FACTORS INFLUENCING ATTENDANCE BY DIABETIC PATIENTS FOR THEIR YEARLY OPHTHALMIC REVIEWS AT A PRIVATE OPHTHALMIC PRACTICE IN EAST LONDON, SOUTH AFRICA

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DISSERTATION SUBMITTED IN FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE: MASTER OF NURSING SCIENCE (MAGISTER OF CURATIONIS) (MEDICAL-SURGICAL NURSING)

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UNIVERSITY OF FORT HARE

2016

DECLARATION

I, NADINE CHRYSTAL ARNOLDS, hereby declare that this study is my original work and that all other sources of reference have been acknowledged. This dissertation has not been previously submitted for a degree at this university or at any other university.

N.C Arnolds

Signature: Date: 14 January 2016

DEDICATION

I dedicate this study to Our Lord Saviour who gave me the strength and wisdom to complete this dissertation, throughout all my trials and tribulations.

In loving memory of my father (Chris Arnolds) who suffered from diabetes, and as a result of his illness it encouraged me to create awareness regarding diabetes and diabetic retinopathy. I also want to thank my mom, (Unity Arnolds) for being an inspiration. You kept me focused to pursue the goals I dreamed of reaching.

ACKNOWLEDGEMENTS

Without the support of the following people this dissertation would not have been possible.

First and foremost I would like to thank Dr S. Cook and Dr A. Boliter for encouraging me to further my knowledge and creating the environment conducive for research. Thank you for having faith in my capabilities and believing in me. I also want to convey my deepest gratitude to the Eye Centre staff for the support and assistance. I appreciate it.

I would also like to thank my supervisor/mentor, Prof E. M. Yako. Thank you for the constructive comments and for always being there when I needed you. I would also like to thank Mr A. Madeya for assisting with data analysis.

My sincere appreciation also goes to the following:

To all those willing to participate in the study, without your contribution the study would not have been possible.

I would also like to thank Fort Hare University for the financial support.

Last but not least I would like to thank my husband and son (Evan and Jordan-Blake) and my family. Thank you for all the support and understanding and for keeping me grounded and motivated.

ACRONYMS

AEF	African Eye Foundation
ADA	American Diabetes Association
AIDS	Acquired Immune deficiency Virus
ARMD	Age Related Macular Degeneration
BDR	Background Diabetic Retinopathy
BRFSS	Behavioural Risk Factor Surveillance System
CFR	Case-fatality rate
DD	Disc Diameter
DESSA	Diabetes Education Society of South Africa
DM	Diabetes Mellitus
DR	Diabetic Retinopathy
DRPQ	Diabetic Retinopathy Patient Questionnaire
ELEH	East London Eye Hospital
FA	Fluorescein angiogram
GEMS	Government Employee Medical Scheme
GP	General Practitioner
HbA1c	Glycocylated haemoglobin
HBM	Health Belief Model
HDL – C	High Density lipoprotein cholesterol
HE	Haemorrhage
HIV	Human Immune deficiency Virus
IDF	International Diabetic Federation
IRMA	Intra Retinal Microvascular
LDL – C	Low density lipoprotein cholesterol
M	Maculopathy
MO	Macular oedema

NPDR	Non Proliferative Diabetic Retinopathy
NSC	National Screening Committee
NVD	New Vessels Disc
NVE	New Vessels Elsewhere
OA	Ophthalmic Assistant
OCT	Optical Coherence Tomography
OL	Other lesion
ON	Ophthalmic Nurse
OSSA	Ophthalmology Society of Southern Africa
P	Photocoagulation
PDR	Proliferative Diabetic Retinopathy
PRP	Pan retinal photocoagulation
R	Retinopathy
SA	South Africa
SDRGS	Scottish Diabetic Retinopathy Grading Scheme
SEMDSA	Society of Endocrinology, Metabolism and Diabetes of South Africa
T1D	Type 1 diabetes
T2D	Type 2 diabetes
TB	Tuberculosis
TRD	Traction Retinal Detachment
UK	United Kingdom
USA	United States of America
VB	Venous Beading
VEGF	Vascular Endothelial Growth Factor
VH	Vitreous Haemorrhage
WHO	World Health Organisation

ABSTRACT

Introduction: Diabetic retinopathies is a complication of diabetes mellitus causing blindness globally, and as patients live longer, cases of diabetic retinopathy increases. Despite efforts to educate patients at their eye visits, yearly follow up visits is still a major challenge.

Key words: Diabetes, Diabetic retinopathy, health systems, non-attendance, knowledge, attitude, behaviour, gender, fear and anxiety

Objectives: The objectives of the study were to investigate the reasons for non-compliance by determining the relationship among the selected factors (knowledge/ confidence/ fear and anxiety) and adherence to yearly reviews.

Methods: Data were collected from adult diabetic patients who attended the private practice for an eye review by the ophthalmologist. The instrument used was a semi-structured questionnaire with sections covering demographics, statements regarding diabetes and diabetic eye care and one section with an open ended question to determine the reasons for non- attendance.

Data analysis: Measures of central tendency were checked and expressed in terms of percentages and tables. The inferential statistics was also conducted to determine the relationship amongst variables. Chi square tests were used to determine the relationship amongst the categorical variables and eye reviews. Spearman's correlation analysis was carried out to determine the association amongst variables, (behaviour, control, stigma and satisfaction). The open ended question was used to analyse the reason for non-compliance.

Results: A total of 300 diabetic patients were randomly selected for the study. The participants were sampled in a stratified way such that each level of compliance is equally represented. The dataset was acceptably complete with very few missing values. The distribution of the participants across the different biographical variables was cross tabulated by compliance with annual reviews. Of the 300 participants, 151 (50.3%) were compliant. The results show that there were more females than males 166 (56.3%), more Africans than any other ethnic group 168 (57.1%), more married

people than any other marital status group 183 (61.0%), more Christians than any other religion 227 (92.3%), and more living with their families than any other living arrangement 223 (74.8%). Of these variables 5 (1.7%) missing values were recorded for gender, 6 (2%) for ethnicity, and 2 (0.7%) for living arrangements, while marital status and religion were complete. The majority of the participants had a secondary school education 130 (43.3%), and most felt that they were in good health 148 (49.3%). As for payment of medical expenses, 255 (87%) had a medical aid, and yet 147 (51.6%) last visited a doctor more than a year from the date of data collection.

Conclusion: Compliance with doctor's visits was found to be associated with positive behaviour and more knowledge and control. Knowledgeable patients were more satisfied with the medical services. Fear of stigma associated with diabetes mellitus was found to be associated with demographic variables such as gender, race, marital status, employment status and educational level. The main reasons for non-compliance were lack of information, negligence, busy work schedules and lack of finance. These results suggested there is a need to raise awareness of eye health and access to affordable medical services.

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CHAPTER 1

ORIENTATION TO THE STUDY

1.1 INTRODUCTION

Diabetic retinopathy is a complication of diabetes mellitus (DM) that causes blindness and, as the prevalence of diabetes increases globally and patients live longer, the cases of diabetic retinopathy are increasing (Khandekar, 2012:178). It is important that clients check their eyes regularly at least annually, so that the onset of diabetic retinopathy can be detected early and appropriate treatment rendered. Yet, in South Africa, only 11% of the population of those with diabetes have their eyes routinely examined for diabetic retinopathy (Thomas, Distiller, Luzio, Chowdhury, Melville, Kramer and Owens, 2013:336). This puts a large proportion of the people living with diabetes mellitus at the risk of blindness.

1.1.1 Background

Diabetes is the fourth leading cause of non-violent death globally (Ngwenya, van Zyl & Webb, 2009:106). Without urgent action being taken, diabetes-related deaths are set to increase by more than 50% over the next ten years (Ngwenya, van Zyl and Webb, 2009:106). Unless preventative measures are taken, 380 million people worldwide will have diabetes by 2025, and 439 million by 2030 (Shaw, Sicree and Zimmet, 2010:1), with the largest increase in the developing countries, of which most are in Africa (Ngwenya, van Zyl & Webb, 2009:106). The International Diabetes Federation (IDF) has estimated that the number of adults with diabetes in Africa will double in 20 years, from 12 million to 24 million in 2030 (Burgess, Msukwa and Beare, 2013: 157).

An estimated 2.9 million people died from diabetes, in the year 2000, i.e. a global case–fatality rate (CFR) of 0.01616. In 2000, the prevalence of diabetes in the World Health Organisation (WHO) African region was estimated at -7.02 million people, out of which 0,702 million (10%) people had Type 1 diabetes (TID) and 6.318 million (90%) had Type 2 diabetes (T2D)(Kirigia, Sambo, Sambo and Barry, 2009:6). The mortality rate of 31% of people with Type 1 diabetes has been described in Addis Ababa, Ethiopia alone (Ayele, Tesfa, Abebe, Tilahun and Girma,2012:35516). About

113,100 people died from diabetes–related causes, 561,600 were permanently disabled, and 6,458,400 experienced temporary disablements (Kirigia, Sambo, Sambo and Barry, 2009:6). This number is likely to be more than double by the year 2030 (Garg & Davis, 2009:140). Most recent estimates indicate there were 171 million people worldwide with diabetes and this is projected to increase to 366 million by 2030 (Sivaprasad, Gupta, Crosby–Nwaobi & Evans, 2012:23). The diabetes tsunami is here and we in South Africa are in trouble (Diabetes Tsunami hits South Africa (article online), (2013:1).

1.1.2 Understanding diabetes

Diabetes mellitus (DM) is a chronic condition requiring complex and lifelong care. (Mollentze, 2007:534). There are two main types of diabetes: Type 1 and Type 2 diabetes. The third type of diabetes is gestational diabetes, which occurs during pregnancy (Winter & Yorston, 2011:2).

Type 1 diabetes is uncommon. It is caused by destruction of the insulin secreting cells in the pancreas, and at present there is no means of predicting or preventing it. It occurs in young people and begins suddenly. This type of diabetes always requires treatment with insulin (Winter & Yorston, 2011:2).

Type 2 diabetes is much more common. It begins gradually and may be completely without symptoms. Until recently, it was thought to affect only people over 40 years old, but it is now found in much younger patients, particularly in association with obesity (Winter & Yorston, 2011:2). Obesity, as a result of an unhealthy lifestyle, puts people at risk of developing DM (Shaik, Shaik, Shaik, and Ahmed, 2008:774). Both environmental factors including changing population lifestyle (urbanisation, calorie excess, physical inactivity) and genetic factors have been implicated as causative factors (Petrie, Pearson and Sutherland, 2011:471). Not all type 2 diabetes will require insulin. Some may be treated with tablets and some may only require weight loss to restore control of blood sugar (Winter & Yorston, 2011:2).

Gestational diabetes involves hormonally induced insulin resistance that occurs during pregnancy due to hormonal changes, genetics and lifestyle factors. Type 1 and Type 2 diabetes are chronic and incurable diseases unlike gestational diabetes that is resolved during delivery (Ramirez, 2008: 85).

1.1.3 Prevalence of Type 1 diabetes

Type 1 diabetes (TID) predominantly affects the population of European ancestry, the highest rates being reported in Finland and Sardinia (Borchers, Uibo and Gershwin, 2010:355). Asian and sub-Saharan African counties report low frequency (Zhang, Xia, Yu, Wang, Chen, Wang and Love, 2008:122). The overall prevalence of diabetes in northern Ethiopia for instance has been reported at 0.3% (Ayele, et al., 2012:35516). The incidence of type 1 diabetes in children younger than 15 is also increasing. The prevalence of diabetes among this group is predicted to rise to 160,000 in 2020, globally (Sivaprasad, et al., 2012:24).

The rapid increase in the incidence of type 1 diabetes is almost a global phenomenon during the last few decades (Green & Patterson, 2001:4). This may represent a true increase resulting from changing environmental or lifestyle factors, or due to improvement in case ascertainment with the existence of diabetic registers across Europe and America, and more reports from developing countries (Sivaprasad, Gupta, Crosby–Nwaobi & Evans, 2012:24). The incidence of obesity has led to a doubling of the prevalence of diabetes globally in the last decade. It is estimated that up to one third of children born in 2000 will develop diabetes during their lifetime in the United States of America (USA) (Gardner and Gabby, 2009:328).

1.1.4 Prevalence of Type 2 diabetes

Type 2 diabetes (T2D) was once considered a disease of the west, but it is now a global health priority. More than 60% of the world's population with diabetes will come from Asia, as it remains the world's most populous region (Sivaprasad, et al., 2012:26). Type 2 diabetes has reached epidemic proportions in the Asia-Pacific region (Tam, Lam, Chu, Tse and Fung, 2009:185).

In the United Kingdom (UK) the white population, rates of known diabetes range from 2 to 4% (Sivaprasad, et al., 2012:26). Type 2 diabetes is more common in ethnic minority (African Americans and non–Caucasians) people who also often have poor glycaemic control. They are also more likely to develop complications of the disease (Adams, Trinacty, Zhang, Kleinman, Grant, Meigs, Soumerai & Ross–Degnan, 2008:917); (Saydah, Cowie, Eberhardt, De, & Narayan, 2007:529). Type 2 diabetes is also common in those who are socio–economically deprived (Strodl & Kenardy,

2006:57). Recently (Amod, et al.,(2012: S1:2) stated that Type 2 diabetes is not a well managed disease, with fewer than 50% of patients meeting glycaemic targets, even in developed countries. The prevalence rate includes adults aged 20 – 79 years (approximately 1.9 million of 30 million adults) (Amod, et al., 2012: S1:2).

Twenty- four million Americans (8%) have known diabetes and 57 million have pre diabetes (Gardner and Gabbay, 2009: 328). By 2050, it is projected that the number of individuals with diagnosed diabetes in the United States will increase to 48.3 million (Zhang, Gregg, Cheng, Thompson, Geiss, Duenas and Saaddine, 2008:1421).

According to the World Health Organisation, India will become one of the major hubs of diabetic population during the next two decades; the number of cases of adult–onset diabetes mellitus will grow to nearly 80 million in 2030 from 18 million in 1995 (Raman, Rani, Rachepalle, Gnanamoorthy, Uthra, Kumaramanickavel and Sharma, 2009:311).

South Africa has self-reported prevalence rates for diabetes of 2.4% in men and 3.7% in women (Mash, Levitt, van Vuuren & Martell, 2008:50). A recent study was conducted in Belville, South Africa, and it was found that the coloured population has the second highest prevalence of diabetes in South Africa (Erasmus, Soita, Hassan, Blanco–Blanco, Vergotine, Kengne and Matsha, 2012: 841), after that of the Indian population. (Erasmus et al., 2012:844) The Indian population has the highest prevalence of diabetes in South Africa (11 to 13%), as they have a strong genetic predisposition for diabetes. The coloureds follow with 8 to10 %., 5-8% among the blacks and 4% among whites (Diabetes Tsunami hits South Africa (article online), (2013:1).

South Africa has undergone significant changes since its independence in 1994. These have been accompanied by rapid urbanisation and economic changes, particularly among the coloured and other non-white population groups. These epidemiological changes are often paralleled by increase in lifestyle diseases such as diabetes, obesity and high blood pressure (Erasmus, et al., Blanco–Blanco, 2012: 841).

1.1.5 The link between diabetic retinopathy as a complication of diabetes mellitus

Diabetic retinopathy (DR) is one of the commonest and easily demonstrable examples of microvascular damage that diabetes inflicts throughout the body (Shah, 2008:500). Diabetic retinopathy has been understood as a micro vascular disease of the eye (Gardner and Gabbay, 2009: 328). At least 10% of diabetics will develop visual impairment secondary to diabetic retinopathy. (Garg & Davis, 2009:140). Everyone with diabetes will develop some degree of DR eventually, most commonly after ten or more years of living with diabetes. (Winter & Yorston, 2011:2). Diabetic retinopathy will be discussed in more detail in Chapter 2.

1.2 PROBLEM STATEMENT

The researcher has observed that most diabetic patients do not adhere to the yearly recommended screening for diabetic retinopathy at the private practice. Non-compliance is directly associated with poor treatment outcomes in patients with diabetes (Sklar, Oh and Li, 2008:270). There is evidence that people who do not attend appointments have more diabetic related complications and more hospital admissions (Paterson, Charlton and Richard, 2010:64). It is also found that most new referrals only attend when they are already experiencing visual problems. Some of these patients have been diabetic for years and have never seen an ophthalmologist. It was also noted that the patients who were seen by the ophthalmologist and were instructed to return, do not do so, and only return when they are experiencing visual problems. There is a high default rate amongst those patients' who are screened, reflecting a poor understanding of the necessity of the screening and the ignorance of the importance to know your diabetic retinopathy level or 'score' (Cook, 2013:449). It is a serious health care concern that poses a great challenge to the successful delivery of health care (Khan, Lateef, Al-Aithan, Bu- Khamseen, Ibrahim and Khan, 2012:26).

Considering of amount of time spends with each patient on their first visit regarding education about their eye disease progress, the researcher found it necessary to investigate and understand why the patients choose not to engage in their follow up visits at this specific institution. Despite the best intentions of healthcare professionals,

the outcomes might not be achievable if a patient is not compliant (Sklar, et al., 2008:269).

It was also noted by the researcher, who is also an ophthalmic nurse at the East London Eye Centre, that patients attending the private practice are getting younger and younger with symptoms of diabetic retinopathy presenting 7-10 years after diagnosis. Most of these patients also tend to have uncontrolled glucose levels and blood pressure, which are the most common risk factors. Delaying progression by better control of risk factors is both effective and improves quality of life (Schmier, Covert, Lau, Matthews, 2009:200).

No study was found in literature on why patients do not come for their annual eye examination in the private sector, despite the fact that most of them are covered by either private medical aid or government medical aid schemes. The question is “Why do patients not attend their annual reviews?”. This prompted the researcher to conduct the study.

1.3 AIM OF THE STUDY

The aim of the study is to determine the relationship amongst the factors of (knowledge, confidence fear and anxiety), and adherence to follow up visits. In addition, the study aimed to find out the reasons for non-attendance among the group that does not keep their yearly reviews at a private practice in East London, with the purpose of screening and preventing advanced diabetic retinopathy, which leads to blindness.

1.4 OBJECTIVES

The objectives of the study are:

- To determine the relationship among selected factors (knowledge, confidence, fear and anxiety) and adherence to yearly reviews in diabetic patients.
- To determine if there is a difference in the factors (knowledge, confidence, fear and anxiety) between the adherent and non-adherent group of diabetic patients.
- To determine the reasons for non- attendance to yearly reviews among a non-adherent group of diabetic patients.

1.5 RESEARCH QUESTIONS

The research questions derived from the objectives are as follows:

- Is there a relationship among selected factors (knowledge, confidence, fear and anxiety) and adherence to yearly reviews in diabetic patients?
- Is there a difference in the factors (knowledge, confidence fear and anxiety) between adherent and non-adherent groups of diabetic patients?
- What are the reasons for non-attendance to yearly reviews among the non-adherent group of diabetic patients?

1.6 SIGNIFICANCE OF THE STUDY

The significance of the study is that if the relationship among the selected factors (knowledge, confidence, fear and anxiety) and adherence as well as the reasons for non-attendance of yearly reviews are known it can be used by health professionals to come up with; strategies to increase attendance to prevent sight threatening diabetic retinopathy. It might also generate training programmes for professional nurses and optometrist to utilise the grading system for referrals.

1.7 THEORETICAL FRAMEWORK

The researcher chose the Health Belief Model (HBM) to guide the study. According to literature HBM was used in similar studies as the present one. It postulates that peoples' behaviour regarding health is related to their perceptions of the severity of an illness, their susceptibility to it and the cost and benefits incurred in following a particular course of action (Bowling, 2002:35). If clients perceive the threat to be great and the benefits outweigh the costs, then they are likely to adopt that behaviour. (Sheridan & Radmacher, 2002:190).

The HBM is presented in figure1.

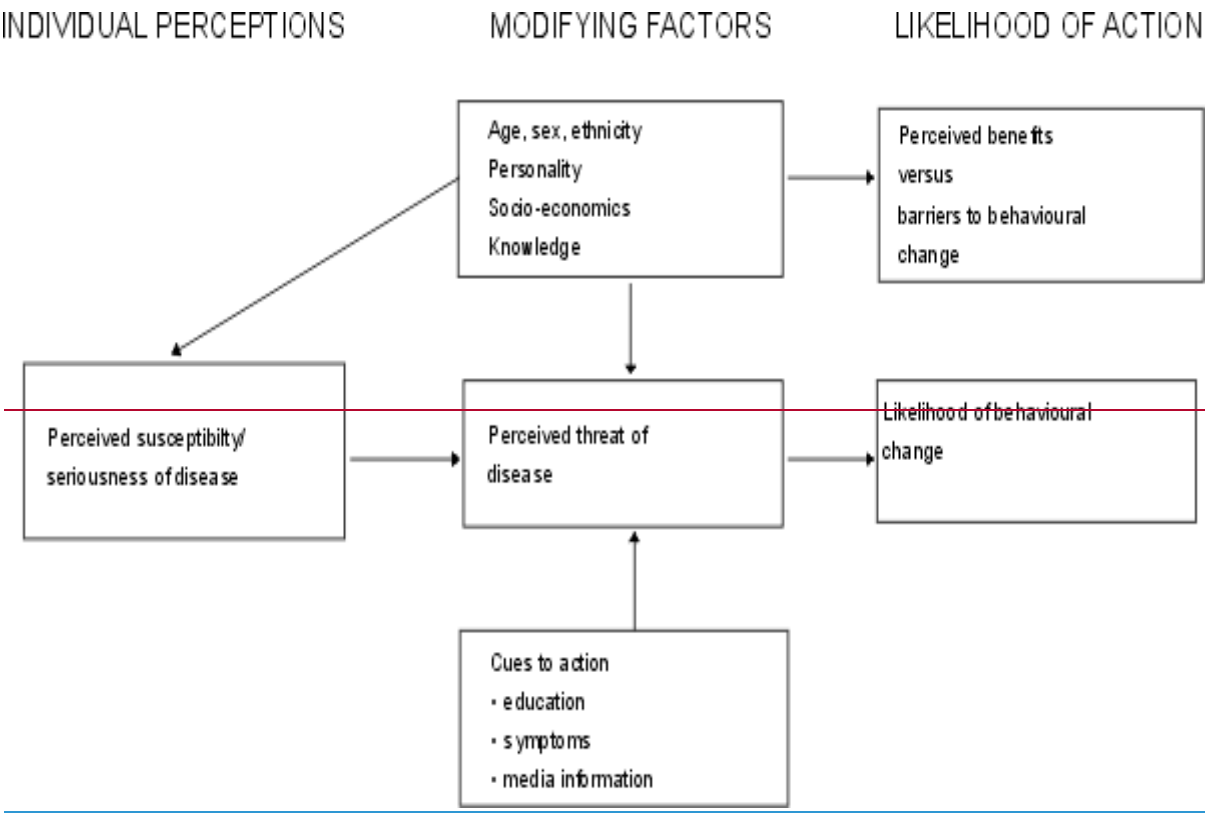


Figure 1: Health belief model

Source: Glanz, Lewis & Rimer (2002:52).

In view of the assumptions of the health belief model, patients are expected to take responsibility, and make informed decisions when they are susceptible to blindness. When they perceive that these problems have serious effects on their lives/eyesight, that there are benefits to early diagnosis and treatment, to retinopathy, and that there are no barriers and that they can afford the treatment, they are most likely to attend their annual follow up appointments.

1.8 DEFINITION OF CONCEPTS

The following concepts used in this study are defined for clarity:

- **Patient:** Patient is one who receives medical attention, care or treatment (The American Heritage Medical Dictionary, 2007). In this study a patient means someone with diabetes mellitus, who needs eye care.

