University of Malawi
KAMUZU COLLEGE OF NURSING

A STUDY OF PSYCHOSOCIAL EXPERIENCES OF PEOPLE LIVING WITH INSULIN – DEPENDENT DIABETES MELLITUS WHO ATTEND CLINICS AT LILONGWE CENTRAL HOSPITAL

By

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(Dip.N., UCM)

A Dissertation Submitted in Partial Fulfillment of the Requirement for the Award of a Bachelor of Science in Nursing

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A Dissertation Submitted in Partial Fulfillment for Degree of a Bachelor of Science in Nursing (Health Services Management) at Kamuzu College of Nursing, Lilongwe, Malawi.

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DECLARATION

I hereby declare that this dissertation is completely a result of my own investigation. This work has not been accepted in substance for any other degree and is not being concurrently submitted in candidature for any other degree.

Candidate: .....

Signature: ..... Date: .....

Supervisor: .....

Signature: ..... Date: .....

DEDICATION

This study is dedicated to my brother, Martin who has insulin-dependent diabetes mellitus and who has lived against all odds to acnieve great success in life despite the condition.

ACKNOWLEDGEMENT

This researcher would like to express gratitude to the research supervisor, Mr. A. Simwaka for the tireless effort and guidance rendered from the time of proposal writing until the development of the research dissertation.

Another vote of thanks goes to Ms. B. Ng'ambi for assisting with the typing of this dissertation. Sincere thanks also go to management, doctors and nurses of Lilongwe Central Hospital – Outpatients Department II (OPD II) for allowing this researcher to carry out this research study there. The research participants who volunteered to participate in this study are also being thanked for having accepted to do so without which the study would not have materialized.

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LIST OF ABBREVIATIONS

AIDS – Acquired Immune Deficiency Syndrome

IDDM – Insulin Dependent Diabetes Mellitus

LCH – Lilongwe Central Hospital

MoHP – Ministry of Health and Population

NIDDM – Non Insulin Dependent Diabetes Mellitus

OPD – Out Patients Department

UK – United Kingdom

USA – United States of America

WHO – World Health Organization

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CHAPTER 1

INTRODUCTION

Diabetes mellitus is one of the chronic diseases that affect mankind. Medically defined, diabetes mellitus is a metabolic disorder resulting from inadequate or lack of insulin in the body. Insulin is a hormone produced by the pancreas and it aids in balancing blood sugar levels. The etiology of diabetes mellitus is not known but scientists attribute it to heredity and autoimmunity.

Diabetes is a serious disease and it has no cure but its course can be controlled through meal planning, regular exercises and medication,
(Kneisl and Ames, 1986). There are two major types of diabetes mellitus, type-I and type-II. Type-I is also called insulin-dependent diabetes mellitus (IDDM) because the pancreas does not produce any insulin at all. Instead, the patient injects daily doses of insulin into the body, a technique he is taught to perform. Type-II is also called non-insulin dependent diabetes mellitus (NIDDM), because the pancreas still produces insulin but the amount is improportional to the body's requirement. The patient gets tablets that aid in improving cellular uptake of glucose. Type-I is very common in young people whereas Type II is common in the elderly.

IDDM is the most delicate of the two types. Resentment, anger, denial, aggression and depression are common emotional reactions exhibited by newly diagnosed IDDM patients. The patient may perceive his self esteem as lessened or lost due to the loss of physiological control over one's body; which is likened to losing a personal asset, (Brown, 1985). Furthermore, to every person, receiving an injection is a painful experience. However, injecting oneself for life is more than the physical pain; it is a form of psychological torture and a social tragedy. There is also the associated risk of complications such as sudden hypoglycemia,

blindness, kidney failure and gangrene of the feet leading to amputation which may cause worry and fear. It is therefore necessary that those caring for IDDM patients consider the physical, psychological as well as social aspects of care.

Background

For a long time, diabetes mellitus has been regarded as a disease of the elite because of its tendency to attack people with good socio-economic status particularly those of the developed world. As reported by Jeffre, Barnes, and Martins (1995), 2% of the population in the United Kingdom (UK) are known diabetics. Of the total number of diabetics in the UK it is estimated that 575,000 people have IDDM. It is further predicted that this figure will increase by 50% by the year 2010, (Aldermann, 2000).

In the United States of America (USA), 5.8 million persons are diabetic according to statistics compiled by the American Diabetes Association, (1986). Dolan and Heitlinger (1983), cited in Kneisl and Ames (1986), estimated the world population of diabetics at 66 million with nearly half of them remaining undiagnosed.

Of late, there has been escalating numbers of diabetic persons in the developing world (WHO, 1989). Malawi has not been spared. The latest statistics that this researcher obtained were of in-patient cases compiled by the Health Information Systems Management Unit of the Ministry of Health and Population in 1996. It is estimated that a total of 190 diabetic patients were admitted to hospitals throughout the country that year. However, this is a gross under-representation of the real situation because many times cases are under-reported while others remain undiagnosed.

Diabetic patients are reviewed at special clinics. In Malawi, these clinics are conducted in all the major hospitals. At Lilongwe Central Hospital alone, at least

fifty (50) clients are seen per clinic day (every Tuesday), per week of which an estimated twenty (20) are IDDM patients. The clients are reviewed after every five weeks. It is, therefore, estimated that a total of two hundred diabetic people attend the clinic, as out-patients, every month. This has posed a challenge to health workers in that they ought to be knowledgeable about the disease if they are to provide good health services; and to advocate for community involvement in the management of the disease. Because of the above, the researcher decided to undertake the study on psychosocial experiences of people with IDDM.

Statement of the Problem.

The physical, psychological and social aspects of life are inseparable in man. However, health workers have a tendency to concentrate on the physical aspect of diabetes mellitus disregarding the psychosocial aspects associated with the condition. As such they leave out a lot to be desired by this group of people. There seems to be a gap between the strict medical definition of diabetes mellitus as a metabolic disorder, and the patient's experience of the disease as a medical but also as a social and a psychological problem. There is need to bridge this gap through research.

Purpose of the Study

The study was conducted in order to unveil the psychosocial experiences of people with insulin-dependent diabetes mellitus.

Specific Objectives of the Study

The study was conducted specifically to:

1. Determine the psychological factors associated with insulin-dependent diabetes mellitus.
2. Determine the sociological factors associated with insulin-dependent diabetes mellitus.
3. Find out if the clients have enough support systems and if they are able to utilise them.

Significance of the Study.

From the findings of this study, health workers will be able to identify the gap that exists in the care of diabetic patients and possibly explore ways of addressing that gap.

