DETERMINANTS OF COMPLIANCE BEHAVIOUR AMONG PATIENTS LIVING WITH DIABETES REFERRED FOR DIABETIC RETINOPATHY TREATMENT IN A GOVERNMENT HEALTH CARE FACILITY IN CAPE TOWN, SOUTH AFRICA

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DECLARATION

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Any sources that I have used or quoted have been cited and referenced.

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ABSTRACT

Background: Untreated and unmonitored diabetic retinopathy (DR) can lead to vision loss. This may have many negative implications on society. Currently, there is a dearth of evidence regarding the factors that influence compliance behaviour to treatment among patients diagnosed with DR in South Africa's public healthcare system. The current study sought to fill this research gap and explore patient-, institution-, treatment-, and COVID-19- related factors associated with compliance behaviour among patients living with diabetes that have been referred for suspected vision-threatening DR in the Northern/Tygerberg sub-structure (NTSS) of Cape Town, South Africa. **Methodology:** A qualitative research approach was used. The study population included 19 years and older South Africans living with diabetes who were screened and referred for vision-threatening retinopathy within the last 18 months at public primary healthcare facilities in the NTSS. Data collection was conducted in the form of in-depth, semi-structured telephone interviews. In total, 13 participants and 2 key informants were interviewed. Thematic data analysis was conducted using taguette.org, a web-based manual coding program. **Results:** The mean participant age was 56 years. Sixty-two percent of the participants were female; 84% had type 2 diabetes mellitus; and 62% were fully compliant with their DR treatment. The most notable patient-related barriers to DR care compliance included forgetfulness and the poor state of health among participants. Fear of going blind on the other hand was an important factor that led to DR care compliance. Despite the lack of in-depth knowledge about how DR manifests, all participants were aware that if not treated, diabetes could negatively impact their vision. The most notable institution-related barriers to DR care compliance included less optimal information received from healthcare service providers, poor referral management by the Retinal Screening Programme, and Tygerberg Hospital's inaccessibility via phone calls. Fear of DR treatment was not found to be a barrier in the current study. All these factors were confirmed by the key informants that were included in the current study. Finally, while the participants and key informants expressed varied views about the role played by COVID-19 on DR care compliance, they all agreed that it had exerted negative connotations on patients' adherence to DR treatment. **Conclusion:** Improved health care services, as well as DR knowledge among people living with diabetes, could increase the uptake of treatment and retinal screening. Diabetes-related educational programmes implemented in the NTSS public health system need to be scaled up and reviewed for efficiency.

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KEYWORDS

Diabetes mellitus

Diabetic retinopathy

Treatment

Retinal screening

Compliance

Non-compliance

Vision loss

Cape Town

Qualitative

COVID-19

LIST OF ACRONYMS AND ABBREVIATIONS

COVID-19	Coronavirus disease 2019
CT	Cape Town
CTM	Cape Town Metropole
DM	Diabetes Mellitus
DR	Diabetic Retinopathy
HbA1c	Glycated Haemoglobin
HIV	Human Immunodeficiency Virus
MDHS	Metro District Health Services
MDR TB	Multidrug-resistant Tuberculosis
NCD	Non-communicable Disease
NGO	Non-Governmental Organisation
NTSS	Northern/Tygerberg Substructure
PDR	Proliferative Diabetic Retinopathy
RDR	Referable Diabetic Retinopathy
RSP	Retinal Screening Programme
SA	South Africa
T1DM	Type 1 Diabetes Mellitus
T2DM	Type 2 Diabetes Mellitus
TB	Tuberculosis
TBH	Tygerberg Hospital
UK	United Kingdom
US	United States