- **Ophthalmic nurse:** An ophthalmic nurse is a registered nurse concerned with the eye. The key role of an ophthalmic nurse, in its broadest sense, is the prevention of avoidable blindness (Kyriacos, Scheepers, Hill and Jordan, 2009:22). In this specific study the ophthalmic nurse is trained to manage a range of eye conditions and work alongside the ophthalmologists assisting in screening for diabetic retinopathy.

- **Compliance and adherence:** The word 'compliance' comes from the Latin word '*complire*', meaning to fill up and hence to complete an action, transaction, or process and fulfil a promise. The term 'adherence' which comes from the Latin word '*adhaerere*', means to cling to, keep close, or remain constant (Aronson, 2007:383). In the study the researcher noted that the diabetic eye patients do not adhere to their yearly diabetic screenings and being non-compliant is directly associated with poor treatment outcomes in patients with diabetes (Sklar, et al., 2008:270).

1.9 SUMMARY

In this chapter the researcher introduced the study overview in terms of the background of the study, the problem statement, and the aims of the study, the significance and the theoretical framework of the study.

The investigator gave detailed information about diabetes and explains a brief link between diabetes and diabetic retinopathy.

In the next chapter an in depth literature review of the study will be presented.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter outlines the in- depth literature review focussing on diabetes retinopathy. International and South African/Africa studies about the reasons for non-attendance of diabetic patients for their eye reviews will be reviewed. The main data base consulted was PubMed, Medline as well as DIARETDB, which is the standard diabetic retinopathy data base.

Key words: Diabetic retinopathy, health systems, education, non-attendance, knowledge, attitude, behaviour, gender and fear/anxiety.

2.1.1 Understanding diabetic retinopathy

Diabetic retinopathy has been understood as a micro vascular disease of the eye, but recent studies have established that diabetes affects the entire neurosensory retina, which means visual function is impaired at or before the onset of microaneurysms in many patients with diabetes (Gardner and Gabbay, 2009: 328). According to the article by: Read & Cook, (2007:56), diabetic retinopathy is the fifth leading cause of global blindness, affecting an estimated 1.8 billion people and is responsible for 4.8% of blindness. According to recent literature it is now the sixth leading cause of global visual impairment, and is included in the list of nine target diseases of Vision 2020, a joint program of the World Health Organisation (WHO), and the International Agency for the Prevention of Blindness (Burgess, Msukwa and Beare, 2013:158).

In diabetic retinopathy (DR), damaged small blood vessels leak into the retina at the back of the eye. Later, the blood vessels become blocked, which leads to formation of abnormal new blood vessels. These blood vessels are fragile and can bleed into the vitreous gel, (Winter & Yorston, 2011:2), causing a vitreous haemorrhage (VH) (Burgess, Msukwa and Beare, 2013:158). They can also pull on the retina causing retinal detachment (Winter & Yorston, 2011:2). It is also accompanied by fibrosis that leads to tractional retinal detachment (TRD) (Burgess, et al., 2013: 158). If blood vessels become damaged in the central part of the retina, this causes diabetic maculopathy, which is characterised by swelling of the retina called macular oedema

(MO) (Winter & Yorston, 2011:2). Clinically two distinct changes can be identified: retinopathy and maculopathy (Sivaprasad, et al., 2012:28).

All these changes can damage vision permanently, and eventually lead to blindness, unless the patient receives treatment (mainly laser treatment). Even then, treatment will only stop or slow down the disease–existing damage to the eye or to the patient's vision cannot be undone (Winter & Yorston, 2011:2). Everyone with diabetes will develop some degree of DR eventually, most commonly after ten or more years of living with diabetes. (Winter & Yorston, 2011:2). Therefore, screening of diabetic retinopathy is worthwhile and provides an opportunity to detect other co morbidities, such as glaucoma and age-related macular degeneration (Cook, 2013:449). Cataracts and recently problems involving the ocular surface, dry eyes in particular have been reported in diabetic patients (Manaviat, Rashidi, Afkhami– Ardekani and Shoja, 2008:10).

2.1.2 Stages of diabetic retinopathy

- **Background retinopathy (BDR)**

  This occurs in most people with diabetes approximately 20 years after the onset of the condition and can therefore affect all age groups from late teens onwards. Usually, no symptoms present until there is macular involvement resulting in impairment of central vision to the eye. (Khan, Wong, Garrod, Gangat, Hiles, Deane and Lawrence, 2010: 296).

  Over 50% of patients do not progress beyond this stage (Shah, 2008:508).Clinical signs include: microaneurysms, hard exudates and haemorrhages (Melendez-Ramirez, Richards and Cefalu, 2010:628).

- **Pre proliferative retinopathy (NPDR)**

  This may develop in the eyes with background retinopathy only. According to (Scott et al.,2008), the eye requires close observation but is not usually treated unless regular follow ups are not possible or vision in the fellow eye has been lost to proliferative disease. It is characterised by the presence of one of the

following: multiple dark blot haemorrhages, multiple cotton wool spots, venous beading and intraretinal microvascular abnormalities (Shah, 2008:509).

- **Proliferative retinopathy (PDR)**

  This is the main cause of visual impairment in people with T1D. Proliferative retinopathy is preventable and treatable before vision is lost (Burgess, et al., 2013:158). It occurs sooner following the diagnosis of T2D, possible because the diabetes has gone on for longer undetected. This stage is characterised by new blood vessels forming in the retina, either on the disc (NVD) or elsewhere (NVE) (Shah, 2008:509). In this form of retinopathy the blood vessels grow into the vitreous humour and bleed, causing a vitreous haemorrhage. Laser therapy, if required, can be used to treat proliferative retinopathy and aims to prevent neovascularisation occurring. A laser beam is applied to the retina, as dead retina will not encourage new vessel growth (Khan, Wong, Garrod, Gangat, Hiles, Deane and Lawrence, 2010: 296). Laser photocoagulation has been shown to be effective if timely treatment is performed (Burgess, et al., 2013: 158). Vitrectomy (surgical intervention) can be used in severe cases to remove the haemorrhage (Khan, et al., 2010:296).

- **Advanced retinopathy**

  This is the end result of uncontrolled proliferative retinopathy. The eye develops retinal tears, or a detached retina, which leads to blindness. Early vitrectomy may improve visual recovery. The individual also requires management of visual impairment by means of visual aids (Khan, et al., 2010:296).

- **Maculopathy**

  The macula is defined as a circle centred on the fovea. If the leakage involves is or is near the fovea, the condition is termed ‘clinically significant macular oedema’. It causes central blurry vision. Depending on severity some cases can be treated with laser treatment (Sivaprasad, et al., 2012:33). Macular oedema is one of the major causes of vision loss in individuals with diabetes (Hirai, Knudtson, Klein and Klein, 2008: 701).Diabetic retinopathy is both preventable and treatable before vision is lost (Burgess, et al., 2013:158).

2.1.3 Classification of diabetic retinopathy

Some ophthalmologists in East London, South Africa, use the National Screening Committee (NSC) classification, to classify diabetic retinopathy (Harding, Greenwood, Aldington, Gibson, Owens, Taylor, Kohner, Scanlon and Leese, 2003:965), and the Scottish Diabetic Retinopathy Grading Scheme (SDRGS), to screen for diabetic retinopathy (Leese, Morrison, and Olson, 2003:962). These classifications are also in use in England and Wales and Scotland (Harding, et al., 2003:965). Classification and grading of severity of DR have been based on ophthalmoscopically visible signs of increasing severity, ranked from a stepwise scale of no retinopathy through to stages of advanced retinopathy (Leese, et al., 2003:963). These classifications adopt a simplified approach to grading retinopathy based on features which a non-ophthalmologist /accredited photographic screener might be faced with in a population of diabetic patients (Sivaprasad, et al., 2012:32). This would include ophthalmic nursing sisters (ON), optometrists, GP's, specialist physicians and endocrinologists (Cook, 2013:450).

2.1.4 Screening for diabetic retinopathy

The Ophthalmology Society of Southern Africa (OSSA) implemented the system for a national DR screening programme. It is anticipated that this will incorporate screening at all levels from the clinic to the specialist (Cook, 2013:450). The aim is also to reduce the frequency of diabetic eye–screening visits, while maintaining safety, by using information technology and individualised risk assessment to determine screening intervals (Aspelund, Thornorisdottir, Olafsdottir, et al., 2011:2525). Retinopathy grades from R0 to R6 and maculopathy from M0 to M2 as illustrated in the table 1 below.

Table 2.1: Diabetic Retinopathy grading, based on the Scottish Retinopathy Grading System

*RO	No lesions (No DR)	Re-screen in 1 year
R1	Blot haemorrhage, microaneurysms and cotton wool spots (Mild non- proliferative or mild pre proliferative)	Re-screen in 1 year
R2	More than 4 blot haemorrhage in one hemi – retina (Moderate or severe non- proliferative)	Re-screen in 6 months
R3	More than 4 blot haemorrhages, venous beading and IRMA (Proliferative retinopathy)	Refer to Ophthalmologist, may need laser
R4	New vessels (Proliferative diabetic retinopathy)	Refer to Ophthalmologist for laser
R6	Inadequate visualisation	Dilate and rescreen and refer
*MO	none	Re-screen in 1 year
M1	Lesions within 2 *DD of macula (Diabetic maculopathy)	Refer to Ophthalmologist
M2	Lesion within 1 DD of macula (Diabetic maculopathy)	Refer to Ophthalmologist
P	Photocoagulation (Small retinal scars throughout the retina)	

OL	Other lesions/ upgradable usually due to cataracts or other lesions referred for assessment.	

*R = Retinopathy, *M = Maculopathy, *DD = Disc diameter, *P = Photocoagulation present, *OL = other lesions/upgradable

(Aspelund, Thornorisdottir, Olafsdottir, et al., 2011:2525).

A mathematical algorithm was created based on epidemiological data on known risk factors to obtain an individualised risk assessment, which is used to determine screening intervals for diabetic retinopathy. Through a website www.risk.is, the algorithm receives clinical data including type of diabetes, HbA1c or means blood glucose, blood pressure and the presence and grade of retinopathy (Aspelund, Thornorisdottir, Olafsdottir, et al., 2011:2525). This risk calculator has been modified for South African conditions in collaboration with Prof. Einar Steffansson, who developed the risk calculator (through a website www.riskafrica.co.za) based on the outcomes observed in a large Danish cohort (Cook, 2013:450), because in applying the algorithm in another country, we need to take into account not just the attendance rates but also different risk factors and incidences of sight threatening diabetic retinopathy (McGhee, Harding & Wong, 2012:477).

Systemic risks is calculated and the outcome drawn onto a ‘rev counter’ that is placed next to the ‘no retinopathy’ photographs. This helps dispel the possible misconception that no retinopathy means ‘no need to control the systemic risks factors’ (Cook, 2013:450). This is given to the patient as a patient held record and patients gets registered on a diabetic retinopathy register/database.

2.1.5 Methodology of image capture in the screening programme and investigations

The methodology of image capturing consists of each eye being dilated with a mydriatic agent such as Tropicamide drops 1%. The screener then proceeds to capture two images of the retina involving the macula and the optic discs (Harding, et al., 2003:966),: however, recent advances in digital camera technology have made it possible to acquire high resolution images of the fundus to enable screening for

diabetic retinopathy (Cook, 2013: 449). Digital imaging is now widely accepted as the screening method of choice, and as seen as an opportunity for motivation of better glycaemic control (Mash et al., 2007:1285).

This is what the researcher, who is an ophthalmic professional nurse, and some ophthalmologists are currently using as well in the private practice in East London, South Africa. The retinopathy grading is based on the Scottish Retinopathy Grading system (Table 2.1).

Additional examination of the peripheral fundus is important, especially in patients with Type 1 diabetes, to avoid overlooking peripheral retinal ischemia and neovascularisation. The microvascular complications in Type 1 diabetes occur much earlier in life, have a more diffuse, accelerated course and have a higher mortality, especially in those aged less than 40 years of age (Melendez–Ramirez, Richards and Cefalu, 2010:628). Direct ophthalmoscopy permits an adequate assessment enhanced by slit-lamp biomicroscopy with a condensing lens (Cheung, Mitchell and Wong, 2010:128). It is still considered as the ideal examination to evaluate the diabetic fundus (Mahesh, Giridhar, Saikumar, Kumar and Bhat, 2010: 165).

Fluorescein angiography (FA) also aids in the clinical assessment of diabetic retinopathy. It highlights microaneurysms and retinal ischemia, and retinal neovascularisation is highlighted as the dye leaks into the vitreous (Cheung, et al., 2010:28).

Optical coherence tomography (OCT) has emerged as a useful imaging modality. It functions as an optical biopsy of the retina, offering high resolution, and three dimensional or cross sectional images that closely approximate the histology of the retina, which is crucial for monitoring progression and treatment response for diabetic macular oedema (Cheung, et al., 2010:128).

2.1.6 Prevalence of diabetic retinopathy

The global prevalence of DR has been reported to be 55% in African Americans, 46.7% in Caucasians and 20.9% in Asians (Thomas, Distiller, Luzio, Chowdhury, Melville, Kramer and Owens, 2013:336). The incidence and progression of DR in Caucasian and other populations have been demonstrated in a number of studies (Tam, Lam, Chu, Tse and Fung, 2009:195).

South Africa has an estimated population of +- 50 million inhabitants, the majority being indigenous Africans (79.5%) with a minority comprising of Caucasians (9%), mixed race (9%) and Asian Indians (2.5%). There is some evidence suggesting that the risk of DR and blindness in South Africa can vary with ethnicity (Thomas, et al., 2013:336). Another study, comparing microvascular complications in black and Indian South Africans showed a high prevalence of retinopathy at 53% (blacks 56% and Indians 45%) (Tesfaye and Gill, 2011, 19:1). To date, the reported prevalence of DR in South Africa's public sector has ranged between 14 and 55% in indigenous Africans, 41% in Caucasians, and 22% and 37% in Asians with diabetes. (Thomas, et al., 2013: 336).

2.1.7 Treatment of diabetic retinopathy

The successful treatment of retinopathy should be based on treating the underlying metabolic conditions that contribute to the development of the retinopathy and specifically treating the specific abnormalities identified in the eye (Melendez-Ramirez, et al., 2010:629).

Laser photocoagulation has been the mainstream of treatment for DR. It continues to be the key intervention, with new technologies allowing faster and less invasive therapies (Cook, 2013:502). The two types of laser therapies for diabetic retinopathy are pan retinal photocoagulation for peripheral retinopathy and macular (focal or grid) laser photocoagulation for diabetic macular oedema. The goal of pan retinal photocoagulation (PRP) is to place laser burns over the entire retina, sparing the central macula to promote regression and arrest progression of retinal neovascularisation (Cheung, et al., 2010:133). Laser is, however, inherently destructive.

The most dramatic recent advance in the management of DR has been the use of intravitreal injections of anti-vascular endothelial growth factor (anti-VEGF) agents. The drug is injected into the vitreous cavity with a needle pointing toward the optic nerve via the pars plan under sterile conditions where the eye is disinfected with povidone iodine. A speculum to stabilize the lids, sterile gloves, local anaesthetic and a sterile drape are needed (Aiello, et.al, 2011:10). These agents have demonstrated an ability to stabilize and control most of the sight threatening DR-related diseases. They are effective against the proliferative and the maculopathic elements of the

disease. In an article by Gardner and Gabbay (2009: 328), in America, it also highlights medical therapies such as intravitreous steroids and /or vascular endothelial cell growth inhibitors which show modest transient benefits that are more effective than laser photocoagulation.

A randomised clinical trial by the Diabetic Retinopathy Clinical Research Network (DRCR.net) found that randomized ranibizumab (anti-VEGF treatment) with prompt (within 3 to 10 days after the initial injection) focal/grid laser, provided better visual acuity outcomes than prompt laser alone (Aiello, et al., 2011:5). This has meant that there is a significant increase in the ability of the ophthalmologist to treat DR and prevent blindness (Cook, 2013: 502).

Vitrectomy (surgical intervention), has been the mainstream treatment for the two blinding complications of advanced retinopathy – persistent vitreous haemorrhage and tractional retinal detachment (Cheung, et al., 2010:133).

2.1.8 Prevention of diabetes and diabetic retinopathy: primary, secondary and tertiary level.

End stage complications of diabetic retinopathy result in severe visual impairment which severely impacts on quality of life and leads to loss of productive life-years (Lopes, 2009:2). Diabetes exerts a heavy economic burden on society. This burden is related to health costs incurred by society in managing the disease, indirect costs resulting in productivity losses due to patient disability and premature mortality, time spent with family members accompanying patients when seeking care, and intangible costs (psychological pain to the family and loved ones)(Kirigia, Sambo, Sambo and Barry, 2009:2). This increasing incidence of diabetes with its subsequent complications in sub-Saharan countries such as South Africa places an even greater burden on health care systems already buckling under the challenges of diseases such as malaria, tuberculosis (TB) and human immune deficiency virus (HIV) (Zemlin, Matsha, Hassan and Erasmus, 2011:3).

At the primary care level, it can be emphasised that diabetes and diabetic retinopathy can be avoided by making healthier lifestyle choices (Winter & Yorston, 2011:2). Globally more than 1 billion adults are overweight and at least 300 million are obese, therefore personal responsibility and education about appropriate food intake and

weight loss and exercise is essential (Gardner and Gabbay, 2009:328). In many African countries, the diet is high in refined carbohydrates (for example, maize meal) (Burgess, et al., 2013:158). Cultural beliefs also play a role; many African communities still see weight gain as a sense of achievement. It signifies dignity, and respect, and shows that you're enjoying wealth and a good life. It is sometimes difficult to change a diet because of cultural and economic reasons (Burgess, et al., 2013:158). Being thin is associated with hardship, trouble at home and serious illness such as TB or HIV/Aids (Diabetes Tsunami hits South Africa (article online), (2013:4).

As the main focus in Africa remains on infectious diseases such as HIV/AIDS, tuberculosis (TB) and malaria, because of their acute nature, there is little awareness around diabetes and its complications Aids (Diabetes Tsunami hits South Africa (article online), (2013:4).

For the management of diabetes, the rate of compliance among patients to diet varied from 25% to 65% and for insulin administration it was about 20%. More than 20 studies published found that compliance with oral medication for type 2 diabetes mellitus ranged from 65% to 85% (Sklar, et al., 2008:269). Early diagnoses followed by good control of blood sugar and blood pressure will reduce the risk of diabetic retinopathy (Winter & Yorston, 2011:2). Patients with any degree of retinopathy and higher glycated haemoglobin (HbA1c) levels and blood pressure are more likely to lose vision than those with better control (Gardner and Gabbay, 2009: 328).

Subsequently, yearly eye examinations are recommended for all diabetic patients to prevent blindness. (Hartnett, Key, Loyacano, Horswell and De Salvo, 2005:387). The legal definition of blindness in England and Wales is 'so blind that they cannot do any work for which eyesight is essential' (Bunce and Wormald, 2008:905). Annual eye examinations would be classified as a secondary prevention.

Tertiary prevention would be to promote adherence to eye screening. The greatest risk factor for loss of vision due to diabetic retinopathy is failure to attend retinal screening and treatment. (Lewis, 2011:10). Non-attendance in chronic disease clinics is an ongoing problem that can increase a patient's vulnerability to serious complications and affect continuity of care (Paterson, Charlton and Richard, 2010:63).

2.1.9 Recommendations for adults with diabetes regarding the risk factors

All adults and children older than ten years of age, with type 1 diabetes, should have an initial dilated examination by an ophthalmologist, within five years of the onset of diabetes (Garg & Davis, 2009:140). In patients with type 1 diabetes, no clinically significant retinopathy can be seen in the first five years after the initial diagnosis of diabetes. However, within 10–15 years, 25–50% of patients show some signs of retinopathy. This prevalence increases to 75-95% after 15 years and approaches 100% after 30 years of diabetes (Crawford, Alfaro, Kerrison and Jablon, 2009:8). Most health professionals do not routinely refer diabetics for routine eye screening, but only when there is an onset of disrupted visual symptoms and complaints about eye sight (Zheng & Adelam, 2010:83). Puberty and pregnancy are well known risk factors for diabetic retinopathy in people with type 1 diabetes. It is often a challenging problem for these youths (Hanna and Woodward, 2013:132); therefore, planned dilated retinal examination should be considered for patients with type 1 diabetes after puberty and during the course of pregnancy (Cheung, Mitchell and Wong, 2010:125).

This is because people may already have type 2 diabetes, before they are aware of the symptoms and up to 20 % of patients with type 2 diabetes have retinopathy at the time of their diagnosis (Garg & Davis, 2009:140). Because the condition is often asymptomatic in its early phase, regular evaluation is critical in the management of diabetic retinopathy (Beynat, Charles, Astruc, Metral, Chirpaz, Bron and Creuzot–Garcher, 2009:50). They should have an initial dilated examination by an ophthalmologist at the time of their diabetes diagnosis (Garg & Davis, 2009:140), and yearly thereafter in people with type 2 diabetes (Cheung, et al., 2010:128). Complications begin at the time of diabetes diagnosis and most patients with diabetes do not have retinopathy, so the greatest therapeutic opportunity is to prevent retinopathy (Gardner and Gabbay, 2009: 329).

Apart from its effects on vision, the presence of retinopathy also signifies a heightened risk of life threatening systemic vascular complications. Presence of retinopathy in its mildest form is associated with a doubling or tripling risk of stroke, coronary heart disease and heart failure, independent of cardiovascular risk factors (Cheung, et al., 2010:124).

As reported by epidemiological studies, the major risk factors for diabetic retinopathy include: duration of diabetes, hypertension, and hyperlipidemia and, most importantly, hyperglycemia (Crawford, et al., 2009:8). To reduce the risk of developing sight threatening DR, the following recommendations are advised:

- Glucose levels between 5-7 mmol/l and always less than 10mmol/l (Thomas, et al., 2013:337). Diagnostic testing for glucose was significantly advanced by the development of home blood glucose testing and the ability to determine total glycosylated haemoglobin (HbA1c) (Rodriguez-Fontal, Kerrison, Alfaro and Jablon, 2009:3).HbA1c which is formed by the attachment of glucose to various amino groups of haemoglobin and has been used since 1977 for the long term (2-3 months) glycaemic control follow up of diabetes has recently been advocated by the American Diabetes Association (ADA) as a diagnostic tool. In 2009, the International Expert Committee of the ADA issued a statement proposing an HBA1c value of 6.5% (48mmol/mol) as a diagnostic level for the diagnosis for diabetes. This value was chosen, as it was found to be the value after which the incidence of retinopathy, a common complication that often is present before the actual diagnosis if diabetes is made is increased (Zemlin, Matsha, Hassan and Erasmus, 2011:2). 1% decrease in glycated haemoglobin (HbA1c) roughly equates to a decreased risk of retinopathy by 40%, progression to vision- threatening retinopathy by 25%, need for laser by 25% and blindness by 15% (Cheung, et al., 2010:125), and the effects are long lasting (Gardner and Gabbay, 2009:328).

- Blood pressure approximately 130/80 mmHg: A blood pressure > 140/90 is considered as hypertensive even if they are already on hypertensive treatment (Thomas, et al., 2013:337). 10mm Hg decrease in systolic blood pressure roughly equates to a decreased risk of retinopathy progression by 35%, the need for laser therapy by 35%, and visual loss by 50% (Cheung, et al.,2010: 124), so diabetic retinopathy does not invariably progress to vision loss (Gardner and Gabbay, 2009: 328).

- Lipids (Cholesterol) as follows: LDL-C less than 2.6 mmol/l, triglycerides less than 1.7 mmol/l and HDL–C more than 1.0 mmol/l (Mollentze, 2007:536).

Patients with elevated serum lipids at baseline are twice as likely to have retinal hard exudates as patients with normal levels (Rodriguez-Fontal, et al., 2009:6).

