

# Perceptions of non-adherence: patients vs health professionals

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## ARTICLE POINTS

**1** Patients may inaccurately report their adherence to diabetes management regimen.

**2** A study compared patients and health professionals' perception as to which aspects of diabetes management regimen they thought would be omitted and what barriers would inhibit full adherence.

**3** There were large incongruities between patients' and health professionals' perceptions, e.g. those concerning medication and exercise.

**4** There were also incongruities with regard to perceived barriers.

## KEY WORDS

- Diabetes management regimen
- Questionnaire study
- Adherence
- Incongruity of perceptions

## Introduction

**Lack of adherence to the behavioural recommendations in diabetes management poses problems for both patients and healthcare professionals. A questionnaire study was carried out to compare patients' and practitioners' perceptions of which aspects of the diabetes management regimen would most often be omitted by patients and why. Incongruities in perception were observed, more in relation to which aspects were omitted than for the reasons why. Findings such as these lead to a more accurate understanding of the difficulties experienced by patients and, consequently, to treatment decisions that improve adherence.**

Studies comparing staff and patient perceptions of adherence have found that agreement is associated with increased patient satisfaction and adherence (Mechanic, 1983), whereas conflict is associated with patients becoming more anxious about their disease and its management (Mason, 1985). Doctors often assume that patients are adhering to treatment when they are not (DiMatteo and DiNicola, 1982).

Using prescription records for the number of dispensed glucose monitoring reagent strips (Evans et al, 1999) found that, in their sample of both type 1 and type 2 patients, regular glucose monitoring was uncommon. It is estimated that between 40–80% of patients under-report their blood glucose levels on at least half the recordings (Mazze et al 1984; Wilson and Endres, 1986). Patients may also report having complied with medical advice when they have not. In a survey by Hixenbaugh et al (1998), 57% of patients reported that they were not always truthful to their health professionals. The main reasons given were fear that the health professionals would be angry and would think that they did not take their diabetes seriously.

## Reasons for non-adherence

Practitioners have a tendency to attribute non-adherence to the patient rather than the treatment. However, when

practitioners make an effort to reach agreement with the patient on adherence problems, they are more likely to say that problems with glycaemic control are associated with medical treatment rather than with the patients themselves (Gillespie and Bradley, 1988). Such improvements in communication are likely to lead to the sharing of decisions and more appropriate and realistic treatment decisions being made.

## Accuracy must be starting point

Information regarding the level of compliance cannot be established unless practitioners ask direct questions and patients are truthful. In a meta-analysis, Hall et al (1988) found that the only provider behaviour associated with patient compliance was the doctors' asking direct questions about patient behaviour. Health care professionals need accurate information about patients' adherence to advice in order to plan effective treatment regimens and patients need to be able to provide that information without fear of reprisal.

Recent research indicates that many involved primary care providers regard diabetes as more difficult to treat than a range of other conditions. They perceive diabetes treatment as ineffective and doubt their own ability to encourage patients to change their behaviours or to educate patients successfully (Larme and Pugh,

1998). However, it is often the case that professionals do not understand the depth of difficulty for the patients involved (Pendleton et al, 1987).

**Study aims**

A study was carried out aiming:

- To compare the perceptions of patients and health care professionals as to which aspects of the diabetic regimen are most likely to be omitted.
- To compare perceptions of the barriers to following treatment.
- To highlight areas of disagreement in order to help health care professionals plan effective treatment programmes.

**Methods**

**Participants**

Two groups of volunteers were assessed using questionnaires. Group 1 consisted of patients with diabetes while Group 2 comprised health professionals involved in diabetes care. Table 1 shows characteristics of the groups.

Group 1 was drawn from a diabetes outpatient clinic at a large hospital and those attending Diabetes UK (formerly British Diabetic Association) patient information days or Diabetes UK regional groups. Patients voluntarily completed a 260-item questionnaire assessing the psychological impact of diabetes.

Group 2 professionals, all attendees of a Diabetes UK conference in Bournemouth, voluntarily completed a 19-item questionnaire.

**Table 1. Characteristics of the two study groups.**

Group 1 (324 patients)
48% were men and 52% were women.
131 diagnosed with type 1 diabetes 193 diagnosed with type 2 diabetes.
Age: mean 48.7 years; standard deviation 14.3 years; range 18–75 years.
Group 2 (36 health professionals)
86% women and 14% men
Age: mean 41.9 years, standard deviation 9.0 years. Range 24–60 years.



*A willingness to communicate on the part of healthcare professionals can lead to more accurate perceptions of adherence issues that the patient may be experiencing.*

**Measures**

**Patient questionnaire**

A questionnaire devised by one of the authors (PH) was used to measure the psychosocial impact of diabetes. The questionnaire comprised several multi-item subscales and some single items.

For the purposes of this article, only the items assessing adherence were analysed. These were two scales, concerning level of adherence and barriers, respectively.

