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Patient perspective

‘How do we find the right patients to consult?’

Charlotte Williamson MA DPhil
Member Board of Trustees, Picker Institute Europe, Oxford, UK

ABSTRACT

Health professionals are urged to consult ‘patients’ about the quality of services and care. But different individuals who come into the category ‘patient’ can have markedly different levels and kinds of knowledge and experience, and can hold conflicting views. This paper looks at two sets of factors that contribute to making the patient side of health care puzzling or confusing. One is the ‘structure’ of the patient side of health care or the differentiation of knowledge and experience within it. The other is a radical/non-radical dimension that is probably independent of the ‘structure’. Comparisons between ‘patients’ and healthcare professionals can help clarify these points.

Keywords: non-radical, patient, patient group, patient representative, radical

How this fits in with quality in primary care

What do we know?
Consultation with patients and users of services is seen as important in providing evidence and support for change and improvement.

What does this paper add?
This paper describes how and why views of services users may vary between patients, patient groups and patient representatives and also between those with radical or non-radical views. It provides a theoretical and practical basis for seeking patient views on health services and care.

Introduction

Health professionals increasingly accept that patients’ views on the quality of the services provided are important and that high-quality care comes from marrying patients’ and professionals’ perspectives.[1] The UK government encourages health professionals to seek patients’ views on various aspects of provision and its quality.[2] Patients do not all think alike, nor do they judge quality in the same way, any more than health professionals do. So the question of which patients to consult can be puzzling. Here I look at two aspects of the patient side of health care that are little understood and make for uncertainty and confusion. The first is the ‘structure’ of the patient side and the distribution of knowledge among its three constituent parts – patients, patient groups and patient representatives.[3,4] The second is a radical/non-radical dimension that contributes to differences of view within each of these three parts. This sounds complicated; but if we compare the patient side of health care with the professional side, similarities and differences make the question in the title easier to answer.

The structure of the patient side of health care

Some patients live through episodes of patienthood, that is, periods in which they are in clinical relationships with healthcare professionals, without wanting to consider healthcare matters further. Others engage with the health service in patient groups or through voluntary or paid work in which they are expected to speak for patients' interests. The variations in knowledge, experience and perspective that develop among what are often just called 'patients' make for much of the difficulty in knowing which 'patients' to consult. 'Patients' cannot always be lumped together, any more than 'health professionals' can, yet they have no certificates to say that they are qualified to be one sort of 'patient' rather than another. But the significance of the variations in their knowledge can be seen by comparing that knowledge with that of health professionals, for example doctors.

All individual doctors have three different kinds or levels of knowledge and expertise. At a first level, they have experience of doctoring almost every day, of giving treatment and care, of day-to-day problems and issues in the health service that affect them. This is personal, 'concrete' knowledge. At a second level, they know about their own specialty – general practice, ear, nose and throat (ENT) surgery, etc. They are familiar with its scientific basis, its accepted standards of care, its problems, its aspirations, the views of colleagues, and the issues and controversies current in the specialty. This is a blend of personal and theoretical knowledge. At a third level, they know about the general ethical and moral stances, the values, the interests and the ideology of the whole profession. This is mostly theoretical, abstract knowledge. These three kinds or levels of knowledge overlap and reinforce each other. Most doctors can draw on any of them at will. In discussions and when asked their views on any issue, they can glide easily from the concrete to the abstract, summoning up argument and evidence to suit whatever level of discourse they are engaged in. Personal experience, the views of colleagues, the latest findings from research, the ethical principles that direct professional action, can be intermingled, according to the topic and to the doctor's point of view and purpose. This, the result of training, experience and study, is a great strength of doctors. It gives them an integrated core of shared knowledge and collegiality that enables them to speak broadly for the interests of their fellow doctors and their profession, even though they may disagree amongst themselves sometimes, just as any group of people does.

By contrast, on the patient side of health care these three kinds and levels of knowledge are not always, or even usually, found in the same person. Instead of being integrated within each individual, they are often split between different individuals: patients, patient group members and patient representatives.[3,4] So we can say that 'patients' (the term here for all three categories together) or the patient side of health care are structurally split.

