The centrality of the patient role in the management of insulin dependent diabetes mellitus

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ABSTRACT

Everybody now pays lip service to the centrality of the patient’s role. We believe that the implementation of this very important principle requires skills, training, time and team work that have not yet been integrated into medical education, practice or job structure. The good intentions remain with only minimal implementation. Some illustrative case reports are presented revealing patterns of response by patients to the challenge of the diagnosis of diabetes mellitus and insulin dependence. Certain cultural attitudes and perceptions are reviewed. The weakness and non-representational nature of pure hospital control of diabetes mellitus where all the right treatment is practiced on a passive recipient is underlined. It is important to assess the patient and his milieu and to gain the patient’s co-operation as an informed participant and honest interactor. The patient is a vital first line of defense. The ease of losing communication lines when the doctor - as is too often the case - has no time is a recurrent experience. Losing lines of communication means accumulation of unanswered questions and of mounting resentment. Research at our department analyzing whether the mechanisms for implementing this fine adage about the centrality of the patient, exists in hospital or in private practice finds many of the basic elements for practical application of this idea lacking. Suggestions are presented so that the gap between good intentions and reality can be covered by education and training of both the medical team and the patients and public. The dilemma of the time needed to respond to the demands of informed patient participation is reviewed. Constructive lessons including the importance of team work, organization, records and diabetic groups are reviewed. The medical profession cannot afford to neglect major potential allies in the health care process in diabetics and in the prevention of acute and chronic complications.

Keywords: New paradigms in health, doctor/patient relation, doctor’s attitudes, patient’s attitude, life crises and diabetes, phases of reaction to chronic disease, multidisciplinary, cross disciplinary case, interactive care.


Insulin secretion is enhanced or inhibited in response to certain specific stimuli. In the insulin dependent diabetic we want to ideally imitate the natural pancreatic responses. The informed patient with a positive life attitude is with himself/herself 24 hours per day whereas, the doctor cannot hope to compete. On a two or three dose insulin regimen many informed decisions and actions can be relegated to the patient with advantage. There is mounting evidence that achieving compliance by submission is counterproductive in diabetes. Intelligent self monitoring can give the specialist excellent insights towards better control and can be an excellent educator to the patient - and doctor - regarding negative and positive forces in behavior, nutrition, intercurrent illness and environment. Yet there are problems. Some, who choose to put their full faith in technology and machinery alone, think that as we shift to new insulin delivery systems with glucose sensors computerized to make their own

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calculations, the patient can be congratulated on relegation to a safe passive role again. In fact this is the subtle educational message going to and fro between some sections of the medical establishment, their students and the public; “we offer the miracle cure using marvelous techniques, technology, equipment and machines, you do not have to do anything, you do not have to take any responsibility.” What happens if there is a system failure? It is interesting to remind the hyper-enthusiasts who think of beta cell implant or pancreatic, pancreatic/kidney transplants as final solutions, that there is no final solution in life. The new multidimensional interactive model in human biology and the new definition of health introducing the concept of interactive personal and social well-being ensures the central role of the patient however, marvelous the ‘cure’ may be. Life is an interactive multidimensional process with continuous feedback and a lot of unpredictable happenings that can only be predicted at likelihood and probability level. The message keeps coming back even through the most powerful computers that the human being is pivotal. Computers have not replaced life. Not yet! We hope that this message remains true and a guide line for all of us humans. We know now that for maintenance of health in any state, a continuous multilevel monitoring has to be made. It is a continuous process performed by multiple feedback mechanisms and by the brain, the autonomic nervous system and the endocrine system. Why do we not use to the maximum then the diabetics’ natural unconscious and conscious continuous surveillance to keep in the best of health and at the best possible advantage towards life? It is logical if we enhance these feedback mechanisms to the maximum that the informed diabetic become his/her own best front line health carer and a magnificent ally to the doctor. We must not forget that the frame of mind educated into the strict passive recipient role of the patient will find it very difficult to apply the centrality of the patient role in practice even though a lip service consensus is universally achieved.

It is much more pertinent to ask what goes wrong when the systems of conscious feedback for health do not operate in the diabetic i.e. the doctor must not just look at the blood glucose levels and the glycosylated hemoglobin figures when things go wrong. In our work and experience there is frequently an identifiable and remediable cause when things are going wrong, out of step with the natural history of the disease. There is always some form of failure of communication or support along the line. We hope by good interactive multidimensional control to strive to make that natural history more and more benign.

Incompletely identified factors generating an indifferent or a negative patient role with failure of self surveillance for health.

