

SEEING THE PERSON IN THE PATIENT

The Point of Care review paper

Joanna Goodrich and Jocelyn Cornwell

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Foreword

There is much to celebrate in today's health service. Patients are treated more quickly than ever and the obscenely long waits that were once such a feature of our system are a thing of the past. We have seen significant progress in the treatment of cancer, stroke, heart disease and mental illness – the big platoons of ill health. Not before time we are learning how to keep people as healthy as possible in addition to responding when they become ill – and in so doing we are beginning to tackle the huge challenge of helping them to manage their long-term conditions.

And yet there is unease about the most important characteristic of any health system – how patients are treated, not in the sense of which medical intervention is offered, but how they are cared for, how they are looked after.

Many have compared the way the health service treats patients unfavourably with the way major companies handle their customers. But it is both more complex and more important than that.

It is of course easy for any vast organisation to seem impersonal, the more so when its staff feel under pressure. In health care we have the added complication that the 'customers' often have little or no choice about where or by whom they are treated. And that is not about to change for a whole host of patients, including the large number who are treated as emergency admissions.

Equally important, the patient is almost invariably more vulnerable than the average consumer – this is often a time of anxiety, discomfort or distress.

Given the size of our National Health Service, there are bound to be examples of poor care. The system may never be perfect, but the aspiration should be to deliver good care to every patient. Currently, there is evidence to suggest that we should be worried about this most fundamental interaction between health care staff and their patients.

That is why we have launched The Point of Care programme. Our ambition is to work alongside frontline staff and their managers and focus attention on patients' experience of health care. We want to begin to understand why too often patients feel marginalised rather than empowered and involved in their care. Above all, together with the professionals who deliver services, we want to explore how the experience of patients can be improved.

As this first report from The Point of Care programme makes clear, some of this is about getting the basics right so that patients are treated as we would wish our loved ones to be treated, with kindness and consideration, and as individuals with their own needs and wishes. At the same time it is about understanding the dynamics of care in a 21st-century clinical environment and making sure the systems are in place to ensure the experience is right every time – no matter which member of staff is involved.

Improving the quality of care has become the focus of NHS reform (Department of Health 2008a), and the quality of every patient's experience is at the heart of what

health care is about. The aim therefore must be to deliver high-quality care for all, all of the time. That may prove not to be possible, but better care and a much greater level of consistency certainly is. We very much hope that The Point of Care programme will make a useful contribution towards that goal and that it will be valued by all those who take part as well as all those who engage with it at every level.

Niall Dickson

November 2008

Preface

This report is intended primarily for hospital board members, clinicians and managers in hospitals. We hope that it will contribute to and provide support for their continuous efforts to improve patients' experience, and that it will also be of interest to patients and their representatives, commissioners and policy-makers.

The purpose of the report is to consider how we can improve the patients' experience of care. The report introduces current debates and dilemmas in relation to patients' experience of care in hospital, presents our view of the factors that shape that experience, and assesses the evidence to support various interventions that are designed to tackle the problems.

To inform this report, and the development of The Point of Care programme, we reviewed the research literature; undertook our own qualitative research with staff, patients and families; and commissioned a small qualitative study with a cross-section of hospital and trust staff and board members in four English trusts (*see* Appendix A, pp 45–49, for details).

Throughout this report we use the terms health professional and clinician to cover all the professions, including allied health therapists. The intention is to be inclusive: where it affects the meaning we have been careful to distinguish between health professionals and support staff. However, we believe that what is said is relevant to all health care staff, and the paper should be read with this in mind.

The experience of a patient's loved ones, family and friends, also plays a significant part in the patient's own well-being and is important in its own right. Where we refer to patients and their experience, we are therefore including patients' relatives and friends in our discussion.

We are aware that there is much good practice (and literature) in fields we have not covered – in mental health and children's services for example – but the scope of The Point of Care programme is currently confined to adult patients' experience in acute hospitals. We hope in the future to extend the programme to other areas of health care.

Introduction

In our times, cutting-edge medicine has been practised in purpose-built hospitals served by armies of paramedics, technicians, ancillary staff, managers, accountants, fund-raisers and other white collar workers, all held in place by rigid professional hierarchies and codes of conduct. In the light of this massive bureaucratisation, it is a small wonder that critiques once again emerged. The hospital was no longer primarily denounced, however, as a gateway to death but as a soulless, anonymous, wasteful and inefficient medical factory, performing medicine as medicine demanded it, not as the patient needed it.

(Porter 2002)

What is the issue?

When people are ill in hospital and depend on others to look after them, it is of fundamental importance to them and their families that they will be cared for with kindness and compassion by everyone they come into contact with.

Care of people who are unable to care for themselves and compassion towards people who are vulnerable has been a basic tenet of medicine since ancient Greek times (Porter 2002). The importance of attending to the ‘how’ as well as the ‘what’ of clinical treatment is widely acknowledged; in the United Kingdom campaigning groups and the media have made it a matter of public concern. In modern times care, compassion and respect for patients is enshrined in the value statements of the health professions (General Medical Council 2007; Nursing and Midwifery Council 2004). We know that health care staff are highly motivated to care for patients with humanity and decency (Department of Health 2007b; NHS Confederation 2008) and identify strongly with the idea that they should care for patients in the way they would want a member of their own family to be treated (Wood 2008).

The way a patient is treated *as a person* has for some time been seen as a cornerstone of quality (Maxwell 1992; Open University U205 Team 1985). Policy-makers and politicians have made patients’ experience a national priority. The obligation to protect people made vulnerable by illness is often expressed and we are moving towards statutory protection of patients under the Human Rights Act 2007 (House of Lords, House of Commons 2007), and to regulators taking much greater responsibility for the quality of patients’ experience (Healthcare Commission 2008b; Health and Social Care Act 2008).

Improving patients’ experience is central to *High Quality Care for All: NHS next stage review* (Department of Health 2008a), and the reason it is important is referred to in the preface to the draft NHS constitution, which sets out certain NHS values including respect and dignity, compassion, and working together for patients:

[The NHS] touches our lives at times of most basic human need, when care and compassion are what matter most.

(Department of Health 2008b)

Most people spend time in hospital at some point in their lives; most are born and die in hospital and it is intrinsically important to protect and look after people when they are acutely ill. However, hospitals are under enormous and diverse pressures including: rising costs; ambitious national targets; changes in medical and nursing education; the European Working Time Directive; intense technological and process innovation; difficulties recruiting, retaining and keeping staff up-to-date; high consumer expectations.

In the United Kingdom, hospital services are consistently rated highly (Coulter 2005; Healthcare Commission 2007c) and doctors are the most respected and trusted professionals (Ipsos Mori 2008). But this sits alongside a deep disquiet about what Porter (2002) calls the 'soulless, anonymous, wasteful and inefficient medical factories' so evident in tabloid newspapers and radio phone-ins, and heard in the stories that patients, relatives and staff tell about their experience of hospitals. The focus of public interest shifts from one thing to another: recently, in the United Kingdom, it has been on cleanliness (notably of toilets and bathrooms), hospital-acquired infections, and neglect of older people in general wards (Healthcare Commission 2007b). While all of these are important in their own right, they are also expressions of an unease about the industrial scale of health care, depersonalisation of staff as well as patients, and the vulnerability of patients in our modern hospitals.

Hospitals throughout the developed world are under tremendous pressure. There have been massive increases in the volumes of activity in both planned and emergency care. In England, over the past 25 years, the number of hospital admissions and discharges has doubled (Tallis 2004). There are about 20 million accident and emergency (A&E) attendances a year; roughly one person in three visits an A&E department at least once a year. Between 2002/3 and 2005/6 alone new attendances rose by more than 37 per cent, or 4.8 million attendances (Wanless *et al* 2007). Total outpatient attendances have risen since the mid-1990s by 6 million (15 per cent).

The trend of trusts is increasingly towards larger institutions and staff establishments. Between 1999 and 2005, the number of hospital consultants increased by 38 per cent; between 1999 and 2004, the full-time equivalent figures for nurses and allied health professionals rose by 21 per cent and 23 per cent respectively. Non-medical NHS staff, including managers, porters and administrative staff, traditionally account for about half of all personnel in the NHS. Between 1996 and 2006, the number of non-medical staff increased by 26 per cent (in full-time equivalent terms).

This growth in size and staff numbers, along with the use of new technology and the increased pace of organisational life, have had knock-on effects on relationships between individuals and departments. On the one hand it has never been so easy to share information. On the other, staff mourn the loss of personal relationships, face-to-face contact, corridor conversations and meetings in the doctors' cafeteria (NHS Confederation 2008).

The increasing specialisation of medicine and nursing, in the context of a continuous striving for greater efficiency, has reduced contact time between individual patients and individual members of staff. Since 1998/9 average length of stay has fallen by more than 20 per cent. Patients are older and are discharged sooner. More people, in more specialties and departments, are involved in looking after the same patient. The typical inpatient day is increasingly broken up; patients spend less time on their own ward and more time being transported around the hospital to investigations and treatments.

Why is it important?

The case for focusing on patients' experience and working out how to intervene to improve it is strong. First, and most important, is a moral and human imperative to protect people when they are weak and vulnerable; to strive towards recovery and healing; and to ensure the humanity of care. The need to do so within complex systems and institutions that are under pressure to increase efficiency and throughput is a fundamental challenge and it is important to find solutions.

The goal of improving experience is also justified clinically and therefore in terms of value for money. Evidence from clinical studies shows that anxiety and fear delay healing (Cole-King and Harding 2001; Norman 2003; Weinman *et al* 2008). Good communication with patients – a basic component of the overall experience – even in intensive care and with patients undergoing surgery, contributes positively to well-being and hastens recovery (Boore 1978; Hayward 1975; Shulldham 1999; Suchman 1993). Good communication is equally important with patients with long-term conditions and enhances effective self-management (Bauman *et al* 2003).

A good experience for patients is also important for business reasons. Patients are increasingly using the internet to share information about their experience in hospital (*see*, for example, www.patientopinion.org.uk, www.iwantgreatcare.org, www.nhs.uk/choices/, www.dipex.org). There is some evidence that, where they have a choice and the information is available, rates of hospital-acquired infections, perceptions of cleanliness and staff attitudes affect where patients want to be referred (Dixon 2008). In the future, hospitals will suffer financial penalties where the quality of care is poor (Department of Health 2008a) and it seems likely that, as patients begin to exercise choice, hospitals that do not focus on patients' experience will have poorer reputations, fewer patients and thus less income. This has been clearly demonstrated in the United States, where hospitals see the quality of patient experience as integral to financial success (Knapp 2006). There are also positive benefits in relation to staff retention and recruitment. Staff want to work in organisations that treat patients as they would want members of their family to be treated (Department of Health 2007b), and quality of relationships with patients positively influences job satisfaction (Cashavelly 2008; Suchman 1993).

The tension between the intended moral and ethical purpose of care and the inevitable day-to-day difficulties of retaining that purpose at the point of care is a shared dilemma of all in health care and is the focus for our inquiry and our practical work. As Raymond Tallis says:

Doctors and nurses have to overcome the universal, congenital tactlessness that afflicts humanity, and under difficult circumstances: the continuous exposure to suffering, to needy people, in a context where the needs and the suffering have to be translated into problems to be solved and solved problems are reckoned up as output. For this, something more than 'customer service' and a narrowly contractual approach to care is required.

(Tallis 2004)

Whereas in the past we might have left the quality of care to the health professionals, the starting point for The Point of Care is to define patients' experience of care as a product of the whole system of care in the hospital, which is in turn influenced by the wider context. We define patients' experience as the totality of events and interactions that occur in the course of episodes of care. Clinical and non-clinical staff at the point of care, and in support services, and senior leaders including non-executives in the boardroom, all contribute to the quality of that experience.

Sources of evidence and methodology

Knowledge of variations in patients' experiences in hospital and of the forces that shape the experience, and measures that will help to improve it, is comparatively new and undeveloped. It is not yet close to the sophistication achieved in theory, policy and practice development in patient safety over the past 10 years (Institute of Medicine 2000; Institute for Healthcare Improvement 2008).

To gain as wide as possible a picture of patients' care, we listened to what patients and staff had to say, looked at the research literature and considered relevant government policy. Our research was carried out in three ways:

- qualitative research with patients and families
- qualitative research with hospital and trust staff in four hospitals
- a literature review.

Research with patients and families gave us first-hand accounts of what it is like to be a patient in hospital today. It gives the human dimension to our analysis of surveys and complaints. The research with staff investigated the different terminology used and how different staff groups felt about the language used. The literature review gave us valuable information on research, policy and practice in this area, as well as shedding light on the issue of communication – the language and terminology used in considering the experiences of patients. What do we mean by patient-centred care, 'the patient experience', quality? If we do not have a common understanding of the terms used, then how can we work effectively on improvement?

Appendix A (*see* pp 45–49) gives details of the methodologies used in the research.

The themes

Section 1 examines the quality of patients' experience in English hospitals today, assessing information from individual stories and large-scale surveys and from the nationwide complaints. We reflect on the limitations and problems with the available sources of information.

Section 2 considers the contribution the literature in health service research and other disciplines has made to our knowledge of the experiences of patients. Key to this is an analysis of the terms, language and concepts used in research, policy and the everyday world of the hospital to discuss patients' experience. In all three areas we find that the concept of 'patient-centred care' is changeable; it means different things to different people, and is defined in ways that reflect and reinforce, rather than transcend the division between the various tribes in health care – the doctors and managers, the doctors and nurses, the clinical versus the non-clinical, and so on.

Faced with the need to define clearly the focus and language of The Point of Care programme as a whole, we prefer to talk about patients' experiences of care and to use the Institute of Medicine definition of patient-centred care as including:

- compassion, empathy and responsiveness to needs, values and expressed preferences
- co-ordination and integration
- information, communication and education

- physical comfort
- emotional support, relieving fear and anxiety
- involvement of family and friends.

(Institute of Medicine 2001)

Section 2 explains the reasons for this choice. It then looks at how research and language have influenced policy and practice.

Section 3 looks at the possibilities for improving patients' experience of care. We analyse the factors that shape patients' experiences; describe a range of interventions for improvement and comment on the evidence to support different approaches. Finally, we describe in detail three interventions at different levels of service delivery that we believe are supportive to staff and have the potential to make a profound and positive contribution to protecting patients from the dehumanising aspects of hospitals.

1 The experience of patients in English hospitals

As techniques to measure the quality of health care proliferate and improve, health professionals are beginning to understand that patients and their families hold unique vantage points as expert witnesses to care. For some time, hoteliers, bankers, car manufacturers, and politicians have been enthralled by information about the public's view of their services, including anecdotes, insights offered by focus groups, and data gathered from large scale surveys. Slow to turn to new fashions, health professionals are now learning that those they serve can make important suggestions as individuals, generate worthy hypotheses in small groups, and provide aggregate data through surveys that describe what is and is not going well and that can document the impact of efforts to improve.

(Delbanco 1996)

Introduction

How does it feel to be a patient in hospital in England in the 21st century? Is it a good experience, a bad one, or is it mixed? Does it vary? If so, in what way, by how much and what are the reasons? Is it due to differences between patients or between hospitals? How much does it depend on the type of treatment the patient is receiving, whether it was planned or was the result of an emergency? Is it getting better or worse? And how does it compare to the quality of patients' experience of care elsewhere, in Europe or the United States?

These questions are fundamentally important for patients and families, as they are for a wider constituency of taxpayers and the general public. Not surprisingly perhaps, given the sheer numbers involved, it is difficult to give meaningful answers: in 2006–7 approximately 29.6 million people attended outpatient appointments; 13 million people were inpatients; and there were 18 million contacts in accident and emergency (A&E) departments in England (Hospital Episode Statistics 2008). We can answer some of the questions, but there are many we can answer only in part: either the data does not exist, or is difficult to interpret or is contradictory.

This section comments on the difficulty of fully capturing patients' experiences of care with a limited repertoire of 'tools' and on the strengths and limitations of methods currently available.

The range of sources drawn on to describe aspects of patients' experience in English hospitals today are:

- stories
- surveys
- complaints.

Stories

If you want to know what it is like being a patient in hospital in England in the 21st century, the best thing to do, as Harvard psychologist Daniel Gilbert puts it, is to listen to patients.

If we want to know how a person feels, we must begin by acknowledging the fact that there is one and only one observer stationed at the critical point of view ... she is the only person who has even the slightest chance of describing 'the view from in here', which is why her claims serve as the gold standard against which all other measures are measured.

(Gilbert 2006)

Hospitals, as working environments and settings for care, are in a constant state of flux. Patients' and families' stories about what happens to them in hospital at any one time illuminate current realities and provide valuable insights into the 'behind the scenes' forces that shape the experience.

Patients' experience of hospital is intrinsically difficult to grasp. It is richly textured and complex. By definition subjective, the experience is such that no one else can know how it works from one moment to the next, how the different aspects of the experience (the process of care, the manner in which it is delivered, the environment in which it occurs, the physical sense of the place) come together, or what they mean for this particular person at this particular moment in their life.

Patients' stories bring the experience to life and make it accessible to other people. There is no shortage of patients' accounts of illness and treatment: patients have tried to communicate in paintings; in memoirs; film; drama; and fiction. Since the turn of the last century, what was once a trickle of written comment in newspapers, journals and other publications has turned into a torrent. Patients' stories, their views on illness and its treatment are in print and on the internet. The growth of social networking websites, along with the contemporary appetite for publicising personal experiences that previously would have been considered too private or too intimate to share, makes it likely this will continue.

Some patients write to help others, some write as 'insiders', as health professionals, as researchers or observers, or simply as private individuals trying to understand and explore the experience of illness and treatment.

The quality of a patient's experience is invariably the result of the interplay of all aspects of the process and the meanings they have for that one person. At their best, patients' narratives communicate vividly the multi-layered texture and complexity of experience in hospital, its intensity and human significance. This account from an episode in the course of treatment for breast cancer captures the interplay perfectly.

Test results can be nerve racking. They turn a complex stream of life into a binary event in which your fate seems to hang in the balance. I was especially nervous about my latest CT results. They would reveal whether the small cancers in my head had been zapped by recent whole brain radiation. Or not. I don't exactly know what 'or not' means, but the idea of blobs of breast growing in my brain (what is my breast doing in my head?!), impervious to radiation or drugs, sounds like something out of a sci-fi movie I'd rather not be in.

Then, a gift when I least expected it – the radiology staff in a scanning unit which supplies Sydney's Royal Prince Alfred Hospital were so lovely – down to earth, prompt, optimistic – that the morning was transformed. My mother and husband had lunch,

coffee, and waited calmly for the oncologist appointment. Although I didn't have the nerve to look at the scans before seeing him – my scan reading is decidedly ropery and neuro-anatomy was always something I was grateful other people were good at – I stopped being a jibbering wreck.

(Donald 2008)

Patients do not naturally differentiate between aspects of care or rank them in order of importance. Everything about the process is a manifestation of the greater whole. Equally, patients' judgements about the quality of the whole are informed by the care they witness others receiving. This is not because they see themselves as the same as other patients. It is because when they witness something happen to another patient, good or bad, they immediately know that the same could happen to them.

We interviewed patients and families (*see Appendix A, pp 45–46, for details*) in late 2006. At the time, among many other priorities and calls on their time, hospital staff and managers were under immense pressure to achieve the four-hour national target for waiting times in accident and emergency; change the pathway for emergency admissions; shorten lengths of stay; and contain and eliminate hospital-acquired infections. In most hospitals, medical hierarchies were changing away from the traditional consultant-led firm, towards consultant teams with teams of junior doctors reporting to them. Junior doctors' patterns of work were changing at the same time as their working hours were reduced to comply with the European Working Time Directive. Meanwhile, nursing hierarchies changed to accommodate the central policy-led introduction of 'modern matrons' and the findings from locally driven skill-mix reviews.

The patients' and families' stories of their experiences, both from our research and from the literature, were widely divergent and rich in individual detail, but there were common themes.

