### Psychosocial aspects of diabetes mellitus

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#### Introduction

An individual's health behaviour is influenced by his or her social, economic, cultural, and physical environment. Medical experts have reported on the psychological components of almost all diseases, particularly chronic illnesses such as diabetes mellitus.

Psychological well-being is itself an important goal of medical care, and psychosocial factors are relevant to nearly all aspects of diabetes management. Lifestyle disorders, such as diabetes, are chronic and require a different yardstick for management. Acute medical conditions usually have defined points of onset, course, cure, or death. Lifestyle disorders are neither so well defined, nor do they depend solely on medical treatment. Lifestyle changes are equally important in addition to medical interventions in the management of chronic medical disorders. Patient participation is crucial in the management of diabetes. In addition to lifestyle changes, patients are also expected to practice self-monitoring of treatment and to be involved in other aspects of prevention of complications, such as proper foot care. All these may appear very burdensome to the patient and this can impact negatively on the overall feeling of well being.

## Psychological aspects of living with diabetes

Diabetes makes many demands on lifestyle and poses debilitating and life-threatening complications which overall have a negative impact on a patient's well-being and social life. In some parts of the developing world with poor healthcare and social support, the economic consequences of living with diabetes can be enormous for the patient, leading to inadequate care and the subsequent development of complications.

Lifestyle management of diabetes involves weight reduction in the obese or overweight patient and a change in dietary habits. This is usually difficult for most patients and imposes a psychological burden on them. A lack of understanding of the disease by their peers, colleagues, and family members also makes it difficult for them to adjust to their new situation.

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In some parts of the world unemployment issues may prove an enormous hurdle for a patient with diabetes. Some employers are prejudiced and ignorantly believe that diabetes will result in poor work performance and/or regular interruptions and absenteeism as a result of frequent hospitalisation and complications. Discrimination in the workplace was reported to be 5–11% in a study in Switzerland.<sup>1</sup>

Diabetes also increases the risk of depression. In a metaanalysis, the odds of having depression was two-fold in patients with diabetes compared with those without.<sup>2</sup> Anxiety and eating disorders have also been reported to be common in patients with diabetes.<sup>3</sup>

At the first Oxford International Diabetes Summit (2002),<sup>4</sup> virtually all (98%) the participants representing medicine, politics, nursing, and patient groups called for psychosocial aspects of diabetes to be included in national guidelines. They put forward that psychosocial factors are critical to successful outcomes in diabetes management. This summit was prompted by the results of the milestone DAWN Study<sup>5</sup> (Diabetes Attitudes, Wishes and Needs) on the psychosocial dimensions of diabetes.

The DAWN Study was the world's largest international psychosocial study in persons with diabetes. It included 5000 people with diabetes and 3000 diabetes healthcare professionals across 13 countries. The results of the DAWN Study showed that as many as 41% of the patients had poor psychological well-being. These psychological problems were recognised by providers as affecting patients' diabetes self-care. However, despite this, only about 10% of these patients received psychological care.

This study also showed that across the world, the relationships that patients have with family members, colleagues at their workplace, or groups of friends, is a critical factor in improving the patient's sense of wellbeing, and leads to more effective self-management of diabetes. People without such networks of support, especially those living alone, are not likely to manage their disease as effectively. In addition, the wide diversity among patients, showing how differences in everyday life and psychology affect the self-management of diabetes, indicates the need for different emotional support packages for different types of patient. There appears to be no universal best practice.

#### Quality of life of patients with diabetes

Quality of life is difficult to define. It is further complicated by related terms being used interchangeably, such as well-being, health status, and satisfaction. How is quality

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of life measured? Generic quality of life instruments give a broad picture of health and illness.<sup>6</sup> A variety of validated forms are available specifically for diabetes: diabetes quality of life measure, well-being questionnaire, diabetes treatment satisfaction questionnaire, psychological adjustment to diabetes, diabetic-specific health beliefs, perceived control over diabetes, barriers to diabetes self-healthcare, etc.<sup>7</sup>

A number of studies have been done to assess healthrelated quality of life in patients with diabetes. 8-10 In general, these studies have been able to demonstrate a reduced quality of life in patients with diabetes. Patients with diabetes have also been reported to have a higher incidence of depression and anxiety than the general population of a similar age. 11

A study of the impact of diabetes on overall quality of life identified four major themes:<sup>12</sup> restriction, being different from others, negative emotion, and adaptation. Adolescents were most bothered about dietary restrictions, and were worried most about the future, specifically diabetic complications. Older adolescents, however, had lower worry and had a better quality of life. A multi-national study from 17 countries and 21 centres involving 2101 adolescents between the ages of 10 and 18 showed that better glycaemic control was associated with fewer worries, greater satisfaction, and better health perception.<sup>13</sup>

Studies in parents of children with type 1 diabetes showed that the parent and immediate family members face physical, psychological, and social stress, especially in the very young. 14 The event with the greatest impact was the frequency of telling others about the child's diabetes, and the greatest worry was the possible development of diabetes complications. Parents of schoolaged children had a higher satisfaction than parents of adolescents. Parents employed various coping strategies such as planful problem solving, positive reappraisal and social support seeking. 15

The quality of life of diabetic patients is significantly reduced in the presence of both microvascular and macrovascular complications.<sup>3-5</sup> Poor quality of life in these patients is attributable to psychological effects of reduced general well-being, lack of acceptance and support from family members, feelings of restriction when complying with treatment, and self-monitoring strategies among others.<sup>3</sup> Vileikyte reported a poor quality of life in patients with foot involvement.<sup>10</sup> An assessment of patients with diabetic neuropathy using the Nottingham Health Profile showed that symptomatic diabetic neuropathy was associated with impaired quality of life in five out of six domains; emotional reaction, energy, pain, physical mobility, and sleep.<sup>16</sup>

# Psychological aspects of screening and diagnosis of diabetes

The fear of being diagnosed with diabetes can be apparent as early as in the stage of screening. This is more so in patients who are enlightened about the disease or

who have a family member with the disease.

