Contextualising accounts of illness: notions of responsibility and blame in white and South Asian respondents’ accounts of diabetes causation

Julia Lawton¹, Naureen Ahmad¹, Elizabeth Peel² and Nina Hallowell³

¹Research Unit in Health, Behaviour and Change, The University of Edinburgh Medical School
²School of Life and Health Sciences, Aston University
³Public Health Science, University of Edinburgh

Abstract We undertook a secondary analysis of in-depth interviews with white (n = 32) and Pakistani and Indian (n = 32) respondents who had type 2 diabetes, which explored their perceptions and understandings of disease causation. We observed subtle, but important, differences in the ways in which these respondent groups attributed responsibility and blame for developing the disease. Whereas Pakistani and Indian respondents tended to externalise responsibility, highlighting their life circumstances in general and/or their experiences of migrating to Britain in accounting for their diabetes (or the behaviours they saw as giving rise to it), white respondents, by contrast, tended to emphasise the role of their own lifestyle ‘choices’ and ‘personal failings’. In seeking to understand these differences, we argue for a conceptual and analytical approach which embraces both micro- (i.e. everyday) and macro- (i.e. cultural) contextual factors and experiences. In so doing, we provide a critique of social scientific studies of lay accounts/understandings of health and illness. We suggest that greater attention needs to be paid to the research encounter (that is, to who is looking at whom and in what circumstances) to understand the different kinds of contexts researchers have highlighted in presenting and interpreting their data.

Keywords: lay understandings, disease causation, diabetes, context, secondary analysis

Introduction

Type 2 diabetes has recently received a high profile within biomedical, public health and social science forums because of mounting concerns about its increasing prevalence. Despite epidemiological evidence that the risk of the disease increases with age and social disadvantage (Roper 2001), has associations with stress (see Schoenberg et al. 2005), and is greater amongst particular ethnic minority groups, biomedical understandings tend to focus upon individual-level risk factors. According to biomedicine, whilst type 2 diabetes may have a genetic component, the disease’s growing prevalence can be attributed to lifestyle changes (poor diet, low levels of physical activity), which can themselves lead to
an additional risk factor: being overweight/obese. In Britain, attention has also started to focus upon ethnic minority groups, especially those with ancestral origins in the Indian subcontinent (who are often termed ‘South Asian’ in the literature to which we refer), since they are at least four times more likely to develop type 2 diabetes than their white counterparts (D’Costa et al. 2000). From a biomedical perspective, a genetic predisposition has been held to be partly responsible for South Asian people’s greater disease susceptibility. However, individual risk factors have also been implicated; specifically, a ‘Westernisation’ of lifestyle following migration (Greenhalgh 1997).

Given the individualised focus of biomedical paradigms, diabetes prevention and management strategies tend to target individuals and emphasise lifestyle modification. Yet many people struggle to follow lifestyle advice, even when given extensive information and advice (Sullivan and Joseph 1998, Snoek 2002). Though the reasons for non-adherence are likely to be complex (and, indeed, the concept of ‘non-adherence’ may itself need to be problematised – see Lutfey 2005), it has been suggested that differences between patients’ explanatory models and biomedical understandings of type 2 diabetes are likely to be very salient (Cohen et al. 1994). Hence, there is a growing interest in looking at patients’ own perceptions and understandings of diabetes causation, and whether, and in what ways, these might differ from biomedical paradigms.

A wealth of sociological work has already examined people’s general understandings of disease causation (Blaxter 1983, Pill and Stott 1985), and their perceptions of specific conditions such as coronary heart disease (Davison et al. 1991, Emslie et al. 2001), stroke (Pound et al. 1998) and osteoarthritis (Sanders et al. 2002). These studies suggest that biomedical teaching may partly inform people’s disease perceptions. Furthermore, they also draw upon other contextual factors and experiences to account for (ill-)health in themselves and others, be these their personal and social histories (Blaxter 1983), the media, and/or observation of people within personal networks and public arenas (Davison et al. 1991).

By highlighting the ways in which understandings of health and illness are contextually informed, such studies have been important in bringing the life-worlds of lay people centre stage. However, with some notable exceptions (e.g. Williams 1990), they have also tended to treat context in relatively restricted ways. ‘Context’, in these studies, tends to be concerned with individual biographies and experiences which are, at the most, grounded in respondents’ socioeconomic circumstances (Backett 1992, Blaxter 1983, Pill and Stott 1985) and/or stage in the lifecourse (Pound et al. 1998, Sanders et al. 2002). What seems to have been left out, or under-explored, is the role of culture (or the macro-context more broadly), an absence which, arguably, may have arisen from these pivotal studies being conducted ‘at home’ rather than ‘abroad’. It is possible that culture has formed such a fundamental part of researchers’ and respondents’ lives that it has been experienced as an ‘absent presence’, in much the same way bodies constitute experiential absences when they function in taken-for-granted ways (Leder 1990).

