A PIL for every ill? Patient information leaflets (PILs): a review of past, present and future use

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This article reviews the usefulness and importance of written information, specifically leaflets, being given to patients. Evidence suggesting how both patient and doctor may benefit from the giving of written information is reviewed. Identification of good practice relating to the content and readability of leaflets is discussed. An argument is put forward that the giving of written information is an under-utilized resource in contributing to improving patient outcomes but that this may be changing with the increasing use of patient leaflet databases. The advantages and disadvantages of computer-generated patient leaflets are discussed and desirable further areas of research on computer-generated leaflets are proposed.

Keywords. Computer systems, health education, medical informatics, pamphlets, physician–patient relationships.

Methodology

References were drawn from a Medline search on patient information and from the authors' collection of material gathered over the past few years. The Medline search was carried out in October 1996 using the search terms "Patient Education", "Health Education" and "Pamphlets". The reference sections of articles were then used as a basis for identifying other sources of information.

Introduction

It is well known that patients forget or misunderstand much of what is discussed during a consultation. This was identified as early as 1972 and as recently as 1997, and seems to be an on-going challenge for physician-patient relations. One study showed that, on average, patients had forgotten half of what the doctor had told them within 5 minutes of leaving the consultation room. In general, people may only retain about

20% of what they hear, but this may increase by up to 50% if there is additional visual or written input.4 It could be argued that good clinical practice should include, whenever possible, the giving of patient education materials in addition to verbal advice, even if the verbal advice is exemplary. The UK Patients' Charter⁵ states that people have the right to clear explanations of proposed treatment. Rising to this challenge, there seems to be a growth industry in providing patient education material on video, audio, computer and the Internet. 6-8 However, the 'humble leaflet'9 remains the most widely used method for conveying health information. In recent years there has been a proliferation of leaflets written for an increasing number of health topics. 10 There are benefits not only to the patient but also to the doctor if the levels of patient understanding and education are enhanced.

The patients' perspective

"Like most patients these days, Mrs Smith was hungry for information. . . . the majority, when visiting their doctor would like printed matter to take away and read." So says a health columnist of the Daily Telegraph. Patients do want more information about their health care. Better communication aided by written information generally increases patient satisfaction. Written information reinforces what has been

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discussed. 14,15 Leaflets can be referred to by patients away from the stressful environment of the consultation room "to refresh and review their knowledge at all stages of their condition". 16

But do patients actually read them? Weinman confirms the desire, use and value of information leaflets by patients.¹⁷ He quotes studies showing that 75% of patients wanted written information with their medication and 80% read them. On the other hand Meredith writes "yet we know that the public ignores much printed literature on health. Research by Budd and McCron¹⁸ has shown that, despite agencies' reliance on leaflets to provide people with information, the public does not use information provided in this way, nor particularly likes doing so." The argument which they use to explain an apparent under-use of leaflets by the public is that many are poorly understood (a point discussed below). They suggest that general information on health is probably least used, but literature on a specific condition is likely to be read more by those whom it affects. It would seem that a leaflet given to an appropriate person as an adjunct to a consultation (about a drug they have just been prescribed or a condition just diagnosed) is what is wanted by patients and what will have the most impact.

Good written information can provide further gains to the patient apart from satisfying their hunger to be better informed. Some doctors may be concerned that providing patients with more information may lead to increased anxiety about their illnesses or treatments.¹⁶ This is not generally so. Good information leaflets can reduce anxiety and do not result in an increase of side effects from treatment. 13,17,19-21 Written information also aids recall of advice^{22,23} which may improve compliance or concordance in treatment. 10,13,24 Evidence also suggests that information leaflets contribute to a better outcome of illness in better-informed patients.²⁵⁻²⁸ This is in step with one of the conclusions of the Toronto consensus statement on doctor-patient communication, that the quality of clinical communication is related to positive health outcomes.²⁹ A recent evaluation of leaflets distributed by the Arthritis and Rheumatism Council confirmed this. For people with rheumatoid arthritis who received an information leaflet, the report states "there was an increase in the knowledge patients had of their condition, there was an associated decrease in their pain and there was an associated decrease in their depression".16 The report also reminds us that better-educated patients are enabled to participate more actively in their own treatment.

