Diabetes Mellitus: Public health enemy no. one or a crusade demonising people with the illness?

Barbara Buttfield, PhD (Sociology)

School of Sociology
Flinders University

barb.buttfield@ozemail.com.au
Diabetes mellitus: Public health enemy no.1 or a crusade
demonising people with the illness?

Introduction

In the early 1990s, I interviewed 62 people with diabetes mellitus. My 1994, PhD, contributed to what was then an evolving literature on illness experience, particularly as articulated by Anderson and Bury (1988). At this time, little was known about how people handled the reality of living with chronic illness and engaged in the sophisticated decision-making required in its management. The study challenged the medical view of the disease and found it largely irrelevant to people’s experience of it. By examining the storied dimensions of illness experience, patients assisted me to construct a fuller understanding of the ways in which meaning and suffering are constituted. With this broadened understanding we are able not only to recognise the parameters of the therapeutic outcome, but intervene sensitively in the project of living with chronic illnesses, translating treatment into a situated ethics of care.

Patients drew my attention to the way they were held hostage, firstly to technology, in this case the constant measurement of blood glucose levels; secondly, the negative and blaming public perception of diabetes generally. In the intervening years this pressure has increased and taken on a more distinctive hue as public health experts signify the increased prevalence of diabetes. We note for example, that in December 2006, the United Nations General Assembly unanimously passed a resolution declaring diabetes an international public health issue. It is now only the second disease after HIV/AIDS to attain that status. While in Australia, over one million people have diabetes and a further two million have pre-diabetes. Type 2 diabetes accounts for almost 90% of cases in Australia (Zimmet and James 2006: 187-188).
The first part of the paper will address the question of why narratives by the patients themselves of their illness experience continue to be vital to any meaningful management of diabetes mellitus. The second part will rehearse many of the unresolved themes from my earlier research which unfortunately continue to resonate. This includes the issue of compliance with medical regimens. The third part of the paper will examine the long overdue acknowledgement (however slight) of the social environment in which this illness experience is located. However in terms of the central dynamic which informs official processes, little has changed in a positive direction. If anything, the unhelpful stigmatisation of the disease has taken on a shrill note.

The importance of the experience of illness?

The systematic collection of stories of illness experience is fundamental to any management of diabetes mellitus by members of the health care system. They give an essential understanding of the meaning and suffering at the core of illness. Moreover they provide insight into what it is like to live with, endure and even live well with a chronic illness. From the point of view of professionals, these accounts set realistic parameters for the therapeutic outcomes and provide a basis for interventions tailored to particular illness experiences. Furthermore, people who live with the condition and their carers frequently become highly skilled at using what is available to handle the way the condition manifests. And yet medicine overlooks this acquisition of patient/carer skills, even though it generally acknowledges that people (patients) provide 99% of their own care. It is unsurprising perhaps that in the absence of this perspective much medical activity in relation to diabetes is simply irrelevant, because it lies outside the central understanding of the wider social processes within which the illness necessarily has to proceed. Like-minded stories of dealing with illness also have the potential to assist the people themselves who are living with chronic conditions. With greater understanding of diabetes one could expect
a reduction in the shrill moralising around the debate which shames and blames people for their
disease. This debilitating shame further confounds the complex array of factors to be managed
by people with diabetes.

Long-term or chronic illnesses, as a consequence of their very nature, are denied solutions. Such
conditions are not by definition curable, they require life-long management. Over the past thirty
years, new medical technologies have been revolutionary in their capacity to maintain and extend
life, while also altering the margins of our embodiment. Treatment has saved people from
immediate death and has shaped the experience of health, sickness and healing by applying
medical interventions and procedures around a linear drive towards specific outcomes. In the
case of diabetes this has served to construct disease management of blood glucose maintenance
levels as the focus: the “endgame”. This objective is based on the belief that diabetes related
disease complications can be avoided or at least minimised when ‘normo-glycaemia’ (normal
blood glucose levels) are maintained, and highlights the extent to which diabetes is largely
conceptualised in biochemical concerns. One implication of this heavy presence of disquiet
about abnormal glucose levels is that health professionals remain relatively ignorant of the
everyday social, emotional, work, family and care consequences of long-term illness. Yet this
reality constitutes the core experience of having diabetes. It incorporates the complex,
sophisticated decisions made by patients and their carers who confront the condition daily, and
who are themselves involved in the patient’s illness reality and who, have experiences of their
own.

