# CPD - Caring for Patients and their Disorders

# **Editorial**

As I write this, it is exactly a month since the attacks on the World Trade Centre in New York City and the Pentagon in Washington DC. The retaliatory bombing of Afghanistan seems to be increasing in intensity. By the time you read this, further developments will certainly have taken place, which will hopefully have been in the best interests of our planet and all the life-forms resident on it.

I have to admit that I am extraordinarily grateful that – as a medical doctor – I have not been geographically near either of these war zones. Large scale devastation is not something most of us have been trained to deal with in our professional capacities – although I suspect we'd all rise to the occasion in whatever ways we're able to should we find ourselves in such circumstances.

This edition is possibly more 'theoretical' than most of the CPD components of the journal have been this year. However, it could well have a major impact in practice.

I first heard about the 'Concordance Initiative' when Dr Nicky Britten visited the Department of Family Medicine at MEDUNSA early last year. So much of what she said fitted in so well with our general family medicine principles and philosophy.

You can find out more on www.concordance.org

As the probability of 'universal' access to antiretroviral therapy looms, I suspect the issue of concordance will become increasingly relevant.

Roy Jobson

# Concordance: A new way of thinking about 'compliance'?

- How do you know that your patients actually take the medications you have prescribed, in the way that you have prescribed them?
- What happens after they leave your consulting room with the prescription you have written, or with the medications you have dispensed?
- Who else do they talk to before (or while) taking their medications?
- How much trust do they put into these surrogate advisers?
- · What control do you have of this process?
- Are you aware of lifestyle or other factors (e.g. affecting the patient's daily routine) which would make it difficult for her/him to comply?
- Do you believe that most of your patients do comply with your therapeutic regimens?
- How do you know?
- Do your patients trust your clinical and therapeutic acumen?
- How do you know?

# **Compliance and non-compliance:**

The simple definition of non-compliance is a 'failure to follow the doctor's "orders" or instructions.' However this concept has been challenged as it has negative echoes of 'blaming the patient' (cf. William Ryan's seminal work 'Blaming the Victim'<sup>2</sup> and the tension between patient autonomy vs patriarchy<sup>3</sup>.)

Compliance traditionally makes an assumption that the patient's role is passive while the prescriber's view is rational, evidence-based, and superior to the beliefs and wishes of patient<sup>4</sup>. It is estimated that 1/3 to 1/2 of all patients make errors with their medications for multiple reasons<sup>5</sup>. A few traditional 'non-compliance factors' are described in Table 1.

It is worth noting that 'doctor factors' in non-compliance are conspicuous by their absence in this particular summary – reflecting the prevailing view that healthworkers have only a limited responsibility in terms of compliance.

Table 1:	
Non-compliance factors:	Examples:
Patient factors in non-compliance	Fear of adverse effects, fear of addiction; 'anti- drug' attitudes (synthetic vs natural)
Medication factors in non-compliance	Complex regimens, adverse effects, lifestyle consequences (e.g. no alcohol)
Disease factors in non-compliance	Asymptomatic disease, swallowing problems, memory loss.

# PATIENT SCENARIO

Ms G was in her late-fifties when I first got to know her. She was a mildly obsessive-compulsive spinster and had worked at a large departmental store since her mother had passed away twenty years before. She had then developed ulcerative colitis and would go to her general practitioner at regular intervals for management of the problem. He had organised a colonoscopy at some stage, and no malignant changes had been found. Ms G continued seeing him until he died. She had however, developed a rather bizarre behaviour pattern in terms of her 'medicinetaking'. After seeing the GP she would go to the pharmacist, collect her prescription, and on the way home (usually by bus), would toss the medications into the nearest rubbish bin. She was adamantly opposed to a suggested prophylactic colectomy. Her ulcerative colitis cleared up completely within a year after she retired from her job, and she went on to live for another thirty 'bowel-problem-free' years, grateful that she did not have to 'wear a bag'.

### **Question One:**

Ms G's behaviour can clearly be described as non-compliant. Into what categories of non-compliance can her behaviour be placed?

#### **Answer One:**

Non-compliance has been described as *primary* when the medication is not even dispensed and *secondary* if it is not taken correctly. Other (overlapping) categories are *intentional* non-compliance and *unintentional* non-compliance. The former may be because the patient rejects the diagnosis, the recommended treatment, or perhaps has a need to maintain a sense of control over her/his condition or life. (This form of non-compliance is well described in adolescents with chronic illnesses e.g. juvenile diabetics.<sup>6</sup>)

In deconstructing the unintentional category of noncompliance a whole range of possible variations begins to emerge: is it a problem with not taking the required amount of medication over a specific time? (e.g. not completing a course of antibiotics); is it a problem with the timing of taking the medication? (e.g. frequency of dosage); is it a problem with the duration over which the medication must be taken? (e.g. anti-TB therapy); is there a problem in terms of what the patient believes about the medication (her condition, its management, etc.)?; is the non-compliance partial or total? In the many settings in which compliance is discussed (e.g. tutorials, ward rounds, OPD settings, CPD seminars) the tendency is to (erroneously) think of compliance as an 'all or nothing' (compliant / non-compliant) behaviour.

