

# Chapter 1

## Ethics

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'Ethics' is derived from the Greek word *ethos*, meaning spirit of a community; this is the collective belief and value system of any moral community, social or professional group (Reeves & Orford 2002). Morals and values are inter-related and integral to society. The study of ethics helps one to consider what kind of things are good or bad and how to decide whether actions are right or wrong. Ethics and the law are closely interwoven, as our laws are usually based on ethics (Holland 2004).

The role of codes of practice in ethical decision making is discussed in this chapter using examples from general practice. The reader will recognise many of the examples cited in the chapter, and will probably be able to describe many more.

In order to assess the effectiveness of codes of practice in making ethical decisions in nursing, one must first consider what is meant by an ethical decision. This chapter examines the codes of practice for nurses, following a brief description of ethical principles. *The Code of Professional Conduct* (Nursing and Midwifery Council 2004) will be referred to as 'the Code', the principles of which may conflict with issues relating to power and authority in the primary healthcare setting. The Code has been reviewed and modernised, and is expected to be rolled out in January 2008 (Nursing and Midwifery Council 2007), but the main principles are unlikely to change.

Doctors and nurses may sometimes forget the rights of patients in the rush to 'get the job done', meet targets and appear efficient. This is an area that nurses can readily address and possibly share with their primary healthcare team colleagues. Informed consent, for both adults and minors, is essential if the patient is to be involved in their care and be autonomous. Patients with a learning disability pose a greater challenge in obtaining informed consent. The issues discussed within this chapter are pertinent to all areas of nursing care, and are referred to throughout the book. There is inevitably some overlap between sections, but this serves to emphasise the importance of certain issues.

The reader is directed to Beauchamp and Childress (2001) for an in-depth discussion on ethical theory.

*The Informed Practice Nurse*, Edwards, M. (2008), Chichester: Wiley.

For convenience the term 'patient' will be used in the text, although it is recognised that many people who consult the nurses are 'well people'.

## **Ethics, philosophies and codes of practice**

### *Ethical philosophies and theories*

The two main philosophies of ethical reasoning, utilitarianism and deontology, have almost diametrically opposed prime principles (Seedhouse 1998). John Stuart Mill and Jeremy Bentham propounded utilitarianism, believing that the ends justify the means and that the right action is the one that offers the greatest good to the greatest number.

Deontology (derived from the Greek word *deon*, meaning 'duty') is the theory associated with Immanuel Kant. It is based on duty and respect for the individual, who must be treated as an end in themselves and never as a means to an end. It is the action itself that is right or wrong; the consequences are less important.

When faced with a moral dilemma where there are two alternative choices, neither of which seems a satisfactory solution to the problem, a decision has to be made based on one's own moral principles and what each person believes to be right. The rules that guide thinking are known as ethical principles. The four principles of biomedical ethics listed below are discussed in depth by Beauchamp and Childress (2001).

Autonomy relates to respecting and preserving people's ability to decide for themselves.

Beneficence is the obligation to provide benefits and balance benefit against risk.

Non-maleficence refers to the obligation to avoid doing harm.

Justice is fairness in the distribution of benefits and risks.

In his text on ethical theory and practice, Thiroux (1980) outlines five ethical principles that he considers to be applicable to all spheres of life, adding honesty to the main four principles (Box 1.1).

#### **Box 1.1 Ethical principles, applicable to all spheres of life (Thiroux 1980)**

- The value of life and respect for persons
- Goodness or rightness
- Justice or fairness
- Truth telling or honesty
- Individual freedom or autonomy

### *The functions of codes of practice*

The three functions of professional codes identified by Burnard and Chapman (1988) are ethical, political and disciplinary. This section will concentrate mainly on the first of these, although the impact of the other two will be clearly shown. Codes of practice are recommended by professional organisations, as many types of human conduct are harmful, although not illegal (Seedhouse 1998).

Codes of practice are meant to inform and reassure members of the public about the quality of the professional service, as well as enhancing the public image of the individual practitioner. The purpose of the code is to inform the profession of the standard of professional conduct required of them in the exercise of their professional accountability and practice (Nursing and Midwifery Council 2004). It can be used to fight for improvements in standards, although this is not always an easy path to take, as will be seen later.

Professional codes also play a part in supporting the status of a profession. A code of conduct has been said to be one of the defining characteristics of a profession (Jaggar, quoted in Chadwick & Tadd 1992). The implication is that those within the group can be trusted to regulate their members and, if necessary, to discipline them if they fail to uphold the high standards of the code.

However, the Nursing and Midwifery Council (NMC) Code of Professional Conduct is issued for guidance and advice, laying a moral responsibility rather than a statutory duty on members of the profession (Young 1989). The Code can be used by a nurse to measure her own conduct, in the knowledge that the requirements of the Code are used by the NMC during trials of misconduct. Failure to comply with the Code may result in a nurse losing her registration. The Code of Professional Conduct is therefore a guide, a political statement and a means of regulating the profession.

### *The emphasis of the Code*

The NMC Code sets out the professional accountability of each registered nurse, midwife and health visitor working in clinical and management settings. Although the Code may have considerable influence over a nurse's resolution of ethical dilemmas, each situation for each person is unique, and is only a guide to decision making. A code may stress the most important considerations that should influence a decision, but a nurse cannot turn to the Code and expect it to provide a moral answer to an ethical problem. Nurses do not leave their moral choices behind when they are at work (Chadwick & Tadd 1992).



**Figure 1.1** Preconditions to accountability (from Bergman 1981).

The Code commits each individual nurse, midwife and health visitor to safeguard and promote the interests of both society and individual patients. It also requires that each shall act in such a way that justifies the trust and confidence of the public, and uphold and enhance the good reputation of the professions. In order for the nurse to fulfil these requirements, emphasis is placed on four main areas: knowledge, skill, responsibility and accountability; these were the basis of the principles of the Scope of Professional Practice (United Kingdom Central Council for Nursing, Midwifery and Health Visiting (UKCC) 1992).

Bergman (1981) listed four preconditions to accountability, which were almost the same as the areas defined by the Code, but also included the need for authority (Figure 1.1).

