AN INVESTIGATION INTO THE RELATIONSHIP BETWEEN FAMILY FUNCTIONING, REGIMEN ADHERENCE, AND METABOLIC CONTROL IN ADOLESCENTS AND CHILDREN WITH INSULIN-DEPENDENT DIABETES MELLITUS

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ABSTRACT

This study investigated the relationship of a number of family characteristics and family function variables, to the metabolic control and extent of adherence to the required health care regimen of twenty-two children and adolescents with insulin-dependent diabetes mellitus (IDDM). The white, intact, middle-class, South African families of these ill children were visited and assessed in their homes. The following scales were utilised in order to obtain quantitative measures; Family Adaptability and Cohesion Evaluation Scales (FACES III), Family Crisis Oriented Personal Scales (F-COPES), Family Strengths, Regimen Adherence Scale. The child's metabolic control was determined from a physiological measure of glycosylated haemoglobin.

All family members living in the home, 12 years of age and older, completed the Perceived and Ideal versions of FACES III. Parents and the doctors caring for the children were asked to complete the regimen adherence scales, while the mother also completed F-COPES and the Family Strengths scales. Clinical and demographic data were also obtained from a family interview.

Parents' and doctors' reports of regimen adherence concurred, but neither were significantly associated with metabolic control. While females were found to be adjudged better adherers to the required regimen than males, there was no gender difference in levels of metabolic control. Dietary difficulties were cited as the biggest problem in regimen adherence for females, while blood-glucose monitoring was the most difficult for the majority of males. No significant associations of metabolic control and regimen adherence, with the child's age, age at diagnosis, and duration of illness, were found.

Except for fathers, all family members' idealised views of Distance from the Centre of Circumplex were positively and significantly associated with metabolic control. Children with poor metabolic control were found to come from families in which individual members desired a more extreme, or "dysfunctional", form of family functioning. Siblings expressing the least family satisfaction had brothers and sisters with better metabolic control. Ill children expressing low satisfaction with family adaptability and cohesion were found to be adhering to their regimens.

A high reported incidence of religious activity as a means of coping with difficulties experienced in the family was significantly associated with families of children with poor regimen adherence. It was also found that religious families were inclined to tend towards rigidity, suggesting that rigidity in association with religiosity

in families had an adverse effect upon regimen adherence. Another hypothesised salutogenic variable that was negatively associated with regimen adherence was the inclination of a family to seek and acquire social support in times of difficulty. Those families which most utilised this strategy in response to difficulties were found to have children with lower levels of regimen adherence.

A series of exploratory investigations was conducted. Unresolved methodological difficulties were noted in the conceptualisation and treatment of data derived from FACES III. Attempts to determine the relative utility of a curvilinear use of FACES III data as opposed to a linear use in predicting metabolic control and regimen adherence, were inconclusive. In assuming a linear conception of adaptability and cohesion, a tendency towards flexibility in the family (mothers' perceptions) was significantly associated with good regimen adherence, while a tendency towards enmeshment, was significantly associated with poor metabolic control.

A further exploratory exercise demonstrated that certain psychosocial variables are "indirectly" associated with metabolic control through their effect upon regimen adherence, while others were "directly" associated with metabolic control.

Finally, discriminant analysis was employed to investigate if combinations of a select few family variables would be able to predict good and poor metabolic control and regimen adherence. Of the examples cited, a combination of siblings' Distance from Centre scores with Sibling satisfaction scores was able to correctly predict good and poor metabolic control in fifteen out of seventeen cases (88.24%). As concerns regimen adherence, a combination of four family coping variables and Family Strengths was able to correctly predict good and poor adherence in twenty-one out of twenty-two cases (95.45%).

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PREFACE

For all the "progress" in modern medicine, for all the new drugs and impressive new technology, for all the astonishing insights into the "mechanics" of the human body, the growing gulf between cost and effectiveness has precipitated a major crisis in health care throughout the developed world.

Today in a socio-economic system that is fundamentally pathogenic, no one should be surprised by increases in the chronic and degenerative "diseases of civilization" - a "civilization" in which millions are victims of stress, pollution and drug abuse, are overfed and under-exercised, are addicted to cigarettes, alcohol and convenience food, and are expected to thrive on mindless work and passive leisure.
The increasing dependence on specialized and high-technology medicine has encouraged doctors to deal with particular parts of the body, often forgetting to deal with the patient as a whole. By reducing health to a series of discrete mechanical functions, modern medicine seems concerned more with *illness* than with the *person* who is ill. ... The notion of individuals taking responsibility for their own health has been almost entirely lost.

(Jonathan Porritt, 1984).

One of the most highly developed skills in contemporary Western civilisation is dissection: the split-up of problems into their smallest possible components. We are good at it. So good, we often forget to put the pieces back together again.

This skill is perhaps most finely honed in science. There we not only routinely break problems down into bite-sized chunks, we then very often isolate each one from its environment by means of a useful trick. We say *ceteris parabis* - all other things being equal. In this way we can ignore the complex interactions between our problem and the rest of the universe.

(Alvin Toffler, in foreword to Prigogine and Stengers, 1984).

The awareness has grown in recent years that human disease, in addition to a pathology, also has an ecology. The understanding of disease, then, must comprehend the pertinent aspect of that ecology if it is to be at all meaningful. The patient's emotional involvement in the family system constitutes a major aspect of that ecology which we can no longer afford to ignore.

(Meissner, 1966).

DECLARATION

Unless otherwise indicated in the text,
this dissertation represents my own work.

CHRIS ALBERTYN
JANUARY 1991

INTRODUCTION

Insulin-Dependent Diabetes Mellitus (IDDM) is a chronic, incurable, endocrine disorder usually diagnosed in childhood or early adolescence. Afflicted individuals, or their caretakers, are required to consciously perform what are usually autonomically controlled metabolic functions of calculating and administering varied amounts of insulin in order to facilitate the physiological process of creating energy from food.

Those diabetics[1] whose blood-glucose levels stray outside of the necessary parameters of metabolic control face potentially fatal acute complications related to hyperglycaemia, hypoglycaemia and ketoacidosis. People experiencing ongoing poor metabolic control are at great risk for developing chronic life-threatening microvascular complications (Anderson & Kornblum, 1984; Cahill, Etzwiler & Frenkel, 1976; Taylor, 1985).

Approximately 75% of people diagnosed as having diabetes die of cardiovascular-renal problems within 30 years of diagnosis (Hanson & Henggeler, 1984). Compared to people considered physically healthy, insulin-dependent diabetics are 25 times more prone to blindness, 17 times more prone to kidney disease, five times more prone to developing gangrene and becoming subject to lower extremity amputations, and twice as prone to heart disease (Ibid).

Good metabolic control can mean increased longevity and may even reverse the presence of short-term complications (Cochran, Marble & Galloway, 1979; White, Waltman, Krupin & Santiago, 1981). The attainment of good metabolic control has become a primary therapeutic goal among health care professionals treating people with diabetes (Hanson & Henggeler, 1984).

No epidemiological studies with regard to IDDM have been carried out in South

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1 *While the term 'person with diabetes' locates the person and not the disease as central, and is preferable, the label 'diabetic' shall also be used in this dissertation as a matter of editorial convenience.*

Africa, though it is believed to be increasing in incidence and most common among the white South African population, but uncommon in South Africans of Indian origin (Robertson, personal communication). A rough estimate of the prevalence of IDDM in white South African children fourteen years of age and younger is two per thousand (Ibid). It is not known what proportion of people with IDDM in South Africa are in an ongoing state of poor metabolic control, but, in other countries, the incidence of people classified as having frequent episodes of hypoglycaemia has been found to be between 16% (Walford, 1982) and 26% (Barnett, Leslie & Watkins, 1980).

Though adherence to the required health care regimen of blood glucose monitoring, daily insulin administration, exercise and special diet, are necessary prerequisites, they do not guarantee the maintenance or establishment of proper metabolic control. Metabolic control has been found to be directly and indirectly, through poor regimen adherence, influenced by a complex and multivariate combination of the biological, psychological and social context in which the individual functions (Anderson & Kornblum, 1984; Hanson & Henggeler, 1984; Johnson, 1980; Sargent & Liebman, 1985).

With increasing acknowledgement across the professional disciplines of the need to embrace a broader contextual framework in the implementation of health care (Herman, 1989), an understanding of the role of the family in the illness process has become an important focus of research work.

> There is an emerging consensus that research on the family has become a priority. Many of us are struggling with the challenge of how to describe and understand better the role of the family in processes of health and illness (Blake, 1989).

Campbell (1986) notes that physicians "are reluctant to believe that psychosocial factors can affect health", though "there is a general consensus within medicine that illness affects the family...". In South Africa, the "average" general practitioner treating diabetics emphasises pharmacological management and tends to regard the role of psychosocial factors as nuisance variables outside of their control (Robertson, personal communication). Internationally, there has been an increasing research interest in attempting to identify those psychosocial variables associated with metabolic control and regimen adherence (Anderson, Miller, Auslander & Santiago, 1981; Bradley, 1988;

Campbell, 1986; Evans & Hughes, 1983; Hanson & Henggeler, 1984; Johnson, 1985; Schafer, Glasgow, McCaul & Dreher, 1983).

It is only relatively recently that the biopsychosocial model (Engel, 1977; 1980) has begun to be explored as a "more scientific" (Antonovsky, 1989) integrative paradigmatic alternative to the dominant biomedical method of understanding and treating the disease process (Capra, 1983). Over the past decade theoreticians in the health care field have become increasingly invested in constructing a metatheory which could satisfactorily bridge the various disciplines and their theoretical constructs on the biological, psychological and social aspects of illness and health (Vetere & Gale, 1987).

The family is the major source of socialisation, stress, and social support for the child in its development (Rutter & Cox, 1985). Along with being the primary context in which health related behaviours are learned and practised (Campbell, 1986), the family is also the most accessible level of the patient's social environment in which health care professionals can intervene (Doherty & Baird, 1983; 1987).

Given IDDM's early onset, and the large-scale behavioural and dietary adjustment required of the child and immediate family, the family environment has been identified as playing an important role in influencing the extent of regimen adherence and metabolic control (Anderson et al., 1981; Hanson & Henggeler, 1984; Johnson, 1985; Koski & Kumento, 1975, 1977; Sargent, 1985).

The presence of certain family relational characteristics has been found to promote successful long-term adaptation to maintaining the required regimented lifestyle, while families of people with ongoing poor adherence to the required regimen have been characterised as environments in conflict and under stress (Koski & Kumento, 1977; Newbrough, Simpkins & Maurer, 1985; Sargent & Baker, 1983).

Likewise, good metabolic control has been associated with functional patterns of family organisation, while, poor metabolic control has been associated with dysfunctional patterns of family organisation (Anderson & Auslander, 1980; Anderson, 1981; Baker, Rosman, Sargent, Nogueira & Stanley, 1983; Minuchin, Rosman, Liebman, Milman & Todd, 1975; White, Kolman, Wexler, Polin & Winter, 1984).

Beyond these very general conclusions however, methodological difficulties have

limited the strength of conclusions that can be drawn as to the nature and interaction of the multiple factors thought to determine the metabolic control of children with IDDM. In particular, family systems oriented research has floundered in its inability to successfully translate complex, and disputed, theories of family function and change into quantifiably testable constructs with which to validate, reject, or modify the predominantly anecdotal, clinically oriented, literature describing the family's role in chronic illness (Campbell, 1986; Fisher, Terry & Ransom, 1990).

The gulf that exists between the quantitatively oriented researcher and practising family theoretician can be attributed to a number of factors. Much of the quantitative research literature concerning IDDM and the family has limited value in that it has:

-: attempted to attribute linear causality to variables that operate within a complex circular causal system (Campbell, 1986; Hanson & Henggeler, 1984).

-: failed to operationalise constructs and axioms into independent, specific, and theoretically congruent research terms (Fisher, Terry & Ransom, 1990; Johnson, 1985).

-: generalised with regard to family functioning while relying on a single index, and, claimed to be studying the 'family' from data gleaned from one member.

-: focused on identifying factors pathogenic to the problem at hand, ignoring those salutogenic[2] aspects that may act as buffers or mediators.

-: failed to clarify the mechanisms by which family functioning, metabolic control, and regimen adherence interact (Johnson, 1985).

1.1 AIMS AND OBJECTIVES OF THIS DISSERTATION

> ... there is some evidence that youngsters in poorer health come from less than ideal family circumstances. How certain family characteristics result in good or poor health is often left unspecified. Certain family constellations may result in poor adherence with treatment regimens. In other cases, the stress of the family's maladaptive functioning may result in metabolic derangements in the child with resultant negative effects. ... Specific mechanisms by which two or more variables (e.g., family functioning and child health) are presumed to relate need to be hypothesised and tested (Johnson, 1985; p.249).

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2 *Lavee, McCubbin, & Olson, (1987) define the term "salutogenic paradigm" as investigating what moves people towards health and well-being, as opposed to the "pathogenic paradigm" of investigating the causes of illness.*

A clearer understanding of the relationships between aspects of family functioning, metabolic control and regimen adherence is of major relevance to health care professionals and families who are involved in the care of individuals with IDDM (Campbell, 1986; Johnson, 1980; 1985; Newbrough et al., 1985; Sargent, 1982; Wilkinson, 1987).

This dissertation attempts to add to this understanding by investigating the reciprocal relationships between a limited number of pathogenic and salutogenic family functioning variables hypothesised to be directly and indirectly associated with metabolic control and regimen adherence.

Before hypotheses can be tested and conclusions drawn from the results, however, variables need to be operationalised from the existing constructs, axioms, propositions and theories. Translating family concepts into testable constructs in health research has been impeded by a number of methodological and epistemological problems (Fisher, Terry & Ransom, 1990). While the concepts constituting the multivariate propositions of family systems thinking about the inter-relation of illness and the family may intuitively be observable, Vetere and Gale (1987) note an "almost convenient" loose and interchangeable definition of terms in systems thinking about the family. Kraemer (1981), herself a practising family therapist, provides another perspective in saying that some axioms of family therapy theory have gained prominence with practising clinicians because they are clinically useful, not because they are theoretically coherent or empirically validated.

From a research perspective, Vetere and Gale (1987) find this situation untenable. As far as they are concerned, irrespective of the methodology employed by a researcher, theory "must allow for an unambiguous and replicable definition of terms" (Ibid).

Chapter two is set aside in an attempt to clarify the theoretical basis upon which this research builds.

The literature pertaining more specifically to family function, metabolic control and regimen adherence is reviewed in chapter three. A number of theoretical models and constructs will be presented, after which a model specific to the research questions of this dissertation will be constructed.

Twenty-two white, middle class, intact families each with a child with IDDM were visited at home. The following self-report scales from Olson's (Olson, McCubbin, et al., 1985) "Family Inventories" were utilised; FACES III, Family Strengths and F-COPES.

The FACES III scales were completed by all family members aged twelve years and upwards (86 people in all). Measures of family coping and family strengths were elicited from the mother. Independent estimates of regimen adherence were obtained from the parents and the health care professional responsible for assisting in the care of the child with diabetes. A reliable, long-term indicator of metabolic control, glycosylated haemoglobin (HbA1c), was obtained from the relevant health care professionals, who as part of their routine practice regularly obtain these measures from their patients.

CHAPTER TWO

GENERAL SYSTEMS THEORY AND THE FAMILY: A THEORETICAL PERSPECTIVE

A theoretical perspective is included here to clarify the central constructs and assumptions upon which this dissertation is based. The chapter begins with a brief overview of the origins and organising principles of General Systems Theory (GST). The methodological difficulties in utilising a general systems paradigm in research into the family are then discussed.

The second part of chapter two outlines the salient aspects of the Structural Model of family functioning (Minuchin, 1974; Minuchin, Rosman & Baker, 1978; Minuchin, Rosman, Liebman, Milman & Todd, 1975) as a systemically oriented consensual view of understanding and working with families in which there is a child with diabetes.

Olson's Circumplex Model of family functioning (Olson, McCubbin, et al., 1983), and more specifically the Family Adaptation Cohesion Evaluation Scales (FACES III) that operationalise the model (Olson, McCubbin, Barnes, Larsen, Muxen & Wilson, 1985), are presented as a means of quantifying the major concepts, assumptions and propositions of family functioning within this structural framework.

The validity of the dominant theories of family function, particularly those that subscribe to an homeostatic notion of family regulation and change, are increasingly being questioned (Chubb, 1990; Dell, 1982; Falicov, 1988; Melitto, 1985; Papp, 1987). The idea of homeostatic mechanisms in the family has held sway for more than a quarter of a century and, to a large extent, has shaped the way in which family therapy theory has conceptualised the family, as well as determined the parameters of much research concerning family function and change (Chubb, 1990; Jackson, 1965). Criticisms of, and alternatives to, an homeostatic view are presented. It is concluded that consideration of the concept of family adaptability and cohesion alone, as generally defined, and as operationally defined by Olson, McCubbin, et al., (1985), would be an incomplete

strategy in attempting to account for the varied responses of families to demands for change.

By way of remedy, it is suggested that, in addition to considering the constructs of adaptability and cohesion, account should also be taken of possible complementary family characteristics and behaviours that may be salutogenic, in that they may act as mediators in families' perception of, and response to, stressors.

It is postulated that the presence of certain coping characteristics in a family's "repertoire" will enhance those families' ability to cope with stressors, and thus have a salutogenic effect in lessening the negative effects of stress upon the child's adjustment to the illness[3] process (Antonovsky & Sourani 1988; Fisher & Ransom, 1990; Lavee, McCubbin & Olson, 1987; McCubbin, 1979; Walker, 1985).

The chapter is concluded by exploring possible stress mediating, or salutogenic, factors that could assist a family to cope. Two inventories, F-COPES and Family Strengths are presented as a means of quantitatively operationalising family factors thought to be important as salutogenic resources.

2.1 GENERAL SYSTEMS THEORY

General Systems Theory (GST) is a set of organising principles postulated in the middle of this century by the theoretical biologist Ludwig von Bertalanffy (1975; 1978). Bertalanffy (Ibid), identified major epistemological and methodological problems in the philosophical premises of most disciplines that assumed a positivist basis and yet called themselves scientific.

Central to the positivist method of coming to know the world is the assumption that

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3 *The term "illness" is distinguished here from the term "disease". Disease refers to the malfunctioning of biological processes, while illness:*

> *... includes secondary personal and social responses to a primary malfunctioning (disease) ... Illness involves processes of attention, perception, affective response, cognition, and valuation directed at the disease and its manifestations ... also included in the idea of illness are communication and interpersonal interaction, particularly within the context of the family and the social network (Kleinman, 1980; p. 72).*

phenomena are objectively occurring events that can be impartially quantified, and then analyzed with a view to generating scientific causal laws that hold for all times and all places. However, developments in twentieth-century physics and the philosophy of science have shown this approach to be inadequate. Borrowing the Greek word "paradigma" (a model), Kuhn (1970) articulated a developmental view of science, in that, at any one period science was dominated by a particular paradigm. In Kuhn's view, this paradigm becomes refined by a process of incorporating, adjusting and explaining new information and knowledge gathered. However, if the paradigm is unable to incorporate the new information gathered and explain it within the bounds of its present paradigm, a crisis develops and a revolution occurs during which the paradigm shifts.

Bertalanffy (1975) describes the scientific disciplines subscribing to a positivist tradition as being in a paradoxical situation.

> Allegedly, positivism was a scientific philosophy based on the solid foundations of modern science, especially physics. But its contentions as to what science is or should be hardly corresponded with the actual practice of science. Not only was positivism remote from reality as given in arts, morals, and human experience in general; it was far remote from what may pass as reality in modern science (Bertalanffy, 1975).

What Bertalanffy was saying was, that in the light of the leaps made by physics - particularly Planck's theory of quanta in 1900, and Einstein's special theory of relativity in 1905 - all disciplines that aspired to be scientific were impelled to re-evaluate their way of coming to know the world, in essence, undergo a paradigm shift and reformulate the entire basis of their methodological and theoretical premises. Essentially, it is argued that an 'objective' description of reality is impossible, and that there are multiple realities, each dependent upon the chosen manner of perception.

The implications of this "quantum leap", or paradigm shift, in physics were major. Capra (1984) describes the changes that took place. The Newtonian view;

> ... is a world view which you would call mechanistic because it sees the world as a machine, made of separate objects working together. ... The various objects are made of basic building blocks which themselves are made of a fundamental substance. Now, this view changed dramatically during the first three decades of this century. For the first time physicists studied atoms, the structure of atoms and then the structure of sub-atomic particles. And they found that most of the classical concepts could not be maintained any longer to describe this new atomic and sub-

> atomic reality. Now, the new view that emerged no longer sees the world as a machine consisting of separate objects, but rather as an organic whole or a network, a web of relationships, which include the observer in a very essential way (p.2).

Bertalanffy presented an alternative paradigm that enabled a multidisciplinary methodological realignment congruent with the philosophical implications of the post-Einsteinian developments in physics. Bertalanffy's GST is a means of transposing the organising principles of the new physics into a coherent way of viewing the world available to the human senses.

> General system principles can be applied to a surprisingly wide range of problems: from the network of reactions in a cell to the dynamics of animal populations, to electrical engineering, and to problems in the social sciences (Bertalanffy, 1975; p.43).

This set of ideas, rather than replacing, encompasses and expands upon the classical Newtonian and mechanistic linear causal paradigm (Ibid). However, rather than reducing problems into separate parts, General Systems Theory emphasises an integrated view of phenomena which derive their main properties from the relationships between components, or subsystems.

Every living organism can be conceptualised as a living system, from the single cell, up to a muscle or organ in the human body; the human body, mind and body. In turn families have also been conceptualised by many as living systems, as have communities, nations, and the globe as a whole (Russell, 1983).

2.1.1 Organising Principles of GST

The concept of a system, per se, is not amenable to precise definition. Firstly, it is the attributes of the objects under study, and the relationships of these objects, and their attributes, to each other that constitute a system. Secondly, it is the observer who defines the system level at which observation shall take place. A general definition of a system is then; " ... a set of objects together with the relationships between the objects and their attributes" (Hall & Fagen, 1956; cited in Vetere & Gale, 1987). Put another way, a phenomenon may be defined as a system if it displays a pattern with "sufficient persistence and identity to justify its designation" (Gorell Barnes, 1985).

General Systems Theory seeks to categorise systems according to the way the parts (or subsystems) are organised and interrelated, and to describe typical patterns of behaviour found throughout (Vetere & Gale, 1987). Central to GST is the assumption that, underlying all these different system levels are very similar principles of organisation (Capra, 1983; 1984; 1988).

Also implicit in this postulation is the notion of a hierarchy of levels of organisation, in which a higher level has properties that do not exist at a lower level[4]. Lower levels of organisation are said to have relational properties which have similar process and shape (isomorphy) to hierarchically related and more complex systems (Gottlieb, 1987).

Fishman (1986) defines isomorphism as "the property of structures that helps the clinician see similarities between contexts". A child for example, being a component subsystem of the family system, will have qualities (physical, behavioral and psychological) which may be identified as characteristic of a particular family. This does not mean to say however, that the individual child has all the characteristics from which a systemic conception of the family can be constructed.

In the above example of the family, the aggregate of family members constitutes the family. But, 'the family' as an entity can only be understood when relationships between members, and with the outside world, are also taken into account. Hence the systems maxim; the nature of the whole is more than the sum of its parts.

Introducing relationships into the equation demands consideration of yet another central concept, time and change. Systems are intrinsically dynamic in nature. That is, the relations between parts are not rigidly determined but evolve over time.

Systems which interact with the environment outside of their own boundaries are called open systems. A system's degree of openness, or flexibility, is determined by the

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4 *Rather than implying domination and control, hierarchy should be read to imply a multi-levelled pattern of organisation in which there are sacred rules (from the Greek words, hieros and arkhia) with power flowing in both directions, creating an interdependent whole. For example, in physical science, the molecular level is usually considered upper and the atomic level lower. Some writers prefer to use the term "level structure" so as not to implicate power relationships (Griffith, Griffith, & Slovik, 1989).*

permeability of its boundaries, or in other words, the amount of communication and exchange that occurs across them.

It is this flexibility that enables systems to adapt to the perceived demands of new circumstances. While an open system may appear to be in a steady state, relational processes are ongoing. A steady state[5] is being maintained by an active process of dynamic regulation in which the system constantly responds and adjusts to information from within and without (Bertalanffy, 1981). In family systems thinking for example, the appropriate adjustment of boundaries between individuals in a family as children grow older (a demand for change from within), enables the family to remain in a stable state. Conversely, if a system does not adjust to demands for change it will lose this stable state. This theoretical thread will be further elaborated upon in the section concerning systems thinking about the family.

To summarise, systems may be conceptualised as existing in a hierarchy of increasing complexity, or put in another way, a succession of boxes within boxes (Cromwell & Peterson, 1983). Defining the level of system complexity on which to focus is a function of the researcher's question and the identifiable relational boundaries that naturally occur. That is, a set of relationships becomes defined as a system when the researcher determines them as a distinct entity for investigation. Components of a defined system, for example members of a family, are simultaneously distinct and interdependent and may be investigated as such (Fisher et al., 1990).

Relationships between members, and groupings of members, in the system under scrutiny, change over time and influence and accommodate each other in a circular rather than cause-effect way (Bloch, 1987). These ideas offer a way of conceptualising family systems, their patterns, and changes over time. However, systemically oriented research concerning the family and health is, methodologically speaking, in its infancy.

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5 Bertalanffy (1981), reserves the term "equilibrium" for closed systems in which the initial conditions determine a final state of rest. In open systems a temporary steady (or balanced) state can be achieved as a result of any number of ongoing regulative processes taking place. It follows therefore that this steady state can become disturbed at any time.

2.1.2 General Systems Theory and medicine

Among western health care professionals, the biomedical model[6] is the dominant means of understanding and treating disease (Antonovksy, 1989; Capra, 1983; Engel, 1977; Herman, 1989). In keeping with a classical Newtonian view, its method emphasises the reduction of phenomena into discrete parts, and then explains the whole as the sum of these parts. The systems view is opposite but complementary. Systemic thinking tries to understand the whole in terms of the sum of the parts as well as the interconnections between those parts. For example, consideration is taken of the characteristics of the individual family members as well as the nature of the relationships occurring within and without the family. In this way the whole becomes more than the sum of its parts. Engel (1977) accords the biomedical model the status of dogma rather than science. Engel argues that in science, a model is abandoned when it fails to account for all the data. In this case the biomedical model of disease remains the dominant approach to understanding and treatment, largely neglecting and failing to incorporate those psychosocial relations promoting and threatening health (Herman, 1990). While this mechanistic approach has produced technological excellence, it has retarded the understanding and implementation of an holistic approach to health care (Capra, 1983).

> Medical science today is no longer able to understand or treat many of the current serious diseases of our time, because it sees the human body as something like a machine made of separate parts. There are different specialists dealing with different parts who very often do not take into account how these parts interrelate, how body and mind are inter-dependent and how this whole organism is embedded in a social system and in a natural environment (Capra, 1984; p.6).

However, there has been an increasing tendency over the past quarter-century to incorporate a systems approach into the field of health care, notably an acknowledgement of the role of the family in health and illness (Antonovsky, 1989; Arbogast, Scratton & Krick, 1978; Campbell, 1986, Ransom, 1987; Vetere & Gale, 1987). Flomenhaft (1982)

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6 *Engel (1977) defines the biomedical model as a set of assumptions based upon molecular biology which explain disease as a deviation from the norm of measurable biological variables, excluding any psychological, social or behavioral dimensions of illness.*

argues that the emergence of the discipline of family medicine is;

> ... symptomatic of a complex sense of discomfort within the health profession and the public at large regarding the depersonalization and episodal discontinuity associated with the scientific advances of clinical medicine (p.7).

This conceptual shift has resulted in much closer interdisciplinary collaboration within the health care field.

> Although the role of the family in family medicine is hotly debated, there is the beginning of a collaboration between family medicine and family therapy to develop a holistic and family-based approach to health care.
>
> Both family medicine and family therapy grew and developed primarily as clinical disciplines in response to the fragmentation and subspecialization in biomedicine and the dominance of psychoanalytic theory in psychiatry (Campbell, 1986; pp.135-136).

2.2 SYSTEMS THINKING ABOUT THE FAMILY

From its beginnings in the 1950s the family therapy movement has developed to a stage where it has become fashionable for social scientists to describe family structure and behaviour in systems terms (Dare, 1985; Vetere & Gale, 1987).

Despite its enthusiastic reception, family system thinking presents serious conceptual and methodological problems when it comes to quantification. Relatively speaking, family systems theories are empirically barren and consequently have been called a system of beliefs rather than proven facts (Dare, 1985; Ransom, 1986; Reiger, 1981). Many of the quantitative research studies in the family systems domain have been attacked for being either flawed in design and/or applying a linear-causal reductionist methodology to a field that demands a systemic integrative approach (Ransom, 1986).

In essence, the researcher's problems begin in attempting to translate complex relational concepts into manageable empirical data.

> General System Theory provides a framework for describing complex, time related interactional behaviour for which traditional sociological and psychological theories are not conceptually or methodologically suited. General System Theory focuses our attention on the role of each family member in the genesis and maintenance of behavioral dysfunction within the family and takes account of the nature of the cultural variables impinging on the family (Vetere & Gale, 1987; p.31).

Thus, the researcher who understands phenomena in systems terms, and wishes to

proceed with a limited quantitative investigation into one aspect of a system, is faced with major difficulties in method and methodology[7].

The set of concepts common to the various family systems theories has not been empirically generated, but have been formulated from experience in clinical practice (Kraemer, 1981).

> Perhaps systems therapists have been far more interested in changing the family, rather than what its essence is. Their theories underpin their actions in changing the family, but does not describe its nature nor how it achieved its form (Bentovim, 1979; p.97).

Vetere & Gale (1987) agree with Bentovim and criticise systems therapists in that the predominantly anecdotal mode of describing their work contains "poorly defined jargon" which "often provides a smokescreen for sloppy, ill-disciplined thinking ..." (p.18). A consequence of this, according to Vetere & Gale (Ibid), is that while the variables and concepts constituting the multivariate propositions and axioms of family systems theory may be observable, they are not easily quantified.

A further problem is well described by Fisher et al., (1990):

> ... the family health researcher is caught in the dilemma of trying to specify a testable model of ordered multiple causation (or system interdependency) without being accused of adopting a lineal causal "epistemology" (p.178).

Also, a number of authors have also begun to question the generalisability of theories constructed and validated in clinical practice on populations that do not necessarily represent the norm (Antonovsky & Sourani, 1988; Campbell, 1986; Turk & Kerns, 1985).

Flaws in theory construction aside, psychometrically assessing and diagnosing a family as functional or dysfunctional has an added problem because of the relative lack of appropriate instruments. Some theorists are now even abandoning the notion of function and dysfunction (Chubb, 1990).

Vetere and Gale (1987) call upon family systems theoreticians to make a concerted effort in clarifying their concepts and rigorously defining their terms. Once clarity has

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7 *Bailey (1987) defines method as the techniques or tools used to gather data, and methodology as the philosophy of the research process.*

been achieved, they argue, these concepts and terms can then be translated into operational definitions and specific observations.

A good theory, according to Vetere and Gale (Ibid), should;

> ... be able to help us identify what variables are worth examining and how such variables should be measured and evaluated ... a good theory ... would indicate which aspects of family life are relevant to the particular issues and questions which concern us (p.35).

The Structural Model of Family Functioning, by placing emphasis on dimensions of family organisation and structure, has been found to have both clinical and theoretical utility in identifying which elements of the problem-defined[8] system to focus on (Johnson, 1985; Kog, Verommen & Vandereycken, 1987; Olson, McCubbin et al., 1983).

As far as quantifying data concerning family functioning and behaviour is concerned, Olson's Circumplex Model (Olson, McCubbin, et al., 1983) and "Family Inventories" (Olson, McCubbin, et al., 1985) simplify, but clarify and enable quantitative assessment of a wide variety of family behaviours and characteristics. The FACES III questionnaire appears, according to Campbell (1986), " ... to be the most carefully designed and tested family assessment instrument presently available" (p.147).

2.3 THE STRUCTURAL AND CIRCUMPLEX MODELS OF FAMILY FUNCTIONING

The Structural Model of family functioning (Minuchin, 1974; Minuchin et al., 1975; Minuchin et al., 1978) has been effectively used and elaborated upon by a number of

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8 *Bloch (1987) makes the important observation that in investigating a problem it is the intervener who delineates the temporal and spatial boundaries of the investigation.*

> *The correct boundaries in time/space do not inhere to the events, which after all are chosen (languaged) by the storyteller; rather, we choose what story to tell by our purposes and relation to it. The emergency-room team, the police investigators, and the psychiatrist all elicit different stories about a stab wound. ... they construct different realities. (p.279).*

family therapists and physicians as a framework for understanding, and working with, the interactions of chronic illness and family, particularly IDDM (Rosman, 1988; Sargent, 1982; 1982b; 1982c; 1983b; 1985; Sargent & Baker, 1983; Sargent & Liebman, 1985).

Like all systems theories of family dynamics, structural family theory is not without its problems.

> It is important to remember that these (theories) offer a way of conceptualising families, family pattern and disturbance in family members, rather than describing measurable phenomena (Gorell Barnes, 1985; p.218).

In this light it is important to briefly outline the parameters of, and problems associated with, structuralist thinking about the family.

Structuralism is a mode of analysis originally developed in the field of linguistics in the early 1900s (Mann, 1983). In the 1960s, at the same time Minuchin began formulating his theories, structuralism regained prominence in the social sciences and humanities; for example, anthropology (Levi-Strauss), philosophy (Althusser and Foucault), and psychoanalysis (Lacan) (Ibid).

Central to the structuralist methodology, and Minuchin's theories, is an emphasis on the systemic and relational nature of social phenomena. The objects under study are defined by their relations to, and differences from, other objects in the same system. Change is explained as resulting from a structural transformation, by which one system of relationships is transformed into another (Mann, 1983).

> Structuralism approaches all human phenomena with the intent of identifying the "codes" that regulate the human relationship (Aponte & VanDeusen, 1981; p.311).

It is assumed that the rules that govern the parameters of the diversity of human relationships are strongly influenced by certain innate and genetically pre-determined structuring forces (Aponte & VanDeusen, 1981). Minuchin (1974) describes families as a system of individuals whose relationships and actions are governed by "an invisible set of functional demands" that organise all family behaviour.

The Structural Model is one way of conceptualising these assumed rules that govern family relationships in particular. The family is viewed as the socio-cultural system

which forms the fundamental basis of the individual's socialisation, and, any pathology that a member manifests is understood in the context of the structure and function of the relational patterns manifest in that person's family (Aponte & VanDeusen, 1981).

While theories and approaches do differ within the family therapy field there are, according to Doherty and Baird (1983), several common core axioms in family systems thinking:

> 1. The family is more than a collection of individuals...
> 2. Families have repeating interaction patterns that regulate members' behaviour...
> 3. Individuals' symptoms may have a function within the family...
> 4. The ability to adapt to change is a hallmark of healthy family functioning...
> 5. There are no victims or victimizers in families: Family members share joint responsibility for their problems (pp.30-32).

According to Minuchin (1974), the purpose of the family is the biological and psychosocial protection of its members, as well as the accommodation to a culture and the transmission of that culture. If this purpose is being fulfilled, then the relational patterns of the family are defined as functional (Aponte & VanDeusen, 1981).

Subsystems in the family are hierarchically organised in a way which regulates power structures within and between subsystems (Ibid). These subsystems within the family have psychological, biological and social characteristics, and are hierarchically made up of each individual, as well as groupings of individuals - for example, parental, spousal and sibling. The family differentiates and executes its functions of mutual support, nurturance, regulation, and socialisation of its members within the structure of subsystems (Minuchin, 1974). For example, a function of the parental subsystem is the nurturance and socialisation of its children.

In assessing family functioning it is crucial to incorporate a developmental perspective which describes and explains what aspects change and how these changes come about (Falicov, 1988). The Structural Model emphasises changes in family structure through a dialectical integration of continuity and discontinuity (Melitto, 1985).

According to the Structural Model, relational patterns between family members evolve over time and govern how, when, and to whom to relate within the family context in specific instances (Minuchin, 1974). Repetitive interactions, guided by established

relational patterns, produce a dynamic balance which ensure a sense of continuity in the family (Andolfi, 1986) (See Table 2.1 below). The theory of change within a family context will be discussed later in this chapter.

In spite of an emphasis on context, family dysfunction is often classified by clinicians according to certain identified dimensions of family transactions, namely; boundary clarity, subsystem hierarchy, coalitions and alignments, and adaptability (Aponte & VanDeusen, 1981; Doherty & Baird, 1983; Vetere & Gale, 1987). While family dysfunction may be attributed to the existence of one particular type of relational dimension[9], every transaction contains, and is influenced by, a combination of dimensions (Aponte & VanDeusen, 1981).

Furthermore, the structures of the patterns themselves are not predictive of whether a family is classified as functional or dysfunctional. It is the "choice" and ongoing adaptation of the relational structure, and its resultant appropriateness within a particular context[10], that explains the presence or absence of pathology (Falicov, 1988). In other words, a certain relational pattern may be associated with clinical problems if that pattern is inappropriate to the developmental requirements of a family in that particular stage of its life-cycle, and/or incongruent with the requirements of the broader systemic context outside of the family.

An outstanding and unresolved problem has been the inability of theorists, researchers, and practitioners to present a unitary and coherent conceptual framework which adequately describes family relational patterns, and explains how they evolve (Andolfi, 1986; Vetere & Gale, 1987). Ransom (1986) outlines the problem in the following way;

The difficulty, in part, is in the difference between clinical knowing and

---

9 *For example, families are often referred to as enmeshed or disengaged. When speaking of a family in this way it is meant to describe the dominant relational structure, associated with the symptom under consideration, as being characterised by enmeshment or disengagement.*

10 *The term "context" may be defined as; Stated or unstated set of rules within which an event or relationship takes place (Berman, 1984).*

knowing for purposes of trustworthy research, ... The sensitivity of the clinician's eyes and ears and the freedom of an integrating human mind give way to (usually only one) fixed and impoverished research "instrument" (p.331).

"To facilitate bridging the gaps that often exist among theorists, researchers, and practitioners", Olson, McCubbin, et al., (1983), have constructed the Circumplex Model of Family Functioning which allows an operationalisation of structurally oriented thinking about the family, particulary with regard to the concepts of adaptability and cohesion.

				Theory of change	
Family therapy approach	Dimensions (What changes?)	Processes (How does it change?)	Dysfunction	Continuous or discontinuous	Directionality
Structural (Minuchin, Montalvo, Rosman, Fishman)	Family organization Boundaries: proximity and hierarchies Age-appropriate attributes	Accommodation Boundary making	Transitional stress—symptom Lack of "fit" between structure and developmental requirement Pace of reorganization too slow or too fast Developmental lag	Families constantly changing while maintaining continuity Fluctuation from usual pattern → amplification → crisis → new level of coping	Normative blueprint Therapeutic crisis parallels developmental crisis and adaptation

TABLE 2.1: Developmental concepts in structural family therapy theory. Adapted from Falicov (1988; p.32).

