

COPING WITH DIABETES: A PARADIGM FOR COPING WITH CHRONIC ILLNESS

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ABSTRACT

Coping is an essential mediator in adapting to chronic diseases such as diabetes mellitus. The psychological factors include adjustment to diabetes, quality of life and well-being. The locus of control also determines how an individual copes with the disease. Men were more effective in coping with diabetes and seemed to live more effectively with it. Therapeutic education has an influence on coping with diabetes. Group support for both adults and children is an adaptive and therapeutic intervention. We present a model for coping with chronic diseases, examining the role of the patient, the physician, and the clinical psychologist. Patients go through a series of adjustments when diabetes is first diagnosed. Some take the opportunity of having the disease to bring new meanings to their relationships or to take control of their lives. Locus of control describes the attribution people make to life events. In chronic diseases, people with internal locus of control think of their ability to cope with illness by their own behavior. Chronic illness may also disrupt the lifestyle because the former way of living must be altered by the limitations of a new management schedule. The family's concept of illness, sick role, its support system and communication, all have a major impact. The family physician and when available the clinical psychologist and social worker, complete the trio in the bio-psycho-social model of coping with chronic diseases.

KEY WORDS: Adaptation; Model; Bio-psycho-social model.

INTRODUCTION

Chronic illnesses such as diabetes are an accompaniment of increasing life span in modern times. They cause distress and demand compliance of complex protocols in management. Coping, thus becomes an essential mediator when adapting to the illness.

Coping with diabetes is a process and the major factors which determine its effectiveness are (a) the patient's appraisal of the illness; (b) the ability to

perform adaptive tasks and (c) the ability to learn and use skills to deal with the related problems. The appraisal or cognitive evaluation of the meaning and significance of the illness is important, as it sets the frame of mind of the person to handle and live with the problem. The tasks for coping with diabetes include those relating to the illness/treatment and those relating to the general psychosocial functioning. These tasks require the patient to achieve control over the symptoms of the illness, adhere to complex treatment regimens and cope with the uncertainty of prognosis. Further, he or she should develop and maintain supporting relationships with the family and friends and continue to set goals and plans for the future. The coping skills to be learned by the patient include seeking information about the problem and its treatment, learning to provide one's own medical care and seeking instrumental and emotional support. It is important for the person to use multiple strategies whenever possible.

Maintaining euglycemia and a eumetabolic state is the ideal criteria for assessing the level of success achieved by the patient in coping with diabetes. Adherence to the treatment regimen and the psychological states of the patient are equally important. The psychological states include adjustment to diabetes, the quality of life and well-being. The personality dimension of locus of control also determines the manner in which the individual copes with diabetes. We review the published literature, and finally present a model for coping with chronic illness.

BIOGRAPHICAL VARIABLES

The gender and age of the diabetic patients have been found to significantly influence the coping process.

Gender

Clear differences in the psychological adjustment to diabetes between men and women are observed with cognitive adjustment to diabetes being easier for men, with women reporting more depressive

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symptomatology (1). Men used more active coping than women, were less avoiding and sought less social support. Longer duration of diabetes significantly correlated with poor emotional adjustment and more depressive symptomatology in men, but not in women. In both men and women, however, better emotional adjustment to diabetes was significantly related with better cognitive adjustment and with lower depression scores. Men and women with lower depression scores also reported better cognitive adjustment to diabetes and higher quality of marital relation. In short, men used a coping style reflecting 'mastery' and 'autonomy', while women's social support seeking behaviour reflected 'dependence on others'.

Compared to women, men showed more effectiveness in coping with diabetes, more satisfaction with the management of diabetes, better rating of health, lesser social worry and better alienation-co-operation (2). In summary, men lived more effectively with diabetes.

Age

Elderly patients, despite physical disability, were able to cope well with insulin injections and their disease (3). They were able to learn, adapt to and accept insulin therapy. There were no significant adverse events associated with insulin use and no negative impact on clinical and biochemical parameters. Further, a relatively large proportion of elderly type I and type 2 diabetics used active task-oriented coping strategies only to a little extent (4). This orientation was more evident among persons with type 2 diabetes. On the other hand, aged persons, as compared to their younger counterparts, experienced more difficulty in living with diabetes (5).