This will also help policy makers in the ministry of Health and Population as well as the in the government of Malawi as a whole to appreciate the need to modify the current policy on drug acquisition in order to make sure that insulin is readily available in hospitals. At the meantime drug acquisition is done on cash budget basis whereby the hospital decides what to buy each month depending on the available cash. As such other items may not be bought if the money is not enough.

In workplaces, management will need this information in order to develop policies for supporting the needs of insulin-dependent diabetic workers.

Families of diabetic persons will also use the findings of this study to understand the relationship between the physical illness and the psychosocial support that their relatives need. So too the community at large.

Definition of Terms

In this study, the following terms will be defined as follows:

i. **Adaptation**: Being able to cope satisfactorily with IDDM.

ii. **Clients:** Used synonymously with persons or patients to mean the diabetic people understudy.

iii. **Coping mechanism**: A strategy used to adjust or cope with effects of IDDM.

iv. **Hypoglycemia:** Low blood sugar levels below 70mg/dl.

v. **Hyperglycemia:** Increased blood sugar levels above 200mg/dl.

vi. **Psychosocial problems:** Other problems other than physical that an individual may face due to his condition. These may be economical, work related or to do with daily life.

vii. **Social support:** A psychosocial resource that includes all environmental factors that contribute to the person's well-being, (Syme and Cohen, 1985, Cited in Cresia and Parker, 1991).

CHAPTER 2

LITERATURE REVIEW

Psychosocial Aspects of Chronicity

Diabetes mellitus, just like many other chronic illnesses has an impact on the psychological and social well being of the patient. Kneisl and Ames (1986) identified psychosocial aspects of chronicity. The psychology related aspects include depression, suicidal thoughts, feelings of isolation, powerlessness due to perceived loss of body control, low self-esteem, fear of unknown (uncertainty) and worries about daily management. The social related aspects include lack of community awareness and knowledge about the disease, employment problems, difficulty disclosing the condition to others and lack of support from family/community/significant others. These factors necessitate psychosocial support in people with chronic illnesses, (Cresia and Parker, 1991).

The Plight of Diabetic People.

Diabetes mellitus is an asymptomatic and invisible disease especially when the blood sugar levels are well controlled. The patient feels different but very few people know that he has a problem. As such, diabetic people receive inadequate psychosocial support and they feel neglected, (Guthrie and Guthrie, 1982).

However, if the blood sugar levels are not well controlled, sudden episodes of hypoglycemia may ensue causing sudden death. Sometimes hyperglycemia may occur though this may not be very dangerous immediately but the diabetic person may develop major complications in the long run, (Kinson and Nattrass, 1984). According to Kneisl and Ames (1986), diabetics are twenty four times more likely to develop blindness; seventeen times more likely to develop kidney

failure; five times more likely to develop gangrene of the feet leading to amputation and two times more likely to develop vascular diseases than the general population. It is believed that these complications can be prevented through proper control of blood sugar levels. The risk of complications is the primary cause of fear and worry in this group of people. As such they need support and reassurance.

Accepting as well as coping with the condition is not easy. It requires one to change his lifestyle, especially eating habits, with the ultimate goal of maintaining a balance in blood sugar levels. Among other things, the patient is supposed to adhere to a special diet, do exercises regularly, attend clinics at intervals, have well-fitting shoes and acquire insulin, syringes and needles constantly. This makes considerable demands on the patient's energy, time and money, (Germain and Nemchik, 1988). As such, a larger percentage of the of the patients' resources is spent on managing the disease, and those with fewer economic resources are likely to face the psychosocial effects of the disease most profoundly, (Guthrie and Guthrie, 1982).

Psychosocial support is of paramount importance in diabetes care. Health personnel and significant others have a major role to play. In other countries, associations have been formed that look after the needs of diabetic people. These associations have for years, made efforts to sensitize the public on the seriousness of the disease through medical writings. However, there is still evidence of little public interest in the disease because, being an asymptomatic disease, it is wrongly perceived as relatively innocent and of concern to older and obese people only, (Kinson and Nattrass, 1987).As a result, it receives very little public attention, consideration and social support unlike other chronic diseases, (Guthrie and Guthrie, 1982).

In the Malawian setting, incidents of diabetic persons collapsing at workplaces are common because they are not given the necessary support. Health

personnel have a tremendous duty to increase public awareness on the seriousness of the disease and the need for people to get involved in its management. The role of the nurse in diabetes management include follow up of newly diagnosed patients, family assessments and teaching, attendance of clinics, community mobilization, liaison with social workers, psychologists, dieticians and other paramedical; as well as visiting workplaces and schools to discuss the needs of diabetic patients with management besides being accessible in times of stress and emergency, (Kinson and Nattrass, 1984). The role of health personnel, therefore, goes beyond assessing the physical well being of these patients when they attend clinics, but also to assess their psychological and social well being.

Studies Done on the Disease

Considerable research has been conducted on diabetes in general and insulin-dependent diabetes mellitus in particular. These studies have not only focused on the individuals who have the condition but also on their families.

Psychosocial Experiences of People with IDDM

Studies have been done which show that people with IDDM experience psychological as well as social problems due to their condition. One such study was done by Callaghan and Williams (1994) who found that diabetics regard the responsibility of maintaining a balance in blood sugar levels all the time as a burden to their psychosocial life. This was so because it requires them to exert conscious effort to control a process that is normally done automatically by the body implying that any change in the way they feel must be considered in the diabetic perspective. This finding was supported by the research findings by, Kyanga's and Barlow (1995) who found that adolescents perceive diabetes as a threat to the balance of life especially in their physical, psychological and social

well-being due to the burden of maintaining blood sugar levels. However in the same study, other adolescents viewed IDDM as a healthy lifestyle because they are provided with information on diet and exercise besides being constantly monitored by health personnel. Likewise, when Ellerton, Stewart, Ritchie and Hirth (1996) studied school- age children with IDDM they discovered that, for this group of children, the main cause of stress is the restrictions associated with the disease and not the disease itself. This implies that they regard the impact of the disease on their social well being as a burden. These findings concur with those of Miller (2000), who found that school age children with IDDM experience curiosity of wanting to know more about the disease because of the daily restrictions that they are subjected to due to their condition. These findings can be attributed to the fact that the diabetic person with good control of blood sugar levels feels normal just like any other person.

Coping with Insulin-Dependent Diabetes Mellitus

For persons with diabetes mellitus, finding a personal meaning is thought to be a positive coping mechanism. Different people adapt differently to similar situations depending on the meaning that they attach to the situation. This accounts for the variations in the adaptation levels of people with insulin-dependent diabetes mellitus.

