ETHICS MAN Daniel K Sokol

Don't forget the relatives

How much should clinicians tell relatives about a patient's condition?

The 25 year old patient had a rare skin disorder called Stevens-Johnson syndrome. She had been in intensive care for several days. One morning, at 9.40 am, her core temperature was 38.5°C. At 10 am it had climbed to 40.5°C. By 1.30 pm it was 42°C. At 4 pm it had risen to 43°C. It reached 44.4°C before she went into cardiac arrest. After 10 cycles of cardiopulmonary resuscitation she was pronounced dead, at 6.13 pm.

Nine months later I represented the patient's relatives at the inquest. They said they had no idea she might die, that no one had bothered to tell them quite how sick she was. "If we had known," the mother said, "we would have stayed with her in that room the whole time." Their complaint is a familiar one.

Historically, the clinician's gaze has been focused on the patient. The patient's intimates have remained in the shadows. The doctor-patient dyad leaves out the family. The Hippocratic Oath states, "Into as many houses as I may enter, I will go for the benefit of the ill." There is no mention of the sick person's relatives.

Question of patient's capacity

Confidentiality, or keeping your patient's secrets, places limits on the extent of the family's involvement. If a patient has capacity, the clinician should check that sharing information with relatives is permitted. If the patient lacks capacity, the General Medical Council's guidance reflects the commonsense position: "It is reasonable to assume that, unless they indicate otherwise, they would want those closest to them to be kept informed of relevant information about their general condition and prognosis."[1]

When a patient is ill, clinicians consider whether that patient knows the diagnosis and prognosis. If not, and if the patient has capacity, the norm in the United Kingdom, the United States, and many other countries is to disclose that information to the patient. Respect for patient autonomy requires it. Yet, clinicians should also consider whether the relatives should be told about the patient's condition.

The family of the patient in my inquest wanted regular updates. They believed that the patient was stable until a registrar rushed to the hospital cafeteria to tell them that she had gone into cardiac arrest. Although the family believed that there was a sudden and catastrophic turn for the worse, the medical notes show a gradual decline over hours. The clinicians suspected she might die. The relatives were clueless.

Talking to the family ranks low in a clinician's list of priorities. In busy times, dealing with other patients may push that task so low on the list that it never gets done on that shift. After checking the patient's observations, noting urine output, calculating fluid balance, reading scans, arranging for tests, phoning colleagues, and conducting other tasks, a doctor may forget to talk to the family. Sharing bad news can also be an unpleasant task for clinicians. Some relatives ask irritating questions, others complain about the patient's management or talk too much, and others are downright rude.

Time well spent

Time is a limited resource in medicine, but keeping relatives informed of the patient's condition is time well spent. Regular discussions set the family's expectations at the right level. They reduce the likelihood of conflict arising from divergent understandings of the patient's true condition. They build trust, show concern, and reflect an appreciation that illness affects not just the patient but can "infect" their loved ones too, causing emotional pain and suffering. They can allow relatives to explain the medical situation to the patient in more meaningful ways or help persuade the patient to follow a course of action. And when patients lose capacity relatives can form valuable allies in making decisions that reflect the patient's values.

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When the patient is in pain or appears distressed, it is particularly important to explain the situation to the family, including the steps taken to minimise the distress. At the inquest the relatives could not understand why the patient struggled to breathe when the anaesthetist could have used the ventilator to breathe for her. It was an upsetting sight. In fact, the anaesthetist wanted to exercise the patient's ailing lungs, but this was never explained to the relatives, who instead believed that the medical team had neglected her. More than any other, the sight of a patient in distress, without any explanation for that distress or reassurance that everything has been done to keep the patient comfortable, can lead relatives to question the quality of care provided. This, in turn, increases the likelihood of complaints.

So accustomed are clinicians to treating sick patients that some barely notice the relatives standing helplessly by the bedside and forget what William Osler reminded the nurses at the Philadelphia Hospital in 1897: "The handing over to a stranger the care of a life precious beyond all computation may be one of the greatest earthly trials."[2] Keeping the relatives informed of the medical situation, good or bad, makes the ordeal more bearable.

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