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Patients' beliefs on the impediments to good diabetes control:

a mixed methods study of patients in general practice

Abstract

Background
Most people with diabetes are not attaining desirable levels of HbA1c (glycated haemoglobin), or of blood pressure and cholesterol, leaving them at risk of developing complications.

Aim
To identify ways of improving diabetes control by gaining insight into patients' attitudes/beliefs.

Design and setting
Questionnaires were offered to patients attending for a diabetes review in the 24 GP practices of North East Hampshire and Farnham Clinical Commissioning Group.

Method
Infrequent attenders were contacted by post. Volunteers then participated in focus groups.

Results
Self-reported medication adherence was good with 83% (98/118) of responders recording ≥9 on a 10-point scale. Patients generally accepted they 'needed' and 'could take' medication. A substantial minority reported 'not liking' taking tablets. Focus groups confirmed this and revealed a reluctance to change lifestyle, with medication reported as a way to evade it. A total of 68 out of 112 responders (60.7%) knew their HbA1c value. However, focus groups identified little understanding of HbA1c, with responders perceiving it as medical jargon. Phrases such as 'stuck-on-sugar' or 'sugarload' were suggested as being semantically easier to understand. The questionnaire revealed trust in clinicians. This was confirmed in focus groups but confounded by frequent reports of healthcare providers giving inadequate/incorrect advice.

Conclusion
Investment in lifestyle change is needed. Participants were reluctant to change and saw medication as a way of avoiding it. HbA1c needs to be better explained. Intuitive phrases such as 'stuck-on-sugar' or 'sugarload' could be adopted into common parlance. Inadequate/incorrect advice seems to be hampering diabetes management and there appears to be a need for more diabetes-trained clinicians.

Keywords
diabetes control; diabetes mellitus; glycaemic control; lifestyle; medication adherence; patients' beliefs.

INTRODUCTION

Research into the impediments to good diabetes control is urgent, as the *National Diabetes Audit*[1] reports that desirable levels of HbA1c, as well as blood pressure and serum cholesterol, are seldom achieved, leaving many patients at risk of developing complications.

Diabetes consumes around 10% of the NHS budget,[2] and prevalence is rising.[3] Hex *et al*[2] estimated that 75–80% of this cost is spent on potentially avoidable complications and only 20–25% on treating the condition. Many authors have shown that medicines adherence in long-term conditions is poor,[4–9] and there is a significant body of work about patients' beliefs regarding medicines and the effect on adherence.[10–13]

The aim of this study was, by exploring the 'lived experience'[14] with an initial emphasis on medication, to elucidate what underlies patients' beliefs and attitudes in order to identify ways of improving diabetes control.

METHOD

This was a mixed methods study of the sequential explanatory type.[15] Questionnaire results were triangulated with propositions both from the literature search and the researchers' own experience, to inform the subsequent focus groups.

Questionnaires, with an information leaflet, were offered by clinicians to consecutive patients attending for a diabetes review in the 24 GP practices of North East Hampshire and Farnham Clinical Commissioning Group between May and December 2014. Patients completed the questionnaires privately at home, returning them by post. An invitation to participate in focus groups was included and patients' anonymity preserved by use of a separate stamped addressed envelope and provision of first name only. Infrequent attenders or defaulters were identified by clinicians, and questionnaires posted to them in an effort to improve validity. Questionnaires with a blue background were handed out in the clinics; green ones were posted to the defaulters.

Exclusions were patients aged under 18 years, those with cognitive decline, dementia, or learning disability, and those whose first language was not English.

The Medicines Engagement Map (MEM™) questionnaire explored three possible reasons for poor adherence:

- practical issues — 'can't take';
- perception — 'don't need'; and
- attitude — 'don't like'.

Responders reported their perception of adherence by placing a cross on a line whose extremes were 'never take a dose' and 'never miss a dose'. The analogue scale was converted to a 1–10 scale.

Additionally, responders were asked if they knew their HbA1c value, and which three diabetes information sources they perceived to be most trusted and useful. While accepting the importance of good blood pressure and lipid management, this study focused on HbA1c: widely recognised as the

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How this fits in

It is known that lifestyle change, medication adherence, and collaborative relationships with clinicians underpin good diabetes control. This study suggests it is lifestyle change that needs prioritising, as medication adherence appears good. Better explanation of HbA1c is required if it is to be meaningful to patients. Incorrect/inadequate advice seems to be common, hampering clinical relationships, patient empowerment, and ultimately, diabetes control.

primary measure of glycaemic control.