Duration of Diabetes

The duration for which the patient was diabetic did not produce any significant changes in the quality of life, well being and adjustment to diabetes among persons with type 2 diabetes (5).

Education

Diabetes mellitus is one of the best examples of a chronic disease in which a therapeutic education has significant influence on the person's ability to cope with the illness. A diabetes education program with three principal tasks – educating educators, therapeutic education for people with diabetes and relatives and general preventive information, significantly improved treatment adherence as well

as knowledge, skills and behaviours to cope with daily self-care (6). Feeling of self-confidence, treatment responsibility and general well being have also increased. Education of newly diagnosed type 1 diabetes patients also improved their ability to cope with the disease (7,8).

Group Support

Group meetings of people having similar problems connected with suffering from diabetes would enable them to share their own experiences and benefit from the experiences of the others. Group support brought about positive changes in attitudes, emotions and behaviour (9). They also reported better orientation in problems of diabetes and experienced better relations with other group members.

Group Support for Children

Group support for children with diabetes would provide them coping skills to foster life-long well being. Early intervention through support groups tailored to the children's age, type of illness and its duration, enhanced the development of coping skills and promoted life-long well being (10).

Family Members Support

Higher percentage of family members of diabetic persons with good well-being, had positive attitudes about diabetes. Further, a significantly lesser percentage of such persons conversed about the disease with their spouses, took their assistance in adhering to the diet schedule, shared anxieties and fears and sought their support in coping with stressful events (11). A self-reliant approach to the management of diabetes enhanced well being of patients with diabetes.

Type of Diabetes and Type of Treatment

Regardless of the type of diabetes and the type of treatment (insulin vs. OHA), perceived internal locus of control significantly enhanced the quality of life of persons with diabetes (12,13).

MODEL FOR COPING WITH CHRONIC ILLNESS

Based on coping with diabetes, we present a model for coping with chronic illness. This model takes into account the role of the patient, the duration of the illness, the family, the physician and the psychologist in coping with chronic illness. These factors affect how the individual perceives his or her illness, what adaptive tasks he or she undertakes in terms of adjustment, and what coping strategies are adopted.

The Patient

The patient's reaction to the initial diagnosis, the role assumed, the developmental stage and locus of control are considered as important variables which determine the quality of coping with chronic illness

Reaction to the Diagnosis

The sequence of three stages which the individual typically demonstrates following a diagnosis of chronic illness are shock, encounter reaction and retreat (14). The first reaction shock, is characterised by bewilderment and the person behaves in an automatic fashion and exhibits feelings of detachment from the immediate situation. These avoidance reactions are a means of maintaining distance from the overwhelming feelings. In the second phase, encounter reaction, the person may exhibit disorganised thinking, and feelings of loss, grief and despair. This is more typical when a diagnosis comes without warning to a seemingly healthy person. The third phase, retreat, is characterised by a denial of the circumstances, along with an acknowledgement of the existence of the health problem. However, in most cases, the reality of the situation returns slowly as the person's ability to cope increases.

If avoidance and denial are maintained over too long a period of time, a person may become immobilised in his or her ability to gather information about the problem. This can prohibit the person from making timely decisions about their treatment or care needs and would result in another family member taking over the decision-making role. Or, it can result in more closer bonding and strengthening each member into a support system. These increases in family bonding and support also may increase healing and promote coping.

While shock is a fairly consistent initial response, some persons who become ill do not become disorganised or evidence avoidance behaviours. They seem much more in control, accept the illness and begin to structure their lives around the necessary accommodations.

Sick Role

When a person is diagnosed with a chronic illness the person may assume a "sick" role by virtue of the diagnosis alone. Such people tend to surrender their responsibilities to others and may discourage the person from maximising their coping abilities. This can result in a shift in the family power and further

encourages the diagnosed person to define him or herself as no longer capable. This sick role may have some advantages, for example, in a disease that runs a particular course, it may give the diagnosed person an opportunity to rest and recover with a respite from the usual responsibilities.

On the other hand, some people may believe that the chronic illness is not a death sentence, but an opportunity to deepen their lives, to bring new meanings to their relationships, to increase their religious affiliations or to take control and "be strong," perhaps for the first time in their lives. As a result, these responses can result in many positive changes in family systems.