The diagnosis of chronic diseases such as diabetes may have a negative impact on the individual's perception of well-being, a study was carried out to determine the effect of being newly diagnosed with diabetes. The screening study was carried out in male outpatients at the Durham Veterans Medical Center in the USA. Using the medical outcomes study short form 36 (SF-36) instrument in 1253 patients, screening for diabetes was shown to have minimal 'labelling effect.' A later study by Eborall et al, 18 confirmed these findings and reported that screening for diabetes did not have significant negative psychological outcomes and that with appropriate counselling and follow up, screening does not necessarily raise concerns or adversely affect well-being. Snoek et al<sup>20</sup> assessed the impact of a diagnosis of diabetes on psychological well-being and health-related quality of life (HRQOL) approximately 2 weeks after diagnosis and compared changes in well-being between screeningdetected subjects and those not found to have diabetes. It was found that screening-detected subjects were not alarmed by their diagnosis and did not perceive the disease to be severe. Similarly Edelman et al<sup>20</sup> reported that one year after notification, HRQOL was no different for patients with a new diagnosis of diabetes and those found not to have diabetes.

Education about primary prevention in offspring of persons with type 2 diabetes resulted in improved awareness about personal risk, but did not cause psychological harm. An early study by Knowler<sup>21</sup> cautioned against the unfavourable aspects of screening. However, from the above it appears that screening for diabetes in the general population in most individuals appears to cause neither emotional stress nor relief. A retrospective study by Beeney et al<sup>22</sup> found that the diagnosis of diabetes was distressing for 60% of responders and 23% had wanted more emotional support at the time of diagnosis. These data were, however, collected retrospectively in outpatients with overt diabetes and not in asymptomatic individuals at a very early stage of the disease.

#### Psychological aspects of treatment

Treatment of diabetes is invariably a lifelong affair. Patients are usually told this at the onset. It is often difficult for many to accept that they have to be on drugs. Drug compliance as in many chronic illnesses may be poor and this results in long-term complications and subsequently poor quality of life. This is even more distressing to type 1 patients who are insulin dependent and have to cope with multiple daily injections. It is a difficult situation to adjust to and often depression results. In young patients with diabetes some of them omit insulin doses out of carelessness and `burn-out' resulting in episodes of ketoacidosis.

In patients with type 2 diabetes previously managed on oral drugs, introduction of insulin for glycaemic control tends to result in psychological distress in a large proportion of patients. Reactions to the introduction of insulin

include feelings of fear of pain from injections, fear of dying from hypoglycaemia, frustration and a perceived lack of control over the progression of the disease.<sup>23</sup>

#### Management

The importance of psychological care of diabetic patients cannot be over emphasised. In the global guidelines for type 2 diabetes as recommended by the International Diabetes Federation<sup>24</sup> certain recommendations were made for psychological care of patients. These are divided into guidelines for standard care and for comprehensive care.

#### Standard care

A whole-person approach should be adopted. Explore the social situation, attitudes, beliefs, and worries related to diabetes and self-care issues. Assess well-being and psychological status (including cognitive dysfunction) periodically by questioning or validated measures. Discuss the outcomes and clinical implications with the person with diabetes, and communicate findings to other team members where appropriate. Counsel the person with diabetes in the context of ongoing diabetes education, and care, and refer to a mental health-care professional with a knowledge of diabetes when indicated. Indications may include: adjustment disorder, major depression, anxiety disorder, personality disorder, addiction, cognitive dysfunction.

#### Comprehensive care

This is similar to the standard care. However a mental health specialist (psychologist) would be included in the multidisciplinary diabetes care team for periodic assessment, and to provide more comprehensive psychological assessment, if indicated. Counselling would be as for standard care, but the mental health specialist in the team would be available to offer psychological counselling, to participate in team meetings, and to advise other team members regarding behavioural issues.

Psychosocial aspects of diabetes care were included to varying extents in the guidelines from the Canadian Diabetic Association<sup>25</sup> and for the first time in 2005 in the American Diabetes Association standards of care.<sup>26</sup>

#### Conclusion

Diabetes is a lifelong chronic metabolic disease which requires lifestyle management and active patient participation in its management. The psychosocial aspects of living with diabetes have been recognised in recent years and this has prompted the establishment of guidelines to ensure that these issues are recognised and properly dealt with by medical practitioners looking after patients with diabetes. This is because it has been realised that psychological disorders in patients negatively impact on their quality of life and ability to handle aspects of their management. This leads to poor glycaemic control and further worsening in quality of life. It is hoped that proper management of these issues will lead to better outcome in patients.

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