2.3.1 The Circumplex Model of Family Functioning

A central requirement of the quantitative aspect of this research is to assess family functioning. The Circumplex Model of Olson et al., (1979, 1980, 1982, 1983, 1985, 1986, 1988, 1989) and the FACES-III questionnaire operationalising aspects of it, enable an assessment of family functioning.

Using the concepts of adaptability and cohesion as its basis, the Circumplex Model identifies sixteen types of marital and family systems. (See figure 2.1). These sixteen family types are categorised into three basic groups; four balanced types with scores on both dimensions in the central levels, eight mid-range types with one dimension balanced and the other extreme, and four extreme types with extremes on both dimensions (See Figure 2.1 below).

While partially based on the pioneering work of Minuchin (1974), the Circumplex Model makes it possible to quantitatively determine the family types described. This is both its strength and weakness. In providing researchers with a concrete tool, the model

has had to dispense with much complexity and hence lose some of the important and more subtle distinctions made in the theorising about family functioning.

The two core constructs of adaptability and cohesion are viewed as common to the multitude of possible interconnected relational patterns and are shaped by each family's own idiosyncrasies and functional needs, its culture, traditions and socio-economic situation (Olson, McCubbin, et al., 1983).

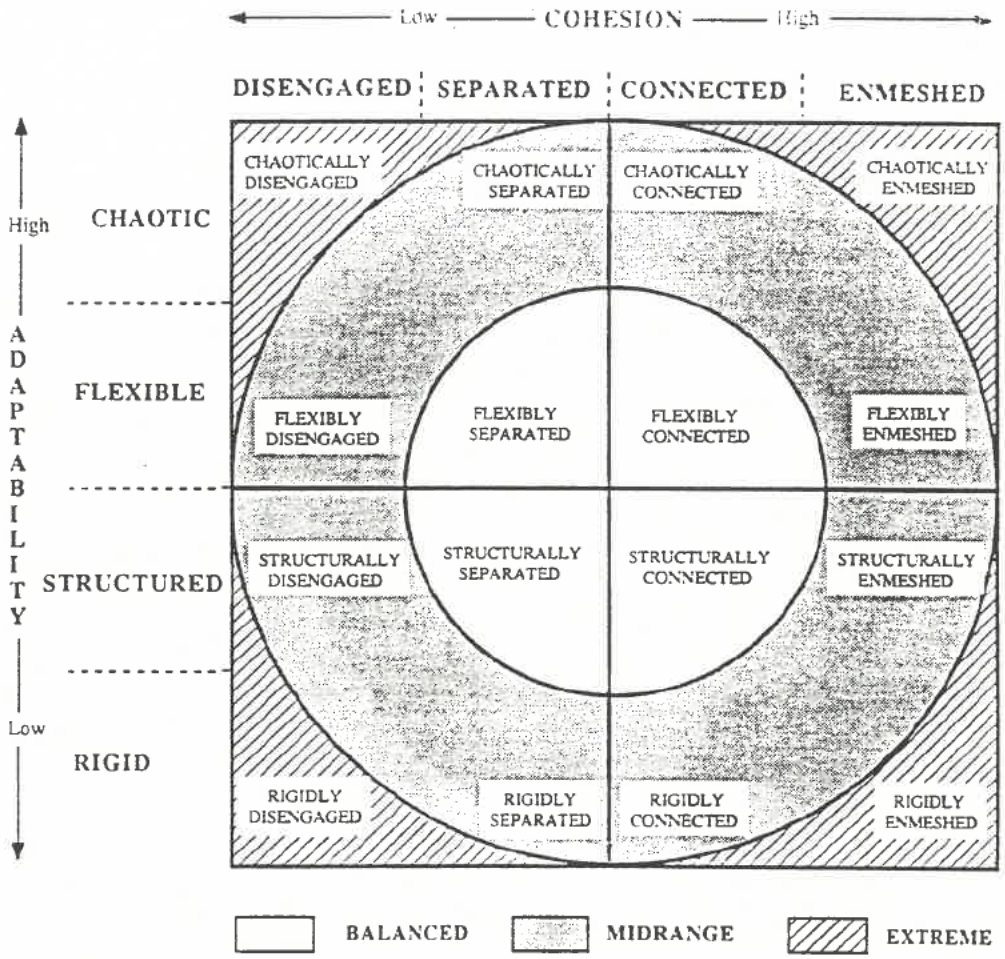

FIGURE 2.1: Graphic Representation of the Circumplex Model
(Olson, 1988) Reproduced with permission of the author.

Three hypotheses have been developed from the model:

Hypothesis 1. Couples/families with balanced (two central levels) cohesion and adaptability will generally function more adequately across the family life cycle than will those at the extremes of these dimensions.

> Hypothesis 2. If the normative expectations of a couple or family support behaviours on one of either the extremes of the circumplex dimensions, the couple or family will function well as long as all family members are satisfied with these expectations.
>
> Hypothesis 3. To deal with situational stress and developmental change across the life cycle, balanced families will change their cohesion and adaptability, whereas extreme families will resist change over time.
>
> (Olson, 1988; pp.62-63).

While the Circumplex Model pays lip service to the concept of communication as a facilitating dimension of family behaviour, this author agrees with Doherty and Baird (1983):

> Despite the importance of communication in families, however, we do not list it as a separate assessment category, because we believe that much "poor communication" stems from larger structural and interactional issues (such as ongoing coalitions) that make effective communication nearly impossible" (p.56).

2.3.1.1 Cohesion

The concept of cohesion pertains to the structure of the system and describes how these structures are related to family function or dysfunction. In this model, cohesion refers to the "emotional bonding that members have toward one another" (Olson, McCubbin, et al., 1983; p.48), and ranges through four levels, from disengaged (very low) through to enmeshed (very high). The dimensions of boundary, subsystem hierarchy, alignment and coalitions have been conceptually subsumed into the category of cohesion (Olson, McCubbin, et al., 1983).

In families characterised as enmeshed, "there is overidentification, so that loyalty and consensus within the family prevent individuation of family members" (Olson, 1988; p.60). At the disengaged extreme there is limited attachment or commitment to the family.

However, family structure in itself is not predictive of family function or dysfunction. With the passing of time, a previously functional structure may come to lead to dysfunction if it becomes inappropriate in a newly evolved developmental, social or cultural context. In other words, if there has been a failure in adaptation, in the general meaning of the word, to changing context. The family's structure must be conceived of

as dynamic in nature, and, in this sense, dysfunction could ultimately be viewed as the result of inappropriate structural changes made during the process of adapting (Falicov, 1988).

2.3.1.2 Adaptability

Olson, McCubbin, et al., (1983) define family adaptability as;

> ... the ability of a marital or family system to change its power structure, role relationships, and relationship rules in response to situational and developmental stress (p.48).
>
> This is a measure of the ability of a family to change when it is appropriate or necessary (Olson, 1988; p.66).

Concepts subsumed into the notion of adaptability include those of family power (assertiveness, control, discipline), negotiation styles, role relationships, and relationship rules (Olson, 1988).

Balanced family systems are those situated in the two central levels of the adaptability dimension - flexible or structured (See figure 2.1). Those families that can appropriately maintain a balance between morphostasis[11] and morphogenesis will adjust best to stressor events (Ibid). Conversely, dysfunctional families are those that are too morphostatic (rigid), or too morphogenetic (chaotic) (Ibid).

Besides loosely defining the need for a balance between morphostasis and morphogenesis, the Circumplex Model does not describe the process of adaptation or clarify why change may occur in some circumstances and not in others.

Referring back to hypothesis three on page twenty-two: balanced families changing cohesion and adaptability in response to stress and developmental change - the complexities of the notion of change are not accounted for. The way in which family change and development is conceptualised has major implications for research and intervention.

There is lively debate within the family systems field over the merits and demerits of various models and assessment strategies. It is however beyond the scope of this

---

11 *The terms morphostasis and morphogenesis have been utilised to represent the two poles around which much of the argument over family adaptability is centered - maintaining stability and promoting change.*

dissertation to make comparisons of the Circumplex Model with other models, for example, the Beavers model (Beavers & Voeller, 1983; Beavers, Hampson & Hulgus, 1985).

2.3.2 Homeostasis, Chaos, Continuity and Change

The systemic notion of family adaptability[12] is an attempt to address the issue of family process, or, how a family comes to change its relational characteristics over time (Melitto, 1985). Two central, and problematic, theoretical issues in the notion of family adaptability are:

> a) accounting for those factors which, during a state of transition, contribute towards, and prevent, the development of a disorganising state of crisis that may be accompanied by symptoms of pathology in family members.
> b) how a system can change while at the same time preserve its integrity and organisational coherence.

Minuchin (1974), described the problem in this way:

> A family must be able to transform itself in ways that meet new circumstances without losing the continuity that provides a frame of reference for its members (Ibid; p.52).

The theorising around these important issues is in itself in flux, and discussion is necessary if the construct "adaptability" is to be used at all. In order to maintain some sense of continuity, and to provide a theoretical frame of reference, the following structure will be used to present the salient points.

2.3.2.1 Change, Stress, and Family Functioning
2.3.2.2 Homeostasis as a metaphor for 'Being and Becoming' in family systems thinking.
2.3.2.3 Criticisms of, and alternatives to, the homeostatic model.

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12 *Olson et al's., (1983) definition of adaptability must be distinguished from the more general use of the word in the discussions that follow. The general use of the term refers to the "goodness of fit" (maladaptive or adaptive) between changes made by a family and the demands of their internal and external context. The Circumplex Model's definition originally omitted any reference to apropropriateness and defined adaptability as the ability of a family to change in response to a stressor, with too little or too much change conceptualised as dysfunctional (Olson et al., 1983). This definition has subsequently been changed to include "the ability of a family to change when appropriate or necessary" (Olson, 1988; p.66).*

Chapter three, in reviewing how family function and organisation and the illness co-evolve, will locate theory of family change in the context of IDDM.

2.3.2.1 Change, Stress, and Family Functioning

> To focus on the family as a social system in transformation, ... highlights the transitional nature of certain family processes. It demands an exploration of the changing situation of the family and its members and their stresses of accommodation (Minuchin, 1974; p.61).

The "stresses of accommodation" experienced by a family may be broadly defined as being of two types. The first, referred to as developmental or normative, occurs as the result of universally predictable periods of developmental transition in the family life cycle[13]. The second, referred to as situational or non-normative, is an unpredictable family crisis which demands adjustment (for example, diagnosis of IDDM).

This process of adaptation (period of transition in which family relationships are restructured) is characterised by a period of instability (contextually-defined imbalance) in which new patterns of behaviour are experimented with (Falicov, 1988). The family has to respond to and cope with a number of stressors:

a) the initial stressor and associated hardships.
b) any other normative or non-normative transitions which are taking place simultaneously.
c) prior strains.
d) the consequences of family efforts at coping.
e) the ambiguity associated with instability (Joselevich, 1988).

Some families cope adequately in the face of these stressors, while others break apart or develop a dysfunctional stability (See figure 2.2 below).

A number of pathways are possible:

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13 *The distinction that Falicov (1988) makes between the concepts "family life cycle" and "family development" is used here. "Family life cycle" refers to those normative or developmental events that take place in all families. "Family development" is:*

> *an overarching concept, referring to all transactional coevolutionary processes connected with the growth of a family. These include processes of continuity and change connected with work or occupational development, ... acute or chronic illness, or any set of events that significantly alters the texture of family life (p.13).*

a) family restabilises around a different set of relational patterns.
b) family accommodates the stressor and stabilises in a manner similar to its original state.
c) family consolidates into an unstable state.

Symptoms arising from maladaptation may develop in a number of ways. Underlying structural problems already present in the family organisation, but not previously manifest, may become intensified, and result in the appearance of symptoms. If the transition to a new stage occurs too quickly or slowly, problems are also likely to occur (Falicov, 1988).

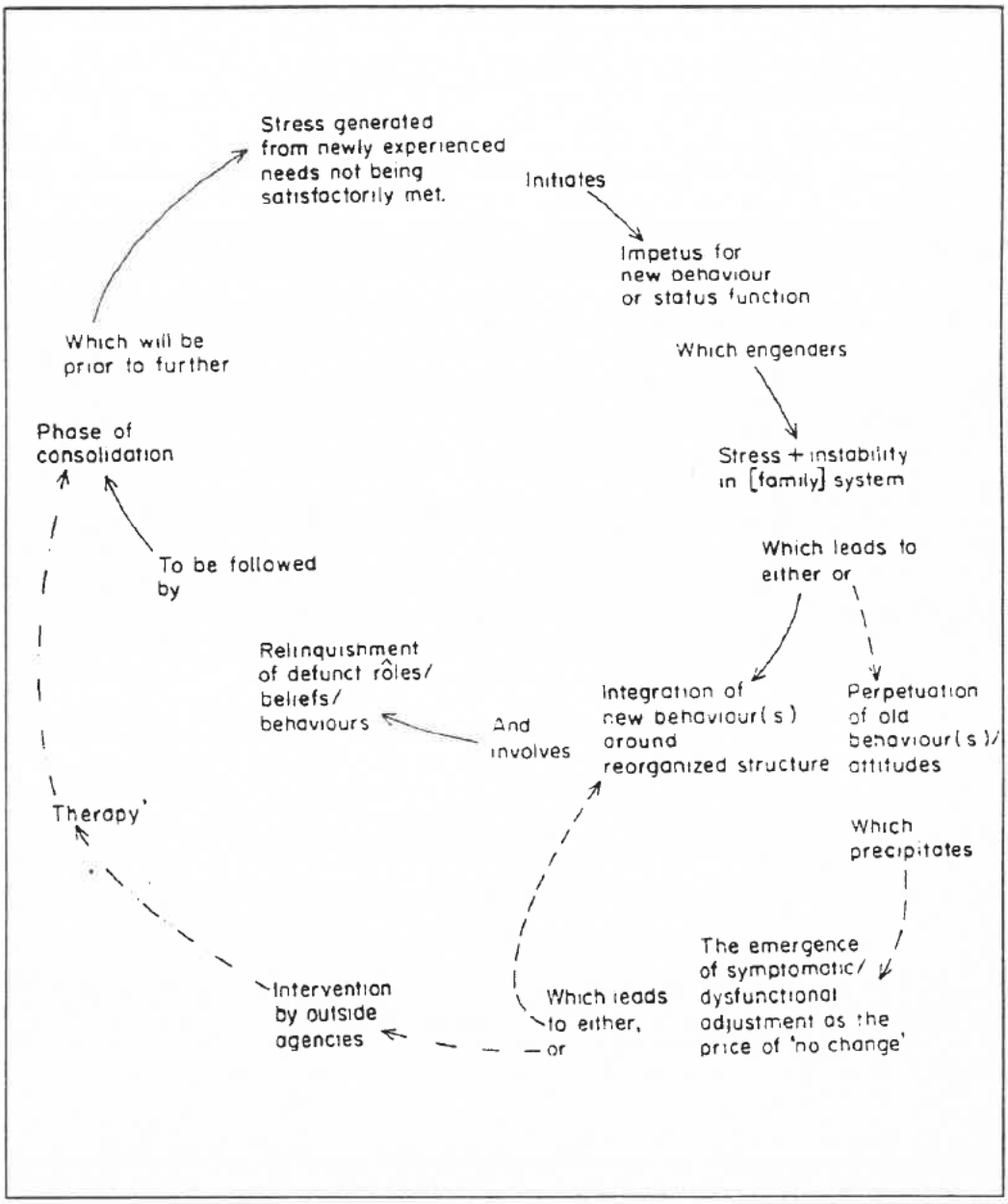

FIGURE 2.2: The circular process of adaptation. From Jenkins (1989; p.101).

Other families may cling to old patterns in the face of stress.

> The label of pathology would be reserved for families who in the face of stress increase the rigidity of their transactional patterns and boundaries, and avoid or resist any exploration of alternatives (Minuchin, 1974; p.60).

Accepting the great variability across families in response to similar sorts of stress, and that there is no stress-free baseline state from which families operate, it has been posited that, it is the ability of families to resolve stressors, their coping abilities, rather than the number and types of stressors, that determines outcome (Antonovsky & Sourani, 1988) (See figure 2.3 below).

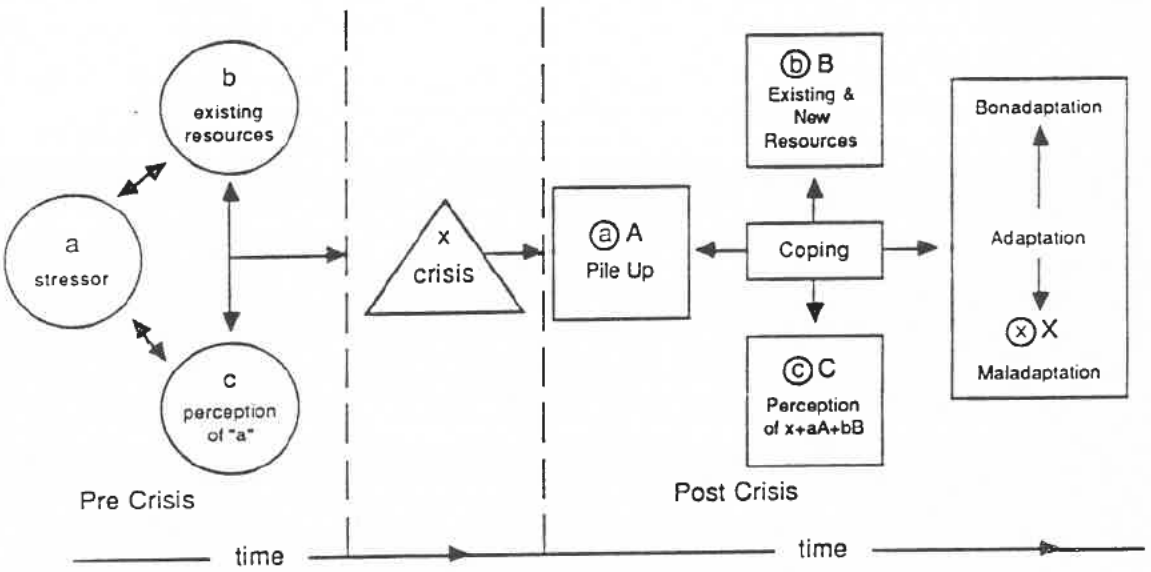

FIGURE 2.3: The Double ABCX Model of Family Adaptation
From Gaudet and Powers (1989; p.93).

Taking the pathways described in figure 2.2 and the mechanisms illustrated in figure 2.3 into account, any pathology, or maladaptation, must be understood in terms of the relationship patterns in which it is embedded, the available coping resources, as well as the way in which those patterns may either generate or reinforce symptoms. Family coping behaviour will be discussed further in section 2.4.1.

Structurally oriented family therapists, like Gottlieb (1987), assume that impaired relationship systems play a part in developing an inadequate solution for a stressful

family development. The longer a family has lived with an inadequate solution, the more rigid it is apt to be when faced with the task of changing its interaction patterns (Bloch, 1987; Doherty & Baird, 1983; Dym, 1987).

In trying to understand family dysfunction, a clinician or researcher must also be cognisant of a broader ecological perspective in that the maladaptive situation may be being maintained or promoted by factors outside of the family system. For example, Aponte & VanDeusen (1981) point out that low income families living in chronically unsupportive and disruptive social conditions are understandably inclined to be rigid in their exploration of alternative family structures in response to any new stressors facing them.

Having described the process whereby families may generate dysfunctional structures in response to stressors, it is necessary to describe a functional response to demands for change. According to Gottlieb, (1987), a functional family would be one in which hierarchies are clear, boundaries are maintained with reasonable permeability between subsystems, and members show affective and cognitive supports for independence and interdependence of function. Where structures become inappropriate during the course of development, a functional family has the capacity to generate new and appropriate ones (Aponte & VanDeusen, 1981). This definition of a functional family is congruent with that of the Circumplex Model:

> Even though a balanced family system is placed at the two central levels of the model, it should not be assumed that these families always operate in a moderate manner. Being balanced means a family system can experience the extremes on the dimensions when appropriate, but they do not typically function at these extremes for long periods of time. ... Conversely, extreme family types tend to function only at the extremes and members are not expected or are able to change their behaviours (Olson, McCubbin, et al., 1983; p.59).

However, problems arise in explaining how a family maintains this balance between permanence and change. Current family theory does not account for the ability of families to change while at the same time maintaining continuity (Melitto, 1985). The metaphor of homeostasis was posited as a means of resolving this theoretical paradox, and has become central to systems thinking about the family:

> It is significant in the development of family theory that it was the observation of homeostatic mechanisms in families of psychiatric patients that lead to the hypothesis of the family as a homeostatic and, eventually, specifically as a rule-governed system (Jackson,1965; p.13).

2.3.2.2 Homeostasis

> People who are interested in systems need to account for stability in the systems they observe. The notion of homeostasis is useful as a description of mechanisms in true organisms. It has come under criticism however, as something that can be applied, without specifying any mechanism, to social systems (Chubb, 1990; p.171).

The original use of the term homeostasis was meant to describe the postulated morphostatic nature of family systems. This notion was challenged as being too limited in that it implied the "counteracting of a deviation from some norm" (negative feedback), and a return to a previous state of relational patterning (Melitto, 1985). The notion of positive feedback was then introduced to accommodate and explain the process of family adaptation whereby family structure does not return to a previous state, but is altered as a consequence of demands for change (Ibid). As can be deduced from the quote below, the term homeostasis has come to imply a constant state of functioning which a family returns to after adapting to a stressor. This may be "a constant state of disequilibrium" (Cooklin, 1987), or a state of balance.

> Homeostasis is the state to which a system tends to return after any disturbance. ... The "steady state" or "homeostasis" of systems theory allows for an image of elements in constant dynamic interaction, through intricate mechanisms that both keep them within an acceptable set of limits and allows a measure of independent variability that, fed back into the system, allow growth and adaptation to occur at an appropriate pace (Gorell Barnes, 1985; p.219).

The Circumplex Model of Olson et al., (1985) subscribes to this self regulatory notion in which positive feedback loops create the potential for change (morphogenesis), while negative feedback loops serve to maintain the status quo (morphostasis).

However, referring back to figure 2.2, it is seen that stress and instability lead to an either/or situation, a bifurcation point in Prigogine and Stengers' (1984) terms. In this scheme of things when a family operates in a morphogenetic manner, the tendency to

preserve continuity and integrity is threatened. When operating in a morphostatic manner, the tendency towards change is inoperative. A system can be sequentially either rigid or labile, but not both at the same time.

> ... in such an analysis there is no provision for the tendencies to change and to preserve to occur simultaneously, which is what would be required for a family to be both flexible and stable (Melitto, 1985; p.92).

While the operationalisation of the Circumplex Model will be used to empirically assess families' levels of functioning in this research, the theoretical basis for the construct of adaptability, informed by the notion of homeostatic mechanisms, is being increasingly challenged as an incomplete means of describing change in family systems (Capra, 1988; Chubb, 1990; Dell, 1982; Falicov, 1988; Melitto, 1985; Papp, 1987; Prigogine & Stengers, 1984).

2.3.2.3 Homeostasis: Criticisms and Alternatives

Dell (1982) claims that the idea of homeostasis or self-regulation is epistemologically flawed in that it does not account for the complexity and diversity of responses that different families with similar relational patterns can make to the same stressor situation. In this sense, the concept of homeostasis is better equipped for conceptualising periods of stability in families rather than change (Chubb, 1990). The organismically-based homeostatic model reinforces a pathogenic notion of family function, prompting searches for those factors that create instability (Falicov, 1988).

> In organisms, any given structure is clearly "in" or "out". The mitochondria of a particular cell are always part of a particular cell. But even a 6-year-old participates in different non-coupled systems, for example the school car-pool and cousins who live in another state. ... People who see social systems as organisms, especially those who see them as homeostatic, also have the problem of accounting for change (Chubb, 1990; pp.170-172).

As far as Chaos Theory is concerned (Chubb, 1990; Prigogine & Stengers, 1984), complex systems maintain their stability because of the multiple fluctuations occurring in response to demands for change. A co-evolution between system and context is continually occurring and its form and nature is "impossible to predict with precision" (Chubb, 1990), in that:

> ... *the same* nonlinearities may produce an order out of the chaos of elementary processes and still, under different circumstances, be responsible for the destruction of this same order, eventually producing a new coherence beyond another bifurcation (Prigogine & Stengers, 1984; p.206).

In this scheme of things a small fluctuation, depending upon context, could have little effect on the stability of the system, or it could, through amplification, result in major change to the overall structure of that system. What needs to be understood is the processes that operate in and influence the transformation of the overall system, rather than the fluctuation that might have started it:

> ... the match is responsible for the forest fire, but reference to the match does not suffice to understand the fire. Moreover, the fact that fluctuation evades control does not mean that we cannot locate the reasons for the instability its amplification causes (Prigogine & Stengers, 1984; p.207).

In other words, while the match started the fire, the presence of lots of drought-parched trees on a windy day were some of the reasons for the fire's amplification "causing" instability. Had that match been lit in a thunderstorm three days later, the raindrop that put it out could be seen as analogous to a mediating factor that absorbs the change into the broader fabric of the system without resulting in instability.

Quite clearly, the organismic homeostatic conception of the family is unable to accommodate or account for the complexities as described by Chaos Theory and that a new way of thinking about change and the family is needed.

Writing from a family development perspective, Falicov (1988) notes a "significant movement" in family therapy and family sociology away "from a focus on homeostatic processes towards an emphasis on change-promoting and evolutionary processes (p.41)."

Accompanying this "significant movement" Falicov (Ibid) notes a number of shifts in approach to understanding the family.

:- **Emphasis on tasks of change, rather than characteristics of stages between transitions:** identify tasks of change and associated pathogenic and salutogenic variables.

> The implication of a focus on stages is that they are long, enduring and structurally stable, whereas transitions are short and fleeting periods of structural instability (Falicov, 1988; pp.37-38).

:- **Delineate what changes, and how it changes:** identify, agree upon and account for changes in family over the life cycle.

:- **Clarify relation between symptom and family change:** Implications for intervention differ depending upon how the symptom under consideration is viewed in relation to the family.

> One way to think about this connection is to view the symptom as a manifestation of the stress that the family is experiencing around the transition events. Another way is to observe that the family is rigidly organized and cannot change its organization to fit the new developmental requirements. A third possibility is that a symptom has a meaning or a function or acts as a "solution" that serves to maintain stability in the face of impending change (Falicov, 1988; p.40).

:- **Complementarity in describing change:** Acceptance of contextually determined fluxing relationship between previously polarized relationships, account for both rather than either/or.

:- **From a deficit to a resource orientation:** a shift away from deficit-oriented concepts towards identifying resources and variety of possible changes.

:- **From universal generalisation to contextual relativity:** increasing sensitivity to cultural and gender-specific diversity instead of normative prototype of American white Protestant nuclear family. "... should *not* assume similar directions and end points among families faced with similar life cycle transitions" (Falicov, 1988; p.43).

2.4 IMPLICATIONS FOR RESEARCH

While the criticisms of "sloppy, ill-disciplined thinking" made by Vetere and Gale (1987) at family theorists may have some validity, the increased rigour resulting from the confluence of family sociology, family development, and family systems thinking does not appear to ease the task of the researcher. Theoretically, there appears to be a shift in emphasis to describing the "between"; the pattern, the process, or in quantum terms, the wave nature as opposed to the particle nature.

In the past, much research has been firmly based in a pathogenic approach which assumed that stressors eventuate in physical and/or emotional pathology and has focused on identifying ways in which families have become dysfunctional, or how family "deficits" have developed (Antonovsky & Sourani, 1988).

The question now arises, what are the implications of this theoretical shift? It has been suggested that research should focus on those factors that act as buffers, or mediators, in determining the extent and nature of change, and ultimately a family's

adaptability (Papp, 1987; Walker, 1985). This approach is being implemented by family sociologists in seeking salutogenic characteristics of healthy populations as opposed to the pathogenic characteristics of clinical populations (Antonovsky, 1989; Antonovsky & Sourani, 1988; Walker, 1985). Antonovsky and Sourani (Ibid) posit that these attenuating factors might also have a direct and positive effect on not getting sick and thus form part of what determines a family's adaptability.

> The salutogenic paradigm does not assume that stress in itself is destructive. Rather, it assumes that the normal state of the human organism is one of entropy, disorder, and disruption of homeostasis. The great mystery to be studied is that of health, given the state of entropy. When applied to family phenomena, the salutogenic approach challenges one to study family well-being following the pile-up of demands and disruption, whether they are non-normative and excessive or are the result of normal change and growth (Lavee et al., 1987; p.860).

Instead of focusing on a single event that supposedly initiates the process of stress and attempting to predict its effects, Fisher and Ransom (1990) agree with Walker (1985), in suggesting it better to concentrate on how family structure and function supports or aggravates the processes involved in responding to multiple and ongoing stressors.

> Emphasis on life events ... has led researchers to overlook everyday stress-related behaviour and to expect uniform responses to given occurrences. ... it is likely that the resources and coping repertoires of individuals, families, and communities will predict more about family process than will information on the contours of a particular event. Thus, although there may be some value in articulating event properties, resources are more critical factors ... and emphasis should be placed on them (Walker, 1985; p.829).

2.4.1 Salutogenic Factors: Illness and the Family.

> One cannot examine the effects of any psychosocial factor on health without considering the concept of stress. Even when stress itself is not being measured, it is often considered the intervening variable between psychosocial processes and illness (Campbell, 1986; p.143).

It is widely accepted that stressors emanating from within and without the family can have a deleterious effect on the metabolic control and regimen adherence of persons with IDDM (Baranowski & Nader, 1985; Hanson et al, 1987, Mengel et al, 1988; Minuchin, 1974; Turk & Kerns, 1985). However, more often than not, the terms 'stress' and 'stressor' have been used in a loose and tautological manner. A stressor is defined as any

life event that requires change in an individual's ongoing life pattern (Holmes and Rahe; cited in Olson, McCubbin, et al., 1983). Stress is defined as the individual's response to stressors, where there is a perceived imbalance between environmental demands and the individual's capacity to meet these demands (Ibid). Stress research has pursued a number of separate and narrow empirical perspectives (Fisher & Ransom, 1990), precisely because of the conceptual difficulties which defy attempts at specificity (Campbell, 1986). Stress has been variously conceptualised as a response (dependent variable), a stimulus (independent variable) and as an interaction (intervening variable).

Research emphasis on the concept of stress, per se, is being slowly abandoned in favour of more specific, definable and measurable concepts, specifically related to resources in dealing with stress (Lavee, McCubbin & Olson, 1987).

A number of authors have sought to develop a dynamic and contextual framework with which to integrate the divergent traditional empirical approaches to stress and the stress process (Antonovsky, 1987; Antonovsky & Sourani, 1988; Fisher & Ransom, 1990; Lavee, McCubbin & Olson, 1987; Walker, 1985).

Falicov (1988) notes that Olson's Circumplex Model has some of the elements of models that are needed to address "the evolutionary aspects of systems and that focus on the dimensions and process of change". The construct of cohesion accommodates the dialectic of proximity, (dependence and autonomy), while adaptability addresses the dialectic of change.

> By adding the study of clusters of stressors and strains and the family's coping resources and satisfaction in the various life-cycle stages, Olson captures all of the basic elements of a state-of-the-art sociological model of family development (Falicov, 1988; p.10).

Olson's (Olson, McCubbin, et al., 1983; 1985) "Family Inventories" consists of a battery of nine self-report questionnaires which were administered to over 1000 "normal, intact" families across the family life cycle, focusing "on the strengths and attributes that help families deal more effectively with stress ..." (Olson, 1988; p.56). The methods of assessment used in this study by Olson and his associates embraced concepts from family stress theory (family resources), family development theory (family life cycle), and family systems theory (family types). (See figure 2.4 below).

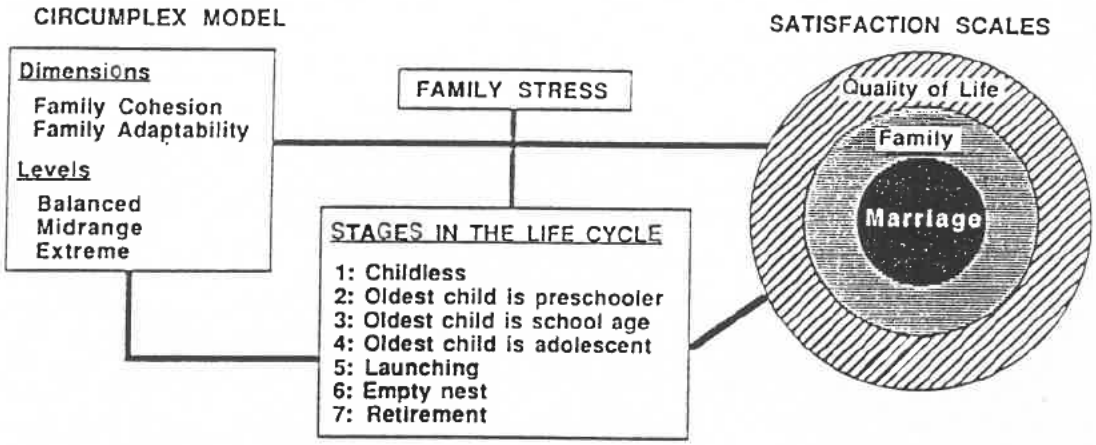

FIGURE 2.4: Conceptual overview of Circumplex Model, Family Stress and family satisfaction (Olson, 1988; p.58).

Olson (1988) writes that the Family Inventories research study was purposely focused on those "enduring" or "coping" families in order to "understand how and why these families appear relatively successful in their adjustments to demands, ..." (p.71). Families identified by the Circumplex Model as "functioning better" were found to have higher levels of family strengths, family coping, and family satisfaction (Olson, McCubbin, et al., 1983). Certain "critical resources", identified by the Family Strengths questionnaire and F-COPES questionnaire, were able to discriminate between high-stress and low-stress families (Ibid). Likewise, a positive relationship was found between family satisfaction and family types (cohesion and adaptability), family strengths (pride and accord), and family coping (social support, reframing, spiritual support, seeking help) (Olson, McCubbin, et al., 1983; p.186).

2.4.1.1 Family Satisfaction

Olson et al., (1985) could find no literature empirically or theoretically investigating the construct of family satisfaction. Family Satisfaction, as an intervening variable, is considered important by Olson and colleagues in that it accommodates a notion of cultural relativity when considering the hypothesis that balanced families function more adequately than extreme families (Olson et al., 1985).

> If the normative expectations of a couple or family support behaviours on one or both extremes . . . (of adaptability and cohesion) . . . they will function well as long as all family members accept these expectations (Ibid; p.47).

According to Olson et al., (1985), the family's levels of adaptability and cohesion are less important than how they feel about these levels. Thus, besides determining a family's levels of adaptability and cohesion, an assessment needs to be made of a family's satisfaction with their perceived functioning on these dimensions.

2.4.1.2 Family Coping

Family coping behaviour involves the management of various dimensions of family life simultaneously (McCubbin et al., 1983; in Olson et al., 1985), and may be defined as the aggregate of skills and abilities of individual family members which make up the potential repertoire of strategies utilised to deal with stressful situations (Olson, McCubbin, et al., 1983). Referring back to figure 2.3 on page 26 (the Double ABCX Model of Family Adaptation) F-COPES was "designed to integrate family resources and the meaning perception factors identified in family stress theory" (Olson, McCubbin et al., 1985; p.121).

Adequate coping behaviours, or resources, would change the stressful circumstances, reduce family tension, and maintain family unity and balance (Ibid). In this sense, coping is a "complex process of acquiring, building, exchanging, and using resources to resist and adjust to the impact of demands" (Olson, McCubbin et al., 1983; p.136).

The authors suggest four basic hypotheses. Coping behaviours can potentially:

1. Decrease the family's vulnerability to stress,
2. Strengthen or maintain those family resources that serve to protect the family from the full impact of problems,
3. Reduce or eliminate the impact of stressor events and their specific hardships,
4. Involve the process of actively influencing the environment by doing something to change the social circumstances to make it easier for the family to adjust to the difficult situation (Ibid).

Two dimensions of family coping are identified, internal and external, each with a number of sub-scales, or strategies (See Table 2.2 below).

STRATEGY	DESCRIPTION
Internal	**The ways in which individual members deal with difficulties by using resources residing within their own family.**
Reframing	The family's ability to redefine stressful experiences in a way that makes them more acceptable and manageable. Reframing assesses how families view change, with respect to their confidence in being able to handle problems.
Passive Appraisal	To balance the more active behaviours included in other factors, this scale focuses more on the less responsive approaches a family might employ when faced with stress. By adopting a more passive approach, responsibility and self-initiative are minimised for dealing with difficulties.
External	**The behaviour individual members employ to acquire resources outside their family.**
Acquiring Social Support	The family's ability to engage actively in utilising resources from relatives, friends, neighbours, and extended family.
Seeking Spiritual Support	The family's ability to acquire spiritual support.
Mobilising family to Acquire and accept help	The family's ability to seek out community resources and accept help from others.

TABLE 2.2: Description of Family Coping Strategies (F-COPES), from Olson, McCubbin et al., (1983; p.142).

2.4.1.3 Family Strengths

Family strengths and family coping together have been typically referred to by family sociologists as family resources. Burr (1973; cited in Olson et al., 1985) defined family resources as the "variation in the family's ability to prevent a stressor event of change in a family social system from creating some crisis in the system". Olson and his colleagues distilled seven constructs from the literature concerning family strengths:

family pride, family support, cohesion, adaptability, communication, religious orientation, and social support (Olson, McCubbin et al., 1983). The questionnaire operationalising the concept of family strengths excluded those concepts already included in the FACES questionnaire, adaptability and cohesion, and was finally reduced to two conceptual dimensions, pride and accord. The construct of pride is intended to identify pride, loyalty, trust and respect attributes, while "accord" is intended to tap a family's sense of mastery or competency (Ibid). The salient research findings were as follows:

> Couples and families possessing these strengths (pride and accord) seemed to function more adequately across the life cycle. They also tended to be more satisfied with their marriages and family lives. These strengths seem to operate as major buffers or resistors to stressful live events. ... high levels of marital and family strengths might serve a significant preventive function for families (Olson, McCubbin, et al., 1983; p.238).

