AN AUDIT OF DIABETIC CARE PROVIDED TO PATIENTS CONDUCTED BY A DOCTOR - NURSE TEAM IN A GENERAL PRACTICE.

By

D. M. Navsa

Submitted in partial fulfilment of the requirements for the degree M. Phil in the Department of Family Medicine / Primary Care in the Faculty of Medicine at the University of Cape Town.

Date submitted : August 1997

Promotor : Dr B. Schweitzer

DECLARATION

I, JR. D. M. NAUSA, hereby declare that the work on which this research is based is my original work (except where acknowledgements indicate otherwise), and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

I empower the University of Cape Town to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

Signed by candidate

Signature Removed

Signature

16/12/97

Date

Acknowledgements

Many thanks to my supervisor, Dr B Schweitzer, for her feedback, guidance and encouragement, throughout the research process. I also wish to thank my co-supervisor, Dr N Levitt, for her suggestions and feedback early in the process. I cannot fail to thank Dr. D. Whittaker whose driving force kept me on track.

I would also like to thank Dr Rachel Jewkes for her assistance with the Focus Group Interview Guide and for facilitating the Focus Group Discussion, as well as Sheila Ntshona for her time and effort to take notes during this discussion.

I owe a great deal to my staff, Sister Zaibunisa Kajee and Rushda Darries, for their assistance, suggestions and tolerance- to you a special thanks.

Many thanks to Ghalieb Harnaker for his time, patience and expertise. Without his help, analysis of the record review would have been difficult.

I wish to thank Moeain Arend for the time he took reading the dissertation and making corrections.

I cannot thank my family enough for their patience, tolerance and encouragement. This project would not have been possible without your love and support.

I remain eternally grateful to my Creator, whose guidance I cannot do without in caring for my patients. To my patients I always remain indebted. It is from them I continue to learn and because of them I continue to grow.

CONTENTS

Summary / Abstract

Introduction: I am a general practitioner in solo practice in Athlone. I work closely with a qualified nursing sister. Many of the patients we attend to have non-insulin dependent diabetes mellitus.

Aim: To implement change in the management of our patients with diabetes by developing a protocol for future improved care.

Objective: To assess the quality of care provided to patients with (NIDDM), by a doctor - nurse team in private general practice.

Method: The study was quantitative and qualitative and consisted of 3 sections: 1) an internal audit based on the retrospective examination of patients' medical records, 2) a questionnaire which was administered to determine patients' knowledge of their disease and 3) a focus group interview which centred around patients' experience of the disease and feelings about the service provided. The interview was audio taped.

Findings: Problem areas identified were sub-optimal record keeping; poor attendance and infrequent eye and foot examinations; patients' knowledge of their disease was limited; certain aspects of doctor-patient and patient-family relationships that may impact negatively on care; fears and anxieties relating to the disease and perceptions of locus of control as external.

1. INTRODUCTION

I am a general practitioner in solo private practice. I have been in private general practice for the past 17 years, working as a locum until April 1994, when I established my own practice. Many of my patients, who come from a low to middle income community, are not able to afford to belong to a medical aid scheme. Some of them receive part of their care at the community health centres, provincial hospitals and from private internal medicine specialists. My practice which is based in Athlone, employs a receptionist and practice nurse.

I am currently enrolled in the M. Fam. Med. course at the University of Cape Town and consequently, have begun to critically reflect on my current practices and the quality of service I provide my patients. This has been further prompted by the fact that the health care system in South Africa is undergoing changes to address previous inadequacies. This country recognises the Alma Ata declaration on Primary Health Care (PHC) as a basis for future PHC services and endorses its emphasis on promotive and preventive care[1]. PHC is first-contact, continuous and comprehensive care. Therefore, I believe general and family practitioners being first-contact doctors, who assume responsibility for families and communities, have a significant role to play as primary health care-givers. Private practitioners have however, often been viewed as curative oriented, neglecting promotive and preventive care. To feature significantly as part of the primary health care system in this country, our practices will have to undergo changes in keeping with those taking place in the other sectors of the health industry.

" One of the signs of a mature profession, is the research carried out by its members on their activities." [2] According to Howie, the studies we carry out should reflect new understandings of disease, new systems for delivery of care as well as changed and changing public and professional beliefs about illness, sickness and health.[3]

I have always viewed most of the diabetics in my care as 'problem' patients because I never seem to be making any progress with them. I have however, come to realise that the 'problem,' not only rests with our patients, but that much of the problem is related to the inadequate care we provide.

I do not have a structured or written protocol for the management of our patients with diabetes whose care, up until now, appears to have been rather haphazard. Since my practice has only been established for two years, this would be an ideal time to determine the quality of care provided to my patients, and to develop a protocol for future management.

This study focused on the patients in our care with diabetes. It is a study, through which I hope, in addition to improving the quality of care we provide, to achieve a better understanding of myself, my patients, my profession and staff.

Furthermore this study not only aimed at assessing the quality of care provided by the care-givers, but also aimed to determine the patients' knowledge of their disease and determine patient satisfaction as a measure of quality of care. This will be discussed further in the literature review.

2. LITERATURE REVIEW

2.1. Definition

Diabetes Mellitus is the most common endocrine disease[4]. It is associated with a chronically elevated blood glucose concentration, and is also characterised by metabolic abnormalities and by major long term complications involving the eyes, kidneys, nerves and blood vessels.[4,5]

2.2 Classification.

The current (1997) World Health Organization (WHO) Expert Committee on the Diagnosis and Classification of Diabetes Mellitus, has just this year, proposed changes to the previous National Diabetes Data group (NDDG) (1979)/ WHO (1980) classification.[6]

In the new classification, the terms insulin-dependent diabetes mellitus and non-insulin dependent diabetes mellitus and their acronyms IDDM and NIDDM have been eliminated. The terms Type 1 and Type 2 diabetes are retained with arabic numerals being used rather than roman numerals. The class named Type 2 diabetes includes the most prevalent form of diabetes which results from resistance with an insulin secretory defect.[6]

The current classification is aetiologically based as follows:[6]

1. Type 1 diabetes (Beta cell destruction usually leading to absolute insulin deficiency)

    A. Immune mediated.

    B. Idiopathic.

2. Type 2 diabetes (May range from predominantly insulin resistance with relative insulin deficiency to a predominantly secretory defect with insulin resistance.)

3. Other specific types.

A. Genetic defects of beta-cell function.

B. Genetic defects in insulin action.

C. Diseases of the exocrine pancreas.

D. Endocrinopathies.

E. Drug or chemical induced.

F. Infections.

G. Uncommon forms of immune mediated diabetes.

H. Other genetic syndromes sometimes associated with diabetes.

4. Gestational diabetes mellitus (GDM)

Patients with any form of diabetes may require insulin treatment at some stage of their disease. Such use of insulin does not, of itself, classify the patient.[6]

2.3. Prevalence

Diabetes Mellitus is the most common metabolic disease world-wide and, in terms of mortality and morbidity, ranks third after ischaemic heart disease and cancer. It is a disease that has significant implications for those affected with it, as well as the broader society.[4]

The prevalence of diabetes mellitus in adults in South Africa is 4% for Whites, 5-8% for Blacks (Of African origin) and 13% for Indians (Of Indian descent). South African Indians have the fifth highest incidence of NIDDM in the world. It is estimated that there are 1,4 million undiagnosed diabetics in this country. [7]

2.4. Determinants and Risk Factors of NIDDM

NIDDM results from the interaction of genetic and environmental factors. (Genetic susceptibility appears to be a prerequisite for the development of NIDDM, but the mode of inheritance is uncertain. [8])

The earliest convincing evidence that familial aggregation of NIDDM was the result of genetic determinants arose from studies of twins. Concordance rates for NIDDM in identical twins, range from about 50% to 90%. This frequency is much greater than among non-identical twins, siblings or other first degree relatives. Although twin studies indicate that there is genetic susceptibility to NIDDM, they provide no information about whether the disorder is caused by one or many genes or about its mode of inheritance.[8]

The occurrence of NIDDM within a population is also related to demographic and environmental characteristics such as age, the degree of obesity, physical activity, dietary habits and degree of modernisation. Even the intra-uterine environment may alter the rate of development of NIDDM.[8]

In a study reported in 1968 by O' Sullivan and Mahan, it was demonstrated that Gestational Diabetes has effects on the offspring and is also a risk factor for the subsequent development of NIDDM in the mother.[9] A prospective study of gestational diabetes among black women, in the USA, showed that over a twenty year follow up period, about fifty percent of women with abnormal glucose tolerance during pregnancy, will develop diabetes, compared with fewer than ten percent with normal glucose tolerance in pregnancy. [9]

2.4.1 Obesity

" The nature of the inherited defect has not yet been elucidated but current evidence suggests that the islet cells are unable to respond completely to the stimulus of a raised blood glucose, perhaps due to an impoverishment of receptors on the islet cell surface." [10] The factor most likely to precipitate the onset of diabetes in those who inherit this weakness, is obesity. Overeating, particularly of carbohydrate foods, leads to increased demands for insulin, and obesity causes resistance in the peripheral tissues to the action of insulin. It is well established that obesity is more common in type 2 diabetes than in controls. In families prone to diabetes, the disorder appears most frequently in those who are overweight.[10] In the light of these findings, weight loss for patients with diabetes mellitus is an important part of management.

2.4.2 Physical Activity

There is evidence that physical activity influences glucose metabolism and is thus important in the primary prevention of NIDDM.[11,12] Plasma glucose and insulin levels during glucose tolerance tests in marathon runners, are lower than those of untrained subjects of similar weight. [13] " This suggests that training or physical fitness increases insulin sensitivity. Conversely, profound physical inactivity e.g. bedrest, is associated with the development of abnormal glucose tolerance and high insulin levels, suggesting that insulin resistance is promoted by inactivity." [14] Yamanouchi et al[15] conducted a study to evaluate the effects of walking combined with diet

therapy on insulin sensitivity in obese NIDDM patients. Subjects were divided into 2 groups: one group was managed by diet alone (D), and the other group managed with diet and exercise (DE). The exercise entailed walking at least 10,000 steps per day on a flat field. While body weight in both groups decreased significantly during the study, the amount of body weight reduction in the group on diet and exercise was greater. After training, the metabolic clearance rate of glucose in the group on diet alone, did not increase significantly, but metabolic clearance rate increased significantly in the group on diet and exercise. The authors thus concluded that walking, which can be safely performed and easily incorporated into daily life, can be recommended as an adjunct therapy to diet treatment in obese NIDDM patients, not only for body weight reduction, but also for improvement of insulin sensitivity.[15]

1.3 Other risk factors

According to Medalie et al.,[16] who studied the development of Diabetes Mellitus in 8688 males in Israel in the early 1970's, the most significant factors associated with the development of diabetes were obesity and peripheral vascular disease. (Other significant factors associated with diabetes were age, raised levels of cholesterol, raised blood pressure, uric acid and low levels of education. (In Kin-Hu, Kinmen,[17] a community based survey was carried out to investigate potential risk factors of NIDDM. A total of 3236 people completed both questionnaire and venipuncture. Sex, ages, education levels, family history, obesity, hypertension, triglyceride, cholesterol levels, and usage of diuretics, were found to significantly correlate with the presence of diabetes.)

In addition to body mass, waist / hip ratio was an independent risk factor. HDL cholesterol was found to be an independent protective factor. A previous history of hypertension was a stronger predictor of diabetes than current hypertension.

2.5. Complications of Diabetes Mellitus

(" The primary prevention of diabetes is a desirable goal, but the prevention of the disease's numerous complications, remains the corner-stone of most diabetes prevention and control programmes. "[18])

NIDDM is an important contributor to premature vascular disease, blindness, renal failure and lower limb amputation. According to Tunbridge, as stated by Dornhost, morbidity and mortality from NIDDM is under-reported as NIDDM is frequently undiagnosed, the diagnosis often being excluded from death certificates and hospital discharge summaries.[19] It is well recognised that diabetics have a three time greater mortality rate compared to non-diabetics, with cardiovascular causes being four and a half times greater in women and two and a half times greater in men, as established in the Framingham study.[20] In NIDDM, although micro-vascular complications do occur, cardiovascular complications predominate. In contrast, micro vascular complications are more common in IDDM. In the average diabetic patient, after twenty years of diabetes, the prevalence of complications is high, with approximately seventy percent having retinopathy, fifty percent neuropathy, forty percent nephropathy, twenty percent heart failure and fifteen percent gangrene.[7]

In late 1983 the American Diabetes Association (ADA), developed a clinical education programme (CEP) for practitioners. The topic was Type 2 diabetes (NIDDM). Included in the programme was a major section about prevention and treatment of complications.[21] As an adjunct to this programme, an evaluation component was implemented to follow the participants' delivery of care after the CEP and to compare data collected before the programme. The study's overwhelming finding was the suggestion that primary care providers were delivering inadequate levels of care for the preventable complications of diabetes. More significant however, was the study's conclusion, that these participating practitioners, were willing to change their practice habits once peer-derived protocols were clearly outlined and demonstrated. [22] In the area of Hoogeveen, in the Netherlands,[23] 19 general practitioners (G.P's) examined their patients with NIDDM, including those under specialist care. The aim was to assess the prevalence of long term complications. A detailed protocol was used and the G.P.'s were trained in the diagnostic procedures. Complications were either already known from the records or newly discovered during screening. In a population of 41940, 14,5/1000 patients with diabetes were identified, 12/1000 NIDDM and 2,5/ 1000 IDDM. Signs and symptoms of late complications were found in many patients: retinopathy (14%), nephropathy (57%), neuropathy (68%) and macroangiopathy (53%). The systemic screening revealed a high number of unknown cases.

2.5.1 Cardiovascular Complications

Atherosclerosis, particularly coronary artery disease (CAD), remains the most important cause of morbidity and mortality in patients with NIDDM in westernised populations, accounting for 50-70% of deaths overall. NIDDM is an important risk factor for CAD. Many other risk factors for CAD, especially an increased prevalence of hypertension, hyperlipidaemia and obesity, are frequently clustered in individuals with diabetes. These risk factors are additive and should therefore be assessed and treated in all patients with NIDDM.[25] Raal et al undertook a study at the diabetes clinic at the Johannesburg hospital, two decades after a previous study there had shown an unacceptably high prevalence of obesity and hyperlipidaemia.[26] The findings of this study highlighted the fact that the clinic's role was largely confined to the control of hyperglycaemia. Important risk factors for CAD, such as dyslipidaemia, obesity, smoking and their serious sequelae continue to be ignored.

2.5.2 Retinopathy

The ADA guidelines for diabetic care include annual eye examinations. A study of eye care for people with diabetes by Brechner et al reported that 'of all adults with diagnosed diabetes in the United States, only 49% had a dilated eye examination in the past year.'[27] Using logistic regression analysis, they found that the probability of a dilated eye examination among people with NIDDM increased with older age, higher socio-economic status and having attended a diabetic education class. No relationship was found between having a dilated eye

examination and race, duration of diabetes, or frequency of physician visits for diabetes or health insurance.

A study conducted by Levitt et al at the community health centres in Cape Town, South Africa, revealed a rarity of recorded eye examinations.[28] The study was an external audit of record reviews of diabetic patients attending these centres. Three hundred and eighty records were reviewed. During 1991 only twelve of these patients (3,2 %) had their visual acuity tested and their fundi examined. The study revealed care to be routinized and reactive, leading the authors to conclude that examination for treatable complications was inadequate. Because of the severity of the complications of diabetes, quality of care is of paramount importance.