Lack of satisfactory patient education about diabetes and allied health subjects. This leads to the accumulation of unanswered questions leading to fear mistrust and resentment.

The phases of response to chronic and ‘incurable’ illnesses initially intruding on normal control. We have an infinite set of variations on the themes of anger, rejection, defeat, passive submission, dependence, rebellion, grief, fear sometimes making distinct identifiable phases and sometime occurring in mixed form.

The role of physical activity and muscular exercise. Lack of concentration on the issue of making peace or re-making peace with the body.

Impractical and inappropriate advice from MD. Frequently insensitive to social, economic, cultural or personal factors. Inflexible and unimaginative dietary regimes. Expensive and unattainable life and health regimens. We have become increasingly aware in our practice of the importance “appropriateness”. This means a good cultural and social profile for each patient.

Encouragement of dependency by spouse or parent or doctor. Creating and maintaining interactive relations with open communication channels is difficult. It is much easier to resort to role play and to a passive/active relationship. The ill person is frequently reduced to the passive partner in a role play relation. Doctors knowingly or unknowingly play that role. ‘Because you are ill, your punishment is to become passive and obey orders. In exchange I will be kind and paternalistic or maternalistic - and shower you with positive emotions’. However, outwardly kind, dependency and passivity is frequently encouraged where it is not needed and where it is stunting and counterproductive. It is encouraged because the active/passive, all knowing/dependent roles represent the only model the main carer/s i.e. the MD has experience with and feels comfortable in.

Isolation and social stigmatization by disease, being ‘different’. (Especially in adolescents and teenagers), leads to various degrees of social deprivation that if not recognized and compensated for will lead to control destabilization and compliance failures.

Life events and health crises. Two brief illustrative case reports are shown, the lessons of these reports are in harmony with the now universal experience of physicians, diabetologists and carers in the domain of diabetes mellitus viz. The significant advantages to be gained in tapping internal motivation and self reliance and in the early diagnosis and sensitive response to the phases and variation of depression, rejection and life events stress.

Two illustrative case reports. Patient 1 - A.T.B., male, diagnosed as an insulin dependent diabetic
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diabetic destabilization. H.L. female, first seen at the age of twenty five, as a recently married bride with a highly eligible and successful young man. Shortly after that, insulin dependent diabetes mellitus was diagnosed. She exhibited in a very illustrative way reactions occurring in patients with chronic ‘incurable’ disease in general but especially with insulin dependent diabetes mellitus during the various phases and crises of life.

At first, she showed “courageous acceptance”. After mild encouragement, she seemed to get over the problem all together. As the various life events unfolded, this positive reaction changed as she spiraled repeatedly into reactions of rejection or denial. She would go into phases of complete non-compliance. Phases of false hope, which left her at the mercy of quacks and abusers of human need. Phases of anger, aggression and rebellion. There was another very distinct phase when both partners after years of infertility became anxious about having children. As the anxiety and insecurity mounted control of diabetes was significantly disturbed. After the various upheavals of middle life events were settled, she plunges into another seriously disturbed lack of control period that was synchronous with the life event changes of the menopause. She was especially disturbed at approaching menopause after a childless marriage. In spite of being a very meticulous well educated and accurate person, she was found repeatedly to overdose herself with insulin by what seemed to be errors of calculation. The result, however, was extremely dramatic; hypoglycemic states that led to frequent hospital admissions in coma or semi-coma. Enormous family dramas were created, associated with enormous emotions of sympathy, compassion, concern. Long sittings with the patient at that stage revealed that the errors of insulin dosage, did not arise entirely out of the blue. They were associated with an occult climacteric depression and suppressed grief and anger at the knowledge of impending menopause with loss of the last hopes of fertility. The tapping of this enormous reservoir of anger and depressions plus time given for explanation was rewarded significantly by better control and by higher degree of candidness with husband, close family and friends, regarding her own reactions, anger, fear and sadness over certain life events. The hypoglycemic dramas had no more function and they ceased.

