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A Literature Review for Nurses
On
The Potential Diabetic Complications in Children And Young Adults

A dissertation submitted to The Middlesex University
in partial fulfillment for
The Award of Bachelor of Philosophy

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In Memory of

Sara Elizabeth Partridge

31.03.59 - 14.05.95

A Dear Friend - Forever Remembered, Never Forgotten.

ABSTRACT

The incidence of Insulin Dependent Diabetes Mellitus (IDDM) in childhood is increasing within the United Kingdom. Prior to the discovery of Insulin in 1922, patients with IDDM died and although treatment with daily insulin injections is now effective in the everyday control of the disease, it does not prevent the individual from developing the long-term complications associated with the metabolic disorder. The majority of research into childhood diabetes and the potential problems due to complications is carried out within the medical field. Although this research is valuable it rarely approaches the problems of diabetes from a nursing perspective. There is however literature available in a number of journals that is written from the nursing point of view encompassing a range of diabetes related topics. The purpose of this dissertation is to review the limited literature found and present the conclusions in a concise and readable form.

The history of diabetes is described emphasising the fact that insulin therapy is still a relatively new treatment. The long and short-term complications associated with diabetes are defined in order that the articles reviewed later in the dissertation can be understood. The methodology of the literature search is discussed and reasons are given for focusing on certain themes that were then further expanded in the review chapters.

The conclusion focuses on the themes that developed such as the need for education, compliance, new developments in treatment, glycaemic control and the role of the Paediatric Diabetes Specialist Nurse. It is hoped that the dissertation will encourage the reader to utilise this information in the provision of care to young people who are affected by IDDM. The information available from the

whole range of the media, including the Internet, is examined and the difficulty that the quality of this information can pose to health care professionals is discussed. The implications for research based nursing practice are explored and ideas for potential research projects as a result of the themes described are suggested.

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CHAPTER ONE

INTRODUCTION

The author of this piece of work is currently employed as a Research Nurse (fieldworker) on the Oxford Regional Prospective Study into Childhood Diabetes (ORPS) and this literature review is being carried out as part of her BPhil. Originally set up in 1985, ORPS is a project designed to map the natural history of the chronic disease Insulin Dependent Diabetes Mellitus (IDDM) in children and adolescents and to detect the early markers to predict complications. It is a longitudinal study which has a cohort of children and adolescents taken from the old Oxfordshire Regional Health Authority (RHA) comprising Oxford, Banbury, Aylesbury, Reading, Kettering, Northampton and Windsor and includes ten different hospitals within these areas. The project has funding from the British Diabetic Association (BDA) until December 31st 1999.

The main aim of ORPS is to determine which children or adolescents may develop the long-term complications of diabetes, by observing the trends in the results of specific annual clinical investigations. If markers can be isolated and recognised, then the care for future generations of diabetic children and young adults can be targeted at the prevention of the horrific long-term complications seen today in the older population e.g. blindness, lower limb amputations, cardiovascular disease (CVD) and renal failure. Until prevention of, or a cure for, IDDM is found, the aim must still be towards the prevention of the complications associated with diabetes. Results of scientific research show that by improving blood glucose control, the risk of developing long-term complications is reduced. Conversely, where poor blood glucose control is evident, the risk of long-term complications is considerably higher (BDA, 1997).

ORPS is specifically looking at the natural history and progression of urinary protein excretion from the minimal detectable level, microalbuminuria, to the precursor of renal failure, macroalbuminuria, and the subsequent development of end stage diabetic nephropathy. Other areas also being monitored include diabetic retinopathy, diabetic neuropathy and function of the autonomic nervous system.

The author joined the well-established study in 1994 following a nursing career that had focused on adult nursing with an interest in cardiology. The department is a research based unit with a strong academic influence, which has a number of permanent and visiting research registrars, and the author has naturally been drawn into increasing her knowledge base, particularly in the medical field of diabetes. As part of the work required for the final report for this study, the author was requested to carry out a literature search on the medical papers particularly pertaining to microalbuminuria and diabetic nephropathy. From an interest point of view an extensive search of the nursing literature was performed using the same topic and this yielded only six articles. The search was then widened to include the broader term of diabetic complications, which highlighted more articles, but certainly not in the quantity expected.

With the spiralling emphasis on the development of nurses within specialist roles – diabetic specialist nurses being no exception – the author was surprised to initially find so little written specifically about diabetic children and the risk of complications. However, as this work has progressed, the author has become more aware of the specific diabetes journals available and these have yielded a more encouraging and richer source of information. There is a surprising lack of literature which is readily available to the nursing profession dealing with the specific long-term complications, most tending to focus on general issues. In view of the limited availability of listed articles, the author has decided to review those found which include the general care of diabetic children that may or may not encompass potential complications.

Chapter Two focuses on the history of diabetes and is included purely to emphasise the fact that although diabetes has been recognised for centuries, treatment with insulin is less than eighty years old. The chapter also provides information on the incidence of diabetes as well as introducing topics that will be included in the developing review.

A description of the literature review process is outlined in Chapter Three. The themes perceived in the articles are described in the subsequent chapters including a specific chapter on case studies, which is an area of particular interest to the author.

Chapter Eight describes the history of nursing research to the present day, the expansion of knowledge and the utilisation of research within practice. The impact of current media trends is examined in Chapter Nine as well as suggestions for future study.

It is one of the purposes of this thesis to show that despite the paucity of the literature that there are articles available to nurses both within the medical and nursing press that is readable, useful and can be used in determining care for a given population. In order to provide research based care, it is necessary for the available knowledge from the various articles to be disseminated. The pertinent information is often not found in the nursing press but in the journals allied to other health care professionals. At first glance this source may look daunting but can be read, understood and implemented into the everyday practice of diabetic patient care. The current emphasis on Primary Health Care should hopefully encourage nurses and doctors to work together towards the same goal, namely the prevention of the long-term complications associated with diabetes mellitus, within a clinic and community setting.

CHAPTER TWO

INSULIN DEPENDENT DIABETES MELLITUS

A Definition of Diabetes

> *"[Gr.* ***Diabetes*** *a syphon, from* ***dia*** *through and* ***bainein*** *to go] a general term referring to disorders characterized by excessive urine excretion (polyuria), as in diabetes mellitus and diabetes insipidus. When used alone, the term refers to diabetes mellitus."*
>
> Dortland's Illustrated Medical Dictionary, 1994, p456.

Insulin Dependent Diabetes Mellitus (IDDM), also referred to as juvenile-type onset or Type I diabetes, is a chronic irreversible auto-immune disease caused by the destruction of the ß-cells of the Islets of Langerhans, situated in the pancreas. Progressive damage leads to the complete absence of secretion of the hormone, insulin, which is responsible for the regulation of blood glucose concentration. In normal physiology glucose enters the cells of the body from the blood stream to provide energy for their metabolism but when there is an absence, or relative lack of insulin, this transport process is halted resulting in high blood glucose levels (Willis, 1995). The term 'insulin-dependent' is defined by the World Health Organisation (WHO) Study Group in their 'Report of a World Health Organisation Study in Diabetes Mellitus' published in 1985 stating that without insulin injections a diabetic person will become comatose and die within days or a few weeks. IDDM commonly presents under the age of 30 but can occur at any age (Watkins, 1998).

Non-Insulin Dependent Diabetes Mellitus (NIDDM), another form of the disorder, is also referred to as Mature Onset Diabetes Mellitus or Type 2 Diabetes occurs in the older population. It can occasionally manifest itself in the younger age group, Mature Onset Diabetes of the Young (MODY), but this is still rare. However more cases are currently being diagnosed and research into the increased incidence is being carried although no results are available at present. NIDDM is characterised by a reduction in the amount of insulin secreted from the pancreas. Treatment is aimed at reducing blood glucose levels and prevention of long-term complications. If the person is overweight at the time of diagnosis, education into losing weight by improving dietary habits is the first line of treatment. Weight loss may lead to the reduction of blood glucose levels and no further treatment required. Oral hypoglycaemic agents is the second line of treatment but if this is unsuccessful, then insulin injections may be the therapy of choice (Watkins, 1998; MacKinnon, 1998).

The Discovery of Diabetes Mellitus

In 1862 Georg Ebers, an Egyptologist, discovered a papyrus dating from 1550 BC in a grave in Thebes describing various diseases, but one in particular characterised by symptoms of excessive urination and great thirst – now understood to be indicative of diabetes mellitus. Therefore, there is undoubted evidence that the disease itself has been recognised since at least the Fifteenth Century BC although Arateus of Cappadocia did not use the term diabetes until the Second Century AD when he described a condition causing an increase in urine output. It was not until the Eighteenth Century AD that the adjective mellitus, meaning like honey, was added to the disease to describe the sweet urine passed by diabetics (Keen and Tang Fui, 1982; MacFarlane, Bliss, Jackson and Williams, 1997).

As early as the Fifth and Sixth Century AD two Indian physicians Susruta and Charuka distinguished that there were two forms of diabetes one of which afflicted older, fatter people and the other which affected thin people who were unable to survive the disease. It is now thought that they were describing NIDDM and IDDM respectively (MacFarlane *et al.*, 1997).

During the Nineteenth Century AD various facets of diabetes mellitus and its presentation were researched by a number of eminent physicians. William Prout (1785-1859) described the diabetic coma with the associated acidotic breathing identified by Professor A Kussmaul (1822-1902). Claude Bernard (1831-78) during the years 1849-55 examined the roles of the pancreas, liver and brain pioneering the theory that the central nervous system was involved in controlling blood sugar levels. He also determined that the sugar found in the urine had originated from glycogen stores in the liver. Bernard's work, particularly that which he had performed on the pancreas, was advanced further in 1889 by Oskar Minkowski (1858-1931) and Josef Von Mering (1849-1908). They found that by removing a pancreas from a dog, the symptoms of diabetes could be mimicked and thus introducing the idea that diabetes was primarily a disorder of the pancreas (MacFarlane *et al.*, 1997).

In 1869, Paul Langerhans (1847-88) described groups of cells in the pancreas, although he was unable to speculate as to their function. It was not until 1893 that Edouard Laguesse (1861-1927) named these structures the Islets of Langerhans in recognition of Langerhans' earlier discovery. Jean de Meyer later assumed in 1907 that these Islets were probably responsible for producing a hormone, which he named insuline, taken from the Latin word *insula*, meaning island (MacFarlane *et al.*, 1997).

During the latter part of the nineteenth century and the early part of the Twentieth Century AD, people suffering from diabetes mellitus died very soon after the onset of the symptoms and despite the pioneering experimental work, the discovery of a treatment was still several decades in the future. A starvation diet was one of the early experimental treatments but this only gave a survival rate of a few months at most and certainly no quality of life.

Finally Insulin was discovered at the University of Toronto in 1921-2 by the collaborative work of the Canadian physiologist Sir Frederick Grant Banting and his student assistant Charles Herbert Best, overseen by the British physiologist John James MacLeod. They were unaware at this stage of Meyer's work from 1907 and his work relating to the hormone insuline. The Toronto team's initial work centred on transplanting of Islet cells into dogs that had induced diabetes following a pancreatectomy. Although not particularly successful, it is ironic that nearly eighty years later this approach is one of the techniques that is being researched as a treatment. Banting and Best then attempted to inject chilled extracts of pancreas into the dogs and this produced an immensely encouraging result with a lowering of the blood sugar levels. The pair later invited biochemist James Collip onto the team in an effort to elucidate the active component and produce a purified treatment of the pancreatic extract. In May 1922 the team from Toronto were the first to produce this purified insulin and were able to report their successful work in the Association of American Physicians in Washington DC entitled "The effect produced on diabetes of extracts of pancreas". Collip was unable to produce enough of the purified insulin to meet the demand of the diabetic population in Toronto. He therefore asked for assistance from the chemists of Eli Lilly and Co of Indiana who became involved in the development and use of insulin. By the end of

1923, insulin was widely available for use across North America and Europe. Prior to 1922, the speed of death in diabetics was rapid but following the discovery and subsequent use of insulin, those patients with diabetes mellitus are now able to live with an acceptable quality of life (MacFarlane *et al.*, 1997).

Since 1922, scientific work has continued on diabetes and its management, treatment and prevention. The increased life expectancy of these patients heralded further problems, which only became apparent with long-term survival when conditions such as blindness and renal failure were seen in this patient population. Sadly despite the well being induced by insulin injections and the prolonged life span, there has been no protection against the chronic damage to the eyes, kidneys, nerves and blood vessels. The long-term complications have thus been a research priority since the discovery of insulin (MacFarlane *et al.*, 1997).

The Incidence of Insulin Dependent Diabetes Mellitus

Metcalfe and Baum (1991) studied the incidence of IDDM in children diagnosed before fifteen years of age in the British Isles during 1988 and showed that there was an incidence rate of 13.5/100,000/year. In comparison with other countries, this was midway between the highest incidence found in Finland of 29.5/100,000/year and the lowest of 1.7/100,000/year in Hokkaido, Japan. Regionally Scotland had an incidence of IDDM three times that found in the Republic of Ireland who had the lowest recorded incidence rate of 6.7/100,000/year. Oxford had a greater than average incidence of 15.2/100,000/year.

A more recent study by Gardner, Bingley, Sawtell, Weeks and Gale (1997) showed that the incidence of IDDM in the Oxford region for the age group 0-15 years had increased by 4% to 18.6/100,000/year from 1985-1996. The most worrying statistic was the increase in the children diagnosed under five years of age where an annual increase of 11% was noted. No explanation for this increase is known although Gardner *et al* speculate that environmental influence *in utero* or early life could be relevant. However Gardner's study was only a regional survey and it is unknown whether a comparable national rise in incidence will be seen.

It is well established that there is a genetic component responsible for the development of IDDM in children (Rich, 1990) but work continues in this field. The continuing advances made in the search for the relevant genes for Type 1 diabetes (IDDM) are summarised by Alcolado (1998) in his commentary in the Lancet. He also highlights that there is now much speculation that it is not only the genes that play a part in the development of Type 1 diabetes that are being searched for but also the ones responsible for those who will develop diabetic complications (Alcolado, 1998).

IDDM is most commonly diagnosed during the spring and autumn. It has been suggested that this pattern may be related to the higher seasonal frequency of viral illnesses although Bingley and Gale (1989) found in the Oxford region with data obtained in 1985-6 that the seasonal differences were not significant. However in Metcalfe and Baum's national study most cases were noted in February and March and the fewest numbers in May and June. Figures for other months of the year were not shown (Metcalfe and Baum, 1991). Gardner *et al* (1997) showed that although the seasonal variation was evident in the older diagnosed children, it was absent in the under five age group. This may be significant when looking at the reasons behind the increase such as environmental factors or as mentioned above the exposure to specific viruses or perhaps the current immunisation programmes. The role that the environment may play in the destruction of the ß-cells is less fully understood (Karvonen *et al.*, 1993). Rothwell, Staines, Smail, Wadsworth and McKinney (1996) observed that children born during spring and early summer had a greater risk of developing childhood diabetes than those born in the winter months. The data were taken from three large independent populations of children born during 1974-88. It was concluded that the environment must be part of the aetiology of diabetes as genetic mechanisms could not be responsible for seasonal determinants. They also conclude that if environmental factors are influential then they will occur *in utero* or during the first year of life. They conclude their article by saying that their observations support the hypothesis that the disease process causing childhood diabetes is precipitated by a viral infection early in life, supporting Bingley and Gale (1989). They do say that further work will be required to look at any environmental factors and the seasonality of births (Rothwell *et al.*,1996).

Monitoring of Glycaemic Control

Blood glucose level is the tool used to monitor the short-term control of an individual diabetic. Patients are able to use a finger prick test at home to measure their blood glucose level at any moment in time. However this does not reflect the overall long-term control. A single blood glucose test will not indicate whether there has been an episode of hypoglycaemia or hyperglycaemia. The measurement of glycated haemoglobin in the laboratory gives an indication of the average blood glucose measurement will have been over the previous few months. As each new red blood cell is produced, part of the haemoglobin molecule reacts with glucose in the bloodstream resulting in a fraction called HbA1 (Sönksen, Fox and Judd, 1996;

MacKinnon, 1998). The result is expressed as a percentage of the total haemoglobin present. Some laboratories will record a sub-component of the HbA1, called HbA1c, which is an almost identical reading, although the normal range varies from laboratory to laboratory depending on the assay used. The HbA1c level recorded gives the basis for the diabetic team to alter insulin doses with the aim to reduce this level to as near normal as possible.