WCP	Western Cape Province

CHAPTER 1: INTRODUCTION

1.1 Background

In 2019, the number of people between 20 and 79 years of age living with diabetes mellitus (DM) in South Africa (SA) was estimated at 4.6 million, making up 12.8% of the total adult population (International Diabetes Federation, 2019). The prevalence of diabetes in the Western Cape Province (WCP), SA, is high and has increased since 1998 (DoH, 2007; NDoH, 2019; Shisana *et al.,* 2013). The South African Demographic and Health Survey (NDOH *et al.,* 2019) found the prevalence of diabetes in the WCP to be over 10%. Moreover, the prevalence of diabetes is expected to increase swiftly in the foreseeable future (Saeedi *et al.*, 2019; Bailey *et al.*, 2016; NDoH, 2019; Mabaso and Oduntan, 2014; Stokes *et al.*, 2017).

Living with diabetes for a long period, especially being an uncontrolled person living with diabetes, increases the chances of complications associated with high and fluctuating blood glucose levels (Thomas *et al.*, 2013; Yau *et al.*, 2012; Giulla, Amador and Zinman, 2003; Ting, Cheung and Wong, 2016). Among these complications is DR, which is one of the leading causes of vision loss in SA (Kempen *et al.,* 2017).

Diabetic retinopathy occurs when the small blood vessels found in the retina of the eye are damaged by high blood glucose levels which could lead to vision-threatening complications (Kanski and Bowling, 2011). The chances of DR being prevalent in a person suffering from DM could be up to 40%, and often in type 2 diabetes mellitus (T2DM), the retinopathy could be present before diabetes has even been diagnosed (Kanski and Bowling, 2011; NDOH, 2002).

Thomas *et al.* (2019) have estimated that the DR prevalence for the African continent was 33.8% for the 2015-2019 period. This was one of the highest regional prevalence rates found in this global study. South African DR prevalence ranged from 25.8% in the private health sector (Thomas *et al.*, 2013) to 63.0% in the public health sector (Mash *et al.*, 2007). Vision-threatening referable diabetic retinopathy (RDR) prevalence ranged from 7.5% (Thomas *et al.*, 2013) to 11% (Mash *et al.*, 2007). Because many individuals living with diabetes in SA have not been diagnosed, the prevalence of DR and RDR may be higher than the afore-mentioned statistics (Beagley *et al.*, 2014; Bertram *et al.*, 2013; Stokes *et al.*, 2017). It becomes important therefore that these individuals are screened so that timely treatment can be offered (Burgess, Msukwa and Beare, 2013). Because individuals do not present with distinct symptoms at the beginning of DR, they tend not to realise that they have the condition until it has advanced and their vision becomes impaired (Lewis, 2015). Vision becomes impaired when people are at a proliferative or advanced stage of retinopathy or present with maculopathy (Watkins, 2003). Unfortunately, lost vision may never be restored (Lewis, 2015).

To prevent the loss of vision, timeous detection is required so that the patients can be diagnosed early and treated if needed. The National Guideline for Prevention of Blindness in SA has highlighted strategies to combat vision loss among DM sufferers in the country. Among these are the pharmacological control of blood glucose levels; annual screenings of the retinae by a trained professional; efficient diagnosis and referral of patients with DR; and treatment of DR by ophthalmologists with the necessary equipment (NDOH, 2002).

Once referred for treatment, compliance is a prerequisite to guarantee the treatment success (Lewis, 2015; Read and Cook, 2007; Burgess, Msukwa and Beare, 2013; Keenum *et al.*, 2016). The challenge faced by service providers in health care facilities is that, often out-patients default on treatment or do not attend clinics regularly (Khandekar, Al Lawati and Barakat, 2011; Chen *et al.*, 2018; Duan *et al.*, 2017; Hua *et al.*, 2017; Keenum *et al.*, 2016). Previous international studies have indicated that after a patient has been referred, 21%-45% do not complete their recommended DR treatment programmes (Lewis *et al.*, 2007; Lewis, 2015; Mtuya *et al.*, 2016). These are unacceptably high figures as the complications of untreated DR, such as permanent vision loss, could lead to people and their families suffering economically and falling into poverty (Hofman, Cook and Levitt, 2014).

