

## Research paper

# Using self-complete questionnaires in a South Asian population with diabetes: problems and solutions

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## ABSTRACT

The aim of this study was to investigate levels of knowledge of diabetes self-care and perceived self-efficacy in carrying out self-care behaviours in individuals with diabetes from South Asian backgrounds who are receiving care in the community. A second aim was to investigate the experiences of the diabetes support workers in administering questionnaires in a study population in which there is a high level of illiteracy.

Participants from a study carried out in general practices in Birmingham, UK, were invited to complete two questionnaires by Asian link workers during their research appointment. After the data collection had finished, the Asian link workers took part in tape-recorded semi-structured interviews to discover what difficulties they had encountered during the data collection period.

The results demonstrated that although more than 60% of those approached agreed to complete the questionnaires, the majority were assisted by the Asian link workers. The in-depth interviews with the link workers suggested that these questionnaire data may not reflect the participants' true level of knowledge or confidence in carrying out diabetes self-care, given the difficulties experienced in administering the questionnaires in this study population.

This study highlights some of the difficulties in collecting data in groups whose written/spoken language is not English, and questions some of the strategies currently used in research and in clinical practice to collect information.

**Keywords:** diabetes, minority ethnic groups, translations

## Introduction

Type 2 diabetes is a major health concern in the 21st century, with the incidence and prevalence of this condition increasing rapidly (Department of Health, 2002). It is a particular problem in the South Asian communities of the UK, as it is over four times more common and the age of onset is earlier compared with white populations (Chowdhury, 2002; Department of

Health, 2002). There are also a number of particular issues with regard to the management of the condition in this group, including a greater risk of cardiovascular and renal problems (Chowdhury, 2002). In particular, cultural and communication differences often make it difficult to provide appropriate support for the self-management of diabetes (Greenhalgh *et al*, 1998; Baradaran and Knill-Jones, 2002; Vyas *et al*, 2003).

The link between self-care and poor outcomes in diabetes is now widely accepted, and the *National Skills Framework for Diabetes* (Department of Health, 2002) recommends the promotion of skills for self-management, two key aspects of which are diabetes knowledge and self-efficacy. However, most research in the UK in this area has been carried out in white or English-speaking populations, and uses self-complete questionnaires to measure health behaviours. The few previous attempts to measure knowledge and self-efficacy in white UK and Asian populations (Dunn *et al*, 1984; Meadows *et al*, 1988; Simmons *et al*, 1991; Hawthorne and Tomlinson, 1999; Sturt and Hearnshaw, 2003) have not focused on the needs of those not able to speak or read/write English. One exception to this has been a small study which recently demonstrated that the use of Asian support workers, or Asian link workers, markedly improves patient outcomes, in terms of increased knowledge and understanding of their diabetes, and improved attendance rates at clinics and at education sessions (Curtis *et al*, 2003). This dearth of research in minority ethnic groups is also reflected in the broader research arena. As Johnson (2006) comments, there are few examples of such research even though this is likely to be the best way of obtaining insights into the needs of these sections of the population.

## The UKAD study

The UK Asian Diabetes (UKAD) study takes place in primary care practices in Coventry and Birmingham, and was set up to identify the most cost-effective and acceptable risk-reducing strategies in the South Asian population with type 2 diabetes. A protocol-driven model of risk factor reduction is being tested, using diabetes specialist nurses, link workers and practice nurses to implement protocols for the strict management of lipids, blood pressure and glycaemic control in general practice (O'Hare *et al*, 2004). Knowledge of and confidence in performing diabetes self-care behaviours were seen as crucial aspects of this intervention. This paper reports the experiences of the Asian link workers, employed to collect data. Two South Asian groups, Mirpuri speakers and Sylheti speakers, have been of particular interest in the UKAD study because they have relatively poor health status and outcomes and because the languages concerned do not have an agreed written form (Johnson *et al*, 2000).