Ophthalmic practices might have to consider an approach to distribute a “know your numbers” brochure, i.e. know your blood glucose levels, cholesterol level, and blood pressure, so that the ophthalmologist can reinforce the importance of risk factors with their patients (Gardner and Gabbay, 2009:329), helping patients making the connection between eye disease and risk factors, and can motivate them to improve their health.

2.2. STUDIES IN SOUTH AFRICA/AFRICA

The health care provider system consists of a large and under-resourced public sector and a smaller, fast growing, private health care sector. Health care varies from the most basic primary health care, which is provided free by the state to ~80% of the population, to highly specialise services available in the private sector (Thomas, et al., 2013:336).

Mollentze, (2007:534) investigating diabetic care and when a specialist referral is needed, claims that diabetic care calls for a team approach. Diabetic care cannot take place in isolation (Navsa, 2003:599). Diabetic care in a resource- constrained environment like South Africa calls for creative ways to make optimal use of scarce resources, and acknowledges that there are still major pitfalls in the management of diabetic patients. The researcher indicates that diabetics in South Africa rely mainly on a medical practitioner or a professional nurse for basic diabetic care including diagnosis, routine follow up and referral depending on the caregivers’ knowledge, skills, and experience and time constraints. Since few primary healthcare nurses in South Africa are trained to screen for diabetic retinopathy, most patients at primary healthcare level will have to be referred to a skilled professional for evaluation (Amod et al., 2012:70). There is a major shortage of diabetic educators throughout South Africa. The major shortage of health workers around the world exists in the African region (Kirigia, Sambo, Sambo and Barry, 2009:2).

The reasons for this include the lack of appropriate accredited courses as well as the lack of appropriate remuneration for diabetic educators. Universities and colleges are

encouraged to develop a diabetes educators' curriculum and accredited courses. In the absence of such courses, the Diabetes Education Society of South Africa (DESSA), and the Society of Endocrinology, Metabolism and Diabetes of South Africa (SEMDSA) approved courses, should be recognised for accreditation. Diabetes educators should be reimbursed appropriately (Amod, et al., 2012:17). They claimed that diabetic retinopathy should be referred to an ophthalmologist as it is not always attainable for the primary care physician to do fundoscopy (Mollentze, 2007:538). Understanding how diabetes affects the neural retina may improve the means to diagnose diabetic retinopathy before symptomatic vision loss and may reduce the personal and economic costs (Gardner and Gabbay, 2009:328). Attempts to improve the rate of fundoscopy in the primary care sector have largely been unsuccessful (Mash, et al., 2007:1285). Given the capacity of the public health system and the financial constraints on patients, seeing an ophthalmologist is not feasible (Mash, et al., 2007:1285).

Winter and Yorston, (2011:3), recommended that managing diabetic retinopathy requires a partnership with many different health care workers to help find people with diabetes and to provide eye care, but it still remains a challenge. In a study conducted by (Mash, et al., 2007:1286) where 400 patients were screened over a period of three months in community health centres in the Cape Flats in the Western Cape Province, it was found that the commitment of some members of the chronic care teams in the retinal project was poor and varied, and some professionals perceived screening of patients as an increase to their workload, although it was rarely done in practice.

Using a sample of 248 consecutive patients with type 2 diabetes, Read and Cook, (2007:56) evaluated the retinopathy status of patients with diabetes in a Cape Town day hospital. In this study population of n=100% it was found that 23.6% (95% confidence interval (CI) 18.3–28.9%), had had previous fundal examinations at some stage of their diabetic history, but 5.2% (95% CI 2.4–8.0), had had regular annual fundoscopy as recommended. It was found that 4.4 % (95% CI 0.0–7.0%) had severe visual impairment due to diabetic retinopathy. It was evident that from these statistics that they were falling way short of the recommended screening protocols. 'Too little too late' probably best summarises the reality of diabetic retinopathy management generally in the public sector in South Africa. They also noted that the tertiary centres

in Cape Town who receive diabetic retinopathy referrals were already working way beyond their capacity (Read and Cook, 2007:56).

Cook, (2013:449), also noted that screening at a primary level is a challenge. Fewer patients are being screened for diabetic retinopathy due to the pressure of too many patients and de- skilling of health workers.

It was found that there was a general lack of awareness among the diabetic patients with regard to the existence of diabetic eye disease, and the importance of screening. Only 10.4% of the patients involved in the study were aware that annual fundoscopy was a requirement (Read & Cook, 2007:56). This emphasises education as part of the screening process. There is no sense of accepting responsibility for their condition (Mollentze, 2007:542). Some diabetic patients experience it as a challenge being diabetic. They had other medical conditions that constricted movement and found eye routine visits becoming a burden (Zheng & Adelam, 2010:82).

Mash, Levitt, Van Vuuren and Martell, (2007:50) recruited 15 facility managers to participate in their study exploring how the annual review of diabetic patients could be improved. The facility managers clearly saw the need to get patients to take more responsibility for and ownership of their condition. The importance of enabling patient self-management in chronic care was also emphasized, and had been highlighted by the World Health Organisation.

In an earlier study conducted by: Shah, Kamdar, and Shah(2009:120), using a sample of 300 patients, assessing the knowledge, attitude and practice of type 2 diabetic patients, the investigators found that despite eight years of average duration of diabetes, 46% knew the pathophysiology of diabetes and nearly 50% knew the complications of diabetes. It was encouraging to find that most still believed in self-care in diabetes. The majority could not afford to buy a blood glucose metre and hence, could not check their blood glucose levels regularly, and 40% still practiced the taking of herbal medication. The limitation of this study is that it only assessed diabetic patients and not diabetic retinopathy, but it gives one an idea of practices.

Dilated indirect ophthalmoscopy coupled with biomicroscopy and standard field stereoscopic 30 degree fundus photography are both accepted methods for examining diabetic retinopathy (Read and Cook, 2007:64). These methods require a degree in

ophthalmology training to assess the fundus accurately and medical officers in day hospitals do not normally stay beyond six months. This does not allow time for adequate ophthalmology training and screening (Read and Cook, 2007:64).

The medical doctors in the clinics are generally practitioners and not ophthalmologists, and the six month training they undergo during their studies is basic education on the management of eye problems, as they rotate between specialities. Posts for ophthalmic technicians and nurses needs to be officially created (Mash, et al., 2007: 1287). One of the major challenges facing the developing countries is the delivery of quality health care due to the financial constraints and lack of trained personnel (Kurji, Kiage, Rudnisky and Damji, 2013:57).

A convenience sample of consecutive non-attending diabetic patients was purposively recruited for the study by Ngwenya, van Zyl, and Webb, (2009:106) to investigate the factors influencing the non-attendance of clinic appointments in a diabetic clinic at a Gauteng hospital. During the study period 520 patients were booked for appointments, and 182 patients missed an appointment. All the patients stated that clinic appointments were important to them and they had various reasons for missing an appointment, with 22% of the responses being forgetfulness. The limitations of this study are that it was a diabetic clinic and not an eye clinic and results were based in the Gauteng public sector.

In a qualitative study conducted by Mshunqane, Stewart and Rothberg,(2012:392) using two focus groups, namely patients and professionals, explored patient's' knowledge about management of type 2 diabetes. Focus group 2 explored health care team experiences, barriers and facilitators of the management of the disease. In-depth interviews were held, using ten participants and eight health care professionals in the focus group 2. Five themes were identified: knowledge, education programmes, behaviour changes, support and the patient centred approach. The study was conducted at the Dr George Mukhari Hospital in Limpopo, South Africa. Some interesting barriers were highlighted in the five themes.

- Knowledge:

  There seems to be a lack of a teamwork approach to manage diabetes. A successful chronic disease approach is dependent on effective, systemic and

interactive communication between patients and service providers with whom they make contact.

A poor understanding of diabetic patients regarding their diet, exercise and medication management is mentioned. There needs to be emphasis on treating the disease continuously even if they don't feel sick. Patients noted lack of finances to manage the disease, especially with regard to food, and being unable to manage time, especially with adherence to medication. Some patients interpreted disease complications as fears.

- Education

Education programmes should be made more public, like the HIV programmes. Diabetic education should be more nurses-based.

Short consultation time and long waiting times were mentioned as barriers.

Cultural issues and stigma regarding diabetes were mentioned especially around losing weight.

There also seems to be a great lack of education amongst patients regarding the need for screening (Cook, 2013:449).

- Behaviour

Not accepting the condition was mentioned as a barrier. It is important to determine the patient's behavioural intention; it will determine the patient's attitude toward the disease, and one needs to understand the attitudes and norms that drive the behaviour. If someone strongly believes there is a cure for the disease, it is very difficult to convince them otherwise. A positive attitude will motivate patients to comply and negative patients will be less motivated.

- Support

Low socio-economic conditions, access to health care and utilisation of medical services were reported as issues of concern. There is a general lack of support from families and friends.

- Patients-centred approach

Limited time for consultation with the doctor was seen as a reason for non - adherence. Additionally, not applying a holistic approach to disease management, was also viewed as a reason for non- adherence.

Ayele, et al., (2012:4), found that the majority of the participants were females (60.4%). The majority, (93.7%) had general knowledge about diabetes and 93.2% had specific knowledge about diabetic self-care. A large proportion of participants had moderate perceived susceptibility (78.4%) and severity (50.5%). 67.1% had less perceived barriers. 13.5% of them had high self-efficacy to self-care practices related to diabetes but only 39.2% followed the recommended self-care practices.

In conclusion the South African literature review highlights the difference in the health care system Thomas et al. (2013) clearly states that the most basic health care is provided by the state to ~80% of the population. The private section is much smaller, but fast growing. Mollentze (2007), as well as Navsa (2003), claims that the public sector is under resourced and that there are many pitfalls in the management of diabetic patients. Amod et al. (2012) agrees with Winter and Yorston (2011), Mshunqane et al. (2012) and Gardner and Gabbay (2009) that the management of diabetic retinopathy requires a partnership and skilled primary care givers is needed. There need to be more courses available for diabetic educators, as staff needs more training, nursing and medical doctors. Mash et al. (2007), and Read and Cook (2007) and Cook (2013), highlighted that given the capacity of the public health system and the financial constraints of the patients, seeing an ophthalmologist is not always feasible, and that the staff is already working beyond their capacity. Screening for diabetic retinopathy requires skill which is mostly not achieved as medical officers in training do not normally stay beyond six months. This does not allow time for adequate training and screening. Screening for diabetic retinopathy remains a challenge.

Ayele et al. (2012) agrees with Mash et al. (2007) and Read and Cook (2007) that patients does not accept responsibility for their condition and does not follow a self-care regime. Cook (2013) also mentions that there seems to be a lack of awareness and the importance of screening amongst patients.

Ngwenya et al. (2009) mentions a few reasons for non attendance ranging from plain forgetfulness, whereas Shah et al. (2009) and Mshunqane et al. (2012) explores other barriers to non attendance like lack of finance, poor understanding, lack of education, stigma, attitude and practices, support and a lack of a holistic approach from health care givers.

2.3 INTERNATIONAL STUDIES

Countries such as the United Kingdom have well established national screening programmes for diabetic retinopathy and all primary health care trusts are expected to have screening uptake rates of more than 98%, ideally 100%. The service objectives of screening programmes include early detection of sight threatening disease and timely referral of these patients to medical retinal services for treatment, with the aim to decrease the rate of blindness due to diabetes-related ocular complications by offering timely treatment (Sivaprasad, et al., 2012:21).

In a qualitative study done by Lewis, (2011:4) involving focus groups and interviews in a rural and urban area to identify some of the reasons why patients fail to attend diabetic eye examinations, it was noted that even though most United Kingdom patients knew that diabetes could affect their eyes, many were not aware that it could lead to severe visual impairment and blindness. There was also a loss of confidence in the health services in the United Kingdom, which led to non- attendance.

A few more reasons were stated in the study by Lewis, (2011:4) such as getting time off work, transport issues in rural areas and clinic waiting times. Cost was noted as a major barrier where patients have to pay for an eye examination and laser treatment (Lewis, 2011:3).

In a cross–sectional study conducted by Khan, Lateef, Al- Aithan, Bu–Khamseen, Ibrahim and Khan, (2012:26) during the period of June 2010 to June 2011 with a sample of 535 diabetic patients in the Al Hasa district in Saudi Arabia, the purpose of the study was to measure the rate of non-compliance and the factors contributing to non-compliance among the diabetic patients. A total of 468 patients participated in the study; 67 refused, giving a response of 87.47%. Regarding the missed appointments it was noted only 7.9% attended regularity, 49.4% missed once or twice and 41% more than once. Reasons mentioned were no transport, forgot the appointment, and some considered the appointment unnecessary (Khan, Lateef, Al- Aithan, Bu–Khamseen, Ibrahim and Khan, 2012:30). Again this study was conducted in a public sector and mainly on diabetic patients and the drug regime, but not with regard to their eyes. Interesting to note was that most of the non-compliant patients were male, and urban area non-compliance was higher as well as those with lower education levels.

Neal, Hussain–Gambles, Allgar, Lawlor and Dempsey, (2005:1) also conducted a study investigating the reasons for missed appointments as it was a common occurrence in primary care in the UK. A postal questionnaire survey and prospective medical notes were reviewed of adult patients missing appointments and the comparison group who attended appointments over a period of three weeks in seven general practices in West Yorkshire. Of the 386 whom missed appointments, 122 responded (32%). Of the comparison group 223 (58%) responded, resulting in 23 case–controlled pairs with complete data collection. Over 40% of the individuals who missed an appointment and participated said that they forgot the appointment and a quarter said that they tried very hard to cancel the appointment, or that was an inconvenient time. A fifth recorded family commitments or being too ill to attend. Older people attended more and also missed at least one appointment more than a year ago. However, estimates for comparison between those who missed appointments and the comparison group were imprecise due to the low response rate.

Only one study has investigated patient's' issues to missing appointments; participants in this study did not feel obliged to keep an appointment in part because they felt disrespected by the health care system.

Boucher, Nguyen and Angioi, (2005:737) conducted a study in Canada evaluating the factors of non-compliance with yearly screening examinations. Out of n=267 (100%) patient's questionnaires that were evaluated, n=54 (9.7%) of those patients had not been screened for over two years; n=15 (28.3%) stated negligence as the main reason. Other reasons for non-compliance with the guidelines included difficulty getting an appointment, the unpleasantness of the examination, and some did not think that the examination for diabetic retinopathy was important. Interestingly n=14 (93%) suffered from type 2 diabetes; all were aware that diabetes represents a threat to vision and they even had a personal acquaintance living with a visual handicap related to diabetes. Further analysis revealed the presence of non-compliance in all socio-economic classes.

It is important for diabetics to comply with their medication, but also with diet, exercise or lifestyle changes (Sklar, et al., 2008:269). A study was done in Texas (USA) by Ramirez, (2008:85). 50 participants with type 2 diabetes were surveyed on a 1-1 basis to identify the factors that causes non-compliance to a health care plan. The survey

focused on diet, medication, physical activity and behaviour. Interesting results included that out of the 50 participants 70% were woman, and 42% were between 51 and 60 years of age. Education levels were equally distributed between elementary and high school levels. 24% lived a sedentary lifestyle and did not exercise. 19% stated that they had no time to exercise. Whereas all were prescribed a healthy diet, only 68% claimed to follow the diet. 24% were not aware of what kind of diet makes a difference in the control of type 2 diabetes. 2% only took insulin when they felt ill, though it was prescribed to them. When asked if they followed the recommendations of their physicians, replies followed such as meal plans were difficult to follow, they used natural remedies to treat diabetes and poor family support. It was clear from this study that the community needed a public health intervention and an information campaign (Ramirez, 2008:86). This study did not touch any eye care recommendations, and just focused on diet, medication and exercise.

Currently means to screen populations at risk of diabetic retinopathy have succeeded in Europe but have had minimal effect in the United States, where individuals are more independent, health care delivery is more fractionated, and population-based incentives for prevention are less. Hence many patients still visit eye care providers with advanced eye disease (Gardner and Gabbay, 2009:328). That clearly indicates that eye care is more palliative (mainly scattered photocoagulation and vitrectomy's), and that does not restore normal vision function. The management of diabetic eye diseases lies in the hands of non-ophthalmic physicians, that mean primary preventative measures, and it is not happening in America. Surgically orientated approaches to late stage eye disease fail to adequately address the Astruc current public health problem, so future efforts must focus on prevention and early intervention, and the role of the ophthalmologist must evolve (Gardner and Gabbay, 2009:328).

In a study conducted by: Beynat, Charles, Metral, Chirpaz, Bron and Creuzot–Garcher, (2009:49-56) in a rural French population of Burgundy where diabetics were screened using a non-mydriatic camera, the aim of the study was to evaluate the yield of diabetic retinopathy screening in a rural population. 1974 patients were screened; there were 103 patients with diabetic retinopathy. In the study some barriers were identified. The barriers to the poor compliance in the study were highlighted as follows: a lack of awareness of the need for eye care especially in the absence of symptoms.

A study conducted by: Chou, Sherrod, Zhang, Barker, Bullard, Crews and Saaddine, (2014:180-188) analysed data from 2006 to 2010 from the Behavioural Risk Factor Surveillance System (BRFSS) database from 22 states in the United States of America. The BRFSS is an annual state-based random-digit-dialled telephone survey of the noninstitutionalized U.S. It was designed to provide information on sociodemographics, chronic illness, health behaviours and access to health care. They examined barriers to recommended eye care among people aged >40 years with diagnosed diabetes. The sample included 27,699 respondents aged >40 diagnosed with diabetes. The most common reported reasons for not receiving eye care in the preceding 12 months were “no need” and “cost and lack of insurance” (39.7% and 32.3%, respectively). Other reasons mentioned were “no eye doctor available”, “no transportation” or “could not get an appointment” (6.4%) and “other” (21.5%). 51% among those with diabetes not seeking eye care were woman and they were in the lower income group, therefore “cost or lack of insurance” was often the main reason given by woman (40.1%). In contrast, “no need” was the reason most commonly given by men (49.6%).

Although this study was conducted in 2004 by: Lacy, Paulman, Reuter and Lovejoy, (2004:54-545), the reasons mentioned are still relevant. The study was conducted in an urban family practice setting in the US to identify the reasons given by patients for not keeping their scheduled appointments. Semi-structured interviews were conducted with 34 adults coming to the clinic for patient care; therefore a qualitative method was used. Participants were selected from sequential patients arriving on selected days in July 2001 and they represented those who were able to overcome attendance barriers at least part of the time. Participants identified three types of issues related to missing appointments without notifying the clinic staff: emotions, perceived disrespect and not understanding the scheduling system. Fear and anxiety was also mentioned about possible procedures and possible bad news. 32 woman and two men were interviewed: all the respondents were adults, 5.8% were African American, 3.7% were European American and the remainder 4% were Hispanic Americans. Twenty-two (65%) mentioned emotional barriers. At times, the negative emotions about going to see a doctor were greater than the perceived benefit of keeping an appointment. Participants described a sense of urgency in scheduling an appointment only when illness struck. Fifteen participants (44%) commented on issues of respect by the

health care system. They were especially annoyed by the waiting time, both in the waiting room and in the examination room. Forty-one percent (41%) of the participants indicated that they did not know what happened in a clinic if they missed an appointment. They believed a no show was actually a positive event for the clinicians and the staff; therefore, they were not aware what a negative impact it had on the work flow and clinic in many ways. Consistent with previous literature/published findings, seven respondents blamed transportation, and three participants identified child care as an issue.

A study conducted in 2011 by Snow and Fulop, (2011:257-259) investigated 'did not attend' rates for the clinic in South East England. Young adults with type 1 diabetes were interviewed. Three types of data was collected: (1) attendance records were analysed for 231 appointments for 102 individuals from November 2008 to May 2010; (2) semi-structured interviews were carried out with 17 patients registered at the young adult clinic; (3) the appointment and cancellation telephone line was monitored over a three week period. Using the data as described above, a purposive approach to sampling for the interview study was employed with 17 participants (nine men and eight women) selected on the grounds of relevance to the questions driving the research – in this case, attendance behaviour. The 'did not attend' rates for the clinic over the period of the study were 15.7%. It was mostly attributed to communication failure and bureaucratic problems. Most weighed the importance of attendance against immediate obstacles such as incompatible work/clinic hours. Respondents also identified fear of being judged for 'poor control' as a major factor in attendance decisions suggesting the higher HbA1c level the less attendance was recorded. The limitation of this study is that is difficult for participants to book an appointment as they had to call in to a telephone operated queuing system and waiting time for an appointment over the phone can last up to 20 minutes. It was a young age group of type 1 diabetic patients and they felt they needed more reminders regarding their appointment time and date, and because of the age group and work commitments, appointments were not flexible and many occasions work was not flexible either. More men were interviewed than woman in this particular study.

A study was conducted in 2010 by: (Paterson, Charlton and Richard, 2010:63-74) with the aim to identify personal, contextual and mediating factors that influence non–attendance in speciality chronic disease clinics. As a methodology literature was

obtained by an extensive search of health and social science computerised journals. Twenty - eight research studies met the criteria for inclusion in the review. Twenty - two of the research studies were quantitative surveys; four were qualitative studies that drew on interviews as the primary data collection strategy, and the remaining two combined both qualitative and quantitative methods. Analysis revealed a myriad of factors encompassed as personal, clinical factors and factors pertaining to nature and the operations of the clinic. Some of the personal and clinical factors mentioned were unacceptable HbA1c levels associated with non-attendance; while clinical factors indicated that people with chronic disease fear that the practitioners will chide them for neglecting their health and, therefore, do not attend scheduled appointments. The primary fear was fear of bad news, fear of the unknown and fear of the treatments. Depression and anxiety were related to the person's inability to attend appointments. Forgetfulness was also determined to be a common reason for non-attendance in several studies (Paterson, Charlton and Richard, 2010:69). A number of studies, especially the qualitative studies, identified employment, conflicting work schedules and difficulty leaving work. Living alone was determined in one study to be a significant predictor of non-attendance; however, most studies did not specifically examine this factor in their survey or interviews.

Although the general emphasis in research on non-attendance has been on personal attributes of the patient, there is an increasing body of research that that explores the health system factors that influence non- attendance, such as lack of accessibility, administration errors, design and delivery of programmes, communication and patient provider relationships, like long waiting times to see the health practitioners or to receive the appointment. It was a major barrier for young people who transitioned from paediatric to adult clinics. Non-attendance indicated rather being 'unable' to attend instead of being 'unwilling' because of their work commitments and/or ill health. Transportation difficulties were also mentioned as a barrier (Paterson, Charlton and Richard, 2010:70). Some participants claimed that the design and delivery of programmes did not meet their expectations (Paterson, Charlton and Richard, 2010:71). Practitioner factors included dissatisfaction with the consultation process, perceiving the care providers regimental and paternalistic. It was noted that these factors applied mostly to follow up appointments instead of first time attendees. Some patients felt that clinic staff disregarded their beliefs, opinions and time commitments.

Some patients in another study suggested the physician's lack of rapport, empathy and understanding, as a reason for non-attendance (Paterson et al., 2010:71).

In conclusion the international study also highlighted the health system. Sivaprasad et al. (2012) mentioned that the screening programme are more established and reaches 98% of the population for screening, although the aim is 100%. Lewis (2011), Lacy et al. (2004) and Neal et al. (2005) mention a loss of confidence in the health care system where patients feel disrespected and do not understand the appointment system. Patients in general are not happy with the administration errors, the design and delivery of the programme and the communication between the patient and the providers. Gardner and Gabbay (2009) states that patients are mostly aware of diabetes and the effect it has on eyes but Chou et al. (2014) states that patients still visits doctors with advanced retinopathy. Boucher et al. (2005), Chou et al. (2014) mentions negligence as a main reason for non- attendance. In the absence of symptoms, patients do not feel the need to see an ophthalmologist. Ramirez (2008) mentions diabetic self care as a challenge. Paterson et al. (2010) and Lewis (2011) mention forgetting an appointment as a major barrier, but also fear and anxiety. The negative emotion about seeing a doctor perceived the benefit of keeping an appointment. Snow et al. (2011) and Chou et al. (2014) mentions working hours not being flexible to appointment times

2.4 SUMMARY

In the literature review various reasons are given as to why patients with diabetes fail to attend follow up visits on a yearly basis as recommended. Various studies revealed patients' reasons for non-attendance, exploring all the possibilities including patients' attitudes, beliefs and practice/behaviour, as well as the state of health care facilities, staff knowledge and skills, and general attitude/commitment of staff. International studies seem to reveal the same barriers regarding diabetes eye screening, despite being developed countries. Diabetic retinopathy is explained in detail as part of the literature review to give some insight into the disease.

