

The Doctor–Patient Relationship

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The essential unit of medical practice is the occasion when, in the intimacy of the consulting room, or sick room, a person who is ill, or believes him- or herself to be ill, seeks the advice of a doctor whom he or she trusts. Such meetings are a frequent and regular occurrence, with over half a million consultations occurring between general practitioners and their patients in the UK every working day and a large number also taking place at a hospital level. Their success or otherwise depends not only on the doctors' clinical knowledge and technical skills, but also on the nature of the social relationship that exists between doctor and patient.

This chapter first examines the general societal expectations that influence the behaviours of doctors and patients in the medical consultation. It then describes some of the conflicts that can be experienced by doctors and different forms and determinants of the relationship between doctors and patients. Finally, the chapter examines the new partnerships that are developing involving shared treatment decision-making between doctor and patient and considers technical aspects of communication including new sources of information and decision aids.

SOCIAL ROLES OF DOCTORS AND PATIENTS

Parsons (1951) was one of the earliest sociologists to examine the relationship between doctors and patients. His interest arose from a broader theoretical concern with how society is able to function smoothly and respond to problems of deviance. Parsons regarded social functioning as partly achieved through the existence of institutionalized roles with socially prescribed patterns of behaviour. We are, therefore, all aware how people are likely to behave when they occupy the role of father, teacher, shop assistant, and so on, and of their expectations of us when we occupy the complementary role of child, pupil or customer. Parsons regarded illness as a form of social deviance because it impairs normal role performance and, if it occurs on a large enough scale, the smooth functioning of society (e.g. families caring for children, educational system, transport system, etc.) will be put at risk. Parsons believed that the amount of illness is controlled through the socially prescribed roles for doctors and patients, which facilitate interaction, and ensure both parties work together to return people to a state of health and normal role performance as quickly as possible.

■ Parsons' model of the sick role and doctor's role

Parsons' description of the roles of doctor and patient is presented as an 'ideal type' model. This abstracts and presents what are regarded as the fundamental features of a particular social organization or social role and is an important method of analysing and describing very complex social phenomena. Parsons depicted the role of sick people as involving four general expectations. First, sick people are allowed, and might even be required, to give up some of their normal activities and responsibilities, such as going to work or playing football. Second, they are regarded as being in need of care. These two expectations and privileges are, however, contingent on the sick person fulfilling the third obligation of wanting to get well as quickly as possible, and the fourth of seeking professional medical advice and, most importantly for the doctor–patient relationship, cooperating with the doctor (Table 4.1).

Parsons points out that the specific expectations of the sick person, such as the number and type of activities the person is expected to give up, will be influenced by the nature and severity of the condition. It is also recognized that not all illness requires people to relinquish their normal social roles and occupy the status 'sick'. For example, much minor illness is coped with without recourse to the doctor and does not require any changes to a person's everyday life (see Chapter 3). Similarly, people with a chronic illness might need to consult the doctor regularly, but rather than occupying a permanent sick role they are generally expected to try to achieve their maximum level of functioning and to occupy the status 'sick' only if they experience a change in their usual health. Parsons thus viewed the sick role as a temporary social role that has been instituted by society with the aim of returning sick people to a state of health and restoring them to fully functioning members of society as quickly as possible. The sick role is also regarded as a universal role, in that its obligations and expectations apply to all sick people, whatever their age, gender, ethnicity, occupation or status in other spheres.

Parsons viewed the role of the doctor as complementary to the role of patient. Just as the patient is expected to cooperate fully with the doctor, doctors are expected to apply their specialist knowledge and skills for the benefit of the patient, and to act for the welfare of the patient and community rather than in their own self-interest. Doctors are also expected to be objective and emotionally detached, and to be guided by the rules of professional practice. Conformity with these general expectations is an essential requirement for carrying out the tasks of diagnosis and treatment, especially when this involves the need to know

TABLE 4.1 Parsons' analysis of the roles of patients and doctors

Patient: sick role	Doctor: professional role
<p>Obligations and privileges:</p> <ol style="list-style-type: none"> 1. Must want to get well as quickly as possible 2. Should seek professional medical advice and co-operate with the doctor 3. Allowed (and may be expected) to shed some normal activities and responsibilities (e.g. employment and household tasks) 4. Regarded as being in need of care and unable to get better by his or her own decisions and will 	<p>Expected to:</p> <ol style="list-style-type: none"> 1. Apply a high degree of skill and knowledge to the problems of illness 2. Act for welfare of patient and community rather than for own self-interest, desire for money, advancement, etc 3. Be objective and emotionally detached (i.e. should not judge patients' behaviour in terms of personal value system or become emotionally involved with them) 4. Be guided by rules of professional practice <p>Rights:</p> <ol style="list-style-type: none"> 1. Granted right to examine patients physically and to enquire into intimate areas of physical and personal life 2. Granted considerable autonomy in professional practice 3. Occupies position of authority in relation to the patient

Reprinted with permission from The Free Press from Parsons (1951).

intimate details about the patient that are not usually shared between strangers or the conduct of an intimate physical examination. Parsons also viewed doctors as enjoying considerable autonomy in executing their professional skills and occupying a position of authority in relation to the patient.