Complications Associated with Insulin Dependent Diabetes Mellitus

If the blood glucose levels are not maintained within the current clinic criteria as defined by HbA1c levels, there is a significant risk of developing the complications associated with diabetes. These can be divided into the acute complications usually metabolic in origin and the chronic diabetic complications. Many of these complications can be avoided by ensuring that patients can manage their own diabetes not only in the treatment of the acute problems but also in the prevention of long-term problems (Farr and Watkinson, 1993).

Acute Complications of Diabetes

Metabolic disturbances are generally responsible for the acute complications resulting from high (hyperglycaemia) or low (hypoglycaemia) blood glucose recordings.

Hypoglycaemia

This can occur as a result of not eating following an insulin injection or the over-treatment of the disorder with insulin. The early warning symptoms associated with a hypoglycaemic event include shaking, sweating, pins and needles around the mouth, hunger, palpitations and occasionally headaches. The event can be alleviated at this stage if a sugary snack or glucose tablet is eaten. If these symptoms are ignored then neurological symptoms due to the lack of glucose in the brain occur such as double vision, lack of concentration, slurring of speech leading onto confusion and behavioural changes. The most serious hypoglycaemic event is unconsciousness resulting in a convulsion or seizure. The emergency treatment of the unconscious patient is either at home with an intramuscular injection of glucagon which will rapidly raise the blood glucose level or in hospital where intravenous glucose can be administered (Watkins, 1998). Diabetic patients need to be educated on ways to avoid the serious hypoglycaemic episodes and to recognise their own early warning symptoms that they experience (Farr and Watkinson, 1993).

Hyperglycaemia

This is when the blood glucose recordings are found to be above the normal clinic level due to either not eating the recommended diet, not administering the prescribed insulin dose, a poor injection technique, lack of exercise or as a result of an infection or illness. Symptoms associated with hyperglycaemia include thirst, polyuria, nocturia, lethargy, and irritability as well as visual changes. Patients need to be taught that occasional hyperglycaemia is to be expected but persistent episodes require treatment with a change in diet, insulin dose or exercise to prevent the recognised long-term problems. If an infection is the cause, advice should be sought from the General Practitioner (GP) or hospital team (MacKinnon, 1998).

Diabetic Ketoacidosis (DKA)

This condition occurs as a result of infections, illness or severe insulin deficiency as a result of errors in insulin administration and is a diabetic emergency. Patients are admitted to hospital dehydrated, drowsy, hyperventilating and possibly hypothermic and hypotensive. Clinical findings include glycosuria, ketonuria, hyperglycaemia as well as metabolic and electrolyte imbalance. Treatment primarily involves slow re-hydration with intravenous fluids and insulin administration and secondly managing the underlying cause of the event (Watkins, 1998).

Chronic Complications of Diabetes

If there is persistent hyperglycaemia in an individual, there is a significant risk of long-term complications occurring although this risk is also associated to the duration of the disease. The high levels of glucose in the blood results in damage to the nervous system and the arterial system in the body and can affect both the small blood vessels (micro-vascular) and the large blood vessels (macro-vascular).

Micro-vascular Involvement

Damage to the micro-vascular system can affect the eyes and kidneys resulting in retinopathy and nephropathy respectively. Diabetic retinopathy is one of the major causes of blindness in developed countries. Diabetic patients should be screened annually for visual impairment and undergo examination of the retina through dilated pupils. The degree of retinopathy is associated with the duration of the diabetes and therefore screening of children and young adults as well as the encouragement to maintain lower blood glucose levels is paramount. If retinal changes are observed through screening, more frequent assessment can be initiated or in some cases laser treatment can be used (MacKinnon, 1998; Farr and Watkinson, 1993).

Diabetic nephropathy is a major cause of morbidity and mortality in people with IDDM (Andersen *et al*, 1983). Screening for microalbuminuria can be undertaken during clinic visits and again by encouraging the diabetic to maintain lower blood glucose levels, the progression to macroalbuminuria and End Stage Renal Failure (ESRF) requiring dialysis treatment or renal transplant can be prevented. It is important to monitor blood pressure measurements in this group of patients, as hypertension can be an early sign of renal impairment.

Macro-vascular Involvement

Macro-vascular damage occurs more commonly in diabetic patients with a long duration of disease who have already developed some micro-vascular damage. It can affect the larger arteries in the body such as those in the brain, heart and peripheries. Damage to the coronary arteries can result in angina or a myocardial infarction whilst damage to the cerebral arteries can result in a Cerebral Vascular Accident (CVA). The peripheral artery impairment can lead to poor blood circulation and combined with neuropathy in the lower limbs may result in the need to amputate the foot or lower leg (MacKinnon, 1998).

Diabetic Neuropathy

Nerve damage as a result of poorly controlled diabetes can affect a number of the body's systems. The presence of neuropathy can be difficult to detect until serious symptoms have occurred. Dysfunction can occur in the nerves controlling the cardiovascular system resulting in a sudden lowering of the blood pressure, the alimentary tract resulting in chronic diarrhoea, the respiratory control system and also in the body's thermoregulatory system. The genitourinary system can also be affected with impotence in men being one of the most distressing problems

(Sönksen, Fox and Judd, 1996; MacKinnon, 1998). Nerve damage can also occur in the peripheral nerves mainly in the feel and legs. Foot care is important in diabetic patients as failure to recognise foot ulcers and treat accordingly can result in irreparable damage and the need for amputation.

The long-term future for children diagnosed with IDDM will be difficult but with the encouragement and appropriate education, the accepted risk of complications associated with the duration of the disease can be reduced. Prior to the discovery of insulin, IDDM patients did not survive, but now careful use of insulin can be used to control blood glucose levels and thereby prevent long-term complications.

The Diabetes Control and Complications Trial

One of the major influences to encourage good glycaemic control has been the Diabetes Control and Complications Trial (DCCT), a ten-year study involving over 1400 patients from the United States of America (USA) and Canada. The patients were divided into two groups according to the absence or presence of early complications (retinopathy and renal disease). Each group was then randomised into either an intensive insulin treated cohort or conventional therapy. The intensive therapy involved three or more insulin injections per day, Self Monitoring Blood Glucose (SMBG) at least four times a day, monthly clinic visits and weekly phone calls. In comparison the conventional group had a maximum of two insulin injections a day, daily SBGM and three monthly clinic visits (DCCT, 1993 and 1994).

The study concluded that tight blood glucose control (defined by an HbA1c measurement) prevented or delayed the onset of complications and the results were so conclusive that the study was halted one year early. The DCCT was unable to formulate an ideal threshold of HbA1c at which complications may occur but it concluded that by achieving as near to normal glycaemia as soon as possible, the diabetic patient would benefit in the long-term (DCCT, 1996). The study convincingly demonstrated that any improvement in control could be beneficial in lowering the risk or halting the progression of complications (DCCT, 1993, 1994 and 1996). However the disadvantage of the intensive treatment was more hypoglycaemic episodes, which some people found acceptable. Some of this group also gained weight, which was deemed to be an adverse side effect by the investigators (DCCT, 1993 and 1994).

The DCCT results are the main instigator for a change in disease management with the reduction of the long-term complications being of paramount importance. Although there were no children under the age of thirteen in the trial, therefore results should be treated with caution (Shield and Baum, 1994), the adolescent participants proved an interesting group to follow. 20% of the DCCT cohort were adolescence and so the results obtained are pertinent to the young adult population of today. The adolescent group had a slightly higher average of HbA1c level although no explanation was offered for this (Drash, 1993). They were found to be the most difficult age group to treat but the investigators felt that it was worth spending the time with them, as the benefit for long-term cost on the health system would be immense (DCCT, 1993)

CHAPTER THREE

AN OVERVIEW OF THE NURSING LITERATURE

A Medline Express search using the parameters of Insulin Dependent Diabetes Mellitus and albuminuria, including microalbuminuria, within the age definitions of child and adolescence was performed up to the end of December 1997. The search was limited to English language papers and it produced approximately three hundred and fifty quantitative research papers with the earliest being from 1962 and the latest, December 1997. A similar search was then carried out within the nursing indexes but the search terms albuminuria and microalbuminuria were unrecognised although by substituting proteinurea for albuminuria, six articles were produced. A less focused search was carried out using the search terms of IDDM, children, adolescents and complications producing a comprehensive list of about forty articles. A visual search of the index books rather than using a computer database was carried out to check whether other articles were being missed because of the search tools being used but this was not the case. The outcome of the search was that there were few articles available within the nursing press on diabetic complications in children and young adults. The search covered the years from 1982 until the present day so limiting the dates was not a factor in producing so few pieces of literature.

As expressed previously, most nursing articles cover all aspects of diabetic complications, whereas the medical literature is more focused on specific clinical problems. As indicated in Chapter Two, the incidence of diabetes is increasing and with the consideration of appropriate data (Gardner *et al*, 1997) it is presumed that this rise will continue. With this expected increase and the accepted mortality figures for ESRF (Andersen *et al*, 1983) it is imperative that nurses screen for diabetic complications. One of the aims of this dissertation will be to show that a combination of literature found from the nursing indexes and that found within the medical journals can be used to the benefit of the patients.

Initial impressions were that the articles discussed various aspects of childhood diabetes and it's long-term complications, although there is no consistent reporting. The author has tried to include articles found within the medical indexes on the specific themes that have developed, although this has not always been possible. The relative lack of nursing literature found initially raised doubts as to whether the search had been comprehensive but on questioning a Diabetic Specialist Nurse (DSN) on this, the DSN agreed with the author's findings. She added that the demands of her clinical work prevented her from performing research and provide the care required by her patients.

There was a wide range of topics covered by the articles found in the search ranging from contraception advice to adolescents (Fennoy, 1989, Betschart, 1996) to care of a newly diagnosed insulin dependent diabetic child (Grey, Cameron, Lipman and Thurber, 1994). There was also one article on Diabetic Ketoacidosis (DKA) (Young, 1995), an acute complication of diabetes mellitus. DKA is not a condition generally associated with long-term complications of the disease but repeated episodes may have far reaching long-term implications for care of the patient.

The target audience of the journals from which the articles were extracted was observed to vary considerably. Some articles were taken from journals available from newsagents such as the Nursing Times, British Journal of Nursing and Professional Nurse, whereas others were only available by subscription e.g. Journal of Advanced Nursing. Articles were also found in specific diabetes journals e.g. Diabetes, Diabetes Care, Diabetes Educator and Diabetes Forecast, as well as diverse publications e.g. Caries Nursing, New Zealand Practice Nurse and Health Education. No hospital library can subscribe to all of these specialist journals as well as the other mainstream publications required in a general hospital library. Therefore in order for an individual to be able to read all the articles obtained from a search, those not held by the library must be ordered through the inter library loan service. This can take time, and money, and for most people with a superficial interest in a topic, this is an undesirable proposition.

The different readership of the journals provides diversity in the approach to childhood diabetes and the long-term complications. Many different groups of professionals from school nurses, practice nurses to paediatric nurses as well as the DSN are involved in the care of the diabetic child. However, although there is a rise in the incidence of childhood diabetes (Gardner *et al* , 1997), the numbers are still relatively low in the population and so a carer may be unfamiliar with changes in practice if exposure to childhood diabetes is limited. The greatest concentration of diabetic children is in the clinical areas of a hospital and therefore the nurses being involved with the children will be the DSN or the Paediatric Diabetes Specialist Nurse (PDSN) and the Clinic Nurse. These are the nurses who should have the access to relevant nursing journals and articles about childhood diabetes and the screening for and the prevention of long-term complications. If their hospital does not hold the specific journals, these nurses may not be aware of the bulk of the nursing literature available about their speciality. Unfortunately, therefore many useful journal articles will be unread by the people most needing them.

Whilst carrying out the search the author has found nine articles which did not appear on the Cumulative Index of Nursing and Allied Health Literature (CINAHL) database when the chosen search words were used. It is unclear why these articles were omitted from the database as the term diabetes mellitus or complication appears in eight of the titles. The author realises that any database used will only be as good as the data entered and that any search will only be as thorough as the search information given for a particular topic. This does not detract from the fact that those performing a less thorough search may miss many useful articles.

The forty-four articles by the CINAHL literature search for review and the nine extra articles found during the search originate from various parts of the world. The majority comes from the USA, about half again from the United Kingdom (UK) and the others from Sweden, Canada, Finland and Belgium.

As the articles have been reviewed, certain themes became evident e.g. microalbuminuria, compliance and the DCCT and the review has therefore been divided into four sections accordingly. Chapter Four concentrates on articles pertaining to physical care of patients such as microalbuminuria, acute and general complications. Psychological aspects of care will be covered in Chapter Five including compliance, adaptation and coping strategies. Chapter Six will concentrate on the miscellaneous articles that do not lend themselves to physical or psychological care such as dentition, role of the PDSN and screening. Case studies are tackled in Chapter Seven because they are a specific method of research. It is hoped that by dividing the review into distinct groups, the overlap between the themes and chapters is minimised but at the same time, demonstrating the diversity of the information to be disseminated.

CHAPTER FOUR

A PHYSICAL PERSPECTIVE

Childhood diabetes

The first of four articles comes from 1989, written by a Senior Registrar in Paediatrics, who is now a Consultant specialising in the field of childhood diabetes. The descriptive article emphasises the problems that diabetes can pose at various stages of childhood covering the topics of presentation and treatment of diabetes and the difficulties faced by parents who have a child who refuses injections or who has learned behavioural patterns for attention. Such behaviours include refusing to eat after an insulin injection resulting in a hypoglycaemic episode that requires treatment with something sweet and therefore nice. Complications are not mentioned until the section considering adolescents, where it is noted that most teenagers would rather run their blood sugar levels on the high side to avoid the embarrassment of a hypoglycaemic episode (Challener, 1989). This fear is also highlighted in other articles to be discussed (Lamb, 1995; Marrero *et al.* 1997). The risk of frequent hyperglycaemia is emphasised but Challener (1989) also identifies that all teenagers tend to believe that they are immortal and nothing will ever happen to them.

Betschart (1993) covers many aspects of diabetes, from its prevalence and incidence in the USA, general therapy, acute complications, developmental considerations and factors associated with poor health outcomes although there is little mention of chronic complications. Under the heading of general therapy the stated goal of management is one that allows normal growth and development, optimal glycaemic control, positive psychological adjustment to the disease and the prevention of the acute and chronic complications of diabetes. Hypoglycaemia and ketoacidosis are referred to as the acute complications stating that both are potentially life threatening if poorly managed. The section on adolescent development describes an interesting point of view, highlighting that it may not only be the diabetes that causes non-adherence to treatment regimes, but that in the unaffected population there would undoubtedly be seen experimentation, rebellion and risk taking as part of a teenager's pursuit of independence. Glycated haemoglobin levels tend to be high in this group, and it may not be due to poor medical management but poor compliance by the individual. Adolescence is often a difficult period and peer pressure can be the most influential force in determining eating habits along with alcohol consumption. Understandably the adolescent diabetic does not want to be seen to be different from his peers. The situation is also difficult for parents who are trying to encourage the development of independence but at the same time are worrying about the future health of their child (Betschart, 1993).

Lamb (1995), a paediatric consultant writes an un-referenced article, which appears to have been generated from the findings of the DCCT and is a reprint from another journal published the previous year (*British Journal of Hospital Medicine, 1994, 51 (9)*). He states that a child-centred team should carry out the diabetes care of children and that the advances in management have enabled children to lead a normal lifestyle and to avoid both acute and chronic diabetic complications. As stated previously, Lamb (1995) reiterates that the ideal long-term goal of management is to prevent children developing into adults with physical or psychological complications of diabetes. He recognises that despite the research carried out there is no cure likely in the near future for diabetes. He emphasises that children should ideally be seen in the clinic four times every year with one of these visits being a specific annual review. This review should include eye examination (for early signs of retinopathy), checking of injection sites for hypertrophy (which can lead to insulin malabsorption), blood pressure measurement and examination of urine for proteinuria (an early signs of renal disease). An HbA1c blood test should be performed at clinic, as well as an assessment for growth and puberty status. Lamb (1995) suggests that the more that children and parents understand about the disorder of diabetes, the lower the risk of complications and that this education should begin as soon after diagnosis as possible, an observation supported by Maffeo (1997). Controversially, in view of other papers such as Andersen *et al.* (1983), Lamb (1995) states that micro-vascular complications are rarely seen in children even after many years of diabetes, although he does recognise that retinopathy can occur in teenagers with poor glucose control.

