

DISCURSIVE PAPER

No decision about me without me: concordance operationalised

Austyn Snowden and Glenn Marland

Aims and objectives. To demonstrate that concordance can be operationalised to the benefit of patients. Concordance can be understood as a composite of knowledge, health beliefs and collaboration.

Background. In discussing any clinical decision, it would be ideal if different views could be incorporated to reach the most coherent decision. This is a definition of concordance, a widely agreed ideal in nursing. There are limits, however, that make the practice of concordance problematic. Sometimes there is little time or willingness to discuss issues in depth. Some views of the world are considered more worthy than others. As a consequence, clinical guidelines currently prioritise easier to measure outcomes of negotiation, such as adherence.

Design. This discursive article argues that prioritising adherence is a fundamental error, incoherent with current strategic rhetoric such as the Department of Health's 'no decision about me without me'.

Methods. The impact of prioritising concordance is contrasted with adherence-based interventions.

Results. Where adherence is a goal of treatment, non-adherence is considered problematic. This value judgment is not useful and does not occur in a consultation that prioritises concordance. However, concordance is difficult to translate into clinical practice. This article shows that concordance can be operationalised by considering it a composite of health beliefs, knowledge and collaboration.

Conclusion. The main thesis is that different behaviours can always be incorporated into a concordance framework. This negates the necessity for adherence as an endpoint in itself.

Relevance to clinical practice. Fifty per cent of people do not take medicines as prescribed. Interventions focused towards improving adherence are only ever partially successful. This is because it presupposes the clinician is right. Concordance by contrast is more coherent with person centred care and thus more likely to generate clinically meaningful outcomes for patients.

Key words: adherence, compliance, concordance, ethics, health beliefs, medicine management

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Accessible summary

- Concordance is the best way to manage medicines.
- Concordance can be conceptualised as the process of a negotiation grounded in participants' knowledge and health beliefs.

- By sharing someone's knowledge and health beliefs, the nurse is showing that they *want* to understand.
- This act of collaboration is functional in itself. It engenders hope and generates better outcomes.
- Concordance therefore renders concepts such as adherence meaningless as endpoints in themselves.

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Introduction

The UK government regards shared decision-making as an ethical imperative which should become a norm in the National Health Service (NHS) (Coulter & Collins 2011). It is surprising therefore that the term ‘concordance’ is not mentioned in the ‘no decisions about me without me’ report, despite affirming that sharing decision-making is appropriate for decisions about whether to take medicine. Instead, the UK government favours the term ‘adherence’ (Coulter & Collins 2011). This article argues that this is a missed opportunity. We show that adherence does not necessarily presuppose shared care and in fact leads to confusion regarding the role and scope of shared care. Conceptual clarity is important if the aim of establishing shared decision-making in the NHS is ever to be realised.

This study uses medicine management for the context of this discussion, but the principles underpinning concordance apply to nursing in general. In brief, concordance should be viewed as the ethical goal of partnership. One of the main reasons this is so difficult is because concordance is difficult to articulate in practice. This study articulates concordance by breaking it down into achievable goals. The place of knowledge, health beliefs and collaboration as manageable aspects of concordance is demonstrated. The reason for focusing on these integrated aspects of decision-making is grounded in the evidence that telling people what to do, no matter how good that advice may be, is only ever partially successful. Strategies that the nurse may take to approach concordance are illustrated.

These strategies are necessary because elucidating someone’s health beliefs is not always a priority (Latter 2011), and collaboration is rarely as good as nurses think it is (Latter *et al.* 2007). Nurses do not engage with evidence as much as they claim to (Nolan & Bradley 2008), and nurses’ knowledge of medicines in particular also leaves room for improvement (Ndosi & Newell 2009). On top of this, or possibly as a consequence, concordance has proved difficult to operationalise and is out of favour in governmental rhetoric.

For example, in 2009, the National Institute for Health and Clinical Excellence (NICE) produced their guideline *Medicines Adherence: involving patients in decisions about prescribed medicines and supporting adherence* (National Institute for Health and Clinical Excellence 2009). On first view, this seems a significant step. The title suggests adherence relates to involvement in decision-making. However, NICE define adherence as:

the extent to which the patient’s behaviour matches agreed recommendations from the prescriber. (p. 1)

We would argue that this misses a crucial step. That is, agreeing with a prescriber is fine as long as it presupposes a concordant discussion. To be fair, the guideline developers make this clear:

Addressing non-adherence is not about getting patients to take more medicines per se. It starts with an understanding of patients’ perspectives of medicines and the reasons why they may not want or are unable to use them. (p. 1)

However, without this precondition grounded in *concordance*, we would argue that an uncritical acceptance of the concept of adherence will subsequently entrench *compliance* directed interventions. The guideline states that it was originally intended to entitle the guideline *Medicine Concordance* but the developers thought this may be ‘unhelpful to healthcare professionals’ (p. 17). Whilst this is understandable because of the complexity of concordance, we suggest changing it to adherence missed an opportunity to be more helpful to service users.