## Methods

In the UKAD study, three Asian link workers were employed as data collectors. Their role required them to contact patients who attended the general practice research sessions, to encourage attendance at these clinics and to organise educational sessions. The remit of the link workers was to work alongside the practice nurses and the diabetes specialist nurses and 'enhance patient understanding and compliance' (O'Hare *et al*, 2004). During their clinic visits, after undergoing a series of clinical investigations, participants from the Birmingham practices were invited by the link workers to complete the Diabetes Management Self-Efficacy Scale (DMSES) and the revised Diabetes Knowledge Scale (DKS-R). The UKAD study was approved by Eastern Birmingham Research and Ethics Committee.

## Questionnaires

The DKS-R was developed from the original Michigan Knowledge Questionnaire (Fitzgerald *et al*, 1998), which was validated in the US. The DMSES was developed and validated for Dutch and US populations (Bilj *et al*, 1999) and has been undergoing revalidation for UK populations (Sturt and Hearnshaw, 2003) and other national populations (McDowell *et al*, 2005). Both these questionnaires were translated into Urdu and Bengali by the Brasshouse Translation Unit, Birmingham, according to standard procedures of translation and back-translation (Bradley, 1994), followed by a consensus meeting between the two different translators and one of the researchers (CL), before final translations were agreed upon. Urdu and Bengali are the 'official' written languages for those speaking Mirpuri and Sylheti, respectively, and as such formed the basis from which the link workers could implement the questionnaires if the study participant was unable to read/write.

Prior to implementation, two of the researchers (CL and SM) met on four occasions with the link workers to discuss the translations that had been carried out, including the particular verbal translation that should be used for Mirpuri. As Mirpuri does not have an agreed written form, the link workers wrote supporting notes in Urdu. Culturally inappropriate terms in the questionnaires were identified and replaced with appropriate words where deemed necessary. As none of the link workers spoke Sylheti, only the Bengali written questionnaire could be used for this section of the study population.

## Procedure

UKAD participants who agreed to complete the questionnaires were invited to do so in a separate clinic room. They were informed that they could complete the questionnaires either by themselves, or with the help of a relative (if available) or the link worker. A note was made in the participant's research file of who completed the questionnaires (including who assisted). If they declined, then a note was made to this effect. On only four occasions were the reasons why they declined recorded, as this had not been agreed prior to the commencement of the study.

In the three months between April 2004 and June 2005, 175 UKAD participants were invited to complete the DMSES and the DKS-R questionnaires. One hundred and seven (61%) people agreed to complete the questionnaires, the majority of whom were assisted by the link workers (see Table 1).

Just over half ( $n = 97$ ; 55%) of those approached spoke Mirpuri as their main language. All those ( $n = 10$ ) who spoke only Pashto (a Pakistani dialect), all but one (eight out of nine) of those who spoke Bengali, and both people who spoke Gujarati declined to take part. Of the 21 people approached whose first language was English, only two (10%) refused to participate. Both men and women were equally likely to decline to take part, although Mirpuri women were somewhat more likely to decline than Mirpuri men (20 women compared to ten men). Numbers were small, however, and therefore no statistical differences could be detected. All four people who declined to participate and recorded a reason for this stated that this was because they felt the questions were too difficult to understand. The age of the sample ranged from 26 to 81 years, with similar ranges for each of the ethnic groups.

After approximately four months it became apparent that there was insufficient time to complete these

two questionnaires while participants were attending clinic for the UKADS main study. Therefore, in order to increase the response rate, the link workers identified particular days when they could invite a number of participants to attend clinic for the sole purpose of completing these two questionnaires. However, despite a number of approaches, the completion rate for the questionnaires remained low. In addition, the link workers reported considerable difficulties with regard to administering the questionnaires, even when UKAD participants had agreed to take part. Consequently, a decision was taken to terminate this part of the study.

## Interviews

In order to understand what aspects of the data collection methods may have been problematic, the link workers were interviewed by one of the researchers (CL). These interviews were tape-recorded and subsequently transcribed and analysed to identify the nature of the problems experienced in administering the questionnaires. These problems are outlined below.