The final article in this childhood diabetes section is an open learning course compiled by a specialist nurse in paediatric diabetes, used as part of the Continuing Education Points (CEP) programme with the Royal College of Nursing (RCN). The areas covered are enhanced by 'Time outs' to perform private study with the submission of an answer sheet for marking and accreditation. Topics include the rising incidence of childhood diabetes and the impact that this will have in its future management in the medical, educational and community fields. The author emphasises that complications in diabetes are associated with poor blood sugar control as well as duration of disease. Thus children who are diagnosed young will have a longer exposure to abnormal blood sugar levels and are therefore at greater risk of complications. Furthermore the conclusion mentions the use of an annual review to assess children's physical development as well as actively looking for early signs of complications along with the reiteration of good control. The hospital team, consisting of the consultant, nurses and dieticians, must work together with the parents with the aim of caring for the child (McEvilly, 1997).

New Developments in Treatment

Ahern and Grey (1996) demonstrate the areas where new developments have been made in childhood diabetes management and how they will affect current practice. After an introduction reviewing the incidence of diabetes in the USA, some of the complications of the disease are mentioned, specifically micro-vascular and macro-vascular problems. They recognise that if there is no progress in treatment regimes, then complications will continue to occur and so current research is striving towards better methods of treating diabetes, hopefully resulting in fewer complications in the future. The author's felt that there should be two objectives in the management of diabetes. The first objective was to return blood glucose levels to as near to normal as possible whilst the second is to prevent the development of complications thus allowing normal growth. These objectives are more likely to be met if the treatment regime allows the management of diabetes to be fitted into the daily routine and not allowed to take over a child's life, a conclusion supported by Greenhalgh (1996). Ahern and Grey (1996) discuss the issue that the child should also be taught to test blood glucose levels, modify insulin doses if a hypoglycaemic episode occurs, maintain a dietary pattern ensuring growth and encouraged to exercise with adequate insulin and carbohydrate cover. Parents and health care professionals should be involved in planning to meet these goals and objectives. The conclusion to this article summarises that as diabetes is a complex metabolic disorder, the most important way to prevent the long-term complications is with intensive treatment. The primary-care team plays an important role in maintaining this ongoing treatment by offering support to the patient and their family thereby allowing a reasonable quality of life to be maintained (Ahern and Grey, 1996).

The cost of diabetes care is discussed by Murphy (1994) and shows how utilising the findings of the DCCT within the health care system can reduce this. She identifies that with the increasing number of diabetic children seen in the UK, there will be implications for future resources, a view supported by Shield and Baum (1994). Diabetes is a chronic disorder and it is well established that complications of diabetes can be attributed to duration of the disease (MacKinnon, 1998) therefore children diagnosed with diabetes have the greatest risk for potential complications in the future (Murphy, 1994). Coping with the diagnosis of diabetes is interestingly compared to coping with death and Murphy (1994) believes that the parents will experience a grieving process as they take on the problems of a sick child following the 'death' of the fit one. This grief reaction is a difficult time for parents and such a diagnosis can exacerbate underlying problems within family dynamics e.g. marital problems. This can in turn lead to the child losing control of the diabetes, or jealousy can be seen in siblings who may feel excluded. However unlike a death, which is a single event, the diagnosis of a chronic condition prolongs the period of loss for months or years and can lead to abnormal grief reactions. It is important that the care team involved with the child and family recognise these feelings within a family and offer the appropriate support, understanding and professional advice. In conclusion, Murphy (1994) highlights the need for ongoing education and support to enable an understanding of diabetes management, with the result that metabolic control is improved and thus reducing the risk of long-term complications.

Microalbuminuria

In July 1991, Rudberg and Dahlquist (1996) performed a preliminary longitudinal cohort study involving 155 children in Sweden from the diagnosis of their diabetes. 17 (11%) patients had developed persistent microalbuminuria. At follow-up of these 17 in 1994, 6 (35%) demonstrated progression of microalbuminuria, 7 (41%) no longer had microalbuminuria and 4 (24%) remained unchanged. In the group who had progressed, there was often a history of early hyperglycaemic episodes, latterly developing an elevated systolic blood pressure and an increased Albumin Excretion Rate (AER). They concluded that the progression of microalbuminuria was predictable in certain individuals. Those who had normalised had better glycaemic control, lower systolic blood pressure and were diagnosed at a younger age (Rudberg and Dahlquist, 1996). Their findings support the need for regular screening and encouragement to lower the HbA1c level.

Another longitudinal study from Sweden with a cohort of 109 patients showed that from the original 27 (25%) patients identified with microalbuminuria, only 5 (20%) showed signs of progression whilst 15 (56%) no longer had microalbuminuria. Therefore the overall progression was less than that demonstrated by Rudberg and Dahlquist (1996) despite the initial 25% of patients found to have microalbuminuria (Bojestig, Arnqvist, Karlberg and Ludvigsson, 1996). Their conclusion for the small number who progressed was similar to Rudberg and Dahlquist (1996) with the emphasis on improved glycaemic control in the non-progressors.

Lawson, Sochett, Chait, Balfe and Daneman (1996) hypothesised that puberty could cause an increase in glomerular hypertrophy and hypertension, two early symptoms associated with the development of diabetic nephropathy. They studied

177 Canadian children and young adults with IDDM of 5 to 10 years' duration at different pubertal stages and duration. The cohort demonstrated an overall increased kidney volume, whereas microalbuminuria was mostly evident in the post-pubertal young adults. The conclusion was that puberty duration had an effect on kidney size and the development of microalbuminuria and the authors postulated that these effects could be caused by the pubertal status on glomerular hypertrophy and hypertension. In view of the findings of Bojestig *et al.* (1996) and Rudberg and Dahlquist (1996) which showed normalisation of microalbuminuria during puberty, it is unclear whether Lawson's study is significant. Despite being poorly written and difficult to interpret the results, Lawson *et al.* (1996) do advocate screening for microalbuminuria and encourage further study into the relationship of microalbuminuria, pubertal duration and changes within the kidney.

Microalbuminuria is discussed in two other articles, one recommending it as a necessary annual assessment tool (Lewis, 1995) and the other in the article by Betschart (1996) pertaining to oral contraception. Both of these papers are discussed further, Lewis (1995) in Chapter Five under the heading of Adolescence and Betschart (1996) under the heading of Contraceptive advice to young diabetic women later in this chapter.

General Complications of Diabetes

At diagnosis, carers and the newly diagnosed diabetic will need to learn about diabetes and its subsequent treatment. There are a number of topics to address including injecting insulin, monitoring of blood glucose levels and care of acute complications. Maffeo (1997), in his descriptive article, believes that, despite the information required at diagnosis, the risks of long-term complications associated with high blood glucose levels should also be taught. He highlights the conclusions of the DCCT and also recognises that nurses play an important role in helping children and their families to cope with the challenge posed by their chronic illness. The acute complications of hypoglycaemia, hyperglycaemia and DKA are explained and advice on their avoidance is given in order to prevent the progression towards complications. He concludes that the past fifteen years of research into diabetes have been a major influence on management of the disease and the appropriate treatment of complications (Maffeo, 1997).

Specific diabetic complications are discussed in two articles. One is written by an American nurse and the second by the Research and Development editor for the *Nursing Times* journal. The first article summarises the medical complications associated with diabetes and quotes figures from a combination of IDDM and NIDDM data in the UK but is not age specific (Willis, 1995). The second article from America is detailed and gives a general overview of diabetic complications but again is not age specific (Haas, 1993). The author does not make clear whether she is referring to IDDM or NIDDM. Haas (1993) discusses the chronic complications of diabetes and suggests techniques that nurses can use to assess, intervene and prevent these complications and aid patient self-management. She states that as a person with diabetes ages, the risk of developing chronic complications will increase and that these affect many body systems. It has long been recognised that disease duration and frequent episodes of hyperglycaemia or DKA are related to the pathology of long term complications (MacKinnon, 1998) but Haas (1993) recognises from her extensive literature search that other factors such as genetic susceptibility may be involved. She includes in her descriptive article sections covering the following potential problems: Macroangiopathy including cerebrovascular disease, heart disease, cardiomyopathy, peripheral vascular disease (PVD) and Microangiopathy including nephropathy, retinopathy, neuropathy and autonomic neuropathy, and the Insensate Foot. Under each section she gives a brief description and the issues on which nurses should focus. Haas (1993) concludes that nurses should assist their patients in the everyday management of their disease, should be able to recognise early symptoms and signs of subtle changes in their body and to encourage optimal blood glucose levels. Intervention, empathy and support to a patient and their family are often the most appropriate nursing skills available.

Willis (1995) highlights that as medical advances are made, patient education will improve and as well as the control of diabetes thereby minimising the long-term complications. This article highlights the specific macro-vascular and micro-vascular complications although the references producing the quoted figures for these complications come from articles in the *Care of the Elderly* journal. This implies that the article relates to the older population but the age group is not stated. The diabetic children however will age in time and therefore the article does highlight future problems that can hopefully be overcome if intervention is started early. The DCCT advocates blood glucose control and subsequently the RCN Diabetes Nursing Forum have recommended this course of action. The reduction in the incidence of diabetic complications can only be achieved if nurses are up to date with current research and implement this knowledge within their practice. The patients should receive better health education, moral support and health promotion as a result.

Hypoglycaemia

Hypoglycaemia is one of the acute potentially fatal complications of diabetes and can cause anxiety amongst children, adolescents and parents alike. Pucznski, Pucznski and Ryan (1992) reviewed the effects of hypoglycaemia on cognitive function and the implications on education. All parents strive for their child to achieve at school, both academically and socially, but long-term cognitive function can be impaired by hypoglycaemic episodes whether these are mild or severe. The authors found that parents would prefer to avoid long-term complications for their children due to hyperglycaemia, but at the same time, prevent the acute problem of hypoglycaemia so metabolic control became important. Following a hypoglycaemic episode the child's ability to concentrate or memorise may be impaired and thus schoolwork will suffer. It is therefore important that those who educate parents about diabetes must also include school personnel in the risks of cognitive impairment during classes if hypoglycaemia occurs. The authors admit that this is a preliminary study and advocate further studies to demonstrate whether impaired cognitive function is related to frequent hypoglycaemic episodes. Snyder and Clarke (1995) examined the role of the school nurse in the assessment of cognitive function associated with hypoglycaemic episodes whilst Sansbury, Brown and Meacham (1997) showed through a preliminary investigation of school age children that duration of diabetes was influential in cognitive function.

In a quantitative study, Marrero, Guare, Vandagriff and Fineberg's (1997) demonstrated that hypoglycaemic episodes can be a frightening and embarrassing acute complication of diabetes, which can understandably induce anxiety in both the child and parents. The hypothesis was that there was a relationship between the fear of hypoglycaemia, glycaemic control and hypoglycaemic avoidance but in addition, history of hypoglycaemic episodes could be influential. The literature review supported the hypothesis and emphasised the lengths to which the child, adolescent and parents will go to avoid the situation. 61 children, aged between 5 and 18, with 31 under the age of 12, were recruited to the study. They had had IDDM for a minimum of one year, used glucose monitors with an in-built memory, and had parents as the main carer (or shared in the case of the adolescents) of the child's diabetes. A questionnaire was used to determine the patient and adult's fear of hypoglycaemia measured using the Diabetes Quality of Life instrument devised from the DCCT, whilst HbA1c and SMBG recordings were used to assess metabolic control. Results were analysed statistically and presented as a quantitative table, with a qualitative descriptive report. Analysis of the results showed that it was the parents of children who had experienced a hypoglycaemic episode resulting in a seizure that had the greatest fear of repeated episodes, a fear that was enhanced if the episode had occurred within the previous year. As a result their SMBG readings were found to be in the higher target range. Surprisingly, the analysis showed that children who had previously experienced a severe hypoglycaemic episode resulting in a seizure did not test their blood glucose level as regularly as those who had never experienced such an episode. Similarly adolescents demonstrated the same tendency towards SMBG tests. Although the adolescents were initially fearful of a seizure, this feeling reduced over a period of time and the investigators proposed that the adolescent may cope better with the trauma of a seizure than a parent of a young child (Marrero *et al.*, 1997). This could be attributed to the fact that parents were witnessing the seizure of their child, which must be frightening. Marrero *et al.* (1997) came to the conclusion that it appeared from the SMBG results in the younger age group that parents were deliberately keeping the blood glucose levels higher in order to avoid potential hypoglycaemia. The fear of hypoglycaemia is very real and reflects the potentially devastating consequences. Education at diagnosis should therefore reflect this with teaching on recognition, treatment and prevention of the acute condition.

Retinopathy

Kovacs, Mukerji, Drash and Iyengar (1995) discuss the conclusions of the DCCT and the overwhelming evidence of hyperglycaemia being one of the factors responsible for the risk of developing diabetic complications such as retinopathy. Kovacs *et al.* (1995) performed a longitudinal study to determine the risk factors for retinopathy using a cohort of 66 children who were followed up for an average of ten years. Glycaemic control combined with psychiatric assessment was monitored as well as the incidence and severity of retinopathy. It was found that it was the duration of IDDM, irrespective of glycaemic control, that determined the level of retinopathy. A surprising finding was that clinical depression preceded retinopathy. They proposed that the depression may be a marker of vulnerability towards the development of retinopathy and could therefore be used to highlight patients at risk of the complication. They suggest that treating a presenting depression may slow the progression of diabetic retinopathy. Again regular screening is recommended to prevent the progression of complications (Kovacs *et al.*, 1995). No further articles have been found to substantiate this interesting finding, which could have implications for future clinical practice.

Glycaemic Control

Dorchy, Roggemans and Willems (1997) in Belgium examined a group of 144 children and young adults to determine whether the glycated haemoglobin level could be improved. They also attempted to correlate the relationship of HbA1c level to the treatment regime, dose of insulin, sex, age, duration of disease, outpatient attendance and home blood glucose monitoring. The work was instigated by the findings of the DCCT and the team achieved a significant lowering of the HbA1c level in 62% of the cohort. They found that this decrease was associated with home monitoring and more frequent outpatient visits but there was no association with sex, age and treatment regime. They concluded that more education at outpatient appointments and the encouragement of self-monitoring led to lowering of the blood glucose level. These quantitative results show the need for education and encouragement of self-interest in children and young adults in order to improve their glycaemic control. They also comment that there were a number of physicians who had concluded from the DCCT that the adolescents must be treated with four injections a day in order to lower the HbA1c level. However these doctors failed to realise that not only was the insulin treatment different but those with a better HbA1c level also had a higher level of input from the health care team with a twenty-four hour telephone help service available. Most diabetic treatment centres in the UK would be unable to reproduce the level of input given in this trial. There is a general lack of resources increasingly seen throughout the National Health Service (NHS) although an increase in resources for treating diabetes would be a money saving investment for the future (Shield and Baum, 1994).

Contraceptive Advice to Young Diabetic Women

During the search, two articles were found discussing contraceptive issues in young diabetic women. The first of these was written nearly ten years ago and describes a small population from Harlem, New York. The preferred method of contraception prior to that time for diabetic women were the various barrier methods mainly because of the lack of research into the use of oral contraception and diabetes.

Fennoy (1989) studied eleven adolescents aged between fifteen and nineteen from a deprived inner city area who were prescribed barrier methods when their metabolic control level was within the clinic criteria. The pregnancy rate over the five years of the follow-up was found to be higher in the eleven patients than the national average for the same age group and although reasons for this are suggested, none were explored further. It was also noted at the time that their diabetes was poorly controlled with HbA1c levels well above the clinic recommendation (Fennoy, 1989). The power of this study suffers from its extremely small cohort but the findings are possibly due to the problems associated with those living in a deprived area and therefore the results should be treated with caution. Fennoy (1989) advocates further research into the introduction of oral contraceptives for diabetic women, because it is the most effective reversible method of contraception. Nine years later, the low-dose combined oral contraceptives can be used in the short term with regular blood glucose levels and blood pressure checks but they are contraindicated in any woman showing signs of micro or macro-vascular disease (MacKinnon, 1998). Fennoy (1989) strongly recommends education with her particular adolescent population for whatever form of contraception is being used.