Unreliable quality

Without exception, all the patients' experiences of care were mixed. None were wholly good or wholly bad. Fundamentally, the stories describe variability in the experience of care, hour by hour, shift by shift, day by day and from ward to ward. The defining feature of patients' experience of care in all kinds of settings within the hospitals was that it was unpredictable and unreliable. Almost everything depended on who was on duty, and beyond that, who was in charge: both factors that to the patients seemed unpredictable.

This was a daughter talking about her mother's care:

Fluid intake was the single most worrying element of the whole thing and it was very basic stuff really. Equally, particularly when she was on the infection control ward, was her output. She had C. difficile and was going to the toilet about 20 times a day. Whenever I asked 'Is it clearing up?'... 'Oh yes, she has not been at all this morning'. But I'd only have to visit for an hour and she'd be going three times. They were either not observing what was happening or not recording what they observed.

This was an experience from a recently published account of five months in a London hospital as an inpatient.

I used to dread the nights when agency staff were allocated to look after me. Not knowing where things were stored, they would be much slower in responding to requests for banal but vital things such as urine bottles. Not knowing me or much of my history, they would also tend to be inflexible and suspicious, doggedly insisting that I should be given drugs that I hadn't taken for days because 'you're still written up

for them on your chart', or getting panicky and rushing to send for a doctor when my temperature was slightly raised although it was doing no more than following a well-established pattern.

(Ludlow 2008)

Seeing the person in the patient

All the patients and relatives talked about the importance of the patient being 'seen as a person'. One woman, for example, had nothing but praise for the care she had received during her 24-hour stay in hospital, even though her (well-documented) need for a special diet had initially been entirely overlooked. In the course of her planned admission for surgery, the ward staff had been unable to offer her anything to eat in the evening. Nevertheless, her assessment after the event was that she had been exceptionally well looked after because staff had handled her so sensitively. The morning after the non-existent supper, the charge nurse had apologised directly, contacted the kitchen, and someone from the kitchen gave her a breakfast she could eat and an apology. 'I felt,' she said, 'that they took account of who I am and my needs.'

The opposite was also true. The failure to 'see the person in the patient' was very deeply felt. This was an ex-nurse, talking about the care of her 87-year-old mother on her admission to hospital following a fall.

Significantly, the ambulance crew were the only people in the entire seven weeks who formally introduced themselves and asked what she would like to be called. Thereafter, for the first six weeks of her admission, she was called Elizabeth, which is her first name, which she has never been called in her life, ever. She's only ever been called by her middle name. But the NHS IT system records your name. All her labels were wrong. In spite of the fact that on a daily basis all of us told the people caring for her that her name is Margaret, and that is what she likes to be called if they want to call her by her first name, all of them called her Elizabeth. And that became very significant when she became confused.

Who is in charge?

When patients spent many weeks in hospital, they found it difficult to find someone in charge – doctor or nurse – to talk to about their care. Two daughters described repeated attempts to find a consultant who would answer their questions and give a view on their mothers' prospects. They had tried secretaries, asked the ward for an appointment, and even simply turned up on the ward at times they hoped would coincide with ward rounds.

When I asked to speak to the doctor in charge they looked at me as if I was completely blown out and said, 'well you can talk to any of them'. I'm saying – 'who's the person that has the lead responsibility?' and they said they could not say that because it was a different person each day... I never got to the bottom of the accountability in the trust. She had a name at the top of the bed but that person did not deliver the care.

Another daughter (herself an eminent, retired doctor) tried and failed over eight weeks to find a consultant to talk to about her 90-year-old mother's care. She was told variously that her mother did not belong to this team; the consultant who had admitted her mother was not responsible for patients on this ward; the 'principal' consultant was in a different specialty, and the consultant was on holiday. Finally, when she did manage to track down a consultant who acknowledged responsibility for her mother, it was only to find that the

conversation was restricted to her medical care. The doctor refused to discuss her nursing care, on the grounds that the nurses took offence if the doctor commented on their work and she was not prepared to risk falling out with them.

Finding a nurse to talk to about a patient's care can be equally difficult.

Whenever I asked that person [the nurse in charge of the shift] they either said they did not know her, did not know she was on the ward, or did not know how she was that day because they were not looking after her. Would I please talk to the nurse in charge of her care!

The patient as a parcel

The fourth theme in late 2006 was about emergency patients being moved repeatedly from ward to ward after their admission to hospital. Some moves were planned: the patient admitted through the emergency department went first to a medical assessment unit and then on to a ward. But most moves did not seem to the patients to be planned, rather they felt the moves were reactive. They were moved because they had acquired an infection; because they had been put in the wrong place to start with; or because their bed was needed for someone else. One patient talked about feeling like a parcel and a consultant talked of patients as 'pushed around like a piece of packaging'.

With every move, patients and relatives worried that the knowledge about them fell away. Arriving in a new environment, with a new group of staff, they would have to begin building relationships again from scratch. One very elderly patient was moved twice in the same night, once at 2am and then again at 5.30am.

She was treated like a parcel. The junior doctor on one ward ordered tests but she moved before the results arrived so they were never received. In one of her moves, she was taken by a porter in a wheelchair to the door of one ward. The nurse in charge came to the door and barred the way, telling the porter: 'You're not bringing her in here'. My mother felt anxious she would be lost inside the system.

Patients' stories have a unique power to engage and move listeners and provide invaluable insights into the relationship between the care process and the patient's world. They provide material from which it is possible to generate hypotheses about relationships between events and causes and are the source *par excellence* for evidence of the reliability and consistency of standards of service over time and in different settings. What they cannot do is tell us whether a particular patient's or relative's experience is typical. How many others have the same or different experiences? Is the experience part of a trend? For this kind of information hospitals need feedback from larger samples and different kinds of measures.

Surveys

Surveys of hospital patients began in earnest in the United States 20 years ago with the pioneering work of Gerteis and others (Gerteis *et al* 1993). Their rigorous approach to developing and testing questions and questionnaires, and selecting sample populations, ensured that the surveys covered topics that patients and relatives felt were important. In the mid-1990s, a team of researchers influenced by the work in the States and working with a member of the original US team, Thomas Delbanco, surveyed patients in 36 English hospitals (Delbanco 1996). This survey was the precursor to what was to become the programme of national patients' surveys in England that has been running since 1997. These national surveys use postal questionnaires to collect data rather than interviewing

patients at home, but in all other respects the methodology – the random sampling of the patient population, the use of structured questionnaires and the content of most of the questions – has barely changed. Questions cover pre-admission procedures, admission, communication with staff, physical care, tests and operations, help from staff, pain management, discharge planning and general questions about satisfaction.

Since 1997, NHS acute hospital trusts have undertaken annual patient surveys and, since 2004, reported the results to the Healthcare Commission. (Before 2004 surveys were variously published by the Healthcare Commission, The Department of Health, the Commission for Healthcare Improvement, National Audit Office and the NHS Executive.) The Department of Health intends the surveys to provide ‘systematic evidence to enable the health service to measure itself against the aspirations and experience of its users, to compare performance across the country, and to look at trends over time’ (Department of Health 1997). Over time, the questionnaires have gradually expanded to include topics of public and/or political interest, notably waiting times, access to single sex wards and perceptions of cleanliness. It is perhaps worth noting that the drift in this direction runs somewhat counter to the integrity of the original methodology that allowed only questions derived from detailed qualitative work with patients.

The Healthcare Commission lays down the survey methodology and the questions it wants answered. Hospitals are free to add questions of their own, but as the questionnaires are typically more than 70 pages long, they are not encouraged to add many. Questionnaires are sent to a randomly selected representative sample of patients on discharge from hospital. Response rates vary between 38 and 75 per cent. In the past eight years, there have been five national surveys of inpatients (2002, 2004, 2005, 2006, 2007); two surveys of outpatients (2003, 2004/5); two surveys of patients in the A&E department (2003, 2004); and one each of patients who used the ambulance services (2004), young patients (2004), and patients in maternity services (2007). There has been one survey of patients with diabetes (2006); two of patients with cancer (2000, 2004); two of each of patients with heart disease (1999, 2004) and stroke (2004, 2005); and one of patients using acute mental health services (2007). There have been five surveys of primary care trust patients (1998, 2003, 2004, 2005, 2006); and four of patients using community mental health services (2004, 2005, 2006, 2007). Altogether (in England to date) nearly 1,500,000 patients have provided feedback on their experience. Of these 722,989 were hospital patients having used ambulance services, inpatients, outpatients and emergency departments. Their response rate ranged from 44 per cent to 64 per cent (Richards and Coulter 2007).

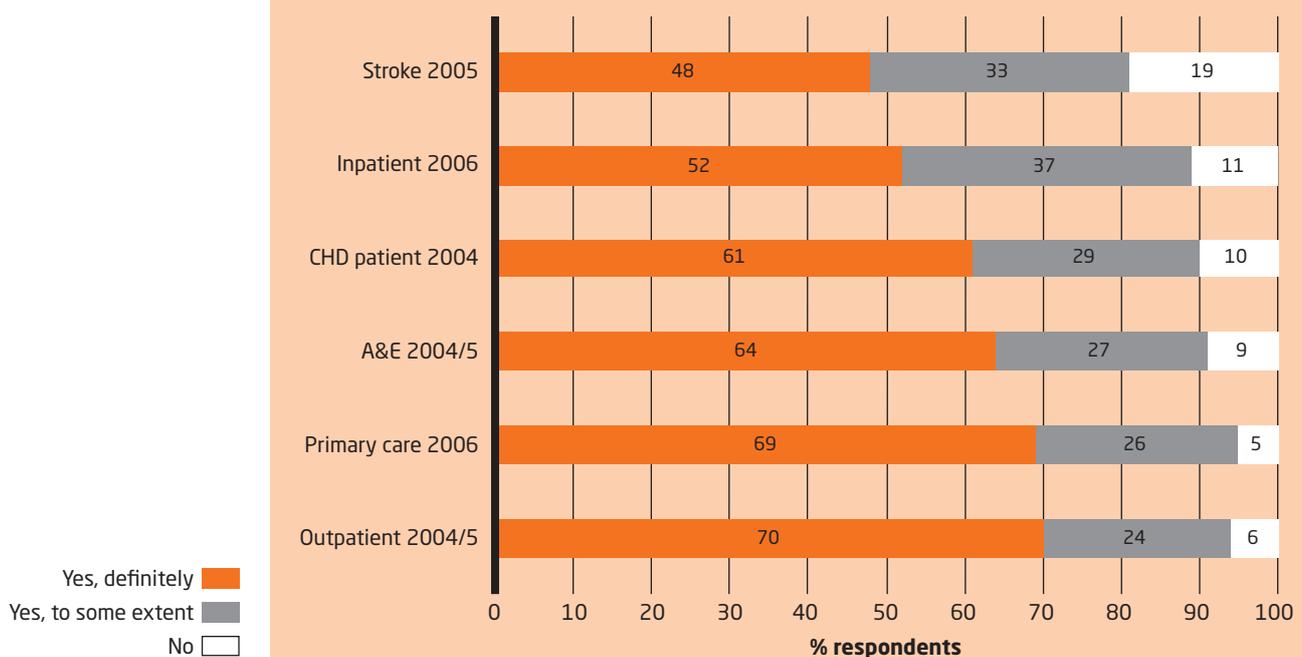
The great majority of NHS hospital patients in England are positive both about the NHS and about care in hospital. In 2007, 92 per cent of inpatients rated their overall care in hospital as ‘excellent’, ‘very good’ or ‘good’. The proportion describing their overall care as ‘excellent’ had risen steadily from 38 per cent (2002), to 41 per cent (2006) and 42 per cent (2007) (Healthcare Commission 2008d). These very positive results do, however, need to be interpreted cautiously. There is evidence from other studies that when asked, patients generally indicate high levels of satisfaction with care, and that high rates of recorded satisfaction correlate positively with a willingness to recommend to others the hospital where they received treatment. But this does not necessarily mean that the experience behind the report was wholly positive. On the contrary, when asked to comment on specific aspects of treatment and the detail of the process of care, the same patients report problems. In one study, 55 per cent of patients who described their care as excellent said they had experienced four or more problems; 13 per cent of those saying the care was excellent reported 10 or more process problems (Jenkinson *et al* 2002).

In a useful report summarising the data from all the surveys carried out since the national programme began, Richards and Coulter conclude that the results accurately reflect the positive effect of national targets on access to hospital and waiting times in emergency departments and show ‘encouraging signs’ of improvements in care in the national priority clinical services: cancer, coronary heart disease, stroke and mental health. Their overall conclusion, however, is that while ‘NHS care has improved significantly in some important aspects and most patients are highly appreciative of the care they receive (...) despite pockets of excellent practice, the service as a whole is still far from being patient-centred’ (Richards and Coulter 2007).

According to their analysis of 75 aspects of hospital care in England, the dimensions patients value most highly are: patient–professional interactions, communications, and being treated as an individual (Richards and Coulter 2007). Broadly they conclude that, in contrast with primary care, the most significant problem in acute inpatient hospital care is the failure of clinical staff to provide active support for patient engagement and that there are ‘worrying signs that care for the majority was still delivered in a paternalistic manner, with many patients given little opportunity to express their preferences or influence decisions’. Feedback from surveys shows more involvement in decision-making in outpatient clinics than in inpatients (see Figure 1, below).

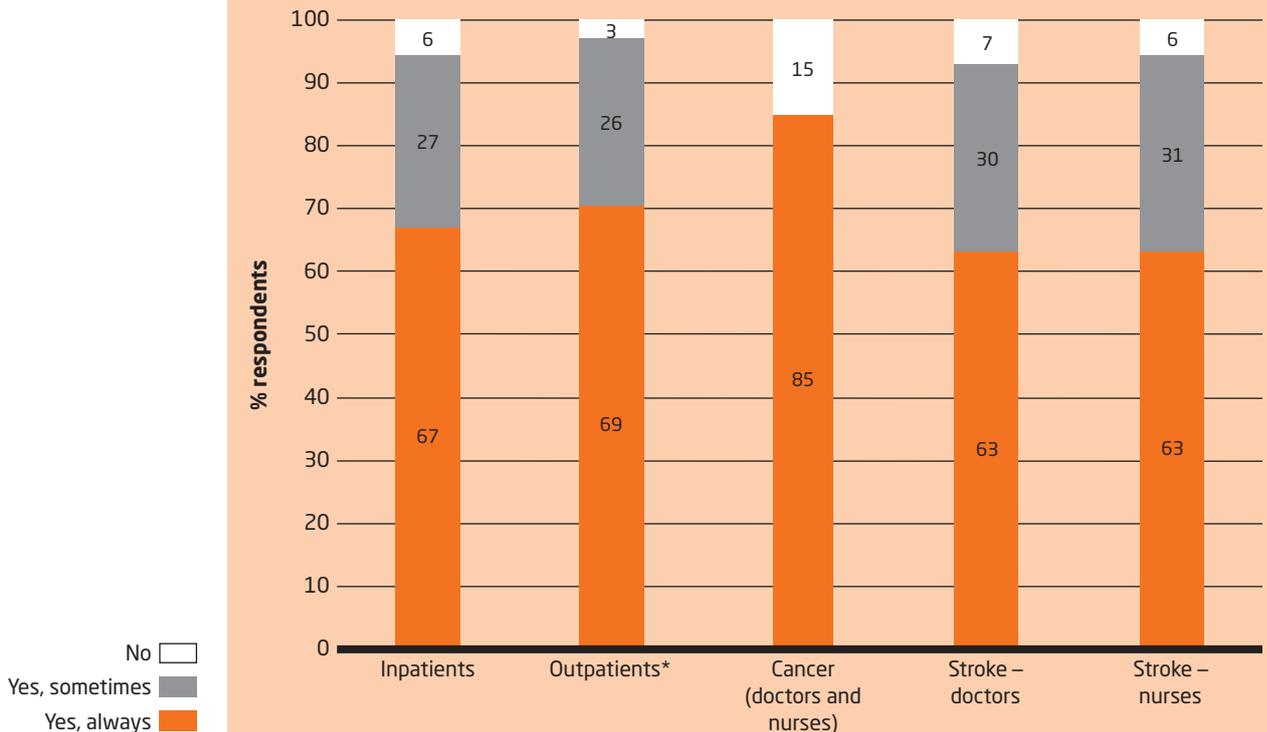
The results from the surveys of specific services (eg, accident and emergency, maternity) and patient populations (eg, patients with cancer, heart disease, and stroke) paint a picture that is more easily interpreted than the results from the generic surveys of inpatients and outpatients. For example, comparing the results across specialties it is immediately apparent that patients’ experience varies (see Figure 1, below) and that doctors working in cancer services may have something to teach their colleagues in other disciplines about information-giving (see Figure 2, opposite).

Figure 1 Patients involved as much as they wanted to be in decisions about care and treatment, England, 2004, 2005 and 2006



Source: Adapted from Leatherman and Sutherland 2008

Figure 2 When you had important questions to ask a doctor, did you get answers that you could understand?



Source: Healthcare Commission 2007c; 2005b, c; National Audit Office 2005

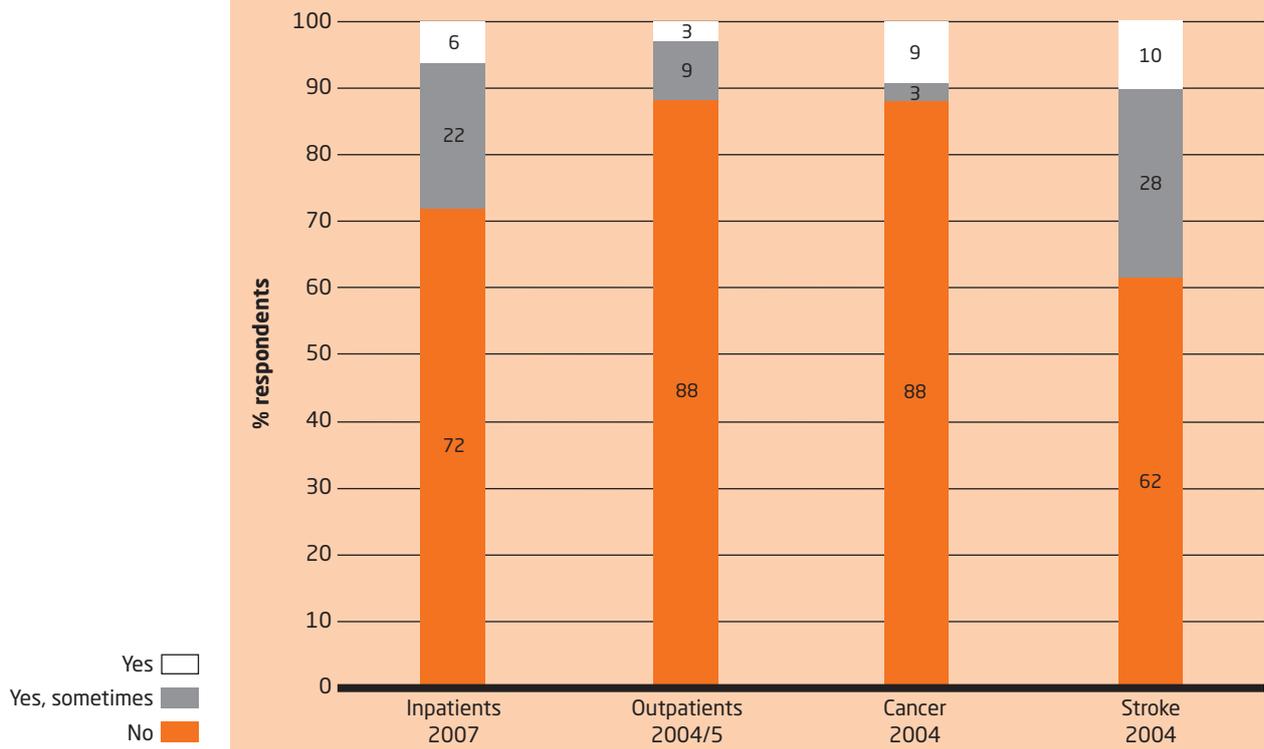
* Two per cent did not have an opportunity to ask.

