

ABSTRACT

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This edition of *Future Hospital Journal* has a focus on person-centred care and explores the dimensions to partnership working at three different levels – consultation, service and system levels. In this introduction, the authors explain what they consider to be the essential components of person-centred care and what needs to be done to embed it at all levels of healthcare delivery. The changing attitudes of patients and the desire of most of them to receive personalised care based on their individual needs, preferences and lifestyles are explored. It is argued that a culture change is needed to make person-centred care the norm and that patients can help deliver this through a more meaningful involvement in medical research, training and education, service reconfiguration and commissioning.

KEYWORDS: Person-centred, personalised care, evidence-based, integrated care, personalisation

Definitions

Hippocrates said ‘it is more important to know what sort of person has a disease than to know what sort of disease a person has’. It is, therefore, surprising that we have only recently started to question the meaning of person-centred care and how treatment and care programmes could be tailored to meet the individual needs of patients and carers. When the NHS was founded nearly 70 years ago, people were delighted to receive free care for conditions they may have tolerated for many years because of their inability to pay for medical treatment. People were grateful recipients of healthcare and the prevailing attitude was that doctors knew best. Patients expected to be told what treatment they were going to be given and it was not the ‘done thing’ to challenge the doctor. Today, attitudes are very different. Health information is abundant, patients expect excellent care, and they are much more likely to complain if it falls short of expectations. More importantly, they want to be treated as individuals whose knowledge, values, preferences, family and social circumstances are acknowledged as being of crucial importance when deciding how to manage their medical care.

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Person-centred care means treating patients as individuals and as equal partners in the business of healing; it is personalised, coordinated and enabling.¹ It is not a medical model and should be regarded as multidisciplinary, recognising that a person may need more than one professional to support them. Working in this way means recognising people’s capabilities and potential to manage and improve their own health, not seeing them simply as victims of disease or passive recipients of care. Most people want to help themselves, so the health system should be geared to ensuring they acquire the knowledge, skills and confidence to do so. Unfortunately, the way care is delivered sometimes has the opposite effect. Overly directive or paternalistic approaches create dependency and undermine people’s confidence to protect their health, prevent illness and manage their own care.² Paternalistic practice styles risk providing inappropriate care that patients would not have wanted if they had been well-informed.³ Professionals often underestimate the extent to which patients are able to take responsibility for their health. Many patients would be willing and indeed eager to do so if their capabilities were recognised, supported and strengthened, instead of being ignored and undermined. For those people with limited or no mental capacity to assume greater responsibility for their care, we should ensure relatives, carers and trained advocates are fully involved in the care planning process.

The good news is that policymakers have recognised the need to promote person-centred care and there are now concerted efforts under way to empower patients by informing, involving and empowering them. This includes strategies to build health literacy, to promote shared decision making, to support self-care, and to encourage co-creation of services. This special issue includes articles describing some of these initiatives in more detail. Here, we discuss some underpinning themes.

Information

Nowadays most people expect to play an active part in decisions that affect them, including healthcare decisions. There is huge public interest in health and healthcare, generating strong demand for information about diseases, symptoms, treatments and care packages. The government-funded NHS Choices website, www.nhs.uk, received 23.4 million unique visitors in 2014, the vast majority of whom were looking for information about their or their family’s health problems.⁴ Professionals sometimes see this thirst for health information as a threat, blaming ‘Dr Google’ for confusing their patients, but it makes much more sense to welcome it as an opportunity to inform

and educate. Of course, it is not just about having information available but about explanation and re-enforcement of support to achieve person-centred care.

When patients come in brandishing documents downloaded from websites, it is a signal that consultation styles need to adapt. Increasingly, patients want to be informed about available treatment options and to be fully involved in deliberations about the best way to treat or manage their condition. Not all health information is reliable or useful; people need help to sort out the wheat from the chaff. Quality standards and certification schemes, like NHS England's Information Standard, are available to help with this task (www.england.nhs.uk/tis). However, help from clinicians committed to working in partnership with patients is even more important, together with access to the right type of information in the right way and at the right time.

Evidence-based patient decision aids can be very useful for helping patients understand the choices available to them (<https://decisionaid.ohri.ca>). Similar to clinical guidelines but written specifically for patients, these decision aids give basic information about conditions, treatment options, likely outcomes and uncertainties. There is good evidence that they can be very effective if used in the right way.⁵ Many such tools are now available on publicly accessible websites and some are even integrated into electronic medical record systems, making them readily available for use during consultations at the touch of a button.⁶

The importance of ensuring that patients have access to reliable information is often underplayed, but this is set to change because of a groundbreaking decision by the UK Supreme Court.⁷ Following their ruling in the case of *Montgomery v Lanarkshire Health Board*, the legal requirement to ensure that patients understand their treatment choices and are given information about the risks as well as the benefits of all reasonable options is now much clearer. The courts have taken the view that patients should be helped to make informed choices, so simply providing information about a treatment that the doctor has chosen and obtaining a signature on a consent form is not sufficient. Shared decision making, where clinicians and patients work together to select tests, treatments or support packages, based on clinical evidence and the patient's informed preferences, is now the legally accepted standard and doctors ignore this at their peril.