In the next chapter the methodology of the study will be presented.

CHAPTER 3

METHODOLOGY

3.1 INTRODUCTION

This chapter discusses the research design and the methodology that was used to conduct the study. It includes the study setting, study population, sampling approach and method, sample size, inclusive and exclusive criteria, the measurement instrument, validity and reliability of the instrument, data collection method, data analysis and ethical consideration.

3.2 RESEARCH DESIGN

The study followed a quantitative research approach and a descriptive correlation research design. This design was deemed appropriate for this study since the researcher was interested in determining the relationship among factors such as knowledge, confidence, fear and anxiety, and adherence to yearly eye reviews in diabetic patients, as well as to find the reasons for non-attendance at yearly reviews among the non-adherent group of diabetic patients.

3.3 THE STUDY SETTING

The study was undertaken in one of four private ophthalmic practices in East London which consists of a private practice, a clinic and the East London Eye Hospital (ELEH). East London is in the Eastern Cape Province of South Africa and is an urban area. The private practice is situated in a popular suburb in East London which is easily accessible by private or public transport. The ophthalmic practice caters for all patients (rural and urban), and also developed the African Eye Foundation (AEF) to help less fortunate patients if surgery is needed. Higher socio - economic patients, and those on a medical aid/insurance, mainly get referred here but there is also a clinic that caters for patients not on a medical aid. The private practice consists of two ophthalmologists, a qualified ophthalmic professional nurse (ON), two ophthalmic assistants (OA) and two optometrists directly involved in diabetic eye screening. The

support team consists of other registered professional nurses and nurses, administration/reception and accountant staff. The working hours are from 08h00 until 17h00, Monday to Friday, and diabetic patients gets seen and reviewed for diabetic retinopathy on a daily basis.

3.4 THE STUDY POPULATION

The target population is all adult diabetic patients, 18 years and older (some self - referrals, others referred from general practitioner's (GP's), physicians and optometrists based in the East London and Buffalo City Municipality area), attending the practice during the study period irrespective of whether they complained of visual problems or not. Some were seen by an ophthalmologist in the past, some have missed their yearly appointments and others are new patients. A minimum of five diabetic patients gets referred for review daily, which translates to approximately 100 patients a month.

3.5 THE STUDY SAMPLE APPROACH AND METHOD

A probability stratified random sampling was used as a method. It is used in situations which the researcher knows some of the variables in the population that are critical in achieving representativeness. Variables commonly used for stratification are age, gender, ethnicity, socio-economic status, diagnosis, geographical region, type of institution, type of care and site of care. In stratified random sampling, the subjects are randomly selected on the basis of their classification into the selected strata (Burns and Grove, 2005:348).

A total of 300 diabetic patients were randomly selected for the study. The participants were sampled in a stratified way such that each level of compliance was equally represented. The dataset was acceptably complete with very few missing values. The distribution of the participants across the different biographical variables was cross tabulated by compliance with annual reviews. Of the 300 participants, 151 (50.3%) were compliant.

3.6 SAMPLE SIZE DETERMINATION

About 500 patients visited the private practice during the period of study. To determine the sample size and hence the number of questionnaires to be distributed the margin of error, confidence level and response rate were considered. The definitions of these concepts are given below:

Confidence level: This is a measure of how sure the researcher needs to be that the sample accurately represents the population, expressed as a percentage (Krejcie and Morgan, 1970:610).

Margin of error: This is a measure of how close to the true population parameter the researcher wants his results to be, expressed as a percentage. For categorical data, a 5% margin is acceptable (Bartlett, Kotrlik & Higgins, 2001:45).

Response rate: The proportion of the population that is expected to complete and return the questionnaire, expressed as a percentage. “Take the sample in two steps, and use how many additional responses are used based on the variance observed in the first step, and use the pilot study results to determine variances in sample size” (Bartlett, et al.,2001,45).

A confidence level of 95% (Bartlett, et al., 2001, 43-50), and a margin of error of 5% (Krejcie et al.,1970:45), are reasonable choices for most social science research studies. In their 2001 paper, Bartlett et al, (2001:43) developed and presented a sample size determination table that is currently being used in most social science research. Based on that table and with a population size of 500, a confidence level of 95% and a margin of error of 5%, the most appropriate sample size for this study were found to be 218. However, the sample was increased by 37%, making a total of 300 participants. The increase was made in order to cater for incomplete questionnaires.

3.7 INCLUSION CRITERIA

All adult diabetic patients 18 years and older who attended the private eye practice, who missed the doctor’s appointment, were included. They needed to be able to communicate in English or IsiXhosa.

3.8 EXCLUSION CRITERIA

The researcher excluded all patients who were not clinically diagnosed as diabetic, as well as those patients whose sight has already been affected by advanced diabetic retinopathy.

3.9 MEASUREMENT INSTRUMENT

The Diabetic Retinopathy Patient Questionnaire (DRPQ) was used to collect data. DRPQ is a semi-structured questionnaire, developed by the researcher with the help of her supervisor. As the participants was private patients but still defaulted attendance we wanted to determine if, specifically knowledge about the disease and diabetic retinopathy, confidence level in their control of the disease and the staff treating them as well as enquiring if fear/ anxiety played a role in non-attendance and attendance. The open ended question was added to explain the reason/s for non attendance. The questionnaire was available in English and isiXhosa; however, the majority of the participants preferred the English version of the DRPQ. It consists of two sections, namely section A and section B (Appendix 2).

Section A covered demographical and general health; age, gender, ethnic origin, marital status, education level, employment, religious affiliation, medical aid status and in general how the participant perceived their heath either as excellent, very good, good, fair or poor. Section A also asked participants to include the year they were diagnosed as a diabetic and if they had ever seen an eye doctor in the past if the visit was more than a year ago.

Section B covered diabetes and eye care. Seven statements were presented regarding knowledge and attitude, using a Likert scale with a score from 1 to 5. One (1) - indicates “strongly disagrees”, (2) - “disagree”, (3) - “neutral/not sure” (4) - “agree” and (5) - strongly agree.

Statements 8- 19 explored the confidence in the participant’s’ ability to control their diabetes as well as their confidence in the health professionals who cared for their eye disease.

The confidence in professional personnel was also measured using a Likert scale with a score from 1 to 5: (1) – “not at all confident”, (2) – “not very confident”, (3) – “neutral” 4 – “confident” and (5) - “very confident”.

Statements 20 to 26 explored the fear and anxiety regarding their eye condition using a Likert scale with a score from 1 to 5: (1) - “none of the time”, (2) – “some of the time”, (3) – “a good bit of the time”, (4) – “most of the time”, and (5) – “all the time”.

The researcher also added an open ended question at the end of the questionnaire, asking the participants to explain the reason/s for not attending their eye appointments.

3.10 VALIDITY AND RELIABILITY OF THE INSTRUMENT

3.10.1 Validity

Two ophthalmologic nurses, the supervisor and the statistician were requested to check the instrument for face and content validity. The pilot study consisted of 30 participants which is 10% of the sample. It was found that questions in the instrument overlapped creating a predictable response. Modifications were done on the instrument to the satisfaction of the parties concerned. Certain questions in the questionnaire were changed and rephrased in different section of the questionnaire, to create clarity and produce a different response relevant to the study.

3.10.2 Reliability

The researcher determined representative reliability by undertaking a pilot study. Reliability demonstrates the consistency of the measurement (Rossouw, 2003:112). A pilot study was conducted to test the questionnaire for clarity of questions. Ten percent of the sample, i.e.30 patients, participated in the pilot study. These participants were excluded from the main study research. Reliability was also checked using Cronbach’s alpha coeffient. The five clusters variables of behaviour, control, knowledge, stigma and satisfaction had high Alpha coefficients ranging from of 0.7 to 0.8. While three variables; appointments and sight changes, treatment cost, induced anxiety/fears

about eyesight deterioration had low Alpha coefficients of 0.48.0.61 and 0.63 respectively.

3.11 DATA COLLECTION

A participant was asked to participate voluntarily as they arrived at the private practice. All the participants met the inclusive criteria, which was adult diabetic patients over the age of 18, who missed their follow up appointments. Those participants with advanced diabetic retinopathy were not asked to participate. The instrument was fully explained and consent was signed before seating in a designated room for privacy. Copies of the research information as well as the researcher's details were given to the participants (Appendix 3). It took approximately five to 10 minutes to complete the measurement tool. The data was collected and verified by the researcher for completeness and consistency. Questionnaires found to be incomplete were excluded.

3.12 DATA ANALYSIS

Measures and central tendencies were checked and expressed in terms of percentages and tables. The inferential statistics were also conducted to determine the relationship amongst the variables. Chi square tests were used to determine the relationship amongst categorical variables and eye reviews. Spearman's correlation analysis was carried out to determine the association amongst the variables, (behaviour, control, knowledge, stigma and satisfaction).

The reasons for non-compliance were determined by using an open ended question. The reasons were clustered into nine main concepts: 1) lack of information, 2) negligence, 3) busy work schedules, 4) lack of finances, 5) no referrals from general practitioners and optometrists, 6) commitment to other illnesses, 7) stigma and fear of diagnosis, 8) poor public medical services, 9) other**.** (Appendix 1 and Appendix 2)

3.13 ETHICAL CONSIDERATIONS

Permission was obtained from the University of Fort Hare Research Ethics Committee (Appendix 6) and the Eastern Cape Department of Health Research Ethics Committee (Appendix 5) as well as the ophthalmologists at the private practice (Appendix 4) to conduct the study.

When approaching patients to participate in the study a verbal discussion took place providing the participants with understandable information in the form of an information sheet. The information sheet included a summary of the research project, an explanation regarding participation in the research project as well as aims and objectives of the study. The information sheet clearly stated the voluntary nature and also indicated that participants were free to decline to participate. All efforts were made by the researcher to ensure that participants understood before participating in the research project. The benefit of the study was explained, and that no risk was anticipated.

The patients who participated in the study were asked to sign a written consent form. Throughout the study confidentiality and anonymity were be maintained, by not mentioning the participants' names, therefore protecting the rights and dignity of the participants. Participants' care was not influenced by participating in the study as the researcher was not involved in direct care for management of their retinopathy.

3.13.1 Respect for persons

The researcher protected the participants from any discomfort and harm, by ensuring privacy and anonymity. The designated room was equipped with a suitable functional/safe chair to sit on with a functional desk and stationary, as well lit room. Any signs of distress were monitored by the researcher while participants were busy filling in the questionnaire, thereby supporting the principal of respect.

3.13.2 Privacy

The researcher supported the participants' right to privacy. This was ensured by anonymity. There was no identification on the questionnaire, only an allocated number for data purposes, therefore supporting the principle of beneficence and justice.

3.13.3 Confidentiality

Patient confidentiality was maintained throughout the study. The researcher will ensured that any data gathered during the study was not divulged or made available to unauthorised people. In cases where the information may need to be published for the benefit of other researchers, the researcher will keep the participants' details anonymous. Data gathered will be kept in a secure place.

3.14 SUMMARY

In this chapter the methodology and research design was explained, as a quantitative approach and a descriptive correlation design was followed.

The design was found to be appropriate since the study sought to find out the relationship among the factors such as knowledge and anxiety and adherence to yearly eye reviews. The study also aimed to find out the reasons for non-adherence to the yearly eye reviews. Chi square tests were used to determine the relationship amongst categorical variables and eye reviews. Spearman's correlation analysis was carried out to determine the association amongst the variables- (behaviour, control, knowledge, stigma and satisfaction). The next chapter will be a representation of the results/findings.

CHAPTER 4

PRESENTATION OF FINDINGS

4.1 INTRODUCTION

In the previous chapter, the researcher discussed the research methodology. This chapter deals with the presentation and interpretation of the results of the statistical analysis of the study data. Cross tabulations of the categorical variables by compliance with annual eye reviews were used to show the distribution of participants. The chi-squared test was used for testing for significance of any associations between the categorical variables and compliance with annual reviews. Where significant associations were detected, follow up tests for the strength and direction of the associations were carried out using odds ratios and these are presented together with their corresponding 95% confidence intervals. All tests for statistical significance were carried out at a 5% level of significance.

4.1.1 Sample description

A total of 300 diabetic patients were voluntarily selected for the study. The participants were sampled in a stratified way such that each level of compliance is equally represented. The dataset was acceptably complete with very few missing values. The distribution of the participants across the different biographical variables was cross tabulated by compliance with annual reviews. Of the 300 participants, 151 (50.3%) were compliant.

The results show that there were more females than males, 166 (56.3%), more Africans than any other ethnic group, 168 (57.1%), more married people than any other marital status group, 183 (61.0%), more Christians than any other religion, 227 (92.3%), and more living with their families than any other living arrangement, 223 (74.8%). Of these variables five (1.7%) missing values were recorded for gender, six (2%) for ethnicity and two (0.7%) for living arrangement while marital status and religion were complete. The majority of the participants had a secondary school education, 130 (43.3%), and most felt that they were in good health, 148 (49.3%). As

for payment of medical expenses, 255 (87%) had a medical aid and 147 (51.6%) last visited a doctor more than a year from the date of data collection.

4.1.2 Variable derivation

Variable cluster analysis was used as a means of data reduction. This analysis revealed eight item clusters with two to five items. To determine if the item clusters reliably measured the same construct, the Cronbach's alpha coefficient was used. Based on that analysis, only five of the eight clusters had Cronbach's alpha values of at least 70% while the remainder had reliability coefficients less than 70%. The items within each of the five item clusters that had reliability coefficients of at least 70% were combined into a single variable. The new variables were derived as arithmetic means of the items within the cluster. This variable derivation procedure is preferable because it maintains the variables within the same range of values as the original items, which makes it easy to link interpretations to the original scale of measurement.

For any onward analysis, the derived variables were used in place of the items they represent. Those items in clusters with low reliability were treated as individual variables in the onward analysis. As such, the 26 items used in this study were reduced to five derived variables and nine items that were treated as standalone variables. The five clusters resulted in five variables labelled as behaviour, control, knowledge, stigma and satisfaction as listed in the table below.

Table 4.1: Results of cluster analysis

Cluster	Items in cluster	Cronbach's alpha	Cluster label
1	KA5, KA6, CONF14, CONF15, FA24	0.70	Treatment seeking **behaviour**
2	CONF8, CONF9, CONF10, CONF11, CONF12	0.70	Diabetic **control**
3	KA1, KA2, KA3	0.72	Diabetic **knowledge**
4	KA4, KA7	0.80	**Stigma**
5	*FA20, FA21, FA22, FA23*	*0.63*	Fears about eyesight deterioration
6	*FA25, FA26*	*0.61*	Treatment cost induced anxiety
7	CONF16, CONF17	0.76	**Satisfaction** with medical services
8	*CONF13, CONF18, CONF19*	*0.48*	Appointments and sight changes

4.1.3 Distributions of patients by biographical characteristics cross tabulated by compliance

Cross tabulations of the patients by compliance with each of the variables was carried out. These are shown as tables in the appendix and are presented below in the form of bar charts for the biographical characteristics only. Below each bar chart is a brief interpretation. The results of this analysis were followed up with tests for significance of potential associations.

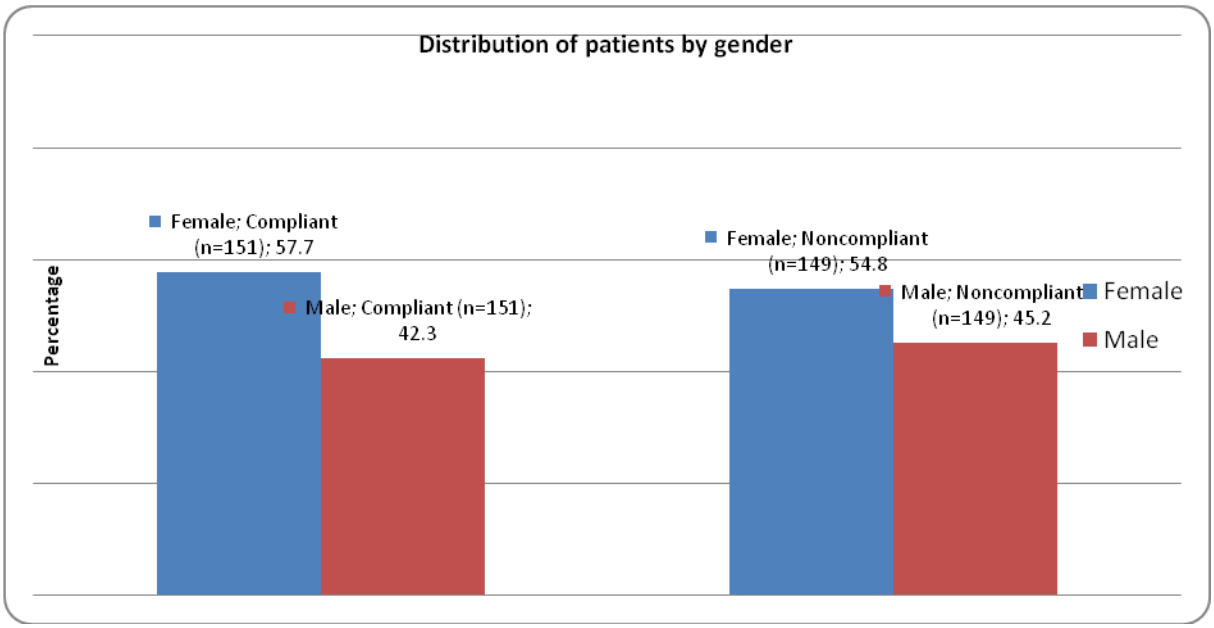


Figure 4.1: Distribution of patients by gender

The distribution is the same for the two compliance groups with females being slightly more than males. This suggests that compliance with annual reviews may not be related to the gender of the patient.

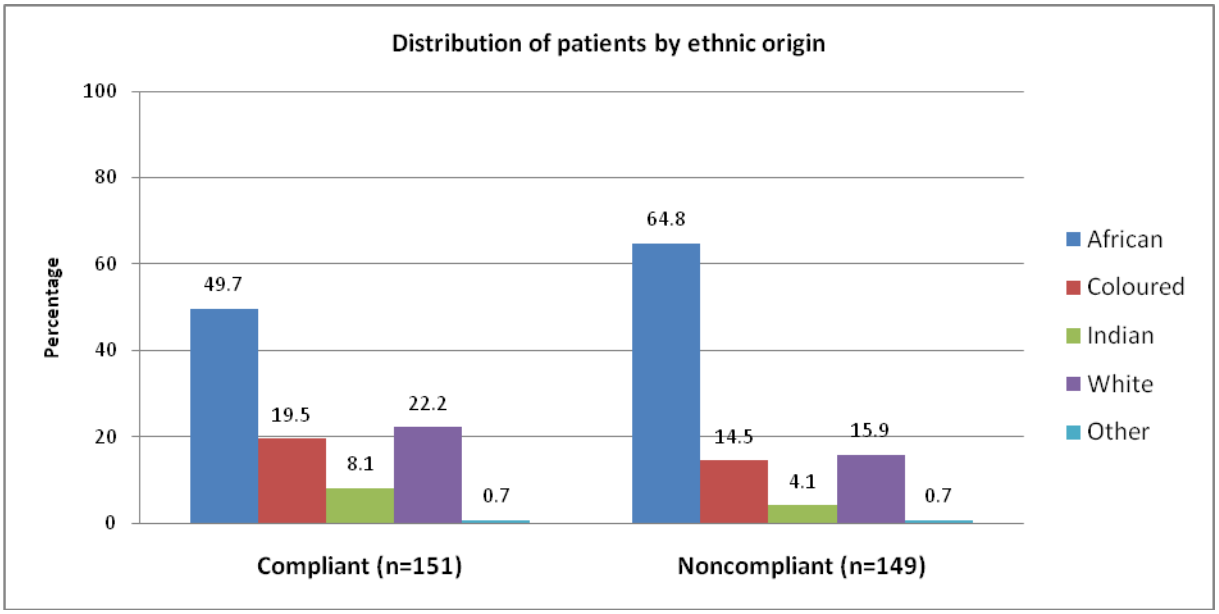


Figure 4.2: Distribution of patients by ethnic origin

Similar to the distribution across gender, the distribution of patients across ethnic groups within each compliance group is the same. Africans are in the majority followed by coloureds, whites Indians, and lastly, other ethnic groups in both compliance groups. There seems to be more noncompliant than compliant Africans as suggested by the 64.8% noncompliant Africans compared to 49.7% compliant Africans. This suggests that there may be a relationship between ethnicity and compliance with annual reviews.

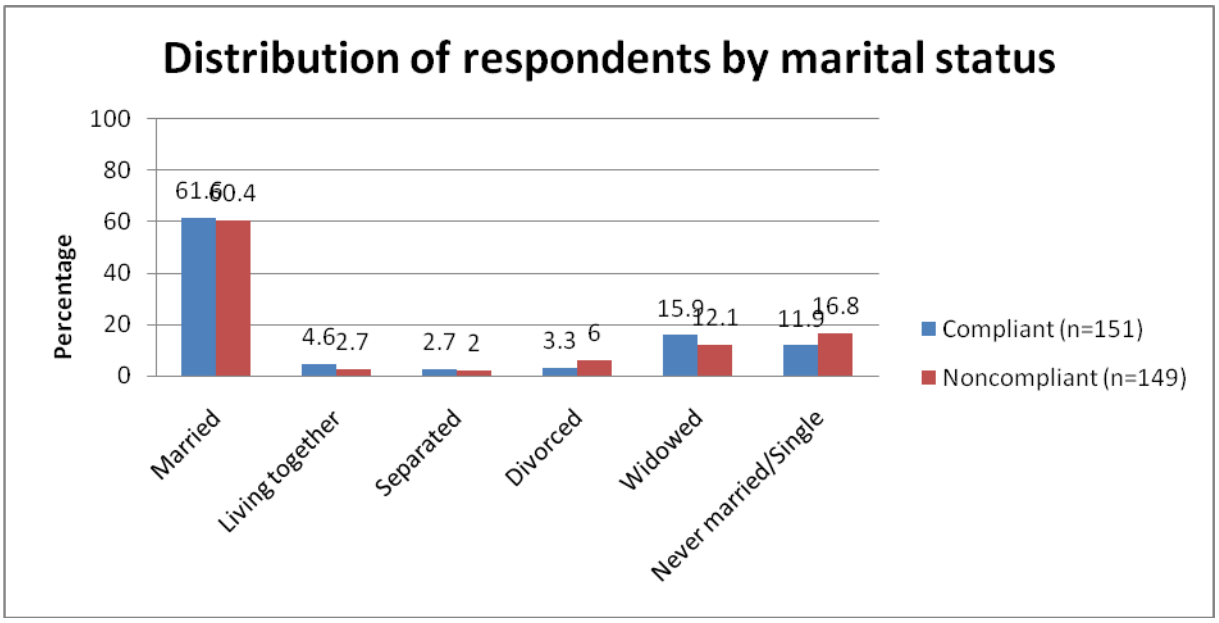


Figure 4.3: Distribution of respondents by marital status

In terms of marital status the two compliance groups are the same. In both cases, the married patients are in the vast majority with 61.6% compliant and 60.4% noncompliant. These were followed by widowed and single/never married whose percentages were in the teens and the last three were cohabitation, divorced and separated whose percentages were in the lower single digits. These bar charts suggest that compliance may not be related to marital status of the patient.

