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From compliance to concordance: barriers to accomplishing a re-framed model of health care interactions

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Abstract

As a framework for organising health care interactions, compliance and adherence have come in for increasing criticism in recent years. It has been suggested that interactions with patients should not be viewed simply as opportunities to reinforce instructions around treatment: rather, they should be seen as a space where the expertise of patients and health professionals can be pooled to arrive at mutually agreed goals. This concept—known as concordance—is attracting increasing interest in health services research within the UK. In this paper, we seek to empirically explore the relevance of a re-framed consultation through qualitative interviews with a small group of English speaking patients of Pakistani origin with a diagnosis of type 2 diabetes.

We suggest that the focus of many respondents in this study on material and structural factors limiting diabetic regimen integration and the emphasis on a ‘doctor-centred’ model of health care interactions represent distinct problems for the accomplishment of the concordance project. However, given that some patients sought greater understanding and appreciation by health professionals of the subjective aspects of living with diabetes, if it is evaluated at the level of health care relationships, rather than health outcomes (such as improved compliance) concordance may well be a significant development for those who suggest that respect for the patients agenda is a fundamental aspect of health care.

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Introduction

As models for conceptualising health care relationships, compliance and adherence have come in for sustained criticism. Although compliance and adherence have been extensively researched, it has been argued that the outcome of much of this work provides ‘little consistent information other than the fact that people do not always follow the doctors orders’ (Morris & Schulz, 1992, p. 295). The main function of such terms (according to some) is ideological: to provide a framework for doctors to express their ideas about how patients *ought* to behave (Trostle, 1988; Britten, 2001).

Notions of compliance and adherence offer clear justifications for attributing blame when patients’ actions do not match the expectations placed on them by health professionals (Donovan & Blake, 1992; Britten, 2001).

There is growing awareness of the limitations of the compliance and adherence models in their application to health care relationships. It is suggested that interactions with patients should not be viewed simply as opportunities to reinforce instructions around treatment (Working Party, 1997; Blenkinsopp, 2001). Rather, health care relationships should be understood as a space where the expertise of both patients and health professionals can be pooled to arrive at mutually agreed goals. Sociological critiques have asserted that the concepts of compliance and adherence do not do justice to the

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complexity and sophistication of lay theorising about illness (Blaxter, 1983; Calnan, 1987; Blaxter & Britten, 1996; Williams & Calnan, 1996), and it has been suggested that health professionals should seek to develop ‘concordance’ with their clients (Working Party, 1997). Concordance has been defined by a multi-disciplinary group of health professionals, academics and members of the pharmaceutical industry in the UK in the following terms:

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. This alliance, may, in the end, include an agreement to differ. 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 (Working Party, 1997, p. 8).

This vision of health care interactions sees the consultation as a space for dialogue and has been contrasted with the paternalistic compliance or adherence model which is characterised by an ‘unspoken assumption that the patient’s role was to be passive’ (Working Party, 1997, p. 8). The principles of concordance are not new (Britten, 2001), however, it is increasingly referred to within health services research and health policy circles (Marinker, 1997; Blenkinsopp, 2001). In contrast to compliance or adherence, it fits more neatly into the political landscape of the National Health Service (NHS) in the UK. Its negotiated approach to health care interactions resonates with the emphasis on consumerism in the NHS (Williams & Calnan, 1996) and is congruent with ideas such as shared clinical decision-making (Charles, Gafni, & Whelan, 1999) and patient-centredness (May & Mead, 1999). The World Health Organisation has long held that patients and health professionals have a right (and a duty) to participate in the delivery of health care (World Health Organisation, 1977, p. 3). Similarly, the English Department of Health is engaged in an Expert Patient initiative (Department of Health, 2000) and a Medicines Partnership Initiative (Medicines Partnership, 2003) both of which seek to harness the experiential knowledge patients amass over the course of their illness. Whilst it can be argued that the discourse around concordance is both a response to the wider epistemological challenge to medicine and a political challenge to professional power, there seems little doubt that user engagement, building partnerships and privileging the patient’s voice, are now firmly on the national and international policy agenda (Small & Rhodes, 2000).