### ***Knowledge and skill***

The Code places on the practitioner the continuing responsibility to maintain and develop their knowledge, skill and competence, through self-assessment and the production of a personal portfolio. Clause 6 clearly states that each nurse must acknowledge personal limits of knowledge and skill and take steps to remedy any relevant deficits in order to meet the needs of patients; a reflection of Thiroux's principle of honesty.

The Code does not say what each nurse must learn, but acts as a guide. A nurse, faced with the dilemma of being asked or instructed to carry out a

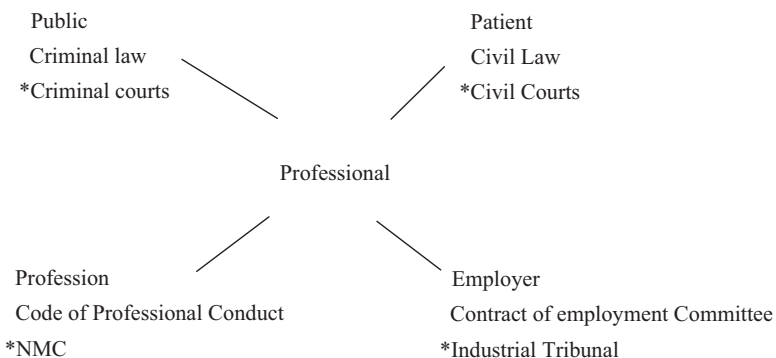
procedure that they do not feel fully competent to do has the support of clear principles on which to act.

The perception of competence can differ between a nurse and the employer (Jones 1996, p.83). This is a common situation in general practice, where the old medical adage of 'see one, do one, teach one' is often quoted. The ethical principles involved here are non-maleficence, the primacy of the patients' interest (respect for persons) and the justification of public trust. Castledine (1992) stressed that an individual nurse should feel safe and secure in their own performance before undertaking any task.

### *Responsibility and accountability*

Responsibility and accountability are closely linked, but not synonymous. Accountability is the acceptance of that responsibility, the willingness to explain one's actions and to receive credit or blame for the results of those actions (Evans 1993). One can be responsible but not accountable, though one cannot be accountable without being responsible (Young 1989). A registered nurse, midwife or health visitor is accountable to the patient, the profession, the law and the employer. This is shown in Figure 1.2, which indicates the groups to whom the registered nurse is accountable, the basis of that accountability and the authority empowered to judge the actions of the nurse in each area.

Practice nurses are developing their role in primary healthcare, often by taking over work that was previously seen as the province of the doctor. This role should develop in response to patient need and through experience gained by post-basic education. In general practice, this development has



**Figure 1.2** Areas of professional accountability.

\*represents the authority empowered to judge the actions of the nurse in each area.

resulted in nurses taking the lead in the management of chronic conditions such as asthma, diabetes and coronary heart disease. The role requires both medical knowledge and nursing skills of education, health promotion and counselling. Patients should be included in all the stages of decision making in their care, thus protecting patient autonomy (Clause 2 of the Code). However, it is all too easy to take on the medical model of treatment and cure, accepting delegation of a task, such as the application of cryocautery, from a doctor (Jones 1996, p 125). Nursing skills can be soon forgotten in the excitement and interest of new technology. Nurses who develop assessment and prescribing skills will be aware of their competencies and accountability.

The degree of accountability within a particular situation must surely be linked to the measure of authority held by the individual, as without that authority, one is not free to make an ethical decision regarding a problem (Tadd 1994). The Code does not mention this concept in relation to accountability, but insists that all practitioners are equally accountable.

### *Issues of power and authority*

In a work situation, conflict may arise between the humanist values of the Code and the authoritarian values of the organisation. Safeguarding and promoting the interests of patients and patients may or may not mean following instructions (Tschudin 1994a).

Challenging action could be considered as advocacy on behalf of a patient. An advocate is one who pleads on behalf of another, influencing those who have power for those without (Reeves & Orford 2002). This is a positive, constructive activity recommended as a role for nursing by the UKCC (1989), particularly where a person is incapable of giving informed consent. The Code, Clause 2.4, includes helping individuals access health and social care, information and support relevant to their needs. The issue of informed consent will be addressed later in this chapter.

### *The nurse–doctor relationship*

Traditionally the doctors made all decisions regarding the care of the patients, and imposed their authority over the work or decisions of other members of the team; work in which they had no particular training or skill. Modern practice has fortunately changed this relationship to one of complementary respect for roles. Chadwick and Tadd (1992) argue that where issues are of an ethical nature, the doctor has no particular expertise and should not hold power. The nurse has a responsibility to point out poor practice, to explain current thinking and, if necessary, refuse to take part in a procedure;

refusing, for example, to assist in minor surgery with unsterile instruments (see Chapter 3), or to apply a dressing that could prejudice wound healing and may cause harm (see Chapter 8).

The doctor's authority in medical matters is only legitimate if they perform correctly. The nurse must intervene if they know or suspect it to be wrong (Chadwick & Tadd 1992). In acting to safeguard the well-being of a patient (Clause 1), the nurse must be aware that although this may mean acting as the patient's advocate, they must not place themselves outside other sections of the law by refusing to co-operate with treatment that the doctor has prescribed (Young 1989, p 206).

If the problem were of a serious nature the nurse may feel it necessary, in order to protect the patient (Clause 8), to report the matter to a higher authority. This may be an informal discussion with the head of the clinical governance committee at the Primary Care Trust, if the nurse does not have a nurse manager. The probable harm, in the form of damage to team relationships, or public mistrust, should it become more widely known, must be weighed against the benefit to patient care. This has been demonstrated by the ability of Harold Shipman to cover his malpractice for so long. No one likes to make a fuss, but nurses have a responsibility to share their concerns.