Individual patients usually operate at the first level. They know about and can describe and judge their own experience of health care. Indeed, they are the only people who can. They can also raise points of satisfaction or concern, sometimes new ones. But they cannot speak for other patients' views or interests; they seldom know what they are. Nor do they usually know what standards for treatment and care should be. They cannot speak, either, about aspects of policies or practices that they have not consciously experienced, although these may have affected their treatment or care for better or for worse.[5] These limitations make it easy to discredit individual patients' views as 'unrepresentative', even when other patients would agree with them, were they asked. But 'unrepresentativeness' safeguards patients collectively, since it prevents undue weight being given to the views of just a few, perhaps isolated, individuals.

Patients' experiences and views about the organisation of their care and the performance of their doctor, nurse, etc are best elicited collectively, through samples for surveys or interviews. About 25 completed surveys will sometimes suffice, though sampling methods need care.[2] Much depends on exactly what questions are asked; there is a tendency to avoid some issues that are important to patients, like their doctor's competence.[2] There is also a tendency to avoid patients who are known to have had distressing experiences, though that excludes potentially valuable information and insight.

Patient group members usually operate at the second level, if they are active members. They know about the experiences and views of other patients like themselves. They know what standards for care should be and which policies, practices and issues are controversial. They may draw up sets of standards they want to see implemented. Patient groups are equivalent to specialties in clinical medicine. Their limitations are the same as those of other specialists: a narrow though deep range of knowledge. Like other specialists, they sometimes hold idiosyncratic views or convictions that seek to limit the treatments available to patients.[6,7] So it is important to consult all relevant patient groups in a locality about plans to develop or reduce services and about standards of treatment and care. No groups should be dismissed as 'biased' merely because their views do not concur with those of health professionals. Consultations should usually take the form of discussions or working parties made up of patient group members and health professionals, in roughly equal numbers.[3]

Patient representatives or advocates usually operate at the third level. They have often developed knowledge and gained experience in several patient groups and in 'patient'–professional committees or working parties. They have a general and abstract knowledge of the interests that all patients have in common. They can explain the 'patient perspective' on major issues like confidentiality, consent and information, issues where professional definitions and views tend to differ regularly from those of patients. They study accounts and surveys of patients' experiences and views and try to keep in touch with some patient groups and patients. They read patient group and professional journals. They are the nearest equivalent of health professional 'representatives' at regional and national level in the royal colleges and professional associations. Neither 'representative' speaks for the views of 'ordinary' patients or of 'ordinary' health professionals, but both speak for their respective interests. The limitation of patient representatives is that, though they can apply theoretical principles to situations, they may lack both the recent personal experience of patients and the detailed specialised knowledge of patient group members. So they may not always be able to identify problematic issues. But patient representatives should be consulted about strategic, ethical and policy matters and changes to patterns of care. They are scarce; but two or three patient representatives in a larger group of health professionals can be enough to speak for patients' interests, based on evidence and argument, just as health professionals should speak for professional interests.[3]

The structural split described reflects the weakness of the patient side of health care.

To compensate for the split, all consultations with 'patients' ideally should involve all three categories. This may sometimes be difficult to organise. But provided that 'patients' are matched to the nature and level of the consultation and that suitable methods of eliciting their views through research or through discussion and debate are used, consultations can be conducted satisfactorily.[3]

Radical/non-radical

Another set of factors that can lead to confusion and uncertainty is a radical/non-radical dimension that runs through both the patient and the professional sides of health care. To be radical is to uproot accepted assumptions and to see beneath the apparent meaning of things.[8] To be non-radical is to accept as non-problematic the prevailing or dominant ideas, beliefs, policies, and practices, the status quo.[8,9] Some health professionals adopt radical positions on some issues because of a personal or professional experience.[10] Some 'patients' do the same. But health professionals may find it harder to identify 'patients'' positions than those of fellow professionals. Radical patient groups challenge majority or dominant views, beliefs and ethics further than non-radicals do.[11] Radical 'patients' disagree sometimes (not all the time) with the prevailing views both of health professionals and of non-radical 'patients'. Sometimes these views starkly conflict. Sometimes they concur but for different reasons. Examples of a non-radical and a radical approach to the issue of referral management illustrate this point.

