

COMPLIANCE, CONCORDANCE AND RESPECT FOR THE PATIENT'S AGENDA

Paul Bissell discusses compliance and concordance as models for framing relationships between patients and health care professionals

This article is based on findings from my doctoral thesis, which set out to explore lay and professional perspectives on compliance with treatment, focusing specifically on people of Pakistani origin with a diagnosis of type 2 diabetes. One of the aims of my thesis was to explore how patients and professionals conceptualised decisions to comply, or not to comply, with the treatment of diabetes.¹ I also wanted to assess the role lay health beliefs (or what is more appropriately referred to as lay knowledge²) played in shaping decisions to comply. As a medical sociologist, I had been influenced by a body of social science research which questioned the paternalistic and authoritarian assumptions of the compliance model^{3,4} and I saw the report of the Concordance Working Party, which called for a sea-change in the culture of both prescribing and relating to patients, as taking this critique into health policy. The Working Party argues that “concordance is based on the notion that the work of the prescriber and patient in the consultation is a negotiation between equals and the aim is therefore a therapeutic alliance between them. . . . Its strength lies in a new assumption of respect for the patient's agenda and the creation of openness in the relationship, so that both doctor and patient together can proceed on the basis of reality and not of misunderstanding, distrust and concealment.”⁵

It continues: “. . . the most salient and prevalent influences on medication taking are the beliefs that people hold about their medication and about medicines in general. These beliefs are often at variance with the best evidence from medical science.”

Given the political salience of this report, I modified the aims of my thesis to include an exploration of the idea of concordance (or health care relationships more generally) with the groups I was studying. What I want to do here is to describe in some detail the experiences of one lay person in order to highlight some pervasive problems with relationships between patients and professionals. In particular, I want to explore what “respect for the patient's agenda” (explicitly referred to in the definition of concordance) means for relationships between patients and professionals.

I use here an extended case study design focusing on the experiences of one respondent. Mrs D was one of 21 English speaking people of Pakistani origin diagnosed with type 2 diabetes whom I interviewed and subsequently reinterviewed for my doctoral thesis. Mrs D and the other lay respondents were recruited from both primary and sec-

ondary care diabetes centres based in north-west England. A detailed account of how I recruited respondents and analysed the resultant data can be found elsewhere.^{1,6}

MRS D'S ACCOUNT

Although born in Karachi, Mrs D had lived in north-west England for most of her life. In her early 40s, she was married with four children and also took responsibility for the care of her elderly mother. Although her husband had experienced periods of unemployment, he was currently employed in a local factory.

When I first interviewed her, Mrs D had been diagnosed with diabetes for about six years and indicated that her treatment consisted of a combination of medication (metformin 850mg) alongside compliance with the diabetic diet and regular exercise. Her formal health care was organised between her general practitioner and a hospital. Mrs D had also been diagnosed with arthritis, hypertension and migraine headaches and also had a very high body mass index.

Mrs D knew she had to eat in concordance with the diabetic regimen and was similarly aware of the requirement to exercise. She knew when and how to take her metformin and monitored her blood glucose levels, speaking about “getting 15s and 16s”. Her knowledge about diabetes had been sharpened by the death of her uncle from diabetes complications. Mrs D herself had experienced episodes of hypoglycaemia, losing consciousness on several occasions.

I asked Mrs D how she found the diabetes regimen and she focused immediately on her difficulties in complying with the diet. She pointed out that as the person in the family responsible for domestic duties, she felt she needed to cook two main meals — one for herself and one for her the rest of her family — because her husband and children typically did not want to eat what she was expected to eat. These difficulties were exacerbated by her relative poverty and a desire to “fit in” with the rest of her family. As she put it:

If I want to cook something separate for myself, then I can't. Cause I've got to cook tea. And it depends what we have in. And we've got something [the children] like, which I shouldn't be having — like, oh I don't know, some sugary thing — then I will often eat that because there

is nothing else. They want some Western-like pudding — I don't know, ice cream. And I want to fit in with them. I can't afford another one. You know? You know, all right things like butter I get for them which I have because I can't afford the low fat version and they like the butter. So, that's one thing — its not good. It's expensive.

Mrs D said she found exercise difficult because of her arthritis and pointed out that she had been mugged once when out walking locally. She was, however, well aware of the medical injunctions to exercise:

And they [say] you should walk a lot with diabetes. Do exercise. And that is something I can't do. The pains that I have, with the arthritis. I can't do much exercise with my diabetes. What I only do, is going shopping. And that's with the kids cause I don't want to go on my own at all. You know, in case I start getting dizzy. It[s] too frightening.”

Mrs D pointed out that the hypoglycaemic episodes had prompted her to maintain higher than recommended blood glucose levels in order to avoid these. Furthermore, she also described having depression which in the past had been treated by a psychiatrist. She said that her depression had been exacerbated by the recent death of her father:

When my dad died just after that, like I was sitting down thinking and I eat more. I eat more. Thinking about it. You[r] diabetes you should control yourself but it is hard. I don't like diabetes. And with other things like my father, like him dying, I start thinking and I sit down and I eat more.

