

Issues of cause and control in patient accounts of Type 2 diabetes

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Abstract

Patients experience considerable difficulties in making and sustaining health-related lifestyle changes. Many Type 2 diabetes patients struggle to follow disease risk-management advice even when they receive extensive information and support. Drawing on a qualitative study of patients with Type 2 diabetes, the paper uses discourse analysis to examine their accounts about disease causation and disease management, and the implications for how they respond to their condition and health services advice. As it is a multifactorial disease, biomedical discourse around Type 2 diabetes is complex. Patients are encouraged to grasp the complicated message that both cause and medical outcomes related to their condition are partly, but not wholly, within their control. Discursive constructions identified from respondent accounts indicate how these two messages are deployed variously by respondents when accounting for disease causation and management. While these constructions (identified in respondent accounts as 'Up to me' and 'Down to them') are a valuable resource for patients, equally they may be deployed in

a selective and detrimental way. We conclude that clear messages from health professionals about effective disease management may help patients to position themselves more effectively in relation to their condition. More importantly, they might serve to hinder the availability of inappropriate and potentially harmful patient positions where patients either relinquish responsibility for disease management or reject all input from health professionals.

Introduction

Type 2 diabetes is a multifactorial condition occurring when the body becomes resistant or insensitive to the insulin-producing function of the pancreas. It causes serious long-term health complications and has significant morbidity (Roper, 2001). Onus is placed upon individuals to self-manage their disease through attention to lifestyle (e.g. healthy diet and/or exercise) as well as (in some cases) taking tablets and/or insulin to improve blood glucose control (Van den Arend *et al.*, 2000). Patients are also normally encouraged to monitor their blood glucose levels, by performing home blood and/or urine tests (Lawton *et al.*, 2004; Peel *et al.*, 2004).

Patients experience considerable difficulties in making and sustaining health-related lifestyle change. Many Type 2 diabetes patients struggle to follow disease risk-management advice (Sullivan and Joseph, 1998) and commitment to disease self-management often decreases over time (Lawrence and Cheely, 1980), even where extensive information and advice is provided (Snoek, 2002).

Health-related behaviour is the focus of much research. Within health psychology, emphasis has

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been placed upon the cognitive aspects of behaviour (Connor and Norman, 1996; Coombes and McPherson, 1997). Others, from a more sociological perspective, have explored the contexts of patient's lives which support or inhibit unhealthy behaviours (Hernandez, 1995; Hepworth, 1999). Despite the differences in approach, much of the research relies on participant responses (whether to psychometric tests, survey questions or qualitative interviewing) which are accepted as a more or less accurate reflection of internal or external realities.

In discourse analysis respondent accounts are seen as socially constructed and context bound (Geertz, 1983; Scott, 1991; Reissman, 1993; Plummer, 1995). Moreover, verbal discourse is seen as the means by which actual life situations structure themselves. (Holquist, 1960). Hence, the focus is upon how events are presented and talked about (Burman and Parker, 1993; Maines, 1993; Somers, 1994; Murray, 1997).

While some discourse analysts focus on discourse practices, others concentrate on the discursive recourses on which individuals draw (Willig, 1999, 2000). Those interested in discourse practices examine different strategies which individuals use to make sense of events and experiences (Edwards and Potter, 1993; Shotter, 1993); Baumeister and Newman, 1994. Some examine the rules and conventions of public discourse which guide the structure of accounts and facilitate the demonstration of cohesion (Ricoeur, 1981; Gergen and Gergen, 1986). Structures used to this end may also enable the reconstruction of negative experiences in a positive way, e.g. as an opportunity for rebirth and growth (Frank, 1993).

Researchers have also explored ways in which individuals achieve objectives in social interaction (Edwards and Potter 1992), such as the presentation of preferred self-images (Mischler 1986). In health research respondents often assume a moral obligation to be healthy (Blaxter, 1997). Given the widely held view that disease is at least to some extent preventable, then it follows that victims of some disorders are seen to be at least partially culpable or to blame for their predicament (Crawford, 1977; Davison and Davey Smith, 1995).

