

Poor diabetic self-management: a psychosocial perspective

Werner Pretorius, Robby Steel

The authors present a simple categorisation of some common reasons patients may manage their diabetes poorly, and offer clinicians strategies for overcoming patient non-concordance. The article presumes that primary responsibility for the management of diabetes lies with the patient, while the role of the clinician is to educate the patient and to support self-management. The authors propose a taxonomy for understanding poor diabetic self-management, based loosely on characters from the TV series *Father Ted*. The patient who does not understand the complexity of diabetes self-management (Father Dougal), the patient who does not believe information provided by clinicians regarding the need to manage diabetes (Father Ted), the patient who has other priorities (Father Jack), and the patient who understands the principles of good self-management, but is unable to implement it effectively (Mrs Doyle). The authors offer a description of each group, together with strategies for the clinician endeavouring to help the patient overcome barriers to effective self-management. The authors' intention in drawing parallels between their categories and characters from a well-known sitcom is to render their taxonomy memorable for busy clinicians. It is not the authors' intention to trivialise serious clinical issues or to cause offence.

It is estimated that up to a third of people with diabetes have psychosocial difficulties, which impact on diabetic management (Grigsby et al, 2002; Rouch et al, 2012; Young et al, 2012). Poor self-management impairs glycaemic control, increases risk of diabetic complications, lowers quality of life, increases cost of healthcare and raises mortality (Lustman and Clouse, 2005; Von Korff et al, 2005; Ismail et al, 2007; Simon et al, 2007; Gonzalez et al, 2008; Koopmans et al, 2009; Nouwen et al, 2010). People with type 2 diabetes and comorbid depression are twice as likely to die within 5 years, compared to those without depression (Winkley et al, 2012). Guidelines, including those from NICE and Scottish Intercollegiate Guidelines Network (SIGN; *Box 1*) highlight the duty of clinicians to recognise psychological difficulties in people with diabetes and to offer psychological interventions.

Detailed analysis of the extensive research literature relating to health beliefs and illness behaviour is beyond the scope of this article. The Health Belief Model (Rosenstock, 1974) is readily applied to diabetes and informs the authors' taxonomy. The model proposes exploring the patients' understanding or beliefs regarding the severity of diabetes and diabetic complications; their understanding or beliefs about their risk of developing complications; their understanding or beliefs about the benefit of fully engaging with services and treatment and any obstacles to positive behaviour change. Where patients do not understand, retain or believe information, it is highly unlikely they will be able to manage their diabetes effectively.

The authors recognise that sound health beliefs are necessary, but not sufficient for good self-management. Some patients with a good understanding of diabetes have poor control, either

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Article points

1. Poor concordance with diabetes self-management is common, especially in diabetic foot clinics, and has adverse consequences for diabetes outcomes.
2. Possible reasons for poor concordance include not understanding advice, not believing advice, having other priorities or being unable to implement advice.
3. Good communication is essential in educating patients about diabetes and how to manage it. The clinician needs to engage with patients at their own level.
4. Treating mental disorder can improve concordance and outcomes relating to both mental health and diabetes.

Key words

- Concordance
- Depression
- Mental health
- Psychosocial issues

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Box 1. Psychosocial recommendations (Scottish Intercollegiate Guidelines Network, 2010).

- Diabetes clinicians should have the skills and knowledge to recognise psychosocial difficulties and judge their severity and the need for referral.
- Regular assessment of a broad range of psychological and behavioural problems in children and adults with type 1 diabetes is recommended (and screening tools may be used).
- In children, this should include eating disorders, and behavioural, emotional and family functioning problems.
- In adults, this should include anxiety, depression and eating disorders.
- Children and adults with type 1 and type 2 diabetes should be offered psychological interventions (including motivational interviewing, goal setting skills and cognitive behavioural therapy) to improve glycaemic control in the short and medium term.

because there is something else of greater current importance to them and thus the management of their diabetes does not take priority, or because they simply appear unable to implement positive behaviour change, despite the best of intentions.

The authors propose a (hopefully memorable) taxonomy for understanding poor diabetic self-management, based loosely on characters from the TV series, *Father Ted*.