According to a study conducted by Baker and Stern (1993), the result showed that one can only accept the responsibility of taking care of himself and complying to the diabetic regimen if he understands what it means to be diabetic. In support of this, Harnandez (1996) found that those people who accept diabetes as part of their life became experts in their diabetes control. Likewise Degazone (1995) found that one of the most common coping strategies among older African – American diabetics was to maintain control over the situation.

In another related study, Wichowski and Kubsch (1997) found that there is a significant relationship between self-perception of illness and compliance with

health care regimen in diabetic patients. Those who had positive perceptions towards the disease complied well to the regime as compared to those who had negative perceptions. However, these two researchers found that there is a difference in self-perception of illness between adults and children.

Perceptions of Diabetic Persons and their Families towards Health Services and other Support Systems.

Research has shown that, in general, diabetic persons are less satisfied with health services and other support systems available. Nyhlin (1990) conducted two separate studies on perceptions of IDDM patients towards health services. One study was conducted on a group that had complications and the other on a group that did not have complications. The findings were similar. The group that had complications perceived the health care system as not being very helpful because health personnel seemed not to show greater sensitivity to individual patients' problems. The other group expressed their fears, worries and difficulties partly caused by what they called a 'rigid streotyped' health care system meaning that the system is not responsive to change but maintains its traditional way of handling the disease as strictly medical. Nyhlin, however, observed that the problems experienced by the respondents had their roots in the organisational or policy issues of the health care system, rather than individual health care personnel. In support of these findings Wikblad (1991) found that health care teams are not meeting the patients' expectations of care. The visits to the outpatient department were found to be frustrating and unsatisfactory to the patient because they centered on laboratory results and not the patient's situation. These findings concur with those of Callaghan and Williams (1994) who found that diabetics had all sorts of expectations towards nursing care. These expectations were classified into three main categories namely person centered care, competent care and accessible care implying that they were not satisfied with the care they were given. Similarly, Germain and Nemchik (1988) found that IDDM patients' concerns about hospitalization were mostly psychosocial in nature in their study. Most of the patients desired that staff members should be

knowledgeable in the care of diabetes mellitus and they recommended change in the health care system.

A further review of literature has shown that the negative perceptions are not only felt by the patients themselves but also by their families. Furthermore, the negative feelings are not only directed towards health services but also towards other support systems, in the community. This is primarily due to fears of uncertainty and unpredictability of the condition as was discovered in a study conducted by Hatton, Canam, Thorne and Hughes (1995). In this study, some parents felt that the survival of their diabetic children depended on them alone. As a result, they were unable to trust anybody with the care of their children or to share their feelings with others and were always worried about the future of their children. Similarly, another group of parents studied by Moyer (1989) was worried about their child's future relationships with parterners and families. Even when they had access to diabetic nurse specialists, their level of concern remained high implying that their psychological needs were not met.

Summary of Literature Review

Literature review shows that although studies have been conducted on insulin-dependent diabetes mellitus, the psychosocial needs of these people still remain unmet. In general, health services are a source of concern for diabetic people. The uncertainty and unpredictability of the condition also seems to be a source of worry and fear among these patients implying that they are psychologically affected. Social problems are also evident from literature due to the restrictions on the patients associated with the condition. However, very little information on their experiences at schools, workplaces and the community in general has been found.

CHAPTER 3

THEORETICAL FRAMEWORK

Roy's Adaptation Model

Roy's adaptation model provides an excellent framework that befits this study. This model is one of the psychosocial models of nursing. The psychosocial models recognise the importance of the effect of the condition on the individual as opposed to the condition alone, (Burke, 1996).

Roy defined man as a biopsychosocial being and an integrated whole. Her assumption was that although systems are studied separately, in reality they are interwoven and balanced to produce a functioning person with inseparable biological, psychological and social needs (Rambo,1984).

These needs stimulate a response to maintain integrity in an individual. Roy further classified the needs into four need states or modes namely the physiological mode, the self-concept mode, the interdependence mode and the role function mode.

The physiological mode is concerned with the body structure and how it works. The self-concept mode is concerned with meeting the psychological needs for integrity, mental functioning and expression of feelings. This mode involves two aspects of man, the physical self and the personal self. These two selves answer the questions 'What am I ?' and 'Who am I ?' respectively, (Rambo, 1984).

The interdependence mode is based on one's need for social integrity and relating with other people. It is concerned with the way people behave in social

relationships or the balance between the need to be independent and the need to rely on others help, attention and care (to be dependent).

Role function is a combination of the self-concept mode and the interdependence mode. It is concerned with the psychosocial integrity. The expectations of both the individual and the society in a particular role performance are involved.

Man responds to one more of these need modes at a time. He is always at a certain point on the health-illness continuum in relation to how he meets these needs. Man is also said to be in constant interaction with the changing environment (world). To cope with this, man uses innate or acquired mechanisms.

Application to the Study.

For the sake of this study, the self-concept mode, the interdependence mode and the role function mode are of paramount importance. All these have an effect on the physiological mode in a diabetic person.

The diabetic patient/client has to integrate the diabetic self into the personal self in order to achieve 'oneness'. This is a psychological process that can be manifested through emotions such as denial, feelings of hopeless and helplessness, uncertainty and many more. To achieve psychological integrity, emotional support may be used as a coping mechanism. The patient can adapt negatively or positively depending on how the situation is handled.

The diabetic person also has to achieve a balance between being independent and being dependent on others for attention and care. The patient's condition does not only affect him but it also affects his family and significant others. Roy believes that being too dependent or being too independent are both maladaptive states. There has to be some balance. Lack of or inadequate social support

systems for the diabetic patient may cause an imbalance in the independent-dependent state; unmet social needs and an imbalance in the physiological mode (destabilization of blood sugar levels) due to stress. Those with inadequate resources (poor socioeconomic status) are more at risk.

The primary role of the diabetic person is that of a 'self-care agent'. This means he has to take care of himself by self-administering insulin injections daily and taking the necessary diet. People (society) around, expect the patient to perform the role adequately to prevent such problems as hypoglycemia. In order to perform this role properly, he has to receive adequate teachings on diet and learn the injection technique so that he can confidently carry out the role. On top of this role, he may have other roles such as student, employee, father, son, mother, daughter and many more, which he/she may also be expected to adequately, perform. Too many roles and expectations cause exhaustion or emotional stress thereby causing a disturbance in the physiological mode. This could pose a danger to diabetic patients.

With this description, one can appreciate the need to use a psychosocial model of nursing in this study. Roy's adaptation model fits well.