Ms G's non-compliance would thus be an unusual secondary intentional non-compliance.

(Another category of intentional non-compliance has been described as *intelligent non-compliance*. This is where a patient independently discontinues the medication or decreases the dose based on a correct interpretation of the clinical situation.<sup>7</sup> Could Ms G intuitively have known that her ulcerative colitis was related to her personality and her work situation? An alternative view could be that she was just extremely stubborn and very lucky not to have developed a colon carcinoma after 20+ years of ulcerative colitis.)

# Question two:

What are some of the consequences of non-compliance?

#### **Answer two:**

The obvious consequence is therapeutic failure, or failure to achieve the therapeutic objectives — assuming that these had in fact been set. Unfortunately these are often just assumed. [The WHO's Guide to Good Prescribing emphasises the role of setting therapeutic objectives as part of rational prescribing. The Guide can be accessed or downloaded from www.who.int/medicines/library/par/ggprescribing/ ]

Other consequences of non-compliance include the development of resistance – such as in MDR-TB and HIV/AIDS.

Another all too common consequence is that the patient becomes permanently labelled as 'bad', 'difficult' or 'a timewaster' by the health worker. This may influence the quality of the patient's care well beyond any particular incident.

A neglected consequence is the 'hidden cost to society' which accumulates as a result of non-compliance. This cost includes wastage (e.g. unused but paid for medications), a minimising of the benefits of therapy (e.g. taking much longer than expected to get better) and the extra costs of treating subsequent morbidity that may have been prevented (e.g. avoidable complications of the original illness developing).<sup>8</sup>

# From Compliance to Adherence

Concerns about the one-sided nature of the concept of compliance led to many practitioners using the term 'adherence', which literally means 'sticking to' (i.e. sticking to a therapeutic regimen). However, this was dismissed as a 'brave but inadequate attempt to find a simple semantic solution to a deep conceptual flaw.'8

A comprehensive 1996 literature review of adherence, was subtitled: 'Taking Medicines to Best Effect'. In the introduction the authors make the following provocative statement: 'There can be few research fields in which so *much* published research has led to so *little* improvement in understanding and effective action, as is the case in that of compliance with, or adherence to, prescribed medication.'9 (my emphasis)

Part of the reason for their statement is that very few of the studies used comparable definitions and measures of compliance/adherence. This is despite the development of numerous innovative mechanisms for measuring adherence. A reliable meta-analysis could not be carried out at that stage.

The review does however give a list of 'Doctor/Pharmacist Factors' which contribute to adherence/non-adherence. These include: 10

- Precision of diagnosis and prescribing (Quality of clinical skills?)
- Doctor/Pharmacist understanding of and commitment to the challenge of adherence
- Quality of Doctor/Pharmacist explanation of importance of taking drugs
- Quality of Doctor/Pharmacist warning of risks of not taking drugs (tailoring these for the individual)
- Regularity and Quality of Doctor/Pharmacist face-to-face reinforcement of importance of taking and risks of not taking drugs
- Quality of Patient/Doctor (healthcare worker) relationship (cf. Balint's 'The drug "doctor")

Note the repeated appearance of 'Quality' as a concept here. In predicting medicine-taking behaviour, the most important

aspects were found to be:

- a) the physical and social vulnerability of the patient (e.g. elderly or psychotic patients)
- b) failures of communication (mainly through discordant health beliefs of doctors and patients). 12

A recent study describes six major groups of 'misunder-standings' between patients and doctors in the UK setting. <sup>13</sup> See Table 2. The table gives an idea of a range of possible misunderstandings that most family physicians may well have encountered at some or other stage in dealing with their patients. What different groups of additional misunderstandings could be described in the South African context?

A revealing report of the kinds of misunderstandings that occur between professionals and lay persons comes from a study in Australia where in a paediatric practice over half the parents interviewed thought that antibiotics killed viruses; three quarters thought that antibiotics were necessary for colds and flu and two-thirds said that they had learnt about antibiotics from their doctors!<sup>14</sup>

# From compliance, via adherence, to concordance

One approach to dealing with the problems around compliance and adherence which has developed in the last five years is known as the 'concordance initiative'. Although this is a UK-based initiative, the principles would probably apply equally (if not more!) in the South African context.

# **Question Three:**What is meant by concordance?

# **Answer Three:**

'Concordance is a new approach to the prescribing and taking of medicines. It is an agreement reached after negotiation between a patient and a health care professional that respects the beliefs and wishes of the patient in determining whether, when and how medicines are to be taken. Although reciprocal, this is an alliance in which the health care professionals recognise the primacy of the patient's decisions about taking the recommended medications.'