The patient who appears not to understand advice: Father Dougal

Diabetic self management is complex and difficult to grasp quickly. Perhaps this patient’s baseline knowledge has been overestimated or the advice has not been explained well. The patient may even have an undiagnosed intellectual impairment. Diabetes is a risk factor for cerebrovascular disease and vascular dementia. The patient may be experiencing cognitive decline due to the micro- or macro-vascular effects of hyperglycaemia and/or the cerebral effects of repeated or severe and prolonged hyperglycaemia (Frier and Sommerfield, 2002).

Strategies to consider

In the diabetes clinic, where time is tight and the focus is on numbers, it is easy to neglect the basic rules of clinical communication: to always determine the patient’s understanding, including factual knowledge, beliefs, misconceptions and priorities. Clinicians should align their starting position with patients and educate them by bringing their understanding closer to the clinical facts.

The simplest way to establish the patients’ baseline knowledge is to get the patient to explain to you what they understand. This will give you an appreciation of how comfortable the patient is with technical terms. Always try to use their language, for example, ‘blood sugar’, rather than ‘plasma glucose’. When giving written advice, it is worth remembering that the average reading age in the UK is 9 years! (Straight to the Source, 2013). If, despite the clinician’s best efforts, the patient is struggling to understand, involve family, partner or carers. Where limited scholastic achievement and/or poor social functioning suggests intellectual disability, explore whether specialist services, such as learning disability teams, are already involved; if

not, consider referral or working in partnership to meet the patient’s needs. When cognitive decline is suspected, consider a brief cognitive assessment. A number of assessment tools are freely available. The authors recommend, in ascending order of complexity: 4AT (Ryan et al, 2013), Abbreviated Mental Test (Hodkinson, 1974), Montreal Cognitive Assessment (Nasreddine et al, 2005), or Addenbrookes Cognitive Examination III (Hsieh et al, 2013).

The patient who appears not to believe advice: Father Ted

In the TV programme, Ted is a habitual cynic — in the parlance of motivational interviewing he is ‘pre-contemplative’ (Miller and Rollnick, 2012), that is, not even ready to think about changing. Often a patient such as this has learned from personal experience to mistrust all authority figures, having felt let down or ill-treated by ‘the system’. Alternatively, rather than a pervasive mistrust of all authority, patients may have experienced or perceived a medical error that has undermined their trust in health care. There may have been a delay in diagnosis; prognostic predictions may have been inaccurate; procedures or treatments may have failed. The patient may have bought into an anti-medical or complementary therapy model.

Occasionally, the patient accepts that there is a problem, but does not believe there is a solution. Freud postulated that denial can be a ‘psychological defence mechanism’ (Baumeister et al, 2002): the individual, faced with a reality that is too painful or threatening to contemplate, instead rejects it, despite evidence in its favour. Denial is best seen as a spectrum from complete denial to minimisation (moving into cognitive behaviour therapy terminology) — where the person can admit the fact, but underplays its severity or personal significance. Where denial is effective in helping the patient cope, there is a danger that breaking it down will lead to the patient feeling overwhelmed or despairing. Therefore, it is important not just to challenge denial, but to replace it with a positive narrative.

Strategies to consider

The clinician should explore what the patient actually believes and try to understand why. This can be time-

Box 2. The World Health Organization's ICD-10 diagnosis of depression.

At least one of these core symptoms, most days, most of the time for at least 2 weeks:

- Persistent sadness or low mood.
- Loss of interests or pleasure.
- Fatigue or low energy.

If any of above present, ask about associated symptoms:

- Disturbed sleep.
- Poor concentration or indecisiveness.
- Low self-confidence.
- Poor or increased appetite.
- Suicidal thoughts or acts.
- Agitation or slowing of movements.
- Guilt or self-blame.

Diagnosis:

- Not depressed — fewer than four symptoms.
- Mild depression (four symptoms).
- Moderate depression (five to six symptoms).
- Severe depression (seven or more symptoms, with or without psychotic symptoms).

consuming, but making the effort to understand a patient's beliefs can save a lot of frustration later on. Where trust is absent, the process of building sufficient trust to secure the patient's engagement in treatment can be slow. One potentially useful strategy, borrowed from clinical psychology, is the 'behavioural experiment' — rather than asking the cynical patient to fully embrace a new approach, the clinician describes a change that might help and supports the patient in trying it for an agreed period. For example, with patients who are reluctant to check their blood sugar, claiming it is too much hassle and has a negligible impact on control, the clinician might propose a 2-week behavioural experiment of twice-daily blood glucose monitoring, while keeping a record of how time-consuming it is, how many hypos the patient experiences and so on.