The doctors' perspective

To offer patients literature as an adjunct to the consultation may be regarded as a sign of respect and caring, whether or not the patient uses it.³⁰ The simple act of

giving some written information may therefore enhance the doctor-patient relationship. However, there may be more tangible benefits.

Improved education of patients may increase their self-reliance and reduce repeat consultations for a recurring problem. One study demonstrated that a health education booklet reduced the number of GP consultations for common childhood illnesses.³¹ In a study of backache in general practice, the use of an educational booklet was associated with a reduction in the number of patients re-consulting with back pain.³² A more recent study showed that a leaflet issued to patients with respiratory infections reduced their re-consultation rates.³³ By implication, reduced re-consultation rates may increase self-care, reduce prescribing and lower the physical burden on health services.

In addition, a GP may sometimes prescribe even when it is not strictly necessary nor expected by patients.³⁴ In one study, 22% of GP prescriptions were felt to be not strictly necessary by the GPs who issued them.³⁵ There are many "disparate factors on the decision to prescribe".³⁶ In some situations, the issuing of a prescription may serve as a strategy to close the consultation.³⁷ For such consultations or in some situations where an illness is self-limiting or medicines can be obtained "over the counter",³⁸ the closing "gift" of an advice leaflet may be an alternative to the closing "gift" of a prescription.³⁹ This may be acceptable to both patient and doctor and needs to be studied further.

For ongoing conditions, Chadwick and Kemple suggest that some leaflets may be good homework for patients between consultations.⁴⁰ For example, giving a leaflet on depression to read before a follow-up appointment to discuss treatment. They also maintain that leaflets may stimulate debate within a consultation and allow patients to ask appropriate questions. Junior doctors, students and seasoned health care professionals alike may also learn from patient leaflets to increase their own understanding and to learn ways of explaining conditions which they can later use with patients.¹⁶

Ideally, the written leaflet to take home should have reflected what has been discussed in a consultation. In practice, some points may have been forgotten to be mentioned. Doctors may be reassured that a leaflet from a reputable source will consistently include a standard amount of information which has previously been thought through in detail. This may have some medicolegal repercussions. To have documented in a patient's notes that 'leaflet x was given' may be used as evidence in a subsequent complaint about poor information. Fawdry goes further and suggests consent forms should read, for example, "I have read, or have had explained to me, the leaflet entitled 'sterilisation of the female' . . . ''.41 This, he argues, may help get round the problem of variable advice being given by junior or new doctors. However, Meredith rightly cautions that "information given in support of oral communication must not be used to shield doctors from their patients". It is not that leaflets should replace a full discussion with a patient but can be thought of as a consistent basis of information which doctor or patient may wish to expand upon.

What makes a good leaflet?

Vast numbers of patient leaflets abound. Their content and quality vary tremendously. "To be effective, it (the leaflet) must be noticed, read, understood, believed and remembered." Are they?

Commentators have often despaired about the poor readability of many leaflets. 41,43-47 Leaflets may not be understood by over a third of the people for whom they were intended.⁴⁷ In order to achieve a wide level of readership, the reading age of a leaflet needs to be seriously taken into account in order to be as "plain as can be".48 Two review articles about patient information both comment that, despite there being a vast amount of literature produced, few studies have been undertaken to evaluate this resource to determine whether health professionals actually get their message across. 10,20 Mayberry and Mayberry insist that "the scientific evaluation of patient information must therefore include tests of both readability and comprehension as well as the long term effects of the material".20 Obviously, not all leaflets are badly written, but a significant number are, and it should be of prime importance to leaflet authors to acknowledge this. At least some patient organizations take a lot of care in the production of their leaflets, including readability assessment and evaluation. 10,16 There is now ample advice from a variety of sources on 'how to write a good leaflet' with respect to style, language, layout, print size. readability, diagrams, colour and numeracy. 1,16,48-50 There are a number of articles and publications that pool and review the evidence for this advice and these are recommended to authors of new leaflets as a resource.51-54 All new patient leaflets should declare an objective score of readability using a standard formula.55,56 However, readability formulae and reading age measures are fallible as they use such criteria as sentence length, syllable count or vocabulary indexes.51,57,58 For instance, the word 'fey' is a short word which scores well using standard measures of readability but is a word that is neither widely used nor understood. Also, readability formulae do not usually take into account such factors as a patient who would normally have acquired specialist vocabulary for his or her illness. For example, a patient with polymyalgia may have come across this word but the word will skew standard reading formulae, indicating that a leaflet may be harder for that patient to understand than it really is. Nevertheless, an objective readability score is a sound starting point for a leaflet to then be peer reviewed by lay people, GPs and self-help groups who could then offer further suggestions for revision.⁵¹

