# The NSF for diabetes: addressing psychosocial issues

Valerie Wilson

#### **ARTICLE POINTS**

Psychosocial needs of the individual and the provision of psychological support are documented in the NSF delivery strategy.

2 Psychosocial issues encountered by those with diabetes include: adherence, motivation and health beliefs, and depression.

3 It is currently difficult to identify and treat psychological distress in individuals quickly – the simplest way to determine if a person has problems is to ask them.

4 The NSF for diabetes highlights the multidisciplinary nature of treating psychosocial issues in diabetes.

5 Diabetes specialist nurses are not equipped to deal with the vast array of potential psychosocial issues patients may have alone.

#### **KEY WORDS**

- Psychosocial issues
- Concordance
- Motivation and health beliefs
- Depression
- Empowerment

Valerie Wilson is a PhD student, Centre for Health Education and Research, Canterbury Christ Church University College

#### Introduction

The importance of psychosocial issues that affect people with diabetes has become more prominent since the publication of the National Service Framework (NSF) for Diabetes: Standards in 2003. NSF Standard 3 highlights the need for structured education and psychological support for individuals with diabetes, with the aim to facilitate and support self-management. This article examines some of the psychosocial issues people with diabetes experience and areas of care delivery which address them.

he National Service Framework (NSF) for diabetes outlines the need for patient-centred care based on the principle of equity. The psychosocial needs of the individual and the provision of psychological support are documented in the NSF Delivery Strategy (Department of Health; DoH, 2003). Additional studies by Lucas and Walker (2004); Pouwer et al (2001); and Skinner et al (2000) have also highlighted the need for patient-centred/ psychosocial care. Recent research suggests that people with diabetes need psychological support to be available. Wilson (2003) supports this view in a survey involving 155 participants with type I diabetes. This survey showed that 92% of the sample did not have a trained psychologist or counsellor attached to their diabetes team.

Diabetes has a psychological impact on the individual with the condition, meaning the person with diabetes managing this complex condition will encounter issues in which diabetes and psychology interact. These include the diagnosis of diabetes and its complications, the cognitive consequences, and the psychological factors influenced by the condition.

During the last 20 years the psychopathology of diabetes mellitus has been identified and characterised. Studies have shown that the rates of psychopathology rise with the longevity of diabetes in adulthood as the burden of

the disease and its complications increase (Anderson et al, 2001; Coates et al, 1998; Peyrot and Rubin, 1997).

### Psychosocial issues for people with diabetes

#### **Adherence**

The term 'concordance' has replaced compliance or adherence with regards to how an individual follows a given medical treatment regimen. Concordance refers to the extent to which the patient follows the recommendations of their doctor or health professional (Simons, 1992). This can be thought of as a type of decision-making. Burns (1991) suggested term 'adherence' was more satisfactory than the term 'compliance' as the latter perpetuates the idea that the patient is passive, submissive, and unable to make their own decisions, implying that if recommendations are not followed by the patient, they are to be blamed. Although patient empowerment supports concordance and does not encompass non-compliance with diabetes regimens in Burns' sense, the individual may make a decision not to concur with their treatment. This view has been suggested as a kind of rational decision-making by Day (1995).

Individuals with diabetes will therefore be faced with a number of behavioural choices, including concordance with their diabetes regimen. Concordance consists of many factors, from those acting on the individual's own health beliefs (Horne, 1997), to a simple inability to manage complex medical regimens (Donnan and colleagues, 2002).

Concordance cannot easily measured because much of the research relies on self-reported behaviours. Pouwer et al (2001) suggested that the extent to which the individual engages in self-care behaviours is the best indicator of the level of concordance. In addition, it is perceived that certain healthcare behaviours, such as following dietary guidelines, monitoring diabetes, engaging exercise, and taking in regular medication are not strongly related to one another, and some aspects of selfcare are therefore more likely to be followed than others. Ley (1992) reported that almost 50% of patients forgot to take their prescribed antibiotic drugs. Other studies suggest that patients may choose to be nonconcordant to their medical regimen as they believe this gives them a better quality of life (Day, 1995).

Concordance has been shown to vary over time and with duration of diabetes (Kovacs et al, 1990). It has also been suggested that many inappropriate behaviours are often sustained or due to the lack of support for the individual with diabetes (Conner and Norman, 1996). Poor concordance is a major barrier to the use of intensive insulin treatments, such as multiple daily injections or pump therapy. This can be the result if the individual is not fully involved in decision-making regarding their treatment options. Multiple treatments are often the only way to provide optimum diabetes management in conjunction with thorough patient education to reduce the risk of complications. This has also been highlighted in type 2 diabetes by the UK Prospective Diabetes Study (1998a and b), which suggested multiple treatments were essential in reducing the risk of microvascular and macrovascular complications. Intensive regimens are only effective, however, if the individual is concordant. Donnan et al (2002) suggest such treatment regimens will be

ineffective without measures to improve concordance.