There is a dearth of data on the determinants of compliance among patients receiving treatment for DR in Cape Town (CT), SA, despite untreated DR being one of the leading causes of preventable vision loss in the country and worldwide (Cockburn *et al.*, 2012; Kempen *et al.*, 2017; Bertram *et al.*, 2013; Chen *et al.*, 2018; Duan *et al.*, 2017; Hua *et al.*, 2017; Zheng, He and Congdon, 2012; Leasher *et al.*, 2016; Khandekar, Al Lawati and Barakat, 2011).

International studies outline a myriad of reasons given by patients who drop out or falter on treatment (Khan *et al.*, 2012; Chen *et al.*, 2018; Hua *et al.*, 2017; Lewis, 2015; Lewis *et al.*, 2007; Mtuya *et al.*, 2016; Chou *et al.*, 2014; Kashim, Newton and Ojo, 2018). Amongst these are personal (i.e., patient-related), health institutional (i.e., service provider-related), and medical (i.e., treatment tolerance-related).

Furthermore, anecdotal evidence suggests that the novel coronavirus (COVID-19) pandemic is adversely affecting treatment compliance behaviour among patients suffering from diabetes and those that have other non-communicable diseases (NCDs). Various reasons have been offered for this, ranging from patients staying away from health services where they access their treatment due to the fear of contracting COVID-19. Moreover, due to national lockdowns most health services have been suspended as a measure to reduce COVOD-19 transmissions among patients and staff (Palmer *et al.*, 2020; Kluge *et al.*, 2020; Tlhabye, 2020; Venter, 2020). Certain COVID-19 measures taken by institutions have negatively affected the availability of primary eye care services in the Metropole (CTM) area of the WCP, as confirmed via telephone interviews on 22 June 2020 with the primary eye care specialists and health workers within the public health sector (personal communications). During these telephone interviews it was concluded that the DR screening initiative within the CTM has been suspended until further notice. This left many vulnerable and disadvantaged patients who relied on public health services with severely limited access to retinopathy screenings, referrals, diagnoses and treatment options.

Non-compliance with DR treatment is a cause for concern, given that failure to comply with treatment guarantees the condition's progression. This then may lead to the advanced stage of retinopathy which often results in severe loss of vision or total blindness (Chen *et al.*, 2018; Hua *et al.*, 2017; Duan *et al.*, 2017; Schoenfeld *et al.*, 2001; Watkins, 2003; Zheng, He and Congdon, 2012; Lee *et al.*, 2000). It becomes important, therefore, to investigate and understand the factors associated with faltering on the recommended treatment for DR in people attending the primary healthcare centres (also known as 'day hospitals') in the CTM area of WCP, SA. This information will inform targeted interventions that can be directed at countering barriers to DR treatment access and uptake; with the ultimate goal being to reduce the burden of vision loss associated with uncontrolled diabetes (Duan *et al.*, 2017).

1.2 Problem statement

While the international evidence highlights a lack of data regarding DR treatment compliance behaviour in socio-economically disadvantaged settings, it suggests that the general non-compliance rate among people treated for DR is unacceptably high (Lewis, 2015; Chen *et al.*, 2018; Duan *et al.*, 2017; Hua *et al.*, 2017; Mtuya *et al.*, 2016; Thompson *et al.*, 2015). Furthermore, global anecdotal evidence suggests non-compliance rates to have been exacerbated by the COVID-19 pandemic. South Africa is no exception to this. There is a general lack of data on the determinants of DR treatment compliance, especially in the CTM area (Cockburn *et al.*, 2012). However, anecdotal evidence suggests an unacceptably high loss to follow-up percentage of patients on DR treatment in the WCP day hospitals and hospitals. These patients either default on treatment uptake or do not show up for scheduled appointments. The reasons for faltering are currently unknown. In our understanding, no researchers have attempted investigating this topic in the South African context, hence an urgent need to do so.