Given that all this seemed highly pertinent to understanding why Mrs D experienced problems complying with the diabetes regimen, I asked her whether she had told any health professionals about these experiences. She said she had not. Rather, she said:

Well, it's like when I go to the doctor, she says I am overweight, that's what is causing everything.

PB: How does that make you feel?

Mrs D: They are blaming me. It makes me bad, it makes me feel bad and I get angry. All they say is you should lose weight and you are overweight, and they don't know its hard . . . it's really hard being diabetic and there is nothing to look forward to. Once, cheeky thing, doctor said to me, she says, you won't live long. She shouldn't have said that to me.

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PB: *And they believe that you can't control your weight — it's not your fault.*

Mrs D: *And they don't know, it's since my father died and I get diabetes. I think and I think and I get depressed. I can't do what I used to do and I get depressed. And they shout at me and say, lose weight or you will die. I know I am a bit overweight but it's so hard. I want to eat with my family. You know, when it gets really hard, I will cheat and I will eat it. And when I get overweight, I think well, if they knew how hard it was. They might not say it to me. You going to die. You going to die. Can they not see it will make me upset?*

From her descriptions, the approach to communicating with Mrs D appeared to consist of reinforcing simple messages to lose weight, alongside warnings about what might happen if she did not. After relating this experience, she went on to speak disparagingly about her own ability to follow the diabetes regimen:

I mean, I've got diabetes, I'm just a lazy thing, I don't bother. You know, when I am in the mood, I want to eat this I will eat it. I know it is bad for me, I know I am taking it and I know it is doing me bad, but I want to eat it, so I do. But my husband, he wouldn't do that. He wouldn't eat bad things if he gets ill. But me no, every person is different . . . everybody is different. And I'm a lazy so and so.

Given what she had said about the problems she experienced complying with the regimen, I wanted to know whether Mrs D believed the health care professionals she was in contact with had any sense of these difficulties.

Mrs D: *I am not sure, it is difficult. I would like them to see what it was like for them to live with [diabetes].*

PB: *So would you wish to be understood more, for them to know about these things?*

Mrs D: *Yes, I think that would be a good thing.*

I discussed in more detail Mrs D's relationship with health professionals. In particular, I asked her about whether she thought she could ask questions or take part in making decisions about her treatment.

PB: *Do you tend to have questions for your doctor when you see her?*

Mrs D: *No. Why would I have questions?*

PB: *What I am trying to get at, I guess, is do you take part in decision-making about your illness, about your diabetes?*

Mrs D: *No, I don't think I do. They tell me what to do. They just tell me, your diet is not under control. So they write to [my GP] and say she is not controlling and she says all right, you was on 500mg and now you're on 850mg. And I feel better now, I'm on 850mg now. . . . No, the doctor doesn't explain. I mean they never said to me, do you like being on tablets?*

PB: *Does the doctor ever ask why you don't always stick to the diabetes diet?*

Mrs D: *No. They just go, right, your blood level's this, your this is this. And then you are out. Nothing else. They're not very helpful. If you say, you are getting pains in your legs, then they say go to your GP and she will sort you out. They never say, why are you not sticking to your diet.*

PB: *Why do you think that is?*

Mrs D: *I don't know. I don't know why they don't. And when you go it's too many patients, and they just check up on your blood and your sugar.*

Thus, in most of her encounters with professionals Mrs D was simply told what she needed to do in order to comply. A relationship based on honesty, openness and respect for her agenda did not figure in her account. Rather, as she put it, once basic acts of clinical surveillance were completed “then you are out”.

DISCUSSION

I am not suggesting that Mrs D's experiences are typical of patients with diabetes and I want to acknowledge the limitations of generalising from a single case study. However, I believe her account raises a number of important questions about relationships between patients and professionals. Some points stand out. Clearly, Mrs D found it hard to comply with the diabetes regimen, but not because she was ignorant about the possible implications of non-compliance for her health. She appreciated the significance of raised blood glucose levels and knew she had to diet, take exercise, take medicines and monitor her glucose levels. Her decision not to exercise was related to her arthritis, and her decision not to eat in accordance with the diabetes diet had its origins in her desire to fit in with her family alongside the perceived stigma of having diabetes and her experience of depression following a major bereavement. Mrs D was also responsible for caring for four children, her husband and her elderly mother within an environment of relative poverty.

