

MEDICINES PARTNERSHIP

HIV: the benefits of concordance

Medicines Partnership is a two-year programme, funded by the Department of Health, aiming to help patients to get more out of medicines by implementing the principles of concordance. Medicines Partnership held a seminar on 20 May in London to learn from the experience of HIV experts and to get some ideas on how their approach to concordance might be applied in other areas of the health service. Joanna Lumb highlights key points from the discussion

Can concordance deliver benefits beyond compliance?

Achieving concordance — partnership between patients and health care professionals in decisions about prescribing — is now seen as essential to ensuring that patients use medicines as intended. But a key question is whether concordance may deliver other benefits beyond just better compliance. The experience of the HIV specialists indicates that this is indeed the case.

One such benefit is that, by encouraging patient self-management, concordance may reduce patients' use of other health services. For example, said HENRY GRAHAME-SMITH, trainer to patients with HIV and inventor of "The Wheel" adherence tool, patients learn to differentiate minor and major side effects: "They understand, for example, that if rash x occurs, they need to seek advice because it is serious, while if y occurs, they can safely self-treat." The ability to identify serious side effects should also increase the safety of treatment.

Another key benefit of the partnership approach is increased patient confidence. In addition, because concordance leads to a better relationship with the health care provider, patients will feel comfortable discussing any problems they might be having with their medicines and returning to the clinic when problems arise.

The concordance model is also seen as a way of acknowledging the uncertainty that still surrounds treatment of HIV infection. "A benefit of this model is being able to share uncertainties with patients while maintaining their confidence, rather than saying 'this is the best treatment' and then six months later having to change your mind and admit to the patient that something else is now considered to be more effective," said JOHN WALSH, consultant in HIV medicine, St Mary's Hospital, London.

Not all patients want the same level of involvement

Although the concordance model is valuable in breaking with the idea of hierarchy, it is important to accept that people do not all want the same type of relationship with health professionals, commented LORRAINE SHERR, professor of clinical and health psychology, Royal Free and University College Medical School, London. True concordance requires a variety of approaches to be available. She referred to the seminal work of health psychologist Claudia Herzlich, who identified a number of different types of patient ranging from the "waterworks" patient who wanted a plumber to fix the problem, to the "PhD", who wanted to find out every detail about his illness and treatment. "The ideal is to match people who want to delegate decisions to a doctor with a doctor who wants to act in that way."

Individualised support is seen as essential. "Empowerment aims to make people as

independent as possible at the level they want. And the key to this is to ask what they want," said LISA KNIGHT, co-ordinator for the living well with HIV mentoring project, Terrence Higgins Trust.

Clearly, some patients do not want to become medicines experts. They are frightened, overpowered or intimidated, particularly at certain times during the course of the disease, and do not want to take responsibility.

Other patients may latch on to the uncertainty surrounding the clinical evidence for antiretroviral therapy as an excuse never to start treatment, even when their CD4 count is very low. JOHN WALSH commented: "At some stage, the right role for the doctor is to say 'we must start now, and I believe this is the best combination for you'."

There is limited information on what factors determine whether patients are

likely to want a two-way interaction or would prefer someone to tell them what to do. Although knowledge, disease type and severity are all likely to be relevant, what works for a particular patient on one occasion may not be appropriate on another occasion. For example, immediately after diagnosis some patients might be scared and want someone to take decisions, while later, when they have had time to reflect, they might want to be more involved. The skill for the health professional is to recognise the patient's needs at any time. There might also be gender or ethnicity differences.

On this last point, Ms KNIGHT said that the HIV patient profile in the UK is changing, with an increasing number of black African patients, who might be more used to a more paternalistic relationship with health care professionals.

Concordance goes beyond the prescription to addressing practical issues

The participants emphasised that a concordant process should not only focus on negotiating agreement on medicine taking. Equally important are the practical aspects of how patients are going to take their medicines. The point was strongly made that there is little value in having a concordant relationship if a patient forgets to take his medicines or has difficulty fitting the regimen into his lifestyle.