In the interviews with 62 people with diabetes, many expressed frustration and sadness at
medicine’s heavy emphasis on blood measures and limited interest in what it meant to live
within a body which happened to generate a particular set of laboratory results, however bizarre.
Interviewees described how they handled their circumstances cognitively, conceptually and with what consequences. For example, a retired wharf labourer with ‘labile’ diabetes (difficult to control and almost impossible to live well with) spoke unequivocally of his doctor’s dictate to avoid ‘pub’ visits. It was clear he tries his best but he had decided that life without socialising with mates, at the pub, once a week was not worth living. He noted:

‘I don’t feel I’m living if I can’t have a beer with me mates!’

Any health practitioner has to locate this man’s diabetes within his life-world. There is little point in seeking his participation in following regimens without taking this into account.

In interviewing these people it was clear that emphasis shifted from a focus on strictly medical matters to how people get through their days – days lived beyond the gaze of health facilities. Interviewees spoke about being confronted with the task of fitting themselves to the temporal rhythms of treatment regimes and therefore of days taking on a fairly predictable shape framed by the self-care routine associated with having diabetes. It was likened to learning how to ‘walk a tight rope’, on one side the danger of hypoglycaemia (low blood glucose), the other hyperglycaemia (high blood glucose). In the background is the ever present fear of disabling complications. A fine line existed between success and failure, a constant tightrope sprung or severed at either end by individual effort or biological might. A mature woman commented:

‘It’s like learning to walk the straight and narrow, never deviating from the path to include those things one expects, or wishes.’

Another comments with frustration:
‘It’s like living as part of a puzzle ... you have to learn where the pieces fit. But then the whole puzzle shifts, sometimes hourly, so you rework it again.’

Still others spoke in less forceful terms:

‘I take it in my stride ... it’s like brushing my teeth. It’s just something you do.’

Most distressingly, when disabling complications evolved despite conscientious adherence to regimens, grief was experienced. A 46 year old woman was facing the threat of a foot amputation. She had been forcibly retired from teaching because of illhealth, now confronted the possibility of blindness. After 37 years of living with diabetes, she experiences accelerated body deterioration, including peripheral neuropathy (loss of feeling in feet), and gangrenous toes rendering her immobile. She commented:

‘In spite of my lifelong effort I am extremely fearful of my decline into total invalidity and dependence.’

Despite her willingness to adhere to regimens of care, she is now disillusioned with medicine’s false promise of control and its silence about the actual disease impact. Her experience of multiple diabetes complications is representative of experiences reported by those long-term diabetes patients interviewed in the study who had adhered faithfully to a strict regime.

These statements encapsulate something of the experience of constraint incumbent within the ‘diabetic-life’. Medicine gives the chronically ill reasons to hope, but at the same time it produces limitations which impact markedly on daily life. It could therefore be presumed that in medical arenas, the patient’s story would be viewed as having the potential to be a powerful conduit of meaning, unravelling the complex relationships between the technologies of medicine
and the subtle ordinariness of day-to-day. So, you might ask: Why do patient perspectives remain largely marginalised despite their power to inform illness?

**What factors militate against the inclusion of this perspective within the medical domain?**

Within medical anthropology there is rich documentation of the social and cultural dimensions of illness experience (Fabrega 1978, Kleinman 1988). Sociologists argue, the latter have received insufficient attention from social and medical scientists (Roth and Conrad 1977, Anderson and Bury 1988). When it is considered it tends to be discussed from within the medical framework predominantly focusing on bio-medical and disease concerns. Although advancements have been achieved (Pierret 2003: 4-22), it could be argued that this corpus of material runs as a parallel discourse to medical accounts of illness and disease. Despite decades of research, patient stories continue to be viewed merely as being juxtaposed to the medical explanation. What typically happens when a study centred on patients’ social worlds emerges if it is noticed, it is regarded from within medicine as being poorly formulated and possibly as the politicisation of medicine’s ‘true’ scientific work. Yet patients’ stories are shaped by the properties of the disease and could inform medical management.