Empowerment is an approach to diabetes care which provides the skills, knowledge and the opportunity for individuals to play an important role in the management of their diabetes. The empowerment model of care is centred on the individual, with a holistic approach to healthcare. Simons (1992) stated that the person with diabetes is the primary decision maker in the empowerment approach, creating a partnership with the health professional that recognises equal status in the relationship. The health professional accepts that they know what is best for the individual's diabetes, but not necessarily what is best for the individual. The role of the health professional is therefore to help the individual make an informed choice about self-management of their diabetes. In this way, the balance of power is shifted so the individual is responsible for their condition, therefore challenging issues of concordance arising from the health professional being the main decision maker.

The management of diabetes, based on the individual's perceptions of illness and treatment, may be able to foster concordance with diabetes management issues.

#### Motivation and health beliefs

Burns (1991) defines motivation as 'consisting of internal processes that spur us on to satisfy some need'. Maslow (1943) described the acquisition of knowledge and understanding as intrinsic ingredients of motivation in his 'Hierarchy of Needs' model. In addition, Maslow emphasised the need for the individual to fulfil their physical, social and cultural needs before being able to address the acquisition of knowledge. In the context of diabetes, Maslow's theory (1943) means little can be achieved by attempting to impart knowledge without first addressing the patient's emotional distress. Burns (1991, p105) described motivation as 'the key to successful performance', which stems from needs

#### **PAGE POINTS**

Concordance has been shown to vary over time and duration of diabetes.

2 The UKPDS suggested that multiple treatments are essential in reducing the risk of micro- and macrovascular complications; however, this is only effective if the patient is concordant.

The management of diabetes, based on the individual's perceptions of illness and treatment, may be able to foster concordance with diabetes management issues.

4 Motivation for selfcare is fuelled by success which, in turn, depends on realistic, achievable goals.

5 Specific health beliefs and behaviours are related to a patient's ability to manage a treatment regimen.

#### **PAGE POINTS**

1 The challenge for health professionals and people with diabetes is to recognise and address factors promoting healthy outcomes selfmanagement.

2 Depression is more prevalent in people with diabetes than the general population.

Depression in diabetes has been reported as chronic and prevalent, reducing concordance and glycaemic control, and increasing risk of endorgan damage.

4 The NSF for diabetes highlights the challenge of recognising psychological processes in determining health and illness behaviours.

5 It has been suggested health professionals use screening questions for patients they feel to be at risk for depression.

Health professionals often find it difficult to identify and treat psychological distress quickly – it has been suggested that the simplest way is to ask the person.

that generate goal-directed behaviours to satisfy them. This view is supported in terms of effective management of type 2 diabetes by Clark and Hampson (2001).

Motivation for self-care is fuelled by success which, in turn, depends on realistic, achievable goals. Again, empowerment has been cited as the key to motivation for diabetes self-care through knowledge, control and ability to implement decisions, and education to evaluate the effectiveness of decision making (Funnell and Anderson, 2003).

The Health Belief Model, proposed by Becker and Janz (1985), regarded the degree of motivation for self-care in individuals with diabetes and identified four dimensions predicting the extent of concordance and motivation. Horne (1997) also found that specific health beliefs and behaviours were related to the ability to manage the treatment regimen. This may be particularly difficult for those who are older, with longdiabetes, secondary complications, such as failing sight, which can affect motivation for self-care. For younger people with diabetes, the most critical feature of the disease may be the perceived severity of the condition and susceptibility to complications. Other people may feel the perceived benefits of self-care activities are the important factor.

The challenge for health professionals and individuals with diabetes is to not only recognise, but to address the factors which promote healthy outcomes in diabetes self-management. Factors such as poor motivation and perceived health beliefs are being addressed in practice, using the empowerment approach and effective patient education to make the person with diabetes the key member of the diabetes team.

#### **Depression**

Depression has been reported to be three times more prevalent among individuals with diabetes than in the general population, meaning as many as 15 % may be affected (Peyrot et al, 1997). Also, lifetime rates of depression amongst people with diabetes have been

reported as 32% by Marcus et al (1992). This is statistically greater than for the general population (Lustman et al, 1998).

A number of cross-sectional studies have been conducted in adults with diabetes, suggesting that the rates of psychological distress are comparable with other chronic diseases (Wilson and Cleary, 1995; Bradley, 1994). Alternative studies suggest that depression occurs more frequently in women with diabetes than men, and is equally common in individuals with type I and type 2 diabetes (Lustman et al, 1998).

Depression in diabetes has been reported as chronic and prevalent, influencing the reporting of diabetes symptoms, reducing concordance, promoting poor glycaemic control, and increasing risk of end-organ damage (Clark, 2003). It is therefore important for depression and psychosocial issues to be identified quickly, and for the appropriate treatment to begin to improve the individual's quality of life.