In the second article, Betschart (1996) recognises the need for education of diabetic adolescents on contraception, sexually transmitted diseases (STD), human immunodeficiency virus (HIV) as well as the risks associated with pregnancy. The advice given to the adolescents should also include the need for optimal preconceptual metabolic control, which notably reduces their increased risk of congenital malformations, the risk of potential pregnancy complications as well as an increased risk of developing diabetic complications. She reiterates that those involved with this particular group of patients should include counselling and contraception within their teaching. One of the side effects of oral contraceptives is hypertension and Betschart (1996) proposes that treatment with ACE inhibitors may be necessary to lower the blood pressure and simultaneously prevent or delay the onset of diabetic nephropathy. She suggests that discontinuing the oral contraceptive would determine if the hypertension could be attributed to its use or if renal damage has already occurred. Therefore Betschart (1996) advocates the regular screening for microalbuminuria and blood pressure measurement. This article is a descriptive review of the current issues in contraceptive care of adolescents and the implications on practice for health professionals on the topic. The most obvious advantage offered by oral contraception is the prevention of an unwanted pregnancy and the low failure rate associated with the pill is an attractive incentive for its use. However the risk of side effects does have to be taken into account prior to administration. Contraceptive education must be included in the general education programme of diabetics and health professionals should not be embarrassed to do so even with girls under the age of consent. An unwanted pregnancy can be more physically and psychologically detrimental than a teenager being prescribed the pill under-age (Betschart, 1996). This article is useful and relevant to those dealing with adolescents of childbearing age within the clinic setting.

CHAPTER FIVE

A PSYCHOLOGICAL PERSPECTIVE

Diabetes and the School Setting

Three different aspects of diabetes care within the school setting are evident; two as a result of the DCCT and the third as a development of a health care plan for a diabetic student. All three are written from an American perspective and so may be less relevant to the British education system. Faro (1995) identifies that school nurses may encounter diabetic students within their caseload. The students will look to the nurse for help and supervision in their everyday care and management of their diabetes. The article is written as a review of changing medical practice as a result of the DCCT and examines how school nurses can help in the promotion of health amongst diabetic pupils in addition to having an awareness of hypoglycaemia. The role of the school nurse will include education of the student and those staff involved with them such as teachers and sports coaches in the management of hypoglycaemic episodes. The majority of hypoglycaemic episodes are due to food being delayed or missed, too much insulin being given or as a result of a change in exercise pattern. Severe hypoglycaemia can be intensely embarrassing for a student who may become confused and disorientated or in the worst scenario have a seizure. Milder hypoglycaemic episodes can result in mental impairment for a period of time that may make studying or concentrating in class difficult as previously mentioned by Sansbury, Brown and Meacham (1997). Snyder and Clarke (1995) also note this point in their following article. Faro (1995) also states that school nurses should be able to recognise the symptoms of hypoglycaemia shown by individual students in order to treat and prevent a more severe hypoglycaemic episode. They may become involved in the care of newly diagnosed diabetics and the potential psychological problems exhibited although as emphasised by Grey, Cameron, Lipman and Thurber (1994) these difficulties may not be observed initially. Faro (1995) concludes that as advances are made in the general management and care of those with diabetes, the school nurse has an ever-increasing role in the development, implementation and evaluation of treatment given to the student. Parents will be very aware from the hospital team that tight glycaemic control is very important and so the help and understanding given by the school nurse will not only be helpful to the student but also reassuring to the parents leaving their children in someone else's care.

Snyder and Clarke (1995) focus on the role of the school nurse in the improvement in the long-term morbidity and the improvement of the quality of life in these children advocated by the DCCT. The authors highlight that the change in the treatment of children recommended by the DCCT will have an impact on the role of the school nurse and the care given to the diabetic children in their school. Snyder and Clark (1995) begin with a brief summary of the conclusions of the DCCT which resulted in the American Diabetes Association (ADA) endorsing the initiation of intensive treatment in all children over the age of thirteen and cautiously in those between the ages of seven and thirteen (ADA, 1993). In order for blood glucose levels to be lowered, a care plan needs to be maintained throughout the twenty-four hour period and since a student may spend a third of his day at school, the school nurse has an important role in this. Her role may include injections and perhaps the more frequent testing of blood sugar levels that will be required especially as new treatment regimes are instigated with a child. Dietary intake will also need to be monitored with the school nurse aiding choices from the school menu. The nurse should understand about the demands of exercise on the body and be able to advise on additional carbohydrate intake prior to exercise or perhaps a lowering of the insulin dose at the preceding meal. The school nurse will become an important part of the team looking after a child and that her help is essential in the promotion of lowering the blood glucose level. She must also be aware of the impact intensive treatment can have on a child and his family, supporting normal development and academic potential enabling the diabetic student to maximise academic strengths but minimise the effects of the disease (Snyder and Clarke, 1995).

The third article found in the search is a specific individualised health care plan that was developed for a student by two nurses. The health care plan is an action plan, influenced by the DCCT findings, devised for the care of students within the school setting. Areas formulated using the nursing process included management, education and psychological assessment. The management care plan concentrated on the long-term need to maintain normal physical and psychosocial development and the short-term requirement of preventing a severe hypoglycaemic or hyperglycaemic episode. The education care plan's goal was that the student developed knowledge about diabetes thus encouraging age-appropriate self-management. The psychological assessment care plan was used to ensure that the student was able to recognise when to ask for help and the ability to discuss his disease with his peers. The fourth health care plan focused on emergency action to be taken in the event of a hypoglycaemic episode. It included information on next of kin, specific diabetic management of the student and a protocol for hypoglycaemic episode written after discussion with the student and parents. There is no specific mention of associated long-term complications although in the management section recognition is given to the need to avoid frequent hyperglycaemic episodes (Rapone and Brabston, 1997).

None of the three articles discuss the role of peers in monitoring of hypoglycaemic or hyperglycaemic episodes. As a diabetic will spend much of the day with his friends, perhaps the school nurse could include them in teaching about diabetes and the acute complications. This could be beneficial to a diabetic child who experiences an embarrassing hypoglycaemic episode whilst at school because his peers could then be helpful and understanding rather than judgmental of strange behaviour. Children can be cruel to peers who are deemed to be different and again the reasons why a snack has to be eaten in a classroom could be an advantage.

Adolescence

Lewis (1995) provides a touching account of the difficulties that diabetic teenagers experience as they develop physically, psychologically and sexually and the need to form an individual personality and independence without having to contend with the everyday care required for their diabetes. The DCCT demonstrated the need to maintain good blood glucose control in the prevention of long-term complications, but this can understandably lead to interference with the everyday activities of teenagers. If diabetes is diagnosed at a young age then it is often the parents who have benefited from education concerning the condition. The adolescents may not have a sufficient knowledge as they strive for independence, and as parents try to impart this knowledge they may be seen by the teenager as being overprotective and rebellion may be experienced. As previously discussed, teenagers attempt to avoid hypoglycaemic episodes by maintaining higher blood glucose levels, achieved by reducing the prescribed insulin dose. Using less insulin also tends to enable the girls in particular to sustain a fashionably slim figure but unfortunately during puberty, these higher doses of insulin are required to regulate the normal pattern of growth and development. Ideally young adults should be seen in a specifically designated adolescent clinic so that they can meet people of their own age with similar problems and anxieties rather than being treated alongside an older population who may show the distressing signs of long-term diabetic complications. Gardiner (1997) supported this observation where most of her cohort believed that they should receive their diabetes care within a specialist teenage clinic rather than at the children's clinic. Challener (1989) emphasises that it is important to encourage good habits at a young age but realises that teenagers in general are often less able to consider the future than adults. Lewis (1995) admits that working with adolescents is mentally demanding and describes the difficulties in not being drawn into a family confrontation between compliance requirements and what the teenager wants. Furthermore she believes that the threat of any long-term complications should never be used as a lever to encourage good metabolic control. Education should be paramount in the care of adolescents, helping them to understand their disease and the long-term implications without allowing it to dominate their lives, supported by Ahern and Grey (1996). Lewis (1995) encourages an annual assessment, which she believes is important to reduce potential complications, and this should include retinal screening, urinalysis for microalbuminuria as well as HbA1c levels.

Bradbury and Jenkinson (1996) support Lewis' (1995) conclusions stressing that adolescence can be a difficult period without the added challenge of managing diabetes as well. Help will be required not only from the health-care team but also from the family in order to prevent the potential long-term complications of the disease process. In order for this to happen the nurses involved need to understand the underlying physiological changes as well as the psychological impact on the young person. The article considers the various ways that nurses can use their skills to help the young adult become more confident in their everyday care and to cope with diabetes. The authors describe both the pathophysiology of glucose metabolism and the effect that the circulating growth hormones during puberty can have on the adolescent and his blood sugar control. They also note that adolescents may not show the early signs or symptoms of progressive and chronic changes but that nurses caring for them should always be aware of the subtle changes as some complications may manifest early in the disease process. The long-term complications are described emphasising that the pathophysiology of the micro-vascular and macro-vascular changes are not fully understood yet but that aiming for as near to normal blood glucose level as possible is helpful in preventing these problems. The nurse's role in the encouragement of their patient primarily involves taking an interest in the young patient and his family. The nurse needs to understand an adolescent before trying to understand the diabetic adolescent. Counselling skills are very important as well as trying to be an empathetic friend. Education is crucial both with the patient as well as with the family and their questions should be encouraged and discussed. The nurses should be able to support the family throughout the development of new skills, whilst encouraging the patient in self-care and complementing good habits. There should also be understanding when difficulties occur, providing empathy without being judgmental. The conclusion to this article explains the unique role the nurse can have with her adolescent patient. Her knowledge and understanding of diabetes means that explanations can be given for the difficulties in maintaining adequate glycaemic control whilst at the same time being aware of the subtle changes taking place within an individual both psychologically and physiologically. In this way and with careful education and care, the potential for long-term complications is reduced. Bradbury and Jenkinson (1996) conclude their article by stating that caring for an adolescent diabetic poses a challenging proposition, which supports the views of Lewis (1995).

Compliance and Adaptation

Compliance with and adjustment to diabetes are two common subjects discussed in several articles. Maffeo (1997), a US Navy Nurse, emphasises that teenagers should be encouraged to understand the risks involved with non-compliance. Namely in the short term, children will have a weakened immune system as a consequence of diabetes and so may be less able to fight the common childhood illnesses such as the viral cold or they may find that skin wounds develop secondary infections. These problems are easily managed but only by reducing the blood glucose level can the risk of long-term micro-vascular and macro-vascular complications be reduced. He believes that all patients should be aware of the potential long-term complications such as blindness, heart disease, kidney failure, strokes, infections, amputation and early death. For younger children, the explanations of these problems should be directed towards the parents. However this type of 'shock' treatment may not be appropriate for everyone and it is important to remember that this article is written from a very personal point of view, not necessarily reflected by the author's seniors within the Department of the Navy, Department of Defence or the US Government. By careful interviewing, it is usually possible to ascertain the levels of information desired by an individual and how much they can absorb at each meeting, remembering that reiteration is another important skill to adopt.

Compliance must be encouraged in the adolescent by the professional team and it is important to involve the family as well. Parents should be advised not to dictate or the adolescent may rebel, supporting both Lewis (1995) and Bradbury and

Jenkinson (1996) in their views. Bradbury and Jenkinson (1996) also address compliance and the role that the nurse can play in promoting good habits with realistic goals therefore aiding the prevention of long-term problems. Health professionals have often had a paternalistic attitude to patients and expect them to adhere to their instructions closely. However although appropriate firmness is required, each adolescent needs individual assessment. In particular the difficulties can be presented when the adolescent diabetic is trying to keep pace with peers who live without the restrictions in their lives imposed by diabetes and many may see their disease as being threatening to their everyday lives as previously stated by Betschart (1993).

A study completed by Kyngäs, Hentinen, Koivukangas and Ohinmaa (1996) assessed whether young diabetics could manage their diabetes and maintain their health despite the usual problems associated with adolescence. The disease impinges on everyday life with the continual worry of hyperglycaemic or hypoglycaemia episodes, coupled with the routine of maintaining blood sugar recordings, injections, exercise demands and dietary needs. If adolescents do not comply with the set regimes they are at risk of developing micro-vascular or macro-vascular complications, again supported by the findings of the DCCT. In a preliminary study a hypothetical model of compliance was constructed after interviewing fifty-one patients. Compliance was deemed to be influenced by motivation, values, attitudes, self-discipline, sense of responsibility, treatment aims and results along with the actions of parents, friends and health care providers. The authors also considered the desirable aspects of care such as health and freedom but also examined the undesirable side of care that included feelings of guilt, conflict, dependence, restrictions and difference. A questionnaire was developed using the hypothetical model, which was then piloted in ninety-one diabetics prior to the official study. The adjusted questionnaire addressed compliance in young diabetics, the meaning of compliance, conditions for compliance, the impact of diabetes and background variables. The answers were graded on a scale from strong agreement to strong disagreement. In the official study there was an 89% response from 389 questionnaires handed out at an outpatient appointment. HbA1c levels, obtained from the patient's notes, correlated well with those who assessed themselves as having good compliance also demonstrated a satisfactory HbA1c level. However 11% of questionnaires were not returned and the investigators have speculated that this group probably included a greater proportion of the poorly controlled non-compliant patients. The results of this study supported previous findings showing that the combination of self-care behaviour and the intervention of health care providers aided compliance. In addition, motivation was highlighted as a main aspect of this study and seemed to be the driving force towards gaining normality within the diabetic's life, an important area to focus on when educating and treating the patients of the future.

A literature review by Burroughs, Harris, Pontious and Santiago (1997) on compliance in diabetes produced thirty-two scientific studies looking at social support, metabolic control and compliance amongst diabetic adolescents and the relationships between them. The authors concluded that as a result of their review they saw adolescents as a complex group and had to be treated as such and that no specific rules for treatment could be formulated. However they implore professionals to allow for teenage problems primarily before diabetic ones and to show empathy. They also believe in the importance of encouraging parents, with the help of the health care professionals, to bestow responsibility to their children whilst maintaining support and understanding.

Two of the articles in this section are very similar in composition. The first, a general paper on chronic illness in children, Grey and Thurber (1991) have chosen to use the example of diabetes mellitus as it has a complexity similar to other chronic childhood illnesses. Thus any other chronic childhood illness could be substituted into the title such as Cystic Fibrosis (CF). They looked at a way of adapting Roy's Adaptation Model that was originally used to devise a psychological adaptation to the field of nursing care. This model of nursing related to the more general perspectives about the causes of human behaviour (Aggleton and Chalmers, 1986). The model derived for this paper attempts to show that the adaptation and response to a certain disease is associated with the psychological reaction to the situation, the influence of individual differences and the pre-existing personal characteristics. Grey and Thurber (1991) produced a detailed literature review and summarised the research findings pertaining to psychological and physiological adaptation to a chronic disease. They conclude that in devising the model, supporting research data shows that the initial diagnosis of diabetes is stressful to children and that adaptation is needed both in metabolic stabilisation and with psychological care. Conclusions drawn from the previous studies indicate that nurses play an important role particularly in identifying problems at the time of diagnosis relating to the adaptation to the life-long disease. Nurses caring for these children need to be closely involved with the young patient and adolescent in order to recognise the existing mechanism of coping for individuals so that the appropriate input of care is given. The timing of education is also important because if a child is maladjusted to his diabetes then efforts will be wasted.

Education is carried out in the hospital setting but can also take place in the Summer Camps in America, and also in the UK that many children are encouraged to attend. Peer pressure is a very influential force on children which whilst at school may be detrimental to diabetes care, the same force can be supportive in the camp situation. Children seeing others managing their own injections and coping well with the everyday difficulties of living with diabetes can be a strong incentive to become self-independent and manage themselves. Many parents comment on the positive effect that these camps can have on their children. Nurses who are involved in the camps should be aware of the intervention needed with the children to encourage the positive areas emphasised above. Grey and Thurber (1991) conclude that the roles played by all members of the caring team, hospital personnel and families, can influence a child's coping mechanism. In addition, the specialist nurses hold a unique position to promote health and address the area of adaptation to a chronic illness.

