Compliance — What's it all about?

— Dr Stanley Levenstein

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Summary

Allergy is responsible for many problems in the paediatric age-group. At times the most difficult problem for the doctor is to decide if the patient is indeed allergic and if so, to what. Skin tests remain the first choice for accurate diagnosis and RAST an important aid in many cases. Treatment consists of avoiding the offending agent if possible, controlling symptoms with appropriate medication and using desensitisation if indicated.

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Curriculum vitae

Stanley Levenstein qualified at Pretoria University and has been in General Practice in Milnerton since 1972. He is Vice-Chairman of the National Council of the Academy of Family Practice and has been actively involved in Academic Family Medicine for many years. Dr Levenstein has a special interest in counselling in general practice and is former President of the SA Balint Society. He is also involved in 'training the trainers' for the Academy's vocational training programme. He is the author of many papers and is the recipient of, inter alia, the Louis Leipoldt Medal and of the first SA Balint/CP Fisons Travelling Fellowship.

From the earliest days of the practice of medicine, doctors have complained about the "problem of patient compliance". Hippocrates wrote that the physician "should keep aware of the fact that patients often lie when they state that they have taken certain medicines". In 1710 during an outbreak of plague a judicial edict was read from the pulpits in the Szabin district of East Prussia to the effect that "all these would be regarded as suicides and their corpses would be publicly hanged who refused to take the prescribed medicines even if these proved to be of no avail".

Today, several centuries later, we have a plethora of publications on the topic of "patient compliance" which have provided a fair amount of information but not a great deal of enlightenment on the underlying issues. Several studies[1] have illustrated compliance-problems with medications prescribed even for short periods of time eg several articles concerning short-term oral penicillin revealed rapid declines in compliance even over the first ten days of therapy.

As far as compliance with medications prescribed over long periods of time is concerned, the rates tend to average out at ± 50% — this is true of such widely divergent settings as children on long-term oral penicillin prophylaxis for rheumatic fever and steelworkers on anti-hypertensive drugs. It will thus be seen that 50% of the medication prescribed by doctors is not being taken or that 50% of patients are non-compliant. Looked at either way, it represents a huge waste of money and an even greater cost in terms of morbidity and mortality.

Numerous studies have been undertaken in an attempt to identify the factors influencing compliance. Different studies have cited different pointers as being of importance. Amongst the factors reported to influence compliance favourably are:

(i) Patient views disease as serious;
(ii) Family stability;
(iii) Patient satisfaction and expectations met;
(iv) Favourable doctor-patient relationship in which patient is involved in the decision-making process;
(v) Private doctor (vs clinic) and seeing same doctor consistently (vs different doctor);
(vi) Mental stability.

Factors militating *against* compliance have been cited to be:-

(i) Complexity of the regimen (this was most significant when four or more drugs were involved);
(ii) Unfavourable doctor-patient relationship;
(iii) Psychological problems (especially mental illness).

The inferences drawn from these studies have been, inter-alia, to attempt to:-

(i) Simplify drug regimens as much as possible on as few drugs as possible and as simple a dosage schedule (eg once or twice daily) as possible; and
(ii) To involve patients in the decision-making process as far as possible.

"Patients often lie when they state that they have taken certain medicines" – Hippocrates

However, the fact remains that in spite of all these studies and the well-intentioned efforts to implement the recommendations arising out of them, patient compliance remains as thorny an issue as ever. As recently as January 1988, articles[2,3,4] to this effect regarding patient compliance with tuberculosis therapy in the Western Cape appeared in the S Afr Med J. And there is no doubt that non-compliance in areas other than the taking of medication eg cessation of smoking, dietary advice, exercise, etc, is of considerably greater magnitude.

