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Patient-centred care – tomorrow's doctors

Christine Hogg

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Comments to be sent to qabme@gmc-uk.org

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'People working in the NHS need to be able to put their patients centre stage, communicating effectively with them, their families and carers. They need to be able to appreciate and respond to the diversity of the population and to recognise and respect patients' rights.'[1]

'Patient centred care' is care that meets and responds to patients' wants, needs and preferences and where patients are autonomous and able to decide for themselves.[2] In the past the paternalistic model of the doctor–patient relationship was accepted. The doctor, often working alone, was the expert who decided what was in the best interests of the patient. Doctors had the knowledge and skills. The doctor's time was valuable and patients expected to be kept waiting. In the 1970s the BMA ran a poster campaign aimed at patients –*'Be a patient'.* Thirty years later BUPA has a poster that promotes a different view of the doctor-patient relationship: *'The patient will see you now, doctor'.*

This briefing looks at social changes that have led to patient-centred care and the implications for medical education and the skills that new doctors need.

The doctor-patient relationship

The quality of the doctor-patient relationship is still central to patients' perception of the care they receive.[3] However, wider changes in society have led to a redefinition of the doctor-patient relationship.

Consumerism and patients rights

Consumerism and the health care market have encouraged a view of health care where patients choose what services they receive, how and where they receive them. While a 'patient' accepts, a consumer 'demands' services. If consumers do not receive the service or results to which they feel entitled, they will complain and seek redress.

Consumerism has been encouraged by Government policy. In 1991 the Patient's Charter was published, including the right to ask for a second opinion and make a complaint. Many subsequent national policy initiatives have aimed to 'empower' patients and strengthen their position in relation to health professionals. These include the national patients survey, patient and public involvement, copying letters to patients, complaints and systems of redress, access to health records, 'league tables' and information on the quality of health services and the Patient Choice initiative.

Consumers need information to decide on the 'best buy'. In the past doctors had clinical freedom, but now medicine is expected to be evidence based and the actions of professionals open to scrutiny. Comparative treatment rates, outcomes and prescribing patterns are recorded and may be publicly available. Doctors are held to account for their actions – through clinical governance and revalidation.

The information revolution

People now have access through the Internet to information that used to be restricted to professionals. Doctors will find that patients ask questions they cannot answer. Many patients with less common conditions may now have more up to date information on their condition than their GP.

People also have access to information professionals hold about them under the Data Protection Act. Under the NHS Plan patients have the right to a copy of any letter written about them by one professional to another. Electronic patient records are planned where patients may keep their own health records on a smart card, the size of a credit card.

New treatments and rising expectations

Scientific advances mean that more medicines and treatments are available. New treatments and miracle cures announced in the media raise hopes and unrealistic public expectations of what medicine can achieve. People may be disappointed or angry if their hopes are not fulfilled. This may lead to an increasing gulf between patients' expectations and the ability of the health service to meet them.

Changing patterns of illness

We are living longer but in poorer health. Earlier diagnosis means we live longer with our conditions. Diabetes, cancer, hip replacements and heart disease are all long-term conditions that we have to learn to live with and manage. Doctors need to work with patients and carers to train and support them to manage the condition.

Diverse population

Society is made up of groups and communities with different languages, cultures and attitudes to health and healthcare. Being a patient is a role people have from time to time – but otherwise patients have little in common. Expectations and perceptions depend on many factors: age, gender, abilities, social class, economic status, past experiences and personal circumstances.
Surveys show wide variations in patients' experience of NHS care.[4,5] A study of eight European countries also found similar results in all countries.[6] Men tend to be less critical than women and people living in deprived areas are more likely to report a poor experience. Young people consistently report poorer experiences than older people [3] and that GPs do not provide enough information.[4] Those who report poor health status are more likely to report poorer experiences [3] and want more information. [4]

People from minority ethnic communities were more likely to report poor experiences than white British or Irish, but there were wide variations between different ethic groups.[3] People from minority ethnic groups are more likely to distrust the opinions of their GP and want a second opinion.[4]

Self help and health promotion

People are increasingly using alternative/complementary therapies, over the counter medicines, health foods, diets and exercise. The doctor of the future will be one of many providers of health care, but may be put under more pressure if people who are the 'worried well' want earlier disease diagnosis and preventive treatment.