The first scale contained 12 items. Four of these were used to determine the more medical aspects of regimen adherence (e.g. taking medication). The other eight were used to assess adherence to lifestyle-related aspects of the regimen, i.e. those requiring substantial behavioural changes.

The second scale used 9 items to determine the reasons for not adhering to the diabetic regimen. Items included psychological factors, e.g. too much emotional stress; situational factors, e.g. lack of time; personal factors; and factors relating to the prescribed treatment. The questionnaire has previously been validated during a pilot study (Warren and Hixenbaugh, 1995).

**Professional questionnaire**

The professional questionnaire, also devised by the same author (PH), measures health professionals' perceptions of the diabetes care they offer patients. Some of the items used in this questionnaire originated from the above and therefore sought

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**1** Patients reported that they mainly omitted eating the right types of foods, the right amount of food and self-monitoring.

**2** Professionals believed that patients would mainly omit maintaining an ideal weight or taking regular exercises.

**3** Patients' main reasons for not adhering to aspects of their treatment were feeling that they were already doing what was realistic and what was important.

professionals' perceptions of which regimen omissions were most common and what reasons there were for non-adherence.

**Analysis**

Data were stored and analysed using SPSS/PC. Between-group analyses were performed using the  $\chi^2$  test.

**Results**

**Adherence regimen omissions**

The largest proportion of patients reported that they omitted eating the right types of foods (59.3%), the right amount of food (49.1%), and checking their blood/urine glucose level (41.0%).

The largest proportion of professionals

believed that patients would omit maintaining an ideal weight (91.4%), taking regular exercise (91.4%), and eating the right types of food (85.7%).

Figure 1 shows that there was incongruence for all omissions. The largest incongruence was seen for maintaining an ideal weight; 91.4% of professionals indicated patients were not maintaining an ideal weight, compared with 36.7% of patients.

**Barriers to adherence**

Two thirds of patients indicated that the major reason for them not adhering to aspects of their treatment was because they felt they were already doing what was realistic. A third indicated that they felt

<b>Regimen area</b>	<b>% of patients who will omit</b>	<b>% of health professionals who think patients omit</b>
Taking medication	3.4	42.9
Taking prescribed dose of medication	5.2	40.0
Taking medication at the correct time	24.7	65.7
Eating the right types of food	59.3	85.7
Eating the right amount of food	49.1	71.4
Eating at regular intervals	36.1	62.9
Maintaining an ideal weight	36.7	91.4
Checking blood/urine glucose level	41.0	62.9
Accurately recording blood/urine glucose level	24.1	65.7
Adjusting food intake and medication when blood/urine glucose is high	17.0	65.7
Taking regular exercise	38.9	91.4
Regular check-ups	5.9	40.0

A significant (P<0.05) difference was observed in all the above regimen areas.

Figure 1. The different aspects of a diabetes management regimen, with percentage of patients who omit those aspects, and percentage of health professionals who believe that patients omit them.

they followed important aspects of their treatment. Health professionals claimed that the main reason for patient non-adherence was because patients felt well (94.3%) and therefore perceived no need to follow a regimen. This was followed by emotional stress (85.7%), and third was the interference that adherence caused to lifestyle (74.3%). Figure 2 shows that incongruency between patients' and health professionals' perceptions was seen in relation to all but three of the barriers.

Over ninety per cent of professionals thought that patients who felt well would not adhere to a regimen, when only 18.9% of patients saw this as a factor. Stress was thought to be a barrier by 85.7% of professionals compared with only 20.1% of patients. Finally, most health professionals (74.3%) saw lifestyle interference as a factor but this was not echoed by patients (21.9%).

**Discussion**

**Perceptions on omissions**

The first aim of this study was to examine perceptions of patients and professionals

with respect to adherence. The findings suggest that although health professionals did recognise the difficulty that patients had adhering to dietary advice, they were much more pessimistic overall regarding the extent to which patients were omitting other aspects of their treatment regimen. There was a possible limitation of the study in terms of the difference in sample sizes of the two groups. However, as health professionals tend to treat large numbers of patients, the resultant ratio of professionals to patients may reflect standard diabetic care (BDA, 1999).

The largest percentage of patients (59.3%) reported that they perceived dietary regimen adherence as the most likely to be omitted, in line with previous research (Glasgow et al, 1997; Ary et al, 1986).

Professionals also saw eating the right types of food (85.7%) as likely to be omitted but they saw this as more problematic than the patients.

Regimen areas that patients reported omitting relatively less often were those linked with medication and attending for

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**1** Health professionals mainly attributed patient non-adherence to the fact that they felt well and therefore did not perceive the need to adhere to a regimen.

**2** Overall, health professionals were more pessimistic overall regarding the extent to which patients were adhering.

**3** There were differences in patient and healthcare professional perception of omission related to medication and regular attendance for check ups.