### *Truth and trust*

Trust has to be earned; it places obligations on the individual nurse, not the least of which is honesty. Clause 3.1 includes the need for information to be accurate and truthful, although Reeves and Orford (2002) raise the issue of being economical with the truth, or telling white lies. Failure to be honest with a patient and answer questions relating, for example, to an incurable disease, because of a moral decision made by medical staff and/or relatives, conflicts with obligations relating to competency, consent and right to information. This is likely to destroy the relationship of trust and confidence. The responsibility to provide information rests with the practitioner and 'if something less than the whole truth is told, it should never be because the practitioner is unable to cope with the effects of telling the truth' (UKCC 1989).

### *Abuse of the individual practitioner*

Nurses have always accepted the need to do their best under difficult circumstances, even to the extent of pretending they can cope, when they clearly cannot (Pyne 1994). Clause 8.4 states that the nurse's first consideration in all activities must be the interests and safety of the patient. Nursing management has a responsibility to draw attention to inadequacy of resources

when an unacceptable workload is placed on individual practitioners (Clause 8.3).

Pyne (1992) urged nurses to support each other in the interests of the patient, but many practice nurses still work alone, so that the need for a system of peer support, with a route to senior nurses within the health authority is vital. Practice nurse forums and clinical supervision are two means of offering and sharing support (see Chapter 9). They can provide guidance to help address a problem, as peers may have dealt with similar scenarios.

The ethical principle of respect for persons applies to colleagues as well as to patients (Tschudin 1994b). Despite Clause 8.3, nurses will still feel vulnerable if they complain about colleagues, although less so if complaining about working conditions or equipment.

### *Confidentiality*

Confidentiality, in the clinical setting, implies respect for information about a patient that has been given in trust. This information will not be passed to other people without the consent of the patient, except where disclosure is required by law, or by the order of a court, or is necessary in the public interest (Clause 5). Breaches of confidentiality should be regarded as exceptional. Clause 5.1 states that the nurse should ensure that patients understand that some information may be made available to other members of the team involved in the delivery of care. Patient-held records involve the patient sharing in, and having ownership of, his own record. Diabetes, rheumatoid arthritis and ante-natal are examples of conditions where records may be shared by a variety of professionals, but the patient must be a partner in this, controlling the flow of information and not just transporting the card.

On occasions a patient may share personal information that they do not want recorded or passed to a third person. They have a right to expect that their wishes will be complied with, for if they cannot rely on respect for confidences, they will be unlikely to seek help when they desperately need it. However, this can pose a dilemma for a nurse. Omitting relevant data from a patient's records may later be detrimental to future patient care, for example issues relating to sexual health or drug abuse.

There are, however, instances when acting in the interest of the patient may conflict with the interest of society; for example, when the information concerns the welfare of a third person who may be at risk, such as a child in a family where there is violence against another person. Clause 5.4 applies where there is an issue of child protection.

The General Medical Council requires that the practitioner should discuss the matter fully with other practitioners and if appropriate consult with a

professional organisation without identifying the person concerned (Korgaonkar & Tribe 1994). If a decision is made not to disclose or provide the information in the record, it must be recorded elsewhere along with the reasons for such action and kept for future reference (UKCC 1987). However, when the patient is alcoholic, or has diabetic retinopathy, and continues to drive, the nurse has a responsibility to report this to the employer, who may then report this to the DVLC.

The question of which members of the primary healthcare team need to have access to information about a specific patient is included in Clause 5.1. It is accepted that it is impractical to gain consent every time information is shared within the team. Patients and carers must be made aware of the need for information to be shared, on occasion, with other health professionals and who those people are likely to be. In a large team there is a greater need for awareness of these issues.

The UKCC document, *Confidentiality* (1987), warned of the danger of careless talk. Sadly this basic human failing is not mentioned in later documents. Discussion of a patient's problems with a colleague in a public place, such as in an office which is open to a waiting area, or on a phone in reception, can cause confidential information to be released into the public domain and bring about complete loss of faith in the service. Even in areas that are reserved for staff, confidential details can be passed around over coffee so that information that a patient shared in confidence with one professional becomes public property.

Although many practices are paper-less, and rarely refer to the old record cards, it is essential to maintain confidentiality of data on the computer screen. This applies equally when partners attend together but do not wish their medical history to be shared, or young people attend with parents but wish to keep a previous consultation confidential.

### Activity 1.1

Consider how your workplace, reception, treatment rooms, computer screens and telephones used by staff threaten confidentiality of patient information. What changes could be made to protect confidentiality?

### *Advertising and sponsorship*

The Code warns against endorsing commercial products (Clause 7.3). A nurse may wish to recommend a blood glucose meter that she believes to be reliable in monitoring diabetes or give out health promotion leaflets or information sponsored by a drug company. This could be considered

manipulation by a commercial concern or may give the impression that the profession as a body recommends a product, when other nurses might disagree (Chadwick & Tadd 1992).

It would be wise to discuss several makes of glucose meter, pointing out their advantages, disadvantages and any independent evaluation, then allow the patient to make their own choice. However, this presents problems when only specified glucose monitoring strips are prescribed from a practice formulary.

Nurses deal with people who are vulnerable and open to suggestion. It is incumbent on nurses to see that literature offered has first been read, to ensure that the message is balanced and unbiased and does not directly promote a product or a company. Also ensure the data is still relevant; old information leaflets may be incorrect. For example, leaflets discussing the benefits of hormone replacement therapy may not have been updated in line with current evidence and practice. It has to be recognised that many practices rely on support from pharmaceutical companies for health promotion literature.

Drug company sponsorship for study days and research projects is especially common to general practice. It is reasonable to assume that the valuable support of a company can lead to the advocacy of a particular product because of greater familiarity.

### **Activity 1.2**

Consider the areas of patient care where you influence the choice of treatment. Do the drug companies who make the products you choose most frequently also provide sponsored educational events for nurses? Can you give examples of judgement swayed by commercial propaganda?

## **Issues of consent**

The legal system in the United Kingdom requires consent from any patient who is about to undergo any treatment or surgical intervention. Without consent from the patient, the nurse or doctor delivering the care may be in danger of being sued for assault and battery. The following text relates to adults, minors and persons with a learning disability.