The same transparency is true in relation to respect and dignity. For some years, inpatient surveys have consistently reported a majority of patients as saying they were ‘always’ treated with respect and dignity (78 per cent), a significant proportion (19 per cent) saying they ‘sometimes’ were, and a small minority (3 per cent) saying they never were (Healthcare Commission 2007c). The feedback is suggestive, but it does not point to where the problems occur or which groups of staff are involved. In contrast, when 37 per cent of women who stayed in hospital after giving birth say they were not always treated with kindness and understanding, it offers an immediate insight into the quality of care on post-natal wards (Healthcare Commission 2007d).

A majority of patients say neither doctors (72 per cent) nor nurses (79 per cent) talk in front of them as if they were not there. Of those responding, 22 per cent and 17 per cent respectively say doctors and nurses do so ‘sometimes’, and 6 per cent say it happens ‘often’ (Healthcare Commission 2007c). In services for patients with cancer the results are better, but in stroke services they are less positive (*see* Figure 3, overleaf). One possible explanation is that in services where patients are more likely to have communication difficulties, health staff may frequently find themselves talking in front of them as if they were not there. At one level this may seem obvious, but the feedback from the patients serves to raise awareness of an important, overlooked problem.

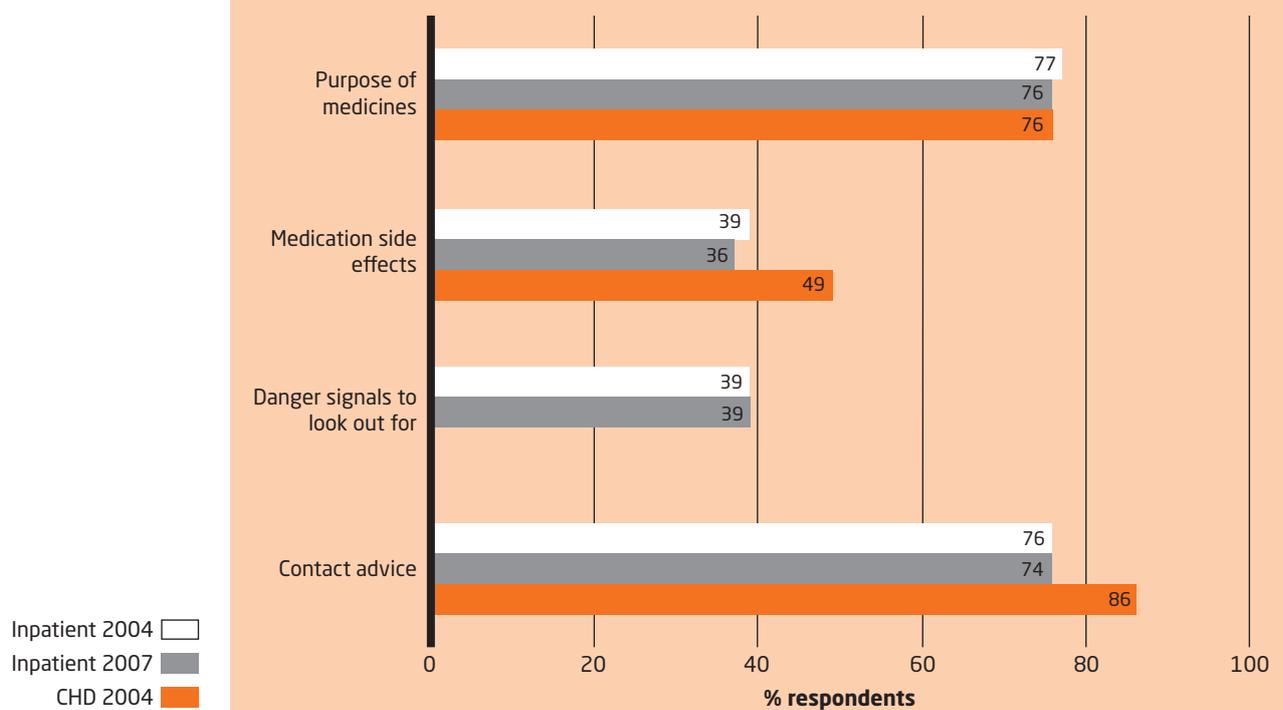
The examples make the point: the more targeted the question, the more useful the results. For example, asked to assess teamwork between doctors and nurses in the abstract 92 per cent of patients say it is ‘excellent’ ‘very good’ or ‘good’. One of the best practical tests of teamwork in action is effective discharge planning. In 2007, almost 40 per cent of patients asked said their discharge was delayed on the day, mainly because they were waiting for

Figure 3 Did doctors/other staff talk in front of you as if you weren't there?



Source: Healthcare Commission 2007c; 2005b, c; National Audit Office 2005

Figure 4 Information received on discharge from hospital, England, 2004 and 2007



Source: Healthcare Commission 2007c; 2005a

medicines; of these, 20 per cent were delayed for more than four hours (Richards and Coulter 2007). Their answers to questions about whether they received the information they should have received about the purpose of medications, their possible side-effects and what to look out for and who to contact should there be a problem, also varied between patient groups (see Figure 4, opposite).

The patients' answers may of course say more about what patients believe they were (or were not) told, than about the quality of teamworking. But as communication and information-giving is itself a function of teamwork, however interpreted, the data are pointing to important problems in relation to co-ordination and communication that are not picked up by asking patients to rate the quality of 'teamworking'.

Complaints

In 2006/7 NHS organisations received 140,000 letters of complaint (Healthcare Commission 2008d). What does this say about patients' experience in hospital? Is the number reassuring, or troubling? The volume of complaints received has been increasing steadily for more than 20 years; the fact that patients complain more today may mean the quality is deteriorating but it could also be related to other factors. It may be an indicator of wider social changes or the result of hospitals encouraging feedback and telling people how to complain. The most common causes of complaints (after all aspects of clinical treatment) are about the attitudes of staff, cancellation or delay of outpatient appointments, and communication/information to patients (Leatherman and Sutherland 2008).

In 2007, 7,500 complaints were referred to the Healthcare Commission because they had not been resolved by the hospital concerned and were eligible for independent (or 'second stage') review. Most people (36 per cent) who complained about their hospital care were concerned about their clinical care and the treatment that was provided. A further 30 per cent made complaints about 'the fundamentals of nursing care, such as hygiene, communication, privacy and dignity, and nutrition'. Concerns about communication included: call bells not being provided or being left out of reach of patients, particularly of elderly patients; a lack of communication and involvement with relatives and carers about care and treatment plans; nurses being 'abrupt' or 'sharp' when speaking to a patient, making the patient feel as if they were a nuisance. Concerns about privacy and dignity included: patients being left in soiled bedding and clothing; personal hygiene needs not being met; clothing being inappropriate or inadequate (gowns not maintaining patients' modesty); bedside curtains or room doors being opened when patients were receiving intimate care (Healthcare Commission 2008d).

The specifics in the complaints vary, but the sense from this data is summed up in this passage from an article in the *British Medical Journal* (BMJ).

Friends and relatives who have been inpatients recently all have similar complaints – never seeing a nurse except when drugs were being handed out, no one offering reassurance or information, days going by without any contact with senior medical staff, virtually having to beg for help moving up the bed or getting to the toilet, repeated requests for analgesia. Two elderly relatives developed pressure sores after straightforward surgery, and one lost six per cent of her bodyweight after a joint replacement because of prolonged nausea that was inadequately managed. It's these experiences, and not the skilful surgery, that patients remember and tell their friends about. And it's these that make patients, especially elderly patients, dread being in hospital.

(Teale 2007)

There is a degree of overlap between complaints data and survey results. We have seen that survey results show that communication and information-giving in outpatients is better than when patients are in hospital, and the complaints resonate with Richards and Coulter's observations about 'worrying signs of paternalism' and patients lacking opportunities to express preferences or influence decisions. But the complaints data (each one telling its own story) illuminate aspects of experience that the surveys ignore: in particular the overwhelming sense of powerlessness felt by patients and families, and the profound impact that lack of care of physical needs has on the person (Patients Association 2008).

A good deal of analysis of complaints data is available in relation to litigation and malpractice claims, but comparatively little research into the relationship between complaints and experience. We do not, for example, know much about who complains or what drives people to complain. We do not know whether the incidents complained about are rare or common. One striking feature of complaints as a source of information about patients' experience, however, is that they are the only place where the involvement of families in what happens to patients in hospital shows up and we see how the significance of the experience is transmitted through informal networks into the wider community. There is very little data on families' experience and observations of care in other sources.

Discussion

Returning to the opening question, how does it feel to be a patient in hospital in England in the 21st century? it is apparent that we have found it difficult to answer. We do not have much data on trends, and it is difficult to know how most aspects of English hospitals compare with those in hospitals in other countries. The information we have is contradictory: broadly, the picture from the survey data is positive, the picture from patients' and families' stories is more mixed, and the complaints data suggest serious grounds for concern.

The national survey data has major strengths. It allows hospitals to be compared, and with time, if the questions remain the same, we will be able to track trends. The data show that, on the whole, patients in London and the south-east are less positive about their experiences than in other parts of the country; patients in specialist hospitals are generally more positive than patients in general hospitals; and older patients everywhere rate their experience of care more positively. They also reveal that patients who are more sick, patients from black and from minority ethnic groups and patients with communication and learning disabilities report much less positive experiences than other patients (Healthcare Commission 2006).

The survey methodology makes generalisation possible, and for that reason surveys are a unique source of information for policy-makers, commentators, patients' organisations, charities and campaigning organisations. They have helped to build the case for improvements in the experience of patients, and validated concerns about patients who are especially vulnerable because they cannot speak for themselves, or because they pose a particular challenge to staff (for example, Help the Aged, Connect UK, Mencap).

In the health service, patient surveys are usually called 'satisfaction surveys' which is a misnomer. Researchers in the field have repeatedly pointed out that the concept of 'patient satisfaction' is problematic and that it is important to go beyond satisfaction to reports of actual experiences (Bate and Robert 2007; Coulter and Ellins 2006). However, it is possible to argue that asking patients to reflect on their experience as a whole taps into public support for the NHS and for NHS staff. Certainly, the more specific and focused the question, the more likely it is to get underneath the politeness required for 'public'

accounts and closer to the 'private' accounts people give when they are less afraid of being judged by unknown others (Cornwell 1984).

Inevitably, survey methodology forces patients to generalise in order to rate their own experience. Many of the questions categorise the presence or frequency of certain experiences by limiting patients' responses to 'always', 'sometimes', or 'no'. Similarly, those that rate patients' agreement with a particular statement usually allow only 'yes, definitely', 'yes, to some extent', 'no', or 'don't know' as response options. Before answering, the patient is asked to reflect on their experience 'as a whole' and decide what to report. This may explain the difference between survey results and the stories. Certainly, the post-hoc overview of experience is very different from the story about what happened along the way and crucially, it misses the definitive significance of the lack of reliability.

Patients' stories, as we saw earlier, bring their experience to life in a way that survey data cannot, but it is difficult to generalise from them. Complaints are stories from one end of the spectrum of experience, and as such important. But beyond knowing that the numbers of complaints are rising, that complaints are mainly about interpersonal transactions and relationships and that the care of older patients is a particular concern, we know relatively little about the areas of care, groups of staff and the circumstances that cause people to complain.

Perhaps we should accept that the question framed in this way is impossible to answer and change it. The question is not 'what is it like being in hospital', but what is it like in this particular clinical service, in this setting and this hospital? What is it like for different patients? And how does it vary over time? In other words, to understand and describe patients' experience we need more detailed information that gets closer to clinical service, care processes and pathways of care, and to the actual settings (this ward, this outpatient clinic) and circumstances (this multidisciplinary team) in which care is delivered.

The next section steps back from experience in hospital. It considers first the language used, and then asks, what can we learn from research into patients' experience? How far has the research influenced the thinking of politicians who shape the wider health care system that influences what happens to patients in hospital? And how far has the research and the policies in this area influenced the staff on the ground who work directly with patients at the point of care?

Key messages

- It is difficult to make meaningful generalisations about patients' experience of care in English hospitals.
- The main sources of information have some strengths and limitations, they can be difficult to interpret and can appear contradictory.
- The national patient survey data are useful for tracking trends and comparing results for different hospitals and patient groups.
- Patients' stories and patients' complaints remind us of the importance of seeing the person in the patient and bringing patients' experience alive.
- We need much more detailed data to understand variations in patients' experience of care within as well as between hospitals, over time and between patient groups.

2 Making sense of 'patient-centred care'

I cannot emphasise too much how important is this battle (and it is a battle) for control of the discourse of care. It is not the pedantry of a fuddy-duddy. It is a supremely political issue, since it determines the place occupied by patients in the considerations of others.

(Kennedy 2004)

Introduction

This section is concerned with our understanding of the language – concepts, definitions and terms – used to talk about patients' experience of care in three inter-related domains:

- health services research and the wider academic literature
- government policy
- the practical, everyday world of staff who work in hospitals.

At every level of research, policy and practice we have found people struggling with concepts, definitions and language. The language of research and policy does not translate well into the everyday language of staff in hospital.

Language and terminology are political issues: they define the terms of debate, shape policy, determine central government priorities for investment, focus performance management and succeed or fail in motivating staff who work directly with patients. In all three domains we find alternative, more or less similar, overlapping terms that mask strong disagreements over patients' experience and what can be done to improve it.

... look at the language used in the discourse about patients. We meet 'patient safety', 'patient consent', 'patient focus' and 'the patient experience' (and there are many more where they came from). By these expressions, the centrality of concern for patients is undermined. It is replaced by a managerial concept: something to be included on an agenda and ticked. The important word, the focus of attention in the expression, becomes an abstraction, whether 'consent' or 'experience', or whatever. It allows the object and the objective of the expression, the patient, to be marginalised. It is no longer about patients, it is about some abstract notion. Change the language, not only to accommodate the principles of grammar but also to stress what is important and you have: 'the experience of patients', 'a focus on patients', 'the safety of patients'. The discourse is completely changed. We are now talking about patients as people, whose experiences and safety are what we are concerned with.

(Kennedy 2004)

The language we use, then, shapes policy, the care given, our understanding of the patients' experience of that care and thus whether or not that care is 'good' and how it can be improved.

Health service research and the academic literature

To find out more about the terms and concepts relevant to patients' experience in hospital, we turned to the published research relevant to patient care, health service research and health care quality. We wanted to see whether and how patients' experience figures in definitions of quality, and to find out what lessons we could take from the literature.

The full details of the search methodology are set out in Appendix A (*see* pp 48–49). In brief, the search began with the terms 'patient-' and 'person-centred' care, but rapidly extended to incorporate other terms, including: family-centred; relationship-centred; patient care; patient-led; personalised; individualised, 'patient experience', humanity, dignity, empathy and compassion. Some of these terms can be found alongside each other in the same text, while others are favoured by a particular discipline. 'Person-centred' care, for example, is used in the literature of nursing and social work, while 'family-centred' care is used mainly by professions working with children and 'relationship-centred' care by those working in care homes.

All the terms are 'complex', have more than one meaning and are the subject of enquiry and debate in what might broadly be termed 'medical humanities' as well as clinical and social sciences disciplines. Partly because there are many different terms, terms are poorly defined or disputed and therefore unstable. Different terms are preferred by different groups, although 'patient-centred care' has emerged as the dominant concept, albeit with contested definitions.

The literature is vast (*see* Further reading on pages 29–30 for a sample).

A significant proportion of the evidence on patients' experience of care, along with descriptive reports of interventions and 'promising practice', is published in non-peer-reviewed nursing, medical and management journals. In recent years, the nursing press in particular has been intensely preoccupied with debates about patients' experience, the causes of substandard nursing care (Corbin 2008, Maben 2008), and campaigns to protect the dignity of patients (Royal College of Nursing 2008, Levenson 2007). In addition, important information about practice, guidance packs and tool kits can be found on the websites of organisations dedicated to health care improvement such as the NHS Institute for Innovation and Improvement (www.institute.nhs.uk), the Institute for Healthcare Improvement (www.ihl.org), the Commonwealth Foundation (www.commonwealthfoundation.com) and more specialised sites such as those of Marie Curie Palliative Care Institute (for the Liverpool Care Pathway – www.mcpcil.org.uk/liverpool_care_pathway) and campaigning organisations and patients' groups (eg, www.helptheaged.org.uk, www.bgs.org.uk/campaigns/dignity.htm).

Definitions of quality

Early definitions of quality use a variety of terms. One early definition had four criteria: 'humanity, efficiency, effectiveness, and equity' (our emphasis) (Open University U205 Team 1985). Another had six criteria, of which two concerned patients' relationship to care: *acceptability*, *appropriateness*, accessibility, equity, effectiveness and efficiency (Maxwell 1992).

The standard definition of quality now recognised internationally is that of the US Institute of Medicine which has six criteria: patient-centred, safe, effective, timely, efficient, and equitable (Institute of Medicine 2001).

Today, patient-centred seems to have become the term of choice in the quality improvement literature (occasionally supplanted by ‘patient and family-centred care’) despite the fact that there are problems associated with it.

Definitions of patient-centred care

Although often rejected by hospital staff as ‘management speak’, the concept of ‘patient-centred care’ is the most frequently used in all three domains when considering the experience of patients. It implies a common vision, but its meaning and what it encompasses is contested.

I never liked it [the term patient-centred care]. It offends everyone, because each health professional thinks he or she is patient-centered. The basic notion to me is trying to see through the eyes of the patient and understand patients’ expectations, perceptions, and experiences, rather than just seeing through our professional eyes. The expression has come to mean an awful lot of different things, as it’s become shop talk. The minute that happens, words take on many different meanings.

(Delbanco 2005)

In a research study of patient-centred communication in primary care, Stewart (2000) defined it as:

... exploring the disease and illness experience; understanding the whole person; finding common ground regarding management; incorporating prevention and health promotion; enhancing the doctor-patient relationship and ‘being realistic’ about personal limitations and resources.

In contrast, in primary care more widely it is conceptualised in terms of aspects of the relationship between patient and primary care doctor that are both complex and subtle and include:

- the bio-psychosocial perspective – a perspective on illness that includes consideration of social and psychological (as well as biomedical) factors
- the ‘patient-as-person’ – understanding the personal meaning of the illness for each individual patient
- sharing power and responsibility – sensitivity to patients’ preferences for information and shared decision-making and responding appropriately to these
- the therapeutic alliance – developing common therapeutic goals and enhancing the personal bond between doctor and patient
- the ‘doctor-as-person’ – awareness of the influence of the personal qualities and subjectivity of the doctor on the practice of medicine.

(Mead and Bower 2000)

Elsewhere it has other meanings. In cancer, it is the strategic goal underpinning the re-organisation of primary, secondary and tertiary services into networks designed around patients’ clinical needs. In care of people with long-term conditions, it denotes approaches to management that explore what patients think, believe, and expect and their confidence about disease management. It is used actively to promote social supports and social and family influences and apply the principles of behaviour change (Bauman *et al* 2003). For patients’ organisations and consumer groups, patient-centred usually means services that listen to patients, take their views seriously and attend to the ‘fundamentals’ or ‘basics’ or ‘simple’ aspects of care: dignity and respect for individuals; well-organised care; clean wards and nutritious food.

Shaller, in a useful review of nine influential frameworks for patient-centred care in the United States, including those of the Picker/Commonwealth Program for Patient-Centred Care, the Institute for Family-Centered Care and the Planetree Association, finds they have six core properties in common:

- education and shared knowledge
- involvement of family and friends
- collaboration and team management
- sensitivity to non-medical and spiritual dimensions of care
- respect for patient needs and preferences
- free flow and accessibility of information.

(Shaller 2007)

The dimensions of patient-centred care

These properties are closely aligned with the Institute of Medicine's definition of patient-centred care, which is the one we find useful in defining the focus of The Point of Care programme because it is the most comprehensive. Its particular attraction is that it incorporates both the 'what' of process and the 'how' of relationship, attitudes and behaviours. The definition has six properties or dimensions (*see box below*).