## Findings

All three link workers were female and spoke English, Urdu and Mirpuri, and two spoke Punjabi as well. All three had been trained to perform aspects of the diabetes annual review, such as urine testing, height and weight measurements, and were experienced in recording medical histories, and translating/interpreting procedures. None of the link workers had used translated questionnaires before. However, all three had had experience in translating in an *ad hoc* manner,

**Table 1** Participants according to language and type of response

Language	Self-completed <i>n</i> (%)	Assisted by link worker <i>n</i> (%)	Assisted by relative <i>n</i> (%)	Declined <i>n</i> (%)
Mirpuri ( $n = 97$ )	2 (2)	63 (65)	2 (2)	30 (31)
Urdu ( $n = 19$ )	0	10 (53)	1 (5)	8 (32)
Bengali/Sylheti ( $n = 9$ )	0	0	1 (11)	8 (89)
Pashto ( $n = 10$ )	0	0	0	10 (100)
Punjabi ( $n = 17$ )	2 (12)	4 (23)	0	11 (65)
English ( $n = 21$ )	10 (48)	7 (33)	2 (9.5)	2 (9.5)
Gujerati ( $n = 2$ )	0	0	0	2 (100)

as and when required. All three link workers reported having enjoyed being consulted and found it helpful to have been part of the process of development of the new translated questionnaires. It also improved their confidence in administering the questionnaires:

‘... that was really useful, yes. We went through the papers you see and then we knew what to say to the patient.’

## Lack of time

There were some common problems in administering the translated questionnaires as well as some specific difficulties. The most common problem was the time required to complete the two questionnaires. Each UKAD participant was allocated 30 minutes in which to have all their medical history, personal details and various aspects of the annual review recorded and also to complete the DMSES and the DKS-R. Even explaining the rationale behind the questionnaires took up time:

‘... some of them were clued up obviously, but mainly I found that Mirpuri people didn’t understand the questionnaire properly and it was time consuming for them.’

‘... in all honesty we found it really difficult to fit in, really hard to fit in, in the timeslot that we had ... the questionnaires alone took about 20 minutes.’

‘Plus we only have half an hour to do the physical examination and it’s hard to fit all of that in.’

## Reactions of participants

A further common problem reported by the link workers was the frequent negative reactions they received from UKAD participants, who were often uncomfortable about their perceived lack of knowledge about the various aspects of diabetes. The link workers felt that some individuals were concerned about giving the incorrect answers:

‘In fact some patients thought we were judging them by how intellectual they were.’

‘... and the fact that they [the questions] were repeated again ... “is this a trick question?” they used to say, “is there a right or wrong answer?”’

Although many of the participants had attended education sessions on diabetes self-care this did not appear, according to the link workers, to impact on their knowledge:

‘Most of them had been to education sessions but they still didn’t understand you see, they didn’t understand most of the words that we were saying ...’

## Assistance from relatives

A small minority ( $n = 5$ ) of participants were assisted by relatives, although this was not encouraged and eventually entirely discouraged by the link workers as it became clear that the knowledge of diabetes that was being measured was not always solely that of the UKAD participant. The link workers described ushering the participant into a separate room and asking the relative to wait behind while the data were being collected.

‘Sometimes the relative would come in and assist them but we found that the patient was then relying on the relative’s answer ... so it was never coming from the actual patient, so we found it was best to take them on their own.’

The link workers reported that this reliance on relatives was more common in older participants, who relied on younger people to communicate with health-care professionals. This was seen to be in contrast with the younger participants who were more likely to speak English:

‘I think that’s a big problem with these [older] Asian patients; they just rely on other people, like their children. We’ve had quite a few patients wanting their children to answer the questions instead of them but we’ve said no, it’s got to be you.’

‘I think the younger generation wouldn’t mind doing it ... they can understand better, but some of the middle-aged people don’t know as much. Even though they’ve lived most of their lives here they still don’t speak English, they rely on other people ...’