2.6. Adequacy of Care

Currently care for patients with diabetes in South Africa, is available at hospital clinics, community health centres and in the private practices of generalists and specialists. There is a lack of information on quality of care in general practice in South Africa, but studies in the United States and Britain have provided evidence of inadequate care in these countries.[29,30] In Denver, USA, Payne et al, as part of a programme to reduce the complications of diabetes in the Denver Department of Health and hospital patient population, conducted a study to determine how frequently preventive care (e.g. fundoscopic examinations, referral to ophthalmologists, foot examinations and assessment of cardiovascular risk factors) was

provided to diabetic patients.[31] Despite frequent visits to primary care clinics, most diabetics did not have a record of care designed to detect complications of diabetes. Furthermore, referral services for detection and treatment of these complications were infrequently used. There was also no uniform method of documenting care that would allow another provider to rapidly ascertain the status of preventive care in a particular patient. The study led the authors to conclude that simply increasing the frequency of visits is not an efficient method of increasing preventive care. Instead, programmes to increase practitioner awareness of appropriate preventive care, chart or computer based reminders, and improved accessibility of referral care was needed.

In 1988, a survey was conducted for the Pennsylvania Diabetes Academy (USA).[32] A total of 610 physicians completed the full survey. The physicians were asked various questions about continuing care patterns for their patients with IDDM and NIDDM. The results suggest the care of patients with diabetes by primary care physicians (PCP) in Pennsylvania, varied significantly in many areas from the standards recommended by the ADA. All physicians reported patient self- monitoring of blood glucose (SMBG) and measurement of glycosylated haemoglobin, considerably less than the recommended standards. Office or laboratory blood glucose monitoring was performed frequently and continued to be a principal of maintaining diabetic control by all PCP's. Routine referrals to ophthalmologists also appeared to be less common than recommended. Virtually all physicians reported examination of the feet, although the examinations were infrequent for many. Reported visit frequency, patient

education and routine measurement of weight and blood pressure, did not differ markedly from the recommended standards.

Hiss et al compared diabetes care and education, at the community level in 1981 and 1991, in order to record progress achieved in the decade of the 1980's, and to determine if there is a gap that must be closed to reach diabetes related objectives for the year 2000.[33] A summary of the changes in diabetes care and education, at community level, between 1980 and 1990 showed a modest but not impressive improvement. Glucose monitoring by the patient, had become standard practice, at least for patients taking insulin. Insulin administration practices had greatly improved. Inclusion of exercise in overall management of people with diabetes was much more common, hypertension was more aggressively controlled and smoking rates for diabetic patients had further declined. " On the negative side, the percentage of NIDDM patients who have received diabetes education has declined, frequency of office visits to treating physician is less and several important categories of care and care outcomes, for which improvement over the 1981 status were clearly desirable, did not change." The most important of the latter, was the apparent lack of change in metabolic control as assessed by glycated haemoglobin levels. Other disappointments included no change or deterioration in foot care practices, less than desired improvement in ophthalmology referrals and the continuing problems patients encounter in understanding and following a diet or receiving guidelines about this supposed mainstay of diabetic management.

2.7 Models of Diabetic Care

Diabetes is increasing in prevalence, but there is more that can be done to prevent the development of serious complications. To cope effectively with the increasing number of patients with diabetes and to ensure that the treatable complications of their disease are identified early, diabetes care in general practice needs to be well organised.

Successful models for care have been described (Home and Walford-U.K.-1984)[30]

1) A group practice organises its own clinic day with support personnel in attendance.

2) In another model general practitioner and hospital clinic form a collaborative organisation, with integrated records and shared resources. Patients see their G.P's most of the time and attend the hospital clinic for assessment periodically. Computerised data systems and electronic mail can enhance the efficiency of such an organisation.

According to McWhinney for successful management of patients with diabetes, a practice requires:[34]

-a patient register,

-a recall system,

-well designed records,

- accessibility to the laboratory and

-the support of a dietitian and a chiropodist.

It is proposed by Copeman that optimal care for patients with diabetes requires the review of many aspects of patient behaviour and a number of regular clinical and biochemical examinatons.[35] " There are difficulties in ensuring this optimal care: patients may forget to

return for review, the general practitioner may find it difficult to remember to perform all the necessary reviews and examination since he or she may see only a few patients with diabetes each week. Often, other more pressing clinical problems have to be dealt with on the same consultation. The answer to these difficulties lies in the establishment of a patient register with a recall system and the use of a check list or a protocol in each patient's record. Setting up and running the register and recall system manually, requires only a small amount of time and effort. But if a computer is available it can be used and can also generate reca techniques, measure visual acuities, test blood and urine for glucose, measure weight and blood pressure. With some training, they can also provide dietary and exercise counselling.

2.8 Audit

Medical audit is a study of some part of the structure, process and outcome of medical care, carried out by those personally engaged in the activity concerned, to measure whether set objectives have been attained and thus assess the quality of care delivered.[36] This is internal audit as opposed to external audit. Quality describes the goodness of our care.[36] Lawrence quotes Black, who identifies four dimensions of quality viz. effectiveness, equity, humanity and efficiency. This emphasizes not only the medical perspective concerned with clinical effectiveness, but also the patients' perception of the care they receive.[36]

" 'Effectiveness' is usually defined as the extent to which an activity achieves its objectives. It follows, therefore, that the effectiveness of a local diabetes service cannot be measured without a clear idea of what it is setting out to achieve." [37]

In 1983 the Royal College of General Practitioners launched its Quality initiative with the following aims:[37]

1. Each general practitioner should describe his or her current work and should be able to say what services his or her practice provides for the patients.

2. Each general practitioner should define specific objectives for the care of his or her patients and should monitor the extent to which these objectives are met.

One of the central proposals in the British Government's 1989 White Paper on reform of the National Health Service was that all doctors should participate in regular and systematic audit.[37] The College and Government gave several reasons for encouraging audit:

- the development of professional education and self- regulation,
- improvement of the quality of patient care,
- increasing accountability,
- improvement of motivation and teamwork,
- aiding the assessment of needs and
- as a stimulus to research.

" It would probably be agreed upon internationally that the main aims of diabetic care, are to

improve and maintain the quality of life.[38] Williams has suggested some objectives by which these aims might be achieved:

1) To identify all those who have diabetes.

2) To involve all those identified in a planned programme of care.

3) To ensure all who are involved in a programme of care have access to an education programme about diabetes.

4) To eliminate emergency hospital admissions for hypo- and hyperglycaemic coma.

5) To eliminate blindness and reduce visual impairment resulting from diabetic retinopathy.

6) To reduce diabetic foot ulceration and limb amputation.

7) To identify diabetic nephropathy in its early stages and reduce the incidence of end-stage renal failure in people with diabetes.

8) To reduce premature mortality due to macrovascular complications.

9) To eliminate foetal wastage in diabetic pregnancy.

10) To eliminate congenital malformations in the diabetic offspring of diabetic mothers.

The assessment of quality of care must be accompanied by efforts to improve the provision of that care, and procedures to ensure that good quality is maintained.

1) Audit of diabetic care in general practice

General Practitioners are becoming increasingly aware of the need for audit, especially in the care of patients with chronic conditions such as diabetes, who are also cared for at hospital outpatient clinics. When compared with hospital clinics, audits on the care of patients with diabetes in general practice in the United Kingdom, have shown inadequate routine follow up, inadequate surveillance of complications and poor blood glucose control.[39,40]

A study on the management of diabetes in general practice in New Zealand (J.Tracey et. al.1988) showed a good standard of care for patients with NIDDM.[41] Blood sugar control as measured by fructosamine was satisfactory. Patients had regular checks by their general practitioner with good attention being paid to diet, blood pressure, weight and retinal changes. However, poor attention was paid to foot care and screening for renal complications. They suggested that the keeping of a register of patients with NIDDM and scheduling patients for routine six monthly check ups, could improve the standard of care without increasing consultation time.

A group general practice in Bristol (UK) , developed a protocol for the care of the diabetic patients in the practice which was based on an audit conducted in 1983.[42] This audit of the 125 known diabetic patients concluded, that all their diabetic patients needed to be identified. Furthermore, there was a need to provide a routine format for regular history taking and examination, develop a recall system for those patients who missed their regular examination, and to improve the knowledge and motivation of the doctors and patients. A second audit

conducted in 1990, reports that many of the standards set were not achieved. The original protocol had been successful in changing the general process of care in the practice but had been unsuccessful in achieving the standards set for diabetes care. Discussions within the practice had resulted in suggestions which included, an increased co-ordination of the use of dieticians, practice nurses and educational material, particularly for patients with newly diagnosed diabetes or those who were new to the practice; a regular annual meeting of doctors and nurses to review the protocol and a simpler system of audit.

The feasibility of continuous audit of process and outcome in diabetes care has been tested in four general practices with organised diabetes care in Newcastle upon Tyne.[43] For all patients with previously diagnosed NIDDM, the data already collected according to published protocols were assembled into a single database. The time and resource costs of this exercise, together with measures of process, complications, risk factors, and metabolic outcomes were analysed. Data were successfully collected at minimal cost where structured records were completed. Recommended processes had been completed in a high percentage of patients, adverse patient outcomes were limited and metabolic output measures not unsatisfactory. The most obvious omissions from the list of outcome measures however, were assessment rates of serious hypoglycaemia (relevant to sulphonylurea and insulin treated NIDDM), hospital admissions for metabolic decompensation and assessment of peripheral neuropathy. The study had shown that with structured diabetes care, including annual review, continuing diabetes audit is both feasible and useful in general practice.

2.9 Patient satisfaction as a measurement of quality of care

Although audit is becoming an increasingly important aspect of medical care, satisfaction of both G.P.'s and patients with service provided, is a relevant but neglected aspect of audit in chronic disorders. [44]

Patient satisfaction may be considered to be one of the desired outcomes of care, even an element in health itself. An expression of satisfaction or dissatisfaction is also the patient's judgement on the quality of care in all its aspects. [45] Although satisfaction is desirable outcome in its own right, it can also influence whether a person seeks medical advice, complies with treatment and maintains a continuous relationship with a practitioner. [46]

Dissatisfaction is usually related to communication, empathy, time and accessibility and the attitudes of health care professionals towards their clients. [47]

The doctor-patient interview is a critical determinant of quality of health care. Studies have demonstrated that the expressive and communication aspects of the interview, directly influence such patient outcome parameters as satisfaction, understanding and retention of information received and compliance.[46]

Patient satisfaction is an increasingly useful measure in assessing consultations and patterns of communication (such as the success of giving information, of involving the patient in decisions about care, and of reassurance).[48]

There are two main approaches to the measurement of patient satisfaction.[49] " The 'direct' approach seeks patients views on their doctors and their personal experiences of seeking and

obtaining care. The ' indirect ' approach seeks opinions on doctors and health services in general. This produces lower levels of reported satisfaction."

"Investigations of patient satisfaction have used a range of interview and questionnaire measures, differing in level of methodological sophistication."[50] Interviews, not only give the impression of requiring less work from the respondents, but also give the flattery and positive reinforcement, which encourages the respondents to give full and detailed answers. " In an interview the respondent may do far more for the researcher than he would in a postal questionnaire, but it may feel much less like work. "[51]

Many patients spend much of their time talking to their fellows about the very subjects the researcher may wish to ask about. For many patients there is a great attraction in talking at length to an appreciative and encouraging person who does not manifest tedium or interrupt the narrative.[51] Focus group interviews are accommodating in this respect (see Focus group interviews under Method).

Problematic in determining patient satisfaction is the interpretation of response which may be coloured by the restricted knowledge patients have of service options, a low expectation of standards and a wish not to be seen as complaining. Furthermore, investigations must cope with situations where patients have only partly formed views or no views at all, because the service under review has impinged little on their consciousness. " There can also be an inability to verbalize attitudes and a differential capacity to express opinions about personal and technical aspects of treatment. "[52]

By questioning patients, one can obtain information about overall satisfaction and also about satisfaction with specific attributes of the interpersonal relationship, specific components of technical care and the outcomes of care. In doing so, however, it should be remembered, that unless special precautions are taken, patients may be reluctant to reveal their opinions for fear of alienating their medical attendants. Therefore, to add to the evidence at hand, information can also be sought about behaviours that indirectly suggest dissatisfaction. These include, in addition to complaints registered, premature termination of care, other forms of non-compliance and seeking outside care.[45]

2.10 Patient education and empowerment

There is an increasing amount of evidence to suggest that patient education for people with a chronic disease is an essential component of effective disease management.[53] Reviews of the patient education literature converge on the general finding that any education is better than none i.e. education in any form (e.g. pamphlets, films, lectures, behavioural modification techniques) is more likely to produce improved regimen compliance and physiologic outcomes than is routine care without formal patient education.[54]

In 1983 the ADA Council on Education, Health Care Delivery, and Public Health issued a resolution concerning third-party reimbursement for out-patient education and nutritional counselling.[55] The resolution asks members of the ADA to take all possible measures to make such coverage available and accessible to patients with diabetes. The policy statement argues

that " studies have shown that education and self-care programmes lead to reductions in hospital days and associated costs ". References were cited to substantiate this statement.

The Diabetes Education Study (DIABEDS), concluded that systematic education can have a demonstrable prolonged effect on patient self-care skills and behaviours and on intermediate indicators of glucose homeostasis and chronic vascular complications.[53]

A study conducted by Raz and Stain demonstrates the possible value of small-group educational meetings in the management of NIDDM patients.[56] The results suggest, that for patients with NIDDM, education may create support that helps modify behaviour and improve diabetes care and control, even if knowledge does not improve significantly.

In a prospective, cohort, controlled trial, Pieber et. al. clearly demonstrate the efficacy of the Teaching and Treatment programme for NIDDM patients in general practice.[57] A moderate weight loss in the intervention group had a significant impact on the metabolic control and a positive effect on diabetes associated risk factors. At the same time, blood glucose control improved and resulted in relevant reduction of average glycated haemoglobin.

A study conducted by the Michigan Diabetes Research and Training Centre, indicated that 'patient empowerment', is an effective approach to developing educational interventions for addressing the psychosocial aspects of living with diabetes.[58] Furthermore, that patient empowerment is conducive to improving blood glucose control.

This approach of educating about diabetes, termed patient empowerment, argues that in caring for their diabetes, patients make choices each day that affect and are affected by their

emotions, thoughts, values, goals and other psychosocial aspects of living with this chronic disease.[59] Further patient empowerment posits that the purpose of diabetes patient education is to ensure that the choices patients make every day in living with, and caring for, diabetes are informed choices.[60] The knowledge needed to make informed choices about daily diabetes care falls into two global domains.[61] The first is expertise about diabetes. This is generally provided in comprehensive diabetes patient education programmes. The second and equally important domain is psychosocial challenges and skills. Because diabetes and its treatment affect the physical, emotional, mental and spiritual domains of a patient's life, education and care should address the impact of diabetes on the totality of that person's life.[61]

3. RESEARCH QUESTIONS

1) How does the care we (my practice nurse and I) provide to our patients with NIDDM, compare with the standards of care recommended by the South African Guidelines for the management of NIDDM at primary care level.

2) How do our patients feel about the service we are providing?

3) What is the experience (attitude, feelings and knowledge) of our diabetic patients with regard to their diabetes?

4. AIM

To perform an audit of diabetic care provided by a doctor-nurse team in a private General practice in Cape Town.

5. OBJECTIVES.

1)To perform a retrospective chart audit of care provided by a doctor-nurse team in private general practice.

2) To determine patients' perceptions of the care provided and experience of their disease through a focus group discussion.

3) To determine patients knowledge, attitudes, experience and practice related to their condition through administering a questionnaire.

6. METHOD

The study was quantitative and qualitative and consisted of three sections:

6.1 Audit

Study Design: Retrospective chart study.

Records of all the patients with NIDDM (74) attending the practice between April 1994 and June 1996, were examined. This period was decided on before the study was undertaken to ensure an acceptable sample size. During this period we only had one patient, a child attending Red Cross Hospital, with IDDM. The population sample also included those patients receiving care outside of the practice as well. Three of the patients were males.

The practice nurse assisted in retrieving data from the records. Variables were recorded on a data sheet for each patient. These included blood glucose, blood pressure, urinalysis, weight, feet examinations, fundoscopy and visual acuity, glycated haemoglobin, serum creatinine and serum cholesterol.

Consultations were analysed according to examinations performed, investigations ordered and referrals made.