Personalisation

All patients want to be listened to and treated with respect and empathy, but this is especially important for people with long-term conditions. Personalised care planning aims to provide support from health professionals that is tailored to the needs of individual patients. It involves a conversation, or series of conversations, between a patient and a clinician when they jointly agree on goals and actions for managing the patient's health problems. Patients' goals in managing their condition may differ from those of professionals, but both are important.⁸ Instead of giving instructions and advice, this approach encourages patients to clarify their own goals, working together with the clinician to identify the help they need to achieve these. Both parties in the conversation need to have a good understanding of each other's priorities. Before talking about symptoms, many patients want the doctor to

ask 'what do I need to know about you before we discuss how to manage your illness?' Studies have shown that this type of collaborative approach can lead to improvements in physical and psychological health and strengthen patients' confidence and skills to manage their health.⁹ The NHS Mandate promised that everyone with a long-term condition would be involved in a personalised care planning process 'that reflects their preferences and agreed decisions',¹⁰ but, to date, progress has been slow, with relatively few patients experiencing proactive, well-coordinated, systematic support.¹¹

Other policy developments designed to support a more collaborative, personalised approach include facilitating patient record access and integrated personal commissioning. Enabling access to their electronic medical records and sending patients copies of referral letters and other important communications are seen as ways to empower patients. It is now a contractual obligation for GPs to offer patients online access to their summary records and by May 2015 almost every GP surgery in England (97%) offered this service, a huge increase from only 32% in April 2014.¹² The ability for patients to review their medical records has not been well publicised and take-up of the offer has been slow, but opening up inter-professional communications to patients is an important symbolic step towards greater empowerment.

The Integrated Personal Commissioning scheme (IPC) goes further in this direction. IPC gives people with complex needs the option of holding an individual budget, which they can use to purchase relevant support. The model, which assumes close involvement of voluntary organisations, includes personalised care and support planning, independent advocacy, peer support and brokerage.¹³ The budget can be directly managed by the service users themselves or managed on their behalf by an independent agency. This scheme, currently being piloted in nine sites around England, is intended to provide better integration of care for people whose multiple needs mean they have to rely on a large number of service providers. The hope is that this form of personal control will lead to improvements in their quality of life, help to prevent crises and reduce the likelihood that they will experience unplanned admissions to hospitals or other institutions.

Skills and attitudes

Working with patients in a more person-centred manner places new demands on health professionals. It requires excellent listening, communication and negotiation skills and the capacity to respond flexibly to people's individual needs. Effective evidence-based medicine is central to what most patients want, but person-centred care cannot be reduced to technical cookbooks. Guidelines and protocols have their place, but they must not be allowed to squeeze out the crucial human qualities of caring and compassion, which are highly valued by patients.

Making person-centred care the norm not only requires a culture shift in the way patients and doctors work together, it also requires the NHS to succeed with its many initiatives aimed at ensuring nurses and doctors deliver care with compassion, dignity and respect. Too often patients complain about a lack of information and difficulty in getting the doctor or senior nurse to sit down and have a conversation with them. Patients are made to feel they are taking up the doctor's time

unnecessarily or that staff are too busy for a discussion. When things go wrong, health professionals often seem defensive and unwilling to admit mistakes may have been made. These scenarios, which are well documented in the report of the Mid Staffordshire NHS Foundation Trust Public Inquiry,¹⁴ may be indicative of resource pressures or weak leadership, but they certainly inhibit progress towards a more person-centred system.

Moving forward

The real world challenges faced by clinicians and healthcare systems in delivering person-centred care should not be underestimated. The greatest barrier to change is probably culture. Clinicians may need to acquire new skills and indeed many need to recognise that new skills are needed. The NHS will continue to struggle with huge financial pressures, often resulting in the rationing of expensive treatments. Integration of health and social care and good coordination between medical specialists is a real challenge for many organisations, yet this is vital for delivering a good patient experience. A whole systems approach to commissioning and a payment system to hospitals that encourages new ways of working, in settings valued by patients, are also of immense importance. And let's not forget the pressures in the system caused by a serious shortage of doctors.

So what is needed to make person-centred care a reality? Firstly, the concept needs to be embedded at all levels of the healthcare system, from government policy to delivery of care by individual clinicians. Initiatives to promote better integration of care should start from an understanding of the patient's perspective, focusing on personalised care planning and care coordination rather than organisational integration. Patients should be invited to help redesign these systems. Professional training is important too; the way doctors and patients interact and negotiate treatment plans should be a core element of undergraduate and postgraduate training for all medical disciplines. From service reconfiguration to medical research, commissioning, training and education, patients can make a valued contribution and help deliver the culture change that is needed to make person-centred care the norm. ■



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