ABC of adolescence

Consent, competence, and confidentiality

This is the second in a series of 12 articles

Vic Larcher

Adolescence represents the final phase in the transition from the dependence of infancy to the autonomy of adulthood. It can be difficult for young people, parents, and health professionals alike, because of the nature and speed of change. Uncertainty over ethical and legal rights and responsibilities may lead professionals to refuse to see adolescents aged under 16 years on their own for fear of incurring parental wrath or even legal action. Disputes may arise in relation to an adolescent's competence to seek, consent to, or refuse medical treatment, and his or her right to confidentiality. In most cases these disputes can be resolved by discussion, compromise, and partnership, but in extreme circumstances the courts may be involved.

Ethical and legal principles

All professionals have a duty to act in the best interests of their patients. Adults have the right to decide what their best interests are and to have their choices respected. Legally, adolescents' rights to make decisions for themselves depend on their ability to do so (called competence). Ethically, however, professionals have a duty to respect the rights of adolescents, irrespective of their ability to make decisions for themselves, provided that to respect these rights does not result in harm to the adolescent or to others (as laid down in the UN Convention on the Rights of the Child).

The legal principle underpinning provision of health care for children (under 18s) in the United Kingdom is that their best interests (welfare) are paramount. Legal duties are defined both by statute—for example, the Children Act 1989 and the UK Human Rights Act 1998—and by common law, which derives general principles from specific cases. UK law respects the rights of families to privacy, autonomy, and minimal outside intervention but acknowledges that parental rights decline during adolescence. In deciding best interests, courts apply the welfare checklist of the Children Act and consider relevant articles from the Human Rights Act.

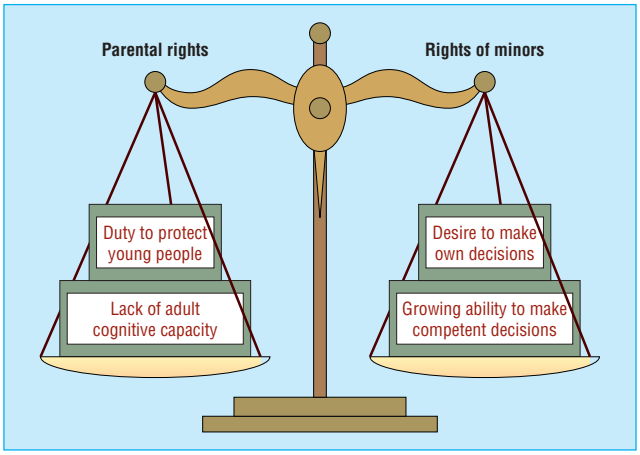
Consent for medical treatment

Obtaining consent for medical treatment respects the right of young people to self determination. To be legally valid, consent must be sufficiently informed and be freely given by a person who is competent to do so.

If young people lack the competence to make decisions, parents have the legal power to consent on their behalf. Matters are more complex when young people are competent but oppose their parents' wishes or refuse treatment.

Competence

Many adolescents are competent in that they possess qualities associated with self determination—that is, cognitive ability, rationality, self identity, and ability to reason hypothetically. Many are able to consider how their actions affect others as well as themselves. In law an adolescent's competence is defined by their capacity to perform the task in question. Some tasks—such as owning pets and driving cars—are defined by age.



Balancing rights and responsibilities in adolescent care

Welfare checklist of the Children Act

- The ascertainable wishes and feelings of the young person concerned in the light of their age and understanding
- Physical, emotional, and educational needs
- Likely effect of change of circumstances
- Age, sex, cultural, religious, and ethnic background
- Harm or risk of harm
- Capability of parents or others to meet the young person's needs

Relevant human rights (UK Human Rights Act 1998)

Article 2—Right to life
Article 3—Prohibition of torture and inhuman and degrading treatment
Article 5—Right to liberty
Article 8—Right to respect for privacy and family life, home, and correspondence
Article 9—Freedom of thought, conscience, and religion
Article 10—Freedom of expression and right to information
Article 12—Right to marry and found a family
Article 14—Right not to be discriminated against on grounds of race, sex, etc, in the enjoyment of other convention rights

Those allowed to give consent for treatment for young people

- The young person if he or she either is over 16 years or is under 16 years and judged to be competent
- Parents, individuals, or local authority with parental responsibility
- A court

Legal definition of competence

"As a matter of law, the parental right to determine whether or not the minor child below the age of 16 will have medical treatment terminates if and when the child achieves sufficient understanding and intelligence to understand fully what is proposed" (Gillick v West Norfolk and Wisbech Area Health Authority [1985] 3 All ER 402HL)

The validity of a child's consent turns on personal capacity as judged by the opinion of a qualified medical practitioner attending him (Age of Legal Capacity (Scotland) Act 1991;S2(4).)