The cause of depression among individuals with diabetes is unknown, but is felt to result from psychological, physical, and genetic factors which vary in different patients (Clark, 2003). The NSF for Diabetes: Standards document (DoH, 2003) highlights the challenge of recognising psychological processes in determining health and behaviours. With this in mind, the diagnosis of major depression can be made when multiple criterion symptoms are present which persist for a minimum of two weeks (American Psychiatric Association, 1994).

Treatment of depression in general, and for those with diabetes, is effective and necessary for patients with the criteria symptoms. Recognition of these symptoms to maximise health outcomes is a multidisciplinary challenge that may be addressed by implementing tactics suggested by Peveler et al (2002). They suggest health professionals employ screening questions for patients they feel to be at risk from depression. Questions, such as 'How have you been feeling lately?' and 'Have you been enjoying the activities you normally enjoy?', have been

shown to detect up to 95% of cases of major depression in medical patients. Improved recognition of depression in patients with diabetes provides the opportunity for improved clinical outcomes and long-term, a better quality of life for the individual.

## Determining psychosocial problems in people with diabetes

It has long been felt that psychologists and diabetologists should work together in identifying psychosocial issues in people with diabetes (Diabetes UK, 2000). One of the greatest difficulties cited by health professionals is identifying and treating psychological distress in individuals quickly (Lustman et al, 1998). Many psychological tests and questionnaires have been developed for this purpose. It has, however, been suggested that the simplest way to determine whether an individual has psychological problems is to ask them (Peveler et al, 2002; Bradley, 1994).

When psychological difficulties are discovered, the usual course of action is referral to a trained psychologist or counsellor. It has been argued whether or not the diabetologist or physician should diagnose and treat patients with psychological problems as diabetologists are less likely to look for or recognise ongoing difficulties (Lustman and Harper, 1987).

This view has also been supported as unrealistic due to lack of training and resources, with the suggestion that a psychologist, psychiatrist or social worker be attached to the diabetes team as was the case in the Diabetes Control and Complications Trial (1993). Limiting recognition of psychosocial difficulties to trained 'experts' also negates the NSF Standards (DoH, 2003), which strongly encourage working across professional and organisational boundaries.

The NSF for Diabetes: Standards document (DoH, 2003) highlights the multidisciplinary nature of treating psychosocial issues in diabetes, providing clinical priorities for the health service to focus on. If diabetes nurses are to

take up this role, they must receive comprehensive accredited training in order to recognise and communicate with individuals experiencing psychosocial difficulties.

A telephone survey conducted of national accredited diabetes courses covering psychosocial issues showed a wide difference in syllabus, psychosocial content, expected self-study, and cost to the NHS or hospital trust. The lowest percentage of psychosocial issues covered was 5% regarding basic acceptance of diagnosis, health behaviours, and concordance. The most comprehensive training course for diabetes nurses had a 50% psychosocial content, including empowerment, working with expert patients, and incorporated Dosage Adjustment For Normal Eating (DAFNE) and Diabetes Education and Self Management for Newly Ongoing and Diagnosed (DESMOND) training to improve patient quality of life.

#### Conclusion

It is clear that with such a vast array of potential patient psychosocial issues, diabetes nurses are not equipped to deal with this alone. To meet this challenge, health professionals must therefore collaborate in order to maximise health outcomes for individuals with diabetes. It is necessary to ask the individual what they require in order to improve their quality of life with diabetes. This should encompass recognition of psychosocial factors which may severely affect the individual's ability to self-manage their diabetes. It is also important to remember that the individual may feel they have complete control of their diabetes and, as a result, have a good quality of life in their opinion.

American Psychiatric Association (1994)
Diagnostic and Statistical Manual of Mental
Disorders (4th edn). Washington DC, American
Psychiatric Association

Anderson RJ, Freedland KE, Clouse RE, Lustman PJ (2001) The prevalence of comorbid depression in adults with diabetes: a meta-analysis. *Diabetes Care* **24**: 1069–78

#### **PAGE POINTS**

Having a psychologist, psychiatrist or social worker attached to the diabetes team is considered unrealistic due to lack of training and resources.

2 The NSF for diabetes highlights the multidisciplinary nature of treating psychosocial issues in diabetes.

3 If diabetes nurses are to take on the role of treating psychosocial issues, they must receive comprehensive accredited training.

A collaboration of health professionals is needed to meet the challenge of treating psychosocial issues to maximise outcomes for those with diabetes.

One of the greatest difficulties cited by health professionals is identifying and treating psychological distress in individuals quickly.