Institute of Medicine's definition of the dimensions of patient-centred care

1. Compassion, empathy and responsiveness to needs, values and expressed preferences
2. Co-ordination and integration
3. Information, communication and education
4. Physical comfort
5. Emotional support, relieving fear and anxiety
6. Involvement of family and friends

(Institute of Medicine 2001)

We can break down each of the six dimensions into sub-headings. For example: physical comfort breaks down into sub-headings on the properties of the physical environment (design, light, space, furniture and equipment, accessibility); management of the environment (warmth, cleanliness, smells, noise); and staff responsiveness to individual patients. Involvement of family and friends is about involvement in caring for individual patients, and group involvement in governance, service design and service planning.

Research into the six dimensions of patient-centred care is uneven and highly specialised and the evidence is full of gaps. Communication and information-giving is disproportionately well researched, and we found systematic reviews in this area. By contrast, the dimensions of involvement of family and friends (of adult patients) and physical comfort, for example, remain relatively unexplored. Other dimensions, for example those exploring the nature of empathy or dignity are addressed through discussion papers.

In the main, for perhaps obvious practical reasons, researchers have focused on one dimension at a time rather than patient-centred care as a whole. Much of the research has been carried out away from real clinical settings, in classrooms and laboratories, but there is a small number of ethnographic and sociological studies of teamworking and real care settings including some evaluations of attempts to improve aspects of patients' and staff experience in UK hospitals (for example, the observational studies of protected meal times; 'safari' ward rounds).

Everyday language used in hospital

Good care

We wanted to find out how staff and managers in hospital think about patients' experience. How much are they aware of and influenced by the research in this field, or by government policy? Our qualitative study (*see Appendix A, pp 45–47*) asked participants to define 'good' care; to tell us how they and their colleagues talk about patients' experience of care; and to give us their views on the common terms used to describe 'good care' by media commentators, academic researchers, and politicians. We also tested the phrase 'seeing the person in the patient' which had emerged in the course of discussion with The Point of Care advisers.

Most people struggled with the concept of '**good**' care.

Er... the process by which someone's needs are met? (Senior doctor)

I think caring is about more than just meeting the needs – there are a lot of things you'd like, as a patient, that are not just needs.

(Senior doctor)

To me it goes beyond the technical delivery – it's the way it's delivered, with humanity and sensitivity.

(Trust director)

As medical staff, we all know what good care is – it's just that we have not got time to do it.

(Senior doctor)

Almost universally, respondents said it was not something they talked about with colleagues; indeed a number told us this was the first occasion they had talked about it at work.

It's not discussed as such – only after things have gone wrong. (Therapist)

Most people mentioned the advice that circulates widely: good care comes from putting yourself in the patient's shoes, or trying to imagine the patient is a friend, or relative. 'Good care' for them was an not abstract concept, it was either an attitude or a narrative.

Just make them welcome, put a smile on your face, and remember that when they come in through the door they're poorly, they've found out something's wrong, and as far as they're concerned, there's only one person in that hospital – that's them.

(Nurse)

Trying to think beyond the medical condition – the simplest things like feeding, going to the toilet – you don't have to have a degree – just a bit of empathy, common sense and experience.

(Doctor)

Sometimes I think the patients feel more comfortable talking to us than they do to the nurses or the doctors – sometimes an old bloke will say to me 'I haven't understood

a word that doctor's just told me, cos he's talking too technical', so you go back to the doctor and ask.

(Porter)

We get patients coming in our ward who don't know what they're coming for. You say, 'well did they not explain it to you?' And they say, 'No, I've never been in hospital before and I did not understand a word they said'. And that's wrong.

(Ward clerk)

'Good', a number of people said, is not the same as 'nice'. Having the patient's interests in mind might well mean confronting the patient with a difficult and painful reality, or trying to persuade them to change their behaviour.

They might want to lie in bed, but that is obviously detrimental to their care, so you have to say 'You've got to get up now'. But patients sometimes see the less confident nurses who let them lie there as 'the caring ones'.

(Nurse)

Patient-centred and other terms

To investigate reactions to the concept of patient-centred care and the sound-alike concepts, the research asked participants to respond to the following words and phrases shown to them on prompt cards:

- basic care
- person-centred care
- patient-centred care
- personalised care
- dignity and respect
- humanity
- customer care.

Without exception, these words and phrases provoked either mixed or negative reactions.

'**Basic care**' appealed strongly to nurses but not at all to staff in other groups. One nurse said it was 'the most important bit', another, it was 'the vital part of what we do – and if you've done the care, you learn about the patient'. To non-nurses, 'basic care' meant 'the unpleasant bits of nursing' or 'the bare minimum'.

People at all levels and all occupational groups agreed that '**dignity**' is important, but interpreted it differently. Managers, some nurses and some support staff saw it as things or actions: single sex wards, an alternative to the hospital gown that opens down the back, ensuring curtains are closed when the patient needs privacy. In other groups, people said dignity was only part of the story.

There's a lot to care that is not encompassed by dignity – like making sure they've got food they like.

(Doctor)

It's almost like putting together a coat of arms with all the values: dignity, humanity, respect and empathy.

(Therapist)

'**Humanity**' resonated with people who felt it implied more compassion and empathy than 'dignity', but others associated it with end-of-life care and others thought it 'extreme'.

Makes me think of death and palliative care and old people and pain – so if I've got a rash and need cream for it, I don't need to be dealt with humanely, just nicely. And if it's not about the extreme, it becomes vacuous.

(Doctor)

A bit third worldly – it's not quite that bad.

(Nurse)

Reactions to **'patient-centred'** care were mixed. Younger doctors seemed to like it; older doctors and managers thought it a laudable but unrealistic objective for the NHS given current resource priorities and constraints.

Unhelpful, meaningless; does not take thinking on into 'how'.

(Manager)

It does not make me want to get out of bed every morning because I want to be more patient-centred.

(Manager)

Some nurses thought it was 'just buzz words', but others said it was the reason why they had come into nursing. Support staff had not heard of it and thought it was meaningless.

One of them words that's been brought out to sound a bit more than it is. Like what a boardroom would come up with. Not a hospital word.

(Support staff)

'Personalised care' and **'customer care'** commanded almost universal dislike. Managers said personalised was a devalued, meaningless term.

I don't care if it's personalised or exactly the same as everyone else's if it's good.

Sounds like some sort of social services package.

Doctors said it was meaningless.

Strikes me as like a lot of terms that are comfortable and say what we're doing – but don't say a lot.

You could probably come up with 50 definitions of what it may be.

Banded around in admin corridors by people who frankly haven't got a clue what it means.

Other staff associated it with policies promoting choice or with 'mechanical care packages'. No one seemed to think it implied a caring attitude.

In much the same vein, there were mixed, but mainly hostile reactions to talking about patients as **'customers'**, although some respondents, notably doctors, thought an awareness of customer service or customer experience would not go amiss.

Customers is British Rail really. The customer demanding something is not the basis of good care.

(Doctor)

By moving toward a more business model are we moving away from caring?

(Therapist)

Imagine people going into theatre and saying to the surgeon, your next customer's here.

(Support staff)

If you thought patients' assessments of our performance were important to our career progression, you'd sit up and take notice.

(Doctor)

As a rule, people said they preferred ordinary, human words for care. The words they suggested were words like:

- respect
- dignity
- sensitive
- understanding
- gentle
- kind
- welcome
- friendly
- comfort
- smile
- compassion
- communication.

The phrase 'seeing the person in the patient' resonated positively with all participants. Asked about a range of descriptive phrases, participants responded:

Yes, seeing the whole patient. Trying to look past somebody as interesting biochemistry.
(Doctor)

Yes, that's the best – that captures a lot of what we've said. (Therapist)

Yes, once that person steps over the threshold they're a different person – it's about understanding that they're scared.
(Support staff)

Policy

Against this backdrop, and mindful of Delbanco's warning about patient-centred care becoming shop talk, we turned to the policy literature to examine the extent to which the evidence from research has influenced health care policy in the United Kingdom. What have politicians set out to achieve in relation to patients' experience? And how have they framed the terms of the debate for their purposes?

Policy-makers have been actively interested in aligning NHS services to patients' wants (as compared with their needs) for more than 20 years. Across the political divide, successive governments have consistently stated good experience for the patient as a policy goal, albeit a goal rediscovered at intervals and re-launched as a new vision.

As we have seen in the other domains (research and everyday use), the language of policy is not precise. Policy refers to patient-centred care, person-centred care, patient-led, and personalised indiscriminately. Terms are confused and used interchangeably – sometimes in the same document. In the National Service Framework (NSF) for Older People (Department of Health 2001), for example, patient-centred and person-centred care are both named as driving principles, based on listening to patients.

Typically, politicians paint broad and ambitious visions for patients' experience of NHS care, translating the visions into practical pledges or targets that focus on a limited subset of the six dimensions of patient-centred care.

The dimensions of patients' experience that have received the most attention from politicians in the recent past are access to care (not, it may be noted, one of the six dimensions, although it could be part of co-ordination and integration); communication and information-giving; responsiveness to need (single sex wards and toilets) and physical comfort (specifically a clean environment). Most recently, compassion has become the focus of political attention.

Political visions and practical commitments

John Major's government set the pattern for what was to follow with the first 'aspirational' vision for hospital patients set out in the Patient's Charter standards (Department of Health 1991). Charter standards were not legal rights but 'major and specific standards which the government looks to the NHS to achieve, as circumstances and resources allow'. The first aspiration – 'respect for privacy, dignity and religious and cultural beliefs', required NHS hospitals to:

... make provision so that proper personal consideration is shown to you, for example by ensuring that your privacy, dignity and religious and cultural beliefs are respected. Practical arrangements should include meals to suit all dietary requirements and private rooms for confidential discussions with relatives.

The second aspiration, reflecting concerns about continuity of care and the quality of nursing, called for every patient ('eventually') to have a named nurse, midwife or health visitor. Meanwhile, the practical pledges in the Charter reacted to immediate political pressure about numbers of patients waiting for operations and the length of waiting lists, cancelled operations and the manner in which hospitals dealt with complaints. They gave patients three 'new' rights with reference to waiting times, information (about cancellations) and speed of response to complaints.

Six years later, the same scenario was repeated. The newly elected (New Labour) government defined quality 'in its broadest sense' ('doing the right things, at the right time, for the right people and doing them right – first time') as the heart of the reform and modernisation programme and explicitly named 'patient experience' and clinical outcomes on the agenda (Department of Health 1997). The Secretary of State, Frank Dobson, wrote that government was 'determined to place quality at the heart of health care' and would pay attention to 'the real needs of patients', in contrast with an emphasis on 'merely counting numbers, ... measuring activity... logging what could be logged' (Department of Health 1998).

In practice, what followed was an even stronger emphasis on counting numbers and measuring activity. The NHS Plan (Department of Health 2000) promised to place patients and their needs firmly at the centre of the modernisation, and 'a health service designed around the patient' translated patients' 'real needs' into national targets on waiting times and access. 'The vision... is to offer people fast and convenient care delivered to a consistently high standard. Services will be available when people require them, tailored to their individual needs.' (Department of Health 2000)

Since 2000, policy-makers have pursued parallel paths in an effort to improve patients' experience in acute hospital. On the one hand they have pledged to improve individual aspects (single 'dimensions') such as access times, hospital cleanliness, rates of hospital-acquired infections and access to single sex wards and toilets. Continuing on from the named nurses of the Patient's Charter, they have singled nurses out as more responsible than other groups of staff for patients' well-being. Initiatives include the appointment of 'modern matrons' and the Essence of Care standards (Department of Health 2001) and the dignity campaign to create 'dignity champions' in every health care organisation (Department of Health 2006).

On the other hand, policy-makers have tried to identify and strengthen initiatives to improve patients' experience by ensuring their voice is heard. These include successive arrangements for new involvement structures such as patient advice and liaison service (PALS) and local involvement networks (LINKS); more and better information about services and service quality; patient choice; stronger rights of redress (creating a patient-led NHS (Department of Health 2005) and more regulation.

At the time of writing, hospital trusts are preoccupied with the policy emphasis on targets related to the hospital-acquired infections MRSA and *C. difficile*, and to the delivery of an 18-week waiting time between referral and treatment for elective care. However, running in parallel is a strong policy strand related to improving patients' experience. This is reflected in the broad vision expressed by the Secretary of State when talking about compassion for patients, and by the health minister referring to his understanding of patients not wishing to be treated like numbers (Department of Health 2008a).

The *NHS Next Stage Review* (Department of Health 2008c) is seen as 'putting quality at the heart of all we do', and patients' experience will be seen – and measured – as an important aspect of quality. The Review commits to providing 'safe, personalised, clinically effective care' and 'locally-led, patient-centred and clinically driven change'. For the first time clinicians are positioned as the new agents of change, with a much stronger emphasis on measures. The discussion of measures has concentrated on patient-reported outcome measures (PROMs) rather than measures of patients' experience. However, it has opened the door to a much more serious investment in development of performance indicators that can be used to set a benchmark for patients' experience in specific clinical areas and drive improvement.

Meanwhile, *World Class Commissioning* (Department of Health 2007c) talks of 'continuing and meaningful engagement with the public and patients', and hospital trusts are obliged to involve patients (Department of Health 2008d) and foundation trusts have governors drawn from members of the public. The draft NHS constitution (Department of Health 2008b) introduces new pledges. In a late echo of the Patient's Charter, it goes back to declaring patients' rights. In the current NHS Operating Framework 2008–2009 (Department of Health 2007a), improving patient experience, staff satisfaction and engagement is a top priority.

The tendency in policy, as in the published research, is still to focus on one dimension of patient-centred care (compassion or dignity, for example) rather than the experience as a whole. But while there may still be problems with finding a language that reflects a common understanding between clinicians and patients, the new emphasis on staff (draft constitution) and clinical engagement (the *NHS Next Stage Review*) is focusing at a system level.

But what is the connection between policy and practice? Gillespie and colleagues, prompted by various policy developments, explored how individuals in the 'intermediate' groups that translate policy into practice – managers, educationalists, professional leaders and officers of patient organisations – made sense of 'patient-centred care'.

As expected, all the groups understood the term differently, developing 'different meanings of patient-centred care to reflect their own particular backgrounds and roles'. In a number of instances, they simply re-branded existing activities as 'patient-centred'. None of them had a full or complete understanding of all the dimensions of patient-centred care. The authors concluded: 'What is missing is a clear recognition among policy-makers, managers and health professionals in the services of the full spectrum of potential activities which constitute patient-centred care, from public involvement to individual interactions.' (Gillespie *et al* 2004)

Discussion

Although participants in the four hospitals in which we conducted our research may have preferred to use ordinary, human terms to talk about patients' experience, it is quite clear that what immediately came to mind focused either on *attitudes* that informed relationships with patients or on *actions* specifically associated with protecting patients' privacy and dignity. Their concept of patient-centred care was no fuller or more comprehensive than that of Gillespie *et al*'s interviewees. They did not appear to be aware of, or influenced by, either the research literature or policy.

Many of the terms used in research and policy are experienced in hospitals as impositions from the outside. Unfortunately, the language in use in research and policy has tended both to reflect and reinforce 'tribal' divisions between professions and groups of staff, rather than to unite them around a common cause.

It is still early days for research into patient-centred care, and it would be desirable and helpful to narrow the concept to a common understanding. The Institute of Medicine's definition of patient-centred care is based on sound evidence and is clear, practical and useful. The dimensions are easily translated for practical purposes and lend themselves to measurement, but it is important continuously to insist on the multi-dimensional aspect of patients' experience of care. Improving patients' experience is inherently complex and a challenge to the whole organisation.

It would be helpful if policy-makers would set their aspirational vision for patients' experience in the context of the organisation and the physical environment. Politicians have tended to single out nursing and nurses in relation to patients' experience. Nursing is important to patients but nurses cannot deliver patient-centred care on their own. To patients it is everything that happens, and relationships and interactions with staff of all kinds that shapes the experience.

To mobilise hospital staff at all levels, senior leaders need to unite them around a common sense of common purpose. The language that does this will be ordinary, accessible, jargon-free and most importantly commonly understood. It will focus on all six dimensions of patient-centred care. It will talk about how the service is delivered, about kindness, courtesy and warmth; it will explicitly acknowledge the importance to patients of their families and involving them, and it will refer to what is delivered and whether the service as a whole feels like it works.

In the final section we consider the factors that shape patients' experience of care, review the evidence on interventions to improve patients' experience and try to identify interventions with the potential to influence the whole system of care in ways that support and enable staff to 'see the person in the patient'.

Key messages

- The standard definition of quality recognised internationally, that of the US Institute of Medicine, has six criteria: patient-centred, safe, effective, timely, efficient, and equitable (Institute of Medicine 2001).
- The concept of 'patient-centred care' is the most frequent in the literature, but means different things to different people. The Institute of Medicine defines patient-centred care as multi-dimensional, with six dimensions.
- Research investment into the six dimensions of patient-centred care has been uneven and highly specialised; the research evidence is full of gaps.
- Successive governments have articulated a vision of a good experience for the patient, although the vision is 'rediscovered' at intervals and re-launched as new.

- Typically, politicians paint broad and ambitious visions for patients' experience of NHS care and translate the visions into practical pledges or targets that focus on a limited sub-set of the six dimensions of patient-centred care.
- Managers, educationalists, professional leaders and officers of patient organisations define patient-centred differently.
- Hospital staff prefer ordinary, human words for care such as respect, dignity, sensitive, understanding, gentle, kind, welcome, friendly, comfort, smile, compassion and communication.
- 'Seeing the person in the patient' resonates positively with staff and managers at all levels.

Further reading

For more detail of the literature on patients' experience in specific areas see:

Nursing, medical sociology and medical anthropology

Delbanco T L (1993). *Through the Patient's Eyes: Understanding and promoting patient-centred care*. San Francisco: Jossey-Bass.

Goffman E (1961). *Asylums: Essays on the social situation of mental patients and other inmates*. New York: Doubleday.

Gordon S, Nelson S (2006). 'Moving beyond the virtue script in nursing: creating a knowledge-based identity for nurses' in Nelson S, Gordon S (eds), *The Complexities of Care: Nursing re-considered*. Ithaca, NY: Cornell University Press.

Greenhalgh T (2006). *What Seems to be the Trouble? Stories in illness and healthcare*. Oxford: Radcliffe.

Greenhalgh T, Russell J and Swinglehurst D (2005). 'Narrative methods in quality improvement research'. *Quality and Safety in Health Care*, vol 14, pp 443–49.

Haggerty JL, Reid R J, Freeman GK, Starfield BH, Adair CE and McKendry R (2003). 'Continuity of care: a multidisciplinary review'. *British Medical Journal*, vol 327, no 22.

Hurwitz B, Greenhalgh T, Skultans V (eds) (2004). *Narrative Research in Health and Illness*. Oxford: Blackwell Publishing.

Kleinman A (1988). *The Illness Narratives: Suffering, healing and the human condition*. New York: Basic Books.

Menzies IEP (2002). 'A case study of the functioning of social systems as a defence against anxiety' in Rafferty A and Traynor M (eds), *Exemplary Research for Nursing and Midwifery*. London: Routledge.

Open University U205 Team (1985). *Caring for Health. Dilemmas and Prospects*. Milton Keynes: Open University Press.

Care-giving in context and actual relationships between practitioners and patients

Borrill C, West M, Shapiro D and Rees A (2000). 'Team working and effectiveness in healthcare'. *British Journal of Healthcare Management*, vol 6, no 8, pp 364–71.

Corner J (2001). *Between You and Me: Closing the gap between people and health care*. London: Nuffield Trust.

Gawande A (2008). *Better: A surgeon's notes on performance*. London: Profile.

Hinshelwood R and Skogstad W (2000). *Observing Organisations: Anxiety, defence and culture in health care*. London: Routledge.

Horobin G and Davis A (1977). *Medical Encounters: The experience of illness and treatment*. London: Croom Helm.

