

# Primary care

## Perceptions and experiences of taking oral hypoglycaemic agents among people of Pakistani and Indian origin: qualitative study

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### Abstract

**Objective** To explore British Pakistani and British Indian patients' perceptions and experiences of taking oral hypoglycaemic agents (OHAs).

**Design** Observational cross sectional study using in-depth interviews in English or Punjabi.

**Setting and participants** 32 patients of Pakistani and Indian origin with type 2 diabetes, recruited from primary care and community sources in Edinburgh, Scotland.

**Results** Respondents reported complex and ambivalent views about OHAs, which reflected their ambivalent attitudes towards Western drugs in general. Respondents considered OHAs to be an important part of the diabetic regimen because they perceived British healthcare professionals to be competent and trustworthy prescribers, and they considered the medicines available in Britain to be superior to those on the Indian subcontinent. Despite this, some respondents made deliberate efforts to reduce their tablet intake without being advised to do so. Reasons for this included perceptions that drugs worked by providing relief of symptoms and concerns that OHAs could be detrimental to health if taken for long periods, in conjunction with other drugs, or without traditional foods.

**Conclusions** British Pakistani and Indian patients' perceptions of their OHAs may partly derive from popular ideas about drugs on the Indian subcontinent. Cultural factors need to be understood and taken into consideration to ensure that these patients are given appropriate advice and to avoid unnecessary changes to prescriptions.

### Introduction

Type 2 diabetes is a serious condition that can lead to complications such as heart disease, stroke, renal failure, amputation, and blindness. It is at least four times more common among people of South Asian origin resident in Britain than in the general population.<sup>1</sup> South Asians also have a higher risk of complications of diabetes and a 40% higher mortality,<sup>2</sup> a situation partly attributable to their blood glucose control being poorer and more erratic than that of white patients.<sup>1</sup> Patients' self management and adherence to drugs are key to good glycaemic control.<sup>3</sup> However, adherence to prescribed oral hypoglycaemic agents (OHAs) is poor,<sup>4 5</sup> and South Asian patients may be less anxious than white patients about adhering to their treatments and may attach less importance to controlling their diabetes.<sup>6</sup> It is increasingly recognised that if adherence is to be improved, patients' perspectives must be better understood.<sup>5</sup>

Patient centred approaches, which focus on the meanings of drugs in patients' everyday lives,<sup>7</sup> have been successfully used to

understand (white) patients' adherence or non-adherence to drugs for conditions such as hypertension and epilepsy.<sup>7 8</sup> In this study, we extended a patient centred approach to a hitherto unstudied area—the attitudes of Pakistani and Indian patients with type 2 diabetes towards, and experiences of, taking OHAs. Our objective was to inform their future care, as minority ethnic patients respond well to health related advice and interventions if these are delivered in ways that are sensitive to their views and cultural backgrounds.<sup>9</sup>

### Methods

We used single, in-depth interviews that encouraged respondents to display their own understandings and meanings and permitted themes and hypotheses to be identified and tested during the study that might not have been initially anticipated.<sup>10</sup> As important information and cultural nuances can be lost when translators are used as part of the interview process,<sup>11</sup> we used a bilingual research fellow (NA) fluent in English and Punjabi to do all the interviews.

### Recruitment and sample

Recruiting South Asian patients can be difficult (particularly when health professionals are the only recruiters), and several methods may be needed to access a sample with broad ranging characteristics and experiences.<sup>12 13</sup> We recruited patients from five general practices in Edinburgh, identified as having a high proportion of Pakistani and Indian patients. Healthcare professionals contacted patients by letter (in English, Urdu, and Punjabi), inviting them to "opt in." We also used face to face recruitment and snowballing to access respondents from Edinburgh's Pakistani and Indian communities, making an effort to include hard to reach groups, such as housebound patients and those who had limited contact with health services and professionals. All respondents were either Indian (n = 9) or Pakistani (n = 23) (the proportions reflect the demography of South Asians in Scotland (2001 census)), aged 18 years and over, and diagnosed as having type 2 diabetes. We excluded Bangladeshis because of the logistical problems of including a third language group and the small numbers resident in Scotland (2001 census). To ensure a diversity of experiences and views, we purposively sampled respondents on the basis of their age, sex, length of time since diagnosis, and preferred language (table). Recruitment continued until no new themes emerged from the interviews. All respondents provided written consent to participation.