Grey, Cameron and Thurber (1991) carried out a study published in the same year as the above article with a very similar reference list but for a different nursing journal. The review of the literature for their second piece is very similar but whereas the first article is descriptive, concentrating on different aspects of adaptation and a summary of previous studies, this article is the results of their study. The team examined the influence of age, coping behaviour and self-care on psychological, social and physiological adaptation in preadolescents and adolescents with diabetes. Well-established tools were used to assess each criterion and the results were analysed by comparison using variance and statistical analysis. It was shown that the older mature adolescents reported higher anxiety levels and depression compared to their younger counterparts. There was also a marked deterioration in the glycated haemoglobin levels in the older age group but that self perceived competence was found to be higher in the least mature individuals. There were significant differences found in the coping mechanisms with the immature individuals tending to openly express feelings whereas the mature group would use diversion therapy and avoidance behaviour such as smoking and drinking although some adopted relaxation. Families were important to the pre-pubertal children for support, whereas the older adolescent did not have the same requirements from the family environment. The discussion highlighted that age and physical maturity do have an important role in the adaptation to childhood diabetes and the results did support previous studies. The authors suggest that a further study would be useful to compare diabetics with non-diabetics to determine whether it is the disease or development that is important in the adapting phases.

Three years later, Grey, Cameron, Lipman and Thurber (1994) carried out the further work that was recommended by Grey, Cameron and Thurber (1991). For the study, each diabetic child was pared up with a control person who was a friend, not chronically ill, of the same sex. The numbers were not equal in the diabetic or control (comparison) group but no explanation for this was given in the paper. Both sets of children and parents were seen within six weeks of the diagnosis of diabetes and various established tools were used to measure the required psychosocial data in both of them. Areas examined were social adaptation, competence, psychological responses, coping, self-care and recent stresses along with health status. Demographic information including age, sex, socio-economic status and sexual maturation were also recorded. The data was analysed using variance. There were no significant differences in the demographic data and no statistical differences were found with the psychosocial data of the two groups. The only notable difference was that the diabetic children tended to be generally more anxious than their peers and the parents reported that the general health status in the diabetic children was worse. Prior to diagnosis, diabetic children appear to have a period of being generally unwell and retrospectively parents can identify with this (MacKinnon, 1998, Sönksen, Fox and Judd, 1994). The study concludes that despite previous papers, the authors were unable to support the idea that children have psychological problems related to the diagnosis of diabetes. They do however recognise that in time these problems may become more evident and they suggest that follow-up of this group will be important to observe the natural history of the development of psychosocial problems. The authors recognise limitations within their data primarily because all the information was obtained by self-reporting or parental reporting and no psychiatric interviews were used to determine adaptation. The authors cite work completed by LaGreca, Follansbee and Skyler (1990) highlighting that preadolescent children appear to cope better with their diabetes care whereas the adolescent children tend to rebel, leading to a higher incidence of hospitalisation and other problems in the latter group. There is no specific mention of complications in this paper but in the introduction the authors comment on the life expectancy of diabetic children being some twenty years less in America than their peers at the age of ten (Grey *et al.*, 1994). They associate this with the long-term complications of illness as a result of chronic hyperglycaemia as is now well documented (MacKinnon, 1998).

Coping Strategies

Boland and Grey (1996) studied school age children to determine their coping strategies and the impact of these strategies on their self-care management or their metabolic control. An extensive literature review showed that children used a combination of cognitive and behavioural coping strategies and that they could be problem or emotion focused. However no work had been done comparing an individual's coping strategy with metabolic control. The sample for this study was 43 school age children aged between 8 and 12 with diabetes diagnosed at least one year previously. Demographic data was taken from each child including age, sex, ethnic group, socio-economic status and number of siblings. The specific treatment regime of each child was also noted. The data gathered was by questionnaire which children completed with the assistance of their parents. The tools used for assessments were all well-established measures. The demographic comparisons showed no significant differences between self-care management, level of glycosolated haemoglobin or coping strategies. Most children used cognitive strategies as opposed to emotional strategies as a way of coping with the stresses within their lives. In fact the investigators found that the children who used cognitive strategies did tend to show a higher level of self-care that reflected in an improved metabolic control level. There was also a significant relationship between age and metabolic control, which therefore needs to be taken into account when assessing coping strategies. The investigators did recognise that there were limitations in the accrued data as some children had enlisted the help of parents and may therefore have answered the questions in an effort to please their parents. The sample was taken from a single hospital where the education methods would be similar and therefore the authors felt that this would produce a certain degree of bias (Boland and Grey, 1996) although perhaps by using a single site may have in fact standardised the findings. Although the cohort was representative of the young diabetic population within the hospital, Boland and Grey (1996) suggest reading the results cautiously and that perhaps in the future taking data from multiple sites may give more validity to the study results and therefore make the study more applicable generally. The investigators conclude that children who develop diabetes have a long struggle ahead in an effort to control their disease combined with the ever-present knowledge that complications may occur if metabolic control is not maintained. This can put an enormous stress onto the individual and so care teams must recognise an individual's coping strategy early in order to help them contend with the disease adequately thus minimising the risk of developing long-term complications.

Gardiner (1997) examined attitudes displayed among young adults to ascertain whether diabetes exerted an influence on emotional maturity, self-esteem and the ability to live a desired lifestyle. Interestingly the availability of appropriate support for adolescents was also examined. She studied a cohort of 59 teenagers with IDDM, between the ages of 13 and 17 based in a Plymouth, UK, paediatric clinic with 60% of the group still attending school and living at home. An anonymous questionnaire was distributed at clinic or posted to each participant. The questionnaire was fivefold looking at the areas of attitude and self-esteem, diabetes control and compliance, family and peer relationships, self-management of diabetes and concern for the future. Statistical analysis of the data produced quantitative data although some qualitative data was available from the open-ended questions. The response rate was 68% with a 60% return rate from the female population. The investigator accepted that there was some bias to her work as those who did not respond to the questionnaire were probably those who did not attend clinic or took less interest in their diabetes generally. She also recognised that the paediatric data base used would not include the older adolescents referred by the GP to the adult physicians care, so there was a lack of questionnaires available from the seventeen year olds. The majority of the group felt they were normal young people who happened to have diabetes, whereas the others felt that they were slightly different from their peers. This finding contradicts Betschart (1993) who stated that the majority of adolescents felt different to their peers. Compliance was generally deemed to be good with the majority of the group testing blood glucose levels regularly, recording blood results in their record books, achieving good control and eating a moderately healthy diet. Five denied blood testing and described their control as only adequate. The significant difference in the compliance data was that the boys never felt overweight whereas more than half the girls claimed to be overweight. Most of the adolescents felt that they should have their diabetes care within a specialist teenage clinic rather than at the children's clinic, a view emphasised by Lewis (1995). Gardiner (1997) established that the majority of the adolescents found their parents to be supportive even when they had taken over the role of management themselves. Other findings included that the girls showed more independence than the boys, dietary habits became a compromise between family members and concerns that ranged from injections to remembering to inject insulin within their busy lives and future career prospects, relationships and their general health. The conclusions from this study showed that this particular group was positive about its diabetes and voiced few concerns. They found that fitting diabetes into their lives, particularly in trying to balance insulin, food and exercise with good metabolic control was the most difficult aspect of having IDDM. Overall most coped well with their disease, but those who do not manage so well need support and help from health care professionals as well as from family and peers (Gardiner, 1991). This study is interesting in that the results are positive which does contradict other articles reviewed that found the adolescent age group generally difficult to manage (Betschart, 1993; Bradbury and Jenkinson, 1996 and Lewis, 1995) with their own agenda of problems. However Gardiner (1991) does recognise that there is bias in her study and it would have been intriguing to have perhaps followed-up the 32% who did not return the questionnaire. They might have yielded stimulating data as to why they did not attend outpatient appointments or what having IDDM meant to them.

Standiford, Turner, Allen, Drozda and McCain (1997) studied adolescents' knowledge of their illness and produced a personal illness model for an individual which enabled the health care team to determine certain behaviour patterns and self-management. The sample studied was a group of 60 children with 30 aged between 10 and 12 and 30 aged 13 to 17. A pilot study revealed that children under the age of ten were often unable to understand or respond appropriately to the intended questions so the minimum age limit was set at ten years. Each child had to have had IDDM for at least two years and be English speaking with parents and children being similarly educated about their diabetes from a major diabetes centre. Each audiotaped interview with the child was confidentially carried out within the hospital, transcribed and the questions analysed separately. The structured interview comprised eight questions about various aspects of diabetes such as where it came from, its affects on the body functions, the severity of the disorder, types of treatment available, the results of treatment given, main problems or complications of diabetes and their worst fears about diabetes. Common themes were noted with the answers and the results were compared within the younger age group and separately within the older ones. When questioned about their worst fears, the older age group tended to mention long-term complications but this was less of a feature in the 10-12 age group. The results showed a good basic understanding of the disease and it's causes within both age groups. Across the two age groups there was evidence of good understanding of self-management although whereas the youngsters appreciated help from parents, the older group preferred help from their friends. The implication from this study is that if the clinician knows the current knowledge base of the patient then education and interventions can be tailored that individual's needs.

Education

The theme of education of children, adolescents and parents commonly occurs throughout this review although it is only Greenhalgh (1996) who concentrates on the education of children and parents and the promotion of the idea that the children are normal, apart from their IDDM, and can lead normal lives. She believes that the children must and do need to develop their independence with support and encouragement. Greenhalgh (1996) makes no mention of specific complications but her paper leans towards the early screening, intervention and treatment of problems as well as the potential problems of anxiety. She also describes early practical problems such as injections and blood tests with little mention of the long-term problems associated with hyperglycaemia or hypoglycaemia.

However Faro (1995) discusses the role of the school nurse in the education of students whereas Lewis (1995) highlights that education is often given to parents instead of the children at diagnosis thus leading to lack of knowledge as the child develops. Despite the specific paper by Greenhalgh (1996), it is noticeable that the subject of diabetes education is somewhat sparse within the reviewed topics. There is mention of the need to teach children, adolescents and parents the basic skills involved with diabetes such as blood sugar testing and injecting of insulin (Challener, 1989; Martin, Kupsis, Novak and Kushion, 1994; Lamb, 1995;

Greenhalgh, 1996 and Maffeo, 1997;). There is also the obvious debate about timing of teaching of the long-term complications (Maffeo, 1997; Lamb, 1995; Bradbury and Jenkinson, 1996 and Grey and Thurber, 1991). Another facet of education is the assessment of the knowledge base prior to teaching (Standiford *et al.*, 1997).

CHAPTER SIX

THE SPECIALIST ISSUES

In this chapter the individual themes determined from the literature review have been grouped together as specialist issues. Although there are concurrent themes mentioned it was felt that each article warranted a separate title and explanation.

Nurse – Led Clinics

Robinson, Sowden and Tattersall (1995) carried out a preliminary case study to examine the utility of a nurse-led clinic within the diabetic department for adolescents and young adults. Their department had pioneered other areas of diabetes care, but there was felt to be a void in the care available to this particular age group. The preliminary study was used to review services currently available as well as the care offered as perceived by the medical team and the DSN along with the patients themselves. 58 patients aged between 15 and 25 years of age, were asked to participate in the study and 49 agreed. Of the 49, 5 failed to attend the outpatient appointment, 14 were used in the pilot study and 30 in the study itself. Because there was an initial response rate of 85%, the investigators believed that this was a representative group of the clinic population. The doctor used a questionnaire to gain appropriate information from each study participant. In addition the DSN had a questionnaire to complete with each subject although it is unclear from the article whether this was performed simultaneously with the doctor or at a separate interview with the patient. The most important observation was that 90% of the patients were aware of the risk of diabetic related long-term complications. Indeed the majority of the patients reported good glycaemic control and this was supported by the medical personnel's perception but the laboratory results did not support these perceptions as 37% of the group had an HbA1c level higher than the clinic recommendation. Thus it is important to distinguish between perception and reality when discussing glycaemic control in the context of promoting good health and preventing complications. Many of the patients reported seeing the nurse in clinic but in fact the nurse involved in completing the questionnaire was unable to identify some of the patients. This may have been either because the patient misinterpreted the question or may have seen another nurse at a previous visit. The article emphasises that adolescents find the risk of hypoglycaemia disturbing as demonstrated by the DCCT (1993 and 1994) and consciously kept their blood glucose levels higher despite the fact they believed their overall control was good. They seemed to be more fearful of acute hypoglycaemia than of the potential complications that may not happen for years ahead due to poor blood glucose control. They tended to live for today, not tomorrow (Robinson *et al.*, 1995), which was a view shared by Challener (1989), Betschart (1993), Lewis (1995) and Bradbury and Jenkinson (1996).

Stress

'Stressed Out' is an unusual article written by Nagenast (1989) aimed directly at teenagers. Although easy to read, no conclusions are drawn and it appears to be written from purely a personal viewpoint. Written by an American nurse who herself has had NIDDM for several years and now working with newly diagnosed IDDM adolescents, she explains the physiology behind stress and how the body reacts to stress with the 'flight and fight' response which leads to an increase in blood sugar levels. She describes stressful events in everyday life and explains that self-appraisal and relaxation techniques can be used to overcome these stresses. The techniques used by the author to combat stress may not necessarily be appropriate or appreciated by all teenagers. This particular group will experience stress from exams, parents, peers as well as in forming relationships and the ideas promoted by Nagenast (1989) of loving yourself and treating yourself when stressed may be less acceptable in other cultures. Grey, Cameron and Thurber (1991) stated that unfortunately drinking and smoking could be used as stress relievers although they also found that some of their adolescents favoured relaxation methods.

Eating Disorders

A literature review about patients with IDDM and eating disorders by Horn and Peterson (1997) again discusses the difficulties faced by adolescents even without the added complication of IDDM. Whilst drawing their conclusion, they support Bradbury and Jenkinson (1996) and Lewis (1995) that eating disorders and IDDM singularly can cause detrimental effects to an individual and that when combined they make teaching and encouraging good metabolic control by the health care team and parents essential (Horn and Peterson, 1997).

Dentition

The article on dentition was an unusual article to find in the literature search but is of some general interest. According to the authors, Karjalainen, Knuuttila and Käär (1997) there had been a few studies carried out to look at caries in diabetics but results so far had been fairly conflicting. Their study was designed to investigate the role of blood glucose levels as a risk factor for caries in children and adolescents with IDDM. The level of caries in a random sample of children in one outpatient department who cared for their teeth similarly and visited the dentist regularly was compared to their HbA1c results. It was shown that children with poorly controlled diabetes had higher decay and filling indices compared to those whose control was better although no significant differences were noted when adjusted for age, age of diabetes onset and duration of disease. In particular those children diagnosed under the age of seven with poor glycaemic control demonstrated a loss in intact dentition. There was a significantly higher level of intact dentition in those whose control was well or moderately controlled. The investigators also found a higher level of yeast in the saliva of the poorly controlled subjects. In conclusion the investigators did find that the level of metabolic control and the presence of caries was related in this age group. The presence of yeast and poor metabolic control may be separate risk factors for the development of caries in diabetics. It is unclear from the article whether the authors believed that the presence of yeast was as a result of the poorly controlled diabetes or whether the presence of yeast caused metabolic imbalance (Karjalainen Knuuttila and Käär, 1997).