<b>Barriers to adherence</b>	<b>% of patients who report such a barrier</b>	<b>% of health professionals who believe this is a barrier for patients</b>
Lack of money *	14.2	40.0
Lack of time *	21.0	48.6
Lack of privacy	7.7	14.3
Too much interference in life *	21.9	74.3
Feeling well, so no need *	18.9	94.3
Do what is realistic	60.8	52.8
Follow what think is important	33.0	25.0
Healthcare professionals ask too much of them *	5.2	47.2
Stress *	20.1	85.7
<b>KEY:</b>		
* Denotes that a significant (P<0.05) difference was observed.		

Figure 2. Different barriers to achieving adherence to a diabetes management regimen, with percentage of patients who report these barriers and percentage of health professionals who believe that patients experience them.

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1 Compared with perceptions of omissions, there was greater congruence between professionals and patients with regard to barriers to adherence.

2 Patients and health-care professionals agreed that 'lack of privacy' was not a reason for non-adherence.

3 Consultations should be structured to elicit specific information from the patients' perspective.

regular check-ups, yet over a third of health professionals considered that these aspects would be omitted. Another large discrepancy concerned the topic of regular exercise: only 38.9% of patients reported they did not follow this recommendation compared with 91.4% of professionals who thought that they were likely to omit this from the regimen. This would seem to suggest that health professionals in this sample were much more pessimistic than the patients.

Forty per cent of health professionals reported that patients were likely to omit every aspect of the recommended diabetic regimen. Significant differences in the proportions of patients and professionals on each aspect of the regimen suggest that patient and professional perceptions were not congruent.

**Perceptions on barriers to adherence**

With regard to the second aim of the study, the perceptions of professionals and patients as to the barriers to adherence were similar in a number of areas.

There was agreement between both groups that 'lack of privacy' was not a reason for non-adherence. Two-thirds of patients and more than half of the professionals reported that omissions were made because patients felt they were doing 'what was realistic'. A quarter of professionals and a third of patients reported that omissions were due to the fact that patients felt that they were already doing 'what was important'.

The largest incongruencies were found with items such as: patients omit because 'they felt well', because of 'emotional stress', and because adherence affects 'lifestyle'. In all these cases a larger proportion of professionals believed these were reasons for non-adherence.

**Conclusion**

Effective treatment plans need to be based on a shared understanding of how patients are managing their diabetes. The results of this study indicate that patients and health care professionals may have different perceptions of the various aspects of adherence. Consultations which are

structured to elicit specific information from the patients' perspective may lead to the development of more effective treatment plans and greater patient adherence to advice. ■

Ary DV, Toobert D, Wilson W and Glasgow, RE (1986) Patient perspectives on factors contributing to nonadherence to diabetic regimens. *Diabetes Care* **9**: 168-72

British Diabetic Association (1999) *Recommendations for the structure of specialist diabetes care services*. BDA, London

DiMatteo MR and DiNicola DD (1982) *Achieving Patient Compliance. The Psychology of the Medical Practitioner's Role*. Pergamon Press, New York.

Evans JM, Newton RW, Ruta DA et al (1999) Frequency monitoring in relation to glycaemic control: observational study with diabetes database. *British Medical Journal* **319**: 83-6

Gillespie CR and Bradley C (1988) Causal attributions of doctors and patients in a diabetic clinic. *British Journal of Clinical Psychology* **27**: 57-76

Glasgow RE, Hampson SE, Ruggiero L, Strycker LA (1997) Personal-model beliefs and socio-environmental barriers related to diabetes self-management. *Diabetes Care* **20**: 556-61

Hall JA, Roter DL, Katz NR (1988) Meta-analysis of correlates of provider behavior in medical encounters. *Medical Care* **26**: 1-19

Hixenbaugh P, Roberts R, Castle B (1998) *Psychological aspects of diabetes*. (Paper presented at the 3rd National Primary Care Diabetes UK Conference (5-6 November), Bournemouth.

Larme AC and Pugh JA (1998) Attitudes of primary care providers towards diabetes. *Diabetes Care* **21**: 1391-6

Mason C (1985) The production and effects of uncertainty with special reference to diabetes mellitus. *Social Science & Medicine* **21**: 1329-34

Mazze RS, Lucido D, Shamoon H (1984) Psychological and social correlates of glycemic control. *Diabetes Care* **7**: 360-6

Mechanic D (1983) The experience and expression of distress: the study of illness behavior and medical utilization. In: Mechanic D (ed) *Handbook of Health, Health Care and the Health Professions*. Free Press, New York: 591-607

Pendleton D, House WC, Parker LE (1987) Physicians' and patients' views of problems of compliance with diabetic regimens. *Public Health Reports* **102**: 21-6

Warren L and Hixenbaugh P (1995) *Psychosocial Needs and Experiences of Adults with Diabetes: Their Relationship to Regimen Adherence from the Patient's Perspective*. Paper presented at the 1995 Annual Conference of the BPS Special Group in Health Psychology, September 6-8 1995, Bristol.

Wilson DP and Endres RK (1986) Compliance with blood glucose monitoring in children with type I diabetes mellitus. *Journal of Pediatrics* **108**: 1022-4