CHAPTER 4

METHODOLOGY

Research Design

This was a qualitative study. An exploratory descriptive design was used. As stated by Denzin and Lincoln 1994), cited in Streubert and Carpenter (1994), qualitative research offers an opportunity to focus on finding answers to in – depth interviews that centre on social experiences, how it is created and how it gives meaning to human life.

Sample

A purposeful sample of 12 insulin-dependent diabetic mellitus persons participated in the study. Only those who had had the condition for two years or more and were able to articulate the experience were interviewed.

Setting

The study was conducted at Lilongwe Central Hospital (LCH) diabetic clinic.

Instrument

Question guides and prompts were used with a section on personal data.

Data Collection

The researcher conducted in – depth interviews using two focus groups of six people each. These interviews were conducted on separate occasions in Chichewa whilst somebody was taking notes. The information was later translated into English.

Data Analysis

Content analysis was used. The data was classified into categories and themes from the major highlights of the discussions were used to analyse the data objectively.

Ethical Considerations

Clearance to conduct the study was sought from the authorities at the Ministry of Health and Population (see Appendix C). Permission to conduct the study at Lilongwe Central Hospital was sought from the Hospital Director and copies were sent to the Principal Nursing Officer and the medical department, (see Appendix D).

The researcher appreciates that every individual has the right to choose whether or not to participate in a study and the right to privacy. Each subject therefore received an explanation of the purpose of the study and its benefits in order to obtain consent prior to participation. Their decision was honored.

Anonymity was ensured through the use of numbers instead of names for identification of the subjects. The information was confidential and known to the researcher alone. The recorded information was destroyed at the end of the study.

Limitations of the Study

The study is not generalizable because of the limited number of participants who were interviewed.

CHAPTER 5

STUDY FINDINGS

5.1 PERSONAL CHARACTERISTICS OF THE PARTICIPANTS

Twelve participants were interviewed. Seven of the participants were males representing 58% whereas five were females representing 42%. Their ages ranged from 22 – 60 years with an average of 36 years. Only those who were able to articulate the experience were interviewed, thus the participants had lived with the condition for over two years, statistically ranging from 3 – 13 years. Each one of them had gone to school, 3 had attempted the junior primary school classes (standard 1 – 5) representing 25%; another 3 had gone up to secondary school representing another 25% and the remaining six had gone up to tertiary education representing 50%. Ten of them were married and 2 were widowed. Out of the 12 participants 2 were office clerks, 2 were teachers, another 2 were security guards, 2 were farmers, one was a nurse, one a welder, one a plumber and one a retired midwife.

5.2 PSYCHOLOGICAL EXPERIENCES OF PEOPLE WITH IDDM

Psychological Aspect

First Reaction to Diagnosis

When asked to describe their first reaction to diagnosis, the respondents narrated all sorts of feelings which have been analysed into four main themes. These are sadness, worthlessness, denial and relief.

a) Sadness

Those who said they felt sad/sorry for themselves (n-4) had never heard of such a disease before and could not imagine taking injections for life. One of them said,

"naturally I fear injections and to be told that I would be required to take them everyday, I felt so sorry for myself."

b) Worthlessness

Those who had feelings of worthlessness (n-3) said they felt they were going to die of the disease because they no longer controlled their bodily functioning. One of them said,

"I felt that my life would no longer be the same I was going to depend on drugs the rest of my life and I felt that life was not worthy living.!"

c) Denial

Some of the respondents (n-2) said they experienced a sense of disbelief for sometime after the diagnosis. They said they believed that doctors had made a mistake and that the diagnosis was not a true reflection of what they were suffering from. As a result, they assigned blame to the food that they were taking and opted to stop taking food completely thereby worsening the situation. As one respondent put it,

" For three days after the being told that i have diabetes i was refusing to eat anything because i believed that it was the food that i was taking that was making me sick. At times i was thinking that the doctors had made a mistake in their judgement and they would reverse the diagnosis in the long run."

d) Relief

Another group of respondents (n-4) said they were relieved upon being told that they had IDDM. Some of them had been on tablets for the treatment of non-insulin-dependent diabetes mellitus with no improvement and things changed for the better when they started taking insulin doses.

However, others had been sick for sometime before the diagnosis and other people thought they had AIDS since they lost a lot of weight. As one healthy-looking woman stated,

> *"People thought I had AIDS. Those who saw me a year ago do not believe that I am alive and well today. I have controlled my blood sugar very well and I feel better. I was relieved after being told that I have IDDM and I believed that I would manage it!"*

Primary Causes of Worry due to the Condition

Every respondent said he/she had accepted the condition as part of life after living with it for sometime. This tallied with their perceptions of the disease as an ordinary one. However, a number of causes of worry due to the condition were mentioned though a few had no worries at all. Table 1 presents the most common causes of worry as mentioned by the respondents. Note that some respondents had mentioned more than one.

Table 1 Primary Cause of Worry in People with IDDM

Cause of Worry	No. of Responses	Percentage (%)
Fear of death due to sudden hypoglycemia	5	41.67
Fear of death due to inavailability of medication	3	25
Inadequate syringes and needles (blunt needles are painful)	3	25
Cost of travel to and from hospital (suggested outreach clinics)	2	16.67
Maintenance of cold chain during transportation and storage of insulin at home	2	16.67
Nothing to worry about because death rate among diabetics is lower than people who have other conditions such as malaria and AIDS.	3	25

Note: Some of the respondents mentioned more than one cause of worry due to their condition.

Social Aspects

Support Seeking Pattern

The majority of the respondents (n-8) said they rarely seek support from significant others in their daily diabetes management such as injections, advise or ensuring that food is readily available. Three mentioned that they normally seek advice from hospital personnel and friend who know more about the disease while one mentioned that she seeks support from

neighbours and children to prepare her food especially in case of a hypoglycemia episode.

Patterns of Disclosure of the Condition to other People.

When asked to mention who they normally disclose their condition to, most of the respondents mentioned more than one relations. However, the majority of the responses were for close relatives. Table 2 shows the patterns of disclosure in order of priority according to frequencies of responses.

Table 2: People who are told about the Condition

Type of Relationship	Frequency of Responses	Percentage
Close relatives	12	100
Close friends	9	75
Colleagues at work	7	58.33
Distant relatives	4	33.33
Neighbours	4	33.33
Village leaders	1	8.33
Church people	1	8.33

Note that distant relatives were least preferred than close friends

Understanding of the Disease by other People

All the respondents except one said other people (friends and relatives) understand diabetes well and they had no problems. The one who said other people do not understand had this to say;

> *"Where I live, IDDM is a very rare condition and for most of the people, it is their first time to hear*

of somebody who injects oneself daily. As a result, I am centre of attraction around the area."