What then, we may justifiably ask, is the issue of patient compliance really all about? There are, of course, a number of aspects to this question, but perhaps we should begin by examining the term "compliance" itself. Roget's Thesaurus[5] lists "obedience" and "observance" as synonyms of compliance, while synonyms of "obedient" include "meek", "biddable", "at one's beck and call" and "under control" Synonyms of "pliancy" (the noun from the adjective "pliant") include "conformity", "softness" and "persuasibility". Synonyms for the latter include "docility", "tractability" and "teachableness", while synonyms of "softness" include "elasticity", "sponginess" and "malleability". I have made these references to Roget's Thesaurus not in order to indulge in a semantic or linguistic exercise, but because I believe the very term "compliance" provides us with an important clue to the nature of the problem which doctors experience in this area. For many doctors it is indeed a matter of expecting their patients to be "pliant" enough to accept their advice and carry out their suggested treatments without demur. When patients fail to do so, they are left feeling surprised and angry, and tend to react in a critical, threatening

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and even disdainful way. Doctors will often classify their patients as "good" or "bad" according to whether they experience them as "compliant" or not. It may be worth reflecting on how doctors would feel if *they* were classified as "good" or "bad" according to whether they were perceived as "compliant" or not in the eyes of patients, ie to what extent they "complied" with patients requests for certain drugs, sick certificates, etc!

Bursztajn[6] et al, in their excellent book "Medical Choices, Medical Chances", refer to doctors who did not seem to know how to care for patients "without exacting compliance in return". They refer to "an implicit contract" whereby a patient "owed" the doctor compliance in return for care.

Albert Jonsen[7], in a paper entitled "Ethical Issues in Compliance", has this to say: — "Three serious sins can be attributed to the physician. The first is carelessness, the blameworthy failure to have the proper information about drugs and procedures, about the patient and the patient's social setting. The careless physician will fail to take reasonable efforts to educate and motivate. The second sin is irrationality, the prescription of medications that are not appropriate for the illness and are thus inefficacious or harmful, either in themselves or insofar as they keep the patient from the more appropriate drug. It would be

The very word compliance provides an important clue to the problem.

monstrous for physicians to pride themselves on achieving high compliance to an ineffective or harmful regimen. Third, the authoritarianism to which physicians are often tempted can be a serious sin. Compliance, it seems is best achieved in a partnership of understanding. The authoritarian physician giving orders without preparing patients for their acceptance

or supporting them in their observance, can undermine compliance."

It seems to me that Jonsen's comments are worthy of closer examination. The first two points, namely carelessness and irrationality would appear to be self-evident. However, a careful look at the facts would indicate that doctor's prescribing habits are not always rational, and that much controversy surrounds the use of certain commonly used drugs. An example is the use of diuretics — numerous studies have indicated that their long term use causes a disturbance of electrolyte and lipid profiles and this has been blamed for the fact that long-term studies of patients successfully treated for hypertension have still failed to demonstrate a reduction in the risk of myocardial infarction in such patients. Even the question of treatment of hypertension itself is by no means clear-cut: John Fry[8], in a paper entitled "The case against treatment for mild-to-moderate hypertension" in the book entitled "Common Dilemmas in Family Medicine", points out that there is no general agreement over when "normal" blood pressure becomes "high". He argues further that in almost one in three hypertensive patients there is a chance that the diastolic blood pressure will fall spontaneously. He postulates that within the spectrum of high blood pressure there are high-risk and low-risk groups that need to be defined, and that it is the low-risk group that make up more than one-half of all hypertensives who do not need therapy.

Doctors often classify their patients as good or bad according to their compliance.

Another example is the treatment of obesity, an activity still pursued with great vigour by many doctors. Recent research and further evaluation[9] of earlier work have shown that obesity is nothing like so serious a health risk as was previously thought. In fact the updated Framingham Study showed that moderate overweight was associated with the lowest mortality rates. In any case, long term treatments for obesity are extremely poor. In Craddock's series only 7 out of 150 patients maintained their ideal weight after 10-18 years.

