Psychosocial and cultural issues in diabetes mellitus

G. R. Sridhar*† and K. Madhu**

*Endocrine and Diabetes Centre, 15-12-16 Krishnanagar, Visakhapatnam 530 002, India
**Department of Psychology, Andhra University, Visakhapatnam 530 003, India

Diabetes mellitus, as a component of the metabolic syndrome may be considered a paradigm of chronic non-communicable diseases. Psychological, social and cultural factors have an intimate role in the course of managing the disease, and in some ways may have a role in the cause of the disease. Inappropriate activation of hypothalamo-pituitary adrenal axis can lead to the metabolic syndrome. Psychological reactions and coping mechanisms operate at the time of diagnosis of diabetes, and continue all through management stages. Generic psychological instruments of health must be supplemented by disease-specific measures such as quality of life, well being, adjustment to diabetes, barriers to care and integration of diabetes. Work in India has shown the prevalence of abnormalities in various components, as well as documented interaction among patients and their families in living with diabetes. A comprehensive biopsychosocial model for living effectively with diabetes must be generated, fine-tuned and finally implemented.

LIFESTYLE disorders, such as diabetes mellitus are chronic and require a different yardstick for management1. 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. Crucial as medical interventions may be, lifestyle changes are equally important in treatment. People with chronic diseases, as a nationwide study in USA showed, are neither old nor disabled2.

Diabetes mellitus is projected to affect Asian Indians most among all others in the world by 2025 (refs 3, 4). It has been described as the ‘most complex and demanding’ of any common chronic disease to manage. A combination of one or all of the following is required: modification of dietary practices, weight management, exercise, monitoring of body fluids (blood, urine), foot care, use of drugs, learning new technical skills such as blood glucose monitoring1.

Diabetes may set in suddenly and without warning, or may be presaged by an apprehensive wait among families where it is prevalent. There is now increasing evidence that psychological stress may result in diabetes mellitus4. In addition psychological issues are crucial in adhering to treatment.

1For correspondence. (e-mail: grsridhar@hotmail.com)
Neuroendocrine responses to stress

Stress is a state of threatened homeostasis, in which a stimulus is interpreted as being noxious. A variety of factors can activate the stress response: psychological, biological and physical. Selye described the ‘general adaptation syndrome’ which results from stressful stimuli. Physiologically the heart pumps more blood, respiration is faster, blood is preferentially sent to the brain and the muscles. Body systems that are not immediately required to counter the acute stress are slowed down (e.g. growth and reproduction). Increased metabolic activity supplies fuel principally to the brain, heart and muscles.

The hypothalamus in the brain produces corticotrophin-releasing factor that stimulates the anterior pituitary to secrete corticotrophin or ACTH. ACTH in turn stimulates the adrenal cortex to secrete stress hormones. Arginine vasopressin, a product of the posterior pituitary is synergistic with CRH in stimulating ACTH. Alone however, vasopressin has little secretagogic activity.

The autonomic nervous system responds rapidly to stress. The sympathetic and parasympathetic limbs of the autonomic nervous system regulate cardiovascular, respiratory, renal and endocrine systems.

The brain ultimately orchestrates the global stress response by fine tuning the secretion of several neurotransmitters: CRH, AVP, opioid peptides, dopamine and norepinephrine, along with prolactin, glucagon, neuropeptide Y and others.

Emotions and psychological stress

Unlike lower animals, the human brain which is more developed, is sensitive to subtle social cues that can affect self-esteem. Threats to self-esteem and fear of losing control over one’s environment can elicit a stress response. The balance between stress and resilience determines an individual’s vulnerability to stress.

This vulnerability depends on both genetic and early life influences. Genetic polymorphisms can affect genes that regulate stress system. Both early and late life events may activate the stress response inappropriately.

