"Cases" and voices: the changing agenda for doctors and their patients

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Change in health care delivery has major implications for doctor-patient communication

The variety and speed of change in the delivery of health care has considerable implications for what has traditionally been called the "doctor-patient relationship". The possibility of improving the communication between patients and doctors was, for a time, one arena in which physicians and social scientists explored some common ground together.^{1,2} With new contexts for care opening up it is timely to revisit this topic to ask about how this relationship is changing, particularly with respect to the question of the patient's voice. By this I mean, the scope for patients to help set the agenda in the course of their dealings with medical professionals.

In their book about the life of a country doctor, Berger and Mohr drew a picture of a man whose practice changed over time, and with experience. Initially, "He had no patience with anything except emergencies or serious illness. He dealt only with crises in which he was the central character; or to put it another way, in which the patient was *simplified* by the degree of his physical dependence on the doctor".³ Later on, after some years, he had developed a different view, in which "the patient should be treated as a total personality, that illness is frequently a form of expression rather than a surrender to natural hazards". This is a movement away from the doctor considering his patients as instances of disease to one where they become "cases" in their own right; or to put it another way, where they become persons through the doctor hearing the patient's voice.

Berger and Mohr's book was published more than 30 years ago, and the humanitarian message it contains, while not unwelcome, probably has quite a different resonance for doctors working in Britain today, either as general practitioners in cities or as hospital specialists. While the idea of treating patients as people remains basic to most doctors' professional ethic, the image of that country doctor spending time listening to his patients' life stories must seem as far away to many of them as the Cote d'Azur on a wet November afternoon.

Thirty years later Marshall Marinker sent out a quite different message to the

medical profession, drawing a contrast between the specialist and the general practitioner.⁴ The task of the specialist, he says, has been "to *reduce* uncertainty, to explore *possibility*, and to marginalize *error*". That of the general practitioner is to mediate between the predicament of the individual and the potential of bio-science: i.e. to *tolerate* uncertainty, explore *probability*, and to marginalize *danger*". He goes on to question the continuation of this "crucial division" on two grounds—one technical and one moral. He concludes that the advance of medical technology will move the grounds of the doctor-patient relationship towards technical efficiency, away from the humanitarian goal encapsulated in the story of Berger and Mohr's country doctor. In fact, Marinker welcomes the relinquishing of this humanitarian ideal as it reflects a traditional aspiration of doctors to be "secular soul surgeons", attempting to treat the person beyond the disease. This, Marinker says, is something for which they have never been trained and no longer have (if ever they did have) the mandate.

I draw upon these two sources to begin from the basic point that ideas about the doctor-patient relationship are changing. In the UK, as in North America, this change is fuelled by developments in the economics and administration of health care delivery.⁵ British doctors have to work with and within the constraints of the NHS. However, this change gains momentum not only from developments in medicine but also from developments in people's lives. These alter how people think about their own and others' health and therefore about what they want from doctors and other health professionals. As a consequence, there have been such rapid changes in recent times that doctors who might depend upon the humanitarian ideal for resisting the pressures of their current working conditions find themselves already overtaken by events. If Marinker is right, then hearing the patient's voice is no longer a viable aim, so that some doctors might feel that they have gone through most of their professional lives without ever having attained this goal

(and some, perhaps, feeling they were forced to abandon it long ago).

The issue about the "patient's voice" does not, however, go away. This is due to changes in how people think about their health, about living with serious illness and about professional expertise. This is a continuation of the relationship of medicine to society, one that goes back to the end of the 18th century. The introduction of the new clinical techniques changed "being a patient" from a question of how to die with contrition to one of how to survive with medical help, and ultimately how to live.⁶ In the last half century the development of new procedures such as endoscopy, of new drug therapies and recently the promise of genetic engineering not only enable survival but provoke questions of how to live when cure is not possible. The growth in the number of self help and support groups relating to specific diseases, together with the spread of the internet and the information revolution, mean that this is no longer just a practical matter (how do I survive?) but an ethical issue (how should I live my life?). The emergence of an ethics of illness means that the voice of the patient is no longer framed solely within the consulting room or the clinic. It is not something to be heard only in response to the ministrations of the doctor, but is an active part of people's use of medical help in a world where they wish to determine their own way of life.

What I am describing here is not empirical observation but a perspective on events. I am underlining the case for the need for new ways of thinking about the doctor-patient relationship. Of course there will be variation among patients in different circumstances, with different degrees of educational and material advantage, and among people of different cultures and subcultures. However, they will all be touched to a varying degree by a medical system that is already accommodating to a world in which it is believed that patients should have a greater say in the management of their illness. And all the while the technological advances in medicine, embracing the subtleties of biomechanics and the possibilities of gene therapy, provoke changes in people's thinking about the limits of health care and the moral and ethical aspects of living. For patients, having a greater say cannot mean being more detached from medicine. If anything they will have to engage more closely with it, though in a different way.