Indeed, when studies have been conducted with ‘exotic’ people, the reverse situation seems to be true: analyses have tended to focus on the broader socio-cultural (i.e. macro-context), rather than biographies and the minutiae of everyday experience (i.e. the micro-context). This is particularly apparent in studies of lay understandings of diabetes causation. Not only have these tended to focus on supposedly marginalised, disadvantaged and/or ethnic minority groups, findings have, in general, been interpreted in terms of folk models which are culturally and historically-bound (Schoenberg et al. 2005). Notable in this respect are Thompson and Gifford’s (2000) and Garro’s (1995) studies of aboriginal populations in Australia and Canada respectively. In both, the authors found that respondents
tended to perceive diabetes as a condition ‘imposed’ from the ‘outside’, specifically as a result of white settlement, an observation which prompted them to interpret respondents’ accounts as serving a broader political, ideological and communicative role. Garro, for instance, speculated that respondents used such accounts to make statements about ‘the disruption and destruction of the Anishinaabe way of life which has been on-going since first contact with the Europeans’ (1995: 45). Thompson and Gifford (2000) similarly concluded that the emphasis their respondents placed on external (rather than self-imposed) events conveyed a sense of disenfranchisement arising from the historically-specific circumstances of white settlement. In their study of Guadalajara Mexicans, Mercado-Martinez and Ramos-Herrera (2002) similarly observed that respondents tended to see their diabetes as being ‘imposed’ by negative emotions such as ‘anger’, ‘fright’ or ‘fear’, and to interpret this lay theorising as being ‘logical’ in light of prevailing cultural paradigms (see also Schoenberg et al. 1998).

These diabetes studies stand in notable contrast to the sociological work presented earlier. Whereas the former has drawn heavily upon culturally and historically specific interpretations, the latter has tended to ground people's disease accounts in the more immediate contexts of their personal experiences and individual biographies. Whether such differences in emphasis (and the different interpretations arising as a consequence) are valid and useful, reflecting differences (i.e. cross-cultural variations) in lay perceptions, or whether they should be better understood as an artefact of specific kinds of research encounters (researchers may, for instance, ‘see’ their data differently if they are conducting research within their own rather than a ‘different’ cultural group) remains a matter for debate.

To engage in this debate, and contribute to the literature on lay understandings of diabetes causation, we capitalised on an opportunity to undertake a secondary analysis of data from complementary studies involving an ethnic minority and an ethnic majority group in the Lothian region of Scotland, and to draw upon the perspectives of an ethnically-mixed research team. One study focused on Indians and Pakistanis with type 2 diabetes, the other on white patients. Both were concerned with looking at respondents’ perceptions and experiences of their disease (in order to inform health service delivery), a key component of which was their understandings of why they had originally developed diabetes. These causal accounts provide the focus for this paper. We should emphasise here that at no point did we assume that the perspectives of either group of participants were more ‘normal’ than those of the other, although, as described below, our ways of seeing and understanding their accounts did evolve as a result of bringing the two datasets together.

As both studies were Lothian-based, respondents had often attended the same clinics and structured education classes. In theory, this should have led to their receiving similar information about type 2 diabetes, although the reliance some Indian and Pakistani respondents’ had on interpreters may have led to this information being simplified, edited and/or miscommunicated (Lawton et al. 2006b).

**Bringing the studies together**

Full details of the studies’ aims, methodologies, recruitment procedures and sampling strategies are provided elsewhere (Lawton et al. 2005a, 2005b, 2005c, 2006a). Briefly, respondents who took part in the first study were recruited via general practices and face-to-face within Edinburgh’s Pakistani and Indian communities and were purposively selected on the basis of their ethnic/religious group, age, sex and diabetes duration. The sample comprised 15 males and 17 females, of whom 23 were Pakistani (22 Muslims, 1 Christian) and 9 Indian (4 Hindus, 5 Sikhs). The age range was 33–78 years (mean = 59 years), and disease duration varied from 1–30 years. All originated from the West or East
Punjab. Since risk of diabetes increases with age, the majority (n = 26) were first-generation migrants, and many (n = 19) described their ability to speak/understand English as being very poor or limited. Whilst social class was not used as a selection criterion, given the well-recognised difficulties of classifying members of ethnic minority groups, there was diversity in the sample in terms of occupation and residence (Lawton 2006a). Respondents were interviewed in their first language (Punjabi or English) by NA from 2003 to 2004. Interviews were informed by topic guides, translated into English when necessary, and transcribed in full.

The second study involved 40 white patients newly diagnosed with type 2 diabetes recruited from general practices and hospital clinics. To capture a diversity of experiences and views, and to reflect the demography of (white) Scottish patients with the disease, sampling took age, gender and socioeconomic status into account (see Lawton et al. 2005a). Data were collected by EP by means of in-depth interviews, informed by topic guides, between 2002 and 2003, which were transcribed in full. For the purposes of the analysis reported in this paper, 32 respondents were selected who matched our 32 Pakistani and Indian respondents as closely as possible in terms of age and sex. This yielded a sample with an age range of 36–77 years (mean = 56 years), comprising 15 men and 17 women.

