

The scope for the involvement of patients in their consultations with health professionals: rights, responsibilities and preferences of patients

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Abstract

The degree and nature of patient involvement in consultations with health professionals influences problem and needs recognition and management, and public accountability. This paper suggests a framework for understanding the scope for patient involvement in such consultations. Patients are defined as co-producers of formal health services, whose potential for involvement in consultations depends on their personal rights, responsibilities and preferences. Patients' rights in consultations are poorly defined and, in the National Health Service (NHS), not legally enforceable. The responsibilities of patients are also undefined. I suggest that these are not to deny, of their own volition, the rights of others, which in consultations necessitate mutuality of involvement through information-exchange and shared decision-making. Preferences should be met insofar as they do not militate against responsibilities and rights.

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Introduction

Over the past quarter of a century, societal support has grown for demands that patients be involved collaboratively in the delivery of health care.^{1–3} Scepticism about medicine and medical care, a preference for improved therapeutic relationships, an increasing shift from acute to chronic ill-health^{4 5} and a narrowing gap between doctor competence and patient knowledge⁶ have contributed to growing social acceptance of the importance of patient involvement in health and health care. In response, recent National Health Service (NHS) reforms have situated patients' demands in a framework of health care managed according to market economic principles mediated in theory by patient choice. This paper suggests an approach to conceptualising the scope for patient involvement in consultations with health professionals.

The patient as co-producer

Patients have been viewed as principal primary health care workers' who deal with most of their own illness most of the time. When professionals are consulted, patients can be viewed as the main beneficiaries of the care they produce in concert with health professionals.⁸ Within consultations, co-production of health care takes place because recognition and management of problems or needs requires involving both the patient and the health professional. Patients' inputs include their manner and attitude, information, and preferences. Technical knowledge resides principally with the professional. Both parties can best contribute to patient care through mutual participation,^{9 10} based on responsibilities^{11–14} and shared decision-making.¹⁵ Co-production of care is based on joint respect¹⁶ and integration of the major interests of patients and professionals, and of other groups such as society.¹⁷

Patient involvement

The scope for patient involvement is based on the rights, responsibilities and preferences of patients. According to the Oxford English Dictionary, "to involve" is to cause to share in an experience or effect. Patient, or user, involvement is what patients do *as* patients. This paper emphasises patients' involvement in consultations where, as co-producers, they help to define the quality of care, and report information on their own health care experiences.⁸ Terms such as "participation" convey the same meaning. In contrast, public involvement emphasises the involvement of lay people as taxpayers who may or may not have special knowledge of the subject under discussion. They may be involved in standard setting, and service development and evaluation for the common good.

Vehicles of public involvement in the NHS include community health councils, Local Voices (an initiative of health authorities) and patient

participation groups.¹⁸ Complementing these “top-down” groups are “bottom-up” groups such as self-help groups and voluntary groups.⁵ Some writers^{19, 20} have distinguished “public action”, defined as activities initiated and controlled by bottom-up groups for purposes determined by them, from the “public involvement” of top-down groups that may seek support for decisions already made and consult on issues yet to be decided. However, this paper focuses only on patient involvement in consultations, and suggests that it can be defined by the rights, responsibilities and preferences of patients.

Patient rights

Involvement by patients is an exercise of their democratic right to influence or not their formal health care, for which they pay through taxation.²¹ The nature of the right to involvement depends on *prima facie* claims that must be met unless competing moral obligations necessitate balancing them to avoid or minimise conflict. Actions that override rights may be justified (infringements) or unjustified (violations). This distinction implies that claims have been defined, and are accepted and enforceable as rights. However, in the UK, patients have no contractual entitlements under NHS agreements.

Charters have been of little proven benefit in ensuring patient rights in consultations. The NHS Patient’s Charter²² for example, states merely that before deciding whether to agree to any proposed treatment, all patients have the right to receive a clear explanation of the treatment, including any risks and alternatives. In September 1995, NHS guidelines were produced for involving patients in local patients’ charters,²³ so that these charters would become relevant to the needs of those whose care they were intended to improve.²⁴ Involvement by patients as well as staff in determining standards and priorities in British general practice has been reported to be feasible.²⁵