To make clear this last point I want to consider the question of the patient's voice from another angle, this time to do with who articulates the patient's view. Some years ago, having been diagnosed with breast cancer, the American essayist Susan Sontag wrote a book titled *Illness*

as *Metaphor* in which she showed that talk about illness shapes society's views of it.⁷ For example, to speak of the patient's "battle against cancer" is to set up an image in which determination and positive thinking not only help counter disease but also casts these qualities as moral requirements in coping with illness. For a patient to fall short of this way of coping means that the person is then open to criticism from others, being saddled with a further burden to that of the disease and its prognosis. However, in her conclusion Sontag did not extend this line of reasoning to focus upon better ways of thinking about illness or the metaphors of society. Instead she argued that what helps patients (with cancer) most was to have this metaphorical baggage stripped away, and for the plain language of biomedicine to be heard. The culmination of a treatise on the cultural basis of illness was an appeal for the medical treatment of disease. In this case, the voice of the patient did not appeal to the psychologisms of personality or stress, but placed the author (as patient) in the hands of the best that physical medicine could offer at the time.

The significance of this position only becomes clear in the light of subsequent responses to Sontag's book. Some medical sociologists criticised her for opting out of the social analysis of illness that she had set up, though others (among whom were those who had also suffered from cancer) understood that patients do not want their experience to be articulated for them by social scientists, who assume that a social perspective is more humanitarian than a biomedical one. The essence here is that people (as sufferers) want to speak for themselves, from their particular situation, for their particular concerns. The important point is not the "voice" itself, but who has the right (and the power) to articulate it. The significance of this critique is only now sinking in to some parts of medical sociology, but it means this—that most patients do not articulate a world of concerns against medicine but that they move between the "voice" of everyday life and the "voice" of medicine as they understand it.⁸ Few people would be surprised to hear that people want medical help where they believe it offers the chance of relief from suffering and cure of their disease. However, this is not to say that people have an unqualified acceptance of doctors' views but that

they wish to have a say in what happens to them, in what bears upon their treatment, and in how they live their life after and during treatment of their disease. Taking the doctor's perspective in the course of receiving medical advice is one such option.

Developments outside the clinic have an important part to play in the way that patients might wish to set the agenda when inside the consulting room. The support group and the internet (these can often appear together) provide the medium for negotiating one's place in society, for determining one's priorities, and ultimately for finding one's voice as a sufferer from a given disease. And yet these sources are not to be thought of as exclusionary of medicine because many of the concerns of such groups, and the content of many web pages, involve just the kind of medical information that patients seek about their disease. What is different now is that access is opened up to public view. Not only that, but patients can make a critical evaluation of the information provided and share with others their experiences of medical care. This contributes to a change in trust on the part of the patient, whose familiar motto of *credat emptor* might well be replaced by one more befitting a provider-client relationship: *caveat emptor*.⁵

This means that new arenas have been created in which the voices of patients and the voices of medicine converse, if not always equally. New drugs and new surgical techniques mean that these voices are more specialised; new and changing social arrangements mean that the arenas in which these conversations take place are more widely distributed than the consulting room. The particulars of medical advances (such as telemedicine) provoke not a general change but disturbances in the *intricacies* of people's biographies. Inasmuch as patients feel that they have more control over their health agendas, it is likely that they will expect less of their general practitioner in respect of advice about life in general. However, the correlate of this is that, in future, patients will come to the consulting room with more specific requests, particular concerns, and suggestions.

If Marinker is correct about the future course of medicine, patients will want to know more, and perhaps say more about the technical advice and assistance on

offer from medical professionals. In essence, the consultation will become more distant from the patient as person. However, because of the intricate links between technology and biography, it is likely that patients will continue to introduce into the consultation those particular aspects of life that are disturbed, enabled or otherwise highlighted by the treatment possibilities offered.

To follow the progress of these changes—to understand them—will require even closer liaison between medicine and social science. This will not be in the cause of developing specific treatments of a psychosocial kind, nor in enhancing doctor-patient communication in general, but in drawing out case examples that show different forms of consultation in a changing world. Up until recently doctors have not needed this liaison with social science because they have felt, correctly, that the consultation was under their control. If research was needed it was to help patients remember or understand the advice they were given. Now, with changes to the worlds of both doctor and patient, there is a need to set out new exemplars of what is happening both inside and outside the clinic and consulting room. Not least, the education of doctors demands this, if in the future patients are to be both helped and heard, though not necessarily in that order.

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