What is the reading level to aim for? Albert and Chadwick suggest that practice leaflets (designed to give information to patients about their general practice) should not exceed a readability age of 12.59 Griffin, writing about leaflets to accompany medicines, states "patient information leaflets should accommodate themselves to the average reading age of the British public which is stated to be about 9", but concedes that "this is no easy demand".60 Although leaflets need to be simple to be understood by most people, a style which is too simple could sound patronizing and may lack interest and 'authority'. One study showed that documents edited to make them easier to read often became less interesting, with readers preferring the original versions. 61 Whatever the readability age of a leaflet, the author should at least know what it is and be satisfied that it is appropriate for the intended recipients.

Clinical content of leaflets

In order to be believed, the clinical content of a leaflet should be correct, balanced and unbiased and according to Meredith leaflets should be "developed independently of commercial interests".9 A large number of leaflets currently used are sponsored by pharmaceutical companies as they are widely available and often free. This may raise a concern over the content of the material, but there is a new and growing concern. The Internet is undoubtedly a rich source of information,62 but there is unease over the variable quality of health information on some websites63 and "unless we evaluate the quality of clinical sites and their effects on users, we risk drowning in a sea of poor quality information".64 A reasonable first start to searching websites for hopefully reliable information for patients may be from academic institutions in the United States⁶⁵ and UK⁶⁶ and other quality websites are becoming available all the time. 67,68

The confidence placed in a leaflet probably increases when written by one of the more reputable organizations. Nevertheless, newly written leaflets from any source should include references—something not seen on many leaflets—and be peer reviewed with specific references to ensure accuracy of clinical content and advice. And further, the challenge to keep the information up to date is admirably put by Walsh—"Since health care changes so rapidly, it is a challenge to keep every piece of our patient education materials up to date. If the materials we give to patients have become outdated, then we are misinforming them."⁴⁹ Newly written leaflets should all be dated—again, something not always included.

A formal testing of a new leaflet on patients may be the final test to ensure that a leaflet is acceptable in content and style. There needs to be a balance between evidence-based advice presented in a readable way with common sense or encouraging remarks. Comments such as "have an early night every week and pamper yourself a little" in a leaflet about herpes simplex⁶⁹ may not be evidence based but may make the leaflet appear friendly and allow the evidence-based material in the leaflet to be absorbed.

The confidence of health care workers who give out leaflets and their patients will be enhanced if they know that a leaflet has been objectively scored for readability, peer reviewed for clinical content, evaluated and finally tested by patients with regular revisions having been made based on user feedback and new knowledge. There is increasingly a case for an independent reviewing body to give some kind of 'kite mark' or standards for rating such factors.

A case for clinical trials?

Mayberry and Mayberry argue for even more stringent testing of patient education material. They state "randomised controlled trials of their efficacy are just as important as any other therapeutic trials . . . before educational packages are marketed, they should be tested on representative groups of patients and their effect on outcomes assessed through randomised controlled trials".20 With the numbers of leaflets being written rising it is difficult to conceive this happening in reality to the majority of leaflets. Nevertheless, if patient information leaflets are to contribute seriously to patients' well-being (and at least to do them no harm) then this must be the standard to aim for. Indeed, such leaflets should be prized and 'prescribed' in preference to others with similar titles which have not undergone such testing. Certainly, for the more serious chronic disorders which require optimum patient education, this goal should be aimed for. There are a number of reports in the literature of leaflets undergoing controlled trials.32,33,70