## Difficulties with questionnaires

There were specific problems associated with each of the two questionnaires. For the knowledge questionnaire, the DKS-R, there were difficulties with terminology and the meaning of specific words or phrases:

‘The knowledge one was alright, but a lot of the words, like carbohydrate, protein, not everybody knew what that was.’

‘Cholesterol ... the patients didn’t have a clue.’

Some English words, such as carbohydrate, did not have an equivalent in Mirpuri, and this meant that there could not be an appropriate translation. As one link worker described, the problems were also compounded by the fact that they were trying to determine how much the patient knew about their diabetes. This was often felt as threatening, as if the link workers were ‘testing them’ on their knowledge of diabetes. However, if they explained the words contained in the questions this would have meant they had given the participant the answers to the questions.

'... some of the words they didn't understand we couldn't explain to them what they were, we wanted to know what *they* knew, what *they* thought of it.'

'... we'd have to tell them what it is and then we've answered the questions for them ... It's not because they know it already it's cos you've helped them out (by giving clues as to what a carbohydrate or a protein is).'

The difficulties with the DMSES were less related to the terminology but more to do with the perceived repetitiveness of the questions. Several questions on the DMSES ask about perceived ability to follow an eating plan when away from home, on holiday or eating out, or at a party. These questions were seen by both the link workers and the participants as virtually the same, consequently causing confusion and sometimes exasperation:

'I ... it comes a point when the questions are answered in a different way, especially ... are you confident when you are ill, would you be able to adjust your medication, are you confident when you are away from home, on holiday, when you are at a party ... they're all similar aren't they?'

'... and the fact that they [the questions] were repeated again ... "is this a trick question?" they used to say, "is there a right or wrong answer?''

For a minority of participants the completion of these questionnaires was a positive experience, and this was the case particularly for the knowledge questionnaire:

'... a few actually said they really appreciated it because it increased their knowledge ... they thought they were really good, and said oh I didn't know that, and then they'd be interested in knowing if they were going to get the correct information and more advice.'

## Discussion

This report demonstrates the difficulties of collecting information from minority ethnic populations in the UK. Further work needs to be done if genuine progress is to be made in our understanding of the pertinent issues affecting the health of these groups, and indeed this view has been recently voiced elsewhere (Dixit, 2003; Johnson and Collins, 2004).

Approximately 25% of the population of Birmingham are of South Asian origin, and people of Mirpuri (Pakistani) and Bangladeshi-Sylheti origin are well represented in this. Diabetes is more common in those of South Asian origin, and this study has important implications for clinical practice. While our translations were accurate, the content of the questionnaires and the actual mode of data collection were both often seen as inappropriate. This was a view held by those both collecting and providing the data. The use of specific terminology in diabetes care, such as

Hb<sub>A1C</sub> (haemoglobin<sub>A1C</sub>), carbohydrate, and even more commonplace taken-for-granted terms such as *away from home* or *on holiday* cannot be assumed to have the same meaning in all cultures. These observations are supported by an earlier study of the knowledge and beliefs of South Asians, in which wide discrepancies were observed in the level of understanding of the term *heart disease* (Rankin and Bhopal, 2001).

Interestingly, in our study we did not observe any differences in understanding of terms such as *heart disease* and *diabetes* in relation to the participants' country of origin. However, Hanna *et al* (2006) reported greater familiarity with English translations of commonly used words than the Urdu equivalent, in people who had lived in the UK for some time. In our study, the link workers reported less understanding among the older participants, whom it was assumed were more likely to have been born outside the UK. This is purely speculative, however, as we do not have information on country of origin for our study. Further research remains to be carried out in order to tease out the differences both between and within different cultural groups.

Recent literature suggests it is crucial to consider the actual concepts being measured when translating questionnaires (Hunt, 1994; Greenhalgh *et al*, 1998; Bowden and Fox-Rushby, 2003; Hunt and Bhopal, 2004). Accurate information cannot be obtained unless those involved have an agreed understanding of the terms or concepts being used. Hanna *et al* (2006) have recently noted some of these difficulties and specifically point to the difficulties in translating questionnaires. One crucial problem is the use of technically correct language in translations that do not reflect the ways in which the majority of people speak, what Hanna *et al* (2006) call 'ordinary people speak'. This leads to inappropriate forms of translation that are compounded when, for example, the official language is a written one (Urdu) but the most commonly used form is only spoken and is not written, for example, Mirpuri.