In health care, however, understanding, intelligence, and experience are important qualities. Over the age of 18 years competence is presumed. In England, Wales, and Northern Ireland adolescents aged 16-18 can consent to treatment but cannot necessarily refuse treatment intended to save their lives or prevent serious harm. Adolescents under 16 may legally consent if they satisfy certain criteria. This is easy for uncomplicated procedures such as venepuncture but is more problematic for complex, risky procedures such as open heart surgery. In Scotland competent children may consent to treatment irrespective of age; a person may make decisions on a young person's behalf only if the young person lacks the capacity to do so.

Competence is context dependent and may fluctuate. Pain, environment, and mental state may reduce competence, but experience of illness may increase it. In law, assessing competence is the doctor's responsibility, though other professionals with appropriate skills may be delegated to help. Refusal to cooperate with assessment should not lead to a presumption of incompetence. Some competent adolescents may wish to share decision making with trusted adults or let others decide for them. Assessment of competence must be done in situations that maximise competence—after giving adequate information in an appropriate environment..

Information

Any competent adolescent can legally authorise medical procedures provided that they have the information that a reasonable person making a choice in similar circumstances would want.

The extent to which parents are involved needs sensitive handling. Adolescents may wish to ask intensely private questions—for example, on sexual matters—that exclude their parents.

Parents may wish to protect young people from painful and distressing facts—for example, about their own illnesses—but failure to disclose such information may cause more subsequent pain and suffering to the adolescent. Some families and cultures may not wish to involve young people in decision making. Adolescents not able or not wanting to make their own choices still have the right to information in a comprehensible form.

Refusal

Refusal is especially problematic when the proposed treatment will prevent death or significant harm and the risk-benefit ratio is favourable—for example, an appendicectomy for acute appendicitis.

When the risk-benefits are more equivocal a wider consideration of best interests is necessary. Legal intervention may be necessary if disputes cannot be resolved by negotiation and mediation. Courts have overturned adolescents' refusal of psychiatric medication, blood transfusion in leukaemia, and heart lung transplantation.

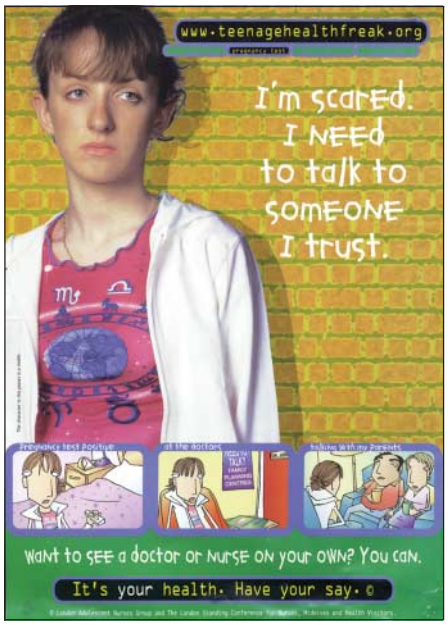
Confidentiality

Teenagers rate confidentiality as one of the most important aspects of medical care as it underpins future relationships with professionals and is based on mutual trust.

They wish to know that information given in confidence will not be divulged to others—for example, parents, school, and police—unless they specifically wish. They may test professional assurances of confidentiality. The right to confidentiality exists independently of the competence to consent to treatment.

