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European Journal of Cancer Vol. 33, No. 8, pp. 1169–1170, 1997
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Printed in Great Britain
0959-8049/97 $17.00 + 0.00

PII: S0959-8049(97)00030-0

Editorial

Understanding Patient Preferences for Involvement in Care

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DURING THE past two decades, there has been increasing emphasis on patient autonomy in the healthcare setting. This ranges from the development of detailed procedures for informed consent for research studies and clinical care to the use of advanced directives for end-of-life decisions. These example situations demonstrate the move away from a paternalistic form of medical practice in which the physician, as an authority figure, often made proxy decisions for the patient. However, the concept of patient autonomy also has relevance to everyday practice, albeit under the less dramatic circumstances of the routine patient–physician encounter.

For some time, we have known that cancer patients prefer to be informed about their medical condition and wish to participate in decision-making about their care [1], with confirmation of this finding in several other studies and healthcare settings [2, 3]. As noted by Fallowfield and associates in a recent paper, "Lack of information can increase uncertainty, anxiety, distress and dissatisfaction. Such problems can also produce misunderstanding about the importance of different diagnostic tests, under- or over-reporting of side-effects and symptoms and may negatively influence motivation to accept treatment [3]." Although there is some suggestion that older patients are less interested in participation in decision-making about their care, all patient age groups want information [1], and all patients seem to need general information about their condition, whether it is positive or negative [3]. The real challenge for the physician is learning how to deliver information in a way that is understandable, informative, and that is tailored to the patient's needs. From the patient perspective, important obstacles are the technical nature of the disease and its treatment; the levels of anxiety and distress that accompany the diagnosis and the encounter with the physician; as well as the need for many patients to participate in decision-making, have their questions answered, and develop a partnership with the physician.

In this issue of the *European Journal of Cancer*, Rothenbacher and associates (pp. 1184–1189) report the results from a systematic comparison of patient and physician assessments of preference for involvement in treatment decisions. The study focuses on hospitalised patients receiving palliative care for cancer, and includes a comparison group of hospitalised patients with non-cancer conditions, as well as a convenience sample of non-hospitalised healthy adults. Pairs of patients and physicians were asked to respond to a single question on preference for decision-making about a treatment that would involve different health outcomes and associated risks. The five-item response categories were ultimately collapsed into three categories of participation: 'active role', 'collaborative role', and 'passive role'. There was a high rate of cooperation in responding to the study questions among patients and healthy controls, with few demographic differences except for younger age and higher education among the healthy controls.

Overall, the non-hospitalised healthy controls expressed the greatest interest in active participation in treatment decisions and the patients with cancer the least ($P = 0.001$). More significant, however, was the finding that the cancer patients most frequently preferred a collaborative form of decision-making (73%), and less often preferred a passive role as compared to the non-cancer hospitalised patients. In the overall sample of 260 subjects, medical and demographic variables that predicted a preference for an 'active role' in treatment decisions included younger age (<60 years), more education (>9 years), being employed and having a higher Karnofsky Performance Status (>70%). These findings are consistent with those in the literature, and suggest that active participation in treatment decisions is a characteristic of healthier patients who are younger and well-educated.

What is especially new and important in this report is the finding of no concordance between the patient and physician pairs on the question of treatment decision preferences. The rate of agreement between patients and physicians in the 145 pairs was found to be no better than chance! Physicians in this study regularly underestimated patient preference for involvement (35.9% of the cases), and also overestimated patients' preferences for involvement (28.2% of the cases). Disappointingly, there was no association between the rate of agreement between physician–patient pairs and the duration of the physician–patient re-

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Received 18 Dec. 1996; accepted 23 Dec. 1996.

lationship or the clinical years of experience of the physician.

How can we understand this situation? Patients in general, and especially those who are seriously ill, are often reluctant to make their needs known to physicians because of the very nature of the relationship. Physicians are perceived as powerful and all-knowing, and questioning the physician may be difficult. Specifically, it may be difficult for the patient to request a collaborative role in decision-making, given the structure of the physician–patient relationship. Younger and more assertive patients may be more likely to express their needs for active participation of collaboration. Given the age and serious illness of the hospitalised patients in this study, it is not surprising that they had not made their needs known to the physicians who were caring for them. However, the fact that a more established physician–patient relationship did not predict greater concordance between the patient and physician is somewhat disappointing, and should be replicated in future studies.

The report of Rothenbacher and colleagues suggests that there are substantial deficiencies in the physician's appraisal of the patient's preferences for involvement in care. Although further evaluation of this situation in other settings might be scientifically valuable, a practical lesson from the paper is that physicians should probably ask patients about their preferences for participation early on in the professional relationship. Simple exploratory questions might include, 'Some people like to know as much information about their medical condition as possible, and participate in making all important decisions. How do you feel about this?' or 'It is helpful for me to know how active you want to be in making decisions about your care now and in the future. Can you tell me what your preferences are?' In my experience, patients often have strong preferences and can communicate them if asked. However, we have to take the lead by asking such questions, as few patents will volunteer the information, and as shown by Rothenbacher and colleagues we usually do not appraise the situation correctly. Patient anxiety will be reduced and satisfaction improved if we are more successful in matching our communication and practice styles to the needs and preferences of the patient. Nevertheless, this remains an important area for future research, as well as for physician training.

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