Patient Information Leaflets in Surgical Practice: A Contemporary Review

Shrestha BM
Sheffield Kidney Institute, Sheffield, UK

ABSTRACT
Undergoing any surgical procedure, however minor this may be, generates a certain degree of anxiety amongst the patients, which is primarily related to the possible postoperative course and complications. Introduction of Patient Information Leaflets (PIL) in routine surgical practice has helped ameliorate this problem significantly and therefore has become a standard practice in the United Kingdom and elsewhere. This review highlights the evidence available in support of the use of PIL and outlines the process of development of PIL in surgical practice.

Key words: Patient, Information Leaflets, Development, Evaluation, Surgery.

Every surgical consultation generates a certain degree of worry amongst the patients as this may culminate in having to undergo a surgical procedure, although the majority of patients attending surgical outpatients do not need an operation. Patients who need operations get worried and wish to know the details of the procedure as this has important implications on short- and long-term planning of their personal commitments. Providing information has become integral to patient care and this is particularly true for vulnerable group of patients such as children, young people, the elderly, and those who are physically disabled, mentally ill or have learning disabilities, who require more time to be spent in explanation of the plan. Every organisation strives to enable surgeons to achieve and maintain the highest standards of surgical practice and patient care through various integrated approaches. The nature of the surgical procedure, complications, recovery period, and long-term outcomes vary one case-to-case basis. However a broad-based information sheet encompassing various issues right from the time of initial consultation to follow-up would alleviate anxieties and smoothen management of operation of any magnitude. This review highlights the role of Patient Information Leaflets (PIL) in surgical practice based on currently available evidence and outlines the process of development of PIL for patients undergoing surgical procedures.

A. EVIDENCE ON PATIENT INFORMATION LEAFLETS
There used to be a wide variation in the practice of providing information to the patients undergoing an operation among the hospitals in the UK, even between individual surgeons within the same hospital; and many of them did not satisfy patient expectations. Currently, providing PIL preoperatively has become a standard practice in the National Health Services of the UK and its positive impact has been demonstrated in prospective studies.

The understanding and eagerness to know about any procedure patients might have to undergo and about the outcome is variable from patient to patient, which is primarily influenced by their age, level of education, intelligence, social circumstances, and the amount of information provided by the surgical team. Dissatisfactions often accrue from patients lack of understanding of the

CORRESPONDENCE:
Mr. BM Shrestha
Sheffield Kidney Institute
Herries Road, Sheffield, S5 7AU, UK.
E-mail: shresthabm@doctors.net.uk

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PIL, if the information provided is not grasped easily. However, the majority of patients feel satisfied if appropriate information is provided to them before surgery. The relationship between the retention of the information and timing of providing PIL to the date of surgery has been assessed prospectively, and it is shown that repeating the details with the patients just before the date of surgery was essential, as important information was forgotten by the majority of patients when they were assessed after six weeks.

People with English as their second language have been shown to have a deficiency in understanding of the PIL, thereby making a strong case for adapting it in languages suitable for ethnic minorities. Use of audiovisual aid in the form of CD-ROM with and without PIL was tested in randomised studies among patients undergoing plastic or colorectal procedures. There studies have shown significant reduction of anxiety and better understanding of the purpose and details of the procedure. Comprehensiveness and proper documentation of information offered to the patients is paramount in event of lawsuits against the surgeon.

More lately, computer-based patient information systems have been introduced to replace traditional forms of PIL and, to a certain extent, face-to-face communication. We have introduced an interactive computer-based information system at our institution in Sheffield, where renal transplant recipients and kidney donors acquire necessary information on issues related to undergoing renal transplantation and donor nephrectomy, respectively, by using the programme.

Obtaining informed consent from a patient is mandatory prior to the patient’s undergoing any form of surgical procedure. It is the duty of the surgeon involved to provide patients with all the necessary information outlined above in both verbal and written forms, and which have to be documented and signed by both parties.

Several prospective randomised controlled trials have examined whether PIL help to improve patient recall during the process of informed consent and they have shown a significant difference between the patients in the group that received PIL and those in the group that did not. PIL is therefore being considered a useful tool for the surgeon to improve the recall of the information given to the patient, in order to facilitate informed consent. The superiority of combination of both verbal and written information compared to one alone has been confirmed in large multicentre studies.

Increasing number of patients is undergoing surgical procedure on a day case basis and the role of PIL is inestimable. Significant impact on pain control and anxiety alleviation is shown among patients operated as day case, both in adults and children. Children have been shown to benefit from PIL if presented directly in the most accessible and flexible form.