The proposed research seeks to fill this research gap and use qualitative research methods to explore the determinants of compliance behaviour among patients on DR treatment who have been referred to Tygerberg Hospital's (TBH) ophthalmology department via a retinal screening programme (RSP) running in the day hospitals of the Northern/Tygerberg sub-structure (NTSS) of the CTM area in WCP, SA.

1.3 Purpose

The outcomes of the current study will be used to fill a gap in the scientific literature regarding factors associated with compliance behaviours among patients referred to receive DR treatment at health care centres in the CTM area. The data arising from this study will also be useful to the managers of the proposed health care centres as it will inform targeted interventions that will be directed at countering barriers to DR treatment access and uptake, with the ultimate goal being to reduce the burden of vision loss associated with uncontrolled diabetes (Duan *et al.*, 2017).

1.4 Aim

To explore patient-, institution-, treatment-, and COVID-19-related factors associated with compliance behaviour among patients living with diabetes that have been referred for suspected vision-threatening DR in the NTSS.

1.5 Objectives

1. To explore the personal-related factors influencing the compliance behaviour among patients on DR treatment
2. To explore healthcare provider-related factors influencing compliance behaviour among patients on DR treatment
3. To explore treatment-related factors influencing compliance behaviour among patients on DR treatment

4. To explore and describe the experiences of health care service providers on the compliance behaviours of patients receiving DR treatment
5. To explore how the COVID-19 lockdown has affected compliance behaviour among patients requiring DR treatment

CHAPTER 2: LITERATURE REVIEW

2.1 Chapter overview

In Chapter 1 we depicted the problem background, aim, objectives, purpose, and the significance of the current research. An extensive electronic search for relevant literature was then conducted and outcomes are presented in the current chapter. Due to the dearth of data on the current topic in SA, we could not find relevant studies done in CT. As such, in the list of the studies discussed in this chapter, we presented a few studies done in the other provinces of SA. We also included information from studies that may not be directly related to DR, but studies from which parallels could be drawn. For instance, studies with similar aims concerning diabetic non-compliance, but with different settings, or studies with a similar setting (CT/WCP) but non-compliance to various other health issues, not necessarily DR, are discussed.

2.2 Introduction to diabetic retinopathy

Diabetic retinopathy is one of the leading causes of avoidable blindness globally that critically affects people of working age (Chen *et al.*, 2018). Diabetic retinopathy is a microvascular disease that affects the small blood vessels in the retina (Sayin, Kara and Pekel, 2015). This disease can be classified as non-proliferative (NPDR) or proliferative DR (PDR) (see Appendix P for classification criteria). Non-proliferative diabetic retinopathy and PDR can be further classified as mild, moderate, or severe, with PDR being vision-threatening. Diabetic macular oedema (DME) is a vision-threatening diabetic maculopathy that may or may not occur with NPDR or PDR (Kashim, Newton and Ojo, 2018). Furthermore, DM can also lead to optic disc oedema, cataract, glaucoma, and ocular surface diseases (Sayin, Kara and Pekel, 2015).

Diabetic retinopathy is a major cause of vision loss among the CT population that has diabetes, but there are effective treatments available that could (if DR was detected and treated on time) prevent vision loss (Cockburn *et al.*, 2012; Chen *et al.*, 2018). Figure 2.2.1 indicates the DR referral process in the NTSS.