Tensions in the doctor-patient relationship

Changes in society have led to a mismatch of expectations that doctors and patients have of each other. Doctors' status and expertise may be challenged, by both articulate patients and other health care professionals. Richard Smith, Editor of the*British Medical Journal*, has outlined the tensions of these changes resulting in increasing dissatisfaction among doctors.

Doctors and Patients: The Bogus Contract[7]

The patient's view

- Modern medicine can do remarkable things: it can solve many of my problems
- You, the doctor, can see inside me and know what's wrong
- You know everything it's necessary to know
- You can solve my problems, even my social problems
- So we give you high status and a good salary

The doctor's view

- Modern medicine had limited powers
- Worse, it's dangerous
- We can't begin to solve all problems, especially social ones
- I don't know everything, but I do know how difficult many things are
- The balance between doing good and harm is very fine
- I'd better keep quiet about this so as not to disappoint my patient and lose my status.

Implications for tomorrow's doctors

It is now recognised that the doctor-patient relationship should be a partnership, with shared decisions. However, there is evidence that professionals still see the benefits of patient involvement differently from patients. They see the benefits to be greater compliance, management and control of patients' health behaviour, rather than sharing decisions.[8]

Doctors of the future will need to help patients make informed decisions for themselves and respect this decision even if it goes against their advice. This takes more time in the consultation and requires key skills.

- Listening and understanding the patient experience
- Communicating with patients
- Using patients' expertise
- Liasing with local communities and user groups

Understanding the patient experience

Patients and professionals often have different perspectives and different expectations about health care. Doctors need to listen actively and try to understand patients' concerns. '*For doctors Parkinson's disease is mostly above the neck, something to do with the substantia nigra. For patients it's mostly below the waist: Can I get my knickers on? Will I be continent?*'[9]

There are experiences that all people go through when diagnosed with cancer, diabetes or Alzheimer's, but other experiences will be personal. People will react differently depending on their family circumstances, culture or religion, previous negative or positive experiences of health care, their age and many other factors. Doctors need to recognise what is important to the patient and family before advising on the best course of action for the patient.

Communication skills

The Health Services Ombudsman has concluded that poor communication, both between professionals and with patients, remains at the heart of many patients' experience of healthcare.[10] Communicating information, such as a diagnosis or test results, is not straightforward and many people are too anxious in a consultation to understand or remember information given to them.

Patients will soon routinely receive copies of letters written about them by one professional to another. Doctors of the future need to write letters in plain language. The most efficient way of doing this is often to dictate the letter in front of the patient as part of the consultation.

All doctors can expect to be the subject of complaints during their career and need to have the skills to deal with the complaint in a way that does not escalate the problem. Patients may express their views in a challenging, aggressive or even violent way. All health professionals are likely to encounter this at some

time and need to understand how to deal with and deflect aggression, anger and violence.

Acknowledging patients' expertise

Research shows that people living with chronic illnesses are often in the best position to know what they need to manage their condition. Provided with the necessary 'self-management' skills, they can make a tangible impact on their disease and quality of life. The Expert Patients Programme is an NHS-based training programme that provides opportunities to people who live with long-term chronic conditions to develop new skills to manage their condition better on a day-to-day basis. Where a patient is an 'expert', the nature of the consultation changes.[11] The expert patient will ask more questions, know what to expect and ask what to look out for and when to seek help. Once the treatment is agreed, they are more likely to comply with treatment and follow clinical advice.

Understanding the wider patient and public perspectives

It is important also for doctors to understand the wider patient and public perspectives. They will need to be able to work with self-help, advocacy and patient groups and refer patients and carers to them for help and support.
User groups can also advise in planning and developing services as well as giving feedback on the quality of the services. Patient participation groups and user networks may be attached to general practice or to hospital departments as well as in the community. In England, Statutory Patient and Public Involvement Forums that replaced Community Health Councils in 2003 provide a contact with local people. Elsewhere in the UK health councils can assist.