Debates over concordance underline the need for empirical research which can shed light on its relevance to those with chronic illness. There is a burgeoning literature exploring compliance and adherence with medical instructions for patients with a variety of chronic illnesses (see Myers & Midence, 1998, for a recent review) and we do not seek to review this literature here. There is also a growing body of research describing the impact of ‘patient-centredness’ on satisfaction with care (Kinmonth, Woodcock, Griffin, Spiegel, & Campbell, 1998) and models of shared decision-making (Charles et al., 1999; Stevenson, Barry, Britten, Barber, & Bradley, 2000). Interesting research has also been conducted in relation to the misunderstandings that arise between patients and doctors in the consultation and the unvoiced agendas of patients in this arena (Barry, Bradley, Britten, Stevenson, & Barber, 2000; Britten, Stevenson, Barry, Barber, & Bradley, 2001). However, to date, there is less research qualitative research which links patients’ concerns about the management of chronic illness with specific reference to the concordance model (Blenkinsopp, 2001; Pollock, 2001). This paper sets out to describe some of the issues of concern to a group of UK based, English-speaking people of Pakistani origin with a diagnosis of type 2 diabetes. We highlight some issues of relevance to this group in coping with diabetes and its treatment, and explore how they spoke about their relationships with health care professionals. Before doing so, we describe some of the research which has looked at the experiences of people living with diabetes.

Living with diabetes—some comments on the literature

There is a long tradition of research into compliance (or adherence) and diabetes (see Warren & Hixenbaugh, 1998, for a review). In recent years the idea of *lay expertise* has been given some prominence—whereby patients gradually come to ‘accept’ their diagnosis, and gain mastery in coping with it (Price, 1993). It has been suggested that the psychological and physical stresses of diabetes call for specific adaptive and coping strategies and that many patients so diagnosed experience difficulty in adapting to the regimen (Miller, 1983; Kelleher, 1988; Nyhlin, 1990). The social context of patients’ lives may have a profound impact on decisions to comply with the treatment regimen. For example, Drummond and Mason (1990) have described that the goals of treatment from the medical perspective are largely concerned with maintaining blood glucose levels within an acceptable band. However, people with diabetes often identify a much broad set of constraints which influence treatment, including work, housing, finance, family, and emotional factors. Drummond and Mason (1990) comment:

dietary non-compliance...does not occur as a result of an idea or whim on the part of the patient (though of course it may) but, rather systematically, as part of competition between constraining factors (1990, p. 46).

Such factors can have significant bearings on patients' decisions to integrate the treatment regimen into their daily lives. Peyrot, McMurry, and Hedges (1987) describe how the decision to adhere to 'tight' or 'loose' control of blood sugar levels is a personal decision based on the desire to control the effects of the illness *and* the treatment on sufferers lives. The authors point out that this has profound consequences for individuals' relationships with physicians given that these decisions can diverge considerably from what is considered medically appropriate. They suggest that some people with (type 1) diabetes saw little correlation between their own actions and their blood glucose levels. However, within their sample, physicians inferred that poor control was a result of personal choice. The differences in the types of knowledge upon which health professionals and diabetics base their assessments can lead to overt conflicts in which physicians accuse diabetic people, when the latter are convinced such assertions are unjust. They suggest that:

This conflict reflects a clash of perspectives so fundamental that it is virtually intolerable and its resolution has important consequences both for the conception of the individual's condition and the nature of the treatment relationship (1987, p. 123).

In keeping with this focus on lay and professional perspectives, Schoenberg, Amey, and Coward (1998) explored the 'stories of meaning' of people with type 2 diabetes. They argue that divergence between lay and professional perspectives on the treatment of diabetes may account for the low rates of adherence to biomedical recommendations and that health beliefs and activities are best understood as connected to an individual's personal history and circumstances. They suggest that it is important for health professionals to understand these stories of meaning and their relationship to health decisions if they are to provide more appropriate and meaningful health care.

There is less research which has explored the problems people from minority ethnic groups experience managing their diabetes. In a study of the factors that influence diabetic management amongst Chinese-Canadian and Euro-Canadian women, Anderson et al. (1995) argue that the contextual features of women's lives, coupled with their ability to access resources and social support appeared to organise the ways in which they managed diabetes. In relation to the difficulties people from south Asian backgrounds living in the UK face integrating the diabetic regimen, it has often been

assumed that cultural, social and religious factors are likely to be important, although researchers differ on the role and extent of these (Kelleher & Islam, 1996; Lambert & Sevak, 1996; Greenhalgh, Helman, & Chowdury, 1998). Like any group that is linked by perceived national, religious, social, political or cultural bonds, south Asian communities often experience cultural stereotyping. As Ahmad (1996) points out, one of the problems of research emphasising the role of culture as a factor determining behaviour, is that it can obscure the structural and material causes of 'negative' health behaviours and can be used as a means of assigning culpability to 'others'. This has important implications for the study presented here. We now go on to describe the approach and the methods used in this study.