An assessment of interventions and appropriateness thereof was measured against criteria recommended by the South African Guidelines for the management of Diabetes Mellitus at primary health care level.[62]

6.2 Questionnaire

This focused on patients' knowledge of their disease. The questionnaire (Appendix 1) was administered to 51,4% (38) of the patients with NIDDM. A sample size of approximately half the total population was decided on. Patients were allocated a number and then drawn from a hat.

I had, either directly or telephonically, spoken to all the respondents and explained the purpose of the questionnaire. They were told how important it was for them to be well informed on the nature of their disease and that it would assist me in providing better care if I knew what it was that they needed to know. They were also informed that the questionnaire would be administered by an assistant and that she would contact them to set up an appointment. The respondents were all keen to assist, despite a few being anxious. To limit bias, the questionnaire was not administered by either myself or the practice nurse. It was administered by a qualified nursing sister who had a special interest in diabetes. The respondents did not know that she was a nurse. It was felt that the respondents might feel intimidated and be less spontaneous, had they known she was a nurse. The questionnaire was administered to the patients in their homes at a time which was convenient for them. The questions were administered in such a manner, so as to pose as little threat as possible to the patients. The purpose of the questions being asked was clearly explained. No names were attached to the answers. Patients' answers were not corrected, and they were asked to discuss any queries with the staff.

6.3 Focus Group Interview

Focus groups were originally used within communication studies to explore the effects of films and television programmes and are a popular method for assessing health education messages and examining public understandings of illness and of health behaviours. They are widely used to examine people's experiences of disease and of health services.[63]

A focus group is a group discussion that gathers together people from similar backgrounds or experiences to discuss a specific topic of interest to the researcher. The group of participants are guided by a moderator (or group facilitator) who introduces topics for discussion and helps the group to participate in a lively and natural discussion amongst themselves. [64] This method provides insight into how a group thinks about an issue, about the range of opinions and ideas, and the inconsistencies and variations that exist in a particular community in terms of beliefs, their experiences and practices. The discussion is usually 'focused' on a particular area of interest and allows the researcher to explore one or two topics in greater detail. Focus groups are also 'focused' because the participants usually share a common characteristic.[64]

The idea behind the focus group method is that group processes can help people to explore and clarify their views in ways that would be less easily accessible in a one to one interview. Group discussion is particularly appropriate when the interviewer has a series of open ended questions and wishes to encourage research participants to explore the issues of importance to them, in their own vocabulary, generating their own questions and pursuing their own priorities. When group dynamics work well, the participants work alongside the researcher,

taking the research in new and often unexpected directions.[63]

The focus group interview in this study was conducted to determine patients' feelings about the service provided. Fourteen patients were invited to participate, and ten attended. Patients were chosen according to whom we (staff and I) thought would be comfortable and uninhibited with each other.

The facilitator was someone unconnected with the practice in order to allow patients greater freedom of expression. The interview was conducted at the conference room of the Health Development Institute in Athlone. Neither I nor members of my staff were present during discussion. The members were however informed that the recording was being made for me to listen to. Consent was obtained verbally by myself and again by the facilitator

Central question for the interview: How do the patients suffering from NIDDM, who attend the practice, feel about the service provided at the practice?

Scope of Inquiry included impressions of physical environment, frequency of visits, waiting time, attitude of receptionist, methods of testing, patients' interpersonal relationship with the doctor and the nurse, access to the doctor etc.

See Interview Guide (Appendix 2)

Method of data collection: Interview was recorded on audiotape. Notes were also taken during the interview.

7. Definition of Terms

NIDDM: Refers to patients with diabetes mellitus who are on oral medication or diet only. These are patients who presented to the practice with a diagnosis of diabetes which was confirmed at the CHC's, other general practitioners and private specialists or were diagnosed at the practice. Diagnosis at the practice was based on a GTT done by a private pathologist or based on a fasting blood glucose of greater than 8 on three occasions or a random blood glucose of greater than 10 on than three occasions.

Hypertension: These are patients who presented to the practice with a diagnosis of hypertension or who were noted to have a blood pressure of greater than 140/90 on 3 occasions or more.

8. ANALYSIS

8.1 Audit

Consultations were analysed according to examinations performed, investigations ordered and referrals made.

A computer and the programme Excel was used. The assistance of a mathematician familiar with statistics and the programme was sought.

Data from the folders were entered on a spreadsheet to determine the distribution of the various variables.

Mean blood glucose and blood pressure measurements were determined, as well as percentage of patients having had visual acuity assessments, fundi and feet examinations. This also applied to investigations ordered (viz glycated haemoglobin and serum creatinine) and referrals made.

8.2 Questionnaire

Analysis was done by hand. This was part quantitative and part qualitative.

8.3 Focus Group Interview

-taped material was transcribed.

-common themes were identified and coded.

9. ETHICS

The protocol was submitted to UCT's committee for approval. Patients were guaranteed confidentiality. This was maintained by not referring to patients by their names during the discussion and by keeping responses anonymous. I was the only person who had and reassured that the nature of their participation would not affect future relationships negatively but was only intended to improve services provided at this practice. Informed consent was obtained.

10.1 Patient Profile

The records of all patients suffering from NIDDM, (74) who attended the practice between April 1994 and June 1996, were reviewed. Seventeen (22,3%) of these patients had attended the practice on one or two occasions only. Sixty-eight (92%) of the patients were older than forty years, 51 (69%) were aged between forty-one and sixty-five years. Thirty-three (45%) percent were pensioners and only 20 (27%) of the patients belonged to a medical aid scheme. Most (58) (78%) patients were of Indian or Malay descent. Seventy-one (96%) were females and 3 (4%) were males.

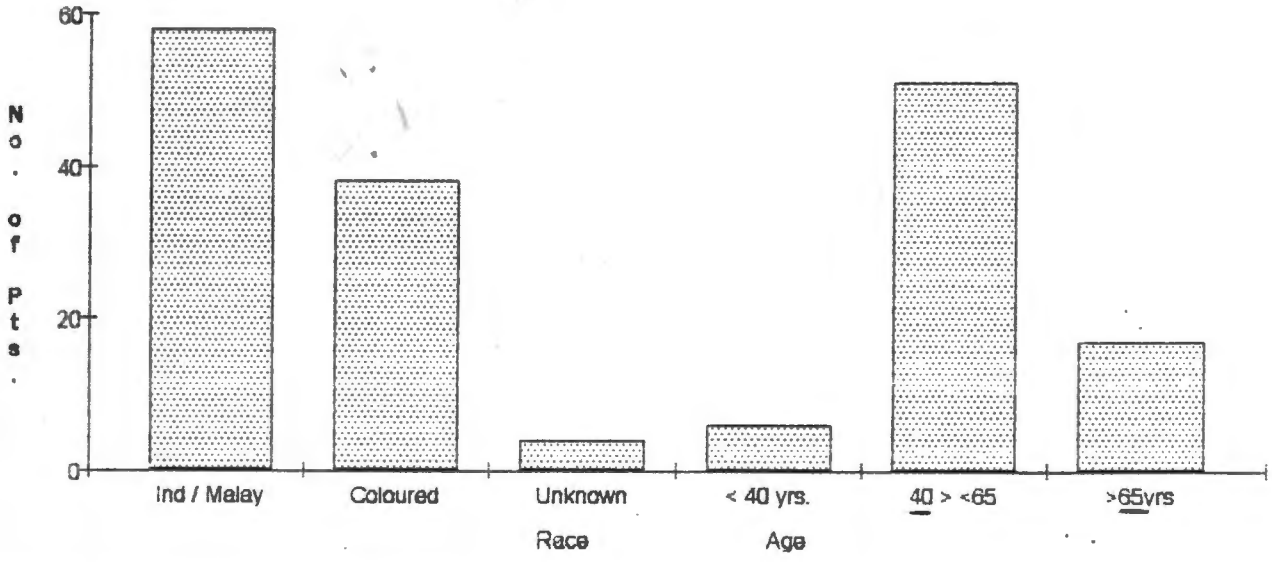

Fig. 1. Race and Age distribution.

Of these patients, 32 (43,3%) were seeing other doctors for their diabetes: 25 (34%) were receiving treatment at the Community Health Centres (Day Hospitals), 4 (5%) from private specialists, 2 (3%) at a secondary level hospital and 1 (1,3%) at a tertiary level hospital.

10.2 Consultations

Patients were seen more frequently by the practice nurse than by the doctor. At times, patients were seen by both the doctor and nurse at one visit.

Total number of visits : 438

Consultations by Doctor : 253 (57,7 % of visits)

Consultations by Nurse : 394 (89,9 % of visits)

10.3 Frequency of Visits

Attendance was based on the number of visits from the time of registration (opening of folder) with the practice or diagnosis of diabetes mellitus and on the interval between visits. All patients were requested to attend monthly or more frequently when necessary. Only 9 (12%) patients attended monthly or more frequently.

10.4 Other Diseases

Of the patients, 57 (77%) had other diseases with hypertension accounting for the majority 37 (50%), followed by ischaemic heart disease 14 (19%), arthritis 4 (5%), asthma 1 (1,3%) and hypothyroidism 1 (1,3%). None of the patients had recorded PVD or cerebrovascular disease.

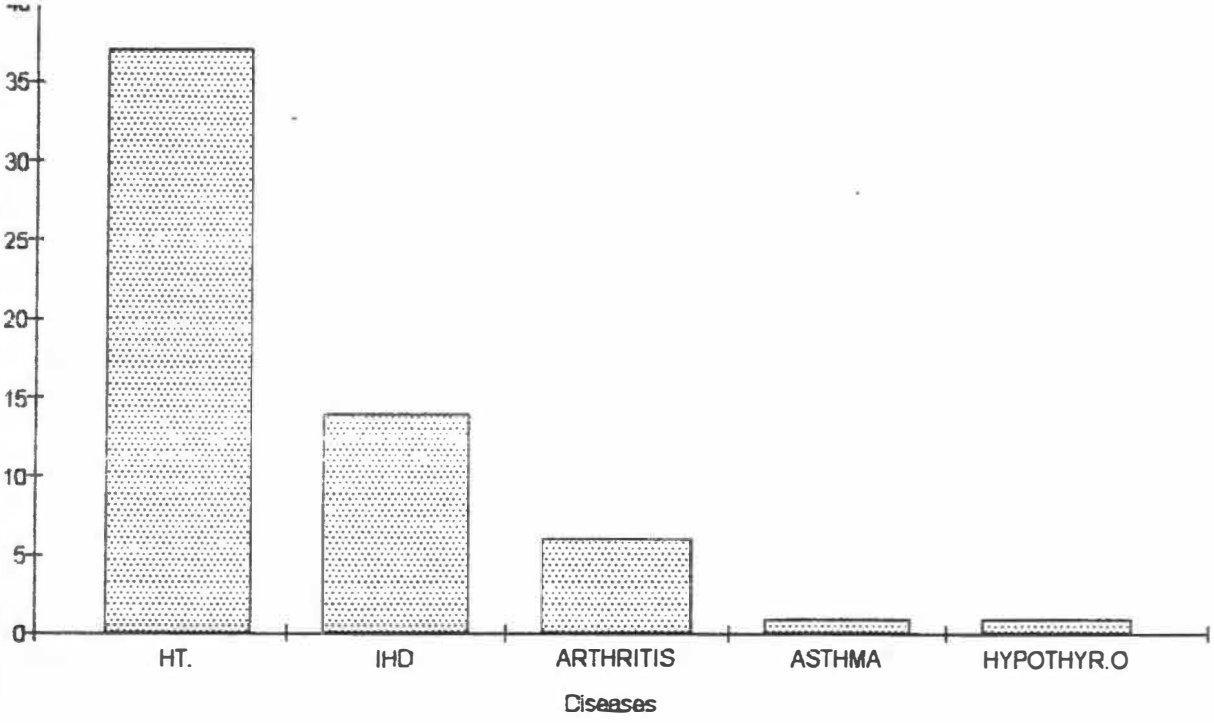

Fig. 2. Other Diseases

Key: HT : Hypertension

IHD: Ischaemic Heart Disease

HYPOTHYR : Hypothyroidism

10.5 Examination Data (Table 1)

1) Blood glucose

Blood glucose (fasting and random) was determined at 402 (92%) visits. Patients who had only attended the practice on one or two occasions, were excluded as their values were not affected by management at this practice. The mean fasting blood glucose (FBG) concentration was 9,4m.mol./l (SD3,7), and the mean random blood glucose (RBG) concentration was 12,5m.mol./l (SD4,7).

These levels were above acceptable levels set by the South African Guidelines for the management of diabetes at primary care level (FBG of 6-8 and a RBG of 8-10 m.mol/l).

2) Blood Pressure

Fifty percent (37) of patients suffered from hypertension. Blood pressure was assessed according to the three most recent readings recorded. Good control was regarded as three consecutive readings of 140/90 or less. Poor control was regarded as three consecutive readings of more than 140/90 but less than 160/95; and levels more than 160/95 was regarded as unacceptable. The South African Guidelines recommends a blood pressure of less than 140/90 for optimal control and views a blood pressure equal to and greater than 140/90 but less than 160/95 as acceptable and readings greater than 160/95 as compromising.

Seventeen patients did not qualify for assessment due to only having attended the practice on one or two occasions. Five patients, who had fluctuating blood pressure readings which did not allow for placement into any of the categories, were excluded.

Good Control	Poor Control	Unacceptable
10	3	2

3) Weight

Although it was policy to weigh all patients at initial visits, weight was recorded for only 59 (77,6%) patients at 123 (28%) visits. There was very little change in weight from visit to visit. The mean difference was a decrease of 0,08 (SD 3,9) kg.

4) Urine Examination

Urine dipstix results were recorded for 74 (100%) patients at 205 (47%) visits. Glycosuria was present in the majority of patients.viz. 79 (73%). The frequency of proteinuria was 24%(18). Proteinuria was found in 12 (32%) patients with hypertension, compared with 6 (16%) of those with normal blood pressure.

5) Ophthalmic Examinations

According to the South African Guideline s, ophthalmic examinations should be performed annually. Fundoscopy and visual acuity examinations were mainly performed in response to patients' symptoms. Referrals to ophthalmologists for ophthalmic examinations, were also mainly in response to patients' symptoms. However, no records of either the examinations or the referrals were made.

6) Foot Examinations

Although it has been policy to examine patients' feet at all initial visits, no records of foot examinations were made, as we tend to write down abnormal findings only. South African Guidelines recommends that patients' feet be examined at all visits.

Table 1. Findings recorded against standards recommended by the South African Guidelines.

Standards of Process	No. Patients	Result No.	%	Standard Achieved Yes/No
All patients should have their urine examined	74	74	100%	Yes
All patients (100%) should have their blood blood glucose tested.	74	74	100%	Yes
All patients (100%) should have their weight recorded.	74	58	79%	No
All patients (100%) with proteinuria should have a serum creatinine measured.	18	2	11%	No
All patients should have a glycated Hb. requested annually.	74	11	14%	No
Serum cholesterol should be determined in all patients.	74	13	17,5%	No
All patients(100%) should have fundoscopy and Visual Acuity examinations.	74	None Recorded		No
All patients(100%) should have their feet examined at all visits.	74	None Recorded		Not achieved
Acceptable FBG = 6-8		Mean FBG = 10,5		No
Acceptable RBG = 8-10		Mean RBG = 14,5		No

10.6. Patient Management (Table 2)

Blood glucose was measured at 403 (92%) visits. Patients who had a blood sugar of less than 4, (random and fasting)- FBG of more than 8 and RBG of more than 10, would be expected to have some change in management. The blood sugar (fasting and random) at the majority of visits 213 (53%) was more than 8 but less than 15. Of these, a change of management was documented at 73 (34,2%) visits.. A fasting blood glucose more than 15 was recorded at 27 (6,7%) of visits and 20 (74%) of these resulted in some change of management. A random blood glucose of more than 15 was recorded at 16 (4%) visits and 12 (75%) of these resulted in some change of management. Recorded changes in management were mostly pharmacological.

