Occasionally in clinical practice, there will be persistent disagreements between patients and doctors about how treatment should proceed. An example is provided in the paper by Kaldjian (2017). A man with a persistent bone infection of his foot refuses to agree to the recommended amputation and choses instead to live with an open wound, hoping that continuing antibiotic treatment will eventually cure the infection. This is what Kaldjian here calls an ‘unshared decision’, where a respectful dialogue involving the patient and doctor about the medical facts, beliefs, values, goals etc. has not led to the patient accepting the treatment plan which the doctor has proposed and believes to be in the patient’s best interests. ‘Shared decision making’ is the central concept in Kaldjian’s paper, which sets out a view of healthcare in which patients with a ‘wellbeing’ model of health encounter doctors who hold a ‘biostatistical’ model of health. Through a harmonisation of these two and a clarification of the goals of care, doctors come up with treatment plans which may be acceptable to their patients and they believe to be in their patients’ best interests. If such plans are accepted by the patient, this is then ‘shared decision making’. I find the model proposed here interesting, indeed provocative, and good to think with, despite it being rather abstract and apparently rather far from the more messy and varied social relationships, and structures, which may characterise doctor–patient encounters across our health services.

However, I remain a little troubled, or indeed confused, by the concept of shared decision making which is central in the arguments here. Shared decision making is taken to signify that doctor and patient have reached an agreed treatment plan and explicitly or implicitly hold the same view of what the goals of treatment should be. At best, shared decision making seems a bit of a misnomer for this process. In what sense is the decision making shared? It would not seem to be divided or apportioned between patient and doctor. Rather, it seems to me to be a more collaborative process in which doctors and patients take rather different roles. The patient is questioned and provides information. The doctor may undertake investigations, tests may be ordered and a diagnosis may be made. The results of these are then conveyed to the patient and a treatment plan, or sometimes a number of possibilities for treatment, are presented to the patient. Doctors propose, patients discuss, question perhaps and then may accept, or occasionally reject, the proposed treatment plan, or a modification of this. If the patient continues in their rejection, in the language of this paper, this then becomes an ‘unshared decision’. But again, calling it an unshared decision does not well describe the social processes that may be involved here. Perhaps our would-be amputee could not face the idea of an amputation and believed that there was a good chance that his infection could eventually be cleared up by the antibiotic treatment.
Also, I find the attribution of different concepts of health to doctors and patients a bit of a simplistic binary. Goals for patients in healthcare may be many and various, but perhaps often very short term and specific. They may, for example, simply wish to be rid of an infection, or have a broken bone mended with no conception of improved health involved. I also wondered about the claim here that when doctors and patients disagree over health plans, it is through a probing of the beliefs and values underlying the goals of care and the differing models for health that dialogue may help reconcile disagreement in shared decision making. Is there any evidence for this from medical practice? What about a little old-fashioned discussion of the likely outcomes of different courses of action? Earlier I mentioned the case history which is outlined in the paper of the man with osteomyelitis of the foot who does not want an amputation. We are not given the medical context here. But it is easy to imagine that anyone might be resistant to the idea that an amputation may be the best answer to an infection; and assuming the patient has been fully informed of the likely outcomes of his course of action, or of going for the amputation, why is it a problem if he decides on the antibiotic treatment? It presumably would always be open to him to return for further discussion should the infection fail to clear up, and in that situation he might agree to the amputation. And doctors should not always assume they are the sole judges of where a patient’s best interests may lie.

I found the section of the paper on the goals of care the least convincing. In many clinical encounters, goals for care can be simply taken for granted, but, when this is not the case, this seems to be an area which doctors may find difficult to discuss. And most of what we are offered in the paper is simply a series of very general considerations which are posed as questions which might guide any discussion with patients, such as ‘how do we explain complicated medical detail about diagnosis in understandable language?’ But following the long list of such questions, Kaldjian then goes on to say, ‘perhaps the most daunting question of all – How can transitions in the goals of care be orchestrated over time during the course of a progressive illness, especially when the goal of living longer needs to yield to the goal of comfort?’ I am simply left wondering why Kaldjian finds this question so daunting. However, having witnessed lives coming to an end in hospitals and at home, I have noticed how difficult some hospital doctors seem to find the transition to the goals of care: it clearly is not easy to give up on life saving. At that point I began to wonder again about the whole thrust of this paper – is this the concept of health, ethics and communication in shared decision making in acute hospital medicine? I suggest these matters may look rather different in other care settings, or indeed when the patient is an infant. In those latter cases, or at least in those which may reach the press, it may be the doctors who believe that it is in the best interest of the baby to cease efforts to treat while parents may want such efforts to continue.

Reference


Martin Richards was Director of the Centre for Family Research and Professor of Family Research at the University of Cambridge until his retirement in 2008. His research interests include social aspects of medicine, bioethics, and families and assisted reproduction. His most recent book is Regulating Reproductive Donation (eds. Golombok et al., Cambridge University Press, 2016). Address for correspondence: Centre for Family Research, University of Cambridge, Free School Lane, Cambridge CB2 3RF, UK. Email: mpmr@cam.ac.uk