The St Vincent Declaration

Surprisingly, only one article mentioned the St Vincent Declaration although it is unclear from the paper whether it is about IDDM or NIDDM patients. The article was written as a result of the St Vincent Joint Task Force Report, 1995, that was drawn up following the St Vincent Declaration in 1990, designed to give guidelines and standards of care for diabetic patients across Europe. MacKinnon (1996) felt that there were many barriers to be overcome before the implementation of the task force recommendations. Newly diagnosed patients may have a fear of diabetes if they have other affected family members who have long-term complications. Patients may feel a failure, often exacerbated by hospital personnel when questioned about dietary habits or lack of blood glucose control, and this cycle of failure should be recognised by the care team. Diabetes affects everyday life and all facets of a person's life including eating, driving, travel, holidays, sex, drinking alcohol and work. If teaching along with reiteration is not given on these aspects of daily living there is a risk of frequent hospital admissions. Diabetes care revolves around imparting knowledge so that the patient can self-manage their condition whilst at the same time encouraging them to telephone a member of the hospital care team if they have a problem. Diabetes care should not revolve around laboratory results and check-ups but should include an education programme to prevent acute or chronic problems. The St Vincent Joint Task Force prioritised the needs of an individual into themes encompassing the role of the patient, education, special needs groups, diabetes registers, shared care and local organisations. The task force encourages self-management of the patient within their knowledge base and suggested that teaching should be provided accordingly. The task force recognised the special needs of specific groups such as children and adolescents. The ever-increasing amount of research and development in the field of diabetes means that health care workers need to be kept updated in order to impart the new ideas to their patients. Patients should have access to specialist diabetes units staffed by teams who practice evidence-based medicine and nursing. The task force also recognises the role of the patient and the family in the care of the individual

Screening for Diabetes

Davidson, Krosnick and Palumbo (1991) explored screening for diabetes although their article is not particularly relevant to either IDDM or children, reflecting mainly on the cost-effectiveness of screening for NIDDM. The reason given for not screening children is that they will be symptomatic on diagnosis and that even by detecting the disease earlier, nothing can be done at present to prevent the diabetes ensuing. Siblings of diabetic children can be tested for Islet Cell Antibodies (ICA) which if positive indicates that the beta cells are already being destroyed but no prediction of when the clinical diabetes will become apparent is possible from a positive result. Whether IDDM or NIDDM, the authors note that it is important that annual screening is performed to detect for the early signs of complications.

Newly Diagnosed Diabetes

A study in Pittsburgh was performed to determine the most commonly seen symptoms in newly diagnosed diabetics on admission to hospital. The cohort for the study consisted of 95 children consecutively admitted who were newly diagnosed insulin dependent diabetic, aged between 8 and 13, with no other systemic illness, no mental retardation and living with parents or guardians within commuting distance of Greater Pittsburgh. The entire cohort was initially hospitalised for control and education. The children were seen within three weeks after discharge and repeatedly after (Charron-Prochownik, Kovacs, Obrosky and Ho 1995). There is no indication of how long these visits continued after diagnosis for the purpose of this study. The results showed that the most common symptoms at first presentation were polyuria, polydipsia, weight loss and nocturia which had been present for an average of six weeks. Laboratory findings showed that 85% of the cohort showed signs of hyperglycaemia, high HbA1c level, glycosuria and ketonuria on admission. Only one young person was admitted in a coma but 22% were designated severely ill and 51% as minimally ill. It was noted that fewer severely ill children were being admitted as records from previous years noted and this was felt to be due to better education amongst the population as a whole. However those children from single parent families tended to present later and were therefore sicker at diagnosis. This was a relatively small study but was comparable to other work completed elsewhere in the States and the investigators felt comfortable in generalising their findings to urban areas where diabetic care continues to be carried out in diabetic centres (Charron-Prochownik *et al.*, 1995).

Diabetes Secondary to Drug Therapy

This specific paper focused on insulin dependent diabetes as a result of drug therapy. The chemotherapy given to a child with acute lymphocytic leukaemia (ALL) may induce IDDM as a secondary disease. The conclusion of the paper is that hyperglycaemia is a complication of chemotherapy either mildly or with ketoacidosis being present and nurses looking after these children must be aware of the condition and monitor accordingly. Education will be needed for children discharged on insulin, the same as for a newly diagnosed diabetic child (Walker, 1988) and it would be sensible for a member of the hospital based paediatric diabetes care team to be involved in this education.

The Role of the Paediatric Diabetes Specialist Nurse

This final paper reviewed the effect of the introduction of a PDSN into a diabetes team and her impact in the first two years compared to the preceding two. It was recognised by the RCN in 1988 that diabetic children had specific needs and that their care should be handled by someone trained as a paediatric nurse with the additional skills of educator, counsellor, manager, communicator and innovator as well as being responsible for their actions (Castledine, 1988). The nurse forms the link between the hospital-based care and that within the community (Lowes, 1997). The conclusion from this evaluation was that the introduction of the specialist post reduced the number of days that newly diagnosed patients spent in hospital. There was a strong emphasis on home management and the rate of immediate readmission of newly diagnosed diabetic children was found to be reduced. The clinic also saw a reduction in children who did not attend their outpatient appointments. The introduction of age-banded education sessions for children, young adults and parents alike were found useful and informative. The study also described the introduction of a parent's support group that had a poor response partly because none of the parents would take responsibility to organise it. The area that caused most concern was that the readmission level of established diabetic children was increased following the introduction of the PDSN. This was thought to be due to the introduction of a twenty-four hour on-call system that allowed children to be seen late in the evening at the hospital. Prior to this introduction, parents who were concerned about their child may have elected to wait until the following morning to see if there was any improvement before contacting the hospital team. This evaluation is of one post only within one hospital but it was felt that the introduction of the PDSN had been overall beneficial with many positive outcomes such as the treatment of newly diagnosed diabetics, outpatient attendance and the introduction of the educational programme. The area still to be addressed is the readmission rate to hospital of the children and Lowes (1997) believes that education on illness management may influence a future reduction in these admissions.

CHAPTER SEVEN

THE CASE STUDIES

A case study is a method of research involving an in-depth investigation of a single unit consisting of an individual, a family, a group or an institution (Polit and Hungler, (1995) and it can be used for both qualitative and quantitative work (Holloway and Wheeler, 1996). The unit undergoes extensive examination usually involving a large number of variables (Burns and Grove, 1997). The majority of nursing students will have some limited experience of writing case studies as part of their learning process and assessment procedures (Clifford, 1997) although the outcome from case study research will generally produce more information (Clifford and Gough, 1990). Although now seen less frequently in the nursing literature than thirty years ago, a case study can give descriptive information and expansion of a phenomenon as well as highlighting the results of a specific therapeutic technique (Burns and Grove, 1997). The holistic approach to a treatment or care plan can be investigated using a single case study thus increasing knowledge and understanding of the given condition and variables (Gray, 1998).

One disadvantage of the case study design is that it may not be reproducible and secondly it is not possible to generalise findings to a variety of settings (Sharp, 1998; Clifford and Gough, 1990). Also there is a loss of subjectivity as a result of the interaction between researcher and subject as well as the lack of objectivity resulting from the use of a sole observer (Polit and Hungler, 1989). Although a case study may not ultimately prove a hypothesis, its findings may help to develop a hypothesis for further research (Gray, 1998; Polit and Hungler, 1989) or indeed the study could be used at an initial stage of a larger research project (Gray, 1998; Hardey, 1994).

All three case studies under review followed the qualitative method of research with two concentrating on the initial treatment and subsequent discharge of a newly diagnosed diabetic children. The third study examines a change in the insulin regime for a child poorly controlled on conventional treatment. The situations described in all three cases could be experienced within any hospital setting but as stated previously they are unlikely to be repeatable with the given reported variables.

The study of a newly diagnosed ten-month-old baby in Michigan, USA written by three paediatric staff nurses and a diabetes educator is a very detailed account of the initial diagnosis and treatment followed by a post diagnosis education period. The main difficulties experienced by the parents, who also had two older children, is in overcoming the insulin injections and performing the blood tests on their small child, which they found distressing. However the coping strategies taught and the support given by the health professionals was helpful. The areas discussed are the team approach during admission and then discharge along with the psychological input required. There is no mention of long-term complications and no indication at which point this part of the education may be instigated. The case study discusses most of the issues concerning a newly diagnosed very young child and the expected responses to the information given to the parents by the hospital team. The nurse's role is believed to be that of liasing between team members and the family as well as an educator and a support to the family. There is detailed discussion of the content of the teaching and advice is offered on strategies for coping with a very young newly diagnosed diabetic child (Martin, Kupsis, Novak and Kushion, 1994).

The second study describes the presentation of a small girl with newly diagnosed diabetes complicated by cerebral and pulmonary oedema which are both rare complications of DKA. The article describes the clinical findings on admission and follows the care given to the child until her discharge. It is an unusual case with a strange presentation but once stabilised the girl was treated in the same way as any newly diagnosed diabetic and allowed to go home where up to the date of the article she has had no long-term affects from the episode (Young, 1995). This article appears in a recognised medical diabetic journal. It highlights a potentially life-threatening presentation of diabetes which could be seen by any doctor or nurse who may not specialise in diabetes care. Therefore this article could impart useful information to a range of health care professionals if it had been submitted to a more general medical journal.

The last case report concerns a child who required a change in her insulin regime to cope with the difficulties she was experiencing with her metabolic control. This case study focuses on a twelve year old girl whose blood glucose control was very poor despite increases in her insulin doses and evidence of good compliance with the set treatment regimes. Her height and weight gain was poor over a period of approximately a year and despite trying different regimes of bolus insulin regimes to no avail and the decision was made to start her on Continuous Subcutaneous Insulin Infusion (CSII). CSII treatment is used where there is poor metabolic control with conventional insulin regimes. With poor metabolic control there is a risk of body stores being used for energy provision rather than the breakdown of the food intake and therefore growth problems can occur, particularly in the adolescents where rapid growth should be expected. The girl was admitted to hospital for twenty-four hours in order that the mechanics of the pump administering the insulin could be explained as well as the expected goals of treatment. The need for vigilance with blood glucose monitoring was emphasised to the girl and her family because hypoglycaemia is a severe side effect of CSII. After discharge, the young girl was expected to measure her blood glucose levels six times during the twenty-four hour period and a member of the diabetic team made daily contact with the family. This contact was reduced over the coming weeks as the family felt more comfortable with the new form of treatment. During the first twenty-four months a substantial growth increase was seen as well as a return to better HbA1c results. Psychologically for the child, diabetes became easier to live and cope with and she reportedly gained in confidence about her condition and life expectations. This may have been in part due to her growth increase and general well being (Boland and Ahern, 1997) but also the input from the hospital team as noted in the DCCT by Dorchy, Roggemans and Willems (1997). Boland and Ahern (1997) recognise that for CSII to be safe and successful, the individual must be well motivated and have family support and so it may not suit all individuals and these issues must be carefully assessed prior to starting this form of treatment. Normoglycaemia is the aim for all diabetic care because growth can be severely altered if there are problems in achieving acceptable blood glucose levels.

In a literature review, it would be remiss not to include individual case studies. As discussed above there are advantages and disadvantages to the technique and despite the limitations of a case study, their content can be interesting and educational. Whilst an individual case report may not be relevant to a specific area of practice, they can be used as a form of learning and can increasing an individual's own knowledge base.

CHAPTER EIGHT

NURSING RESEARCH AND NURSING PRACTICE

Research can be defined as:

> "The systematic investigation into and study of materials, sources, etc. in order to establish facts and reach new conclusions.
>
> An endeavour to discover new or collate old facts etc by the scientific study of a subject or by a course of critical investigation."
>
> The Concise Oxford Dictionary, 1991, p1022

Nursing Research - The History

Nursing research is the search for the truth or a reason for something using data collection and analysis appropriate to the subject being studied. It involves a process of questioning a phenomenon in an orderly and systematic way and is a method of problem solving. The research can occur in a laboratory, in a clinical setting or in an environment such as the home, classroom or in the community. It should lead to the development of a knowledge base or an improvement of the current nursing practice and ultimately the delivery of care (Greenwood, 1984; Polit and Hungler, 1989; Millor, Haber, Carter, Feldman, Hott and Jacobson, 1992).

Florence Nightingale (1820-1910) was the first documented nurse researcher when she became involved in the care of injured and sick British soldiers in a hospital in Scutari during the Crimean War (1853-56). She was so appalled by the lack of sanitation that by using quantitative research she was able to show a marked reduction in the death rate from about 45% to 2% by the introduction of improved hygiene and care given (Burns and Grove, 1997; Lane, 1978). Nightingale's work was centred on the collection of data using numbers, as she believed that no one would listen to her without presenting hard facts in the form of statistics. This belief was no doubt enhanced by her friendship with Dr William Farr who was a medical statistician who was interested in the morbidity and mortality statistics of the whole population. They were later to work together following the Crimean War (Nuttall, 1983).

This quantitative method of raw data collection and its evaluation to produce statistical results is well understood and accepted particularly in the field of Physical and Biological Science. It also remained the dominant method used in nursing research during the 1950s and 1960s. However in the 1970s and 1980s there was a move towards the method called qualitative research, the roots of which were seen predominantly in the Social and Behavioural Sciences. The move towards the qualitative method appears to be quite natural as nursing is felt to have its roots more within the Social Sciences rather than with the Physical and Biological fields (Melia, 1982, Millor *et al*, 1992; Rolfe, 1994). The progression of research into the 1990s saw a move to use a combination of qualitative and quantitative research methods producing a research strategy called triangulation which represented an integration of the two research approaches (Morse, 1991; Cowman, 1993). The two methods may be used in conjunction or by using one method to obtain a result or conclusion that is deemed essential in the planning of the other method (Morse, 1991).

Methodology in Research

As explained above there are two main methodologies associated within nursing research, qualitative and quantitative. Both of these approaches are well understood and there are distinct differences between them and therefore the method adopted for a particular subject will reflect the expected outcome of the data analysis.

Quantitative research focuses on numbers, often in the form of statistics whereas qualitative research concentrates on words, produced as speech or writing (Porter, 1996).

Quantitative Research

Millor *et al* (1992) describe quantitative research as the objective, systematic empirical process where by data is collected and converted into numbers for analysis and interpretation which is generalizable. Quantitative research is used primarily where a hypothesis requires testing using evidence of causal relationships between variables. The researcher obtains data that can be easily quantified such as weight, or data that can be assigned a numerical value from like a sliding scale for pain. It is designed to be bias-free and the study aims to understand the whole organism, experience or phenomenon (Millor *et al*, 1992, Clarke, 1995; Morse and Field, 1996). Millor *et al* (1992) state that the reasons above show why the quantitative approach to nursing research is often criticised as being reductionistic. Reductionism is the attempt to understand the whole by breaking down the complex information gained into simple smaller components (Carter, 1996). There will always be a place for quantitative research within the field of nursing for areas such as clinical trials of nursing practice (Millor *et al*, 1992).

Qualitative Research

Qualitative research is described by Millor *et al* (1992) as the subjective, systematic inquiry which can increase the understanding of a phenomenon as a result of interpretation of life experiences. Porter (1996) states that qualitative research aims to search for a reason rather than a cause for an event and at the same time to offer an understanding of the interpretations rather than to explain them as in quantitative research. The data obtained by historical documents, direct observation or in-depth interview produce linguistic descriptions that cannot be quantified (Millor *et al*, 1992). Because the data cannot be manipulated statistically, the findings are often said to be soft data as opposed to the hard facts derived from quantitative research (Morse and Field, 1996). The idea of a qualitative study is to examine the whole, without imposing any form of control to allow an understanding of a phenomenon. As a result of this, Millor *et al* (1992) state that qualitative research is particularly appropriate to theory building studies as it examines the subject holistically in response to life events experienced by differing groups of people. Qualitative research can produce a vast amount of transcript data and therefore the numbers of subjects is usually much smaller than in a quantitative study. The individuals are not generally a random sample but a group selected by the researcher that she feels will yield the most information surrounding a phenomenon (Morse and Field, 1996). It is with this in mind that a qualitative study is deemed to be biased by the researcher and that production of an exact replica of the study is unlikely. Therefore the results are not reproducible, as would be the case in a quantitative study where a replicate study should be able to be completed with similar outcomes.

