

Practice research report

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Exploring the wide range of terminology used to describe care that is patient-centred

The language that hospital staff use to describe patient care can differ from that found in research and policy documents, so terms must be chosen carefully

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ABSTRACT Goodrich, J. (2009) Exploring the wide range of terminology used to describe care that is patient-centred. *Nursing Times*; 105: 20, 14–17.

Background During the planning phase of The King's Fund's The Point of Care programme, we undertook a literature review, starting with the term 'patient-centred care'. We soon discovered the term not only had different meanings for different people but also that there were many related phrases with specific connotations in various professional contexts. When looking at the terminology that policymakers use, it seems that different terms – variations on 'patient-centred care' – have been favoured over the years.

Aim and method We decided to carry out our own research to investigate what language staff working in hospitals preferred to use when describing their care of patients. We collected data using focus groups and paired and single in-depth interviews.

Results It seemed that the language hospital workers preferred to use was different, and that staff (some groups more than others) did not like much of the language that academics and policymakers use.

Conclusion It is important when working in a hospital context to use language that staff prefer.

CONTEXT

The aim of The King's Fund's The Point of Care programme is to improve patients' experience of care in hospital, and to help staff deliver the sort of care they would like for themselves and their own families. The focus of The Point of Care programme

BOX 1. A HEALTH PROFESSIONAL'S VIEW ON THE TERM 'PATIENT-CENTRED CARE'

'I never liked it [the term]. It offends everyone, because each health professional thinks he or she is patient-centred. The basic notion to me is trying to see through the eyes of the patient and understanding 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.'

Source: Delbanco (2005)

is on care in acute hospitals. Our concern is with all healthcare professionals, including support staff, who are involved with patients and families.

THE RESEARCH LITERATURE

Patients' experience, or patient-centred care, is seen as a key aspect of quality of care (Department of Health, 2008a; 2008b; 2008c). Early definitions of quality used a variety of terms. One definition had four criteria for the quality of health care: 'humanity, efficiency, effectiveness and equity' (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 (IoM), which has six criteria: *patient-centred, safe, effective, timely, efficient and equitable* (IoM, 2001). We therefore decided to take 'patient-centred' as the starting point of a literature review that looked at evidence of efforts to improve patients' care. First, though, we needed to see how others had understood the concept,

and that is the focus of this article.

We quickly discovered that we needed to extend the search in order to incorporate other similar or sound-alike terms including: family centred; relationship-centred; person-centred; 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. Discussion and research appear in what might broadly be termed 'medical humanities' as well as clinical and social sciences disciplines.

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 concerned with debates about patients' experience, the causes of substandard nursing care, and campaigns to protect patients' dignity (RCN, 2008).

'Person-centred' care is often used in the academic literature of nursing practice development and encompasses both nurse and patient. 'Relationship-centred' care is used mainly in the literature on older patients, care homes and patients with dementia, and encompasses staff, the patient and the patient's family. In social work, 'personalised' care is often used (particularly concerning the way a person can plan and pay for their own care), while 'family centred' care is used in the literature on children's care. The words 'compassion' and 'humanity' appear most in medical and medical humanities journals, but 'dignity' or 'respect' is the preferred term in nursing and health service management research (although 'compassion' has appeared here more recently).

See Box 1 for a view on using the term 'patient-centred care'.

DEFINITIONS OF 'PATIENT-CENTRED CARE'

There have been some attempts to define exactly what lies behind the term 'patient-centred' in primary care (Mead and Bower, 2000; Stewart et al, 2000) and elsewhere. In cancer care, for example, it is the strategic goal underpinning the reorganisation of primary, acute and tertiary services into networks designed around patients' clinical needs. In the care of people with long-term conditions, it denotes approaches to management that explore what patients think, believe and expect, and also their confidence about disease management (Bauman et al, 2003).

For patients' organisations and consumer groups, patient-centred usually means: services that listen to patients; taking their views seriously; and attending to aspects of care such as dignity and respect for individuals, well-organised care, clean wards and nutritious food.

For The Point of Care programme, we adopted the IoM's (2001) definition because it is the most comprehensive, and is based on the work of the Picker Institute, a charity that studies patients' experiences. The particular attraction of the definition 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 2).

LANGUAGE USED BY POLICYMAKERS

We turned to the policy literature in order to examine what politicians have set out to achieve in relation to patients' experience, and how they have framed the terms of the debate for their purposes over the past 20 years. Good experience for patients has been rediscovered at intervals and relaunched as a new vision.

The language of policy documents and guidance is not precise. It refers to patient-centred care, person-centred care, patient-led, and personalised. Terms are sometimes confused and used interchangeably – sometimes in the same document.

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* (DH, 1991). Aspirations included 'respect for privacy, dignity and religious and cultural beliefs' and

BOX 2. INSTITUTE OF MEDICINE'S DEFINITION OF THE DIMENSIONS OF PATIENT-CENTRED CARE

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

Source: IoM (2001)

for every patient ('eventually') to have a named nurse, midwife or health visitor.