### ***What is consent?***

Consent to any medical or surgical intervention is a legal arrangement based on the notion of a contract between two equal parties (Alderson 1995). There

is some debate as to whether equality exists between these two parties. The health professional would appear to have the upper hand by having greater knowledge of the procedure being undertaken. This may create barriers between the health professional and patient in such a way that: the patient feels coerced into something against his will; and some doctors claim it is unfair to burden patients with technicalities they would not understand.

Some patients prefer to be kept in the dark and accept a suggested treatment; others will require information about all the choices on offer, and then make a decision; while a third group will want all the information and then trust the health professional to make the right decision for them (Reeves & Orford 2002).

Although some patients may wish to take the submissive role and allow decisions to be made for them, this decision making is not the role of the health professional. Information regarding the procedure must be imparted to the patient who is then enabled to make their own decision – informed consent. This issue will be discussed later.

### *Express and implied consent*

Consent can be given in three ways; expressly, implied or hypothetically (Reeves & Orford 2002). Express consent is usually in the form of writing, an example of which is the pre-operative consent form, but includes a nod of the head, or a verbal yes. Parents or guardians who attend with a child for vaccination would normally expect to sign a consent form.

Nurses working within general practice will usually encounter implied consent. It would be assumed that a patient who voluntarily attends a flu clinic and proffers an arm for vaccination has given implied consent to the procedure. However, women may be sent to the nurse by the doctor for vaginal swabs, but do not understand the implication of a positive chlamydia result. Hypothetical consent will rarely be encountered by the nurse, but includes an advance directive, or living will, which is discussed later in the text.

Although, legally, verbal consent is as valid as written consent, written consent is easier to produce in cases of litigation (Leung 2002), and can be scanned into patient computerised notes.

Many general practices offer training facilities, so a patient may find a student nurse, family planning student, medical student or GP registrar present during the consultation. Written consent should be obtained prior to the consultation, to give patients the opportunity to decline the observer if they so wish before they are confronted with the learner. This is particularly relevant for intimate consultations such as cervical cytology, when the woman may prefer not to have either a male or female learner in attendance.

Even if there is no objection it is important that the patient is allowed to control the flow of information. The requirements of the student must not take precedence over the need to seek consent.

### ***Consent in English law***

It is a basic rule of English law that no one has any right to touch another person without their consent. A nurse may not, therefore, do anything to a patient without obtaining their agreement. The importance of this law is to ensure that patients understand and agree to the treatment suggested. Consent must not be coerced and the benefit of any intervention must outweigh any harmful effects (Bird & White 1995).

Exceptions to this law involve some aspects of nursing care. This exception also permits the nurse to care for unconscious patients, which may be a simple faint or the need for cardio-pulmonary resuscitation in primary care.

### ***Competence to consent***

A person must be of adult years and sound mind to be capable of giving consent (Rodgers 2000). Informed consent for medical or surgical procedures may be hindered by illness, stress, mental illness or a learning disability (Chadwick & Tadd 1992). A person who is mentally incapable of understanding the nature of the treatment cannot consent to treatment. Mental competence must be assessed before obtaining valid consent. The Mental Health Act Code of Practice 1983 para. 15.10 stated that certain criteria are necessary for a person to be able to consent to treatment (Box 1.2).

If a patient is unable to give consent due to a psychological disorder, illness or stress, the relatives usually have to shoulder the burden, although the final decision will lie with the doctor. A diagnosis of mental illness does not

**Box 1.2 The criteria necessary for a person to be able to consent (Mental Health Act 1993 para 15.10)**

The patient:

1. understands what the treatment is and why he/she needs it
2. understands in broad terms the nature of the treatment
3. understands the benefits and risks
4. understands the consequences of not having the treatment
5. possesses the mental capacity to make a choice.

necessarily mean that the ability to give valid consent is affected. Fullbrook (1994) argued that the question of a patient's competence to consent to treatment is rarely raised unless there is an issue of non-compliance. He also states that the capacity to make a decision is judged in relation to the importance of the intervention. This scenario can be related to general practice. A patient who, after consultation with his general practitioner, decides against a minor surgical procedure, would have his decision respected. If this same person refuses major surgery, his mental competence could be questioned. The reader may have cared for women with advanced breast cancer who choose not to have surgery, and found it difficult to accept this decision.

Competence to consent can therefore be linked to a question of conforming. An individual has a right to make their decisions, but mental competence may be questioned if the final decision fails to conform to society's expectations. Standards may be the norm for either an individual or society. Usually when such a conflict arises the final decision is made by the person with the most authority and knowledge.

### *Consent for patients with learning difficulties*

Mentally compromised patients are said to be unable to, or not allowed to, exercise their autonomy to its fullest extent because the ability to make autonomous decisions must be competency based (Fullbrook 1994). However, mental competence is not easily measured and may require expert analysis. This is a complex process, and in clinical practice the assessment of mental competence tends to be value judgements based on social and personal values (Hepworth 1989).

Consent for patients with severe learning difficulties, or the senile, who are regarded as incompetent to give valid consent, is usually sought from a third party. Relatives, carers or friends may be able to give an indication of the patient's wishes (Reeves & Orford 2002). Although relatives are often asked to make surrogate decisions on behalf of the patients, Fullbrook (1994) suggests that they may be mentally incompetent themselves, due to stress that may affect rational judgement.

Hanford (1993) raises ethical issues surrounding disability. She states that 'disability is rarely, if ever, given consideration in ethics teaching, even though autonomy is central to the concerns of the disabled'. This can relate to physical or mental disability. Hanford raises concerns about the moral stance professionals assume in ethical deliberations, which is central to any discussion on ethics and disability.

Nurses who care for patients with a learning disability may well have encountered the challenge of competence and consent. The three main areas of concern include immunisation, contraception and cervical cytology. These

are invasive procedures that may be difficult to explain in a language the patient understands. Many of the patients who live in the community will have a key worker who has a deeper understanding of their patient's mental ability. It may be necessary to defer a procedure until the key worker can obtain the necessary consent.