Metabolic syndrome and hypothalamic-pituitary adrenal axis

In obesity circulating levels of the adrenal cortical hormone cortisol may be either normal or low. Environmental stress can result in obesity. Bjorntop postulated that stress could activate the sympathetic nervous system and result in the metabolic syndrome through hormonal dysregulation. Difference in response among individuals to the same stimuli may be responsible for the same stress being perceived as ‘distress’ or ‘eustress’. Hypothalamic-pituitary adrenal axis (HPA) was more active in centrally obese men and in the pre-menopausal centrally obese women. Central android obesity and peripheral gynecoid obesity may be associated with differential regulation of HPA. Preferential deposition of fat in the abdomen may be due to activity of enzymes that metabolize glucocorticoids. The enzyme 11 beta HSD exists in two isoforms: type 1 (11 beta HSD1) and type 2 (11 beta HSD2). The type 2 isoform irreversibly inactivates cortisol and corticosterone, oxidizing their 11 beta hydroxy groups to metabolites which bind only weakly to hormone receptors. The type 1 isoform principally found in the liver catalyses both the inactivating and activating reactions. Stress-related metabolic response may be modulated by the different enzyme isoforms. The 11 beta HSD oxoreductase activity in subcutaneous abdominal fat tissue was high in obesity, which may activate local glucocorticoid receptors, further promoting obesity. 11 beta HSD activity in the placenta may also be responsible for adverse effects on the fetus, by allowing stress hormones to pass through the placenta. Intrauterine exposure to stress may activate the HPA axis. In populations undergoing health transition metabolic syndrome and low birth weight may be linked through activation of HPA. In experimental animals prenatal exposure to dexamethasone, the glucocorticoid hormone caused lower birth weight, permanent elevation of blood pressure and hyperinsulinism. A resetting of neuroendocrine pathways may be responsible for this constellation of changes. Therefore maternal exposure to stress may also contribute to later components of the metabolic syndrome, along with maternal undernutrition.

The Hoorn Study tested the Bjorntop hypothesis. Chronic psychological stress was correlated with prevalence of type 2 diabetes mellitus and with visceral adiposity. Over 2000 adults aged 50–74 years without known diabetes mellitus were evaluated for the number of major stressful events during the preceding five years. Oral glucose tolerance test was given after the history was elicited. It was found that the number of stressful events was positively associated with the prevalence of newly diagnosed diabetes.

Psychological reactions at the time of diagnosing diabetes

A variety of psychological reactions may occur at the time of diagnosis of diabetes:

Denial

As a defense measure one may believe there could be a mistake in the test or the report. It is a reaction against some restrictive or uncomfortable situations. Up to a point denial is a normal reaction but it can keep from taking proactive measures to overcome ill health.
Anger

Anger at the time of unexpected, unwanted or uncontrollable change may be normal. However the expression of anger should not be hurting to oneself or others.

Guilt

Guilt may occur in a realistic or unrealistic situation. It may be useful, example by feeling guilty about events under one’s control and correcting them.

Depression

Depression may result from unpleasant, uncorrectable situations. It may be similar to denial, but should not become overwhelming or long lasting. It may be countered by talking over one’s feelings, or becoming involved in distracting activity or by making changes, one at a time. If depression is persistent, professional help is needed.

Acceptance

Acceptance and resolution may take up to 12 months after the diagnosis of diabetes. It requires an understanding of diabetes, and is consolidated when successful glycemic control is established within the parameters of one’s lifestyle.

Quality of life, well being, social support and coping in diabetes mellitus

When quality of life was assessed in individuals with diabetes mellitus and with impaired glucose tolerance, more subjects with impaired glucose tolerance rated their general perceived health as being excellent to good (72.23% with diabetes mellitus, 83.49% with impaired glucose tolerance).

Considering that diagnosis of chronic diseases such as diabetes mellitus 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. Using the Medical Outcomes Study Short Form 36 (SF-36) instrument in 1,253 outpatients, screening for diabetes was shown to have minimal ‘labelling effect’. Similarly 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.

Studies in children with type 1 diabetes mellitus

A study of the impact of diabetes on overall quality of life identified four major themes: restrictions, being different from others, negative emotion and adaptation. Adolescents were most bothered about dietary restrictions, and were worried the most about the future, specifically diabetic complications. Older adolescents, however, had lower worry and had better quality of life. A multi-centric multi-national study from 17 countries involving 2101 adolescents between the ages of 10 and 18 showed that lower glycosylated hemoglobin (i.e. better medium term glycemic control) was associated with fewer worries, greater satisfaction and better health perception. Both the parents and the health care team perceived the burden of disease as being lesser in adolescence than in the younger age. There was no correlation of scores between adolescent and parent or between adolescent and health professionals. Personal models of diabetes could be proximal determinants of self-care in diabetes. Adolescents beliefs about diabetes and its treatment were important in influencing self-care, emotional well-being and glycemic control. Similarly both friends and family were important sources of support to adolescents with diabetes. Family support predicted good self-management. Acceptance of the disease and a sense of coherence correlated with educational level.