Conformity to Special Diet in Social Gatherings

When asked how they ensure that they adhere to special foods when they are in a social gathering such as a funeral or a wedding, the majority of the respondents said they make special arrangements to have a special diet. Others said they take packed meals, others do not conform, (that is they eat anything but alter their insulin dosages accordingly) while others simply avoid attendance to such gatherings. Table 3 shows the responses and their frequencies.

Table 3: Methods of Conformity to Special Diet in Social Gatherings

Response	Frequency	Percentage (%)
Makes special arrangements for a special diet	5	41.67
Takes own packed meal	3	25
Doesn't conform (alternates insulin dosages)	2	16.67
Restricts movement to such gatherings	2	16.67

Those who said they make special arrangements for a special diet or take their own food said they don't feel isolated to be taking a different type of food in a social gatherings and that diabetics need not be tempted to eat non-diabetic foods.

Those who do not conform to special diet in social gatherings stated that culturally, they would not refuse to eat food that is prepared in such occasions as funerals. However, one of them admitted that he gets

tempted to eat one or two cakes and drinks especially at weddings. However, it was interesting to hear that,

> *"I move around with my insulin when I go to a wedding. There, I will take the food that everyone takes but judging from how much I have eaten, I will get an additional small dose of insulin such as 5 I.U., then I will adjust my evening dose accordingly."*

On the other hand, those who said they do not attend such gatherings most of the times said they viewed diabetes as a limiting factor to long journeys and social gatherings.

5.3 DIABETES MANAGEMENT

Knowledge

When the participants were asked what kind of knowledge one needs in order to manage the disease properly, most of the respondents (n-7) pointed out that one needs to be alert for the signs and symptoms of either hypoglycemia or hyperglycemia all the time and manage accordingly. To do this, one has to know how to differentiate between these two extremes. As one of the respondents said,

> *" You need to be your own doctor. I have a copy of the said signs and symptoms which I have photocopied and distributed to my friends for them to read and understand."*

On the same topic, some respondents (n-2) said that diabetics ought to have a sense of self-control when it comes to sexual activity. They said diabetics should reduce sexual activity because too much of it may deplete their energy reserves and one can faint as a result. However,

others implied self control in terms of avoiding being tempted to eat non-diabetic foods such as fried foods, sugarly foods, red meat or too much carbohydrates.

On daily diabetes management, the respondents mentioned eating breakfast then injecting insulin before work, small frequent feeds at work and moving around with sweets as part of daily life. Generally, the respondents showed that they have satisfactory knowledge on diabetes management.

Effectiveness of Discharge Teachings

When asked to give their opinions regarding the effectiveness of the teachings they got on discharge from hospital after diagnosis, most of the respondents were equally divided between those who regarded the teachings as helpful and those who regarded them as not helpful.

Those who said it was not helpful mentioned inavailability of the required foods at home as the primary reason due to economic problems. On the other hand, those who regarded it as very helpful or merely helpful had seen a major change in their condition after strictly following the teachings they got on discharge from hospital.

Diabetics' Expectations During Hospital Visits

When asked to narrate their expectations when they come to the hospital, the responses given in Table 4 below were given.

Table 4: Diabetics' Expectations During Out-Patient Visits

Response	Frequency	Percentage %
Prompt attention	8	66.67
Receive drugs always	3	25
To receive food	3	25
To receive further education on diabetes management	2	16.67
To be seen by the doctor even if it is not the review date	2	16.67
To receive travel warrants	1	8.33
To be given identity cards	1	8.33

Note that the majority of the respondents expected to be attended to promptly. As one man said:

> *"We come here very early in the morning hoping that we are going to have our fasting blood sugar checked before we eat anything. However, we are tempted to eat before our fasting blood sugar check, because the OPD does not open until 9.00 am and we can not brave the hunger. However, nurses and doctors do not know about this. They assume that we haven't eaten anything, and when the results are exaggerated the doctor's decision is affected. Even when they shout at us that our fasting blood sugar levels are high, we know that is not a true picture and we just ignore the advice. Much as this is happening, we also wish to know our real fasting blood sugar levels and we would be glad if they started opening the OPD in time."*

Those who came from a far said they expected to be given food at the hospital, travel warrants, identify cards and to be reviewed by the doctor even if it is not their review date. Some claimed that they are sent back if they come on any day other than scheduled despite their reason for coming on that particular day. Others said it is expensive for them to come for the diabetic clinics at the hospital due to economic hardships and were asking if it would be possible for the doctors and nurses to conduct outreach clinics.

It was also revealed that sometimes drugs are not available at the hospital. Those who opt to buy go either to mission hospitals or private pharmacies where they get a single vial at K800 or K1,800 respectively. However, others said insulin is readily available at district hospitals where there are fewer cases and if they don't get any at LCH, they go to a district hospitals such as Dedza to get some. This provided a learning experience for others who did not know.

CHAPTER 6

DISCUSSION

6.1 PSYCHOSOCIAL EXPERIENCES

The findings of this study indicate that the majority of the respondents were psychologically affected upon being told that they have IDDM. This is particularly true for those who had sudden onset and who had never heard of the disease before. This implies that the respondents has problems understanding what the disease is all about and how it starts, possibly due to lack of information about the disease.

The findings also reveal that most of the respondents still had something to worry about years after onset of the disease despite having accepted it as part of life. Among the causes of worry, fear of death due to sudden hypoglycemia ranked high implying that these people constantly feel insecure and uncertain about their lives. These findings concur with those of Callaghan & Williams (1994), who found that the desire to avoid hypoglycemia and possible loss of consciousness appeared to be a goal for all participants in their study on people living with diabetes. This implies that people with IDDM have to exert conscious effort to take over what is normally an automatic and unseen physiological process which is blood sugar regulation implying constant psychological truma.

These findings signify a disturbance in the self-concept mode as in Roy's Adptation model. The patients may adapt negatively (such as through neglecting the diabetic regimen) or positively (such as through complying with the diabetic regime) to the condition depending on how they perceive their problem. Health workers, and nurses in particular have a challenging

task of providing the necessary support to ensure that these people adapt well to the situation.

The study also revealed that other respondents were labelled as AIDS patients because they had lost a lot of weight prior to diagnosis. These people felt a sense of relief upon being told that they have IDDM and not AIDS. These findings compounded with the responses given by some participants that they do not have anything to worry about because death rate among them is lower than in people with other conditions such as AIDS, portray the type of attitude that people have towards AIDS, though this may also be interpreted as a coping mechanism. This gives an impression that if they were to be given a choice they could prefer to have IDDM than AIDS despite the fact that both are incurable diseases. This can be attributed to the fact that Malawian communities regard AIDS as a disease resulting from promiscuity (Mgawadere, 2000).

