Prospective clinical trials as a model for patient-centred care

An authoritative and well researched report from two of the UK’s most influential national bodies, the Commission for Health Improvement (CHI) and the Audit Commission, has already been influential in setting the agenda for cancer care in England and Wales [1]. This service review, entitled NHS Cancer Care in England and Wales, is aimed at the general public as well as those with a specialist interest. It seeks not only to analyse the present state of cancer services—warts and all—but also to provide formal benchmarks and address national levels of progress following recommendations from the 1995 Calman–Hine Report, itself widely recognised as an important watershed in the development of oncology services in the UK [2].

The document regards the concept of patient-centred care as critical to the pursuit of quality. Though a somewhat nebulous concept, patient-centred care is usually defined in terms of the need for professionals working directly with patients to give careful attention to their individual needs and concerns, offering choice where appropriate, together with full information on the implications of making certain decisions. The CHI document makes clear that patients should be given full attention by a doctor (and all other health professionals), be treated with humanity and honesty, and wherever possible, by a specialist or team able to offer good continuity of care. As the authors of the report pointed out, all of these points lie at the heart of the principles of the Calman–Hine Report.

These points relating to patient-centred care might at first sight appear to sit uncomfortably with the many demands relating to participation in a prospectively controlled clinical trial for cancer—especially where the treatment choices are randomised, and the patient required to understand and agree to a highly unfamiliar concept. Although there is now universal agreement that prospectively controlled clinical trials offer the best opportunity for assessing new treatments [3], patients remain wary so our rate of recruitment remains relatively low [4]. Some clinical trials are remarkably (even unexpectedly) successful where others fail completely—even though, when first put forward, the initial research proposal always seems such a terrific idea at the time! [5]. Furthermore, leading clinicians remain both unconvinced and anxious about the future of academically (rather than industrially) sponsored clinical research [6, 7]. Despite these and other difficulties, particularly the thorny issue of informed consent [8]—the message seems clear enough: the benefits of clinical trials are now becoming more apparent to clinicians and patients alike.

Clinical trials certainly represent good value for money, uncovering important benefits and providing an excellent opportunity for built-in quality audit, but the role of cancer trials as a means of ensuring patient-centred care has not as yet been recognised, though in truth the relationship is clear enough. Patient-centred care, with its emphasis on individual needs and concerns, should recognise that both parties (patient and doctor) have important responsibilities. A mutually respectful adult relationship demanding treatment with humanity and honesty (a key phrase from the CHI/Audit Commission Report) rightly or wrongly requires that uncertainties as to best outcome should be expressed with clarity and candour, in the hope that the patient will respond positively to the doctor’s frankness. A more open relationship than has traditionally been offered should clear the way for description and explanation of the appropriate current clinical trial, whether locally, nationally or internationally led. Some trials have high levels of recruitment (e.g. in children’s cancers and haematological malignancy), so why not all?

Perhaps the most ambitious of all the variety of doctor–patient partnerships is as cooperating participants in a prospectively randomised and controlled clinical trial. Each makes a committed contribution not only to the care of the individual concerned, but also to clinical science in general. Since access to clinical services is widely regarded as central to the concept of patient-centred care, why not access to clinical trial innovation as well, in the knowledge that patients enrolled in clinical trials achieve the highest standards of care? According to CHI, “patients rarely seem to be actively involved in deciding what is to happen to them”, an issue regarded in the document as lying well within the general remit of patient-centred care (CHI Report pp 28–29). This at least would be a shortcoming greatly improved by the wider application of clinical trial research.

The Calman–Hine Report [2], the National Cancer Plan [9] and the Manual of Cancer Services Standards [10] all point to patient participation as an essential component of quality. Greater patient involvement through clinical trial participation should ensure not only a more rapid accrual of worthwhile information but also the respect, sensitivity and best possible standards of treatment, which represent the essence of patient-centred care.

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