Parsons' analysis identifies the general expectations that guide the behaviour of doctors and patients, and shows how these roles facilitate interaction in the consultation, as both parties are aware how each other is expected to behave. The institutionalized roles of sick person and doctor also function to reduce the potentially disruptive effects of illness in society. This is partly achieved through the role of the doctor in officially legitimating illness and acting as a gatekeeper to the sick role, thus preventing inappropriate occupancy and enjoyment of the privileges of the sick role, such as time off work or financial benefits, when this is not justified by the patient's medical condition. In addition, the expectations placed on both doctors and patients ensure that people who are officially sanctioned as sick are returned to a state of health and normal role performance as quickly as possible (see Chapter 13).

■ Conflicts in the doctor's role

Although Parsons' analysis emphasizes the consensual nature of the roles and relationships between doctors and patients, in reality, tensions and strains often exist. One set of tensions arises from conflicts between doctors' own values and those of some of their patients. This is particularly likely to occur in relation to abortion, homosexuality, AIDS and other conditions or behaviours invested with moral evaluations. There are also conflicting

demands placed on doctors in terms of their requirement to act in the best interests of their patients and their duty to serve the interests of the state. As Parsons recognized, doctors serve the state as agents of social control in their role as gatekeepers to the sick role with authority to determine who is 'healthy' and who is 'sick', but also have an obligation to act in the best interests of individual patients. When patients request, or even demand, a sick note, problems can arise for the doctor in determining whether disease exists and the designation of 'sick' and privileges of the sick role can be justified. For example, back pain is the major reason for time off work but it is often difficult to determine its cause or severity except by relying on patients' reports, which could present problems in evaluating the legitimacy of their claims to the sick role. In such situations of uncertainty, should doctors give priority to the interests of the patient, or to their societal function in ensuring that people do not malingering or occupy the sick role inappropriately? Similarly, should doctors inform the licensing authority if they are aware that a patient diagnosed with epilepsy is driving a car and thus contravening the state's regulations, even if they know how important it is for the patient to drive, and should doctors inform patients who are thinking of being tested for human immunodeficiency virus (HIV) of the potential problems of being diagnosed as a carrier for insurance premiums when this might discourage testing?

A further source of conflict for doctors arises from the competing interests of individual patients and the wider patient population. For example, doctors are often involved in rationing scarce resources of staff time, beds and medical equipment and might have to decide which patients should be given a transplant or undergo other medical procedures, as well as the priority to be assigned to treating different cases. In the absence of clear and explicit criteria, such choices rest on the judgement of individual clinicians. A recent illustration is the decision made by some consultants not to administer tests and carry out coronary artery by-pass surgery on people who continue to smoke. This is based on the argument that scarce resources should not be spent on people who smoke, as such people have longer hospital stays and less chance of recovery than non-smokers, and treating them deprives patients who have never smoked or who have stopped smoking. However, such reasoning raises questions of how far the notion of culpability and self-inflicted ill health should extend. For example, what is the situation in the prescribing of nebulizers to asthmatic smokers and the treatment of drunken victims of road accidents?

Doctors can also experience conflicts between maintaining the confidentiality of the doctor-patient relationship and disclosing information to a patient's parent or spouse. This raises the question of whether medical confidentiality is absolute or whether there are any situations when interests are best served by passing on information about a patient. For example, are there any circumstances in which a doctor at a clinic should disclose that a patient has acquired immunodeficiency syndrome (AIDS), or is positive for HIV, when this is against the patient's wishes? Such situations frequently pose dilemmas for doctors and raise questions concerning their primary duties and responsibilities, as well as possibly presenting conflicts in relation to their own beliefs and values. However, there are powerful arguments to support the view that priority should be given to maintaining the confidentiality of the doctor-patient relationship. In particular, this has the benefit of preserving patients' trust in doctors and their willingness to consult and discuss their problems freely in the future; destroying this trust undermines the very foundation of the relationship between doctor and patient.

■ Psychosocial and clinical outcomes

The social interaction between individual doctors and patients is a major determinant of the success of the consultation in terms of both patients' and doctors' satisfaction

with the encounter and the clinical outcomes achieved. For example, although information communicated by patients is central to diagnosis and treatment decisions, unless patients feel at ease and are encouraged to talk freely they might not disclose problems that are troubling them, or express their worries and concerns. Indeed, it is well known that some patients who feel very embarrassed or worried about a problem will initially present with a condition that does not give rise to these feelings and forms a 'ticket of entry' to the consultation. Whether such patients disclose the real problem that is troubling them, or whether this remains 'hidden', often depends on what they perceive as the general atmosphere of the consultation and the opportunities for discussion. It is also estimated that about 10% of patients do not have their prescription filled by the chemist, which suggests that the consultation might not have been successful in identifying these patients' problems or resulted in treatment that was unacceptable to the patient.