Six years later, the newly elected Labour government began a 10-year programme to reform the health service. Strategy documents and policies began increasingly to refer to the ambition to create a 'patient-centred NHS'. Quality improvement was central to the reform and modernisation process, expressed as 'quality in its broadest sense' with 'patient experience' talked about alongside clinical outcomes (DH, 1997).

Creating a *Patient-led NHS: Delivering the NHS Improvement Plan* (DH, 2005) again set out how the quality agenda would be delivered. The term 'patient-led', closely related to the concept of choice, was used to describe services with particular values or attributes. *Patient-led services* would ensure patients were treated with *respect, dignity and compassion*.

The tendency in policy, as in published research, has been to focus on one of the IoM dimensions of patient-centred care but not the experience as a whole. For example, the NHS Dignity in Care campaign aimed to create 'dignity champions' in every healthcare organisation (DH, 2006).

Most recently, a strong policy strand has emerged that aims to improve patients' overall experience. The NHS Next Stage Review (DH, 2008a) puts 'quality at the heart of all we do', and patients' experience is to 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'. Lord Darzi, the report's author, speaks of the vision for the health service for the next 10 years, which involves four key elements – an NHS that is fair, personal, effective and safe.

The NHS Constitution (DH, 2008b) introduces new pledges. In a late echo of *The Patient's Charter*, it goes back to declaring patients' rights and speaks of them being treated with *compassion and respect*.

In the current *NHS Operating Framework* (DH, 2008c), improving patient experience is a top priority and hospitals will have to report on three aspects of quality: safety, efficiency and *patient experience*.

THE EVERYDAY LANGUAGE OF HOSPITALS

Given the imprecise use of language uncovered so far, we decided to try to find out what language we should use when working with hospital staff. We carried out qualitative research with healthcare managers, professionals and support staff. Our aims were to explore: the terms and concepts people use to talk about patients' experience; how the language and terminology varies between groups; and how people feel about current policy language (Wood, 2008).

The data was collected in 2008 in four acute trusts in England using a mix of focus groups and paired and single in-depth interviews with around 30 staff. They were drawn from a range of professional groups: qualified nurses; junior doctors; healthcare assistants; mixed support staff (ward domestic/porter/receptionist/ward clerk); allied healthcare professionals (therapists from different disciplines); consultants; trust non-executive

BOX 3. PARTICIPANTS' DESCRIPTIONS OF GOOD CARE

- '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).
- 'If you ask all patients what was good, they say "Oh, the staff were so friendly!" Sometimes you just need a friendly face' (nurse).
- 'Care is not necessarily giving them treatment. They might have just wanted a hand with a wash, or giving them a towel, or just a chat! So they know you're there for them' (nurse).
- 'If you think of your own mum, you'll not go far wrong' (care assistant).

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directors; chairs of trusts; trust executives; and trust middle managers.

We first asked participants to define what they thought was meant by 'good care'. Most struggled with the concept:

'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).

Almost universally, respondents said it was not something they talked about with colleagues; indeed a number told us this was the first time they had discussed 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 that the patient is a friend or relative. 'Good care' for them was not an abstract concept – it was either an attitude or a narrative (see Box 3, p15).

Using prompt cards

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, all the words and phrases on the prompt cards 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 that 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 patient 'dignity' was important, but interpreted it differently. Managers, some nurses and some support

BOX 4. VIEWS ON THE TERM 'CUSTOMER'

- 'It's not right, because the majority of patients don't actually want choice because they don't know enough or can't make a choice in a confused and vulnerable state. So they still say, "What do you think?" or "Tell me what's best?"' (nurse).
- '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).

- 'They'll be asking us to say "Have a nice day" next!' (nurse).

- 'It makes it sound like there's no care either way. You're just giving them something and they're taking. There's no relationship in a "customer"' (nurse).

staff viewed 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 that 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-Worldy – 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 health service 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 they had decided to join the profession. 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.'

'Bandied 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' (see Box 4).

As a rule, people said they preferred ordinary, human words for care. The words they suggested included respect, dignity, sensitive, understanding, gentle, kind, welcome, friendly, comfort, smile, compassion and communication.

The phrase 'seeing the person in the patient' resonated positively with all participants:

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

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

CONCLUSION

This article has shown that the language of research and policy clearly does not translate well into the everyday language of healthcare professionals and support staff in hospital. It is important to use terms carefully. There is a time and place to use academic and technical language (and being clear and rigorous about what we mean by it). It is extremely important that we use 'everyday' language if we want to mobilise hospital staff at all levels of the health service, and enable them to share a sense of common purpose addressing all six dimensions of patient-centred care.

The words that resonate with people at all levels of the organisation seem to be the ordinary, human words for care such as dignity, understanding and comfort, rather than management speak and policy jargon, which can be seen as imposed on the hospital staff from outside. ●

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