The Qualitative – Quantitative Debate

Thus far the two approaches of research methodology and the history of nursing research have been summarised and in some studies it is appropriate to use both approaches. Goodwin and Goodwin (1984) feel that a combined approach would give increased value to many studies. In large studies there may be many questions to be answered and by using a combined approach of the research methodologies it can only enhance the reliability and validity. Polit and Hungler (1989) believe that a combination of both qualitative and quantitative research methods enhances the understanding of human behaviours, problems and characteristics, all of which are traditionally associated with qualitative research. They also emphasise that the use of a numerical system allows the researcher to analyse the large amount of data often produced from qualitative research. This is not a statistical approach to data analyses but it can be helpful in interpreting the volume of manuscript of interview transcripts. Mason (1993) supports Polit and Hungler (1989) and says that a nursing orientated study can contain both scientific and artistic data and therefore the use of both methods can be an appropriate way of answering the posed questions. Artistic data is derived as a result of qualitative research whereas scientific data is produced as a result of quantitative research. Mason (1993) states that there may be problems using a combined methodology because there is a danger that the two methods used may give contradictory data and the validity of the study could be compromised. Also two methods that yield different data may give a more disjointed result than if only one method had been adopted. She does conclude that by using one approach for the main body of the work, that the other method could be used as reflection thus combining two methodologies (Mason, 1993). Gorenberg (1983) emphasised that nurses have been using scientific enquiry in their methods of research since the time of Florence Nightingale and that the research tradition is now being developed to reflect the unique domain of nursing. Gorenberg (1983) also advises that before choosing a methodology, a researcher should first decide the question to be asked and then how it will be answered. Simmons (1995) agrees with this observation and states that in research, not only will the research question determine the approach chosen but also that the research methods should be appropriate to the nature of the research question (Simmons, 1995). There is always scope to change the original hypothesis and research methodology but researcher bias must be avoided. Although Gorenberg's paper dates from 1983, it shows that research tradition is forever changing with time. A method that has been used in the past may not be considered to be adequate in the future as researchers strive for more answers to a problem and therefore as the research tradition evolves problems are answered more satisfactorily (Gorenberg, 1983). Duffy (1985), Corner (1991), Carr (1994) and Begley (1996) have further examined the subject of triangulation or combining methodologies. Morse (1991) was not convinced by triangulation, as both methodologies are so different. For example, the sample size would not be appropriate for both methodologies although she does note that it may not be necessary to use the same sample. However, she does support its use believing that a study will be strengthened thus developing theory and knowledge (Morse, 1991). This is a view from 1991 and Begley (1996) shows the advances that have been made towards new developments within nursing research and the methodologies used.

Nursing Knowledge

A knowledge base comes from a general exposure to different facets and areas within everyday working and home lives. Increasing knowledge within a field comes from the everyday experiences of coping with new and challenging problems, both those encountered in working lives and those experienced personally. Barbara Carper (1978) is the recognised nurse theorist on patterns of knowing within nursing integrating practical and theoretical knowledge. She describes four distinct patterns of knowledge: -

-Empirical knowledge – the science of nursing
-Aesthetic knowledge – the art of nursing

-Personal knowledge

-Ethical knowledge.

The science of nursing knowledge comes from tried and tested laws and theories that enable phenomena to be explained or analysed. Manley (1997) recognises that it can be difficult to apply this nursing knowledge to individual patients, as human beings are so complex. Science encourages the breaking down of a problem into parts, which therefore does not allow for a holistic approach to care. Almost all of the reviewed articles will increase empirical knowledge with many of the articles being quantitative studies that would substantiate this knowledge.

The aesthetic knowledge of nursing focuses on the craft of nursing and includes intuitive knowledge. It comes from experience within a chosen field and allows a person to know what to do or as a result of developed expertise becomes second nature in a given situation. Carper (1978) also expands the art of nursing to encompass empathy and the ability to experience another's feelings. A number of the reviewed articles describe the importance of empathy particularly with the young adults as it leads to their encouragement (Maffeo, 1997, Bradbury and Jenkinson, 1996, Greenhalgh, 1996, Lewis, 1995, Betschart, 1993; Challener, 1989). It could be argued that the three case studies would also provide aesthetic knowledge for future care, although at the time of their inception all would have certainly been considered empirical in nature (Boland and Ahern, 1997, Young, 1995; Martin, Kupsis, Novak and Kushion, 1994).

Personal knowledge comes from within, being triggered by how a person views himself and it is an essential component within the patient-nurse relationship but only one reviewed article truly expresses this type of knowledge. Nagenast (1989) describes her own experience of stress and how to cope with it, in combination with some empirical knowledge that is encountered in the introduction.

Ethical knowledge concerns knowing what is right or wrong. Moral decisions have to be made thus adding to previous knowledge. It also relates to ensuring that no harm but only benefits come to a patient, and this attitude encourages advocacy. No articles reviewed were particularly pertinent to this area of knowledge but in utilising findings it is important to consider ethical knowledge and the impact of care on patients.

Carper (1978) recognises that although each pattern of knowledge is essentially distinct, they are interrelated and interdependent with each other. All nurses use Carper's patterns of knowing and integrate them into their own everyday practice. The ability to learn and impart knowledge is undoubtedly one of the most important skills possessed by a nurse but how well this knowledge is used can impact on the nurse-patient relationship and the long-term management and care goals.

This review has shown the extent of topics covered by research studies, personal experience, reviews of current treatment and management as well as case studies. All of these pieces of work provide valuable information and suggestions for future care some of which will be relevant to an area of practice and some which will not. In the nursing of children and young adults it is important to use those articles pertaining to the particular age group although this group will age and other articles will then become relevant. In the current climate of Post-Registration Education and Practice (PREP) set up by the United Kingdom Central Council (UKCC) in 1994 it is necessary for time to be given to study and keeping abreast of current trends and changes (UKCC, 1995). However a DSN may have difficulty in reading all of the relevant articles both from not only a time point of view but also the availability.

Implications for Nursing Practice

The fashionable concept at present is Evidence-Based Practice (both within nursing and medicine) and nurses working in all areas of practice will be aware of the implications of this. As discussed throughout this literature review there is evidence that children with diabetes will develop long-term complications and therefore it is important to use the most up to date treatment regimes and screening to ensure that the minimum of complications are seen in the future. However this ideal is not always possible as time constraints, funding and the present lack of nurses within post can reduce the effectiveness of the service. Increasing an individual's knowledge as shown by Carper (1978) is possible within everyday practice but the application of research findings may not be so easy. The new journal *Evidence-Based Nursing* published in 1998 recognised that there is an increasing gap in knowledge between researchers and practitioners. The editors of the journal hope that by reviewing some of the numerous research papers produced that short précis of articles will enable information to be disseminated to those nurses working in a particular area of practice (DiCenso, Cullum and Ciliska, 1998). Mulhall (1998) hopes that the journal will offer practitioners the ability to read research papers, critically appraise them and then utilise the conclusions in practice. Many nurses believe that they do not have the time or skills to base their practice on research (Stevens, 1997; Mulhall, 1998) but this journal offers a concise and understandable introduction. To date there have been no articles specific to this thesis reviewed in the journal but it has only been in production for a year.

Putting research conclusions into practice can encounter problems not least of which is the need to change. Changing an area of practice is recognised to be difficult (McIntosh, 1995) because nurses are guided by traditions, which they are often reluctant to change. Walsh and Ford (1991) recognise that the personal commitment to traditional beliefs can cause a resistance to change.

Despite reluctance to change practice, the current trends within the health service demand it and the need for cost-effective care, therefore it is important to look to the future. In children and young adults with IDDM it is important to screen for the early signs of complications so that treatment can be initiated and the need for technical expensive care in the future can be avoided thus saving money in an already struggling NHS. For example screening for microalbuminuria, as indicated by Viberti *et al* (1982), may prevent the subsequent development of ESRF and the need for dialysis or renal transplant. However it can be difficult to persuade purchasers to provide money at this early stage. If there is no research to support the need for early screening (Burton, 1998) then as Hardey and Mulhall (1994) explain, fund holders and purchasers may be reluctant to release money without knowing the potential benefits and future savings.

This literature review does not highlight any particular area where research could be beneficial but overall covers a number of topics including scientific laboratory findings, psychological problems encompassing compliance and adaptation and specific nurse groups. There are undoubtedly areas where research findings could be applied to current practice although some of the papers are from America where the health service structure is different to that in the UK. The DCCT findings, discussed in Chapter Two, are leading to a change in practice in the USA as shown by Ahern and Grey (1996) and should also be instigated within UK practice. The DCCT study was performed in the USA and although the conclusions are important, the care provided with monthly clinic appointments and weekly phone calls could not be reproduced in the UK with the current limited resources available (Shield and Baum, 1994). Therefore the provision of care that is offered must be of the highest standard within the resources available.

Care for people with diabetes in Europe has been derived from the St Vincent Declaration of October 1989 instigated by the WHO which recognised that diabetes mellitus was a major and ongoing health problem of all ages and in all countries. In 1992, a task force was set up in the UK to implement the goals described by the St Vincent Declaration and to set up the priorities of care in order to attain them. The main goals were to improve the health generally and the quality of life of those with diabetes, and to prevent the associated complications and cure diabetes through research programmes. The declaration concluded that there were special problems for children and young adults such as the increased incidence of diabetes in this age group in the UK and also the devastating effect on the family dynamics. Also because of their young age they have a longer time to develop complications and the hormonal changes during puberty can make the maintenance of good blood glucose control more difficult. The declaration recommends that a team specialising in the management of diabetes and children must provide the care given to children and young adults and that the necessary social, economic and emotional support is available. The need for collaboration on transfer from the children's clinic to an adult diabetes care team is also highlighted, as well as the need for liaison between other carers involved with a child such as in schools or the Primary Health Care Team (PHCT). The need for ongoing education for those with diabetes and their families is also expressed as well as the importance of imparting knowledge from the diabetes care team to other health professionals who may be involved in the care of a diabetic patient (BDA and Department of Health (DOH), 1995). The education, either written or oral, should be appropriate to the age group and must be offered to the family, school, college or university as required. The specific educational aims of the care team should be insulin treatment, nutrition allowances, self-management where appropriate, blood glucose maintenance, prevention of complications, social needs and psychological support (MacKinnon, 1998).

A directive from the BDA in November 1997 furthered the goals of the St Vincent Declaration with the recommendations to include GPs in the care of diabetic patients. The BDA also recognises that children constitute a special group and that it is necessary to have good liaison within the hospital and community to ensure the high standard of care expected. They also highlight the need for care to be knowledge-based and to take account of research reports locally, nationally and internationally (BDA, 1997). The directive also emphasises the need to make the general public aware of the disease. This advise may have been as a result of a MORI survey published by The Times newspaper which showed that funding research into diabetes was considered to be a low priority by the public. The BDA's response to the survey was that they were unable to issue grants to every person wishing to undertake research into diabetes due to lack of funds. The MORI survey also showed that the public was ignorant of the life-threatening complications of the disease. (Editorial, The Times, 1997).

Clearly from the St Vincent Task Force recommendations there are a number of areas on which to concentrate care. Ideally children and adolescents should have their primary care provided by the hospital diabetes care team which should include a paediatric diabetologist (or a paediatrician/physician with an interest in diabetes), a DSN, a dietician, a social worker and a chiropodist. An annual assessment by an ophthalmologist is also recommended and for the adolescent patient a psychologist should be available within the care structure (Walker, 1991; MacKinnon, 1998).

The role of the DSN has developed over the last four decades in the UK and he or she is an important member of the hospital primary care team. MacKinnon (1998) describes the DSN as a trained nurse who has extended her knowledge and skills in diabetes management. The role includes that of an educator, manager, researcher, communicator and innovator who can be responsible for her actions. Walker (1991) also includes the skill of counselling within her list of desirable attributes. She also recognises that the role of the DSN can be somewhat diverse involving work within the hospital clinics or wards, home visits and planning education sessions on an individual or group basis. There should also be liaison with colleagues in nursing as well as other disciplines to ensure a high standard of care is delivered. Walker (1991) recognises the need for research-based practice and the need for professional development which is required in all nursing specialities.

Generally in the UK the DSN works with a physician or paediatrician involved with diabetes and is based within the hospital and/or the community. The specialist nurse will be the link with other health professionals either in the hospital or in the community. In many parts of the country the DSN provides out of hours cover giving advice over the telephone which may prevent an emergency situation arising. The DSN is the person most intimately involved with newly diagnosed children and is therefore an invaluable resource for all areas of care. It is important therefore to aim for a good nurse-patient-family relationship from an early stage in order to provide the best care available to the patient (RCN, 1993).

One of the most notable recurring themes in this review is the essential need for ongoing support, education and reiteration to the diabetic children and young adults. As described above, the DSN is the member of the primary care team who will be responsible for co-ordinating this need for education and support. Teaching and education begins at diagnosis and will become an important and necessary part of care at all follow-up appointments or at other times as required. With young children the teaching may have originally been addressed to parents but with the older children and young adults, the teaching should be directed at the patient as well. As the young children grow older, it is imperative that topics discussed with the parents at diagnosis, which at the time the children were too young to understand, are reiterated. There are other topics which will be pertinent to certain age groups such as the recognition of hypoglycaemia with the young children and smoking, driving, alcohol and contraception in the adolescents. Therefore the diabetes care team will need to have an ongoing agenda of topics to be discussed.

Children and young adults with diabetes are encouraged to lead as normal a life as possible but the literature review has emphasised the difficulties of coping with adolescence even without the upheaval that diabetes can impose. Tactful and careful support is needed as well as empathy to ensure that health is maintained. Teenagers, as a general rule, are concerned with the present rather than the future and are unable to recognise that they might be involved in an accident or an incident (Roye, 1995). An educator can use scare tactics to encourage people to look after themselves and perceive problems before they occur but this is not always a suitable method of teaching especially for the young. Empathy is an important communication skill to possess as a teacher when talking to patients and can be learnt although many people attracted to the caring professions may have natural empathy. Baillie (1995) recognises that in forming a nurse-patient relationship, empathy cannot be ignored and is certainly required if an honest and productive ongoing relationship is to be secured.

The DSN therefore needs to acquire the skills described by Walker (1991) and MacKinnon (1998) in order to carry out the everyday role required. One of the most important skills will undoubtedly be as the educator or teacher to the patient, family and other health care professionals involved in care. In order to undertake the role of an educator or teacher, the DSN must possess a sound knowledge base in diabetes. Ideally the DSN will have completed the English National Board (ENB) 928 Course in Diabetes Nursing Care to complement the general registration (MacKinnon, 1998) although other recognised courses are available (Walker, 1991). If the DSN role chosen involves children then further education will be advisable in this area and a District Nurse or Health Visitor qualification may also be advantageous (RCN, 1993; MacKinnon, 1998).

Education in relation to hypoglycaemia would be pertinent to everyday practice. Alleviating fear of this acute complication, as highlighted by Marrero *et al* (1997) amongst others, whilst maintaining blood glucose levels within the lower range but avoiding the hypoglycaemic range, must be encouraged. Achievement of this would help to prevent hyperglycaemic episodes which are known to be associated with long-term complications (MacKinnon, 1998).

The articles focusing on the school environment may not provide reproducible ideas for the UK because as stated in the review the education system is different in the USA. There are school nurses within the UK boarding school system and they will need to be updated on current trends and treatments involved with their young diabetic children. The DSN should be involved with this part of education to fellow professionals.

Gardiner (1997) demonstrated the need for designated adolescent clinics and in view of her article relating to coping strategies, this must be a priority and a way forward. Addressing teenage pressures and empathising with them in an appropriate environment is helpful. Such an environment may also encourage teenagers to attend clinic with people in their own age group and allow the recognition for the need to self-care. 'Shock' treatment is referred to in the review and in some cases is necessary but many teenagers respond better if they are not faced with the harsh realities of long-term complications every time there is a clinic visit. Also highlighted in the review is the need to recognise individual coping strategies, which is a skill to be adopted. Continuity of care by the DSN/PDSN will undoubtedly help with this, as the individual family dynamics are understood.

Timing of education on complications is important as the patient/health professional relationship develops. There is conflicting information from the reviewed articles regarding the timing of education that can be offered ranging from at diagnosis to whether it should be directed to the child and/or parents. Assessment of baseline knowledge of the patient and family at diagnosis is important in order to offer appropriate education. The time of diagnosis may not be the most appropriate time to give families yet further information but if asked, the doctor or DSN may be required to give relevant information. Families may already have experience with diabetes complications but it may be more appropriate to withhold certain information and gradually introduce it in future clinic visits.

The DSN will also be involved with the ongoing education requirements of fellow health professionals. School nurses have already been mentioned but other people will include practice nurses, ward nurses, nurse students (pre or post registration) plus any other health care professionals already involved with certain families.

CHAPTER NINE

CONCLUSION

The author's primary goal when undertaking this review was to demonstrate the lack of nursing literature available pertaining to microalbuminuria in diabetic children and young adults - the first title draft. This was unfortunately proved early during the initial literature review with the majority of articles found in the medical literature index. As a nurse, the author felt unable to critique this literature as there was a lack of background knowledge on the pathophysiology and biochemistry component of the articles. Therefore the goal changed and the author began to look at the nursing literature available on the more general topic of diabetic complications in children and young adults producing the diversity of topics seen in the review. As the author expressed earlier in this work, there is information available but it is not always easy to find.