Patients' satisfaction with the consultation depends on their perception of the doctors' interpersonal and clinical skills, and might in itself have a positive effect on the pain and other symptoms experienced. For example, a longitudinal study of patients attending neurological clinics for the diagnosis and treatment of severe headache showed that, for half the patients seen, the main factor related to a reduction in symptom severity was the patients' satisfaction with the initial consultation. Of particular importance was being given information and advice they felt was relevant to their worries and which enabled them to make sense of their symptoms and achieve a sense of control over their illness (Fitzpatrick et al 1983). Similarly, a series of randomized control trials of patients with diabetes mellitus, hypertension and peptic ulcer, indicated that the amount of emotion (positive or negative) expressed by doctor or patient, and the quality of information sought by patients and given by doctors, formed important influences on patients' functional capacity and physiological measurements on follow-up, and their satisfaction with care (Kaplan et al 1989). Another beneficial effect of the social relationship between doctor and patient is what has been termed the 'placebo' effect (which literally means 'I will please'). This is calculated to account for as much as one-third of the success of any drug (Beecher 1955). To take account of this healing effect, trials of new drugs often involve the administration of an inert substance to a control group for comparison.

The social interaction between doctor and patient can also influence doctors' own feelings of satisfaction. For example, failure to elicit patients' worries and interpretation of symptoms can sometimes lead doctors to believe that patients have consulted inappropriately and that their time and skills are being wasted. This can be illustrated in relation to consultations for childhood respiratory conditions, which account for 30% of all consultations for children aged below 11 years. Many of these consultations are for a condition that is 'trivial' from a biomedical perspective. However, a study of mothers who had consulted their general practitioner for this reason revealed that their decision to consult was often due to fears that their child would experience long-term chest damage, or even die from choking in phlegm or vomit or through an asthma attack or cot death, and there was also a common belief that antibiotics were required to break up the phlegm (Cornford et al 1993). Eliciting and addressing such lay beliefs could avoid potential conflicts and enhance doctors' job satisfaction, as well as promoting the quality and effectiveness of patient care.

TYPES OF DOCTOR–PATIENT RELATIONSHIP

The significance of the social relationship between doctor and patient for the clinical, psychosocial and behavioural outcomes of the consultation has resulted in considerable attention being given to the various forms and determinants of this relationship. Whereas

Parsons identified the general societal expectations that guide the behaviour of doctors and patients, his portrayal of an asymmetrical relationship in which the doctor occupies the dominant position by virtue of his or her specialist knowledge and the patient merely cooperates (a 'paternalistic' relationship), is viewed as only one possible form of relationship between individual doctor and patient. Other forms arise from differences in the relative power and control exercised by doctors and patients (Table 4.2). In reality, these different models perhaps do not exist in pure form, but nevertheless most consultations tend towards one type.

■ Models of the doctor–patient relationship

A paternalistic (or guidance–cooperation) relationship, involving high physician control and low patient control, describes Parsons' model where the doctor is dominant and acts as a 'parent' figure who decides what he or she believes to be in the patient's best interest. This form of relationship traditionally characterized medical consultations and, at some stages of illness, patients derive considerable comfort from being able to rely on the doctor in this way and being relieved of burdens of worry and decision making. However, medical consultations are now increasingly characterized by greater patient control and relationships based on mutuality.

A relationship of mutuality is characterized by the active involvement of patients as more equal partners in the consultation and has been described as a 'meeting between experts', in which both parties participate as a joint venture and engage in an exchange of ideas and sharing of belief systems. The doctor brings his or her clinical skills and knowledge to the consultation in terms of diagnostic techniques, knowledge of the causes of disease, prognosis, treatment options and preventive strategies, and patients bring their own expertise in terms of their experiences and explanations of their illness, and knowledge of their particular social circumstances, attitudes to risk, values and preferences.

A consumerist relationship describes a situation in which power relationships are reversed; with the patient taking the active role and the doctor adopting a fairly passive role, acceding to the patient's requests for a second opinion, referral to hospital, a sick note, and so on.

A relationship of default can occur if patients continue to adopt a passive role even when the doctor reduces some of his or her control, with the consultation therefore lacking sufficient direction. This can arise if patients are not aware of alternatives to a passive patient role or are timid in adopting a more participative relationship.

Different types of relationship, and particularly those characterized by paternalism and mutuality, can be viewed as appropriate to different conditions and stages of illness. For example, in emergency situations it is generally necessary for the doctor to be dominant, whereas in other situations patients can be more actively involved in treatment choices and

TABLE 4.2 Types of doctor–patient relationship

Patient control	Doctor control	
	Low	High
Low	Default	Paternalism
High	Consumerist	Mutuality

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other decisions regarding their care. However, considerable variation in the nature of the relationship between doctor and patient cannot be explained entirely in terms of the patient's medical condition, but is also influenced by the expectations of doctor and of patient and the structural context of the consultation.