If we add to the above examples the indiscriminate prescribing of antibiotic drugs and psychotropics it becomes clear that we doctors have no reason to be complacent.

The comments that have been made thus far could be misinterpreted as being a kind of therapeutic nihilism. I would like to emphasise that this has not been my intention or my meaning. There are many instances where patients could have derived great benefits if they had been more compliant and conversely also many cases where the outcome of non-compliance has been a tragic one. However, the point that has been made is that the question of compliance/non-compliance is a complex one, which does not justify a dogmatic approach on the part of the doctor.

I now turn to Jonsen's[7] third point, ie doctors' authoritarianism and the question of patient participation in the decision-making process. As mentioned earlier, these factors have been shown to be of great importance in numerous compliance studies.

Doctors do not have a good track record as far as involving patients in the decision-making process is concerned. In a major study[10] conducted in general practice in the UK, involving over 600 consultations it was found that doctors tended to limit the exchange of ideas in consultations (eg by ignoring or cutting short patients' attempts to explain their symptoms or problems) and controlled the way information was given to patients (eg by withholding information that would reveal the doctor's own uncertainty or ignorance) in order to maintain their professional power and authority. Another interesting finding from the study was that patients from higher occupational backgrounds were more likely than those from lower ones to be active in consultations or to ask questions, or to express doubts about the doctor's diagnosis, treatment, etc. The authors express the view that "the discomfort and evasion implicit in the present experience of consultations" could well be reflected

in (amongst other things) patient non-compliance. They also point out that while many doctors offer time as an excuse for not sharing ideas with patients, there is some evidence to indicate that the opposite is the case ie if the patient is allowed to express his real fealings, fears, etc about drug treatments for example, there is less likelihood of time, money, (and drugs!) being wasted because of the problems being expressed in other, more negative ways, eg psycho-somatic symptoms.

Hoffie Conradie[11] in an article on Compliance to TB outpatient treatment in the SA Family Practice Journal, points out that "The problem of non-compliance is rarely one of knowledge". He says that attitudes such as non-compliance is "bad" behaviour or compliance is the "expected behaviour", need to be changed to a non-judgemental approach to compliance. He concludes: — "It is important to remember that establishing the regime with and for a particular patient may take at least as much time and skill as does establishing the diagnosis. Finally, perhaps the most important determinant of compliant behaviour is a doctor-patient relationship which allows for mutual participation and trust".

A patient owed the doctor compliance in return for care!

It seems as though the value of greater patient participation is supported by patients themselves. Gawie Pistorius[12] reports on a survey conducted in the Department of Family Practice at the University of the Orange Free State in which 83,6% of the patients who completed questionnaires requested greater participation in the management of their own problems. Many patients felt that more patient participation would lead to greater trust and confidence in their doctor, and to greater compliance.

At this point I would like to address the question of "patient participation" in the decision-making process more closely. There has been much emotional debate on this topic and some rather loose bandying about of ideas. On the one hand there are still those doctors who cling to the old authoritarian notion that the doctor knows best and the patient must do as he/she is told or suffer the consequences; at the opposite extreme we have the argument that the patient knows just as much as the doctor, so the doctor has no contribution to make to the decision-making process. Both these viewpoints, in my opinion, miss the point. The point is *not* whether the doctor has more or less knowledge than the patient, but the fact that doctor and patient each have a different *kind* of knowledge. The doctor's knowledge is of a comparatively more objective nature, the patient's more subjective, embracing such entities as the patient's previous and current life experiences (including experiences of illness), his bodily sensations, and his intuitions. Both these inputs have a vital contribution to make to the decision-making process, neither is more important than the other. As Tuckett[10] et al put it in their book "Meetings Between Experts", (subtitled 'An Approach to Sharing Ideas in Medical Consultations') the patient is also an expert of a kind. The doctor fails to make use of the patient's expertise at his and the patient's own peril.

Compliance is best achieved in a partnership of understanding.

