Summary points

The notion of compliance is explicitly coercive; the danger of concordance is that the coercion remains but is concealed

The rhetoric of both compliance and concordance endorses excessive prescribing uncritically

Patients need different information, not more of the same, and more honesty about the uncertainties of medical knowledge is urgently needed

The Medicines Partnership should be investing more in techniques that help patients to make their own decisions based on their own values and priorities

Doctors have a responsibility to use their professional knowledge to envisage how patients' health could be improved, but they have no right to impose that vision on patients unless they lack the capacity to make their own decisions (when, under English law, a doctor is obliged to act in the patient's "best interest"). With this exception, there is no place for coercion in health care and, when it occurs, the profound comfort is how often patients arrange to subvert it through the tried and tested strategy of non-compliance.

Contributors and sources: IH has been a general practitioner in inner London since 1975 and has been chair of the Committee on Medical Ethics of the Royal Society of General Practitioners since 1998. In preparing this article, IH searched Medline for the terms "compliance" and "concordance." Concordance yielded no useful information as this sense of the word is not recognised by Medline. IH also searched the internet for both terms using the Google search engine.

Competing interests: None declared

1 Royal Pharmaceutical Society of Great Britain. *From compliance to concordance: achieving shared goals in medicine taking*. London: RPS, 1997.
2 Marinker M, Shaw J. Not to be taken as directed. *BMJ* 2003;326:348-9.
3 Donaldson MR. Re T (adult: refusal of medical treatment). [1992] 4 All ER 649-64.
4 Medicines Partnership. www.concordance.org, www.medicines-partnership.org (modified 12 Sep 2003).
5 Hodgkin P. Medicine, postmodernism, and the end of certainty. *BMJ* 1996;313:1568-9.
6 Million Women Study Collaborators. Breast cancer and hormone-replacement therapy in the million women study. *Lancet* 2003;362:419-27.
7 Thornton H, Edwards A, Baum M. Women need better information about routine mammography. *BMJ* 2003;327:101-3.
8 Bashir A, Asif M, Lacey FM, Langley CA, Marriott JF, Wilson KA. Concordance in Muslim patients in primary care. *Int J Pharm Pract* 2001:9(suppl):R78.
9 Carter S, Taylor D, Levenson R. *A question of choice—compliance in medicine taking*. London: Medicines Partnership, 2003.
10 Pollock AM, Price D. New deal from the World Trade Organization. *BMJ* 2003;377:571-2.
11 Col N, Fanale JE, Kronholm P. The role of medication non-compliance and adverse drug reactions in hospitalizations of the elderly. *Arch Intern Med* 1990;150:841-5.
12 Rochon PA, Gurwitz JH. Optimising drug treatment for elderly people: the prescribing cascade. *BMJ* 1997;315:1096-9.
13 Tuckett D, Boulton M, Olson C, Williams A. *Meetings between experts: an approach to sharing ideas in medical consultations*. London: Tavistock, 1985.
14 Metcalfe D. The crucible. *J R Coll Gen Pract* 1986;36:349-54.
15 Zbigniew H. Damastes (also known as Procrustes) speaks. In: *Report from the besieged city and other poems*. Oxford: Oxford University Press, 1983.
16 Butler CC, Kinnersley P, Prout H, Rollnick S, Edwards A, Elwyn G. Antibiotics and shared decision making in primary care. *J Antimicrob Chemother* 2001;48:435-40.
17 Dowell J, Jones A, Snadden D. Exploring medication use to seek concordance with "non-adherent" patients: a qualitative study. *Br J Gen Pract* 2002;52:24-32.

Concordance and children's use of medicines

Emilio J Sanz

Doctors are expected to encourage patients' involvement in treatment decisions, but what about children? This article considers the issues

Department of Pharmacology, School of Medicine, University of La Laguna, 38071 La Laguna, Tenerife, Spain

Emilio J Sanz
reader in clinical pharmacology

esanz@ull.es

BMJ 2003;327:858–60

Concordance is usually established between two people, doctor and patient, but the use of drugs in children always involves a third partner, the parents. Developing concordance with children in their health care raises several questions with no straightforward answers. For example, should children have a more active role in taking decisions about health and drugs than they currently do? Should greater emphasis be placed on informing parents about the disease and its treatment or on direct communication with their sick child? From what age should children be addressed directly about their illness? What is really relevant for them? Do children's and parents' perceptions about the usefulness and risks (efficacy), rules, and use of drugs coincide?

This article, based on qualitative studies of children's perceptions and attitudes to health, disease, and drug use, presents information that, though by no means providing the "right" answers to the above questions, might be useful when considering the options.

Methods

Most studies of patient compliance and the health education of children refer to the professional view and address compliance with drug use, usually related to specific disease treatment. Few address the general issue of how to improve compliance (or to create concordance). In spite of some outstanding systematic reviews from the Cochrane Consumers and Communication Group,[1–3] few studies have examined patients' perspectives about drugs, and even fewer have studied children. Hopefully, the new Cochrane Qualitative Research Methods Group will address the topic.