Since IDDM is not in any way associated with sexual transmission, one is likely to be comfortable to be told that he/she has IDDM and not AIDS. This assumption directly relates to the finding in the study that people with IDDM are able to disclose their condition to a cross-section of people wherever they live unlike people with AIDS. In response, they get the necessary understanding, support and care from significant others. For example, in social gatherings such as funerals or weddings most of the respondents said they are provided with special meals and that they don't feel isolated to be eating something different because people understand their condition. As one of them put it:

> *"people are used to my problem. When they see me at a wedding or a funeral, they prepare the necessary food without having to be told."*

This finding is contrary to the writings of Guthrie & Guthrie (1982) that diabetes receive very little public attention, support and care unlike other chronic diseases. The support that Malawian diabetics are accorded can be attributed to the Malawian culture in which the sick are accorded the necessary care they deserve. This implies that whether they are well, society still regard diabetics as sick people.

However, there were others who said they eat anything in special gatherings but only reduce the intake because they are bound by cultural norms to eat communal foods, which is also true according to Malawian culture. However, only one participant admitted that he gets tempted to eat non-diabetic food during such occasions, which is a natural response.

6.2 DIABETES MANAGEMENT

Knowledge

The findings of this study show that people with IDDM have vast knowledge on diabetes care, some of which is not found in textbooks. Using this knowledge, they are able to make independent decisions on their daily diabetes management hence their claim that they are their own doctors. Notable was their ability to detect hypoglycemia or hyperglycemia and manage accordingly. As one of them confidently said,

> *"I always listen to my body and I know when my blood sugar is low or high. Depending on my assessment, I decide whether to take more food or whether to adjust my insulin doses upwards or downwards. Sometimes I skip a dose altogether."*

In a study by Degazone (1995), similar findings came out which prompted the researcher to state that knowledge about diabetes facilitates problem-

solving skills and increases a sense of personal control in people with IDDM. Personal control is a very important aspect of diabetes care because it enables one to live up to societal expectations.

Trevelyan (1990) who is a diabetic himself wrote that it is essential for diabetics to be expert self-doctors because this gives them the freedom to carry out the tasks their doctors expect of them. In essence therefore, one needs knowledge in order to adequately perform the role function and the interdependence mode as in Roy's Adaptation Model. This involves the use of mental judgement to strike a balance between choosing when to act independently and when to dependent on others for assistance. In so doing, Roy believes that one can reach a sense of psychosocial integrity.

Support in Relation to Diabetes Management

Most of the respondents indicated that they do not require much support in relation to their diabetes management except that they have to have ready food or packed meals all the time which somebody has to prepare for them. At work, most of the respondents said they take packed meals and sweets in case of emergency. However, none of them mentioned that the employer provides them with food, yet some of them do energy consuming jobs such as welding and plumbing. This implies that employers do not consider the plight of diabetics at work most likely due to the fact that there are no occupational health services in place. Occupational health services are necessary in diabetes care in order to maintain a continuous check on the well being of these people. Although no one mentioned that diabetes affects their job performance, employment can affect diabetes management as timing of injections and meals do not always fit unpredictable work situations (Callaghan & William, 1994).

Effectiveness of the Discharge Teachings

All diabetics receive special teachings on discharge from hospital. The goal of diabetes education is to enable the newly diagnosed diabetic to become as independent of the health service as possible to resume his normal life, (Mulkeen, 1989). This aspect was included in this study in order to find out how these people appraise the discharge teachings they received after living the experience. It is believed that they way one perceives the discharge teachings may have an effect on the quality of relationship that develops between that person and health personnel as well as their level of compliance to the diabetic regimen.

The findings of this study shows that the respondents were equally divided between those who perceived the discharge teachings as helpful and those who perceived the teachings as not helpful. Those who had positively appraised the teachings had strictly followed the instructions where as the others had not done so due to inavailability of the required foods at home.

The typical diabetic diet involves lowering carbohydrate intake, fat intake, increasing vegetable intake and stopping taking sugar completely among other things. In addition one has to do a lot of exercises to keep fit (Guthrie & Guthrie, 1982). This contravenes the typical Malawian diet and lifestyle. The Malawian diet involves taking lots of carbohydrates (nsima) with a little vegetable. Malawians also like to take a lot of sugar in their tea and porridge yet they do not exercise much. It would, therefore, be a big challenge to a newly diagnosed Malawian adult with IDDM to change their lifestyle. This gives an impression that those who followed the hospital teachings strictly were ready to face the challenge whereas those who did not were not ready to face the challenge and used the inavailability of foods at home as a scapegoat. On the other hand, it would be true that some don't have the required foods at home due to

economic hardships. This concurs with the writings of Germain & Nemchik (1988) that diabetes care makes considerable demands on the patient's resources so much so that those with fewer economic resources are likely to face problems. This has implications for the teaching of diabetes care. Health personnel have a tendency to teach diabetes care in the same manner regardless of the patient's background. The findings of this study seem to suggest that an assessment of the home situation in terms of availability of resources should always be the first step before the patient is taught what to do at home otherwise the teachings may be regarded as unrealistic and one may not comply.

6.3 EXPECTATIONS DURING OUT-PATIENT VISITS

Various expectations were cited in relation to what the people with IDDM wish to see when they attend their clinics. Notable were their expectations for prompt attention and receipt of drugs (insulin) and food at the hospital.

Prompt Attention

Prompt attention was mentioned in relation to the time the outpatients department (OPD) is opened. Normally, diabetic people are advised to come before they eat anything so that they can have a sample of their fasting blood sugar taken. As such they come in very early in the morning before breakfast and they bring with them their insulin and food or money to buy food. These people expect health personnel to be considerate and attend to them as priority patients because they can not survive on an empty stomach. However, what happens is that they are made to wait until 9.00 am when the OPD opens and they are tempted to eat something. As a result they resort to cheating for fear of being shouted at as mentioned by the respondents. In Wikblad's study (1991) patients also acknowledged that communication with health professionals is based on a certain level of dishonesty compounded with their inability to report the truth to avoid the risk of receiving negative responses from doctors and

nurses. Patients in this study reported the same problem but added that much as this is happening, they too wish to know the true picture of their fasting blood sugar. This trend to a greater extent defeats the whole purpose of running diabetic clinics because if the patients can not have their fasting blood sugar checked, then the doctor's decisions become invalid.