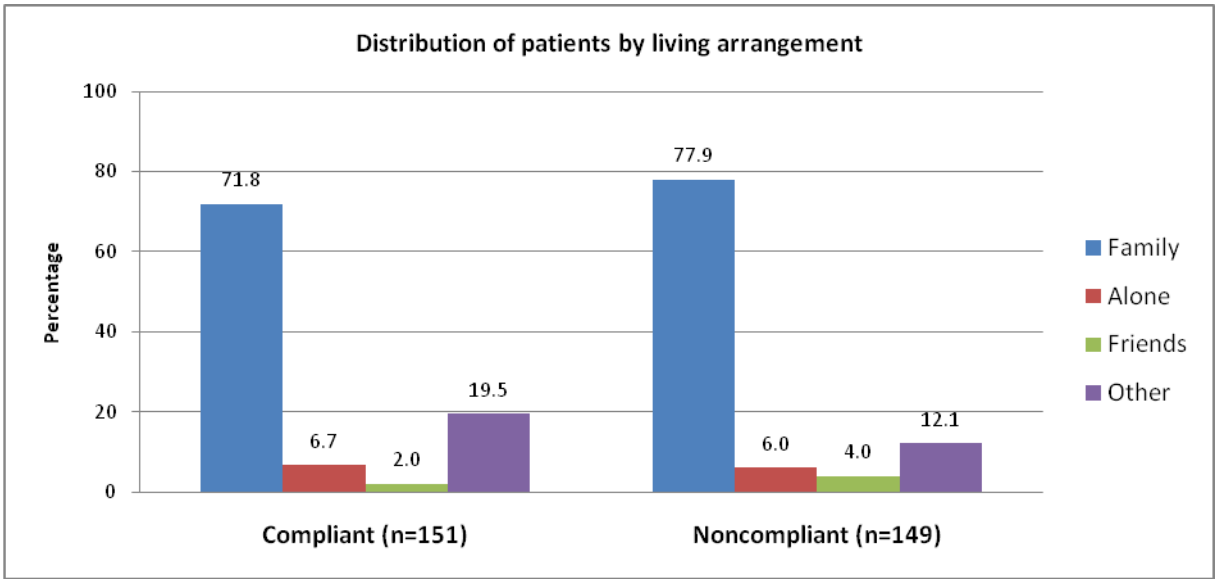


Figure 4.4: Distribution of patients by living arrangements

The vast majority of patients lived with their families with 71.8% and 77.9% in the compliant and noncompliant groups, respectively. These were followed by those in other living arrangement which had 19.5% in the compliant group and 12.1% in the noncompliant one. Very few lived alone or with friends. These distributions look so much alike that they suggest that a patient's living arrangement may not be influential in their decision to comply with annual eye reviews.

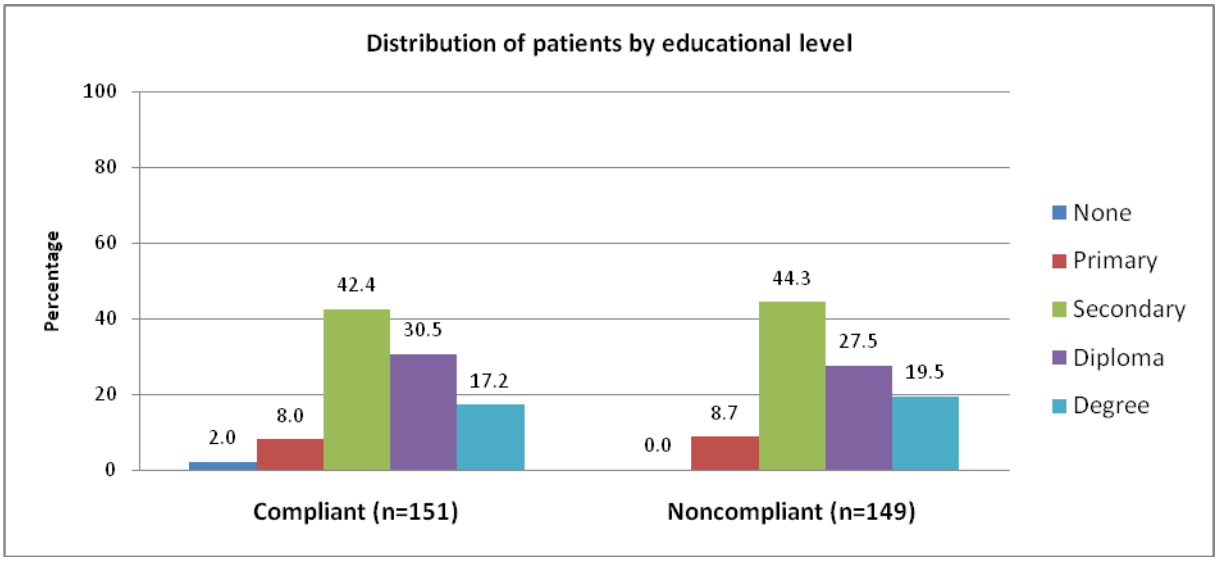


Figure 4.5: Distribution of patients by education level

The distributions by educational level are the same for the two compliance groups with the majority having secondary school education, followed by diploma then degree level education. These three educational levels represented at least 90% of the patients in either compliance group. These distributions do not suggest that there is an association between compliance and educational level.

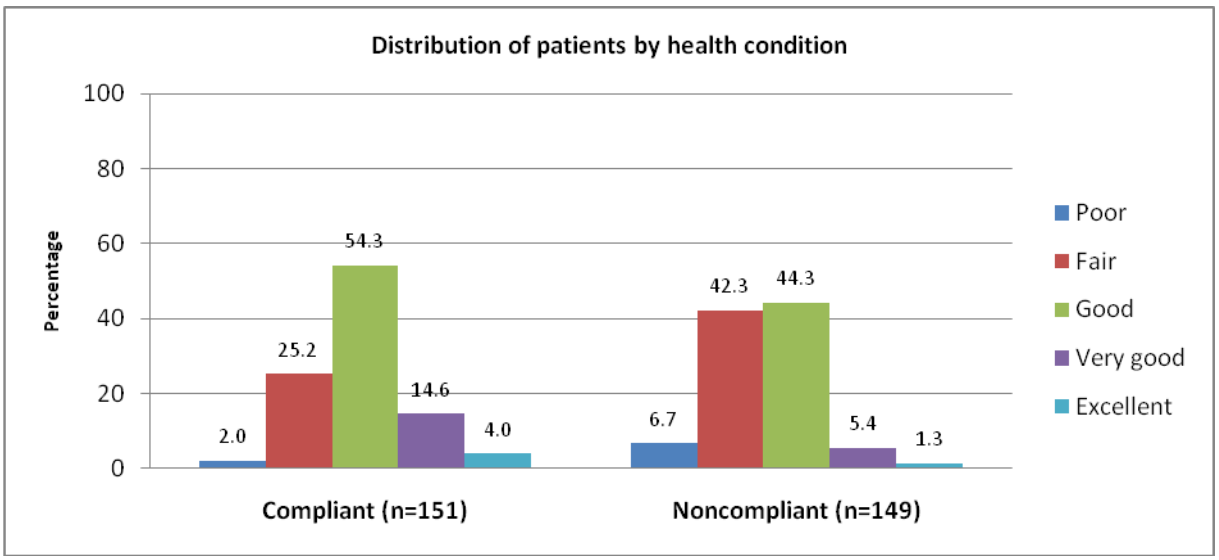


Figure 4.6: Distribution of patients by health condition

The distribution by health condition shows that there are far more patients in good health (54.3%) within the compliant group. This is followed by fair condition with 25.2% then very good condition with 14.6% with the remainder being in either poor or excellent health condition. The picture is different for the noncompliant group. In the

noncompliant group, there were just about as many patients in fair health (42.3%) as those in good health (44.3%). There were also just as many in very good health (5.4%) as those in poor health (6.7%). This seems to suggest that compliance might have something to do with the patients' self-evaluation of health condition.

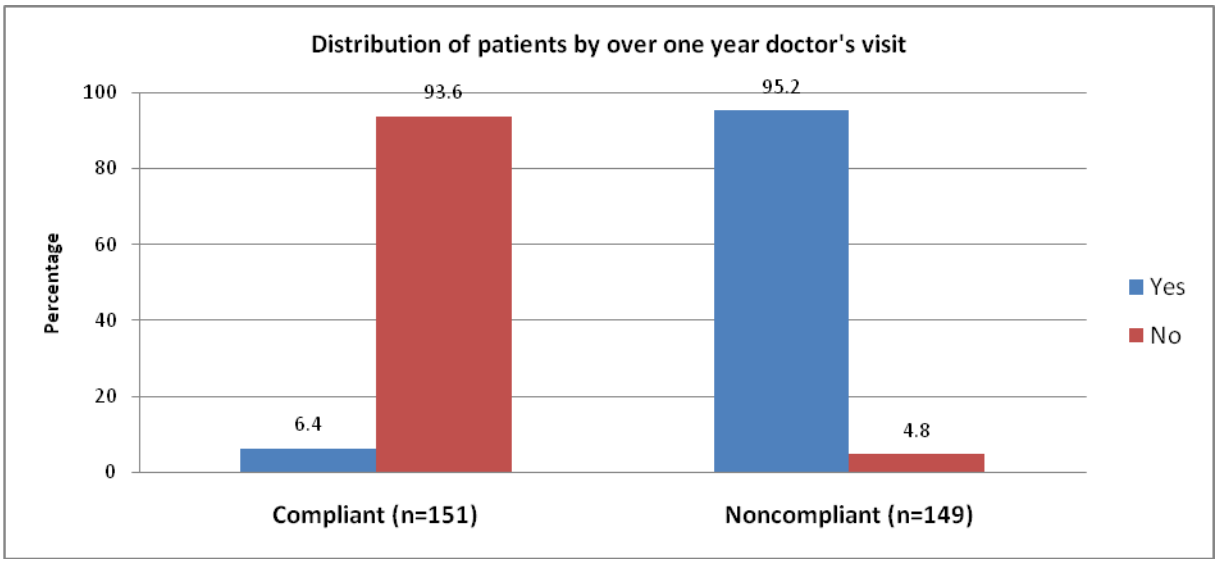


Figure 4.7: Distribution of patients by over one year doctor's visit.

The distribution of patients by last visit to the doctor shows that most of the compliant patients' last visit to a doctor was less than a year ago (93.6%) while for the noncompliant group the majority (95.2%) last visited a doctor more than a year ago. This suggests that frequent doctor's visits are consistent with compliance with annual eye reviews.

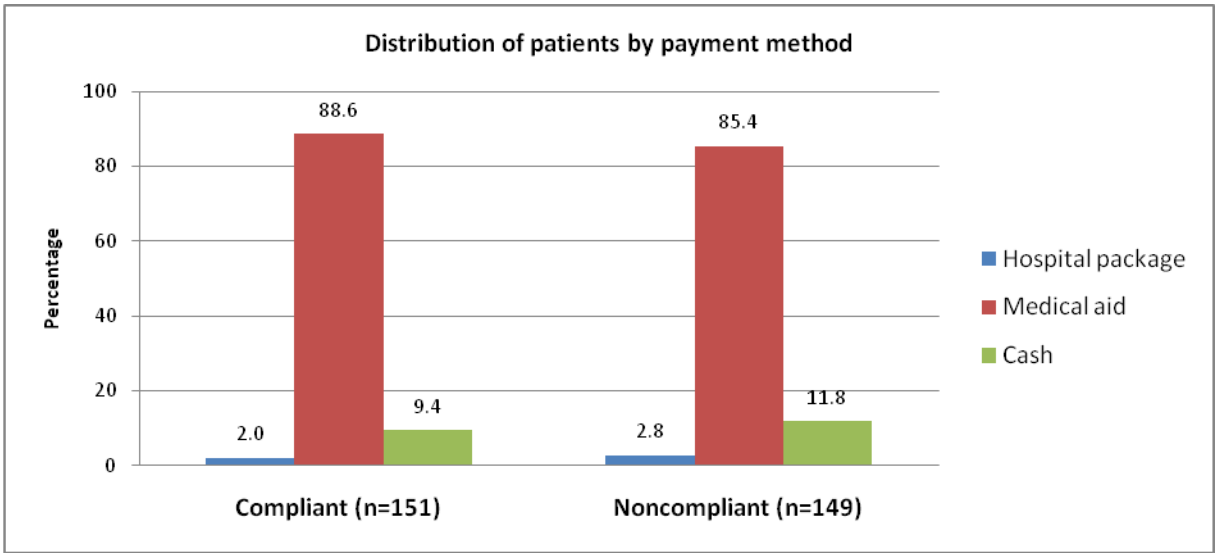


Figure 4.8: Distribution of patients' payment methods

For both the compliant and noncompliant groups, the vast majority had a medical aid scheme, followed by out of pocket payment and very few, less than 3% in both groups, pay for their medical expenses through a hospital package. The similarity of the distributions suggests that there is no association between compliance and payment method.

4.1.4 Significance of associations between compliance and biographical characteristics

As a follow up to the graphical analysis, chi-square tests for associations were carried to test for significance of associations between compliance and biographical characteristics. The results of the analysis are shown in the table below. These results show that compliance with annual eye reviews is significantly associated with religion, self-reported health condition and last doctor's visit.

Table 4.2: Chi-square tests for significance of associations between compliance and patient characteristics

Characteristic	Chisq	df	p-value
Gender	0.25	1	0.613
Ethnicity	7.39	4	0.117
Marital status	4.14	5	0.530
Religion	12.61	4	0.013
Living arrangement	3.99	3	0.263
Education	3.51	4	0.477
Health condition	20.21	4	<0.001)
Doctor's visit	224.61	1	<0.001
Payment method	0.67	2	0.717

A follow up analysis to determine the strength and direction of the associations was carried out and it revealed that those who visited the doctor within the past year were by far more likely to be compliant than those who did not. They were 282.6 times as likely to comply compared with those who visited a doctor more than a year prior to the current visit. The 95% confidence interval for the odds ratio was 103.1; 775.1.

As for the self-reported health condition, those with excellent or good or very good personal health were equally likely to comply with annual eye reviews and they were

more likely to comply compared to those with poor or fair health. Those with poor health were 0.1 times as likely to comply while those with fair health were 0.2 times as likely to comply as those with good to excellent health. The 95% confidence intervals for the odds ratios of those poor and those with fair health were (0.02; 0.42) and (0.10; 0.55), respectively. In this observation the ratio clearly indicates those in excellent or good health were more compliant than those with fair or poor health

While religion had shown significant association with compliance, it was found that all religions were equally likely to comply. The 95% confidence intervals of all the odds ratios for religion range from lower limits below 1 to upper limits above 1. This shows that the odds ratios themselves are not significantly different from 1. Odds ratios equal to 1 are indicative of equality of odds and hence lack of significance of associations.

4.1.5 Significance of associations between compliance and the stand alone variables

To determine if the nine items that belong to those clusters whose reliability coefficients were lower than 70% have any association with compliance, the chi-squared test for independence was used. The results in the table below show that compliance is significantly associated with commitment to eye health, frequency of discouraging feelings about eye health, knowledge of diabetic eye disease and information about the relationship between diabetes and eyesight.

Table 4.3: Chi-square tests for associations between compliance and stand alone items

Characteristic	Chisq	df	p-value
Confidence in noticing eye changes	9.25	4	0.055
Confidence in getting convenient appointment	5.73	4	0.22
Commitment to eye health	38.13	4	<0.001
Frequency of discouraging feelings about eye health	11.59	4	0.021
Fearfulness about future of own eyesight	6.8	4	0.146
Feeling the need for more diabetic knowledge	20.31	4	<0.001
Regrets about delayed diabetes information	46.27	4	<0.001
Anxiety about cost of eye treatment	3.61	4	0.462
Anxiety about owing doctors/insufficient medical aid	3.86	4	0.425

Odds ratios for those variables that turned out to have significant associations with compliance were computed in order to determine the strength and direction of the associations. The results are presented in the table below.

4.1.6 Strength and direction of associations

As a follow up, odds ratios and their 95% confidence intervals were computed and the results are shown in the table below.

The results show that those with little or no confidence in committing to their personal eye health are significantly less likely to comply with annual reviews compared to those with medium to extreme confidence. The odds ratios for the no and little confidence in committing to personal eye health were both 0.2 and their 95% confidence intervals were (0.10; 0.34) and (0.11; 0.56), respectively.

Participants who never or seldom feel discouraged about their eye health are more likely to be compliant with annual eye reviews. In fact those who never feel discouraged are 2.2 times as likely to comply and those who seldom feel discouraged are 2.9 times as likely to comply compared with those who sometimes to always feel discouraged about their eye health. In both cases, the 95% confidence limits are greater than one, which is indicative of a positive association.

Those who never or seldom feel that more knowledge of diabetic eye disease would reduce their fears are more likely to comply than those who sometimes to always worry about their knowledge of the diabetic eye disease. They are about three times as likely to comply as those who sometimes to always worry. On the other hand, participants who never or seldom feel that they should have known about the diabetes-eyesight relationship earlier are more likely to comply with annual reviews. In fact, they are 4.8 times and 8.1 times as likely to comply as those who sometimes, often or always feel they should have known about the link between diabetes and eyesight.

Table 4.4: Odds ratio estimates for statistically significant associations

Statement	OR	95% CI
Commitment to eye health		
None	0.2	(0.10 ; 0.34)
Low	0.2	(0.11 ; 0.56)
Moderate	0.7	(0.29 ; 1.53)
High	0.8	(0.78 ; 1.59)
Extreme	REFERENCE	
Frequency of discouraging feelings about eye health		
Never	2.2	(1.17 ; 4.15)
Seldom	2.9	(1.39 ; 5.96)
Sometimes	2.0	(0.89 ; 4.33)
Often	1.1	(0.50 ; 2.58)
Always	REFERENCE	
Feeling the need for more diabetic knowledge		
Never	3.1	(1.59 ; 5.87)
Seldom	3.3	(1.54 ; 6.91)
Sometimes	1.8	(0.93 ; 3.60)
Often	1.4	(0.72 ; 2.79)
Always	REFERENCE	
Regrets about delayed diabetes information		
Never	4.8	(2.77 ; 8.49)
Seldom	8.1	(2.80 ; 23.37)
Sometimes	0.8	(0.29 ; 2.03)
Often	1.0	(0.42 ; 2.35)
Always	REFERENCE	

4.1.7 Summary of univariate analysis.

The above analysis looked at the distribution of patients cross-tabulated by compliance and each of the biographical characteristics and the stand alone items. Results based on the tests for associations between compliance with doctor's' visits, and each of the variables, only four items and two biographical characteristics showed statistically significant associations. The two biographical characteristics were self-reported health condition and time since last doctor's visit and the four items of were commitment to eye health, frequency of discouraging feelings about eye health, need for more diabetic knowledge and regrets about delayed diabetes information.

The results suggest that:

i). Patients in good to excellent health are more compliant than those with fair or poor health.

ii). Patients who visited the doctor less than a year prior to the current visit are more compliant than those who had their last visit more than a year prior to the current visit.

iii). Patients with lower commitment to their eye health are less likely to be complaint than those with higher commitment.

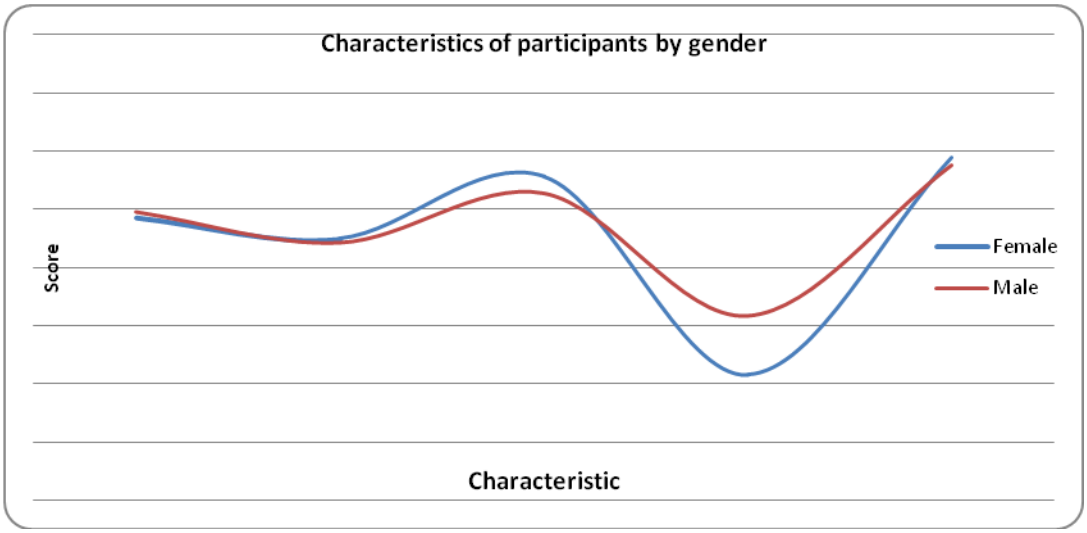
iv). Patients who never or seldom feel discouraged about their eye health are more likely to be compliant than those who sometimes to always feel discouraged.

v). Patients who feel they need more diabetic knowledge and those who regret having known about diabetes and its relationship with eyesight rather late are more likely to comply.

4.2 ANALYSIS OF DERIVED VARIABLES

The exploratory graphical analysis of derived variables was carried out using means plots. All five variables were plotted on the same graph for each of the biographical characteristics. Follow up tests for statistical significance was carried out to determine the significance of the differences suggested by the exploratory analysis. Before carrying out the tests for significance, tests for normality of the derived variables were carried out. The results showed that all the derived variables were not normally distributed. As a result, the nonparametric tests for statistical significance were adopted for onward analysis. For testing for significance of differences in the variables across binary categorical variables, the Mann-Whitney test was used instead of the Student's-test. Where the categorical variables had more than two categories, the Kruskal-Wallis test was used instead of the one way analysis of variable (ANOVA). To test for the significance of pair wise correlations of the derived variables, the Spearman's correlation analysis was used instead of the Pearson's correlation analysis.

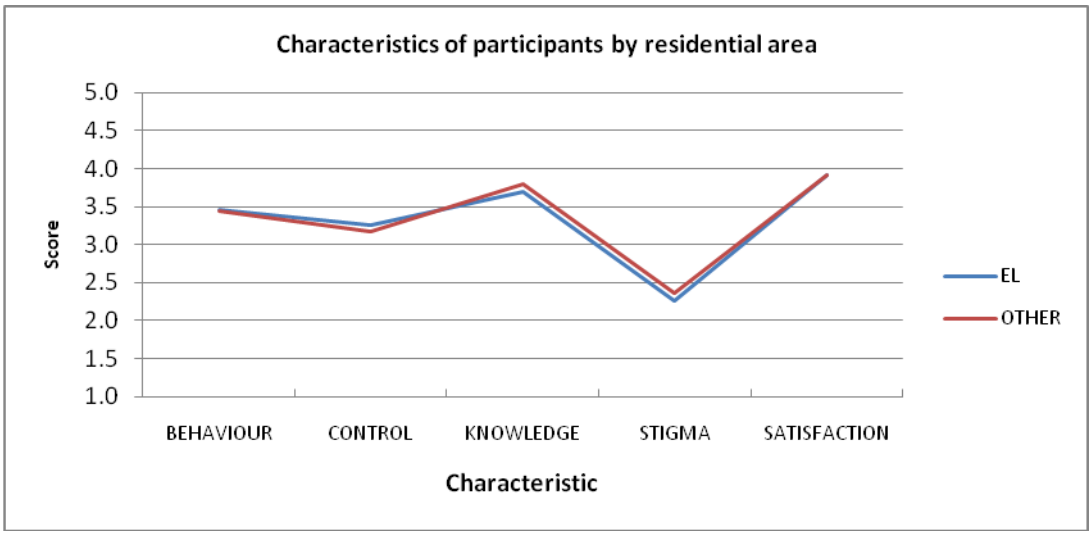
The graphs for each of the biographical characteristics are presented below with a brief interpretation given below the graph followed by the test for statistical significance.



