

12 Towards an integration of psychological and medical perspectives of diabetes management*

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The importance of psychology in diabetes research and treatment has gradually become more widely recognised by physicians and other health professionals but separation rather than integration of psychological approaches is still all too apparent (*The Diabetes Annual/1*). At the 1985 Spring meeting of the medical and scientific section of the British Diabetic Association, only 1 of the 139 papers presented focussed on psychological or social aspects of the disease. An interested Martian visitor might have understood that diabetes was a disease affecting the pancreas, but would have had few clues as to what kind of creature the pancreas was housed in! The problem is not solved by having one paper or, in the case of *The Diabetes Annual*, one isolated chapter, on 'psychological aspects of diabetes'. The index of the first volume of *The Diabetes Annual* gives only 2 references to psychology other than references to the chapter on psychological aspects. A perusal of the book itself confirms that indeed it is hard to find mention of diabetic patients as individual people with a wide variety of thoughts and feelings, concerns and responsibilities.

In the first edition of *The Diabetes Annual*, Bradley (Ch. 21) reviewed some specific applications of psychology to diabetes management including the use of stress management techniques and other behavioural approaches to enhancing self-care. The continuing progress of this research will not be reviewed in the present chapter which will concentrate on important areas which were not dealt with before.

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This chapter will focus on the individual with diabetes in family, social, and health service contexts. Research dealing with adult patients with diabetes is mainly concerned with the individual patient in the health service context. Research into treatment of children with diabetes on the other hand, is far more likely to be concerned with the child's family and with the role of other family members in diabetes management. During a consultation, few if any paediatricians would insist that the parents wait outside if the child wants the parents to be in the room; few young children would allow the doctor to get away with any such high-handed behaviour without a lively display of anger with screams and tears or uncooperative withdrawal. Adult patients are, for the most part, too well socialised to make vocal protests. They know that consideration of the convenience, needs and preferences of the physician often take precedence over consideration for the patients and their families.

Family and social environment

Children with diabetes

Studies of children with diabetes and their families have tended to focus on the impact of family factors on the child's diabetes control. Various methods have been used to assess the family environment. These methods have ranged from unstandardised psychiatric interviews (1), through indices of family stability such as frequency of divorce (2) to the use of scales with established reliability and predictive validity such as the Moos Family Environment Scale (FES) (3). The consistent finding that emerges from these studies is that poor diabetes control is most often found in children from less stable homes and from homes with more adverse psychosocial factors in the family. In a retrospective study of 30 children with recurrent ketoacidosis, White and colleagues (4) found that most of the children lived in families with substantial psychosocial dysfunction. The significance of these findings is diminished, however, by the limitations of the research design. There was no comparison group of diabetic children who had not experienced recurrent ketoacidosis. Aside from families with evidence of gross dysfunction, there is less evidence of the influence of the pattern of family relationships on the child's diabetes control.

Diabetes control may be affected by the family environment both directly and indirectly: the family may act as a stressor, affecting diabetes control via neurohumoral routes or, the family may affect diabetes control via the behavioural management of diabetes (5). Studies which have

attempted to relate family factors to diabetes control have for the most part been cross-sectional in design. It is rare to find any consideration of the factors mediating the links between family influences and diabetes control. A study by Schafer and colleagues (6) was an exception. In their study of 34 adolescents attending a diabetes summer camp, they found weak non-significant relationships between aspects of family functioning, assessed by the Moos FES, and HbA_{1c} measures of diabetes control. They did, however, find that the FES measure of family conflict was significantly correlated with the reported frequency of blood glucose testing: the more conflict, the fewer the tests performed. In addition, they found that the reported number of blood glucose tests performed was negatively correlated with HbA_{1c}. Thus, the FES measures did not predict diabetes control though they did predict one aspect of reported treatment adherence which in turn was shown to be related to diabetes control.

The psychophysiological pathway mediating the association between family factors and diabetes control in children has rarely been studied directly although frequently invoked in descriptive accounts of family life and diabetes control (7-9). In the pioneering work of Minuchin et al (10) with children with diabetes, patterns of communication in the family were measured at the same time as blood hormone levels. There have been no further reports of similar studies of children and their families.

Relatively few studies have been concerned with the effect on the family of having a child with diabetes. Ferrari and colleagues (11) compared family functioning in 45 families. Fifteen of the families had a child with epilepsy, 15 had a child with diabetes and 15 had a child with no chronic illness. Families of children with epilepsy were found to differ from the families with diabetic and healthy children on numerous descriptive measures of family functioning. Families of children with epilepsy were found to be less cohesive (as measured by the Rochester Adaptive Behaviour Inventory) than families of the other 2 groups. The presence of a child with diabetes in the family did not seem to differentiate these families from those with only healthy children on the measures of family functioning used in this study.

