Information leaflets

The printed word can supplement but not replace a consultation

In the early years of the NHS patients were given little explanation of their illnesses or the treatment proposed for them. Those with cancer or progressive neurological disorders such as multiple sclerosis were rarely told their diagnoses; those with terminal disease were seldom even told that they were dying. Much has changed for the better, and clinicians do now make an effort to communicate, but investigations by bodies such as the Audit Commission have shown that too many patients are still uninformed or ill-informed.[1]

Research has consistently shown that patients are more likely to continue with drug treatment if they have been told what the treatment is intended to achieve, what side effects may occur, and that alternative treatments are available.[2] The same seems to be true of screening. The more time and effort that is given to explaining the purpose of the test and the possible outcomes, the more likely are people to comply.[3] Conversely, patients who do not understand the purpose of a test are likely to refuse it.

The first screening tests that came into general use, such as measurement of the blood pressure, have been around long enough for their existence and purpose to be part of general knowledge. More recent tests need more explanation, especially if the disorder for which the test is done is one unfamiliar to most people. Explanation is especially important for tests which have a high rate of recall of people who will prove to be false positives: anxiety in the waiting period can be reduced by an effective explanation of the purpose of the recall and the likely outcomes.[4] As more tests for genetic disorders and for the identification of genetically determined high risk categories come into general use the public will need much more information, and in many cases one solution will be the distribution of a leaflet.

Printed information leaflets do help. No matter how much time and care is given to an explanation by a clinician patients rarely absorb all the essentials. Tests of recall consistently show that within five minutes of a consultation patients cannot remember half the information given to them. Probably much of it was never absorbed: understanding is impaired by anxiety, by unfamiliar surroundings, by physical distress, and by separation from family and friends.[5] Elderly persons find new concepts more difficult to understand.

In an ideal world many of these communication defects could be solved by providing printed information to supplement the consultation. The information pack should consolidate by repeating everything the doctor or nurse told the patient (making sure that there are no conflicts in the advice given in writing and by mouth). The written material can go into greater detail, providing background information for those who want it.

Anyone planning to write and design an information leaflet has a mass of expert advice available.[6] Writing simple English isn't easy (which explains why journalists on tabloid newspapers are highly paid for their difficult work).[7] Short words and short sentences help. Use the active not the passive voice. The explanation has to be clear, precise, and unambiguous. Describing tests or equipment as "special" does not help understanding. Do not gloss over hazards and possible discomfort or pain. Ask a critical friend (ideally with no medical background) for an opinion, and take notice of what he says. Design is important, too. Get advice on the size and design of the type face, on colours, and on illustrations. Do not assume that glossy, expensive looking material is best. Some research has shown that simple line drawings are more effective than highly coloured pictures. Cartoons and photographs may be offputting rather than helpful.[2]

Producing a leaflet will not, then, be an easy task. Health professionals intending to write one should first ask whether they need to start from scratch. Very probably another health authority, a national charity, or the Health Education Authority may have one that has been tried and tested and will need just a few sentences added to take account of local conditions, give addresses, and so on. If no existing model is available it is still worth looking at leaflets in current use for related disorders or tests to see what designs and approaches have been developed. Find out which leaflets have been tested, and with what results.

Rigorous evaluation may give unwelcome results. Patients tend to tell their doctors what they think the doctors want to hear, and their comments need to be examined critically. For example, research into screening for cystic fibrosis has shown that most people given leaflets and replying to questionnaires say they found the literature useful, and in one study more than 90% said they found the text "easy to understand". More detailed questioning showed, however, that more than one third of couples who found the text easy to understand had not understood it: they gave a wrong answer when asked their risk of carrying the cystic fibrosis gene.[8]

At page 15 Patnick *et al* describe how they revised the leaflet on the NHS breast screening programme to take account of research evaluations – which had shown, for example, that blue was less frightening than red as a colour for the text – and how they then tested the provisional redesign in focus groups. These included women aged 35 to 64 and a study in depth used women from two different socioeconomic groups. Discussion in the groups showed that one sentence about screening women under 50 was being misinterpreted and that the women did not like the photographs, which used models who looked "too serious and too old". Careful testing of this kind is essential if information material is to achieve its aims.

Health professionals should not, however, assume that all their communication problems can be solved by providing leaflets, even if they have been carefully evaluated. They should certainly not assume that a leaflet or booklet makes individual counselling unnecessary. University graduates who are worried about something are likely to go to a library and look up a reference book, but most people are not in the habit of using written information to solve their problems. They prefer to ask friends or neighbours or phone up telephone information services. We need to bear in mind that response rates to questionnaire surveys rarely exceed 80%, reflecting the one fifth of the population who prefer not to have anything to do with written material.

These include some people who are actually functionally illiterate, those with poor comprehension of the written word (and for whom even very simplified health education booklets are ineffective), and those from immigrant communities who have not learnt much English. (Translating leaflets into minority languages does not necessarily solve that problem: many immigrants who cannot read English cannot read their own language, either, and hospitals have learnt that direction symbols may often be more effective than multilingual written signs.) In Britain 33% of men and 40% of women have no educational qualifications at all; for the over 60s these figures are 55% and 70%.[9] We should not expect people who rarely read anything to follow a written explanation of concepts such as recessive inheritance. How long did it take us, as students, to grasp the basics of genetics?

Leaflets, booklets, and even large medical encyclopaedias answer a demand from some patients for more information about their illnesses and about screening tests. The articulate section of the population will inform itself, and many others will make use of material if it is given to them. But we should not forget the substantial minority who read with difficulty if at all, who have learnt to conceal their lack of literacy because they are ashamed of it, who will deny any anxiety because they fear displaying their ignorance. This group needs to be given time in face to face consultation.

36 College Crescent,
London NW3,
United Kingdom

A J SMITH

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