Methods

The study set out to elicit the views and experiences of a group of patients with a common chronic illness as a vehicle to explore experiences and understandings of treatment in the context of the concept of concordance. People of Pakistani origin were chosen as a target group given that there is a relatively small literature in this area and given that south Asian communities experience a much higher rate of diabetes than the White British population (Balarajan & Soni Raleigh, 1993). A decision was taken to interview English speaking people on the grounds that the use of interpreters would be likely to add a layer of complexity to the interpretation of the interview data (Temple, 1997).

The study adopted a qualitative approach with the aim being to explore the meanings and understandings of patients in depth (Mason, 1996). Respondents to the study were recruited by health professionals working in two primary practices and one secondary care diabetes centre, located in the north west of England. The process of recruitment involved health professionals asking patients with type 2 diabetes who were of south Asian origin if they would take part in a study exploring their experiences of managing type 2 diabetes. They were provided with written information and then could either get in touch with the researcher, or pass their details on to a health professional who then forwarded on their details. The recruitment began in late 1998 and a total of 16 south Asian people were recruited through this means. Recruiting staff did not keep a log of how many patients refused to take part. However, a further 6 respondents were obtained through the process of 'snowballing' whereby interviewees reported that they knew individuals in their family group, or local community who also had diabetes. A total of 21 patients who identified themselves as being of Pakistani origin were included in the analysis that follows. An interview

guide was developed. All the interviews were tape-recorded (with the respondents consent) and tapes were transcribed by the first author. All respondents were interviewed in their own homes and usually, though not exclusively, on their own.

An attempt was made to adhere to the broad principles of grounded theory (Glaser & Strauss, 1967). The initial process of analysis involved listening to tapes, reading and re-reading transcripts, making notes on the transcripts and writing down ideas concerning interpretations of the data, and the analytical categories that the first author was producing from them. The grounded theory approach of constant comparison was used to achieve this. Categories were checked against new cases to see whether they remained relevant or whether they had to adapted or modified. The categories that the first author produced were then verified by the second author following initial analysis. Where there was not full agreement over the codes or the interpretation of respondents statements, these were then reviewed. Notwithstanding this, the analytical categories that were produced from this process of brooding, the production and mind-maps and frameworks of analysis are essentially those of the first author's.

Interviewing people from 'different' ethnic backgrounds

The principal investigator was a white British male interviewing people who had been born in Pakistani, or who had parents born in Pakistan. Some researchers, such as Ahmad (1993), argue that black researchers (or researchers from the same ethnic or 'racial' background) are more likely to obtain a fuller picture, or a more nuanced description of the views of the group being researched. Reviewing these arguments, Kelleher (1996) suggests that whilst there are very positive reasons to encourage black people to research their own communities, there are also a number of arguments against matching researchers to respondents. Firstly, such a decision might increase the tendency to use black researchers only for research within the black community. In addition, there are other important markers of identity between people besides ethnicity or 'race' (Phoenix, 1995; Song & Parker, 1995).

These authors cast doubt on the need to 'match' the ethnicity (or any other characteristic) of the researched group with that of the researcher. They also highlight the fact that there are likely to be multiple axes of difference and commonality in the interaction between researcher and respondent. Kelleher (1996) makes the point that having researchers who are not from the same ethnic background does not preclude them from having experience of discrimination in some way and may provoke discussion or the asking of both different and difficult questions. We would suggest that there are no a

priori reasons, which preclude white researchers (or those from any background) from researching the experiences of minority ethnic groups. Whilst we had concerns about a white researcher interviewing people of Pakistani origin, we did not think that this precluded an exploration of their concerns.

Findings

In the interviews, we were concerned to provide a space for respondents to speak about the problems they faced integrating the diabetic regimen. Respondents were initially asked very general questions about what it was like to live with diabetes, how it impacted on their lives and how they coped with what health professionals had told them they must do to manage the regimen, and how this linked to other aspects of their lives (family and domestic responsibilities, work, employment, housing). The interview then considered their experiences of relationships with health care professionals.