■ Influences on the doctor–patient relationship

A major determinant of the nature of the doctor–patient relationship and the extent and forms of communication within the consultation is the doctor's clinical practice style. Two polar types of consultation style have been identified, based on video-recordings of consultations; these have been designated 'doctor-centred' and 'patient-centred' (Byrne & Long 1976).

A doctor-centred consultation is characterized by the traditional Parsonian model and paternalistic approach, based on the assumption that the doctor is the expert and the patient merely required to cooperate. Doctors adopting this approach focus on the physical aspects of the patients' disease and employ tightly controlled interviewing methods to elicit the necessary medical information. Questions were thus mainly of a 'closed' nature, such as 'how long have you had the pain?' and 'is it sharp or dull?'. These questions aim to provide information to enable the doctor to interpret the patient's illness within his or her own biomedical disease framework, while providing little opportunity for patients to express their own beliefs and concerns.

At the other end of the continuum are doctors whose consultation style conforms to a 'patient-centred' approach. These doctors adopt a much less controlling style and encourage and facilitate their patients to participate in the consultation, thus fostering a relationship of 'mutuality'. An important feature of this approach is the greater use of 'open' questions, such as 'tell me about the pain', 'how do you feel?' and 'what do you think is the cause of the problem?'. This approach also requires that doctors spend more time actively listening to patients' problems through picking up and responding to patient cues, encouraging patients to express their own ideas or feelings, clarifying and interpreting patients' statements, and generally using a more participative style with the various options presented and discussed with patients.

Studies show that individual doctors can be classified fairly consistently as holding either doctor-centred or patient-centred consultations. This suggests that doctors develop a particular consulting style and do not vary this significantly in relation to the patient's problems. However, doctors classified as having a patient-centred style tend to be the most flexible, showing the greatest ability to respond to differences in patients' needs or the circumstances of the consultation.

These differences in communication style reflect not only doctors' communication skills but also differences in their attitudes and orientations to the medical task. Doctors who hold a strictly disease-centred model talk in terms of what has been referred to as the 'voice of medicine' (Mishler 1984). They thus focus almost exclusively on the objective description of physical symptoms and the classification of these within a reductionist biomedical model, with the aim of reaching a differential diagnosis as quickly as possible and prescribing appropriate treatment. By contrast, doctors taking a more patient-centred approach aim to understand patients' own illness framework in terms of their subjective experience and meanings of illness, to identify possible psychosocial causes of illness onset and the impact of chronic and disabling illness on the patient's self concept and everyday activities, and to understand patients' beliefs, priorities and preferences for treatment (Box 4.1). This approach to the medical task requires that the doctor listens to the 'voice of the patient', and facilitates and encourages the patient's active involvement in the consultation and communication of his or her beliefs, feelings and the psychosocial context of their illness experience.

BOX 4.1 Key aspects of a of patient-centred consultation

- Biopsychosocial perspective (willingness to become involved in the full range of difficulties patients bring to their doctors and not just their biomedical problems)
- Patient-as-a-person (understanding the individual's experience of his or her illness)
- Sharing power and responsibility (mutual participation of patient and doctor)
- Therapeutic alliance (creating a situation in which the patient feels able to be involved in treatment decisions)
- Doctor-as-a-person (doctor is aware of and responds to patient cues)

From Mead & Bower (2000).

Influence of time

General practice consultations average about 6 minutes, although this obscures wide variations, with the actual length of consultations ranging from about 2 minutes to over 20 minutes. Pressures of time encourage a more tightly controlled doctor-centred (or 'paternalistic') consultation with less attention paid to the social and psychological aspects of a patient's illness. As a result, fewer psychological problems are identified and more prescriptions are issued (Howie et al 1992). However, the doctor's own approach to medicine and practice style appears to exert a more important influence on the content of consultations than the time available. This was demonstrated by an experiment in general practice in which the time available for consultations was increased to 10 minutes (Ridsdale et al 1992). As a result, all doctors asked more questions. However, other skills, such as facilitating patients to participate and explaining the nature of their medical problem, were employed more frequently only by those doctors who already emphasized these aspects of communication. Doctors who usually employed these behaviours least frequently tended to do more of what they already did, such as asking closed questions, rather than changing their style of communication, and did not usually take advantage of the extended consultation time available. By contrast, general practitioners with a more patient-oriented approach often preferred to run over time, and possibly kept other patients waiting if they felt it was necessary to spend additional time with a particular patient. These doctors might also deliberately restrict their list size, so that they can provide what they regard as good-quality care. This suggests that the length of time available for consultations is itself partly a function of practice style, as well as the pressures of time serving to constrain the consultation. However, although a more participative, patient-centred consultation does require greater time, giving sufficient time to listen and respond to patients' worries and concerns can reduce the number of return visits and hence the total consultation time for an episode of illness.