That is, the principle of concordance is implicit in the latest NHS strategy document *Equity and Excellence: Liberating the NHS* (Department Of Health 2010). The founding principle of this document is:

We will put patients at the heart of the NHS, through an information revolution and greater choice and control

Shared decision-making will become the norm: no decision about me without me. (p. 4)

Shared care is concordance, not adherence.

Background: concordance, compliance and adherence

Concordance is not a synonym of compliance or adherence. Concordance is a way of working together with people. For example, in relation to medicine-taking, concordance entails a collaborative process incorporating the hopes, beliefs and actions of prescriber and recipient. The aim of a concordant alliance is to maintain an optimal therapeutic effect from medicine-taking, not to inculcate compliance or adherence, although these may be the *outcomes* of concordance.

In other words, compliance and adherence are not considered universally bad within a concordant framework. They are simply distinct concepts. Where confusion arises is that concordance, compliance and adherence are all used interchangeably within the literature. This is more than a semantic issue. For example, Latter *et al.* (2007) conducted a study designed to ascertain the degree to which nurses were practising the principles of concordance. This is an

Table 1 Definition of terms

Term	Definition
Concordance	The process of developing a mutually agreed treatment plan
Compliance	The act of following an instruction
Adherence	The process of sticking with a course of treatment

important study because the nurses thought that they were practising the principles of concordance, whereas the study found that they were not. Latter *et al.* found that the *language* of medicine management had changed. Instead of talking about compliance, nurses talked about patients 'concording with their medicine regimes'. In practice, however, medicine management activity remained focused on the goal of compliance. Conceptual clarity is therefore a fundamental starting point in any discussion of concordance. The terms concordance, adherence and compliance are defined in Table 1. They are all very important concepts in their own right, and all have a place in good nursing, but they are not the same.

Method

To illustrate the function of shared care grounded in the principles of concordance, this study analyses two very straightforward examples of health consultation. The examples have been chosen for their simplicity to highlight the importance of knowledge, health beliefs and collaboration. They are not intended to be representative of complex consultation. The purpose of the examples is to contrast concordance-based interventions with discordant interventions in general.

Concordance can be conceptualised as collaboration grounded in mutual understanding of both parties' knowledge and health beliefs. All of these themes are requisite to a positive outcome, and we will show that this conceptualisation of concordance is useful with whatever decision-making strategy the participants have. It acknowledges that some people want nothing to do with health decisions, whereas others want to be intimately involved. However, articulating these themes and typologies makes concordance more understandable, and hence more attainable and helpful than NICE (2009) suggest.

One of the most consistent criticisms of the philosophy of partnership in health care is that it generally involves a relationship of unequal partners, and in that the health professional is usually in possession of specialist knowledge and expertise the other partner does not have (Barker 2011, Coffey & Byrt 2011). However, this is not prohibi-

tive, and it could be argued that this is the case in any partnership at any given time. The examples below (Snowden 2012) illustrate this:

Example 1: I (AS) went to the dentist recently for a check-up. I have a good relationship with my dentist. She remembers me from one appointment to the next and seems genuinely interested in her job. She always explains what she is doing and why and asks me pertinent questions about my oral hygiene and any problems I may have had since the last visit. On this occasion, I had had some pain on my upper left molar region whilst eating hot or cold food. She paid particular attention to this and closely examined the area of concern. She told me my gums were receding a little and that this could be the likely cause of my distress. She asked me how I brushed my teeth and what sort of toothbrush I used. As a result of this conversation, she suggested I try an electric toothbrush instead, as my particular brushing action could be making things worse. She told me it would be more boring as I just have to hold the brush in one place but I said I would do it for the sake of my gums. She also suggested I use a particular brand of toothpaste and apply a little to the sensitive area at night. I subsequently took her advice and complied with the treatment plan.

Example 2: A close friend went to a GP for a first appointment. There was no existing relationship but the GP was professional and courteous and appeared engaged. The GP asked about the problem, and my friend explained the unusual recent loss of vitality and enthusiasm combined with sleep problems and diminished appetite. The GP asked further clarifying questions to rule out recent trauma or other causal factors, establish the pattern of sleep problems and to ascertain the length of time these problems had persisted. The GP also asked if there had ever been any thoughts of self harm and my friend said no. The GP then informed my friend they were probably depressed and prescribed an antidepressant. My friend thanked the GP and left the surgery. The prescription was never collected.