Age and Life Stage

The age and life stages of the patients have a significant influence on their ability to cope with chronic illness.

Children and Adolescents

The perception of the illness by the parents of children with a chronic disease significantly influenced the role they play in helping the child to cope with the illness (15). Parents of children with chronic diseases rated the diseases that their own children had as less serious than those of other children. Moreover, there were less negative feelings about the disease than the one their child did not have. This ability of the family to see others' problems as worse than their own, tends to increase their ability to cope.

Peer relationships may become problematic if chronic illness occurs in later childhood or early adolescence. Peers can be cruel and may make it more difficult for the child to develop a social network. When this happens, the family may overcompensate and become strongly protective of the child, meeting more of the child's needs than are necessary. Such over-compensation may inhibit the child's developmental task mastery or the child can become rebellious in an attempt to push out of the boundaries.

If the family attempts to maintain the adolescent's health without encouraging their maximum input, adolescent rebellion may be expressed in refusal of treatment or medication. When the day to day activities of a family are adjusted by an ill child's needs, other family members especially other siblings may become angry and resentful at the same time, as they experience guilt for any attention they do receive. A diagnosed child's care often took away

from the needs or restricted the other children in the family (16). Siblings in a family with an ill child adapt best when schedules, visits, and vacations, were adjusted to the total family's needs, wherever possible, rather than entirely to the diagnosed child's requirements. When sibling's identities and importance in the family are supported and appreciated, less resentment and anger are likely.

When a family encourages the ill child's involvement in his or her own career and decision making, the child's confidence and coping ability are maximised. A mother's ability to adjust, correlated strongly to overall family adaptation (17). Where mothers were depressed, siblings and other family members had negative feelings toward the ill child. Moreover, when families are unable to express their frustrations, fears, and angers, the family's ability to accommodate to the changes, was weakened.

Adults

When chronic illness occurs in early adulthood, it may interfere with people's ability to marry, have children, or become successful in their careers. In middle adulthood, illness can be perceived as disrupting the family and work systems. Mid-life is the time when people are established in their roles and couples are often readying themselves for their retirement in good health.

Chronic illness in mid-life changes the roles of the couple as well that of the family members. An illness that compromises ability to do basic hygienic tasks upsets the sexual and social boundaries and results in a change from an intimate couple relationship to a caregiving and care-receiving one. Redefinition of the relationships from that of lovers to companions is a difficult task. Care giving may also change family's roles when there is a loss of control over body functions. A parent-child dynamic change occurs and the ill person becomes ashamed of his or her inability, may withdraw or react angrily and/or may become despondent. Finding new meanings for accommodations to the relationship must be made in the context of communication between the partners. Encouraging participation of the ill spouse to the fullest extent throughout the course of the illness, maximises the quality of the relationship.

Elderly

Belief systems about ageing often affect the way families respond to chronic illness in this later stage

of life. If illness is defined as an anticipated expected component of advancing age and elderly people are not expected to be able to care for themselves, then their care may be taken over by family members. If they themselves share this notion, they may relinquish themselves to the care giving situation. Comments like "I'm old" are often synonymous with "I'm feeble" or "unable". These self-determinations may result in self-fulfilling prophecies that are often encouraged by well meaning health care providers or children who become parents to their elderly parents.

If elderly persons are unable to care for themselves they should not be encouraged to do so. Yet, many older people do not succumb to these definitions and fight hard to maintain their independence and self-sufficiency. They refuse care, sometimes to their families distress. The family's definition of itself as caregiver of its elderly members determines its willingness to give care and the style of care giving. A spouse, siblings or children may provide the care giving needs of the elderly. In long term relationships, spouses usually have a vision about caring for one another in old age and are most comfortable when they can carry these out. Their scripts incorporate "till death do us part". Often at times, children interfere with these efforts in fear that the well parent's health is being irrevocably compromised. This interference may disrupt the lifetime promise and the well spouse caregiver responds to family pressure by giving up the role or keeping the family at a distance.