Implications for medical education

New doctors need to be able to operate in a very different world than the world for which the doctors who teach them were trained. It is important that trainers are selected and the quality of teaching monitored to ensure that patients' autonomy and their perspectives are respected in all teaching programmes. Teachers and trainers set an example to new students and provide role models for them both in the classroom and in placements in hospital and community when they are most impressionable. Some of the most experienced clinicians may have clinical skill in treating conditions but not at listening or communicating with patients.

Curricula development

When curricula are reviewed, lay people and community members can be asked to comment on the content and balance, or to join an advisory group to look at developments. People from the voluntary sector can be asked to comment on the content of particular areas, such as mental health, diabetes or disabled children.

Patients in health care settings

At the most basic level patients are involved in medical education through opportunistic contact with students on wards or in the community. How this is done indicates the sensitivity and respect that trainers accord to patients. Every medical school should have guidelines for patients, teachers and students on how to involve patients that acknowledge that patients may find sharing potentially painful issues distressing or be expected to undergo repeated examinations.[12]

Guidelines and information given to patients should be discussed with user and patient groups and should cover:

- How patients are recruited and prepared beforehand
- How informed consent is obtained from each patient
- Advice to students – including appropriate dress and behaviour and how to deal with problems and difficult situations
- How feedback will be obtained from the patient.

Patients in examinations

Patients may also be used in professional medical examinations away from a clinical setting where they may be recruited and supervised by people with no clinical training. Patients can also help to assess students. One study found that lay people, nominated from consumer groups, can reliably assess doctors' communication skills.[13]

A survey of UK medical schools found enormous variations in arrangements and in remuneration. All schools had experienced adverse events during examinations.[14] The paper recommends that medical schools should have guidelines for patients participating in medical examinations.

Points that need to be covered in local guidelines		
Before the day:	**On the day**	**After the day**
Information to patients Consent Reasonable payment Availability of and access to medical records	Legal and ethical duties of care to act in an emergency Availability of equipment to manage deterioration in the patient's condition and emergencies Access to staff able to use the equipment available Management of patients seeking advice or treatment Confidentiality and protection of patient information.	Debriefing about adverse events Communication with patient's regular health care team Storage or disposal of data.
Sayer, M et al. Use of patients in professional medical examinations: current UK practice and the ethico-legal implications for medical education. BMJ 2002; 324:404-7.		

Patients as teachers

Expert patients can be used in teaching, giving presentations, facilitating seminars, providing personal tuition and giving feedback on performance. A literature review of the role of patients and teachers found that learners all reported positive experiences, many valuing insights and confidence gained from practising skills on patients.[15] The review concluded that when patients are given adequate support, training and remuneration they can be colleagues, not just a teaching resource.

It is important that patients involved in medical education are from different age groups, educational backgrounds, cultures and ethnicities. Local community and patient groups can advise on recruitment.

Physical examinations

Patients have been involved directly in teaching students how to undertake physical examinations, in particular musculoskeletal examinations, pelvic and male genito-rectal examinations, and in relation to children's development disabilities, dementia and cancer. Training can increaselearners' respect for patients and deepened their understanding of the experience of disease. Communication skills

Patients can also be involved as teachers of communication skills, either in role play or in assessing communication skills of students. In one US study 'standardised patients' assessed the performance of students given communication training. This significantly improved students' competence in communication as well as their skills in relationship building, organisation and time management, patient assessment and negotiation and decision- making compared to a control group.[16]

Trainers have also been used to teach doctors basic interview skills. In one study trainers, working in pairs, were recruited through the local mental health user group and led sessions inviting trainees to reflect on what they expect from a visit to another professional and imagine what they would feel as a psychiatric patient. They then observed and commented on role play. Trainees found that the patient trainers had a genuinely different perspective to contribute, though a few found the 'democratic' approach challenging and felt the users were too narrow, focusing too much on their own experiences.[17]

The patient experience

Learning can be centred on what patients and carers have to say about their experiences. Durham University has a two-year module following the life cycle from conception to terminal care. Participants include a young boy with Down's

syndrome and his mother, an adolescent with spina bifida, a family in which the mother is expecting a baby, and patients with long-term health problems, looking at the impact on family life.[18]

Finally…

Patient centred care is a core part of the vision in *Tomorrow's Doctors* that sets for standards for medical schools used in quality assurance by the GMC The GMC would welcome any examples of good practice that visitors come across.