Results

In both cases, the health professional was in the possession of relevant expert knowledge. Both competently ascertained the problem and explored it in enough detail to come to a rational conclusion. Subsequently, one course of treatment advice was followed and one was not. This ratio is a microcosmic snapshot of compliance in UK, given that only 50% prescriptions are taken as directed (Healthcare Commission 2007). This study makes no judgement on whether the courses of treatment proposed were correct or not. Instead what this study argues is that this ratio of 50% adher-

ence could be improved by practising the principles of concordance. This position does not presuppose that more prescriptions should be taken as directed. Perhaps less should be written.

Within each of the examples described previously, there are two people with potentially differing health beliefs, differing knowledge and perhaps different views of what a consultation should entail. The place of knowledge, health beliefs, medicine-taking typology and collaboration will be discussed in turn to offer explanations for the differences in outcome between examples 1 and 2. Collaboration will be discussed, and the role of mutually defining health beliefs and medicine-taking behaviour will constitute the bulk of the article. For the sake of space, the role of knowledge will be very briefly discussed first, as the suggestion that the nurse should know what they are doing is probably the least contentious.

Knowledge

Knowledge is in many ways the most straightforward aspect of any consultation. It is not a sufficient condition, but it is a necessary condition, in that without it no amount of collaborative discussion around health beliefs would be complete. For example, when prescribing psychotropic drugs, without in depth knowledge of pharmacodynamics and pharmacokinetics even the best relationship will not be able to address the most fundamental questions: for example, Why am I taking this medicine? Are they effective? What are the side effects (Gray *et al.* 2010)? To answer these questions, the prescriber needs to know what the medicine is for, what it is supposed to do and how it is supposed to do it.

To answer these questions in any meaningful way, it is also essential to have a critical understanding of the role and function of medicine in mental health. For example, the notion of side effect is essentially a pharmacocentric marketing ploy (Barondes 2003, Bentall 2003) in that a 'side effect' in one person is a desirable effect in another (Mitchell 2007). Medicines can only be fully understood from a value-free perspective (Moncrieff 2007). Knowledge in this sense therefore includes the capacity to differentiate between what they actually do in a biochemical sense and what they are claimed to do in a marketing sense. Without this knowledge, the nurse will be unable to answer Gray *et al.*'s (2010) questions in any meaningful manner.

So, to help in example 1 in essence, you would have to have the knowledge of a dentist. You would need to know the causes of gum disease and the prognosis with and without intervention, along with a critical appraisal of evidence-based remedial action. In example 2, you would at least

need to understand symptomatology of depression, classification systems, assessment criteria, an understanding of the pharmacological properties of the proposed treatment and the medical history of the recipient. In both cases, you would also need to understand the limits of your knowledge to remain safe. In both consultation examples, the professionals were highly knowledgeable. The dentist and GP diagnosed the problem from accurate and contextually appropriate assessment and suggested a coherent treatment plan grounded in expert understanding. The fact that one plan was followed and the other was not was not a function of knowledge. However, neither plan could have been constructed without knowledge.

Health beliefs and medicine-taking typology

People have different health beliefs and these beliefs have a significant impact on subsequent behaviour, including actual outcome of treatment. Consider the placebo effect by which an inert substance exerts a therapeutic effect. Benedetti has spent an entire research career trying to understand the neurobiological underpinnings of this mechanism and produced some fascinating evidence. He has shown that if people take diazepam without knowing they have taken it, then it has no anxiolytic effect (Benedetti 2009). Pain can be reduced in people who believe they are receiving pain relievers, even when they are receiving opioid blockers, as long as the *administrator* of the medicine also believes it will relieve the pain (Benedetti *et al.* 2005). The beliefs and behaviour of everyone involved in medicine management therefore have an impact on the efficacy of that medicine.

To structure investigation into this issue, Marland and Cash (2005) developed a grounded theory aimed at understanding medicine-taking beliefs and behaviour in mainstream psychiatry. They identified three broad types of behaviour, illustrated below. The clinical utility of this is that there may therefore be a benefit to recognise which type of behaviour people exhibit to tailor further intervention accordingly. The types were the following:

- 1 *Deferential compliant type*. This type defines the person who leaves all medicine-taking decisions to the prescriber and complies even in the absence of insight.
- 2 *Direct reactive type*. The person denies the need for medicines and ceases to take medicine when well to assert wellness, or in reaction to side effects or stigma.
- 3 *Active discernment and optimising type* includes people with the ability and will to reflect on past experiences. This type is further divided into two stages:
 - *Experimental-reflective stage* - the person insightfully and actively experiments to achieve the optimum

medicine regime. This can be carried out unilaterally or in concordance with the prescriber. It may involve reducing the medicine taken to see whether beneficial effects can be maintained and side effects reduced and 'recovery testing', which is ceasing to take medicines to prove or disprove their need.