Consultations between patients and doctors (particularly in certain parts of South Africa) are [most] often concerned with two (or more!) contrasting sets of health beliefs. Concordance recognises that the health beliefs of the patient, although different from those of doctor, nurse or pharmacist, are no less cogent, and no less important in deciding the best approach to the treatment of the individual. The Concordance initiative aims to help patients and prescribers to make as well informed a choice as possible about diagnosis and treatment, about benefit and risk, to collaborate fully in a balanced therapeutic alliance, and so to optimise the

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Table 2: Groups and Examples of misunderstanding between doctor and patient

GROUP	EXAMPLES
I. Patient information unknown to doctor	Patient fails to mention relevant aspects of history to doctor
	Doctor unaware of patient's views about medications or anxieties about symptoms or treatment
	Doctor has inaccurate perception of what patien wants
	Doctor unaware of patient's use of complementary alternative medicine or OTC medications
	Doctor unaware that patient has changed the dosage or that patient is confused about dosage of medication
2. Doctor information unknown to patient	<ul> <li>Patient does not understand drug action, or confuses it with another drug's action</li> </ul>
	Patient unaware of correct dose
	<ul> <li>Patient wants information and doctor does not realise this, or thinks that patient does not need to know, or will not understand</li> </ul>
3. Conflicting information given	<ul> <li>Patient confused by conflicting advice from doctor and other sources of information (e.g. pharmacist? another doctor?, family?)</li> </ul>
4. Disagreement about attribution of side effects	Misunderstandings or disagreements about the cause(s) of side effects
5. Failure of communication about doctor's decision	Patient does not understand, remember, or accept diagnosis
6. Relationship factors	Patient does not understand treatment decision
	Power and status needs of doctor
	<ul><li>Need to be liked (patient and/or doctor)</li><li>Hidden agendas</li></ul>

potential benefits of medical care. (my parentheses) [This definition can be found at the concordance website mentioned in the editorial.]

In the area around Ga-Rankuwa Hospital/MEDUNSA, the majority of the population are seTswana speakers. Does acknowledging the health beliefs of these patients as being

no less cogent and no less important than those of the health worker, imply that health professionals working in this geographical area should have some knowledge of so-called 'traditional' illnesses? (For example: moriti we letsoele; makgame; kgetlane.) What about healthcare workers in a predominantly isiZulu-speaking community? or those in xiTsonga- or seSotho-speaking areas? For if we do not know or understand

these health beliefs, we surely cannot acknowledge them or incorporate them into a 'negotiation' nor can we 'collaborate fully in a balanced therapeutic alliance.'

Interestingly, concordance makes allowance not only for shared decision-making about health and therapeutic options — but also about how the very decisions themselves will be made. Does concordance not begin to sound suspiciously like what many family physicians in South Africa have been taught in terms of the 'patient-centred' consultation?

**Table 3:**Nine Additional Statements about Concordance

- The word concordance was coined to describe an approach to bringing patients into a full therapeutic partnership. It was not introduced to be a politically correct synonym for compliance.
- 2. The word concordance was intended to describe more than a new style of consultation: it was intended to signal a new relationship between the patient and the prescriber.
- 3. Compliance involves one person, the patient: concordance involves at least two people a patient and a prescriber.
- 4. Health professionals should bear in mind that a patient's decision-making preferences may change with time and circumstance.
- 5. If a patient has relatively more authority, control or power in the consultation, it follows that the prescriber will have less.
- If the concordant agreement is that the patient will choose a treatment other than that proposed by the prescriber, the prescriber may be faced with clinical and legal responsibilities that cannot be fully discharged.
- 7. Non-compliance can be perceived by the prescriber as a failure of care. However when the decision not to follow the recommended regimens of treatment forms part of a concordant agreement, it may come to be perceived as a success of care.
- Sometimes concordance will result in the patient's decision to decline taking the treatment as advised. The patient's rejection of the recommended treatment is not to be the basis of the health professional's rejection of the patient.
- 9. In pursuit of concordance, compliance is neither a sufficient aim, nor a necessary outcome of the negotiation.

The similarity is recognised in the last of 'Ten statements about Concordance' which says: 'Although a concordant consultation must be patient-centred, something more than patient-centredness is necessary to bring about a concordant understanding.' But what lies beyond patient-centredness? One possibility is a 'relationship-centred' consultation. How would this be different from the patient-centred consultation? What would it mean in terms of everyday practice?

The other nine statements about Concordance are summarised in Table 3.

These statements form part of an educational framework which can be downloaded from the Concordance website. Each statement should be critically analysed and possibly reformulated in the light of our own consultation styles and individual practice circumstances. The challenge is to implement these Concordance principles (ideals?) to whatever extent each of us is able.

#### Possible Ethical Issues raised by Concordance

Many of the ethical issues usually raised as part of medical ethics could take on an extra dimension in the concordance context. Some specific examples to consider would be: a person with the rare body dysmorphic disorder wants a healthy limb amputated; active euthanasia; and even DOTS. Finally if we're going to re-think 'compliance', perhaps we also need to re-think 'prescribing'. What would the concordant equivalent of prescribing be?

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