Integrating the diabetic regimen

When asked about their experiences of living with the diabetic regimen, the majority of respondents asserted that they had experienced difficulties at some point. Respondents pointed out that making modifications to the daily patterns of living (in particular, the requirement to eat in accordance with the regimen and to take regular exercise) were the most difficult aspects of the regimen to integrate.

The majority of respondents indicated that they were aware of the need to make changes to their diet, to take exercise, monitor their blood or urine and (for those that were taking medication) to do so. Only one respondent suggested that he did not know what he was expected to do to manage his diabetes: his knowledge of diabetic management appeared to be confined to an awareness that he needed to avoid foods with sugar in them. Overall, a small number (3) asserted that they had been able to adopt the necessary dietary and lifestyle changes. All of these respondents were male, and stated that they had received help from their wife and family to eat more appropriately. One man, for example, pointed out that his wife now cooked largely fish and chicken for the family's main meal, and he had begun to take regular walks.

On the other hand, the majority of respondents suggested that—to varying degrees—they had found it difficult to modify their diets and to take regular exercise. For example, one male respondent who had been diagnosed for 5 years, with relatively minor diabetic complications reported that:

The diet is not good, not good. And I don't stick to it, no. If I had to stick to that all the time, I don't know where I would be...I do cheat...I do have things I shouldn't have.

PB. Can you tell me more about what you cheat on?

Well, I will eat biscuits and sweets and things and salty crisps, nuts.

PB. Why do you do that when you know you are supposed not to?

Sometimes, I just want to have something, something, you know that I like (R8).

It was common for respondents to refer to a variety of *constraints* on regimen integration, principal amongst which was material resources or poverty. It was suggested that appropriate diabetic management imposed additional financial burdens on patients and their families, over and above the costs of everyday living. These included the need to buy fresh fruit and vegetables, fish, chicken, other flours and rice which were unrefined rather than refined. Many felt some of these were items which might not ordinarily be bought and imposed an additional financial burden. One asymptomatic woman, diagnosed with diabetes for 1 year talked about the difficulties of living with diabetes on a low income in the following way:

Money is the main thing. I don't work, my husband is out of work now, for 6 weeks. When we get money in [from social security] then we have food for the family. After that, we don't, we live on what we have. And I have to eat whatever we have.

PB. Does that mean that your diet suffers as a result?

I eat anything. Yes, I will eat what...it is...that we have (R13).

Some of the women with diabetes pointed out that needing to prepare two separate meals—one that all the family would eat and a separate one for themselves—was both time consuming and imposed additional financial burdens. Although aware that it was possible to produce meals that both they and their families could eat, there were occasions when this was not considered inappropriate—for example, when family or friends visited or on special occasions. Some also suggested that children did not always want to eat the 'healthy' meals that were prepared for the diabetic member of the family.

Accommodating the demands of irregular or demanding working patterns was also considered a problem for those respondents who worked. Two of the male respondents worked as taxi drivers. One reported that although he had been told by his GP that his blood sugar levels were unacceptably high, he still resorted to eating inappropriately (for example, eating bars of

chocolate, consuming drinks high in sugar) because of the difficulties of obtaining food that was considered healthy when he was at work. His diabetes was controlled via diet and metformin and because he reported regularly raised blood glucose levels, he had been told by his doctor that his therapy would need to change to insulin in the near future. This had provoked considerable anxiety because he believed he would no longer be able to work as a taxi driver (current legislation prohibits those taking insulin from driving certain classes of vehicles).

In some accounts, clusters of factors acted to constrain patients ability to integrate the diabetic regimen. For example, one 41 year old woman, married with 4 children had been diagnosed with diabetes for over 6 years and treatment consisted of dietary modifications, exercise and metformin tablets. She had experienced episodes of hypoglycaemia and had also been diagnosed with hypertension, arthritis and migraine headaches. Like many of the respondents, she reported that she had made attempts to integrate the dietary aspects of the regimen and regularly monitored her blood glucose levels. However, she experienced difficulties modifying her diet and taking exercise. Her difficulties in complying with the dietary regimen were initially couched in terms of the desire to enjoy 'normal' food stuffs.¹ She went on to describe how financial hardships and family responsibilities impinged on treatment choices and asserted that taking exercise was difficult for her because of the arthritis she experienced. In addition, following a hypoglycaemic episode, she had become anxious about a recurrence which, prompted her to maintain higher than recommended blood glucose levels. Because she had been found unconscious and alone by her husband following one hypoglycaemic episode, she had subsequently made efforts to spend less time alone, but this has been thwarted by a physical assault on her in the local community. What she described as depression had been exacerbated by the death of her father. The impact of these experiences was related in the following way:

PB. How do you think all this has affected you?