In a longitudinal study of the psychological and social sequelae of the diagnosis of diabetes on the parents, Kovacs (12) determined that those parents who had no marital problems at the time of diagnosis of their child's diabetes, continued to be free of marital problems one year later. Conversely, those with histories of marital distress continued to experience difficulties. Although no standardised instruments were used to assess marital adjustment in this study, the findings suggest that, at least in the first year after the diagnosis of diabetes, pre-existing levels of marital adjustment were unaltered.

In considering how a family responds to a child's diabetes, some writers have stressed the importance of determining the meaning of the diabetes to the individual family rather than assuming that diabetes will necessarily have uniform implications (7, 13). In a survey of 84 mothers of children with diabetes, Banion and colleagues (14) asked the mothers to rate how problematic they found 11 areas of diabetes management. Overall, the most problematic were future concerns, hypoglycaemia and diabetes control. Least problematic were injections, help or support of others, and finances. The importance of these factors varied, however, according to the age of the children, the duration of the illness and the socio-economic status of the mothers.

Adults with diabetes

In contrast to studies of families of children with diabetes which have tended to focus on the impact of family life on the course of the diabetes, of those few studies of adults with diabetes which have been concerned with the individual patients' family and social environment, most have examined the impact of the adults' diabetes upon other members of the family.

In a descriptive article based on 12 parents with diabetes, Anderson and Kornblum (15) considered how the diabetes affected the children in such families. They pointed to several areas of family life which they suggested might be affected by the parent having diabetes: issues concerning family planning, the impact of the parent's fluctuating emotional state on family relationships and the psychological development of their children. In an empirical study Hadden and colleagues (16) compared the emotional state and academic achievement of 123 children of insulin-dependent mothers with 124 children of mothers who did not have diabetes. There were no significant differences between the 2 groups of children on any of the outcome variables. The results of this study, viewed against the descriptive report of Anderson and Kornblum (15) highlight the importance of using empirical data to verify clinical impressions.

Surrige and colleagues (17), in a descriptive study of 50 adults with insulin-dependent diabetes, found that increased feelings of fatigue and energy loss were the main effects of having diabetes reported by 31 of these patients. The symptoms were reported to be worse in the evening than in the morning; hence leisure activities were more affected than work activities. The authors stated that these two symptoms resulted in disruption to family life, although no evidence for this was given. It is perhaps more interesting to consider not just whether a person has diabetes, but

to consider how well their diabetes is controlled and to examine the relationship between diabetes control and family life. In an intervention study involving 84 adults with insulin-dependent diabetes, Mazze and colleagues (18) examined the relationship between the psychological well-being of patients and glycaemic control. Comparisons were made at entry to the study and 36 weeks later, between patients' scores on measures of anxiety, depression and quality of life, according to their level of glycaemic control. There were no significant differences among the personality profiles (measured by the Emotions Profile Index) of those in good, average or poor control throughout the study. Those patients in whom glycaemic control worsened showed increases in anxiety and depression levels. Where diabetes control improved, quality of life (measured by the Problems Check List) improved. These results suggest that psychological well-being may be directly affected by glycaemic control.

Relatively few studies of adults with diabetes have considered how family environment or social context may affect diabetic control. This question was addressed in an elegant study by Arnetz (19) who considered the influence of social understimulation on the glycaemic control of elderly people only some of whom had diabetes. Of the 60 elderly people who participated in the study, half were randomly allocated to a psychosocial activities programme, and half acted as the control group. Over a 6-month period, significant improvements were reported in the HbA_{1c} levels of members of the experimental group compared with those of the control group members. This difference was not, however, due to an improvement in glycaemic control in the experimental group but to a deterioration in control of those in the control group. There could be several explanations for this but it was not discussed by the author. This study does nevertheless demonstrate that the frequently reported deterioration of diabetes control in elderly people may have something to do with the social consequences of ageing. Deterioration of diabetes control is not necessarily an inevitable result of the relentless physical process of ageing.