Receipt of Drugs

People with IDDM can not survive without insulin. It is therefore, vital for them to receive the drug at every clinic visit. Failure to obtain free insulin means one has to obtain the drug some where else. However, this study revealed that the cost of insulin is just too high for the ordinary Malawian ranging from K800 – K1, 800 per vial. Those who can not afford buying are compelled to travel to neighbouring districts in search of the drug. This has implications on their economic and psychosocial well-being as other respondents mentioned it as one of the causes of fear. The inavailability of drugs in hospitals is blamed on the current cash budget system being used. With the system a hospital budget is made on the available cash and since insulin is an expensive drug, the hospital may decide not to buy it in order to save money for other uses. This affects the poor diabetic who can not afford to buy the drug.

Receipt of Food

Some respondents mentioned that they expect to be provided with food when they come to the clinic because they come from afar. This means that when they come early in the morning to have their fasting blood sugar checked, they stay on up to 1.00pm when the doctor starts to review them. With additional delays at the pharmacy, the patients stay at the hospital the whole day. However, they are not supplied with food. They have to fend for themselves to get lunch. This researcher feels that it is the responsibility of the hospital to provide food to these people with special

consideration to their problem otherwise the system makes additional demands on their economic resources. Furthermore these are people who can not survive on an empty stomach therefore health personnel should not aggrevate their condition by keeping them hungry the whole day.

6.4 DIABETIC PEOPLE'S EXPECTATIONS AND THEIR RIGHTS

- A thorough look at the respondents' expectations shows that they tally very well with their rights as laid down by the Working Group of the National Diabetes Advisory Board of South Africa (1997), turn to appendix E for a list of these rights. The fact that these people mentioned expectations that tally with their rights implies that their rights are not being respected. This further implies that the care, which they receive, is substandard most likely because health personnel in Malawi do not know these rights. This is attributed to the fact that Malawi does not have a national policy on diabetes management contrary to the 1989 World Health assembly's resolution that all member countries develop such policies.

6.5 IMPLICATIONS

Implications to Nursing Practice

It has been revealed from this study that people with insulin – dependent diabetes mellitus have vast psychosocial experiences, which affect the way they adapt to self-management of the disease. Notably, fears and worries due to lack of information, unpredictability and uncertainty associated with the disease are rampant among these people. The period immediately after diagnosis seems to be the most trying time. It has also been revealed that people IDDM have all sorts of expectations from hospital personnel when they attend out-patient clinics implying that they are not satisfied with the quality of care that is given.

Practicing nurses, therefore, have a big responsibility. Firstly, they need to provide support, reassurance and the necessary information once a diagnosis of IDDM is made on a patient. Nurses need to look at these patients in totality as biopsychosocial beings and not the biological aspect only, applying Roy's Adaptation Model. At the same time, patients should be looked at as an individual because their levels of adaptation differ. Similarly when they come to the diabetic clinic, nurses should always assess their needs in all aspects of life and not only checking blood sugar. This will guide the nurse in planning the kind of care to be given.

Secondly, there is need for all practicing nurses to revisit the rights of diabetic people and apply them in practice. Most of the expectations mentioned by respondents in this study are relevant to the rights of diabetic people. Therefore, application of these rights in practice would assist to improve their satisfaction with care delivery and consequently the quality of care rendered.

Thirdly, practicing nurses should assume an advocate role for their diabetic patients so that all health personnel should provide them with satisfactory care. To add meaning to the diabetic clinics, health personnel should ensure that the OPD is opened in time so that fasting blood sugar should be checked.

Implications to Nursing Management

The role of nurse managers is diabetes care would be to provide guidance to nurses on how people with IDDM should be cared for. To do this nursing management needs to develop a philosophy of nursing that should cater for the needs of people with diabetes. From that philosophy, relevant policies, objectives and standards should be developed to provide the necessary guidance to nurses as they care for diabetic people. Using

the set standards, nurse managers should evaluate the quality of care being rendered as well as identifying areas that need to be improved.

Implications to Nursing Education

This study has implications for nursing education as well. Results of the study have shown that to a certain extent nurses are not meeting the psychological and social needs of people with IDDM. Student nurses are nurses of tomorrow and if things are to change in diabetes care, these are the people to target. It is therefore, necessary that all nurse education institutions revise their curriculum to incorporate the psychosocial aspects of diabetes when teaching diabetes care.

The content should also include the home-based diabetic and not only the ones admitted in hospital as has been taught in the past. This will ensure that the graduates prepared are ready to work comfortably with people with diabetes in all aspects of life. Such graduates will be in line with 'the kind of nurse needed in the 21st Century' as recommended by the International Council of Nurses and the World Health Organization in the contribution to nursing education. This kind of nurse is dynamic and looks at the patient in totality unlike the traditional physiological approach.

Implications for Nursing Research

This researcher did not come across any study done in Malawi on diabetes. Since the sample involved in this study was small and thus not generalized, there is need for further studies to compliment this one on experiences of people with diabetes in Malawi. In so doing, more knowledge will be generated that can give a good base for the management of the disease in this developing world. Lack of research-based literature for Malawi implies that whatever diabetics are being taught at the moment is borrowed from the developed countries where the experiences of diabetics there are completely different from our situation.

6.6 CONCLUSION

The purpose of this study was to unveil the psychosocial experiences of people with insulin – dependent diabetes mellitus (IDDM) who attend clinics at Lilongwe Central Hospital. The findings of this study reveal that people with IDDM have various psychosocial experiences, which affect the way they adapt to self-management of the disease. The data was analysed using content analysis in order to classify it into categories, which were later related to one another.

From the findings, it can be concluded that psychosocial support is a very important aspect of diabetes management. The physiological adjustment taking place in the diabetic person needs to be coupled with psychological and social adjustment so that the person should cope well with the disease. This is a process that requires understanding and support from significant others. Since the biopsychosocial aspects of man work in unison, a defect in one affects the others.It is therefore necessary to maintain a balance in all these aspects for dibetics to live a healthy life.

However, the results of this study can not be generalized because the sample was too small.

6.7 RECOMMENDATIONS

1. There is need to incorporate experienced people with diabetes in health care teams so that their vast knowledge can be utilized to develop new ways of managing the disease.

2. Occupational health services should be put in place to cater for the needs of diabetic workers in workplaces.

3. Support the formation of a diabetes association, which will be the voice of diabetics nationally.

4. Government should seriously consider the plight of people with diabetes and develop a policy to look into the needs of these people at national level as a way of implementing the resolution of the 42nd World Health Assembly on diabetes (1989).

5. Special nurses should be trained to provide services to diabetic people including follow up.

6. Promote public awareness of the disease and the rights of diabetic people.

7. Encourage donor funding in support of programs aimed at assisting diabetic people.

6.8 ISSUES FOR FURTHER RESEARCH

There are other areas that need further research. These are:

1. Conduct further research on diabetes such as scientifically proving the earth pot (mtsuko) filled with sand and water as a cooling system instead of a refridgerator at home.