2.5 SUMMARY

This chapter has presented an overview of the central theoretical constructs and assumptions to be used in this dissertation when referring to the family, its structure, function, development, and the manner in which change takes place. Systems thinking about the family has, to a large extent, been developed by practising family clinicians, and as a consequence, been underscored by a pathogenic, deficit approach. Research attempting to use the family systems framework has been frustrated by the difficulties inherent in operationalising its theoretical concepts. The validity of the dominant organismically-based concept of homeostasis in relation to families and family change is being increasingly questioned, and replaced by an emphasis on evolutionary change-promoting factors. Also, along with the growing congruence between family development theory, family stress theory and family systems theory, there is a growing call for a process conception of families in which salutogenic and pathogenic factors are given equal consideration.

This research intends to investigate the relationships that exist between a number of salutogenic and pathogenic aspects of family functioning and two important outcome variables in the illness experience of insulin-dependent diabetes mellitus, metabolic control and regimen adherence. The clarification of a theoretical approach to

understanding the family has not only helped in indicating "what aspects of family life are relevant to the particular issues and questions which concern us", but also in identifying "what variables are worth examining" ... and how "such variables should be measured and evaluated", meeting Vetere and Gale's (1987) requirements for what constitutes good theory.

Chapter three reviews both theory and empirical work concerning the manner in which psychosocial factors in general, and family factors in particular, are related to metabolic control and regimen adherence in children with IDDM.

CHAPTER THREE

REVIEW OF LITERATURE

INSULIN-DEPENDENT DIABETES MELLITUS: METABOLIC CONTROL AND THE FAMILY

Chronic illnesses have become the dominant medical management problem in the western world (Antonovsky, 1989). Half of all people in the United States of America over 65 years of age, and one in four between the ages of 45 and 65 are restricted by at least one incurable chronic illness (Gilliss, Doherty, Needle & Campbell, 1989). As concerns younger people, ten million children in the United States, approximately one in ten of the total, are afflicted with a chronic illness (Gaudet & Powers, 1989; Magrab & Calcagno, 1978; cited in Johnson, 1985).

The success of biomedicine in prolonging the lives of people diagnosed as having diseases such as IDDM, epilepsy, haemophilia and cystic fibrosis, has resulted in chronically ill children comprising nearly 50% of all American paediatricians' practice (Johnson, 1985). In effect, the increased life expectancy of chronically ill children has provided the modern health care practitioner and affected families with a new set of iatrogenic risks and stresses, "significantly and profoundly" altering the "whole course of the lives of the individuals and the family" (Christ, 1982).

The illness event presents the family with demands for change that, if not appropriately accommodated, can aid in establishing a developmental course that can have pathogenic consequences for the disease's prognosis, the emotional well-being of the ill child and other family members, as well as for the functional adequacy of the entire family system (Baker, 1987; Bloch, 1986; Mullins & Olson, 1990; Sargent & Liebman, 1982; Varekamp, Suurmeijer, Rosendaal, van Dijck, Brocker-Vriends & Briët, 1990).

The ecological, or system, approach to understanding chronic illness has generated complex and "intellectually compelling" descriptions of the processes that occur as

chronic illness and family structure and function co-evolve and interact (Herman, 1990). From a research point of view however, methodological problems have limited the contribution of any quantitative approach to an improved understanding of the role of the family in affecting the course of chronic illness (Anderson & Auslander, 1980; Campbell, 1986; Johnson, 1980, 1985). Family disturbance has been linked to childhood psychopathology in both physically healthy and chronically ill populations (Gorell Barnes, 1985). However, this relationship is not unidirectional, in that family problems have been found to arise due to health problems in the child (Koski & Kumento, 1975), and family problems have also been identified as a precipitating factor in the emergence of health problems (Anderson & Auslander, 1980; Johnson, 1980).

3.1 THE NEED FOR METABOLIC STABILITY

Before the discovery of insulin in 1922, the aim of medical care was the prolongation of the remaining two to three-years of the life of those people diagnosed as having IDDM (White & Santiago, 1985). While the availability of exogenous insulin has increased the lifespan of diabetics considerably, 75% of diabetics still die of associated complications within 30 years of diagnosis (Hanson & Henggeler, 1984). The focus of modern therapy is now aimed at avoiding or minimising these complications by attempting to achieve ongoing near normal blood-glucose levels (Ibid).

The short-term consequences of poor metabolic control (imbalances in blood-glucose levels) are, hypoglycaemia (too little sugar), hyperglycaemia (too much), and ketoacidosis (excessive production of ketoacids), all of which have incapacitating symptoms which, if untreated, can ultimately result in death (See Figure 3.1 below).

In the long-term, continually high levels of sugar in the blood have been shown to damage the eyes, kidneys, nerves, fine blood vessels, and other parts of the body (Anderson, 1981; Robertson, undated). According to Robertson, (Ibid) "virtually *all* diabetics have *benign* eye, nerve and renal complications, what is not certain is why a percentage of these become malignant and proceed to organ damage" (p.32). Diabetes is the leading cause of blindness in the United States (Brownlee-Duffeck, Peterson, Simonds, Goldstein, Kilo & Hoette, 1987).

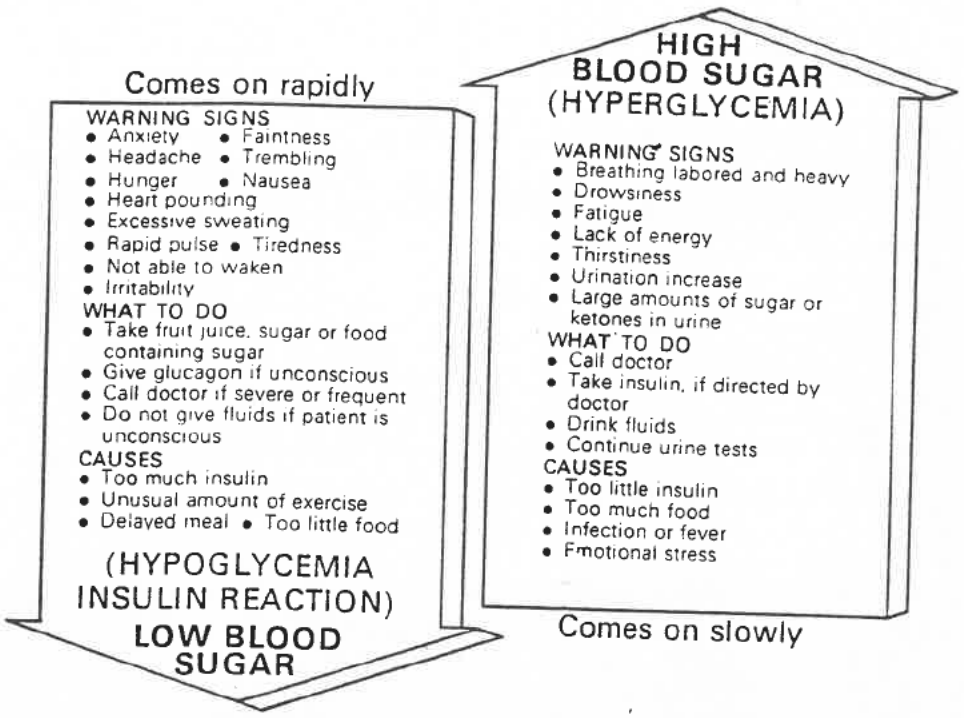

FIGURE 3.1: Hyperglycaemia and Hypoglycaemia in context
(From Anderson, 1982; p.20).

The medical management prerequisites for good metabolic control, simply put, are to keep blood-glucose levels as constant as possible by balancing food intake, energy expenditure, and amounts of insulin administered. Advances in pharmaceutics are such that, from a purely biomedical perspective, the physiological aspects of the disease can be comprehensively controlled.

However, the influence of psychosocial factors is accepted as accounting for much of the variance in levels of metabolic control in children with IDDM. The possible pathways of influence have been described as occurring directly through psychophysiological mechanisms (Baker, Minuchin, Milman, Liebman, and Todd, 1975; Tattersall & Walford, 1985), and via the child not adhering to, or not being able to adhere to, the required treatment regime (Anderson & Auslander, 1980).

3.1.1 Incidence of metabolic instability

The definition of what does and does not constitute metabolic stability is a moot point.

Consequently, estimates of the proportion of people in "poor control" are relative. Anderson (1982) defines "good control" as no sugar in urine 95% of the time and an HbA1c value of 10%, though he readily admits that this degree of control is rarely achieved. Anderson et al., (1981) report that the mean HbA1c concentration for 290 children (10 - 20 years) with IDDM being seen at the Diabetes Research and Training Centre in St Louis, Missouri, in the U.S.A., was 11,9 $\pm$ 2,7%. Only 6% of these children had values below 8,4%. Anderson et al., (Ibid) categorised 25% of their sample as having "good control" (HbA1c $\leq$ 10%), while 21% of the children were classified as having poor control (HbA1c $\geq$ 14%).

Another indication of how well a child is coping with the demands of IDDM is the frequency of hospitalisation. Out of a population of 1229 children with IDDM, Potter, Clarke, Gale, Dave & Tattersall, (1982), found that 9% had been admitted to hospital in an hypoglycaemic coma over a period of one year. Walford, (1982) put the annual figure of patients requiring treatment for severe hypoglycaemia at 16% of the population. Goldgewicht, Slama, Papoz & Tchobroutsky, (1983) found that 26% of patients they studied had at least one severe hypoglycaemic reaction in a year. These and other epidemiological studies document the extremes though, and, according to Tattersall & Walford (1985), are an underestimate of the true frequency of metabolic instability.

Disputes on the numbers of diabetics with difficulties in maintaining metabolic control notwithstanding, the very existence of this population of people with ongoing poor metabolic control requires that the search for, and understanding of, possible contributing factors be extended to encompass the child's social and psychological context.

3.2 UNITS AND ELEMENTS OF ANALYSIS

Over the past sixty years a substantial body of literature concerned with psychosocial factors related to IDDM has accumulated. During this time, mirroring changes in

psychology as a whole, the unit[1] of analysis has been expanded from focusing on the individual in isolation to considering the social context in which that individual functioned. For example, in keeping with the specificity hypothesis of psychosomatic medicine in the 1940s and 1950s (Weiss, 1977), there was much unsuccessful research concerned with attempting to identify a diabetic personality type (Campbell, 1986; Tarnow & Silverman, 1981).

In the 1970s when poor metabolic control was conclusively associated with subsequent microvascular complications, regimen adherence and metabolic control became important dependent variables in research endeavours (Anderson & Auslander, 1980). While individual characteristics associated with metabolic control were still of interest to the researcher, the work of Minuchin and his colleagues (Baker, Minuchin, Milman, Liebman & Todd, 1975) was a turning point in the acknowledgement of the role of the family as a central psychosocial factor in determining the course of chronic illness (Coyne & Anderson, 1988; Bradley, 1988). Along with the increasing acceptance of the social context of the ill child as the appropriate unit of analysis, new approaches to family assessment enabled the elements of a relational analysis to be operationalised (Anderson et al., 1981; Cromwell & Peterson, 1983; Evans & Hughes, 1987; Fisher, Terry & Ransom, 1990; Schafer, Glasgow, McCaul & Dreher, 1983).

While a family systems approach might emphasise process and relational aspects in families, this does not imply a disregard of possible influences in systems hierarchically higher or lower than the family system. Implicit in the systems view is a recognition of the possible influence of elements of analysis other than family functioning (Cromwell & Peterson, 1983). In the face of a potentially limitless number of combinations of social, psychological, and biological factors that could contribute to the determination of

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[1] *The "unit" of analysis is defined here as the system level at which the researcher is directing the enquiry, for example, IDDM and the individual, IDDM and the family. The "elements" of analysis refer to those aspects of the "unit" pertinent to the research question, for example, physical well-being, personality, family functioning. "Variables" are the operationalisation of the concepts used to describe aspects of elements, for example, metabolic control, Type A personalities and family cohesion.*

illness outcome (Hanson & Henggeler, 1984; Rosman, 1988; Sargent, 1982, 1983), it is necessary to reduce the focus of attention to those factors identified as central to the questions being asked. This reduction of focus is not contrary to a systems view. As Fisher et al., (1990) put it:

> ... family systems, and their external social and physical environments, are empirically and analytically decomposable; otherwise they would not be systems. ... a family focus is not violated when some elements within the family are identified and assessed and others are excluded or controlled (p.180).

The primary purpose of this review is provide a conceptual framework within which to understand the psychosocial aspects of IDDM, and then to outline those elements and variables which have been quantitatively shown to be associated with metabolic control and regimen adherence. Following on from there decisions need to be made, taking population accessibility and availability of resources into account, about which elements to include, which to exclude, and which can be controlled for in defining the research focus.

This review begins by locating the illness experience of insulin-dependent diabetes mellitus in its systemic context. The nature of the relationship between metabolic control and regimen adherence is then discussed. A broad overview of research concerning the observed relationships between metabolic control and individual biological and psychological factors is then presented. Following that, the review focuses more specifically on the theory and research concerning the nature of the relationship between family organisation and functioning, and metabolic control. In summary, the implications for researching the relationship between family functioning, metabolic control and regimen adherence will be discussed.

3.3 TOWARDS A CONTEXTUAL UNDERSTANDING OF IDDM

> If you are diabetic, learning to control your blood sugar is your best insurance for the future. ... Taking care of your diabetes is like being captain of an American football team. In American football, when your team has the ball, you the captain must decide whether to run, throw or kick the ball (Anderson, 1982; pp.6-7).

Since the discovery of insulin in 1922, people with diabetes have, in theory, been able

to "dictate the run of play". However, there are times when all people with IDDM do not "have the ball" and, furthermore, there are those "conscripted" players whose circumstances are such that conditions outside of their "field of play" may, more often than not, dictate the final score.

> The evidence is substantial that the metabolic control of adolescents with diabetes is related to a myriad of biological, psychological, familial, extrafamilial, and health care system variables. ... In the light of the serious and demanding nature of IDDM and the grave complications that may possibly be attenuated by good metabolic control, a greater consideration of the adolescent's family-ecological context seems a therapeutic priority (Hanson & Henggeler, 1984; p.12).

The health care professional, faced with a patient in ongoing poor metabolic control, needs to assess the entire life situation of that person and focus on that aspect of the patient's system, which, if changed, will be most likely to bring about an improvement in the problem at hand (Sargent, 1982).

The family environment has been identified as that psychosocial system which:

a) has the single most direct impact upon metabolic control and regimen adherence (Kaplan, 1982; Rosman, 1988; Sargent, 1982, 1985); and,
b) is most accessible and susceptible to effective health care intervention (Gorell Barnes, 1985; Bloch, 1987; Doherty & Baird, 1983, 1987; Rosman, 1988; Fisher, Terry & Ransom, 1990).

Gonzalez et al., (1989) have, according to the types of stresses experienced, delineated two distinct temporal phases in the typical response pattern (coping styles) of families faced with a chronic illness, the acute diagnostic phase, and the chronic phase. According to Kaplan (1982), the origins of many of the long term psychosocial problems associated with chronic illness can be traced to the diagnostic stage of the disease when the individual and his or her family are initially required to adapt.

3.3.1 Challenges posed by the diagnosis of IDDM

The diagnosis of IDDM presents the ill child and his or her family with severe, acute cognitive, emotional, and behaviourial challenges, the outcome of which are dependent upon the ability of the family to mobilise its resources in order to accommodate the demands for change (Sargent & Baker, 1983). During this acute phase, it is appropriate that the child's illness experience becomes a central focus in the family and that patterns

of response, including the re-negotiation of roles, boundaries and routines in the family are altered to meet these demands (Gonzalez, Steinglass & Reiss, 1989; Rissman & Rissman, 1987; Rosman, 1988; Sargent, 1982) (See Table 3.1 below).

> Like the hypoglycaemic diabetic, the family has an upset "psychosocial metabolism" which requires adjustment. After a brief struggle during which critical decisions are made, a new and persevering pattern of living emerges. ... A transitional period is brief because the disturbance is precipitated by change (and) sets in motion forces whose goal is to regain an equilibrium as free from the turmoil and dysfunction of crisis as possible (Kaplan, 1982; p.40).

Those families in which the least structural change has to occur in order to meet the challenges listed in Table 3.1 below may be considered optimally adapted (Rosman, 1988).

Cognitive Challenges	**Emotional Challenges**	**Behaviourial Challenges**
* To understand illness, symptoms and treatment * Learn new routines (injections, testing, diet management) * Appreciate limitations imposed by illness * Understand which areas of child's life are not affected by the illness * For all family members to agree upon the above.	* Potential for guilt and blame * Response to feelings of helplessness and suffering * Potential for decrease in self-esteem and increase in dependency * The patient may become source of emotional pain for family * Finality of diagnosis coupled with uncertain prognosis	* Mastery of treatment regimen, assignment of roles, integration of tasks into existing behaviourial routines of family * Patient and family must develop effective relationships with health care professionals * New ways of maintaining normalcy in behaviour, abilities and self-esteem must be developed as fully as possible * Necessary responses must be developed for medical emergencies.

TABLE 3.1: Psychosocial Challenges of IDDM for Child and Family.
Adapted from Sargent and Baker (1983; p.584).

According to Gonzalez et al., (1989), unless there were prior malfunctionings in the family environment, the intense interventions of health care professionals and other social supports serve, in the short-term at least, to weather the crisis and stabilise the family and the disease.

Difficulties arise when the initial crisis situation is replaced by a situation in which the development and growth needs of all family members, as well as other stressors, challenge the family to reconsider its response mode (Frey, 1984; Gonzalez et al., 1989; Rosman, 1988; Sargent, 1982).

A failure to balance the needs of the ill child and other family members results in what Kaplan (1982) calls a "disorder of change", which at the very least, puts the child at risk for developing a long-term pattern of poor metabolic control, and increases the likelihood of an ongoing unstable family climate being established (Kaplan, 1982; Sargent, 1982; Sargent & Baker, 1983).

How successfully the child and family cope with this "crisis of change" (Kaplan, 1982), is influenced by a number of pre-existent and/or emergent individual and social factors, as well as family structural, organisational and process variables (Kaplan, 1982; Rosman, 1988; Sargent, 1982). The hypothesised pathways in which these demands become accommodated is discussed later in this chapter (section 3.6) when studies concerned with role of the family in the illness experience of IDDM are reviewed.

3.4 METABOLIC CONTROL AND REGIMEN ADHERENCE

In a review of over 500 studies on regimen adherence in various illnesses, Haynes, Taylor and Sackett (1979; cited in Rissman & Rissman, 1987) found that between twenty and sixty percent of patients failed to comply with prescribed regimens. Chronic diseases requiring long-term treatment were associated with lower compliance than episodic or short-term problems (Ibid).

Much of the recent research into issues of regimen adherence has shifted from the individual as the unit of analysis, and the Health Belief Model as the primary element, to a family systems perspective in which the family environment is viewed as the context in which health care behaviours are promoted, prevented and practised (Baranowski & Nader, 1985; Rissman & Rissman, 1987). It is argued by proponents of a systems view that many of the individual factors that have been associated with poor regimen adherence are themselves a "product of systemic factors", particularly family functioning (Hanson & Henggeler, 1984).

In their comprehensive review of the literature, Baranowski and Nader (1985) conclude that family process variables, as opposed to demographic and socio-economic factors, are more likely to affect regimen adherence. Also, Baranowski and Nader (Ibid) conclude that "there may be no aspects of family life that maximise compliance, but many aspects that inhibit and detract from compliance" (p.69). This latter conclusion, however, may be the result of much of the research having an exclusively pathogenic focus.

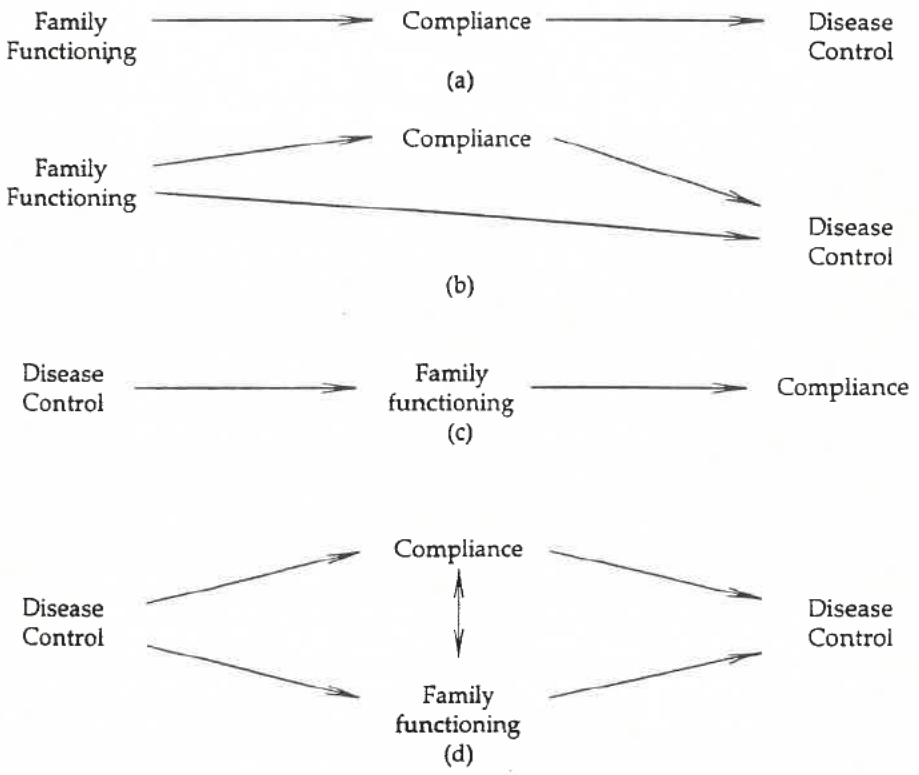

FIGURE 3.2: Models of family, compliance, and disease control relationships. (a) Linear sequential model (b) Parallel influence model (c) Linear sequential model (d) Double parallel influence model. From Baranowski & Nader (1985; p.71).

Given that many of the same family functioning factors that have been shown to negatively affect regimen adherence have also been associated with poor metabolic control, the mechanisms whereby family functioning and regimen adherence interact to

affect metabolic control are not fully understood (Baranowski & Nader, 1985). A major reason for this lack of clarity can be ascribed to methodological shortcomings in which most of the studies have been cross-sectional in nature and have relied on correlational analyses to investigate hypothesised relationships (Campbell, 1986; Johnson, 1985).

It has variously been posited that; a) family functioning affects adherence, which in turn affects control, b) family functioning directly affects control as well as adherence, c) poor control leads to additional problems in the family, which in turn leads to poorer adherence and family functioning, and d) a combination of all three. (See Figure 3.2 above). Implicit in the above models is the acceptance of a process of change. Also, while family functioning is seen in relation to control and adherence, the role of other factors such as individual and biological differences need to be controlled for.

From a systems perspective, it is generally accepted that there are two basic pathways by which psychosocial factors can influence the extent of metabolic control:

1. The stress experienced by one or more variables emanating from any one of a number of systems in which the child is embedded can have a direct negative effect on the physiology of the diabetic child.

2. The stress experienced from factors emanating from one or more of the systems levels in which the child is living may create conditions in which control is disrupted through the patient's maladaptive behaviour in response to that environment (ie. non-adherence to required regimen).

The above conception accounts for the conclusion that, while proper adherence to the required regimen is a necessary prerequisite for good metabolic control, it is not sufficient in that improving adherence does not necessarily improve metabolic control (Daneman, Wolfson, Becker & Drash, 1981). What is not clear though, is which psychosocial factors in the individual and the family mediate in influencing the extent to which stress does have an impact. Also not clear are the pathways and mechanisms along which these factors operate to influence metabolic control. Psychosocial characteristics of the individual and the family may be conceptualised as shaping the way in which stress impacts upon metabolic control. In turn, both individual characteristics of the ill child and the family may influence the extent of regimen adherence. What is not clear is which factors, irrespective of the extent of regimen adherence, impact directly upon

metabolic control, and which factors influence both metabolic control and regimen adherence.

3.5 INFLUENCES ON METABOLIC CONTROL AND REGIMEN ADHERENCE

While the primary area of focus of this research is upon the role of family factors in influencing metabolic control and regimen adherence, there is a substantial body of literature that has identified a number of biological and individual variables that need to be accounted for in any research endeavour. There is also a growing body of literature which points to extra-familial factors, such as the health care relationship (Bradley, 1988), that also influences the quality of diabetes management. However, it is beyond the scope of this study to consider these in any detail.

3.5.1 Biologically determined factors

Aside from genetically predetermined strengths and weaknesses, physical illness, infections, and hormonal changes during puberty, have all been shown to temporarily mitigate against good metabolic control (Danowski, Ohlsen, Fisher & Sunder, 1980).

Hormonal changes during adolescence are known to wreak havoc with control in some children and not others (Hamburg & Inoff, 1982; Anderson, Miller, Auslander & Santiago, 1981). The number of children in poor control rises during adolescence and then declines (Johnson, 1980). Adolescent females have also been found to have worse metabolic control than males (Anderson et al., 1981, Hamburg & Inoff, 1982).

Anderson et al., (1981) found that girls between the ages of 14 and 16 had significantly higher HbA1c levels than boys of the same age (13.5% vs 11.4%; $p \leq 0.03$); and were also higher than girls in the 11-13 and 17-19 age groups (11.7% and 12.2% respectively). Overall, girls' HbA1c scores were higher than boys' (12.6% vs 11.2%) in their group of 58 (ages 11-19).

Simonds, Goldstein, Walker & Rawlings, (1981) concurred with Anderson et al., (1981) and found that the 23 girls in their study had significantly higher HbA1c levels than the 29 boys (13-19yr).

However, Simonds, et al., (1981), also found that adolescent females were significantly higher on body weight percentile curves than males and suggested that both

poor control and increased weight could be the result of greater noncompliance in meal plans on the part of the females. This explanation is supported by the findings of Anderson et al., (1981) that "the majority" of mothers of children in poor control stated that diet was the hardest aspect of the regimen for their child. Dietary compliance requires regular meals of particular kinds of foodstuffs. Dining out and socialising can also present added temptations to transgress. Carney and Schecter (1982, cited in Hanson & Henggeler, 1984) found that diabetic children had significantly worse metabolic control if there were "illegal" snacks in the household and family members ate these in front of the child.

In a study of 147 adolescents, Brownlee-Duffeck et al., (1987) concur in finding that females' HbA1c scores were higher than males, but found no significant correlation of regimen adherence with gender.

Jacobson et al., (1981), also turn to family related factors to understand the significant difference they found in adherence behaviours between early adolescents (13-15yrs) and pre-adolescents (9-12yrs). They posit that while the pre-adolescent is still more directed by parental values and goals, the developmental upheavals and added strains in relations with parents during adolescence can lead to decreased adherence to the prescribed regimen.

Another variable that has been put forward to explain the higher incidence of diabetic instability during adolescence has been the associated increase in normal life stressors during this period (Coddington, 1972). There have been no conclusive findings concerning the relationships between metabolic control the child's age, age at diagnosis, and duration of IDDM (Hanson & Henggeler, 1984).

In summary, both age and gender are significant factors that must be considered in research concerning metabolic control and regimen adherence. However, these research findings shed little light on the possible pathways of interaction with intermediary psychosocial variables such as stress and poor regimen adherence.

3.5.2 Individual Factors

Characteristics of the ill child associated with metabolic control have been the subject of much inconclusive research. For example, while knowledge about diabetes care is

accepted as necessary prerequisite to enable proper adherence to the required regimen, the relationship between knowledge and metabolic control is unclear. Some studies (Etzwiler & Robb, 1972; Orr, Golden, Myers & Marrero, 1983) found no correlation between the child's knowledge about diabetes and metabolic control. On the other hand, Geller and Butler (1981, cited in Hanson and Henggeler, 1984) found that 27 percent of hospitalisations for diabetic complications over a one-year period were the result of inadequate patient knowledge and regimen adherence. To complicate the picture, Hamburg and Inoff (1982), found that knowledge was negatively correlated with metabolic control, and hypothesised that some individuals had become knowledgeable about IDDM in failed attempts at improving their poor control.

Mothers, having been identified as being primarily responsible for supervising diabetes management in pre-adolescent children, have been the focus of much research. In their comprehensive review of the literature, Anderson and Auslander (1980) conclude that childrearing attitudes are closely related to regimen adherence levels and metabolic control, with "perfectionistic, overcontrolling" mothers having rebellious children with satisfactory adherence; "indifferent or rejecting" maternal styles resulting in maladjusted children with low levels of adherence, while the children of "tolerant, consistent and flexible" mothers were both well-adjusted and in satisfactory metabolic control.

TABLE 3.2: Impact of IDDM on Adolescent Development

Aims and problems of adolescence	**How IDDM interferes**
1. Physical and sexual maturation	Delayed sexual maturation Small stature "Invasion of privacy" by physical examinations
2. Independence from parents and establishment of a unique personality	May lead to parental overconcern and battles about diabetes
3. Conformity with peer group	Meals have to be eaten on time, "junk" foods are forbidden
4. Self consciousness	Hypoglycaemia exposes the adolescent as different
5. Self-esteem	"Defective" body image
6. Economic independence	Discrimination by employers "Loading" of insurance premiums

From Tattersall and Lowe (1981; p.517).

As regards the psychological characteristics of the child, poor emotional adjustment has been associated with greater problems in achieving good adherence and metabolic control (Johnson, 1980). However, in comparison with non-diabetic children, conclusions are conflicting. An epidemiological study by Lavigne and Burns (1981; cited in Sargent, 1985) found that chronically ill children are more than twice as likely to have serious emotional or behaviourial problems than physically healthy children. On the other hand, Simonds (1977) matched 80 diabetic children with a non-diabetic control group and found no significant difference in psychiatric status or conflict between the poor-control group and "normals".

Another variable that has been the subject of differing results is the self-esteem of the diabetic. In one of few longitudinal studies, Jacobson, Hauser, Wolfsdorf, Houlihan, Milley, Herskowitz, Wertlieb & Watt, (1987) found that adolescents were less adherent than pre-adolescents and that the individual's self-esteem, perceived competence, social functioning and behaviourial symptoms were predictive of adherence over a period of 18 months. An important implication of this finding is that psychosocial assessment soon after diagnosis may assist in identifying those children at risk for later adherence difficulties. However, Simonds et al., (1981) found no difference between the self-esteem of those adolescents in good and poor control, while Anderson et al., (1981) found adolescents in good control to have higher self-concepts.

While poor psychosocial adjustment in the child has been associated with poor metabolic control and regimen adherence, there appears to be no significant psychological difference between diabetics in good control and "healthy" children. The work of Lewis & Khaw (1982) lends support to the argument that any psychosocial maladjustment identified in the child would also be associated with dysfunctional family relational patterns. Lewis & Khaw (Ibid) compared behaviour problems in three groups of children, "normals", cystic fibrosis, and asthma, finding that while the groups did not differ in family functioning, there was a significant relationship between family adaptability and cohesiveness and the number of behaviour problems reported.

Another disputed relationship is that between metabolic control and regimen adherence. Of the four studies located that investigate the relationship between metabolic

control (all using HbA1c as an index) and regimen adherence, two found a significant association and two did not. In a study of 52 adolescents, Simonds et al., (1981), designed four different self-report questionnaires (two for ill adolescent and two for the mother) to assess self-care and compliance to the regimen. Not one of the four scores was found to discriminate between children in good metabolic control and poor metabolic control. This finding was confirmed by Linn and Linn, (1983) in a study of 100 men. Using their own scale to assess regimen adherence they found no significant correlation with HbA1c levels. In a stepwise multiple regression analysis, a combination of depression and regimen adherence accounted for only four percent of the variance in metabolic control.

On the other hand, Schafer et al., (1983) found a significant correlation between HbA1c and regimen adherence (a questionnaire developed by the authors) in a sample of 34 adolescents ($p \leq 0.001$). Using a far larger sample, 147 adolescents, Brownlee-Duffeck et al., (1987), also found a significant positive relationship between good metabolic control (HbA1c) and patient self-report on their own 15-item questionnaire designed to determine adherence ($p \leq 0.001$). Upon closer analysis, it was found that the seven items concerning dietary compliance were most closely associated with metabolic control.

A major problem with the above studies is that there appears to be no accepted standardised method of assessing regimen adherence. Simonds et al., (1981) explain their non-significant findings by suggesting that some factors, including family ones, may negatively impact on metabolic control directly, irrespective of regimen adherence. The fact that their sample consisted of children from rural areas may be a possible factor if reduced availability of social supports is taken into account. As concerns the relationship between metabolic control, regimen adherence and family factors, Schafer et al., (1983) found that a number of individual psychosocial measures and the conflict subscale of the Family Environment Scales were positively associated with regimen adherence and not metabolic control, leading them to conclude that;

> ... it is important to distinguish between the use of psychosocial measures to predict control versus their use to predict regimen adherence. As expected, the psychosocial measures employed in this study were more related to adherence

than metabolic control (p.497).

In summary, not only is much of the above research conflicting, it also sheds very little light on the relative influence and interaction of psychosocial, demographic and biological factors, and regimen adherence on metabolic control. Some factors are thought to impact upon metabolic control without affecting regimen adherence, reducing control but maintaining adherence, while others are thought to impact upon regimen adherence which in turn impacts upon metabolic control. These possible relationships need to be explored further.

3.6 CO-EVOLUTION OF ILLNESS AND CONTEXT

The foundations of a family's relational and structural characteristics can become greatly altered during the time period in which it attempts to stabilise from an 'acute response' to the diagnosis of the illness, to a 'chronic response' of ongoing coping (Kaplan, 1982). Rosman, (1988), delineates the possible outcome options:

> ... there is considerable variation in the adaptational outcomes for different families, with many, or even most, managing to recover a reasonably normal balance while providing adequate care. Others remain in a state of disequilibrium, stabilize into a dysfunctional structure, or stabilise but provide inadequate care (p.296).

The quality of the overall management of the child's diabetes, adherence and metabolic control, is influenced by specific and repetitive patterns of family interaction, which in poorly organised families can initiate and/or maintain poor adaptation (Sargent, 1982).

Conversely, the family is influenced by the consequences of continual poor metabolic control which can lead to a re-organisation of the family in which a self-maintaining chronic pattern comes into being.

> In this model, we find mutual influences among the family, the child, and extrafamilial factors of primary import and that any given element is both caused and causative at any particular time. Extra-familial factors and features of family organisation, which can maintain maladaptive responses in diabetes with poor medical control and psychosocial difficulties, can also be mobilised to achieve good control and functional psychosocial adjustment (Sargent, 1982; p.131).

Established response patterns become a template from which future experiences are dealt with (Bloch, 1987). Bloch (Ibid) agrees with Kaplan (1982) in pointing to two

factors that increase the likelihood of a pattern becoming durable, early experience and frequency. Response patterns which are established early on in the illness/context[2] interaction, and those that occur frequently are the ones that are likely to be replicated in the future. "Whenever a problem endures it becomes inextricably woven into the social fabric in which it exists" (Dym & Berman, 1987). Or, as Doherty and Baird (1983), put it:

> The longer a family has lived with the problem, the more rigid the family system is apt to be when faced with the task of changing its interaction patterns (p.53).

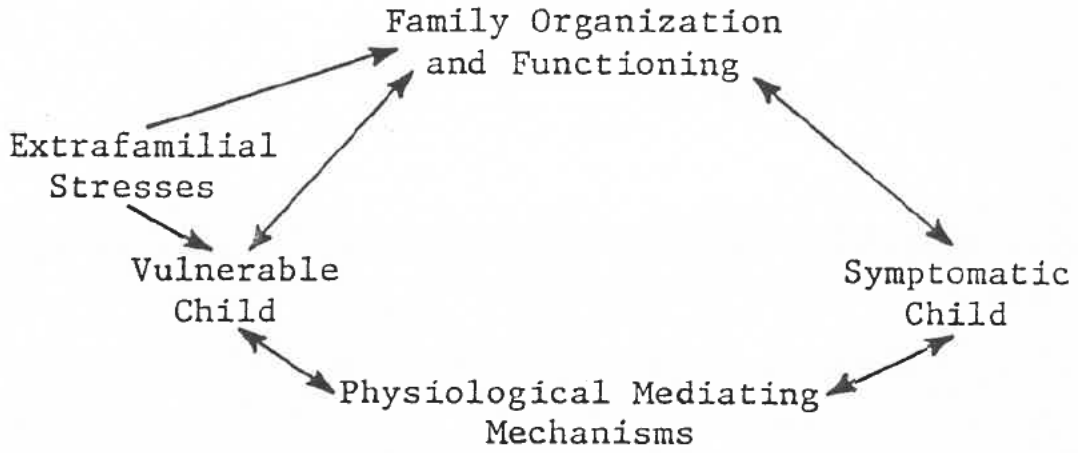

FIGURE 3.3: Open Systems Conceptual Model of IDDM

(From Sargent, 1982; p.131).

The illness and its context coevolve over time in a series of actions and reactions which result in an improved "fit" with each other. Given this circularity in which the temporal relationship between cause and effect is interchangeable, the manifestation of poor metabolic control or regimen adherence in the psychosocial and physiological context needs to be understood in terms of a co-determinative interactive process rather than static and linear cause-effect terms. In essence, illness and context create evolutionary niches for each other.

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2 *It must be pointed out that while this sub-section is describing the process of co-evolution in terms of family relational structures and illness, the context is a lot more complex in that contributions to the "fit" are also made by the biology, physiology and psychology of the ill child, as well as the health-care system and the larger socio-cultural context in which all this is embedded.*

> In social situations, in particular, the creation of a "demand", and even of a "need" for this demand to fulfil, often appears as correlated with the production of goods or techniques that satisfy that demand (Prigogine & Stengers, 1984; p.196).

A useful metaphor for conceptualising the interaction and co-evolution of all these variables is the analogy of a spider's web, used by Weiss (cited in Gorell Barnes, 1985):

> The meshes [of the web] orient themselves in such a pattern that tensions and pressures are in equilibrium throughout the fabric; just change that balance by severing one of them and all the others will immediately alter their positions, orientations, angles and lengths in such a manner as to assume a new distribution of forces and come to rest once more. All of them operate as if each one of them received cues about what the others are doing in that collective action.

Taking the analogy further, the literature is unclear as to how the properties of each element combine to form the overall organisation of the web. The web's integrity is dependent upon which element is under stress, where in the web that element is situated, as well as the tensile strength of the individual fibres themselves.

Attempts at adapting to a stressor may trigger a "solution" which in itself is maladaptive and create a climate predisposed to worse control. In this sense, attempting to pinpoint the original "cause" of poor control becomes a futile exercise in that origin and maintenance are seen as separate. Ongoing poor metabolic control has become part of the spider's web.

> ... [the] current utility of a characteristic or structure is not a guide to historical origin. Some characteristics are by-products of evolution or appear in response to other circumstances, but are then available and reinforcing, if advantageous. We see a similar relationship between family characteristics and the symptom - *however* it arose (Rosman & Baker, 1988; p.130).