B. DEVELOPING PATIENT INFORMATION LEAFLETS

Written information is essential for the patients and for their carers, who act as a back-up to verbal information and help in alleviating anxieties of the patients and their relatives. Ideally, an information leaflet should be available to patients before surgical consultations so that a broad understanding of various issues involved is addressed during the consultation.

A PIL should contain views of the patients, carers and surgical team on the condition, treatment and follow-up plan, which means past experience of managing the condition must be included and the PIL modified whenever appropriate. A surgeon will be the best person to draft a PIL and this should be endorsed by other experienced team members. In practice, a surgeon who undertakes operative procedure becomes the most responsible person in the team for any complications and patient dissatisfaction. Written information must be in a language that is familiar to the reader and at a level they will understand. A PIL first drafted must be piloted and evaluated fully. PIL must be evaluated regularly and amended accordingly. It is important to realise that everybody can not read the PIL, and that audio- videotapes can be used for communicating the same information. Simple diagrams are also helpful when describing information about procedures involving parts of the body.

The information should include:

1. Details of preadmission programme or unit visit for children and young people - seeing the environment and meeting staff members reduces anxiety for patients and carers.
2. Information about the unit and the stay- the arrival time, transport and communication facilities, likely duration of stay, visiting hours and role of relatives.
3. Procedure information – why surgery is needed, what the procedure involves, pain control, recovery after surgery, how to care at home, return to normal activities, possible problems and follow-ups.
4. Anaesthetic information- possible options of anaesthesia, fasting time and how the patient feels after having an anaesthesia.
5. Information about clinical risks- that is, complications following any procedure. Any complication with incidence of greater than 1% should be highlighted.
APPENDIX-1
INFORMATION LEAFLET TO PATIENTS

HAVING AN OPERATION

The majority of people coming to surgical outpatients do not need an operation of any sort. This leaflet answers some questions for the few who do. The thought of having an operation can be frightening for anyone. This leaflet will give you some useful tips which may help you and the medical team. By understanding ‘why’ and ‘what’ is happening to you, you can play your part. As a patient you have the right to quality care and to share in the decisions on how best to solve your health problems. This leaflet cannot give detailed information on operations* but it should help you to decide what information you might like to know or which questions you need to ask about your illness, treatment or operation and recovery.

1. YOUR VISIT TO THE HOSPITAL DOCTORS

Appointments are often brief, so it can be a good idea to think in advance about the questions you might like to ask the doctor.
Questions to ask might include:

- Why do I have to have an operation?
- What different types of treatment are available?
- What are the benefits of each?
- What exactly does the surgery involve?
- How long will it take?
- Will I need a local or general anaesthetic?
- Will I need any stitches?
- Will there be any scarring?
- How long will I need to stay in hospital?
- How long will it take to recover?
- Will I need time off work?
- What are the side effects or risks?
- How long will I have to wait for this type of surgery?
- How much notice will I be given?

Remember you are welcome to take a friend or relative into the consultation with you. Make a note of any questions you might have or take this leaflet with you.

2. ADMISSION TO THE HOSPITAL

When you arrive for your operation, you will meet the nurses who will have particular responsibility for your care and be told their names. They should check that the details they have about you are correct and ask you what you would like to be called during your stay, e.g. Rosie Smith, Rosie or Mrs Smith. The nurses will then be responsible for letting all the other staff know your preferred name. Whilst you should already have had a chance to ask questions about the nature of the operation and to ensure that you are clear what the procedure involves, its benefits and risks and why you are having it, you may still have certain questions or worries that you would like answered. You should feel free to ask questions or to discuss any concerns with ward staff and, if you require a more detailed discussion, with one of the surgical team. You will be asked whether you still agree to proceed with the operation just before it takes place and your signature will be witnessed by a member of the healthcare team.

You might also like to ask the ward staff:
- What happens now?
- Can I still eat or drink?
- What will I feel like after the operation?

3. THE MEDICAL TEAM

You will meet a great many doctors and healthcare workers while in hospital. You may be asked for the same details by several members of the team. It can be confusing trying to work out just what they all do! Never be frightened to ask, particularly if they do not have a name and job title on their badge. You should always feel
comfortable about asking any member of staff who they are if you are not sure. Before your operation you will see an anaesthetist, who is a doctor in charge of pain management. You may like to ask him or her questions such as:

- How soon (if at all) should I expect to feel pain after the operation?
- How long will the effects of the anaesthetic last?