Perhaps the limited extent to which adults with diabetes have been considered in the context of their families is a reflection of a general tendency of researchers working from a medical perspective to focus on the characteristics of the disease and treatment prescribed and to give little consideration to the characteristics of the person with the diabetes and to psychological differences between individuals. Individual differences have been examined when studying problems which could have been caused by some action or inaction on the part of the patient. All too often attention is focussed on personality characteristics which are highly resis-

tant to change rather than on beliefs, attitudes and feelings which are far more susceptible to environmental influences. Indeed it seems that studies of personality characteristics have been undertaken more with a view to apportioning blame than with the aim of reaching a clearer understanding of the causes of the problems and taking steps to improve matters.

Individual differences between patients

Measurement of psychological differences

Personality factors

Measures of personality and intelligence continue to be used unproductively in a variety of studies. The personality of patients assessed with the Emotions Profile Index (18) was found to have no relationship with the level of their glycaemic control. Another study (20) compared mean personality profiles measured by the MMPI of 6 patients before using continuous subcutaneous insulin infusion (CSII) with those of 24 patients who had some experience of CSII. It is hard to imagine what rationale could be given for the authors' expectation that CSII use changes the very personality of the user. Furthermore, others have pointed out that use of mean profiles on the MMPI can be highly misleading (21).

General measures of psychological state

More useful than trait measures of personality are measures of psychological state including measures of anxiety, depression, and general well-being. A variety of such scales have been used in numerous studies to evaluate the impact of treatment on psychological well-being (e.g. 20, 22, 23).

Diabetes-specific measures of beliefs about diabetes

In the first volume of *The Diabetes Annual* (Ch. 21) a good deal of attention was given to developments in the measurement of diabetes-related health beliefs and attributions. Slow progress continues to be made in this area. Authors are becoming increasingly aware of the need to develop diabetes-specific measures of patients' beliefs and attributions (e.g. 6, 24, 25) together with measures of psychological state which are appropriate for the population studied (26).

Diabetes knowledge scales

A number of scales to measure knowledge of diabetes have been developed over the past 2 years in response to the need for evaluating the

efficacy of education programmes (27–29). These multiple choice scales can be scored quickly and easily and parallel forms are available for use before and after educational intervention. Johnson (30) has recently published a useful review of the literature concerning patients' diabetes-related knowledge, attitudes and behaviour. The few studies which have examined the relationship between knowledge and diabetes control have found mixed results (30). There are a number of possible reasons for the discrepancies between studies in the nature of the relationships found between knowledge and diabetes control. One possible explanation is that a knowledge scale may include items which would not be expected to be related to diabetes control. Thus, items on foot care may deal with information which is essential for healthy feet but is not essential for improving diabetes control. Similarly, items concerned with precautions which should be taken during intercurrent illness may be essential for avoidance of diabetic ketoacidosis but these items are not essential for improving diabetes control. It would be useful to analyse different kinds of questions separately and to have a series of knowledge scales for different purposes with items relating specifically to different outcome variables.

The development of knowledge scales provides a good example of a valuable trend towards a long-range view of psychological applications in diabetes research. There is here a recognition that resources are well spent in developing measures which can be used in a variety of future studies rather than researchers having to cobble together new measures for every new project and repeatedly reinventing the square wheel.

Some authors have pointed out the importance of tailoring education to the needs of the individual (33). The use of knowledge scales in evaluation of educational interventions emphasises the extent of individual differences in terms of differences in pre-intervention levels of knowledge and differences in the amount of improvement in knowledge attributable to the intervention. It is to be hoped that such differences are not simply attributed to personality and intelligence but that the possibilities of using a wide range of methods for improving knowledge should be studied especially for those at the lower end of the distribution.

Reliability and validity of measures

Many authors, in describing the use of general measures of anxiety, depression or locus of control in studies of people with diabetes, have emphasised that the scales have known reliability and validity (e.g. 20, 22, 32). The references given, however, were to normative data from general population samples rather than from samples of people with diabetes. It is not hard to imagine that a person with diabetes would score differently on certain items of scales intended to measure, say, obsessionality or anx-

ity simply as a result of the demands of their treatment regimen and the threats posed by the diabetes itself. As far as we know no one has examined the reliabilities of commonly used general scales using data from diabetic populations. Although occasionally the details provided have not been adequate (33) most authors of new diabetes-specific scales have provided sufficient details including appropriate psychometric analyses to allow the reader to assess the nature of the scales and their suitability for use in other studies (e.g. 24, 25, 28).

Measurement of psychophysiological differences between patients

Differences between patients in personality, psychological state, knowledge and beliefs have been recognised readily by health professionals who have seen the need for investigations into the extent of such differences and the role of such variables in numerous studies.

