

How is patient-centred care understood by the clinical, managerial and lay stakeholders responsible for promoting this agenda?

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Accepted for publication

19 January 2004

Keywords: patient-centred care, policy implementation

Abstract

Aims and objectives This study explores how the term patient-centred care is understood, particularly by those who are involved in translating the concept from a theoretical idea into a practical application. It examines the ways in which intermediate level stakeholders such as health service managers, educationalists, professional leaders and officers of patient bodies understand and promote patient-centred care among health professionals actually delivering patient care.

Design Qualitative interview study.

Setting and participants Interviewees were drawn from groups and organizations from four categories: health agencies and regulatory bodies, Royal Colleges and other professional bodies, educational institutions, patient and user groups and consumer organizations.

Main variables studied The meanings and understandings of patient-centred care, commitment to implementing patient-centred care and barriers and opportunities to implementation.

Results and conclusions Patient-centred care covers a range of activities from patient involvement in individual care to public involvement in health policy decisions. Current Department of Health policy has made patient-centred care a priority, but has not clarified exactly what it means. Thus, health professionals, educationalists, managers and patient representatives have all developed different meanings of patient-centred care to reflect their own particular backgrounds and roles. The individual aspects of patient-centred care have been neglected in policy terms and important research findings have not been incorporated into policies to change the attitudes and behaviours of health professionals. Developing a shared understanding of patient-centred care which encompasses all its components is an important role for the new Commission for Patient and Public Involvement.

Background

'Patient-centred care' has become a ubiquitous phrase in National Health Service (NHS) policy

documents, in modernization plans for the service, in managers', health professionals' and politicians' public statements.¹ The development of patient-centred care has taken place against a

background of social, organizational and professional changes. These include challenges to traditional medical paternalism, the rise of consumerism in health-care and increased access for patients to information on health.² The resulting panoply of initiatives covers activities ranging from individual encounters between patients and health professionals to major organizational changes in local and national health institutions.

Among the recent organizational changes made in the name of increasing patient-centred care are the Commission for Patient and Public Involvement and stakeholder councils in new Foundation Hospitals.^{3,4} Pre-dating this a considerable body of academic research has evolved which addresses the minutiae of relationships between patients and professionals and explores ways to achieve a more equal, patient-centred approach to decision-making.^{5,6} Much of this work has focussed on general practitioners and has generally neglected the non-medical professions involved in patient care. This is an important gap given the trend for nurses and others to take on tasks previously performed only by doctors. Moreover, research on general practitioners in training suggests that the development of a theory of patient-centred care has had only limited impact on clinicians' encounters with patients in practice.⁷

Aims and objectives

The extent to which the concept of patient-centred care affects the relationship between health professionals and patients at ground level is not known. This study aimed to explore how the idea of patient-centred care is understood, particularly by those who are involved in translating the concept from a theoretical idea into a practical application.²

Prior to finalizing the research design, two key underlying ideas were defined which refined the precise objective within the overarching research aim. First, one of the areas for exploration was the ways in which 'patient-centred care' was understood. Background

research showed that there are a range of definitions of patient-centred care in the literature which typically include aspects such as patients' needs, wants and preferences, the need to share information and involvement in decisions between patients and professionals and the need for a wide understanding of the patient's world.⁸ However, the range of understandings in the literature also includes activities along a continuum from organizational initiatives to involve the public in service design and planning to the individual interactions between patients and health professionals. At the start of the study it was decided that the particular focus of our research would be at this latter level of individual relationships between clinicians and patients.

Secondly, underlying our approach is a concept of a policy implementation pathway linking central policy-makers (such as politicians and civil servants at the Department of Health), through intermediate level stakeholders (such as officers in professional bodies, health service managers, educationalists in medical and nursing schools and user representatives) to health professionals (doctors, nurses and others) on the ground who actually deliver health-care. Our sample was drawn from intermediate level, although we recognize that the boundaries between the categories are not always clear and that policy making is not a one-way process. From the above context we further refined the objective of this study: to examine the ways in which intermediate stakeholders such as health service managers, educationalists, professional leaders and officers of patient bodies understand and promote patient-centred care among health professionals actually delivering patient care.

Methods

Our research aims and objectives were exploratory and it was decided that qualitative methods would be the best way to elicit the full range of views from a theoretical sample made up of respondents at the intermediate level we had identified.