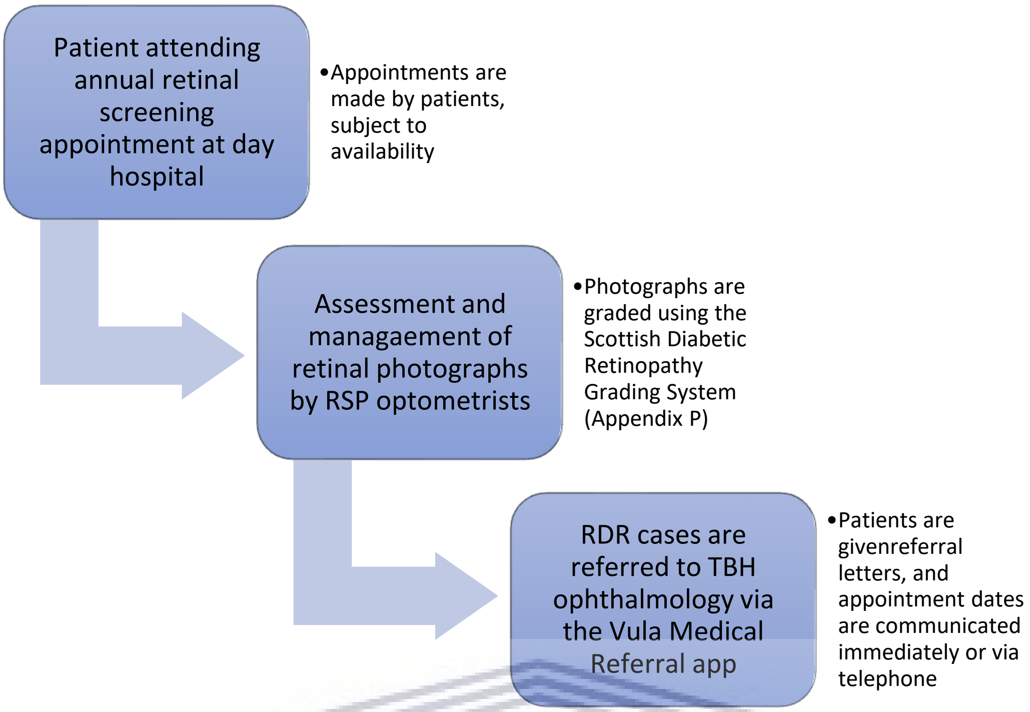

Figure 2.2.1: Referral pathway in the target NTSS setting *(personal communication: Mabotja, 2020)*

Once referred to TBH Ophthalmology, a treatment plan for RDR is prescribed by the treating ophthalmologist, guided by the specific case (personal communication: Mabotja, 2020). Diabetic retinopathy treatment typically consists of laser photocoagulation and/or intravitreal anti-vascular endothelial growth factor (anti-VEGF) injections (Kanski and Bowling, 2011). Photocoagulation treatment is done to halt the fluid and blood leakage within the retina as well as to taper off abnormal blood vessels. Anti-VEGF injections are used to inhibit the growth of new and abnormal blood vessels (Kanski and Bowling, 2011). These treatments are typically administered over multiple outpatient-based visits. Patients must be advised that laser treatment could lead to peripheral and central vision defects, however, without intervention DR could cause severe vision loss (Kanski and Bowling, 2011). More severe cases of DR could indicate surgical intervention, such as a pars plana vitrectomy, to remove blood from the vitreous and scar tissue from the retina (Kanski and Bowling, 2011).

Healthcare adherence relies on patient behaviour and compliance with what has been advised and prescribed by the treating medical professional. However, non-adherence seems to be a major problem reported globally (Mtuya *et al.*, 2016; Khandekar, Al Lawati and Barakat, 2011; Lewis, 2015; Hua *et al.*, 2017; Duan *et al.*, 2017; Chen *et al.*, 2018). Non-adherence can include the failure: of a patient to take the prescribed medication, to making lifestyle changes, to adhere to appointments made with treating medical professionals, as well as to show up for necessary eye tests (Khan *et al.*, 2012). Non-adherence to long-term treatment of chronic diseases is estimated to be 50% worldwide, and the percentage is estimated to be even higher in developing countries (WHO, 2003). Treatment adherence also tends to decline over time (Khan *et al.*, 2012).

