

The doctor's perspective:

Dr Antonio Piga, University of Torino Thalassaemia Centre

Dr Antonio Piga heads one of the best known reference centres in the world for treatment of thalassaemia. In his view, the terms "compliance", "adherence" and "concordance" all refer basically to the same thing: the voluntary cooperation of the patient in following a prescribed regimen, including timing, dosage and frequency.



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In general, the adherence rate for long-term treatments is around 50% and much lower for lifestyle prescriptions. In thalassaemia, adherence – particularly to iron chelation – is crucial to survival and better health. Dr Piga reviewed methods for assessing compliance, and emphasised the obstacles to optimal compliance, both emotional and physical.

Obstacles to compliance

One of the obstacles is the so-called "patch" phenomenon: Transfusion does not cure; it compensates the anaemia, giving life and well-being, but also carrying damaging factors as viruses and iron, which has to be removed continuously by chelation. Even when successful in maintaining optimal chelation, the patient is always between the devil (iron toxicity) and the deep blue sea (chelation toxicity). Further, the patient cannot directly feel or experience the effects of both iron damage and iron chelation, so she/he can only realise how harmful it can be after many years of poor chelation, when damage is already done. Compliance is therefore a function of trust, that is to say of the quality of the doctor-patient relationship. Other factors for non-compliance include body image issues, the daily reminder of the condition and feeling "different", and the need to be constantly committed to the treatment.

On the emotional side, chronic disease may expose both patients and health professionals to feelings of impotence, frustration, negation, refusal or disinterest. Patients and doctors alike may be susceptible to search for a "magic solution". Patients, perhaps, do not always realise that their doctors also experience such feelings, since the doctors may activate defensive mechanisms that range from emotional detachment to over-involvement. Both prevent the possibility of a well-balanced and close doctor-patient relationship.

The challenge of the patient's choice

Health professional attitude and health services models have evolved over the years towards greater cooperation,

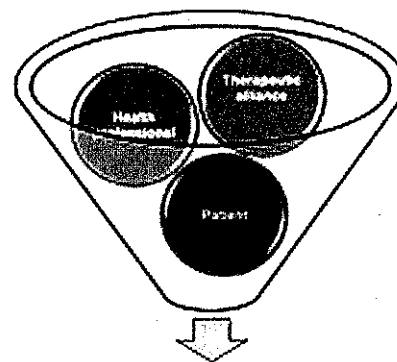
although there are still doctors whose attitudes could do with improving. The traditional paternalistic model ("the good patient obeys") is unfortunately still popular. The information transfer model ("the capable patient chooses adequately") leaves the incapable patient behind. The ideal model, the alliance model ("let's face it together") is difficult to be achieved. There are still remarkable differences between countries and cultures, however.

According to modern thinking, the patient's view takes precedence. This raises challenging questions about choice and responsibility: if the patient's choice falls substantially short of "safe" levels of treatment according to evidence-based guidelines, then the doctor may be left with a burden of responsibility that is hard to manage – emotionally, ethically and legally. Patient-centred care, and what the patient desires or can bear, may come into conflict with good medical practice and seriously compromise desirable health outcomes.

How to achieve concordance with good medical outcomes?

In thalassaemia, the problem of compliance has been alleviated to some extent by the advent of oral chelators, but it is noteworthy that they have not done away with the problem. Key elements to improve compliance include full and sincere information to the patient; accurate assessment of compliance with a listening and caring approach; and removal of practical obstacles to optimal compliance. More generally, a change in the culture of the doctor-patient encounter is needed. This does not mean just improving communication skills, although these are important, but an evolution of the whole relationship to be based on mutual respect – both for the doctor's professional opinion, and for the patient's personal decisions.

Compliance is therefore a function of trust, of the quality of the health professional-patient relationship, which considers the emotional as well as the physical obstacles to chelation, and should be a well-balanced and close one. Compliance, therefore, can well be considered as a marker of the quality of care.



Optimal compliance

Optimal compliance includes the patient and health professional as joint actors in a mutually respectful therapeutic alliance.