Those interested in discursive resources concentrate on the mobilization of culturally available explanations, exploring accounts for the ways in which they draw upon a range of available socio-cultural discourses (Willig, 2000). Here, discourse is defined as a system of statements constituting an object. Discourses are identified through the constructions which individuals talk into existence (e.g. individual responsibility for health), how these constructions position subjects (e.g. as at fault or to blame), and how they might refer to and depend upon other discourses. Discourses are understood to accommodate different subject positions which represent individuals in different ways. They also have implications for what individuals say and do (Harden and Willig, 1998). As discursive positions pre-exist the individual, subjectivities may be constrained by the actual discourses which are available. Equally, individuals may actively take up subject positions and deploy discursive constructions offering positions that assist them to meet objectives within particular social contexts. Hence, discourses can position people, as well as people positioning themselves, and these positions can potentially limit their thoughts and actions (Burr, 1995; Willig, 1998).

Patients have been described as a discourse community because they share common ways of speaking about some health/illness-related issues (Bakhtin, 1981; Morris, 1996; Warren, 1997; Little *et al.*, 2003). The shared vocabulary of patients has been argued as representing its members as victims of circumstance—individuals to whom things happen (Little *et al.*, 2003). Hence, research has highlighted how patients tend to portray themselves as helpless, ignorant of disease causation and dependent upon health professionals (Yardley and Beech, 1998). However, as Yardley and Beech argue, where lifestyle factors are known to contribute to known risks associated with a disease there is an alternative position open to patients, not as passive victims, but as makers of their own destiny.

The paper explores some discursive resources mobilized by a sample of individuals with Type 2 diabetes when describing their responses to the

condition and the implications of the positions which they adopt for management of the disease.

Study aims and methods

The study set out to examine newly diagnosed Type 2 diabetes patients' experiences and views of diabetes services, explore the implication of service provision for ways in which patients think about and self-manage their condition, identify what informs patient preferences for diabetes services, and provide recommendations for future diabetes care.

The sample comprised 40 patients in Lothian, Scotland, clinically diagnosed as having Type 2 diabetes within the previous 6 months. The size of sample was deemed large enough to capture a wide span of patient experiences, yet not so large to be unmanageable for in-depth analysis. Data were collected by means of repeat, in-depth interviews over 1 year (three interviews per patient: at baseline, and 6 and 12 months later), thus enabling patient perspectives to be captured at several points during the post-diagnostic period.

The sample comprised 19 women and 21 men aged between 21 and 77 years, and from a wide range of socioeconomic backgrounds. All participants were white with the exception of one Pakistani woman. All respondents had received a fairly standardized diabetes education package as part of their post-diagnostic care. With the exception of one insulin-treated participant, respondents were treated by diet alone or diet and oral agents (metformin and/or gliclazide). Over half the participants ($n = 23$) managed their diabetes with diet only at the time of the interviews.

Ethical approval for the study was obtained from Lothian Health Board Local Health Care Co-operatives (LHCC). Recruitment took place in 16 practices (in four LHCCs) and three hospitals in Lothian. The LHCCs spanned poor and affluent areas. [LHCCs in Scotland are voluntary groupings of GPs and other local health care providers, and are intended to strengthen and support the primary health care team in delivering local care. LHCCs are part of the management structure of the Primary

Care Trust (PCT). There are 70 LHCCs in Scotland, based on natural communities. The exact scope of each LHCC is determined by agreement among member practices and the PCT management.]

Semi-structured interview schedules, which were used for all three rounds of interviews, were informed by the study's research questions. Interviews were approximately 1 hour in length. Patients were encouraged to talk about their contact with health professionals during and following diagnosis, perceptions of their condition and their commitment to adhering to diabetic regimens, the source of any perceived (health) concerns, and satisfaction with (and preference for) different types of services.