Older spouses who give up responsibilities often feel that they have deserted their ill spouse and may become depressed and withdrawn. Other times, the well spouse caregiver continues the care, even though it may compromise their own health. Environments that support older persons belief systems and independent decision making, wherever possible, should be encouraged.

Locus of Control

Locus of control describes the attributions people make to events occurring in their lives (18,19). In the context of chronic illness people with an "internal locus of control" are more likely to think that their ability to overcome a serious illness is determined by themselves and their behaviours. They verbalise things like, "If I give in to this, I will get sicker," or "I'll decide what is best for me!" They also tend to make their own informed decisions about their care and adhere to the regimens they believe will work.

People with an external “powerful other” locus of control are more likely to believe that professionals or others outside themselves determine their illness successes or failures. These individuals believe that the outcome of their illness is determined by their doctor and generally leave their care in the hands of a medical professional, basically doing only what they are told.

Chance locus of control is exhibited by people who believe that luck, fate or God determines their successes and failures. Persons with a chance locus of control will say things like, “ If I’m lucky, I’ll get over this” or “If my time is up, it’s up, and nothing I can do can change that.”

As people move from middle to older age, their notions of chance or powerful other locus of control tends to increase and they are more likely to turn to medical professionals to make their health related decisions (20). People who optimise their health by living healthy lifestyles, believe that they can determine their own health status. People who exhibit less stress and those who tend to cope with serious illnesses, tend to have stronger internal loci of control.

DURATION OF THE ILLNESS

Chronic illness profoundly disrupts the lives of patients as they find themselves having to let go of their former way of life and adapt to the limitations of their illness. Although most chronically ill patients are able to achieve a high quality of life, many tend to experience the following psychological problems:

Denial

Chronically ill patients may unconsciously prevent themselves from acknowledging the reality of the situation. Denial may serve the purpose of protecting the patient from the shock of the diagnosis, may be adaptive at first to help the patient cope and can be effective in reducing stress if there is nothing one can do to control the situation. However, if denial persists it can lead to nonadherence, interfere with adjustment to the disease, and may result in delay of seeking treatment or fail to seek care.

Anxiety

This is experienced at the time of diagnosis and may intermittently recur throughout illness, e.g., in anticipation of receiving test results, appointments for medical treatments, ongoing fear of recurrence, or uncertainty about whether they can depend on others for support (health professionals, wife, co-

workers). Anxiety complicates the patient's ability to function and results in poor coping.

Depression

Not only does depression produce distress for the patient, but can also interfere with the coping process. Patients with severe depression are less likely to comply with physical therapy, less likely to return to work, experience more marital discord as they tend to withdraw and become increasingly helpless.

Interpersonal Distress

Chronic patients may withdraw from others and have problems maintaining or developing new relationships. The family and friends of the chronically ill patient may have problems adjusting to the chronic illness. Sometimes family members’ social support needs are not met because the patients are highly dependent upon them. If so, the family may need support services.

THE FAMILY

Individuals and their families deal with a wide range of issues when a chronic illness enters the family. Some of these issues are considered below.

Family’s Definition of Health and Illness

The meaning the family members give to health and illness contributes to their ability to set boundaries around a health problem. Finding an appropriate place for the illness so that it does not become the central focus of the family serves to limit the boundaries of the disease. When boundaries are not established and maintained, the illness invades all aspects of the family system. The individual’s physical limitations become the family’s limitations and the plans and activities for all members center around the activities associated with the illness (going to doctors, taking medication, etc.). In such cases, the families should be provided the necessary assistance to deal with the problems based on the family’s strengths, style of relating, and previous useful solution strategies.

Family Scripts and Experiences with Illness

These have implications for the functioning of the family system and its ability to adapt. If, for example, the family has ideas that the illness could have been prevented or that it was caused by themselves or another family member, then a place for blame is sought, i.e., the family diet was not healthy because it was not a priority of the person preparing the meal,

or the ill person worked too many hours on his/her job, or the children caused “too much stress”. These types of thought process attempt to explain or offer some level of control over what looks like an uncontrollable situation. Hostility, low self-esteem, and other negative patterns may develop as the family system is threatened. These patterns tend to create distance from the problem or create distance between family members, often closing down communication and leaving little room for accommodation to the new situation. In some cases, blame is sought outside the family system and it is usually directed toward the medical profession, i.e., the doctor incorrectly diagnosed the ailment or took too long to recognise it. In these cases, there is a loss in faith in the medical system which may result in the delay of necessary treatment.