The analysis was undertaken by JL, a white, British researcher, and NA, a Pakistani of Punjabi descent. JL and NA read all interviews before jointly coding for any talk which captured: respondents’ understandings of diabetes causation in themselves and others; causes of health and illness in general; and any factors and considerations underlying and informing their causal accounts (the software package NUDIST was used to facilitate data coding and retrieval). These coded data formed the focus for further, in-depth analysis, with JL and NA meeting regularly to identify themes, troubleshoot ideas, and reach agreement on the interpretation. All coded material was initially analysed as one dataset. Differences and similarities in respondents’ accounts were identified, and linked to respondent characteristics, issues and experiences which were grounded in, and emerged from, the data. After notable differences were observed in the ways in which the two respondent groups accounted for their disease, we decided to treat material from the two studies as distinctive datasets in a final analysis which was comparative. As these group-based differences appeared to transcend other (potential) differences, such as those relating to religious beliefs and practices (Ismail et al. 2005), diabetes duration (Hunt et al. 1998) or the experience of having, or not having, a family history of the disease (see Hunt et al. 2001), they form the focus of the findings reported below.

A methodological note

The experience of bringing together data from different respondent groups, and drawing on the perspectives of ethnically heterogeneous researchers led, we believe, to richer analysis than would have been possible had just one dataset and/or researcher(s) from one background been involved. This situation particularly applied to the ways JL and NA initially perceived the data from their own cultural/ethnic group, and how their ‘ways of seeing’ these data evolved during the analysis. Initially, both regarded aspects of the data from their own group as being obvious, banal and in need of little explication, beyond attempting to situate and understand the nuances of individuals’ accounts in relation to their personal histories and everyday experiences (i.e. the micro-context). By contrast, data from the ‘other’ respondent group was perceived as ‘exotic’, unfamiliar and intriguing, particularly as far as notions of responsibility and control were concerned. Encountering exoticness and difference in this way prompted, and enabled, both researchers to ‘see’ the broader backdrop which underpinned the accounts of respondents who shared their cultural/ethnic backgrounds.
Thus, combining the two datasets created ‘presences’ where there had hitherto been ‘absences’ from each researcher’s perspective, prompting the erstwhile implicit role of the macro-context to enter the analysis.

Findings

Respondents of both studies presented diverse and multifaceted accounts to explain their diabetes onset. These accounts often appeared to derive from their personal experiences of the disease, observations of its presence or absence within their family and other networks, and information gained from the media (a situation most commonly described by white respondents), healthcare professionals, family members and acquaintances (i.e. micro-contextual experiences). Yet, we also observed some striking, but subtle, differences between the two groups’ accounts, suggesting that culturally-informed meanings, experiences and interpretations were at least partly at play. As we shall now show, while there were some differences in the kinds of explanations offered (i.e. whether respondents made recourse to lifestyle, genetics and/or other factors), more salient and telling were the differences in the ways in which respondents presented and involved themselves in the processes by which they had become unwell. To set the scene, we begin with two very different responses to a question we asked respondents about why they thought they had developed diabetes. The first comes from a white, 51-year-old retail assistant, Christine.\(^1\) The second is from Bushra, 58, a Pakistani Muslim who had migrated to Scotland in the late 1960s to join her husband. Bushra’s sister had accompanied her and, for a time, their families ran a small business together before a feud occurred.

The role of self in the onset of diabetes

Christine: Probably the lack of exercise n’ eating the wrong stuff I would think that’s probably what’s caused it. Plus, as I say, I was having chocolate, which was the wrong thing.

Bushra: I got blood pressure because of worry, because my son, when he was married, he was married into my sister’s home. My sister lives here, and then we had a bit of conflict. We also had a shop together and then divorce was given to the girl, and then my son and my sister and I were separated because of that, and that’s why I got blood pressure. My sister was very good to me. We got married at the same time and we came here together. Our businesses were together, everything was. She used to come and go from our house everyday because I was quite ill and she would come and find out how I was doing. She was younger than me and now she does not see me, now we are separated. That’s the reason why I got blood pressure. And that’s how I got sugar.

Both respondents attributed their diabetes to a wrongdoing in their lives. However, how they chose to represent this wrongdoing (in terms of what went wrong and why) differs notably. On the face of it, Christine provided a fairly straightforward explanation in which she linked her own lifestyle, specifically ‘eating the wrong stuff’ and a ‘lack of’ exercise’, to her diabetes onset. Bushra, by contrast, made no recourse to lifestyle; rather, she accounted for her diabetes in terms of severed social networks. For her, several factors were
interrelated: social and contextual factors gave rise to emotional and psychological strain which, in turn, manifested itself as hypertension and caused her diabetes. Bushra’s explanation thus focuses on ‘external’ causes over which she appears to have had little or no control; namely, on a disharmony inflicted by her life circumstances. Christine’s account, in contrast, centres upon her own actions and behaviours. Thus, whereas Christine identifies herself as being to blame, Bushra pointed to her circumstances, and not herself, in accounting for her disease.

The next comparative example brings these group-based differences further to the fore. Pauline, a 58-year-old Scottish shop assistant, and Manzoor, 61, an Indian Hindu, employed as an administrator, both attributed their diabetes to an excessive consumption of chocolate. Both thus appear to have highlighted the same cause; the nuances of their accounts, however, as we shall now see, are quite different.

