

CASE STUDY

When the patient's family refuses care: a practical ethical dilemma

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We walked into the clinic of our nongovernmental organisation to find a young man sprawled on the floor face down and crying in pain. We were told that Velu (name changed), an Irula tribal from a village about six km from the clinic, had been fetching water from the well when he had felt a sharp pain in his abdomen, cried out and fainted. He regained consciousness in a few minutes and was brought to the clinic in severe distress. He was gasping for breath and said every deep inhalation was making the pain in his abdomen worse. Even the slightest movement elicited severe pain. The look on his face was of anxiety and fear. His abdomen was rigid; this was the protective mechanism of nature whereby any damaging process taking place inside is walled off, and movements are restricted as much as possible to limit damage. His blood pressure was 70 / 0 mmHg and his pulse was fast and thready. These were indications that his condition was serious. Most likely there was a puncture in either the stomach or small intestine, leading to spillage of its contents into the abdominal cavity.

We started treatment with intravenous fluids to raise Velu's blood pressure, preparing him for transfer to a tertiary care centre for immediate exploratory surgery and correction of the defect. He was in severe pain and begged us to send him to the hospital as fast as possible. We spoke to his brother who had accompanied him and asked him to inform his family. In a few minutes, his brother returned with a request to send the patient back home as they were not interested in going to the tertiary hospital.

Here was a robust young man with a potentially treatable condition, whose family chose not to pursue the treatment suggested by us. We tried explaining the gravity of the situation, the need for immediate referral and probably an emergency, life-saving surgery. The family wanted to take their son home and treat him with traditional medicine. We spoke to the brother, the father, the head of the tribe, and the village health worker (trained by our organisation) and pleaded, threatened and even ordered them but nothing worked. And while all this was happening Velu's pain was worsening.

We knew that the stories of relatives or neighbours being overwhelmed by the unfamiliar and possibly unfriendly environment of the tertiary hospital often deter marginalised people from seeking healthcare. So we offered to escort them to the tertiary hospital and stay with them till proper treatment was initiated. Even this did not make a difference.

We felt strongly that since Velu, a mentally competent adult, was eager to get treatment, he should be sent to the tertiary centre. But that would mean going against the wishes of his family, whose support he would ultimately need for any follow-up and continued care. Moreover, in the tertiary centre they would not admit a patient without a relative in attendance. A consenting adult who is in dire need of specialised medical attention was being denied it by uninformed but well meaning relatives. Should we allow this to happen? Important ethical principles were being violated. The patient's autonomy was not given voice and the best treatment was being rejected. We were in a quandary.

After much deliberation, we came to a decision. In marginalised communities such as the Irula tribes, social cohesion is strong. Placing our faith in the benefits of this cohesion, we let the family take Velu back home to his village, after clearly explaining the diagnosis and the possible consequences of refusing our recommended treatment. We documented the case as "discharged against medical advice". At the time of discharge, his blood pressure was still low and he was in an unstable condition.

It did not need much expertise to diagnose an acute abdomen in Velu and to know that he needed immediate referral. To our mind, only a surgeon's scalpel could have set the problem right. At the very least he needed to be seen by a surgeon and possibly get an ultrasound scan to rule out any dangerous complication. But this did not happen and Velu was taken home.

While the four pillars of ethics: autonomy, beneficence, non-maleficence, and justice are useful to guide us in most of our clinical practice situations, there are gray areas such as these where the practice of ethics becomes fluid. Had Velu not belonged to a marginalised community, with its own reservations and apprehensions about modern healthcare, this situation may not have arisen.

We visited Velu at his home the same evening. A faith healer had been summoned and after her ministrations, the young man had made a dramatic recovery. This made us wonder if this had been a self-limiting form of acute abdomen, an exaggerated response to some form of milder abdominal condition, or whether it was truly a paranormal healing experience. The next day Velu walked into the clinic and thanked us for our care. Behind him were his father, mother,

brother and wife. He shyly told us, "I want my wife to have her pregnancy check up with you."

What exactly happened to Velu and the reasons for his almost miraculous recovery are fit subjects for a separate paper. However, the episode leads to a number of questions related to ethics and the interaction between alternative cultural / belief systems:

- At what point does non-maleficence within the framework of modern medicine need to give in to autonomy, especially when the alternatives chosen are systems of healing that we do not understand?

- At what point does our responsibility towards the patient stop - even if they refuse our form of treatment?
- What is our obligation to interact with, and create openings for, interaction with practitioners of other systems of medicine?
- How does one respond to a subsequent event of a similar nature given that the clinic and the community have had a certain experience?

We are still not sure whether we could have done things any differently, and this case remains a continuing ethical puzzle for us.

Response: caught between two world views

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As a trained allopathic practitioner myself, two decades ago I found myself in similar circumstances (1) and appreciate the dilemma of the young doctors. Since this analysis is after the event, it must be read as a tentative explanation of the confusion we often create for ourselves.

Historical influences on a doctor's professional behaviour

The beginnings of this story must go back to the time when we clinical practitioners, along with the rest of the scientific community, adopted positivism as the way that knowledge was constructed. A positivist approach emphasises "facts" as perceived by the five senses as the basis of empirical evidence. When these facts are shared by a community of "objective observers", the common ground becomes the basis of "truth" or "real" knowledge. In fact, the positivists would say this is the only truth, proven and set in stone. Interpretation does not play a role here, as the shared observation is considered to be true (1).

However, this knowledge is still from a particular point of view, however closely shared. Western science, in its claim to be objective, separated the observer from the observed and was willy-nilly given pride of place in the hierarchy of knowledge. Medicine, claiming to be a science, needed to be free of "subjective values" (1). This is one limb of a doctor's training; the attitude imbibed from it has repercussions which we shall see as we proceed.

While positivism has its strengths, it appears that its methods cannot be applied to all knowledge. In the biomedical

arena, the fact remains that, given clinical data, "normality" needs framing in the context of function and the individual. I remember the classic reflection of this in the popular "road to health" charts of the 1970s, where thousands of mothers, including myself, agonised that their babies were not achieving the desired weight for age (2). It took a while to set a norm for Indian babies, and I was left wondering if the norm for tribal babies was not different (given the specificity of the genetic pool). Second, and more important, for the doctor, "illness" is itself both a pathological and social construct. I have seen tribal women with sickle cell anaemia and a haemoglobin count of 6 grams carrying firewood home without complaints of feeling "unwell". If my observations seem anecdotal, I quote from Tauber's *Patient autonomy and the ethics of responsibility* (3:32)

Medicine both exists in, and helps create, the categories of disease and illness, which are defined and treated as part of a complex web of human values. I will flesh out this claim in detail below, but suffice it to note here that recent scholarship has emphasized how social values play into the understanding of disease, whether viewed from the perspective of psychic influences (e.g., Shorter 1988), in terms of the formulation of gender identity (e.g., Ehrenreich and English 1979; Brook 1999), as determined by cultural standards (Kleinman 1980; Good 1994), or as supported by implicit epistemological (Foucault 1973) and metaphysical assumptions (Kirmayer 1988; Fadiman 1997). Each of these