Graph 4.1: Means plot of derived variables by gender

Behaviour, control and satisfaction seem to be the same for males and females while females seem to have slightly more diabetic knowledge and less fears about stigma associated with diabetic eye disease than the males.

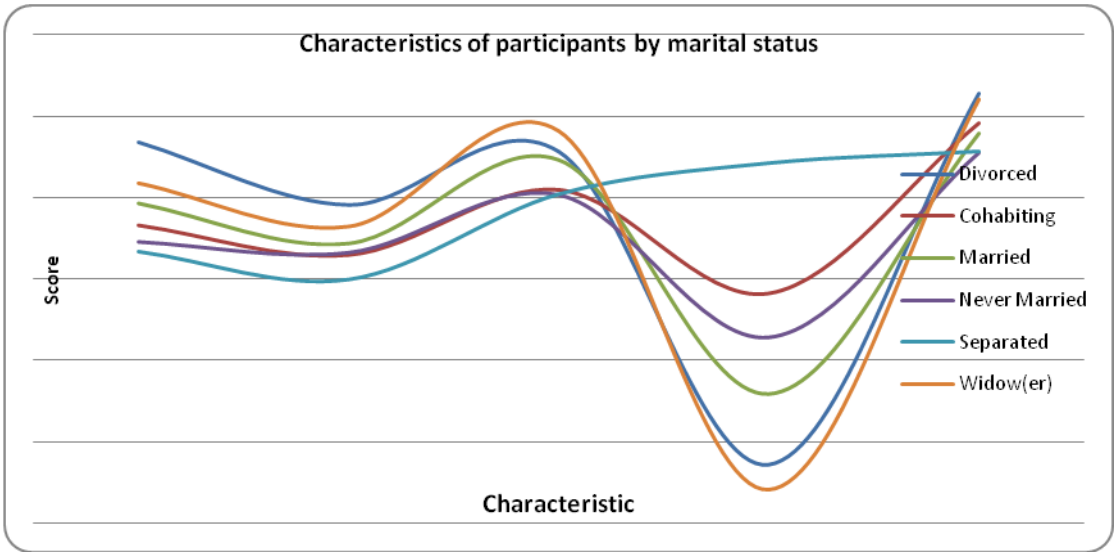
Since gender has only two categories the Mann-Whitney test was used to determine if the differences reflected in the graph above are statistically significant. The results showed that only stigma significantly depends on gender (Z=3.6; p=0.0003). The mean stigma scores for females and males were 2.2 and 2.8, respectively. The test for significance shows that the difference between these two mean stigma scores is statistically significant. This means that males have significantly more fears of stigma than females. Based on this result, it can be concluded that males are more likely to hide their diabetic status compared to their female counterparts.



Graph 4.2: Means plot of derived variables by residential area

Residential area was classified as East London and other. Other residential area refers to places out of East London. These included King Williams Town and surrounding areas, Grahamstown, Queenstown, Butterworth and places in the former Transkei region. All variables seem to be the same regardless of which residential area the participants come from. Satisfaction with medical services had the highest mean score followed by diabetic knowledge and the least was the stigma means score.

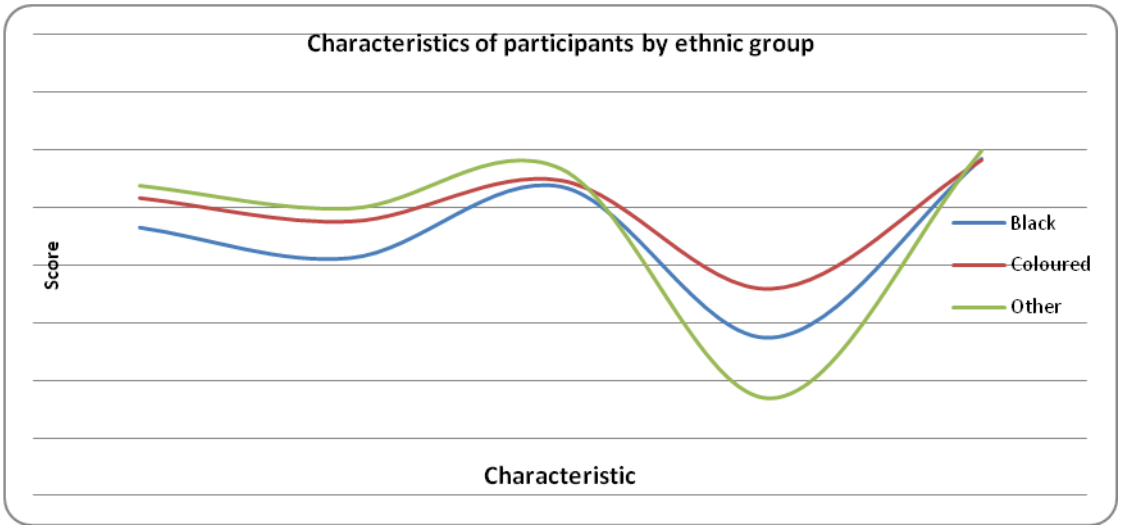
The Mann-Whitney test was used to test for the significance of effects of residential area on the variables of interest. As suggested by the graph, tests for statistical significance confirmed that a patient's residential area does not influence his/her behaviour, control, knowledge, stigma and satisfaction. As such, where a patient comes from may not be useful in determining the patient's responses.



Graph 4.3: Means plot of derived variables by marital status

Divorced patients seem to have higher behaviour and control than the rest. Those were separated had the greatest fears of stigma while the widowed ones have the least. No significant differences are visible in terms of satisfaction and knowledge. This suggests that marital status may not be having an effect on satisfaction and knowledge while possible effects are suggested for behaviour, control and stigma.

The Kruskal-Wallis test was used to determine the significance of the effects of marital status on the variables of interest. While the graph above may be suggesting possible marital status effects on behaviour, control and stigma, the tests for statistical significance showed that this is not the case. Only the stigma scores were found to be significantly dependent on marital status (KW=21.5; df=5, p=0.0007). The Kruskal-Wallis test confirmed the graphical analysis results that patients who are separated are most fearful of stigma associated with diabetes followed by those who are in cohabitation and those who are either divorced or widowed are least fearful of stigma.



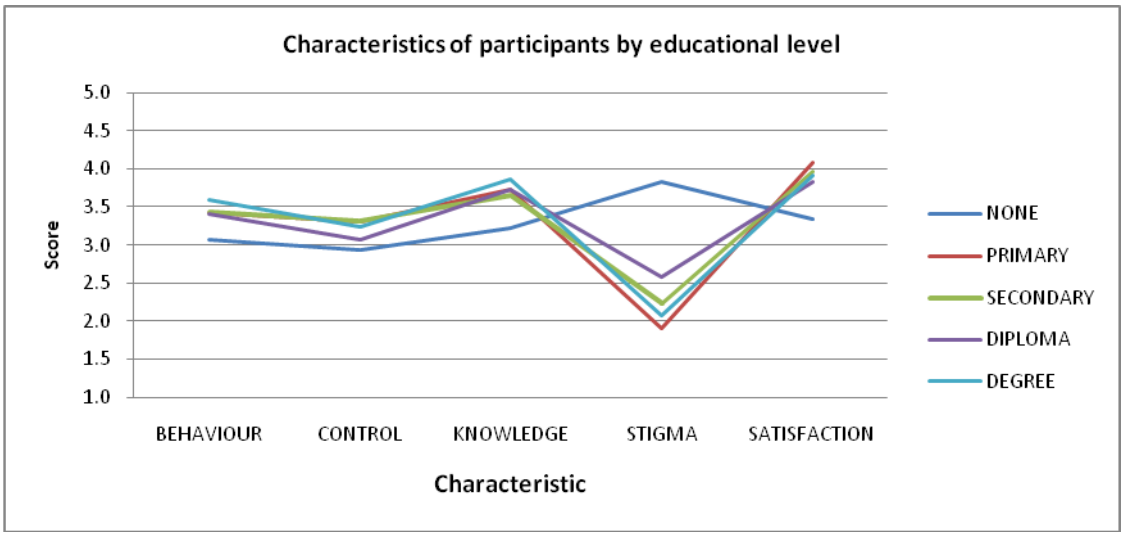
Graph 4.4: Means plot of derived variables by ethnic group

Ethnic origin was collapsed into three groups, namely black, coloured and other. The group' other' is made up of Indians and whites. This collapsing was based on the fact that the sample had very few whites and it felt reasonable to combine these with Indians who were also not overwhelmingly represented in the sample. Based on these categories, the above graph shows that all ethnic groups have just about the same knowledge and satisfaction.

For behaviour and control, patients from the other ethnic group have the highest mean scores followed by those from the coloured group and the blacks had the lowest mean scores on these variables. As for the stigma variable, coloureds have the highest stigma mean score followed by blacks and the other ethnic group has the lowest. This suggests that behaviour, control and stigma depend on ethnic group. The dependence

is such that patients in the other ethnic group have the most positive behaviour and control and the lowest fears of stigma compared to coloureds and blacks.

However, these graphical results are yet to be confirmed with tests for significance of the differences observed on these variables across ethnic group and the Kruskal-Wallis test was used for that. The results of the test for significance confirmed that only control (KW=15.5; df=2; p=0.0004) and stigma (KW=14.1; df=2; p=0.0008) depend on ethnic group. The differences in behaviour were just by chance since the test for statistical significance failed to detect any significance in those differences. The statistical analysis carried out confirms the graphical analysis results that coloureds have the greatest fear of stigma and that blacks have the least control.

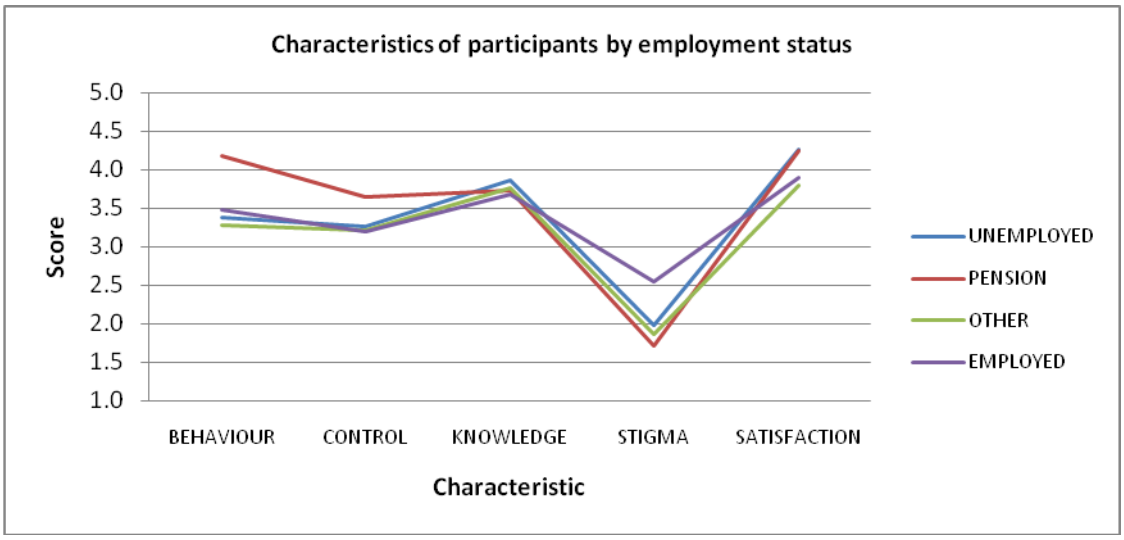


Graph 4.5: Means plot of derived variables by educational level

The above graph shows that those with no formal education are different from those with some form of formal education for all five variables and are followed by those with diploma level education. This graph suggests that educational level may have an effect on all five variables with the most effect being on the stigma scores. It appears the uneducated patients have a much higher fear of stigma than those with some education.

While the graph may have suggested possible education effect on all variables, the Kruskal-Wallis test detected statistically significant effects on behaviour (KW=11.6; df=4; p=0.023) and stigma (KW=10.9; df=4; p=0.028) only. The results show that those with no education at all have the lowest mean behaviour score of 3.1 which was found to be significantly lower than that of all the other educational levels and those

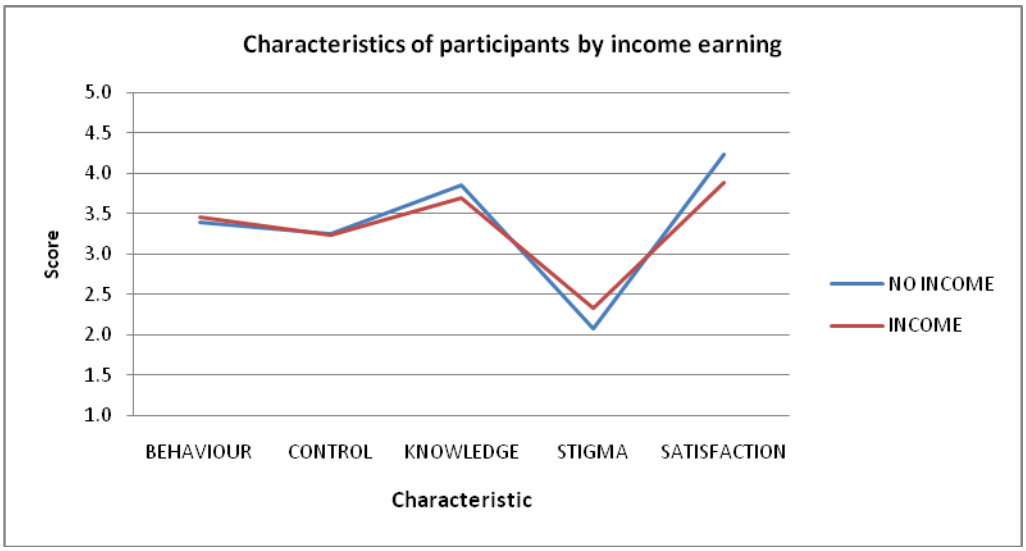
with a degree had the highest behaviour score of 3.6 while the rest were tied at 3.4. With regards to stigma, the uneducated ones had the highest fear of stigma with a 3.8 mean score followed by those with a diploma level of education with a mean score of 2.6 while the rest of the educational level had mean scores of between 1.9 and 2.2. This shows that behaviour and stigma depend on educational level suggesting that an improvement in education would shift patient behaviour and stigma in a positive direction.



Graph 4.6: Means plot of derived variables by employment status.

The patients who are on pension seem to have significantly higher behaviour and control scores compared to the rest of the patients. There does not seem to be any differences in knowledge and satisfaction scores across the employment status categories. Employed patients seem to have more fear of stigma than the rest of the patients. Based on this graph, employment status seems to have an effect on behaviour, control and stigma.

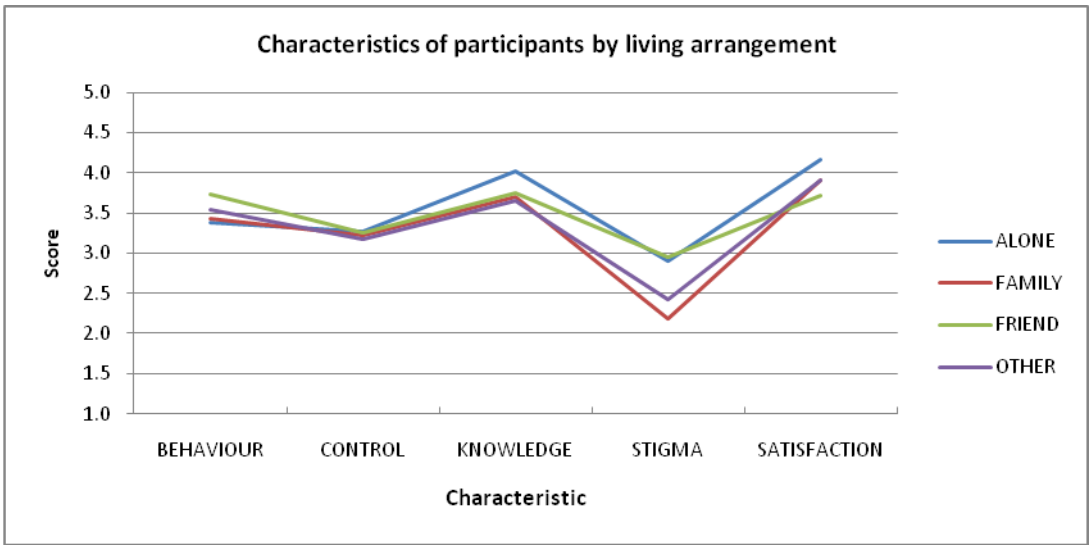
However, on performing a test for statistical significance only stigma was picked up as significantly dependent on employment status (KW=17.3; df=3; 0.0017). The mean stigma score for the employed patients was 2.6 while the rest of the employment status categories it was between 1.7 and 2.0. This shows that the employed patients have significantly more fear of stigma associated with diabetes than the rest of the patients.



Graph 4.7: Means plot of derived variables by income earnings

Employment status was re-categorised to derive a new variable labelled income earning. For this variable all patients except the unemployed are classified as earning some income. For this variable, there does not seem to be any significant differences in behaviour and control and some slight differences in knowledge, stigma and satisfaction.

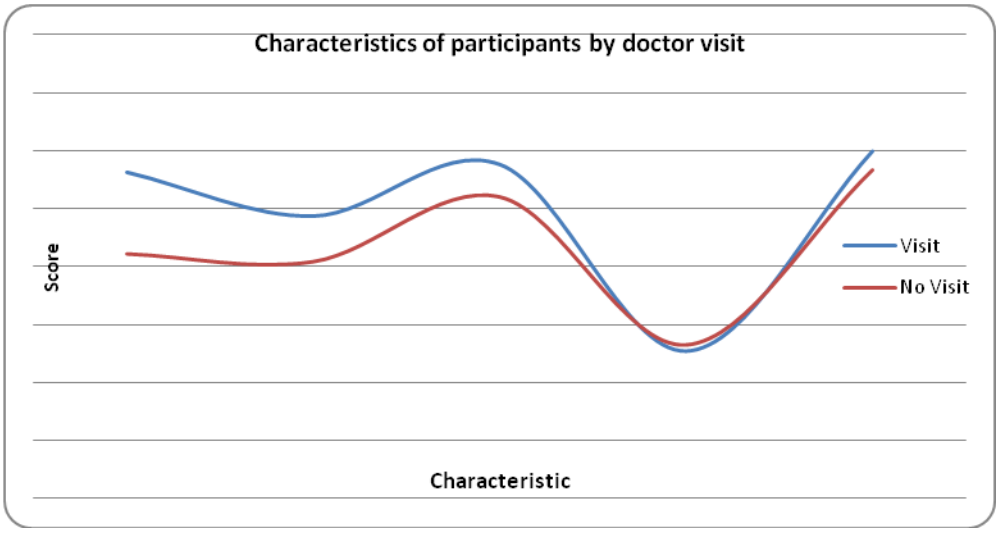
On carrying out a Mann-Whitney test it came out that income earning, as defined above, only affects satisfaction (Z=2.2; p=0.026). The effect is such that those with some form of income are more satisfied with the medical services than those without.



Graph 4.8: Means plot derived variables by living arrangement

The graph suggests behaviour, control and satisfaction may not be dependent on the patient's living arrangement. However, those who stay alone seem to have more knowledge than those living under any other arrangement and the same fears of stigma as those who live with a friend. The graph shows that those living alone or with a friend have more fears of stigma than those living under some other arrangement who, in turn, have more fears than those living with their families.

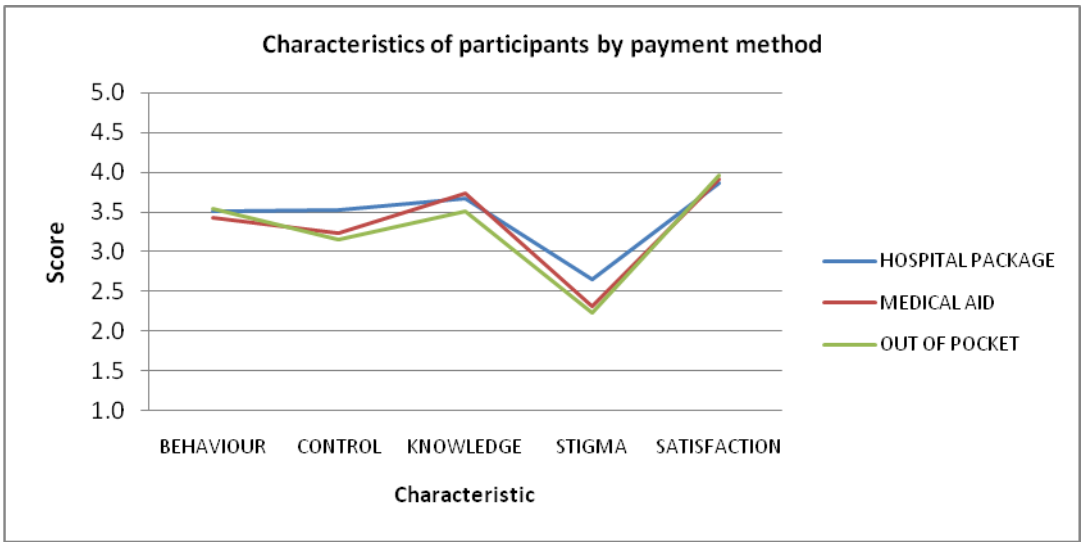
While the graphical analysis may have suggested some differences depending on the living circumstances of the patient, the test for statistical significance did not detect any of those differences as being statistically significant. As such, it can be concluded that who a patient lives with does not have any impact on their behaviour, control, knowledge, stigma and satisfaction.



Graph 4.9: Means plot of derived variables by doctor's visit

Patients who had visited a doctor within a year of the current visit were classified as compliant and those who did not as noncompliant. There seems to be no differences between those who had visited the doctor within a year of the current visit and those who did not, in terms of stigma and satisfaction with medical services. However, those who did visit the doctor in that time period seem to have more knowledge and control as well as more positive behaviour than those who had not visited a doctor within a year of the current visit. This suggests that doctor's visit may have significant effects on those three variables.

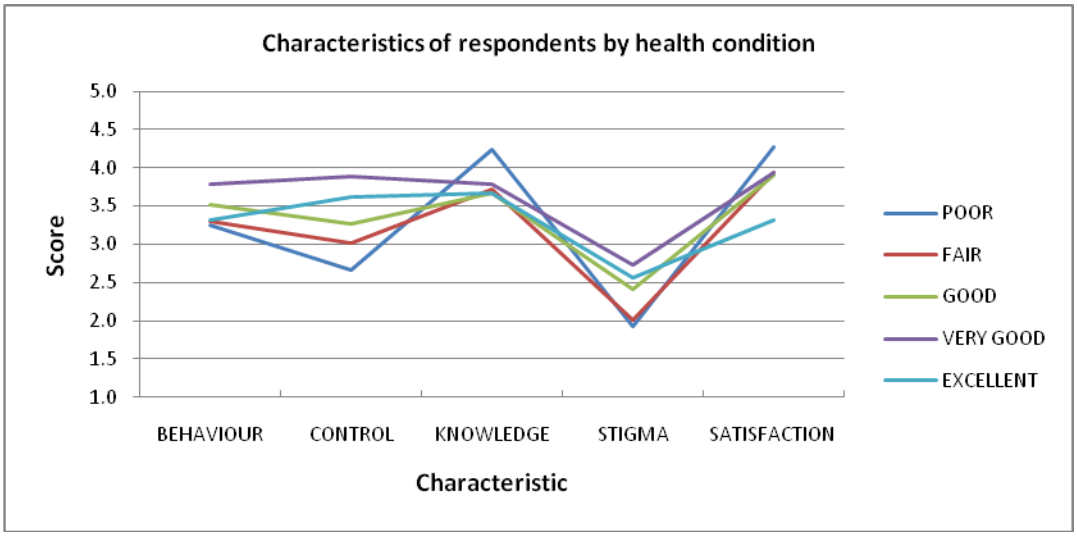
On carrying out the Mann-Whitney test, it was found that whether a patient visited a doctor within a year of the current visit had a bearing on their behaviour (Z=4.2; p<0.0001), control (Z=3.6; p=0.0003) and knowledge (Z=2.9; p=0.003). Since doctor's visit is a proxy for compliance, it can be concluded that compliance is associated with the patient's behaviour, control and knowledge. The association is such that those who have been complying with their doctors' visits have a more positive behaviour, more control and more knowledge than those who have not been complying. It can, therefore, be concluded that improving the behaviour, knowledge and control of patients' results in higher compliance.