When my dad died just after that, like I was sitting down thinking and I eat more. I eat more. Thinking about it. You 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 (R14).

It was clear that although a small number of respondents had been able to make changes to their lifestyles and to integrate the diabetic regimen, many had been unable to. In particular, women experienced

¹So, more focused questioning then revealed structural factors rather than individual preferences.

considerable difficulties integrating the diabetic regimen and balancing its demands against other concerns. Overall, despite one individual who asserted that he knew little about how to manage his diabetes, it was apparent that most respondents had some awareness about how they should be managing their diabetes. However, they had either chosen not to, or asserted that a variety of material constraints impinged on regimen integration. Given this background on the types of problems patients' experienced in coping with the diabetic regimen, we now move onto consider how respondents spoke about their encounters with health care professionals. In particular, we focus on how the problems they had alluded to above were articulated and negotiated in these encounters.

Respondents' experiences of health care interactions

Throughout the interviews, respondents spontaneously referred to instances of care, or interactions with health professionals which had occurred over the trajectory of their illness. The majority of comments were largely positive, and as we shall see, based around an acceptance of the expert role of the health professional within the consultation. Whilst the majority of respondents were careful never to overtly criticise their health care professionals by name, some respondents did report instances of care which had caused consternation. One episode was described by respondent 14.

Well, its 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?

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 [voice goes quiet] 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.

PB. And you believe that you can't control your weight, it's not your fault?

And they don't know, its 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? (R14)

This approach had served to exacerbate her depression and as a result, accentuated her retreat into comfort eating. She was asked if she felt she was understood in her encounters with health professionals.

PB. So do you think they know what is going on for you, in your life?

I am not sure, it is difficult. I would like them to see what it was like for them to live with it (diabetes).

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

Yes, I think that would be a good thing and there is diabetic nurse who knows where I go. She is good and knows about these things, but doctor does not (R14).

After having described this experience, she went on to speak disparagingly about her own ability to follow the medical 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 (R14).

The reference to how food provided a source of enjoyment and succour in the face of depression and censure from health professionals is highly apposite in terms of understanding the motivational factors shaping integration of the dietary regimen. The mixture of anger at not being understood alongside the self-recrimination at not being able to meet the demands of a diabetic diet provides an interesting example of the ways in which the moral overtones of the 'compliance' model come to be taken on board by people with diabetes in their attempts to accommodate both medical proscriptions and the exigencies of everyday life. Although the vicissitudes of lay theorising about attributions of blame in relation to coping with the diabetic regimen are well captured in the above excerpt, it was by no means the only example from this study.

Others made passing references to the difficulties they faced in living with diabetes, although they were perhaps less striking examples. For example, one woman said:

The doctor, he not know how we live, he not know about us and how we live.

PB. You mean?

Diabetes is hard. It is hard illness to live with. He not understand that. I cannot work, cannot cook like I did. Bending down hurts and my fingers are not good for preparing food [R2].

During the interviews, an attempt was made to introduce and describe what a concordant model of health care interactions might look like in practice. There was an evident difficulty in discussing such a notion with lay respondents. The term ‘compliance’ was very rarely used by respondents and it seemed highly unlikely that the term ‘concordance’ would have much explanatory meaning in practice. Initially, the notion of concordance was introduced through providing a simple description: that it involved talking with doctors and nurses about any problems patients had about diet, exercise, medication (or any aspect to do with diabetes) and then making an agreement with the doctor about what to do. The difference with concordance was that this would allow the patients an equal say in this process. Respondents suggested that they could already ask their doctor (or nurse) questions about their diabetes if they so wished. On the other hand, the idea that the patient might have an equal say in the consultation seemed unfamiliar to many patients. One person said:

The doctors are trained to tell us what to do.

PB. You could discuss the problems you are having in the rest of your life—like your housing, work or any of those things and tell the doctor how much they are effecting you.

