What do patients really want to know?

A 60-year-old male patient presents to his primary care physician complaining of recent fatigue. The work-up reveals iron-deficiency anaemia due to carcinoma of the ascending colon, which has extensively metastasized to the liver. Had this illness occurred in the early 1960s, when a paternalistic approach to medicine was at its height, the physician might have chosen to tell the patient that he has some inflammation, that he should take oral iron supplements twice a day, and come to see him in 2 months. Today, the physician will likely draw a diagram for the patient indicating the location of the primary tumour and its spread, and tell the patient that the condition is incurable and invariably fatal with a median survival of a few months. He or she will possibly suggest aggressive chemotherapy plus iron—discussing with the patient in detail each potential adverse drug reaction, however rare, as well as the relative futility of these treatments. No doubt the physician will also point out the increased risk of colorectal cancer in his siblings, who should be regularly screened, starting at the age of 40. This approach embodies the current emphasis on patients’ autonomy and informed participation in all medical decisions related to their diagnosis or treatment.

Could the pendulum from physician’s paternalism to full patient autonomy have swung too far? To answer that, one would have to look at the data. It would have to show overwhelming patient support for a policy of detailed and uninhibited truth disclosure by physicians—no matter how grave or discouraging the truth is. Considering the widespread acceptability and marked impact of current practices, such data are surprisingly meagre, selective and inconsistent. Many studies provide in-depth detail of what physicians do in different places regarding truth-telling to their patients, particularly to patients with cancer. The New York Academy of Science even devoted a whole issue of their journal to the problem. From that, and other sources, we learn that physicians’ policies and practices toward informing cancer patients differ somewhat, but remain ignorant as to the much more relevant issue of the patients’ own wishes. Patients are often quoted as wishing to know as much as possible, whether it is about their having cancer or about any foreseeable adverse drug reaction that may affect them. A closer look, however, at the studies that examine patients’ preferences, reveals two striking facts, which have received little attention.

First, the patients whose opinion vis a vis truth disclosure was sought in most studies were patients already diagnosed with cancer. We were able to identify very few studies which targeted patients with other medical conditions ‘before the fact’ of a cancer diagnosis. The opinions of cancer patients who were already told of their illness, and were interviewed while waiting for another oncology consultation or treatment, are likely to be skewed. They are not entirely relevant to the question of what to tell patients when they do not know the diagnosis. Thus, they can hardly be relied upon to truly reflect patients’ unbiased wishes, and should not be used in forming policy decisions.

Second, in contrast with the commonly held view, a considerable number of patients express significant reservations about their doctors being completely frank with them regarding their condition and prognosis. For example, among 250 cancer patients in Scotland, 4% did not want to know whether they had malignant disease (too late, they had already been told!) and 9–10% did not want to know either about their progress or their chances of cure. Similarly, another study revealed that 15% of 80 cancer patients desired to have minimal detail about their illness. A recent large study on the information needs of 2331 patients with cancer in Britain yielded unexpected findings. Although most patients wanted as much information as possible, a substantial minority of 13% preferred to ‘leave it up to the doctor’ or ‘to have information only if it was good’, thereby signalling significant reservations about overall truth disclosure. This tendency is even more evident when patients seen for medical
conditions rather than cancer are evaluated concerning their wishes to learn of a serious illness which their physician may diagnose. In three different studies conducted in Western countries, 17–20% of 284 patients disagreed with the notion that the patient should be told of his having incurable cancer (references 7 and 8, and Schattner & Tal, unpublished data). Looking at specific subsets of patients (e.g. patients >70 years of age, males, Japanese), the data show that the number of patients opting for limited disclosure might all but increase.8,11 Given the large cultural diversity in most developed countries today, individual patients’ preferences may be even more varied than we expect.

Clearly, more studies are needed to fully map patients’ true wishes to know or not to know details of a grave diagnosis such as cancer or dementia. Results might show a considerable heterogeneity between patients, which is hitherto not fully realized. Until then, we must be ready to appreciate that a substantial minority of patients may not want to know everything about their condition, particularly if that information is pessimistic or highly threatening. Hope is an essential mechanism of coping with a grave diagnosis such as cancer or dementia. Results might show a considerable heterogeneity between patients, which is hitherto not fully realized. Until then, we must be ready to appreciate that a substantial minority of patients may not want to know everything about their condition, particularly if that information is pessimistic or highly threatening. Hope is an essential mechanism of coping with a grave diagnosis such as cancer or dementia.

Anecdotal evidence suggests that full insight might actually be detrimental to some patients.14 Until we know more, a cautionary note is indicated. Patients seem heterogeneous in their information requirements. Not all patients want to know everything all the time. Full uncensored disclosure, which is insisted upon by one patient, may be utterly undesirable to another. Respecting patients’ autonomy should include identification of those patients who wish to know less, and complying with their choice. Rather than yield to overriding patient autonomy, discretion and individual consideration are called for. The extent, depth, timing, and technique of truth disclosure must then be tailored to the individual patient’s wishes. To really know them, patients should perhaps be asked to indicate their preferences well before they become ill, in analogy to ‘do not resuscitate’ orders or a consent to organ donation.

References