2. The statistical records that this researcher got from the Ministry of Health and Population were of in-patients and deaths from the disease. However, there are no statistics on the estimated number

of people who have diabetes in Malawi. There is need to establish these numbers through a national survey.

3. There is need for a national study on the experiences of people who have diabetes in Malawi. This would be a general study on all aspects of life.

4. There is also need for a study on the experiences of families and guardians of diabetic people and how they cope with the problem.

5. There is also need for a study on the experiences of adolescent diabetics since these are a risk group who is already in crisis. It would be assumed that diabetes would be an additional crisis for adolescents.

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APPENDIX A

PSYCHOSOCIAL EXPERIENCES OF PEOPLE LIVING WITH INSULIN - DEPENDENT DIABETES MELLITUS

ID CODE:- ☐

DEMOGRAGHIC DATA

1) Age:-.....

2) Sex
- Male ☐
- Female ☐

3) Level of education
- None ☐
- Standard 1-5 ☐
- Standard 6-8 ☐
- Tertiary education ☐
- University ☐

4) Occupation (specify type of job)

.....

5) Marital status
- Married ☐
- Single ☐
- Widowed ☐
- Divorced ☐

6) Number of year since diagnosed ☐

PSYCHOLOGICAL ASPECT

7) When you were told that you have insulin- dependent diabetes mellitus what was your first reaction?

8) What is your primary cause of worry regarding your condition?

SOCIAL ASPECT

9) Do you normally seek help in your diabetes care? From who?

10) How do you manage diabetes at work?

11) Do you think other people understand diabetes?

12) If you needed support , what kind of support would it be?

13) What kind of people do you normally disclose your condition to?

14) Since you are restricted from eating some other foods due to your condition how do you manage your condition when you go to a social gathering such as a wedding or a funeral?

KNOWLEDGE ABOUT DIABETES

15) What knowledge do you need in order to manage diabetes properly?

16) How effective would you say was the teaching you got on discharge from hospital?

PERCEPTIONS TOWARDS HEALTH SERVICES

17) What are your expectations of diabetes care when you come for check up?

18) If insulin is not available in the hospital, where do you get it? At what cost?

APPENDIX B
CONSENT FORM

Dear Participant,

REQUESTING YOUR CONSENT TO PARTICIPATE IN A RESEARCH STUDY.

I am a student at Kamuzu college of Nursing, pursuing a post –basic Bachelor of Science degree in Nursing.. Currently I am conducting a study on psychosocial experiences of people with insulin-dependent diabetes mellitus. I would therefore like to request for your consent to participate in the study.

This study aims at unveiling experiences other than physical that people with IDDM go through (face) because of their condition. In participating in this study, you will be required to respond to questions which the interviewer will ask you. There are no risks associated with your participation in this study.

To ensure anonymity, no names will be used. Only the principal researcher and the research advisor will access to the responses which will be tape recorded. Tape recording will be done inorder to ensure that responses are understood word by word. The information will destroyed at the completion of the study .Thank you for giving in your time.

FOR THE PARTICIPANT

I hereby give consent to participate

Signature: .....

Date : .....

APPENDIX C

University of Malawi,
Kamuzu college of Nursing,
Private Bag 1,
Lilongwe.

September 27, 2000.

The Secretary,
Ministry of Health and Population,
P.O. Box 30377,
Capital City,
Lilongwe 3.

Through: The Research supervisor (MR. A. Simwaka).
Kamuzu College of Nursing,
Private Bag 1,
Lilongwe.

Dear sir,

SEEKING NATIONAL CLEARANCE TO CONDUCT A RESEARCH STUDY.

I am a student at Kamuzu College Of Nursing pursuing a post-basic Bachelor of science in Nursing programme. In partial fulfillment of the course, I am required to carry out a research study. My study will be on psychosocial experiences of people with Insulin Dependent Diabetes Mellitus (IDDM) who attend clinics at Lilongwe Central Hospital. I intend to carry out the study between October and December,2000.
I would therefore like to seek clearance to conduct the study at one of the institutions under your ministry.
Awaiting your reply.

Yours faithfully,

L .Mkutumula (Mrs.)
(Principal researcher).

APPENDIX D

University of Malawi,
Kamuzu college of Nursing,
Private Bag 1,
Lilongwe.

12 April, 2001

The Hospital Director,
Lilongwe Central Hospital,
P. O. Box 149,
Lilongwe.

Through : The Research Supervisor (Mr. A. Simwaka).
Kamuzu College of Nursing,
Private Bag 1,
Lilongwe.

Dear Sir,

REQUEST TO USE YOUR INSTITUTION AS A SETTING FOR A RESEARCH STUDY.

I am a student at Kamuzu college of Nursing pursuing a post-basic Bachelor of Science in Nursing programme. In partial fulfillment of the course, I am required to carry out a research study. My study will be on Psychosocial experiences of people with Insulin - Dependent Diabetes mellitus who attend clinics at Lilongwe Central Hospital.

I would therefore like to ask your permission to interview diabetic persons who come to your institution for clinics. A total of twelve diabetic persons will participate. I intend to collect data between October and December 2000 but I will conduct a pilot study early October.

Participation will be voluntary and results will be communicated to concerned parties.

Thanking you in advance.

Yours faithfully,

L. Mkutumula (Mrs).
(Principal Researcher).

CC: Principal Nursing Officer.
Hospital Administrator.
Head of Department (Medical Wards)
Senior Nursing Sister (Out-Patients Department)
Unit Matron (Out-Patient Department
Personal copy

APPENDIX E

RIGHTS OF DIABETIC PEOPLE

- to be managed by appropriately trained caring health personnel who are knowledgeable in the disorder.

- An accurate diagnosis, appropriate and acceptable therapeutic strategy and the right to be referred to a higher level of care.

- Comprehensive and on-going education in self-care and counselling, these should be subsidised by the state or be reimbursed by private medical aids.

- Appropriate treatments with affordable, quality medications and self-monitoring materials regularly supplied and identification bracelets.

- Effective surveillance for detection and management of the illness and its complications through consultation with and/or referral to specialist services and comprehensive feedback.

- Easy access to rehabilitative services.

- Regular assessment of the quality of care delivered by each facility and the need to ensure adequate community involvement in identifying and planning health care programmes.

- No employment, financial or other discrimination ratified by the law.

- Adequate psychosocial support to ameliorate hardships caused by the diabetes.

- Adequate care and supervision of detainees and prisoners who have diabetes.