Pauline: Well I thought it was eating so many sweeties . . . I thought maybe this [diabetes] is making up for all the years of, I’ll give you an example, when I was having my . . . third child n’ I told my mum I was expecting, she went absolutely ballistic right cos a third child. My granny had 13 and she says ‘what, are you trying to up yer granny..?’ [laugh] I was about 28 then, y’know, n’ eh ‘how did you fall pregnant?’ I says ‘well how everybody falls pregnant’, ‘but you were taking the pill’ n’ I says ‘I forgot the pill’ . . . She says ‘if there was a bloody Mars Bar you wouldna have forgot that would you’. So that’ll give you an idea o’ how much sweeties I used tae eat. When I was younger, I’d rather have a Mars Bar than a meal.

Manzoor: It’s the result of eating the wrong kind of food. You see I was a vegetarian for most of my life . . . It’s funny because when I first came to the UK . . . I used to live on Mars Bars because there was nothing that I could eat, right, in a student sort of environment. They were only catering for non-veg[etarians]. I mean nowadays it’s much different because veg[etarianism] is sort of, in this era, a lot of people are on that sort of diet. But in those days there was nothing. And so the landladies couldn’t make stuff for me, so I was forced to eat sugary things.

Pauline’s account contains detailed talk about the conception of her third child which, superficially, seems to have nothing to do with her diabetes onset, but, rather, is an example chosen to convey her love of chocolate. However, her way of metaphorically describing her uncontained desire for chocolate seems to be indicative of a particular mindset, one pervaded by guilt. Indeed, by comparing missing a pill and falling pregnant with eating far too much chocolate and getting diabetes, Pauline presents herself as being irresponsible, and as now having to live with the consequences.

Whilst Manzoor also claimed to have consumed an excess of Mars Bars, he made recourse to external factors to account for this. For him, it was the circumstances arising from his migration in the 1960s that presented him with a lack of opportunities to make ‘healthy’ dietary choices. Indeed, Manzoor’s vegetarianism was not a matter of personal preference, as his Hindu faith places prohibitions on meat consumption. Hence, by moving to a meat-oriented society (as Britain was in the 1960s), he was left with no choice but to eat the limited, non-meat alternatives available, principally chocolate. By presenting matters in this way, Manzoor thus inferred that, had more vegetarian food been available, he would not have had to consume an abundance of sugary foods and, hence, he would not have become a diabetic. Thus, he appears to project the blame for his diabetes onto a culturally unaccommodating environment, rather than himself.
Attributing blame: contextualising responsibility and control

Internalising responsibility: causal accounts and the risky self

Many white respondents, like Christine and Pauline, seemed to draw upon a common discourse to account for their diabetes, one which resonates with ‘Western’ public health ideology, which emphasises personal responsibility for health, achieved through discipline, self-control and adherence to a healthy lifestyle (Lupton 1993; Petersen and Lupton 1996). Indeed, not only did these respondents tend to implicate biomedically-recognised risk factors (e.g. a poor diet, overweight/obesity, physical inactivity, and/or genetics), many also indicated a strong sense of personal culpability, by pointing to an ‘unhealthy’, pre-diabetes lifestyle and, associated-ly, a lack of self-control. For instance, Vera, a 58-year-old retail manager, attributed her diabetes to ‘eating all of the sugar and stuffing myself’, a perspective echoed by Andy, a 40-year-old manager, who put his diabetes down to: ‘gluttony n’ no exercise whatsoever’.

In striking contrast to Indian and Pakistani respondents, such as Manzoor above, white respondents rarely sought external explanations and/or presented mitigating circumstances to account for their ‘unhealthy’, pre-diabetes lifestyles. On the contrary, they talked extensively about personal failings and weaknesses, such as being ‘a complete glutton’, ‘being sweet-toothed’, and having ‘a weak spot’. In so doing, most presented themselves as being to blame for their diabetes, an issue which Andy (who weighed 19 stone at diagnosis), conveyed explicitly when he described how he had ‘had to work very hard at staying very overweight’. Allan, a 65-year-old retired tradesman, similarly made his sense of culpability (and subsequent self-chastisement) apparent when, after highlighting his former propensity for ‘drinking brandy n’ smoking n’ eating all the rubbish’, he claimed that, ‘I cannot blame anything else bar myself for being so stupid’.

By presenting themselves as being responsible for their diabetes onset, white respondents also expected others to judge them negatively. For instance, Ellen, a 40-year-old former healthcare assistant, blamed her diabetes on being overweight – an attribution which had partly arisen from her observation that, in the nursing home where she had previously worked, ‘I never nursed a diabetic who was slim’. As well as chastising herself for ‘abusing myself with sweets and everything over the years’, Ellen shared the sense of embarrassment she felt every time she attended her diabetes clinic, where: ‘I go in and say “I’m diabetic”, n’ I think, “look at myself, no wonder you’re diabetic cos you’re fat”’. These anxieties were shared by Andy who did not tell his friends he had diabetes until he had successfully lost weight because ‘if I was still massive they would judge me even more’. Indeed, Andy seemed willing to shoulder responsibility for the onset of his disease partly because this served as a strategy by which he could present himself as now acting responsibly, fulfilling a socially-sanctioned ‘duty’ to look after his health. As he put it: ‘cos it’s been self-inflicted, I’ve got a duty to myself to do the best I can with it... the biggest duty in the world for me is to manage it properly and responsibly’. Other respondents who had young children, likewise, were keen to stress that they were now policing their children’s diets as well as their own, thereby presenting themselves as acting as responsible parents.