However, none of the charters has provided patients with legally enforceable rights in health care²⁶ or is likely to benefit patients “living in conditions of partial citizenship ... who lack the means to negotiate for their own health”.²⁷ Consequently, charters have been reported to provide a poor mechanism for patient involvement *per se*¹⁸ and to be frequently a public relations exercise.²⁸ They have also prompted concern that government league tables will be used to label some practices, including those without charters, as poor performers.²⁹

Patient responsibilities

In legal terms, since patients have no contractual entitlements to NHS care, professionals cannot claim that patients have contractual duties or responsibilities in health care.²⁶ Nevertheless, the longstanding notion that patients have responsibilities is supported by the ethical tenets of non-maleficence, beneficence and justice, and by the concept in civil law of contributory negligence. The concept of patient responsibility has also acquired political currency from the recent drive towards user involvement in decision-making about care and from developments associated with need and demand for primary care services. For example, the 1996 doctor-patient campaign and, more recently, patient leaflets produced by the Royal College of General Practitioners have highlighted the need for increased responsibility by patients when considering use of general practice care. The NHS Patient’s Charter²² suggests how patients can help the health service by acting responsibly but the suggestions do not explicitly refer to consultations.

These initiatives emphasise access, services and self-care rather than patient involvement and responsibilities in consultations. The nature and the scope of these responsibilities have not been clearly defined or agreed in declarations on health care delivery³⁰⁻³² and in health services literature.¹¹⁻¹⁴ This may be because such undertakings could be perceived to be paternalistic, a direct threat to patient autonomy and driven by a desire to contain costs.³³ However, I believe that defining the boundaries of patient responsibilities can both respect patient autonomy and benefit society by setting limits on the abuse of personal choice. Therefore, I wish to suggest that patients have responsibilities for (non)involvement in consultations where two conditions are met: (1) the consequences do not deny the rights of others, and (2) patients are personally accountable for the level and nature of their own involvement.

The first condition demonstrates how patient responsibility cannot be separated from protection of the rights of others. This nexus is “untidy” however because one use of the term, responsibilities (or obligations, requirements or duties, with which the term, responsibilities, is sometimes interchanged) is what we “ought to do”. Such “oughts” are personal ideals that are not required by morality and are neither based on nor generate corresponding rights that other people can claim. Therefore, linking rights and responsibilities requires attention to the context in which each takes place.

In addition, if a particular form of *involvement* would deny the rights of others, the responsibility is to avoid involvement based on a negative responsibility for non-maleficence.³⁴ Where *non-involvement* by patients would deny other's rights, there is a positive responsibility for involvement based on obligatory beneficence. In each situation, patients have a responsibility not to deny others essential elements of their humanity and moral agency; the responsibility is *to* others rather than *for* others.³⁵

In patient-professional consultations, this means that patients have responsibilities to avoid both "consumerist" interactions,³⁶ in which professionals merely provide information and implement patients' preferred interventions^{14 15} and "paternalistic" interactions, in which professionals take total responsibility for decisions and outcomes of treatment. To protect the rights of the patient and professional, each party has a responsibility for mutuality of involvement and control. This necessitates that both parties collaboratively define and manage the patient's problems and needs through agreements that each party endorses and is obligated to uphold.

Second precondition

The second precondition of patient responsibility is that patients, as well as professionals, be accountable for their own contributions to decisions resulting from consultations. This precondition legitimises a more equal relationship between professionals and patients. It may limit patient autonomy but, I wish to suggest, the needs of society must trump those of the individual. Patients should be accountable for choices made against professional advice (for example choices that deny others' rights) that affect the wellbeing of society.

Before patients can be held accountable, they must have access to formal care and the practical freedom not to deny the rights of others. This freedom depends on their abilities to recognise responsibilities, identify and evaluate alternative responses, and follow decisions once made on the basis of adequate resources. In reality, patients do not always have the resources to act responsibly, and their concepts of the nature and severity of problems, their health needs, and their views of appropriate health-seeking and utilisation behaviour might not accord with those of professionals. Little congruence has been reported, for example, between the attitudes of patients and professionals on responsibilities for controlling insulin-dependent diabetes mellitus.³⁷ Psychological stress may also absolve patients from accountabil-

ity for their actions (hence the legal concept of diminished responsibility).

Patients need access therefore to information and other resources in order to support future choices and share responsibility for them.³⁸ Both patients and professionals must be educated to respect each other's needs, preferences, capabilities and constraints, and to collaborate in search of agreements that promote not merely individual health but also the public health for the common good. Professionals may aid patient involvement and responsibility through strategies including treatment decision aids, multimedia interactive programmes and co-production of, and access to, personal health records.