Health professionals have been slower, however, to recognise the extent of differences in patients' experience of their diabetes. In particular it has often been assumed that all patients experience similar symptoms of hypoglycaemia. Indeed, Mutch and Dingwall-Fordyce (34) went so far as to assess the 'knowledge of the symptoms of hypoglycaemia in elderly diabetic patients'. In this study, the authors did not allow for the possibility that the nature of the symptoms experienced may actually vary from one person to the next.

A number of psychologists working in different research centres have been investigating the relationships between physical symptoms and blood glucose levels and between mood and blood glucose levels (35 - 37) and have recently drawn attention to the dangers of assuming that all patients have similar symptoms of hypo- or hyperglycaemia. They recommended (38) that patients should be taught to discover for themselves their own reliable and personally relevant cues to different levels of blood glucose. A simple procedure was outlined for teaching patients to learn this skill.

Use of psychological measures of individual differences

Although some progress is being made in the development of diabetes-specific measures of knowledge and beliefs, these measures have not always been used appropriately. A major block to progress in appropriate uses of such measures is that few physicians have recognised a need to measure systematically the psychological differences between patients. This problem has been particularly apparent among physicians involved in evaluating new treatments. One instance of this is in research into CSII.

Many physicians have volunteered advice about the selection of 'psychologically suitable' patients for CSII (39–42). Words like 'emotionally disturbed', 'motivated' and 'compliant' have been liberally used in describing those patients who are and those who are not supposed to be 'psychologically suitable'. Some authors have recognised that there is no consensus about which patients are suitable for CSII (43, 44). More often, however, authors have assumed that there is no controversy and that their personal beliefs about patients' suitability are both obvious and correct. The reader is all too frequently invited to accept as fact assessments based solely on personal opinions. It is, for example, a commonly accepted though entirely unsubstantiated opinion that depressed individuals should not be offered CSII therapy. As long as physicians believe this, there will be no possibility of discovering whether or not depressed individuals would benefit from CSII. The unsubstantiated beliefs of physicians about the psychological suitability of patients for different forms of treatment may have profound implications for the care those patients receive.

When CSII first became available for study in small scale research projects, many physicians believed that CSII use would be the cause of depression and anxiety amongst patients. This belief was examined in some small scale studies but no supporting evidence for it was found (20, 22, 23). In fact, psychological well-being was found to be more likely to improve than to deteriorate with CSII use in these studies. The studies were, however, not without their problems. Two of the papers supplied no details of how the patients were selected for CSII use. The third paper (20) listed 3 selection criteria, one of which was that the patients should have 'no psychological problems'; the authors did not elaborate on what constituted a psychological problem. It is clearly difficult to generalise from the findings of such studies when selection criteria are unspecified or when insufficient details are given.

Research evaluating the use of CSII has provided a further example of how the clinical impressions and personal assumptions of physicians may be misleading. In a feasibility study of CSII the patients reported their reasons for choosing CSII (45). These differed markedly from the patients' reasons for CSII choice postulated by the physician before the actual responses of the patients had been examined (43). The patients' reported reasons for wishing to use CSII turned out to be very similar to the reasons why the physicians recommended CSII: better glycaemic control and reduced risk of complications.

The importance of systematic measurement of individual differences between patients may go unrecognised in the face of physicians' reliance on untested beliefs. There is mounting evidence that physicians' own

beliefs may well be as important in determining the kind of care a patient receives as any beliefs held by the patients.

Individual differences between health care professionals

Individual differences between health care professionals have been considered far less frequently than individual differences between patients as factors influencing the health outcome of patients. This relative neglect has not been restricted to diabetes-related research but can be noted throughout research in other areas of general medicine. The lack of interest in the beliefs and behaviour of health care professionals may be understood in terms of a view of medicine as the direct application of a pure medical science. The assumption underlying this view is that practitioners have near identical beliefs and practices, as a result of their rigorous scientific training. Given this view of medicine the beliefs and attitudes of health professionals will appear to be quite irrelevant.

Of the few studies which have focused on health professionals, several have been concerned with physicians' and nurses' knowledge of diabetes (46, 47). Whenever doctors' or nurses' knowledge of diabetes is assessed, the conclusion invariably leads to a call for more education. Whether more education for health professionals will influence the management of their patients' diabetes is another question. Researchers in Indianapolis (48) conducted a randomised controlled study to determine whether physician and patient education improved clinical outcomes. Eighty-five doctors and 532 of their patients were randomly assigned to 1 of 4 groups: (1) routine education; (2) intensive patient education; (3) multifaceted physician education; (4) physician and patient education. After 11 months, patient outcomes (measured by fasting blood glucose levels and body weight) were significantly better for those patients in group 4 (both physician and patient education). At 2 years follow-up of 181 of these patients, however, improvements in weight and glycaemic control were no longer discernable (49). The authors suggested that continuing programmes of education may be needed in order to effect long-term improvements in diabetes control. As shown in studies which have considered patient knowledge of diabetes in relation to management and diabetes control, knowledge is necessary but not sufficient for effective health care.