Even when white respondents considered themselves to have an increased (genetic) risk, arising from a self-identified family history of type 2 diabetes, most still shouldered responsibility for becoming unwell. A good case in point is Callum, a 36-year-old civil servant, who, based on his observation that both maternal grandparents had had the disease, initially speculated that the it might have ‘been there in the genes just waiting to happen’. However, the notion of a genetic predisposition (which, arguably, could have absolved him of blame) did not suffice as an explanation. Instead, Callum went on to...
speculate that ‘it might never have happened’, had it not been for his ‘habit of having consistently over a few years, a bar of chocolate with my morning coffee, a bar of Toffee Crisp with my afternoon coffee, having a big glass of strawberry milk, and two or three biscuits at night’. In Callum’s mind, ‘that’s been enough to kind of trigger things now’, his choice of the term ‘trigger’ conveying the idea that his over-indulgent lifestyle, which he ‘put down to my own ignorance’, had been responsible for bringing his diabetes out of his genes and into bodily existence.

This notion of individual responsibility seemed so omnipresent that on occasions when white respondents did not perceive themselves as fulfilling the criteria of ‘candidacy’, derived from their own ‘lay epidemiology’ (see Davison et al. 1991), they were left floundering for an explanation. For instance, Helen, a 70-year-old ‘homemaker’ (as she described herself), neither regarded herself as having a family history of type 2 diabetes, nor did she consider her pre-diabetes lifestyle to have been ‘unhealthy’, particularly in comparison to that of her sister, who had remained free of the disease. Indeed, she juxtaposed her own self-restraint in which ‘I could get a box of chocolates . . . and I could have it for a month before I finished it’ with her sister’s tendency ‘to scoff the lot, you know’. As Helen’s experiences of ‘living a healthy life and eating a plain, simple diet’ contradicted her understandings of disease causation, she concluded that ‘I don’t know why I’ve got it’. Mark, a 57-year-old engineer, constitutes a more extreme example. His diabetes was originally diagnosed during a hospital admission for pancreatitis during which his blood glucose levels went ‘sky high’, although they fell following treatment. Having told the interviewer that he had always adhered to what he saw as a healthy lifestyle, in which ‘I was very active’ and ‘we don’t take sugar’, he went on to speculate that his high blood glucose levels might have been due to his pancreatitis, and to conclude that: ‘I don’t know if I’m diabetic or not’.

Externalising responsibility: causal accounts and risky contexts

The notion of individual responsibility, central to white respondents’ accounts, was notable by its absence from those provided by Pakistani and Indian respondents. Indeed, some of these respondents were dismissive when asked why they thought that they had developed diabetes, which suggested that a line of questioning which implicated the self in the onset of the disease, and the notion of ‘candidacy’ underpinning it (Davison et al. 1991), may have been ethnocentric. For instance, Zarina, a first-generation Pakistani Muslim (aged 69), responded tersely and simply as follows ‘don’t know why I got sugar’. Nazish, 67, also a first-generation Pakistani Muslim, provided a similar answer: ‘it just happened’.

Narish’s notion of diabetes being a disease which ‘happened’ to her, rather than one she had brought on herself was typical amongst this respondent group. Pakistani and Indian respondents made recourse to a variety of factors to account for their disease (only some of which were concurrent with biomedically-recognised risk factors). Nevertheless, most presented factors outside their control as being directly, or indirectly, to blame. For example, many of those who implicated a family history seemed content to present this as the sole explanation (in contrast to white respondents, such as Callum above, who claimed the disease had also been ‘triggered’ by something they had done themselves). Balraj, a 55-year-old, British-born Indian Sikh tradesman, is a case in point. He described his disease as coming from ‘my father to my oldest brother and then to me . . . and my sister has it, she’s my wee sister. It just runs in the tree’. For others, diabetes seemed to have such an all-pervading presence in their families and communities, that they perceived the disease as being an inevitable, ‘biographically anticipated’ feature of their lives (see Williams 2000). Rahat, a 51-year-old Pakistani Muslim, who had lived in Britain for almost 30 years, and was married to a shopkeeper, recounted how:
almost in every family many members have it. In our family two of my brothers have it, my father had it. I’ve heard that maybe my mother had it too. My sister-in-law also has it, one of them does, and in her family everyone has it. It’s so common. No one gets away with it.

The attribution of the disease to ‘external’ factors was also evident amongst those who accorded a central role of Allah’s will in dictating their health and destiny. As Javid, 54, a first-generation Pakistani Muslim shopkeeper suggested, ‘whatever disease comes about will come from Allah, so what can you do?’ This somewhat fatalistic sentiment was echoed by a fellow Pakistani Muslim, Shahbaz, 68, who suggested that ‘the coming time’s in Allah’s hands’, and also by Indu, 45, an Indian Sikh who described her disease as being ‘what our Master (God) wants to happen’.

