# The impact of diagnosis with diabetes: what does the literature say?

# Anna Clarke

## **ARTICLE POINTS**

1 At diagnosis, the patient's perception of diabetes and the impact of diagnosis should be explored.

2 The emphasis at diagnosis is often on the medical management of the condition rather than the psychological needs of the patient.

3 Age has an effect of diagnosis.

A patient's perception of diabetes affects the impact of diagnosis.

 $5^{\rm The \ impact \ of \ diag-}_{\rm nosis \ with \ diabetes} will affect the educa-tional process.$ 

# **KEY WORDS**

- Diagnosis
- Impact
- Patient concerns
- Knowledge
- Education

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# Introduction

The concerns of patients at diagnosis of diabetes are poorly described in the literature. In this literature review, fear of complications and of getting worse were the two main topics of concern. Most studies support assessing the level of patient knowledge of diabetes at diagnosis and the provision of updated information by healthcare professionals. The patients' view of the diagnosis and their long-term priorities should be considered when treatment options are determined. Practitioners should allow patients to freely express their concerns and explore their perceptions of the illness during a consultation.

urrent trends in the care of people newly diagnosed with type 2 diabetes means that patients must absorb information about their diabetes, change the habits of a lifetime and adopt new behaviours in a short period of time (Woodcock and Kinmouth, 2001). In addition to this, they must cope with the medical management of their condition; i.e, how to monitor their diabetes, recognise problems early and know how to treat or seek treatment for these problems.

The emphasis at diagnosis is often on the medical management of the condition rather than the psychological needs of the patient (Beeney et al, 1996 and Hellman, 1990). Healthcare professionals should have knowledge of the issues which are of concern to people who have been newly diagnosed so that misconceptions can be dispelled and existing knowledge built on.

## **Before diagnosis**

Patients may have a limited understanding of diabetes before diagnosis. Individual exposure is different and will influence the perception of vulnerability, which will in turn influence information absorption, prioritisation of actions and willingness to engage in healthy behaviours. Understanding what diabetes means to the newly diagnosed individual will assist in the development of literature and education programmes to promote informed choice. The concerns of patients at diagnosis

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aim of this literature review was to look at current research on the impact of diagnosis of type 2 diabetes on the individual.

## **Review of the literature**

Articles were obtained through the use of computerised databases. Most of the literature was from the US and Australia. In drawing on this literature, it is important to remember that diabetes care in these countries is much more formalised than in Ireland, with much more emphasis on protocols, standards and audits.

#### Impact of diagnosis

Everett and Kerr (1998) liken the diagnosis of diabetes to bereavement. The Listening Project (Diabetes UK, 2001/2002) found that people with diabetes reported shock, lack of understanding and fear at diagnosis to such an extent that they were unable to take in any other information. Beeney et al (1996) found patients were distressed at the time of diagnosis with emotions ranging from anxiety, shock, anger or denial. The degree of emotional distress experienced was associated with a younger mean age at diagnosis. Lo and MacLean (1998) also showed a correlation between greater emotional impact of diagnosis and younger age at diagnosis.

Woodcock and Kinmonth (2001) provided evidence that patients in a primary care setting might be more concerned with the physical aspects of diabetes and how they look and feel, rather than the



technical aspects of diabetes management. This study emphasised the need to focus on educating patients that current blood results affect how they feel now but might also determine their future wellbeing.

#### Positive emotions at diagnosis

Many people hold positive views about their health and do not make the connection between their current behaviour and the possibility of becoming ill later in life (Murphy and Kinmonth, 1995). Dunning (1998) reported that people viewed diabetes as a serious condition but more than half of participants in her study felt that they were unlikely to develop complications. Lo and MacLean (2001) proposed that this was most likely due to an oscillation between accepting the diagnosis and refusing to accept that it applied to them.

Koch et al (1999) reported that some individuals were relieved that the diagnosis was only diabetes. Similarly, Adriaanse et al (2002) found in a study of 20 people that only one person was concerned about the diagnosis. In addition, the patients did not perceive the condition to be severe.

#### Severity of the condition

The patient's perception of how serious diabetes is will affect the way a he or she copes at diagnosis (Lo and MacLean, 2001). Healthcare professionals need to have a sound knowledge of their patients to determine coping strategies as these may oscillate between determination to cope and refusal to accept that their illness has implications for them (Murphy and Kinmouth, 1995). Using the threat of developing future complications will have limited effect as the majority of people diagnosed with type 2 diabetes believe they will not develop complications (Dunning, 1998).

# Management of type 2 diabetes

The first line of treatment for a patient with type 2 diabetes is a healthy diet with a reduction in overall calorie intake if the individual is overweight, combined with regular physical activity. Oral medication or insulin therapy may be necessary, at some point in time, for many people.

The management of type 2 diabetes may

be seen to proceed along a continuum from the simple to the more complex. For many patients and some healthcare professionals the continuum is falsely viewed as representing degrees of disease severity, with the term 'mild' used to describe diettreated diabetes and 'serious' to describe insulin-treated diabetes (Dunning, 1998).

#### **Beliefs**

Type 2 diabetes self-care is often based on the individual's adoption of medical recommendations aimed at controlling blood glucose and cardiovascular risk factors. Diabetes differs from other medical conditions in that the person with diabetes is not an object of care but a key player in achieving health outcomes. Many studies emphasise that patients at diagnosis rate risk of complications as low on the agenda (Woodcock and Kinmouth, 2001) and fail to make the association between glycaemic control and the development of ill health (Beeney et al, 1996).