Studies in parents of children with type 1 diabetes

In type 1 diabetes mellitus, the parents and immediate family members face physical, psychological and social stress, especially in the very young. Having a child with diabetes mellitus most affected the parental life satisfaction. The event with the greatest impact was the frequency of telling others about the child’s diabetes. The greatest worry was the possible development of diabetes complications. Parents of school-aged children had higher life satisfaction than parents of adolescents. Parents employed various coping strategies such as planful problem solving, positive reappraisal and social support seeking. Fathers were more likely to use distancing independent of whether the child was a boy or girl, in contrast to mothers who used all coping strategies when the child was a girl.

Studies in type 2 diabetes

Quality of life in type 2 diabetes mellitus is an important health outcome measure. In addition to medical treatment, social support, health education and psychological care are also required. A judicious blend of generic as well as disease-specific psychological instruments is required to measure quality of life and well being. Scales have been designed encompassing cognitive and disease-specific dimensions, while accounting for cultural beliefs and specific norms.

In the United Kingdom Prospective Diabetes Study, complications of the disease were shown to affect the quality of life (QOL), whereas the treatment measures
(intensive versus aggressive) did not affect QOL. This is consistent with an earlier study, which showed that poor metabolic control and co-morbid conditions were related to poor QOL. Over time, insulin therapy was eventually related to poorer QOL.

QOL was compared with metabolic control in 94 outpatients with type 2 diabetes who were referred for insulin therapy. QOL improved in the total group with a reduction of mean blood glucose.

In contrast to this report, another study followed up 461 persons randomized into standard care or group with monitoring with diabetes nurse specialist. The group who was monitored reported better mood, independent of glycemic control. Monitoring and discussing psychological well being had favourable effects on the moods, even though metabolic control did not improve. This is similar to our study on a smaller group who were followed up by a psychological research scientist, where improved well being occurred independent of glycemic control.

It is therefore important that the balance between metabolic control and QOL be considered. Care must be taken not to sacrifice metabolic control with exclusive focus on well-being aspects, and vice versa. The purpose of QOL assessment is to improve patient satisfaction with metabolic control.

QOL and complications of diabetes

It may seem intuitive that QOL is adversely affected by complications by diabetes, but few formal studies were carried out. Aside from the sub study in the UKPDS referred to above, complications were evaluated separately. Involvement of the foot had a negative impact on the QOL. Currently active foot ulcers and amputation resulted in a poorer QOL than those with healed ulcers, without amputation. Lower limb ulcers had a negative impact not only on the patients but also on the caregivers. Therefore prevention and management of foot involvement in diabetes must pay attention to improving mobility, and by counselling. Symptomatic diabetic neuropathy was associated with impaired QOL, on the following scores: emotional reaction, pain, physical mobility and sleep. In a recent report, sleep problems were directly associated with health-related QOL. These are particularly relevant to India, where we have shown that both sleep disturbances and symptomatic peripheral neuropathy were common. There is also preliminary evidence that sleep deprivation may activate the hypothalamic-pituitary-adrenal axis and lead to the metabolic syndrome.

QOL studies in fine-tuning management strategies

Studies on well being and QOL may be useful to fine tune management plan to improve well being and compliance. Continuity of care in the diabetes clinic was associated with better well-being. These measures can be implemented with little extra financial burden. On the contrary there should be a consideration of how the physician perceives and is comfortable with the management relation with the patient. Not only can health care givers be affected by the burden of treating persons with chronic unrelenting diseases, but also it may dictate the doctor–patient relationship to ensure better glycemic control and QOL. Even in primary prevention of diabetes, inappropriate hope must not be offered. Whereas offspring of type 2 diabetes mellitus perceived greater threat of developing diabetes and hypertension themselves, they also engaged in health care behaviours to lower the risk. On the contrary, first degree relatives with type 1 diabetes wrongly assumed that life style changes can minimize the risk of developing diabetes.