### Data collection

NA did the interviews in English and Punjabi. Respondents were informed that NA was not a healthcare professional and were

Characteristics of sample	
Characteristic	No of respondents
<b>Age (years)</b>	
30-50	6
51-60	10
61-70	13
≥71	3
<b>Sex</b>	
Male	15
Female	17
<b>Years since diagnosis</b>	
0-5	9
6-10	10
11-15	5
≥16	8
<b>Self reported fluency in English</b>	
High	13
Moderate	6
Low/nil	13
<b>Religion</b>	
Muslim	22
Christian	1
Hindu	4
Sikh	5
<b>Recruitment source</b>	
General practice	12
Community	20
<b>Oral hypoglycaemic agents prescribed</b>	
Sulphonylurea	4
Metformin	12
Sulphonylurea plus metformin	13
None (diet controlled)	3
<b>Head of household's occupation*</b>	
Professional/higher managerial	7
Semiskilled (manual/non-manual)	16
Unskilled	7
Unknown	2

\*Or former occupation for retired people.

reassured about confidentiality. All interviews were conducted in a sensitive and non-judgmental way. Among other topics, interviews explored respondents' perceptions of and views about OHAs in a culturally and contextually sensitive way that took account of the broader features of their lives (box 1). Interviews normally took place in respondents' homes, averaged one hour, and were tape recorded with their consent. NA translated interviews into English (when necessary), and they were transcribed in full. NA was assisted by a Pakistani and an Indian translator. They checked tapes against the transcripts and were available for troubleshooting when words or concepts did not easily translate from Punjabi to English. We contacted some respondents after the interviews to clarify issues and validate findings.

### Analysis

The study was informed by grounded theory, which involves concurrent data collection and analysis, together with systematic efforts to check and refine developing categories of data.<sup>14</sup> Themes and hypotheses identified in early interviews informed questions in later interviews. Team members independently reviewed interview data, and regular meetings were held to explore respondents' underlying reasoning, discuss deviant cases, and reach agreement on recurrent themes and findings. We used NUD\*IST, a qualitative data indexing package, to facilitate coding and retrieval of data. We coded interviews according to the areas described below.

## Results

Twenty nine of the 32 respondents had direct experience of taking OHAs (table). Respondents reported complex and ambivalent views about OHAs, which related to their ambivalent views about Western medicines in general. As reported below, respondents' perceptions of drugs led some to adjust their OHAs in ways that conflicted with medical advice. Responses did not differ according to type of treatment, method of recruitment, or characteristics of respondents outlined in the table.

### Initial reactions to taking OHAs

Respondents expressed some initial trepidation about taking OHAs, as they perceived this change to their regimen as signifying that their condition had deteriorated and that they had taken on the identity of a sick person:

"I was devastated [about being prescribed glipizide]. I wasn't happy at all. But it was explained to me that diabetes always progresses, no matter how careful you are." (R1, Pakistani, female)

"If you start taking them, you become a patient." (R11, Indian, male)

### Perceptions of OHAs

Despite their initial concerns, most of the respondents prescribed OHAs perceived them as an essential part of their diabetic regimen:

"If I didn't take them then I would be in danger." (R10, Pakistani, male)

"Once you start on these then you have to be on them for the rest of your life. So either you do that, or you risk dying. So you have no choice but to take the medicine." (R12, Pakistani, female)

The perceived importance that respondents attached to OHAs stemmed partly from their perception that these drugs were more effective and of a better quality than those that could be obtained on the Indian subcontinent:

"I don't think you can get the same kinds of medicine that you can get here, you know, like metformin. This is one of the most important drugs to take for it." (R2, Indian, male)

"See, in Pakistan, the medications are not right, they're just a waste of time, waste of money. I mean these [referring to OHAs] are the real stuff. These are what really work." (R7, Pakistani, male)

Additionally, respondents considered British healthcare professionals to be competent and trustworthy prescribers. Most had had experiences of professionals and services on the Indian subcontinent (because they were first generation migrants or they had made extended visits to relatives) and used these as a benchmark against which to assess the quality of care received in Britain. Many respondents described health professionals on the

#### Box 1: Topics covered in interviews

- Current and past diabetes treatment regimens
- Experiences of taking oral hypoglycaemic agents (OHAs) and other drugs (including perceptions and understandings of symptoms and side effects)
- Perceived efficacy of OHAs and other drugs (including complementary therapies) in the short term and long term
- Commitment to adhering to OHAs and others regimens; changes in commitment over time
- Experiences of health care and health professionals in Britain and abroad
- Perceptions of past, present, and future health

Indian subcontinent as untrustworthy, because they saw them as lacking training and expertise, giving preferential treatment to the wealthy and their own friends or relatives, and having a financially vested interest in prescribing ineffective medications:

“You know how it is there, our doctors don’t really pay attention. They are more concerned with the amount of money they are making. First they will give you a lighter medication, which will make you go back to them again and again until they give you something else. And by that time, you will be feeling better anyway.” (R13, Pakistani, female)

In contrast, British health professionals were seen as “dealing with everybody the same . . . they will treat according to their condition” (R16, Pakistani, female), because they were paid directly by the NHS and the NHS did not gain financially from prescriptions being dispensed to patients. Because respondents were confident that their OHAs had been appropriately prescribed, most claimed that they had not sought out other treatments for their diabetes, such as herbal remedies, either in Britain or during visits to the Indian subcontinent.

### Self regulation of OHAs

Despite attaching considerable importance to their OHAs, less than half the respondents prescribed these drugs reported taking them as prescribed. Fifteen people described how they deliberately and routinely adjusted the amount of tablets they took. With one possible exception, all these respondents said that they would never exceed recommended dosages. Instead, they attempted to reduce their tablet intake. Various factors seemed to influence their self regulation practices.

Many respondents believed that drugs, including OHAs, worked by providing instant relief of symptoms. Hence they often saw it as unnecessary to take all of their OHAs when they felt well: “You just can’t be bothered taking them for the sake of it” (R27, Pakistani, female). Most claimed to be fully adherent only on occasions when they felt lethargic or unwell:

“Sometimes you do say that to yourself, you know, you say to yourself, ‘Oh I feel fine and I’ll take one today, I won’t take two.’” (R27, Pakistani, female)

“They said that I need to take three, but for the last three months I’m just taking them twice a day. It’s just when I feel I’m tired I take another one. If I’m fine then I won’t.” (R26, Pakistani, male)

Some respondents also described how they deliberately skipped tablets to circumvent or mitigate unpleasant short term side effects, without consulting or reporting these to health professionals:

“So when I took them I would feel so much heat and I would suddenly become dizzy. So then I didn’t take them.” (R23, Pakistani, female)

“Sometimes I don’t take them, you know, they make you dry if you take too many.” (R21, Pakistani, female)

Other respondents reported that they reduced their OHA intake when they were fasting or they had to skip a meal, usually without seeking medical advice. These respondents were reluctant to take their OHAs without eating traditional foodstuffs, such as curries and chapattis, as these foods were perceived as having strengthening and fortifying properties that balanced out, or counteracted, the side effects of their OHAs:

“If you keep on taking tablets and not eating strengthening foods like roti, then they will affect you. If you eat strengthening foods . . . they will not produce dryness.” (R16, Pakistani, female)

A few Pakistani respondents said that health professionals had advised them to alter their OHA intake during Ramadan and, because of this, they thought they could reduce their tablets

on other occasions, even though they had not been advised to do so.