While the strands of the web may be subject to multiple and interdependent primary and secondary stressors, they can also be viewed as potential resources which can act as buffers to help maintain good control. Change in the self-maintaining chronic patterns which perpetuate poor metabolic control can be made by altering that part of the contextual surround which is found to be closely associated with the illness pattern, the family. Not only does the family, as the child's primary social context, play an important role in determining the quality of diabetes management, (Marrero, Lau, Golden, Kershnar & Myers, 1982), it is also easily accessible and vulnerable to intervention

(Doherty & Baird, 1983, 1987).

As concerns chronic illness in general, and IDDM in particular, the work of Minuchin and his colleagues at the Philadelphia Child Guidance Clinic (Baker et al., 1975; Baker, Rosman, Sargent, Nogueira & Stanley, 1983; Liebman, Minuchin & Baker, 1974; Minuchin, 1974; Minuchin, Rosman & Baker, 1978; Rosman, 1987, 1988; Minuchin, Rosman, Liebman, Milman & Todd, 1975; Rosman & Baker, 1988; Sargent, 1982, 1982b, 1982c, 1983, 1983b, 1985; Sargent & Baker, 1983; Sargent & Liebman, 1985), has been central in promoting a structurally oriented family systems understanding of the role of the family in the illness process. Central to the systems framework in which IDDM is understood by these authors is the recognition of a circular and multifactorial relationship between the disease, the child's emotional well-being, and the family's functioning (See Figure 3.3 above).

3.7 THE FAMILY, METABOLIC CONTROL AND REGIMEN ADHERENCE

As mentioned in chapter two, there are three basic approaches to investigating the family; family stress theory (See figure 2.3) which emphasises family resources, family development theory which emphasises the family life cycle, and family system theory (See figure 2.2) which emphasises family types.

The concept of stress, when it has been included in family system oriented research, has been viewed in terms of the effects of particular types of stressors. On the other hand, family stress oriented research has shifted to a salutogenic approach, seeking out those aspects of the family that mediate, or act as a buffer, in family members' experience of and response to stress. A developmental framework is implicit in the Structural Model but less central to the family stress approach. The challenge facing theoreticians and researchers is to effectively integrate these theories (Fisher et al., 1990).

As concerns the family and IDDM, the theory and research reviewed below is firmly grounded in either a classical linear-causal approach, or a systems one. Except for one study in which reported parental support of regimen adherence was considered (Hanson, Henggeler & Burghen 1987), no published research could be found concerning possible

salutogenic aspects of the family that lessened the effects of stress upon metabolic control.

3.7.1 Stress, coping and metabolic control

Past research into stress and IDDM suggests that metabolic control is susceptible to stress through direct action of stress hormones (Hanson et al., 1987; Tarnow and Silverman, 1981), as well as affecting free fatty acid levels in the blood (Minuchin et al., 1978), and blood sugar and urine ketone levels (Brand et al., 1986). People with IDDM respond to stress primarily through their metabolic system in much the same way that some people with asthma respond through their respiratory system (Tarnow & Silverman, 1981). Children with IDDM vary considerably in the degree to which they are affected by stress and it is thought that both social and physiological variables mediate in the impact of any stressor (Brand et al., 1986)

Social support in the form of special groups and friends, and the absence of economic difficulties have been shown to be a moderator of life stress and associated with good adherence to the regimen (Cobb, 1976; Jacobson et al., 1987; Janis, 1983; Swift et al., 1967). Peer group influences, as well as stresses from the school and broader social environment have been reported as affecting affect regimen adherence and metabolic control (Sargent, 1985). As in the family level, a circular mode of interaction between the diabetes and the social environment is posited. Stress-related hyperglycaemia can lead to absenteeism from school and peer activities, which in turn promotes additional stress and impedes psychosocial functioning (Sargent, 1985).

The family's ability to cope with stress has been suggested as an important moderator variable that can lessen the detrimental impact of stress on the diabetic child. (Cobb, 1976; Hanson & Henggeler, 1984).

A cooperative family climate and a home environment with low levels of conflict are associated with higher levels of metabolic control in diabetic children (Koski & Kumento, 1977; Swift, Seidman & Stein, 1967). High levels of stress within the family unit have been positively associated with the child's level of blood glucose control (Anderson and Auslander, 1980; Anderson, Miller, Auslander & Santiago, 1981; Hanson and Henggeler, 1984; Hauenstein, Marvin, Snyder & Clarke, 1989; Johnson, 1980).

Hanson (1983; cited in Hanson & Henggeler, 1984) found that negative stressful everyday events were associated with increases in blood glucose levels.

A study by Jacobson, Rand, and Hauser, (1983), found that those patients sensitive to stress were more prone to developing retinopathy, compared to a control group of diabetic patients less sensitive to stress. Jacobson et al., (Ibid), examined the impact of stress, as reported on the Sarason Life Events Survey, and found that negatively experienced stress was significantly correlated with HbA1c levels among patients with proliferative retinopathy. This relationship was not significant in the low stress control group who did not have proliferative retinopathy. These results again underscore the interdependent relationship between physiochemical and psychological factors, suggesting that those patients sensitive to stress may be more likely to develop retinopathy. Irrespective of whether the source of this stress is intra-familial, extra-familial, expected or sudden, the family's ability to mediate its impact has been hypothesised to be an important intervening factor (Brand et al., 1986).

Using multiple regression to investigate the stress mediating effects of social competence and parental support in 104 pairs of adolescent diabetics and their mothers, Hanson, Henggeler, and Burghen (1987) found that the child's social competence buffered the negative association between stress and metabolic control. Hanson et al., investigated the relationships between metabolic control (HbA1c), regimen adherence (self-report and observation), stress (Adolescent Family Inventory of Life Events), social competence (Perceived Competence Scale for Children; mothers completed the Social Competence Scale of the Child Behaviour Checklist), and parental support (Diabetes Family Behaviour Checklist which measured adolescents' perceptions of parental support pertinent to IDDM). Multiple regression analysis indicated that stress was associated with metabolic control when the effect of adherence was controlled for. Both stress and adherence were directly associated with metabolic control ($p \leq 0.012$ and $p \leq 0.004$ respectively). Stress was not significantly associated with adherence ($p \leq 0.22$), indicating that the effect of reported stressful life events on metabolic control was not mediated by regimen adherence. The negative association between stress and metabolic control was significantly buffered by a combined index of the child's social competence

($p \leq 0.039$). The child's social competence was found to be a resource in that the metabolic control of children with high competence was not affected by additional stress.

On the other hand, parental support was positively associated with adherence but not metabolic control.

> Although stress accounted for a relatively small amount of the overall variance in predicting metabolic control, we believe that the findings have important implications for the treatment of adolescents under poor metabolic control. In addition to their traditional emphasis on the promotion of adherence behaviours, health care professionals should consider the possibility that problems in achieving metabolic control are being exacerbated by environmental stressors or low social competence. For example, poor control might be linked with the stress of family conflict or with problems in peer relations (Hanson et al., 1987; p.532).

Hanson et al., (Ibid) conclude that stress is directly linked with metabolic control and that the mechanism of this linkage is probably physiological. The findings of this research are significant in that they shed light on the possible pathways and mechanisms that exist in the relationships between stress, coping resources, adherence and control. The suggested physiological linkage between stress and metabolic control is supported by a number of other studies.

Hinkle (1950; 1951; 1952, cited in Tarnow and Silverman, 1981) found that while both non-diabetics' and diabetics' responses to stress included changes in urine, plasma glucose, and plasma ketones, the metabolic response of diabetics was greater. Hinkle's (1951, Ibid) findings that insulin requirements were affected by stressful life situations - even more so in "labile" diabetics - led him to hypothesise that diabetes was a "disorder of adaptation". (Ibid). The work of Minuchin and his colleagues supports this hypothesis.

> In Minuchin's (1978) psychosomatic families, it is not the level of conflict that is relevant. In fact, many of these families compulsively avoid conflict. Rather, the issue is one which concerns the pathways of conflict and the manner in which the psychosomatic child is trapped, or traps himself, in parental conflict in order to detour it (Abelsohn, 1985; p.65).

3.7.2 Minuchin's Psychosomatic Family

Baker, Minuchin, Milman, Liebman & Todd, (1975) identified a group of "psychosomatic" diabetic children who, despite adhering to their insulin regimen, had

repeated episodes of ketoacidosis every three to four weeks. When these children were removed from their family environments and hospitalised the diabetes came under control without any significant change being made to the treatment regimen. It was concluded that the reciprocal influences between family and disease variables were determining the course of diabetes in these children.

This group of children was found to share certain traits:

> they are somewhat immature, have difficulty handling stress, have marked problems expressing anger, are highly compliant and, at times, are manipulative of parents and medical staff (Sargent & Baker, 1983; p.587).

Baker, Minuchin, Milman, Liebman, and Todd, (1975) then tested the hypothesised association between family and disease by monitoring the free fatty acid (FFA) levels of family members during a series of family tasks designed to evaluate family characteristics. Families were classified into "psychosomatic" and "nonpsychosomatic" groups (See Table 3.3 below). The family interaction was videotaped and then rated.

TABLE 3.3: Diabetes and emotions: an abbreviated classification system

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I. Nonpsychosomatic
   - A. Emotional disturbances associated with onset of diabetes
     1. Idiogenic
     2. Iatrogenic
   - B. Emotional disturbances not associated with onset of diabetes
     1. Behavioural problems with metabolic consequences
     2. Manipulation of illness causing metabolic problems

II. Psychosomatic: emotional difficulties cause metabolic derangements
   - A. Recurrent ketoacidosis with frequent hospitalisations not due to any organic cause
   - B. Chronic nausea and vomiting associated with acetonuria, causing repeated absences from school

(From Baker et al., 1975; p.333).

From this first part of the study it was found that the interaction patterns in families with a "psychosomatic" diabetic child had five distinct features:

1. Psychological overinvolvement or enmeshment between family members.
2. Overprotective concern.

3. Rigid family interaction patterns.
4. Lack of effective means to solve family conflicts.
5. Involvement of the sick child in parental conflict.

TABLE 3.4: Outline of Family Interview (From Baker et al., 1975; p.339).

Time	Phase	Specimens every 15 minutes	
8 a.m.		Insertion of I.V.	
8:30 - 9	I	Equilibration	Parents are settled in interview room, child in observation room behind one-way mirror.
9-10:30	II	Diagnostic interview	Structured interview designed to explore family's handling of idiogenic conflicts.
9-9:30	Stage 1.	Conflict Induction	Psychiatrist tells parents to discuss a family problem and leaves.
9:30-10	Stage 2.	Induction of spouse conflict	Psychiatrist returns and allies himself with one spouse against the other.
10-10:30	Stage 3.	Role of child	Psychiatrist brings child into interview room and tells parents and child to help each other decide how they should change.
10:30-12	III	Recovery period (Specimens every 30 minutes)	Family goes to game room. No medical personnel are present.
12 noon		Debriefing	Interviewer and paediatrician meet with family to answer questions. If therapy is indicated or requested, family meets therapist.

Subsequently, based on observations, the family's interaction patterns were said to

reinforce the symptoms while, in turn, the symptom maintained family stability (Minuchin, Rosman & Baker, 1978).

The second part of the research study involved a diagnostic family interview during which FFA levels of family members were monitored by means of an intravenous insertion (See Table 3.4 above). The FFA levels of all family members rose during the conflict induction stages. The FFA levels of the "psychosomatic" group of children compared to both the behavioural and normal groups were significantly higher ($p \leq 0.03$ and $p \leq 0.002$ respectively) (Rosman & Baker, 1988).

Upon introduction of the children into the interview situation, the FFA levels in the parents and the behavioural and normal groups of diabetics dropped, while the "psychosomatic" diabetic child's levels remained high. The difference between the groups of children was significant in normals compared to "psychosomatics". During stage three it was found that in the "psychosomatic" group that the more the ill child's FFA levels went up, the more his or her parents' levels went down ($p \leq 0.02$) (Ibid). In the behavioural group the trend, while not significant, was the opposite. The FFA levels of 6 of the 8 parents of behavioural diabetics went up upon introduction of the children, while 5 of the 7 FFA levels of the "psychosomatic" parents went down (Ibid). During the recovery period the FFA levels of the normal and behavioural groups went down significantly more than the "psychosomatic" group ($p \leq 0.002$) (Ibid).

The authors concluded that while the family was not necessarily the original source of the child's problems, family interactions served to develop and maintain the "psychosomatic" syndrome by directly affecting the metabolic control of those diabetic children who were physiologically hypersensitive.

According to Rosman and Baker (1988), the distinction between types of diabetics seems to have been lost on subsequent researchers who, in looking for an association between family interactional patterns and metabolic control appeared to have generalised the identified pattern of "psychosomatic" families to all families studied.

Bradley (1988) points out an unintended negative consequence of this pioneering work. She argues that the ideas of Minuchin and his colleagues with regard to family structure and diabetes have too often been used by health care professionals as a

convenient explanation for poor control, abrogating them from having to look any further for other possible intervening variables.

> The problem is not that Minuchin et al., focused on the family in their particular work but that other health professionals have done so in a manner that is neither appropriate nor constructive and have cited Minuchin et al. to justify their actions (p.2).

Bradley goes on to point out that poor control may be "more constructively" attributed to "problems with the health care system including inadequacies in the education and training of patients and their families". She contends that adequate education and training at the time of diagnosis could prevent the deterioration in family environment which may develop as a result of poor control.

What Bradley does not acknowledge though, is that there is also the possibility that there are some families in which an unstable environment precedes the diagnosis of diabetes and, if not identified, can nullify all the education and training provided. Furthermore, poor metabolic control in physiologically hypersensitive diabetic children could also be upset by stressful factors operating from without the family sphere of influence (e.g. school examinations).

Pickup (1985) confirms, from a different perspective, the work of a Minuchin and his colleagues. Writing in the same book as Pickup (Ibid), Tattersall and Walford (1985), conclude that "brittle" diabetics:

> ... are niether 'mad' nor 'bad' but indulge in potentially dangerous behaviour, partly because they are ignorant of its consequences but more often because it 'pays' in the sense of fulfilling other needs, whether for love, shelter, approval or escape from an otherwise insoluble conflict (p.76).

3.7.3 Brittle Diabetes

Though controversial in its definition, the term "brittle diabetic" is used by Gill, Husband, Walford, Marshall, Home & Alberti, (1985), to describe those patients who "defy attempts at stabilisation, and whose life is constantly disrupted by episodes of hypoglycaemia or hyperglycaemia". Out of a sample of 33 patients (27 females, 6 males) identified as brittle diabetics, Gill et al., went on to diagnose psychological and family problems as the main aetiology in 11 (6 males, 5 females), therapeutic error in five (3

of whom also had psychological difficulties), one with factitious hypoglycaemia, and classified the remaining 19 females as idiopathic.

While there was evidence of metabolic features affecting control in this idiopathic group (impaired subcutaneous insulin absorption, exaggerated response to insulin withdrawal, and hyperlactaemia), 10 of the 19 girls were subsequently either caught, or admitted to, interfering with their therapy.

> In some patients this behaviour secured or maintained hospital admission in order to avoid intolerable domestic circumstances, but there was not always such an obvious motive (Ibid; p.33).

The authors speculate on the causative mechanisms of this syndrome and come to the conclusion that;

> ... all the girls began their careers by inducing instability for emotional reasons (probably within the limits of normal adolescent diabetic behaviour). Escalation of insulin doses, continued cheating and repeated admissions could then complete a chain of events leading to a state of chronic hyperglycaemic instability, from which the patient cannot escape - this phase being what we have called severe 'idiopathic diabetes mellitus'. The instability may now be thought of as an 'acquired metabolic' problem, though cheating may still play a part in some patients at this stage (Ibid, p.38).

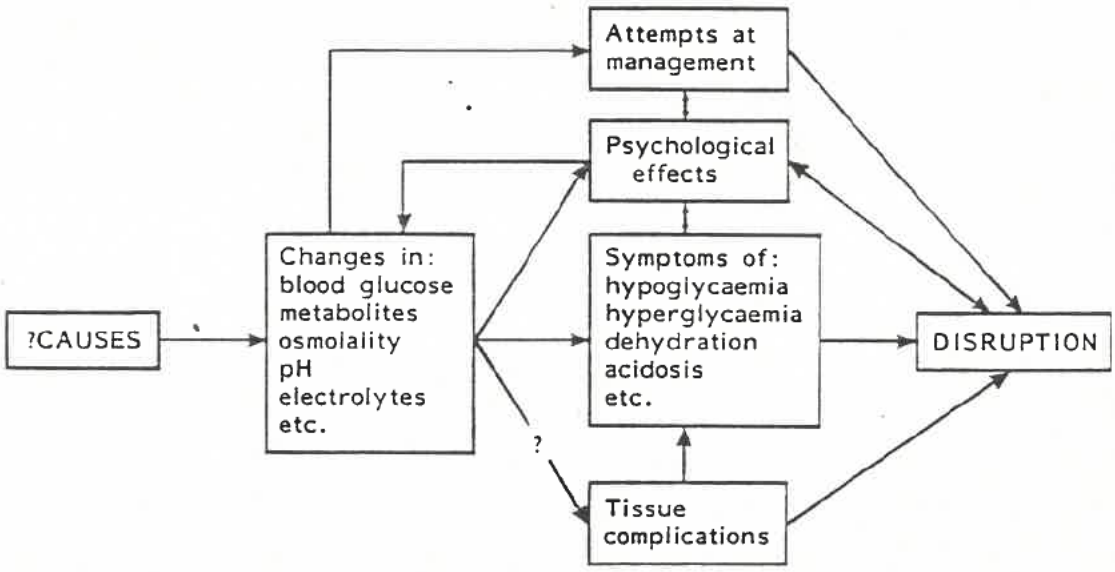

FIGURE 3.4: The chain of some interconnecting circumstances which lead from the primary cause(s) of the difficult diabetes syndrome to its result: serious disruption of life and lifestyle (From Pickup, 1985; p.7).

Figure 3.4 above outlines the possible chain of events that result in the disruption of the

individual's and the family's life.

Pickup (1985), while outlining a number of physiochemical methods of quantifying brittle diabetes, also suggests that brittle diabetics may be distinguished from normals by the number of acute hospital admissions occurring during the previous year. White, Kolman, Wexler, Polin, and Winter (1984), in discussing the "labile diabetic", state that if a child is hospitalised twice in one year;

> ... this is a serious problem, usually related to one or more of three causes: (1) poor medication or dietary compliance; (2) intercurrent illness; or (3) emotional stress, usually from within the child or family environment (p.753).

The hospitalisation rates of "brittle diabetics" referred to by Pickup (1985) are however higher. For example, in one group of 12 children studied, Pickup (Ibid) reports that three had spent more than nine months in hospital and four had been admitted on ten or more occasions. Keen (1985) describes this population of brittle diabetics as representing one percent of all people with IDDM and being "nearly always young, often in their teens or early twenties and ... overwhelmingly more girls than boys".

While the above model has been applied to an extreme and small group of people with IDDM, it serves to highlight the close inter-dependence between complex metabolic regulatory mechanisms, regimen adherence, and stress emanating primarily from the patient's family (Keen, 1985). From a group of 33 brittle diabetics it was found that psychological and family problems, most likely to be initially mediated by "wilful metabolic sabotage", were determined to be the major cause of instability in 22 of them.

Keen (1985) raises the question whether emotional problems emanating from the family environment are the consequence or cause of the brittle state.

> Domestic discord, parental problems, broken families, overdependent relationships and personal maladjustments have frequently been described in the life history of brittle patients; but they are not absent from the life history of many stable diabetics. (Ibid).

In the absence of any unique stimulus to distinguish brittle from other diabetics, Keen concludes that it may be the physiological response that is abnormal. Thus, there is no initial difference between potential brittle diabetics and those in poor control. The difference lies in the self-perpetuating physiological responses that come into play after

a sustained period of poor diabetic control (Ibid).

In summary, it is again highlighted that the original "causes" of poor metabolic control may come to be replaced by an evolving combination of other factors. As indicated in Figure 3.4 above, the psychological effects of this poor control interact with management, which in turn combine with a number of physiological pathways to result in disruption. There is an extensive body of clinically-based anecdotal literature, and an increasing number of quantitative studies, which complement both the psychosomatic and brittle diabetes models in describing the nature of family organisation and functioning associated with metabolic control and regimen adherence. This section is concluded by reviewing some of that literature.

3.7.4 Family functioning, metabolic control and regimen adherence

The family systems literature abounds with rich and compelling descriptions of cases illustrating the reciprocal impact of IDDM and family function and organisation (Doherty & Baird, 1987; Fisher & Ransom, 1990; Gaudet & Powers, 1989; Rosman, 1988; Sargent, 1982; 1982b; 1983), to list but a few.

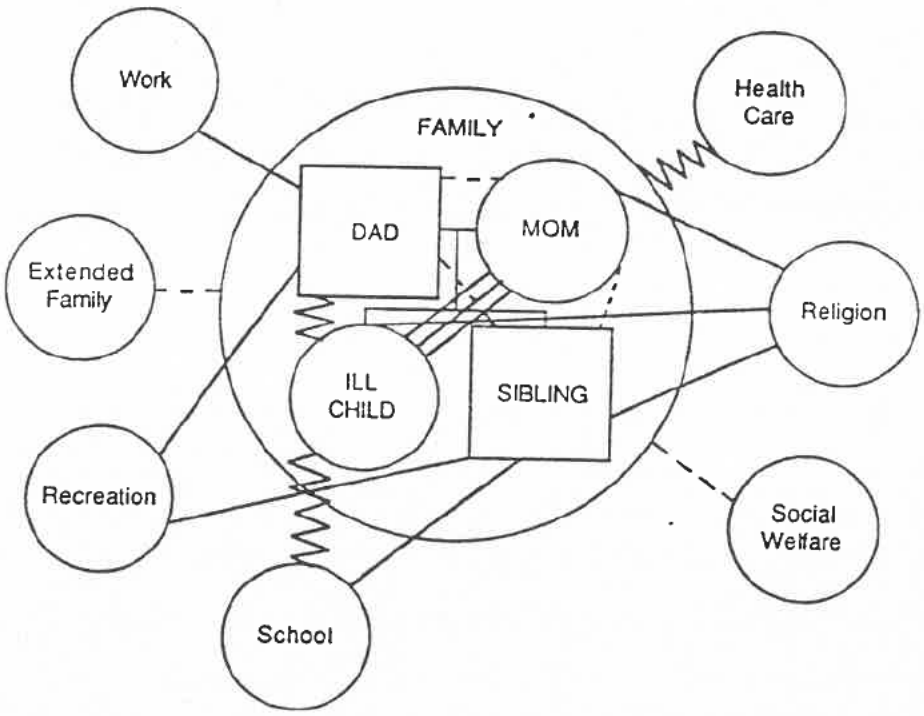

FIGURE 3.5: Ecomap of a Chronically Ill Child's Family
(From Gaudet & Powers, 1989; p.94).

While factors other than family organisation and functioning are acknowledged as contributing to the overall management of IDDM, the focus of attention is upon the relationships between; individual family members, individual family members and other systems, and the family and larger systems outside of it.

Though each case description does have its unique context, the way in which the structural descriptions are punctuated highlight a number of contexts that are common in families with children in poor control. Gaudet and Powers (1989) have gone as far as describing "typical relationships in the family system with a chronically ill child" (See Figure 3.5 above).

According to Gaudet & Powers (1989) the above ecomap is typical[3] of the relationships in a family system with a chronically ill child.

> After the diagnosis ..., the relationship between the father and mother typically becomes strained because of the father's initial denial of and the mother's overprotective reaction to the problem. The father usually becomes overinvolved in work, spending long hours away from home to avoid dealing with the reality of the situation, which results in emotionally distant relationships with the mother and children. Often his workaholic behaviour appears justified, since insurance seldom covers all the medical expenses. The mother, in turn, may form a coalition with the ill child, neglecting her other children, because most of her energy is expended in dealing with the pileup of stressors for which she alone feels responsible. ... The mother, then, is typically given an inordinate amount of responsibility in gaining access to adequate health care and social educational services. The entire family, however, tends to become more and more isolated as former plans and social patterns are interrupted and put on hold. The marital relationship is at risk as well, since emotional losses begin to pile up and marital strain increases (Gaudet & Powers, 1989; pp.95-96).

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3 *Generalisations about the "family", as illustrated in the above ecomap, only really apply to white, middle class, intact, heterosexual and sex-role stereotyped families (Candib, 1989). The families studied in this dissertation appeared to conform to the above description, with 13 of the 22 mothers (59%) describing themselves as housewives. It must be noted that only 23% of mothers in white South African families are not employed outside of the home (Shops and Shopping, 1985). While the Circumplex and Structural Family Therapy frameworks assume normative positions with regard to hierarchy, structure, and roles, the parameters of this position should be taken as specific to the family configuration described above, and should not be read to mean that alternative family configurations are less than ideal or less functional.*

The above description encapsulates the use of structural concepts common to many of the case studies. To summarise some of the common points, disengaged spousal subsystems place excess responsibility on the mothers for ensuring adequate health care, who, in turn become overly submerged, or enmeshed, in their parental function with the ill child. Under stress, the family does not possess the flexibility to seek alternate solutions to respond to developmental transitions and other stressors. Rigid boundaries may become established between families and external systems, isolating them from extended support networks. Other families may become too open to intrusion by well-meaning but disruptive and poorly informed helpers

Conflict between parents may become increasingly focused on, and expressed through, disagreements in relation to the sick child, increasing the risk of behavioural problems in the child developing, or being exacerbated. In some cases a pattern may develop where an acute detioration in the child's health status serves a centrifugal function of diverting attention away from marital or other conflict and focusing it upon the immediate needs of the child. With deteriorating metabolic control, management of the illness becomes a further focus of conflict for the parents. The mother's responsibility for ensuring proper management is reinforced by the physician who communicates with her and seldom sees the father. With time, the enmeshed relationship between mother and child threatens the development of increased autonomy and independence as the child grows older (Rosman, 1988; Sargent, 1982, 1983).

While descriptive reports are undoubtedly effective in providing practising clinicians with a powerful framework for understanding and working with the family and IDDM, it appears that terms like, for example, enmeshment, rigidity, and flexibility, have become relative and reified.

These differences in the use of terms, and differences in theoretical assumptions, have led to a number of published accusations and counter-accusations. Coyne and Anderson (1988), for example, severely criticise the work of Minuchin and his colleagues, claiming, amongst other things, that their interpretations are flawed and that the concept of the symptom having a function leads to an adversarial response to the family. Coyne and Anderson (Ibid) point out that even though much of the data for the

1975 study were never published "it is the text, and not the data, ... that has captured the attention of the field" (p.118).

In response, Rosman and Baker (1988) provide the "missing" data and reconfirm the conception of the symptom coming to serve a function in the "psychosomatic diabetic". Rosman & Baker (Ibid) also point out that over time aspects of the illness, both positive and negative, are shaped and accommodated within the family environment. Rosman and Baker conclude by suggesting that it is not their fault if other clinicians have over-generalised their psychosomatic model to all people with IDDM:

> If some have erroneously applied the model in a global way to the wrong patients, we will criticise them ... for lack of precise and rigorous thinking (p.131).

While the use of assessment instruments in the quantitative literature should allow for concurrent reliability in comparing studies and conclusions drawn, there are significant methodological problems, not least of which is that "instruments for measuring family functioning are still at a primitive stage" (Campbell, 1986; p.148).

3.7.4.1 Quantitative Studies

Families with diabetic children in good metabolic control have been found to be low stress environments in which the mothers are not overwhelmed by anxiety (Anderson & Auslander, 1980). Simonds (1977) in comparing 80 diabetic children with a "normal" control group, found that the divorce rate of families with children in good control was "unusually low" compared to both the normal and poor control groups, a finding which led Johnson (1980) to suggesting the hypothesis that "good control may be associated with unusually healthy or well-integrated families".

In reporting a five-year follow-up of 53 children (10 - 21 yrs) with IDDM and their families, Koski and Kumento (1977) found that the family environment of children with poor metabolic control was "chaotic, like living on a razor's edge" (p.44). Furthermore, intergenerational boundaries were diffuse and the ill children were affected by unresolved marital conflicts. By contrast, the families of children in good control were characterised as stable with clear boundaries.

Grey, Genel and Tamborlane (1980) investigated the relationships between psychosocial adjustment, family functioning (Family Functioning Index), self-esteem, and

metabolic control (24-hour urinary glucose excretion), in 20 children between the ages of 6 and 13 and found that poor metabolic control was positively associated with psychosocial maladjustment ($p \leq 0.05$), but not family functioning.

Hanson, Henggeler, Rodrigue, Burghen and Murphy (1988) compared the metabolic control (HbA1c) and regimen adherence of 30 diabetic adolescents in intact families with 30 diabetic adolescents in father-absent families and found that regimen adherence in the father-absent group was better ($p \leq 0.02$), but that there were no differences in levels of metabolic control. Hanson et al., conclude that the father-absent adolescents had adapted to the absence by assuming greater responsibility for their own health care.

Perceptions of fathers as being dominant and controlling were found to be predictive of poor metabolic control ($p \leq 0.05$) in a study of 40 adolescents by Marrero, Lau, Golden, Kershnar and Myers (1982). Conversely, adolescents who perceived their fathers as supportive and encouraging of autonomy were in good control ($p \leq 0.05$). While none of the perceptions of mothers' behaviour were significant, Marrero et al, (Ibid) noted trends in which adolescents in poor control perceived their mothers as being more rigid and protective.

A number of studies have used Moos' Family Environment Scales (FES) (cited in Anderson et al., 1981), to assess family functioning. Anderson et al., (1981) in a well designed cross sectional study of 58 adolescents and their mothers, found high cohesion ($p \leq 0.01$) and low conflict ($p \leq 0.05$) as reported by the adolescents on the FES to be associated with good metabolic control. Mothers' perceptions of cohesion ($p \leq 0.90$) and conflict ($p \leq 0.21$) were not predictive. Shouval, Ber, and Galatzer, (1982) found significant correlations between good metabolic control and high levels of cohesion. However, high levels of cohesion as measured by the FES were found by Wertlieb, Hauser and Jacobson (1986) to be associated with behaviour symptoms in diabetic adolescents. Unfortunately, Wertlieb et al., were comparing a group of diabetics with a control group of "normals" and did not assess metabolic control. Schafer et al., (1983), also using FES, found that only the conflict scale was predictive of HbA1c levels, high levels being associated with poor control ($p \leq 0.05$).

Cederblad, Helgesson, Larsson & Ludvigsson, (1982; cited in Campbell, 1986), using Olson's Family Adaptability and Cohesion Evaluation Scales (FACES), found that good metabolic control was significantly related to the mother reporting high adaptability in the family, while poor control was related to high family cohesion as reported by the father. Evans and Hughes (1987), found that diabetic adolescent's reports of low family adaptability (tendency to rigidity), as measured by FACES II, correlated with poor HbA1c levels ($p \leq 0.05$). With regard to cohesion, Evans and Hughes noted a trend for families tending towards enmeshment to have children with poorer control.

3.7.4.1.1 Family function and regimen adherence

Quint (cited in Anderson & Auslander, 1980) identified two basic responses in families to the required treatment regimen. In the group where adherence was generally good, the regimen was incorporated into ongoing family routines. In the second group, the treatment demands created recurring crisis events within the family.

A number of authors have found poor family functioning to be consistently related to failure to adhere to the required regimen (Becker, 1975; Schultz, 1980), while highly organised family environments, as assessed by the Family Environment Scale, were associated with good adherence (Shouval, Ber & Galatzer, 1982; Wertlieb, Hauser & Jacobson 1986).

Wertlieb et al., cautioned however, that, in the light of the strivings for independence and autonomy during and before adolescence, a family's emphasis on control, limits and rules could "spark" behaviour symptomatology in non-diabetic adolescents. Borrow, Avruskin & Siller, (1985) explored the relationship of mother-daughter interaction to adherence and found that adolescents with poor adherence had interactions with their mothers that were more emotionally charged and confrontational.

3.7.5 Summary

The above review has compartmentalised its consideration of factors found to be associated with metabolic control. This division, while artificial, partly reflects the fragmented approaches and understanding of the problem. Factors considered included emotional, demographic and physiological characteristics of the ill child, the role of stress, regimen adherence, and finally, family functioning.

The child's developmental stage, gender, emotional well-being, and the additional presence of acute illness have been shown to have a bearing on metabolic control. As concerns age at diagnosis and duration of illness, the findings are inconclusive. Research focusing exclusively on individual factors has failed to clarify the relationship between these factors and intervening variables such as stress and regimen adherence.

Family system oriented theory has outlined phases of adaptation to the illness and described how the illness and its context co-evolve, highlighting the complexity and interdependence of the relationships between organisational and structural aspects of the family, the child, and extrafamilial factors.

Stress has been shown to directly affect metabolic control through direct action on stress hormones, and indirectly in affecting the behaviour of the ill child, more particularly, regimen adherence. However, the ways in which stress, metabolic control, regimen adherence and family functioning interconnect is not clear. The number of stressful life events experienced by the ill child has been positively associated with metabolic control, while the family's ability to cope with stressors is thought to be an important intervening variable. Children experiencing high levels of stress have been shown to be susceptible to physiological complications associated with poor metabolic control.

The work of Minuchin and his colleagues, and studies on "brittle diabetics", have suggested that a home environment characterised by instability, conflict and certain structural patterns, directly and indirectly mitigate against good control, which, if repeated long enough, result in further physiochemical vulnerability in susceptible individuals. What is not certain though is which aspects of the family, both positive and negative, impact on metabolic control by supporting or demoting regimen adherence, and which aspects amplify or buffer the direct impact of stress on metabolic control.

Given the way in which illness and context co-evolve, only a carefully designed longitudinal study might be able, in specific families, to determine which came first, poor control or family dysfunction. A child from a poorly functioning family that is diagnosed as chronically ill is at risk for developing serious emotional and social problems, as well as exacerbating the negative effects of his or her illness (Pless,

Roghmann & Haggerty, 1972). Likewise, it is possible that a previously functional family may co-evolve with a situation of poor control into a dysfunctional state.

Both clinically based observations and quantitative studies are in agreement that family structure and interaction patterns have an important bearing on the child's metabolic stability and degree of adherence to the required regimen. While methodological snares have weakened some of the conclusions that can be drawn from most of the quantitative studies, there is some consensus that poor control is associated with rigid families in which there is a high level of conflict (Johnson, 1980; Hanson & Henggeler, 1984; Anderson & Kornblum, 1983; Campbell, 1986). However, as far as enmeshment or cohesion is concerned, the research is contradictory (See Table 3.5 below). The construct of cohesion has been shown to have little concurrent validity among self-report measures, as well as with observational descriptions. A number of authors argue that this is not unexpected as these scales are measuring different aspects of the same construct (Cromwell & Peterson, 1983; Oliveri & Reiss, 1984; Reiss, 1983).

In investigating an outcome that is dependent upon the complex interplay of multiple factors, it is not surprising that methodological difficulties temper the certainty of any conclusions that can be drawn. Independent variables have ranged from patient's knowledge about diabetes care (Goldstein, et al., 1980), individual psychological characteristics of the child (Tavormina, et al., 1976), family functioning (Anderson et al., 1981), psychosocial stress (Jacobson et al., 1983), and the physician-patient relationship (Solowiejczyk & Baker, 1981).

Studies have been justifiably criticised for drawing nebulous conclusions from research designs that have been theoretically groundless, predominantly cross-sectional in nature, not accounted for intervening variables or controlled for others, utilised constructs that have not been specific or independent, and have studied unrepresentative populations (Anderson & Auslander, 1980; Campbell, 1986; Johnson, 1980, 1985).

Many of the quantitative "family" studies reviewed above have relied on the perceptions of one or two family members, usually the mother and ill child. In those studies where the perceptions of more than one member was solicited, some members' perceptions were associated with adherence and/or control while others' were not.

TABLE 3.5: Summary of association of family factors, adherence, stress and stress mediating variables to metabolic control.

Good Control	Poor Control
Family function	**Family function**
High cohesion (Anderson et al., 1981; Hanson & Henggeler, 1984; Shouval et al., 1982)	***High cohesion*** reported by father (FACES) (Cederblad et al. 1982, cited in Campbell, 1986).
Rigid families in association with external locus of control (Evans & Hughes, 1987).	***Enmeshed families*** (Minuchin et al., 1975).
Good adaptability (Evans & Hughes, 1987) High adaptability in mother (Cederblad et al., cited in Campbell, 1986).	***Rigid families*** (Minuchin et al., 1975)
Distinct inter-generational boundaries (Koski & Kumento, 1977).	Boundaries between generations unclear (White et al., 1984).
Effective communication patterns (Sargent & Baker, 1983).	***Chaotic families, low cohesiveness*** (Anderson et al., 1981; Koski & Kumento, 1975, 1977)
Parental role flexibility (Sargent & Baker, 1983).	Over protective (Minuchin et al., 1975)
Stable families (Janis, 1983; Koski & Kumento, 1977; Swift et al., 1967)	Unstable families (White et al., 1984).
Regimen Adherence	**Regimen adherence**
Effective control of child's behaviour (Sargent & Baker, 1983).	Poor mother-daughter interaction (Borrow et al., 1985).
Father-absent families (Hanson et al., 1988).	Lack of parental support (Hanson et al., 1987).
Good family dietary patterns (Carney & Schecter, 1982; cited in Hanson & Henggeler, 1984).	Family conflict (Schafer, et al., 1983).
Parental involvement (Anderson et al., 1981).	Conflictual parent-child relationship (White et al., 1984).
	Poor parental leadership (Sargent & Baker, 1983).
	Overt marital strife (Sargent & Baker, 1983).
	Serious external stress (Sargent & Baker, 1983).
	Lacking support from peers (Borrow et al., 1985).
Stress and mediating variables	**Stress and mediating variables**
Coping skills - ie. how well family deals with multiple stressors (Baker et al., 1983; Delbridge, 1975; Koski & Kumento, 1975, 1977; Minuchin et al., 1975; Tarnow & Silverman, 1981/2).	High stress (Hanson et al., 1987; Johnson, 1980; Linn & Linn, 1983).
Social competence as a buffer between stress and poor control (Hanson et al., 1987).	Negative stress (Hanson & Henggeler, 1984; Hanson, 1983; Jacobson, Rand & Hauser, 1983, 1985; Jacobson, Hauser & Wolfsdorf, 1987) (Brand, Johnson & Johnson, 1986; found minimal relationship $p < .06$).
Positive stress (Hanson & Henggeler, 1984; Hanson, 1983)(No significant difference between high stress and low stress reported by Brand, Johnson & Johnson, 1986; Hauenstein et al., 1989).	Poor conflict resolution Minuchin et al., 1975).
Good social support (Hanson & Henggeler, 1984; Janis, 1983).	High conflict (Anderson, et al., 1981).
Reliance on parents for social support (Marrero et al., 1983).	Marital conflict (Koski & Kumento, 1987).
Good peer relationships (Grey et al., 1980).	Isolated families (Koski & Kumento, 1987).
Low family conflict (Anderson et al., 1981; Johnson, 1980; Simonds et al., 1981; Swift et al., 1967).	

