

Editorial

Are physicians aware of what patients know about what physicians know?

Patient 'informed consent' to a diagnostic or therapeutic procedure is considered the gold standard in 'Western' medico-legal practice. Patient autonomy in decision making as an ethical principle in health care is believed to be best guaranteed by 'informed consent'. Patients are expected to decide what's best for them after having received all of the necessary information from the health professional. Clinicians and researchers have adopted the concept of 'informed consent'. Nevertheless, it is also challenged from various viewpoints. Gattellari et al. present data in their paper on 'Misunderstanding in cancer patients: Why shoot the messenger?' questioning the concept and, more specifically, the process, of obtaining 'informed consent' [1]. The authors address the issue of whether denial (of fear) may affect patient understanding of the extent of their disease, and the treatment goals and the likelihood of achieving them. Their good news is that a smaller proportion of patients (17%) failed to understand the extent of disease (localised as opposed to metastatic) or the treatment goal (curative rather than palliative) than in a similar study 10 years previously (33%) [2]. However, 24% of patients with localised disease believed that they had metastatic cancer and 20% of patients treated with curative intent believed that they were receiving palliative treatment. Only a few patients were able to correctly estimate the likelihood of their achieving the treatment goal (18% cure, 13% prolongation of life and 18% palliation). Patient denial and perception of the clarity of physician information pointed to patient misunderstanding. Physicians overestimated patient understanding and failed to identify patients who misunderstood their information.

These findings raise several questions regarding the study of denial in cancer patients. In the work of Gattellari et al. denial is considered a multidimensional (cognitive, emotional, and behavioural) construct related to coping with cancer. They adapted the Cardiac Denial of Impact Scale, but it did not prove useful in assessing all of the dimensions of denial, so the search for a better research tool is still in progress. The study population was biased, since patients acknowledged the cancer diagnosis and were compliant with the treatment; only the denial of the emotional aspects related to the disease could be detected. As the authors point out in their discussion of the results, denial may have an adaptive function depending on the stage of disease, and may vary over time. Denial has been found to be maladaptive by delaying diagnosis of cancer. However, some form of denial may be associated with a survival benefit [3]. Denial must also be looked for in health personnel dealing with cancer patients. Is it possible that the physician's

denial can lead to overestimation of patient understanding and failure to identify patients who misunderstand information? An important minority of patients in the study presented by Gattellari et al. has an overly pessimistic view of the extent of their disease or of the treatment goal. This indicates that other coping strategies or affective states not assessed in the study may distort the processing of information by the patient. Patient misunderstanding may occur in both directions, under- or overestimation of the severity of the disease.

It is impossible to study denial without looking at what physicians tell their patients and the manner in which they do it. Can a physician expect patients to fully understand the information he gives and to use it in making decisions? In the literature on patient-physician communication much emphasis is placed on the fact that patient information and, specifically, the breaking of bad news must be seen as a process comprising different goals, such as patient information and implementation of treatment plans, evaluating patient understanding and coping, developing a therapeutic relationship and providing adequate support. Informing patients must be considered a lengthy process. Denial has to be considered from its impact on the patient's ability to seek and accept help in serious physical illness. Within this framework denial has to be accepted if the patient is neither denying his illness nor behaving maladaptively to it. For example, the clinician has to decide whether, when and at what level denial should be addressed. The patient must have the resources (e.g., coping strategies other than denial) to deal with (negative) emotions, a patient's environment has to be adequately supportive, and the physician-patient relationship must be stable enough to address (maladaptive) denial. Useful communication techniques are confrontation, clarification and interpretation [4]. Again, addressing denial is a process over time and not a single event.

In physician-patient communication training, the physician is encouraged to provide and request feedback, e.g., about the patient's understanding of critical information. Physicians often have difficulty in adopting this basic communication technique [5]. They are afraid of offending the patient by checking as to whether he understands the information he has just been given. In certain circumstances this may be a form of physician denial. Here, I would like to address another issue that in my opinion has received too little attention in the literature on physician-patient communication and shared decision-making. How do we inform patients about probabilities? What do patients understand about probabilities? How do patients deal with probabilities? Can

patients use probabilistic information to make informed decisions? [6]. In Gattellari et al.'s paper a patient's estimate of the likelihood of achieving treatment goals was poor. This may be explained by the difficulties of both the physician, in communicating probabilities, and the patient, in dealing with probabilistic information. What is the relevant information from the patient's perspective? [7]. Is it relative or absolute risk? Or is it merely a qualitative yes or no type of evaluation depending on personal and contextual factors, e.g., whether or not he has the disease, whether or not he is cured, whether or not he needs treatment? The individual patient cannot be 30% alive or cured. Patient interpretation of verbal terms of probability depends on the severity of outcome and age [8]. Patient evaluation of the meaning of risk differs from clinical or epidemiological risk itself. A patient's past experience, his history, his education, his individual reality all shape the manner in which he perceives and deals with risk and uncertainty; his decisions will be governed by his subjective assessment. Further research is needed to clarify these issues. Debate is necessary in order to reach a consensus on how to communicate about probabilities. Communication skills will prove more and more relevant in providing state-of-the-art health care. Fortunately, they can be taught.

M. E. E. Sabbioni
Medical Division C.L. Lory-Haus
Inselspital
Bern, Switzerland

References

1. Gattellari M, Butow PN, Tattersall MHN et al. Misunderstanding in cancer patients: Why shoot the messenger. *Ann Oncol* 1999; 10 (1): 39–46 (this issue).
2. Mackillop WJ, Stewart WE, Ginsberg AD et al. Cancer patients' perceptions of their disease and its treatment. *Br J Cancer* 1988; 58: 355–8.
3. Goldbeck R. Denial in physical illness. *J Psychosom Res* 1997; 43 (6): 575–93.
4. Ness DE, Ende J. Denial in the medical interview. Recognition and management. *JAMA* 1994; 272: 1777–81.
5. Tomamichel M, Sessa C, Herzig S et al. Informed consent for phase I studies: Evaluation of quantity and quality of information provided to patients. *Ann Oncol* 1995; 6 (4): 363–9.
6. Edwards A, Prior L. Communication about risk – dilemmas for general practitioners. *Br J Genet Pract* 1997; 47: 739–42.
7. Wolf AMD, Becker DM. Cancer screening and informed patient discussions. Truth and consequences. *Arch Intern Med* 1996; 156: 1069–72.
8. Mazur DJ, Merz JF. How age, outcome severity and scale influence general medicine clinic patients' interpretations of verbal probability terms. *J Genet Intern Med* 1994; 9: 268–71.