Criteria for testing competence

The young person should be able to:
- Understand simple terms, nature, purpose, and necessity for proposed treatment
- Understand benefits/risks/alternatives and effect of non-treatment
- Believe the information applies to them
- Retain information long enough to make a choice
- Make a choice free from pressure



Adolescents have the right to receive information in a form and at a pace that they can assimilate and in an environment that respects their privacy and dignity and spares them embarrassment

Coercion

- Subtle forms of coercion on young people are common
- Failure to provide adequate time or facilities to receive and reflect on information may be coercive, even if unintentionally so
- Adolescents may feel that unquestioned agreement with authority figures such as doctors and parents is required
- Pressurising adolescents to make decisions when they feel neither happy nor confident to do so may be coercive

Unlike for competent adults, an adolescent's right to refuse treatment depends on the circumstances

Refusal and forced treatments

- Forcing adolescents to have treatments they do not want may produce long term psychological harms and lack of cooperation with future treatment
- Overriding an informed, sustained refusal by a competent adolescent is therefore only justified in extreme circumstances
- If adolescents refuse a minor or elective procedure, the procedure should be postponed
- The use of even reasonable physical restraint or force to provide treatment cannot be sanctioned unless the strongest possible justification exists
- Every attempt should be made to understand reasons for refusal and to remedy them
- Legal intervention should be used only when all other means of negotiation, including a careful explanation of the rights of all parties, have failed

Situations in which confidentiality for adolescents is especially important

- Contraception
- Request by an unaccompanied young person for contraception or abortion
- Sexually transmitted infections
- Substance misuse, particularly illicit drugs
- Mental health issues

Objections to disclosure of information should mainly be honoured. Disclosure of information may be required by law or for the purpose of protecting the adolescent or others from risk of serious harm—namely, in the public interest. The adolescent should be told that information will be disclosed and the reasons for it.

Professionals may obtain practical guidance about disclosure from their own professional organisations or from their trust's legal services. Information leading to personal consequences—for example, informing agencies of a patient's epilepsy—should not be disclosed without consent unless public interest or legal obligation require it.

Particular problems may arise if an abused adolescent refuses permission to disclose information to social services or the police. Information about incompetent patients can be disclosed because it is in their best interests, and there is a statutory obligation to investigate abuse.

Similarly, attempts should be made to persuade competent adolescents to permit disclosure. In the face of sustained refusal, disclosure must be justified by a belief that there is a serious risk of harm to the adolescent or to others. Adolescents should be informed of the intention to disclose unless to do so would place them at further risk of harm.

Matters relating to sexual health—such as contraception, treatment of sexually transmitted diseases, and termination of pregnancy—are also problematic in that issues of competence and confidentiality may coexist. Legal guidance in handling such situations does exist and is equally applicable to issues other than contraception. Adverse consequences may follow if an adolescent's concern about confidentiality leads them to specialist clinics that do not have access to their full health records.

Communicating with adolescents about treatment options and establishing competence

General principles

- Treat adolescents as you would competent adults unless you have reason to doubt their competence
- Guarantee confidentiality unless there are specific reasons to break it
- Make every effort to involve their family (Fraser guidelines)
- Use open ended questions that prompt discussion
- Use colloquialisms but not jargon
- Be non-judgmental—make no presumptions about the young person's views or abilities
- Aim to increase their competence
- Encourage young people to express their own views
- Challenge expectations that adults hold decision making power

Specific issues

- Ascertain what the young person knows about their illness or problem and its treatment
- Ascertain their personal experience of illness
- Ascertain their previous experience of decision making for their condition or issue—for example, whether they have been previously involved with parents' decision making

Practical methods to help ensure confidentiality

Have a surgery or clinic policy on confidentiality

- Ensure all staff know the policy and agree to interact with adolescents confidentially
- Put up posters for staff areas about the professional duty of confidentiality and details about legal and ethical issues
- Ensure staff are aware that young people are legally allowed to examine their own health records (if competent to do so and disclosure is unlikely to cause significant harm)
- Ensure confidentiality when appointments are booked and during telephone calls

Make sure adolescents are aware of confidentiality policies

Ensure that adolescents are aware of confidentiality policies and practices of the surgery or clinic—for example, through waiting room posters

Consider the implications of confidentiality

Consider the implications for confidentiality of non-therapeutic activities that require sharing of anonymised data, which may be disclosed without consent but with the knowledge of the adolescent concerned—such as audit, research, teaching, service planning

Situations in which confidentiality should not be kept when dealing with young people

With a competent young person

- Disclosure of history of or current sexual abuse
- Disclosure of current or recent suicidal thoughts or significant self-harming behaviour
- Disclosure of homicidal intent

With an incompetent young person

- Any situation in which there is a significant risk of harm to the adolescent or to others

Fraser guidelines* on young people's competence to consent to contraceptive advice or treatment

A young person is competent to consent to contraceptive advice or treatment if:

- The young person understands the doctor's advice
- The doctor cannot persuade the young person to inform his or her parents or allow the doctor to inform the parents that he or she is seeking contraceptive advice
- The young person is very likely to begin or continue having sexual intercourse with or without contraceptive treatment
- The young person's physical or mental health or both are likely to deteriorate if he or she does not receive contraceptive advice or treatment
- The young person's best interests require the doctor to give contraceptive advice or treatment, or both, without parent consent

*Gillick v West Norfolk and Wisbech Area Health Authority [1985] 3 All ER 402HL

Conclusions

Issues of consent and confidentiality are central in many clinical interactions with adolescents. Services that are not considered confidential are considerably less likely to be used by young people. Those who work with young people must have a clear understanding of consent and confidentiality and also ensure that the services they work in have policies and practices that increase confidentiality and competence among teenage patients.

"Good parenting involves giving minors as much rope as they can handle without an unacceptable risk that they will hang themselves" Lord Donaldson in Re W [1992] 4 All ER 627-633

Much the same can be said for adolescent medicine

The poster is published with permission of London Adolescent Network Group.

Competing interests: None declared.

BMJ 2005;330:353–6

Further reading and resources

- British Medical Association. *Consent, rights and choices in health care for children and young people.* London: BMJ Books, 2001.
- Royal College of Paediatrics and Child Health. *Responsibilities of doctors in child protection cases with regard to confidentiality.* London: RCPCH, 2004.
- General Medical Council. *Confidentiality: protecting and providing information.* London: GMC, 2000.
- Alderson P, Montgomery J. Health care choices: making decisions with children. London: Institute for Public Policy Research, 1996.
- Department of Health. *Best practice guidance for doctors and other health professionals on the provision of advice and treatment to young people under 16 on contraception, sexual, and reproductive health.* London: DoH, 2004. (Gateway reference No 3382.)
- "Confidentiality Toolkit" (a pack designed to help general practice teams review and develop their policy on confidentiality), available free from the Royal College of General Practitioners (tel 020 7581 3232; email sales@rcgp.org.uk).

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The ABC of adolescence is edited by Russell Viner, consultant in adolescent medicine at University College London Hospitals NHS Foundation Trust and Great Ormond Street Hospital NHS Trust (rviner@ich.ucl.ac.uk). The series will be published as a book in summer 2005.

A memorable patient

Miss Fortitude

When I took her on as my patient, she made it clear that she did not hold the medical profession in high regard. She had worked for many years in a medical students' hostel and had seen us with our youthful exuberance and excesses. She now lived alone on the 10th floor of a tower block, and I always ended my visits to her going to the window to admire the magnificent view over the city.

Her body was crumbling: she was confined to a chair with an osteoporotic spine, and her neck seemed to have collapsed so that her head apparently sprouted from her upper chest at a crazy angle. Yet her mind remained as sharp as a pin: she was constantly pointing out my mistakes or omissions, much to my embarrassment. Our discussions about her treatment and conditions felt more like discussions with a colleague rather than with a patient.

The only family was a nephew in another town, represented by a photograph from the 1970s, the colours taking on strange hues as the event it depicted faded into the past. I was curious to know why she hadn't married, but it would have been inappropriate to ask and I never did.

I had respect and affection for her. Despite her isolation and frailty, she never complained. She rarely bothered us at the surgery, and if she requested a visit I was pleased to go, knowing that it was justified. On her 90th birthday, I took her a card—something I have never done before or since for a patient—knowing that few others would be celebrating that great achievement.

One day, while working for the out of hours service, I received a request to visit. On my arrival it was clear that she was seriously ill and barely comprehensible. There was only one place for her. As I spoke to the admitting doctor on the telephone, I noticed a movement from the corner of my eye. Her arm was moving slowly from a flexed to an almost extended position. Then her body was motionless. After checking her, I told the admitting officer that I would not be sending her in after all.

I felt honoured to have been present with this remarkable woman, my patient and friend, when her life ebbed away.

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We welcome articles up to 600 words on topics such as *A memorable patient, A paper that changed my practice, My most unfortunate mistake,* or any other piece conveying instruction, pathos, or humour. Please submit the article on http://submit.bmj.com Permission is needed from the patient or a relative if an identifiable patient is referred to. We also welcome contributions for "Endpieces," consisting of quotations of up to 80 words (but most are considerably shorter) from any source, ancient or modern, which have appealed to the reader.