Sample selection

We used theoretical sampling to identify the 'intermediate level' groups from which our respondents would be drawn. A list was drawn up of all the relevant organizations or types of organizations. Choices had to be made about which organizations to contact, so a combination of explicit conceptual and pragmatic decisions were made. Key factors included the need to include a range of medical specialties and to encompass health professionals other than doctors. Both professional and regulatory bodies were included. Patient and user groups were chosen to span a number of different conditions. Most of the national organizations were London-based and for pragmatic reasons, it was decided to confine the sample of educational institutions to London also. For conceptual reasons, we included organizations responsible for both undergraduate and postgraduate training for medical, nursing and other health professionals.

The final sample was drawn up to reflect all these considerations. It spanned the range of user and health professional organizations operating at the intermediate level as previously defined. In each case the chief executive or equivalent of the organization was contacted by letter which included brief details of the study. The recipient was asked to pass the letter on to another individual if they considered them more appropriate potential respondents. A further element of 'snowball sampling' was included, as interviewees were all asked to suggest other potential participants. The groups from which the interviewees were drawn are shown in Table 1.

Data collection

We conducted 47 semi-structured interviews of *c.* 1.30 h each during the early part of 2002. These included five preliminary interviews, which allowed us to refine the interview questions and the composition of our sample. Guide questions were developed to reflect the key areas of interest – the meanings and understandings of patient-centred care, commitment to implementing patient-centred care and barriers and

Table 1 Groups and organizations from which interviewees were drawn (number of interviews in each category are shown in brackets)

Health agencies (including the Modernisation Agency, the Commission for Health Improvement, and the National Institute for Clinical Excellence) and regulatory bodies such as the United Kingdom Central Council for Nursing, Midwifery and Health Visiting (UKCC) (10)
Royal Colleges (including General Practitioners, Nursing, Obstetricians and Gynaecologists, Paediatricians, Pathologists, Physicians, Psychiatrists and Surgeons) and other professional organizations (including Occupational Therapists and Health Visitors) (15)
Educational institutions – medical, nursing and midwifery schools and organizations responsible for postgraduate clinical training of health professionals from all backgrounds (12)
Patient and user groups and consumer organizations including the National Schizophrenia Fellowship, the Alzheimer's Society, Carers UK, the National Asthma Campaign, the Cystic Fibrosis Trust and the Consumers' Association (10)

opportunities. One researcher (RG) conducted all the interviews. The interviews were recorded and transcribed and a field diary was kept. The key interview questions are shown in Table 2.

Data analysis

The content of all the interview transcripts' was initially analysed by one researcher (RG), according to the constant comparative method.⁹ Patterns and themes in respondents' accounts were identified and a number of key themes emerged. The results followed the categories

Table 2 Key interview questions

What is meant by 'patient-centred care'?
How is patient-centred care understood by key stakeholders? Before being asked this question, respondents had already been informed that the focus of the study was at the individual rather than the organizational end of the patient-centred care spectrum
Is there a commitment to promote patient-centred health-care?
What is currently being done to forward patient-centred care?
What are the barriers to the provision of patient-centred care?

implied in the guide questions listed above. In particular, from respondents' different understandings of patient-centred care a typology of meanings emerged which reflected respondents' professional backgrounds. The results were further refined through systematic reading and comparison of all the transcripts and a search for disconfirming evidence. A proportion of the interview transcripts was also read blind by a second researcher (DF), in order to provide an independent view. There followed an iterative process during which preliminary results were presented more widely to the steering and reference groups and further refined consequent to their comments. Membership of these groups included academics, members of user groups, health service managers and policy-makers.

Box 1 The diversity of meanings of patient-centred care

'Patient-centred care, yes, what does it mean? I think my role is to find out'

Health agency, chief officer

If it's not a relationship, if it's not a partnership between professional and patient, it's not going work, the patient is not at the centre ... the professionals brings the technical expertise, and what the patient brings is the individual experience. You need both to be acknowledged to make it successful for the patient

Patients' organization officer

'I keep them informed'

Senior officer of a medical Royal College

'Patient-centred care involves engendering confidence in me and having a relationship with a patient'

Senior officer of a medical Royal College

'You need to ask people. Care may be provided with the patients' best interests in mind, and with the best will in the world, but if you don't ask them how do you know?'