Table 2. Management of Diabetes.

FBG	No Intervention	Diet/Education	Diabetic Rx change	Referral/	No. visits
m.mol./l	0			Admission	n = 403
< 4	75%	0%	25%	0%	4
>8-<15	65%	9.8%	25.7%	%0	163
> 15	22.2%	18.5%	66.6%	3.7%	27
RBG					
<4	0%	0%	0%	0%	0
>8-<15	66%	16%	14%	0%	50
>15	31.2%	25%	50%	0%	16

Fifty-four (73%) of the patients were prescribed oral medication. Of those taking medication, 39 (72%), were prescribed a sulphonylurea. The majority of these patients, 22 (56%), were on monotherapy and 17 (43,5%) took it in combination with a biguanide. Metformin was the only biguanide prescribed. It was prescribed as monotherapy to 17 (27,7%) of the patients on

medication. Of all the patients on medication, 2 (3,7%) were on maximum doses of treatment. Twenty (27%) patients were managed on diet onlywith a mean FBG of 7,1 (SD 2,1) and a mean RBG of 10,8 (SD 3,2).

Laboratory investigations were seldom requested. Although 18 (24%) patients had a recorded proteinuria, a serum creatinine was requested for only 5 (7%) of these patients. Glycosylated haemoglobin was requested in 12 (16%) of patients and a total serum cholesterol in 13 (17,5%) patients. There was only one referral to a higher level of care. There were no records of referrals to dieticians or chiropodists.

11. RESULTS OF THE QUESTIONNAIRE

11.1 Presentation of Data

The results of each question are presented individually. Each section is numbered and introduced with the question which was posed. As questions were open-ended, the responses often provided more than just quantitative information. The results are presented in both quantitative and descriptive formats. The number (No.) in the tables refers to the respondents which is expressed as a % of the total number interviewed (n= 38).

11.2 Process

Sister Karelse found all the respondents (38), 35 females and 5 males, welcoming and keen to assist, except for one, who she says, made her feel that she was intruding. There were no refusals. A few patients initially appeared anxious but relaxed later during the interview. The questions were not just posed as written in the questionnaire, but she also had to ensure they were correctly understood without introducing bias. The patients' responses were written down during the interview. She spent, on average, thirty minutes with each respondent.

11.3 What is your understanding of Diabetes?

Most of the patients' understanding of their disease is generally consistent with medical perception. The respondent's understanding of diabetes is that it is an illness related to diet, especially sugar and fatty foods and that it causes fatigue and feelings of ' just not being well.'

Their understanding of diabetes also includes a raised blood sugar, non - functioning pancreas and lack of insulin. Their perceptions of diabetes are also expressed in terms of its complications.

Patients' understanding of Diabetes

Expressed in terms of:

	No.	%
Diet	**16**	**42,0**
Complications	**8**	**21,0**
Sugar	**6**	**15,7**
Lack of Insulin	**4**	**10,5**
Fatigue	**4**	**10,5**
Pancreas	**3**	**7,8**
Chronic Illness	**2**	**5,3**
Other	**4**	**10,5**

Notable Descriptions

i) Diet

Some of the respondents who related diabetes to diet, expressed it in terms of deprivation:

" *I eat very little....now even less."*

" I cannot eat all I like to. "

" Ek voel nie lekker nie.....en somtyds is daar nie altyd die kos wat mens kan bekostig nie. "

(I don't feel well and sometimes there isn't always the food which one can afford.)

ii) Complications

Various respondents expressed their understanding of diabetes by the effects it had on their bodies, viz. tiredness, itching of the perineum, poor healing of cuts, effects on the eyes, kidneys and feet, dry mouth and gangrene.

iii) Sugar

Respondents associated diabetes with sugar being high or dangerous. One person gave a very graphic description of the dangers of sugar.

" The moment sugar enters the body ...because the pancreas is not working, it's as if a lot of ants are attacking you."

iv) Chronic Illness

." It's a chronical sickness if you don't care about your body ."

" To me it's a sickness you will never get rid of."

v) Other

Diabetes was also associated with nausea, dry mouth and loss of *" lus vir lewe ."*

One person associated diabetes with' *too much acid in the stomach'* and another, who is definitely diabetic, responded to the question with denial :

" I don't feel sick.....my blood is fine.....I'm not diabetic."

11.4 Why do you think you have the disease?

Respondents believe they have the disease because it is familial or hereditary. The disease was also seen to be related to incorrect diet, pregnancy, age, trauma and stress.

Causes of Diabetes	No.	%
Hereditary.....	**17**	**44,7**
Incorrect Diet.....	**5**	**13,0**
Pregnancy.....	**2**	**5,3**
Age.....	**1**	**2,6**
Trauma.....	**1**	**2,6**
Stress.....	**1**	**2,6**
'Don't know'.....	**5**	**13,0**

Notable Descriptions

i) Incorrect Diet

Of those who mentioned incorrect diet, most respondents mentioned sugar, one also mentioned " *eating too much bread* " as a cause.

ii) Pregnancy

Two respondents related their illness to pregnancy as follows :

" *With my third baby they found I had sugar."*

" I had sugar everytime I got pregnant."

iii) Trauma

" I put my condition down to the fall I had three years ago....broken ankle...after three months the leg was never right."

iv) Stress

" I think my husband caused it.....he is so nerve wrecking."

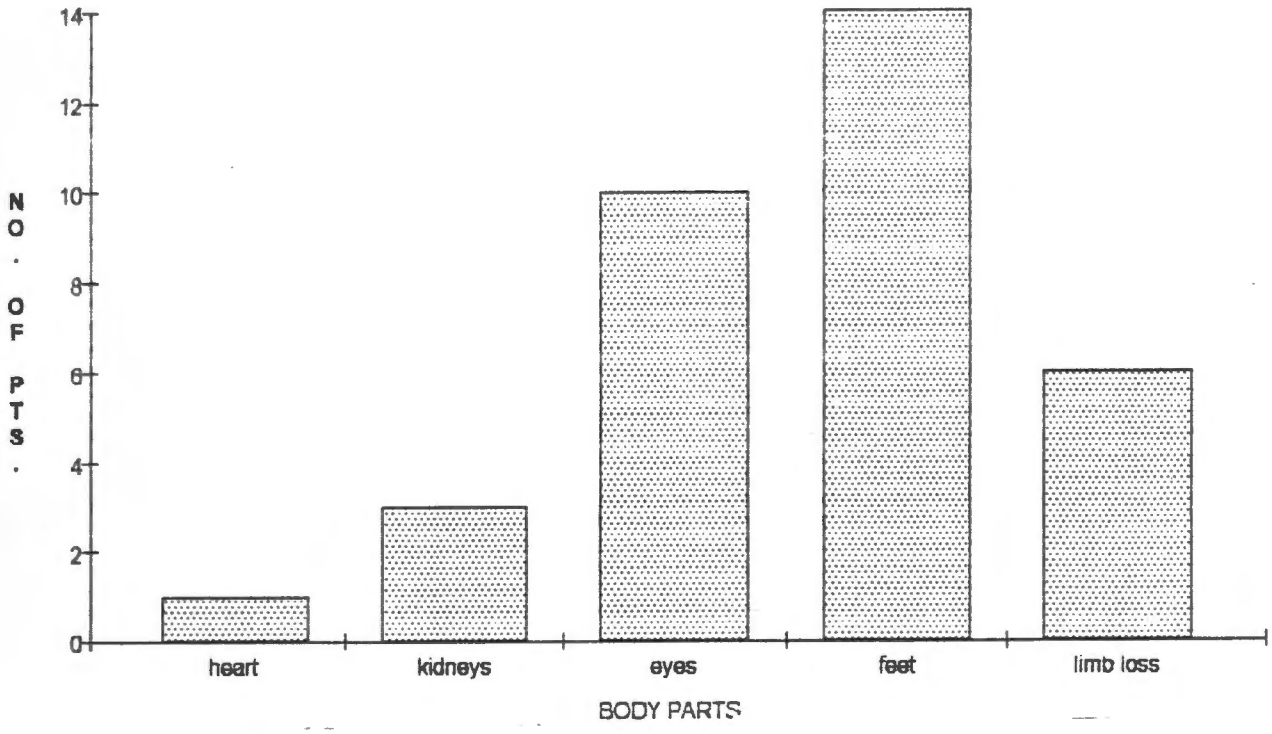

Fig. 3. Affected body parts.

One respondent mentioned the **heart, kidneys, eyes and feet.** Three respondents mentioned three of these organs, five mentioned two and twelve mentioned one.

Other organs mentioned were the **spine, stomach, brains, liver, vagina, pancreas, joints, arms, fingers and muscles.**

11.6 How are these organs affected?

i) Feet and Limbs

	No.	%
Itchy feet	**4**	**10,5**
Gangrene	**3**	**7,9**
Loss of a limb	**1**	**2,6**
Heal slowly	**1**	**2,6**
Fungal infections	**1**	**2,6**
Numb toes	**1**	**2,6**
Lame tired legs	**1**	**2,6**

The remaining respondents did not mention how the feet and limbs may be affected.

ii) Eyes

	No.	%
Blindness	**3**	**7,9**
Cataracts	**1**	**2,6**
Impaired vision	**1**	**2,6**

The remaining respondents did not mention how the eyes may be affected

iii) Private parts

	No.	%
Vaginal itch	**2**	**5,3**

11.7 How are your feet affected and what precautions should you take with them?

All the respondents discussed the current condition of their own feet, which was either, " *not affected,* " or affected as follows :

" *I only got corns .... "*

" I get fungus feet ... "

" Both big toe - nails discoloured and hard."

" My toes are sore, especially the big one on the right foot .... also ulcers on my right leg. They were going to give me a by-pass in the toe .... I'm glad I didn't take it."

" *My feet did swell.*" (Two other respondents mentioned swelling.)

" *My feet is very tired."*

" Die voete pyn onder die sole en my bene is somtyds lam."

(The soles are painful and my legs are lame at times.)

One respondent, who had not suffered from gangrene, mentioned gangrene.

11.8 What precautions do you take with your feet?

For most of the respondents this amounted to cleaning and drying the feet well and rubbing or massaging them with creams or lotions. Wearing comfortable footwear was mentioned by two (5,3%) patients, cutting the toe nails with care, by one (2,6%) and attending to cuts and sores by another (2,6%).

Other practices were :

"... *and I use wintergreen to massage my toes."*

"Mustn't bump my feet, dry well between my toes, soak my feet in fish oil and water."

"Especially between the toes must be dried out very well ... clean socks, comfortable shoes."

"I am particular with my feet ... you must keep your feet dry, cut the toe nails well - across."

" I must wear the right shoes also look after my diet."

"I wear orthopaedic shoes ... massage them, soak them ... apply a little mustard and the creams."

11.9 How may your eyes be affected?

	No.	%
Blindness	**9**	**23,6**
'Blurring of vision'....	**7**	**18,4**
Cataracts.....	**3**	**7,9**
Itchy eyes.....	**1**	**2,6**

Notable Descriptions

One (2,6%) respondent did not indicate how the eyes may be affected, but appreciated the need to have the eyes examined,

" As I said the eyes must be tested, but my eyes is fine."

Some of the other respondents attributed various other eye conditions to diabetes.

" Eyes are affected ... it feels thick and watering."

" My right eye gets red here in the corner."

" The one eye just started paining now ... my left eye is dead."

Another respondent treats her eyes.

" Die oe is sometimes alright maar hulle se ek het miskien die cataract in die linker oog en ek was die oog met borasic powder."

(Sometimes the eye is alright, but they say I might have a cataract in the left eye and I wash the eye with boracic powder.)

11.10 What are the best means to improve your blood sugar?

Judging from the responses, the majority of the respondents understood this question to mean control of blood sugar.

i) Diet

The majority of the respondents , thirty-two (84,2%) related control of their diabetes to diet. This included avoiding sugars, sweets and fatty foods and eating boiled foods. Knowing this did not necessarily mean this is what they did.

This is how some of them expressed their views on diet and control :

" I'm suppose to go on a diet but I don't have a diet sheet. I don't like too much cake or luxury line. I don't like fat. I don't take breakfast. Tonight I eat side plate food."

" Little less celebrations. "

" I know I am a diabetic. I know it is a serious sickness. I know it is what you eat. Too much sugar too much fat. I do sometimes eat forbidden foods.'

" My sugar level I can improve by eating the correct food... but I eat everything."

ii) Exercise

Four (10,5 %) respondents mentioned exercise as a means to improve their blood sugar level and another seemed to allude to it.

iii) Diet and Exercise

Four (10,5%) respondents mentioned both diet and exercise as the best means to improve their

blood sugar level.

iv) Medication

Three (7,9%) respondents view medication as also being important in controlling their diabetes. Of these, two (5,3%) mentioned medication in combination with diet.

v) Herbs

Two (5,3%) respondents who thought diet was important, also mentioned herbs.

" *In between I take a little herbs. I take bhoegoe and wilde als. Also I must concentrate on what I eat. Veggies very good."*

" I think I can use some herbs..like guava leaves...also I must eat the right food."

vi) Reduce smoking

For one (2,6%) respondent it was important to reduce smoking ,

" *Well it's basically to stick to your diet and exercise and not smoke a lot."*

11.11 If you are on medication, what is it and how does it work ?

All the respondents who are on medication know the names of the tablets they are taking. Their only understanding of how it works is that it keeps the sugar under control, with the exception of one respondent who was able to offer a better explanation,

" *It helps to increase the insulin content in the body which has an effect on the carbohydrates."*

For another respondent, medication helps when there is a lapse in diet control :

" I eat cake or cooldrink, this tablet helps and I drink a lot of water."

Some interpreted the question, " how does it work ? " in terms of its effect on them rather than the mechanism with which it acted.

" It must help me because my sugar stay mainly fine."

" Yes, Minidiab...To me I don't feel sick...so far the tablet works well."

" I am on Metformin and Glibenclamide...well I don't feel sick so it must be working alright."

11.12 Do you believe it helps?

All those respondents taking medication do believe it helps, except 1 (2,6%), who expressed uncertainty :

" I don't know if the tablets help. Look if my sugar is 18 and I take herbs it comes down to 5 - 7. I must take herbs and tablets to satisfy my mind."

For another respondent it is not only the prescribed medication which helps :

" It helps me a lot, but as I say I use the Dutch Medicine when I take luxuries. I think the tablet helps me a lot."

For one respondent the medication is seen to counteract an incorrect diet :

" Yes I do,(believe it helps) *that's why I sometimes eat wrong."*

Another however, believes it helps when the diet is managed correctly :

" Dit help ja, veral as ek die regte kosse eet."

(It helps yes, especially when I eat the correct foods.)

11.13 Do you take anything else other than what has been prescribed?

Twenty (52%) of the respondents do not take anything else other than the medication and or diet prescribed.

Alternative Treatment	No.	%
*Dutch Medicines	11	29,0%
Herbs	4	10,5%
Wilde Dagga	3	7,9%
Apple Cider Vinegar	2	5,2%
Soda Water	2	5,2%
Boegoe	1	2,6%
Lemon juice	1	2,6%
Guava Leaves	1	2,6%
Wonderwood drops	1	2,6%
Calcium root	1	2,6%

***Dutch Medicines included Als, Lewens Essence, Balsum Vita, Versterk Druppels and Wonderkroon Essence.**

11.14 When do you take your medication?

Number of patients on medication : 28

Number of patients taking a Sulphonylurea : 15

Number of patients taking a Biguanide : 6

Number of patients taking both Sulphonylurea and Biguanide : 7

Table 3. Taking of medication in relation to meals and time of day.