David Sackett[13] in a paper entitled "A Compliance Practicum for the Busy Practitioner" suggests that before any attempt is made to find and help the patient with low compliance, the practitioner must, inter alia, answer the question whether the patient is a free, informed, consenting partner in this intervention.

This brings me to another hotly-debated question, namely the *giving of information* to patients. Here once again we have doctors divided into two opposing camps. There are those who argue that the giving of information is a waste of time as the patient neither understands nor is interested in what the doctor is telling him. In support of this view they cite the bored expressions on patients' faces when regaled with medical lectures, and the comments made by certain patients that they accept the doctors judgement so he should just tell them what to do. On the other hand there are those who argue that without full information about his condition and treatment, the patient is not in a position to make appropriate decisions and is less likely to comply with treatment. Once again, both arguments are off the mark. For it is not information *per se* which is of importance to patients, but a particular *kind* of information which is of importance to the particular patient and which necessarily differs from one patient to another. One patient requiring

A patient is more likely to comply with treatment if it makes sense to him.

treatment for hypertension, for example, may want to know what the risks are of his having a stroke with or without the medication the doctor wishes to prescribe, while another may want to know whether the pills the doctor recommends are likely to result in his becoming impotent. It is therefore of the utmost importance that rather than launch into long treatises on medical conditions and their treatment, the doctor should first attempt to ascertain what the *patient* understands about his/her condition and the need for

treatment. It does, after all, stand to reason that a patient is more likely to comply with treatment if it makes *sense* to him — the doctor cannot assume that what makes sense to *him* will necessarily make sense to the patient.

From what has been said thus far it should be clear that treatment decisions are much more complex than is commonly supposed, from the point of view of both the doctor and the patient. Both approach the situation from a position of *uncertainty:* the doctor knows (or should know) that response to treatment is always unpredictable to a lesser or greater degree, that treatment regimens (such as diuretics which were mentioned earlier) which may be considered highly efficacious at a certain time may later prove to be useless and even harmful; the patient for his part is faced with the uncertainty of the implications of the doctor's diagnosis and suggested treatment for his future health, marital and family life, work situation, etc. How can doctor and patient, both to some extent groping in the dark, cope with the uncertainty which faces them? One way this uncertainty has been dealt with frequently up till now has been to *deny* it. The doctor may manifest this denial with a dogmatic and authoritarian set of instructions to his patients which seem designed to portray the doctor as the bearer of immutable truths. The patient in his turn, may deal with his own uncertainty either by slavishly adhering to the doctor's assertions (and suppressing all his own deep and agonising misgivings about them) or else dismissing what the doctor says entirely and manifesting what is ordinarily described as "non-compliance". Either way, we are dealing with a highly unsatisfactory situation: a patient who is faced either with a threat to his sense of control over his own life or a threat to his life itself.

The doctor must always be ready to hear the patient's reasons for being unwilling to comply.

What then, is a more appropriate way for doctors and patients to deal with the uncertainty which is a feature of every management decision in medicine? Bursztajn[6] et al attempt to answer this question by postulating the need for doctors and patients to learn to "gamble" together in the decision-making process. Their use of the word "gamble" requires clarification: it is different from the ordinary English usage of the word which refers either to the playing of random games of chance or to the compulsive pathological activity of certain individuals in settings such as casinos or racetracks. As described by Bursztajn[6] et al, "gambling" is based on the recognition that there are no certainties in medicine, only *probabilities* of certain occurrences which may be judged with a lesser or greater degree of accuracy. Constructive, co-operative gambling between doctor and patient would imply a mutual examination of *all* the factors involved in assessing the probable advantages and probable risks of a particular course of action. Actually doctors are engaging in this kind of "gambling" all the time, often without realising it. What Bursztajn et al have called for is the conscious application of these principles in consultation with the patient. To use the example of hypertension yet again: the doctor needs to be aware not only of the likely benefits of therapy, but also the risks, the incidence of side-effects, etc. The patient has to consider, for example, the effects of drowsiness (a common side effect of anti-hypertensive medication and one which Bursztajn et al describe as "a high cost indeed for an active person who may have experienced no symptoms and no apparent disability from the disease itself") on his work — and family life. His response to this consideration will depend inter-alia, on his own personality make-up and life circumstances.