- *Consolidation stage* - in which the service user has found an effective way of using medicines and is reluctant to consider any changes.

Using this typology as an example, it can be seen that if *concordance* is prioritised as an outcome instead of adherence or compliance then concordance can be achieved with any of these beliefs and behaviours. It does not matter what peoples' beliefs or actions are; only that everyone understands them. This equation of course also includes the nurse and would require the nurse to reflect on their own beliefs about the treatment they are prescribing and to clarify the impact of these beliefs. By testing these assumptions in practice, both parties have an opportunity to align their interactions to the optimal outcome, which needs to be *mutually defined* (see Fig. 1).

This 'mutual definition principle' offers an explanation for the differences in behaviour between the two examples. I (AS) am happy to leave treatment decisions to my dentist. She knows more than I do about my teeth and I value her input. However, even without knowing that I value her opinion, there is clearly something more going on than me simply following instructions. At no point were any assumptions made by the dentist, and there was implicit agreement that the treatment plan would suit me personally. We agreed on the course of action. This type of interaction suits me personally because in the language of the typology in this type of interaction I am an 'active discerning' type. I like to be involved and am happy to reflect on past experience. I will now 'actively experiment to achieve the optimum [dental] regime'. The dentist's actions aligned with the type of actions needed for concordance in this case.

The second person in the examples on the other hand may fit into the direct reactive or active discernment type. We do not know. All we know is that they are not deferential compliant. If the GP had recognised that their assumptions may not be correct and that my friend's health beliefs may be of relevance in this consultation then they could have asked. If they had, they may have found out that my friend had no intention of taking these medicines. Whatever the reason, a different strategy would have emerged by finding out the second person's health beliefs.

Peoples' beliefs about health are therefore a fundamental aspect of concordance. Treatment will be less successful if it is discordant with how people view their world. Regard-

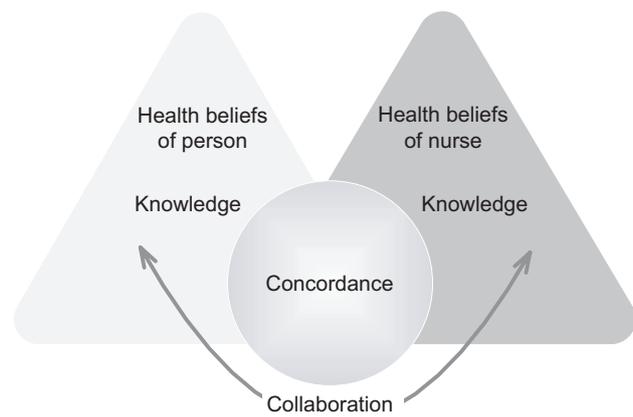


Figure 1 The construction of concordance.

less of health beliefs concordance can always be achieved as long as the specific needs of the particular *relationship* are met. We would argue this is a transferable aspect of any nursing intervention.

Collaboration

Collaboration is difficult, and not just because of the complex power issues alluded to above. There are more straightforward aspects. From a purely practical perspective collaborating does not necessarily save time and therefore may not be seen as an option for busy clinicians. This probably goes some way to explaining the outcome in example 2. There is also evidence some nurses feel they have not got the skills to operate in a truly collaborative manner (Snowden *et al.* 2011). Clinicians consistently express fear of opening 'cans of worms' they feel unable to manage (Latter *et al.* 2010). As found in Marland and Cash's (2005) typology, there is clear evidence people may not expect or want anything to do with medicine-taking decisions. For example, Stenner *et al.* (2011) found that regardless of the level of information patients wanted, when it came to making decisions about treatment, most preferred the nurse to use their professional judgment to offer the best treatment option for them.

However, this can and should still be a *collaborative* process (Shattell *et al.* 2006). It puts onus on nurses' knowledge of medicines' actions and interactions, because in these cases, the recipient is relying on the health professional to tell them everything they need to know. These 'deferential compliant' people still need to understand and be understood, and this can only be achieved through collaboration. Although this is increasingly recognised as a worthy aim there is evidence that nurses may not be giving people the information they actually need (Ekman *et al.*

2007). This can be more usefully envisaged as discordant rather than non-adherent.