	Total	*S	*B
No.of patients claiming to take their medication correctly in relation to meals and time of day.	16 (57%)	10 (45%)	7 (54%)
No. of patients claiming to take their medication at the correct time of day but unknown in relation to meals.	6 (18%)	4 (15%)	2 (17%)
No. of patients claiming to take their medication at the correct time of day but incorrectly in relation to meals.	5 (18%)	3 (14%)	0
Skipped a dose because of side effects.	1 (4%)	0	1 (8%)
Took morning dose correctly but evening dose incorrectly.	1 (4%)	0	1 (8%)

*** S : Sulphonylurea**

***B : Biguanide**

11.15 What symptoms would you experience if your blood sugar dropped too low ?

Eleven (28,9%) patients responded to the above question by saying they had never experienced their blood sugar dropping too low. Two (5,2%) respondents stated they did not know. The other respondents described autonomic symptoms :

	No.	%
Dizzyness	13	34,2%
Shaky	4	10,5%
Sweating	2	5,2%
Feeling Hot	2	5,2%

Affected level of consciousness was described as :

Drowsy	1	2,6%
' Dose off'	1	2,6%
Groggy	1	2,6%
Coma	1	2,6%

11.16 What would you do if you experienced these symptoms?

The majority twenty-four (63%) of the respondents acted or would act appropriately by eating or drinking something sweet. One (2,6%) respondent mentioned going to a doctor. Seven (18,4%) respondents did not know what to do. Two (5,2%) respondents replied that they had never experienced these symptoms. One (2,6%) respondent took *'herbal stuff'* and

another respondent replied, *" I go lay down or I sit."*

11.17 What are the symptoms you would experience when your blood sugar is too high?

Respondents were not very knowledgeable about the symptoms of hyperglycaemia. Twenty six (68%) of them had no idea about the symptoms of hyperglycaemia and the remaining respondents knew of the following symptoms :

Six (16%) respondents mentioned *"drinking lots of water or fluid"*.

Two (5,6%) respondents mentioned " *passed lots of urine*" .

One (2,6%) respondent said you could go into a coma.

Other respondents either did not know or answered that they had never experienced their blood sugar being too high. Other symptoms mentioned were those suggesting fatigue, headaches and those affecting their eyes, viz :

" *My focus is not right."*

"..eyes get sugary in the corners."

" My eyes get a little weak."

11.18 What would you do in such a situation?(i.e. When blood sugar is high)

When asked what they would do if they suspected their blood sugar was high, only six (16%) of the respondents said they would seek medical help. Five (13%) respondents would rely on their diet to correct their blood sugar, one (2,6%) believed in exercise as well and three

(7 ,9%) relied on their medication.

" If you watch your diet you okay."

" I behave myself .... I diet strictly and exercise and there we are back to normal."

" When that happens I would drink a lot of water and double my sugar tablets."

Ten (26%) respondents did not know what they would do in such a situation.

Eight (21%) respondents believed they required rest.

" Then I just relax for the day."

" I drink a lot of water and rest."

" I take suncodin tablet and lie down."

There were those who also relied on alternative treatment.

" I start drinking the bitter stuff."

" I take the herbal stuff and go lie down."

" I cut back on my eating and take dutch medicines, it really works."

11.19 What infections are you more likely to develop with diabetes?

Thirteen (34%) of the respondents were familiar with a vaginal infection.

Nine (23,6%) respondents associated their illness with symptoms of a urinary tract infection.

" I got burning when I passed water."

" Could be a bladder infection."

" I get infection in my kidney and bladder."

" I've noticed that the wee-wee burns."

It was also expressed in terms of a symptom not experienced.

" I never get any infections. I havn't been through that yet. My water is okay, it dosn't burn or itch."

Skin infections were expressed as sores or pimples by five (13%) respondents.

" I've heard people say you can get pimples and cuts that take a long time to heal."

Infections of the toes and feet	**2**	**5,2%**
Ear infection	**1**	**2,6%**
Dental abscess	**1**	**2,6%**

None of the respondents mentioned lung infections.

12. RESULTS OF THE FOCUS GROUP DISCUSSION

12.1 Context

The Focus Group was held at the Health and Development Institute in Athlone at 7.00 pm. I chose a venue other than my rooms, in an attempt to avoid bias. The venue was also central and convenient for most members to attend. Transport was arranged for those who required it. I was not present during the discussion but met with the group afterwards to serve tea and eatables. The discussion was held in the conference room. Seating was arranged around a circular table so that everyone faced each other. Dr. Rachel Jewkes facilitated the group discussion and Sheila Ntshona took notes.

12.2 The Facilitator and Note-taker

Dr. Rachel Jewkes is a medical doctor, experienced in qualitative research, working for the Medical Research Council. She had read my protocol and had guided me in developing the interview guide for the focus group. Sheila Ntshona is a qualified nursing sister who has a special interest in Community Geriatrics and has been involved in conducting a qualitative study.

12.3 The Group Members

Fourteen patients were invited and ten attended. A few members had indicated that the time of day might be inconvenient. One of the members was a teacher, one a minister in the church and another self-employed as a hawker. Of the remaining seven, four were pensioners and three were housewives. They were aged between twenty-three and eighty-six. All except for the minister, were or had been married. The members were not known to each other, except for some who had met in my rooms. Five of the members had associated hypertension and five of the members had a family history of diabetes. The duration of their diabetes ranged from eight months to twenty-five years.

12.4 Process

According to the note-taker, the atmosphere was a relaxed one and the participants became more relaxed as the discussion progressed. She did however, feel that the discussion tended to be dominated by one or two members. My impression on listening to the tape-recording was that two members did tend to dominate the group, but that there was reasonable participation by the others. There were times when discussion amongst the participants became very animated and many people spoke at the same time. These sections were difficult to transcribe.

The dominant members were managed reasonably well by the facilitator and discussion was allowed to flow. At one stage however, several questions were posed simultaneously and

were lost to the group. At the end of the discussion, a summary which could have provided the participants with an opportunity to validate their responses, was not made. The facilitator was able to adhere to the interview guide to a great extent, but members chose to focus on aspects of greater importance to themselves.

12.5 Themes

1. Being Diabetic-----What it means.

- **a) Responses to being diabetic.**
- **b) Locus of control.**
- **c) Fears.**

2. Perceptions and Understanding of Diabetes.

- **a) Causes of Diabetes.**
- **b) Complications.**
- **c) Sources of Information.**

3. Management of Diabetes.

- **a) Diet.**
- **b) Exercise and being Weighed.**
- **c) Medication.**
- **d) Alternative Treatment.**
- **e) Tests.**

4. Diabetics and their Care-givers.

12.5.1 Being Diabetic-----What it means.

a) Responses to being Diabetic.

i) 'Shock'

Being given the diagnosis of diabetes was experienced as a ' *shock*' by some of the members.

"I've been diagnosed eleven months ago. At first it came as a shock because in my mind it was always that it was hereditary."

" ....I went to the nurse, she took my urine and everything...then I was diagnosed and I was shocked as I didn't expect it at all."

" I am a diabetic for fifteen years now and after the initial shock wore off you know, you learned to school yourself."

ii) Acceptance of change

Acceptance of being diabetic and the many changes it demands, has not been easy for most of these patients, but despite this they express a positive and encouraging attitude towards their illness.

"At the beginning I didn't accept it but now I do and am handling it quite well. My diet has changed, my way of life has changed....I've actually lost quite a lot of weight since I found out I have got diabetes and I have accepted it."

The oldest member of the group encouraged others in the group to accept their diabetes.

"I said to the doctor, one day I felt like ginger beer and on account of having diabetics I can't

and he says 'No, now and then you can treat yourself'- so ladies don't be afraid, truly don't be afraid...it's nothing to be worried because many people think, ' Aag you going to die now,' and look I've been twenty - five years with it and I don't know how long still I'm going to live because I'm eighty-six."

For others it was not easy. One member who is extremely overweight had the following to say about being diabetic :

".....so it's a battle, it's definitely a battle, but anyway we are still trying," and from another,

" *I heard it, was surprised but just had to continue in the work that I am doing. I'm trying to cope."*

b) Locus of control

For me, a very relevant aspect of this study was the doctor-patient and patient-family relationships. The doctor was portrayed as a rather authoritarian figure.

i) Doctor-patient relationship

She's very helpful and very strict also," (author's emphasis) and from another member,

" Your blood is taken and if she feels it's gone up she will reprimand you very strictly.."

When asked whether they had any difficulty in making an appointment, several members replied :

" *She instructs you to go. "*

" I want to say that Dr. Navsa or through her nursing sister always reminds you, like they know I move around a lot ' don't forget to take your tablets with you '... you are constantly reminded.....I always hear the words, ' Don't forget to take your tablets, it's important that you stick to them." The patient's tone of voice was very much that of a berated child mimicing its parent.

The doctor was also parentified in other instances.

"I tell the doctor, ' I've been naughty..I ate some chocolates, ' and the doctor said," well now and then is nothing. "

"Although I am not on a strict diet, I sometimes do, I am sometimes a bit naughty."

I found the above responses disturbing for two reasons Firstly, it gave me a sense of patients not feeling in control of their illnesses, and secondly it made me reflect on my approach to patients with diabetes, which demanded patient compliance to obtain metabolic control.

The health beliefs model states that the ability to change is related to one's perception of locus of control. According to the traditional medical model, the patient is passive and seeks help from the medical team who provides the treatment i.e. the locus of control is external. In contrast, diabetic care depends on the active participation of the patient as the treatment is mainly that of lifestyle change. This requires the patient to have an internal locus of control.[63] Many patients with a strong sense of external locus of control, may attempt to rely on techniques, and devices which will take over control from them. This is clearly inappropriate

with a disease such as Diabetes Mellitus.

ii) Patient-family relationship

Another interesting finding of this study was the patient - family relationships. These patients suffering from diabetes, found themselves being treated as children by their children and spouses.

" My daughter, whenever I am eating the wrong stuff, she will come and take it away from me and she makes me very cross when she does and she will never give it back to me. "

They resent being constantly *"watched and reminded"* , which only serves to make them *"feel guilty"* and for this reason, some members do not want their family accompanying them on their visits to the doctor.

Lacroix mentions how diabetes affects families in different ways.[66] When a child is diagnosed as a diabetic, the parents become very involved. In adulthood certain people may try to conceal their diabetes from close relatives or alternatively gain advantages as a result of the illness. He has also found that the patient's partner may often accept the condition or, in turn, assume the role of guardian, controlling and even forbidding certain things. This illness has even been blamed for couples separating.[66] This is further indication of how important it is to counsel family members of diabetics to offer support while still respecting the autonomy of the person with diabetes.

c) Fears

For some of my patients, being diabetic means living in fear and anxiety.

i) 'Suffering' and death

" *I've been diabetic for the past ten months. It worried me a lot for the simple reason my mother was a diabetic and I saw her suffering, but I suppose why she suffered, she never knew she was diabetic and only when she went into a coma you know and they rushed her to hospital and they found out she was a diabetic and you know in a few months time she died because the treatment was finished, and because of her my mind tells me its going to happen to me, so I am a little bit edgy about it.* "

ii) Pregnancy

When asked about fears in relation to having babies, the youngest member of the group answered :

"I've got a friend and she is also diabetic and she had problems when she was pregnant, so it actually worries me a lot. "

Diabetics have been found to harbour feelings of severe anxiety, guilt or embarassment which significantly inhibit their ability to cope[65]. Many patients may be crippled by overwhelming anxiety or guilt. These feelings may seriously inhibit diabetics from obtaining appropriate

support from their family or peers. Since beliefs and coping behaviour were found to be related to glycosylated haemoglobin levels,[65] it is important that these issues be recognized and addressed. It is also important to recognize the potential that we as doctors have, to reinforce feelings of anxiety or guilt.

iii) Loss of employment

The teacher who is also a widow, expressed fears of losing her job if it became known that she was diabetic.

" Now at the present moment I'm teaching and my colleagues don't even know that I am a diabetic and I don't want to tell them for the simple reason, now some people must go.....they look at the age and the diabetes and they think you can go, so I don't say anything. When there's functions, birthdays, they say come, come and I also come, come and in the back of my mind I must tell them ' Woman what are you doing ? ' but I can't, I can't tell them because I still need the money. "

The fear of losing employment because of having a chronic illness, is a very real one, and in many instances a very justified one. This particular member who expressed this fear is well known to me. Eating has always been the only coping mechanism she has known for dealing with the stresses in her life. Living with diabetes and having to hide this from her colleagues, has placed a tremendous burden on her. Asking her not to resort to the only way she knows

how to deal with this, was viewed as a death sentence being passed on her. Eating indiscriminately at school, is not only a means for dealing with her anxiety, but also serves, she believes, to hide her diagnosis.

iv) Complications

Another member expressed her concern about developing complications.

" Lately I have, especially after watching this programme on television about this young girl and she was diagnosed as diabetes, and then as she grew older she then had blood pressure and it had affected her kidneys so much that she is now waiting on a kidney transplant. After watching that and me having diabetes and blood pressure, it made me think, so I have been quite careful lately."

Another member recalls losing a friend.

"*....her leg was cut off and she passed away. "*

The youngest member expresses another concern.

"That's what worries me all the time, having your limbs cut off, and I always think, my baby is small, she is a year and a half and I think, I may be thirty and my leg is removed. What is my daughter going to think of me ?.....Things like that go through my mind a lot. "

12.5.2 Perceptions and Understanding of Diabetes

a) Causes

i) Hereditary

Diabetes is thought to be ' hereditary' by some of the participants, but others who did not have it in the family, were not so certain.

" *Look if they said it is a hereditary, my mommy died at the age of eighty - three, she wasn't a diabetic.* "

ii) Hypertension

Aside from it being hereditary, hypertension as a cause, is raised by another member.

" *I've been diagnosed eleven months ago, at first it came as a shock because in my mind it was always that it was hereditary. My mother died last year at the age of eighty - five and she was diagnosed after she was seventy years old as a diabetic, and we said, my sister and I as a trained nurse said, ' It's only because she's getting old and the organs are giving in, '....I also saw a TV programme on diabetics and a list was on the TV of what causes diabetics and on top of the list was high blood pressure, and I know because that is a family thing with us. My mother was on blood pressure treatment from the age of forty - eight and of course I was diagnosed at the same time with high blood pressure and then I realized that blood pressure caused the problem.* "

Other members express surprise at this.

iii) 'Wrong diet'

" I think the cure is your diet, I think wrong diet is the cause of lots of illnesses. "

It occurs to someone to question her perception, that the person suffering from the illness, is necessarily at fault.

" I read a lot and I am always reading about children who have diabetes.....A little boy in Seapoint View who was born with diabetes, so maybe you say to yourself, somewhere along the line you went wrong with your diet or your weight or your blood pressure, but what do you do when you are born with it or a child of seven gets diabetes. "

v) Pancreas

The pancreas is mentioned by the oldest member of the group.

" Both sides neither had it, but I think you have something in your body, the pancreas, that doesn't work, so I just said, ' Oh that little machine is dead it doesn't work, '.....you see I believe that it's something in one's body that doesn't work, is not functioning properly. Now my son-in-law, his sugar's very bad and he said, 'Ma yours is still working, whereas mine is completely dead.' "

vi) Stress

The possibility of stress as a cause for diabetes is raised.

" Is your diabetic, which very often goes together with your high blood, is it only aggravated if you do not stick to your diet or could it also be affected by other things like your work?"

There is general consensus that ' *it could be stress.* '

b) The way diabetes affects one.....' your body tells'

Most of the participants felt they could tell when their sugar was high, by the effect it had on their bodies.

" *Your body tells you exactly where you go wrong, and your focus, and I drive a lot when my hubby is in hospital, most times he's in hospital, and I have looked and I thought, ' Oh heavens and I just had an eye test last year,.'....all those little signs. You get sleepy at odd hour of the day, you feel you just want to get on that bed and to hell with the world, you want to sleep now. You get an overwhelming feeling that, Oh God! I must go and lie down now, and you can wake up at 4 o' clock in the afternoon, that's another sign. And yet when it's down, you have got all the energy in the world.* "

The effect of diabetes on the eyes was also expressed by another member.

" *My son - in - law, he's got it very bad, he can hardly see.....it affects the eyes.* "

A ' vaginal itch' was another association with diabetes.