In the same way inappropriate use of self home blood glucose monitoring in type 2 diabetes persons who are not using insulin was counterproductive and led to greater distress.

Other aspects of conception in diabetes self

Social support contributes to physical and psychological well-being. Individuals with type 2 diabetes mellitus tended to create stories of meaning of their diabetes ‘by linking their current management strategies’ with past history. Similarly impaired access to specific positive memories was associated with poor adjustment to type 1 diabetes mellitus. Other aspects such as spirituality and personal transformation were related to well-being and positive outcomes.

Psychological instruments, scope and limitations

Psychological instruments for use in diabetes mellitus must be developed with the same rigour as other clinical measures. Generic quality of life and well-being instruments give a broad picture of health and illness. They can be used across populations to assess the psychological burden of disease. However generic instruments cannot be used to assess specific conditions, such as diabetes mellitus, because symptoms from the disease itself may mimic those due to depression or other psychological conditions. A variety of such instruments is available for use in diabetes mellitus.

Psychological measures are employed to evaluate well being and quality of life on different domains including physical, psychological and social functions. A variety of validated forms are available: diabetes quality of life measure, well being questionnaire, diabetes treatment satisfaction questionnaire, psychological adjustment to diabetes, diabetes-specific health beliefs, perceived control over diabetes, barriers to diabetes self-care, etc.
Quality of life measure

The diabetes quality of life measure used in the Diabetes Control and Complications Trial (DCCT) is conceptualized to measure the patient’s ‘personal experience of diabetes care and treatment’. Responses are given on a five-point scale. Summing the responses to core items and dividing by the number of core items in the subscale obtains scores. Higher the score, better the QOL.

Well being questionnaire

The well being questionnaire provides a measure of depression, anxiety and various positive well-being. It is specific to diabetes, unlike the Beck Depression Inventory, where somatic symptoms of diabetes may be mistaken for symptoms of depression. The focus on well being questionnaire is on cognitive symptoms. Each item is scored on a 0 to 3 Likert scale. Four subscales assess depression, anxiety, energy and positive well-being. This measures both positive aspects of well-being and negative states of anxiety.

Diabetes treatment satisfaction questionnaire

Diabetes treatment satisfaction questionnaire measures satisfaction with diabetes treatment regimens. It is useful in clinical trials evaluating new technologies. It is not designed to measure satisfaction with other aspects of diabetes care service. Interpretation of the diabetes treatment satisfaction must be done in conjunction with other measures including metabolic control and well-being.

ATT39: Psychological adjustment to diabetes

This measures the psychological adjustment to diabetes. It is sensitive to the psychological process unique to diabetes. The rationale for this is, blood glucose levels are affected both by stress-related neuro hormonal perturbations as well as indirectly by compliance to treatment. It is a 39 item self-report measure with attitudinal statements related to patient’s perception of disease and treatment. The psychological adjustment instrument measures how far diabetes is integrated into the patient’s lifestyle and personality.

Diabetes-specific health beliefs

The purpose of this scale is to measure beliefs about diabetes and its complications. It evaluates the psychological processes rather than outcomes, and can be used to understand how the patient’s beliefs are associated with their behaviour. Four belief factors are determined: perceptions of severity of disorder, vulnerability to disorder, benefits of treatment and barriers to treatments. The health belief measure gives a framework for conceptualizing the beliefs.

Perceived control of diabetes

Measures of perceived control of diabetes provide understanding of patients’ preferences for treatment options. Perceptions of patients and health care professionals may be discordant. The use of this instrument is to try to bridge the dichotomy. Three subscales are employed: personal control, medical and situational control. It measures psychological processes rather than outcomes.

Locus of control (LOC) refers to ‘expectations of control over future events’. It may be internal (i.e. the individual expects to be able to control the events) or external (i.e. the individual has no expectation of personal control). Multidimensional locus of control scales is being currently developed.

Barriers to self-care

This evaluates the social-environmental factors in diabetes, and seeks to improve compliance. It identifies environmental and cognitive factors that interfere with diabetes self-care. Thirty one-item statements are given to the subjects. The scale produces an overall barriers score. The current scale has been validated on adults with type 2 diabetes mellitus.

