

The psychological impact of living with diabetes

Half of those suffering from Diabetes are completely unaware of their condition.



Diabetes is a chronic disorder of the endocrine system in the regulation of blood glucose. The two main types of diabetes are Type 1 and Type 2. With Type 1 diabetes, the **beta cells** of the pancreas no longer make insulin because the body's **immune** system has attacked and destroyed them. Treatment for Type 1 diabetes is by regular insulin injections combined with food choices and regular exercise. Type 2 diabetes usually begins with insulin resistance. Treatment of Type 2 diabetes includes insulin injections, oral medication and diet.

Complications and Quality of life

Associated with long-term complications including blindness, heart and blood vessel disease, stroke, kidney failure, amputations, and nerve damage, diabetes is widely recognized as one of the leading causes of death and disability and in 2006 was the seventh leading cause of death in the USA.

In addition to the physical limitations and complications, diabetes can have a significant impact on the individual's psychological and behavioural functioning including, emotional well-being, family and social functioning and psychological distress.

The impact on patient's **quality of life** resulting from having diabetes is significant, first, because patients tell us that the way they feel is important to them and secondly, from research we know that better emotional and psychological health leads to better self-care and health outcomes. Whereas HbA1 levels can inform us about how good or bad the patient's glycaemic control is, what it cannot tell us is how the patient is feeling and the impact this might be having on adherence to treatment.

The emotional well-being of the patient is often sub-clinical in the sense that for example, expressed anxiety or depression are not clinically defined as a major depressive disorder, but are directly related to the patient's response to the diabetes. These might include for example, feelings of anxiety or distress due to a fear of hypoglycaemia and other complications, restriction in carrying out normal daily activities, or feelings of being down, all of which can impact on the patient's level of treatment adherence. Evidence of the impact of severe co-morbid depression in people with diabetes are well documented and that diabetes-related distress accounts for much of the variance in depressive symptoms which in turn can be associated with HbA1 levels.

When it comes to managing diabetes and preventing complications, what makes the difference is a focus on improving self-management skills, reducing diabetes-related distress and improving clinician-patient communication.

Because the management of diabetes requires the active participation of the patient, the importance of evaluating the impact of diabetes on the psychological and behavioural functioning has resulted in approaches to quantify the patient's psychological and behavioural functioning based on patient self-report, which as part of a larger group of measures, are referred to as patient reported outcomes (PROs).



How can we best use a PRO to improve patients lives?

Doctor/patient communication – effective communication between the health care professional (HCP) and patient is obviously essential, but, often the more emotional issues are not raised during the consultation and or go undetected. Getting a patient to complete a PRO prior to seeing the HCP can be a useful means of spotting potential problems. For example, noting that the patient was reporting that they were feeling more anxious than during their last visit. During my own research when interviewing a woman with Type 1 diabetes, she expressed fear of going out before lunch and as a result would stay at home, planning her days around the afternoon. Clearly here was a breakdown in communication and identification of the problem coupled with some simple advice on insulin adjustment would have prevented this unnecessary stress.

Establishing treatment benefits – This is one of the commonest means of using a PRO, normally done as part of a formal clinical trial when treatment A is compared with treatment B in terms of improving the emotional and behavioural functioning of the patient. However, with the growing emphasis on real world data PROs will play an increasing role in collecting patient self-report in an every day setting unconstrained by the requirements of a clinical trial.

Identifying need – PROs can provide valuable information on specific patient groups For example, investigating the prevalence of psychological morbidity in the local secondary care population of people with Type 1 diabetes or type 2 diabetes in order to determine appropriate treatment provision.





The challenges

PROs can be used to improve the patient's emotional well-being, reduce stress and enhance management. However, there are some very real challenges we need to face. For example:

- How can we best embed PROs into the decision making process?
- What are the practical issues to overcome?
- How can we combine PRO data with other clinical data?
- Do PROs tell us everything we need to know?
- Do clinicians 'want' or 'believe' in PROs?

The last point is particularly relevant – Do clinicians want or believe in PROs? Only in a culture where clinical practice values equally the psychological and biomedical processes and outcomes will PROs play a significant part in diabetes care.

About Health Outcomes Insights

Health Outcomes Insights is an independent research consultancy serving academia, life science researchers, healthcare agencies and the pharmaceutical industry, get targeted answers to patient behaviour, experience and health outcomes across a range of conditions and diseases – with particular expertise in diabetes.

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