Narrative based medicine[1,2]

Editorial

'As things now are, the demands of delicacy are more imperative than those of discussion,' Galen

One of Kit Ounsted's gnomes was that Developmental Medicine was the 'Science of Biographies'. I wrote about the need to discern the individual Predicament in any medical consultation[3]. The components of a Sickness are dominated by bioscientific concern with Diseases and Illnesses[4]. I argued that since Diseases are things, tangibles, they are largely amoral. Illnesses, though, are experiences, enactments, but might be roles or just claims and so have moral connotation because the claim is not just of the sickness but also of such advantage in the moral order as comes from being sick. Predicaments, not the environment but just exactly how we are placed in the world, are often of intense moral concern. The Predicament of a child is discerned, not diagnosed. It is discernable from the fabric of the biography.

The relevance of Biography only becomes evident if doctors learn something about how to obtain biographies and how to study them. So Biography has to be a material part of medicine, especially in severe and chronic sickness, even if it is a presumptuous term for the limited facet that we can know. The relevant Predicament should be a part of the communications doctors make about any sickness[5,6]. The Predicament *qualifies* the facts of the Disease and the Illness. 'Their ambivalence about the proposed surgery is not just that he has Down syndrome, but that the mother felt too old to be pregnant and he is not her husband's child and is unwanted by either of them.' We have therefore to traffic in biographies not only in consultation correspondence, but also as items for research, for example, into outcome.

A distressing Predicament when described, even in a few words, can nevertheless be very revealing and personal. 'A notable English film star, driving alone, at night, through Los Angeles, drew towards the kerb…' might describe a certain situation that could be evocative for a particular individual, even though the actress I am writing about was stopping for an early paper.

Sensitivity about data with this power made medical editors and the General Medical Council in the UK decide that biographical material was inadmissible except with the subject's express consent to the particular wording if there is a chance that the patient would recognise himself or herself. 'Minerva's' photographs in the BMJ of loops of bowel carry the permission consent, as testimony to this wisdom. An account of a Predicament of medical interest that would not be recognisable to its subject is probably a lie. Telling lies is certainly unethical; but so, apparently, is telling an important truth if the subject does not want it told.

Some of medicine is little affected, because it relies on the good will of decent helpful people with ordinary Diseases and Illnesses. Elsewhere, problems arise from these ethical strictures in the passage of medical information.

The least is that it is not necessarily of benefit to a person to know they have become an object of medical interest. This only happens with certainty when the patient is asked for permission to describe them. If harm is likely to be done, it is no less harmful if they refuse. Asking the question, 'do you mind if I write this about you?' confirms absolutely that they are the subject in question. Were the details not recognisable by any other than the participants, then the only way the subject would ever be likely to know would be through our asking them.

Then, medical Predicaments that are of importance would have wide application and patients might easily see themselves in vignettes that do not actually represent them. Many notable English film stars in Los Angeles sometimes draw towards kerbs, whether to buy early editions of newspapers or for some other amusement.

The worst effect of the proscription is that it precludes communication about items of intense medical concern where the patient would not give consent, such as relate to various degrees of abuse of the public medical services, or abuses of trust, or forensic matters.

To my view, the profession, the professional bodies and medical editors have failed to defend the profession's need to traffic in true human Predicaments. A nice ethical question arises as to whether it is proper for a parent who is not acting in the best interests of the child, or who is abusing the public's health service, to retain the right to preclude medical description of the child's consequent condition. Another is whether a minor can properly either give, or withhold consent. The emergence of interest in the human Predicament under the rubric of Narrative Medicine, although that is a more negotiated process, is therefore of intense ethical as well as medical interest. Given prurient media and intrusive internets how do we resolve the dilemmas to which it gives rise?

DOI: 10.1017/S0012162203000288

David C Taylor

References

1. Greenhalgh T, Hurwitz B. (1999) Why Study Narrative? *BMJ* **318:** 38–40.
2. Charon R. (2001) The patient-physician relationship. Narrative medicine: a model for empathy, reflection, profession, and trust. *JAMA* **286:**1897–902.
3. Taylor D. (1979) The components of sickness: diseases, illnesses, and predicaments. *Lancet* **10:**(ii) 1008–9.
4. Taylor D. (1982) The components of sickness: diseases, illnesses, and predicaments. In: Apley J and Ounsted C, editors. *One Child. Clinics in Developmental Medicine No. 80.* London: Spastics International Medical Press (Mac Keith Press). p1–13.
5. Taylor D, Harrison R. (1976) On being categorised in the speech of others: medical and psychiatric diagnosis. In: Harre R. *Life Sentences*. London: John Wiley & Sons.
6. Taylor D. (1985) The Sick Child's Predicament. *Aust & N Z J Psych* **19:**130–7.