Other scales

A variety of scales are available to evaluate fear of hypoglycemia, measurement of diabetes knowledge, cognitive function, self-care activities, etc. Similarly extensive research is being done to validate and fine tune the existing scales across patient populations and different cultures.

Data from India

Women with type 2 diabetes mellitus reported poorer quality of life compared to men. People below 40 years of age reported better satisfaction with management, and had better quality of life. Duration of diabetes did not have a significant influence on well-being. There were gender differences in well-being: men had better adjustment, particularly with coping and integration of the illness. Among working men, those with diabetes perceived a poorer quality of life, well being and greater fatigue, compared to controls.

In a study on the barriers to care and perceived control, diet and exercise were considered important in the management of diabetes mellitus. People using insulin reported higher personal and medical control compared
to those on tablets, but experienced greater barriers to exercise and taking insulin. On partialling out the influence of these two on biographical variables, there was a positive correlation between the chance dimension of LOC and diet, exercise and glucose testing barriers. There were negative correlates between LOC dimensions of foreseeability, personal control and diet barrier.

In a 12-month follow up study, psychological well-being improved as a result of counseling, personal attention and possibly the supply of medicines independent of glycemic control.

Recently we evaluated social support in diabetes mellitus ($n = 249$; 146 men, age $49.25 \pm 11.3$ years, duration of diabetes $6.13 \pm 6.11$ years; 103 women; $48.29 \pm 11.71$ years, duration of diabetes $5.36 \pm 5.37$ years).

**Attitude towards disease.** More than 60% ($n = 137$) of spouses of patients believed that the disease could be managed effectively.

**Attitude towards the patient.** About 65% ($n = 145$) of spouses felt that the problem of diabetes was minor which requires minimum support. More than 60% of the children felt their parents were normal.

**Knowledge about the disease.** More than 85% ($n = 193$) of the spouses had fairly good knowledge about the disease.

**Support in adhering to treatment (diet, exercise, medications).** Most of the men ($n = 102$) received support from their spouse in adhering to diet (Figure 1). Most of the men ($n = 99$) and a little under half the women ($n = 36$) motivated themselves to exercise (Figure 2). More women ($n = 33$) than men ($n = 23$) depended on the spouse to go for exercise. Seventy to ninety percent of both men ($n = 127$) and women ($n = 82$) depended either on themselves or on their spouses in taking medications (Figure 3).

About half of both men and women with diabetes conversed about the disease. About a quarter conversed about the disease with their family members, who in turn spoke with the doctor (Figure 4).

This information may represent changing social and family norms either as a whole or specific to families with chronic non-communicable diseases. It can be used to help in improving compliance to treatment. A recent publication showed that the quality of marriage prospectively predicted diabetes-related quality of life.

---

**Broad concept of quality of life**

The concept of quality of life originated in the economic sciences, where financial adequacy did not always translate into individuals’ self-satisfaction. The term was first used in the early 1950s in a different context, to express concern over ecological dangers of unlimited economic growth.

Over time, subjective well-being perceived by patients was recognized to be important in medical care and research. With more number of people having chronic diseases, care rather than cure became the focus of treatment.

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. At the broadest context it encompasses dimensions of human experiences ranging from those associated with physical necessities of life to those with achieving personal fulfillment. The scope was narrowed to health-related quality of life (HRQOL) which is a ‘concept encompassing a broad range of physical and psychological characteristics and limitations, which describe an individual’s ability to function and to derive satisfaction from doing so.’ While there is no consensus yet, most researchers consider that quality of life is a multidimensional construct, encompassing psychological, social and physical well-being.

A discussion of the broad ethical, political and economic components of QOL was published in a book edited by Amartya Sen. Philosophical theories on good quality of life may be classified into hedonistic, preference satisfaction and ideal theories of a good life. The major issue in ethical judgement is whether it should be objective or subjective. Ideally a composite based on both should be available, but subjective judgement cannot be looked down upon, merely because it is subjective. At a deeper level, subjectivity may operate in many of the objective measures as well.