A patient from my own practice, for example, resisted taking pills for his hypertensive heart disease because his wife was much younger than he was, and he feared that (a) symptoms like drowsiness and impotence might antagonise his wife and (b) the very act of taking tablets was a reminder to his wife and himself that he was a "sick old man", something which he desperately

wanted her not to believe. It needs to be pointed out that such considerations are not merely incidental, but are crucial factors in the equation which doctor and patient must jointly attempt to resolve. As Bursztajn put it: "Such treatment decisions and the manner in which they are made are part of the diagnosis and thus themselves become causes of the patients' condition. For example, by participating in the decision-making, the patient may become more relaxed and therefore may show a lower blood pressure reading. This, too, is part of the treatment to which the patient is observed to respond".

Another example is that of malignant disease where the doctor's knowledge of survival-rates with or without various forms of treatment, risk of side-effects of treatment, etc have to be considered with the patient's attitude to life and death, health and disease, etc. Bursztajn[6] et al cite the example of an 85 year old man with widespread cancer of the colon who has developed intestinal obstruction and is rushed to hospital in a confused state. The surgeon performs a physical examination, and proceeds quickly to perform a colostomy. The authors argue that the patient may have had a number of good reasons not to want this operation, eg the operation might have left him less comfortable and more dependent on medical assistance, and possible brain damage from the anaesthesia, possibly promoting dementia and leaving the patient more helpless than before. Whatever the costs of the surgery, if it didn't stand a reasonable chance of making the patient *more* comfortable and better able to take care of himself, he may well have felt that at this point there would be little benefit in prolonging his life by such extreme measures. Given the patient's wishes (he had previously indicated that he did not wish to have any heroic measures which would prolong his life) and his condition, it is not at all clear that he should have been operated on.

A final example is from my own recent experience. An elderly asthmatic woman presented with severe broncho-spasm. She had already used her broncho-dilator inhaler and nebulised broncho-dilator therapy at home to no avail. She was in a distressed state. I administered an ampoule of aminophyllin intra-venously which resulted in a slight improvement but I was still far from happy with her condition. I told her that I felt it would be best if I referred her to hospital for further intensive treatment. She protested strongly against this suggestion. When I asked her why she objected to hospitalisation, she replied, struggling to speak properly, that she felt very "lonely" when she was in hospital.

I now found myself in a predicament with this "non-compliant" patient. If she did not go to hospital, her condition might deteriorate, possibly with a fatal outcome. On the other hand, if I were to try to force her to go to hospital, might not the effects of a broncho-dilator drip, oxygen, etc be cancelled out by the terror (for this woman) of the hospital experience, to say nothing of the emotional suffering itself. I informed the patient that if she did not go to hospital there was a risk that her condition might get worse and that she could even die as a result. She said she was prepared to accept that risk.

I then said I would give her a cortisone injection, the advantages of which might only be felt after a few hours. She agreed that if there was no improvement after some hours she would go to hospital accompanied by her son, who would stay there with her.

She phoned me the next day and told me that she was feeling better. She had only begun to feel better several hours after the cortisone injection, but after that she had felt all right. She said that she had phoned to thank me for my concern. I said that I was pleased that she was feeling better. "But I phoned to thank you for your *concern*" she insisted, her tone of voice indicating that she felt I had not understood her correctly, "You were so obviously *concerned*".