The best use of leaflets

It has been argued that one of the most important aspects of a 'good' leaflet is that it needs to be noticed.⁴² Placed among a mountain of other leaflets, the glossiest and most colourful may perhaps have the highest profile in the waiting room. However, evidence suggests it is the one placed in the patient's hand by the health professional that is noticed the most, read most and has the most benefit.⁷¹ Griffin and Griffin comment on a survey which 'found that although people of all ages obtained their health information from a variety of sources, the information they valued most highly was that provided by the GP . . . GPs are ideally placed to

influence patients' behaviour and overall, 80% of respondents were very or fairly satisfied with the treatment or advice provided by their GP''.⁶⁰ A GP's gift of a leaflet with the authoritative recommendation to read it will have most impact and even more so if the doctor goes through the leaflet with the patient, pointing out important points rather than simply issuing it at the end of a consultation.⁷¹ Leaflets should not be solely left lying around in the hope that the right person may notice them and pick them up. Written information should be targeted at those who would most benefit from them as part of their planned health care programme,⁷² and those who give it should be confident of its quality.

Storage, retrieval and distribution of leaflets

The Arthritis and Rheumatism Council produced 1 446 000 leaflets during 1994-1995.16 One might assume that for a common chronic disease such as arthritis, at some stage along the line a leaflet would be given to a patient by somebody. However, more than half the patients surveyed with arthritis did not recall having received a leaflet at all in the past.16 There is little published relating to how often health workers gave literature to patients. A Danish study⁷³ concluded that most GPs (97%) used health education material but that the use was variable. Only 34% reported daily issuing leaflets during consultation, 47% reported weekly use of leaflets and 20% issued leaflets less often than weekly. Frequency of use was generally higher in female and younger GPs. On average, GPs used health education material on 10 different topics. The main reasons given for health education material not being issued were that they felt the patients would not use it or that it was not necessary. Another study looked at the frequency of distribution of leaflets by health visitors. This too demonstrated a wide variation of issuing leaflets.74 The variation was partly explained by health visitors personal beliefs about the appropriateness and value of leaflets, and a reluctance to use commercially sponsored leaflets was a factor mentioned by some.

These two reports are in contrast to a study where 90% of patients of a general practice in the USA wanted written information in connection with the consultation. This apparent conflict between doctors and patients attitudes to the use of written information was echoed by the Arthritis and Rheumatism Council's study which states "there was a conflict of opinion between the professionals and the patients about the dissemination and availability of leaflets. The patients favour free access to information whilst the consultants and allied health care professionals wish to exercise more control over distribution of the material."

Storage problems of pre-printed leaflets have been commented on as another reason for poor use of leaflets. In the report on health visitors' use of leaflets it states "some health visitors were resentful of receiving large numbers of un-requested booklets and leaflets . . . And storage space could be a problem. A number reported simply discarding all such material."74 Fawdry writes on excessive numbers of leaflets being produced for his speciality. He comments "in practice, such booklets or pamphlets almost always end up unused and outdated in drawers and cupboards despite the best of intentions",41 and advocates computerization to be the way forward. Even more so is the experience in general practice. Good use could be put to a vast array of leaflets, but to keep an up-to-date supply of such leaflets is an onerous task.

At present the frequency of use of leaflets in UK general practice is unknown. It is probably not dissimilar to that in Denmark, with quite variable frequency of distribution but most doctors perhaps sticking to a relatively small number of familiar titles for common situations. In 1990 Kitching wrote of the situation in the UK: "patient information leaflets are to become a normal feature of health care in this country. Their advantages and benefits are evident, but they require careful preparation and support of oral information at the point of delivery." Eight years on it would seem that patient information leaflets continue to be an underutilized resource, and possibly vastly so.