Referral management is the scrutiny of general practitioners' (GPs') referrals by a third party with the power to pass them on to the named specialist in secondary care, or redirect them to another specialist in secondary care, or to pass them back into primary care.[12–14] It has been opposed by some GPs and hospital specialists for various reasons, including its threat to doctors' clinical freedom and its potential for undermining trust in general practice.[13] In spite of opposition, it is being introduced in some parts of the country. 'Patients' were not consulted before the scheme was introduced, but the chief executive of a patient organisation, the Skin Care Campaign, has published an excellent article opposing it.[15] He argues that referral management will delay patients' access to diagnosis and treatment by dermatologists and that GPs who lack the training and experience necessary to make prompt and accurate diagnoses of complex and difficult skin diseases cannot safely be substituted for dermatologists.[15] Dermatology could be undermined as a specialty.[15] Second guessing GPs' decisions about referrals insults them and removes 'patient choice' as promoted by the government.[15] He also co-signed a letter to *The Times* from doctors pointing out the risks to patients and to the future of dermatology.[16] His views are non-radical: they support the status quo, as it recently was; and they oppose the scheme with the same arguments that very many doctors would use. Indeed, similar cases against referral management could be made for all secondary care specialities.

The same conclusion, that referral management is undesirable, could also be reached by more radical arguments. First, the decision to refer a patient should be a shared decision between patient and GP. It is a negotiation in which each is free to request a referral or to refuse it. Each acts autonomously, respecting the autonomy of the other, in coming to that shared decision. The process may be brief and implicit. The patient may accept the doctor's advice so readily that the decision may appear to be the doctor's only. Nevertheless, the patient's autonomy, not just the doctor's, is denied when a third party, not present at the consultation, overrides that shared decision, even if confirming it. Second, issues of patient consent to a third party, not directly involved in that patient's care, having access to clinical information about him or her, seem not to have been considered. Who the reviewers will be and whether the patient will be told their names; to whom the reviewer will be accountable if delays or errors in diagnosis occur; how the patient can contest the reviewer's decision; and whether the reviewer will have access to the patient's electronic health record in future, are other issues to do with patient autonomy as well as with patient safety and confidentiality, that also seem to have been largely disregarded, even by doctors criticising the scheme. Third, and paradoxically, an aspect of referral that worries patients – whether their GP will fail to refer them when they should be referred – will be untouched by the scheme, which deals only with referrals made.

These arguments are radical because they focus on the implications for patients, especially for patient autonomy, in ways that doctors opposing the scheme mostly have not. They challenge any assumption that a referral is simply a matter of a doctor's decision, whether the patient's doctor or a reviewing doctor. In addition, patients have not agreed that there should be three people in the relationship between them and their GP. This is a major change of which many patients will be unaware. Nevertheless, patient autonomy is a value subscribed to in medical ethics. So here, radical arguments can complement rather than conflict with non-radical arguments.

Alternatively, radical and non-radical views can clearly conflict. Then they may evoke intense and prolonged resistance. The controversial issues of whether GPs should be entitled to remove patients from their practice list without prior notice, and of whether home births should be available, have long histories and have generated much discord.[17,18] Radical views, however, can alert professionals to new issues or to new trends in patients' perceptions, expectations and values; they can offer new insights that can help professionals develop their practice; and they can help move health care forward in ways that meet society's values and norms. Moreover, what is considered radical today, can become accepted and commonplace tomorrow. So although radical views can be uncomfortable, they should not be deliberately avoided when seeking patients' or patient groups' or patient representatives' views. Like radical professional views, they contribute to the vitality and development of health care.

Identifying 'patients'

Patients can be sampled in various ways, depending on the purpose of the consultation. Lists of local patient groups can be obtained from Councils of Voluntary Service. Patient representatives are harder to find, but national patient groups and the patient liaison groups of the royal colleges and professional associations may be able to give the names of knowledgeable and experienced individuals, or advertising locally may produce applicants who can be shortlisted and selected after interview.[19]

Conclusion

The patient side of health can seem puzzling. Its structural split and its conflicts of views contradict the idea that the 'right' patient exists somewhere, if only he or she could be found. Patients' views are of fundamental importance. But they cannot entirely substitute for patient groups' and patient representatives' contributions, based on other kinds and levels of knowledge. Again, a radical/non-radical dimension probably informs many of the views of all three categories of 'patient'. This needs to be recognised and accepted. The patient side of health care is complex but not mysterious. Consulting the 'right' patients can be feasible and rewarding.

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CONFLICTS OF INTEREST

None.

ADDRESS FOR CORRESPONDENCE

Charlotte Williamson, Dalby Old Rectory, Terrington, York YO60 6PF, UK. Tel: +44 (0)1347 888 244; email: charlotte@wmsn.freeserve.co.uk

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