Analyses presented here are based upon the interview transcriptions. We (the authors) proceeded by familiarizing ourselves with the data by reading and re-reading the interview transcriptions. As the data set was sizeable, we used computer-supported software (NUD*IST) to store and manage the data. We identified discursive constructions in the data (across the whole dataset) and explored ways which these were grounded within the biomedical discourse. These constructions were compared and contrasted in terms of similarities and contrast in content. This analytic process led us to identify different subject positions accommodated within the wider biomedical discourse on which the respondents' accounts drew. In the following section, pseudonyms have been used to protect respondent anonymity.

Findings

In accounting for both causation and management of the disease, respondents drew differentially upon aspects of the biomedical discourse and in doing so assumed different subject positions in relation to their condition. The paper identifies two discursive constructions which positioned respondents quite differently in relation to their condition. We have labeled these constructions, which are illustrated below, as 'Down to me' and 'Up to them'.

Here we draw largely on the accounts of two respondents because the 'extreme' contrasting

positions which they represent throw into sharpest relief the different descriptions of disease causation and management. It is important to note, however, that the majority of respondents mobilized both constructions simultaneously when describing the management of their condition. First, we consider Andy, whose account of both disease causation and management is built around the concept of self-determinacy.

Down to me: Andy

Andy, a 40-year-old man who was prescribed tablets upon diagnosis, represented the most extreme position among those respondents who implicated their own behaviour in the development of Type 2 diabetes. When asked what factors contributed to his development of Type 2 diabetes, Andy explained:

Well I was a complete glutton... I would have well, I'd eat all the time basically you know and nibble and pick away you know. I would never have breakfast, but come sort of 10 o'clock it would be the sausage rolls and the tomato sauce and then a proper full lunch at lunch time, sweets throughout the afternoon, meal at night and a big snack later on at night, punctuated by various trips to the kitchen and the fridge...it was just gluttony and no exercise whatsoever. [Interview 1]

Andy's claims to 'gluttony' are substantiated by his description of eating routines where the intervening period between large meals is punctuated by frequent snacking of high-fat and high-sugar food-stuffs. Poor eating patterns and diet content are compounded in Andy's account by under-exercise and sedentary leisure pursuits. In assuming full responsibility for the development of Type 2 diabetes, Andy assigns no importance to risk factors for the development of the condition outside of his control. Moreover, in portraying himself as the 'cause' of the condition, Andy takes full responsibility for disease management, buying wholeheartedly into the concept of self-determinacy. Hence, he minimizes the role of medical support and input into disease management. When asked what sup-

port he received from others when managing his condition, Andy responded:

My support is just all from within. I don't need anybody to say that I'm doing it right all the time. I know I'm doing it right. I'm doing everything I possibly can to remain perfectly healthy and probably [I] am perfectly healthy now. If things started to—if they got worse or progress then yes I would probably want, you know, support of that type. [Interview 1]

The success which Andy claims for a rigorous diet and exercise regime is evidenced in his account of phenomenal weight loss and the disappearance of classic diabetes symptoms (e.g. excessive thirst and frequent urination). While Andy acknowledges that the positive responses that he receives from health professionals (as well as friends and family) are a boost to 'the old self-confidence', he presents himself as wholly self-motivated in that he (does not) 'rely on their encouragement at all to keep-keep on with it'. Only the possible failure of his regime to control his diabetes at some future time, would, Andy claims, prompt him to seek outside (medical) assistance and support.

Moreover, Andy's description of himself as 'never better' leads him to reconstruct diagnosis of Type 2 diabetes as a positive rather than a negative experience:

For the first time in my life I thought well I'm not big anymore. I really feel really good...yeah, so it's things like that that really motivate you to carry on when you realize that it's—what's happened to me. I think ideally was a good thing not a bad thing. [Interview 1]

When Andy is asked in his second interview about any developments in his disease management, he describes how he initiated a treatment change:

When I was put on metformin it was almost sold as a good one that would help lose weight as well. So now that the weight's gone my initial thought was 'well maybe I need to change what I'm on'. But I just asked when I was down there I said 'Is there any merit in me just coming off

everything for a trial period?' and she [the doctor] said 'Well we can certainly give it a try as long as you monitor it fairly closely and if you see it [blood glucose level] creeping up and creeping up then obviously come back and we'll review it'. [Interview 2]

Above, Andy describes how medical professionals defer to his expertise in diabetes management. However, Andy acknowledges this expertise is applicable only to his present (asymptomatic) condition. Should the signs (such as increased blood glucose levels) indicate evidence of any deterioration of Andy's condition ('if you see it creeping up') in the future, then the authority of medicine will once again be bought to bear on the situation.