Graph 4.10: Means plot derived by payment method

There does not seem to be significant differences in all variables across the different payment methods. However, a slight difference is visible in the stigma scores as those on a hospital package have a slightly higher stigma than the medical aid and out-of-pocket patients.

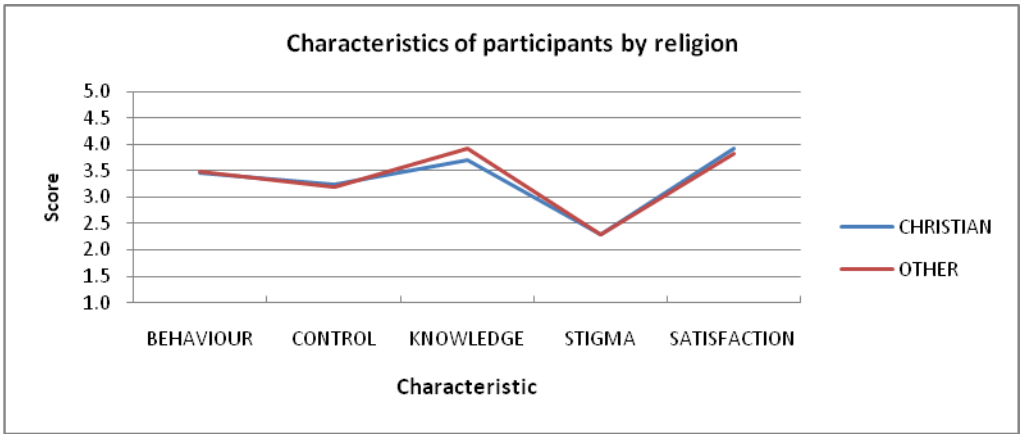
Results of tests for significance showed that methods of payment for medical services have no link with the patients' behaviour, control, knowledge, stigma and satisfaction.



Graph 4.11: Means plot derived variables by health condition

This graph shows differences in all five variables depending on the patient's self-reported health condition. Those who evaluate their health condition as very good have more positive behaviour than the rest of the patients. In terms of the control variable, all five health condition groups seem to be different with those in very good health ranking highest followed by those in excellent condition and those in poor health having the lowest control score. However, those with poor health have the highest knowledge score and lowest fears of stigma and those in excellent health condition are the least satisfied with medical services.

On carrying out a test for statistical significance, it was found that self-reported health condition of a patient is related to the patient's fear of stigma associated with diabetes. The Kruskal-Wallis test showed that those in poor or fair health condition have the least fear of stigma and those in very good health conditions have the most fear of stigma. This shows that the healthier a patient feels the more the fear of the stigma they have.



Graph 4.12: Means plot of derived variables by religion

The graph above and the one below exhibit a very similar pattern. The difference that may be visible on these two graphs is very slight. The graphs suggest that religion and income may not have any significant effects on all five variables. Note that religion has been re-categorised into Christian and Other since very few patients were of a religion different from Christianity. On carrying out a test for statistical significance it was found that religious beliefs of patients have no link with their behaviour, control, knowledge, stigma and satisfaction.

4.2.1 Correlation analysis

The Spearman's correlation analysis was carried out on the five derived variables. The results showed that these variables are significantly positively correlated, though some of the correlations are weak. It was found that control has a statistically significant correlation with behaviour ($r=0.24$; $p<0.001$). This means that patients with more control also have positive behaviour.

Knowledge and behaviour were also found to be significantly positively correlated ($r=0.27$; $p<0.001$). As such, patients with more knowledge also have a more positive behaviour. Satisfaction was found to be significantly positively correlated with both knowledge ($r=0.14$; $p=0.0156$) and behaviour ($r=0.19$; $p=0.001$). This means that patients with more knowledge have more positive behaviour and are more satisfied with the medical services.

Stigma was significantly correlated with behaviour ($r=-0.17$; $p=0.005$), control ($r=-0.16$; $p=0.005$) and knowledge ($r=-0.19$; $p=0.0087$). All the correlations are negative which

means that the patients who are more fearful of stigma associated with diabetes are the ones with negative behaviour, less control and less knowledge.

4.3 SUMMARY

The analysis of the derived variables involved testing for statistical significance of dependence of those variables on biographical characteristics and of correlations among themselves. The results showed that religious beliefs, place of residence, living arrangement and payment method have no significant effects on the derived variables. The statistically significant outcomes that emerged from this study are listed below for the biographical characteristics and correlations.

4.3.1 Biographical characteristics

- Male patients are more fearful of stigma associated with diabetes than females.
- Fearfulness of stigma associated with diabetes depends on marital status of the patients such that separated patients are most fearful while the divorced or widowed are least fearful of stigma.
- The coloured community is most fearful of stigma and the blacks have the least control.
- Educational level affects behaviour and stigma such that the least educated have the most negative behaviour and are most fearful of stigma.
- Employed patients are most fearful of stigma associated with diabetes than the rest of the patients and those with some form of income are most satisfied with the medical services.
- Compliance with doctor's visits is associated with positive behaviour and more knowledge and control.
- Patients who feel they are healthier are more fearful of the stigma associated with diabetes.

4.3.2 Correlation analysis

- Patients with more control also have a more positive behaviour.
- Knowledgeable patients have more positive behaviour and more satisfaction with the medical services.
- Patients who are more fearful of stigma associated with diabetes have more negative behaviour and less knowledge and control.

4.4 REASONS FOR NON-COMPLIANCE

The reasons given for noncompliance were:

- Lack of information (29.5%),
- Negligence (16.1%),
- Busy work schedule (14.1),
- Lack of finance (9.4%),
- No referral from general practitioners and optometrists (6.0%),
- Commitment to other illnesses (5.4%),
- Stigma and fear of diagnosis (4.0%),
- Poor public medical services (3.3%) and
- Other (12.2%). The reasons referred to as 'other' included relocation of eye doctor or patient, family commitments, transport problems, absence of eye specialist in home area and unsuitable appointment dates.

These results suggest that there might a need to raise awareness of eye health and access to free medical services. All these reasons can be addressed through awareness campaigns if such campaigns target both patients and employers. Free mobile eye clinics are known to be making rounds in rural areas. However, it is mostly the elderly who take advantage of these services. With improved awareness, even the younger people will end up making use of such clinics. Besides, these services should be broadened to include the poor urban communities as well.

CHAPTER 5

DISCUSSION, LIMITATIONS OF THE RESEARCH, SUMMARY OF THE STUDY AND RECOMMENDATIONS

5.1 INTRODUCTION

In this chapter the results of the study will be discussed. The aim/goal of the study was to determine the relationship amongst the factors (knowledge, confidence and fear/anxiety) and adherence to follow up visits and if there is a relationship amongst these factors, and also if there is a difference in the factors (knowledge, confidence and fear/anxiety between the compliant and non–compliant group of diabetic patients. Additionally, the aim was also to find out the reasons for non-attendance among the group that does not keep their yearly reviews at a private practice in East London. The study was descriptive in nature.

5.2 SOCIO DEMOGRAPHIC CHARACTERISTICS

5.2.1 Gender

In this study the majority of the study population was female, but the distribution was roughly the same between the two groups with 57.7% in the compliant group and 54.8% in the non - compliant group (Figure 4.1). These findings are consistent with the self-reported prevalence rates for diabetes of 2.4% in men and 3.7% in females, indicating more female prevalence (Mash et al., 2008:50). In the current study the investigator found that compliance to annual reviews was not related to gender. This is contrary to the findings in the study of Khan, Lateef, et al. (2012:26), in which the investigators noted that most of the non–compliant patients were male. The probable reason for the difference is that the study was conducted in the Al Hasa district of Saudi Arabia; the majority of males were from the urban area.

5.2.2 Ethnic Origin

East London is a city situated in the Eastern Cape Province; which has one of the highest numbers of Africans in South Africa. Approximately 86.3% of the population in this province is black, followed by coloured, white Indian and 'other', 8.3%, 4.7%, 0.4% and 0.3% respectively (Ethnicity and language (article on line),2011:5).

In both groups Africans are in the majority: 64.8% non–compliant and 49.7% compliant, followed by coloureds, whites, Indians, and lastly, other ethnic groups. There seems to be more non–compliant Africans. This is in agreement with the study done by Thomas et al. (2013:336) that reported that the global prevalence of diabetic retinopathy reported was amongst the African Americans. Ethnic disparities continue to exist in the management of diabetes, particularly among people of African descent with type 2 diabetes (Noakes, 2010:148).

5.2.3 Marital status and living arrangements

In terms of marital status, both the compliant and non-compliant groups were the same. The vast majority were married (figure 4.3), and regarding living arrangements both groups lived with families, which means they are committed to their families. In this particular study the investigator found that family commitments were mentioned as a reason for non-compliance. Mshunqane et al. (2012:392), mentioned that most patients who missed their appointments had a general lack of support from family and friends. Perhaps, prioritising "family needs" - contributes to whether a patient will comply with an annual eye review or not.

5.2.4 Education level

In terms of the education level, in both groups the majority have a secondary school education, followed by a diploma and then degree level education. These education levels represent 90% of patients in either group. Although there is no association between compliance and education level in this particular study, (figure 4.5), a study conducted by Ayele et al. (2012:5521), stated that individuals with elementary education status were around four times more likely to perform self-care (in diabetes), than those individuals unable to read and write. Moreover, the current study was conducted in a private health facility, where the clients had a higher level of education.

5.2.5 Payment methods

The vast majority in the compliant and non-compliant groups had a medical aid scheme, which suggests there is no association between compliance and payment methods (Figure 4.8). This is a private practice, and most participants are able to afford treatment and consultation because they are on medical aid/ insurance that covers most of the costs, though some private patients mentioned lack of finance (9.4%) which concurs with the study conducted by Lewis, (2011:4), where most patients mentioned cost as a major barrier, as they had to pay for eye examinations and treatment which included laser treatment which can be expensive, which is surprising as the NHS in the United Kingdom covers most hospital treatments and screenings (Scanlon, 2010:2). It appears that "cost" in the United Kingdom is more related to increase hospital visits as more treatments are needed because of the severity of diabetic retinopathy according to (Schmier, et al., 2009:200). Cost is also a barrier, especially when patients are travelling from a rural area (Beynat, et al., 2009:49). Cost is also a huge barrier in the public sector in South Africa, due to minimal or unavailable resources and equipment to handle the number of patients. The healthcare facilities are fairly basic and are provided to approximately ~80% of the population, whereas, the private sector has highly specialized services, as illustrated by (Thomas, et al., 2013:336). To the researcher's knowledge no study has addressed the cost of diabetic retinopathy in South Africa and sub Saharan Africa, although this information is critical for policy makers to highlight the importance of introducing cost effective interventions for primary prevention and subsequently detection and treatment of diabetic retinopathy (Burgess, et al., 2013:159).

5.3 ASSOCIATION BETWEEN COMPLIANCE AND BIOGRAPHICAL CHARACTERISTICS

5.3.1 Health condition

It is clear from (figure 4.6), that the compliant group self - evaluate their health condition as good (54.3%). In (Table 4.2) illustrating a chi-square significance of 20.61, self-reported health condition and those with excellent or good or very good

personal health were equally likely to comply with annual reviews compared to those with fair or poor health. This picture is very different in the non-compliant group where there were just as many fair health patients (42.3%) as those participants in good health (44.3%). In this particular study it suggests that if a person is in good health and value his/her health they would be more inclined to attend regular appointments as suggested in order to stay healthy, as (figure 4.7) suggested that the compliant group stay within their yearly follow up appointments (93%), also illustrated in (Table 4.2) with a chi-square significance of 224.61, whereas the non-compliant group last visited a doctor more than a year ago (95.2%). According to the study by Adams, et al. (2008), poor glycaemic control seems to be a barrier to attendance rates. It concurs with Snow and Fulop's study (2011) which also high-lights that a high HbA1c level may lead to non-attendance. It concurs with the study by Zheng and Adelam, (2010) that indicates that patients only attend when there is a disruption in visual symptoms and complaints about eyesight which also concurs with the Health Belief Model that was used as the theoretical framework for the study. It postulates as stated by: Bowling (2002), that people's behaviour in relation to health is related to their perception of the severity of their illness. The non-attendant group could have possibly not been aware of the possible risk factors associated with diabetic retinopathy as reported by many epidemiological studies including Crawford et al. (2009), which includes the duration of diabetes, hypertension, and increased lipids and, most importantly, hyperglycaemia.

5.3.2 Doctors visits

According to results of the study it was revealed that those who visited the doctor within the past year were far more likely to be compliant than those who did not (Table 4.2). One of the reasons could be they were referred for screening in time and had the care givers availability with knowledge and skill, which in literature by Mollentze, (2007:534), is mentioned as one of the pitfalls in screening. These patients were probably aware that annual fundoscopy/ review are a requirement, contrary to the study done by Read and Cook, (2007:56) which clearly indicates that patients were not aware that annual fundoscopy was a requirement. It could be that these patients also knew the pathophysiology of diabetes and the complications of diabetes, and

therefore believed in self-care as mentioned in literature by: Shah, Kamdar and Shah,(2009:120).

5.4 ASSOCIATION AND STAND ALONE VIARABLES

5.4.1 Commitment to eye health

The results show that those with little or no confidence in committing to their personal eye health are significantly less likely to comply with annual reviews compared to those with medium to extreme confidence as illustrated in (Table 4. 3 and 4.4). It concurs with earlier investigations by Mollentze, (2007:542) and Mash, Levitt, Van Vuuren and Martell, (2007:50), where they mention that there is no sense of responsibility amongst patients for their condition, and it was also highlighted by the WHO. One of the reasons mentioned in literature according to Zheng and Adelam, (2010:82), is that most diabetic patients have other medical conditions and finds routine eye visits a burden. Sometimes they also find it difficult to understand what the ophthalmologist is explaining to them. This breakdown in communication can make them reluctant or unable to comply with information given by health care workers (Nkumbe, 2008:26). When the open ended questions were answered, 16.1% mentioned negligence and 14.1% mentioned busy work schedules.

5.4.2 Frequency about discouraging feelings about eye health

The results indicate that participants who never or seldom feel discouraged about their eye health are more likely to be compliant with annual eye reviews than those who sometimes or always feel discouraged (Table 4.3 and 4.4). Why? According to literature by: Mshunqane, et al., (2012:392), a positive attitude will motivate patients to comply and negative patients will be less motivated, and Lacy, Paulman, Reuter and Lovejoy, (2004:541–545) mentioned fear and anxiety was also mentioned about possible procedures and possible bad news.

5.4.3 Feeling the need for more diabetic eye knowledge

The results indicate that those who never or seldom feel that more knowledge of diabetic eye disease would reduce their fear are more likely to comply than those who

sometimes to always worry about their knowledge of the diabetic eye disease. The participants who worry about their eye disease they are three times more likely to comply (Table 4.3 and 4.4). These findings are consistent with the findings of the study conducted by: Mshunqane, et al., (2012:392).

They reported that the patients in their study probably had a positive attitude. Gardner and Gabbay, (2009:328) reiterated that patients should know about diabetes, and how it affects the retina.

5.4.4 Regrets about delayed diabetic information

The results indicate that participants who never or seldom feel that they should have known about the diabetes and–eyesight relationship are more likely to comply with annual reviews. In fact they are 4.8 times more likely to comply as those who sometimes, often or always feel they should have known about the link between diabetes and eyesight (Table 4.3 and 4.4). A reason could be that these patients already knew about diabetes and the link with eyesight as they had screening and were educated at their time of diagnosis. Winter and Yorston (2011:3), indicate that partnerships with many different health care workers need to take place to provide eye care. In a private practice it is much easier for patients to be referred and screened as costs are seldom a problem. However, 6.0% of the participants of the study mentioned that they were never referred by their general practitioners or optometrists. The results are almost similar to the study done in France by Beynat, et al., (2009: 49–56) where 6.8% patients has never seen an ophthalmologist. Mollentze (2007:534), - clearly states a specialist referral is needed for all diagnosed diabetics. One of the reasons could be lack of appropriate accredited courses to identify the degree of retinopathy and when to refer as stated by: Amod, et al. (2012:17). The attempts to improve the rate of fundoscopy in the primary care sector have been largely unsuccessful (Mash, et al., 2007:1285). Read and Cook (2007:56) found that there was a general lack of awareness amongst the diabetic patients with regard to the existence of diabetic eye diseases and the importance of screening. It is a different story in the under–resourced public sector (Thomas, et al., 2013:336). The open ended question results show that 3.3% of participants mentioned poor public medical services. Those patients had experience in visiting the public sector and attended the private practice for a second opinion.

5.5 DISCUSSION OF DERIVED VARIABLES

5.5.1 Diabetic control

The study significantly revealed that:

- Africans had the least diabetic control.
- Compliance with doctor's' visits is associated with more diabetic control.
- The study also revealed that diabetic control seemed to be the same for males and females.

The Africans were in the majority of the participants in the study and the Xhosa speaking population dominates the Eastern Cape Province. Due to urbanisation most live a sedentary lifestyle and do not exercise and most are not aware of what kind of diet makes a difference in the control of type 2 diabetes (Ramirez, 2008:86). The study conducted by Shah, et al., (2009:120), suggested the practice of type 2 diabetic patients are that the majority of them cannot afford to buy a glucose metre and hence, could not check their blood glucose levels regularly. Patients also noted lack of finance to manage the disease, especially with regard to food and unable to manage time, especially with adherence to medication (Mshunqane, et al., 2012:392). The results also concur with the findings by Owsley et al. (2006:2797) where they noted that African Americans do not make eye care a priority and that control of glucose is the only important thing for prevention of complication. The challenge remains in addressing the progressive deterioration of glycaemic control over time (Noakes, 2010:148).

Compliance with doctor's' visits is associated with more diabetic control**.** These patients still believed in self-care in diabetes, they know the pathophysiology of diabetes as well as the complications of diabetes, therefore compliant to doctors' visits (Shah, et al., 2009:120) but it is not always the case, as patients in the United States, where individuals are more independent, health care delivery are more fractioned, many patients still visit eye practitioners with advanced eye diseases (Gardner and Gabbay, 2009:328).

Although the study results indicate diabetic control seems to be the same between males and females, literature indicated mixed results. Ayele, et al., (2012:35515) conducted a study to identify self-care behaviour amongst patients with diabetes. The results of their study indicated that the majority of the participants were females (60.4%). They had specific knowledge about diabetic self-care and followed the recommended self-care practices. On the contrary, the survey conducted by Ramirez (2008:86) focusing on diet, physical activity, medication and behaviour, concluded that out of the 50 participants 70% were woman, stating they had no time to exercise. Snow and Fulop (2011:257) however noted that more men did not attend appointments identifying fear of being judged for poor control, and a higher HbA1c was recorded. It was revealed that, residential area, living arrangements, payment methods and religious beliefs had no link to diabetic control.

5.5.2 Treatment seeking behaviour

The result of the study significantly reveals that:

- The level of education was associated with client's behaviour. The patients with the lowest level education were less likely to comply.
- Compliance with doctor's' visits is associated with positive behaviour.
- The study also revealed that treatment seeking behaviour seems to be the same for both males and females.

The results concur with the study conducted by Cook (2013:449) that there seems to be a great lack of education amongst patients regarding the need for screening.

Mshunqane et al. (2012:392) conducted a study that noted that a positive attitude will motivate compliance and negative patients will be less motivated. Positive patients realize diabetes management is a lifelong endeavour and a key to staying positive is ongoing follow up visits and continued assistance with management needs. (Gucciardi, De Melo, Offerheim and Stewart, 2008:34). On the contrary mainly negative attitudes were mentioned like fear and anxiety was about possible procedures and possible bad news (Paterson, et al., 2010:63-74), therefore neglecting their health. Boucher et al. (2005:737) also stated negligence as the main reason for non-compliance, and some participants reported self-blame as a reason for running

high blood glucose levels, by straying from the diet or not taking enough exercise (Noakes, 2010:153). The concept of blame and shame were highly salient. Participants described feeling judged and blamed by others for bringing T2DM on themselves. This was sensed as reflecting negatively on their personal character (Browne, Ventura, Mosely and Speight, 2013:003387). At times, the negative emotion about going to see the doctor was greater than the perceived benefit of keeping the appointment (Lacy et al., 2004:541).

Mostly men (39.7%) gave the reason “no need” to see an eye doctor. It concurs with the study conducted by Sinclair and Delvecchio (2004:151), where respondents did not consider going for an eye examination as long as they did not have visual changes, and these were mostly woman (51%); in the lower income groups the main reason was “cost or lack of insurance”, for not seeking eye care (Chou, et al., 2014: 180).

5.5.3 Stigma

According to the study a variety of results were indicated:

- Males have more fears of stigma than females and are more likely to hide their diabetic status compared to their female counterparts.
- They were employed, and viewed themselves as healthy,
- Those patients who self-reported poor or fair health had the least fear of stigma.
- It was also found that those with the lowest education level were equally fearful.
- It was found that the coloured community has the highest fear of stigma.
- Those participants who are separated are more fearful of stigma, than those who are divorced or widowed.

Although more males reported fears of stigma and more participants amongst the coloured community, the study conducted by Mshunqane et al. (2012:392), highlighted cultural issues and stigma regarding diabetes especially around losing weight and mainly in relation to black females, which contradicts the results of this study. Paterson et al. (2010:63) also indicated that patients with chronic disease fear that the practitioners will chide them for neglecting their health, and therefore

do not attend scheduled appointments. The coloured community do not talk about diabetes as there is a stigma and taboo attached to the condition. Most are secretive and proud people and believe in suffering in silence. Some also feel ashamed to disclose their condition (Noakes, 2010:153).

The study concurs though with the study conducted by Beynat et al. (2009:49), where they mention that younger patients who are employed, and had to plan their appointments around their work schedules and social life, had a stigma against diabetes, especially those with a short duration of diabetes and in the absence of symptoms. Older people attended more appointments according to the study conducted by Neal et al. (2005:1), and in the study they were the ones who reported poor or fair health, which concurs with the results that highlights the lowest fear of stigma.

The study conducted by Boucher et al. (2005:737) revealed that the presence of non-compliance was present in all socio-economic classes which contradict with this study where it was found that those with the lowest education levels were equally fearful.

According to the study, those participants who were separated showed more fear of stigma. One of the reasons for this could be that they had poor family support (Ramirez, 2008:86). Thus living alone was determined to be a significant predictor for non-compliance (Paterson, et al.,2010:69). Japanese adults with type 1 diabetes reported cancellation of marital engagements and divorce following disclosure about their diabetes; it is unclear from the study why this occurred. Perhaps the healthy partner did not want to marry an “ill” partner or not start a family with someone with a hereditary disease, thus creating the stigma. As a result, people with diabetes may attempt to conceal their condition from others, leading to constant anxiety (Schabert, Browne, Mosely and Speight, 2013:5).