Respondents’ reluctance to take more OHAs than they saw as necessary also stemmed from their perception that, by virtue of being more potent and efficacious than medicines available on the Indian subcontinent, OHAs could have hazardous effects. These respondents articulated concerns that, if taken in excess or over long periods, OHAs could be detrimental to their health:

“Yes, they told me to take it everyday, but I said ‘do I want to die by taking it everyday. . . I don’t want to die by taking so many.’” (R4, Pakistani, female)

“Already I am dull, my body is, by taking so many tablets.” (R23, Pakistani, female)

Indeed, some respondents attributed the onset of their diabetes to drugs that they had been prescribed for other conditions, such as asthma, anaemia, and pneumonia. These respondents also expressed anxieties about the long term health implications of taking their OHAs in conjunction with other drugs.

“Initially it was just two metformins a day, and then it was increased to four by the doctor. And then there’s blood pressure tablets to take and then aspirins and so on. So it all adds up and, y’know, if you take seven, eight pills a day and you wonder [laugh] is it the right thing? This can’t be good for me in the long run.” (R2, Indian, male)

In a few cases, respondents also believed that taking several medications together could counteract their individual effects:

“Instead of giving too many tablets why don’t they give one instead? Like you drink tea and it’s good for your health, but if you drink tea too hot or you add something to it then there is no point in drinking the tea. It’s only worth it if you could have two tablets instead of say 50.” (R25, Pakistani, male)

### Self regulation strategies

Given their concerns about taking tablets in excess, some respondents had devised strategies to reduce their intake of OHAs.

#### *Self monitoring*

Most commonly, respondents self monitored their blood glucose (sometimes in conjunction with physical activity) and took all their tablets only when they considered their readings to be high:

“And now in the morning I take three pills, sometimes two, meaning I check it [blood glucose] and according to that I do or don’t take all the pills.” (R5, Pakistani, male)

In some cases, respondents were unaware of appropriate levels for blood glucose control. One man, for example, claimed that he only took all of his prescribed tablets when “it goes out of control at 18 or 19.” (R26, Pakistani male)

#### *Reducing food intake*

A few respondents described how they deliberately reduced the amount of food they consumed, or skipped meals, so that they could take fewer tablets:

“I have missed tablets many times [laughs].”

Interviewer: “Do you take all of your tablets after your breakfast?”

“Sometimes I will take two when I don’t spread too much jam on my toast or even sometimes I don’t even spread any. If I feel like a bit of a pleasure then I will put some on and then I will take the extra tablets.” (R19, Pakistani, male)

## Discussion

By adopting a patient centred approach, we identified various factors that may influence Pakistani and Indian patients' adherence to oral hypoglycaemic agents. These included confidence in British healthcare professionals as prescribers, perceptions of Western medicines as efficacious, expectations that drugs should provide instant relief of symptoms, and beliefs that Western medicines can have detrimental effects if taken in excess or without traditional foodstuffs. Respondents had to balance these competing concerns, which could lead them to self regulate their OHAs in ways that they saw as rational but that went against medical advice.

Reviews of the literature on adherence to drugs have shown that non-adherence is a problem across all patients groups and is especially common among people who have no symptoms or have unpleasant side effects.<sup>15 16</sup> Although it would be problematic to argue that our findings are specific to British Pakistanis and Indians, some underlying cultural factors may be present. Popular ideas about medicines, derived from the Indian subcontinent, may have informed the ways our respondents perceived and took their OHAs. On the Indian subcontinent, people commonly self medicate, make selective use of prescribed drugs, and abandon drugs that do not provide prompt relief of symptoms.<sup>17 18</sup> This might explain why some respondents adjusted their OHAs without seeking medical approval and according to the presence or absence of symptoms. Likewise, our respondents' concerns about taking OHAs in excess may have derived from popular ideas on the Indian subcontinent that Western drugs are powerful but inherently dangerous.<sup>19</sup>