I think this interaction illustrates the points I have been trying to make very well. The issue that concerns us is not merely the narrow matter of "compliance", but concern for the patient as a whole-concern, respect, and an attempt to understand the patient's world as reflected in the treatment situation. In fact I would like to regard this paper as an appeal to all of us to look *beyond* compliance towards truly holistic patient care.

Of all the drugs used in general practice, the one most commonly prescribed, yet least understood, is the doctor himself.

Marie Campkin[14] in a chapter entitled "Why don't you listen to me, for a change", in the book entitled "While I'm here doctor", has this to say: "Just as we prescribe a decongestant for sinusitis, an analgesic for a sprain, or an antacid for a dietary indiscretion, so we may also discuss smoking, eating and drinking in a fairly superficial way with those patients for whom this seems appropriate. But discussing the patients' habits is not a substitute for attempting to get to grips with the underlying distress of which seriously self-destructive behaviour may be the presenting symptom. Nor is assuming an obligation to alter his behaviour an adequate alternative to looking with the patient at his whole life to see how, or indeed whether, he can make some changes.

"No matter how strongly he believes that the patient should follow the proferred advice, a doctor must always be ready to hear the patient's reasons for being unable or unwilling to comply. In this way he may sometimes find a route to a new understanding and tolerance of the patient's life and problems. Fruitless repetition of argument and admonition can reduce the whole relationship to a stalemate. The patient might

become reluctant even to present with new and possibly important symptoms for fear of further scolding, or out of guilt that as they must be of his own making he has no right to complain. What price health education then?" she concludes.

Her point is well-made: compliance is but one aspect of the complex mosaic which is the patient's world-view and the society in which he finds himself. As far as the latter aspect is concerned, we can again refer to Yach's[3] recent paper on TB patient compliance in the Western Cape. He points out that the lowest levels of compliance were found among blacks and the unemployed and suggests that fundamental changes in the social and economic status of deprived groups are required to overcome major impediments to compliance.

He pleads for a region-wide compliance-improving plan which needs to take cognisance of the realistic problems of ensuring high levels of compliance in townships where political instability is likely to be a problem for some time.

As far as the individual doctor and his patient are concerned, we would do well to remember Michael Balint's[15] aphorism that of all the drugs used in general practice, the most commonly prescribed, and yet least understood, is the doctor himself. He pleaded for a closer study of the "drug doctor" in order better to understand its indications, contra-indications, dosage, side-effects, etc. I believe that the better we are able to understand and judiciously use the drug doctor, the further we will have moved away from the outdated and inappropriate pre-occupation with "compliance" as though it were some sacred cow to be pursued and preserved at all costs. As we approach the 1990s let us rather attempt to advance beyond compliance and towards a *cooperative* effort with our patients in order best to help them face the increasingly difficult choices which lie ahead of them.

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From the Journals

Energy expenditure and intake in infants born to lean and overweight mothers

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Abstract We investigated the contributions of low energy expenditure and high energy intake to excessive weight gain in infants born to overweight mothers. The subjects were infants of 6 lean and 12 overweight mothers, recruited soon after birth. Total energy expenditure and metabolizable energy intake were measured with a new doubly labeled water method over a period of seven days when the infants were 3 months of age, and the postprandial metabolic rate was measured by indirect calorimetry when the infants were 0.1 and 3 months of age. The results were related to weight gain in the first year of life.

No significant difference was observed between infants who became overweight by the age of one year (50 percent of infants born to overweight mothers) and those who did not, with respect to weight, length, skinfold thicknesses, metabolic rate at 0.1 and 3 months of age, and metabolizable energy intake at 3 months. However, total energy expenditure at three months of age was 20,7 percent lower in the infants who became overweight than in the other infants (means ± SE, 256 ± 27 and 323 ± 12 kJ per kilogram of body weight per day; $P < 0.05$). This difference could account for the mean difference in weight gain.

These data suggest that reduced energy expenditure, particularly on physical activity, was an important factor in the rapid weight gain during the first year of life in infants born to overweight mothers.