Philosophical and theological discussions about humanity, empathy, and the nature of suffering and spirituality in the medical humanities

Adson MD (1995). 'An endangered ethic – the capacity for caring'. *Mayo Clinic Proceedings*, vol 70, pp 495–500.

Barritt P (2005). *Humanity in Healthcare, the Heart and Soul of Medicine*. Oxford: Radcliffe.

Cassell EJ (1982). 'The nature of suffering and the goals of medicine'. *New England Journal of Medicine*, vol 306, no 11, pp 639–45.

Clark, D (2008). 'Total pain, disciplinary power and the body in the work of Cicely Saunders, 1958–1967'. *Social Science and Medicine*, vol 49, no 6, pp 727–36.

Clark D (2005). *Cicely Saunders – Founder of the Hospice Movement. Selected letters 1959–1999*. Oxford: Oxford University Press.

Frank AW (2004). *The Renewal of Generosity: Illness, medicine and how to live*. Chicago: University of Chicago.

Klitzman R (2008). *When Doctors Become Patients*. New York: OUP.

Neuberger J (2004). *Caring for Dying People of Different Faiths*. Abingdon: Radcliffe.

Sweeney K (2000). 'Uniqueness in clinical practice: reflections on suffering' in Dixon M and Sweeney K (eds), *The Human Effect in Medicine*. Abingdon: Radcliffe.

Personal stories

Bauby J (1997). *The Diving Bell and the Butterfly: a memoir of life in death*. London: Harper Perennial.

Diamond J (1999). *C: Because cowards get cancer too...* Vermilion.

Didion J (2005). *The Year of Magical Thinking*. New York: Knopf.

Helman C (2002). *Doctors and Patients: An anthology*. Oxford: Radcliffe.

Ludlow C (2008). *Shadows in Wonderland: A hospital Odyssey*.

Paget M (1990). 'Life mirrors work mirrors text mirrors life'. *Social Problems*, vol 37, no 2, pp 137–48.

Picardie R (1999). *Before I Say Goodbye: Recollections and observations from one woman's final year*. London: Penguin.

3 What do we know about how to improve the experience of patients?

At times, in medicine, you feel you are inside a colossal and impossibly complex machine whose gears will turn for you only according to their own arbitrary rhythm. The notion that human caring, the effort to do better for people, might make a difference can seem hopelessly naïve. But it isn't.

(Gawande 2008)

Introduction

In previous sections we have argued that from the patient's point of view, every detail of every interaction and physical environment shapes the unique quality of the experience. We have offered a multi-dimensional definition of patient-centred care. It is apparent from listening to patients that the experience of being in (or even in contact with) hospital, in all its complexity, is produced by the social processes of the health system as a whole. Every detail is shaped by the actions, attitudes and behaviours of individual members of staff, that are in turn shaped by their personal experience and values (including professional values) and attitudes, and by their colleagues. They are also shaped, in ways that are more difficult to discern, by the practices, opportunities and limitations of the organisation in which they work; the wider health care system and the wider political and social context in which it operates.

At a fundamental level, change and improvement to patients' experience of care will only come about with the willing co-operation and effort of all staff – both those in direct contact with patients and those not. Staff are motivated by the desire to provide high-quality patient care (Department of Health 2007b), but patients' experience will not be improved simply by individual acts and commitment. Recent evidence from organisations that have reputations for providing excellent patient care shows that it means transforming hospital cultures and ordinary working practices ('the way we do it around here'). This is an immense, complex task requiring serious investment at both strategic and operational levels. Recent research into the pre-conditions for successful social innovation by the Young Foundation (Mulgan *et al* 2007), shows us that it is likely that real change will occur only when two conditions are met. First, the 'felt need' for the patient to be seen as a person will have to be more effectively articulated as a demand, putting pressure on the system. Second, the demand needs to be matched by the supply of tried, tested and effective interventions.

Where should staff and senior leaders with an interest in improving patients' experience in hospital focus their effort? With staff who work directly with patients? With the senior leaders on the board and executive? Or with middle managers? What kinds of intervention are more likely to achieve positive results? And why? Who should lead the efforts to improve? And what kinds of support will they need to be effective?

To answer these questions, we need to understand more about the factors that shape patients' experience of services. This section presents an analytic framework for understanding factors that shape patients' experience; reviews the lessons from the limited research available on interventions designed to improve patients' experience; and describes a small number of interventions for which there is either sufficient supporting evidence, or the case for support is sufficiently analytically robust to suggest that it is likely to achieve positive results.

A framework for the analysis of factors underlying patients' experience

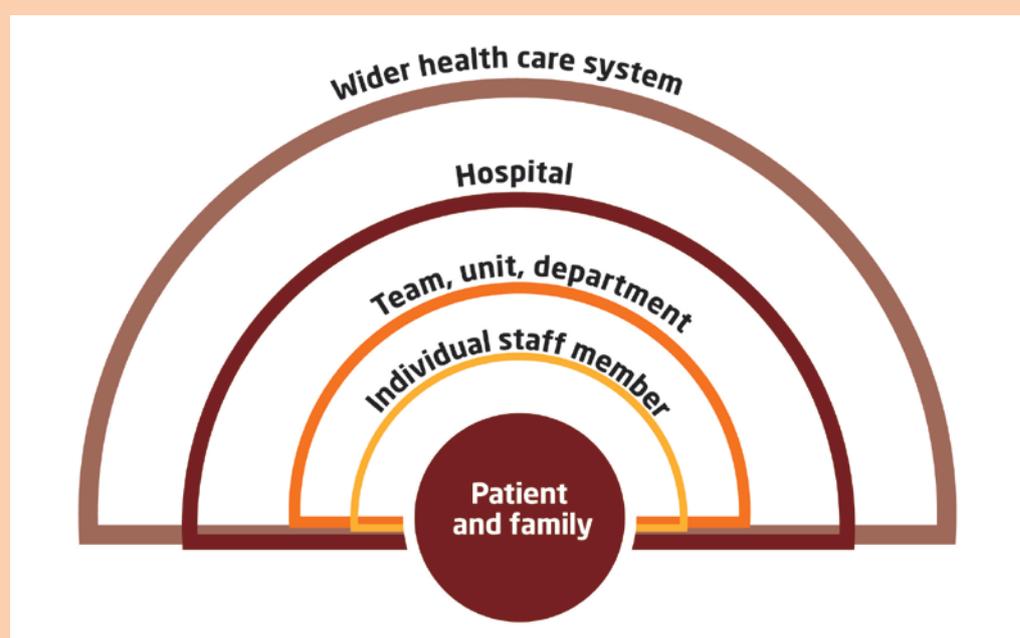
There are a number of useful frameworks for analysing health organisations (Bate *et al* 2008; Taylor-Adams and Vincent 2004) and systems (Leatherman and Sutherland 2003, 2008). Leatherman and Sutherland offer a simplified model of health systems in modern industrial societies with four levels:

- national
- regional
- institutional
- individual.

Retaining the simplicity of the model, we have adapted it to provide a sharper focus on the factors shaping patients' experience in hospital. Combining the national and regional levels into a single level covering the wider context in which hospitals operate, we have separated the elements 'clinical service provision' and 'individual accountability' into two distinct levels:

- individual interaction between patient and staff member
- the level of the clinical micro-system (Wasson *et al* 2008) which may be a department, a ward, or a clinical pathway (*see* Figure 5, below).

Figure 5 A framework for the analysis of factors influencing patients' experience



Source: The Point of Care programme

Patients' experience in hospital is shaped, directly and indirectly, by organisational and human factors interacting in dynamic and complex ways at all four levels. The past decade of research has contributed significantly to understanding the determinants of quality particularly in relation to clinical effectiveness and patient safety (Davies *et al* 2000; Ferlie and Shortell 2001; Ovretveit 2003; Vincent 2001), but our understanding of the factors that shape patients' experience is less well advanced.

As a starting point, we find the four-level framework (with our distinction between organisational and human factors as above) useful. Together they provide the tools for discussion and analysis of the apparently infinite variety of patients' experiences as they occur over time: within the same clinical micro-system, in different clinical micro-systems and within clinical micro-systems in different hospitals.

Individual interaction between patient and staff

This is the most immediate level of experience for patients and families. The box below lists factors that shape staff–patient interactions at this level.

Factors shaping patients' experience at individual level		
Organisational factors	Human factors	
Staff	Staff	Patient
Education, training, qualifications	Morale	Clinical need
Induction, preparation	Experience	Mental and physical capacity
Job description	Health status	Ability to speak for self
Accountability	Tiredness, stress, well-being	Spoken English
Delegated responsibilities	Professional and personal attitudes, values	Age
Permanent, temporary status	Support	Social status
Supervision, appraisal	Spoken English	Active family or other support
		Depression, anxiety, fear

At a fundamental level, being a patient equates with feeling powerless. Some patients are objectively more powerless than others, by virtue of youth or age, sickness, ignorance, fear, anxiety, pain, mental incapacity or physical and communication difficulties. Some are more vulnerable for social reasons: staff disapprove of them (for example patients who self-harm) or they are unpopular because they are drunk, dirty, smelly, unco-operative or aggressive or noisy (Goffman 1961; Jeffery 2001; Stockwell 2002; Royal College of Psychiatrists 2006).

Even highly educated, knowledgeable, articulate people can feel powerless. This is an extract from an account by acclaimed novelist Hilary Mantel of accompanying her husband to hospital.

In the late afternoon he sees his GP. She sends him to hospital with a note. He can hardly stand upright now. Twenty-four hours after that first attack, he is lying white as paper on a trolley in A&E. It is an ordinary evening, quiet enough – no inner-city brawls here in Surrey, no drunks. And yet, within minutes of arrival, you feel you

have been rolled in misery and grime. Everyone is frightened, everyone is suffering or watching someone else suffer. There is no privacy, and the panic is polyglot; notices offer interpreters, translators, signers, but in practice the staff just shout. It is an odd idea of 'emergency', this. No doctor comes. There is no pain relief. There is no information.

Hours pass. We draw the curtains around ourselves. We hold hands. Our breathing seems to synchronise. There is nothing to say or do. It is not appendicitis, as the GP suggested – the pain is moving to the wrong side. From time to time I push the curtain aside, collar someone. 'Yes, yes', they say. 'Oh, I will.' 'Just coming.' Then they disappear and I never see them again. A pain-killing drip is put up. Ten minutes later it's taken down. He is rolled off the trolley, taken for x-ray. By now it hurts him to move. I think he might die. All around me, in the cubicles, the past is being folded away, lives collapsed like tents, and journeys beginning to the new camping grounds of sickness, disability, loss of self.

(Mantel 2008)

The capacity of individual staff members to respond sensitively to patients is always at risk for a number of reasons. Individual health care professionals become socialised into 'ways of doing and behaving' that may be at odds with their professional education and their initial reasons for becoming a doctor, nurse or therapist (Maben 2008). Of necessity, clinical and administrative staff must categorise events that are unique, profoundly significant and personal to the patient, and turn them into matters of routine ('one of this group of patients', 'this type of problem', 'this procedure') (Strong 1977; Tallis 2004). If they are not addressed, the natural human defences used to cope with daily contact with strangers who are partly dressed, sick, suffering, in pain or dying, inevitably create working practices that protect the staff but are insensitive to patients (Menzies 2002). Patients may be less at risk in outpatient departments and day case units than when they are inpatients, but all formal clinical and care settings have the potential to de-personalise and de-humanise care-giving.

To address this level of interaction, the questions senior hospital leaders need to ask and answer are about how to:

- protect patients who are especially at risk of insensitive treatment
- foster and promote compassion and empathy
- select staff who have the capacity to see the person in the patient, and empower them to speak up on patients' behalf when and if the wider system fails them
- define the behaviours that are and are not admissible
- provide ongoing support.

The clinical micro-system (team, unit or department)

The clinical micro-system is the immediate environment that shapes relationships and interactions between patients and staff. The box opposite lists organisational and human factors at this level. In general, people who work in hospital belong to at least two different teams: their peers (for example qualified nurses, health care assistants, junior doctors, consultants, porters, managers); and the multidisciplinary team in the clinical micro-system, the unit, or department (for example the clinic, ward, team, kitchen, office).

Factors at clinical micro-system and team level

Organisational factors

Performance management and measures
 Governance and accountability
 Division of labour
 Clarity/conflicts over job demarcation and boundaries
 Access to ICT
 Operating procedures
 Record-keeping
 Skill mix
 Deployment
 Capacity management – match between demand and supply
 Stability of staffing: eg, vacancies, use of locums, bank and agency staff

Human factors

Leadership
 Morale
 Communication
 Experience in team
 Flexibility
 Team ethos, values
 Priorities

Many staff working in hospital, especially in senior roles, belong to many teams. This does not alter the importance of team factors; rather it serves to illustrate the immense complexity of organisational life in hospital.

Team factors have profound, often hidden, effects on the quality of relationships and communication between patients and staff. For example, direct contact time between patients and staff members is a subtle, important determinant of quality of relationship and communication, but these are also profoundly affected by organisational and human factors that are changeable and remain hidden.

At Maidstone and Tunbridge Wells NHS Trust, for example, patients and families complained that the lack of nurses led to ‘patients not being fed, call bells not answered, patients told to empty their bowels or bladder “in the bed”, poor hygiene practice, and general disregard for privacy and dignity’. The Healthcare Commission investigation into the trust found that there was indeed a nurse shortage, but it was compounded by other factors: a cap on the use of bank and agency staff, high bed occupancy, a poor physical environment, too few single rooms, the culture of the wards, demoralisation of the staff and failures on the part of senior professionals to speak up and of management to listen (Healthcare Commission 2007a).

Evidence from the Magnet hospitals in the United States shows that significant investments in nurse staffing, high ratios of qualified to unqualified nursing staff and high levels of educational attainment among nurses are associated with high levels of patient satisfaction (Aiken 2002). But investing in more nurses will not necessarily improve patients’ experience if the nurses spend their time on other duties. The NHS Institute for Innovation and Improvement has evidence from acute hospitals in England that nurses spend up to 40 per cent of time on so-called ‘non-productive’ activities

such as paperwork; fetching, carrying and searching for missing items; and shift handovers (Nolan 2007). The Institute has shown that by focusing effort, the amount of time nurses spend on 'non-productive' work can be reduced. But while individual nurses may choose to spend more time with patients, the team as a whole is unlikely to do so spontaneously unless the team leader pays attention to the attitudes, values and defences that allowed staff to depersonalise contact with patients in the first place. Positive reinforcement and support for nurses and care-givers is required to sustain the hard emotional work (sometimes called 'emotional labour') of continuously caring for people who are suffering.

At this micro-system level, the questions for senior leaders are about how to:

- promote behaviours within teams that are associated with positive experiences for patients
- make communication within and between teams effective
- resource teams adequately
- deploy staff to match demand efficiently
- stabilise staff groups and clinical processes
- develop team leaders
- hold teams accountable for reliable, consistent quality care on every shift, every day of the week, every week of the year.

The institutional level

It is invariably difficult to discern the contribution management and senior leaders make to well-run services. How do we identify their contribution to staff treating 'the person inside the patient'? Services that work well give the appearance of effortlessness. If and when a problem occurs, staff members act to resolve the problem promptly and seem to know what to say and how to make amends. In contrast, when quality is poor, the way staff deal with problems invariably makes them worse. At that point management failings are often glaringly obvious.

The actions and words of senior hospital leaders – by which we mean board members, senior executives and senior clinicians – have a profound influence on what happens to patients. They shape the culture of the hospital: the priorities of managers and staff; how they behave, towards each other and towards patients and families; and how staff feel about the services they provide and the organisation.

According to the Healthcare Commission, the gross failures in service quality that have been subject to investigation (Healthcare Commission 2008a) are invariably associated with senior leaders failing to show interest in the experience of patients and staff and failing to focus systematically on service quality. The box opposite lists the factors at institutional level that protect patients.

Factors at institutional level needed to protect patients

Technical

Set direction

Ensure delivery

Maintain governance

Have adequate information about trends and potential issues at ward and specialist level

Human

Create an open culture in which staff feel able to voice concerns

Create a culture of effective teamworking

Model enabling and supportive management styles

Expect and encourage professional staff to speak out on behalf of patients

Source: Adapted from Healthcare Commission 2008a

Quality assurance is one thing, but quality improvement is another. Shaller (2007) has found that hospitals in the United States with a reputation for service excellence, which he calls 'patient-centred organisations', have seven success factors in common. In these organisations, senior leaders feel directly responsible for the fate of staff and patients, and take their role in determining the quality of care and patients' experience seriously.

- They actively inform themselves about the quality of the service that is on offer, visiting clinical units and wards, talking to staff and patients in lifts and corridors and clinics.
- They receive training in patient safety and quality improvement and devote time at board and committee meetings to listening to and learning lessons from individual case reviews and groups of patients and families.
- They develop and resource strategies for improving quality of care, and use communication within the organisation to make sure staff understand the strategic goals and their role in achieving them.
- They invite patients and families to participate in hospital committees and decision-making structures at all levels.
- They use measures for service quality and have a variety of sources of information about patients' experience including mystery shoppers, patient surveys, open days, focused discussions with groups and telephone surveys.
- They provide a supportive work environment for care-givers, and pay a great deal of attention to the quality of the physical environment.
- They are innovative in their use of technology to support patients and families with information.

The wider context

Evidence from the Healthcare Commission (Healthcare Commission 2008a) and other research (Fulop 2004) shows that senior leaders fail more often in organisations that are subject to particular external threats such as forced mergers and re-configurations of services, forced re-organisations and responsibility for substantial capital projects. Frequent changes at senior level are also detrimental.

Understanding the wider context that helps quality to thrive is fundamentally important if senior leaders are to run hospitals that deliver high-quality patient care. To date, factors beyond the control of senior leaders have had a profound, frequently detrimental influence on the conduct of business inside hospitals. They have created the conditions for failure and success, shaped organisations' priorities and drawn senior leaders' attention away from service quality. Some factors are the direct result of national policies and strategies. Others stem from decisions made at European level such as legislation on employment and immigration. Yet others have to do with wider changes in the economy and society.

Hospital strategies and plans are directly affected by national NHS priorities, the actions of health care regulators, the actions of performance managers in the wider system, and the financial rules and regulations governing contracts. In the past decade, hospitals have been under significant pressure to achieve national targets for access, cleanliness and finance. Health regulators have assessed annual performance against a 'balanced scorecard' that includes patient survey results, but the weight of the performance management system has been concentrated on a limited set of national priorities.

Recently, policy-makers have signalled their expectation that the performance of the NHS will be measured in terms of clinical outcomes, and patients' perceptions of clinical outcome (patient-reported outcome measures – PROMs). They expect the wider policy changes – patient choice, Payment by Results, the quality supplement that will penalise hospitals for poor quality, and world-class commissioning – to deliver improvement in clinical quality and 'personalised care'. Time will tell how effective the measures will be.

The *Next Stage Review* (Department of Health 2008a) makes quality the organising principle for the NHS, with the NHS Executive calling for 'deep cultural change', 'radical changes in behaviour at an individual, team, organisation and system level', and committing itself to 'aligning the entire system' to drive improvements in clinical quality and personalised care. It is helpful that the impact of the wider system on hospitals and the need for deep cultural change is acknowledged. Boards need to see quality improvement as their responsibility, to consider the purpose of care and the realities on the ground where it is delivered and to support teams and individuals.

Evidence on the effectiveness of interventions to improve patients' experience

Active efforts to improve aspects of patients' experience, mainly but not solely in nursing, can be traced back to the 1960s (Menziez 2002; Revans 1964; Smith 2008) through primary nursing and nursing development units (NDUs) in the 1980s and 1990s, to the present (Black 1992). Medical students have been taught communication skills since the 1990s. Over the years, hospitals have invested in 'customer care' training for groups of staff. The Picker Institute and the NHS Clinical Governance Team Patients Accelerating Change (PAC) programme have been helping groups of staff in a number of hospitals involve patients and use their survey results to improve practice since 2000 (Sweeney 2005). And all over the country there are local award-winning initiatives such as 'The Patient Line of Sight' (*see box opposite*).