At the third interview, there has apparently been no sign of deterioration to Andy's condition. Here, in response to a question about how he currently feels about his health, Andy marshals evidence from his blood glucose self-monitoring to substantiate the case that currently he has no health problem warranting medical intervention:

I don't even consider myself having diabetes you know because the blood sugar has stayed within normal ranges since the first sort of month or two after being diagnosed...while I'm managing it myself then I don't need any real intervention at the moment from anybody else. I don't know how effective the service would be if I wasn't managing it myself or if it was taking a hold you know I couldn't manage it myself. [Interview 3]

The success of self-management in Andy's case leads him to speculate that he may not have diabetes currently. Andy does not, however, question the original diagnosis and nor does he assert that things will not change, for the worse, in the future. Although unprepared to speculate on the efficiency of diabetes services at present, he entertains the possibility of a future in which services may be required.

Up to them: Sandra

Sandra is also 40 years old; however, unlike Andy, her diabetes was controlled by diet only. In direct

contrast to Andy, Sandra represents the extreme position of respondents who described both the cause and management of the condition as outside of their control. When Sandra is asked, 'What do you think, if anything, has caused you to get diabetes at this point?' she says:

It's hereditary and things like that, or your age like 40 plus they tell you. I thought it was due to the chocolate that I'd been eating but I've since found out it's not—nothing to do with that. It's in your system anyway you know, with what I've been told anyway, being hereditary and stuff like that. [Interview 1]

Above, Sandra mobilizes the opinion of 'others' to, first, substantiate her current understanding that the onset of the condition is outside of her control, and, second, to absolve her from responsibility and/or blame. Although not explicitly citing medical opinion, by referring to 'hereditary factors' and 'age' she identifies risk factors for the condition accommodated within biomedical explanations. Moreover, in the following extract, Sandra indicates an awareness that lifestyle behaviours as well as medical therapies are important in addressing the condition. However, in response to a question about why she continues to eat chocolate, Sandra juxtaposes lifestyle and medication as two alternative (as opposed to complementary) ways in which she may respond to her diabetes:

I'm thinking well, as [my husband] says 'Well you don't really want to be on tablets so you'll need to watch yourself and keep it [blood glucose] down'. I says 'But if the tablets are going to keep me alive for the rest of my life I'd rather be on them'. [Interview 1]

Above, Sandra deploys her husband's words to reflect advice which we might expect to hear from health professionals. That is, by following lifestyle advice she may slow down or halt the progression of the disease which will mean there is less chance that she will need to progress to medication. However, Sandra rationalizes that if medical intervention will ultimately control her condition then, for her, that is the preferred option. Indeed,

when asked whether she had made any changes to her lifestyle, Sandra intimates that her initial resolve to cut down on sugary foods has already dwindled:

....not that I've had a 'Mars' bar [laugh] but you know like the 'Roses' [chocolates] the other day you know. Before maybe say February, March I would not have had them 'Oh no I'm no having them', whereas Friday there I was having two or three you know. So a wee bit lackadaisical the last couple of weeks. [Interview 1]

In her second interview, Sandra's description of a 'bad' day in her dietary regime indicates that (1) she understands what foods she should be avoiding and (2) that her resolve to avoid them has further diminished:

...more on the plate than normal. And then your pudding would be—it would be ice cream or choc ices that I normally have in for the wee one, but she's—there's not there just now. But maybe a bowl of ice cream with sprinkles on the top which I was never having before you know because ice cream is one of the things that sets you off as well you know. [Interview 2]

In contrast to Andy, Sandra sees health professionals as fundamental to her disease management. That Sandra does not always observe their advice does not diminish their importance in her account. When asked about her recent contact with health services Sandra describes a visit to the practice nurse:

I came out feeling happier because I got the result I wanted you know. I'd been in and I'd let, I'd got it off my chest. I told her everything. That I'd been bad. I wasn't looking forward to going in you know.... But saying that, it wouldn't be as bad as going in to see, going in to the hospital right enough. That would have been worse. But saying that, I did come away feeling—well I'm getting weighed in a month so that'll help me with my weight you know. And she's taken my bloods and I know it's going to be high, so I'll get told off when I go back you know. [Interview 2]

Although Sandra 'wasn't looking forward' to the appointment with the practice nurse because she

had not followed her advice ('been bad'), she derives some relief ('got it off my chest') from the encounter. In the event, this encounter was better ('not as bad') as it could have been, because it was not at the hospital (where she expects to receive greater censure). Moreover, the results from blood tests, which she anticipates will indicate her non-compliance with dietary recommendations, are not due for a month. Although she has shared her non-compliance with the nurse, she has come off lightly and, in her own words, 'got the result I wanted'.

When, in her third interview, Sandra is asked about any changes to her therapeutic regime, she indicates that her compliance with dietary advice has lessened to the extent that she now expects to be put onto medication:

I was going to get told to go on tablets and that because that's how bad I've been. I mean really not bothering what I was eating you know. [I] just decided that was it you know. I just thought 'Och to hell' I'm going to enjoy myself.... And then I went to, I went to the nurse and she gave me a row. So that was good. [Interview 3]

Above, Sandra claims to make little or no attempt to manage her condition. The rationalization that she has chosen to enjoy herself implies that the (unjoyful) task of disease management must necessarily fall to others—in this case the diabetic nurse. It is interesting that Sandra interprets disapproval from the diabetic nurse as positive. Unlike Andy, the motivating aspect of health professionals' input in Sandra's account is reduced to censure and disapproval.

Interestingly, Sandra's stated preference to relinquish control of her condition to health professionals is not restricted to their traditional medical role, but spills over into other areas of her life. She would, by her own account, have health professionals, 'come in and just fill my cupboards and the fridge and the freezer with what I was to have'. Here, Sandra's willingness to surrender all responsibility for her condition is wholly at odds with current medical prescription for active patient involvement in matters of disease management.

Composite positions

In the majority of respondent accounts, descriptions of disease causation did not reflect the extreme positions portrayed by either Andy or Sandra. In most cases, respondents, like Callum, attributed the onset of Type 2 diabetes to a combination of factors perceived to be both within and outside of their control:

...it's been (explained) by the—the diabetic nurse and from my own kind of reading, I—I think it—it—it's been passed down through a generation, skipped a generation, and—and has been a genetic [pause] issue. It might never have happened, it probably has happened because over the past few years I have increased the amount of er sugars I have in my diet. [Interview 1]

The extent to which respondents portrayed the importance of lifestyle modification in the management of their disease varied. While Andy depicted his own input as central to disease management, for others it was just part of the story. When asked about the input from medical services, Pauline, for example, indicates the importance of both medical therapies and attention to lifestyle in disease management:

...they [health professionals] gave you that confidence that if you're ill now you're going to feel a lot better in a few months time, you know, once you get all your treatment and you stick to this diet thing and that you'll feel a lot better. And, they're going to watch you and they're going to look after you and you felt that's good. [Interview 1]

Respondents like Pauline placed value upon input from health professionals and said they responded well to (and were motivated) by their praise. Bob, for example, who said that he wanted 'to go to the hospital and I want them to be as pleased again', identifies approval as an important source of motivation.

However, while many respondents did attach importance to their own agency in disease management they were nevertheless perplexed to find, like

Diane, (either from health professionals or experientially) that despite their best efforts, management of the condition was not wholly within their control:

I've had a spell of 2 or 3 days as I had recently when I know I've been really hot on the diet you know really, really good erm and perhaps done a bit of exercise and I find that the (blood glucose) readings are high. You know, for goodness sake. [Interview 1]

Where lifestyle changes do not bring about the expected improvements and where desired outcomes are not achieved, respondents appear uncertain about the value of their own endeavours to manage the condition. Diane, at her third interview, said, for example, 'I wouldn't say it's out of control but I don't feel as though I can do an awful lot about it'. In the extract below, Douglas draws on his own experiences to query the necessity of maintaining a strict dietary regime.