" *How I found out was actually that my vagina also started itching and I went to doctor and that day my sugar level was seventeen."*

" *Actually when I menstruate then my vagina itches on the outside, "* an experience recalled by two other members.

There was also a perception that diabetes affects the legs and feet. One member asked:

" *I want to know whether any of you experience pain in your legs. Is that normal for diabetes? "*

Several members agree.

" *I was reading in a medical journal today and they say a very important thing in a diabetic's life is your feet. (*Another member agrees *) You must never have a bath and dry your feet half way, you must dry your feet and rub them with a cream. I've got that Ingrams cream, and you must dry your feet and rub them every morning because it stays in my mind. "*

Others agree.

" *.....because I lost a friend of mine, her leg was cut off and she passed away. "*

" That's what worries me all the time, having your limbs cut off.."

The possibility of problems with pregnancy was also mentioned.

The group was asked if their sugar ever got too low and if they knew what was happening when it did get too low.

" *Yes you know....I landed in Groote Schuur Hospital, I collapsed, heart attack.* "

They were then asked what they do when it gets too low.

" You take a sweet thing, a chocolate."

" The nursing sister warns you that if you feel dizzy you must know it's too low and you suck something sweet. "

c) Sources of Information

Aside from the doctor and nurse, the participants had other sources of information.

" *I also saw a TV programme on diabetes and a list was on the TV of what causes diabetes.."*

" .....especially after watching this programme on television about this young girl and she was diagnosed as diabetes....."

As is mentioned later, herbs features in the treatment of their illness. Where did they hear about herbs?

" *A friend of mine's got diabetes.* "

" My husband. "

Another source is, *" those who sell herbs on the parade,"* who *"tell you what's good for what."*

" Well I went to the health shop in Claremont and asked them if they had something for diabetics and they have what's called diabetic herbs. "

An unexpected source was revealed by one member.

" I was reading in a medical journal today and they say a very important thing in a diabetic's life is your feet. "

12.5.3 Management of Diabetes

a) Diet

Diet is a theme which features strongly throughout the discussion. Patients clearly appreciated the importance of dietary control.

" I've had diabetes for twenty-five years and I am strictly on diet and I attend the Day Hospital and the private doctor, but in 1983 I had heart collapsed , my sugar was very low but I survived that, that's 1983, so I stayed strictly on my diet and I attend the Day Hospital every month and they say fine, my sugar is just right, or just a little bit low or a little bit high and it doesn't worry me, no it doesn't worry me, because I go everywhere , I look after myself , because if you don't look after your own health how can you survive? That is why diet...I've got my diet sheet here,I give it to the people and I tell them,' look there's enough to eat, only you must eat the right food.' "

" I think the cause is your diet, I think a wrong diet is the cause of many illnesses. "

" Treatment of diabetes is very non-threatening, yet demands great discipline, because look

us just taking tablets, who are not on insulin. For example we are all aware of what the forbidden foods are. It just takes discipline and it can be corrected. My mother was diabetic, on tablets, but controlled the diabetes with diet."

For another, although herbs were important, diet still featured. When asked if it was necessary to stay on medication if the herbs helped, the reply was :

" It's not the herbs, it's the herbs and diet."

Despite appreciating the importance of diet and being constantly reminded by their care -givers, family and friends about this, many had extreme difficulty complying.

"... try very hard to keep my diet, but at times I just can't stop myself, it's very difficult."

.Another member states emphatically,

"I can't diet. "

When asked what was most difficult about diabetes, many members felt it was the diet.

The difficulties of dieting are related to perceptions of foods which are allowed and those which are forbidden, the number of meals required and *" not being able to help yourself."*

"...I'm very fond of cheese, now here I was told I must not have such a lot of cheese, it's not good for the other sickness, for the stomach and so on. " (She continues describing her meals. *) " Now lunch time, midday we have our meals, that's everything boiled, just chicken or fish, no red meat, no red meat at all, it's not good for any high blood pressure or diabetics. "*

" *I'm allowed only three fruits a day....."*

" *But a diabetic is supposed to have five meals hey?*" This is confirmed by another member.

She continues :

" That makes it so difficult because if you want to lie in a bit in the morning, like this morning I got up 10 o' clock and I went to the bathroom and I had my breakfast at 11 o' clock, so where do you fit the other meals in. "

Having other illnesses complicates matters.

" Well you know if you've got a gastric stomach you've got to eat, you know, you stay hungry, you must eat. "

One patient's perception of what the diet entails, makes it unacceptable.

" *For one, steamed foods are not on with me.*" (Agreed upon by many.)

Another issue which affects the ability to adhere to diet, is the work of the person.

" I'm working with fruit and vegetables everyday and I can't get rid of eating fruit the whole day, that is it's like it's on my mind the whole day. This fruit is in front of me, I'm just eating the whole day. "

Having to prepare separate meals for families, also makes it difficult managing the diet.

" It is very difficult because we are cooking for them and then you must make yours separate and that's the time that it's difficult, (some agree) *and you think just do it once and it's finished and klaar. "*

Another person felt she could not influence what was cooked, but rather what she could eat of

what was cooked.

" I'm unmarried but I have my sister and her family living with me, so I have my meals with them and I feel I don't want to be too prescriptive about what, so I select really what I eat. "

Travelling and eating out also adds to their difficulties.

" I'm often away from home too and then I find it a little difficult, being away not wanting to tell where ever I am that I am on a special diet. I select the food but it isn't that easy. "

Why don't they tell?

".....it becomes very difficult, then I would try to eat what I can, but they also try to give you their traditional dishes and then you don't want to really hurt the feelings. "

Even for those who do tell their hosts when they eat out, managing their diet is also made difficult.

" And then you get people that say, 'Don't worry about diabetes, just this one time.' "

"...only one time, don't worry about it, just have a piece. "

Some have made adaptations to help them adhere to the diet.

" I don't eat a lot but I just pick out what I must have, I stay mostly on my diet."

" I make sure that if I am going to attend any function I have my supper at 6 o' clock, I'll have a cup of tea at the function, but I won't eat."

However, several members respond to this by saying :

" That's very difficult."

b) Exercise

The importance of exercise with regard to diabetes control is expressed by several members, but not acceptable to all. All members agree that they have been told by me to exercise. Some see it as yet another trial.

"... another one I can't do... "

" not exercises "

Some showed the intention but also that good intentions may not be enough.

" She (me - the doctor) *made me join the gym."* This patient no longer attends a gym.

" I've got an exercise bike, but I hardly use it. "

The positive effect was noted by others.

" *I've noticed that when I do a lot of walking my sugar level drops ."* (Agreed upon by others.)

" Yes, walking does help."

" I also find that when you are active that day you've got all that energy, I can sit in front of the T.V. and watch until the flag goes up."

From the eighty-six year old member :

" You know at my age I do a lot of exercises. Exercise is very good for a person. It brings your weight down ."

c) Weight Loss

Just like managing diet, weight reduction proves to be difficult.

In response to the question : " Do you get weighed everytime you come up?"

(all laugh) *" Yes, that's the biggest problem! "*

" Losing weight is the worst thing in the world."

One member would rather not look at the scale nor hear about her weight, but resolves...

" today I'm going to start," (with her diet).

d) Medication

Taking medication is problematic to some members and *'part of their meals'* to others. One member tells of her husband having to take nine tablets everyday and sometimes getting so fed up that he stops taking them and ends up in hospital. Although she feels the same way about taking her tablets, there is a sense of, *" I daren't stop."* The feeling is shared by another member.

" Sometimes you get fed up with all the tablets."

While for others :

"Oh they have become part of my meals. "

" Mine's only half a tablet, I don't even feel it."

e) Alternative treatment

I had previously been unaware of the wide range of alternative treatment used by my patients. Several members used *'guava leaves,'* one mentioned *' bitters...a piece of wood'* and another *' parsley.'* Also mentioned were *herbs, garlic, soda water* and *ordinary water.*

One member is wary of the combination with medication.

" My stepfather he was a diabetic, he is a diabetic and sometime last year he went almost into a coma because his sugar level dropped because of drinking this and that and taking his medication , he landed in hospital."

Another member who takes *'diabetic herbs'* from a health shop, is uncertain about its efficacy.

" Well I don't know what is working, whether it's the diet or that both may be working."

One person admitted to adding sugar to the herbs.

Most of the alternative treatments used are safe, however they may take the focus away from lifestyle change. In view of the wide use of alternative treatment and patients' expressed difficulty in complying with prescribed diet and exercise, the use of alternative treatment, may well serve as an external locus of control. Of particular concern is the belief by one member of the focus group, that control of her diabetes may be due to the alternative form of treatment and hence there being no longer a need to take the prescribed medication. What is of even greater concern is the patient's unwillingness to discuss this with her doctor.

f) Tests

According to the group, Urinalysis is not sensitive and the finger-prick is unpleasant.

To the question - " Do you test the sugar yourself, " the answer is :

" I can't do it my dear, even if you use the tape, it doesn't give me the correct reading like if you go to the doctor."

The explanation offered,

" You know you get the tape for the urine, you can only judge on the colour, the sugar level is above ten then you only trace it on the tape."

From the one member who does home-testing on blood :

" I'm so used to it now, you can hardly feel the prick because ..."

Someone else interrupts :

" *But you do feel a bit tense."*

Another response to the pin-prick :

" I hate it, I hate it ! "

When asked to mention one thing about the way I organize my practice and the way I care for diabetics, that they could change if they could, the response was :

" I wish there was another method of taking the blood sugar."

This was echoed by everyone else.

" Oh! Yes. "

" That's one thing. My fingers are quite numb. Do something else in place of the prick. It's very sore, especially older people, you young people have flesh on your fingers."

12.5.4 Diabetics and their Care-Givers

Group members expessed positive feelings about me (the doctor) , the nursing sister and receptionist.

" She's (me, the doctor) *very, very helpful."* (several)

"She's very helpful and very strict also."

I was seen as being strict, but having the patients' interest at heart - - another parentified image.

" .... *your blood is taken and if she feels it is gone up, she will reprimand you very strictly."*

How does this member feel about being told this.

"Well I see that it's for my own good."

The member also later adds :

"... and you feel that it is good to go there because a check and a monitoring is being kept on you."

Another member's response to being checked and monitored was :

"I think it is important that your doctor actually cares and shows interest in you."

Access to me as their doctor does not appear to be a problem.

"She's always there for you, it depends entirely on how you handle it ."

According to several members, waiting hours are not too long.

"You know what days the surgery is busy, that kind of thing and what time of the day to go so you more or less juggle."

"I explained my difficulty about seeing and the nursing sister would say, come here, ask for me and I'll do you straight away and I feel they are very co-operative in that way."

The following was said about the nursing sister :

"I feel she is very competent and she also plays a role in asking you if you are sticking to your diet and careful and I think there is a very good understanding between that nursing sister and Dr Navsa."

From another member, for whom time is an important factor :

"I actually think it works excellent, you know, its so much time saving ."

Another important factor in favour of the nursing sister is that some members would prefer discussing any concerns they had with her rather than with me.

It would however, appear that my being female favoured a better relationship.

"I prefer a lady doctor, a lady doctor gives you more of a feeling of communication, you know, you seem to look at a man and you think, 'should I tell him, ' ... but she opens to you."

"She allows you to open up to her."

Some members mentioned time as a factor, especially one who attends a Community Health Centre.

"Well at the Day Hospital it's different, you get there 7 o'clock and I come out there 2 o'clock, because you have to go three places."

Another responds to this :

"I can't handle that."

12.6 Summary of Results of Focus Group Discussion.

The major finding of this focus group discussion was the difficulty relating to dietary control, despite constant 'reminders' and an appreciation of its importance. Some of the difficulties stem from unacceptable perceptions of what the diet entails, having to prepare separate meals for families and just not being able to 'help themselves'. Other important findings were; a perception of patients not feeling in control of their disease and of the locus of control as being external; doctor-patient relationships which left the author feeling parentified and portrayed as authoritarian; unhelpful patient-family relationships; patients' experience of the illness which included reactions of 'shock' to the diagnosis, anxiety and fears relating to suffering, loss of employment and the development of complications and the use of alternative treatment

13. DISCUSSION

13.1 Record Review

13.1.1 Quality of Data

Record reviews are used widely to evaluate quality of care. This retrospective approach however, has disadvantages in that not all information may have been recorded. Although record keeping in this practice has been less than satisfactory, the high percentage of visits at which blood glucose was recorded, suggests that these records are a reasonably good reflection of the care provided.

13.1.2 Demographics

The high percentage of females reflects my practice population and may be due to my being female. A number of my patients (34%) are also receiving care at the Community Health Centres (CHC). Some patients with chronic illnesses are given appointments to see the doctor at the CHC's only every six months. This, as well as the long waiting periods, as indicated by one of the members of the focus group, may explain why patients still find the need to attend a private general practitioner. This disjointed care is wasteful and could even prove dangerous if patients took the same medication from both - as there is no communication between the service providers in the private and public sectors. I feel it is imperative for some structured collaboration between private and public doctors in order to

meet the needs of the patients in a safer and more cost effective way.

It is not surprising that 78% of this practice's diabetic population belongs to the Indian-Malay group. The disease has its greatest incidence amongst this population group in South Africa and my practice is situated within close proximity to the suburbs of Rylands and Gatesville, previously regarded as ' Indian Townships'.

13.1 3 Attendance

Diabetic patients at this practice have been required to attend at least once a month or more frequently, when necessary and have usually only been issued with a month's supply of medication. The very poor attendance at the practice does not allow for the provision of optimal care, since it means patients are not taking their medication everyday and there is no regular check on control. Surgery hours, which provide services every morning but only two evenings a week, may well contribute to the poor attendance although this was not mentioned in the focus group. Although many of the patients are pensioners, most of them are dependent on their working relatives for transport. Another contributing factor may be cost and the frequency of visits required. Only 27% of the patients belong to a medical aid scheme and many of the remaining patients have often indicated to me their reluctance to attend when they do not have 'cash' available. Lack of knowledge and appreciation for the need to attend regularly may be another contributing factor. Waiting time, access to the doctor and staff relations, according to members of the focus group, does not appear to be a problem.

Patients seem to be caught between the problems of cost of private care and the inconvenience at the Community Health Centres. Some of them overcome these problems by attending the practice for regular follow up and only attending the public service to obtain their medication. Once again formal and stuctured arrangements between the public and private sector in this regard, may well facilitate matters for improved care and reduce patient load on the public sector. In terms of policy at this practice, it may also prove more practical and cost effective to have patients whose diabetes is stable attend less frequently eg. thrice monthly.

13.1.4 Associated Diseases

The high incidence of hypertension is not surprising, since this is a common association of diabetes. It may be surprising that none of the patients had recorded peripheral vascular disease (PVD), in view of the Framingham Study where there was an incidence of more than 50% of absent foot pulses in diabetic females and similar results in males. The absence of recorded PVD may well be a true reflection of no PVD in these patients, as I examine patients' feet for peripheral pulses at all initial visits and tend to record abnormal findings only. I have however not been examining for peripheral neuropathy routinely.

13.1.5 Examination Data

The mean fasting and random blood glucose levels of 10 and 14 m.mols/l respectively, are above the acceptable levels according to the South African Guidelines, which recommends a

fasting blood glucose of 6-8 m.mols/l and random blood glucose of 8-10 m.mols./l. Poor attendance, lack of knowledge, poor compliance related to diet and exercise, may all be contributing factors. Patients' attitudes and beliefs, my approach and counselling techniques (see focus group), may be other factors accounting for suboptimal care.

The absence of recorded fundoscopy, is also a reflection of poor record keeping i.e. a tendency to record abnormal findings only, as these are examined routinely at all initial visits. Testing for visual acuity however, has only been performed in response to patients' symptoms. This may be related to the fact that these examinations are time consuming. Testing for visual acuity could be delegated to the practice nurse. It is pertinent to note that the guidelines for the management of type ii diabetes mellitus at primary care level in South Africa, includes an examination of the feet at every visit and an annual examination of the eyes.