The Patient Line of Sight: Royal Surrey County Hospital Trust: Winner of the Health Service Journal's Patient Centred Care Award 2005

This project was based on the premise that patients experience their care and treatment as involving the whole organisation; they do not think in terms of the silos of wards and clinics that staff work in. Working with an organisational development expert, a change team, made up of staff from a range of grades across the hospital, gathered stories from patients. The hospital board was updated regularly and supported the project. The patients' stories transformed the way staff thought of care: changes were made in wards and clinics, and fragmented services were joined up. After about a year visible and positive results included: a reduction in length of stay in some wards; fewer days' sickness absence on the wards involved; improvement in cleanliness; improvements in nursing leadership. And patients enjoyed better services; in particular, staff were spending more time talking to elderly patients and providing them with personal care.

Source: Thomas 2008

Overall, however, the evidence of the effectiveness of interventions to improve patients' experience is patchy, fragmented, and tends to be descriptive. With the exception of studies that focus on the dimension of communication in patient-centred care, relatively few studies set out to demonstrate that particular interventions produce positive changes. Those that do describe patient-centred approaches but rarely measure the outcomes or analyse the relationship of cause and effect. The mechanism that connects the two remains a 'black hole'.

There is, however, a wealth of reports on interventions and tools designed to treat selected human and organisational factors at individual and team levels (Bridges *et al* 2008; Bridges and Nicholson 2008; Cummings 2008; Cunningham and Kitson 2000b; Forbat 2008; McCormack *et al* 2004; Nolan 2006, 2007; Association of UK University Hospitals 2008). The majority of the interventions are for use with only one professional or staff group (Brooker *et al* 2004; Cunningham and Kitson 2000a, 2000b; McCormack *et al* 2004; Royal College of Physicians 2007; Williams and Rees 1997) and are well documented, but not independently evaluated. They do however, provide practical examples of interventions, and helpful reflections about results, about how to refine the design and processes involved and how to sustain the effort.

Selected interventions

Following our analysis of patients' experience as a product of the whole system of care, we searched for interventions with the potential to influence the system as a whole, rather than its individual parts. The literature on learning organisations suggests that interventions that tackle only one process or part of the system risk disturbing the balance of the system as a whole, and may have unintended effects on other parts of the system. It is not difficult to think of examples from the NHS to illustrate the point. Over recent years, reductions in bed numbers for efficiency gains have produced high rates of bed occupancy that have, in turn, made it even more difficult to contain infections in hospital. Efforts to achieve targets for waiting times in A&E have resulted in some patients being kept waiting in ambulances outside the hospital, and patients being kept on trolleys in corridors outside the A&E department. For these reasons, we have excluded interventions that focus on a part of the system or a single staff group.

The concept of a leverage point in a system – where the smallest efforts can make the biggest differences – is described by Senge (1990). Interventions that have leverage are

‘small, well-focused actions that can produce significant, enduring improvement if they’re in the right place’. Our search for actions with leverage was also informed by the conclusions of an influential review of the evidence on the spread of good ideas in organisations (Greenhalgh *et al* 2004). Following Greenhalgh, we developed a set of criteria that we used to identify interventions as likely to achieve system-level change (*see* box below).

Criteria for selecting interventions

- Directly reflects or is compatible with a systems perspective
- Is described with enough practical detail to make it possible to replicate elsewhere
- Is flexible, and can be adapted to different environments
- Has been sustained or spread beyond the place where it originated
- Has been subject to an external process of assessment or evaluation

Source: Adapted from Greenhalgh *et al* 2004

Based on these criteria, we have identified an intervention or approach for each level identified above (individual, micro-system and institutional) that we believe has the potential to make a significant contribution to improving patients’ experience of care in hospital.

The individual level: Improving the relationship between care-givers and patients

Care for care-givers. Making compassion the core activity – the Schwartz Center

The Kenneth B Schwartz Center is a non-profit organisation based at Massachusetts General Hospital. It was founded by the family of a patient (Schwartz 1995) with a mission to ‘provide support and advance compassionate health care, in which care-givers, patients and their families relate to one another in a way that provides hope to the patient’.

The Center carries out programmes to educate train and support care-givers in ‘the art of compassionate health care’, and to strengthen the relationship between patients and care-givers, something they believe has become increasingly stressed over the past few decades. Their largest single programme is Schwartz Center Rounds®: monthly one-hour sessions (Rounds) where care-givers from many disciplines come together and discuss difficult emotional and social issues arising from patient care.

The Schwartz Center’s work is evidence-based: they cite research which shows that compassion and empathy makes patients more forthcoming about their symptoms and concerns, yielding more accurate diagnoses and better care; enables greater understanding of factors that motivate a patient to participate in prescribed therapy; and leads to therapeutic interactions that directly affect patient recovery (Halpern 2001). Training doctors to manage their emotional responses openly may also improve clinical judgement and reduce work stress (Yedidia 2007).

The Rounds are part of what the Schwartz Center describes as a new paradigm for a compassionate care principle: that it needs a lifetime of support, regular guidance, and repeated reinforcement. This principle was strengthened following a consultation with staff in 54 hospitals in 21 states who were asked to discuss the question ‘what makes for

a compassionate patient–care-giver relationship?’ and to provide practical suggestions (Sanghavi 2006).

External evaluation of the Schwartz Rounds reached a number of conclusions (Goodman Research Group 2008).

- Care-givers perceived increased insight into the non-clinical aspects of patient care after Rounds, greater feelings of adequacy responding to patients’ social and emotional issues, are more focused on the effects of illness on patients’ lives and more compassionate towards patients and their families.
- Care-givers reported improved teamwork as a result of Rounds, a better appreciation for the roles and contributions of their colleagues, better communication with their co-workers and more openness to giving and receiving support from their co-workers.
- Care-givers feel that Rounds support them in their patient care and decrease their feelings of stress and isolation.
- The greater the number of Rounds attended, the better the care-givers’ interactions with patients and better their teamwork.
- Attending with co-workers increased the impact of Rounds.
- An unanticipated positive outcome was that care-givers reported changes in practices and policies in their department and wider hospital (to become more patient-centred) after Rounds were implemented. In particular, care-givers report increased or improved communication and teamwork within the department and between the department and hospital.

The Rounds have spread throughout the United States and now take place at 148 sites in 29 states, and have involved 27,000 clinicians (The Schwartz Center 2008).

The clinical micro-system level: Creating and supporting partnerships between staff and patients to improve service quality

Experience-based design

Experience-based design (EBD) is a methodology for working with groups of patients and staff to improve services developed for health care settings by Paul Bate and Glenn Robert. Drawing on the knowledge and ideas of the design sciences and design professions, where the aim of making products or buildings better for the user is achieved by making the users integral to the design process itself, the focus is on how patients and staff move (or are moved) through the service and interact with its various parts (Bate and Robert 2006). Patients work with staff to ‘co-design’ improvements in the experience of using the service (mapping the subjective as well as the objective pathway of care). The involvement of patients and staff on an equal footing is much deeper than that in ‘patient involvement’ projects where patients are often treated as objects for study, rather than partners. How the service ‘feels’ or is experienced is seen as equally important as how fit for purpose it is (functionality) and how safe it is.

Bate and Robert have given a step-by-step guide to the methodology and illustrated it with the case of a 12-month pilot, funded by the NHS Institute for Innovation and Improvement, in head and neck cancer services at Luton and Dunstable NHS Foundation Trust. The methodology has since been used in other clinical specialties and hospitals in England and Australia. The act of bringing patients and staff together to hear the others’ stories about how they experience the service works as a dynamic catalyst for change and improvement.

During the pilot, patients and staff worked together to identify the key ‘touch points’ (or ‘moments of truth’) which had shaped their personal experiences of the head and neck service. This then enabled them to work together to prioritise and then implement – through 70 separate actions – a total of 43 improvements. Two of these improvements have directly increased the efficiency of the head and neck service (for example, the throughput of patients at the outpatients clinic), four have improved patient safety (eg, expanding staff competencies on the post-surgical ward), while the remainder – the majority (37 improvements) – have improved the experience of the service (eg, giving patients a choice as to when their feeding tube should be fitted). Of these, 12 related to better information provision at various points of the patient journey, 11 related to changes in the physical environments experienced by the patients, 9 related to changes in staff behaviour and 4 related to a desire for greater support mechanisms (particularly involving other patients). (Bate and Robert 2007)

The institutional level

The Planetree Association

Planetree was founded in 1978 by a patient, Angelica Thierot, who was disheartened by her own experience of hospital care, which she felt was de-personalising. Her vision of a different type of hospital was one in which patients would become active participants in their own care and well-being.

Planetree began by developing libraries of information for patients and has developed into a non-profit organisation providing education and information. It facilitates efforts to create patient-centred care in a collaborative community of health care organisations in the United States, Canada and Europe.

The Planetree model of care is a patient-centered, holistic approach to healthcare, promoting mental, emotional, spiritual, social, and physical healing. It empowers patients and families through the exchange of information and encourages healing partnerships with care-givers. It seeks to maximize positive healthcare outcomes by integrating optimal medical therapies and incorporating art and nature into the healing environment.

(Planetree 2008)

The key features of the Planetree method, which contribute to the success and spread of the model include:

- work and ownership with senior leaders to develop an organisational strategy to drive improvement in patient-centred care
- multidisciplinary and multi-professional training for all staff in the 10 core principles (see box opposite), mainly through one- and two-day retreats
- an accessible language for expressing the desired culture and values
- positive and continuous reinforcement of Planetree values and principles with awards and recognition for individuals
- an emphasis on the built environment.

(Martin 1990)

One weakness of the Planetree model is a lack of publicly reported measures and a lack of transparency and external evaluation. Planetree is working to rectify this, and is developing an accreditation system that will assess the degree to which hospitals are succeeding in delivering patient-centred care.

The Planetree proclamation for patient-centred care: a public declaration used by Planetree-designated hospitals

- A patient is an individual to be cared for, not a medical condition to be treated.
- Each patient is a unique person, with diverse needs.
- Each staff member is a care-giver, whose role is to meet the needs of each patient.
- Our patients are our partners and have knowledge and expertise that is essential to their care.
- Our patients' family and friends are also our partners and we welcome their involvement.
- Access to understandable health information is essential to empower patients to participate in their care and it is our responsibility to provide access to that information.
- The opportunity to make decisions is essential to the well-being of our patients. It is our responsibility to maximise patients' opportunities for choices and to respect those choices.
- Our patients' well-being can be enhanced by an optimal healing environment, including access to music and the arts, satisfying food, and complementary therapies.
- To effectively care for patients, we must also care for our staff members by supporting them in achieving their highest professional aspirations, as well as their personal goals.
- Patient-centred care is the core of a high-quality health care system and a necessary foundation for safe, effective, efficient, timely and equitable care.

(Planetree 2008)

The Planetree model combines a philosophy of care with practical approaches and tools for organisations and individuals (Frampton 2003). To date, the model has been implemented in acute and critical care departments, emergency departments, long-term care facilities, outpatient services, and ambulatory care and community health centres. The model is flexible: hospitals ranging in size from small rural hospitals with 25 beds to large urban medical centres with more than 2,000 beds have adapted the model to suit their own needs.

Discussion

The analysis of the factors that shape patients' experience of care, design and implementation of interventions to improve it, and evaluation of those efforts is relatively undeveloped. Planetree, the Picker Institute, the Commonwealth Fund and the Schwartz Center have been active in this area for a number of years, but until recently there has been relatively little research into patients' experience, and even less research that is informed by a systems perspective. However, funders are beginning to take a more active interest in patients' experience and the underlying factors that shape it. We expect to see rapid expansion in the research activity in the near future both in the United Kingdom, with NHS research and development funds, and in the United States where the Picker Institute and Commonwealth Fund continue to research in this area.

We do not yet have a great range of effective interventions to improve patients' experience. If, as seems likely, governments continue to identify patients' experience of care as a priority area, we expect the opportunities to develop and test interventions to grow in much the same way that the opportunities to test and evaluate interventions in the safety arena took off after the publication of *To Err is Human* (Institute of Medicine 2000) and *An Organisation with a Memory* (Donaldson 2002).

As yet we still know very little about the interventions at policy level that will make a positive difference to patients. We are beginning to understand the role of hospital senior leaders better, and can see the value of creating a single narrative about the quality of service for patients that says: high-quality services for patients are timely, clinically effective, efficient, safe *and* patient-centred. Senior leaders are taking responsibility for the impact the wider organisation has on the behaviours and actions of staff who work directly with patients. And with more research, and more support for developing, testing and evaluating interventions for improvement in a wide range of clinical settings and institutions, we can expect to see real and positive benefit to patients and families.

Key messages

- Patients' experience of being in (or even in contact with) hospital, in all its complexity, is produced by the social processes that create the workings of the health system as a whole.
- The ambition to improve patients' experience of care will be realised only with the willing co-operation and effort of all staff in direct contact with patients and if the wider organisation provides support and encouragement.
- Patients' experience in hospital is shaped, directly and indirectly, by organisational and human factors interacting in complex ways at four levels: the individual member of staff, the team and clinical micro-system, the institution and the wider health system.
- The four-level framework, together with the distinction between organisational and human factors, provides the tools for analysing the apparently infinite variety of patients' experiences in different clinical settings.
- Leadership for improvement at team and institutional levels is absolutely necessary. The actions, words and behaviours of leaders are critically important.
- Overall, the evidence of the effectiveness of interventions to improve patients' experience is patchy, fragmented, and tends to be descriptive.
- The majority of interventions that have been tried are for use with only one professional or staff group. They are well-documented, but not independently evaluated.
- There are a small number of interventions with the potential to make a significant contribution to improving patients' experience of care in hospital.

Research methodologies

The research for this report was carried out in three ways:

- qualitative research with patients, families and staff to explore the quality of care
- qualitative research with hospital and trust staff to explore terms and concepts
- a literature review.

Qualitative research with patients, families and staff

Between April and September 2006 Jocelyn Cornwell (JC) carried out qualitative interviews with patients and hospital staff to find out what good and poor care feels like and whether it is possible, through their accounts, to get at what lies behind the experience. The research informed the original proposal for funding for The Point of Care programme.

Patients

JC interviewed eight patients plus two daughters who talked about their mothers' care in hospital (patients C and D in the list below).

The patients and the two daughters were recruited through informal networks and purposively. JC enquired as widely as possible, through contacts at the Healthcare Commission and personal networks, for a mix of men and women of different ages and with a range of problems (emergency admission, elective procedures, day case surgery), who had recent experience in acute hospitals. The hospitals the patients had attended were geographically dispersed across the United Kingdom.

The interviews were semi-structured and recorded. Following the interviews the notes were written up and the complete set of interviews was analysed to draw out common themes. All names have been changed.

Staff

All the staff interviewed worked at the same London teaching hospital (*see* list overleaf). Access to the staff was secured via a consultant contact and was agreed with the CEO and director of clinical governance. All staff worked in emergency admissions and medical wards. All staff were interviewed on their own, with the exception of the ward clerks who were interviewed together. Individuals received an invitation from the consultant's secretary and it was clear that they were entitled to refuse to take part. No names were given or noted by JC, and staff were assured anything they said would be anonymised. All the interviews were conducted on wards and in offices in the hospital, either during the day or in the evenings. The staff interviews were analysed in the same way as the patient interviews.

Following all the interviews, JC sent her notes to the informant asking for comments or amendments. A small number of informants sent comments.

All tapes have been deleted. Notes of interviews are on file.

Details of patients and staff interviewed

Patients

- A. Male, aged 50, cancer diagnosis, major surgery (leg amputation) followed by three weeks inpatient care (two hospitals).
- B. Female, suspected cancer, day surgery unit + overnight stay (one day case unit).
- C. Female, 87 years old, admission through emergency department for suspected community-acquired pneumonia, acquired *C. difficile* infection. Seven weeks in hospital (four wards, three medical teams).
- D. Female, aged 91, fall and fracture of vertebrae, emergency admission, seven weeks (four consultants, three wards).
- E. Female, in her 50s, emergency admission and rehabilitation, neurological disease, 12 weeks in hospital (three wards).
- F. Male, in his 60s, cancer, surgery and chemotherapy, six weeks (one ward).
- G. Male, 60, stroke, emergency admission and rehabilitation, six months in total (four wards).
- H. Female, in her 50s, cancer, two episodes of surgery in 12 months followed by six months combined chemo and radiotherapy (two wards).
- I. Male, in his 60s, emergency surgical, arterial problem, seven days (two wards).
- J. Male, in his 60s, emergency admission, complications following surgery, blood disorder, three weeks (one ward).

Staff

- A. Consultant physician, care of the elderly
- B. Consultant respiratory physician
- C. Specialist registrar, medicine
- D. Junior house officer
- E. Charge nurse, medical assessment unit
- F. Ward sister, medical ward
- G. Staff nurse, medical assessment unit
- H. Staff nurse, medical ward
- I. Ward clerk, medical ward
- J. Ward clerk, medical ward

Qualitative research with hospital and trust staff

Lala and Wood market research consultants were commissioned by The Point of Care programme to conduct research across a spectrum of health care management, professionals and support staff, to explore the terms and concepts they use to talk about patients' experience and how patients are treated, individually.

This learning would also provide guidance for the language used in communicating The Point of Care programme.

Specific objectives for this research were:

- to investigate the language hospital staff use about patients' experience in hospital
- to investigate how the language and terminology varies between groups (eg, according to profession/job title, status, age)
- to explore with members of staff their own feelings about language currently used to describe the patient and their experience of care.

The research was conducted by Victoria Wood between 17 January and 4 March 2008 at the following locations:

- The Churchill Hospital (Oxford Radcliffe Hospitals NHS Trust)
- The Queen's Medical Centre (Nottingham University Hospitals NHS Trust)
- Weston Park Hospital (Sheffield Teaching Hospitals NHS Foundation Trust)
- Royal Free Hospital (Royal Free Hampstead NHS Trust).

All respondents were employees of the trusts concerned, though not necessarily of the particular hospital where the interviews took place.

The sample was purposive and two qualitative methodologies were used.

- Five mini-focus groups of approximately 75–90 minutes duration. Each comprised 3–5 individuals from each of the following groups:
 - junior doctors
 - qualified nurses
 - health care assistants
 - mixed support staff (ward domestic/porter/receptionist/ward clerk)
 - allied health care professionals (therapists from different disciplines)
- Nine individual or paired depth interviews of approximately 20–60 minutes duration, from the following:
 - consultants (3 interviews)
 - trust non-executive directors (2 interviews)
 - chair of trust (2 interviews)
 - trust Executive (1 interview)
 - trust middle manager (1 interview)

All interviews and focus groups were recorded, and the transcripts from the recordings were analysed to produce a final report. The report has not been published, but copies can be obtained by contacting pointofcare@kingsfund.org.uk

Literature review

Patient-centred care is a complex term, cutting across disciplines in health care. The existing research literature is modest. For these reasons our initial intention to conduct a systematic review was revised and our review sought to analyse and describe a broad and dispersed literature using a wide variety of search techniques, designed to include materials rather than exclude them.

With help from The King's Fund librarians we:

- searched electronic databases – Medline, Cinahl, ASSIA, Cochrane Library, HMIC, National Electronic Library for Health, National Research Register, British Library
- searched specialist websites
- followed up references in key papers and 'related links' on key papers
- hand-searched key journals, both peer-reviewed and non-peer-reviewed
- searched grey literature – through the internet, hand-searching and following word-of-mouth leads.

We started looking broadly at patient-centred care using a range of search terms, which we refined a number of times. Our search terms included patient-centred/patient-centred care, person-centred/person-centred care, relationship-centred/relationship-centred care, personalised care, patient care, humanism, humanity, pastoral care, patient experience and patient satisfaction.

We started searching for papers published in the last five years and then went back further. We looked only at literature in English. We looked at acute hospitals first and then broadened to primary care and other settings such as hospices.