Further details of the subconscious and unconscious dynamics operating in patients with insulin dependent diabetes mellitus. Diabetics, especially when young and insulin-dependent, may go through several very relevant psychological reaction phases on the road to achieving a healthy and balanced adaptation to their diabetic state. Some of these features are parallel in other diseases that are chronic and “incurable”. Please note that these

since the age of one and a half years. This led to a great parental anxiety and complete parental, especially maternal taking up of responsibility towards the disease. As he grew out of childhood from the ages of 8 to 12, his diabetic control went completely out of hand. This led to an even firmer maternal grip and greater anxiety but no real improvement. Because he was ‘diabetic’ he was not allowed any respite from the dependent “little” child role. There were frequent hospital admissions with a terrifying list of hyperglycemic states, ketoacidotic comas alternating after discharge with severe hypoglycemic episodes. The parents became distraught. The break-through came after 3 years of the above nightmare scenario when the son was many times on the danger list in various hospitals. Long sittings with the 11-12 year old patient were allowed by the new doctor, during which it was surprising how many unanswered questions and harbored resentments the patient had and how little he knew about diabetes. The doctor noted that every time the patient was asked a question, the mother and sometimes the father answered but never the patient (the “answer for him or for her syndrome”). He had been given so little information about diabetes which was nevertheless the force that had dominated his life for as far as he remembered. He had therefore, perceived himself as the subject of chronic assault by his mother and the medical profession. This assault was symbolized by the ‘punitive’ injections three times a day. He was struggling at all levels to break the pattern. It was decided, despite his relatively young age, and having explained his condition to him carefully, to transfer the responsibility to him entirely regarding the insulin injections and urine analysis and periodic visits for monitoring after a blood check. During the first year after this fundamental but simple change of course, he did not have a single hospital admission, he did not have any hyperglycemic comas, he had a few hypos which rapidly diminished in frequency and his diabetic control figures changed dramatically.

Before the positive results of patient participation and ‘empowerment’ in this case were apparent, there were critical confrontations with the mother who accused the doctor of risking the child’s life and of transferring responsibility to a mere child”. However, after an initially extremely difficult period, the mother was completely won over as an ally. In his early teens, he was successfully linked to a diabetic group and that seemed to represent yet another break-through allowing normal puberty, normal growth and maturation in a supportive social milieu across potential barriers of isolation and stigmatization that had already started to take hold of him.

Patient 2 - Life cycle events and occult depression as a significant but frequently overlooked factor in
phases may not be so sharply cut in real life as in the description but that they represent underlying dynamics and can intermingle and interact with elements of a healthy non conflict dominated adaptation. Understanding the many frequent conflicting dynamics is important.

**Initial phase of “courageous” acceptance, even indifference.** This seems very admirable to start with, but that phase is superficial and short-lived. It is not based on a full realization of the issues and challenges involved.

**Phase of disbelief, rejection, denial, false hopes.** This phase may be amplified by early temporary remission phenomena known to take place in the early stages of IDDM, but, unfortunately, the “honeymoon” remission, as it has been called, is closely followed by a return of symptoms and by rising insulin dependence plunging the patient deeper into reflection or anger.

**Phases of anger, resentment, aggression, rebellion.** These are phases associated with many problems on the interpersonal relations level, and significantly with active non-compliance with medical treatment and other therapeutic measures such as diet and optimal life pattern.

**Phase of reactive depression.** This important change is frequently not diagnosed, because of its very gradual and subtle development. It is a phase associated with a passive form of non-compliance to therapeutic needs. In its severe forms this non-compliance may be a powerful but generally unsuspected force in the causal pathogenesis of poor control and of dramatic hypoglycemic attacks. It may also be central to the surfacing and/or aggravation of symptoms due to peripheral neuritis, autonomic neuropathy and sexual dysfunction. Patients in the early stages of this phase are vulnerable to pursue indiscriminately any alternative path that offers hope. They may become victims of dubious practices dangerous to their health or, on the other hand, they may find useful support in parallel alternative practices - for example, yoga or expression groups. Provided that they maintain an integrative, honest and non-exclusive connection with their treating doctor (it is up to the doctor to help them in this), this period may be unexpectedly valuable. If this chronic reactive depression is not resolved, the end stage is of a patient who submits to the realities of his disease - more in a spirit of defeat than in a spirit of active reality adjustment. It is a patient who is reasonably compliant to the therapeutic demands but in a very passive and unresolved way. Many doctors erroneously think this is satisfactory compliance. If these transitions are understood and thereby are negotiated effectively with the help of the treating doctor, health carers, the patient can be supported into the healthy phase of active acceptance of the realities of chronic disease without despair, depression or passive submission.

The diabetic can achieve a determination to live a full life, all the more challenging - and therefore, all the more rewarding in the end - because of the added set of limitations that have to be surmounted in the process.

In this context also diabetic associations and similar group organizations have a fundamental and indispensable complementary support role to play together with the medical profession and health carer teams.