3.8 IMPLICATIONS FOR RESEARCH

> The lack of adequate information and programs in the area of paediatric illness has been a problem because chronic illness is becoming a major life stressor for an increasing number of children and their families (Gaudet & Powers, 1989).

The question is, what constitutes "adequate information"? While piecemeal, the above review has highlighted some factors that should be included in any attempt to understand why it is that a child remains in a state of poor metabolic control. While it is clear that stress, individual factors, regimen adherence, and family functioning impact upon metabolic control, the way in which these aspects combine and influence one another is unclear.

The clinically-based structurally oriented literature provides the health care professional with an integrated conceptual framework which takes account of all of these variables, and also makes recommendations for intervention. According to Sargent, (1982), this approach;

> ... expands the physician's alternatives for intervention at any point in the course of the chronic illness, while directly amplifying his power in problem situations (p.138).

It seems that part of what constitutes "adequate information" is quantitative confirmation and further clarification of these observations.

> Physicians, as those who treat physical illness, are reluctant to believe that psychosocial factors can affect health. Rather, it is assumed that psychological changes which occur in illness are all the result of a change in health. This prevailing attitude in medicine is the result of at least three factors: 1) It is difficult to demonstrate empirically that psychosocial factors affect health, and many of the studies are of poor quality. 2) The mechanisms by which psychosocial factors affect health are poorly understood. 3) If psychosocial factors are "merely" the result of illness, and do not affect health directly, then many physicians would view them as nonessential aspects of their work (Campbell, 1986; p.137).

In the absence of any overall integration of the processes in which observed quantitative punctuations occur, even when added together, many research findings are of little assistance or relevance to the physician involved in the health care of people with IDDM (Antonovsky, 1989; Bloch, 1989; Herman, 1990; Sargent, 1982). An understanding of the broader treatment system, and ways in which it can be optimally

utilised, is essential if effective health care intervention is to occur (McDaniel, Bank, Campbell, Mancini & Shore, 1986).

However, due to the complexity of clinically-based systemic theories of family life, and a lack of methodological sophistication, the academic, empirically oriented body of knowledge concerning the family and IDDM is limited, conflicting and has concentrated on identifying "what" exists and done little to explaining "how" it exists. According to Johnson, (1986), the research literature lacks theoretical clarity and specificity in terms of definitions of constructs:

> Although it is reasonable to assume that family functioning influences child health and adjustment (and vice versa), the mechanisms by which this occurs are often left unclear. For example, family variables are frequently correlated with child health variables, but the intervening variables (e.g., ..., compliance with treatment tasks) are left unmeasured (pp.246-7).

It is essential that the formulation of research questions, and designs, into family factors affecting metabolic control and regimen adherence, and the subsequent interpretation of results, be informed by the following:

> a) a broad systemic understanding of the processes that may be set in motion when a child is diagnosed as having IDDM;
> b) the postulated mechanisms whereby family functioning, and intervening variables such as adherence to the prescribed regimen, affect metabolic control.

That the majority of children with diabetes do not have difficulties in maintaining metabolic control and regimen adherence, also directs that the adaptive and coping mechanisms of these families should be investigated.

According to Prigogine and Stengers (1984), the best way to investigate complex phenomena and their inter-relationships is by constructing models which can then be tested:

> We are trained to think in terms of linear causality, but we need new "tools of thought": one of the greatest benefits of models is precisely to help us discover these tools and learn how to use them. ... We come to problems where methodology cannot be separated from the question of the nature of the object investigated. ... basic choices must be made between various approaches to collective phenomena. ... We believe that models inspired by the concept of "order through fluctuations" will help us ... and even permit us in some circumstances to give a more precise formulation to the complex interplay between individual and collective aspects of behaviour. From the

> physicist's point of view, this involves a distinction between the states of the system in which all individual initiative is doomed to insignificance on the one hand, and on the other, bifurcation regions in which an individual, an idea, or a new behaviour can upset the global state (Prigogine & Stengers, 1984; pp.204-206).

3.8.1 Defining the research focus

As maintaining good regimen adherence and metabolic control are primary goals in the care of the diabetic, it is important that factors influencing them be clearly identified and their pathways of influence be understood. If certain family factors are associated with good adherence and control, and others are found to be a disruptive influence on adherence and control, these findings can have treatment implications for the management of the illness process.

Furthermore, if the instruments used are predictive of adherence and/or metabolic control, they might be useful in screening families of newly diagnosed diabetics for potential problems which may mitigate against the achievement of good adherence and/or control. An early and preliminary assessment could warn a physician of possible family dysfunction that has previously been associated with poor adherence and/or control.

Referring to the above quote from Prigogine and Stengers, the investigation of family factors associated with metabolic control and IDDM is one of those problems where the methodology cannot be separated from the nature of the question being investigated. The possible ways in which metabolic control is influenced by combinations of other factors inside and outside of the family is infinite. In this sense, the problem-defined system of illness and family retains some sense of continuity through "order through fluctuations".

Even though there are multiple influences upon the problem-defined system, a number of influences can be said to be more central than others, in that their impact on control and adherence is more direct. In other words, there are some identifiable aspects of the system which, if altered, can directly demote or promote control and adherence.

The review of literature has highlighted a number of factors that should be included

in any model of psychosocial factors affecting metabolic control (See figure 3.6 below). First, the part played by regimen adherence must be included in the problem-defined system. The review has indicated that regimen adherence mediates in the determination of metabolic control in some cases and not in others. Therefore, its position in the model reflects this possibility, making it one corner of the triangle - "X".

Another corner of the triangle would be family adaptability and cohesion and how they intervene in amplifying or reducing the impact of stress on the ill child. The concept of stress has been variously included in research studies concerned with metabolic control. What has transpired from these past two chapters though, is that, within limits, the way in which stress is mediated is more important than the typology and quantity of that stress. In this scheme of things then, stress per se could be excluded from the problem-defined system. It was argued in chapter two that the concepts of adaptability and cohesion were theoretically grounded in a pathogenic paradigm and it would be insufficient to consider them as the only category of family-related mediating factors in the way a child responded to stress. It was argued that it was necessary to complement the inclusion of these elements by adding a consideration of possible family factors that might promote health. While previous studies have not focused on possible salutogenic family factors that may assist the child in coping with stress, chapter two concluded that the constructs of family satisfaction, family strengths and family coping might be central.

While the individual adjustment of the child has been identified as influencing metabolic control, and should ideally be included for assessment within the problem-defined system, it could be excluded in that the Structural Model views the child's emotional well-being as contingent upon structural properties of the family (Abelsohn, 1985; p.xxi). However, the child's age and gender do need to be controlled for as they have been shown to be associated with metabolic control and regimen adherence.

In referring to Figure 3.6 below, the pathways along which stress can affect metabolic control seem more complex than just direct or indirect. If one accepts the structural premise that the child's emotional well-being is contingent upon structural properties of the family, there can be no "direct" effect of stress on the child's

physiology. It is argued that, in addition to a genetically determined constant, a child's perception of any stressor and the way in which he or she responds to it is also shaped by and learnt from his or her social context, primarily the family.

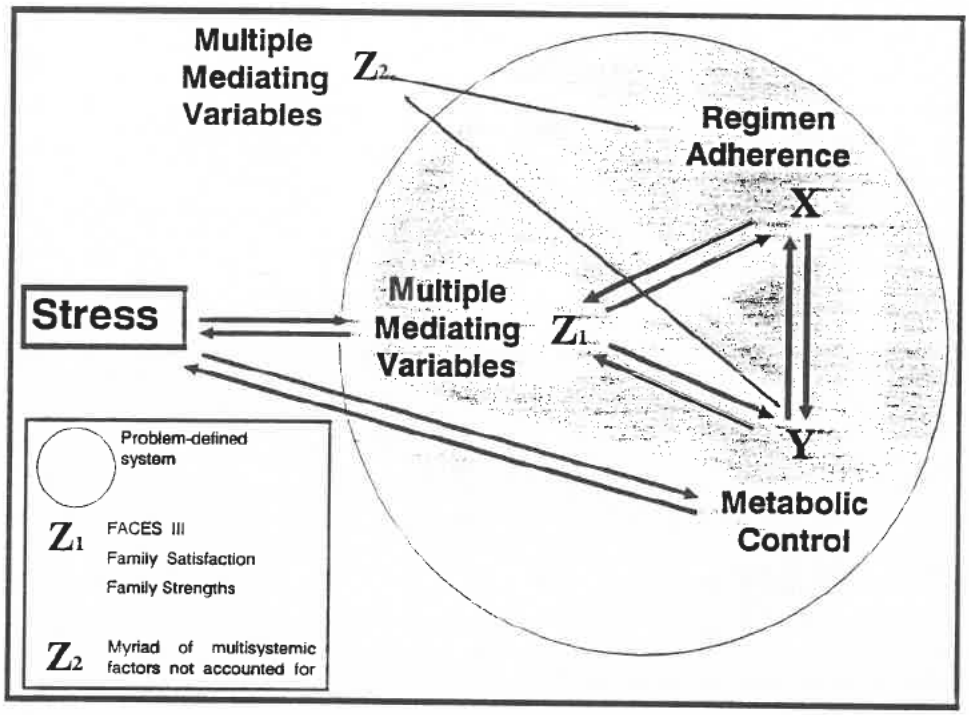

FIGURE 3.6: Model of the problem-defined research focus of this dissertation.

While it could be argued that, for example, a dysfunctional family structure, or the absence of certain coping behaviours, are a source of stress in themselves, this author takes the position that these structures and characteristics serve to amplify or reduce the effects of other stressors. For example, while a particular conflict in the family may have a lot to do with an enmeshed dyad, it is that particular conflict that creates the stress being experienced by the ill child, not the enmeshed relationship. The enmeshed relationship may serve to assist the child in dealing with the stress, or it may have the effect of amplifying the effects of the stress. In this sense then, the family factors listed under "Z1" are conceptualised as variables that serve to either buffer or amplify the

ultimate effects of stress on metabolic control. From point "Z1", the effect of the stress may be "direct", and/or "indirect" in that it may be further amplified or reduced as a result of the degree to which the child adheres to the required regimen.

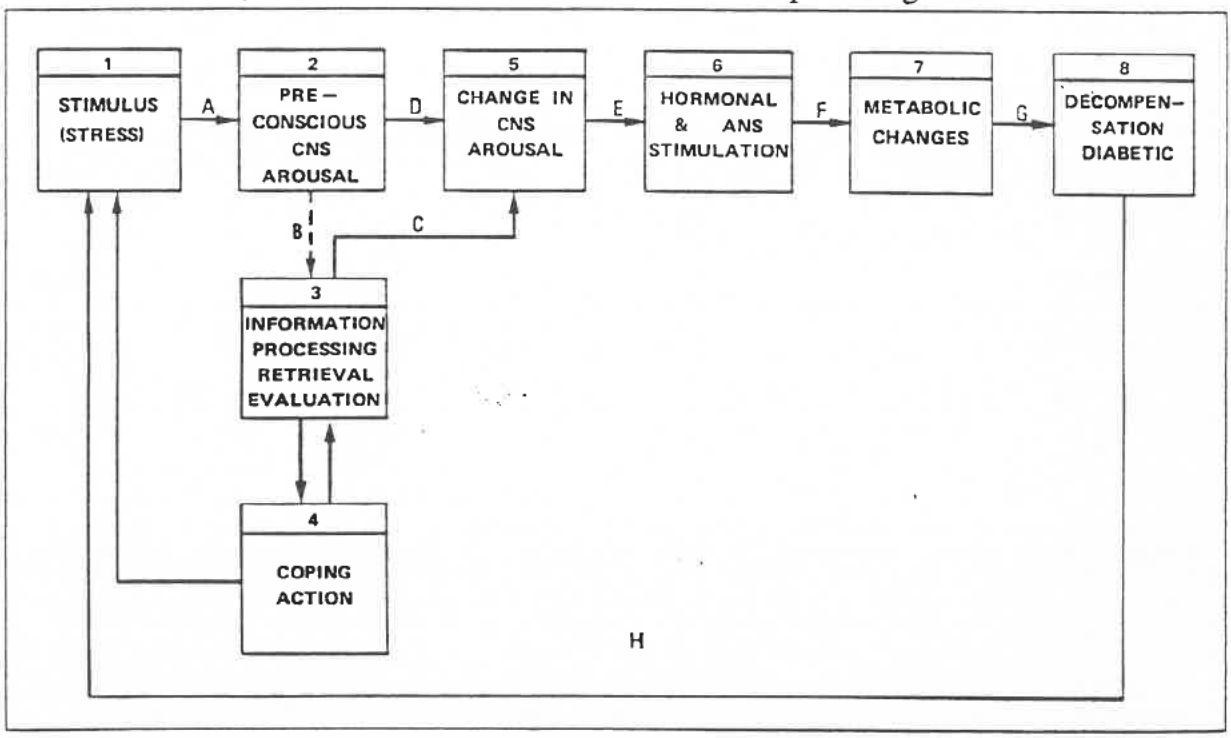

FIGURE 3.7: Schematic representation of the process by which psychological stress is mediated into physiologic reaction. (From Tarnow & Silverman, 1981; p.35).

While the distinctions between "direct" and "indirect" may seem fine, they are important in highlighting that the "beginning" and the "end" of the pathways under consideration are stress and metabolic control respectively. However, as already discussed, what happens to the "stress" before the "endpoint" of metabolic control appears to be more important than the "intensity" or "frequency" of particular stressor events.

While Tarnow and Silverman (1981) outline the temporal pathway by which stress comes to act upon metabolic control at the system level of the individual (See Figure 3.7 above), the psychosocial mediating aspect of "coping action" could be expanded to incorporate the family and other mediating variables (See figure 3.8 below).

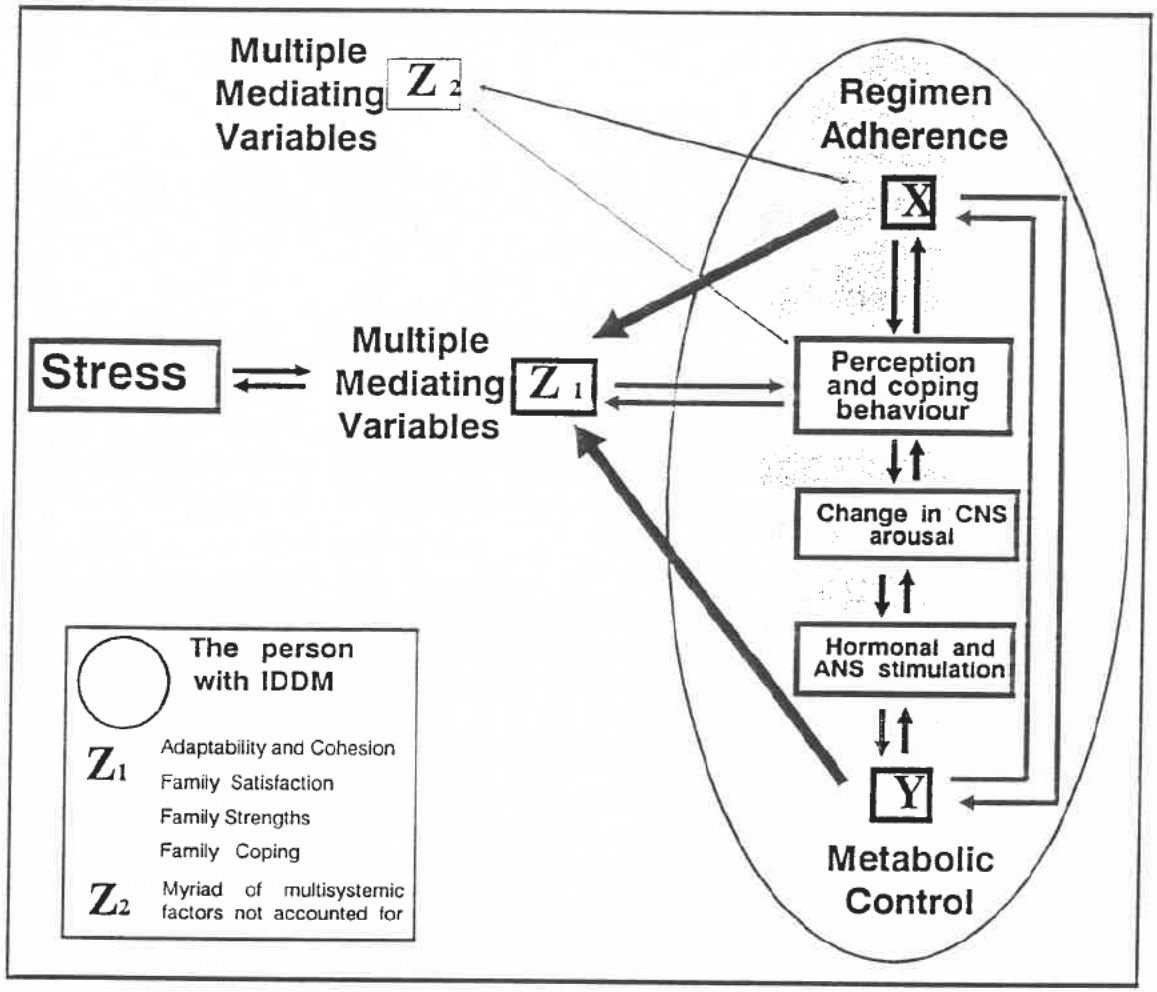

FIGURE 3.8: Expanded conceptual model outlining pathways between stress and metabolic control

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The coping actions of the child, delineated in step four of figure 3.7, are in response to the stress and may amplify or nullify it. In keeping with structural assumptions, the child's coping actions should be isomorphic with the family's coping behaviour, and would also be assisted or hampered by the factors listed under "Z1" in figure 3.6.

In other words, as concerns the role of psychosocial factors, all changes in metabolic control are primarily a stress response. What this research is focusing upon is the extent and nature of the association between an individual's metabolic response

to stress (Y), regimen adherence (X), and the hypothesised stress-mediating family factors listed under "Z1".

Having delineated the basic parameters of the research model, all that remains is to design an investigation that will assist in confirming or denying if these factors are associated with metabolic control, and then attempt to clarify the pathways and relationships between them.

CHAPTER FOUR

RESEARCH METHODOLOGY AND METHOD

4.1 INTRODUCTION

The predominant means employed by social scientists in the study of social phenomena has been based upon the conception that the method and methodology employed should emulate what are thought to be those of the physical sciences (Bailey, 1987). In adopting this classical positivist approach it is assumed that social phenomena are objectively occurring events that can be impartially quantified, and then analyzed with a view to generating scientific causal laws that hold for all times and all places. As discussed in chapter two, in the light of developments in physics early this century, this paradigm is no longer adequate.

> All description thus implies a choice of the measurement device, a choice of the question asked. In this sense, the answer, the result of the measurement, does not give us access to a given reality. We have to decide which measurement we are going to perform and which question our experiments will ask the system. Thus there is an irreducible multiplicity of representations for a system, each connected with a determined set of operators (Prigogine & Stengers, 1984; pp.224-225).

The literature reviewed in chapter three suggests that there are certain identifiable family characteristics, both salutogenic and pathogenic, that may be associated with the health care behaviour and the physical well-being of the individual with IDDM. Based on the review of literature, and informed by the Structural paradigm of family functioning, a model was constructed (See figures 3.8 and 3.6) in order to guide the research process. While regimen adherence and metabolic control will be assigned the status of dependent variables for the purpose of statistical analysis, the model indicates that unidirectional causality and temporal priority of the independent family variables is not implied.

The questions generated from the model can be categorised into four broad categories. The first set of questions seek to clarify the ability of the Circumplex Model of Family Functioning, as operationalised by FACES III, to discriminate between good and poor metabolic control and regimen adherence respectively. While the literature

reviewed suggests that family function and organisation are associated with control and adherence, the certainty of these conclusions is tempered by conflicting results obtained from different assessment instruments and research designs. High levels of family cohesion, for example, have been associated with good and poor levels of metabolic control.

Also, a number of previous investigations have employed spurious methods of statistical analysis in their use of FACES III (Evans & Hughes, 1987; Lindegger, 1988; Pillay, 1989) in that they have applied traditional linear analysis, using parametric statistics, to the curvilinear constructs of adaptability and cohesion. However, as all of them report significant results, exploratory investigations using a linear conception of these constructs is merited.

A further problem with regard to past literature is that some studies have "overinterpreted" the results of cross-sectional studies of the "family" by ascribing causation on the basis of correlational data obtained from individual family members (Campbell, 1986). While transactional data cannot be generated from studies using the self-report method of data collection, validity can be improved in obtaining relational family data by comparing individual scores with those of other family members. Olson et al., (1985) describe a number of ways in which relational data can be generated from the FACES III scales.

The second set of questions are concerned with identifying possible salutogenic family factors that may buffer the effects of stress on regimen adherence and metabolic control. This set of questions is more exploratory in nature than the first in that there appears to be no research documenting the association of possible salutogenic family coping variables with metabolic control and regimen adherence. However, the theoretical basis of the constructs described in chapters two and three do allow for the generation of specific hypotheses.

The last two sets of questions address a higher level of methodological complexity in that they attempt to clarify the pathways along which these variables relate to one another. Firstly, what combinations of variables, individually identified as significantly associated with control and/or adherence in the correlational phase of the

data analysis, would best be able to discriminate between children with good and poor control and adherence? The last question seeks to explore the pathways along which these family variables operate. For example, are some variables more "indirectly" associated with metabolic control via their influence on regimen adherence, and vice versa?

While hypotheses can be generated with regard to the first two sets of questions, the last two are exploratory and based upon the "select and reduce" process advocated by Fisher et al., 1990).

4.2 STATEMENT OF HYPOTHESES

The relational nature of the data gathered from different family members on FACES III means that a variety of scores on each variable will be generated, each reflecting a different aspect of the same reality. It is expected that some family members' perceptions may show significant associations with the dependent variables, while others might not. There is insufficient information, theoretical and quantitative, to enable the generation of hypotheses as to which measures of the same variable might and might not be significant. There also appears to be some confusion concerning the linear versus curvilinear nature of the constructs of cohesion and adaptability. As a result, only very tentative hypotheses concerning some of the constructs assessed by FACES III can be put forward.

Hypothesis 1: Metabolic control and regimen adherence
There is a significant positive relationship between metabolic control and a) the parents' report, and b) the physician's report, of the child's regimen adherence, with good control associated with good adherence.

Hypothesis 2: Regimen adherence
There is a significant positive correlation between parents' and doctors' reports of regimen adherence.

Hypothesis 3: Metabolic control and distance from the centre
There is a significant positive correlation between metabolic control and Distance from Centre of Circumplex, as defined by the Circumplex Model, with families of children in good control being classified as closer to the Centre of Circumplex.

The perceived and ideal versions of the combined family score as well as the individual

members' scores will be compared to HbA1c levels.

Hypothesis 4: Regimen adherence and distance from the centre
There is a significant positive correlation between Distance from Centre of Circumplex, as defined by the Circumplex Model, and a) parents' and, b) doctors' reports of regimen adherence, with families with children having good adherence being classified as closer to the Centre of Circumplex.

The perceived and ideal versions of the combined family score as well as the individual members' scores will be compared to adherence.

Hypothesis 5: Metabolic control and family satisfaction
There is a significant negative relationship between family satisfaction and metabolic control, with higher satisfaction associated with good control.

Hypothesis 6: Regimen adherence and family satisfaction
There is a significant positive relationship between family satisfaction and regimen adherence as reported by a) the child's parents, and b) the physician, with higher satisfaction associated with good adherence.

Hypothesis 7: Metabolic control and family coping
There is a significant positive relationship between the utilisation of family coping strategies and metabolic control, with an increased use of coping strategies associated with good control.

Hypothesis 8: Regimen adherence and family coping
There is a significant positive relationship between the utilisation of family coping strategies and regimen adherence as reported by a) the child's parents, and b) the physician, with an increased use of coping strategies associated with good adherence.

Hypothesis 9: Metabolic control and family strengths
There is a significant positive relationship between family strengths and metabolic control, with an increased presence of family strengths associated with good control.

Hypothesis 10: Regimen adherence and family strengths
There is a significant positive relationship between family strengths and regimen adherence as reported by a) the child's parents, and b) the physician, with an increased presence of family strengths associated with good adherence.

4.3 EXPLORATORY INVESTIGATIONS

4.3.1 Family types, family adaptability and family cohesion

Due to the conflicting conclusions of past studies, and theoretical disputes over the curvilinear hypothesis of the Circumplex Model of Olson, McCubbin, et al., (1983) (Beavers & Voeller, 1983; Green, Kolevson & Vosler, 1985; Lee, 1988b), specific hypotheses concerning the relationship of family adaptability and cohesion to regimen adherence and metabolic control are not possible. While curvilinear notions of family adaptability of cohesion should preclude any linear analysis and correlation with adherence and control, the only study located that was concerned with metabolic control that used FACES (Evans & Hughes, 1987), ignored the curvilinear hypothesis and found that family adaptability, as perceived by the diabetic child, correlated significantly with metabolic control ($p \leq 0.05$). Two other studies, (Lindegger, 1988; Pillay, 1989) also utilised a linear conception of adaptability and cohesion and found statistically significant relationships between raw adaptability and cohesion scores with dependent variables. However, a problem arises in that linear and curvilinear conceptions are mutually exclusive.

For this reason, both approaches will be explored for their ability to discriminate between good and poor adherence and metabolic control. From a linear point of view, Pearson Product-Moment correlations of all the individual family adaptability and cohesion scores will be undertaken with both regimen adherence and metabolic control. From the curvilinear point of view, each family member's perceived score on adaptability and cohesion will be classified, using standards supplied by Olson McCubbin et al., (1985), into balanced or extreme types. These two scores are then combined in order to classify that individual's perception of his or her family type as either balanced, mid-range, or extreme. An overall family type, composed of the combined individual scores is also determined. These manipulations result in three scores being generated for each family member and three more representing the overall family, meaning fifteen scores for a family of four. A series of Chi-square analyses will be conducted with groups categorised into good and poor control and adherence.

While the theoretical debate concerning the linearity of the concept of cohesion is

beyond the scope of this dissertation, the methodological inconsistencies in the operationalisation of the Circumplex Model need to be addressed as they are directly applicable to the present study.

It is deemed important that all individual family members' scores be taken into account, as opposed to using an only an "overall" score, as there appear to be some logical inconsistencies in rationale, construction and use of the Circumplex Model.

All three versions of FACES were developed and refined by using "normal" populations. In the case of FACES III the authors derived their definitions of, and quantitative cut-off points for, balanced, mid-range and extreme families based on data from a study of 1000 "normal" (Lutheran American) families (Olson, McCubbin et al., (1985). As evidence of the discriminatory power of the Circumplex Model, Olson, McCubbin et al., quote ten studies of clinical populations in which the Circumplex Model of family types was able to distinguish between "problem" and "non-symptomatic" families.

However, in the very next paragraph of the manual, Olson, McCubbin et al., (Ibid), suggest that the curvilinear hypothesis on cohesion does not apply to "normal" families. From their study of 1000 "normal" families, the authors note that "there appears to be a linear relationship between cohesion and change in family functioning" with higher levels of cohesion and change "associated with better family functioning" (p.14). They then go on to explain this finding:

> A primary reason for this is that normal families represent only a narrow spectrum of the range of behaviour on these two dimensions. As a result, there are very few of the "normal" families that ***legitimately*** fall into the extreme types (Ibid; p.14). (emphasis not in the original).

How is it possible that a model in which cut-off points for categories are derived from "normal" populations is only applicable to "clinical" populations? To all intents and purposes, the population of families with diabetic children in their study could be considered "normal". Yet, looking at Table 4.1 below, 40 of the 78 respondents (51%) perceived their families to be extreme on at least one of adaptability or cohesion (Full listing of scores in Appendix G, page 183). Of those 40, eleven perceived their families to be extreme on both dimensions.

A further problem arises in the variance of perception of family types within the same family. On closer inspection, a number of the studies quoted by Olson, McCubbin et al., (1985) classified family type based on the reports of one and sometimes two family members. As can be seen from Table 4.1 below, "family type" varies depending upon which family member is asked.

In their manual Olson, McCubbin et al., (1985) direct that combined family adaptability and cohesion scores be computed by finding the mean of the individual scores (p.36). The family type score is then determined by using the supplied cut-off scores. A number of statistically-related problems remain unresolved with the Circumplex Model's notion of family types. First of all, taking just one family member's scores on adaptability and cohesion, the range in scores is diminished by reducing these scores to two categories, balanced or extreme. Scores reflecting extremely low cohesion and extremely high cohesion are given the same value, despite the noted linear relationship in "normal" populations. The nature of the variance is then further distorted by combining scores on adaptability and cohesion into one category, balanced, mid-range or extreme. The problem becomes really compounded when a "family type" is to be classified on the basis of more than one member's response, as can be seen below from the data generated in this study.

TABLE 4.1: Frequency distribution of perceived family types as reported by individual members, plus combined family mean type

	Balanced	Mid-range	Extreme	N
Index Patient	8	5	4	17
Mother	11	7	4	22
Father	14	7	1	22
Sibling	5	10	2	17
	38 (49%)	29 (37%)	11 (14%)	78
Combined Family Type	16 (73%)	6 (27%)	0 (0%)	22

The designation of combined family type is based upon the mean of the family members' adaptability and cohesion scores which results in a distorted "smoothing out" of the

opposite extremes.

Because the sample size in the present study is small compared to the large number of potentially unstable scores, the significance level will be reduced to $p \leq 0.01$ for computation of the Pearson Product-moment correlation matrix, Chi-square and Fisher's exact probability tests.

4.3.2 Regimen adherence and metabolic control

Referring to the model proposed in chapter three (See figures 3.6 and 3.8), two exploratory questions will be addressed. Firstly, by means of discriminant analysis, a search will be made to identify which combination of variables is best able to discriminate between good and poor metabolic control and regimen adherence respectively. Combinations of variables from each of the hypothesised family mediating constructs in Z1 will be submitted to discriminant analysis. As there are many possible scores that could be included in these analyses, variables that are either theoretically significant or, show a significant Pearson correlation with the dependent variable, will be considered.

Discriminant analysis "is the statistical technique most commonly used to investigate" which combinations of multivariate data can best predict the classification of cases into the groups defined by the dependent variables (Norusis, 1985; p.75). Norusis (Ibid) provides an example, parallel to the aims of this exploratory investigation, in which discriminant analysis was used to determine which combination of variables from sex, APGAR, age, time, weight, PH, treatment and respiratory therapy, was best able to predict an infant's survival in infants diagnosed as having respiratory distress syndrome. In the same way, this study seeks to explore which stepwise combinations of variables best predict the categorisation of cases into good and poor control and adherence.

While the mathematics involved in two-group discriminant analysis are similar to multiple regression analysis, discriminant analysis performs well on small sample sizes (Norusis, 1985).

The second exploratory question seeks to establish the relative association with metabolic control and regimen adherence of a small number of variables, the varying emphases of these variables along the pathways of $Z1 \rightarrow X$ and $Z1 \rightarrow Y$. Referring back

to figure 3.6, and the review in chapter three, it has been suggested that some family variables may act more "directly" on metabolic control (Z1 → Y) and others more "indirectly" via regimen adherence (Z1 → X → Y). The relative emphasis of these variables on the different pathways will be determined by comparing their correlation coefficients within the same pooled within-groups correlation matrices that are computed as part of the discriminant analyses.

4.4 METHOD

4.4.1 Subjects

Twenty two intact, white, middle-class, South African nuclear families living in the greater Durban and Pietermaritzburg areas, each with an insulin-dependent diabetic child between the ages of 10 and 20 were included in the study. All of the children with IDDM had been insulin dependent for at least a year and none of them had been unexpectedly admitted to hospital in the twelve months prior to the interview. Thirteen of the children with diabetes were female with their mean age being 14,4 years and mean duration of illness being 6,2 years, and nine were males with a mean age of 14,6 years and mean illness duration of 5,5 years (See Table 4.2 below).

TABLE 4.2: Age, gender and duration of IDDM of ill child

	N	Mean	Range
Age (yrs)	22	14,5	10 - 20
♂	9	14,6	10 - 20
♀	13	14,4	10 - 20
Duration (yrs)	22	5,9	1 - 17
♂	9	5,5	2 - 14
♀	13	6,2	1 - 17

As concerns developmental stage, all of the families fit into stages four and five (families with adolescents, and families with the eldest child having left home) as described by Olson, McCubbin, et al., (1985). The average age of the mothers was 42,3 years (SD = 5,07), the fathers, 46,2 years (SD = 5,80) and the siblings closest in age to the ill

child, 16,1 years (SD = 3,90). The mean number of children in each family was 2,68 (Range = 2-5). For 19 of the 22 families this was the first marriage for both parents.

While no formal measure of socio-economic status was obtained, the home visit and family interview indicated little variance among the families, with all of them owning their own homes and being able to afford private health care for their ill child. Thirteen of the 22 mothers (59%) described themselves as housewives with their family being economically sustained by the fathers' income alone.

As far as the educational level of the parents is concerned, there were four families in which both parents had university first degrees or higher, nine families in which both parents had matric or its equivalent, five families in which one parent had matric or its equivalent, and four in which both parents had completed standards eight or nine.

Other than the child with IDDM, no family members had a chronic illness or physical handicap, emotional difficulties, behavioural or educational difficulties (as reported by the mother).

4.4.2 Procedure

Written consent to use FACES III, Family Strengths and F-COPES was sought and obtained from the authors.

Three medical practises identified as specialising in the care of children with IDDM were visited in Durban (2) and Pietermaritzburg (1). All three of the doctors contacted had post-graduate specialist qualifications. The purpose and nature of the intended research was explained and their assistance was requested in introducing the author to families in their practices that were intact, white, middle-class, and had a child with IDDM.

The families were informed by their doctors of the research project by means of letter, direct contact or telephone, and were asked if they would be interested in participating. Thirty-four families were identified as meeting the required criteria. In one of those families however, the teenage child with IDDM had recently had an abortion and the doctor concerned requested that the family be excluded. Of the 33 families contacted only one refused. Upon learning of their agreement to participate in the research the author contacted either the mother or the father by telephone and

arranged a time whereby all family members living in the household could be interviewed and assessed in their home.

Each home visit lasted an average of one hour. The purpose and nature of the research was described in broad terms to the families, and the absolute confidentiality of each family member's responses was guaranteed. Questions were invited and answered. It was the author's experience that these families volunteered much unsolicited information concerning the experience of living with someone who had IDDM and the adjustments that had been made. Once all questions had been answered, one of the parents was asked to sign an informed consent form, after which a structured in-depth family history interview was conducted (See Appendix A, page 173). Demographic details were solicited from each family member. The parents were also asked if any of their children, in their opinion, had any noteworthy emotional or behavioural problems.

Before handing out the questionnaires to individual family members the completion procedure was explained and members were encouraged to ask for clarification if they were uncertain or did not understand a question. It was emphasised that there were no right or wrong answers and confidentiality was again assured.

Ten of the families interviewed were excluded from the final analysis for a number of reasons. In seven of the families the age of the ill child ranged from two to seven years, with the duration of illness in three of those being less than one year. In one family the child with diabetes also had cystic fibrosis, and in another the father was physically handicapped and confined to a wheel chair. The data from the last of the ten excluded families was incomplete. Both the father and a brother had urgent business elsewhere and were expected to be late. After an hour and a half of waiting the author had to leave for another appointment. The mother had not yet completed all of her questionnaires and said that she forward them by post, along with and the FACES III questionnaires which she would ask her son and husband to complete. The completed questionnaires were never received.

All family members 12 years of age and older were given both the perceived and ideal version of FACES III to complete. Of the 22 children with IDDM, 17 were old enough to complete FACES III, while at least one sibling was able to complete the

questionnaires in 17 of the families. In addition, the mother and father were asked to complete a questionnaire concerning regimen adherence, and the mother was also given the Family Strengths and F-COPES questionnaires to complete.

4.4.3 Instruments

4.4.3.1 Family Adaptability and Cohesion Evaluation Scales (FACES III)

The Family Adaptability and Cohesion Evaluation Scales (FACES III) (See Appendix B, page 174) are one of a battery of marital and family assessment instruments devised by Olson and his associates (Olson, McCubbin et al., 1985). FACES-III comprises two 20-item self-report five-point Likert scales (1 = almost never, 5 = almost always) soliciting a perceived and an ideal description of family adaptability and family cohesion.

Each version has ten items designed to measure family adaptability and ten items designed to measure family cohesion. The combination of the scores on the dimensions of family adaptability and family cohesion enable an identification of family types according to the Circumplex Model. Norms and cut-off points for each of the four levels of adaptability and cohesion (based on a survey of 1000 primarily white, Lutheran American families) are provided according to stages of the family life cycle.

4.4.3.1.1 Reliability and Validity of FACES III

Test-retest reliability scores over a four to five-week period are good (Cohesion: r = .83; Adaptability: r = .80) (Olson, 1986). Alpha reliabilities for FACES-III are relatively good (cohesion = .77; adaptability = .62). Correlations with social desirability are weak (r = .35 for cohesion; r = .00 for adaptability) (Olson et al., 1985).

Research by Bilbro and Dreyer (1981) on FACES, the original version of FACES-III, brought into question its discriminant and convergent validity. However, Edman et al., (1990) point out that using discrepancies between family members' perceptions of their own family as an indication of poor convergent validity is not valid as these differences in perception may be very real. Using a different design, Edman et al., (1990) conclude that FACES-III has both discriminant and convergent validity.

The FACES III questionnaires appear, according to Campbell (1986), " ... to be the most carefully designed and tested family assessment instrument presently available" (p.147). However, as already discussed, there appear to be some problems with the way

in which data is generated from the completed questionnaires.

4.4.3.1.2 Data Analysis using FACES III

Each family member generates four initial scores, (adaptability perceived and ideal, cohesion perceived and ideal) from which a wealth of comparative statistical data, reflecting a variety of family relational aspects can be generated. The curvilinear hypothesis of the Circumplex Model dictates that raw scores generated require analyses involving frequency distributions, chi-square for example, as opposed to traditional linear analytic methods of using mean scores (e.g. analysis of variance and t-tests).

Olson et al., (1985) do however describe two orthogonal linear scores, suitable for correlational analysis, that can be generated from the questionnaires, Distance from Centre of Circumplex, and Family Satisfaction.

Family Satisfaction

A measure of individual members' satisfaction with their family systems can be generated by determining the inverse of the sum of the discrepancy between perceived and ideal scores on adaptability and cohesion. A measure of individual satisfaction on each of adaptability and cohesion can also be obtained in the same way. The total family satisfaction score is obtained by determining the inverse of the mean of individual perceived/ideal discrepancy scores (Olson et al., 1985; p.26).