Equally important, we would argue, is the mode of collecting data from minority ethnic groups. Our study demonstrates the difficulties inherent in collecting data using self-complete questionnaires. Several recent studies have reported success using face-to-face interviews carried out by trained multilingual researchers (Hawthorne and Tomlinson, 1999; Rankin and Bhopal, 2001; Lawton *et al*, 2005). Furthermore the use of lay members of the community or service users has been seen as a useful way forward (Rankin and Bhopal, 2001; Johnson, 2006). In our case this involved the need for assisted completion or finding other ways of collecting data that do not involve having to complete questionnaires in a written form.

The success of any information collection exercise relies heavily on those doing the collecting. The link

workers in this study were all highly trained in working with people with diabetes and using standard forms for the collection of personal and medical information. However, none of them had experience in using translated questionnaires before, and this could have impacted on how they worked in this regard. If the link workers were unsure of how to use these questionnaires this may well have influenced patients' willingness to take part. It may also have been possible to have gathered more data with regard to reasons for refusal and other demographic and social information. This would have given greater depth to our research findings, and could lend support to future decisions about collecting data in this population. Training and experience in the administration of translated questionnaires and maximising response rates are thus critical. The link workers agreed that the time taken to develop an agreed form of Mirpuri to be used when required was invaluable, although, as there is no agreed written form, this relies on the link workers' memories. The high refusal rate in those participants who spoke Bengali/Sylheti was simply because none of the link workers spoke either of these languages, thus making communication difficult. This is not an issue confined to research but one that confronts all health services staff, i.e. that of attempting to meet the needs of all sections of the patient population in an equitable manner.

## Conclusion

This study has highlighted some of the difficulties in collecting data in groups whose written/spoken language is not English, and raised questions about some of the strategies currently used to collect information. It is important to question assumptions that are often made about the utility of translated questionnaires for use in minority ethnic groups, in terms of the particular language/dialect used as well as the specific terminology used. It is clear from our experiences that the role of the link worker is of primary importance. Equally valid, we believe, are the experiences of the 'researched' or service users, whose input into both research and clinical practice is becoming increasingly important. Consultation with both health service workers and services users in the development of alternative, valid, coherent modes of data collection seems to be the only appropriate way forward.

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## REFERENCES

- Baradaran H and Knill-Jones R (2004) Assessing knowledge, attitudes and understanding of type 2 diabetes amongst ethnic groups in Glasgow, Scotland. *Practical Diabetes International* 21:143–8.
- Bowden A and Fox-Rushby JA (2003) A systematic and critical review of the process of translation and adaptation of generic health-related quality of life measures in Africa, Asia, Eastern Europe, the Middle East, South America. *Social Science and Medicine* 57:1289–306.
- Bradley C (1994) Translation of questionnaires for use in different languages and cultures. In: Bradley C (ed) *Handbook of Psychology and Diabetes*. Switzerland: Harwood, pp. 43–55.
- Chowdhury TA and Lasker SA (2002) Complications and cardiovascular risk factors in South Asian and Europeans with early onset type 2 diabetes. *Quarterly Journal of Medicine* 95:241–6.
- Curtis S, Beirne J and Jude E (2003) Advantages of training Asian diabetes support workers for Asian families and diabetes health care professionals. *Practical Diabetes International* 20:215–18.
- Department of Health (2002) *National Service Framework for Diabetes Standards of Care Document*. [www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationSPAndGBrowsableDocuments/fs/en?CONTENT\\_ID=4096591&chk=R41ZhQ](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationSPAndGBrowsableDocuments/fs/en?CONTENT_ID=4096591&chk=R41ZhQ)
- Dixit J (2003) Cultural evolution. *Diabetes Update* 22–7.
- Dunn SM, Bryson JM, Hoskins PL et al (1984) Development of the diabetes knowledge (DKN) scales: Forms DKNA, DKNB, and DKNC. *Diabetes Care* 7:36–41.
- Fitzgerald JT, Anderson RM, Funnell MM et al (1998) The reliability and validity of a brief diabetes knowledge test. *Diabetes Care* 21:706–10.
- Greenhalgh T, Helman C and Chowdhury AM (1998) Health beliefs and folk models of diabetes in British Bangladeshis: a qualitative study. *BMJ* 316:978–83.
- Hanna L, Hunt S and Bhopal R (2006) Cross-cultural adaptation of a tobacco questionnaire for Punjabi, Cantonese, Urdu and Sylheti speakers: qualitative research for better clinical practice, cessation services and research. *Journal of Epidemiology and Community Health* 60:1034–9.
- Hawthorne K and Tomlinson S (1999) Pakistani Moslems with type 2 diabetes mellitus: effect of sex, literacy skills, known diabetic complications and place of care on