...it [diabetes] seems to contradict itself. I know it's the pancreas maybe sometimes it works and sometimes it doesn't but it just seems to be that when I have a glass of Coca Cola it [blood glucose level] seems normal. So am I allowed a can every night? [Interview 3]

Some respondents, like Graham, claimed only to 'feel better because I'm taking medication'. This was supported in his account by the post experiential rationalization that 'lifestyle can cause it [diabetes] but can't cure it'.

In a few cases, respondents like Christine drew on their success in controlling their blood glucose levels to (1) query whether they had the disease and/or (2) justify deviating from a strict dietary regime:

...obviously I'd managed to bring it [blood glucose reading] down. Because I was—I know when I went into the hospital I was down to about five, five/five, and then as I say I came down to four or five...I was in the diabetic part, but very low. ...I thought 'Why was I there?'. I sort of come home and, I must admit, came home and I binged and I thought well 'If I'm not diabetic I can have a big pie...'. [Interview 1]

Discussion

Research has shown how individuals respond to the constraints of the body in different ways and this is reflected in the stories they tell (Gadow, 1980). Our respondents described how events relating to, and effects of, the illness became integrated into their lives (Garro, 1992). We acknowledge, however, that respondent understanding that Type 2 diabetes may be preventable may have influenced them to exercise damage limitation when accounting for the onset of the condition and their responses to it.

As evidenced in previous studies, our respondent stories started with their reflections on the causes of the condition (Williams, 1984). However, while clear differences between patient and medical explanations of disease causation have been identified in previous research (Cohen *et al.*, 1994), in our study the issue was less clear cut. Two discursive constructions identified in respondent accounts were 'Up to you' and 'Down to them', both of which were drawn on variously by the vast majority of the respondent group. To reiterate, in medical explanations of Type 2 diabetes, both genetic and lifestyle factors play a role in disease causation and outcomes. Patients with Type 2 diabetes must grasp the complicated message that medical outcomes related to the condition are partly, but not exclusively, within their control. However, while both constructions we identified are accommodated within biomedical discourse on Type 2 diabetes, the onus is very much upon the 'Up to you' construct which emphasizes the role of the individual in managing the condition.

Our respondents varied in the way in which they privileged particular risk factors over others. It is important to acknowledge here that while patients have received a fairly standard education package, their life experiences differed. Some respondents, for example, had relatives with Type 2 diabetes and we expect this to influence the extent to which these patients attributed diabetes to hereditary factors.

Our respondent explanations of the causation of their condition were linked to disease management and, in particular, their own perceived role in that

management. Those who emphasized the importance of lifestyle in disease causation were more likely to identify lifestyle as an important aspect of disease management and themselves as responsible for managing the condition. Conversely, in accounts of those who emphasized genetic factors, control over and responsibility for disease management was shifted to the domain of health professionals. Although many of the challenges that the respondents faced were the same, their responses differed. In Andy's story, for example, contracting the condition constituted a turning point in his life. In his account Andy sets up the necessary conditions for behaviour change, which then becomes an inevitable outcome. Conversely, an inevitable outcome of the way in which Sandra's account is constructed is that control and management of her Type 2 diabetes is relinquished to health professionals.

Where respondents located the main cause of their condition as outside of their control, health professionals were identified as 'the experts'. Here the patient's role, in respect of managing the condition, was depicted as passive rather than active. Responsibility for disease management was described as the domain of health professionals and, in matters of self-management, respondents sought to avoid censure rather than coveting praise. In a few accounts, health professionals' censure was deployed to absolve respondents from the responsibility of self-regulation and therefore from assuming any responsibility for managing their condition.