Patients are already held accountable through limitations on their access, in terms of cost and coverage, to private health insurance.³³ Moreover, rationing is implicit in the referral system, and other expensive and cash-limited services and procedures are not offered to some patients whose lifestyle choices contradict professional advice and reduce the likelihood of personal benefit.³⁹ I favour such rationing only where there is evidence that intervention is more costly than non-intervention and where it denies intervention to others whose likelihood of benefit is, by comparison, greater. Patients are not accountable in law for many personal health choices that harm others, but patients may be held accountable in terms of their own, and others', sense of morality.

Demands for patient accountability invite the accusation of "victim blaming".⁴⁰ Nevertheless, wrong-doing is not necessarily deserving of blame, as demonstrated by the case of strict tort liability.⁴¹ Indeed, accountability may be positive and tantamount to praiseworthiness. Attributions of freedom and responsibility to patients are potentially empowering when prospective rather than retrospective.³⁸ The foregoing discussion emphasises patients' personal responsibilities to others, including professionals and other patients. There is, by comparison, less agreement on whether patients have responsibilities to themselves and, if so, whether abrogation of these affects claims to health care.

Patient preferences

Patient preferences, where they exist, are informed by prior experiences, clarification of values and awareness of personal needs. The involvement of patients is influenced by their knowledge of rights and responsibilities and their abilities to form and articulate preferences within limits defined by characteristics of professionals, the unequal nature of the patient-professional relationship and the health service. Patients may

also need to negotiate solutions to conflicts between preferences and responsibilities. However, many professionals fail to make explicit the "rules of consultation"⁴² and to resource patients to engage in such dialogue. Many patients eschew an active role in consultations unless the provider initiates one,⁴³ and professionals therefore have an obligation to clarify and address patients' information needs.

Patients may form preferences for information-sharing that differ from those for their style of decision-making. For example, in patient-centred consultations, where patients' view are actively sought⁴⁴⁻⁴⁵ patients may take a passive role in decision-making by wanting the professional to make the final decision on treatment, at least when they have a serious illness.⁴⁶ Other patients want to help make decisions,⁴³ albeit under conditions that include having the knowledge required for full participation,⁴⁷ being able to assign different values to alternative outcomes when there is more than one appropriate treatment option,⁴⁸⁻⁴⁹ and not anticipating or fearing regret after making a decision.⁵⁰

Patients who favour minimal involvement in decision-making may feel pressure nevertheless to participate actively in this process,⁵¹ which would suggest a need for individualised care.⁵¹ Wilson⁵² has suggested that what patients want should prevail unless they have given the professional a mandate to decide for them. However, as noted above, for professionals to accept this responsibility, as wanted by some patients,⁴⁷⁻⁵³ is to put a potentially unfair burden on professionals and to deny patients' moral agency.³⁵

Conclusion

In the UK, the government and medical profession have placed on centre-stage the issue of patients' growing expectations of and demands for health care. The general message has been that patients' rights are not unlimited and should be exercised responsibly. However, this message has focused largely on patient access in primary care and no party has defined appropriate involvement by patients in their consultations with professionals. This paper has suggested that patients are co-producers of formal health care whose potential for involvement in consultations depends on their rights, responsibilities and preferences. Patients have responsibilities not to deny others' rights in ways for which they can be held accountable. This responsibility necessitates mutuality of involvement in consultations, including information-exchange and shared decision-making. In the NHS, patient rights and responsibilities are based on ethical rather than contrac-

tual entitlements, and may legitimate preferences which should be accommodated insofar as they do not militate against the responsibilities and the rights of others.

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News and notes

European Group on Ethics in Science and New Technologies

The European Commission has set up a European Group on Ethics in Science and New Technologies in succession to its previous group of advisers on the ethical implications of biotechnology. The members of the new group are: Mme Noelle Lenoir, France; Ms Paula Martinho da Silva, Portugal; Professor Stefano Rodota,

Italy; Dr Anne McLaren, UK; Professor Marja Sorsa, Finland; Mr Octavi Quintana-Trias, Spain; Professor Peter Whittaker, Ireland; Professor Ina Wagner, Austria; Professor Göran Hermeren, Sweden; Professor Gilbert Hottois, Belgium; Professor Dietmar Mieth, Germany, and Professor Egbert Schrotten, The Netherlands.