Patient leaflets with medicines

The importance of patient leaflets to accompany medicines has been recognized and acted upon. Patient leaflets are to become mandatory accompaniments to all medicines that are dispensed in the UK by December 1998.^{76,77} This has been seen as "arguably the most important development in patient information for a decade". 78 An evaluation of a small number of leaflets to be introduced with prescription medicines in Britain was undertaken and the report summary states "the 1,809 patients who received the leaflets knew more about their medicines, especially their side effects and were significantly more satisfied than the 1,601 who were not given additional written information . . . and almost everyone, 97%, thought they were a good idea".79 This confirms the notion that better-informed patients are more satisfied. However, this study was a pilot evaluation with leaflets handed over to patients. Whether this level of satisfaction is maintained with package insert prescription information leaflets80 ('stuffer sheets') has been contested.81 Package inserts are often thin, multiply folded and printed in small type, presenting barriers to physical readability, cannot be updated if changes occur before the expiry date of the pack and may be perceived as lacking in importance and relevance, a belief which this method of delivery may bring about.82 Evaluation studies, in the UK, of package inserts so far has shown that the effectiveness and reaction to leaflets has been mixed with the leaflets' being described as offering only a 'cuddle factor',83 not increasing knowledge84 and giving excessive information.85 One of the main problems with the prescription information leaflets included in drug packs is that they are rarely condition specific, as drugs can usually be prescribed for a number of conditions. It is likely that personalized computer-generated patient leaflets to be given out by pharmacists or other health professionals may have advantages and have been advocated as the way forward,78 as is widely practised in the United States.82 A study conducted in the UK showed that training and encouragement of pharmacists is necessary if the full benefit of leaflets is to be realized.86 This is likely to be a finding relevant to all health professions who have a role in the issuing of leaflets. Other studies have shown that professional attitudes to patient information can influence frequency of issue and confidence in their efficacy.87,88

Computer-generated leaflets

Kahn writes "Computer generated handouts can be stored, edited, updated, retrieved and printed on demand. The computer readily accommodates the need for customisation and personalization."89 His article, written in 1993, lists 30 commercial software packages available in the USA which included patient leaflets to print out. The UK is beginning to catch up with the recent introduction of at least two comprehensive patient information software packages suitable for use in the GP setting. 90,91 The number of leaflets available is large and continues to grow, with few storage problems. There is no reason why the number of leaflets on computer packages cannot grow to be as fully comprehensive as needed or requested by the users. Regular upgrades will enable the content to remain up to date. Search facilities enable quick access to a leaflet. The wider use of the Internet and scanners provides a means for individual doctors to compile their own collection of leaflets.

A further appealing aspect is the way in which computerization will raise the profile of leaflets, allowing them to be noticed—and therefore possibly used more widely. In 1995, 55% of UK GPs reported using desktop computers during consultation. This figure is undoubtedly rising, along with the number of practice nurses using computers. Computer protocols daily remind us of routine tasks to perform for chronic disease management and health promotion. Computers in practice may be responsible for increasing the number of preventive tasks by as much as 50%. Computer protocols can remind doctors and nurses to "issue leaflet"

for a variety of situations and the leaflet can be available on the computer. One means may be the use of computerized clinical-decision support systems. 93 One such system is PRODIGY, which is a pilot project in English general practice which offers clinical recommendations to GPs in consultation. The Phase one PRO-DIGY Interim report states that, of the GP responders who use the system, "82% of GPs express the opinion that additional patient advice leaflets would be useful".4 This has been responded to, and the Phase two PRODIGY clinical recommendations now routinely have attached patient information leaflets, reminding the GP that they are available to be printed out whenever the therapy options are accessed.95 This principle could be applied to other standard information sources such as the electronic British National Formulary (BNF) or databases using keyword searches.

Another advantage of computerized leaflets, if incorporated into a clinical software system, is that, when issued, an electronic entry can be made to the patients electronic health care record. A potential benefit from this is evidence of written advice having been given to a patient. For example, when prescribing antibiotics to women on the contraceptive pill, evidence that an appropriate leaflet has been issued may add weight to any subsequent dispute about correct advice having been given should a pregnancy ensue. In addition, the data entered may provide a valuable tool for audit, research and clinical trials of the use and effectiveness of a variety of patient information leaflets.

Authors of patient leaflets intended for widespread use should now consider an electronic format in addition to any paper version. Health care professionals will be using the computer more and more. They may soon be requesting a disk with the information on, a website reference to download the material or ask for the leaflet to be incorporated into standard databases (updated automatically via modem) rather than further contributions to the mountain of leaflets being amassed in various surgeries and clinics.