Data were entered into a survey database and extracted to an Excel spreadsheet for analysis. No statistical analysis was planned.

Questionnaire findings were explored in three focus groups, each of 60–90 minutes' duration, involving 11 participants in total. Ten participants had type 2 diabetes — only one had type 1 diabetes.

Focus groups ran consistently, using the same moderator and observer. After obtaining permission, the discussions were recorded and subsequently transcribed. Two investigators indexed the transcripts separately by extraction of key words.[16] Themes evolved from these key words. To strengthen validity, the themes were identified independently by each data-coder and then compared. The two data-coders came from different disciplines with contrasting perspectives and biases: one from general practice and one from public health. It was planned that any disagreement or variation between coders would be resolved by discussion and arbitrated by the third author. However, no differences of opinion occurred and the same themes emerged independently.

Table 1. Characteristics of study responders (*n* = 118)

Characteristic	*n* (%)
Sex	
Male	62 (52.5)
Female	54 (45.8)
No answer given	2 (1.7)
Age	
18–25	1 (0.8)
26–35	3 (2.5)
36–45	4 (3.4)
46–55	21 (17.8)
56–65	28 (23.7)
Over 65	61 (51.7)
Ethnicity	
White British	108 (91.5)
Asian British	4 (3.4)
Asian	3 (2.5)
Black	2 (1.7)
No answer given	1 (0.8)
Type of diabetes	
Type 1	20 (16.9)
Type 2	93 (78.8)
Don't know	4 (3.4)
No answer given	1 (0.8)
Type of medication	
Insulin injections	39 (33.1)
Other injections	7 (5.9)
Oral medication	98 (83.1)

RESULTS

A total of 93 blue and 25 green questionnaires were returned, giving a total sample of 118. The response rate is unknown owing to uncertainty regarding the number of questionnaires distributed by practices.

Responder characteristics (Table 1) aligned with local demography, which is approximately 86% white British. The marginally higher percentage (91.5%) of white British in this study is explained by the 4% Nepalise population (Gurkhas), clustered around Aldershot and Farnborough, having been largely excluded on grounds of language.

Questionnaire findings

The following questionnaire results provided the basis for the focus group discussions.

Medication adherence. The majority of responders (83%, 98/118) reported their medication adherence as ≥9 on a 10-point scale (Table 2).

- Practical issues — 'can't take': Most participants (93%, 94/101) agreed or strongly agreed that they *could take* their medication, without practical difficulties.
- Perception — 'don't need': Responders accepted *needing* medication, although 43% (*n* = 40, 40/94) were unconcerned about having diabetes. Not all responders answered this question.
- Attitude — 'don't like': The results were varied but the main reasons for not liking medication were concerns over long-term side effects (41.2%, 40/97) and unhappiness about having to take tablets for the rest of their lives (43.9%, 47/107).

Knowledge of HbA1c. Table 3 shows that an overall 61% of responders (68/112) reported knowing their HbA1c value: 65% (13/20) and 60% (55/92) for type 1 diabetes and type 2 diabetes, respectively.

Little difference was found in medication

Table 2. Overall self-reported medication adherence

Medication adherence	Self-reported adherence score ≥9 on a 10-point scale	Self-reported adherence score <9 on a 10-point scale	Not answered	% with self-reported adherence of ≥9 on a 10-point scale
Self-reported adherence (whole sample)	98	18	2	83.1%
Self-reported adherence of clinic attenders (blue questionnaires)	77	14	2	82.8%
Self-reported adherence of infrequent attenders/ defaulters (green questionnaires)	21	4	0	84.0%

adherence between those who knew their HbA1c and those who did not. Of those who did know it, 58/68 (85%) reported adherence as ≥9 on the 10-point scale. Of those who did not know, 37/44 (84%) reported the same level of adherence (Table 3).

Likewise, those who knew their HbA1c value to be 'good'[17] reported similar levels of adherence to those with poorer control (Table 4). The lowest Quality and Outcomes Framework HbA1c target of 59 mmol/L was used as the indicator of good control.[17]

It appears from this analysis that knowledge of the HbA1c value, irrespective of its level, has no relationship with self-reported adherence. The possible exception is for patients with type 1 diabetes, although responder numbers were very small.

Information sources: most useful and most trusted. Responders were asked to indicate their three most useful and most trusted sources of information about diabetes (Table 5). GPs were ranked highest in both categories, followed by diabetes specialist nurses, and practice nurses. It is possible that responders had never seen a diabetes specialist nurse and confused them with practice nurses.