#### Health belief model

The Health belief model offers a theoretical framework to predict the likelihood of a person taking recommended health actions. According to the model, the factors important in healthcare decisions are:

- Perception of the severity of the condition
- Belief of susceptibility to illness
- Value of the benefits of action
- Barriers to the proposed action
- The physical and emotional costs of actions
- The cues that stimulate action.

The healthcare professional as educator needs to be aware of how the patient perceives their medical condition and its impact on their life so that teaching methods and imparted knowledge promotes positive health decisions.

The complications of untreated diabetes are life threatening and this can instil fear in the individual if they have the belief that this is what will happen to them. Fear is a powerful motivational factor and can both assist and inhibit health behaviours (Dunning and Martin, 1999). However, fear can trigger denial (Green and Kreuter, 1991), which in turn may lead to poor selfcare behaviours. Wichowski and Kubsch

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1 The psychological state of an individual will affect their ability to absorb and recall information.

2 Health professionals should be sensitive to the psychological factors present at the time of diagnosis.

3 Gaining insight into the impact of diagnosis on an individual's life enables professionals to provide a more responsive and patient-focused care. (1997) proposed that non-compliance was a form of denial of ill health and was due to a negative perception of their condition.

#### **Psychological factors**

Health professionals and individuals may view ill health in different ways - the professional's view is based on scientific knowledge or personal experience, whereas the patient's view is based on their experience of the condition (Hellman, 1990). The non-concordance of perceptions of illness prevents the uptake of health-related advice. Studies on patientprofessional interactions emphasise the need to explore the experience of illness and understand the whole person to find common ground regarding management. Callaghan and Williams (1994) argue that understanding a disease process must include an understanding of the concerns of those who live with the condition.

#### Implications for practice

The psychological state of an individual will affect their ability to absorb and recall information (Redman, 1997). Therefore, health professionals should be sensitive to the psychological factors present at the time of diagnosis (Richards and Morris, 2001). However, current diabetes management protocols give low priority to the emotional or psychological needs of a person at diagnosis. Further research into this area from a patient prospective is warranted.

It is important that education programmes for DSNs focus on the social and personal support of patients as it pertains to their ability to self-manage their condition. Due to the increasing number of patients presenting for diabetes education, group education is gaining popularity. Patients should have the opportunity to explore the impact of the diagnosis prior to assignment to group education so that all barriers to self-management are addressed. Currently, it is through the intuitive reasoning of experienced DSNs that this occurs informally. It is imperative that less experienced DSNs acquire skills either through taught modules or mentoring. Gaining insight into the impact of diagnosis on an individual's life enables professionals to provide more responsive and patient-focused care.

#### Conclusion

In conclusion, the literature available on the impact on an individual of being diagnosed with type 2 diabetes is limited. This literature review should be extended to include other chronic illnesses and recent qualitative studies. Further investigation will help facilitate education programmes for newly diagnosed patients, which are appropriate to their needs. The information may also assist health professionals to recognise what different sub-groups of patients feel at the time of diagnosis. In this way, healthcare professionals can clarify the information needs of different groups and facilitate group education sessions.

- Adriaanse M, Snoek F, Dekker J et al (2002) Screening for type 2 diabetes: an exploration of subjects' perceptions regarding diagnosis and procedure. *Diabetic Medicine* **19(5)**: 406–11
- Beeney L, Bakry A, Dunn S (1996) Patient psychological and information needs when the diagnosis is diabetes. Patient education and counselling 29: 109–16
- Callaghan D, Williams A (1994) Living with diabetes: issues for nursing practice. *Journal of Advanced Nursing* 20: 132–39
- Dunning P (1998) How serious is diabetes; perceptions of patients and health professionals. (unpublished doctorate study, Deakin University, Fitsroy, Australia
- Dunning T, Martin M (1999) Health professionals' perceptions of the seriousness of diabetes. *Practical Diabetes International* **16(3)**: 73–77
- Everett J, Kerr D (1998) A picture of the impact of newly diagnosed type 2 diabetes. *Journal of Diabetes Nursing* 2(6): 170–75
- Green L, Kreuter M (1991) Health promotional planning: an educational and environmental approach. Mayfield, Toronto.
- Hellman C (1990) Culture, health and illness: an introduction for health professionals. 3rd edn. Butterworth-Heinmann, Oxford.
- Koch T, Kralik D, Sonnack D (1999) Women living with type 11 diabetes: the intrusion of illness. Journal of Clinical Nursing 8(6): 712–22
- Listening Project Report (2001/2002) Needs of the recently diagnosed: report and recommendations. Diabetes UK, London
- Lo R, MacLean D (1998) The non-insulin-dependent diabetic: success and failure in compliance. *Australian Journal of Advanced Nursing* **15(4)**: 31–40
- Lo R, MacLean D. (2001) The dynamics of coping and adapting to the impact when diagnosed with diabetes. *Australian Journal of Advanced Nursing* **19(2)**: 26–32
- Murphy E, Kinmonth A (1995) No symptoms, no problem? Patients' understanding on non insulin dependent diabetes. *Family Practice* 12(2): 184–92
- Redman B (1997) The practice of patient education. 8th edn, Mosby, St Louis
- Richards G, Morris M (2001) Psychological issues. Psychological aspects in the diagnosis of type 2 diabetes. Diabetes and Primary Care 3(2): 52–55
- Woodcock A, Kinmouth A (2001) Patient concerns in their first year with type 2 diabetes; patient and practice views. Patient Education and Counselling **42**: 257–70
- Wichowski H, Kubsch S (1997) The relationship of selfperception of illness and compliance with health care regimens. Journal of Advanced Nursing 25 (3): 548–53