Most common, however, were those accounts in which respondents linked their diabetes onset to their migration to Britain. These accounts seemed to capture and convey in deep and powerful ways the dilemmas and pressures respondents had experienced by virtue of transplanting their lives to a country which was culturally and spatially far separated from their own, and which, ultimately, for them, caused them to become unwell. Ali, for instance, was a 48-year-old Pakistani Muslim, who, like other first-generation male immigrants, originally moved to Britain to take up temporary employment in manual and unskilled occupations (in his case, factory employment), in order to earn money for his extended family on the Indian subcontinent. Ali had originally intended his stay to be temporary. However, like others (see Ballard 1994, Shaw 2000), he made Britain his permanent home after his wife and children joined him, and subsequently wanted to settle there. As a consequence, Ali had become geographically separated from other members of his extended family for whom he saw himself as having a continued responsibility. This separation, as his account highlights, gave rise to detrimental consequences to himself:

It [diabetes] is because of stress . . . I had a lot of stress due to the family, like, if I was leaving them behind, how was I to move them forward. And when I did move forward [by migrating] then I thought of how to bring the family I had left behind forward . . . to the same place as I was. Because in our culture, even if you’re married you still have to think of your sister and their children, you have to think of your mother and father – I mean there’s no old people’s home in Pakistan, we have to do everything ourselves . . . So I thought like this a lot, so I think the mistake was made here.

Ali, as we have seen, highlighted the stress arising from the pressures of fulfilling social roles and obligations as causing his diabetes. Specifically, he referred to a culturally-mandated sense of family responsibility which precipitated his migration to Britain, and also meant that, as well as looking after his wife and children in Britain, he felt obligated to care for relatives remaining in Pakistan. Indeed, by making reference to the unavailability of old people’s homes in Pakistan and saying ‘we have to do everything ourselves’, he pointed to a collective concept of personhood, wherein one’s own interests are subjugated to those of others. As such, Ali presented himself as being blameless for his diabetes (and the stress he saw as causing it); as being subjected to culturally-dictated circumstances over which he had little control.

This sense that one’s life (and health) was dictated by one’s circumstances was evident in other accounts. Hameed, a 66-year-old Pakistani Muslim, for instance, had initially moved to Britain to work as a bus driver, although he had subsequently set up and now managed a successful retail business. Despite having only been diagnosed a year earlier, he attributed
his disease to the poor post-migration lifestyle he had led in the 1960s (and over which he saw himself as having had ‘no control’), in order to fulfil his role as family provider.

Hameed: I think I have sugar because firstly the way we slept was wrong, secondly the way we ate was not right.
Interviewer: This is when you were driving the buses?
Hameed: Yes, when driving buses. . . . And there was just no control over life [laughs] we were overworked. We used to work a lot, we used to overwork, like we used to go on the buses and do two shifts before we came back.
Interviewer: So you’re saying it is because of the way your lifestyle was?
Hameed: Yes because the lifestyle was not good, we had no control.

Others perceived their diabetes and/or the factors they saw as giving rise to it, as attributable to the more general experience of being what Hussain and Bagguley (2005) have termed a ‘visitor’, living in a ‘foreign country’. Manzoor (above) is a good case in point – he blamed his diabetes on a high-sugar diet, which, for him, was necessitated by moving to a non-Hindu, meat-oriented culture. Several respondents, in similar ways, held the excessive consumption of a ‘Western’ product – medications prescribed by their British healthcare professionals – responsible for their disease. For instance, Rashida, a 58-year-old Pakistani Muslim who ran a shop with her husband, pinpointed an occasion eight years earlier, when she was admitted to hospital following a severe asthma attack, and was given a high dosage of steroids:

For my asthma, they gave me tablets and they were sweet tablets [steroids], and I had to take eight tablets all at once . . . I stayed [in hospital] for a week and they gave me all those tablets, and because of that I got sugar . . . I was angry that I got sugar because of their medication.

Rashida, then, like others, attributed her diabetes to an external cause; in her case, medications she had had to take to ameliorate the symptoms of acute asthma. The actual timing of her diagnosis (which, as she later described, occurred during her hospital stay) is salient in understanding her causal account. The sense of anger and injustice she conveyed, and her identification of the steroids as being ‘their medication’, is also telling. By intimating that ‘their [i.e. white/British] medication’ had had health-damaging effects, she may not simply have been expressing her sense of misfortune at having become unwell through no fault of her own, she may also have been conveying more general, negative, feelings about settling in Britain. Indeed, elsewhere in her account, Rashida talked at length about feeling isolated, the difficulties of navigating the British healthcare system as a non-English speaker, her sadness about being separated from family in Pakistan, and, in common with other respondents, her concerns that sustained exposure to the ‘goray’ [white people] and their morals was undermining traditional family values in ways she felt powerless to change. Specifically, she expressed her sorrow that her own children wanted more freedom and independence, a situation which (elsewhere) she attributed to the influence of their white peers.


For Rashida, then, like other Pakistani and Indian respondents, causation accounts may not simply have captured and conveyed a sense of lack of control over, and responsibility
for, their own health, but also a lack of control over the broader contours of their past, present and future lives.