The lack of weight loss may be related to poor compliance and ineffective dietary intervention. Advice on diet and exercise has always been a strong feature of this practice. I may however, be setting unrealistic and unachievable goals for my patients and might have to find better ways of motivating them and providing them with practical hints for dealing with problems such as eating out. (see focus group) More frequent referrals to dieticians should also be considered.

13.1.6 Summary of Record Review.

Problem areas identified have been poor record keeping, especially relating to eye and foot examinations and referrals made, poor attendance by patients, inadequate weight loss and less frequent eye and foot examinations than is advised by the South African Guidelines. It was also established that a substantial number of patients attend both the private and public sector for care, necessitating the need for structured collaboration between these sectors.

13.2 Questionnaire

The purpose of the questionnaire was to determine patients' knowledge of diabetes mellitus. Judging from the responses, it would appear that many of the questions were ambiguous. Respondents may have understood the questions to be directed at their own experiences only. This would be a limitation of the study which could have been prevented had the questionnaire been piloted. The interviewer however, did indicate that she was satisfied that the patients did understand the questions correctly and that they were clear on the purpose of the interview. If this is correct, it would have to be assumed that much of the patients' knowledge of the disease was limited to their personal experiences.

Although the patients' understanding of diabetes was generally in keeping with conventional medical perceptions, their knowledge was incomplete. In-depth interviews would be necessary to obtain further knowledge of patients' understanding of the illness. As with the

focus group, understanding of the illness was predominantly in terms of dietary restrictions and complications. Further exploration of issues underlying some of the responses will be necessary during consultations, eg. there was a sense of deprivation in certain answers such as "*I cannot eat all I like to*". We need to address the issue of diet in a more positive way, focusing on what should be eaten rather than what to avoid.

Another interesting answer to this question and one which would be important to explore further, is the following : "*I don't feel sick....my blood is fine...I'm not diabetic*" Denial of a disease is not often so explicit during consultations, but may often be the underlying cause of poor compliance and disease control. Improving this patient's knowledge of diabetes without attending to the psychological barrier will not improve control and prevention of the long term complications of the disease. It should always be considered that our patients may not have progressed beyond the stage of denial in the grieving process, when they appear to be 'problematic'.

Patients' knowledge or expressed beliefs on why they have the disease was scanty. The most frequently mentioned (almost 50%) cause of the disease was hereditary or familial. It was interesting to note the belief that diabetes was due to trauma or stress. This might express the need of patients to attribute their illness to something.

Respondents were not well informed of how the disease affects their bodies and the symptoms

produced. They appeared to be particularly ignorant of the effects on their feet (one respondent mentioned gangrene) and on their eyes, less than 30% mentioned blindness and only three respondents mentioned cataracts.

When asked what was the best way to improve blood sugar, the majority (88%) of patients mentioned diet. This may be a reflection of how often diet is emphasized at the practice. In contrast only four respondents mentioned exercise, despite always being advised on both. This may reflect a culture in which exercise as a form of recreation, has never featured prominently. Patients are routinely asked about exercise at this practice and it is estimated that less than 10% of the practice population are actively engaged in any form of exercise including regular walking. This may also account for the negative attitude to exercise expressed in the focus group.

All the patients who were on medication could communicate the name of the medication and believed it worked. It is acceptable that their only appreciation of how it worked, was that it kept the sugar under control. It does however also appear that being aware of its effect has led some patients to be less cautious with their diets. This highlights the need to continuously emphasize the need for diet control and exercise to those who are on medication.

A relevant number of patients (48%) were self-treating with alternatives to what is conventionally prescribed. This would appear to contradict the belief that the medication

works or may be a shift (knowingly or unknowingly) from assuming responsibility for diet control and exercise.

Although just over 50% of patients were able to mention one or two of the autonomic symptoms of hypoglycaemia, it is disturbing that many were not aware of any symptoms, especially considering that Sulphonylureas were the most frequently prescribed oral treatment. It is also disturbing to note that although the majority of respondents (68%) appropriately respond to these symptoms by eating or drinking. Only one respondent considered seeking medical help. Respondents were even less knowledgeable about the symptoms of hyperglycaemia (60% had no knowledge of it). At the least, it would be important that patients recognise the symptoms of polyuria and polydipsia as signs of hyperglycaemia. Only 20% of respondents said they would seek medical help should they suspect their blood sugars to be too high.

Few people knew about infections associated with diabetes. Urinary tract infections, vaginal itch and skin infections were mentioned by some, the majority were not aware of any related infections.

Summary of Questionnaire

The respondents' understanding of diabetes mainly centred around the need for dietary control and the complications of the disease. Although many believed they had the disease because it was familial, a clear knowledge of risk factors was not expressed. Patients were not satisfactorily knowledgeable about the complications of diabetes. Their knowledge on foot care was limited as was their knowledge on the symptoms of hypo- and hyperglycaemia. Although patients expressed the importance of diet in the control of their disease and were well versed with the medication they were taking, they did not appear to appreciate the importance of exercise in the control of their disease.

13.3 Conclusion

Several problem areas in the primary care of patients with diabetes attending this practice have been identified in this tripartite study. Amongst these were suboptimal record keeping, poor attendance, unsatisfactory blood glucose control, inadequate weight loss and infrequent eye and foot examinations. It was also established that a substantial number of patients attend both the public and private sector for care, indicating a need for structured collaboration. Exploration of the patients' experience of the disease revealed: perceptions of patients not feeling in control of their disease and the locus of control as external, unhelpful relationships with their doctor and family members and unrecognized fears and anxieties. It was also established that patients' knowledge and understanding of their disease was limited.

14. LIMITATIONS AND BIAS

14.1 Questionnaire.

One of the major limitations of this study was the fact that the questionnaire had not been piloted. As mentioned in the discussion, had this been done, ambiguity relating to the questions could have been avoided. Another limitation was that the interviewer had not received any specific training in administering the questionnaire nor was she clearly instructed about not posing a question differently to patients or providing examples. This does lead to concern that the questions may not have been standardised for all patients.

14.2 Focus group.

The fact that I had contacted the patients intially and that they were aware that the recording of the discussion was for me to listen to, may have introduced bias to the responses. However, judging from the responses which appeared to be open and spontaneous, this would not seem so. A limitation of this study, however, was the fact that the Facilitator had not been subjected to an interview to determine any bias she may have introduced.

15. RECOMMENDATIONS

15.1 Patient Register and Recall System

A computer based register was established during the course of this study and is now in place. Records of patients with diabetes can now be identified by means of a coloured sticker. It is also recommended that appointment dates, which are changed at each visit, be entered on the computer which could then be used to generate recall letters automatically. An alternative would be a simple card index on which the appointment is entered. This will be taken out with the patient's record at each visit and refiled either alphabetically or by date of next appointment. At periodic intervals a designated member of staff should check either the computer or card and contact those who have not attended. At the same time however, patients should be educated on the importance of regular attendance and encouraged to take responsibility. Extending surgery hours to include another evening or two may have to be considered in the future. It is also recommended that patients whose diabetes is stable, be seen at thrice monthly intervals instead of monthly.

15.2 Protocol

In order to improve the effectiveness and quality of care provided at this practice, a protocol adhering to the South African Guidelines will be established and discussed with staff at regular intervals. Records of patients with diabetes should hold a health care check list which will

include examinations and tests to be done at regular visits and those which require review at six monthly and annual visits. All patients should be referred to an ophthalmologist annually. During the course of this study, patients who were unable to afford an ophthalmic assessment privately, were referred to a provincial hospital. It is also recommended that patients be referred to dieticians and podiatrists if they can afford these services.

Many of the tasks of review and examination of patients with diabetes can be delegated to a practice nurse. It has been determined in this study that patients are seen more frequently by the practice nurse than by the doctor. At present she is testing urine and blood for glucose and measuring weight and blood pressure. It is also recommended that she measures visual acuities and be taught to inspect patients' feet. Although she does provide dietary and exercise counselling, I would like her to receive further training in this field. I have discussed this with the nursing sister in charge of the Diabetic Clinic at Groote Schuur Hospital, who has recommended that the practice nurse attend their clinic for further training.

15.3 Education and Support

Education is a key part of diabetes care at all levels, not least in general practice. I feel that this practice should make better use of of quality resource material. The use of videotapes in particular, may be of greater interest to patients. Assistance from the local Diabetes Association will be sought in this regard.

The approach which I had adopted towards my patients with diabetes, viz. compliance based, has been shown to be an inappropriate conceptual structure for the practice and evaluation of diabetes education.[59] Education of our diabetic patients should move beyond just the transfer of knowledge and metabolic control. In managing our patients with diabetes, we should determine the impact of the disease on all aspects of their lives, viz. the physical, emotional, mental and spiritual dominion of their lives. It is relevant to note that in a study of individual consultations in patients with diabetes, peptic ulcer and hypertension, clear cut differences were shown in outcome according to the quality of the interviews. [65] It was noted that greater learning and improved self management occurs in those who have undergone interviews in which physicians are less dominant, do more listening than talking, enable patients to ask more questions and obtain information relevant to them. The lesson for me is to modify my interviewing behaviour to enable my patients to adopt a more active role in the interview.

Group education for people with diabetes is an effective means, not only of providing information and skills, but also of providing mutual support and allowing the sharing of experiences.[56] Members of the focus group expressed their appreciation of meeting with other patients with diabetes to share experiences. I would recommend that this practice arrange for the meeting of small groups with the aim of providing information and skills, either through discussion or video recordings, and allowing patients to discuss problems they may be having in coping with their disease. These sessions could be facilitated by myself or the practice nurse (for which I feel we require training) , or by an individual already experienced in providing

this service. Since dietary control is extremely difficult for most patients, the assistance of a dietician as a facilitator for such group education programmes, would be extremely useful.

One of the most striking implications of this study for the author has been the need for the awareness of, and a sensitivity to, patients' reactions to being diagnosed and to being diabetic. Diabetes diagnosed after the age of forty-five years is one more abrupt, concrete confrontation with mortality. Patients with onset in midlife and later, usually know that they are more imminently vulnerable to sickness, loss of function, loss of bodily parts and disability, than are their spouses, contemporaries and most younger people with diabetes.[67]

These patients are vulnerable to a decrease in self-esteem, especially if they have suffered more recent losses than positive life events. They could be prone to self-blame or to blaming others and may need help to boost their self - esteem and restore their morale.

Since heredity plays a strong role in NIDDM, many of the over forty-five year old patients know relatives who died after developing physical complications due to diabetes. This makes their fears and anxieties very real. Just as important it is for us to inform and educate our patients about the complications of diabetes, so do we doctors and nurses need to be aware of and recognise the accompanying emotions evoked by the advice and information we provide. A statement from a diabetic patient of a Swiss psychologist clearly expresses this :[65]

" *When aiming at motivating us to control our diabetic condition, some of you frighten us by evoking complications. This warning is inadequate and may have an inverse effect. With this*

in mind, some of us decide rather to take advantage of good living than to observe restrictions."

We should also be aware of, and sensitive to the fears and anxieties of our patients who are working people, especially those over the age of forty-five years. It is important to recognise and understand the risks of informing an employer of the disease viz. not getting the job, possible transfer to another department, losing a job and being considered an invalid. It is also important to recognise that statutory protection of patients with chronic illness against discrimination, on its own, is not effective. Educating the wider public about the disease and the implications for those who have it, is more likely to change attitudes. Aside from educating the non - diabetic population of our practices, we as the educators of patients with diabetes, should also teach our patients to educate others about their disease.

Some of the difficulties patients experienced with dietary control implied the need for consultation with, and counselling of, family members of patients with diabetes. Research has shown that counselling the family about diet, is more efficient and effective than counselling one individual.[67] Prescribed dishes, while keeping within standards for diabetic control, should also be appetizing and close to traditional dishes patients are accustomed to. The implications of this is that dietary changes should be negotiated with patients, eg. emphasis on meal planning with the addition of a favourite food or earning more to eat through exercise.

In order to provide further support for these patients, I believe meetings with and counselling of family members of patients with diabetes, should be an established part of protocol.

The extensive use of alternative treatment implies more than just the need for an awareness and knowledge thereof by doctors and nurses. We, the care-givers of patients with diabetes, should also provide our patients with the opportunity to discuss their ideas and beliefs about these various forms of treatment, without having to fear our responses and being made to feel guilty.

15.4 Recommendations for Adherence

" The degree to which a patient follows a doctor's advice depends not only on that patient's characteristic and circumstances, but also on how the patient experiences the doctor." [68] I strongly share this author's feelings on what this entails, viz. that: Ideally we should be seen as respectful, interested and thorough. Our behaviour and emotional responses should be consistent and reliable. We should help our patients to manage medication, meal plans and exercise over the years, even in the face of stress; give a full explanation of facts with clarification of choices and reason to hope; elicit patients' views and past experiences, with acknowledge of the patients' strengths; arrive at an interpretation of the facts congruent with that of the patient and ask about adherence in follow up visits, and trying to understand any non-compliance.

Also that we may further increase our usefulness by : explaining benefits of management in positive terms, such as feeling and functioning even better; determine patients' understanding of recommendations and explore the reasons for patients' misunderstandings and use clear neutral language. Terms such as 'eating over the meal plan' sounds better than ' cheating on the diet,' 'managing the meal plan' and 'exercise to feel well' is clearer and more neutral than ' achieving good control' and 'measuring blood glucose ' sounds less clinical than ' testing '. Many patients prefer being described as ' people who have diabetes ' and not as ' diabetics '.[68] People may have personal preferences about terminology, to which we should be sensitive.

15.5 Public / Private Collaboration.

As indicated, patients having to attend both the private and public sector are tremendously disadvantaged in terms of continuity of care. Patients inform me that with the introduction of a system at the Community Health Centres, whereby they are only allowed to see the doctor at six monthly intervals. Patients are often seen more frequently at the practice where they have easy access to the doctor. This places me in a better position to assess and affect diabetes control. However, these patients cannot afford to buy their medication at private sector prices and, therefore need to obtain their medication from the Community Health Centres and can only do so with a prescription from a doctor in the public service. Suggestions to the senior administrators in the public service from private practitioners, (via the South African Academy of Family Practitioners) for collaboration between the private doctors and the

CHC's have been met with no enthusiasm. (Ref. Dr. D. Hellenberg). I feel strongly that the system should allow for patients to attend their private practitioners and to obtain their medication from the CHC's as this will allow for better continuity of care and a safer service. Many patients are doing this anyway, without informing the doctors at the public service, for fear of being sent away. It will also save many elderly patients from having to travel long distances and spending long hours waiting to see a doctor and often (as I am told by my patients) being turned away because there are too many patients to attend to. Allowing patients to attend their private doctors will also reduce the patient load at these centres and thereby allow for the provision of improved care. The Provincial Department of Health has circulated a notice to staff at the CHC's not to dispense medication to patients coming with scripts from private practitioners.(Appendix 3) The notice implies that patients who are able to pay a private practitioners' consultation fee, should be able to afford their medication privately. This is discriminatory to say the least. I can appreciate the authorities concern that should this be allowed, the system will be open to abuse. I would therefore as a start, recommend that pensioners be allowed to attend their private practitioners and obtain their medications at the CHCs.

15.6 Re-evaluation.

It is recommended that interventions to be instituted, be evaluated with a re-audit in 3 years time.

16. RESEARCHER'S FEELINGS AND EXPERIENCE OF THIS STUDY.

The experiece of doing this study has been of great personal relevance to me. It not only dealt with diabetes as a subject, but was directly related to my practice and to patients for whom I care. The experience of exposing myself and my inadequacies in caring for patients with diabetes, has been a major development in my ongoing growth as a family practitioner. For me, an important outcome of this study, is the realization that self-evaluation on an ongoing basis is essential to the provision of adequate and effective care. More daunting however, is the challenge with which I am now faced, which is to affect change and to maintain optimum standards of care. During the course of this research, I have been critically appraising my approach to all other patients, particularly those with chronic illnesses such as hypertension and asthma, and comparing it to recommended guidelines. Much more fascinating to me and incredibly more challenging, have been my attempts to identify the psycho-social factors impacting on these illnesses and how patients with chronic illnesses affect their families. I have begun to appreciate just how complex the problem of diabetes control can be. This realization coupled with continuing self-education, can only be of benefit to my patients.