Praise and encouragement from health professionals was identified as an important motivating factor in accounts where respondents identified lifestyle behaviour as an important part of disease management. However, where lifestyle was presented as the key to disease management, and as respondents became more confident in the management of the condition, the importance of praise given by health professionals tended to diminish. While this response is to be expected and welcomed by health professionals, there is a risk if the importance of their input is diminished in the respondent's eyes to the extent that they do not anticipate a future in which their condition necessitates medical input.

In addition, successful management of the condition through adherence to lifestyle regimes was used in a minority of accounts to either cast doubt on the diagnosis and existence of the condition, undermine its seriousness and/or, in extreme cases, deny its existence.

It has been noted in the literature that accounts of disease causation may be informed experientially and thus reconstructed retrospectively by patients (Kelly, 1986; Hunt *et al.*, 1998; Schoenberg *et al.*, 1998). Where expected improvements from lifestyle change did not materialize and where patients' condition deteriorated, the importance of these factors in disease management were undermined. In these cases, approval from health professionals was unobtainable, and patients were left to ponder the reasons why this was so and/or face the prospect of taking medication. In this scenario medication may become synonymous with personal failure and successful disease management, through lifestyle change, an unobtainable goal.

It can be argued that it matters little whether or not patients' accounts of causation are indeed *post-hoc* rationalizations which are experientially based. What matters more is that patient constructions which draw on the biomedical discourse around Type 2 diabetes may position patients poorly in respect of their disease management. That is, while we acknowledge that patient constructions, which have some foundation in current medical understanding, are a valuable resource for patients to make sense of their condition, equally they may be deployed in a detrimental way.

Patient narratives about their responses to illness conditions may provide a useful resource for those attempting health-related behaviour change, in several ways. Narratives can make certain kinds of experiences and shape them over time. Frank (Frank, 1993) writes about the concept of self-conscious change through telling certain types of stories. The telling and retelling of the story confirms and reaffirms the new identity, and, in so doing, can help to sustain change and provide protection against relapse into previous behaviours.

Moreover, the telling of stories may assist in moving understanding events from the private to the

cultural or collective sphere. The work of Gillies (Gillies, 1999) suggests that through stories individuals may receive opportunities for access to alternative and arguably more empowering subject positions. In other words, accounts provided by individuals who successfully manage their condition may be important not only for sustaining lifestyle change, but also for others with the condition who are faced with the prospect of change.

In addition, accounts of successful management of the disease demonstrate how a positive outcome is obtainable from a negative experience (Frank 1993). That is, the negative illness events (disease onset) was retrospectively positioned positively in Andy's account because it constituted a disruption that allowed his 'unhealthy' lifestyle behaviour to be simultaneously disrupted. Not only was the negative experience reconstructed as positive, but also the difficult task of lifestyle change was repositioned in as easier than anticipated. These types of stories may serve a valuable purpose in undermining the prominent social understanding that changing lifestyle behaviour is an extremely difficult, if not impossible, endeavour.

Implications for health professionals

Patients constructions of disease causation have been used to make services more user friendly (Mercado-Martinez and Ramos-Herrera, 2002). A clear message from our research is that, despite receiving similar information and advice about the condition, respondents differed in their interpretations about the cause of diabetes. These interpretations had implications to their responses to the condition. There are likely to be many factors underpinning these interpretations and 'correcting' patients' beliefs is not a straightforward matter. However, professionals may need to solicit patient's own accounts of their condition in order to help them achieve appropriate changes in lifestyle.

The study suggests that some patients may even deploy censure or disapproval from health professionals as a way to absolve themselves from the responsibility of making health-related changes. While this may not be representative of many patients, it does indicate one way in which a

paternalistic approach to care can be counter-productive. While there is no simple way to help patients take the responsibility of self-management, it may be appropriate to support patients to make their own decisions about disease targets and life-style change, rather than giving advice and censuring those who ignore it.

It is important that patients understand the condition may progress despite optimal lifestyle management. Where patient expectations are either unrealistically high and/or not met fully, the importance that they attach to maintaining lifestyle changes is potentially undermined. In some cases this may mean addressing a patient's mistaken belief that their condition has been cured. It is also important to ensure that patients understand that even if they do progress to need medication, this does not mean that they no longer need to follow recommended dietary and other changes.

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