We did not apply rigid inclusion and exclusion criteria to the literature. Because the number of potential papers was small we were reluctant to exclude any, and only excluded those that in our judgement were irrelevant or unclear. We imported our search results to a database and then weeded, keeping papers that could be relevant to the programme in the future.

Once our initial searching had generated a list of papers and documents, we then searched 'related links' and tracked citations. We also hand-searched key journals and followed up references in the papers we found. Efforts to identify grey literature were made through browsing and personal contacts.

Where we found systematic reviews and randomised control trials we obtained copies of the whole study. Since these proved to be few in number we followed references to any promising studies (in terms of intervention or reported outcome), both quantitative and qualitative, in peer-reviewed journals. We also obtained in full anything of interest in the grey literature.

We found a number of literature reviews, some of which were described as systematic, relevant to The Point of Care. Randomised control trials are rare but there are a great number of qualitative research papers, many of which were descriptive.

We found reports of interventions and 'promising practice' published elsewhere (not in peer-reviewed journals) including the nursing press, websites and reports from organisations such as patient groups. We found papers that have discussions which provide insight about, for example, humanity, empathy and spirituality. Book sections also provide useful descriptions or discussion of what good patient-centred care might look like.

The search of electronic databases yielded only a small number of papers but this was not entirely surprising. Reviews of complex evidence (certainly true in the case of patient-centred care) are defined as addressing broad questions and synthesising qualitative and quantitative evidence, usually from multiple and disparate sources. Greenhalgh and Peacock describe a systematic review of complex evidence in which only 30 per cent of sources were obtained by the protocol defined at the outset of the study (database and hand searches), 51 per cent by ‘snowballing’¹ (emerging as they went along, for example by following up references) and as many as 24 per cent by personal knowledge or personal contacts (Greenhalgh and Peacock 2005). This differs from Cochrane reviews of therapeutic interventions where most high-quality primary studies could be identified by searching four standard databases.

Our approach to tracking down book sections and other grey literature followed ‘informal approaches’ as described by Greenhalgh and Peacock (2005): ‘Strategies that might seem less efficient (such as browsing library shelves, asking colleagues, pursuing references that look interesting, and simply being alert to serendipitous discovery) may have a better yield per hour spent and are more likely to identify important sources that would otherwise be missed’.

¹ Snowball’ methods such as pursuing references of references and electronic citation tracking are described as especially powerful for identifying high-quality sources in obscure locations. They calculated that one useful paper was found for every 15 minutes of searching in this way whereas it took a month to hand search a total of 271 journal-years, from which they extracted only 24 papers for the final report – an average of one paper per nine hours of searching.

The Institute of Medicine's definition of patient-centred care: a review of the literature

IoM dimension	Scope	Sources	Description
Co-ordination and integration	Continuity of care	Haggerty <i>et al</i> 2003	Key literature review. Three types of continuity of care – informational, management and relational – ‘for patients and their families, the experience of continuity is the perception that providers know what has happened before, that different providers agree on a management plan, and that a provider who knows them will care for them in future’
		van Servellen <i>et al</i> 2006	Review of the clinical trial literature to see to what extent informational, management and relational continuity of care are associated with quality care indicators
	Teamworking	Borrill <i>et al</i> 2000	Research (survey of multidisciplinary team working and effectiveness), which shows that improved teamworking is good for the mental health not only of the staff but also of patients
		West 2004	Book that provides support for improving teamworking
	Discharge	Holzhausen 2001	Carers UK survey with carers to find out experience of hospital discharge. Makes 10 recommendations.
		Kydd 2008	Example of qualitative study that illustrates patients’ experience of delayed discharge
	Work patterns and shifts	Ahmed-Little and Bluck 2006	Examines and quantifies current and future impact of European Working Time Directive on availability of junior doctors
		McVicar 2003	Literature review on nurses’ perceptions of workplace stress; identifies shiftworking as main source of distress
	Staffing levels	Kane <i>et al</i> 2007	Literature review (US) – found greater number of registered nurses on staff associated with reduction in number of hospital-related deaths
		West <i>et al</i> 2008	Systematic review of staffing levels in intensive care – found impact on mortality
		Bergstrom <i>et al</i> 2005	SDO-funded systematic literature review – found higher nurse staffing and richer skill mix (especially of registered nurses) are associated with improved patient outcomes – this compares with finding of Healthcare Commission report (2005d)

IoM dimension	Scope	Sources	Description
Involvement of family and friends	Governance	Shaller 2007	Review of patient-centred organisations – found family involvement to be one of the crucial factors contributing at an organisational level to success and refers to Institute for Family-centred care guidelines
	Family-centred care	Shields <i>et al</i> 2006 Shields <i>et al</i> 2007	Shields <i>et al</i> (2006) is a summary of qualitative studies excluded from a Cochrane review (Shields <i>et al</i> 2007) on the use of family-centred care in children's hospitals. Authors think there is useful learning on how to involve families: negotiation is important, as is awareness that it might involve cost to families
		Corlett and Twycross 2006	Literature review highlighting the need for nurses to negotiate with parents about involvement in their child's care
		Andershed 2006	Literature review looking at relatives' involvement in end-of-life care
	Family-centred rounds	Sisterhen 2007	Literature review describing what they are
Support for family	Harding and Higginson 2003	Literature review on how best to support families (palliative care setting)	
Physical comfort (may include dignity)	The built environment	Chaudhury <i>et al</i> 2005	Reviews literature on advantages of single rooms for patients in terms of safety and satisfaction; finds that single rooms reduce risk of hospital-acquired infections and have positive therapeutic effects on patients
		Leino Kilpi <i>et al</i> 2001	Review that explores concept of privacy
		Whitehead and Wheeler 2008	Literature review of research and policies related to patients' privacy and dignity
		Ulrich 1984	Early study showing that physical environment make a difference to recovery after surgery
		Lawson and Phiri 2003	Research study funded by NHS Estates demonstrating important impact of architectural environment
		Arneill and Devlin 2003	Literature review describing themes in research, including role of ambient environment (sound, light, art) and emergence of specialised building types for defined populations
		CABE 2004	Report on positive role of hospital design in the recruitment, retention and performance of NHS nurses (includes literature review and qualitative and quantitative research)
Arts and health	Staricoff 2004	Literature review – looks at health outcomes	
Compassion, empathy, responsiveness to needs, values and expressed preferences (may include dignity)	Compassion Support for delivering compassionate care	NHS Confederation 2008	Discussion paper
		Sanghavi 2006	Demonstrates thinking behind and evidence base for Schwartz Rounds
		Goodman Research Group 2008	Evaluation of Schwartz Rounds
	Dignity	Baillie 2007	Qualitative study, illustrates impact of nurses' behaviour on patients' dignity
		Chochinov 2007	Discussion paper that has stimulated subsequent debate
		Royal College of Nursing 2008	Campaign paper
		Whitehead and Wheeler 2008	Literature review looking at patients' understandings of privacy and dignity
	Cultural competency	Kontos 2006	Literature review of observational studies of intercultural doctor-patient communication
	Emotional intelligence	Akerjordet and Severinsson 2008	Literature review looking at use of emotional intelligence to improve nurse leadership
Birks and Watt 2007		Literature review examining use of emotional intelligence in health care and its impact on patients – not conclusive	

IoM dimension	Scope	Sources	Description
Emotional support, relieving fear and anxiety	Spirituality	Kliewer and Saultz 2006; Orchard 2008 Hoover 2002 Clark <i>et al</i> 2003 Cotton <i>et al</i> 2006 Mowat H 2008	Examples of books that provide guidance for health care staff Journal article that explores impact of caring on awareness of spirituality in nurses Literature review to ascertain whether patients' emotional and spiritual needs are important and whether hospitals are effective in meeting these needs Literature review describes positive association between 'spiritual coping' and health outcomes for adolescents Scoping review of recent research
	Suffering	Cassell 1982 Sweeney 2000	Influential discussion paper Book, reflecting on suffering and clinical practice
Information, communication and education	Information for patients: Impact on Pain	Shulldham 1999	Literature review that demonstrates that communicating well and giving patients good, clear information before surgery results in less pain and better recovery
		Boore 1978; Hayward 1975	Two earlier nursing studies that illustrate this
	About going into hospital	www.pifonline.org.uk www.which.co.uk	Guidance on good practice for producing patient information
	When discharged from hospital	Johnson and Sandford 2005	Cochrane review. Only two trials met inclusion criteria – both about providing information to parents of children leaving hospital – both found providing written and verbal information more effective than written information only
	Communication and psychological well-being	Fallowfield 2002	Good communication has a positive impact on psychological well-being for palliative care patients (one example from large body of work from this author)
	Doctor–patient communication	Stewart 1995	Systematic literature review found correlation between effective doctor–patient communication and improved health outcomes. Identifies components of effective communication
		Lewin <i>et al</i> 2007	Cochrane review showing some interventions to promote patient-centred care do increase patient-centredness of doctor–patient consultation. Components of interventions in primary study tabulated, including doctor's communication. With useful descriptions of components of interventions in primary studies
		Mead and Bower 2002	Literature review showing some relationship between patient-centred doctor behaviour in primary care (including communication) and health outcomes, but not definitive
	Nurse–patient communication	Kelleher 2006; Russell 1999	Single studies in ICU setting illustrating important impact of communication between nurses and patients' families
		Rowe <i>et al</i> 2001	Literature review – demonstrates importance of good communication between midwives and women in maternity care
Rhodes <i>et al</i> 2006		Literature review (using Joanna Briggs Institute methodology) showed importance of pre-admission contact; provision of specific education and information; and improving communication skills	
Allied health professional–patient communication	Parry 2008	Literature review looking at effectiveness of interventions with AHPs to improve communication performance	

IoM dimension	Scope	Sources	Description
Information, communication and education <i>continued</i>	Health literacy	Coulter and Ellins 2006	Literature review includes health literacy and concludes that well-designed written information has little effect on own but combined with oral information can improve patients' experience and reduce use of health service resources
		Coulter and Ellins 2007	Shorter report of this study
	Shared decision-making	Gaston and Mitchell 2005	Systematic literature review showed almost all patients with advanced cancer wanted full information but only two-thirds wished to participate actively in decision-making
		Ziegler <i>et al</i> 2004	Literature review to determine information needs, experiences and views on decision-making among patients with head and neck cancer
		Say <i>et al</i> 2006	Literature review (of quantitative and qualitative studies) investigating the factors that influence patients' preference for involvement in decision-making
		Thistlethwaite <i>et al</i> 2006	Review of decision aids and related research and shared decision-making and known outcomes

References

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- Ahmed-Little Y, Bluck J (2006). 'The European Working Time Directive 2009'. *British Journal of Healthcare Management*, vol 12, no 12, pp 371–4.
- Aiken LH (2002). 'Superior outcomes for Magnet hospitals: The evidence base' in McClure ML, Honshaw AS (eds) *Magnet Hospitals Revisited: Attraction and retention of professional nurses*, pp 61–81. Washington DC: American Nurses Publishing.
- Akerjordet K, Severinsson E (2008). 'Emotionally intelligent nurse leadership: a literature review study'. *Journal of Nursing Management*, vol 16, no 5, pp 565–77.
- Andershed B (2006). 'Relatives in end-of-life care part 1: a systematic review of the literature the five last years, January 1999–February 2004'. *Journal of Clinical Nursing*, vol 15, no 9, pp 1158–69.
- Arneill AB, Devlin AS (2003). 'Health care environments and patient outcomes: a review of the literature'. *Environment and Behavior*, pp 665–94.
- Association of UK University Hospitals (2008). 'Acuity/Dependency Tool'. Association of UK University Hospitals website. Available at www.aukuh.org.uk/members/documents/1AcuityDependencyToolImplementationResourcePack.pdf (accessed 8 October 2008).
- Baillie L (2007). 'The impact of staff behaviour on patient dignity in hospitals'. *Nursing Times*, vol 103, no 34, pp 30–31.
- Bate P, Mendel P, Robert G (2008). *Organizing for Quality: The improvement journeys of leading hospitals in Europe and the United States*. Oxford: Radcliffe.
- Bate P, Robert G (2007). *Bringing User Experience to Healthcare Improvement*. Oxford: Radcliffe.
- Bate P, Robert G (2006). 'Experience-based design: From redesigning the system around the patient to co-designing services with the patient'. *Quality & Safety in Health Care*, vol 15, pp 307–10.
- Bauby J (1997). *The Diving Bell and the Butterfly: A memoir of life in death*. London: HarperPerennial.
- Bauman AE, Fardy HJ and Harris PG (2003). 'Getting it right: why bother with patient-centred care?' *The Medical Journal of Australia*, vol 179, no 5, pp 253–6.
- Bergstrom N, Horn SD, Smout RJ, Bender SA, Ferguson ML, Taler G, Sauer AC, Sharkey SS, Voss AC (2005). 'Nurse staffing and healthcare outcomes: a systematic review of the international research evidence'. *Advances in Nursing Science*, vol 28, no 2, pp 163–74.
- Berwick DM (2004). *Escape Fire: Designs for the future of health care*. San Francisco: Jossey-Bass.
- Birks YF, Watt IS (2007). 'Emotional intelligence and patient-centred care'. *Journal of the Royal Society of Medicine*, vol 100, pp 369–74.

- Black G (ed) (1992). *Nursing Development Units: Work in progress*. London: King's Fund Centre.
- Boore J (1978). *Prescription for Recovery*. London: Royal College of Nursing.
- Borrill C, West M, Shapiro D, Rees A (2000). 'Team working and effectiveness in healthcare'. *British Journal of Healthcare Management*, vol 6, no 8, pp 364–71.
- Bridges J, Gray W, Box G, Machin S (2008). 'Discovery interviews: a mechanism for user involvement'. *International Journal of Older People Nursing*, vol 3, pp 206–10.
- Bridges J, Nicholson C (2008). 'Service improvement using patient narratives: engaging with the issues'. *International Journal of Older People Nursing*, vol 3, pp 217–22.
- Brooker D, Edwards P and Benon S (eds) (2004). *Dementia Care Mapping: Experience and insights into practice*. London: Hawker.
- Cashavelly BJ (2008). 'The forgotten team member: meeting the needs of oncology support staff'. *Oncologist*, vol 13, pp 530–8.
- Cassell EJ (1982). 'The nature of suffering and the goals of medicine'. *New England Journal of Medicine*, vol 306, no 11, pp 639–45.
- Chaudhury H, Mahmood, A, Valente M (2005). 'Advantages and disadvantages of single-versus multiple-occupancy rooms in acute care environments: a review and analysis of the literature'. *Environment and Behavior*, vol 37, no 6, pp 760–86.
- Chochinov HM (2007). 'Dignity and the essence of medicine: the A, B, C and D of dignity conserving care'. *British Medical Journal*, vol 335, pp 184–7.
- Clark PA, Drain M, Malone MP (2003). 'Addressing patients' emotional and spiritual needs'. *Joint Commission Journal on Quality and Safety*, vol 29, no 12, pp 659–70.
- Clever SL, Ford DE, Rubenstein LV, Rost KM, Meredith LS (2006). 'Primary care patients' involvement in decision-making is associated with improvement in depression'. *Medical Care*, vol 44, no 5, pp 398–405.
- Cole-King A and Harding K (2001). 'Psychological factors and delayed healing in chronic wounds'. *Psychosomatic Medicine*, vol 63, pp 216–20.
- Corlett J, Twycross A (2006). 'Negotiation of parental roles within family-centred care: a review of the research'. *Journal of Clinical Nursing*, vol 15, no 10, pp 1308–16.
- Commission for Architecture and the Built Environment (2004). *The role of hospital design in the recruitment, retention and performance of NHS nurses in England (Executive Summary)*. London: CABI.
- Congressi LRD (2006). 'Four days in a strange place'. *Journal of Health Services Research and Policy*, vol 11, no 2, pp 122–4.
- Connect website. Available at: www.ukconnect.org (accessed on 8 October 2008).
- Corbin J (2008). 'Is caring a lost art in nursing?' *International Journal of Nursing Studies*, vol 45, no 2, pp 163–5.
- Cornwell J (1984). *Hard-earned Lives: Accounts of health and illness from east London*. London: Tavistock.
- Cotton S, Zebracki K, Rosenthal SL, Tsevat J, Drotar D (2006). 'Religion/spirituality and adolescent health outcomes: a review'. *Journal of Adolescent Health*, vol 38, no 4, pp 472–80.
- Coulter A (2005). *Trends in Patients' Experience of the NHS*. Oxford: Picker Institute.

- Coulter A, Ellins J (2007). 'Effectiveness of strategies for informing, education and involving patients.' *British Medical Journal*, vol 335, pp 24–7.
- Coulter A, Ellins J (2006). *Patient-focused Interventions: A review of the evidence*. London: Health Foundation.
- Cummings GG (2008). 'The relationship between nursing leadership and nurses' job satisfaction in Canadian oncology work environments.' *Journal of Nursing Management*, vol. 16, pp 508–18.
- Cunningham G and Kitson A (2000a). 'An evaluation of the RCN clinical leadership development programme: part 1.' *Nursing Standard*, vol 15, no 12, pp 34–7.
- Cunningham G and Kitson A (2000b). 'An evaluation of the RCN clinical leadership development programme: part 2.' *Nursing Standard*, vol 15 no. 13/14/15, pp 34–40.
- Davies H, Nutley S, and Mannion R (2000). 'Organisational culture and quality of health care.' *Quality & Safety in Health Care*, vol 9, pp 111–19.
- Delbanco TL (2005). 'Patient-Centered Care and Communication: An Expert Interview With Tom Delbanco MD'. Medscape website. Available at: www.medscape.com/viewarticle/498177 (accessed on 6 November 2008).
- Delbanco TL (1996). 'Quality of care through the patients' eyes.' *British Medical Journal*, vol 313, pp 832–3.
- Department of Health (2008a). *High Quality Care for All – NHS Next Stage Review final report*. London: Department of Health.
- Department of Health (2008b). *NHS Constitution*. London: Department of Health.
- Department of Health (2008c). *Our NHS Our Future: NHS Next Stage Review interim report*. London: Department of Health.
- Department of Health (2008d). *Real Involvement: Working with people to improve health services*. London: Department of Health.
- Department of Health (2007a). *The NHS in England: The operating framework for 2008/09*. London: Department of Health.
- Department of Health (2007b). *What Matters – What Matters to our Patients, Public and Staff*. London: Department of Health.
- Department of Health (2007c). *World Class Commissioning*. London: Department of Health.
- Department of Health (2006). *Dignity in Care*. Department of Health website. Available at: www.dh.gov.uk/en/SocialCare/Socialcarereform/Dignityincare/index.htm (accessed on 8 October 2008).
- Department of Health (2005). *Creating a Patient-led NHS: Delivering the NHS improvement plan*. London: Department of Health.
- Department of Health (2001). *National Service Framework for Older People*. London: Department of Health.
- Department of Health (2000). *The NHS Plan: A plan for investment, a plan for reform*. London: The Stationery Office.
- Department of Health (1998). *A First Class Service: Quality in the new NHS*. London: Department of Health.