A person is more likely to give valid consent if the explanation is appropriate to the level of their assessed ability (Rumbold 1993). Nurses can utilise the expertise of their learning disability nurse colleagues to ensure that patients with limited mental competence receive quality care. These nurses have the skills and tools to help the patient understand a procedure. Clause 3.6 in the Code states that criteria for treatment must be in the patient's best interests when they are not legally competent.

### *Informed consent*

The concept of informed consent has existed for many years within the medical profession. Cadoza in 1914 stated that 'Every human being of adult years and sound mind has a right to determine what shall be done with his body; and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable for damages' (cited in Rumbold 1993).

Informed consent has been defined as the patient's right to know what is entailed, before any procedure is carried out (Chadwick & Tadd 1992). This includes an explanation of any hazards or complications, and the expected final outcome of treatment. Beauchamp and Childress (2001) discuss the complexities of different commentaries about informed consent.

Simply, within general practice, it is the nurse's responsibility to ensure that the patient is fully informed about any procedure or treatment, even when they have given implied consent by attending the surgery. The patient will be competent to understand and decide voluntarily, having been given accurate information that they can understand and authorize the agreed plan of care.

The patient must be given all the relevant information in order for consent to be obtained. In England there is no actual law that stipulates how much information is given, but it is the health professional's duty to ensure that there is no undue pressure or influence on the patient. These issues emphasise the link between consent and autonomy in allowing individuals to be autonomous, and permitted to make their own decisions regarding their healthcare.

Beauchamp and Childress (2001) argue that informed consent does not exist genuinely between professional and patient, as the patient can never fully understand the information they are given. This reinforces the issue of an unequal contract between health professional and patient. As mentioned above,

stress and illness may influence the patient's ability to make a rational decision even if all the information has been provided. It may be appropriate in some instances to defer a treatment until informed consent can be obtained.

### *Main principles of informed consent*

Although some patients are unable to form an informed opinion, it must be remembered that everyone has the same rights and the two main principles must be (Rumbold 1993):

- Give people the respect due to any human being
- Ensure that the person is protected from harm

If a person is unable to give informed consent, it is considered good practice to discuss any proposed treatment with the next of kin (National Health Service Management Executive (NHSME) 1990), although the doctor does not have to obtain their consent as the final decision in law rests with the doctor. Failure to obtain consent or adhere to a competent refusal may result in legal action, or disciplinary proceedings against the practitioner (Rodgers 2000).

### *Cultural issues*

Regard must be given to the cultural backgrounds within the practice population when considering informed consent in both adults and children. Difficulties with language can clearly have an impact when obtaining consent for treatment (Box 1.3). An interpreter may be required for patients whose first language is not English. This may be a child or relative, which creates problems with sensitive issues and patient confidentiality, although without an interpreter, the patient is unable to give informed consent. Access to telephone or personal interpreters is difficult and expensive, and may not be commonly considered in primary care.

#### **Box 1.3 Examples where language barriers may prevent the nurse obtaining informed consent**

- Parents who do not speak or understand English are unable to give informed consent to a procedure for their child
- Administering of vaccines, including influenza
- Prescribing diabetic medication and insulin
- Undertaking any bodily examination, including cervical smears
- Travel advice, including choice of malaria prophylaxis.

Consulting with patients with a speech or hearing disability presents similar problems, although writing information or using information leaflets can overcome some of these difficulties.

### *Minors and consent*

A minor is legally defined as someone younger than 18 years and this is an important patient group to consider when examining issues of consent. Children are dependent on their parents or carers for their health and safety. Most parents look to health professionals to help them make the right choices to ensure that their children grow up with healthy lives. It is customary in the United Kingdom to obtain the consent of a parent or guardian before carrying out treatment on a minor, although there is no statute law stating that a child cannot give consent to, or refuse, treatment. *The Best Interest Standard* refers to the legal assumption that parents act in their children's best interests (Beauchamp & Childress 2001, p 102). To be able to consent, a parent must have sufficient information to weigh up the risks and benefits of a procedure. Failure to provide this information may lead to the consent being invalid.

It is not uncommon for a minor to refuse treatment, for example an immunisation, but the parent gives consent. Legally, if the parents have given consent the nurse may give the injection, although forcing the child to be immunised against their will could be construed criminal assault (Kline 1995). If the child fully understands the implications of the vaccine and has a valid reason for refusing, the nurse should heed the child's request.

Conversely, a child may give consent for a vaccine but the parent refuses. If the child is under 16 years, has the maturity to understand the implications and wishes to have the vaccine, the nurse may legally give the injection (Kline 1995).

The Children Act 1989, section 3(5) provides guidance for nurses dealing with emergencies in primary care when a minor is accompanied by someone without parental responsibility, for example a school teacher, or a carer. Safeguarding or promoting the child's welfare is paramount.

#### **Activity 1.3**

An unaccompanied 14-year-old boy presents in the surgery with a tetanus-prone laceration following a football injury. He is due his school leaving vaccination. Practice policy is to vaccinate only with consent of the parent or guardian. Consider the legal implications and prepare a protocol for future management of this scenario to discuss at the next practice meeting.

A competent child aged over 16 years can consent to treatment, and this cannot be overridden due to the Family Reform Act 1969 (Rodgers 2000). The subject of consent in minors was raised during the Gillick case of 1981 (Cox 1994). The issue of prescribing oral contraception to underage girls without parental consent is a major issue. Parents have duties to their children, but children also have rights. The court ruled that any parental rights were terminated when the child achieved sufficient understanding and intelligence to make an informed decision about medical treatment. This is now referred to as the *Fraser guidelines*. Children under 16 years can give valid consent to treatment if they have sufficient maturity and intelligence to understand the nature and implications of the proposed treatment (Leung 2002).

The key issue in child consent is that a child who is capable of making a reasoned decision has a right to be involved in the decision-making process. Children need to be fully informed in the same way as any other patient.

### *The nurse's role*

Nurses can play a crucial part in helping patients to enjoy more equality with doctors in issues of consent (Box 1.4). The nurse has the ability to explain clinical information clearly and listen to patients' anxieties and concerns. Nurses also have the ability to realise that consent is an emotional and rational process (Alderson 1995). Clause 3 of the Code offers guidelines on consent. It does not dictate actions. The Code states that nurses must safeguard the interests of individual patients; the interests of the public and the patient must predominate over those of the practitioner and profession.