- diabetic knowledge, reported self-monitoring management and glycaemic control. *Diabetic Medicine* 16:591–7.
- Hunt SM (1994) *Cross-cultural Comparability of Quality of Life Measures*. International Symposium on Quality of Life and Health. Berlin: Blackwell, pp. 25–7.
- Hunt SM and Bhopal R (2004) Self report in clinical and epidemiological studies with non-English speakers: the challenge of language and culture. *Journal of Epidemiology and Community Health* 58:618–22.
- Johnson MRD (2006) Engaging communities and users. Health and social care research with ethnic minority communities. In: Nazroo JY (ed) *Health and Social Research in Multiethnic Societies*. London: Routledge, pp. 48–64.
- Johnson MRD and Collins GS (2004) Getting it right in multi-cultural research. *BMJ* 328:7431.
- Johnson MRD, Owen D, Blackburn C and Nazroo J (2000) *Black and Minority Ethnic Communities – Health and Lifestyles*. London: Health Education Authority.
- Lawton J, Ahmad N, Hallowell N, Hanna L and Douglas M (2005) Perceptions and experiences of taking oral hypoglycaemic agents among people of Pakistani and Indian origin: qualitative study. *BMJ* 330:1247–61.
- McDowell J, Courtney M, Edwards H and Shortridge-Baggett L (2005) Validation of the Australian/English version of the Diabetes Management Self-Efficacy Scale. *International Journal of Nursing Practice* 11:177–84.
- Meadows KA, Fromson B, Gillespie CC *et al* (1988) Development, validation and application of computer-linked knowledge questionnaires in diabetic education. *Diabetic Medicine* 5:61–7.
- O'Hare P, Raymond NT, Mughal S *et al* (2004) Evaluation of enhanced diabetes care to patients of South Asian ethnicity: the United Kingdom Asian Diabetes Study (UKADS). *Diabetic Medicine* 21:1357–65.
- Rankin J and Bhopal R (2001) Understanding of heart disease and diabetes in a South Asian community: cross-sectional study testing the 'snowball' sample method. *Public Health* 115:253–60.
- Simmons D, Meadows KA and Williams DR (1991) Knowledge of diabetes in Asians and Europeans with and without diabetes: the Coventry Diabetes Study. *Diabetic Medicine* 8:651–6.
- Sturt J and Hearnshaw H (2003) Measuring outcomes: self-management, empowerment and self-efficacy. *Diabetic Medicine* 20(Suppl 2):78.
- van der Bijl JJ, van Poelgeest-Eeltink A and Shortridge-Baggett L (1999) The psychometric properties of the diabetes management self-efficacy scale for patients with type 2 diabetes mellitus. *Journal of Advanced Nursing* 30:352–9.
- Vyas A, Haidery AZ, Wiles PG *et al* (2003) A pilot randomized trial in primary care to investigate and improve knowledge, awareness and self-management among South Asians with diabetes in Manchester. *Diabetic Medicine* 20:1022–6.

#### CONFLICTS OF INTEREST

None.

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