Patient characteristics and behaviours

Although having less power than doctors in the consultation, patients can nevertheless influence the interaction by their willingness or otherwise to ask questions and assume a more participative role. It appears that younger people are more likely to expect a relationship of mutual participation than elderly people. Patients with a high social and educational level also tend to participate more in the consultation in terms of asking questions and asking for explanations and clarification than patients from a lower socioeconomic background and educational level. This possibly reflects their greater knowledge and confidence and the smaller status gap between doctor and patient. For

example, a study of 1470 general practice consultations showed that only 27% of working-class patients sought clarification of what the doctor had said, compared with 45% of middle-class patients. These requests for information by patients in turn led to fuller explanations being given by doctors and a rather longer consultation (Tuckett et al 1985). However, despite these differences, patients' desire to participate in the consultation generally increases over the course of an illness as they gain more knowledge and understanding of the condition. Thus patients are often passive and unquestioning during initial hospital consultations, whereas by the second or third consultation they generally initiate questions themselves and take a more participative approach.

Interaction in the consultation and the information and explanations provided by doctors has been shown to reflect their assumptions of the interests of different patient groups (Street 1991). For example, there is some evidence that doctors volunteer more explanations to some groups of patients, including more educated patients and male patients, even when the explanation is not explicitly requested by the patient. Some patients can therefore be doubly disadvantaged; because of both their passive communication styles and the doctor's (mis-) perceptions of their informational needs and desires.

Influence of structural context

A particular feature of general practice is the opportunity for personal continuity of care, with doctors and patients often knowing each other over a long period. Consultations therefore often take place in a familiar context and can benefit from the doctor's prior awareness of the patient's social situation, past history and concerns. By contrast, patients rarely experience this personal continuity in a hospital situation. In addition, communication on the ward is frequently limited by patients' feelings of a lack of privacy and difficulties of interaction can arise if the doctor or medical team stand at the end of the bed rather than coming close to and preferably sitting at the same level as the patient.

The content of consultations is also influenced at a macro level by the system of financing of health care. Consultations financed on a fee-for-service basis generally occupy a longer time and doctors' practice style is more patient-oriented than when they are paid on a per capita or salaried basis. This is because a fee-for-service payment is often associated with a greater availability of resources, there is less institutional pressure to achieve a high patient throughput, and doctors feel a greater need to achieve a high level of patient satisfaction. Patients who are paying on a fee-for-service basis also tend to expect a longer consultation and a full discussion with the doctor and are frequently more active in asking questions.

PARTNERSHIPS IN TREATMENT DECISION MAKING

■ Models of decision making

One aspect of the doctor–patient relationship that is now receiving particular attention is the roles of doctors and patients in treatment decisions. Three main models of medical decision-making – paternalist, shared and informed decision-making – correspond with the three main types of doctor–patient relationship (Table 4.3). The traditional paternalist model regards the doctor, as medical expert, as solely responsible for treatment decisions with the patient expected merely to cooperate with advice and treatment. By contrast, relationships of mutuality regard shared decision-making as the ideal. This requires that both parties are involved in the decision-making process, share information, take steps to build a consensus about the preferred treatment and reach agreement (consensus) on the treatment to implement (Box 4.2).

TABLE 4.3 Models of treatment decision-making in a doctor–patient dyad

Analytical stages		Paternalistic (intermediate)	Shared (intermediate)	Informed
Information exchange	Flow	One way (largely)	Two way	One way (largely)
	Direction	Doctor → patient	Doctor ↔ patient	Doctor → patient
	Type	Medical	Medical and personal	Medical
	Amount ^a	Minimum legally required	All relevant for decision-making	All relevant for decision-making
Deliberation		Doctor alone or with other doctors	Doctor and patient (plus potential others)	Patient (plus potential others)
Deciding on treatment to implement		Doctors	Doctor and patient	Patient

^a Minimum required.

BOX 4.2 Four Requirements for Shared Decision making

1. Both doctor and patient are involved in the decision-making process
2. Both parties share information
3. Both parties take steps to build a consensus about the preferred treatment
4. An agreement (consensus) is reached on the treatment to implement

Based on Charles et al (1999)

A third model, the informed model, involves a partnership between doctor and patient based on a division of labour. Initially, the doctor communicates to the patient information on all relevant options, and their benefits and risks, so as to enable the patient to make an informed treatment decision. Information transfer is therefore seen as the key responsibility and only legitimate contribution of the doctor to the decision-making process, with the deliberation and decision-making being the sole prerogative of the patient. This model thus forms the extreme opposite of the paternalist model and, in some cases, patients might have decided on a broad course of action before entering the surgery and press the doctor to cooperate.

