# Take one at bedtime and you'll soon feel worse

## Are your patients following the regimen you prescribed?

→ Claire Laurent

Many cancer patients, intentionally or by mistake, fail to take their medication as prescribed. Understanding why can help doctors encourage their patients to stick with the treatment.

Most patients, when faced with a diagnosis of a life-threatening disease, feel they would 'do anything' to survive. It would therefore seem reasonable to expect that if you offer a treatment protocol that promises additional survival, if not a cure, this would be grasped by patients and closely followed.

But that doesn't account for human nature. For all kinds of reasons many patients, including cancer patients, fail to take their medication. For many, the drugs make them feel worse than their cancer, others forget – perhaps because they are in denial about their illness or maybe they feel so well on the treatment that they forget they are ill.

If these reasons appear trivial, it is because they are often symptoms of more fundamental underlying problems to do with how the patient understands their disease and the proposed treatment, and how the patient and doctor work together. In recent years, increasing attention has been paid to this issue, and it is now known that the whole nature of patient adherence to treatment is very complicated and requires understanding and negotiation by health-care professionals if their patients are to fully benefit from the treatment they prescribe. This can only happen if doctors become more aware that there may be a problem.

In an editorial in the *British Medical Journal* (326:348–349), Marinker Marshall and Joanne Shaw say that doctors tend to think non-adherence is a problem for other doctors, so when a prescribed drug fails to produce the benefit they expect they often respond by varying the dose or choosing another medicine rather than by talking to their patient about how closely they are following the prescribed drug regimen. This can lead to serious consequences – not just for the individual patient but also for understanding therapeutic benefit as well as on financial costs.

A growing awareness of the need for greater communication between doctor and patient on this issue has been accompanied by a change in the language used. The World Health Organization, in a report entitled *Adherence to Long Term Therapies: Evidence for Action*, recommends the term 'adherence' rather than the more traditional term 'compliance', arguing that 'compliance' implies an imbalance in the doctor/patient relationship: the doctor is in charge and the patient must do as they are told.

CORBIS

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'Adherence', in contrast, is a more neutral term, simply designating "the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes – corresponds with agreed recommendations from a health-care provider."

The word promoted by many health practitioners today is 'concordance'. This goes further than 'adherence'. According to Giselle Jones (*BMJ* 327:189), the concordant model is one of shared understanding. It's about shared decision making and an agreement that respects the wishes and beliefs of the patient. What it should not be, she stresses, is a gift-wrapped version of compliance.

In the UK, the Department of Health has given its backing to the Medicines Partnership (www.medicines-partnership.org), an initiative set up to encourage a move from 'compliance' to 'concordance'. It is calling for more appropriate

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prescribing and a different approach to patient adherence. Patients comply with treatment, says the Medicines Partnership, when they understand and accept the diagnosis, agree with the treatment proposed and have had their concerns about the medicines specifically and seriously addressed. Part of the cultural shift for doctors entails a recognition that the patients’ own beliefs about their illness, their treatment and what works for them might be at odds with those of the medical profession.

### SIZE OF THE PROBLEM

Research shows that about half of the medicines prescribed for people with chronic conditions are not taken (*Lancet* 348:383–386). Lesley Fallowfield, professor of psychosocial oncology at the Brighton and Sussex Medical School, in the UK, who co-authored a study on non-adherence in breast cancer (*Eur J Cancer* doi:10.1016/j.ejca.2006.03.004), says, “We know from our research that around 40% of women with breast cancer, be that in a chemoprevention, adjuvant or more advanced setting, do not take their oral drugs as prescribed.”

According to Michael Mauro of the Center for Hematologic Malignancies at the Oregon Cancer Institute, Canada, the overall average compliance amongst all CML patients prescribed Glivec (imatinib) was 75%. Speaking on a telephone educational programme organised by the Leukaemia and Lymphoma Society this February, Mauro said that 50- to 70-year-old men were the most compliant, whilst younger men were the least compliant, with up to 20% of them failing to take their medication properly. He suggested the difference might be that the older men were more likely to have wives who supported them through the treatment.

Benjamin Gesundheit is a paediatric oncologist at the Hadassah Hospital in Jerusalem. He argues that for young people, the discipline of adhering to a drug regimen can be particularly difficult. Speaking at the 4th International conference on Teenage and Young Adult Cancer Medicine earlier this year, he said that young people don’t want to be told what to do at an age when they just are beginning to make their own decisions. Young people are also more likely to be risk takers than older people.

The evidence shows that the reasons for non-adherence are many and varied. The WHO says adherence is simultaneously affected by several factors. These include: social and economic factors, the health-care team/system, the nature of the disease and its therapies as well as what it calls ‘patient-related’ factors.

In the study of adherence amongst breast cancer patients, the authors found that the issue was not necessarily related to sociodemographic factors such as level of education or race. The key factors were whether the therapy had adverse side-effects, and whether it was complex and/or lasted longer.

According to Fallowfield, the most common reason for non-adherence in breast cancer is quality of life. Women may take ‘drug holidays’ if they are experiencing side-effects such as hot flushes, which might not be life-threatening but

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can make life miserable. In one study of adherence to treatment amongst breast cancer patients, she found that women aged between 40 and 49 years were less likely to adhere to medication than both younger and older patients. While this could simply be an 'artefact' of the numbers in the study, she thinks "it's more to do with that age group experiencing an early menopause and being blown over by that along with everything else going on in their lives."