Discussion

Both white and Pakistani and Indian respondents presented varied and multifaceted accounts to explain their diabetes onset. These accounts seemed to be connected to, and informed by, respondents’ specific, and sometimes idiosyncratic, circumstances. We also observed remarkable within-group consistencies regarding the ways in which they located and allocated responsibility for their disease onset. Indian and Pakistani respondents placed particular emphasis upon their life circumstances in general, and, in many cases, those arising from moving to Britain in particular. This included not having access to the right kinds of food or medication, having to work too hard, stress arising from family responsibilities, and the disease having an invidious presence amongst family and community members. As such, they often presented their diabetes and/or the factors they saw as giving rise to it as being moulded by their circumstances, and thereby, in some senses, inevitable. By contrast, white respondents tended to implicate their own lifestyle ‘choices’ and personal ‘failings’ in their disease onset, and thereby to depict themselves, rather than their circumstances, as being to blame. Indeed, this notion or discourse of individual responsibility seemed to be so powerful that those white respondents who were unable to provide an explanation for their diabetes onset still made recourse to it, if only to refute its relevance in their particular case.

Clearly, the (different) ways in which our respondent groups internalised or externalised responsibility for their diabetes calls for an interpretative approach which moves beyond the micro-context and the minutiae of everyday experience to embrace broader (i.e. cultural) paradigms. As Bury contends, when ‘lay people construct and present narratives of their experiences they do so within cultural settings which provide specific forms of language, clichés, motifs, references . . . which allow and constrain what is said and expressed’ (2001: 278). In other words, within a particular society or context certain culture-bound, ‘core narratives’ exist, which both reflect and fashion experience, and through which, as Crawford suggests, “[d]ominant values and categories for understanding reality (and the social arrangements they signify) are reaffirmed (1984: 61–2). In support of this kind of broader, interpretive perspective, one can see, for instance, a resonance between the notions of personal responsibility our white respondents expressed and the rhetoric of modern Western individualism, in which people are supposedly the authors of their intentions and agents of their own lives (Lukes 1973, Rose 1990). Indeed, internalising responsibility for one’s diabetes should not simply be understood as a culturally-framed admission of failure. On the contrary, as Radley (1993) has pertinently suggested, self-blame could be regarded as one strand in the modern Western discourse of self-legitimation and, as such, may serve to bolster and legitimise the modern Western concept of selfhood.

Conversely, the ways in which Pakistani and Indian respondents externalised responsibility for their disease could be understood as reflecting and reinforcing the tenets and values central to what Dumont (1970) and others working within the anthropological tradition (e.g. Mauss 1985, La Fontaine 1985) have termed a ‘holistic’ culture. According to these commentators, within holistic cultures such as India (which formed the focus of Dumont’s analysis), the individual does not exist as a moral or conceptual category as such. Rather, people are enmeshed within kinship structures and political, economic and religious systems which define who and what they are. This situation leads to a ‘socio-centric’ concept
of self (Dumont 1970), to a ‘body-self’ which, as Kleinman has similarly observed, ‘is not a secularised domain’; rather, it is ‘an open system linking social relations to self, a vital balance between interrelated elements in a holistic cosmos’ (1988: 11). Indeed, as suggested above, by attributing their diabetes to ‘external’ factors, Indian and Pakistani respondents appear to have been conveying the more general experience of living a life dictated by their circumstances (such as the culturally-mandated obligation to work hard and earn money for kin). Arguably, then, and given the notion of inevitability conveyed in many of their accounts, the onset of their diabetes may have been perceived as a marker of a socio-centric identity, as a form of ‘biographical reinforcement’ (Carricaburu and Pierret 1995) which signified that one was living a life for the greater good. By contrast, and as already indicated, for white respondents, the disease seemed to be presented as a sign of individual failure, as a ‘biographical disruption’ (Bury 1982), which necessitated, and enabled, the reflexive construction of a new, morally responsible self (see Giddens 1991).

This ‘individualistic’/’holistic’ distinction appears to be a useful and plausible way of accounting for different notions of responsibility the two respondent groups expressed. However, we would also caution against embracing simplistic ‘us’/’them’ dichotomies too wholeheartedly. Not only is the notion of the modern Western ‘individual’ being subjected to ever greater scrutiny (e.g. Hallowell 1999), the dichotomy between individualism and holism has also been challenged. Morris (1994), for instance, has questioned whether the dichotomy may have been over-determined on the grounds that perceptions of self-interest and personal autonomy have been identified in studies of Indian life-histories. As he usefully speculates, because these kinds of perceptions may not have been articulated through the Western ‘language’ of individualism, they may have previously gone unnoticed by Western researchers.

Other explanations may thus be needed to complement and/or counterbalance those already offered. It is possible, for instance, that the different kinds of accounts we observed may be (partly) an artefact of the different sampling procedures employed in the two studies. As noted earlier, all our white respondents had been recently diagnosed, whereas many Indian and Pakistani respondents had had the disease for many years. Since people’s understandings of causation may evolve over time (see Linn et al. 1982), it is possible that the two respondent groups’ different temporal relationships to their diabetes may have led to different disease perceptions. Indeed, in their interview study, Hunt et al. (1998) present a persuasive case for the idea that, rather than simply predicting treatment behaviours (as the Health Belief Model would suggest), diabetes concepts may arise from the perceived success or failure of treatments, such as attempts at dieting. In other words, ‘patients’ concepts about the relationship between their behaviour and illness may not so much determine their self-care activities, as reflect their experiences of trying to gain control over their disease’ (1998: 964). It is possible, then, that had white respondents had diabetes for longer and, hence, had had more experience of attempting, and failing, to achieve good glycaemic control, they might have made greater recourse to ‘external’ factors in their causal accounts (one needs to be mindful of the evidence that the body’s production of insulin tends to decrease over time, irrespective of self-care attempts). We would not, however, wish to over-emphasise this kind of explanation given the homogeneity we observed in our Indian and Pakistani respondents’ perspectives, irrespective of how long they had lived with their condition.

