Editorial

Surgical guidelines: more useful to physicians than to patients

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There is ample evidence that surgical techniques significantly affect cancer clinical outcome and, consequently, optimization of these techniques is highly desirable. The aims of surgical guidelines are indeed to enhance surgical quality control, to reduce surgical variation, to facilitate the homogeneity of groups in clinical trials, to minimize inconsistencies in staging patients with gastric cancer, and to promote standardized documentation.

Our Japanese colleagues are to be congratulated for their efforts in achieving this goal by preparing and disseminating guidelines for the treatment of gastric cancer to their national surgeons. However, the adoption of guidelines for popular use, as reported in the article by Ichikura et al. [1] is a new and unusual initiative. In fact, many important Western institutions have booklets for patients, which are mainly intended to explain to the patient the general features of a therapy and its complications in order to achieve a better compliance with the treatment. In fact, this more easily occurs when patients are active, well aware of what is going on, and not passive subjects as far as medical procedures are concerned.

Unlike Western booklets, these Japanese guidelines for popular use (which I have not read) seem to contain “color illustrations, detailed descriptions of surgical procedures and postoperative complications, and survival rates”, hence they appear to be quite detailed and focused on technical surgical aspects of the therapy and on the final outcome as well.

What are the messages in the article by Ichikura et al.? There are two: one regards the methodology of the investigation and the other regards the final findings.

The methodology of the study was likely suboptimal. First, in order to assess whether it is useful for patients with gastric cancer to read the guidelines, it would be

necessary (a) to define what is meant by “useful.” One could reasonably conceive of this as better compliance with therapy by patients, with a reduced need for analgesics and tranquilizers, or some other benefit resulting from an ad hoc psychological investigation and assessment; and (b) to compare two randomized groups of patients, one given the guidelines and the other not. Finally, it is essential that the contents of guidelines for popular use be clearly understood by patients who are nonexperts.

Cognitive psychology has demonstrated that giving information to patients is not an easy process. The ability of a patient to make a decision requires four intact cognitive functions: the ability to understand the information relevant to the decision; the ability to appreciate the situation and the consequences of alternative approaches; the ability to rationally evaluate the information in the context of a coherent set of goals or values; and, finally, the ability to communicate choices to caregivers regarding care.

Major problems probably occurred at this level. In fact, of the initial 97 patients receiving the guidelines for popular use, only two thirds filled in the questionnaire and 87% (only 59% of the total) read approximately the whole text. This means that the aim of disseminating the information failed in about half of the patients. Moreover, only 58% of patients (about one third of the original number) were able to understand almost all the content of the guidelines. Finally, about one third of patients reported negative aspects of reading the guidelines, considering that it increased their anxiety about the disease or its treatment. Therefore it appears a little naïve to accept the answer of the majority of patients who reported having found it useful to read the Guidelines.

The true message of the article is something else, however. It is the almost unexpected finding that although the guidelines were deemed useful and not considered worthless by the majority of patients,

more than half admitted they expected “their treatment be based on their doctor’s own experience without sticking to the Guidelines”. Again, 87% of patients would prefer to “follow the doctor’s suggestion” should the proposed treatment conflict with the recommendations of the guidelines. This means that despite the merits of the guidelines, the patient’s first source of reference for determining the proper treatment is the surgeon.

In conclusion, despite some flaws in methodology the message is quite clear. (1) Patients put more trust in their surgeons than in written guidelines. (2) The efforts of contemporary (mainly Western) society to acquaint patients with their condition (diagnosis and prognosis), considering that without information there is a lack of freedom in making any choice, should be mitigated by the following considerations: (a) Communication (not simply information) is far less easy than expected. (b) Although the Nuremberg Code states that a doctor–patient relationship is based on the rights of patients — the right to choose, the right to know, and the right not to be harmed —

patients also have the right *not* to know. This was recently stated at the Council of Europe in Chapter III, Article 10, paragraph 2 of the Convention of Human Rights and Biomedicine, which came into force on 10 September 1996. It states: “Everyone is entitled to know any information collected about his or her health. However, the wish of individuals not to be so informed shall be observed.” (c) In fact, the majority of patients have already made their own choice, which is to give total proxy to their own surgeon.

This may be a new lesson for Western surgeons. Perhaps we should learn not only surgical techniques for gastrectomy from our Japanese colleagues, but also their way of taking care of their patients and hence gaining their unconditional trust.

Reference

1. Ichikura T, Ogawa T, Majima T, Saigusa A, Yaguchi Y, Sakamoto N, et al. Evaluation of the Japanese Gastric Cancer Association’s Gastric cancer treatment guidelines for popular use. *Gastric Cancer* 2004;7:41–45.