Taking antiretroviral medicines is recognised to be challenging. So, once the patient has agreed to start treatment or to change their drug regimen, it is important to consider practical issues. Approaches include encouraging patients to develop a cue to help them remember their tablets (or remember whether they have taken them), eg, by keeping the tablets next to their toothbrush, or sticking a reminder note on the front door, and use of dose administration aids which they can fill up themselves. "Concordance experts have often been dismissive of devices like Dosette boxes — they are not the only answer but they can certainly help and we offer them to most patients starting antiretroviral drugs," said HEATHER LEAKE-DATE, principal pharmacist, HIV and sexual health, Brighton and Sussex University Hospitals NHS Trust. Other important issues that need to be discussed with patients include where they will store their tablets, how they

can take them privately if others do not know their status, or how they can fit them in with shift working.

Some patients live in constant anxiety that they are going to miss a dose, according to JOHN WALSH. "Concordance has to be about patients being happy taking their medicines rather than medicines dominating their lives. This means giving them information about how much leeway they have with their medicines and what to do if they miss a dose, so they do not panic if they are two hours late."

Addressing all these issues means the need for longer medical consultations. Dr Walsh said that he has the luxury of clinic appointments lasting 20 minutes (as compared with, say, 10 minutes in other specialties) and this enables him to move away from strictly medical issues. A general medical consultation tends to concentrate on disease and treatment, with little attention to taking a social history. "Yet I see this as an important part of the consultation — for example, where are they living, have they got somewhere to keep their drugs, are there other ill people in the family and do family members know about their illness? I could not imagine giving someone antiretrovirals without having this information."

An interesting observation made by HENRY GRAHAME-SMITH was that

there is a blurred distinction between intentional and unintentional non-compliance; some patients do truly forget their medicines but others, he believes, say they forget while in reality they do not make it a priority to take the tablets, perhaps because they are not immediately to hand. This in turn is a reflection of patients' views and beliefs about their medicines. On the other hand, patients may fully understand and agree with the decision to start antiretroviral therapy, but find that practical difficulties and side effects are overwhelming once they actually embark on treatment.

Giving patients more information is only helpful if it is personalised

Referring to the health psychology literature, LORRAINE SHERR said that a concordant approach requires doctors to have some understanding of the science of human behaviour. One aspect of this is that information has relevance to patients only if it is seen to be personalised. For that reason, a patient leaflet on its own is often ignored. It becomes more effective if the health professional draws attention to the information in it, and is really effective if the professional adds something relevant to the patient to it in his or her own handwriting. However, written information is a vehicle for dialogue rather than a substitute.

One point that was highlighted was the importance of ensuring that patients receive consistent information from different health professionals. Confusion could be caused if conflicting advice is given about practical aspects of taking medicines (eg, whether or not tablets should be taken with food) and this may happen particularly when the opinion of a health professional differs from the information given in the manufacturer's patient leaflet. Conflicting advice reduces patient confidence and detracts from concordance.

How might HIV experience transfer to other specialties?

The experts believed that concordance could, and should, transfer to other therapeutic areas but that, since it has not happened yet, some encouragement is required.

The change in culture of the doctor-patient relationship that occurred with HIV had specific triggers. The disease was new and frightening, and this gave freedom to depart from strict medical models of care to try new approaches. In addition, patients were well educated and vociferous. "I don't know what would have happened if HIV had first occurred in pregnant women in Rwanda rather than gay men in New York," said LORRAINE SHERR. She saw the essentials for culture change as "pushy patients, willing doctors — plus uncertainty, which makes the health professionals involved a bit humble".

To follow the HIV example, there is a need to encourage patients to be more demanding — at present few conditions are seen to have vocal patients. Doctors also have to be convinced of the benefits of adopting this sort of approach.

HEATHER LEAKE-DATE noted that while much attention is paid to patients' health beliefs and views about medicines, there is a parallel "belief system" within the health care team, with doctors being in a

position to decide whether there is going to be multidisciplinary team involvement and the extent of patient involvement. "It is a case of how can we develop a service that is more responsive to patients' needs and much of that is about attitudes."

On resource implications, the point was made that it is relatively easy to make a case for culture change in a condition such as HIV where drugs are expensive and where a high level of adherence is needed for treatment success. For a condition such as hypertension, where drugs are cheaper, a concordant approach might still be cost-effective because of long-term health gains, but the benefits might not be so immediately obvious.

In summary, specific issues encouraged implementation of concordance in HIV and some of these, for example, use of complex drug regimens and the need for high levels of adherence, might not be applicable to other specialties. However, there is much common ground and the view was that steps should be taken to promote the principles of concordance. For HIV specialists, the new challenge is to preserve the gains achieved so far so that, as treatment becomes better established and more "routine", practice does not revert to the traditional medical model.