User group organization officer

'They have to be able to tell their story. The system needs to be designed around the people, not around professional organizations'

Patients' organization officer

Results

The diversity of meanings of patient-centred care

There was a considerable diversity in understandings of patient-centred care (Box 1). Several respondents talked about the notion placing the patient at the centre of the care process, but what exactly this meant was not well-articulated. Even among professionals working to promote patient-centred care, its meaning was not necessarily clear. Several interviewees highlighted the importance of health-care relationships as 'partnerships'. This understanding of patient-centred care encompassed the need for shared information and decision-making between patient and health professionals. Despite the vagueness as to the meaning of patient-centred care, two distinct strands of meaning emerged, which tended to vary according to the professional affiliation of respondents. Those drawn from health professional groups were more likely to adopt a medical model of patient-centred care, with professional priorities determining patients' needs. Thus, definitions of patient-centred care from these respondents reflected the need for health professionals to inform patients and engender trust in patients. In contrast, respondents from user groups often described patient-centred care in the context of a social or whole person model of health. However, despite stressing the need for good communication, often what user representatives described were ideas for patient involvement in the planning and delivery of services rather than individual face-to-face encounters.

Re-branding existing activities as patient-centred care

Following from the diversity of understandings of patient-centred care, there was a tendency for the different groups to re-brand existing activities within their own areas of professional training and service delivery as 'patient-centred care' (Box 2). This happened in three main areas of communication skills, quality assurance and public participation.

Box 2 Re-branding existing activities as patient-centred care

'I always try to make sure they (patients) understand what is being said to them'

Medical teacher and consultant

'A lot of marks go on how they (medical students) interacted ... how they extracted the information'

Medical school dean

'Patient-centredness is about the outcomes of care, the humanity of care, the quality of care, the patient's experience – all those things that matter to patients'

CHI Officer

'Quite a lot of college business is not something that desperately needs a lay perspective'

Senior officer of a Royal College

'We would involve patients in drawing up our guidelines'

Senior officer of a Royal College

Communication skills

Educators of health professionals collapsed patient-centred care into the teaching of communication skills. Whilst there is no doubt that communication and consultation skills are crucial components of patient-centred care, they are not the whole of it. Good communication skills are central to eliciting information from patients but research has also defined a second vital component of patient-centred care which is the negotiation of shared decisions.⁶ Our work confirms that this second function tends to be neglected. Whilst educators were describing their *teaching* practices they tended to focus on communication skills. However, in some cases when describing their own *clinical* practice they talked more broadly about sharing power and decision-making with patients, thus reflecting a wider understanding of patient-centred care than they brought to their teaching practice.

Quality assurance

Among respondents who were primarily managers of health services, meanings of patient-centred care were often vague and did not tend to reflect concerns such as shared decision-making in clinical encounters. For this group perceptions of patient-centred care were

grounded in quality assurance and tended to focus on easily measurable activities. Where more specific understandings were given, they included clean wards, staff courtesy, food quality and waiting time. These partly reflect concerns often raised in patient satisfaction surveys, but clearly not reflecting the totality of patient concerns.

Public participation

At a central policy level, patient-centred care has been mainly understood as public participation in health services and policy. This applies at the level of central policy initiatives such as patient advocacy, patient advice and liaison services and patients' forums in NHS trusts. This understanding was also reflected by participants particularly from Royal Colleges, albeit with a limited view of the extent to which patient perceptions should influence decisions. Although public involvement is part of a more democratic service, and may lead to increasingly patient-centred approaches to service delivery, it remains distinct from what goes on in face-to-face encounters between patients and clinicians. The relationship between activities at the two ends of the spectrum is not clear.

Barriers to change

The final theme to emerge was what respondents described as barriers to patient-centred care, based on insights and experiences from working in and with the service (Box 3). Barriers (and opportunities) were identified in three main areas – professionals' attitudes, resources and social divisions.