Maintaining Equilibrium

When an illness compromises the diagnosed member’s physical capabilities and personality characteristics, there is a constant struggle on the part of the person to maintain equilibrium. In some cases, this struggle creates growth, development, new closeness and trust in the primary or family relationships, as needed shifts in roles, power and responsibilities emerge. However, in other cases, as the person’s self care capabilities decrease, resentment, jealousy, and/or feelings of overburden may occur, as the family relationships deteriorate. The task of maintaining the family support and intimacy is ongoing for all members. In order to effectively accommodate and regain equilibrium, it is helpful for family members challenged by serious illness, to receive information about the expected patterns of the particular disorder or illness and the resultant practical and emotional demands these patterns may create for them over time (21).

Communication

It is helpful for family members to address their mythical notions about the illness in light of the medical realities about the health problem, and to “language” their fears with each other. Open communication for all family members is crucial. Living with secrets can encourage fear and guilt. Since all family members may be anticipating loss, it is helpful to discuss the issues of health care, living wills, powers of attorney and finances. This may help the family to keep their affairs in order at a time when they are under tremendous stress.

Family Members Involvement in the Coping Process

Disengagement may occur among family members who cannot cope or are unable to give care in ways that are acceptable to themselves. Others may become so enmeshed in the symptoms and disease entity that it becomes difficult to distinguish between the sick member and the others who are well. While the ill person is still able to maintain his or her past roles or tasks with some modifications, the enmeshed family might usurp that ability and elicit a lack of competence. When the sick role becomes assigned to an individual with a previously dependent spouse, that spouse when encouraged may become stronger and better functioning. But, as they do so, there is an obvious shift in the power in the relationship away from the ill spouse.

Hospitalisation and Changes in Family Structure

When a person enters a hospital or other medical in-patient facility, the family’s identity is lost as is the ill person’s. The rules and behaviours specific to that family is disregarded as the hospital rules become the governing forces. The ill person may take on the role of the “good patient”, giving over their destiny to the medical staff. The non-assertive family, in such situations feels safe that someone in authority has taken over the care taking. In other situations, patients and their families fight hard not to give up their rights and roles to the hospital facility and the personnel. The complication of maintaining one’s independence and needing to be cared for is a difficult balance. Family members often rebel against the routine and the limited access they have, not only to each other but to information about care. Anger is not an uncommon emotion, and it interferes with care giving.

THE FAMILY DOCTOR

A bio-psycho-social approach to helping patients with chronic illness requires that medical practitioners embrace families in their treatment of illness and expand their perspective from an individual medical model to a social systemic model.

A treatment plan for adult patients, stresses three major issues (22). Firstly, patients need to feel that they are understood (the doctor should elicit associated symptoms, clarify complaints, explore social and family factors etc). Secondly, the doctors need to change the patients agenda (give feedback about physical examination, reframe complaints etc).

Lastly, the doctors must make links between the patients' physical symptoms and their psychological disturbance (links to life events, explain links between emotions and symptoms etc). In general practice this can be a very helpful way to work, reducing workload, and in addition, the workload of those doctors who will care for the patient in the future. So, every physician needs to address, in every consultation, the biological, psychological and social component of all "physical" symptoms, and therefore of chronic physical illness, without fixating on one component at the expense of another..

The specific functions of the General Practitioner are to:

- Provide all the information about the illness to the family members and encourage them to talk about the illness and their emotional responses to it. The patient and the family members should be encouraged to normalise their anger. One long consultation often allows families to open up and communicate feelings suppressed for years. It is important for the General Practitioner to remain neutral and not take sides when this happens
- Encourage the patient and the family members to become self advocates in obtaining information and identifying resources.
- Though all the family members who are available and willing should be involved in caring for the patient, it is imperative that the patient should stay in charge of his illness. Certain health care skills may be taught to the family members.
- The needs of the family should be balanced with the needs of the patient. It is important to identify signs of trouble either in the family or the carers as early as possible and the doctor should try to do something about it.