A measure of family satisfaction is especially important in identifying cases where scores of family members indicate satisfaction with their families even though the Circumplex Model categorises that family as an extreme type. Conversely, while perceptions of the family may concur, the relative extent of individual dissatisfaction with the status quo is indicated.

Distance from Centre of Circumplex

Distance from Centre of Circumplex (DFC) indicates the distance of an individual's, or a family's, combined cohesion and adaptability scores from the centre of the Circumplex Model. Statistically speaking, the advantage of the DFC score over Family Types is twofold. Firstly, it is a linear score generated from a comparison with a standardised constant based upon the mean score of the respondents in the 1000 families. As can be

seen from Table 4.3 below, these mean scores are not all that different to the ones generated in the present study.

The second advantage of the DFC score over family types is that the original variance in individual scores is maintained, allowing for a continuum of scores as opposed to discrete categories, an interval level of measurement as opposed to nominal.

The limitation of the DFC score is that it does not indicate the direction of the score, for example, a chaotically enmeshed family type could have the same score as a rigidly disengaged family type. Formulae for computing individual, couple and family DFC scores occur on page 34 of Olson et al., (1985). Both perceived and ideal discrepancy scores will be considered as it is likely that the "ideal" scores of family members will reflect normative conceptions particular to each family. Associations having a significance level of $p \leq 0.05$ will be considered.

TABLE 4.3: Comparison of mean adaptability and cohesion scores with norms provided by Olson, McCubbin et al., (1985). (Standard deviations in brackets)

	COHESION		ADAPTABILITY	
	Present Study	Olson's norms	Present Study	Olson norms
Index Patient	39.7 (6.1)	39.8 (5.4)	23.9 (6.3)	24.1 (4.7)
Mother	40.8 (4.4)	39.8 (5.4)*	26.3 (5.6)	24.1 (4.7)
Father	38.6 (4.3)	39.8 (5.4)	25.3 (4.7)	24.1 (4.7)
Sibling	35.8 (8.2)	39.8 (5.4)	24.4 (6.2)	24.1 (4.7)
Total	**38.7 (4.1)**	**37.1 (4.5)**	**25.1 (4.3)**	**24.3 (3.3)**

* No distinction is made by Olson, McCubbin et al., between family members concerning the norm scores of individuals.

4.4.3.1.3 FACES III: Multiple measures and Type I errors

The large number of scores that can be generated from FACES III reflects the different relational aspects of individual and combined perceptions of family adaptability and family cohesion. The resultant "subject to variable ratio" is heavily skewed, increasing the possibility of generating Type I errors and dependencies across domains.

Fisher et al., (1990) argue that such a risk "may be worth the price" in that each

variable, while possibly correlated with other family variables, may make a unique contribution in itself and that multiple measures of a phenomenon as non-deterministically complex as the family are justified. Olson et al., (1985) also advocate multiple measures:

> Since it is relatively inexpensive and easy to run a variety of chi-square analyses, it is recommended that a series of analysis be computed to attempt to reveal the most salient findings (p.32).

4.4.3.2 F-COPES: Family Crisis Oriented Personal Evaluation Scales

The Family Crisis Oriented Personal Evaluation Scales (F-COPES) is a 30 item self-report scale, rated on a five point scale, developed to identify effective problem solving and behavioural strategies utilised by families in difficult or problematic situations (See Appendix C, page 176). As discussed in chapter two, the instrument has two dimensions: 1) Ways in which a family uses resources from within the family to cope with stressors - measuring confidence in problem solving, ability to reframe family problems, and family passivity; 2) Ways in which a family uses resources from outside of the family to aid in coping with stressors - measuring use of religious resources, extended family, friends, neighbours, and community resources.

Olson, McCubbin et al., (1985) list extensive reliability and validity checks used in the final development of the instrument. The final instrument was tested on a sample of 2740 people with Cronbach's Alpha being computed on split halves for each of the five factors as well as the total score. The overall alpha reliability for both samples was 0.86 and 0.87 respectively. As concerns the five individual factors, the lowest alpha score was for the "Passive Appraisal" subscale (0.62) while the "Acquiring Social Support" subscale indicated an alpha reliability of 0.84. Test-retest reliability over a period of seven weeks was computed as 0.81 for a sample of 119 respondents.

4.4.3.3 Family Strengths

The Family Strengths scale is a twelve-item self report questionnaire developed to tap those variables which enable families to weather normative and unexpected crises in the family (See Appendix D). Respondents are asked to agree or disagree on a five point scale on positively and negatively worded items relating to two dimensions: 1) family pride, seven items identifying pride, loyalty, trust and respect attribute, and 2) Accord,

five items tapping the family's sense of competency.

The same sample (N = 2740) was used in determining validity and reliability as in the F-COPES scale. Cronbach's Alpha was computed on split halves for each item, the two factors (Pride - 0.88; Accord - 0.72), and the total score (0.83). Test-retest reliability for the factors of Pride and Accord were 0.73 and 0.79 respectively. The author could not locate any studies that had used this scale, nor any evidence of concurrent validity with regard to the constructs measured. The rationale for using Family Strengths is largely exploratory.

4.4.3.4 Regimen Adherence Scale

While there is no single accepted method for assessing regimen adherence, reports from the ill child, physician, or the parents appear to be the most popular. Naturalistic observation in order to obtain a measure of the child's adherence has been largely discounted as, according to (Brownlee-Duffeck et al., (1987), it and would tell more about the patient's capabilities rather than typical adherence behaviours.

In order to increase the reliability and validity of a measure of the ill child's regimen adherence, and to explore any possible differences in perceptions, both physician reports and parental reports were solicited. The scales employed are derived from those used by Jacobson et al., (1987) and elicit responses concerning behaviours judged by paediatric diabetologists to be important areas of diabetes self care (See Appendix E & F). Four levels of behaviour with regard to diet, metabolic monitoring, and insulin administration were defined and the respondents were asked to rate the patient as excellent, good, fair, or poor on each of the three adherence behaviours. The maximum score of 12 indicated excellent adherence. The scores were split into two equal groups, good and poor adherence, by means of a median split of children with scores of 8 and below, and scores above 8.

Parents were also asked to indicate which aspect of the regime was most difficult for their child to adhere to, diet, injections, or blood glucose monitoring.

4.4.3.5 Metabolic Control: Glycosylated Haemoglobin HbA1c

Glycosylated haemoglobin levels (HbA1c) are the most reliable physiological indicators of mean long-term blood glucose concentrations for up to three months before

measurement (Symonds et al., 1981). This measure is used by medical professionals treating people with diabetes as a long-term indicator of glycaemic control and is expressed as a percentage. The HbA1c level closest to the time of the family visit for each patient was obtained from the attending health care professionals and used as the index of diabetic control. The doctors concerned were requested to complete the regimen adherence scale on each patient before retrieving and providing the HbA1c levels of each child. All of the scores obtained can be seen in Appendix G. The HbA1c scores were split into two equal groups (median split) of "good" control HbA1c $\leq$ 13% and "poor" control, HbA1c $>$ 13%.

CHAPTER FIVE

RESULTS AND DISCUSSION

This chapter presents and discusses the results of the investigation. All computation was conducted using the Statistical Package for the Social Sciences (SPSS, 1983).

The review of literature in chapter three indicates that the ill child's age, gender, frequency of unexpected diabetes-related hospitalisation, and emotional well-being have, in some studies, been significantly associated with metabolic control and regimen adherence. Other possibly significant variables such as socio-economic status, family developmental stage, and race, were controlled for in the sample selection, and in this regard it is assumed that these families constitute an homogenous group. As concerns hospitalisation and emotional well-being, the family interview indicated that none of the children had been unexpectedly hospitalised for diabetes-related complications in the twelve months prior to the interview, nor, in the mothers' opinions, did any of their children have noteworthy emotional or behavioural difficulties.

5.1 Age, gender, metabolic control and regimen adherence

In order to determine if there was any significant association between the ill child's age and gender, and metabolic control and regimen adherence, Pearson's Product-Moment Correlations were computed.

TABLE 5.1: Pearson's product-moment correlations of metabolic control and regimen adherence with age and gender (N=22)

	HbA1c	Adherence Parents	Adherence Doctor
Age	0.071	-0.216	-0.166
Gender	-0.163	0.140	0.395*

* $0.02 \leq p \leq 0.05$

As can be seen from Table 5.1 above, the ill child's age is not significantly correlated with either adherence or metabolic control, but doctors' reports of adherence are marginally correlated with gender, with females reported as better adherers than males ($p \leq 0.05$). In order to explore these gender differences further, mean scores for males and females were separately calculated for HbA1c, regimen adherence, age and duration of illness.

TABLE 5.2: Age Illness duration, HbA1c, Adherence - mean scores and range by gender

	N	Mean	Range
Age (yrs)	22	14,5	10 - 20
♂	9	14,6	10 - 20
♀	13	14,4	10 - 20
Duration (yrs)	22	5,9	1 - 17
♂	9	5,5	2 - 14
♀	13	6,2	1 - 17
HbA1c (%) (High score ≈ poor control)			
	22	12,74	7,8 - 23,1
♂	9	13,32	8,5 - 23,1
♀	13	12,16	7,8 - 15,5
Adherence (Excellent adherence would score 12)			
Parent Report	22	8,4	5 - 11
♂	9	8,1	5 - 11
♀	13	8,6	7 - 11
Adherence Doctor Report	22	8,5	5 - 12
♂	9	7,5	5 - 12
♀	13	9,2	5 - 12

The difference in mean HbA1c scores between males and females noted in Table 5.2 above are due to the one male score of 23,1%. If this score is removed and the male mean re-calculated, it is almost the same as the female score, (12,11% vs 12,16%). In

spite of the similarity between males and females on HbA1c, it is interesting to note that both the parents and doctors rated the females as better adherers. A number of studies reviewed found that the HbA1c scores of females were significantly higher than those of males (Anderson et al., 1981; Simonds et al., 1981).

The finding of Simonds et al., (Ibid) that the most difficult part of the regime for females was diet, is confirmed in this study. Ten of the 13 (77%) females' parents indicated diet was the most difficult requirement, while blood glucose monitoring was reported as the most difficult aspect for 6 of the 9 males (67%). The higher adherence rating for females could possibly be explained by this difference in that parents could conceivably perceive maintaining a proper diet as more important than performing the required number of blood-glucose tests per day. The effects on the ill child of skipping a meal are, to all intents and purposes, immediate and the physical and behavioural consequences noticeable. The effects of skipping a blood-glucose test are not that immediately dramatic. The literature, and this study, have noted that females do have more difficulty in adhering to diet than males. Thus, in an inverse way, it is possible that those females adhering to dietary requirements are seen as "more" adherent than males exhibiting the same behaviours.

Hormonal differences between males and females during adolescence are likely to be compounding this effect which implies that females have to "try harder" than males to achieve similar levels of control.

5.2 Metabolic control and regimen adherence

Hypotheses 1 and 2:

Hypothesis One which states a positive relationship between metabolic control and regimen adherence must be rejected as no significant correlation ($p > 0.05$) between metabolic control and either of the adherence measures was found (See Table 5.3 below). Hypothesis Two, which states a significant positive relationship between the reports of regimen adherence of the doctors and the parents is accepted. A Pearson Product-Moment correlation between the two reports of adherence is highly significant ($p \leq 0.005$) (See Table 5.3 below).

As concerns the relationship between metabolic control and regimen adherence, the trend was in the expected direction, with high HbA1c levels (poor control) negatively associated with high adherence scores (good adherence), with the doctors' reports of adherence approaching significance at the five percent level ($r = -.342$; $p \leq 0.06$).

While HbA1c is a universally accepted and precise indication of long-term metabolic control, the assessment of regimen adherence is an unresolved problem facing all researchers (Brownlee-Duffeck et al., 1987) and it could therefore be possible that the questionnaire used was not entirely adequate. However, the highly significant correlation between parent and doctor report of adherence reduces the likelihood of this explanation as it indicates good concurrent validity.

TABLE 5.3: Pearson product-moment correlation matrix of HbA1c and Regimen Adherence scores

	HbA1c	Adherence Parents	Adherence Doctor
HbA1c	1.000	-.110	-.342
Adherence Parents		1.000	.573****

**** $0.001 \leq p \leq 0.005$

A more likely explanation for the lack of a significant association between metabolic control and regimen adherence would be that this relationship is co-determined by the presence or absence of a number of intervening psychosocial variables, among others. As mentioned in the review of literature, Linn and Linn (1983) found that a combination of depression and regimen adherence accounted for only four percent of the variance in a stepwise multiple regression predicting metabolic control. This adds weight to the notion that certain psychosocial factors may be impacting "directly" upon metabolic control and not via regimen adherence. The implication of this is that attempts at improving metabolic control by focusing on the improvement of regimen adherence alone would be ineffective. Both salutogenic and pathogenic psychosocial factors in the ill child's environment need to be identified. Treatment strategies then need to be

formulated that could amplify or ameliorate these identified factors.

5.3 Metabolic control, regimen adherence, and distance from the centre

Hypotheses Three and Four:

Hypothesis Three which states a significant positive correlation between metabolic control and Distance from Centre of Circumplex can only be accepted for the "ideal" version of DFC and not the "perceived" version (See Table 5.4 below).

Hypothesis Four which states a significant positive correlation between regimen adherence and Distance from Centre of Circumplex is rejected as no statistically significant relationships were found (See Table 5.4 below).

TABLE 5.4: Pearson's product-moment correlations of Distance from the Centre (DFC) with HbA1c and Regimen Adherence

	HbA1c	Adherence Parents	Adherence Doctor
PERCEIVED			
Index Patient	.230	.216	.303
Mother	.303	-.084	.290
Father	-.267	-.321	-.111
Sibling	-.096	-.018	.117
Total	.187	.045	.144
IDEAL			
Index Patient	.556***	.114	-.068
Mother	.441**	.049	-.234
Father	.241	-.028	.013
Sibling	.567***	.289	.210
Total	**.571****	**.163**	**-.080**

**** $0.001 \leq p \leq 0.005$

*** $0.005 \leq p \leq 0.01$

** $0.01 \leq p \leq 0.02$

Metabolic Control

As can be seen from the above table, all of the "ideal" DFC scores, except for the fathers', were significantly and positively associated with metabolic control, indicating

that HbA1c levels are higher (poor control) in children from those families in which members had a family ideal that was further from the centre.

There are two possible explanations for the majority of "ideal" scores and none of the "perceived" scores being significantly associated with HbA1c. Firstly, knowing that this study was investigating the relationship between the way families coped and the well-being of the diabetic child, family members, when asked to describe their families as they were, (perceived), might have been inclined to "protect" the family by not revealing any "socially undesirable" aspects of their family's functioning. In this sense, denying the existence of extremes would divert any "blame" for problems associated with the diabetes away from the family or members other than the ill child. When asked to describe their own "ideal", individual members might have felt less threatened as they were not "giving away" any family details, but were providing their own normative socially desirable conceptions of how they thought families should be with regard to adaptability and cohesion. These normative conceptions would of course be shaped by their experience of their own family, and its broader socio-cultural context.

TABLE 5.5: Perceived and Ideal Family Distance From Centre - mean scores and standard deviations

	N	Perceived	Ideal
IP	17	7,16 (4,74)	7,64 (4,51)
Mother	22	6,39 (3,69)	9,63 (3,53)
Father	22	5,42 (3,52)	6,06 (3,13)
Sibling	17	8,64 (6,53)	8,07 (4,11)
Total	**22**	**5,42 (2,86)**	**7,35 (3,15)**

A second explanation turns to the notion of family satisfaction. In this scenario it is accepted that the "perceived" scores are true reflections of family cohesion and adaptability. Table 5.5 above shows that except for siblings, all family members in the sample reported an ideal DFC that was more extreme than their perceived scores. Compared to those mothers with children in good control (DFC Perceived = 5,98 / Ideal = 8,12 / difference of 2,22) the mean DFC scores of mothers with children in poor

control are higher (Perceived = 6,41 / Ideal = 10,76. / difference of 4,35). In other words, mothers with children in poor control felt that bigger changes to the way their family functioned were necessary compared to those mothers of children in good control. These differences in the means of mothers with children in good control and poor control could, however also be used in support of the first explanation.

While no conclusive interpretations can be drawn from the significant associations between DFC Ideal and HbA1c, the association does add weight to the notion that family dysfunction, in a relative as opposed to an absolute sense, is associated with metabolic control. Further clarification is needed on what it is in the family that the perceived and ideal DFC scores are tapping, and how this relates to metabolic control.

Turning to Hypothesis Four, the statistically non-significant relationship between all of the DFC scores and both regimen adherence reports does suggest that both perceived and ideal conceptions of family distance from centre have no effect on the extent of the child's adherence to the regimen. That "ideal" DFC has been associated with metabolic control, might be an indication that family functioning mediates the effects of stress in a "direct" way (Z1 → Y).

The author was unable to locate any other studies with which the above results could be compared. Further research with regard to idealised, as opposed to perceived, conceptions of family adaptability and cohesion may be valuable in understanding the role of family members' expectations and desires for change within their family.

5.4 Metabolic control, regimen adherence and family satisfaction

Hypotheses Five and Six:

Hypothesis Five stating a significant positive relationship between metabolic control and family satisfaction cannot be accepted. The only one (sibling) out of the possible five family satisfaction scores significantly correlated with metabolic control was in the opposite direction to that predicted ($p \leq 0.02$) (See Table 5.6 below).

Similarly, Hypothesis Six, stating a significant positive relationship between regimen adherence and family satisfaction cannot be accepted. The significant relationship between Doctors' reports of adherence and the ill child's score on family satisfaction is

in the opposite direction to that predicted, with high adherence associated with low satisfaction ($p \leq 0.05$).

The significant association between low levels of satisfaction in the sibling and good metabolic control in the ill child would seem to suggest that the healthy sibling with a brother or sister in good control is adversely affected in some way. Given that the siblings in this study are adolescents, this explanation is not implausible. Wertlieb et al., (1986) noted that increased attempts at setting limits and rules in the family in order to improve metabolic control could spark behaviour symptomatology in adolescent siblings, a finding generally supported by Haley (1980) in his discussion of the consequences of adolescents preparing to leave home. A number of authors have noted the emergence of negative behaviours in siblings of ill children, including jealousy, competition for parents' attention, and hostility towards the ill sibling (Ferrari, 1984; Lavigne & Ryan, 1979; Taylor, 1984).

Should further research confirm this negative association between metabolic control and sibling family satisfaction, it would have important implications for intervention. Such a finding would suggest that any interventions aimed at improving metabolic control would best be achieved with an approach of "family as patient" (Arbogast, 1978; Broder, 1975) and be cognisant of any possible "symptom substitution" that might occur (Marshall & Neill, 1977).

TABLE 5.6: Pearson's product-moment correlations of family satisfaction with metabolic control and regimen adherence

	HbA1c	Adherence Parents	Adherence Doctor
FAMILY SATISFACTION			
Index Patient	-.295	-.280	-.474*
Mother	.075	.346	.197
Father	-.044	.133	-.013
Sibling	.502**	.229	.150
Total	**.025**	**.178**	**.017**

** $0.01 \leq p \leq 0.02$

* $0.02 \leq p \leq 0.05$

A possible explanation for the finding that the ill child's low level of satisfaction is significantly associated ($p \leq 0.05$) with good reports of adherence by doctors, could be that those adolescent diabetics with good adherence are following the required regime as a result of imposed rules and restrictions rather than of their own volition. In the light of the strivings for independence and autonomy occurring during adolescence the strict enforcement of limits and rules that do not apply to healthy peers could lead to dissatisfaction. Further research on this aspect could be of value as it is possible that a lack of flexibility (rigidity) on the part of parents anxious to ensure proper adherence may have the opposite effect.

Inasmuch as family satisfaction might be an indicator of conflict in the family environment, it seemed plausible to hypothesise that dissatisfaction with family functioning would be positively associated with both metabolic control and regimen adherence. A number of authors have found high levels of conflict in the family to be associated with poor metabolic control (Anderson et al., 1981; Koski & Kumento; 1987) and regimen adherence (Borrow et al., 1985; Schafer et al., 1983; White et al., 1984). While possible explanations for associations opposite to those predicted could be suggested, it is also likely that differences between perceived and ideal scores on adaptability and cohesion are not the most suitable measure of family satisfaction.

Further study of the association between family satisfaction of individual family members and metabolic control and regimen adherence is needed before any firm conclusions can be drawn.

5.5 Metabolic control, regimen adherence and family coping

Hypotheses Seven and Eight

Hypothesis Seven stating a significant positive relationship between family coping and metabolic control cannot be accepted as none of the coping dimensions assessed was statistically significantly associated with metabolic control (See Table 5.7 below).

Hypothesis Eight stating a significant positive relationship between the utilisation of family coping strategies and regimen adherence cannot be accepted as regimen adherence, as reported by doctors, was negatively associated with increased utilisation

of three of the five individual coping categories assessed, while mothers' reports showed no significant associations (See Table 5.7 below).

5.5.1 Metabolic control and family coping

Referring to hypothesis seven and Table 5.7 below, none of the assessed coping strategies approach statistical significance in their association with metabolic control, suggesting that there is no significant difference in the utilisation and availability of internal and external coping resources between families with children in good control and poor control.

TABLE 5.7: Pearson's product-moment correlations of family coping strategies with metabolic control and regimen adherence

	HbA1c	Adherence Parents	Adherence Doctor
Acquiring Social Support	.041	-.236	-.380*
Reframing	.120	-.230	-.258
Seeking Spiritual Support	.064	-.312	-.551****
Mobilising Family	.179	-.144	.020
Passive Appraisal	.264	-.101	-.472**
Total Score	**.101**	**-.224**	**-.277**

**** $0.001 \leq p \leq 0.005$

*** $0.005 \leq p \leq 0.01$

** $0.01 \leq p \leq 0.02$

* $0.02 \leq p \leq 0.05$

NOTE: A high HbA1c score means poor control, while a high regimen adherence score means good regimen adherence.

To further investigate this finding the mean scores on the F-COPES subscales, and the total, were calculated separately for good and poor control groups. As can be seen from Table 5.8 below there is a clear trend for families with children in poor control to utilise the listed coping strategies and behaviours more than families of children in good control. This trend is in the opposite direction to what was hypothesised. In attempting to make sense of this finding and the more significant one concerning regimen adherence,

it must be remembered that the diabetes had been present in all families for an average of more than five years, giving the illness and context time to co-evolve.

TABLE 5.8: Mean scores on F-COPES of families with children in good and poor metabolic control

	Good Control	Poor Control	Combined Mean
Acquiring Social Support	67.36	71.50	69.33
Reframing	58.09	69.40	63.48
Seeking Spiritual Support	36.73	45.30	40.81
Mobilising Family	71.18	79.30	75.05
Passive Appraisal	55.91	76.20	65.57
Total Score	**58.73**	**71.00**	**64.57**

Mailick (1979) points out that there are differences in coping requirements between the diagnostic and chronic phases of illness:

> A successful resolution of the first stage provides the potential for later successful adaptation to the second, but in some cases the coping mechanisms that were most useful in the initial diagnostic period need to shift or change (p.123).

As already mentioned, the diagnostic phase of the illness, as well as other events of crisis proportions, require the relegation of other demands to a secondary status while resources are mobilised to re-establish stability. Assuming that the mobilisation of a greater variety of resources to respond to a stressor event also means proportionately less attention to other demands, the following explanation could be plausible.

It is possible that families of children in poor control have not altered their coping responses from those learnt or utilised during crisis events like the diagnostic phase, while families of children in good control were able to shift from a crisis-oriented response mode to one more appropriate to the chronic phase of the illness. This line of thought implies that, in the mobilisation of coping resources in response to a stressor, other day-to-day demands are "put on hold". During a crisis the "benefits" of "mass mobilisation" outweigh the costs of putting demands on "hold". However, if this crisis response mode is rigidly employed as a "stock response" to stress, an inability to balance stressor with appropriate response, this may result in the "costs" of "mass mobilisation"

outweighing the "benefits" of stabilisation.

An alternative explanation might be that the increased mobilisation of resources is a reflection of a higher "background" level of stress in the family, which, in themselves leads to poor control and/or adherence. It is likely that both these explanations could apply. However, longitudinal study from the time of diagnosis is necessary to confirm or refute the above hypotheses.

5.5.2 Regimen adherence and family coping

Turning to hypothesis eight, it must be noted that while the mothers' reports of regimen adherence were not significantly associated with family coping, the trends were in the same direction as the significant doctors' reports (See Table 5.7 above). It could be speculated that the doctors' reports of adherence were, in part, informed by the frequency with which mothers sought increased support and assistance in attempting to facilitate better regimen adherence, thus explaining the closer association between doctors' reports of regimen adherence and family coping strategies.

The stress-response rationale used in discussing the negative correlation between good metabolic control and family coping can be equally applied to the findings concerning regimen adherence. Once again, the correlational analysis does not permit ascribing temporal priority to either variable.

Of the three F-COPES scales that are significantly correlated with adherence, the family's willingness, or need, to acquire spiritual support is statistically the most significant ($r = -0.551$; $p \leq 0.005$). As can be seen from Table 5.9 below the difference in religiosity between families with children in poor control and good control is striking. High levels of religiosity are associated with poor regimen adherence.

As it is highly unlikely that the manifestation of poor regimen adherence resulted in a conversion to religion, or, that seeking spiritual support results in poor regimen adherence, there must be intervening factors associated with families being actively religious that mitigate against good adherence behaviour. Assuming a linear conception of family adaptability, there is a significant negative correlation between mothers' perceptions of family adaptability and Seeking Spiritual Support ($r = -.3987$; $p \leq 0.033$). This finding suggests that the more religious a family is, the greater is its

tendency towards rigidity on the adaptability dimension. This would indicate, in the context of ill children seeking to develop greater independence and autonomy, that the reduced flexibility in application of rules and limits results in the ill child demonstrating its autonomy and independence by "taking control" and not adhering to the regimen.

TABLE 5.9: Mean scores on F-COPES of families with children reported by doctors to have good and poor adherence

	Good Adherence	Poor Adherence	Combined Mean
Acquiring Social Support*	57.45	81.27	69.33
Reframing	52.82	74.18	63.48
Seeking Spiritual Support****	19.64	62.00	40.81
Mobilising Family	75.55	74.64	75.05
Passive Appraisal**	51.64	79.55	65.57
Total Score	**52.73**	**76.55**	**64.57**

**** $0.001 \leq p \leq 0.005$
*** $0.005 \leq p \leq 0.01$
** $0.01 \leq p \leq 0.02$
* $0.02 \leq p \leq 0.05$

The above interpretations are made with great caution in that none of the other family members' perceived adaptability scores are significantly correlated with the Seeking Spiritual Support (SSS) sub-scale. All the correlations are however also in the negative direction. Further research is necessary to confirm or refute these findings, and to explore what other intermediary factors may exist in the relationship between religiosity and regimen adherence.

Turning to another coping variable significantly associated with regimen adherence, Acquiring Social Support (ASS), "measures a family's ability to actively engage in acquiring support from relatives, friends, neighbours and extended family" (McCubbin, Larsen & Olson, 1985; p.120). As with the SSS subscale, it was found that families with children having poor regimen adherence were more likely to engage a wider variety of

possible resources in times of difficulty than families of children with good regimen adherence ($p \leq 0.05$). In this case none of the family members' perceived adaptability or cohesion scores is significantly associated with ASS. Like the Seeking Spiritual Support scale, the ASS scale is an external (mobilising resources outside of the family) coping strategy, which suggests once again that the increased mobilisation of external support by families with children in poor control could reflect a lack of resources within the family, and that this behaviour reflected either a) a learnt "stock response" in dealing with all demands and stressors, or, b) a higher "background level" of stress in these families resulting in help being sought from wherever it might be available.

The last coping variable significantly associated with regimen adherence, Passive Appraisal (PA), appears to be similar to the concept of Locus of Control (Lefcourt, 1982). PA assesses the "family's ability to accept problematic issues, minimising reactivity" (McCubbin et al., 1985; p.124). Respondents are asked to indicate, on a scale of 1 (strongly agree) to 5 (strongly disagree), how their families react when faced with difficulties or problems. Items include; "Knowing luck plays a big part in how well we are able to solve family problems; Believing if we wait long enough the problem will go away." (See Appendix C on page 175 for full questionnaire).

By the mothers' reports, families of children with poor adherence utilise Passive Appraisal strategies significantly more often than families with children with good adherence ($p \leq 0.02$). In Locus of Control terms, it might be expected that families of children with poor adherence may have a greater external locus of control.

That these families do utilise Passive Appraisal as a coping mechanism at times, "ignoring the problem", seems to support the hypothesis of a "higher background level of ongoing stress" as more plausible. However, it is interesting to note that PA, like "Seeking Spiritual Support", is also negatively associated with mothers' and total perceived family adaptability ($r = -.4565$; $p \leq 0.02$, and $r = -.4034$; $p \leq 0.03$ respectively), indicating greater family rigidity associated with increased use of passive appraisal. To complete the picture, the mothers' perceptions of family adaptability are significantly associated with the doctors' reports of regimen adherence ($r = .4604$; $p \leq 0.015$), with increased rigidity associated with poor adherence (positive correlation of

high adaptability score associated with good adherence).

If a linear conception of family adaptability is accepted, the above results and interpretations emanating from the testing of hypotheses seven and eight lead to the tentative proposition that families of children with poor adherence are experiencing greater stress than those of children with good adherence. While families of children with poor adherence do employ more problem-solving and behavioural strategies than families of children with good adherence, their lack of flexibility (tendency towards rigidity) means that these behaviours are not selectively (effectively) utilised. On the other hand, families of children with good adherence utilise a smaller set of problem-solving and behavioural strategies in response to stress, but with greater effect in the mediation of stress (flexibility enabling variation of response).

A longitudinal study would be necessary to confirm or refute the above proposition. If it is confirmed, this would necessitate a re-evaluation of the hypothesis of McCubbin et al., (1985) (families operating with more coping behaviours focused on both levels of interaction will adapt to stressful situations more successfully), to incorporate the intervening construct of family adaptability.

In summary, the relationship of coping behaviours to regimen adherence in particular, and metabolic control to a lesser extent, has been found to be such that families of children with poor regimen adherence use significantly more coping behaviours and strategies than families with children in good control. While not significant, the relationship between metabolic control and family coping behaviours is in the same direction as that of regimen adherence and coping. This difference between metabolic control and regimen adherence suggests that the stress mediating effects of family coping act more "indirectly" on metabolic control by their closer association with regimen adherence ($Z1 \rightarrow X \rightarrow Y$), than "directly" on metabolic control ($Z1 \rightarrow Y$).

5.6 Metabolic control, regimen adherence and family strengths

Hypotheses Nine and Ten

Hypothesis Nine stating a significant positive relationship between family strengths and metabolic control cannot be accepted as no statistically significant correlation between

these two variables was found (See Table 5.10 below).

Similarly, Hypothesis Ten, stating a significant positive relationship between family strengths and regimen adherence cannot be accepted as no statistically significant correlation between these two variables was found (See Table 5.10 below).

TABLE 5.10: Pearson's product-moment correlations of family strengths with metabolic control and regimen adherence

	HbA1c	Adherence Parents	Adherence Doctor
Family Strengths	-.080	.171	.110

The Family Strengths scale was developed by Olson, Larsen, and McCubbin, (1985) to tap a limited number of characteristics that had been theorised as "strengthening families". The expansive theoretical concept of family strengths is, by the authors' own admission, nearly impossible to measure (Ibid, 1985; p.141). This twelve-item scale which was developed to measure "pride" and "accord" within the family was not able to discriminate between good and poor control and adherence.

As no reference to previous studies which have utilised this scale could be found, it is difficult to gauge the concurrent validity of these findings. Looking at the individual items in the scale (See Appendix D on page 178), it would appear that the concepts assessed are too global for their sum to be representative of a single construct. Key words employed in the seven items assessing "Pride" include the qualities of, loyalty, pride, trust, sharing confidences, expressing feelings, and respect. For "Accord", the five items encompass conflict, repetition of problems, being critical of other family members, and worry.

In conclusion, it is not possible to offer any interpretation of the correlations of the Family Strengths scale with regimen adherence and metabolic control.

5.7 Exploratory investigations

5.7.1 Curvilinear versus linear notion of the FACES III scales

As there is contention over the validity of the Circumplex Model's curvilinear hypothesis of family cohesion and adaptability, it was decided to explore the statistical relationships

of both conceptions to determine which of the two best discriminated between good and poor control and adherence. As mentioned in chapter four, a number of studies, in breaking the statistical rules of a curvilinear conception, have found significant associations of these constructs with their dependent variables when they employed linear parametric statistical analyses (Evans & Hughes, 1987; Lindegger, 1988; Pillay, 1989).

In a well designed study Walker, McLaughlin, and Greene (1988), investigated the ability of FACES II to discriminate between families of healthy adolescents and families of adolescents with functional somatic complaints. Two sets of analyses were conducted. The first employed a series of statistical analyses with adolescents categorised into family types as defined by the Circumplex Model. The second set of analyses used a curve-fitting regression analysis to determine the ability of linear and curvilinear conceptions of adaptability and cohesion raw scores to predict psychophysiological symptoms.

Concurrent confirmation of the difference between the somaticising group and the healthy group was confirmed using a self-report measure of psychophysiological symptoms (Health Opinion Survey) and Self-Esteem (Rosenberg Self-Esteem Inventory).

Among their findings Walker et al., (Ibid) found that higher cohesion and higher adaptability were associated with lower symptom levels and concluded that adaptability and cohesion as measured by FACES II "... bear linear rather than curvilinear relationships to health and well-being" (p.323). As regards the categorisation of Circumplex family types based on the curvilinear hypotheses, Walker et al., concluded that it was "not useful" in distinguishing healthy from symptomatic families.

In the same vein, a series of correlational and Chi-square analyses were computed to determine the ability of curvilinear and linear conceptions of families FACES III responses to discriminate between good and poor control and adherence.

5.7.1.1 Family type, metabolic control and regimen adherence

Following the recommendations of Olson, McCubbin et al., (1985), a complete series of two-by-two Chi-square analyses were conducted comparing family types (balanced as opposed to mid-range and extreme) and metabolic control (good and poor control), and family types and regimen adherence (both doctors' and mothers' reports of good and

poor regimen adherence).

Not one of the fifteen sets of analyses computed meets the one percent level of significance criterion. In order to facilitate comparison with correlations generated using a linear conception of these variables, a Pearson Product-Moment correlational matrix was generated from the same data used for the Chi-Square analyses. As can be seen from table 5.11 below, only five of these correlations are significant at the five percent level.

TABLE 5.11: Pearson's product-moment correlations of perceived family type (balanced vs mid-range and extreme) with metabolic control and regimen adherence

	HbA1c	Adherence Parents	Adherence Doctor
INDEX PATIENT FAMILY TYPE			
Cohesion			
Perceived	.070	.409*	-.070
Combined Coh/Adap			
Perceived	.291	.417*	.181
FATHER FAMILY TYPE			
Cohesion			
Perceived	0.000	0.000	-.471**
MEAN FAMILY TYPE			
Cohesion			
Perceived	.240	.436*	.074
Combined Coh/Adap			
Perceived	.132	.450*	.368

** $0.01 \leq p \leq 0.02$

* $0.02 \leq p \leq 0.05$

Of these five correlations, three of them concern the perceived family type concerning cohesion alone (balanced types being separated or connected; extreme types being disengaged or enmeshed). Upon closer inspection however, the directionality of fathers' scores is opposite to that of correlation with the ill children's scores, increasing the likelihood of these correlations being spurious, Type I errors.

5.7.1.2 Metabolic control, regimen adherence, and family adaptability and cohesion as linear scores

Using the one percent level of significance criterion again, none of the cohesion and adaptability raw scores was significantly associated with metabolic control and regimen adherence. It is interesting to note that, at the five percent level, the mothers' scores are the most predictive.

TABLE 5.12: Pearson's product-moment correlations of family adaptability and cohesion raw scores with metabolic control and regimen adherence

	HbA1c	Adherence Parents	Adherence Doctor
INDEX PATIENT			
Cohesion Ideal	.449*	.171	.138
MOTHER			
Cohesion Perceived	.465**	.127	-.127
Adaptability Perc	.159	.092	.460**
Adaptability Ideal	.389*	.095	-.061
TOTAL			
Cohesion Perceived	.476**	.210	-.138
Adaptability Ideal	.360*	.127	.073

** $0.01 \leq p \leq 0.02$

* $0.02 \leq p \leq 0.05$

Looking at the directionality of the significant "Cohesion Perceived" scores in their association with metabolic control, higher scores on cohesion are associated with poorer control (high HbA1c score indicates poor control).

Of the adaptability scores, only the mothers' and total ideal scores were significantly associated with metabolic control, with high adaptability associated with poor control. The only score to discriminate between good and poor adherence was the mothers' perceived adaptability score, with high adaptability associated with good adherence.

While Walker et al., (1988) found that the mothers' and the ill child's adaptability and cohesion scores were unable to discriminate between symptomatic and nonsymptomatic families, the linear association they found was in the opposite direction

to that of the study. That is, high cohesion and adaptability scores were associated with lower symptom levels. This finding is partially supported by Cederblad, Helgesson, Larson & Ludvigsson (1982), who found high levels of adaptability (as reported by the mother) to be associated with good metabolic control, while high levels of cohesion (as reported by the father) were associated with poor metabolic control. On the other hand, Evans and Hughes (1987) found that low levels of adaptability, rigidity, (as perceived by the ill child) were significantly associated with good metabolic control of adolescent diabetics. Evans and Hughes also found a non-significant correlation in which the trend indicated that high cohesion was associated with poor control, supporting the findings of Cederblad et al., (1982).

Splitting the mothers' cohesion scores into groups according to good and poor metabolic control, mothers of children in poor control perceived their families as enmeshed (43,10) while mothers of children in good control perceived their families as connected (38,82) ($p \leq 0.02$). However, little can be made of this significant association as the perceived cohesion scores of other family members were not significantly associated with either metabolic control or regimen adherence.

TABLE 5.13: FACES III mean scores (Standard deviations in brackets)

	N	Perceived	Ideal
COHESION			
Index Patient	17	39,71 (6,11)	42,47 (3,73)
Mother	22	40,82 (4,40)	45,09 (4,21)
Father	22	38,64 (4,33)	41,86 (4,30)
Sibling	17	35,76 (8,16)	40,71 (6,62)
Total	**22**	**38,73 (4,08)**	**42,56 (2,65)**
ADAPTABILITY		Perceived	Ideal
Index Patient	17	23,94 (6,29)	27,82 (6,81)
Mother	22	26,31 (5,56)	29,77 (5,38)
Father	22	25,27 (4,66)	26,36 (4,55)
Sibling	17	24,35 (6,16)	28,35 (4,64)
Total	**22**	**25,11 (4,30)**	**27,76 (3,87)**

From a methodological and interpretive point of view, further information is needed before it could be said that any one family member's perceptions of their family are more frequently predictive of symptoms or problems within the family. From a theoretical and mathematical point of view, clarity is needed with regard to the combination of individual scores to provide an overall "family" score.

