the major concepts involved in the subject under investigation. Their contents are best determined in consultation with nurses and physicians in the field. This quality of a test is called content validity. The test score should also relate to actual patient behaviour in the present (contemporary validity) or the future (predictive validity), ie does a test score correlate with good adherence to treatment and so with better outcome? The higher the degree of validity the greater is its value for decision making.

Such tests have to be updated as knowledge about a disease and its treatment changes. A good example of such an approach is the kidney disease questionnaire devised by Devins et al [50].

Conclusion

Patient education does not consist simply of needs assessment, information giving and its evaluation. Patient education is an on-going process which needs periodic reinforcement. Although physicians and the lay population may differ in their opinions about whether patients should be provided with emotionally charged information, various surveys have shown that the vast majority of people believe they should be told if they have cancer or other potentially fatal diseases. In practice, information can reduce anxiety levels and consultation rates [51–53]. Patients have a right to know about all aspects of their illness. This knowledge
must be the foundation for any therapeutic alliance between doctors, nurses and patients.

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