For example, Snowden's (2008) review of effective interventions in medicine management in older adults found the only interventions to be consistently successful were those described as 'individually tailored' interventions (p. 118). None of the interventions targeted towards compliance or adherence were successful because they omitted the most important aspect of medicine management in this group: concordance. The only successful interventions accounted for concordance.

In an attempt to operationalise this in a structured manner, Latter *et al.* (2010) found nurse prescribers could be taught to improve their communication skills. This is pertinent to the principles of concordance because Latter *et al.* (2010) focused on teaching nurses how to elicit patients' beliefs about their medicines to better support their medicine-taking. The results were significant and showed that there is considerable space for better collaboration. Whilst we do not understand why (Benedetti 2009), it seems that if people believe their medicine can do what they think it should do then it has a better chance of achieving that outcome. It is therefore important to understand what people think the medicine should do *to them*.

In the first example, both the patient and dentist had a clear discussion to the end of getting rid of my occasional toothache. We both agreed to focus on this as the central problem. We found out together that I was ineffective at teeth brushing and we agreed together a course of action. I have subsequently carried this out. This collaboration is the missing link in example 2. The GP clearly had extensive knowledge about the aetiology and symptomatology of depression. They may have even prescribed an appropriate antidepressant for this severity and type of depression. However, the consultation was a waste of time because at no point was the recipient of the prescription asked their view on what they thought about this course of action.

Discussion

Concordance and coherence

Health belief models have been recognised as important since at least the 1950s. Although the links between these models and subsequent behaviour is not clear (Carpenter 2010), there is little doubt that understanding someone's health beliefs enables more collaborative discussion and improves insight into the reasons people may or may not follow an agreed treatment plan. In a practical sense, eliciting someone's health beliefs is straightforward, and

there are many ways of framing this discussion (McCann *et al.* 2008).

In a more general sense, regardless of specific content the purpose of health belief models is to construct some sort of risk-benefit analysis. From a concordance perspective, the health belief models facilitate the provision of relevant individualised information to help answer the following question: what is the risk to me of taking this course of action? Is that risk worth the benefit?

In example 1, the risk to me was fairly minimal. It mainly consisted of boredom as I always seem to have something else to do and therefore have a tendency to rush brushing my teeth. The benefit of slowing down and using a more appropriate technique far outweighed this particular risk. I shall sacrifice a little time to hang on to my teeth. Person 2 on the other hand may have considered the risk too high. To know this for sure, the GP needed to ask what my friend thought about the diagnosis and proposed treatment. In essence then, this is an incredibly simple intervention. Ascertaining someone's health beliefs is simply a matter of asking. Latter *et al.* (2010) show how important this simple action is:

I asked a gentleman, 'what are your beliefs around diabetes? 'What does it mean to you?' And he just turned round and said, 'I'm going to lose my legs.' He's a gardener I'd been seeing for a year up until that point and I thought, 'how do I not know this about you?' (Community matron 2, cohort 3, 1 month interview; Latter *et al.* 2010, p. 1133)

The act of gathering information fulfilled a dual role. It not only indicated clinical levels of distress and its cause, but also gives a signal that the clinicians *wanted to know*. The impact of this is both simple and effective, and further studies have shown that this interest is reciprocated. People who feel that their clinicians are genuinely interested in them are more likely to try to follow the agreed treatment plan (Swanson & Koch 2010, Latter 2011, Stenner *et al.* 2011).

Relevance to clinical practice

Concordance is achievable but requires a different set of priorities to that currently articulated in national guidelines. This difficulty is a function of incoherence between the attempts to align person centred care with a predetermined outcome based agenda.

Concordance by contrast is an end in itself. It is more coherent with shared care than adherence or compliance, but has been rejected by guideline developers because of its complexity. By breaking concordance down into the manageable and measurable constructs of knowledge, health beliefs and collaboration, this study has argued that

concordance is not only ethical, but also practically achievable. For example, mental health nurses are demonstrably good at collaborating with people with severe mental health problems (Shattell *et al.* 2006). Elucidating someone's health beliefs can simply be the product of a single question and recognising that asking it is important (Latter *et al.* 2010). The need for evidence-based knowledge to augment these skills is increasingly recognised (Hemingway *et al.* 2011). This progression all needs clear direction, though, because the language of shared care is currently embedded in an adherence framework, which cannot be enacted as shared care.

Concordance is best practice. When concordance is achieved, adherence naturally follows where appropriate, as the mutual agreement, and not the outcome of this agreement, has been prioritised. This is why current national guidelines for medicine management (NICE 2009) have to evolve to recognise this, as they presently have these fundamental priorities the wrong way round.

Contributions

Study design: AS, GM; data analysis: AS, GM and manuscript preparation: AS, GM.

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