Doctor is not there to do that, doctor is there to give us medicine, to make, to tell us what is wrong and then we take medicines (R5).

Examples of what discussion with health professionals might mean in practice were also suggested: an example of a patient experiencing side effects from their medication and who had chosen to stop using it was also presented. In response to this, the most common theme was that the patient should continue using the medicine. Respondents generally noted that if they were experiencing a problem with their medication, then they would bring this up with either their doctor or their nurse. For example:

PB. One thing is, if you were having a side effect from your medicine, you could discuss it with your doctor, or the nurse.

Yes, yes, I see. But this has happened and I talk with doctor about it. And he tell me it will pass and it did.

PB. So you can already do that?

Oh yes, if want to ask questions, then I do already. I can do that with doctor. He say we can do that (R12).

Perhaps the clearest indication of the difficulties patients had with discussing care with their health professionals was shown by the extent to which there was silence after the concordance model was illustrated. It seemed apparent that most patients ‘doctor-centred’

model of the consultation whereby they invested the doctor with authority and expertise and expected them to provide them with guidance about their illness. For example, one patient who had some experience of working within the health service suggested:

I think we expect them to tell us what to do, and I know we did when I worked on the ward, and patients do too.

PB. So, what might it be like, then, having the opportunity to talk with your doctor, or to make an agreement about care?

There isn’t time in this world is there? I don’t know what it will be like...some you can already talk to now. Some you cannot. I think it would be difficult for some patients...you know—what do you want to do mrs so and so...it might be very odd. As patients, you just expect to be told (R10).

This was the only patient to reflect on the potential dilemmas of a more concordant model of care. On the other hand, a small number were positive about the possibility of a model of care which involved discussion and or understanding. For example, the patient who had criticized her GP for asking her to loose weight without understanding the reasons why she found it hard to loose weight made the following remarks.

PB. OK, so you have said that the doctor should understand why you cannot lose weight?

Yes, doctor has not understood that depression is caused by the things I’ve said. And that when I am depressed I eat too much.

PB. So. Would it be better if they did? Did understand why you can’t lose weight?

Yes, that is much better. Its much better for them to know why. To say I am a lazy thing, and not know about the other things in my life, that stop me.

PB. And do you feel you can say these things to your doctor?

No, never. I would never do that with my doctor.

PB. Why is that?

I would not do that. There is not time (R14).

Respondent 10 returned to this point. She suggested that relations between the people of Pakistani origin and health professionals were typified by a high degree of reticence and deference. Such an approach made it problematic for both parties to enter into discussion about care or treatment, thus potentially undermining the concordance model. She said:

I’ve seen it happen. They’ll be waiting to ask questions about their medicines or what have you and then not feel like they can when they get in there. I’ve felt like that myself, haven’t you? Its like you don’t think you can ask any questions when you get in the room with the doctor. What you have got to

remember is that the doctor has a lot of authority. To Asians, the doctor is a person with high status and its difficult sometimes for them to ask questions (R10).

There were a range of responses to the suggestion that doctors might adopt a more 'concordant' approach to health care interactions. As a relatively unfamiliar idea to many it was apparent that it challenged some of the learned rules and behaviours underpinning health care interactions. On the other hand, for some who had experienced difficulties complying with treatment, it was clear that a greater degree of understanding was of concern to them.

Discussion

From compliance to concordance?

The data presented suggests that whilst almost all respondents appeared to have some insight into the nature of the diabetic treatment regimen, what was striking were the repeated references to structural and material factors and the ways in which these mediated individual decisions to integrate the regimen into their lives. At the same time, not even a loose approximation of the idea of concordance (at least in terms of the idea of promoting discussion and dialogue) figured in their depictions of encounters with health professionals.

It proved highly illuminating to explore respondents' experiences of health care interactions. In attempting to describe an alternative to a directive model of health care interactions, that there was some apparent difficulty in getting patients to grasp what negotiation, discussion and partnership might mean in practice. Of course, this may have been a failure of the research approach, confined as it was to face-to-face interviews. However, the fact that respondents had difficulties comprehending this may simply reflect how rare such encounters were and how divorced they were from the reality of their interactions with professionals. The largely 'doctor-centred' model of health care interactions that these respondents described seems a long way from the approach advocated by those championing a more democratic and inclusive model (Working Party, 1997). Indeed, this is congruent with recent empirical work exploring the scope for shared decision-making in the consultation. Evaluating 62 consultations between doctors and patients, Stevenson et al. (2000) found little evidence that both parties participated in any meaningful sense in the consultation, and thus found little basis on which to build a consensus about preferred treatment.