At this point it might be worth bearing in mind the gendered aspects of domestic life and their impact on coping with illness, given that other research has shown that women often put the health and well being of others before that of themselves.^{7,8} Indeed, Mrs D clearly did not give primacy to her diabetes and sometimes responded to the exigencies of life by “comfort” eating.⁹ Food, after all, was one resource over which she had some degree of control and which also gave her pleasure — it was just that it was denied to her by the diabetes regimen. However, whatever we may think of Mrs D's decisions, they cannot be explained by reference to faulty “lay beliefs”, which were somehow at variance with the best medical evidence.⁵

The above represents the context for Mrs D's decisions. In terms of her encounters with professionals, she pointed out that she had been told that she would die if she did not lose weight. Whatever the intentions of the person who said this, it had

clearly not motivated her to diet. Although the professional who said this to her may only have been repeating the medical evidence, such an approach borders on blaming her. As many authors have pointed out, blaming the victim is a pervasive feature of medical encounters and can have a profound impact on patients' identity, dignity and self-respect.^{8,10,11} Others have pointed out that the compliance model views failure to comply as a form of deviance or moral weakness.^{3,4} In Mrs D's case, she appeared to have internalised these moral injunctions and blamed herself for her “failure” to diet, referring to herself as a “lazy so and so”.

Where does this take us in terms of understanding health care relationships? First, the compliance model can degenerate into victim-blaming, with the consequence that relationships between patients and professionals become dysfunctional. Secondly, professionals do not always appreciate the problems some patients experience attempting to comply — particularly, or especially, where that involves making long-term modifications to what we do in our day-to-day health-related activities. They fail to appreciate this for a host of reasons, which I cannot discuss in detail, but which include time, training, a desire on the part of health professionals to distance themselves emotionally from patients and because health care is, at its core, a job, with all the distractions, monotones and routines that attach to jobs.^{12,13} In short, it can seem a whole lot simpler to blame patients for their “failure” to comply than to seek explanations for their actions in the wider social environment or the psychosocial context of their lives.

In Mrs D's case, a strong argument can be made for linking her decisions about not complying with the diabetes diet to the wider social and psychological environment or context. In sociological parlance, Mrs D's case reveals something about the differential impact of social structure over agency.^{14,15} Social structures typically refer to the relationships between different elements of a social system or society: for example, social, economic, political, religious and other institutions may be said to constitute elements of the social structure. Agency, by contrast, refers to the power of individuals to operate independently of the constraints of those structures. In simple terms, Mrs D's choices (agency) were mediated or constrained by the social context of her life. The problem with compliance is that in simply providing instructions to patients about how they should act, it fails to take into account the limiting aspects of social structures, preferring to see actions as resulting from individual choice, with the consequence that victim-blaming can follow from this.

Presumably, a concordant approach might rectify this situation. Mrs D did not appear to be seeking to take part in decisions about her care. Indeed, she was under few illusions about taking part in decisions about her treatment. In her encounters with professionals she expected to be told what to do. Other research has pointed to a similar lack of engagement in the consultation with models of shared decision-making.¹⁶

Nonetheless, although Mrs D may not have explicitly sought either discussion or a sharing of decisions about treatment (in the way the concordance model suggests) she did seek greater understanding and appreciation from health professionals about her life situation and how hard she found it to comply. Concordance could provide a framework for health professionals to understand and, perhaps more crucially, to respect the dilemmas Mrs D faced in her life. Indeed, Kleinman¹⁷ has made a powerful case for a similar approach to the consultation. Respecting the patient cannot realistically go hand in hand with an approach to patients based on victim-blaming and imputations of moral failure. I would argue that an attitude of respect for the patient is fundamental to the successful accomplishment of the concordance model. What is more, as in so many other spheres of health care it seems unlikely that respect, trust or openness can be reduced to a set of procedures or guidelines; rather, it is more to do with a philosophy or an attitude towards patients and relationships more generally.¹⁸

Having said this, removing imputations of morality and connotations of failure from health care relationships is likely to be extremely difficult to achieve in practice, given what some anthropologists have referred to as the soteriological (or salvationist) foundations of Western medicine. For example, Good¹² said: "The moral and soteriological core of the experience that is present, present for the ill and their families, present as an underlying assumption of those who enter the profession, present among physicians and their patients confronting life threatening conditions, and present too within the routinised practices through which objects of medical care are constructed so that they can be treated medically . . . it is precisely the conjoining of the physiological and the soteriological that is central to the constitution of medicine as a modern institution."

There is not space here to continue with this discussion but readers might wish to reflect on it. However, the final point I want

to make is that attempting to remove imputations of morality from health care encounters is unlikely to have much impact on patients' ability to comply with diabetes regimens. In Mrs D's case, a blame-free environment will not help her to comply because the material and psychological barriers that she described remain, whatever strategy is used to communicate with patients. This needs to be acknowledged openly.

Concordance should not be thought about as compliance by another name, and its primary end point is not enabling patients to get more from their treatment or their medicines (although, of course, this may well happen). Concordance is about establishing an approach to health care relationships based on respect, within a blame-free environment.

Some 12 months after I first interviewed Mrs D, I returned to find she was still being told she might die if she did not lose weight. Given that National Health Service employees are now encouraged to work within a blame-free environment, can we not think about extending this to encounters with patients as well?

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