When first undertaken, the author believed that there would be a wealth of information easily available but as stated repeatedly this has not been the case. Working with DSNs in various visited hospitals has shown that the current workload is not conducive to allowing time for study, or for reading all the articles found for this review. There is a support group available for nurses working within the field of diabetes run through the RCN – the Diabetes Nursing Forum. This forum has developed with regional groups offering support from neighbouring health authorities rather than purely nationally (Cradock, 1991). This is an important innovation as peer support is invaluable particularly when discussion of current individual problems can take place. Perhaps a further step forward would be the introduction of a journal type club where current relevant articles could be discussed.

The increasing number of diabetic children and young adults who will attend the children's clinic and be seen by the DSN will continue. The knowledge base held by this one individual will be so important in the beginning of teaching new diabetics that the work needed to keep up to date will be essential. Time must be found to extend one's own knowledge but the author accepts that this is not always easy and peer or care team support will be necessary. Discussing various topics within a care team can enhance a knowledge base and encourage further reading or study. Being given time and funding for relevant study days or courses is also important as this encourages those with similar nursing backgrounds or working environments to listen to new information and talk through problems or concerns.

This project has taken time but the author hopes that it shows the diverse amount of relevant nursing and medical articles there are available to read. Although these may not all be easy to obtain, some are, and any nurse working within diabetes can only benefit from the varying topics discussed as this author has. On beginning this review, the author had limited knowledge about the field of IDDM in children and young adults as well as the number of areas that research was currently being undertaken. On completion, the author feels that her own knowledge base has increased and although not a trained DSN, does now feel in a position to answer questions posed by patients, parents and other health professionals. Carper's (1978) pattern of knowledge have been used, subconsciously, with practical experiences of clinics, listening to other members of the care team as well as using the very basic knowledge from past experiences coming together.

In retrospect, this review has attempted to discuss the specific topic of childhood diabetes and it's implications, although the search revealed a limited number of articles pertaining to the specific topics, a number of other articles concerning unexpected diverse topics were obtained. The review has shown the areas where studies have been performed and some of these could be expanded by concentrating research on particular areas. Examples of these include:

The impact of diabetes in children and/or parents in this country.
The problems faced by adolescence in the UK with or without diabetes.
The impact of media stories or the Internet on children or parents.
The need and benefits of specific young adult clinics.

The incidence of diabetes mellitus, both insulin-dependent and non-insulin dependent, is increasing in the UK as emphasised in Chapter Two. Even with the increased knowledge on minimising the effects of the long-term condition, complications will continue to occur despite every effort to prevent them. Media coverage of the disorder can be a useful tool in making the general public aware of the presenting symptoms of diabetes. Diagnosing children and young adults with IDDM is generally straightforward as the symptoms come on suddenly and they will be admitted to hospital generally unwell as a result of high blood glucose levels. Recent high profile athletes have heightened the awareness of diabetes. Steven Redgrave, the Olympic Rowing Gold medallist, developed diabetes in 1997 and his efforts in continuing to train for further medals is an inspiration to all diabetics (Hawkes, 1997). Jonathan Lower had long discussions with The Jockey Club regarding his future in horse racing. He has now been able to start racing again under strict guidelines but it has proved that despite having diabetes, an athlete should be allowed to compete at the highest level within his sport (Dobson, 1997).

The *Nursing Times* has recognised that there is a need for diabetes education by producing a new diabetes supplement which is to be published quarterly. It is the result of collaboration between themselves and the BDA and should help to make general nurses aware of the increasing incidence of both Type 1 and Type 2 diabetes within the UK. The editor points out that all currently practising nurses have an important role in the education of people affected by diabetes and the aim of the supplement is to assist such nurses (Cradock, 1998).

Recently there has been a new journal published, which is aimed at the professionals working within the field of diabetes nursing called the *Journal of Diabetes Nursing*. With its advent it is possible that relevant articles may be concentrated in the publication making it easier for those working with diabetic patients to find the relevant articles. Areas currently covered are research, clinical articles, professional issues, case studies as well as current news updates. The journal should become essential reading for all nurses working within the field of diabetes and could become a forum for discussion. The journal could also be used to advertise forthcoming conferences or study days which form an important part of post-registration training and continuing education. These study days offer nurses the opportunity to broaden their knowledge whilst keeping up to date with changes in management or care.

Another area of increasing information dissemination is that of the Internet via the World Wide Web (WWW). It is an information service across the world that is available to anyone with a telephone, a modem and a computer. From experience, the author has seen parents attend clinics with printed copies of information they have found on the Internet, posing many questions for members of the care team.

In the UK, the BDA has a web-site giving general information about diabetes, it's incidence and treatments as well as their recommendations for care of various problems such as hypoglycaemia. There is also some information about current research projects but this is not in great detail. There is a report of the DCCT and a description of the effects of its conclusions on one individual. Internationally there is an enormous amount of information on various facets of diabetes, particularly from the USA and Canada. When the author first began this review, the Internet was used to gain information but because the majority was pertaining to America, little has been utilised but it was interesting to see the areas covered. There were summaries available of journal articles, web pages inviting questions from doctors or nurses about diabetic topics as well as an invitation from a Californian team to have a kidney biopsy and aid their research into renal damage. Equipped with this type of information, parents can be a forceful entity in a clinic demanding the best for their children and often wanting to know why treatments differ in America and Britain. However it is important to remember that the Internet reports are not peer reviewed as in published journals and so the information could be misleading. Parents and patients have access to the whole range of the media where reports are written, not necessarily by medical of nursing personnel which will interest them and provide them with information for discussion. The care team must have adequate knowledge in order to deal with these questions posed. Diabetes can be a debilitating disease for some people with, as discussed, long-term complications. Patients themselves or parents naturally want the best opportunity for a good quality of life but research that is performed in America may not be applicable in the UK and it can take time for the findings from research to be utilised within practice. Members of the care team need to keep up to date with current media news and have answers ready for discussion with the diabetic child or parents.

What started out as a search for microalbuminuria within the medical literature has been completed as a literature review of journal articles pertaining to diabetes in childhood and the potential complications. It has opened the eyes of the author to the long-term problems of diabetes but with the hope that research is current and ongoing and that new treatments will be found. Disappointingly this does not appear to be within the field of nursing research at present but this is not surprising as diabetes is primarily a biochemical disorder and therefore much of the research is clinical. This can be seen to be mechanical and not very individualistic but that is the disadvantage of quantitative research which requires a hypothesis to be proved, usually as a result of statistical data. The advantage of quantitative research is that statistics can be presented so that the best care available can be given for a symptom or a diagnosis.

When examining feelings, emotions or the holistic care of a patient, qualitative data is invaluable. Diabetic children or young adults will be cared for primarily within the medical domain but it will tend to be the nurse assigned to them who will care for them holistically. Nurses are therefore the professional group to take the qualitative approach to care forward and in time and with the relevant resources can examine their work to enable the children of tomorrow to have a brighter future.

Despite the paucity of available literature, the articles reviewed have produced diverse and useful information as well as areas for discussion. Throughout this review the area of long-term complications has been emphasised and the need to prevent them by addressing the management and care of the children and young adults. The nurses assigned to work with this particular group need to be aware of changing practice and screening techniques as well as the psychological requirements of these individuals. The importance of recognising individual coping strategies has been emphasised as well as understanding how young people cope and adapt to not only their diabetes but also their adolescent years. Education by the nurse is paramount in the care of these people but without a sound knowledge base this will not be possible. This review has enabled the author to view her own work differently and be much more aware of information given to her by patients and families. This search for relevant literature has ensured that the author has updated her own knowledge so that it can now be put into practice. The review has demonstrated that diabetes is a disorder with serious long-term complications which can be ameliorated by well-informed carers thereby allowing this young age group the brightest of futures.

(25680 Words)

APPENDIX ONE

ABBREVIATIONS

ACE	Angiotensin Converting Enzyme
ADA	American Diabetes Association
AER	Albumin Excretion Rate
ALL	Acute Lymphocytic Leukaemia
BDA	British Diabetic Association
CEP	Continuing Education Points
CF	Cystic Fibrosis
CINAHL	Cumulative Index of Nursing and Allied Health Literature
CSII	Continuous Subcutaneous Insulin Infusion
CVA	Cerebral Vascular Accident
CVD	Cardiovascular Disease
DCCT	Diabetes Control and Complications Trial
DKA	Diabetic Ketoacidosis
DSN	Diabetes Specialist Nurse
ENB	English National Board
ESRF	End Stage Renal Failure
GP	General Practitioner
HIV	Human Immunodeficiency Virus
HLA	Human Leukocyte Antigen
ICA	Islet Cell Antibodies
IDDM	Insulin Dependent Diabetes mellitus
MODY	Mature Onset Diabetes of the Young
NHS	National Health Service

NIDDM	Non-Insulin Dependent Diabetes Mellitus
ORPS	Oxford Regional Prospective Study
PDSN	Paediatric Diabetes Specialist Nurse
PHCT	Primary Health Care Team
PREP	Post-Registration Education and Practice
RCN	Royal College of Nursing
RHA	Regional Health Authority
SMBG	Self Monitoring Blood Glucose
STD	Sexually Transmitted Disease
UK	United Kingdom
UKCC	United Kingdom Central Council
USA	United States of America
WHO	World Health Organisation
WWW	World Wide Web

APPENDIX TWO

GLOSSARY

Albumin	A type of simple protein, varieties of which are widely distributed throughout the tissues and fluids of plants and animals.
Albuminuria	The presence of albumin in the urine.
Aldosterone	A hormone released form that helps to maintain an electrolyte balance within the body.
Analysis	Methods of organising, sorting and scrutinising data in such a way that research questions can be answered.
Angina	Cardiac pain which occurs on exertion owing to insufficient blood supply to the heart muscle.
Angiopathy	Any disease of the blood vessels or lymphatic system.
Angiotensin	A polypeptide occurring in the blood causing vasoconstriction, increased blood pressure and the release of aldosterone from the adrenal cortex.
Bias	Any influence that produces a distortion in the results of a study.
Cardiomyopathy	Any disease that affects the myocardial tissue of the heart.
Cardiovascular Disease	Any abnormal conditions characterised by dysfunction of the heart and blood vessels.
Case Study	A research method that involves a thorough, in-depth analysis of an individual, group, institution or other social event.
Cohort	A group of persons with a common statistical characteristic.
Comparison Group	A group of subjects whose scores on a dependent variable are used as a basis for evaluating the scores of the experimental group. The term comparison is generally used instead of control group when the investigation does not use a true experimental design.
Convulsion	A seizure.
Cystic Fibrosis	An inherited disorder causing abnormally thick secretions of mucus and elevation of sweat electrolytes.
Data	The pieces of information obtained in the course of a study.

Diabetes Mellitus	A disorder due to the deficiency or ineffectiveness of the endocrine secretion of the pancreas, insulin.
Electrolyte Balance	The maintenance of the correct balance between the different elements in the body tissues and fluids.
Findings	The results of the analysis of the research data.
Glomerular Hypertrophy	An increase in the size of the cells of the glomerulus.
Glomerulus	The structure within the kidney composed of blood vessels involved in the process of excreting urine.
Glucagon	A protein produced by the Islets of Langerhans which encourages liver stores of glycogen to be released to raise the blood sugar level.
Glycogen	The form in which carbohydrate is stored in the liver and muscles.
Glycaemic control	Regulation of blood sugar levels within the body.
Glycosolated or Glycated Haemoglobin	The percentage of haemoglobin to which glucose is attached reflecting the previous two – three months average blood glucose.
Glycosuria	Abnormal excretion of glucose in the urine.
Haemoglobin	A complex protein compound in the blood that carries oxygen to the cells from the lungs and carbon dioxide away from the cells to the lungs.
Hormone	A chemical substance that is generated in one organ carried in the blood stream to another where it exerts a regulatory action.
Hyperglycaemia	A greater than normal level of glucose in the blood.
Hypertension	High blood pressure.
Hypoglycaemia	A less than normal level of glucose in the blood, usually caused by administration of too much insulin, excessive secretion of insulin or dietary deficiency.
Hypotensive	Low blood pressure.
Hypothermic	Reduction in the body temperature.
Hypothesis	A statement of a predicted relationship between the variables under investigation.

Incidence	The number of times an event occurs.
Intramuscular	Within muscle tissue.
Intravenous	Within a vein.
Insulin	The endocrine secretion of the pancreas, which regulates sugar metabolism and ensures complete fat combustion.
Interview	A method of data collection in which one person asks questions of another either face to face or by telephone.
Ketonuria	Presence of excessive amounts of ketones in the urine as a result of uncontrolled diabetes in which fat stores are rapidly broken down for metabolism.
Macroangiopathy	Any disease of the large blood vessels.
Macro-vascular	Pertaining to the large blood vessels.
Metabolic	Relating to metabolism.
Metabolism	The sum of the chemical and physical changes occurring in body tissues.
Methodology	The steps, procedures and strategies for gathering and analysing the data in a research investigation.
Microalbuminuria	The presence of minute quantities of albumin in the urine, not detectable on routine analysis.
Microangiopathy	Any disease of the small blood vessels, often applied to vascular changes in diabetes.
Micro-vascular	Pertaining to the small blood vessels and capillaries.
Morbidity	The rate at which an illness or abnormality occurs in a particular area or population.
Myocardial Infarction	A heart attack due to lack of blood to the heart muscle.
Normaglycaemia	A glucose level in the blood within normal levels.
Mortality	The death rate, which reflects the number of deaths per unit of population in any specific region, age group, disease or other classifications usually expressed as death rate per 1000, 10,000 or 100,000.
Nephropathy	Any disease of the kidney.

Neurological	Of the nervous system.
Neuropathy	Any disorder affecting the nervous system.
Nocturia	Excessive production of urine at night
Objectivity	A desired quality of research using the scientific approach; refers to the extent to which two independent researchers would arrive at similar judgements or conclusions
Oedema	An effusion of fluid into the tissues.
Palpitation	Rapid and forceful contraction of the heart of which the patient is conscious.
Pancreas	The gland in the body that secretes insulin.
Pancreatectomy	The surgical removal of all or part of the pancreas.
Pathophysiology	The study of biologic and physical manifestations of disease as they correlate with the underlying abnormalities and physiologic disturbances.
Peripheral Vascular Disease	Any abnormal condition that affects the blood vessels outside of the heart and the lymphatic vessels.
Phenomenon	A fact or occurrence that appears or is perceived especially one of which is the cause is in question. Pleural is phenomena.
Pilot study	A small-scale version, or trial run, done in preparation of for a major study.
Plasma	The fluid part of circulating blood.
Polydipsia	Excessive thirst characteristic of diabetes.
Polypeptide	A chain of amino acids.
Polyuria	The excretion of an abnormally large amount of urine.
Prevalence	The number of all new and old cases of a disease or occurrence of an event during a particular period of time.
Proteinuria	A condition resulting from an increased permeability if the kidney tubules allowing plasma proteins to be excreted into the urine.
Qualitative Research	A systematic, interactive approach used to describe life experiences and give them meaning.

Quantitative Research	A formal, objective systematic process to describe, test relationships and examine cause and effect interactions amongst variables.
Questionnaire	A method of gathering self-report information from respondents through self-administration of questions in a paper and pencil format.
Rate	A numeric ratio, often used in the compilation of data concerning the incidence and prevalence of an event.
Reliability	The degree of consistency or accuracy with which an instrument measures the attribute it is designed to measure.
Retina	The innermost coat of the eyeball, formed of light sensitive nerve cells and fibres, from which the optic nerve leaves the eyeball and passes to the visual area of the brain.
Retinopathy	A non-inflammatory eye disorder, resulting from changes in the retinal blood vessels.
Research	Systematic enquiry that uses orderly scientific methods to answer questions or solve problems.
Sample	A subset of a population selected to participate in a research study.
Seizure	A sudden, violent, involuntary contraction of a group of muscles.
Statistic	An estimate of a parameter, calculated from sample data.
Subject	An individual who participates and provides data in a study.
Theory	An abstract generalisation that presents a systematic explanation about the relationships among phenomena
Treatment	A term used to refer to an experimental intervention or manipulation.
Validity	The degree to which an instrument measures what it is intending to measure.

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