As doctors become more aware of the psychological components of physical illness, it is important to realise that a counselling or behavioural medical intervention can have an effect which translates into more effective care. Some of the significant observations are that the greatest changes in patient behaviour occurred in diabetes, ischemic heart disease, airway disease and hypertension (23), a 70% reduction in visits to the doctor in a chronically ill population following a 10 week biofeedback and stress management programme (24) and similar results in patients with cardiovascular disorder (25).

The process of just carefully listening to the patient was found to be usually sufficient to permit the development of trust and enhance the quality of life and well being of the patient (12).

THE PSYCHOLOGIST

Since chronic illnesses typically involve lifestyle adjustment, there is much scope for psychosocial interventions by health psychologists. Social support, either formally or informally organised, may be useful for both patient and his or her carers. Some chronic conditions may provoke fear and anxiety within the patient's usual social circle and so the health psychologist must struggle to combat the stigma associated with this disorder. Cognitive-behavioural strategies for coping may be described, encouraged, modelled and reinforced. The psychologist provides direct services to the patient via promotion of health behaviours and treatment of psychological problems and also provides consultation to the medical team on how to incorporate psychological principles into patient care to enhance clinical outcomes.

Nearly all patients with chronic illnesses, evidence lapses in adherence at some point during the course of their illness. The rate of non-adherence fluctuates as a function of the regimen task (26-29). Human nature, the complexity of the regimen, and the chronicity of the illness also contribute importantly to non-adherence. Non-adherence is often mistakenly attributed to inadequate knowledge about proper care. Many other psychosocial factors contribute significantly to this problem, such as inadequate social support, time pressures, stress, and health beliefs that are incompatible with the regimen (29-31). The psychologist can provide treatment to develop new healthful behaviours, enhance existing healthful behaviours, and extinguish unhealthy behaviours. Non-adherence may also be a manifestation of more serious psychological problems, such as depression, anxiety, or eating disorders. These problems may be treated effectively with psychotherapy or psychotropic medication (32-34).

Stress is common in chronic illness and is brought on by ordinary daily hassles (e.g., driving in traffic, conflict with family members, work deadlines), negative life events (e.g., death of a loved one, financial problems, divorce) and the additional burdens of coping with chronic illness. Stress may have direct effects on health and indirect effects on health via disruption in behavioural patterns and routines (e.g., eating and sleeping). The psychologist can be a valuable resource in identifying maladaptive

reactions to stress and can help patients to develop more useful and effective methods of coping (35).

OBJECTIVES OF PSYCHOLOGICAL TREATMENT IN CHRONIC ILLNESSES

- To improve adherence to the treatment regimen
- To promote pro-diabetic coping behaviours (e.g., diet and exercise)
- To extinguish high-risk health behaviours (e.g., smoking, high fat intake)
- To improve family functioning as it relates to communication and problem-solving
- To provide support for subclinical distress related to the illness
- To evaluate and treat psychopathology, particularly depression, anxiety, and eating disorders
- To refer for psychoactive medication as needed

With both children and adolescents, the psychologist can provide information to the diabetes treatment team about psychosocial development and how best to resolve some of the struggles between parents and youth that may be an impediment to proper diabetes management. In addition, the psychologist can assist parents in negotiating control with their child over the diabetes treatment regimen.

APPLICATION OF THE MODEL

The model is based on the bio-psychosocial approach to chronic illness, but more emphasis is given to the patient and the family, since they are the people who have to handle the problems associated with the illness. It is assumed that the basic variables that determine the process of coping with chronic illness are the gender and age of the patient and duration of the chronic illness. These primarily influence the patient's and the family's perception of the illness and their emotional reaction to the same. The roles to be assumed by the patient and the care giver are based on this perception. The locus of control of the patient also influences the manner in which the patient adheres to the treatment regimen. Apart from educating the patient with regard to the illness it is also necessary that the patients learn to balance hope against despair and find some purpose and sense of meaning in the changed circumstances. Optimism should be fostered. A religious or philosophical orientation could

also assist to some extent. The significance of family and social support should be appreciated, as they can be useful in adaptation. They also provide the emotional and informational support that is very critical to successful coping. The services of the physician and the psychologist should be utilised to successfully cope with chronic illness.

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