The evidence gathered above is inconclusive with regard to the relative utility of a curvilinear (family types) as opposed to a linear (raw scores) conception of adaptability and cohesion in being able to discriminate between good and poor metabolic control.

The concurrent validity between family assessment instruments assessing these and other dimensions is poor. A number of authors have argued that this is not unexpected as these scales are measuring different aspects of the same construct (Cromwell & Peterson, 1983; Oliveri & Reiss, 1984; Reiss, 1983). However, if family research is to have any applied utility, researchers and practising clinicians need to know that they are "talking the same language". Given the apparent state of confusion at present, clarification of the linear/curvilinear status of the FACES III Circumplex constructs, and the way in which the data are to be treated are crucial. Ransom (1986) contends that;

> ... current inattention to basic issues of measurement - of exactly what is being measured, how the data are entered into analysis, and how results are described - is as serious a methodological problem and threat to validity as the design, sampling, and control issues plaguing family research ... (p.333).

5.7.2 Pathways between select family factors, regimen adherence and metabolic control

The following analyses are exploratory in nature, and assume a linear conception of cohesion and adaptability. Consequently, any interpretations made must be viewed in this cautionary light. The statistical manipulations utilised in this section are conducted primarily to explore possible avenues of future research that could be undertaken to clarify two issues. Firstly, the health care professional's task would be made a lot easier if both salutogenic and pathogenic family factors in relation to metabolic control and regimen adherence were conclusively identified. If the pathways along which these factors operated were understood, the health care professional could implement family-

oriented strategies for amplifying salutogenic aspects present and ameliorating pathogenic ones. Secondly, the assessment of family factors at the time of diagnosis could come to have a valuable preventative function in that the combined presence of some family variables may be able to predict individuals at risk for developing patterns of poor control and/or regimen adherence.

The first exploratory question concerns the pathways along which some variables may be operating in their association with metabolic control. Referring back to figure 3.6, and the review in chapter three, it has been suggested that some family variables may act more "directly" on metabolic control (Z1 → Y) and others more "indirectly" via regimen adherence (Z1 → X → Y). Rather than proceed with an exhaustive case-by-case analysis, five examples from this study will be presented to demonstrate the relative contributions of individual variables to both paths.

The relative contributions of these variables can be determined by comparing the correlation coefficients in the pooled within-groups correlation matrix that is computed as part of the discriminant analysis (Norusis, 1985; p.108). When computing the discriminant analyses for the mothers' reports of adherence, metabolic control and doctors' reports of adherence were included for analysis in the pooled within-groups correlation matrix, allowing an internal comparison of metabolic control and doctors' reports of adherence.

The five individual scores were chosen from Cohesion, Adaptability, F-COPES, Family Satisfaction, and Distance from the Centre. As both individual and sibling scores were included in this particular discriminant analysis, the complement of cases with no missing values was reduced to thirteen (one family with both sibling and ill child scores missing, and eight families with either sibling or ill child scores missing).

Of the select few variables included in the pooled within-groups correlation matrix, only the "Seeking Spiritual Support" subscale of F-COPES had a greater significant association with regimen adherence than with metabolic control (See Figure 5.1 below). As already discussed, children who come from religiously active families tend to have significantly poorer adherence to the required regimen. Figure 5.1 below indicates that this variable is minimally associated in a "direct" relationship with metabolic control, but

significantly associated with regimen adherence.

Should this finding be confirmed in future studies, clinicians could then be alerted to the possibility of adherence problems developing in children who come from actively religious families. What needs to be clarified though, is what aspects associated with religiosity are negatively impacting upon regimen adherence behaviours.

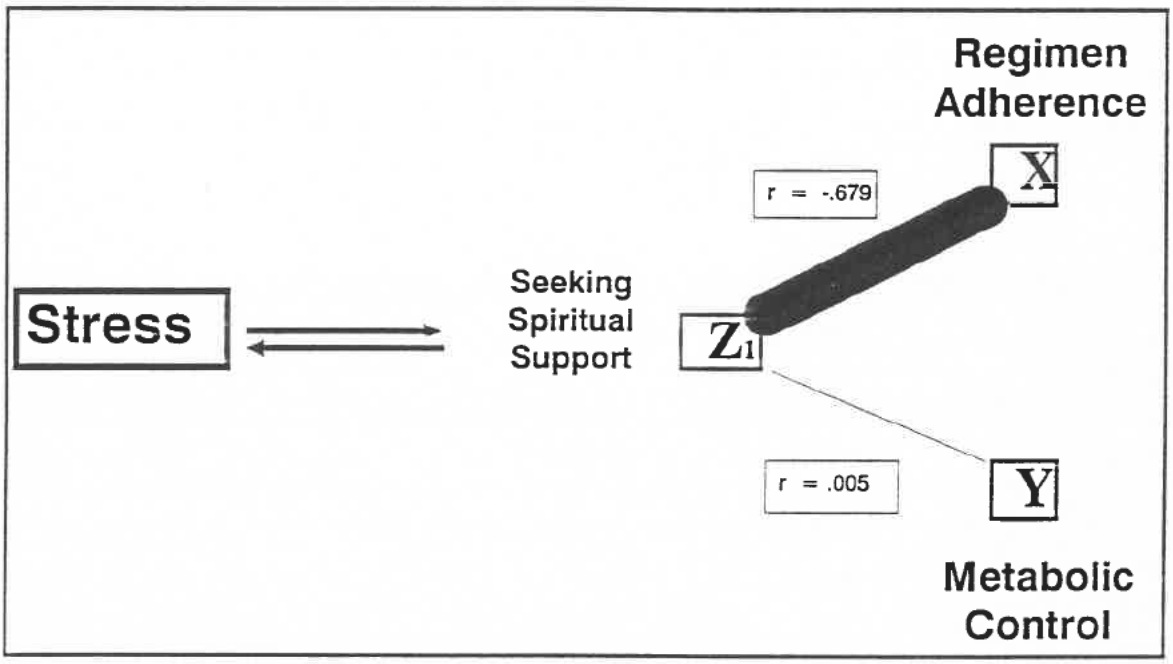

FIGURE 5.1: Pooled within-groups correlation coefficients of the F-COPES Seeking Spiritual Support subscale, with metabolic control and doctors' reports of adherence

Figure 5.2 below shows mothers' perceptions of family cohesion to be more closely associated with metabolic control than with regimen adherence, suggesting that the more enmeshed a family is, the greater is the likelihood that this pattern of functioning will amplify the child's experience of stressors and their direct impact upon metabolic control. While previous studies that have used the construct of cohesion, as measured by FACES, also found high cohesion (tendency towards enmeshment) to be associated with poor metabolic control (Cederblad et al., 1982; Evans & Hughes, 1987), the term

"enmeshment" as used in FACES III cannot necessarily be equated with that used by Minuchin and his colleagues (Ransom, 1986; Evans & Hughes, 1987).

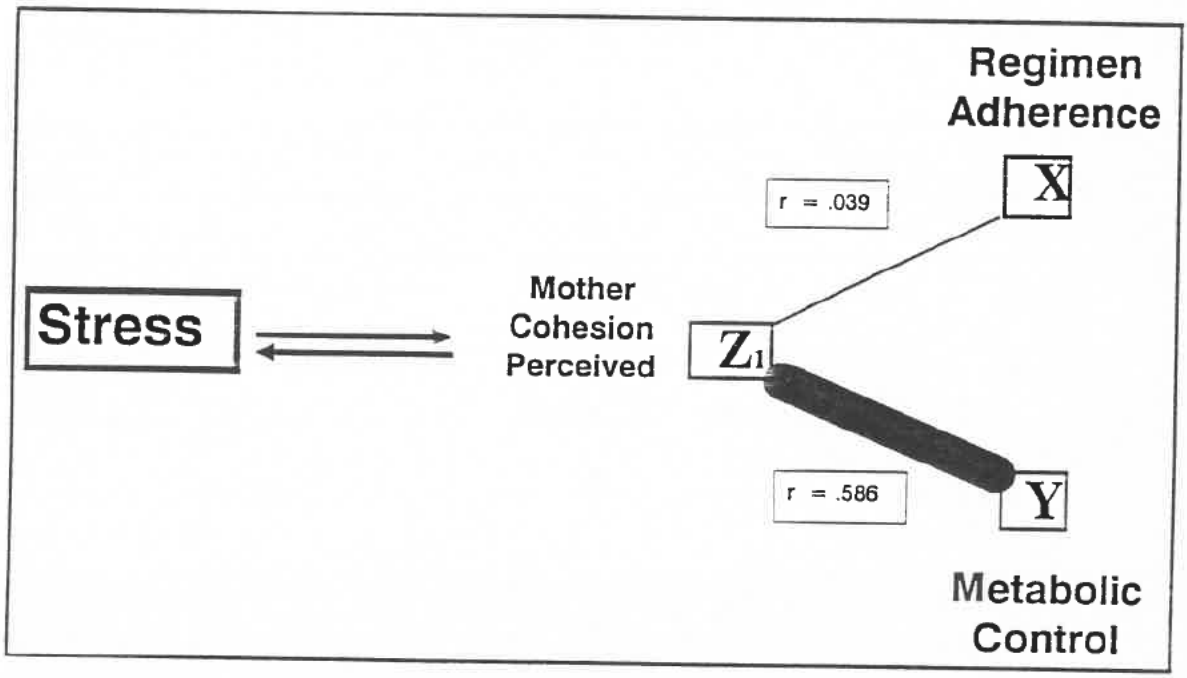

FIGURE 5.2: Pooled within-groups correlation coefficients of Perceived Cohesion (mother), with metabolic control and doctors' reports of adherence

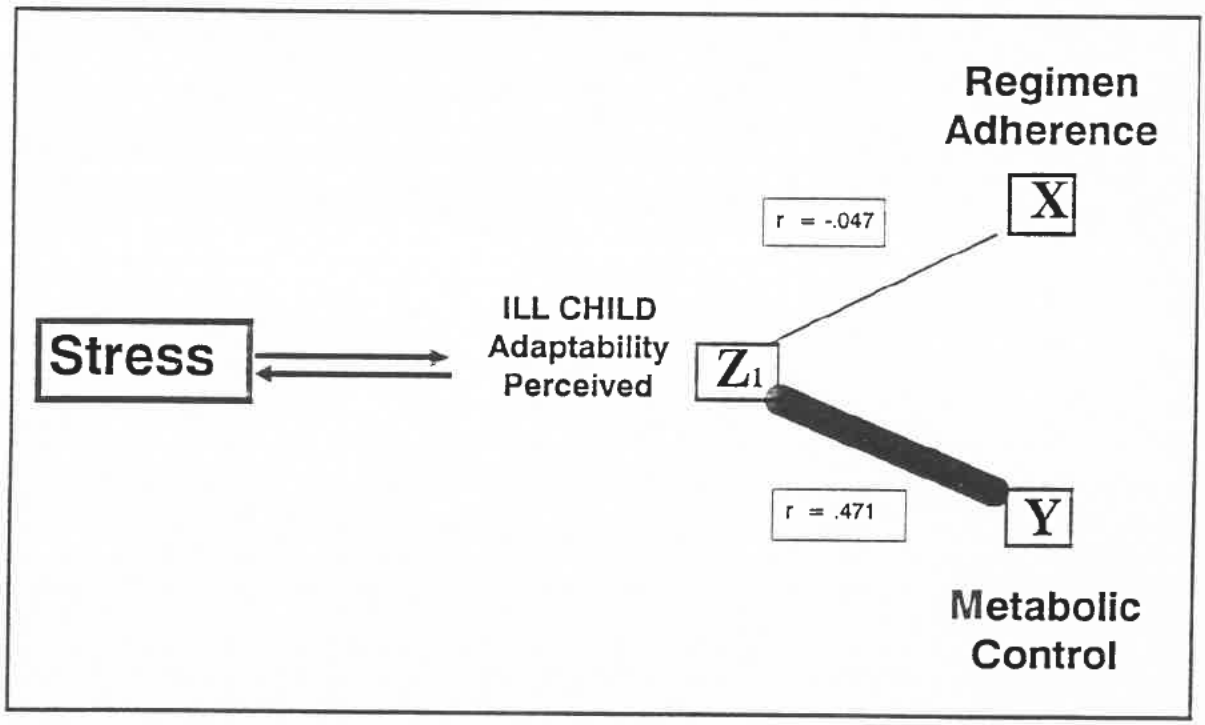

FIGURE 5.3: Pooled within-groups correlation coefficients of Perceived Adaptability (Ill child), with metabolic control and doctors' reports of adherence

High scores on family adaptability, on the other hand, as perceived by various family members have been associated with good metabolic control (Cederblad, et al., 1982). Evans and Hughes (1987) found the contrary to be the case when they found low adaptability (rigidity), in association with an external locus of control in the ill child, to be predictive of good metabolic control.

As can be seen from Table 5.3 above, low scores on family adaptability (as perceived by the ill child), while not significant in this small sample size, are associated with good metabolic control. While the relative association of the ill child's perceived family adaptability with metabolic control and regimen adherence has been illustrated, it must be stressed again that this association could be altered, as in the analogy of the spider's web (Gorell Barnes, 1985), by the introduction of a seemingly unrelated factor into the equation.

The inter-relatedness of family factors was clearly demonstrated in the finding that sibling family satisfaction was inversely related to the ill child's level of metabolic control. As can be seen in Figure 5.4 below, however, the sibling's family satisfaction was also positively related to regimen adherence (not significant in this small sample size), with high satisfaction related to good regimen adherence.

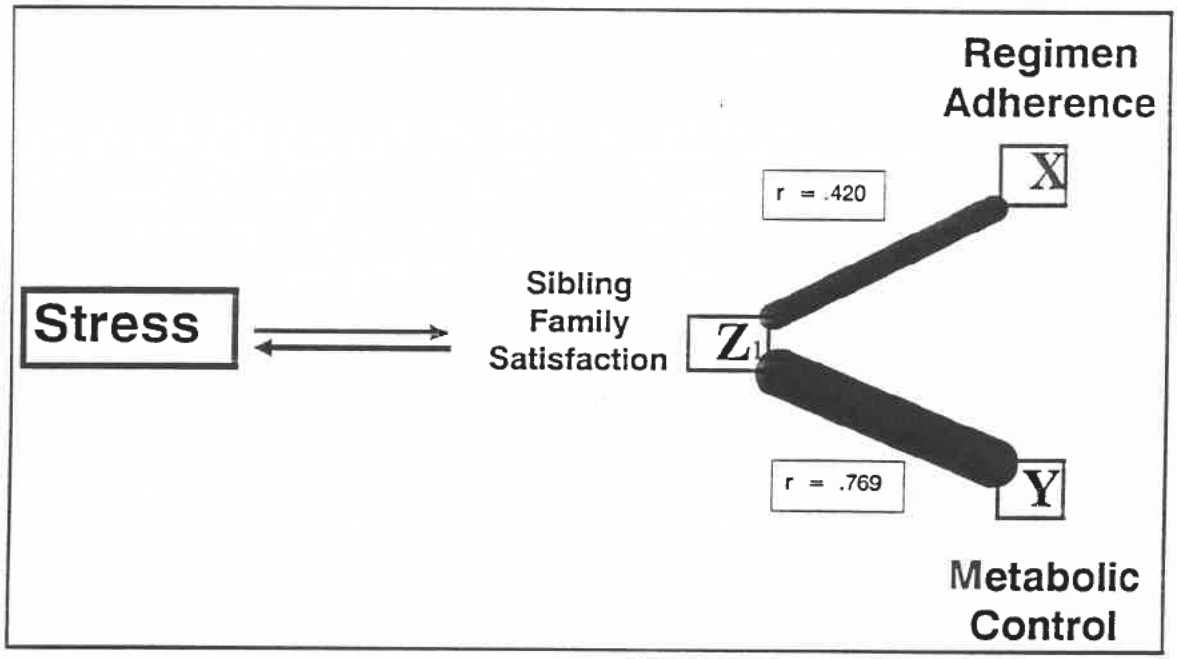

FIGURE 5.4: Pooled within-groups correlation coefficients of Family Satisfaction (Sibling), with metabolic control and doctors' reports of adherence

The last of the examples concerns the ill child's ideal distance from the centre. While increased ideals in DFC are associated with poorer metabolic control and regimen adherence, the association is heavily weighted in the Z1 → Y direction.

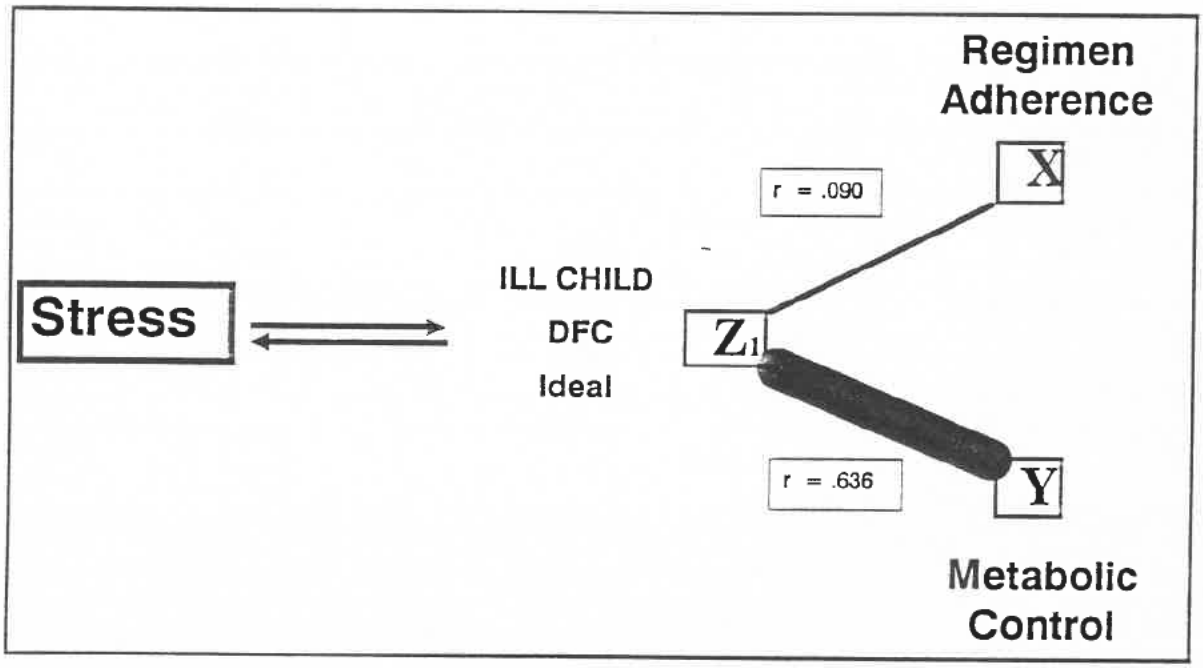

FIGURE 5.5: Pooled within-groups correlation coefficients of Ideal Distance from the Centre (Ill Child), with metabolic control and doctors' reports of adherence

In conclusion, the diagrams above serve to illustrate that it is possible, albeit crudely in this case, to identify the pathways along which family variables operate in their positive and negative effects upon metabolic control. However, these factors should not be viewed in isolation from one another as it is likely that combinations of the same factors in different proportions may have widely varying outcomes in their effect upon metabolic control and regimen adherence. The sample size utilised in the present study is too small to allow for advanced statistical procedures such as path analysis to be conducted on multiple variables.

5.7.3 Discriminant analyses

As there are a large number of possible combinations of variables in this study that could be clustered for discriminant analysis, only a limited sampling has been included in this exploratory exercise. As mentioned in chapter four, the rationale for the choice of

variables for inclusion in the analysis was based on the significance of their correlational associations with metabolic control and regimen adherence.

Of all the variables included in the discriminant analyses, perceived and ideal family types were least predictive. When used as linear scores, a number of the adaptability and cohesion scores included in combination with scores from family satisfaction, family coping, and distance from the centre assessments, were found to be highly predictive. Also, the Family Strengths scores, when combined with other variables, were found to have predictive value.

5.7.3.1 Predicting good and poor metabolic control

The combination of two sibling scores, Ideal Distance from the Centre and Family Satisfaction, was able to correctly predict 88,24% of the seventeen cases into the categories of good and poor metabolic control.

TABLE 5.14: Discriminant analysis - Metabolic control by sibling Family Satisfaction and Ideal DFC

		Predicted Group Membership	
	N	Good Control	Poor Control
Good Control (Actual)	10	9	1
Poor Control (Actual)	7	1	6
Percent of grouped cases correctly classified			88.24%
Chi-Squared = 12.463		(DF = 2)	$p \leq 0.002$

Standardised Canonical Discriminant Function Coefficient	
Ideal DFC	.7721[1]
Family Satisfaction	.6960

The inclusion of both mothers' and doctors reports of adherence into the above function had the effect of reducing the predictive capacity of the equation to 82.35%. A discriminant analysis with a combination of mothers' and doctors' reports of adherence

[1] *The greater the Standardised Canonical Discriminant Function Coefficient, the greater is its predictive value in the combined equation.*

as sole predictors was only able to correctly predict 63.4% of cases into good and poor metabolic control. A combination of Family Strengths, Doctors' reports of adherence and the ill child's ideal DFC, on the other hand, was able to predict 82.35% of cases into the correct groups (See Table 5.15 below).

TABLE 5.15: Discriminant analysis - Metabolic control by Ill Child's Ideal Distance from the Centre, Family Strengths, and Doctors' reports of adherence

		Predicted Group Membership	
	N	Good Control	Poor Control
Good Control (Actual)	8*	7	1
Poor Control (Actual)	9	2	7

Percent of grouped cases correctly classified 82.35%
Chi-Squared = 12.878 (DF = 3) $p \leq 0.005$

Standardised Canonical Discriminant Function Coefficient	
Ideal DFC	.941
Family Strengths	.623
Doctor Adherence	.393

* The distribution of cases in the good and poor control categories is different from that of Table 5.14 because Table 5.14 was concerned with families of siblings who completed the questionnaires while Table 5.15 is concerned with families of ill children who completed the questionnaires.

While a combination of the Family Coping and Family Strengths scores was unable to predict metabolic control, it was found to be highly predictive of Doctors' reports of adherence.

5.7.3.2 Predicting good and poor regimen adherence

As can be seen from Table 5.16 below, a combination of Family Strengths and Family Coping was highly predictive of regimen adherence as reported by the doctors, correctly classifying 21 of the 22 cases into good and poor adherence categories (95.45%). The only Family Coping score that was not predictive in combination with the rest was Passive Appraisal. This suggests that the effects of a family's passive or active stance in

the resolution of problems are neutralised by the presence or absence of other Family Coping variables and Family Strengths.

TABLE 5.16: Discriminant analysis - Doctors' reports of regimen adherence by Family Coping and Family Strengths

		Predicted Group Membership	
	N	Good Control	Poor Control
Good Control (Actual)	11	10	1
Poor Control (Actual)	11	0	11
Percent of grouped cases correctly classified			95.45%
Chi-Squared = 17.26		(DF = 5)	$p \leq 0.004$

Standardised Canonical Discriminant Function Coefficient	
Family Strengths	.900
Acquiring Social Support	- .742
Seeking Spiritual Support	- .649
Mobilising Family	2.277
Family Coping Total	-1.732

Looking at the Canonical Discriminant Function Coefficients, it is interesting to note that increased utilisation of the two external family coping behaviours, Acquiring Social Support (ASS) and Seeking Spiritual Support (SSS) is associated with poor regimen adherence, while increased use of the internal strategy of mobilising the family in response to difficulties is associated with good regimen adherence.

In the final example, a combination of a salutogenic factor (high adaptability) and an identified "pathogenic" factor (Seeking Spiritual Support) is able to predict 81.82% (18 out of 22) of cases into good and poor regimen adherence as reported by doctors (See Table 5.17 below).

In conclusion, a limited number of significant discriminant analyses has been presented as an example of the predictive power of combining family factors that are thought to be associated with either metabolic control and/or regimen adherence.

TABLE 5.17: Discriminant analysis - Doctors' reports of regimen adherence with Seeking Spiritual Support Family Coping subscale and Mothers' Perceived Family Adaptability

		Predicted Group Membership	
	N	Good Control	Poor Control
Good Control (Actual)	11	9	2
Poor Control (Actual)	11	2	9

Percent of grouped cases correctly classified 81.82%
Chi-Squared = 10.002 (DF = 2) $p \leq 0.007$

Standardised Canonical Discriminant Function Coefficient	
Seeking Spiritual Support	-.637
Mothers' Perceived Adaptability	.694

5.7.4 Summary

To summarise the exploratory aspects of this study, the evidence for or against a curvilinear or linear conception of family adaptability and cohesion as measured by FACES III was inconclusive and served to highlight the difficulties in "bridging the gaps that often exist among theorists, researchers, and practitioners" (Olson, McCubbin, et al., 1983).

The exploratory set of discriminant analyses has served to demonstrate the predictive utility of combining a number of family variables. However, further exploratory research is necessary in order to more clearly pinpoint those family variables that, a) are easily determined, and b) have consistent predictive powers with regard to metabolic control and regimen adherence. This select set of analyses has demonstrated two important points. First, there are combinations of family factors that are highly predictive of metabolic control and regimen adherence. Second, different family factors are predictive of regimen adherence and metabolic control respectively. If future research is able to isolate a relatively small and consistent group of predictive family variables for each of

adherence and control, this may come to have great value in identifying at risk families.

A longitudinal study, from the time of diagnosis, of family characteristics and functioning, and their relation to adherence and metabolic control is necessary in order to identify any patterns occurring in the co-evolution of illness and context. Despite the present chasm that exists between the congruence of constructs utilised in clinical description, and self-report measures of family characteristics and function, the limited study above indicates that self-report methods could be developed to the point where they could be effectively employed in the applied clinical context.

CHAPTER SIX
CONCLUSION

Insulin-dependent diabetes mellitus has appropriately been called a "disease of adaptation" by Kaplan (1982). In losing the capacity to autonomically regulate the insulin-dependent components of it physiology, the ill child becomes prone to debilitating and life-threatening fluctuations in his or her metabolism. In order to reduce the amplitude of these physiological oscillations, the ill child is required to carefully monitor its context and learn to make the appropriate adjustments.

This process of learning to maintain an ongoing adaptation in a climate of increased sensitivity to flux has an isomorph in the family of the ill child. The diagnosis of diabetes upsets the family metabolism and requires a period of restructuring and reorganisation to incorporate the demands associated with the illness. Families with a "metabolism" unable to make the necessary adjustments become at risk for frequent, ongoing, "hypoglycaemic" episodes.

The concept of isomorphy equips the health care professional with a tool that, if carefully developed, could become very useful in helping to identify children and families who, in response to the diagnosis of IDDM, are at risk for developing patterns of mutually reinforcing instability. Before intervention of this nature becomes conceivably possible, the "physiology", pathways, and mechanisms of the child's psychosocial context need to be described and understood.

At this stage, the consensual view and common language, or paradigm, with which to punctuate, describe and come to know these psychosocial factors, their mechanisms and pathways is in itself in a state of flux. While the family environment has been identified as that psychosocial system which has the single most direct impact upon metabolic control and regimen adherence, the "state of the art" of "knowing the family" is "primitive, but promising" (Ransom, 1986).

In essence, this study has attempted to contribute towards an increased knowledge of those family factors thought to be impacting upon metabolic control and regimen adherence. This study could not ignore the methodological problems inherent in the field, and, wherever possible, has qualified the research process by attempting to outline, the assumptions and difficulties inherent in the utilisation of a family systems paradigm.

6.1 SUMMARY OF FINDINGS

This investigation has found both expected and unexpected results. Some of the interpretations attached to these findings must be regarded as tentative and requiring confirmation or refutation by further study.

While significant concurrence between reports of regimen adherence by doctors and mothers was found, the child's degree of regimen adherence was not significantly associated with metabolic control, leading to the interpretation that this relationship is mediated by other biological, psychological and social factors in the ill child's environment.

As concerns individual constants, females were found to be better adherers to the required regimen than males. There was however no difference in male and female levels of metabolic control. This finding confirms those of a number of previous studies and appears to be related specifically to difficulties surrounding diet, and hormonal flux, in adolescent females. No significant associations of metabolic control and regimen adherence, with the child's age, age at diagnosis, and duration of illness, were found.

While findings with regard to the association of individual family characteristics as expressed by individual family members must not be understood in isolation, the methodological complexity and associated uncertainty made integration a difficult task. Not only is it mathematically difficult to express the variety of individual responses in one "overall" family score, it is difficult to interpret an observed statistical relationship that is significant for only one or two out of four individual family members' reports.

A further problem in interpretation is assuming that each member of a given population, for example mothers, can have the same role and function within all the families. Looking at this particular population studied though, the apparent prevalence

in assumed sex-role stereotypes allows a modicum of generalisation with regard to within-sample homogeneity.

A broad overview of the family scores indicates a clustering of perceptions in which there was general consensus between the mothers', the ill children's and the siblings' scores. The fathers' reports, on the other hand, were noticeably different and least predictive of metabolic control and regimen adherence. Conversely, mothers' scores appeared to be most often associated with regimen adherence and metabolic control. Also of note, is that some of the "ideal" scores on FACES III were in some instances more closely associated with the dependent variables than the "perceived" scores.

Moving onto specific findings, except for fathers, all family members' idealised views of Distance from the Centre of Circumplex were positively and significantly associated with metabolic control. In Circumplex terms, children with poor metabolic control came from families in which individual members desired a more extreme, or "dysfunctional", form of family functioning. The family members' "perceived" Distance from Centre of Circumplex was, however, not significantly associated with either regimen adherence or metabolic control.

The complex inter-relationships operating within families was demonstrated by the finding that low levels of family satisfaction, as reported by the healthy sibling, were found to be significantly associated with high levels of metabolic control. Low levels of satisfaction as reported by the ill child were associated with a high degree of regimen adherence. These findings were interpreted in the light of possible conflict between rigidity in parents enforcing strict discipline to ensure the ill child's adherence to the regimen, and the developmentally appropriate strivings for independence and autonomy of the adolescent children.

A high reported incidence of religious behaviour as a means of coping with difficulties experienced in the family was significantly associated with families of children with poor regimen adherence. It was also found that religious families were inclined to tend towards rigidity and it was concluded that the religiously associated reduction in flexibility in the family had an adverse effect upon regimen adherence. Another hypothesised salutogenic variable that had pathogenic outcomes when present

in quantity, was the tendency to acquire social support in times of difficulty. Those families which most utilised this strategy in response to difficulties were found to have children with lower levels of regimen adherence. In general, children from families inclined to utilise resources within the family more often than seeking assistance and support from outside of the family, were found to be better adherers to the regimen.

Attempts to integrate these findings concerning family coping led to the tentative hypothesis that families of children with poor adherence are experiencing greater levels of ongoing stress than those of children with good adherence. While families of children with poor adherence do employ more problem-solving and behavioural strategies than families of children with good adherence, their lack of flexibility (tendency towards rigidity) means that these behaviours are not selectively (effectively) utilised. On the other hand, families of children with good adherence utilise a smaller set of problem-solving and behavioural strategies in response to stress, but with greater effect in the mediation of stress (flexibility enabling variation of response). Such an interpetation would suggest that implementing an action that allows "goodness of fit" between solution and problem is more central to outcome than the extent of a family's repertoire of available "solutions".

A series of exploratory investigations was conducted in an attempt to clarify possible means of integrating individual data on the family and its relationship to metabolic control and regimen adherence, into complex and more meaningful relational wholes. As a result of confusion with regard to the linear versus curvilinear nature of adaptability and cohesion as used by the Circumplex Model, the way in which these data have been statistically managed has varied. This crucial methodological problem remains unresolved. Attempts to determine the relative utility of a curvilinear use of FACES III data as opposed to a linear use in predicting metabolic control and regimen adherence, were inconclusive.

Assuming a linear conception of adaptability and cohesion, a tendency towards flexibility in the family (mothers' perceptions) was significantly associated with good regimen adherence, while a tendency towards enmeshment, was significantly associated with poor metabolic control.

A further exploratory exercise was able to demonstrate that certain psychosocial variables affected metabolic control "indirectly" through their effect upon regimen adherence, while others "directly" affected metabolic control. For example, it was graphically demonstrated that the Family Coping variable, Seeking Spiritual Support, impacted upon metabolic control "indirectly" via its mediating effects upon regimen adherence. Conversely, family cohesion, adaptability and satisfaction, were shown to have a greater "direct" mediating effect upon metabolic control, than on regimen adherence.

Finally, discriminant analysis was employed to investigate if combinations of a select few family variables would be able to predict good and poor metabolic control and regimen adherence. Of the examples cited, a combination of siblings' Distance from Centre scores with Sibling satisfaction scores was able to correctly predict good and poor metabolic control in fifteen out of seventeen cases (88.24%). As concerns regimen adherence, a combination of four family coping variables and Family Strengths was able to correctly predict good and poor adherence in twenty-one out of twenty-two cases (95.45%).

6.2 LIMITATIONS OF THIS STUDY

A major limitation of this study is its small sample size. The reasons for this are two-fold. Firstly, the population of people with diabetes is relatively small. It is estimated that, in the Durban metropolitan area, there are between twenty-five and thirty new cases of IDDM among the white population every year (Robertson, personal communication). The second restraint on obtaining an adequate sample was the limited resources available to the researcher.

Although 87 individual family members completed the FACES III questionnaires, they represented the families of 22 children with IDDM. This small sample size made any reliable use of advanced statistical methods, such as path analysis, unreliable or impossible.

Furthermore, the representativeness of this sample is limited in that selection procedures, and difficulty in accessing more families who met inclusion criteria, resulted

in a skewed sample of "non-problem families". A number of families identified by their physicians as "problem families", were, for reasons beyond the control of the researcher, excluded from being interviewed, or from being included in the final data analysis.

While defining good and poor regimen adherence and metabolic control by means of a median split seems common practice, the limited sample allowed only two groupings. As it happened, the median for metabolic control was not different from that in many other studies, so the relative labels of "good" and "poor" control were not entirely misplaced. Powers of inference and comparison would have been increased if upper and lower quartiles of a large sample could have been designated as "good" and "poor", with the remainder classified as "fair". Likewise, a larger sample could have allowed for analyses of covariance of linear variables with age and gender.

Problems of statistical inference are further compounded by the high ratio of family dimensions assessed compared to the number of cases. However, in view of the complexities of family oriented research and the lack of concurrence over what factors are central in affecting metabolic control and regimen adherence, an exploratory over-inclusion of variables could be defended.

A further limitation of this study, common to all studies of the family, is the chasm that exists between theory and the methodological pitfalls inherent in quantifying its constructs, particularly in the use of self-report measures to obtain indices of family organisation and function. Also, some of the data from FACES III has been treated as if it were linear, contrary to the theoretical injunctions of the Circumplex Model.

While a cross-sectional experimental design is less ideal than a longitudinal one, the limited resources available prevented any consideration of repeated measures over time. A reliance on cross-sectional methodology is limited in its ability to accommodate the conception of the family as a dynamic entity that changes structurally and functionally along its life-cycle. The largely correlational approach utilised in this study was unable to assign temporal priority in terms of "cause" and "effect", all that could be determined was the extent of the association between two variables. In this particular case, an inability to assign "cause" and "effect" is not a major issue as it is accepted that illness and context co-determine one another over time, and factors presently associated with

poor control, for example, may be totally unrelated to the factors responsible for its initiation.

However, sample size aside, a further limitation of this cross-sectional design was the informal control for socio-economic status, and limited account taken of the influence of extra-familial factors that would also contribute to poor control and adherence. Had the sample size been bigger, it would have been desirable to introduce an experimental control to account for the different doctors and their relationships with the ill children and their families.

In the final analysis, this study serves to raise more questions than it answers. Very limited interpretations can be made from the fragmented data that could not be statistically and methodologically integrated. Furthermore, these findings can only be generalised to white, middle-class, intact, financially secure South African families, a population group who already have privileged access to the best that health care can offer.

6.3 SUGGESTIONS FOR FUTURE RESEARCH

Given the increasing emphasis on preventative medicine (Gillis, Doherty, Needle & Campbell, 1989; Marcus, 1989; Tal, Gil-Spielberg, Antonovsky, Tal & Moaz, 1990), an improvement in the reliability and clinical utility of family function assessment instruments must be a priority. Immediate priority must be given to remediating the methodological pit-falls that are associated with FACES III in particular, and family assessment instruments in general. The utility and reliability of all present research into family functioning and health is greatly limited by these methodological shortcomings. Concerted effort needs to be made by both researchers and practising clinicians in order to improve congruence across concepts and constructs commonly utilised.

As concerns family functioning and IDDM, future research needs to be conducted with an applied goal in mind, namely the clear and unambiguous identification and empirical description of patterns of combined family characteristics and relational factors that are closely associated with promoting or demoting good metabolic control and regimen adherence. At this premature stage of knowledge accumulation, reliable, in-

depth, description of homogenous groupings appears more useful than comparative studies with other illnesses. Given the present state of methodological infancy in quantitative family assessment, cross-cultural family studies are not recommended at this stage.

A comprehensive longitudinal study, from the time of diagnosis, of the evolving relationship between regimen adherence, metabolic control, and a limited number of clearly identified and relevant family factors, could be very useful in assisting with the ultimate development of a clinically useful and valid family function screening instrument.

The work of Smilkstein and his colleagues (Good, Smilkstein, Good, Shaffer & Arons, 1979; Smilkstein, 1975, 1984) in attempting to design a Family APGAR test, could be expanded upon and applied to families of children diagnosed as having IDDM.

A central issue in considering the development of family function assessment instruments for use in clinical practice is a balance between reliability and ease of administration and interpretation (Smilkstein, 1975). Instruments need to be developed that would assist the health care professional making the diagnosis of IDDM in noting "clinical red flags" (Doherty & Baird, 1983) in the family functioning domain that place those children at increased risk for being unable to achieve adequate metabolic control and regimen adherence.

The schizophrenia research field appears to be well advanced in the use of a vulnerability/stress model for prognostic purposes (Goldstein, 1990). The concept of expressed emotion (EE) in the family (Leff & Vaughn, 1985; cited in Goldstein, 1990), is receiving increasing research attention as a family-based prognostic indicator of schizophrenic relapse (Bebbington & Kuipers, 1988; Birchwood, Hallett & Preston, 1988). Central to the EE appraoch is a vulnerability-stress model which identifies a stressful family environment as characterised by high rates of criticism directed at the index patient, and/or a high degree of "emotional overinvolvement" (Goldstein, 1990). Goldstein (Ibid) cites a number of studies in which the presence of high levels of expressed emotion have been shown to have prognostic value in predicting relapse.