Thus, to my eyes 15 years on, notwithstanding the considerable increase in publications on illness experience within contemporary health and illness research literature, the findings are largely ignored by medicine, and when portrayed, appear to be viewed as adjunct to the ‘real game’, the disease. Patients, people with diabetes remain fundamentally marginalised despite their power to inform us about the illness and its management. It appears that professional and conceptual cultures militate against integration of these perspectives leaving the disorder
characterised by concern with its aetiology (cause) and apparent increasing rates, in other words, cast in bio-medical terms.

**The problematic issue of self regulation, self management or ‘compliance’ with medical regimens.**

Given this emphasis on diabetes as a disease, much medical effort aims to bring blood glucose levels to within ‘normal range’. This concern relies on regimes which medicine expects patients to follow. The issue of ‘compliance’ with medical regimen has long been a concern to health care practitioners and as a consequence, by people with diabetes. The sacred ideal of ‘tight control’ imposes additional burden on patients. My study highlighted how the problem of holding to the regimen is held to lie with the patient and non-adherence is neither understood in its own terms, nor accorded rationality. That is, the only acceptable ‘gaze’ is the professional stance looking at the passive and obedient client. Sufferers who managed their condition found that they called medicine’s ‘compliance’ model into question. Many felt that medical staff lacked even basic understanding given the increased suffering inflicted by the systematic imposition of medical technology, such as ongoing anxiety about fluctuating blood levels. This evolving patient perspective provides a much needed corrective to the common medically-centred viewpoint on compliance. The study revealed the inadequacies of the compliance literature and its simple obedience model. People with diabetes self-regulate their own regimen because in the end they must manage their own condition.

People had their own ideas about following medication, exercise and dietary instruction. They brought their knowledge of the disease and strategies to evaluation of the effect of interventions. So called ‘non-compliance’ may be the result of unrealistic medical regimens that are not
compatible with the context of people’s lives. Moreover, like fellow sufferers of chronic
disorders such as arthritis, many interviewees evaluated the therapeutic efficacy of drugs in
achieving specific outcomes. This at times led to a patient’s decision to vary medication (Arluke
1980, pp, 84-86). A young man evaluated his regimen:

‘Too many pills (anti-diabetic) are bad for me....make me feel sleepy and groggy, so I cut
back the dose so I can work’.

After months following orders, his response was as stated which demonstrates how core beliefs
are deeply embedded in each individual’s tacit system of personal knowledge. Far from being an
irrational act, when viewed from the patient’s perspective it may be seen as a rational empirical
method of testing drug efficacy. In fact this capacity to evaluate one’s day-to-day care, is the
very conduct relied on by medicine when problem solving or crisis avoidance is to be managed
in ongoing care beyond the realm of hospitals. For best care standards, medicine needs to be
partnered with the patient and carers in ongoing disease management.

Interviewees generally reported feeling burdened by the necessity for the incorporation of
regimen management within their daily lives, of feeling ‘fed up with the whole scene and its
necessity for regimens, doctors and orders’.

Restrictions imposed by the condition were variously reported:

‘It is the constancy of having to walk the straight and narrow and handle
inevitable barriers in day-to-day living with diabetes.’

and

‘…having diabetes means always thinking about taking care of that ......

