Pergamon

European Journal of Cancer Vol. 31A, No. 12, pp. 1917–1918, 1995
Elsevier Science Ltd
Printed in Great Britain
0959–8049/95 $9.50+0.00

0959-8049(95)00529-3

Editorial

Who Shall Decide?

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> *Who shall decide, when doctors disagree,*
> *And soundest casuists doubt, like you and me?*
> Alexander Pope, 1688–1744.
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> *I beseech you, in the bowels of Christ,*
> *think it possible you may be mistaken.*
> Oliver Cromwell, 1599–1658.

NOT ONLY doctors disagree. With the abdication of professional paternalism has come an ever increasing variety of input to medical decisions. Nurses, social workers, occupational and physical therapists, chaplains, relatives, self-appointed advocates and, of course, patients have joined the doctor in the executive team. Not surprisingly, consensus is often the first casualty, and, logically, at least some of the diverse opinions must be 'mistaken'. It is unrealistic to yearn for a return to the efficiency of a committee of one. Today's patients increasingly tend to prefer maximum information, open communication and involvement [1]. Analysis of any systematic trends in the opinions of the various professional groups, whose opinions might also become involved, is therefore important if we are to reach decisions that are in the best interest of the patient, and which are sensitive to individual patient preferences.

The report by Bremnes and associates (pp. 1955–1959) in this issue represents such an analysis. Opinion varies as to the proper role of chemotherapy in the treatment of inoperable non-small cell lung cancer [2]. An overview of studies in which chemotherapy had been compared to supportive therapy found evidence of a small increase in survival duration, and recommended the use of chemotherapy [3]. Overall, data on the impact of chemotherapy on quality of life in such patients are meagre. Economically, it has been found to be cheaper to give chemotherapy than to withhold it, largely because of a reduction in hospitalisation [4]. Although this might imply an improvement in quality of life, another study found that chemotherapy had no advantage in improving performance status [5].

In northern Norway, it seems that professional groups differ in their acceptance of a hypothetical toxic chemotherapy. There was only slight variability between the professional groups when they were asked what degree of palliative benefit would be sufficient to justify treatment. However, the scenario offering a prospect of cure revealed a much wider difference of opinion. Surgical nurses most closely paralleled a generally conservative patient opinion, while oncologists were the most aggressive. Surgeons, oncology nurses and healthy controls gave intermediate opinions.

So the surgical nurses got it right. Or did they? Respondents in this study were not asked to make a judgement on behalf of the patient, but rather to say what they themselves would accept. Age differences between the patient and professional groups were acknowledged by the authors as important to understanding the ranking of group opinion. If analysis was confined to patients under 50 years of age (similar to the professional groups), it was the oncologists who most closely agreed with patient opinion, while all other groups were unduly conservative.

If we take the opinion of the patient as the gold standard, major questions still arise as to the stage of the decision process or treatment at which that opinion should be sought. Essentially, the decision to accept a particular form of therapy involves the assessment of a balance between the benefits a treatment may offer, and the adverse effects it may involve. If the patient has not experienced the therapy in question, he or she has a poor basis on which to judge the severity of its side-effects. It may, therefore, be better to ask patients who know the effects first hand, and use their answers to assist the choices of future patients. In one such study, we investigated patients who had experienced moderately toxic chemotherapy as adjuvant treatment for breast cancer. In general, they considered that quite small improvements in survival would make the treatment

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Received 30 Aug. 1995; accepted 7 Sep. 1995.

worthwhile [6]. However, if we limit studies to patients who have had chemotherapy, we will necessarily disenfranchise those patients who, for whatever reason, did not undergo treatment. Even among those who did, it is possible that patients may tend to give answers which support and rationalise their own decision. On this point, a similar study performed in the U.K. by Slevin and colleagues [7] offers some reassurance that patient opinion was reasonably stable. In their study, half of the patients completed the questionnaire again 3 months after starting treatment, and the answers given by these patients did not alter significantly from their pretherapy opinions.

The information on which patients base their opinions may be disturbingly inaccurate. In a recent survey, Black and associates [8] asked women about their quantitative risk of developing and of dying of breast cancer, and the degree to which mammographic screening would reduce this risk. Reasonably accurate perception of both the degree of risk of the disease and the potential benefit of the intervention should be necessary prerequisites to informed decision about screening. These are scientifically determinable questions, not matters of opinion. Almost without exception, the women overestimated both their degree of risk, and the available benefits from screening mammography. Respondents overestimated their risks of death from breast cancer by more than 20-fold, and the degree of protection from screening 6-fold. Both inaccuracies would tend in the same direction, to generate a higher level of demand for the screening service, which might not be supported by a more accurately informed clientele. Even if, as a matter of public policy, screening were considered desirable in this age group, it is scarcely defensible to encourage its adoption on false grounds.

Of course, disagreement was also evidence between doctors in both studies. In Norway, surgeons were much less likely to accept chemotherapy than oncologists. Since Norwegian oncologists deliver both radiotherapy and chemotherapy, the Norwegian study could not explore the dramatic difference between these disciplines which was evident in the British study [7]. Radiation oncologists in Britain were markedly more conservative than the patient group, while medical oncologists most closely approached the view of the patients. The diversity of medical opinion raises the real risk that patient care will be driven by the paternalistic nihilism of a particular doctor, so that the patient may never be consulted about a treatment which they might, if asked, have preferred.

The use of surrogates will never be more than supplementary to the judgement of the clinicians involved in making decisions in each particular case, and the degree to which any surrogate group matches the circumstances of the individual must be constantly borne in mind.

The trend away from paternalism does not imply abdication of responsibility. As medical professionals, we need to ensure that patients have an appropriate and adequate level of accurate information. We need to assist them to the extent required by each individual patient with the processing, interpretation and application of that information to their individual case, in the light of our own experience and opinion. Studies like that of Bremnes and colleagues (pp. 1955–1959) remind us of the fallibility of our personal preferences as a guide to the treatment of our patients, and keep us mindful of our responsibilities to our patients delivering quality health care in the contemporary environment.

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