The emphasis Pakistani and Indian respondents placed upon their life circumstances might not simply have arisen from a socio-centric concept of selfhood, but also from a way of ‘seeing’ the world which itself arose from moving to a ‘foreign’ country. Many such respondents described encountering unfamiliar lifestyles and values in Britain, and it is possible that this experience of observing ‘difference’ might have led to their reflexively
engaging with erstwhile taken-for-granted values and practices of their own. In other words, Indian and Pakistani respondents might have made greater recourse to context than white respondents because this context was more ‘visible’ to them, an issue which could be explored further by looking at diabetes accounts amongst those remaining on the Indian subcontinent, as well as undertaking more extensive work with those born and raised in Britain.

Reflecting upon the findings in these kinds of ways returns us to the key question raised for debate; namely, whether the different emphasis researchers have tended to place on micro- or macro-contextual factors should be understood as reflecting cross-cultural variations in the ways lay people perceive and/or account for disease onset, or if, instead, greater attention needs to be paid to the research encounter – that is, to who is looking at whom and in what circumstances – and how this might ‘frame’ what is seen and understood. (Another area for critical explication might be the disciplinary backgrounds to which researchers belong, and the specific theories and genres informing their perspectives, an issue, regrettably, beyond this article’s scope.) Our position should now be fairly clear. Engaging with two datasets simultaneously not only created a way of seeing our data which was multifaceted, but also – and this is key – enabled us to explicate positions salient to our interpretation, even when these were not explicitly articulated by our respondents (for example, the role of ‘individualistic’ cultural paradigms in informing our white respondents’ notions of personal responsibility). Such an experience has thus alerted us to the limitations which may arise when research is confined to one cultural/ethnic group or one setting. In the absence of comparative data, those conducting studies ‘at home’ (or with people from the same ethnic group as their own) may be more inclined to regard certain (culturally-informed) aspects of their respondents’ perspectives as being ‘normal’ and self-evident, and thus as not requiring, or prompting, critical explication. Conversely, those conducting research ‘abroad’ may be drawn into looking at what seems ‘exotic’ and ‘unfamiliar’ to the detriment of examining the ways in which everyday and/or idiosyncratic experiences also inform people’s disease perceptions. As our experience suggests, to do full justice to the richness and complexities of illness accounts, a broad approach is required, one which embraces micro- and macro-contextual factors, explicates multiple positions (including those not immediately ‘visible’ to us and/or articulated by our respondents), and, ultimately, as Bury (2001) contends, recognises that illness narratives take many forms, have many uses, and serve many purposes.

Making the research ‘useful’

Finally, whilst endorsing the notion that illness narratives should not be treated as some form of ‘unalloyed subjective truth’ (Bury 2001), we would also like to take heed of Williams’s (1993) suggestion that they should not be thought of as being so abstracted from reality that nothing useful can be said to health professionals and those working in applied disciplines. There may, for instance, be an important lesson to be learnt by those who use behavioural/lifestyle factors as proxy measures of self-responsibility (e.g. Blaxter 1997), particularly in analyses involving ethnic minority groups. As our Pakistani and Indian respondents’ accounts have usefully highlighted, even if people do implicate lifestyle factors (e.g. poor diet, lack of physical activity) in their disease onset, this does not necessarily indicate that they see themselves as being to blame.

We have also highlighted a lack of resonance between the individualistic paradigms contained within Western diabetes education approaches/models which aim to promote self-efficacy (Knight et al. 2006), and the socio-centric concept of selfhood conveyed by Pakistani and Indian respondents. Given the sense of inevitability, and lack of self-efficacy, these respondents expressed, current educational approaches are unlikely to strike a
responsive chord, an issue which clearly needs consideration by those attempting to develop culturally-competent services. It is also important to recognise that the biomedical perspective is itself a cultural ‘way of seeing’, one which, like the rhetoric of individualism underpinning it, needs to be subjected to critical scrutiny. Indeed, some commentators have started to question whether biomedicine’s emphasis upon individual-level risk factors may lead to patients being positioned poorly in relation to their disease (Parry et al. 2006). Frankel et al. (1991), for instance, have voiced concerns that, by propagating ‘simple messages concerning individual risk factors’ which are ‘at best only a partial presentation of the epidemiological evidence’ (1991: 428), health education/promotion approaches may result in scepticism. Whilst we would contend that the epidemiological perspective, like that of biomedicine, needs to be problematised, we nonetheless share such concerns. Indeed, our findings indicate that diagnosis is one arena where scepticism may arise, since patients may question whether they have diabetes if they are unable to reconcile their own understandings and experiences with discourses which exalt individual risk factors to a central and exclusive domain.

Address for correspondence: Julia Lawton, Research Unit in Health, Behaviour and Change, School of Clinical Sciences and Community Health, The University of Edinburgh Medical School, Teviot Place, Edinburgh EH8 9AG
e-mail: J.Lawton@ed.ac.uk

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Note

1 All names used are pseudonyms

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