I don’t want my life to be just a ‘diabetic life’!’
While not disregarding their diabetes, these informants refused to be defined by their illness. Yet diabetes altered awareness of self and led to a heightened sense of watchfulness of body and self; a more burdensome self-awareness than most of us has to handle. What is to be noted in contemporary medicine’s reliance on ‘self-care’ strategies, ‘regimes’ or ‘patient education’ programs, is the paradox posed by these tools of management. Intriguingly, since each of these tools is both emancipating (believed to reduce incidence of disease complications and/or immediate ill effects from diabetes) is also constraining (in that one is encouraged, perhaps ‘forced’, to adopt dietary, medication and exercise elements within one’s daily routine). For some people, patient education was perceived to be an ‘instrument of subjugation’. From medicine’s view the patient, the receiver of instruction must be a general receiver, without too many individual traits, not a real person, but transformed into the norm in order to comprehend the message as it was intended. In other words rendering people, as objects, but importantly rendering them as self-monitoring subjects. Yet informant comments gathered in the course of my study reflected an investment in ‘self-regulation’ of one’s own regimes rather than ‘compliance’ with doctor’s orders. For example, people reduced prescribed insulin doses to avoid hypoglycaemia and increased the dose when they had an infection. These pre-emptive efforts were well justified if a crisis was to be avoided.

Medicine’s focus on ‘compliance’ is yet one more deceptively over-simplified explanation from which the medical model readily draws. It further underscores the contrast between the illness lifeworld and medicocentrist perspectives. Moreover, it illustrates the fact that personal desires are not always subordinated to medical prescription and that biomedical ideology cannot be imposed by force.
**Conclusion**

This paper has examined some of the main insights from my 1994 study, findings which still resonate today. In reviewing what paths the self management debate has taken since 1994, it is clear that the search continues still for the elusive "magic bullet" for identification of the barriers to modifying patients’ aberrant conduct in line with over-simplified medical directives. Medicine is likely to achieve more kindly and better management if it listens to patients’ accounts of how they adjust to and manage their illness within the context of their lifeworlds thereby partnering with patients and their carers in ongoing management.

Since mid 1970s, health promotion and health education services have claimed that the more spent on prevention the lower will be health costs. In Australia millions of dollars has been invested in influencing behavioural change aimed at lifestyle modifications (reducing obesity and increasing exercise) and has yet to prove successful (Sammut 2008). Programs designed to increase levels of physical activity have not changed obesity levels which continue to rise thereby increasing the risk of diabetes. It would appear that simply offering health information does not translate into better outcomes. Tackling obesity is not as responsive to health messages as smoking has been. Today we continue to remain ignorant as to the reasons why people make unhealthy choices. Obesity is due to a raft of causes that some commentators, health professionals and the public may disregard when representing it in terms of ‘over consumption and inadequate exercise’. A rigid model of compliance based on simple messages that obese individuals are ‘bad’ people and that obesity constitutes a new social crime is not likely to alter the situation. Locating food choices in complex life worlds seems a more promising approach.
but requires augmenting with understandings drawn from health determinants such as environmental factors, socioeconomic characteristics, as well as biomedical factors and health behaviours.
References


Abstract

This paper reviews major findings of my 1994 interviews of 62 people with diabetes mellitus and finds the same patient issues remain unaddressed. Much medical opinion still claims that patients who maintain regimens of ‘tight’ control when compared to those under relaxed diabetes care, lowered their risk of delayed complications markedly. Yet the degree to which ‘tight’ control actually brings with it avoidance of long-term complications, is at best contested at worst highly questionable. Treatment still draws from the established perspective of constant and meticulous regulation, aided by insulin and/or anti-diabetic medications, directed at avoidance of all untoward consequences of being diabetic. Much of this effort seeks to impose rigid systems of care upon patients rather than incorporating a realistic and still effective patient-derived approach. It is therefore necessary to ask the question: at what cost is the tight control objective attained? When complications emerge, it is the patient who carries the burden not simply of her/his failing health but also of the medical and social attitudes that construe complications as resulting from poor patient ‘compliance’ rather than attempting to grasp how patients live with diabetes within complex life-worlds. Exposure to illness experience perspectives provides an opportunity to translate treatment into a situated ethics of care, rather than an over simplified obedience model.

Key words: long-term illness, experience of illness, diabetes mellitus, self-regulation.