**Analyzing the practical reality of the care situation in the light of the above information.** Mounir NA, in her 1995 M.S.C. thesis on Endocrinology at Azhar University Department of Endocrinology,18 analyzed the attitude of doctors towards the management of diabetes mellitus. She used a sample of 62 doctors involving general practitioners and specialists. She made in-depth interviews and observed performance at the clinic, hospital or center. She developed a questionnaire which was arabized and culturally adapted from Anderson et al,19 by Hassan, El Baz, Fawzy, Sadek and Mounir.18 The final form of the scale had 8 subscales and 40 items. Statistical analysis of the data was performed from the responses. Attitudes were eventually subdivided into: desirable, undesirable and indifferent. Some pertinent results are presented in Table 1. These include (1) the perception of doctors of the importance of special training for health education skills. (2) Patient autonomy: The doctors appreciation of active participation of patients and allowing them to make decisions about management. (3) The compliance issue as an internally motivated force. (4) Team Care: The belief in the importance and efficacy of team work in diabetes management. (5) Doctors appreciation of the difficulty and delicacy of the management of diabetes. (6) Doctors attitude towards conducting patient education in the outpatient setting. (It is interesting that even with the relatively low positive response, it was consistently noted that the outpatient setting available was not fit as an educational setup on several counts. An indicator of the recurrent “discrepancy between good

<table>
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<th>Item</th>
<th>Desirable</th>
<th>Indifferent</th>
<th>Undesirable</th>
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<td>23%</td>
<td>64%</td>
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<td>44%</td>
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intention and reality syndrome).

In fact the findings keep underlining that we have so far not covered enough ground in the natural and necessary development of the health caring relational models.

**Recommendations.** The shift of medical education, practice and research towards the patient centered, multidisciplinary, dynamic team models.

In the light of accumulating data, it has become almost unethical not to change the model of care in certain diseases; insulin dependent diabetes mellitus standing out as a prime example. As outlined in many studies there are now urgent economic, social, health and human considerations that necessitate the change of the caring model from A to B and even C. Research suggests that the public spontaneously, but largely in secret, is shifting to model C. They are more and more making their own choices and taking charge of their own health. If they are misinformed and are censured or punished rather than helped and supported by the medical profession, then the tide of an unstoppable movement will wreak a lot of unnecessary damage to the profession and to the public in its wake. Overworked doctors need allies. They have them in the form of nurses, nutritionists, students, patients, family, community and parallel therapists. They need to accept and teach allies. They need to incorporate this new orientation in medical curricula, in training and in research. Are they ready? Certain aspects of this new orientation and some of the doctors’ new allies deserve special mention.

**The patient comes of age.** The double importance of proper information for patient, the public at large and non-medical carers. It is a truly dramatic change. Changes are necessitated in how we educate doctors and what we educate them. A wholly new gamut of skills is needed. Patients need to be educated into the new paradigm. Non-medical carers whether in the community or in the family need information and basic skills. The all powerful and effective mass media need to respond to the new patient centered multidimensional and cooperative care models. They generally love the spectacular and the dramatic and would much rather focus on dramatic transplant surgery than on the difficult, patient, persevering multidiscipline team work of prevention, research and control of chronic non-dramatic diseases. Still they can be taught to change attitude by various means. Economic realities and the threatened environment are now powerful allies for the patient centered models in health care.

A new interactive role for nurses, carers, nutritionists, physiotherapists, complementary therapists and psychiatrists. For the most effective contribution to the health and well-being of the diabetic all these interactants must have matrices
within academia and within the community where they can analyze their actual and potential contributions, co-ordinate and divide their efforts appropriately.

**Diabetic organizations and societies**. These are ideal “in-the community” matrices for harmonizing the co-operation between academia and parallel interactants in the health care process of diabetic patients. They should concentrate on getting the many disparate interactants together and in enhancing higher efficiency participatory care. They should encourage and sponsor cross-disciplinary and multidisciplinary research with concentration on prevention as well as patient centered therapy. They should set up and sponsor genetic counseling services in co-operation with their medical and geneticist counterparts. On the other hand, social stigmatization and isolation are important destabilizing stress forces and dangers in chronic disease and in diabetes. The re-formation of “society” by individuals who could be otherwise individually isolated, stigmatized persecuted or over-patronized is always a positive and vital step forward. They represent an ideal springboard for social action; using the patients’ conflict dominated phases including anger against diabetes in a constructive manner to fight diabetes in the community and in themselves being thus, socially useful and individually therapeutic at the same time.

**References**