The Camberwell Family Interview, (Leff & Vaughn, 1985; cited in Baldwin, Baldwin

& Cole, 1990) encompasses the concept of EE and is designed to elicit expressions of feelings and emotions from the parents about the child. Exploratory research on the prognostic utility of the concept of EE with regard to families of children with diabetes seems warranted.

If the health care professional is able to identify and detect indicators of risk, she or he could then refer that family for more detailed assessment. Such a preventative strategy would reduce the necessity for what Kaplan (1982) calls "humpty dumpty work". Kaplan (Ibid) notes that problems between illness and context develop over time, beginning during the diagnostic phase, and becoming so ensconced in the family milieu that;

> By the time treatment is instituted, family problems are often as overwhelming to health professionals as they are to the families. The professional finds himself confronted with the impossible task of trying to put broken eggs together again (p.39).

In addition to the need for an early assessment of family functioning;

> There is also some indication that identifying, before and during the transition period, such family variables as the disruption of time schedules, the number of new decisions involving disagreement among family members and the degree of pretransition family conflict can help therapists assess the degree of distress that a family experiences during transitions and can facilitate the selection of an effective treatment approach (Worthington, 1987).

However, the immediate task for future research is the reliable identification of family factors that are consistently associated with good and poor metabolic control. Carefully designed longitudinal studies could then begin to trace the development of these factors over time, and ultimately refine consideration down as far as reliably possible to a limited number of observable, or measurable, family factors highly predictive of future metabolic control and regimen adherence.

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APPENDIX A

FAMILY INTERVIEW SHEET

FAMILY NAME: _____ DATE: _____

Father: Name: _____ Age: _____

Educational Level _____ Occupation _____

Position in family of origin _____

Sex and age of siblings _____

Granparents: Age, if dead when and how, place of residence

PGMo _____

PGFa _____

Mother: Name: _____ Age: _____

Educational Level _____ Occupation _____

Position in family of origin _____

Sex and age of siblings_____

Grandparents: Age, if dead when and how, place of residence

MGMo _____

MGFa _____

Marriage: Date _____ 1st? _____

Still births or miscarriages? _____

Other medical problems in family besides IDDM? _____

_____

Unexpected hospitalisations in past year viz IDDM? _____

Children: Names, Ages, Level of Education, Any behavioural or emotional difficulties?

1. _____

2. _____

3. _____

4. _____

APPENDIX B

FACES III - PERCEIVED VERSION

Please read each statement and decide for each one how frequently on a scale that ranges from 1 (Almost Never) to 5 (Almost Always) these best describe your family now

1	2	3	4	5
Almost Never	Once in a while	Sometimes	Frequently	Almost always

DESCRIBE YOUR FAMILY NOW:

____ 1. Family members ask each other for help.
____ 2. In solving problems, the children's suggestions are followed.
____ 3. We approve of each other's friends.
____ 4. Children have a say in their discipline.
____ 5. We like to do things with just our immediate family.
____ 6. Different persons act as leaders in our family.
____ 7. Family members feel closer to other family members than to people outside the family.
____ 8. Our family changes its way of handling tasks.
____ 9. Family members like to spend free time with each other.
____ 10 Parents and children discuss punishment together.
____ 11 Family members feel very close to each other.
____ 12 The children make the decisions in our family.
____ 13 When our family gets together for activities, everybody is present.
____ 14 Rules change in our family.
____ 15 We can easily think of things to do together as a family.
____ 16 We shift household responsibilities from person to person.
____ 17 Family members consult other family members on their decisions.
____ 18 It is hard to identify the leader(s) in our family.
____ 19 Family togetherness is very important.
____ 20 It is hard to tell who does which household chores.

APPENDIX B

FACES III - IDEAL VERSION

Please read each statement and decide for each one how frequently on a scale that ranges from 1 (Almost Never) to 5 (Almost Always) these best describe as you would ideally like your family to be

1	2	3	4	5
Almost Never	Once in a while	Sometimes	Frequently	Almost always

IDEALLY, HOW WOULD YOU LIKE YOUR FAMILY TO BE:

____ 21 Family members would ask each other for help.
____ 22 In solving problems, the children's suggestions would be followed.
____ 23 We would approve of each other's friends.
____ 24 The children would have a say in their discipline.
____ 25 We would like to do things with just our immediate family.
____ 26 Different persons would act as leaders in our family.
____ 27 Family members would feel closer to other family members than to people outside the family.
____ 28 Our family would change its way of handling tasks.
____ 29 Family members would like to spend free time with each other.
____ 30 Parents and children would discuss punishment together.
____ 31 Family members would feel very close to each other.
____ 32 The children would make the decisions in our family.
____ 33 When our family gets together for activities, everybody would be present.
____ 34 Rules would change in our family.
____ 35 We could easily think of things to do together as a family.
____ 36 We would shift household responsibilities from person to person.
____ 37 Family members would consult other family members on their decisions.
____ 38 We would know who the leader(s) was our family.
____ 39 Family togetherness would be very important.
____ 40 We could tell who does which household chores.

APPENDIX C

F-COPES (Family Coping Scale)

This questionnaire is designed to record effective problem solving attitudes and behaviour which families develop to respond to problems or difficulties.

PLEASE NOTE: **When answering the questions DO NOT take only your response to the diagnosis of diabetes into account. Rather, respond as you think you might to all crises, difficulties or problems.**

DIRECTIONS:

Read each statement and decide how well it describes your attitudes and behaviour in response to problems and difficulties in general. If the statement describes your response VERY WELL, then write a 5 into the column on the left, indicating that you STRONGLY AGREE. If the statement does not describe your response at all, write a 1, indicating that you STRONGLY DISAGREE. If a statement describes your response to some degree, select a number, 2,3, or 4 to indicate how much your agree or disagree with the statement.

RESPONSE CHOICES				
1	2	3	4	5
Strongly Disagree	Moderately Disagree	Neither Agree Nor Disagree	Moderately Agree	Strongly Agree

WHEN WE FACE PROBLEMS OR DIFFICULTIES IN OUR FAMILY WE RESPOND BY:

____ 1. Sharing our difficulties with relatives.
____ 2. Seeking encouragement and support from friends.
____ 3. Knowing we have the power to solve major problems.
____ 4. Seeking information and advice from persons in other families who have faced the same or similar problems.
____ 5. Seeking advice from relatives (grandparents etc.).
____ 6. Seeking assistance from community agencies and programs designed to help families in our situation.

RESPONSE CHOICES				
1	2	3	4	5
Strongly Disagree	Moderately Disagree	Neither Agree Nor Disagree	Moderately Agree	Strongly Agree

WHEN WE FACE PROBLEMS OR DIFFICULTIES IN OUR FAMILY WE RESPOND BY:

____ 7. Knowing that we have the strength within our own family to solve our problems.
____ 8. Receiving gifts and favours from neighbours (eg. food babysitting etc.).
____ 9. Seeking information and advice from our doctor.
____ 10 Asking neigbours for favours and assistance.
____ 11 Facing problems "head on" and trying to get the solution right away.
____ 12 Watching television.
____ 13 Showing that we are strong.
____ 14 Attending Church services.
____ 15 Accepting stressful events as a fact of life.
____ 16 Sharing concerns with close friends.
____ 17 Knowing luck plays a big part in how well we are able to solve family problems.
____ 18 Exercising with friends to stay fit and reduce tension.
____ 19 Accepting that difficulties occur unexpectedly.
____ 20 Doing things with relatives (get-togethers, dinners etc.).
____ 21 Seeking professional counselling and help for family difficulties.
____ 22 Believing that we can handle our own problems.
____ 23 Participating in Church activities.
____ 24 Defining the family problem in a more positive way so that we do not become too discouraged.
____ 25 Asking relatives how they feel about the problems we face.
____ 26 Feeling that no matter what we do to prepare, we will have difficulty handling problems.
____ 27 Seeking advice from a minister.
____ 28 Believing that if we wait long enough, the problem will go away.
____ 29 Sharing problems with neighbours.
____ 30 Having faith in God.

APPENDIX D

FAMILY STRENGTHS SCALE

Please rate the following items as they apply to your family.

RESPONSE CHOICES				
1	**2**	**3**	**4**	**5**
Strongly Disagree	**Moderately Disagree**	**Neither Agree Nor Disagree**	**Moderately Agree**	**Strongly Agree**

____ 1. We can express our feelings.

____ 2. We tend to worry about many things.

____ 3. We really do trust and confide in each other.

____ 4. We have the same problems over and over.

____ 5. Family members feel loyal to the family.

____ 6. Accomplishing what we want to do seems difficult for us.

____ 7. We are critical of each other.

____ 8. We share similar values and beliefs as a family.

____ 9. Things work out well for us as a family.

____ 10. Family members respect one another.

____ 11. There are many conflicts in our family.

____ 12. We are proud of our family.

APPENDIX E

REGIMEN ADHERENCE QUESTIONNAIRE - PARENTS

Please fill in your surname: _____

If you the parent are still responsible for the undermentioned activities please indicate this below and then proceed rate yourself on the categories.

1. Which of the following three requirements does your child find the most difficult to adhere to?

Circle one:

Diet **Injections** **Blood glucose monitoring**

---

2. How do you rate your child's adherence to the required **diet**?

Circle one category:

Excellent: Eats the right kinds and amounts of food **90%** of the time. Almost all meals and snacks are had at nearly the same time every day. Is well adjusted and has no problems with food.

Good: Eats the right kinds and amounts of food **50%-90%** of time. Meal and snack time is regular between **50% and 90%** of the time. Does not cheat with sweets, biscuits etc. Does not skip meals or snacks.

Fair: Eats the right kinds and amounts of food about half the time. Meal and snack time is regular **50%** of the time. Occasionally skips meals/snacks and/or cheats with sweets, biscuits etc.

Poor: Makes little or no effort to stick to prescribed eating behaviours. Eats sweets etc. and/or skips meals and snacks regularly. Food is a problem area.

---

3. How do you rate your child's blood glucose monitoring?

Circle one category:

Excellent: Checks blood glucose levels three to four times a day. Keeps a record of blood glucose levels.

Good: Checks blood glucose levels two to three times a day. Keeps a record of blood glucose levels.

Fair: Checks blood glucose levels on average once a day. Does not keep a record.

Poor: Checks blood glucose levels sporadically or not at all.

---

4. How do you rate your child's required insulin administration?

Circle one category:

Excellent: Technique, timing, and rotation of injections excellent. Good at balancing insulin dosage with blood glucose levels, excercise, and diet.

Good: Technique, timing, and rotation of injections excellent. Never misses injections. Occasionally has to adjust prescribed insulin dosage according to needs.

Fair: Will only change insulin dosage when told to do so. Occasionally misses an injection, or is very late.

Poor: Skips dose or forgets often. Refuses second shot when needed.

APPENDIX F
REGIMEN ADHERENCE - DOCTOR REPORT

EXCELLENT - 4	GOOD - 3	FAIR - 2	POOR - 1
Diet			
Amount of food and timing of eating consistent 90% of the time; well adjusted	Amounts and timing consistent 50% - 90% of the time; no sweets.	Amounts and timing consistent 50% of time; eats sweets infrequently.	Little to no effort; eats sweets.
Metabolic monitoring			
Home blood glucose monitoring 3 to 4 times a day. Keeps a record of levels.	Home blood glucose monitoring 2 times a day. Keeps records of levels.	Home blood glucose monitoring once a day.	Sporadic or no monitoring.
Insulin			
Technique, timing, and rotation excellent; adjusts appropriately as indicated by blood glucose monitoring, excercise and diet.	Technique, timing, and rotation excellent; always taken; occasional adjustment of dose.	Changes dose only with advice; occasionally missed or very late.	Skips dose or forgets often; refuses second shot when needed.

Without taking their glycosylated haemoglobin levels into account, could you please rate the following patients according to the above table of adherence behaviours.

After having done this, could you please fill in the most recent HBa1c reading and the date on which it was taken.

XXXXXXX XXXXXX

Diet:

Excellent **Good** **Fair** **Poor**

Metabolic monitoring:

Excellent **Good** **Fair** **Poor**

Insulin:

Excellent **Good** **Fair** **Poor**

HBa1c level _____% Date _____

XXXXXXX XXXXXX

Diet:

Excellent **Good** **Fair** **Poor**

Metabolic monitoring:

Excellent **Good** **Fair** **Poor**

Insulin:

Excellent **Good** **Fair** **Poor**

HBa1c level _____% Date _____

APPENDIX G
RAW DATA

	Age	Duration of diabetes (years)	HBA_{1C} (%)	Adherence (Moth's est)	Adherence (Dr's estimate)	Adherence (Average)
Family 1:						
IP Male	15	2	10,5	8	5	6,5
Mother	45					
Father	48					
Brother	26					
Family 2:						
IP Female	12	2	9,0	9	9	9,0
Mother	39					
Father	42					
Brother	16					
Family 3:						
IP Male	15	5	23,1	9	5	7,0
Mother	39					
Father	40					
Brother	10					
Family 4:						
IP Female	20	17	14,1	10	7	8,5
Mother	56					
Father	60					
Sister	19					
Family 5:						
IP Female	13	4	15,5	9	11	10,0
Mother	42					
Father	43					
Brother	16					

	Age	Duration of diabetes (years)	HBA_{1C} (%)	Adherence (Moth's est)	Adherence (Dr's estimate)	Adherence (Average)
Family 6:						
IP Female	16	11	13,7	11	12	11,5
Mother	40					
Father	42					
Sister	14					
Brother	9					
Family 7:						
IP Male	10	6	10,2	11	12	11,5
Mother	40					
Father	42					
Sister	16					
Sister	14					
Family 8:						
IP Male	18	14	15,5	5	6	5,5
Mother	49					
Father	54					
Family 9:						
IP Female	10	4	11,2	8	7	7,5
Mother	43					
Father	47					
Sister	15					
Family 10:						
IP Male	20	5	12,1	5	7	6,0
Mother	45					
Father	56					
Brother	22					
Sister	16					

	Age	Duration of diabetes (years)	HBA_{IC} (%)	Adherence (Moth's est)	Adherence (Dr's estimate)	Adherence (Average)
Family 11:						
IP Female	16	4	15,5	7	5	6,0
Mother	42					
Father	49					
Family 12:						
IP Female	18	5	7,9	8	11	9,5
Mother	42					
Father	44					
Brother	16					
Family 13:						
IP Male	13	5	12,2	6	5	5,5
Mother	32					
Father	36					
Brother	12					
Sister	8					
Family 14:						
IP Female	10	5	14,2	6	6	6,0
Mother	41					
Father	50					
Brother	13					
Brother	5					
Family 15:						
IP Female	12	10	15,1	8	12	10,0
Mother	49					
Father	52					
Sister	15					

	Age	Duration of diabetes (years)	HBA_{1C} (%)	Adherence (Moth's est)	Adherence (Dr's estimate)	Adherence (Average)
Family 16:						
IP Female	16	5	8,0	8	11	9,5
Mother	33					
Father	38					
Sister	15					
Brother	12					
Family 17:						
IP Male	12	2	8,5	9	9	9,0
Mother	42					
Father	46					
Sister	16					
Family 18:						
IP Male	17	9	14,0	9	8	8,5
Mother	46					
Father	48					
Sister	19					
Family 19:						
IP Male	12	1	13,8	11	9	10,0
Mother	42					
Father	46					
Brother	7					
Brother	3					
Family 20:						
IP Female	15	5	7,8	11	11	11,0
Mother	40					
Father	45					
Sister	18					
Brother	4					

	Age	Duration of diabetes (years)	HBA_{1C} (%)	Adherence (Moth's est)	Adherence (Dr's estimate)	Adherence (Average)
Family 21:						
IP Female	14	5	15,1	9	12	10,5
Mother	41					
Father	42					
Brother	16					
Sister	8					
Family 22:						
IP Female	16	4	11,0	8	8	8,0
Mother	43					
Father	47					
Sister	16					

N = 22	IP Age	Duration	HBA_{1C}	Adherence (M's Est)	Adherence (Dr's Est)	Adherence (Average)
Total	320,0	130,0	275,0	185,0	186,0	185,5
Mean	14,5	5,9	12,5	8,4	8,5	8,4

	COHESION			ADAPATABILITY			CIRCUMPLEX FAMILY CATEGORY				
	Perceived (P)	Ideal (I)	(P-I)	Perceived (P)	Ideal (I)	(P - I)	Perceived			Ideal	
Family 1:											
IP ♂	41	43	- 2	25	28	- 3	CF	(b) (b) (b)		CF	(b) (b) (b)
Mother	37	47	-10	26	36	-10	SF	(b) (b) (b)		EC	(e) (e) (e)
Father	30	40	-10	30	34	- 4	DC	(e) (e) (e)		CC	(b) (e) (m)
Brother	24	37	-13	22	24	- 2	DS	(e) (b) (m)		SS	(b) (b) (b)
MEAN	**33**	**41,75**	**- 8,75**	**25,75**	**30,50**	**- 4,75**	**SF**	**(b) (b) (b)**		**CC**	**(b) (e) (m)**
Family 2:											
IP ♀	*	*	*	*	*	*					
Mother	44	47	- 3	30	26	4	EC	(e) (e) (e)		EF	(e) (b) (m)
Father	39	40	- 1	17	28	-11	CR	(b) (e) (m)		CF	(b) (b) (b)
Brother	40	42	- 2	22	21	1	CS	(b) (b) (b)		CS	(b) (b) (b)
MEAN	**41**	**43**	**- 2**	**23**	**25**	**- 2**	**CS**	**(b) (b) (b)**		**CF**	**(b) (b) (b)**
Family 3:											
IP ♂	37	39	- 2	21	26	- 5	SS	(b) (b) (b)		CF	(b) (b) (b)
Mother	39	50	-11	22	34	-12	CS	(b) (b) (b)		EC	(e) (e) (e)
Father	47	45	2	26	23	3	EF	(e) (b) (m)		ES	(e) (b) (m)
MEAN	**41**	**44,6**	**- 3,6**	**23**	**27,6**	**- 4,6**	**CS**	**(b) (b) (b)**		**EF**	**(e) (b) (m)**
Family 4:											
IP ♀	47	45	2	31	36	- 5	EC	(e) (e) (e)		EC	(e) (e) (e)
Mother	43	48	- 5	24	36	-12	CS	(b) (b) (b)		EC	(e) (e) (e)
Father	44	47	- 3	23	29	- 6	ES	(e) (b) (m)		EF	(e) (b) (m)
Sister	47	48	- 1	29	36	- 7	EF	(e) (b) (m)		EC	(e) (e) (e)
MEAN	**45,25**	**47**	**- 1,75**	**26,75**	**34,25**	**- 7,5**	**EF**	**(e) (b) (m)**		**EC**	**(e) (e) (e)**

	COHESION			ADAPATABILITY			CIRCUMPLEX FAMILY CATEGORY			
	Perceived (P)	Ideal (I)	(P - I)	Perceived (P)	Ideal (I)	(P - I)	Perceived		Ideal	
Family 5:										
IP ♀	47	50	- 3	22	18	4	ES	(e) (b) (m)	ER	(e) (e) (e)
Mother	46	47	- 1	27	25	2	EF	(e) (b) (m)	EF	(e) (b) (m)
Father	40	43	- 3	22	23	- 1	CS	(b) (b) (b)	CS	(b) (b) (b)
Brother	46	48	- 2	22	21	1	ES	(e) (b) (m)	ES	(e) (b) (m)
MEAN	**44,75**	**47**	**- 2,25**	**23,25**	**21,75**	**1,5**	**ES**	**(e) (b) (m)**	**ES**	**(e) (b) (m)**
Family 6:										
IP ♀	34	42	- 8	13	21	- 8	SR	(b) (e) (m)	CS	(b) (b) (b)
Mother	43	48	- 5	22	28	- 6	CS	(b) (b) (b)	EF	(e) (b) (m)
Father	40	38	2	23	22	1	CS	(b) (b) (b)	CS	(b) (b) (b)
Sister	40	40	0	24	33	- 9	CS	(b) (b) (b)	CC	(b) (e) (m)
MEAN	**39,25**	**42**	**2,75**	**20,5**	**26**	**- 4,5**	**CS**	**(b) (b) (b)**	**CF**	**(b) (b) (b)**
Family 7:										
IP ♂	*	*	*	*	*	*				
Mother	43	48	- 5	22	28	- 6	CS	(b) (b) (b)	EF	(e) (b) (m)
Father	40	38	2	23	22	1	CS	(b) (b) (b)	CS	(b) (b) (b)
Sister	40	40	0	24	33	- 9	CS	(b) (b) (b)	CC	(b) (e) (m)
Sister	34	42	- 8	13	21	- 8	SR	(b) (e) (m)	CS	(b) (b) (b)
MEAN	**39,25**	**42**	**2,75**	**20,5**	**26**	**- 4,5**	**CS**	**(b) (b) (b)**	**CF**	**(b) (b) (b)**
Family 8:										
IP ♂	34	37	- 3	20	12	8	SS	(b) (b) (b)	SR	(b) (e) (m)
Mother	44	49	- 5	25	28	- 3	EF	(e) (b) (m)	EF	(e) (b) (m)
Father	36	39	- 3	23	28	- 5	SS	(b) (b) (b)	CF	(b) (b) (b)
MEAN	**38**	**41,6**	**- 3,6**	**22,6**	**22,6**	**0**	**CS**	**(b) (b) (b)**	**CS**	**(b) (b) (b)**
Family 9:										
IP ♀	*	*	*	*	*	*				
Mother	47	46	1	22	35	-13	ES	(e) (b) (m)	EC	(e) (e) (e)
Father	41	46	- 5	18	21	- 3	CR	(b) (e) (m)	ES	(e) (b) (m)
Sister	43	47	- 3	21	28	- 7	CS	(b) (b) (b)	EF	(e) (b) (m)
MEAN	**43,6**	**46,3**	**- 2,7**	**20,33**	**28**	**- 7,6**	**CS**	**(b) (b) (b)**	**EF**	**(e) (b) (m)**

	COHESION			ADAPATABILITY			CIRCUMPLEX FAMILY CATEGORY				
	Perceived (P)	Ideal (I)	(P - I)	Perceived (P)	Ideal (I)	(P - I)	Perceived			Ideal	
Family 10:											
IP ♂	38	38	0	20	27	- 7	CS	(b) (b) (b)		CF	(b) (b) (b)
Mother	31	47	-16	23	27	- 4	DS	(e) (b) (m)		EF	(e) (b) (m)
Father	31	34	- 3	22	28	- 6	DS	(e) (b) (m)		SF	(b) (b) (b)
Brother	26	36	-10	16	23	- 7	DR	(e) (e) (e)		SS	(b) (b) (b)
Sister	32	43	-11	21	28	- 7	SS	(b) (b) (b)		CF	(b) (b) (b)
MEAN	**31,6**	**39,6**	**- 8**	**21**	**25,4**	**- 4,4**	**SS**	**(b) (b) (b)**		**CF**	**(b) (b) (b)**
Family 11:											
IP ♀	44	46	- 2	19	34	-15	ER	(e) (e) (e)		EC	(e) (e) (e)
Mother	44	45	- 1	18	21	- 3	ER	(e) (e) (e)		ES	(e) (b) (m)
Father	34	43	- 9	23	29	- 6	SS	(b) (b) (b)		CF	(b) (b) (b)
MEAN	**40,6**	**44,6**	**- 4**	**20**	**28**	**- 8**	**CS**	**(b) (b) (b)**		**EF**	**(e) (b) (m)**
Family 12:											
IP ♀	37	44	- 7	25	27	- 2	SS	(b) (b) (b)		EF	(e) (b) (m)
Mother	37	48	-11	28	27	1	SF	(b) (b) (b)		EF	(e) (b) (m)
Father	32	40	- 8	29	25	4	SF	(b) (b) (b)		CF	(b) (b) (b)
Brother	29	35	- 6	20	31	-11	DS	(e) (b) (m)		SC	(b) (e) (m)
MEAN	**33,75**	**41,75**	**- 8**	**25,5**	**27,5**	**- 2**	**SF**	**(b) (b) (b)**		**CF**	**(b) (b) (b)**
Family 13:											
IP ♂	47	44	3	33	36	- 3	EC	(e) (e) (e)		EC	(e) (e) (e)
Mother	38	44	- 6	23	23	0	CS	(b) (b) (b)		ES	(e) (b) (m)
Father	34	39	- 5	28	25	3	SF	(b) (b) (b)		CF	(b) (b) (b)
MEAN	**39,6**	**42,3**	**2,7**	**28**	**28**	**0**	**CF**	**(b) (b) (b)**		**CF**	**(b) (b) (b)**
Family 14:											
IP ♀	*	*	*	*	*	*					
Mother	43	40	3	26	33	- 7	CF	(b) (b) (b)		CC	(b) (e) (m)
Father	43	47	- 4	24	22	2	CS	(b) (b) (b)		ES	(e) (b) (m)
Brother	41	44	- 3	25	28	- 3	CF	(b) (b) (b)		EF	(e) (b) (m)
MEAN	**42,3**	**43,6**	**- 1,3**	**25**	**27,6**	**- 2,6**	**CF**	**(b) (b) (b)**		**CF**	**(b) (b) (b)**

	COHESION			ADAPATABILITY			CIRCUMPLEX FAMILY CATEGORY			
	Perceived (P)	Ideal (I)	(P - I)	Perceived (P)	Ideal (I)	(P - I)	Perceived		Ideal	
Family 15:										
IP ♀	43	46	- 3	40	33	7	CC	(b) (e) (m)	EC	(e) (e) (e)
Mother	45	37	8	41	38	3	EC	(e) (e) (e)	SC	(b) (e) (m)
Father	41	49	- 8	38	31	7	CC	(b) (e) (m)	EC	(e) (e) (e)
Sister	37	36	1	37	35	2	SC	(b) (e) (m)	SC	(b) (e) (m)
MEAN	**41,5**	**42**	**- 0,5**	**39**	**34,25**	**4,75**	**CC**	**(b) (e) (m)**	**CC**	**(b) (e) (m)**
Family 16:										
IP ♀	36	38	- 2	21	24	- 3	SS	(b) (b) (b)	CS	(b) (b) (b)
Mother	35	46	-11	32	30	2	SC	(b) (e) (m)	EC	(e) (e) (e)
Father	42	45	- 3	25	32	- 7	CF	(b) (b) (b)	EC	(e) (e) (e)
Sister	35	41	- 6	22	29	- 7	SS	(b) (b) (b)	CF	(b) (b) (b)
Brother	38	46	- 8	34	28	6	CC	(b) (e) (m)	EF	(e) (b) (m)
MEAN	**37,2**	**43,2**	**- 6**	**26,8**	**28,6**	**- 1,8**	**SF**	**(b) (b) (b)**	**EF**	**(e) (b) (m)**
Family 17:										
IP ♂	45	40	5	22	29	- 7	ES	(e) (b) (m)	CF	(b) (b) (b)
Mother	39	38	1	32	27	5	CC	(b) (e) (m)	CF	(b) (b) (b)
Father	39	44	- 5	28	27	1	CF	(b) (b) (b)	EF	(e) (b) (m)
Sister	39	41	- 2	39	30	9	CC	(b) (e) (m)	CC	(b) (e) (m)
MEAN	**40,5**	**40,75**	**- 0,25**	**30,25**	**28,25**	**2**	**CC**	**(b) (e) (m)**	**CF**	**(b) (b) (b)**
Family 18:										
IP ♂	45	45	0	28	32	- 4	EF	(e) (b) (m)	EC	(e) (e) (e)
Mother	47	49	- 2	33	34	- 1	EC	(e) (e) (e)	EC	(e) (e) (e)
Father	38	46	- 8	25	26	- 1	CF	(b) (b) (b)	EF	(e) (b) (m)
Sister	36	42	- 6	28	31	- 3	SF	(b) (b) (b)	CS	(b) (b) (b)
MEAN	**41,5**	**45,5**	**- 4**	**28,5**	**30,75**	**- 2,25**	**CF**	**(b) (b) (b)**	**EC**	**(e) (e) (e)**
Family 19:										
IP ♂	*	*	*	*	*	*				
Mother	40	42	- 2	35	39	- 4	CC	(b) (e) (m)	CC	(b) (e) (m)
Father	39	40	- 1	25	32	- 7	CF	(b) (b) (b)	CC	(b) (e) (m)
MEAN	**39,5**	**41**	**- 1,5**	**30**	**35,5**	**- 5,5**	**CC**	**(b) (e) (m)**	**CC**	**(b) (e) (m)**

	COHESION			ADAPATABILITY			CIRCUMPLEX FAMILY CATEGORY			
	Perceived (P)	Ideal (I)	(P - I)	Perceived (P)	Ideal (I)	(P - I)	Perceived		Ideal	
Family 20:										
IP ♀	24	38	-14	19	30	-11	DR	(e) (e) (e)	CC	(b) (e) (m)
Mother	34	36	- 2	22	22	0	SS	(b) (b) (b)	SS	(b) (b) (b)
Father	39	42	- 3	33	16	17	CC	(b) (e) (m)	CR	(b) (e) (m)
Sister	23	45	-22	17	26	- 9	DR	(e) (e) (e)	EF	(e) (b) (m)
MEAN	**30**	**40,25**	**-10,25**	**22,75**	**23,5**	**- 0,75**	**DS**	**(e) (b) (m)**	**CS**	**(b) (b) (b)**
Family 21:										
IP ♀	37	46	- 9	24	37	-13	SS	(b) (b) (b)	EC	(e) (e) (e)
Mother	37	41	- 4	26	34	- 8	SF	(b) (b) (b)	CC	(b) (e) (m)
Father	38	32	6	28	33	- 5	CF	(b) (b) (b)	SC	(b) (e) (m)
Brother	21	21	0	20	24	- 4	DS	(e) (b) (m)	DS	(e) (b) (m)
MEAN	**33,25**	**35**	**- 1,75**	**24,5**	**32**	**- 7,5**	**SF**	**(b) (b) (b)**	**SC**	**(b) (e) (m)**
Family 22:										
IP ♀	39	41	- 2	24	23	1	CS	(b) (b) (b)	CS	(b) (b) (b)
Mother	42	49	- 7	20	24	- 4	CS	(b) (b) (b)	ES	(e) (b) (m)
Father	43	44	- 1	23	24	- 1	CS	(b) (b) (b)	ES	(e) (b) (m)
Sister	41	48	- 7	26	29	- 3	CF	(b) (b) (b)	EF	(e) (b) (m)
MEAN	**41,25**	**45,5**	**- 4,25**	**23,25**	**25**	**- 1,75**	**CS**	**(b) (b) (b)**	**EF**	**(e) (b) (m)**

KEY: (b) - balanced (m) - mid-range (e) - extreme

DR - Disengaged/Rigid
DC - Disengaged/Chaotic
SF - Separated/Flexible
CS - Connected/Structured
ER - Enmeshed/Rigid
EC - Enmeshed/Chaotic.

DS - Disengaged/Structured
SR - Separated/Rigid
SC - Separated/Chaotic
CF - Connected/Flexible
ES - Enmeshed/Structured

DF - Disengaged/Flexible
SS - Separated/Structured
CR - Connected/Rigid
CC - Connected/Chaotic
EF - Enmeshed/Flexible

	DISTANCE FROM CENTRE				FAMILY	FAMILY	F-COPES
	Perceived (P)	Ideal (I)	Circumplex (P)	(I)	SATISFACTION %	STRENGTHS Norm Scores	Norm Scores
	b = balanced	m = mid-range	e = extreme				
Family 1:	**5,01**	**7,35**	m	m	**7,41//10,34**		
IP M	1,50	5,04	b	b	20,00		
Mother	3,38	13,9	b	**e**	5,00	63	93
Father	11,34	9,9	**e**	m	7,14		
Brother	15,94	2,8	**e**	b	6,66		
Family 2:	**3,45**	**5,25**	b	m	**13,64// 8,82**		
IP F	*	*	*	*	*		
Mother	7,24	7,45	m	m	14,28	56	8
Father	7,14	3,91	m	b	8,33		
Brother	2,11	3,80	b	b	33,33		
Family 3:	**3,45**	**7,56**	b	m	**8,57// 5,35**		
IP M	4,18	2,06	b	b	14,29		
Mother	2,25	14,21	b	**e**	4,35	23	89
Father	7,45	5,32	m	b	20,00		
Family 4:	**7,84**	**13,55**	m	**e**	**9,75//13,33**		
IP F	9,97	12,99	m	m	14,29		
Mother	3,20	14,45	b	**e**	5,88	67	99
Father	4,34	8,71	b	m	11,11		
Sister	8,71	14,45	m	**e**	12,50		
Family 5:	**7,03**	**13,55**	m	**e**	**23,53//27,32**		
IP F	7,50	11,88	m	m	14,29		
Mother	6,84	7,26	m	m	33,33	98	80
Father	2,11	3,38	b	b	25,00		
Brother	6,55	8,77	b	m	33,33		

	DISTANCE FROM CENTRE				FAMILY	FAMILY	F-COPES
	Perceived (P)	Ideal (I)	Circumplex (P)	(I)	SATISFACTION %	STRENGTHS Norm Scores	Norm Scores
	b = balanced	m = mid-range	e = extreme				
Family 6:	**4,30**	**4,53**	b	b	**10,00//8,96**		
IP F	12,52	3,80	m	b	6,25		
Mother	3,83	9,08	b	m	9,09	82	91
Father	1,12	2,37	b	b	33,33		
Sister	0,80	8,90	b	m	11,11		
Family 7:	**4,30**	**4,53**	b	b	**10,00//8,96**		
IP M	*	*	*	*	*		
Mother	3,83	9,08	b	m	9,09	82	91
Father	1,12	2,37	b	b	33,33		
Sister	0,80	8,90	b	m	11,11		
Sister	12,52	3,80	m	b	6,25		
Family 8:	**1,71**	**5,63**	b	m	**11,11//10,00**		
IP M	7,10	12,42	m	m	9,09		
Mother	4,30	9,99	b	m	12,50	28	80
Father	3,96	3,98	b	b	12,50		
Family 9:	**7,03**	**9,27**	m	**e**	**9,09//9,38**		
IP F	*	*	*	*	*		
Mother	7,5	12,54	m	**e**	7,14	67	57
Father	6,22	6,93	m	m	12,50		
Sister	4,46	8,19	b	m	9,09		
Family 10:	**7,02**	**2,11**	m	b	**7,69//8,20**		
IP M	4,48	3,41	b	b	14,29		
Mother	8,87	7,76	m	m	5,00	23	91
Father	9,05	6,17	m	m	11,11		
Brother	16,00	3,96	**e**	b	5,88		
Sister	7,80	3,83	m	b	7,69		

	DISTANCE FROM CENTRE				FAMILY SATISFACTION	FAMILY STRENGTHS	F-COPES
	Perceived (P)	Ideal (I)	Circumplex (P)	(I)	%	Norm Scores	Norm Scores
	b = balanced	m = mid-range	**e** = extreme				
Family 11:	**5,13**	**7,74**	m	m	**8,33// 7,50**		
IP F	6,61	11,68	b	**e**	5,88		
Mother	7,41	6,05	m	m	25,00	19	99
Father	5,90	5,85	b	b	6,66		
Family 12:	**4,22**	**5,08**	b	m	**8,00// 9,38**		
IP F	2,94	5,10	b	b	11,11		
Mother	4,80	8,70	b	m	8,33	63	93
Father	9,21	0,93	m	b	8,33		
Brother	11,55	8,41	m	m	5,88		
Family 13:	**4,14**	**5,83**	b	m	**15,00//10,00**		
IP M	11,45	12,62	**e**	**e**	16,66		
Mother	2,11	4,34	b	b	16,66	56	93
Father	6,99	1,20	m	b	12,50		
Family 14:	**4,59**	**6,73**	m	m	**13,64// 9,38**		
IP F	*	*	*	*	*		
Mother	3,72	8,90	b	m	10,00	44	89
Father	3,20	7,50	b	m	16,66		
Brother	1,50	5,73	b	b	16,66		
Fam 15:	**15,16**	**10,98**	**e**	**e**	**10,26// 8,45**		
IP F	16,22	10,85	**e**	m	10,00		
Mother	17,68	14,18	**e**	**e**	9,09	28	71
Father	13,95	11,50	**e**	**e**	6,66		
Sister	13,20	11,54	**e**	m	33,33		

	DISTANCE FROM CENTRE				FAMILY	FAMILY	F-COPES
	Perceived (P)	Ideal (I)	Circumplex (P)	(I)	SATISFACTION %	STRENGTHS Norm Scores	Norm Scores
	b = balanced	m = mid-range	e = extreme				
Family 16:	**2,57**	**6,90**	m	m	**9,09// 8,62**		
IP F	4,90	1,80	b	b	20,00		
Mother	9,24	8,56	m	m	7,69	50	66
Father	2,38	9,46	b	m	10,00		
Sister	5,24	5,04	b	b	7,69		
Brother	10,06	7,32	m	m	7,14		
Family 17:	**6,53**	**4,93**	m	m	**11,43// 7,06**		
IP M	5,61	4,90	b	b	8,33		
Mother	7,94	3,41	m	b	16,66	19	40
Father	3,98	5,10	b	b	16,66		
Sister	14,92	6,02	**e**	b	9,09		
Family 18:	**5,60**	**10,04**	m	**e**	**16,00//15,38**		
IP M	6,50	9,46	b	m	25,00		
Mother	11,45	13,51	**e**	**e**	33,33	67	62
Father	2,01	6,48	b	m	11,11		
Sister	5,45	7,24	b	m	11,11		
Family 19:	**5,95**	**11,65**	m	**e**	**14,23//25,00**		
IP M	*	*	*	*	*		
Mother	10,90	15,06	m	**e**	16,66	4	11
Father	1,20	7,90	b	m	12,50		
Family 20:	**7,95**	**2,57**	m	b	**5,13// 3,66**		
IP F	16,60	6,00	**e**	b	4,00		
Mother	6,17	4,34	m	b	50,00	28	22
Father	8,94	8,39	m	m	5,00		
Sister	18,24	5,54	**e**	b	3,22		

	DISTANCE FROM CENTRE				FAMILY SATISFACTION	FAMILY STRENGTHS	F-COPES
	Perceived (P)	Ideal (I)	Circumplex (P)	(I)	%	Norm Scores	Norm Scores
	b = balanced	m = mid-range	**e** = extreme				
Family 21:	**4,55**	**8,19**	b	m	**8,16//7,59**		
IP F	2,80	14,30	b	**e**	4,55		
Mother	3,38	9,97	b	m	8,33	44	5
Father	4,30	11,83	b	**e**	9,09		
Brother	19,24	18,80	**e**	**e**	25,00		
Family 22:	**3,61**	**7,73**	b	m	**15,38//15,00**		
IP F	0,80	1,63	b	b	33,33		
Mother	4,65	9,20	b	m	9,09	39	22
Father	3,38	4,20	b	b	50,00		
Sister	2,25	9,95	b	m	10,00		