Of course, it does not follow that a more concordant approach to health care interactions is necessarily inappropriate to the people studied here. The data from

this study provide a level of support for interactions with health professionals that foster shared *understandings* (if not shared decision-making) about the experiential aspects of diabetes and the material and biographical context in which regimen integration has to be accomplished. As we have seen, one respondent noted that the material and psychological aspects of her life impinged on her ability to effectively manage diabetes and suggested that greater appreciation of this by professionals would have been welcomed. A number of women spoke about domestic responsibilities and child-care, the care of older relatives and having to provide food where the needs of the person with diabetes had to compete with other priorities. Clearly, the ways in which gendered roles and responsibilities impinge on regimen integration is an area that requires more research within this population. Overall, poverty, material disadvantage and gendered roles emerged as important factors in many respondents' accounts concerning the management of the treatment regimen. That this should be so is perhaps not surprising given the quantitative evidence concerning the level of material disadvantage experienced by Pakistani people living in the UK (Nazroo, 1997).

The concerns raised by respondents represented the broad canvass against which regimen integration had to be accomplished. As we have seen, it was suggested by some respondents that these concerns were not always understood or appreciated by health professionals. In this sense, what some patients were desirous of, was not taking part in the consultation *as such* (in the way that a shared clinical decision-making model might imply); rather, they were concerned that aspects of their biography and their life situation might be more appropriately understood by health professionals.

To some degree, these points underline the relevance of a more biographically focused model of care. Kleinman has argued that 'the interpretation of illness narratives is a core task of the work of doctoring' (Kleinman, 1988, p. xiii). He is concerned with developing a method for 'sensitively soliciting stories of illness...which amounts to a brief medical psychotherapy for the multiple, ongoing threats and losses that make chronic illness so profoundly disruptive' (Kleinman, 1988, p. 10).

In arguing for a re-framed clinical encounter, it might be appropriate for concordance to be linked more explicitly to a biographical approach to the consultation, which may at least address some of the more critical comments made by respondents in this study. Support for this argument is provided by recent work on the doctor patient consultation by Barry, Stevenson, Britten, Barber, and Bradley (2001). Using Mishler's (1984) typology of consultation styles in an analysis of the outcomes of consultations between patients and doctors in conjunction with qualitative interviews with

patients, they suggest that it was those patients presenting with chronic illness and whose ‘lifeworld’ voice was ignored, who had the worst outcomes from the consultation. In a study of Chinese-Canadian and Euro-Canadian patients with type 2 diabetes, Anderson et al. (1995) highlight the importance of understanding the complex factors in which human experience is embedded and its relationship to diabetic management.

We recognise the evident difficulties in achieving shared understandings given temporal and resource limitations—something which many patients themselves alluded to. Patients from this (and other populations) may also prefer to withhold sensitive or personal information from health professionals, which may well detract from the successful operationalisation of a more concordant model of care. Nonetheless, in this study, achieving greater mutual understanding of the difficulties associated with integrating a pervasive treatment regimen, and for some, ameliorating the negative impact of victim blaming was of relevance. Having said this, the desire on the part of some respondents for health professionals to keep imputations of morality and self-worth outside of the medical encounter is likely to be a notoriously difficult enterprise to achieve in practice, given the soteriological basis of Western medical practice (Good, 1994). However, it is at least arguable that such a goal is more likely to be achieved through an approach to medical encounters based on emphasising the integral worth of patients’ accounts about illness and the potentially therapeutic value of listening to the concerns of patients.

Concordance and the material constraints on regimen integration

Concordance may represent a step towards rapprochement in the medical encounter. However, it cannot ameliorate the material barriers to regimen integration that were a pervasive feature of accounts in this study. Such a finding is not out of step with other qualitative studies amongst minority groups with diabetes (Greenhalgh et al., 1998). In a review of research into the medication and treatment related problems amongst minority ethnic groups, Joshi (1998) has noted ‘poor adherence may be as much, if not more, related to structural than to attitude barriers’ (1998, p. 273).