Another strategy borrowed from clinical psychology is the use of a third person narrative — "if you had friends who had diabetes and not checking their blood sugars, what advice would you give them and why?" For a highly defensive patient, this indirect approach may be less threatening than direct clinical advice.

On rare occasions, lack of trust or unusual beliefs may be a manifestation of a disordered personality or mental illness. Psychiatrists recognise a number of different personality disorders, including 'paranoid' (constitutionally suspicious and quick to take offence) and 'emotionally unstable' (a tendency to rapid swings in emotion and an inability to tolerate distress). If the lack of trust is part of a wider picture encompassing disjointed thinking, persecutory ideas or hallucinations, the patient may be suffering from a psychotic disorder. Similarly, if patients express an irrationally negative view of their prognosis, they may be suffering from depression.

The patient who has other priorities:

Father Jack

Father Jack is very clear what his priorities are. Some patients, despite understanding and believing advice about diabetes management, may have other priorities too, even if they are not as outspoken as Jack! There may be pressing issues that make it hard to take in complex advice, including financial difficulties, housing problems, lack of job security, family crises or relationship breakdown. For example, patients may continue to work shifts, despite knowing that this impairs their diabetes self-management, because

they need the job. Some patients still feel a strong sense of stigma or shame and hide their diabetes from work colleagues or friends, thus making it difficult to monitor and treat appropriately while in the presence of others.

Another concept familiar to most clinicians is secondary gain: being ill can bring advantages such as being excused from responsibilities, being cared for, securing an income from benefits or preventing a partner from ending a relationship (Fishbain et al, 1995). For some patients the benefits associated with poorly controlled diabetes outweigh the risks. Occasionally, a patient will consciously feign or induce symptoms (for example, deliberately withhold insulin to precipitate diabetic ketoacidosis (DKA) or deliberately inject too much to induce hypoglycaemia). Psychiatrists differentiate between 'malingering', where a patient feigns or induces illness for some demonstrable gain, such as money or time off work, and 'factitious disorder' (previously known as Munchausen's syndrome) where there is no obvious gain (Steel, 2009).

Adolescents can be difficult to treat as they are more likely to live in the present and the threat of diabetes complications in future is outweighed by the threat of social exclusion or rejection in the present — they would rather fit in with their peer group by partying than risk being labelled 'square' by acting responsibly to minimise the risk of future diabetic complications (Weissberg-Benchell et al, 1995).

Patients with eating disorders (or in the wider sense, disordered eating) are faced with two fears: the immediate fear of weight gain and the less immediate fear of developing diabetic complications. Often the immediate fear wins out and insulin is omitted to aid weight control (Young-Hyman and Davis, 2010). Denial or minimisation may play a part in this process.

One characteristic feature of substance dependence (including alcoholism) is the prioritisation of use over other activities. Money may be spent on substances rather than healthy food or lifestyle. While intoxicated, monitoring blood glucose and administering insulin and other medications are liable to be totally overlooked.

Strategies to consider

Where patients' choices are driven by other priorities, clinicians need to put themselves in patients' shoes

“Mrs Doyle is a creature of habit; even when she fully understands and believes advice, without experiencing any competing priorities, she will fail to change her ways.”

to understand what is driving their decision-making. Where there are significant social stressors, the clinician may be able to use his/her knowledge of local services to guide the patient to appropriate support. Clinicians working in diabetes should remain alert to signs of substance dependence and eating disorders and be willing to refer to specialist services or at least to share information with the patient's GP.

An approach called motivational interviewing (MI; Miller and Rollnick, 2012) can help encourage patients towards positive behavioural change. MI is a conversational style that aims to improve motivation to change: the patient is described as shifting from the “pre-contemplative stage” (not even thinking about change), through the “contemplative stage” (starting to think about change), to the “planning stage” and finally to the “implementation stage”. MI involves engaging in a non-judgemental and compassionate manner, while deliberately invoking and building on ambivalence about the current situation to plant the seeds of change. MI courses (typically 1 or 2 days) are widely available and the authors would encourage all clinicians working in diabetes to learn more about this potentially helpful technique.