I regret that I was not personally involved in facilitating the focus group dicussion and administering the questionnaire. Developing experience in these fields must be enriching and essential for conducting qualitative research. There were also some issues arising out of the questionnaire, which I would have been quite keen to explore. The positive side to this is that issues which I feel needed to be explored, can be addressed during consultations.

Conducting and writing up this research has not only been a rewarding experience, but also a taxing one for both me and my family, since it was extremely time consuming and necessitated many sacrifices. Having to consult the literature to the extent I have had to, has been a great lesson for future self-education. More challenging for me, has been the need to systematically organize facts and thoughts and put these in writing, a process I realize very necessary even in general practice, but rarely accomplished. Although I still have much to learn in this regard, writing up this dissertation has given me a sound footing in this direction.

17. REFERENCES.

1. African National Congress. *A national health plan for South Africa.* ANC May 1994.

2. Smith J : *Health for all-A utopian.* S.A. Fam. Practice Nov. 1987: 453-55.

3. Howie J.G.R. *Research in general practice.* Chapman and Hall 1989.

4. Huddle K, et al. *Practical Diabetes Management.* Wits Diabetes Group. Johannesberg 1994

5. Foster D.W. *Diabetes Mellitus.* Ed: Isselbacher C.J. , Braunwald J. D. et al In: *Harrison's Princples of Internal Medicine.* 13th Edition. Volume 2. Mc Graw Hill, USA 1994.

6. The Expert Committee on the diagnosis and classification of diabetes mellitus. *Report of the Expert Committee on the diagnosis and classification of diabetes mellitus.* Diabetes Care 1997; 20(7):1183-97.

7. Ellis C. *Diabetes mellitus.* S. A. Fam. Prac. Oct. 1994;581-90.

8. Bennett PH., Bogardus C, et al. *Epidemiology and Natural History of NIDDM:Non-obese and Obese.* Ed. Alberti KGM, DeFronzo RA. et al. In:*International Textbook of Diabetes Mellitus.* John Wiley and Sons. England 1998.

9. O' Sullivan JB, Mahan CM. *Prospective study of 352 young patients with chemical diabetes.* New Eng. J. Med. 1968; 278:1038-41.

10. Bloom A, Ireland J.*A Colour Atlas of Diabetes.* 2nd edition. Wolffe Publishers Ltd. Holland 1992

11. Gulliford MC. *Controlling Non-insulin dependent diabetes mellitus in developing countries.* Int. J. of Epidemiology. 1995;24 (l):S53-9.

12. Bogardus C, Ravassin E. et al. *Effects of physical training and diet therapy on carbohydrate metabolism in patients with glucose intolerance and NIDDM.* Diabetes 1984;33:311-18.

13. Lohmann D, Leibold F. et al. *Diminished insulin response in highly trained athletes.* Metabolism 1978;27: 521-4.

14. Lipman RI, Praskin P. et al.*Glucose intolerance during decreased physical activity in man.* Diabetes 1972;21:101-7.

15. Yamanouchi K, Shinozaki et al.*Daily walking combined with diet therapy is a useful means for NIDDM patients, not only to reduce body weight, but also to improve insulin sensitivity.* Diabetes Care 1995;18(6):775-8.

16. Medalie. JH, Papier CM, et al.*Major factors in the development of Diabetes Mellitus in 10,000 men.* Archives of Internal Medicine. 1975;135:811.

17. Choui P, Liao MJ, Tsai T. *Associated risk factors of diabetes in Kin-Hu, Kinnen.* Diabetes Research and Clinical Practice. Dec. 31 1994; 26 (3):229-35.

18. Deeb LC, Phillips F. *Interventions among PCP's to improve care for preventable complications of diabetes.* Diabetes Care.1988; 11(3):275-80.

19. Dornhost A, Mervin PK. *Primary, secondary and tertiary prevention of NIDDM.* Postgraduate Med. J.1994; 70(826):529-35.

20. Garcia MI. McNamara PM. et al. *Morbidity and mortality in Diabetes in the Framingham population:Sixteen year follow up study.* Diabetes 1974;23:105.

21. ADA. *The Physicians guide to type 2 NIDDM: Diagnosis and treatment.* New York, American Diabetes Association 1984.

22. Mazze R, Deeb L, Palumbo PJ. *Altering physicians practice patterns - A nation wide educational experiment: Evaluation of the clinical education programme of the ADA.* Diabetes Care 1986; 9: 420-25.

23. Reenders K, DeNobel E,. *Diabetes and its longterm complications in general practice: A survey in a well defined population.* Family Prac. 1993; 10(2): 169-72.

24. Pyorala K, Laakso M, Uusitupa M. *Diabetes and Atherosclerosis: an epidemiological review.* Diabetes Metabolism Review. 1987;463-524.

25. Kannel Wb, McGee DL. *Diabetes and Cardiovascular risk factors: The Framingham Study.* Circulation 1979;59:8-13.

26. Raal FJ, Taylor D. et al. *Comprehensive management of NIDDM.* SAMJ 1996;86(8):7-13.

27. Brechner RJ, et al. *Ophthalmic examination among adults with diagnosed diabetes mellitus.* JAMA 1993; 270:1714-1718.

28. Levitt NS, Zwarenstein MF et al. *Public sector primary care of diabetes-A record review of quality of care in Cape Town.* SAMJ Aug.1996; 86 (8): 1013-17.

29. Smith CK, Taylor TR, Gordon MJ. *Community based studies of diabetes control: Programme development and preliminary analysis.* J. of Fam. Prac.Mar.1982; 14(3):459-67

30. Home P, Walford S. *Diabetes care Whose responsibility.* BMJ.1984; 289:713.

31. Payne T, Gabella B. et al. *Preventive care in diabetes mellitus: Current practice in health care system.* Diabetes Care 1989; 12 (10):745-47.

32.Jacques CHM, Jones RL, et al. *Reported practice behaviours for medical care of patients with diabetes mellitus.* Diabetes Care Aug. 1991; 14 (8): 712-7.

33. Hiss R, et al. *Community diabetes care: A 10 year perspective* Diabetes Care. Oct. 1994; 17 (10): 1121-34.

34. Mc Whinny IR. *A Textbook of Family Medicine.* Oxford Univ.Press. New York 1989.

35. Copeman RC.*A systematic approach to diabetes care.*Diabetes Care. Aug. 1990; 19(8): 1175-83.

36. Lawrence M.*What is Medical Audit?* Ed. Schofield T, Lawrence M. In:*Medical Audit in Primary health care.*: Oxford Univ. Press. New York 1993.

37. Schofield T. *The purpose of medical audit.* Ed's: Schofield T and Lawrence m. *Medical Audit in Health care.* Oxford Univ. Press. New York 1993.

38. Williams RR,. *Outcome indicators for diabetes services - What do we have and what do we need?* Community Medicine 1989 11(1): 57-64.

39. Fletcher BRG. *Looking after diabeteics in general practice: A trainee project.* J. of Royal College of Gen. Prac. 1977; 27: 85-88.

40.Hayes TM, Harries J. *Randomised controlled trial of routine hospital clinic care versus routine general practice care for type ii diabetes.* BMJ 1984, 289: 128-130.

41. Tracey J, Young B, Sayers A. *The management of diabetes in general practice.* N. Zealand Med.J. Jul. 1988; 450-53.

42. Kemple TJ and Hayter SR. *Audit of diabetes in general practice.* BMJ 1991;302: 451-3.

43. Tumbridge F, Millar J, Schofield P et al. *Diabetes care in general practice: An approach to audit of process and outcome.* British J. of Gen. Prac. July 1993; 43: 291-5.

44. Walker DJ, Griffiths ID and Leon C. *Referrals to a Rheumatology unit An evaluation of the views of patients, consultantants.*Annals of the Rheumatology diseases. 1991; 50: 926-29.

45. Donabedian A. *The quality of care: How can it be assessed.* JAMA Sept. 1988; 260 (120): 1743-48.

46. Korsch B, Gozzie E, et al. *Gaps in doctor - patient communication doctor - patient interaction and satisfaction.* Pediatrics 1968;42: 855-69.

47. Hill J, Bird HA, et al. *Survey of satisfaction with care in a Rheumatology outpatient clinic. Annals of rheumatic Diseases.* 1992; 52: 195-97.

48. Savage R, Armstrong D. *Effect of a general practitioners consulting style on patients satisfaction: a controlled study.* BMJ 1990; 301: 968-70.

49. Wilkin D, Hallam L, Doggett MA. *Measures of need and outcome for primary health care.* Oxford Unv. Press. 1993. 230-260.

50. Ley P. *Communicating with patients: improving communication, satisfaction and compliance.* Croom Halm Ltd. 1988:1-13.

51. Katefrench B. *Methodological considerations in hospital patient opinion surveys.* Int. J. of Nursing Studies.1981; 18: 7-32.

52. Mangen SP, Griffith JH. *Patient satisfaction with community psychiatric nursing: a prospective controlled study.* J. of Advanced Nursing. 1982; 7: 477-82.

53. Mazzuca SA, Moorman NH et al. *The Diabetes Education Study: A controlled trial of the effect of diabetes patient education.* Diabetes Care. Jan/Feb. 1986; 9:1

54. Mazzuca SA. *Does patient education in chronic diseases have therapeutic value. J. of Chronic Diseases.* 1982; 35: 521-29.

55. ADA. *Third Party Reimbursement of outpatient education and nutrition counselling.* Diabetes Care. 1994; 7: 505-6.

56. Raz I, Soskolne V, Stein P. *Influence of small group education session on glucose homeostasis in NIDDM.* Diabetes Care. 1988; 11 (1) : 67-71.

57. Pieber TR, Holler A et al. *Evaluation of a structured teaching and treatment programme for type ii diabetes in general practice in a rural area of Austria.* Diabetic Medicine. 1995;12(4):349-54.

58. Funnell M, Anderson RM, et al. *Empowerment: an idea whose time has come in diabetes education.* Diabetes Educ.1991; 17:37-41.

59. Anderson R, Funnell M, Barr P, et al. *Learning to empower patients.* Diabetes Care.1991; 14: 584-90.

60. Anderson R, Funnell M., Arnold MS. *Beyond compliance and glucose: educating for patient empowerment.* Ed's; Ribken H, Caldwell JA, Taylor SL. In: Diabetes . Elsevier.New York. 1991. 1285-9.

61. Anderson RM, Funnell M, Arnold MS. et al. *Patient empowerment : Results of randomised controlled trial.* Diabetes Care. July 1995; 18:7.

62. SEMDSA consensus document. *Type ii Diabetes Mellitus Clinical Guidelines at primary health care level.* SAMJ April 1997; vol 87 no. 4 (PART 3) 493-512.

63. Kitzinger J. *Introducing focus groups.* BMJ July 1995; 311: 299-302.

64. Dawson S, Manderson L. Tallo VL. *The Focus Group Manual.* UND/ WORLD BANK/ WHO. *Special programme for Research and Training in Tropical Disease.*

65. Day JL *Why should patients do what we ask them to do?* Patient Education and Counselling. 1995;26: 113-118.

66. Lacroix A. *Patients' experience with their disease: learning from the differences and sharing the common problems.* Patient Education and Counselling. 1995;26: 301-312.

67. Mc. Daniel S, Campbell TL, Seaburn D. *Family Oriented Primary Care. A Manual for Medical Providers.* Springer Verlag. New York 1989.

68. Holmes DM. *The Person and Diabetes in psychosocial context.* Diabetes Care.1986;9(2):194-206.

APPENDIX 1

DIABETES QUESTIONNAIRE

1. What is your understanding of diabetes?

2. Why do you think you have the disease?

3. Which parts of your body are mainly affected by diabetes?

4. How are they affected?

5. How are your feet affected and what precautions should you take with them?

6. How may your eyes be affected ?

7. What are the best means to improve your blood sugar level?

8. If you are on medication, what is it and how does it work?

9. Do you believe it helps?

10.Do you take anything else other than what has been prescribed to you ,for your diabetes?

11. When do you take your medication?

12. What symptoms would you experience if your blood sugar dropped too low ?

13. What would you do if you experienced these symptoms?

14.What are the symptoms you would experience when your blood sugar is too high?

15. What would you do in such a situation?

16. What infections are you more likely to develop with diabetes?.

Appendix 2

FOCUS GROUP INTERVIEW

Central Question for Interview

How do the patients suffering from NIDDM, attending the practice, feel about the service provided at the practice?

Scope of inquiry

Impressions of physical environment.

Frequency of visits.

Surgery Hours.

Waiting time.

Attitude of Receptionist.

Feeling about home-testing for blood sugar and methods of testing at surgery.

Health education - Diet
- Exercise

Treatment

Patients autonomy - How they manage their illness or how would they prefer to manage their illness?

How different providers fit together - or compare - this in terms of advice and management.

Patients interpersonal relationship with Doctor.

Patients interpersonal relationship with Nurse.

Access to Doctor.

Some Sample Questions

1. What do you think is important for a Doctor's waiting room to have?

2. What are your feelings about the practice's requirements regarding visits? (these are monthly and more frequently when medication is introduced or altered.)

or

How often do you feel your blood sugar and urine should be checked?

3. Surgery hours at your doctor's Practice is different to that of other practices (Mon - Thurs, 9.00am -12.30pm, Evenings Mon and Thurs only - 4.00pm - 6.30pm. Fri and Sat, 9.00am - 12.00 noon. Closed Public Holidays and Sundays.

How do you feel about this?

4. Many patients complain about the time that have to spend at Day Hospitals and other hospitals and in some Doctors' surgeries. How does the waiting time at this practice affect you?

5. There are many practices which do not have a Nurse in attendance. What difference, if any, do you feel the Nurse makes to the practice?

6. Are there some issues you feel more comfortable discussing with the Nurse rather than the Doctor or vice versa - if so, why?

7. What is the reaction of the Nurse and Doctor when your sugar is high or satisfactory? How does this make you feel?

8. What does it feel like having your weight checked regularly and again how do you feel about the Doctor or Nurses comments?

9. What do you do - other than what the Doctor and Nurse tells you to - when your sugar is not controlled? Do you have any remedies of your own? Do you tell your Doctor about these? Do you receive advice from anyone else other than a Doctor or Nurse?

10. Is there anything different about the way your diabetes is dealt with at this practice as

compared to the other practices or the hospitals?

11.What do other people say about the way they are treated?

12.Are you happy with the information or knowledge that you have about Diabetes?

13.Is it easy for you to understand what the Doctor and Nurse tell you about diabetes?

14.Most times you see the Nurse for regular urine and blood checks. At these times is it a problem for you to get to seeing the Doctor when you want to?

Provincial Administration: Western Cape

Department of Health

Signed by candidate

Signature Removed

File : H3/0/8/1

Enq Mr J Brink

Exten : 483-4288

Date : 25/9/96.

Signed by candidate

Signature Removed

REE PRIMARY HEALTH CARE SERVICES: PRESCRIPTIONS BY PRIVATE OCTORS

It has been brought to the attention of the Department that patients visit their private doctors, pay the normal consultation fee and are then referred to the nearest primary health care facility with a prescription in order to obtain free medication.

This procedure is against the policy of the Department and therefore not acceptable, except in cases where patients are referred by General Practitioners under contract with certain benefit/sick funds.

If a patient prefers to be treated by a private doctor, prescribed medicines will have to be obtained through the private sector.

Please ensure that the contents of this circular is brought to the attention of all staff and patients.

Signed by candidate

Signature Removed

Signed by candidate

EAD OF DEPARTMENT Signature Removed

NK75/96/et