With many long-term conditions such as diabetes, hypertension, schizophrenia and epilepsy, if the patient stops taking their medication they quickly begin to notice symptoms. Cancer patients don't necessarily have this tangible and immediate connection between medication and relief from the disease. "Rather," says Fallowfield, "they just experience noxious side-effects, so in behavioural terms it makes sense to stop taking something that makes you feel sick or gives you vasomotor problems."

## Bridging the gap

Understanding this behaviour is essential if health-care professionals are to help their patients stick to their treatment. Doctors may be confident that a particular therapy works and not taking it will result in a poor health outcome, but patients will, understandably, want to take account of their own experience of how the drug works for them, which may be telling them something very different. Bridging this gap is the transition towards concordance.

Jan G, a patient with chronic myeloid leukaemia who runs Leukaemie-online (www.leukamie-online.de) for German-speaking patients, agrees that side-effects can be important when you are on a medication for any length of time. He says, "For those drugs that have strong side-effects, adherence depends on whether patients feel the drug might save their life, but take away all quality of life. Some might decide to stop taking the medication/ chemotherapy and resume 'normal' life, taking the risk that it might reduce how much time they have left."

One study of adherence to tamoxifen over five years (Lash et al. *Breast Can Res Treat*, doi:10.1007/s10549-006-9193-0) found that 31% of women who started tamoxifen failed to complete the five-year recommended course, despite the fact that five years of treatment confers a significant benefit beyond one to two years of tamoxifen. Reasons given included severe side-effects and having an additional prescription added to their treatment. Interestingly, patients with more prescription medications at baseline were *less* likely to discontinue, as were patients who had a positive view of the drug and an improving view over follow-up.

Other evidence has shown that patients may not adhere to their treatment if they don't know enough about the advantages or disadvantages of taking it, when they don't feel unwell (so don't feel in need of treatment), or when they do feel unwell but find the therapy makes no perceptible difference or makes them feel worse.

Not all non-adherence comes down to a deliberate decision by the patient, however. Sometimes patients just get it wrong – they either don't understand the regimen or they forget to follow it. Again, there are a variety of reasons why this might happen. They may have been told one thing by the doctor, another by a nurse and something else again by the pharmacist. Consistent, clear and accurate information is therefore essential.

Research shows that patients forget up to 80% of what they hear in a clinical consultation, and almost half of what they do remember is incorrect, so health professionals have to think hard about how to ensure that medication regimens are understood and likely to be followed.

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### An hour's investment

Gesundheit says it is important to explain the treatment thoroughly. "I dedicate an hour to explaining everything to them: each drug, what it is for and how long they have to take it. This hour is a good long-term investment, because I see much less non-compliance and misunderstanding."

He says this explanation has to be repeated at intervals and emphasises that clinicians must always remember that the early part of the discussion will be forgotten as the patient may be in shock from hearing their diagnosis. Gesundheit advises that it is important to gain the support of other family members or friends in the management of treatment. He adds that talking to patients about their treatment regimen can often encourage them to open up about themselves and their illness. "It's a very good opportunity to understand the patient."

He also suggests a number of techniques that might help patients remember their regimen. A written contract between clinician and patient or a home diary where the patient records that they have taken their medication can help. More consultations or a home support person to clarify the responsibility of drug administration can improve adherence. At the high-tech end of the market is the Medication Event Monitoring System (MEMS). These are microprocessors in the cap of standard medicine bottles. Every time the bottle is opened it is regarded as a presumptive dose. Any patterns in non-adherence will become apparent over time – but this is an expensive way to monitor compliance and does not address the reasons why a patient is not taking their medication.

Doctors can routinely address the issue of adherence at patient consultations. One way to do this is simply asking the question: "How are you managing with your medication?" – patients are often more accurate about non-adherence than adherence. Doctors also routinely run blood tests to monitor the disease and treatment effects. These can be checked for inconsistencies with the drug regimen.

It is also important not to assume that the patient has the literacy skills to follow the information on medicine bottles or on the literature that comes with them. It is estimated that between one-quarter and three-quarters of adults do not have the minimum reading skills needed for coping with the demands of modern life. A report by the OECD, *Literacy in the Information Age*, (OECD 2000) found at least 15% of adults had only the most rudimentary of reading skills in 14 of the 20 countries studied: Australia, Belgium (Flanders), Canada, Chile, Czech Republic, Hungary Ireland, New Zealand, Poland, Portugal, Slovenia, Switzerland, the UK and the US.

Doctors need to be aware that patients who cannot read are likely to have developed all sorts of coping mechanisms to cover up their poor literacy skills. It is important to go through everything very thoroughly with every patient, and make sure that they have understood.

Some simple strategies that can help doctors communicate clearly are detailed at www.askme3.org, a project of the Partnership for Clear Health Communication in the US. The project title refers to the three questions they advise patients always to ask:

1. What is my main problem?
2. What do I need to do?
3. Why is it important for me to do this?

Ensuring adherence or concordance with treatment is about involving the patient, one way or another, in a dialogue that tackles these three issues, so that the doctor can be sure the patient understands what is wrong with them, what they need to take/do and when, and how the treatment can help.

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