- Becker MH, Janz NK (1985) The health belief model applied to understanding diabetes regimen compliance. *Diabetes Educator* 11: 41–47
- Bradley C & Gamsu DS (1994) Guidelines for encouraging psychological well-being: Report of a Working Group of the World Health Organisation Regional Office for Europe and International Diabetes Federation European Region. St. Vincent Declaration Action Programme for Diabetes. Diabetic Medicine 11: 510–16
- Burns RB (1991) Essential psychology 2nd Edn, Kluwer Academic Publishers: 104; 244; 310
- Clark M (2003) Identification and treatment of depression in people with diabetes. *Diabetes and Primary Care* **5**: 124–27
- Clark M, Hampson SE (2001) Implementing a psychological intervention to improve lifestyle self-management in type 2 diabetes. Patient Education and Counselling 42: 247–56
- Coates VE, Boore JR (1998) The influence of psychological factors on self-management of insulin dependent diabetes mellitus. *Journal of Advanced Nursing* **27**: 529
- Conner M, Norman P (1996) Predicting health behaviour. Open University Press, Buckingham
- Day JL (1995) Why should patients do what we ask them to do? *Patient Education and Counselling* **26** (1–3): 113–18
- Department of Health (2003) National Service Framework for Diabetes: Standards Document. DoH, London
- Diabetes Control and Complications Trial (1993)
  The effect of intensified treatment on the development and progression of long-term complications of insulin dependent diabetes mellitus. New England Journal of Medicine 329: 977–86
- Diabetes UK (2000) What diabetes care to expect Diabetes UK, London, p9
- Donnan PT, MacDonald TM, Morris AD (2002) Adherence to prescribed oral hypoglycaemic medication in a population of patients with type 2 diabetes: a retrospective cohort study *Diabetic Medicine* 19: 279–84
- Funnell MM, Anderson RM (2003) Patient empowerment: a look back, a look ahead. *The Diabetes Educator* **42**: 454–64
- Horne R (1997) Representation of medical and treatment: advances in theory and measurement. In: Petrie KJ, Weinmann J (Eds) Perceptions of health and illness: current research and applications. Harwood Academic, London, 155–88
- Kovacs M, Ivengar S, Goldston D, et al (1990) Psychological functioning of children with insulin-dependent diabetes mellitus: a longitudinal study. Journal of Paediatric Psychology 15: 619–32

- Ley P (1992) Improving patients' understanding, recall, satisfaction and compliance. In: Broome A (1992) Health Psychology Processes and Applications London, Chapman & Hall
- Lucas S & Walker R (2004) An overview of diabetes education in the United Kingdom: past, present and future. *Practical Diabetes International* 21: 61–64
- Lustman PJ, Clouse RE, Freedland KE (1998) Management of major depression in adults with diabetes: implications of recent clinical trials. Seminars in Clinical Neuropsychiatry 2: 15–23
- Lustman PJ, Harper GW (1987) Non-psychiatric physicians' identification and treatment of depression in patients with diabetes. Comprehensive Psychiatry 28: 22–27
- Marcus MD, Wing RR, Guare J, et al (1992) A lifetime prevalence of major depression and its effects on treatment outcome *Diabetes Care* 15: 253–55
- Maslow AH (1943) A theory of human motivation. Psychology Revised **50**: 370
- Peveler R, Carson A, Rodin G (2002) Depression in medical patients. *British Medical Journal* **325**: 149–52
- Peyrot M & Rubin RR (1997) Levels and risk of depression and anxiety symptomology among diabetic adults. *Diabetes Care* **20**: 585–90
- Pouwer F, Snoek FJ, van der Ploeg HM, et al (2001) Monitoring of psychological well-being in patients with diabetes: Effects on mood, HbA<sub>1c</sub>, and the patient's evaluation of the quality of diabetes care: a randomised controlled trial. Diabetes Care 24: 1929–35
- Simons M (1992) Interventions related to compliance. Nursing Clinics of North America 27: 477–84
- Skinner TC, Cradock S (2000) Empowerment: what about the evidence? *Practical Diabetes International* 17(3): 91–95
- Talbot F, Nouwen A (2000) A review of the relationship between depression and diabetes in adults: is there a link? *Diabetes Care* 23: 1556–62
- UKPDS Group (1998a) Intensive blood glucose control with sulphonylureas or insulin compared with conventional treatment and risk of complications in patients with type 2 diabetes (UKPDS 33). Lancet 352: 837–53
- UKPDS Group (1998b) Effect of intensive bloodglucose control with metformin on complications in overweight patients with type 2 diabetes (UKPDS 34). Lancet 352: 854–65
- Wilson VL (2003) Survey of information and support needs of people with type I diabetes. Journal of Diabetes Nursing 7(7): 272-77
- Wilson IB, Cleary PD (1995) Linking clinical variables with health-related quality of life. Journal American Medical Association 273: 69-6

Collaboration of health professionals to meet this challenge must therefore take place in order to maximise health outcomes for individuals with diabetes.