It must be strongly emphasised that this was a primary care study and most responders are unlikely to ever have seen a hospital doctor with regard to their diabetes and therefore the results are not reflective of the true position.

Table 3. Responders' knowledge of personal HbA1c value and self-reported adherence

Responders' type of diabetes	Knew their HbA1c *n* (%)	Self-reported adherence score ≥9 on a 10-point scale *n* (%)	Did not know their HbA1c *n* (%)	Self-reported adherence score ≥9 on a 10-point scale *n* (%)
Type 1 (*n* = 20)	13 (65.0)	13 (100)	7 (35.0)	5 (71.4)
Type 2 (*n* = 92)[a]	55 (59.8)	45 (81.8)	37 (40.2)	32 (86.5)
Total (*n* = 112)	**68 (60.7)**	**58 (85.3)**	**44 (39.3)**	**37 (84.1)**

[a]*Six responders did not answer the question.*

Focus groups

Questionnaire findings informed the focus group discussions, exploring in particular:

- the high self-reported adherence despite *National Diabetes Audit*[1] reports of poor diabetes control;
- understanding of HbA1c and what it means to participants; and
- relationships with healthcare professionals.

Three themes were identified: perceptions of living with diabetes, barriers to good control of diabetes, and enablers of good diabetes management.

Perceptions of living with diabetes. The word 'shock' was frequently used regarding diagnosis:

'To be perfectly honest being diagnosed was a shock ... I've never felt any side effects or any kind of detrimental health effects and it really did come as a shock.' (Male >70 years)

Later in the course of the disease this changed, and the condition was trivialised as inconvenient or a nuisance:

'To me it means it's a pain to be perfectly honest. I'm annoyed I've got it because it's just inconvenient really with the tablets.' (Male 65–70 years)

The feeling of inconvenience appeared to diminish the impetus for lifestyle change:

'I was aware I should reduce all sugar, yeah, and change my diet ... as far as reducing sugar that has been truly difficult.' (Male, 40–45 years)

Barriers to good control

Perceptions of medication

When asked about the good self-reported adherence, there was comment in one of the groups that perhaps responders were lying, or at least lying to themselves. However, despite this, all three focus groups confirmed their own good adherence — that is, other people might not be telling the

Table 4. Responders' knowledge of their own HbA1c value (≤59 or >59 mmol/l) and self-reported adherence

Responders' type of diabetes	Knew their HbA1c ≤59 *n* (%)	Self-reported adherence score ≥9 on a 10-point scale *n* (%)	Knew their HbA1c >59 *n* (%)	Self-reported adherence score ≥9 on a 10-point scale *n* (%)
Type 1 (*n* = 13)	6 (46.2)	6 (100)	7 (53.8)	7 (100)
Type 2 (*n* = 55)	29 (52.7)	23 (79.3)	26 (47.3)	22 (84.6)
Total (*n* = 68)	**35 (51.5)**	**29 (82.9)**	**33 (48.5)**	**29 (87.9)**

truth but we do adhere.

There were many remarks about *not liking* medication, particularly metformin: *'Horse pills.'* (Male 50–55 years)

'It's the rigmarole, remembering to take the tablets, get a drink 'cos it does need a drink to get them down. I just don't like them; don't like the taste of them.' (Male 50–55 years)

'I hate them. It's not the taking of them that's the problem, it's just the idea of pumping all those drugs into my body.' (Male 60–65 years)

Lack of lifestyle change

Taking medication was seen as a way to avoid lifestyle change:

'I don't think I've changed a lot in my habits. I'm taking the metformin and I'm just, sort of assume it's doing its job and I just carry on as normal.' (Male 60–65 years)

'... you can take the medication but you could also be taking sweets and everything else on top of it.' (Male 40–45 years)

Table 5. Responders' most useful and most trusted sources of diabetes information

Information source	Most useful sources of information *n* (% of responders)	Most trusted sources of information *n* (% of responders)
GP	73 (61.9)	83 (70.3)
Diabetes specialist nurse	62 (52.5)	74 (62.7)
Practice nurse	42 (35.6)	37 (31.4)
Internet	32 (27.1)	10 (8.5)
Diabetes UK	25 (21.2)	30 (25.4)
Other people who have diabetes	17 (14.4)	11 (9.3)
Books and magazines	14 (11.9)	8 (6.8)
Hospital doctor	11 (9.3)	20 (16.9)
Pharmacist	7 (5.9)	13 (11.0)
Friends and family	3 (2.5)	5 (4.2)

Without symptoms there was widespread reluctance to change lifestyle, often needing specific events to trigger the will to change:

'It's only when they say "you've got a problem with your kidneys", it's like the wakeup call ... you think I've got to do something about this.' (Male 40–45 years)

Triggers included life assurance being declined, complications developing, and impending insulin initiation.