Legal standards of consent are based on the concept of what the reasonable doctor decides to tell the patient. A nurse who gives a patient more

#### **Box 1.4 The role of the nurse in issues of consent for nursing care**

The nurse should:

- use language which the patient can understand
- ensure the patient understands the procedure/treatment
- utilise an interpreter where necessary – defer a procedure unless the event is life-threatening (e.g. cardiac arrest)
- remember that children are capable of giving informed consent
- not undertake any procedure for which consent is not informed
- liaise with key worker or general practitioner when mental illness or incapacity prevents the patient giving informed consent

information about the risks than the doctor wishes could be placed in a difficult position (Rumbold 1993), but withholding information is contrary to the NMC guidelines.

## **Respect for patient autonomy in general practice**

It is essential that healthcare workers understand the concept of autonomy, in order to individualise healthcare. Although the terms autonomy and self-determination are often used interchangeably in ethical textbooks, autonomy will be used throughout the following text. This section will consider the general issues of autonomy pertinent to practice nurses.

### ***What is autonomy?***

Autonomy is derived from the Greek *autos* (self) and *nomos* (rule, governance or law) (Beauchamp & Childress 2001, p 57). An autonomous person has the ability to be able to choose for themselves or more extensively to be able to formulate and carry out their own plans or policies. The autonomous person also has the ability to govern their conduct by rules and values, and is said to be self-determining.

#### **Activity 1.4**

Reflect on a recent situation in your practice when a patient was not involved in their treatment plan. An example of this could be in respiratory care, when the choice of inhaler device is reliant on the practice drug formulary. Do they have a choice of inhaler device? Consider how this situation could have been managed to enable the individual to exert their autonomy.

### ***Ethical issues***

The principle of autonomy is commonly regarded as the first principle of contemporary biomedical ethics. Within healthcare autonomy can only occur if the patient has at their disposal the necessary information to consider a course of treatment consistent with their beliefs and wishes. Nurses are also autonomous people who do not blindly follow orders but respect their patients' wishes. Autonomy of the nurse and autonomy of the patient appear to be increasingly interdependent.

The principles of autonomy and individuality would suggest that patients should be entitled to information about their condition. Bird and White (1995) suggest that healthcare professionals must provide all the appropriate information required by a prudent patient to make an informed choice, even when it is not requested. This is contrary to the belief that it is a denial of autonomy to force unwanted information on those who have clearly indicated that they do not want it (Lindley 1991). The patient is now required to read and sign a consent form, which mentions risks of the procedure, prior to minor surgery. If the patient fails to read the form he is qualified to act autonomously, but fails to do so (Beauchamp and Childress 2001).

### *Sharing information with patients*

Healthcare professionals have a moral obligation to give patients as much unbiased information as possible with which to make informed autonomous decisions (Rowson 1993). Seedhouse (1998) discusses autonomy as a quality, making the distinction between *creating autonomy* and *respecting autonomy*. It is not possible for someone to make a decision of their own free will if they do not know the options open to them.

It is unfortunate that some professionals consider it morally acceptable to give selected information to a patient, believing it to be in the best interests of the patient to do so. This may deny the individual a chance to make an informed choice, reduce his autonomy and increase anxiety. An example of this is when discussing a new medication. If the prescriber fails to explain the potential risks/benefits of medication options, patient autonomy is reduced. This may result in a loss of trust and confidence in the profession. It is hoped that nurse prescribers will redress this with their prescribing practice.

Refusal to disclose relevant information may deprive people of the power to make important decisions affecting their lives. This leads to dilemma in truth telling. Where a doctor fails to answer questions about diagnosis and prognosis truthfully, the nurse is expected to refer these questions back to the practitioner. She may, however, feel comfortable to field some questions by determining the patient's current knowledge and then answer appropriately. Relevant internet websites, help lines or societies such as the Parkinson's Society, may be useful resources for patients to gain more in-depth knowledge about their condition, treatment options and prognosis.

Although there may be occasions when beneficence overrides respect for autonomy, such as acting for the patient's good, there should be few occasions for this to affect nursing care. These issues may become more relevant as the nurse's role in general practice expands.

### **Activity 1.5**

Mr White is a 55-year-old manual worker. During a routine health check you discover that his blood pressure is 170/110mm/Hg. He asks you what this means and if this is serious. Consider what information you want Mr White to share with you, and what you are competent and comfortable to share with him. You may achieve increased compliance in lifestyle management if you discuss the implications of unmanaged hypertension. You may, however, increase his anxiety. Justify your decision to share or withhold unbiased information from your patient.

### ***Consent and autonomy***

Informed consent and autonomy are linked by the presumption that mature adults are expected to be mentally competent and have a capacity for autonomy. There is a moral requirement to show respect for this autonomy.

If the patient has the capacity it is necessary to ensure that they understand the nature and consequences of a choice. Efforts to dissuade the patient are acceptable, and even morally obligatory in some instances. The nurse has a role to help family and carers to come to terms with a patient's choice and to respect it.

A concern with patient autonomy as an ethical issue can pose problems in the delivery of care. Wright and Levac (1992) consider that it is arrogant, insulting and violent to label families as noncompliant when they do not respond to nursing intervention.

### **Activity 1.6**

The practice receives points for administering influenza vaccine to patients in at risk groups every year. The flu campaign targets these patients with an invitation, then a phone call. The patient is reminded at every consultation. The patient notes are flagged. Consider the ethical implications of this policy. Devise an argument to present to the practice meeting for respecting patients' autonomy. This may require a modification in the initial policy.

Suggestion: eligible patients have an information leaflet and/or discussion about the vaccine benefits and side effects. The patient can then make an informed decision whether or not to accept the offer. This decision should be respected.

It is important that the individual is able to make a voluntary decision about their treatment. Consent obtained through coercion or manipulation is not regarded as true consent. Manipulation includes giving information to influence the individual, or withholding information that alters a person's understanding. This is then not informed consent. It could be argued that, in some instances, nurses who encourage parents to allow their children to be vaccinated have used an element of (unintentional) manipulation to achieve this result.