Attitudinal change

Patient-centred care may require a redistribution of power between professionals and patients. The extent to which this has happened in practice is not known. Our research revealed awareness that wider changes were influencing the relationship between patients and professionals. From users' viewpoints there was also evidence of professionals' reluctance to change, even after events such as the Bristol Inquiry,¹⁰

Box 3 Barriers to change

'We will never go back to that state where there was unrivalled trust in medicine'

Nursing and Midwifery Council Officer

'Health professionals have changed very little, even after Bristol. Doctors and nurses, their agenda is to hold on to their power base'

User group, senior officer

'We can talk about how to provide a more patient-centred service, but then I have to get through a clinic bursting at the seams with patient appointments, and the best I can do is simply get through them'

Senior officer, Royal College

'We have about 25 000 asylum seekers, we have tuberculosis levels which are the same as Ethiopia, we are 150 General Practitioners down – patient-centred care in the east of London, it's a laugh. Basically it's just crisis management'

Medical consultant

'Patient-centred care is very sporadic when you are dealing with individuals who are disempowered in every other aspect of their lives'

Midwife

'How can we provide patient-centred care if we cannot even speak directly to our patients?'

Nurse teacher

which are seen as landmarks in the relationships between professionals and patients.

Resources and structures

There was a strong theme among health professionals that patient-centred care could not be furthered in the present climate of underfunding, low staffing levels and low morale. Patient-centred care is seen as expensive in an already overstretched service, although some strands of research have specifically explored this issue and demonstrated that changes can be made within limited resources.¹¹

Social divisions

The lack of financial resources was cited as a particular barrier among patients who are socially disadvantaged or from different minority backgrounds. Respondents also cited social, linguistic and cultural attributes as additional

barriers to achieving the shared understanding of health and health-care which is needed for patient-centred care and shared decision-making.

Discussion

The above findings should be interpreted in the light of certain limitations. A frequent criticism of this type of qualitative work is that the sample of respondents is not statistically representative. However, it did span the range of user and health professional organizations operating within the theoretically defined sampling frame. Furthermore, this research is unusual in that it specifically looks at managerial, lay and non-medical clinical inputs into the patient-centred agenda. These perspectives are generally neglected but are crucial for its implementation. Thus, there may be a scope in future for more systematic, quantitative research with these groups but the present work provides an essential starting point.

Dieppe and Horne warned against use of the phrase merely as a sound bite and noted that the failure adequately to define the concept might lead to its misinterpretation and inappropriate use.¹² Our research suggests that this is indeed what is happening. The concept of patient-centred care is complex and contested. This has certain consequences. Inevitably, different groups and individuals tend to focus on different aspects, reflecting their own professional roles and interests. Implementing a policy such as patient-centred care requires patients and professionals to feel ownership of the concept, so this process of refining the meaning to fit individual views may be necessary. However, the variety of understandings of patient-centred care among respondents also reflects a lack of clarity and leadership from policy-makers, despite their widespread use of the term. There is also interesting evidence of a divergence of views between clinicians and managers. This relativistic view has been problematic. In the first place the diversity of views meant that the individual players did not have an awareness of the full range of activities comprising patient-centred care, with the danger that important aspects were

missed out altogether. Furthermore, the use of the term made by policy-makers and the general thrust of policies has focused on systems and organizations rather than on what actually happens at the level of individuals. What is missing is a clear recognition among policy-makers, managers and health professionals in the service of the full spectrum of potential activities which constitute patient-centred care, from public involvement to individual interactions.

The emphasis from policy-makers on the organizational rather than the individual end of the spectrum seems paradoxical given that only a minority of patients will ever be involved in the planning and organization of services but virtually all will come into contact with health services at an individual level. It may be that policy-makers see this individual end as a clinical matter more properly the concern of clinicians and health professionals than of managers. As a result policy is not reflecting important evidence on patient involvement. The findings of this study highlight a gulf between the increasing literature on shared decision-making and our respondents' understandings. The new Commission for Patient and Public Involvement has been presented as one means of encompassing this whole spectrum at policy level, but it remains to be seen how it will achieve this.³ An important role for the new Commission will be to ensure that the growing body of academic research on patient-centred care, which focuses largely at the individual end of the spectrum, is reflected more in policy developments to change the culture of the service and the attitudes and behaviour of health professionals. Such changes need to be mediated through exactly the same groups as provided our interviewees – educationalists, professional leaders, policy-makers, managers and user groups. Until a more complete understanding of patient-centred care is accepted, the further development of patient-centred care mediated by these professionals is unlikely. The Commission should clarify the different meanings and develop a shared

understanding which encompasses the full range of activities.

Acknowledgements

The work on which this paper was based and supported by the Edgar Lawley Foundation. Author would like to thank all the interviews who gave their time to this project.

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