The drawbacks of computer-generated patient leaflets

Printing is viewed as a drawback by some. The introduction of patient leaflets to the PRODIGY project has been largely welcomed. However, printing issues have been a recurring theme of concern. At present, many UK GPs print out prescriptions on fairly primitive printers whose main purpose is to issue standard prescription forms (FP10s). To print leaflets quickly and maintain a reasonable quality will demand an investment in higher quality printers. Apart from the printing cost, there is some concern as to how long it will take to issue a leaflet. Some pamphlets are too long

realistically to ever be printed as part of a consultation. However, many fact sheets and leaflets require only a side or two of paper. One compromise would be to print out several copies of a top 10 or 20 and store them in a folder which could be regularly replenished by a member of staff.41 Less commonly used leaflets could be printed as the need arises. However, some doctors comment on liking the fact that a leaflet can be personalized with such things as the patient's name, the practice name, additional 'in-house' advice or the address of the local self-help group. The short printing time can be used to explain to the patient what is on the leaflet, with a personalized gift³⁹ of a leaflet 'especially printed for the patient'. Also, as discussed earlier, this may on some occasions be an alternative to the printing of a prescription.

Further cost considerations are the price of the software packages. The majority of paper leaflets, in the UK, are generally provided free by various bodies including patient self-help groups, ^{16,51} pharmaceutical companies, ⁸⁰ the Community Health Council and the Health Education Council. The currently available electronic packages are not free to GPs, although one UK GP software provider includes patient information leaflets as a standard feature of the clinical software. GPs have had previous costs of computerization eased to a variable extent by computer reimbursement schemes from Health Authorities. If computerized patient leaflet packages prove their worth, then a good case could be made to include reimbursement for them.

Another disadvantage is the limitation in the presentation of computer-generated leaflets. The importance of the use of style, format or layout to optimize a leaflet's attractiveness has already been discussed. Diagrams, graphics, colour and varied layout are all possible and undoubtedly will soon complement computer-generated leaflets, but the reality at present in most UK general practices is A4 text pages printed by monochrome printers. Nevertheless, it could be argued that the most important attribute of a leaflet to be effective is for it to be given personally to a patient by a health professional. If computerization increases the number of appropriate people receiving written health information, the trade-off may be less glossy presentation.

Summary

- Patient information leaflets do affect health outcomes: patients want them and use them.
- The giving of patient leaflets is a resource which is under-utilized by health professionals.
- Many leaflets have been poorly written, but there is now ample advice on how to remedy this.

- Patient information leaflets should be evidence based as far as possible, peer reviewed, contain references, be dated, give an objective measure of readability and be evaluated.
- Clinical trials to demonstrate the effectiveness of patient information leaflets in health outcomes should be considered.
- Computerized databases of patient leaflets may increase the number stored, noticed, retrieved easily and given to patients. This may be an effective way to give personalized information to patients in general practice and other primary care settings, including pharmacies.
- The computer tagging of patient records will be a useful tool in auditing and researching the use and impacts of patient information leaflets.
- Any author writing a new patient information leaflet intended for a wide audience should consider producing it in an electronic format in addition to any paper format.
- Further research is desirable to confirm the acceptability of computer-generated leaflets to patients and professionals, to demonstrate whether computerization increases the numbers of leaflets issued, whether this has a significant impact on patient outcomes and whether they are sometimes used as an alternative to printing a prescription.

Conclusion

The use of computers in General Practice has been shown to improve patient outcomes. 92,93 The use of computerized clinical information systems are envisaged to expand "to assist in the management of the patient care plan and to supply information to the doctor and patient".7 Patient information leaflets may improve patient outcomes and should routinely become part of these systems.^{89,95} Used wisely, leaflets should help bridge the information gap clearly identified in physician-patient relations^{2,3} facilitating concordance in pharmaceutical and non-pharmaceutical health care therapies. 96 Moreover, computerization should result in a significant increase in the number of leaflets reaching their intended recipients and may therefore significantly improve health outcomes for a variety of medical conditions.

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