### *The nonautonomous patient*

Some people prefer not to make a decision about their treatment and rely on the doctor or nurse to make that decision. These people are described as being nonautonomous. Seedhouse (1998) suggests that many people are content to be instructed although independent choosing should be encouraged. If it is clear that it is the patient's own wish to leave the decision making to the professional, this decision should be respected. A patient who is very ill may choose to be nonautonomous only until their health improves.

### *Refusal of treatment*

An action of battery is a legal suit that may be brought against a nurse if treatment is given in the face of an explicit refusal to treatment (McHale 1995). There is no power in statute or case law to remove a patient to hospital for treatment unless they fall under the Mental Health Act 1983. Where a patient declines care, the refusal should be respected. Although it is hoped that practice nurses would not encounter this scenario they must be aware of the implications of such action. Examples of refusal of treatment include choosing not to take medication for hypertension, even when there is a risk of a stroke, and not taking preventative asthma medication despite needing regular reliever therapy.

### *Patient autonomy and the practice nurse*

It would appear that patients and their families are now more informed regarding healthcare and patient rights. The *Patients' Charter* (DH 1993) developed an increased awareness of a person's right to self-determination. Health related topics regularly appear in national and local newspapers and in many weekly and monthly magazines. Media articles and access to the internet have resulted in many more people questioning proposed and

current treatment options, and they attend the surgery armed with internet print-outs and media articles. There is an increasing expectation that decision making should be both fully informed and collaborative. Healthcare professionals have come to recognise and respect the autonomy of individuals, moving away from prescriptive management towards a negotiated contract of care.

Essentially all nursing actions invade a person's privacy, and although most of these actions are considered necessary, and consent is given implicitly, it should not be taken for granted. The patient should be allowed to exercise the right to say no.

Involving patients in making decisions is said to improve health and promote patient welfare (Chadwick & Tadd 1992). Real care involves a partnership of nurse and patient/patient. Chadwick and Tadd suggest that using the word client instead of patient implies that the person receiving care is an autonomous chooser. It could be argued that a client is a person who is paying for a service. Within healthcare, private patients pay at the point of use, while those receiving National Health Service treatment pay through their national insurance contributions.

Patients from higher social classes receive more explanations voluntarily than those from lower social classes, although demand for information and advice is widespread among all social groups (Townsend, Davidson & Whitehead 1992). This issue may need addressing to ensure that all patients are empowered to be autonomous, whatever their social group, ethnicity or disability.

Patients should be offered information, which if accepted, must be delivered at a level the patient and family/carer can understand, with audio-visual or written support for patients to read and absorb at their own pace.

Refusal to consent is an area that may cause concern within general practice. Patients who refuse to attend reviews for certain conditions can now be exempted from target figures. Harassing patients in order to achieve targets violates their autonomy and should be discouraged. Although the advantages of encouraging patient autonomy are recognised, there are several reasons why nurses may be reluctant to encourage such participation (Box 1.5) (Saunders 1995).

Encouraging autonomy is time consuming, but can result in improved treatment concordance that may save further surgery appointments and/or reduce patient morbidity (Edwards 1996).

Conversely, it could be argued that patients are denied autonomy when they cannot access a drug or treatment, due to financial restraints in the practice or health service budget. In the case of new drugs which are promoted in the media, an open discussion about risk/benefits of these products

**Box 1.5 Reasons why nurses may be reluctant to encourage patient autonomy**

These include:

- feeling threatened by the patient having a stronger role in the partnership
- being asked too many questions
- patients should put their trust in the nursing and medical staff
- fear that the nurse's role will be eroded as more patients self-care
- tasks are completed faster and more thoroughly if the patient remains a passive recipient of care.

can reassure the patient, who may be happy to continue with their current prescribed treatment.

***Autonomy in health promotion***

Although lay people need to develop the confidence and competence to take responsibility for their own health, the whole concept of health education raises ethical questions. Banning smoking in public places has created a regular debate in the media and nursing press. The proposed policies take no account of patient choice.

Health educators have to respect the rights and autonomy of the individual to choose their lifestyle, despite the primary remit for the prevention of disease (see Chapter 4). Health promotion features strongly in a general practice workload. Advice on lifestyle changes must be individualised and sensitive, respecting the patient's culture and social values. The role of the nurse includes spending time with the patient identifying their social norms and values. A person who makes an informed decision not to follow a healthy lifestyle following a health screening programme should have their decision respected, even when this may impact negatively on their future health. Nurses can only inform and advise.

***Advocacy and autonomy***

Gates (1994) addressed many of the arguments surrounding advocacy and nursing. As an advocate for autonomy, the nurse assists the patient to make an authentic decision that meets their own values and lifestyle. The nurse may also act as the patient's advocate if decisions made by others conflict

with the person's wishes. If a nurse is unable to act on a patient's behalf, the patient should be referred to a local independent advocacy scheme. Each Primary Care Trust has a Patient Advocacy Liaison Service (PALS), to which the patient can be referred, and who will act for the patient.

### ***Autonomy and trainees***

Thompson, Melia and Boyd (1994) discussed the ethical issues of using patients during nurse or doctor training. Students, doctors and nurses receive training in general practice. They develop many skills, including taking cervical smears and minor surgery. Patients may be uncomfortable with the thought they are 'on camera' during videoed consultations during registrar training due to lack of understanding. It should be explained to the patient that it is the doctor who is being recorded, and not the patient.

Patients should be allowed to consent or refuse examination or treatment by a learner even when this restricts training opportunities, without this decision affecting future care and with permission sought prior to the learner meeting the patient.

### ***Living wills (advance directives)***

Living wills are recognised as valid documents in civil law. They are advance directives that allow patients to take some control over end-of-life decisions. This includes refusal of treatment in advance or to state their preference for treatment to continue should they become too ill to make their own choice or to express that choice. Practice nurses are unlikely to follow advance directives within their professional role, but may be asked to read, witness or discuss the concept of the living will during a consultation.