Of particular value are several international studies supported by the European Union that compared healthy and asthmatic children in their knowledge, perceptions, and expectations about health, diseases, and treatment.[4–6] The data presented in this article are based on those sources, and as such represent a review of the literature about children and drug treatment.

Drugs and children: the triangle of communication

The triangle of communication between health professionals, parents, and children has only recently gained attention in research; mainly in the social sciences and focused on children aged 7-11 years old. Most of the following statements apply only to this age group. Older children and adolescents are increasingly treated as grown ups and are gradually accommodated into the general characteristics of concordance for adults. Less research has been done with younger children, whose limited experience and understanding would seem to preclude more direct communication with them.

Doctor-parent communication

Paediatric consultations usually involve a doctor questioning the mother about her child's symptoms, examining the child, and giving advice to the mother. Children are normally left out of the communication loop and are addressed directly only for a more or less polite welcome and farewell. However, children are knowledgeable and overhear a great deal. Children often correct their mother's account or even ask the doctor directly, although the adults do not expect such behaviour.

Doctor-child communication

Exploring the knowledge of healthy children about their diseases (using qualitative methods, with drawings from the children and semi-structured interviews) has generated a substantial body of knowledge. In most homes, drugs are spread all over the house, and children have ready access to them.[7] But children are generally able to properly distinguish drugs from sweets or foodstuff and tend not to take them just for fun. They recognise that drugs have side effects, even though few children reported actually experiencing any, and know that taking drugs without being ill is dangerous and could even lead to death.[8]

Drugs are seen as aids to recovery, but the same value is normally given to other "health remedies," such as staying at home or in bed, special foods or drinks, special clothes, and, often, special care such as presents and being pampered. Children up to 11 years old seldom attach a preventive value to drugs, and they find it hard to understand why someone should take drugs when "not actually being ill." The mechanisms of action of drugs are seen as magic (especially for injections), and colours and tastes are not normally associated with particular indications or diseases (although this might be more relevant at younger ages). Children are familiar with the more commonly used drugs, often knowing them by their commercial names.

Quite a different picture is drawn by children with asthma. Their degree of autonomy in the use of drugs is considerable. Even children as young as 7 years old were able to give clear explanations about their disease and the drugs used and their main characteristics—how they work and when they should be taken and at which doses.

Living with asthma is mainly a process of negotiation—children with their environment (including peers, teachers, siblings, and friends); parents with the doctor, school teachers, and other family members (to ensure that "environmental requirements" are met at home, at school, on holidays, etc); and children with their parents, on one side trying to gain greater freedom and independence and on the other trying to control symptoms that might be dangerous.

Doctors play a part in these complex negotiations, but are by no means at the centre of it. Parents' attitudes to the disease (whether they see it as a chronic disease or as repetitive crises) influence their children's knowledge and perceptions. Children with asthma use their drugs alone most of the time, keep their drugs as their own property, remind their parents for refills, and can adjust the frequency and intensity of inhalations. They are alone, or only with other children, on most of the occasions when a crisis occurs. They quickly look for help but show good management of the initial steps.

Though a common chronic disease, asthma has its own peculiarities and might be different from other chronic diseases in childhood, such as diabetes and epilepsy. It is impossible to address all those differences in this article**,** but Bluebond-Langner's descriptions of the "private world of dying children"[9] is useful in revealing the attitudes of children at the other end of the spectrum of illness.

These studies show there is much room for improvement in doctors' direct communication with children. Children with a chronic disease will often be directly responsible for their drugs and treatment, and, even for occasional illnesses, children might wish to take some responsibility for treatment, overseen by their parents.

Ten guiding principles for teaching children and adolescents about medicines

1. Children, as users of medicines, have a right to appropriate information about their medicines that reflects the child's health status, capabilities, and culture
2. Children want to know. Healthcare providers and health educators should communicate directly with children about their medicines
3. Children's interest in medicines should be encouraged, and they should be taught how to ask questions of healthcare providers, parents, and other care givers about medicines and other therapies
4. Children learn by example. The actions of parents and other care givers should show children appropriate use of medicines
5. Children, their parents, and their healthcare providers should negotiate the gradual transfer of responsibility for medicine use in ways that respect parental responsibilities and the health status and capabilities of the child
6. Children's medicine education should take into account what children want to know about medicines, as well as what health professionals think children should know
7. Children should receive basic information about medicines and their proper use as a part of school health education
8. Children's medicine education should include information about the general use and misuse of medicines, as well as about the specific medicines the child is using
9. Children have a right to information that will enable them to avoid poisoning through the misuse of medicines
10. Children asked to participate in clinical trials (after parents consent) have a right to receive appropriate information to promote their understanding before assent and participation.

The principles were developed by the Division of Information Development, United States Pharmacopeia (www.usp.org), as a result of the open conference "Children and medicines: information isn't just for grownups" held in Washington, DC, in 1996

Parent-child communication

Exploring the communication between parents and children in relation to health and drug use is difficult.[10] The above mentioned studies revealed remarkable discrepancies between children's perceptions of their autonomy in the use of drugs and the autonomy "reported" or "conceded" by the parents. Children tend to be happy taking care of their own drugs (even if mother is putting the syrup on the spoon) and report "taking the medicines by themselves" but not on their own decision.