Perceived inadequacy of lifestyle advice

Much comment was made about deficient lifestyle advice, specifically dietary:

'I still find challenging, the amount of contradictory information about diet ... where do we find this reliable source of information, for me it's the biggest headache.' (Male 45–50 years)

'... knowing what you absolutely can eat and knowing there are things you absolutely can't eat and how you can possibly vary within diet.' (Male >70 years)

More detailed, definite, and even didactic advice was sought:

'Yes, I'd like them to be a little more authoritarian with me and say, "This is what you need to do, this is the kind of strict diet I expect you to stay on."' (Male >70 years)

'... you've got to take this seriously, you've got to do something, you've got to be a bit more prescriptive about it in terms of the doctor not being so lenient.' (Male 45–50 years)

Conflicting advice from healthcare professionals

Conflicting advice was commonly but not universally reported, allowing patients to be selective about what they heard:

'... look at your weight, it's obviously not weight, not diet induced, so if you want a sugar in your tea then have one.' (Male 60–65 years)

'And I'm thinking he's too strict, my first one, miles too strict ... I was quite happy to see this other one because I could have another sugar in my tea.' (Male 60–65 years)

Some participants reported difficulties in finding a suitable clinician:

'I was prescribed tablets ... and then I was switched to the diabetic specialist doctor

and that doctor said, "Try these, these are much better."' (Male 50–55 years)

Lack of understanding of HbA1c

HbA1c was poorly understood, with participants responding to questioning on how they knew if their disease was under control by describing how they felt rather than by blood parameters:

'I think it's my belt, I can tell by my belt because it's, because I've lost two notches on my belt.' (Male 65–70 years)

'I will tend to sense it if I've sort of indulged excessively.' (Male 45–50 years)

'I feel aches and pains. I feel tiredness in my legs ... I'm thinking my sugar level is a bit high.' (Male 40–45 years)

'I just [tend] *to think my blood sugar is under control with the metformin.'* (Male 65–70 years)

A minority of patients reported that blood sugars were an indicator of control, but no-one volunteered HbA1c as the primary measure.

Some had a reasonable grasp of what HbA1c was, especially those who had attended 'structured education', but most participants deemed it medical jargon:

'... it doesn't really matter to me is the 4.2 or 42 or whatever it is.' (Male 65–70 years)

'It's a load of gobbledygook to be honest.' (Male 60–65 years)

'It's medical jargon.' (Male 60–65 years)

'It's something the nurse or the doctor asks me to get, yeah, so I do and they look at it and they're either pleased with it or not.' (Male 60–65 years)

When asked for suggestions as to how they might better engage with HbA1c as a concept they proposed the use of more intuitive phraseology such as 'stuck-on-sugar' or 'sugarload'.

Enablers of good diabetes management. Despite reports of conflicting advice, there was a high degree of trust in healthcare professionals:

'They get to know you. They've got all your figures and records.' (Female 50–55 years)

Seeing the same doctor or nurse was perceived as important, as was the need for regular reinforcement:

'... it's always the same GP here, I wouldn't see any of the other GPs for this sort of thing.' (Male >70 years)

'For me, I just see the same person and it's not, there are no inconsistencies at all. I see the practice nurse.' (Female 50–55 years)

'... you go to see a doctor 3 months down the line, 6 months down the line, you do forget.' (Male 40–45 years)

DISCUSSION

Summary

Participants viewed taking medicines as a way of evading lifestyle change. Clinic attenders and defaulters both reported similar good adherence. This is despite a substantial minority reporting as 'don't like' in the questionnaire.[18] This builds on previous work that patients considered medications more important than changing their lifestyle,[19] which is seen as difficult,[20] and more less easy than taking pills.[21] Study participants often did not recall having received clear lifestyle advice, particularly about diet.[21,22] There is strong evidence that motivational interviewing can facilitate lifestyle change.[23–25] It appears from this study that there is a need for increased provision of such services because a few minutes with a GP or practice nurse a few times a year is insufficient to address the habitual behaviours that contribute to the condition.