There may also be further questions you wish to ask the nursing staff, the consultant, the physiotherapist, or any other members of the team and you should feel free to do so.

4. AFTER YOUR OPERATION

Always let someone know if you are in pain or bleeding because the medical staff or a nurse will be able to give you advice and get you help. Never hesitate to ask if you have any concerns. You may like to ask:

- What should I be trying to do on my own, e.g. going to the bathroom or getting out of bed?
- How long will it be before I am back doing these things?
- How long will it be before I can go back to work?
- When can I drive a car?
- Is there anything I should avoid doing?

5. BEFORE YOU LEAVE HOSPITAL

To help your recovery when you get home, there may be questions you wish to ask before you leave hospital, such as:

- When will I be back to normal?
- How much pain, bruising or swelling should I expect?
- What side effects should I expect?
- When and where will the stitches be removed?
- What will I be able or unable to do when I get home?
- Will I need to return to hospital or to my GP?
- Who can I contact if I need advice when I get home?
- What facilities are available for rehabilitation and support?
- Is there anything I can do to prevent future problems?

6. OUT MORE

The hospital may be able to provide you with leaflets about your condition and operation. There may also be a society or support group that can offer further information about your condition. NHS Direct (tel: 0845 46 47) will be able to put you in touch with support groups and tell you about useful books and leaflets. The Royal College of Surgeons of England website also has further information about organisations which can provide help and advice at www.rcseng.ac.uk. Local libraries can also be a great source of help. To ensure you receive the best possible care, many different healthcare professionals will be involved in your treatment. The Royal College of Surgeons of England has produced A Guide to Hospital Surgical Staff, which may be helpful in explaining the role of each of the different members of the team and can be found on the website. Alternatively, the hospital may have a list of its own which you might find helpful. However, you should always feel comfortable about asking any member of staff when you are not sure. This leaflet is for adults. We have produced separate information for children available from your NHS Trust or The Royal College of Surgeons of England website.

7. WHAT ELSE YOU CAN DO

As a patient you have a right to a high standard of care. There are certain things you can do to help achieve this:

- Ask questions and let staff know if there is anything about your treatment that you do not understand.
- Give medical staff complete information about how you are feeling or any medication you are taking. Follow the advice that you are given and take the medication as prescribed.
- You are likely to recover more quickly if you are fit and healthy. A healthy diet, stopping smoking and cutting down on alcohol will all aid your recovery.
A model PIL designed by the Patient Liaison Group of the Royal College of Surgeons of England is attached (Appendix-1), which outlines sets of questions and the answers to which the patients and relatives are expected to ask and know about before and after undergoing any operation. It is not possible to draft answers to all possible questions as the answer to each question will depend on the procedure they undergo. However, in tertiary referral centres where similar procedures are carried out repeatedly, frequently asked questions and their answers are provided in the PIL or in the websites for individual procedures. Additional information if required by the patient is given verbally by the team. Good quality information is fundamental to facilitate patient involvement. Enhancing patient participation is a priority for renal services, where patients’ involvement is tantamount to the success of renal replacement therapy, both in dialysis and renal transplantation.

C. EVALUATION OF PATIENT INFORMATION LEAFLETS
It is essential to evaluate the quality and effectiveness of the PIL from time to time using robust assessment tools involving patients and care-takers and make amendments to address their deficiencies. A recent study involving retrospective interviews of patients’ perception on the use of thromboembolic deterrent stockings (TEDS) in one of the UK-based hospitals has shown little or no information from health care staffing regarding TEDS, which has raised the issue of informed consent and patient empowerment and subsequently amendment in practice was brought about by enforcing both verbal and written information.

Similarly, a recent survey to evaluate the quality of PIL about renal replacement therapy across the renal units in the UK showed lack of uniformity of information provision and also difficulty in comprehending information.

This calls for the establishment of a centralised system of generating PIL with approval from the stake holders and to assess their adherence regularly.

CONCLUSIONS
Current evidences endorse PIL as a useful adjunct to the management of patients undergoing surgical procedures as this not only boosts patients’ confidence on the system, but also simplifies over-all management. In health-care networks, where PIL is not in routine practice, it is a good idea to introduce this in Teaching Hospitals first followed by gradual progression to Peripheral Hospitals. Regular evaluation and amendments are required to make the PIL more robust and reliable.

REFERENCES