In practice, the three models of treatment decision-making described by Charles et al (1999) often do not exist in pure form and they therefore allow for intermediate approaches. For example, a variant of the traditional paternalist model, sometimes referred to as the ‘professional as agent’ model, describes a situation where the doctor continues to assume responsibility for directing the healthcare utilization of the patient but makes the treatment decision, assuming either that he or she knows or has elicited the patient’s preferences for future health states, life choices, and so on. In addition, it is acknowledged that a clinical encounter can often involve a hybrid of elements of more than one model. For example, a consultation might initially be characterized by a two-way information exchange between doctor and patient but, if problems arise in achieving a shared decision, the clinician might then use the power imbalance in the relationship to persuade the patient to follow his or her advice, often with a promise of a subsequent review of the situation. This is illustrated by

Waissman (1990), who describes the initial process of negotiating to reconcile doctors' and patients' choices regarding the use of home or hospital dialysis for children with renal disease, and also shows how the doctor's decision and choice of home dialysis was later renegotiated by parents and other arrangements made if they continued to have difficulty in managing the dialysis at home. Another mixed scenario occurs where a doctor who favours a shared decision-making model thinks, as the interaction proceeds, that the patient has gained enough confidence and gathered enough information to make the decision on his or her own. At this point, the process might shift from a shared to an informed model as a result of the learning that has occurred during the interaction itself.

■ Shared decision making and treatment choices

The rights of patients to be involved in making informed choices about their health care, including the requirement that informed consent should include a discussion of treatment options, has been endorsed by the NHS reforms of 1991 and the Patient Partnership strategy (NHS Executive 1996). This endorsement of shared decision-making in medical care has been encouraged by the interaction of a number of social and medical factors. One influence has been patients' increased medical knowledge, which has been made possible by the greater access to medical information through the media, internet and other sources. In addition, prevailing social values endorse individual autonomy and responsibility, with younger patients thus having a greater desire to take personal control, although a consumerist ideology also engenders more critical attitudes to medical and other services (Coulter 1997).

Another impetus for shared decision making comes from the increasing prevalence of chronic illness in the population. This means that patients are often required to manage their illness on a long-term basis, taking responsibility for monitoring symptoms and adjusting their treatments, with this being facilitated by a more equal partnership with doctors in the management of the illness. In addition, for many conditions it is necessary to make choices between treatment options and to balance the various risks and benefits (both short- and long-term), often in situations of considerable medical uncertainty (Logan & Scott 1996). This has been associated with considerable variations in professional decision making and supports the view that patients should contribute their preferences and priorities directly to this process. Moreover, there is evidence that doctors frequently make inaccurate guesses about patients' concerns, and that doctors' and patients' preferences and treatment choices often differ, although the direction of these differences varies for different conditions. For example, studies of cardiovascular conditions suggest that patients are more averse to drug treatment than health professionals and would prefer higher thresholds for beginning antihypertensive treatment, because they value the benefits of this treatment less than doctors do and are more distressed about side-effects. By contrast, patients often wish to receive prescriptions for upper respiratory tract infections in situations where doctors regard this as inappropriate (Montgomery & Fahey 2001). Similarly, studies conducted in the USA, where surgical rates are relatively high, indicate that some informed patients with mild symptoms resist prostatectomy and hysterectomy in situations where these procedures are advocated by specialists. A greater patient voice and shared decision making does not, therefore, necessarily increase demands on services and could ensure that resources are employed more appropriately and increase the effectiveness of care.

Shared decision making has received particular emphasis in relation to the prescribing of drug treatments. Traditionally, studies have identified that about 50% of patients with chronic conditions do not take their treatment as prescribed, with major reasons being

because they do not share the doctors' view of the appropriateness of the drugs prescribed, or are worried about immediate side-effects or possible long-term harmful effects of the drugs. The aim is to explore these issues by adopting a shared decision-making approach and to reach a 'concordance' between doctor and patient (Box 4.3). Achieving concordance does not necessarily mean that both parties are convinced that a particular drug or other course of action is the best possible treatment for the patient. In some situations, where both parties have differing preferences and views, they might achieve concordance and endorse a particular treatment as part of a negotiated agreement. In particular, this could occur when there is not a true situation of equipoise (equipoise occurs where options really are options) as for example in the demand for antibiotics to treat viral infections. In this case, although a 'shared decision' is reached, it could more accurately be described as an informed decision that reflects the doctor's preference (Gwyn & Elwyn 1999). However, in such situations the concordat reached can then be reviewed at subsequent consultations and changes agreed. What is important is that both parties participate in communicating their views, concerns and preferences and share responsibility for the final decision. The aim of concordance in relation to prescribing decisions is thus to achieve the best use of medicines compatible with what the patient desires and is capable of achieving, rather than the traditional approach of imposing a medical decision that the patient can challenge only through non-compliance after they leave the consultation.

■ Patients' preferences for participation

The emphasis on shared decision-making model raises questions of whether and when patients desire to be involved in this way. This has been found to depend partly on a patient's state of health; patients in crisis situations or who feel weak or distressed might prefer to have decisions made for them rather than being more actively involved. Differences in the desire for involvement also reflect the complexity of treatment choices. For example, studies of patients with breast cancer and with colorectal cancer identified 20% of the former and 4% of the latter preferring an active role in terms of making their own treatment decisions, with 17% of patients with colorectal cancer and 28% of patients with breast cancer preferring to share responsibility with the doctor for deciding which treatment was best for them. However, 78% of patients with colorectal cancer and 52% with breast cancer preferred to leave the decision to the doctor, although generally wanting the doctor to consider their opinion (Beaver et al 1999). The higher proportion of patients with breast cancer wishing to be actively involved in decision-making might reflect the clear treatment choices with little impact on survival, as well as the younger age of these patients. These differing desires for involvement identify a key challenge for health professionals: to be sensitive to individual patients' needs. However, most patients desire information about their condition and treatment, even if not wishing to actively participate in treatment decisions.