As a corollary, quality of life is affected by disease processes, and evaluation in these disease states gives a narrower focus, viz. the health-related quality of life (HRQOL). One must not infer that HRQOL instruments provide the broad physical, social, psychological, philosophical and ethical dimensions of QOL concept. However, most functional capacities must consider both an individual’s behaviour as well as environmental resources.

It is crucial to consider both subjective assessment of the patient and objective health measures. A final composite decision would be a trade-off among various components.
Relevant to women with diabetes having worse quality of life than men\textsuperscript{73}, this difference spans even in those without diabetes. Economic, cultural and political factors could be responsible, including differential access to medical care\textsuperscript{74}.

**Psychological, social and economic aspects in coping with diabetes**

Effective coping with chronic diseases such as diabetes is a process. It is determined by: the patient’s appraisal of...
the illness, the ability to perform adoptive tasks, to learn and use skills for overcoming the problems. Type 2 diabetes mellitus

Resources for effective coping include baseline health, positive beliefs, social skills and support, and material resources to cope with the disease. In addition to cognitive coping, stress can be reduced by appraising the health situation, believing one is in control of one’s life and focussing on the positive aspects. Relaxation techniques and physical exercise also help in coping with stress.

Patient biographical variables in coping

Men appear to cope with the disease better than women. Similarly elderly persons adapted better to treatment for management of diabetes. Education about the disease, support from one’s family and peers also contribute to effective coping. The concept of ‘sick role’ assumed by the patient is equally important: when responsibilities are surrendered as a result of diabetes, ‘family power’ may shift away, and the individual considers himself or herself incapable of taking personal care. Similarly diabetes in childhood places greater strain in the adolescent gaining independence.

Denial, anxiety and depression may compromise one’s ability to cope with the disease.

The role of others in coping

The role of the family is important in how coping occurs, as alluded to above. The family’s definition or concept of illness, the ability to perform adoptive tasks, to learn and use skills for overcoming the problems depending on the age. Child’s conceptualization with emotional pain could be a factor in the coping process. Similarly the parental influence and their cognitive appraisal also influences how the child and the family cope with the demanding disease.

Studies in India have shown the need for planned psychological treatment programmes in children with type 1 diabetes and their parents. Such programmes improved compliance and reduced negative emotions.

All these point to the importance of culturally appropriate interventions to improve compliance to treatment. One must consider the knowledge and belief systems, health and illness practices, while communicating.

Coping as the central process in management

Coping techniques are one of the most crucial skills in present day living. Stress has been shown to deplete one’s resources, which must be repleted. A variety of resources can be used, such as religious faith, social network, money, personal energy and emotional sense of security. Social support helps in many ways: by physical and material help, and by emotional support.

A positive outlook or optimism is an invaluable resource that protects against disease and aids in rapid recovery. Intriguingly, efforts are being made to develop optimism in those who are not innately optimistic. Different aspects in promoting optimism include a perceived competence in facing the situation, presence of positive feelings about oneself, ability to view oneself in positive light, which may all result in better health-related outcomes.

Type 1 diabetes mellitus

In addition, children and adolescents who generally present with type 1 diabetes, face difficulties in developmental tasks depending on the age. Similarly children and adolescents who generally present with type 1 diabetes, face difficulties in developmental tasks depending on the age. Child’s conceptualization with emotional pain could be a factor in the coping process. Similarly the parental influence and their cognitive appraisal also influences how the child and the family cope with the demanding disease.

Studies in India have shown the need for planned psychological treatment programmes in children with type 1 diabetes and their parents. Such programmes improved compliance and reduced negative emotions.

All these point to the importance of culturally appropriate interventions to improve compliance to treatment. One must consider the knowledge and belief systems, health and illness practices, while communicating.

Coping as the central process in management

Coping techniques are one of the most crucial skills in present day living. Stress has been shown to deplete one’s resources, which must be repleted. A variety of resources can be used, such as religious faith, social network, money, personal energy and emotional sense of security. Social support helps in many ways: by physical and material help, and by emotional support.

A positive outlook or optimism is an invaluable resource that protects against disease and aids in rapid recovery. Intriguingly, efforts are being made to develop optimism in those who are not innately optimistic. Different aspects in promoting optimism include a perceived competence in facing the situation, presence of positive feelings about oneself, ability to view oneself in positive light, which may all result in better health-related outcomes.