Health professionals need to be aware of the meanings and understandings that Pakistani and Indian patients attach to OHAs and other drugs and the implications these may have for their diabetes and other self care practices. Health professionals should try to establish how these patients actually take their OHAs, as elevated glucose or glycated haemoglobin levels might be due to missed doses rather than underprescribing. In these cases, patients should be counselled about the importance of adherence, including the rationale for and long term nature of treatment. Given that patients may attempt to balance their drugs with certain foodstuffs, dietary beliefs and practices should be explored as part of the consultation. Although Muslim patients would benefit from advice about adjusting doses when they are fasting,<sup>20</sup> care should be taken to ensure that mixed messages are not sent out. If patients see it as acceptable to alter their OHA intake when fasting, they may think that they can do so on other occasions, without seeking advice.

If patients perceive side effects as an inevitable byproduct of taking OHAs, they may not present promptly when they feel unwell or volunteer side effects in consultations. Consequently, both side effects of their drugs and intercurrent illnesses may not be managed appropriately. This suggests that health professionals should question Pakistani and Indian patients directly and opportunistically about any side effects and health problems they may be having. They also need to stress the importance of presenting if problems arise.

Key to improving adherence is good health provider-patient communication (box 2).<sup>12</sup> For Pakistani and Indian patients, this may require not only an understanding of the cultural factors that inform their beliefs and practices about treatment but also that mechanisms are in place to ensure the effective transfer of information. Bilingual link workers may have an important part to play here, given their potential to provide a cultural bridge between health professionals and patients.<sup>21 22</sup>

## Strengths and limitations

This is the first qualitative study to look in depth at British Pakistani and Indian patients' perceptions and experiences of taking OHAs. Our method enabled us to access our respondents' views without using translators during the interviews, thereby enhancing the quality of the data. As we did not have access to respondents' clinical records, and did not use a longitudinal design, we cannot determine the effect of adjustment of OHAs on glycaemic control. A further limitation arises from the absence of qualitative work involving members of the general population or other minority ethnic groups that can be used for comparative purposes. Given that these groups also encounter problems adhering to their OHAs, this should be a priority for future research.<sup>7</sup> Finally, as this study focused on Indian and Pakistani patients, most of whom emigrated from the Punjab region in the north of the Indian subcontinent, this may limit the generalisability of the findings to other South Asians. However, the literature from southern part of the Indian subcontinent indicates that perceptions of drugs and self prescription practices are very similar to those observed in northern regions.<sup>23 24</sup>

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### Box 2: Key recommendations for health professionals

In order to identify and counter beliefs that may influence adherence to oral hypoglycaemic agents (OHAs), health professionals should:

- Be aware that some Pakistani and Indian patients may adjust OHA treatment according to symptoms
- Ask patients in a non-judgmental way if they adjust their drugs themselves
- Explore individual patients' understandings of and concerns about taking OHAs
- Be aware that some Pakistani and Indian patients perceive the need to balance "strong" OHA drugs with dietary changes (that may not be appropriate to their diabetes management)
- Ask patients if (and how) they adjust their diet because of their OHA treatment and vice versa
- Ask patients directly about any symptoms they attribute to their diabetes and their treatment

### What is already known on this topic

Poor adherence to prescribed oral hypoglycaemic agents (OHAs) presents a serious problem for professionals who deliver diabetes care

British South Asian patients have poor blood glucose control compared with white patients and may be less adherent to their treatment regimens

Adherence can be improved when patients are approached in culturally sensitive ways

### What this study adds

British Pakistani and Indian patients have ambivalent attitudes towards OHAs, which may partly derive from popular ideas about Western drugs on the Indian subcontinent

Pakistani and Indian patients' beliefs about Western medicines may lead them to self regulate their OHAs in ways that seem rational to them but go against medical advice

Health professionals need to establish how and why patients take their OHAs in order to improve adherence and glycaemic control

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