BOX 4.3

Concordance

'Concordance is based on the notion that the work of the prescriber and patient in the consultation is a negotiation between equals and that the aim is a therapeutic alliance between them. This alliance may, in the end, include an agreement to differ. Its strength lies in a new assumption of respect for the patient's agenda and the creation of openness in the relationship, so that both doctor and patient together can proceed on the basis of reality and not of misunderstanding, distrust or concealment.' (Marinker 1997, p 8)

DOCTORS' COMMUNICATION SKILLS

Doctors frequently overestimate the amount of information they have provided to patients, and also believe that patients are satisfied with the communication they received during a consultation, as it is difficult for patients to convey dissatisfaction in the consultation. However, the most common complaints about doctors by patients and the public relate to communication, and particularly that doctors do not listen, will not give information and show a lack of concern or lack of respect for the patient. As a result, large numbers of patients leave the consultation without asking questions about things that are troubling them or do not receive what they regard as a satisfactory response. A recent qualitative study based on 35 patients aged 18 years and over consulting 20 general practitioners, found that only four of the 35 patients voiced all their concerns during the consultation (Barry et al 2000). The most common voiced concerns related to symptoms, requests for diagnoses and prescriptions. The most common unvoiced concerns were worries about possible diagnosis and what the future holds, ideas about what is wrong, side-effects, not wanting a prescription, and information relating to social context such as housing, work or social networks. Concerns that were not raised often led to specific problem outcomes, such as major misunderstandings, unwanted prescriptions, non-use of prescriptions and non-adherence to treatment.

■ Content and process skills

Patients' perceptions of inadequacies of communication arise partly from *what* doctors communicate (content skills). This refers to the substance of questions and the information gathered, including the emphasis given by doctors to understanding the patient's perspective (ideas, concerns, expectations, impact of condition on everyday life, etc.), and the treatments they discuss. The content of communication is influenced by a number of practical and situational factors (time available, initial or subsequent visit, NHS or private patient) but most importantly by how doctors perceive the nature of the medical task and their relationship with patients.

There are also questions of *how* doctors communicate (process skills). This refers to how they discover the history or provide information, the verbal and non-verbal skills they use, how they develop a relationship with the patient, and the way they organize and structure the communication, including the emphasis given to actively listening to patients, facilitating and encouraging their questions, and discussion of worries and concerns. Process skills relate to five stages and tasks of the consultation (Box 4.4). The skills required to achieve each of these stages are now taught in specialist communication courses and involve both verbal and non-verbal behaviours.

BOX 4.4 Communication Skills and Steps to be Achieved in the Consultation

1. Initiating the session (establishing the initial rapport and identifying the reason(s) for the consultation)
2. Gathering information (exploring the problem, understanding the patients' perspective, providing structure to the consultation)
3. Building the relationship (developing rapport and involving the patient)
4. Explanation and planning (providing the appropriate amount and type of information, aiding accurate recall and understanding, achieving a shared understanding and planning)
5. Closing the session

From Silverman et al (1998).

Patients are regarded as particularly sensitive to and observant of the non-verbal communications conveyed by their doctors, because illness usually involves emotions such as fear, anxiety and emotional uncertainty. Patients therefore often look for clues to assess the situation. By maintaining eye contact, looking attentive, nodding encouragingly and using other gestures, the doctor can provide positive feedback to the patient and facilitate his or her participation. By contrast, continued riffling through notes, twiddling with a pen or failing to look directly at the patient convey disinterest and result in patients failing to describe their problems or to seek information and explanation. Similarly, the patient's body language and eye contact can convey whether he or she is feeling tense, anxious, angry or upset (Lloyd & Bor 1996). Indeed, it is estimated that in a normal two-person conversation the verbal component carries less than 35% of the social meaning of the situation, and that 65% or more is carried by the non-verbal components such as eye contact, gaze, facial expression and posture. Physical proximity and the relative positions of doctor and patient in the consulting room also influence interaction. Seating of equal height and the lack of a physical barrier between participants encourage communication. This was demonstrated by an experiment in which a cardiologist removed the desk from his clinic on alternate days. When the desk was removed, 50% of the patients sat back in their chair and in at-ease positions, whereas only 10% did so when he was sitting behind his desk, with a corresponding decline in the amount of communication by patients (Pietroni 1976).