5.5.4 Satisfaction

The study revealed that patients with some form of income were more satisfied with medical services than those without.

Kurji, et al. (2013:57) mentioned one of the major challenges facing the developing world is the delivery of quality health care given the financial constraints and lack of personnel. Eighty percent of the population in South Africa only receive the most basic primary health care which is provided by the state, and highly specialized services are available in the private sector (Thomas et al., 2013:336). The study setting was in a private practice where most patients are on a medical aid/insurance and are able to afford the services of the ophthalmologists. They were, therefore, more satisfied with the services. However, there was also dissatisfaction mentioned amongst some patients with more income as they felt annoyed by waiting times, in the waiting-room, and in the examination room. At times they believed that a no show was actually a positive event for the doctors and staff, not being aware of the negative impact it had on the work flow in many ways (Lacy et al., 2004:541). Many patients mentioned work commitments and appointments not being flexible as a reason for not being satisfied with services (Snow and Fulop, 2011:257).

Mash et al. (2007:1285) stated that given the capacity of the public health system and the financial constraints on patients, seeing an ophthalmologist is not feasible. On a primary level fewer patients are being screened for diabetic retinopathy due to the pressure of too many patients and de-skilling of health workers (Cook, 2013:446). Mollentsky, (2007:538) indicated that it was not always attainable for the primary care physician to do fundoscopy. There is also a major shortage of diabetic educators throughout South Africa (Amod et al, 2012:67-70). Mshunqane et al. (2012:392) claim dissatisfaction is high in low socio-economic patients, especially with the public health care system.

Read and Cook, (2007:56) best summarise the reality of diabetic retinopathy management in the public sector of South Africa as “too little too late”, and those tertiary centres who receive diabetic retinopathy referrals are already working way beyond their capacity, which means there are too many patients (Cook, 2013:446).

When it comes to the patient centred approach, many felt that the doctors did not spend enough time with them during consultations and there was not a holistic approach to the disease (Mshunqane et al., 2012:392). Therefore they did not attend appointments, because they felt disrespected by the health care system (Neal et al., 2005:1). The study conducted by Lewis (2011:4) in the United Kingdom stated that patients also mentioned loss of confidence in the health system, mentioning clinic waiting times as a reason for non-attendance. Transport issues and cost also seems to be a major reason for non attendance as literature highlights it in both South African and international studies (Khan et al., 2012:26).

5.5.5 Diabetic and diabetic retinopathy knowledge

The result of the study significantly states that:

- Females seemed to have more diabetic knowledge than males.
- Those who visited the doctors in the time period as instructed seemed to have more knowledge.

It was found that there is a general lack of awareness among diabetic with regards to the existence of diabetic eye disease, and only 10.4% of the patients involved in the study conducted by Read and Cook (2007:56) were aware that annual fundoscopy was a requirement. The study conducted by Beynat, et al.,(2009:49), in France found that only a minority of the patients (33%) had an annual fundus examination. Cook, (2013:449) also states there seem to be a great lack of education amongst patients regarding the need for screening. Patients with less frequent information were less likely to take diabetes self-care (Ayele, et al.,2012:35515). That concurs with the findings of the study that those patients who do not visit the doctors on an annual basis have less knowledge and awareness regarding their eye disease. The reason could be a lack of knowledge amongst health care workers, lacking the clinical skills regarding eye screening (Read and Cook, 2007:64), and therefore not being able to educate and advice patients appropriately. Mshunqane et al. (2012:392) clearly state that a team approach is needed to manage diabetes. A successful chronic disease approach is dependent on effective, systemic and interactive communication between patients and service providers. General practitioners most of the time are the first stop in the journey of diabetic patients. Therefore, the way the patients are being managed

at this stop has the greatest impact on the services provided by the secondary care facility (Ibraheim and Rehman, 2008:1).

Ayele, et al., (2012:35515), conducted a study where the main objective was to identify predictors of self-care behaviour among patients with diabetes. The findings indicated that majority of the participants (60.4%) were female. 93.7% had general knowledge about diabetes and 93.2% had specific knowledge about diabetic self-care. It concurs with the results of this study that more females than males had specific knowledge about diabetes. (Chou, et al. (2014:180) study examined barriers to recommended eye care and found that most of diabetics not seeking eye care was woman (51%).

5.6 SUMMARY

The result of the study highlighted positive behaviour and negative behaviour and how knowledge, stigma, control and satisfaction correlate with the behaviour. It was noted that positive behaviour indicated that the patient's condition was more controlled. Patients also seemed to be knowledgeable regarding their condition and were more satisfied with medical services as they were interested in understanding the disease and possible complications. Lack of knowledge and poor diabetic control were indicated as negative behaviour in the study. The study participants were more fearful of the stigma associated with diabetes.

5.7 LIMITATIONS OF THE STUDY

The following limitations in the study were identified by the researcher:

The study was conducted in a private practice, concentrating mainly on rural, high socio-economic patients. The researcher could have provided more valuable information if the study was conducted in the public sector with a variety of patients from all areas, and inclusive of poor communities. Because of methodological challenges the findings of this study may not be generalised to the entire Eastern Cape Province.

5.8 RECOMMENDATIONS

Based on the findings of the study the following recommendations are made:

Patient education needs to be prioritised in order to create awareness regarding diabetes and diabetic retinopathy. A number of strategies should be used in patient education such as health talks at the clinic, television and modern technology.

More research studies using other methods involving public institutions in the entire province should be conducted in order to generalize the findings.

Each professional involved with diabetes and diabetic eye care should take it upon him/her to strive to acquire knowledge and skills that are relevant to the practice.

A bigger study which includes patients from the public health facilities needs to be conducted.

5.9 CONCLUSION

Compliance with doctor's visits was found to be associated with positive behaviour and more knowledge and control. Knowledgeable patients were more satisfied with the medical services. Fear of stigma associated with diabetes mellitus was found to be associated with demographic variables such as gender, race, marital status, employment status and educational level. The main reasons for non-compliance were lack of information, negligence, busy work schedules and lack of finance. These results suggested there is a need to raise awareness of eye health and access to affordable medical services.

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LIST OF APPENDICE

APPENDIX 1: Diabetic Retinopathy Patient Questionnaire (English version).

DIABETIC RETINOPATHY PATIENT QUESTIONNAIRE

Study ID:
Site: The Eye Centre, East London
Date:

Section A

Please fill in the blanks or mark the appropriate boxes with a tick .

Demographical Information and General Health

Gender: | Male | Female |

Age: Diabetic since :

Residential Area: If you have seen an eye doctor in the past, was the visit more than a year ago? | Yes | No |

Ethnic Origin

African	Coloured	White	Indian	Other

Marital Status

Married		Seperated	
Never Married		Living Together	
Divorce		Widow / Widower	

Education Level

Never attended school		Diploma	
Primary		Degree	
Secondary			

Employment (Which of these describes best what you are doing at the moment)

WFull Time work		Unemployed	
Part Time Work		Grant Recipient	
Student		Other	

Religious Affiliation

No religion	Christian	Hindu	Muslim	Other

Family Support

Lives Alone	Lives with Family	Lives with Friends	Other Living Arrangements

Medical Aid Status

Full Medical Aid	Hospital Package	Private / Paying Cash

In general would you say your health is?

Excellent		Fair	
Very Good		Poor	
Good			

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Section B

For each of the following statements /questions, kindly indicate what your views are by, rating your response as per the scale provided.

Mark with X in the box appropriate to your response.

Please respond to all the items of the questionnaire. There are no right or wrong answers.

Diabetes and Eye Care

Knowledge and attitudes regarding diabetes in general and diabetic eye disease.

Statements	Strongly Disagree 1	Disagree 2	Neutral / Not Sure 3	Agree 4	Strongly Agree 5
1. Diabetes is a lifelong diesease that cannot be cured.					
2. Diabetes affects the whole body.					
3. Diabetes affects the eyes.					
4. I do not want people to know that I have diabetes.					
5. Yearly eye visits to an eye doctor is important whether you experience eye problems or not?					
6. You would rather seek alternative eye treatment before you go to an eye doctor. (For example: homeopathic practitioners or traditional healers)					
7. I do not want other people to know that diabetes is affecting my eyes.					

Confidence in one's ability to control diabetes and the health professionals who treat it.

Statements	Not at All Confident 1	Not Very Confident 2	Neutral 3	Confident 4	Very Confident 5
8. How confident do you feel controlling your blood sugar?					
9. How confident do you feel controlling your blood pressure?					
10. How confident do you feel that you are able to follow a healthty diet?					
11. How confident do you feel that you are able to exercise?					
12. How confident do you feel that you are able to take your medication as prescribed by your doctor?					
13. How confident do you feel that you can notice changes in your eyesight?					
14. Do you feel confident enough to seek help if you notice changes in your eye sight?					
15. How confident do you feel that the treatment you receive is helping your eye sight?					
16. How confident do you feel that the doctors and nurses has given you enough time during your consultation?					

Confidence in one's ability to control diabetes and the health professionals who treat it. ***(Continued)***

Statements	Not at All Confident 1	Not Very Confident 2	Neutral 3	Confident 4	Very Confident 5
17. Do you feel confident that the doctors and nurses listen to your concerns and involve you in decisions regarding your eye care?					
18. How confident do you feel that the reception staff give you an appointment suitable to your needs?					
19. How confident do you feel that other social obligations / responsibilities won't affect you attending your eye appointments? (For example; work commitments, family commitments, transport etc)					

Fear and anxiety regarding your eye condition.

Statements	None of Time 1	Some of Time 2	A Good Bit of the Time 3	Most of the Time 4	All the Time 5
20. How often do you feel discouraged about your eye condition?					
21. Are you fearful about the future regarding your eyesight?					
22. Do you think if you know more about diabetic eye disease you would be less afraid?					
23. Do you feel that you should have been informed earlier that you need to have your eyes checked with an eye doctor as a diabetic?					
24.Do you often ask questions about things you dont understand regarding your treatments and eye condition?					
25. Do you feel anxious about the high cost of treatment for your eyes.?					
26. Do you feel anxious about owing money to the doctors if your medical aid does not cover the cost?					

27. If you did not attend your eye check up, please state the reason(s). (Skip this question if you did atttend.)

Thank you for your participation in this study.

Appendix 2: Diabetic Retinopathy Patient Questionnaire (IsiXhosa version).

DIABETIC RETINOPATHY PATIENT QUESTIONNAIRE

Study ID:
Site: The Eye Centre, East London
Date:

Section A

Khetha impendulo echanekileyo ngokuthi wenze uphawu luka -X

Iinkcukacha Zokuhlala neMpilo ngokubanzi

Isini: | Indoda | Obhinqileyo |

Iminyaka:

Indawo ohlala kuyo:

Uhlanga:

African	Coloured	White	Indian	Olunye uhlanga

Isimo sokutshata

Utshatile		Wohlukene nomlingani wakho	
Zange watshata		Uhlala nomlingani wakho	
U-devosile		Umhlolo/Umhlolokazi	

Imfundo

Zange waya esikolweni		Unediploma	
Upase amabanga aphantsi		Unedegree	
Upase amabanga aphezulu			

Imo yomsebenzi (Oku kukuchaza indlela ophangela/osebenza ngayo)

Uyaphangela		Awuphangeli	
Uqeshwe okwethutyana		Urhola imali yesibonelelo sikaRhulumente	
Ungumfundi		Eminye imisebenzi	

Inkolo (Khetha inkolo okholelwa kuyo)

Awunayo inkolo	UbuKrestu	IsiHindu	Muslim	Enye inkolo

Inkxaso ngokwentlalo

Uhlala wedwa	Uhlala nosapho lwakho	Uhlala nezihlobo	Enye imeko yokuhlala

Isimo seMedical Aid

Unayo ekubhatalela yonke into	Ibhatelela ukulaliswa esibhedlele kuphela	Ubhatala imali

Ungathini ngesimo sempilo yakho ngokubanzi

Womelele ngokugqithisileyo		Ayikho buthathaka kodwa ayomelelanga kakhulu	
Womelele kakhulu		Ibuthathaka	
Womele			

Section B

Kule mibuzo ilandelayo khetha oko ukucingayo ngokuthi ukhethe ibhokisi emele iimbono zakho.

Phawula ngo X kwibhokisi efanelekileyo ukubonisa impendulo yakho.

Kumele uphendule yonke imibuzo. Akukho mpendulo ilungileyo okanye engalunganga.

Iswekile kunye nonyango lwamehlo

Ulwazi lwakho oluphangaleleyo malunga nesigulo seswekile kunye nameho

Statements	Ndiyavuma kakhulu	Ndiyavuma	Andiqinisekanga	Andivumelani	Andivumelani kakhulu
1. Iswekile sisigulo sobomi esingena kunyangwa					
2. Iswekile ichaphazela umzimba wonk					
3. Iswekile ichaphazela amehlo					
4. Ukundwendwela ugqirha wamehle kubalulekile nokuba amehlo akakuchaphazeli					
5. Ungatsho ukuba inkolo/inkcubeko yakho inefuthe ekubeni undwendwele ugqirha wamehlo					
6. Ungajonga olunye uncedo phambi kokuba uye kugqirha wamehlo					
7. Andifuni ukuba abantu bazi ukuba ndineswekile kwaye ichaphazela amehlo					
8. Andiziva ndikhululekile ekubeni ndichazele abanye abantu ngesimo samehlo am.					

Ukuzithemba ekukhathalaleni iswekile nogqirha abajongene nezeMpilo

Imibuzo	Ndizithembe kakhulu	Ndizithembile	Andiqinisekanga	Andizithembanga kakhulu	Andizithembanga kwaphela
9. Uzithembe kangakanani ekukhathalaleni isimo sakho seswekile?					
10. Uzithemba kangakanani ekujongeni isimo segazi okanye ipresha?					
11. Uzithemba kangakanani na ekulandeleni ukutya okuyimpilo?					
12. Ingaba unalo ituba lokulolonga umzimba wakho?					
13. Uzithembe kangakanani ekuwulolongeni?					
14. Ingaba unako ukuqaphela xa amehlo akho enengxaki efuna ubonane nogqirha wamehlo?					
15. Ubathembe kangakanani oogqirha kunye noomongikazi xa becacisa imeko yamehlo akho kunye nonyango olufumanekayo					
16. uziva njani ngonyango olufumanayo lwamehlo?ingaba uluthembile olunyango?					
17. Ingaba oogqirha noomongikazi bakunike ithuba elaneleyo lokuthetha kunye nokubonana nogqirha?					

Ukuzithemba ekuthathalaleni iswekile kunye noogqirha abajongene nonyango nezeMpilo

IMIBUZO	Ndibathembe kakhulu	Ndibathembil e	Andiziva ndibathembile le okanye ndingabathe	Andiqinise kanga	Andibathemba nga kwaphela
18. Ingaba ubathembile oogqirha noomongikazi ekumameleni izimvo kunye nezikhalo zakho?					
19. Uziva njani ekubeni oogqirha bakwenze inxalenye xa bethatha izigqibo malunga nemeko yakho yezonyango					
20. Ingaba abasebenzi okanye onobhala bakwaqirha bakunika ixeshalokubonana nogqira elifanele iimfuno zakho?					

Uloyiko kunye nexhala malunga nemeko yakho yamehlo

Statements	Ngamaxesh a onke	Amaxesha amaninzi	Ngamanye amaxesha kodwa hayi kakhulu	Ngamanye amaxesha	Andinalo uluyoko okanye ixhala nangeli
21. Ingaba uziva uphelelwe ngumdla malunga nemekho yakho yamehlo?					
22. Ingaba unalo uloyiko oloyiko okanye ixhala malunga nengomso lamehlo akho?					
23. Uninga ukuba xa usazi banzi ngezifo okanye izigulo lungancipha uloyiko					
24. Uninga ukuba bekumele uxelelwe ngethuba xa udinga ukubonana nogqirha ukuze ajonge amehlo uneswekile?					
25. Uba nexhala malunga namaxabiso aphezulu onyango lwamehlo?					
26. Ingaba uziva unexhala lokuba netyala lemali kagqirha xa i-medical aid ingakhange ibhatale iindleko?					
27. Ingaba uyayibuza imibuzo ngezinto ongaziqondiyo malunga amayeza kunye nonyango l wamhehlo?					

28 Ukuba akhange uyonjonga ukuhlolwa kwamehlo bhala isizathu sakho. (tsiba ukuba iobuza xa ukuzile)

Ndiyabulela ngokuthatha inxaxheba kolu phando.

Researcher's name Signature Date

Appendix 3: Consent to participate in research study

CONSENT TO PARTICIPATE IN RESEARCH STUDY
Title of the research

Factors influencing attendance by diabetic patients for their yearly ophthalmic reviews at a private ophthalmic practice in East London, South Africa

Researcher

Nadine Arnolds

Aim/purpose of the study

The aim of the study is to explain and describe the factors/reasons influencing non attendance of diabetic patients for their yearly reviews.

You are requested to participate in the study. You will be asked to fill in a questionnaire in a private room specifically for the duration of the study. Participation or non participation will have no impact on you in any way. Answering the questionnaire will take about 10 minutes.

Potential risk

There are no risks or discomfort associated with your participation in the study.

Potential benefits

You will not directly benefit from your participation in this study, however the significance/benefits of the study is that if the reasons for non-attendance are known they can be used in coming up with;

- Strategies to increase attendance to prevent sight threatening diabetic retinopathy. It can also be used to
- Educate patients and other health professionals about eye diseases and create awareness regarding the importance of regular screening.
- Regular ‘free – of – charge” screening sessions might generate involving the rural clinics and poorer communities involving professional nurses and optometrists.
- It might also generate training programs for professional nurses and optometrist to utilize the grading system for referrals.

Privacy and Confidentiality

Confidentiality will be respected. Unless required by law, no information that might directly reveal or indirectly reveal your identity will be released or published without specific consent to the disclosure.

Participation or withdrawal from the study

Taking part in this study is your choice. There will be no penalty if you decide to decline. You are free to withdraw from this research study at any time. You choice to withdraw will not affect you relationship with the private practice.

Contact details

If you have any questions, concerns or complaints about research you may contact my supervisor Dr E Yako on 043 704 7376 or eyako@ufh.ac.za

I can be contacted on 043 743 4334 or nadine@eyecentre.co.za

Rights of the research subject

For questions about your rights while participating in this study, you may contact the institutional review board at the University of Fort Hare, The research Ethics Committee at 043 704 7588

My signature below indicates that I have agreed to participate in the study, and a copy of the consent form was supplied to me.

Signature of participant …….. Date.....

Investigator's signature…… Date.....

Appendix 4: Permission to conduct research from the Institution.

DRS COOK & BOLITER
THE EYE CENTRE

To: Nadine Arnolds

Date: 14 May 2014

Re: **PERMISSION TO CONDUCT RESEARCH**

We hereby grant you permission to conduct research on the "Reasons for non - attendance of diabetic patients to their yearly ophthalmic review at a private practice in East London", at The Eye Centre.

This permission is granted subject to the following conditions:

- You obtain ethical clearance from the Human Ethics committee of the relevant University and from the Department of Health.
- The institution incurs no cost in the course of your research.
- That access to staff and patients will not interrupt the daily provision of services.
- That prior to the research you will liaise with relevant staff and make arrangements with them that is convenient for all sectors.

Yours sincerely

Dr A Boliter

Dr S Cook

18 St James Rd, Southernwood, 5201, East London,
Eastern Cape, South Africa.
Phone: +27 43 743 4334 **E-mail:** care@eyecentre.co.za
Fax: +27 43 743 0359 **Web:** www.eyecentre.co.za
reg. 2000/018243/21 | Vat No. 4910 189 226 | Prac No. 026 000 2604183
Directors: Dr. SPC Cook, Dr AR Boliter

THE EYE CENTRE
EAST LONDON

APPENDIX 5: Permission to conduct research from the Department of Health.

Eastern Cape Department of Health

Enquiries:	Zonwabele Merile	Tel No:	040 608 0830
Date:	02nd May 2014	Fax No:	043 642 1409
e-mail address:	zonwabele.merile@impilo.ecprov.gov.za		

Dear Ms N Arnold 043 743 0359

Re: Reasons for non-attendance of diabetic patients to their yearly ophthalmic review at a private practice in East London

The Department of Health would like to inform you that your application for conducting a research on the abovementioned topic has been approved based on the following conditions:

1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having a written approval from the Department of Health in writing.
2. You are advised to ensure, observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants.
3. The Department of Health expects you to provide a progress on your study every 3 months (from date you received this letter) in writing.
4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Epidemiological Research & Surveillance Management. You may be invited to the department to come and present your research findings with your implementable recommendations.
5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.

DEPUTY DIRECTOR: EPIDEMIOLOGICAL RESEARCH & SURVEILLANCE MANAGEMENT

APPENDIX 6: Ethical Clearance Certificate.

University of Fort Hare
Together in Excellence

ETHICAL CLEARANCE CERTIFICATE

Certificate Reference Number:	YAK031SARN01
Project title:	**Reasons for non-attendance of diabetic patients to their yearly ophthalmic reviews at a private practice in East London**
Nature of Project:	Masters
Principal Researcher:	Nadine Arnolds
Supervisor:	Dr E Yako
Co-supervisor:	

On behalf of the University of Fort Hare's Research Ethics Committee (UREC) I hereby give ethical approval in respect of the undertakings contained in the above-mentioned project and research instrument(s). Should any other instruments be used, these require separate authorization. The Researcher may therefore commence with the research as from the date of this certificate, using the reference number indicated above.

Please note that the UREC must be informed immediately of

- Any material change in the conditions or undertakings mentioned in the document
- Any material breaches of ethical undertakings or events that impact upon the ethical conduct of the research

The Principal Researcher must report to the UREC in the prescribed format, where applicable, annually, and at the end of the project, in respect of ethical compliance.

Special conditions: Research that includes children as per the official regulations of the act must take the following into account:

Note: The UREC is aware of the provisions of s71 of the National Health Act 61 of 2003 and that matters pertaining to obtaining the Minister's consent are under discussion and remain unresolved. Nonetheless, as was decided at a meeting between the National Health Research Ethics Committee and stakeholders on 6 June 2013, university ethics committees may continue to grant ethical clearance for research involving children without the Minister's consent, provided that the prescripts of the previous rules have been met. This certificate is granted in terms of this agreement.

The UREC retains the right to

- Withdraw or amend this Ethical Clearance Certificate if
  - Any unethical principal or practices are revealed or suspected
  - Relevant information has been withheld or misrepresented
  - Regulatory changes of whatsoever nature so require
  - The conditions contained in the Certificate have not been adhered to

- Request access to any information or data at any time during the course or after completion of the project.

- In addition to the need to comply with the highest level of ethical conduct principle investigators must report back annually as an evaluation and monitoring mechanism on the progress being made by the research. Such a report must be sent to the Dean of Research's office

The Ethics Committee wished you well in your research.

Yours sincerely

Professor Gideon de Wet
Dean of Research

11 March 2014

APPENDIX 7: Editor's certificate

8 Nahoon Valley Place

Nahoon Valley

East London

5241

23rd December 2015

TO WHOM IT MAY CONCERN

I hereby confirm that I have proofread and edited the following master's thesis using the Windows "Tracking" system to reflect my comments and suggested corrections for the student to action:

Factors influencing attendance by diabetic patients for their yearly ophthalmic reviews at a private ophthalmic practice in East London, South Africa by Nadine Arnolds, a dissertation submitted in fulfilment of the requirements for the degree of Master of Nursing Science (Magister of Curationis, Medical-Surgical Nursing), Department of Nursing Science (Faculty of Health Sciences), University of Fort Hare.

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Disclaimer: Although I have made comments and suggested corrections, the responsibility for the quality of the final document lies with the author in the first instance and not with myself as the editor.

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