Developing concordance with children

Concordance in health care with children is multifaceted: drugs are part of the picture, but equally important are the special food, the special care, and love (see figure). The same should apply with adults. Communicating health decisions is not only giving technical advice on drugs, it involves the whole world of the patient. For these reasons, the notion of compliance represents a very restricted view of reality. Concordance needs to accommodate all these other factors as well, and the first of these is the communication that children offer to their healthcare providers.

A drawing by a 10 year old Greek girl: "This is me when I had a sore throat. I am in bed drinking hot tea. On the table, by my bed, there is a bottle of medicine and a spoon to take it with. My mum is bringing me a flower—because flowers mean health"

Several years ago, "ten guiding principles for teaching children and adolescents about medicines" were developed (see box).[11] Currently, through national and local activities and websites, many organisations are following up with the initiative of empowering patients to "ask questions" and thereby participate actively with their healthcare providers.

Etymologically, concordance comes from the Latin "concordare," and that from "con-corde" (literally, with the same heart). Applying concordance means trying to get two people's hearts to beat in unison. Concordance implies not only the best technical solution to the problem (the body), but also the best approach to the disease and how to live with it (the mind, the heart, the soul, the psyche). Perhaps the change is too deep to be taken at once, but the strategies and philosophy behind the concepts are appealing.

Having the same "heart" as a child is a challenge: clinicians have to come down from their exalted position to the ground, to discover the meaning of children's lives and play. This requires more stamina and flexibility from health professionals, but children always give a full heart when they feel they are being taken seriously. Concordance with children is demanding but most rewarding.

Summary points

Paediatric consultations traditionally involve a two way conversation between doctor and parent, with the child having a purely passive role

However, children are familiar with the concept of illness and treatments and are capable of taking a more active role

In particular, children with asthma are often highly autonomous, taking responsibility for treating their condition and taking care of their drugs

Achieving concordance with children means more than just achieving the best technical solution to an illness (the body), but also the best approach to the disease and how to live with it (the mind, the heart, the soul, the psyche)

I thank Deanna J Trakas, leader of the COMAC, ASPRO I, and ASPRO II research projects,[4–6] for her help in correcting the text.

Competing interests: None declared.

1 Haynes RB, McDonald H, Garg AX, Montague P. Interventions for helping patients to follow prescriptions for medications. *Cochrane Database Syst Rev* 2002;(2):CD000011.
2 Scott JT, Entwistle VA, Sowden AJ, Watt I. Communicating with children and adolescents about their cancer. *Cochrane Database Syst Rev* 2001;(1):CD002969.
3 Lewin SA, Skea ZC, Entwistle V, Zwarenstein M, Dick J. Interventions for providers to promote a patient-centred approach in clinical consultations. *Cochrane Database Syst Rev* 2001;(4):CD003267.
4 Trakas DJ, Sanz E. *Studying childhood and medicine use. A multidisciplinary approach.* Athens: ZHTA Medical Publications, 1992.
5 Trakas DJ, Sanz E. *Childhood and medicine use in a cross-cultural perspective: A European concerted action.* Luxembourg: European Commission Directorate-General XII Science, Research and Development, 1996.
6 Bush PJ, Trakas DJ, Sanz EJ, Wirsing RL, Vaskilampi T, Prout A, eds. *Children, medicines, and culture.* New York: Pharmaceutical Products Press, 1996.
7 Sanz E, Bush P, García M. Medicines at home: the contents of medicine cabinets in eight countries. In: Bush PJ, Trakas DJ, Sanz EJ, Wirsing RL, Vaskilampi T, Prout A, eds. *Children, medicines, and culture.* New York: Pharmaceutical Products Press, 1997:77-105.
8 García M, Sanz E, Aramburuzabala P, Almarsdottir A. Concepts of adverse drug reactions among children in eight countries. In: Bush PJ, Trakas DJ, Sanz EJ, Wirsing RL, Vaskilampi T, Prout A, eds. *Children, medicines, and culture.* New York: Pharmaceutical Products Press, 1997:193-209.
9 Bluebond-Langner M. *The private worlds of dying children.* Princeton, NJ: Princeton University Press, 1978.
10 Aramburuzabala P, García M, Almarsdottir A, Sanz E, Polaino-Llorente A. Decision makers in the treatment of childhood illness in Madrid, Tenerife and Chapel Hill. In: Bush PJ, Trakas DJ, Sanz EJ, Wirsing RL, Vaskilampi T, Prout A, eds. *Children, medicines, and culture.* New York: Pharmaceutical Products Press, 1997:155-73.
11 Bush PJ, Ozias JM, Walson PD, Ward RM. Ten guiding principles for teaching children and adolescents about medicines. *Clin Ther* 1999;21:1280-4.

Endpiece

It's never the time

The time to make your mind up about people is never.

Donald Ogden Stewart, script writer, quoted by Katharine Hepburn