Research reviewed elsewhere (*The Diabetes Annual/1*, Ch. 21) has provided some limited support for the hypothesis that differences in patients' beliefs will be related to different levels of diabetes control. Health professionals have also been found to vary in their beliefs about diabetes (50,

51). That these beliefs may influence how physicians approach management of their patients' diabetes is suggested in a study by Weinberger et al (52). They compared 12 physicians who were 'more successful' in caring for their patients with 12 'less successful' ones, success of physicians being defined by the glycaemic control of their patients' diabetes. While knowledge about diabetes did not discriminate between the 2 groups of physicians, their beliefs about diabetes did: the more successful group believed more strongly than the less successful group in the benefit of strict blood glucose control in reducing the likelihood of diabetic complications. In another study of 61 physicians and 428 adults with diabetes, Hiss and co-workers (53) found significant differences between the management and diabetes control of patients looked after by physicians aged under 40, compared with those looked after by physicians aged over 40: patients with insulin-dependent (Type 1) diabetes who consulted younger physicians used home blood glucose monitoring more frequently and had lower mean HbA_{1c} levels than comparable patients cared for by older physicians. If a causal relationship lay behind this statistical association then the direction of the causality is rather clear providing we accept that the speed of ageing of physicians is not influenced by their patients' HbA_{1c} levels! However, in neither of the papers described above (52, 53) was the possibility considered that patients might have chosen to consult physicians whose beliefs and behaviours were compatible with their own. Weinberger and colleagues discussed other limitations of their cross-over study and recognised the importance of considering the interactions between physicians and patients for promoting effective management of diabetes. The existing evidence would support Weinberger and colleagues' suggestion that continuing medical education programmes may be more influential in improving patient care if they were geared towards identifying and changing physicians' attitudes rather than depending solely upon transferring new medical information (52).

Towards an integration of psychological and medical perspectives

A major barrier to the effective integration of psychology into diabetes management and research is that for the most part a medical perspective guides the formulation of questions, the design of investigations and the analysis and interpretation of data. The contribution of psychology is usually in the form of psychological measures which are used within the existing medical framework. The enthusiasm of physicians for using scales to measure psychological factors such as levels of depression or the nature of health beliefs is not matched by their knowledge or understand-

ding of psychological models. The psychological constructs are tacked onto the medical perspective with little thought about their suitability or relevance. The findings from these studies are often inconsistent and can be highly misleading.

The power of psychology is vested in two of its characteristics: its methods and its theoretical models. The methods guide the selection and development of instruments to measure the variables under study, the design of investigations and the data analysis. The theoretical models shape the hypotheses to be tested, the selection of variables to be measured and the interactions to be studied. A psychological model may embrace not only the beliefs, attitudes and behaviour of the subjects under study but also the beliefs, attitudes and behaviour of the experimenter conducting the study. The personal characteristics of the psychologist not infrequently provide variables for study; the characteristics of physicians and other medical researchers are variables of equal interest.

Physicians and other medical researchers are not immune from the cognitive bias which leads people to look for and attach greater weight to evidence confirming their beliefs while avoiding or devaluing contradictory evidence (54). In diabetes research physicians tend to be far more interested in results suggesting that poor diabetes control is associated with particular personality characteristics of the patients than they are in the findings that the beliefs of the physicians themselves are associated with different degrees of diabetes control in the patients. There has been a mass of published research on patients' personalities but only very few published papers on the beliefs, attitudes, knowledge and behaviour of physicians. Research published on the characteristics of physicians has indicated that their beliefs may be an important variable in determining the glycaemic control of their patients. The evidence provided by such studies is at variance with the view physicians may have of themselves as rational thinking beings who apply scientific facts in uniform fashion and who are concerned with the medical treatment of diabetes in patients who seem to them to be frequently irrational and uncooperative.

Psychologists hold very different views of physicians and patients from those held by physicians themselves. Psychological research is guided by very different models of human behaviour from those used in medicine. It is not enough for psychologists and physicians to use each others' terminology: it is important that they appreciate the conceptual models behind these terms. For diabetes research to benefit from psychology it is essential that research is guided by both medical and psychological perspectives.

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