- Department of Health (1997). *The New NHS Modern Dependable*. Cm 3807. London: The Stationery Office.
- Department of Health (1991). *The Patient's Charter: Raising the standard*. London: Department of Health.
- Didion J (2005). *The Year of Magical Thinking*. New York: Knopf.
- Dixon S (2008). *Report on the National Patient Choice Survey – January 2008 England*. London: Department of Health.
- Donald A (2008) 'Tests'. British Medical Journal website. Available at <http://blogs.bmj.com/bmj/2008/05/01/anna-donald-tests/> (accessed on 1 May 2008).
- Donaldson L (2002). 'An organisation with a memory'. *Clinical Medicine*, vol 2, no 5, pp 452–7.
- Edson M (2000). *Wit*. London: Nick Hern Books.
- Fallowfield L (2002). 'Truth may hurt but deceit hurts more: communication in palliative care'. *Palliative Medicine*, vol 16, no 4, pp 297–303.
- Ferlie EB, Shortell SM (2001). 'Improving the quality of health care in the United Kingdom and the United States: a framework for change'. *The Milbank Quarterly*, col 79, no 2, pp 281–315.
- Forbat L, Cayless S, Knighting K, Cornwell J, Kearney N (2008). 'Engaging patients in healthcare: an empirical study of the role of engagement on attitudes and action'. *Patient Education and Counselling* (in press).
- Frampton SB, Gilpin L, Charmer PA (eds) (2003). *Putting Patients First: Designing and practising patient-centred care*. San Francisco: Jossey-Bass.
- Fulop N (2004). 'Organisational turnaround: lessons from a study of "failing" health care providers in England'. Paper presented at the 2004 Annual Research Meeting, June, San Diego.
- Gaston CM, Mitchell G (2005). 'Information giving and decision-making in patients with advanced cancer: a systematic review'. *Social Science & Medicine*, vol 61, no 10, pp 2252–64.
- Gawande A (2008). *Better: A surgeon's notes on performance*. London: Profile.
- General Medical Council (2007). *Consent: Patients and doctors making decisions together. A draft for consultation*. London: GMC.
- Gerteis M, Edgman-Levitan S, Daley J, Delbanco TL (1993). *Through the Patient's Eyes: Understanding and promoting patient-centred care*. San Francisco: Jossey-Bass.
- Gilbert D (2006). *Stumbling on Happiness*. New York: Knopf.
- Gillespie R, Florin D, Gillam S (2004). 'How is patient-centred care understood by the clinical, managerial and lay stakeholders responsible for promoting this agenda?' *Health Expectations*, vol 7, no 2, pp 142–8.
- Goffman E (1961). *Asylums: Essays on the social situation of mental patients and other inmates*. New York: Doubleday.
- Goodman Research Group (2008). *Schwartz Center Rounds Evaluation Report*. Cambridge, MA: Goodman Research Group.

- Greenhalgh T, Robert G, MacFarlane F, Bate P, Kyriakidou O (2004). 'Diffusion of innovations in service organizations: systematic review and recommendations'. *The Milbank Quarterly*, vol 82, no 4, pp 581–629.
- Greenhalgh T, Peacock R (2005). 'Effectiveness and efficiency of search methods in systematic reviews of complex evidence: audit of primary sources'. *BMJ*, vol 331, pp 1064–5.
- Haggerty JL, Reid RJ, Freeman GK, Starfield BH, Adair CE, McKendry R (2003). 'Continuity of care: a multidisciplinary review'. *BMJ*, vol 327, no 22.
- Halpern J (2001). *From Detached Concern to Empathy: Humanizing medical practice*. Oxford: Oxford University Press.
- Harding R and Higginson IJ (2003). 'What is the best way to help caregivers in cancer and palliative care? A systematic literature of review of interventions and their effectiveness'. *Palliative Medicine*, vol 2003, no 17, pp 63–74.
- Hayward J (1975). *Information – A Prescription Against Pain*. London: Royal College of Nursing.
- Health and Social Care Act 2008* (c14). London: The Stationery Office.
- Healthcare Commission (2008a). *Learning from Investigations*. London: Healthcare Commission.
- Healthcare Commission (2008b). Memorandum by the Healthcare Commission. UK Parliament website. Available at <http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/40/40we59.htm> (accessed on 8 October 2008)
- Healthcare Commission (2008c). *National NHS Staff Survey 2007*. London: Healthcare Commission.
- Healthcare Commission (2008d). *Spotlight on Complaints*. London: Healthcare Commission.
- Healthcare Commission (2007a). *Investigation into Outbreaks of Clostridium difficile at Maidstone and Tunbridge Wells NHS Trust*. London: Healthcare Commission.
- Healthcare Commission (2007b). *Caring for Dignity – A National Report on Dignity in Care for Older People While in Hospital*. London: Healthcare Commission.
- Healthcare Commission (2007c). *Survey of Adult Inpatients in the NHS 2007*. London: Healthcare Commission.
- Healthcare Commission (2007d). *Women's Experiences of Maternity Care in the NHS in England*. London: Healthcare Commission.
- Healthcare Commission (2006). *Variations in the Experiences of Patients Using the NHS Services in England. Analysis of the Healthcare Commission's 2004/2005 Surveys of Patients*. London: Healthcare Commission.
- Healthcare Commission (2005a). *Coronary Heart Disease: survey of patients 2004*. London: Healthcare Commission.
- Healthcare Commission (2005b). *Outpatient Department: Key findings*. London: Healthcare Commission.
- Healthcare Commission (2005c). *Survey of Patients 2005: Stroke*. London: Healthcare Commission.
- Healthcare Commission (2005d). *Ward Staffing*. London: Healthcare Commission.

- Help the Aged website. Available at: www.helptheaged.org.uk (accessed on 8 October 2008).
- Holzhausen E (2001). *You Can Take Him Home Now: Carers' experience of hospital discharge*. London: Carers National Association.
- Hoover J (2002). 'The personal and professional impact of undertaking an educational module on human caring', *Journal of Advanced Nursing*, vol 37, no 1, pp 79–86.
- Hospital Episode Statistics website. Available at: www.HESonline.nhs.uk (accessed on 8 October 2008).
- House of Lords, House of Commons (2007). *The Human Rights of Older People in Healthcare*. London: The Stationery Office.
- HC 378-I. (2006–07) London: The Stationery Office.
- Institute for Healthcare Improvement website. Available at: www.ihl.org/IHI/Topics/PatientSafety/ (accessed on 5 October 2008).
- Institute of Medicine (2001). *Crossing the Quality Chasm: A new health system for the 21st century*. Washington DC: National Academy Press.
- Institute of Medicine (2000). *To Err is Human: Building a Safer Health System*. Washington DC: National Academy Press.
- Ipsos Mori (2008). *Trust in Professions 2007: Public awareness of physicians and trust in professionals: research study conducted for the Royal College of Physicians*. London: Royal College of Physicians.
- Jeffery R (2001). 'Normal rubbish: deviant patients in casualty departments' in Davey B, Gray A, Seale C (eds), *Health and Disease: A reader*, pp 363–8. Buckingham: OUP.
- Jenkinson C, Coulter A, Richards N, Chandola T (2002). 'Patients' experiences and satisfaction with health care: results of a questionnaire study of specific aspects of care' *Quality & Safety in Health Care*, vol 11, pp 335–9.
- Johnson A (2008). Speech at NHS Confederation conference, Manchester, 18 June.
- Johnson A, Sandford J (2005). 'Written and verbal information versus verbal information only for patients being discharged from acute hospital settings to home: systematic review'. *Health Education Research*, vol 20, no 4, pp 423–9.
- Kane R, Shamliyan T, Mueller C, Duval S, Wilt T (2007). 'The association of registered nurse staffing levels and patient outcomes: systematic review and meta-analysis'. *Medical Care*, vol 45, no 12, pp 1195–1204.
- Kelleher S (2006). 'Providing patient-centred care in an intensive care unit'. *Nursing Standard*, vol 21, no 13, pp 35–40.
- Kennedy I (2004). *Learning from Bristol: Are we? An essay by Professor Sir Ian Kennedy*. London: Healthcare Commission.
- Kliwer S, Saultz J (2006). *Healthcare and Spirituality*. Oxford: Radcliffe.
- Knapp C (2006). 'Bronson Methodist Hospital: Journey to excellence in quality and safety'. *Joint Commission Journal on Quality and Patient Safety*, vol 32, no 10, pp 556–63.
- Kontos PC (2006). 'Cultural differences in medical communication: a review of the literature'. *Patient Education and Counseling*, vol 64, no 1, pp 21–34.
- Kydd A (2008). 'The patient experience of being a delayed discharge'. *Journal of Nursing Management*, vol 16, no 2, pp 121–6.

- Lawson B, Phiri M (2003). *The Architectural Healthcare Environment and its Effect on Patient Health Outcomes*. London: The Stationery Office.
- Leatherman S, Sutherland K (2008). *The Quest for Quality: Refining the NHS Reforms. A policy analysis and chartbook*. London: The Nuffield Trust.
- Leatherman S, Sutherland K (2003). *The Quest for Quality in the NHS: A mid-term evaluation of the ten-year quality agenda*. London: Nuffield Trust.
- Leino Kilpi H, Valimaki M, Dassen T, Gasull M, Lemonidou C (2001). 'Privacy: a review of the literature'. *International Journal of Nursing Studies*. Oxford, vol 38, no 6, pp 663–71.
- Levenson R (2007). *The Challenge of Dignity in Care – upholding the rights of the individual*. London: Help the Aged.
- Lewin SA, Skea ZC, Entwistle V, Zwarenstein M, Dick J (2007). 'Interventions for providers to promote a patient-centred approach in clinical consultations' (Cochrane Review). *The Cochrane Database of Systematic Reviews 2007*, issue 2.
- Ludlow C (2008). *Shadows in Wonderland: A hospital odyssey*. London: Hammersmith Press.
- Maben, J (2008). 'The art of caring: invisible and subordinated: a response to Corbin: "Is caring a lost art in nursing?"' *International Journal of Nursing Studies*, vol 45, no 3, pp 335–8.
- Maben J, Latter S, Macleod Clark J (2007). 'The sustainability of ideals, values and the nursing mandate: evidence from a longitudinal qualitative study'. *Nursing Inquiry*, vol 14, no 2, pp 99–113.
- Mantel H (2008). 'Diary: Hilary Mantel'. *London Review of Books*, 14 August.
- Martin DP (1990). 'The Planetree Model Hospital Project: an example of the patient as partner'. *Hospital and Health Services Administration*, vol 35, no 4, pp 591–601.
- Maxwell R (1992). 'Dimensions of quality revisited: from thought to action'. *Quality in Health Care*, vol 1, pp 171–7.
- McCormack B, Manley K, Garbett R (2004). *Practice Development in Nursing*. Oxford: Blackwell.
- McVicar A (2003). 'Workplace stress in nursing: a literature review'. *Journal of Advanced Nursing*, vol 44, no 6, pp 633–42.
- Mead N, Bower P (2002). 'Patient-centred consultations and outcomes in primary care: a review of the literature'. *Patient Education and Counselling Journal*, vol 41, no 1, pp 51–61.
- Mead N, Bower P (2000). 'Patient-centredness: a conceptual framework and review of the empirical literature'. *Social Science & Medicine*, vol 51, pp 1087–110.
- Mencap website. Available at: www.mencap.org.uk (accessed on 8 October 2008).
- Menzies IEP (2002). 'A case study of the functioning of social systems as a defence against anxiety' in Rafferty A, Traynor M (eds), *Exemplary Research for Nursing and Midwifery*. pp 111–42. London: Routledge.
- Moore A (2008). 'Service improvement: dignity by design'. *Health Service Journal*, 7 July.
- Mowat H (2008). *The Potential for Efficacy of Healthcare Chaplaincy and Spiritual Care Provision in the NHS*. Aberdeen: Mowat Research.

- Mulgan G, Ali R, Halkett R, Sanders B (2007). *In and Out of Sync: The challenge of growing social interventions*. London: NESTA.
- National Audit Office, Department of Health (2005). *Tackling Cancer: Improving the patient journey*. London: The Stationery Office.
- NHS Confederation (2008). *Compassion in Healthcare: The missing dimension of healthcare reform?* London: NHS Confederation.
- National Health Service Act 2006* (c41). London: The Stationery Office.
- Nolan A (2007). 'Productive ward: releasing time to care'. *Health Service Journal*, vol 117, no 6052, pp S1–S19.
- Nolan M, Brown J, Davies S, Nolan J, Keady J (2006). 'The senses framework: improving care for older people through a relationship-centred approach'. *Getting Research into Practice (GRiP)*.
- Norman D (2003). 'The effects of stress on wound healing and leg ulceration'. *British Journal of Nursing*, vol 12, no 21, pp 1256–63.
- Nursing and Midwifery Council (2004). *The NMC Code of Professional Conduct: Standards for performance, conduct and ethics*. London: NMC.
- Open University U205 Team (1985). *Caring for Health. Dilemmas and Prospects*. Milton Keynes: Open University Press.
- Orchard H (2008). *Spirituality in Health Care Contexts*. London: Jessica Kingsley.
- Ovretveit J (2003). *What are the Best Strategies for Ensuring Quality in Hospitals?* Copenhagen: World Health Organization/Health Evidence Network.
- Parry R (2008). 'Are interventions to enhance communication performance in allied health professionals effective, and how should they be delivered? Direct and indirect evidence'. *Patient Education and Counselling*, vol 73, no 2, pp 186–95.
- Patients Association (2008). *NHS complaints: Who cares? Who can make it better?* Harrow: Patients Association.
- Planetree website. Available at: www.planetree.org (accessed on 8 October 2008).
- Porter R (2002). *Blood and Guts: A short history of medicine*. London: Allen Lane.
- Revans R (1964). *Standards for Morale: Cause and effect in hospitals*, Nuffield Hospitals Trust. Oxford: Oxford University Press.
- Rhodes L, Miles G, Pearson A (2006). 'Patient subjective experience and satisfaction during the perioperative period in the day surgery setting: a systematic review'. *International Journal of Nursing Practice*, vol 12, no 4, pp 178–92.
- Richards N, Coulter A (2007). *Is the NHS Becoming more Patient-centred? Trends from the National Surveys of NHS Patients in England 2002–07*. Oxford: Picker Institute.
- Rowe RE, Garcia J, Macfarlane AJ, Davidson LL (2001). 'Improving communication between health professionals and women in maternity care: a structured review'. *Health Expectations*, vol 5, pp 63–83.
- Royal College of Nursing (2008). *Defending Dignity – Challenges and opportunities for nursing*. London: Royal College of Nursing.
- Royal College of Physicians (2007). *The Right Person, in the Right Setting – First Time: Report of the Acute Medicine Task Force*. London: Royal College of Physicians.

- Royal College of Psychiatrists (2006). *Better Services for People who Self-harm: Quality standards for healthcare professionals*. London: Royal College of Psychiatrists. Available at: www.rcpsych.ac.uk/cru/auditselfharm.htm (accessed on 26 November 2008).
- Russell S (1999). 'An exploratory study of patients' perceptions, memories and experiences of an intensive care unit'. *Journal of Advanced Nursing*, vol 29, no 4.
- Sanghavi DM (2006). 'What makes a compassionate patient–caregiver relationship?' *Joint Commission Journal on Quality and Patient Safety*, vol 32, no 5, pp 283–92.
- Say R, Murtagh M, Thomson R (2006). 'Patients' preference for involvement in medical decision making: a narrative review'. *Patient Education and Counselling*, vol 60, no 2, pp 102–14.
- Schwartz KB (1995). 'A patient's story'. *Boston Globe Magazine*, July 16.
- Senge PM (1990). *The Fifth Discipline: The Art and Practice of the Learning Organization*. New York: Doubleday.
- Shaller D (2007). *Patient Centered Care: What Does It Take?* Oxford: Picker Institute and The Commonwealth Fund.
- Shields L, Pratt J, Davis L, Hunter J (2007). 'Family-centred care for children in hospital' (Cochrane review). *Cochrane Database of Systematic Reviews*, issue 1.
- Shields L, Pratt J, Hunter J (2006). 'Family-centred care: a review of qualitative studies'. *Journal of Clinical Nursing*, vol 15, no 10, pp 1317–23
- Shuldham C (1999). 'A review of the impact of pre-operative education on recovery from surgery'. *International Journal of Nursing Studies*, vol 36, pp 171–7.
- Sisterhen LL (2007). 'Defining family-centered rounds'. *Teaching and Learning in Medicine*, vol 19, no 3, pp 319–22.
- Smith P (2008). 'Compassion and smiles: what's the evidence?' *Journal of Research in Nursing*, vol 13, no 5, pp 367–70.
- Staricoff R (2004). *Arts in Health: A review of the literature*. London: Arts Council England.
- Stewart MA (2000). 'The impact of patient-centered care on outcomes'. *Journal of Family Practice*, vol 49, pp 796–804.
- Stewart MA (1995). 'Effective physician-patient communication and health outcomes'. *Canadian Medical Association Journal*, vol 152, no 9, pp 1423–33.
- Stockwell F (2002). 'The unpopular patient' in Rafferty AM, Traynor M (eds), *Exemplary Research for Nursing and Midwifery*, pp 23–41. London: Routledge.
- Strong P (1977). 'Medical errands: a discussion of routine medical work' in Davis A, Horobin G (eds), *Medical Encounters: The experience of illness and treatment*. London: Croom Helm.
- Suchman A (1993). 'Physician satisfaction with primary care office visits: Collaborative Study Group of the American Academy on Physician and Patient'. *Medicine Care*, vol 31, no 12.
- Sweeney G (2005). 'The patients accelerating change project: does it make any difference?' *Clinical Governance*, vol 10, no 1, pp 72–83.
- Sweeney K (2000). 'Uniqueness in clinical practice: reflections on suffering' in Dixon M, Sweeney K (eds), *The Human Effect in Medicine*, pp 27–39.

- Tallis R (2004). *Hippocratic Oaths: Medicine and its discontents*. London: Atlantic.
- Teale K (2007). 'What's wrong with the wards?' *British Medical Journal*, vol 334, p 97.
- The Schwartz Center website. Available at: www.theschwartzcenter.org/programs/rounds.html (accessed on 8 October 2008).
- Thistlethwaite J, Evans R, Tie RN, Heal C (2006). 'Shared decision making and decision aids – a literature review'. *Australian Family Physician*, vol 35, no 7, pp 537–40.
- Thomas H (2008). 'Engaging patients to understand and improve their experience of attending hospital'. *Journal of Communication in Healthcare*, vol 1, no 1, pp 78–87.
- Ulrich R (1984). 'View through a window may influence recovery from surgery'. *Science*, vol 224, pp 420–1.
- van Servellen G, Fongwa M, Mockus DE (2006). 'Continuity of care and quality care outcomes for people experiencing chronic conditions: a literature review'. *Nursing and Health Sciences*, vol 8, no 3, pp 185–95.
- Vincent C (2001). *Clinical Risk Management: Enhancing patient safety*. London: BMJ Books.
- Wanless D, Appleby J, Harrison A, Patel D (2007). *Our Future Health Secured? A review of NHS funding and performance*. London: The King's Fund.
- Wasson, JH, Anders SG, Moore LG, Ho L Nelson EC, Godfrey MM and Batalden PB (2008). 'Clinical Microsystems, Part 2. Learning from micro practices about providing patients the care they want and need'. *Joint Commission Journal on Quality and Patient Safety*, vol 34, no 8, pp 445–52.
- Weinman J, Ebrecht M, Scott S, Walburn J, Dyson J (2008). 'Enhanced wound healing after emotional disclosure intervention'. *British Journal of Health Psychology*, vol 13, no 1, pp 95–102.
- West E, Mays N, Rafferty AM, Rowan K, Sanderson C (2008). 'Nursing resources and patient outcomes in intensive care: A systematic review of the literature'. *International Journal of Nursing Studies* (in press).
- West M (2004). *Effective Teamwork. Practical lessons from organizational research*. Oxford: Blackwell.
- Which? website. Available at: www.which.co.uk (accessed on 8 October 2008).
- Whitehead J, Wheeler H (2008). 'Patients' experiences of privacy and dignity. Part 1: a literature review'. *British Journal of Nursing*, vol 17, no 6, pp 381–5.
- Williams J, Rees J (1997). 'The use of "dementia care mapping" as a method of evaluating care received by patients with dementia: an initiative to improve quality of life'. *Journal of Advanced Nursing*, vol 25, pp 316–23.
- Wood V (2008). *The King's Fund – 'The Point of Care': A report on the findings of qualitative research among healthcare professionals*. Unpublished (available on request from The Point of Care programme).
- Yedidia M (2007). 'Transforming doctor–patient relationships to promote patient-centered care: lessons from palliative care'. *Journal of Pain Symptom Management*, vol 33, pp 40–57.
- Ziegler L, Newell R, Stafford N, Lewin R (2004). 'A literature review of head and neck cancer patients information needs, experiences and views regarding decision-making'. *European Journal of Cancer Care (Engl)*, vol 13, no 2, pp 119–26.