The sense that activities linked with maintaining health exist in a state of competition with other factors deriving from an individual’s social, material and cultural context is, of course, not new (Drummond & Mason, 1990; Anderson et al., 1995). In this study, diabetes was a part of the shifting terrain of patients’ lives which was accorded priority, but not necessarily the highest priority. In other words, respondents frequently drew attention to the profoundly unequal effects of structural or socio-economic inhibitors on diabetic

integration as against individual preferences. Moreover, the impact of these concrete socio-economic factors (poverty, gendered roles, material disadvantage) was often articulated through the language of personal choice (and non-choice).

These findings represent a problem for those who might hope to see improved health outcomes come out of the application of concordance in the consultation. Although a ‘concordant’ approach to the consultation might extend health professionals’ understandings of the ways in which food may be used as a consolation or compensation for the demands of everyday life, it does nothing to ameliorate the barriers to successful diabetic management mentioned here. Indeed, the research base indicates that in relation to diabetes (and other conditions) there is little strong evidence that patient centred consulting practices are effective in improving health outcomes (Padgett, 1988; Kinmonth et al., 1998; Warren & Hixenbaugh, 1998; Mead & Bower, 2002).

However, there may be a further problem with the concordance project. Concordance is intended to re-orientate the consultation towards negotiation and discussion, emphasising respect for the patient’s agenda and offering the option for both parties to differ about the goals and terms of treatment. (Working Party, 1997). However, as it is currently articulated, concordance also retains a focus on modifying patients’ health beliefs through a re-framed consultation, with the aim of bring these into line with medical exhortations. As the Working Party assert:

...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 and frequently...receive scant attention (1997, p. 9).

One way of interpreting this is to suggest that concordance provides an opportunity to explore patients’ beliefs about treatment. However, in this study patients’ beliefs did not appear to be the most salient factors influencing treatment decisions. Patients in this study were well aware of the need to eat in accordance with the precepts of medical science, about the need to exercise, monitor their condition and to take their medication, a finding congruent with other studies of people with type 2 diabetes (Johnson 1984; Dunn, Beeney, Hoskins, & Turtle, 1990; Beeney & Dunn, 1990). Whilst the respondents in this study may not have possessed a sophisticated vocabulary to describe their illness and its treatment, their beliefs did not appear to be markedly at variance with those of the medical model of treatment. The concordance model appears to posit that a re-framed consultation will provide a forum for the elicitation, and presumably the modification of

beliefs that are found to be at variance with medical science. In its application, practitioners will need to be careful that this does not replicate one of the basic objections to the compliance paradigm. That is, in substituting the idea of faulty beliefs for faulty (or non-compliant) behaviours, concordance may provide another vehicle for the imposition of medical views about how patients ought to behave (Trostle, 1988).

Some conclusions

Concordance is congruent with more general trends in public sector organisation, most notably, a new model of management which sees benefits in establishing partnership and collaboration. It is also possible to view concordance as a concept, which deflects attention from the material circumstances of patients' lives, in the absence of a political commitment to address these concerns. This may be so, but as Small and Rhodes (2000) show in their research, greater patient involvement in health services, can, if effective, positively shape the lives of patients. Although we recognise the major difficulties to achieving this, we would endorse their comments in the context of the debate about concordance.

An ethic of user involvement must frame all encounters the ill person has and inform the perspectives of the care provider. It has to grow in and through structures, practices, expectations and responsibilities. It is a philosophy and not a procedure. In this, it is like democracy or justice. It is about privileging the voice of those most effected by ill health and saying it is just to do so (2000, p. 221).

If operationalised in such a manner, and if evaluated at the level of health care relationships, rather than in connection with health outcomes (such as improved compliance) concordance may well be a significant development and adds further weight to those who suggest that respect for the patients agenda is a fundamental aspect of health care (Popay & Williams, 1996).

Note 1: We do not wish to imply that 'cultural' factors were unimportant in shaping decisions concerning the integration of dietary aspects of the diabetic regimen (although we do wish to guard against an unreflexive and static notion of 'culture' as an 'explanation' for health behaviour). Researchers have highlighted the symbolic importance of food to south Asian people (Joshi, 1995; Kelleher & Islam, 1996) and some researchers have suggested that that as members of a culture which values conformity and deference rather more than individuality and difference, people of south

Asian origin may take the views of other family members into account to a greater extent than is common within Western cultures (Sinha & Tripathi (1994). This study has not attempted to empirically assess the validity of such arguments.

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