A major advantage of living wills is that they can promote discussion, especially when broaching difficult subjects (Haas 2005). Practice nurses often have a close rapport with their patients, and may be the person the patient approaches to discuss sensitive issues.

The Mental Capacity Act (2007) allows patients to choose their end-of-life care. These decisions may be discussed in practice meetings, or cancer care team meetings, so it is helpful for the nurse to be forewarned. An advance statement only comes into force when a patient is unable to make decisions.

## **Summary**

Effective decision making is an integral part of the clinical role of the practitioner, involving risk taking within the parameters of the professional

accountability placed on each registered nurse. Indeed, the *Report of the Heathrow Debate* (Department of Health 1994, p308) reiterates a comment that 'nurses will not have arrived until they are sued'. It is hoped that this will not be the case.

The professional trend towards negotiated, autonomous nurse–patient healthcare has enabled a move away from the old paternalistic methods, where health professionals knew what was best for the patient, although it is important to recognise that some patients still prefer to follow instructions without information, accepting the doctor's or nurse's advice. The patient's role is changing from one of grateful recipient to active consumer. It has been argued that although completely autonomous decision making is a myth, the person seeking the informed consent should allow the individual the freedom to make their own choice, although deciding a person's autonomous interests is a difficult matter.

Clause 3.2 of the Code reinforces the nurses' role in respecting patients' involvement in planning and delivery of care. Nurses have a duty to inform patients of their rights and assist them to ask questions and express their opinions. Nurses who are not comfortable in this role may benefit from reflection and training to develop the necessary skills to fulfil this duty.

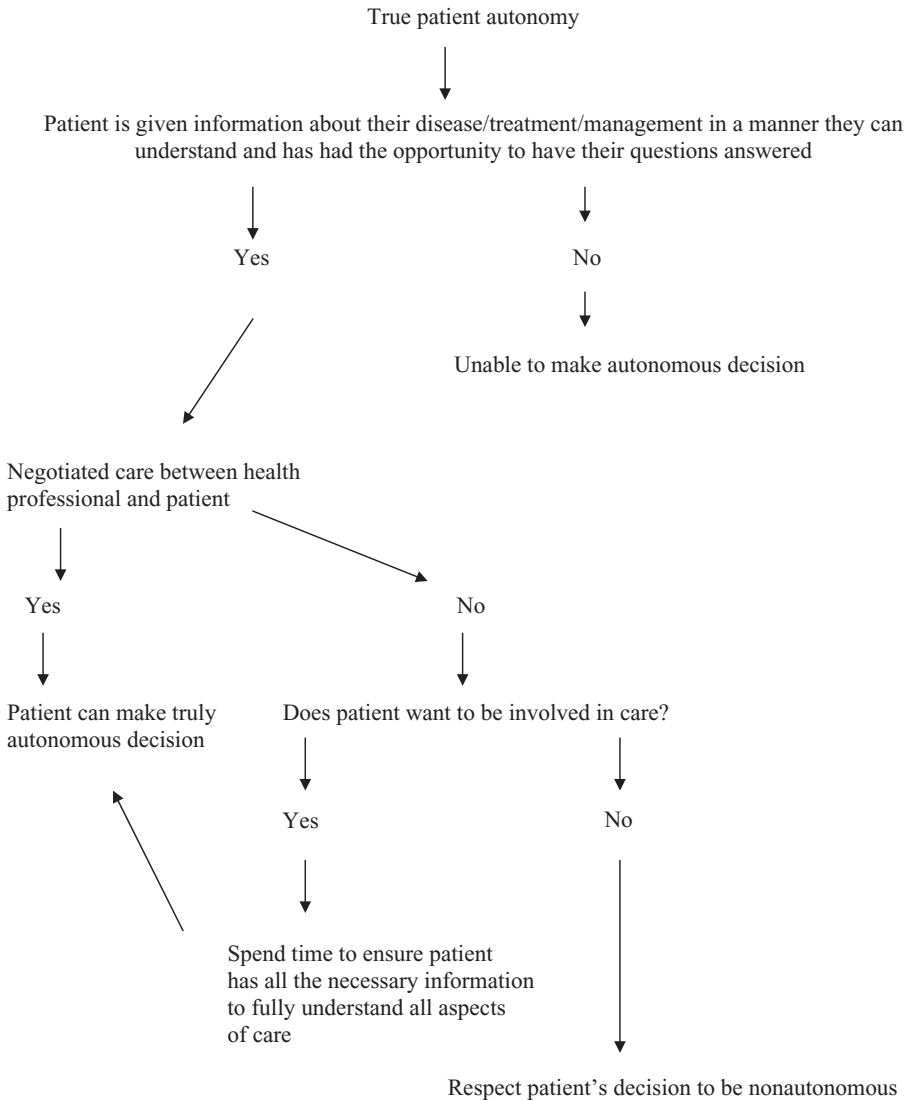
The nurse has a duty to respect patients who prefer to be nonautonomous and passive in their care, preferring the nurse or doctor to make all the decisions about their care. Patients should be offered information about their disease, treatment and general management, and allowed to accept or reject this offer (Figure 1.3).

One of the central aims of nursing in 2008 and beyond is the development of autonomous practitioners who are better able to assist patients to cope and take decisions. Individualised patient care recognises the patient as a person, and not as an object of clinical practice. The fear of patient litigation may increase patient autonomy in the future. Respect for the individual requires that each person must be treated as unique and as an equal to every other person. There are few areas where a person cannot, if they choose, be autonomous in their healthcare.

## Key points

- The Code lays a moral responsibility rather than a statutory duty on members of the profession
- The Code makes the practitioner responsible for maintaining and developing their knowledge, skill and competence
- A person must be fully informed to be able to consent to a procedure or treatment

- A person must have the mental capacity in order to be fully informed
- Children have a right to be involved in their healthcare
- Treatment without consent may be considered assault
- Some patients prefer to be nonautonomous
- The nurse must respect a decision to refuse care or treatment
- The nurse may need to act as advocate to enable a patient to assert their autonomy.



**Figure 1.3** True patient autonomy.

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