The current emphasis on shared decision making places particular demands on doctors' communication skills, because it is necessary for doctors to transfer technical information to patients about treatment options, risks and their probable benefits in as unbiased, clear and simple way as possible. This is a particular challenge in situations where the availability of reliable evidence is limited, or when decisions need to be made within the time constraints of a normal consultation. In addition, doctors might need to help the patient to conceptualize and weigh the risks versus the benefits, to share their treatment recommendations with the patient and/or affirm the patient's treatment preference, while being careful not to impose their own values about the best treatment onto the patient. Specialist training programmes are therefore being introduced to assist doctors in assimilating the philosophy and skills required for involving patients in decision making. In addition, direct doctor-patient communication is increasingly complemented by decision-boards, audiotapes, linear videotapes and computer programmes. These help to overcome the constraints of time and the demands of providing complex information in non-technical language, and might help facilitate treatment choices.

■ Special situations and groups

Particular challenges of communication and demands on doctors arise in disclosing a diagnosis of cancer and giving other 'sad or bad' news. Traditionally, doctors withheld such information for as long as possible. This was often justified as being in the patient's own interest, although maintaining a patient's uncertainty once the diagnosis was firmly based might also have been functional for doctors in protecting them from the stress associated with such disclosures. A more open approach is now generally adopted, supported by patients' desire to be informed and the effects that this can have in reducing uncertainty and promoting positive coping. For example, Jenkins et al (2001) found that 87% of hospitalized cancer patients interviewed desired all the information about their disease, good and bad, and 98% preferred to know whether or not their illness was cancer. The 13% who stated that in general they preferred to leave disclosure of details up to the doctor tended to be older patients (over 70 years of age) but they still wanted to know certain specific details. However, although the vast majority of patients with cancer want a great

deal of very specific information concerning their condition and treatment, such information must, of course, be handled sensitively and might involve eliciting and responding to patients' personal worries, such as the pain they might experience, the side-effects of treatment, how they will feel and what they will be able to do. However, the difficulties experienced by doctors in coping with patients' emotional responses mean that they often develop routinized forms of disclosure to inform patients about the diagnosis of a terminal condition, rather than responding to an individual patient's needs.

Doctor–patient communication can also present particular challenges in relation to recent immigrants and refugee groups if their command of English is poor or if they are not familiar with the organization of health care and the expectations of service providers in the NHS. In addition, doctors' lack of familiarity with different cultural beliefs regarding the causes or meanings of illness, and different beliefs about appropriate treatments, can form barriers to doctor–patient communication (see Chapter 10).

Doctors who become patients are also a group who can experience particular problems in the doctor–patient relationship. A study of recently sick doctors found that some doctor-patients complained that they were not given information about their illness or were not counselled appropriately because it was assumed that they were already adequately informed, whereas they felt a need to occupy a more usual patient role and for the treating doctor to provide relevant clinical information and discuss their illness as they would with any other patient (McKevitt & Morgan 1997). Other doctor-patients thought they were too involved in the decision making and management of their illness because the treating doctor was unable to take control of the consultation. Some also commented that their doctor seemed embarrassed to treat them, with these problems being most common where the treating doctor was of a lower grade or younger than the patient. Most doctors commented that they found it instructive to experience the doctor–patient encounter from the patient's perspective and some suggested that this transformed their professional sympathy into empathy.

CHANGES IN THE DOCTOR–PATIENT RELATIONSHIP

The increasing size of general practices, together with the greater involvement of nurses, health visitors, counsellors and other health professionals in the provision of primary care, means that continuity in terms of the relationship between an individual general practitioner and patient is increasingly replaced by relationships with different members of the primary care team. This identifies a challenge of achieving good interprofessional communication and continuity of care among members of the team to maintain the quality of interaction and provision of individualized patient care.

The philosophy of patient-centred care and the shift towards shared treatment decisions also require new methods of involving consumers in the initial development of clinical guidelines that provide a framework for practice (Wersch & Eccles 2001). Shared decision making is also being facilitated by new courses and educational interventions to enhance these skills and competencies among health professionals. Interactive and multimedia systems are also being developed to provide patients with the information they want to receive at a pace acceptable to them, and to support an individual's treatment choices with individualized data. More generally, greater access to high quality medical information on the internet will increase the numbers of 'information-rich' patients who can bring detailed and often complex questions to their doctor and desire to participate in decisions regarding their care.

A technological development with implications for the doctor–patient relationship is the widespread use of computers in the consultation. This can have a significant impact on communication, and especially on the information disclosed by patients. However, the effects

of computers have been found to be influenced by whether patients are seated in a position to have access to the computer screen, and on the doctors' ability to maintain their personal touch in terms of their verbal skills and eye contact with patients (Ridsdale & Hudd 1994). Also of increasing importance with greater computerization is the need to assure the confidentiality of patient data, thus maintaining the essential trust between doctor and patient.

A further development is the expanding use of telemedicine as a means of delivering health care. This gives rise to the increasing possibility of patients engaging in teleconsulting, often from their own homes, thus expanding access to care. However, it will also present new challenges in establishing a relationship between individual patients and healthcare providers, and facilitating their communication.

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