Points to consider in inspections

1. What experience and/or training do teaching staff have in providing or understanding patient-centred care?
2. How do medical school teaching staff see the trends towards patient-centred care?
3. How do they incorporate principles of patient-centred care into teaching programmes?
    - Understanding the patient experience?
    - Communication skills?
    - Working with patients as partners?
4. Is there a strategy for involving patients as trainers in these areas?
5. Do the criteria are used to appoint trainers for placements ensure that trainers understand and support patient-centred care?
6. How is the quality of teaching for students on placements monitored?
7. Are there mechanisms for students to give feedback about trainers?
8. Are lay people or user groups involved in commenting on curricula development?
9. Has the medical school any links with local voluntary patient groups to advise on the curricula and programme planning?
10. Does the medical school have written guidelines for preparing patients, getting informed consent and feedback from patients in teaching:
    - In health care settings?
    - In examinations?
11. Have the guidelines and information to patients been discussed with patients or their representatives?
12. Are students aware of the guidelines?
13. How does the medical school ensure that patients invited to share their experiences represent the diverse range of experiences of patients and carers?

14. Where patients are used as trainers, are resources provided for training patients, supporting and remunerating them?
15. Are there any examples of good practice that can be shared with other medical schools?

Further information

General

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Coulter, A and Magee, H. The European Patient of the Future. 2003. Open University Press.

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Support for professionals

Developing Patient Partnerships: The DPP is a health education charity established in 1997 that aims to help health professionals to manage the demand for their services and encourage patients to manage their health care. http://www.dpp.org.uk/

Preparing Patients for Partnership: The 4 Ps provides programmes that support professionals to introduce and review patient and public involvement in health. http://4ps.com

Health in Partnership: this website provides summaries of 12 research projects funded by the Department of Health on different aspects of patient and public involvement.Department of Health, 2004, Patient and Public Involvement in Health: The evidence for policy implementation. * www.healthinpartnership.org

Patients' experiences

*Commission for Health Improvement.*Unpacking the Patients' Experience: Variations in the NHS Patient Experience in England. 2004. This shows the variations in patients' experiences of NHS care based on an analysis of national patients surveys in 2002 and 2003. www.chi.nhs.uk/4539_survey.pdfT.

DIPEx is a website that provides accounts of patients' experiences of particular conditions and treatments. It was set up by two doctors after their own experiences of illness. A pilot site was launched in July 2001 on hypertension and prostate cancerand since then new conditions/illnesses have been added. http://www.dipex.org/

Expert Patients Programme is an NHS-based training programme that provides opportunities to people who live with long-term chronic conditions to develop new skills to manage their condition better.
Department of Health, 2001, The Expert Patient: a New Approach to Chronic Disease Management for the 21st Century.* http://www.expertpatients.nhs.uk/
Health Service Ombudsman – reports on investigations give examples of patients' experiences and what can lead patients to complain.
http://www.ombudsman.org.uk

Copying letters

Department of Health. Copying Letters to Patients, Good Practice Guidelines* 2003
http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/PublicAndPatientInvolvement/CopyingLettersToPatients/

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* Department of Health Publications can be downloaded or ordered by post, telephone, fax or email. Department of Health , PO Box 777, London SE1 6XH Telephone: 08701 555455, Fax: 01623 724524

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14 Sayer, M et al. Use of patients in professional medical examinations: current UK practice and the ethico-legal implications for medical education. BMJ 2002; 324:404-7.

15 Wykurz, G, Kelly D. Developing the role of patients as teachers: literature review. BMJ 2002; 325: 818- 821.
16 Yedida MJ et al. Effect of Communications Training on Medical Student performance. JAMA 2003, 290 1157 1165
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18 Department of Health. Medical Schools: Delivering the Doctors of the Future. 2004.