The term HbA1c did not hold much meaning for participants. The National Institute for Health and Care Excellence recommends discussing HbA1c with every patient,[26] yet only 60.7% of participants knew their HbA1c value, albeit this is a higher proportion than in other studies.[27,28] HbA1c, the clinicians' cornerstone, meant little to participants, appearing to have little relationship with medication adherence and not translating into diabetes self-efficacy.[27] This may be partly explained by the fact that participants found the term HbA1c alien, as if from a foreign language.[29] Such semantic difficulties have been described before.[30] Responders suggested that HbA1c might mean more if everyday language were used, and proposed the use of intuitive phrases such as 'stuck-on-sugar' or 'sugarload' as a solution. Variations for other languages would need to be sought.

Responses to the questionnaire showed trust in healthcare professionals.[20,31] The poor result for hospital doctors is unlikely to

be accurate because this is a primary care study most respondents would never have seen a secondary care physician on this issue. With trust and detailed knowledge of patients' circumstances, primary care is in an ideal position to manage diabetes,[19] yet the *National Diabetes Audit*[1] consistently reports poor control. An explanation may partly reside in the frequent reports of inadequate or incorrect advice observed previously by Vermeire *et al*,[21] where participants wondered 'whether guidelines even existed'. This demotivates responders and may explain why diagnosis was described as a 'shock',[22,32] evolving into a 'nuisance', until the 'trigger'.[32,33] Perhaps reluctance to change lifestyle is sometimes being compounded by conflicting clinical advice.

As previously observed,[34] participants often reported changing clinicians in search of a more positive therapeutic relationship,[33,35] and then valued continuity[34,36] and regular reinforcement.[22,33] Possibly many patients never find a suitable clinician, because, as Rayman and Kilvert[37] commented, not all practices have staff with sufficient expertise. This has obvious implications for disease management.

Strengths and limitations

This study fills a gap, appearing, after an extensive literature search, to be the only such UK primary care study since 1988.[20] This is particularly pertinent because approximately 80% of patients with diabetes are managed in primary care rather than secondary care. Construct validity was strengthened by having two data sources; the questionnaire results informed the focus groups, enabling an in-depth exploration of causality. Another strength is that poor attenders/defaulters were reached in an effort to strengthen external validity by making the sample more representative. It is possible, even likely, that only 'good adherers' responded, including infrequent attenders/defaulters. However, if this were the case, as these potentially more motivated patients reported difficulties, such impediments are likely to be magnified in the overall diabetes population. The same themes ran through all three focus groups with no new themes emerging in the last group, implying saturation.

A limitation is that medication adherence and HbA1c knowledge were both self-reported, which risks overestimation. Direct methods such as triangulation with prescribing information are more accurate,[38] but are costly and impractical. Uncertainty over the exact response rate is also a limitation.

Comparison with existing literature

Self-reported adherence was high, similar to a study by Broadbent *et al*,[19] higher than a study by Sweileh *et al*,[18] and far higher than for direct methods,[38] but other similar studies also used self-reporting. No other studies had a comparable design, taking information from questionnaires as well as focus groups. Some were questionnaire only,[18–20,27] focus group only,[21,22] or semi-structured interview only.[32,33,35] Recruiting poor attenders/defaulters aimed to achieve a more representative sample than other studies that had surveyed attenders in hospital clinics,[18,19,22,32,35] thereby only reaching actual attenders who may be more motivated. Vermeire *et al*[21] recruited when patients filled their prescriptions at pharmacies, which in itself indicates an intention to adhere. Only Nair *et al*[33] attempted to reach the less motivated, whereas Thompson *et al*[20] adopted a population approach by post.

Implications for research and practice

This research is from the patient's perspective and unanswered questions remain regarding the clinician's perspective. Clinicians' views on the importance, in asymptomatic patients, of good glycaemic control, as well as addressing blood pressure and cholesterol, could be investigated, as could their triggers to intensify treatment.

This study suggests that lifestyle change services should be more widely available with referral being routine, as for structured education programmes and retinopathy screening. Linkage to the proposed health trainer programme for non-diabetic hypergylcaemia might be a way forward. HbA1c should be explained more clearly to patients, possibly using more intuitive language such as 'stuck-on-sugar' or 'sugarload'. Diabetes management in primary care appears to need prioritising and be better resourced. There is a need to ensure that appropriate expertise in diabetes care exists in each practice, group of practices, or locality, ideally with continuity of care.

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Ethical approval

Ethics committee approval was received from Liverpool Central REC, reference number 14/NW/0177.

Provenance

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Competing interests

The authors have declared no competing interests.

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