The patient who seems unable to implement advice: Mrs Doyle

The character Mrs Doyle is a creature of habit; even when she fully understands and believes advice, without experiencing any competing priorities, she will fail to change her ways. Patients like this may have pressing social or environmental issues that impair their ability to put advice into practice. As in the case of Father Jack, clinicians should strive to put themselves in the patient's shoes. Some people lack motivation or discipline in all areas of life, perhaps as a personality trait, so it may not come as a surprise that some patients with diabetes are poorly motivated or undisciplined regarding self-management of their condition.

Anxiety about and avoidance of hypoglycaemia, can lead to over compensation with resulting poor diabetes control. Needle phobia (blood-injection-injury phobia) obviously impacts on the patient's ability to monitor and administer insulin, again leading to poor diabetes control.

Sometimes a patient who is usually highly motivated and disciplined appears to lose his/her way. This may be due to depression or despair. The

bidirectional association between diabetes (and other chronic medical conditions) and depression (*Box 2*) is well established. Meta-analysis has shown that patients with depression are 37% more likely to develop type 2 diabetes (Knol et al, 2006) and patients with diabetes are twice as likely to develop depression (Anderson et al, 2001). Patients are significantly more likely to be depressed when they have diabetes and two or more comorbid chronic conditions (Egede, 2005). Estimates of the prevalence of depression in the diabetic population vary from 8% to 25%, with studies using expert structured diagnostic assessment and diagnosis yielding about 10% (Gavard et al, 1993). The combination of depression and diabetes is associated with poor outcomes, increased service use and double the mortality rate over five years (Ismail et al, 2007).

One can think of despair as the opposite of hope. Diabetes, being a progressive condition, leading to possible multiple complications and serial losses can destroy patients' hopes and dreams. Despair can also affect families, carers and clinicians. Diabetic complications are common and increase over time. Fifteen years after diagnosis with type 2 diabetes, 5.4% of patients have suffered cerebrovascular accident, 13.4% have peripheral vascular disease, 25.9% have retinopathy, 14.2% have nephropathy and 29.1% neuropathy. Poor glycaemic control is a risk factor for developing diabetic complications, but clearly complications like retinopathy and neuropathy also impact practically on the patient's ability to monitor and administer insulin.

Strategies to consider

Patients who generally lack motivation or discipline or those in despair may benefit from MI, to move them gradually towards making positive behavioural change. Another approach, again borrowed from clinical psychology, is ‘problem solving’. The patient who feels overwhelmed is encouraged to draw up a comprehensive list of their current problems and then supported in devising a plan for each one. This approach often provides a clear rationale for action and action is the antidote to despair.

Given the prognostic significance of comorbid depression in diabetes, all clinicians should be alert and able to recognise the symptoms. An interesting study in terminally ill oncology patients (Chochinov et al, 1997) found that a single screening question — “Are you depressed?” — enjoyed high sensitivity and

specificity as a screening tool for clinical depression (as confirmed by structured diagnostic interview by a trained mental health professional).

For those who prefer a structured approach, the Hospital Anxiety and Depression Scale (HADS) was developed (Zigmond and Snaith, 1983) to screen for anxiety and depression in general hospital patients. It excludes symptoms common in physical illness and thus reduces the risk of false positives or over diagnosis. There are seven items (rated from 0–3) each for anxiety and depression. For anxiety (HADS-A) a score of 8 gave a specificity of 0.78 and a sensitivity of 0.9. For depression (HADS-D) a score of 8 gave a specificity of 0.79 and a sensitivity of 0.83. Depressed diabetic patients respond to treatment with antidepressants (Lustman et al, 2000), as well as psychotherapy (Ismail et al, 2008).

Conclusion

The authors hope that the model presented in this article offers clinicians a helpful framework for conceptualising psychosocial barriers to effective diabetic self-management. Addressing these factors directly, or referring a patient to services that can offer support or treatment, can improve the patient's ability to manage their diabetes.

There is increasing awareness among managers and commissioners that tackling psychosocial factors affecting patients with chronic conditions can reduce acute presentations, hospital admissions and length of stay which, in turn, frees up NHS capacity (NHS England, 2014). A good example of fully integrated biological, psychological and social care for diabetes is the 3 Dimensions for Diabetes service operating in King's College Hospital and Guy's and St Thomas' in London. ■

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“Addressing these factors directly, or referring patients to services that can offer support or treatment, can improve patients’ ability to manage their diabetes.”