For the current study, compliance is defined as adherence to taking prescribed medication, showing up for scheduled appointments, as well as scheduling follow-up appointments (Patel *et al.*, 2010).

2.3 Diabetic retinopathy and compliance

A study conducted in San Francisco, California by Chen *et al.* (2018) to identify factors that lead to non-compliance to DR treatment among working-age patients living with diabetes found that 46% of the patients were non-adherent to their treatment. In fact, in this study, an average of 18.9% of appointments was shown to be missed by patients. It was also shown that missed-appointment prevalence by patients with mild NPDR, moderate/severe NPDR, and PDR were 19.6%, 17.4%, and 19.4%, respectively (Chen *et al.*, 2018). Another study done in a public health-sector or “Safety-Net” clinic in America found that 82.1% of patients that were referred for urgent DR care did not obtain treatment within the first week of referral, despite them not being required to pay for that necessary treatment (Keenum *et al.*, 2016). The authors of this study also found that 64.8% of the patients who required an annual follow-up treatment did not comply (Keenum *et al.*, 2016). Overall, only 29.9% of the patients included in the study returned for the recommended care within the prescribed time frame (Keenum *et al.*, 2016). According to reports by the United Kingdom National Health Service, 19%-23% of patients who were urgently referred for DR treatment were not seen within the prescribed time frame (NHS, 2017). Furthermore, 17%-31% of non-urgent DR referral cases were not seen within the prescribed time frame (NHS, 2017). In yet another United Kingdom study it was found that 16% of patients referred for DR did not attend any ophthalmology appointments and 7% failed to attend the first treatment appointment but were seen by an ophthalmologist at a later stage (Jyothi *et al.*, 2009).

In a qualitative study done in China’s Beijing Chaoyang Hospital (a hospital that caters for mostly affluent community members), it was found that 54.6% of patients that were referred for DR treatment concluded their laser treatment program. The rest, 27.9% did not start the treatment (Hua *et al.*, 2017). This meant that in this study, there was a non-adherence rate of

45.4%. The authors of this study also noted that, in a similar study done in 1994, a compliance rate of about 85% was found. In this study, the high compliance rate was thought to be attributed to participants having been informed about their DM and DR severity through a "blindness prevention education program" (Hua *et al.,* 2017). However, the authors deemed their findings not generalisable in the broader population (Hua *et al.*, 2017).

In a quantitative study done in Tanzania by Mtuya *et al.* (2016) to investigate factors that lead to non-compliance among patients living with diabetes that are referred for DR treatment, it was found that only 24.6% of the patients complied with the scheduled appointments. This meant that 75.4% of participants were non-compliant with their advised treatment.

2.4 Factors related to compliance behaviour

Below, the literature is discussed based on factors influencing DR treatment compliance behaviour. These reasons have been divided into patient-related factors, service provider-related factors, treatment-related factors, independent factors as well as COVID-19-related factors (Khan *et al.*, 2012; Chen *et al.*, 2018). In this regard, the conceptual framework (Figure 2.4.1) proposed by Whitehead and Dahlgren (1991) was adopted and adapted to fit the current research. All the aforementioned factors that influence DR compliance could be categorised into various levels of the social determinants of health based on Figure 2.4.1. For instance, in this figure it is shown that DR compliance factors are interrelated. These factors include individual factors (i.e. immediate factors - including age, gender, health status, financial trade-offs, health beliefs, the fear of medical procedures and forgetfulness); and community and societal factors (i.e. underlying determinants – including familial and societal support, as well as education and services offered by healthcare providers) that influence the immediate factors. Finally, there are the so-called basic determinants, which relate to socioeconomic and environmental circumstances. These determinants affect both the underlying and individual factors and include accessibility of health services and COVID-19. All these factors, therefore, fit perfectly into the current research's overall aim; hence, the sections included in this document will be unpacked stepwise using this conceptual framework.

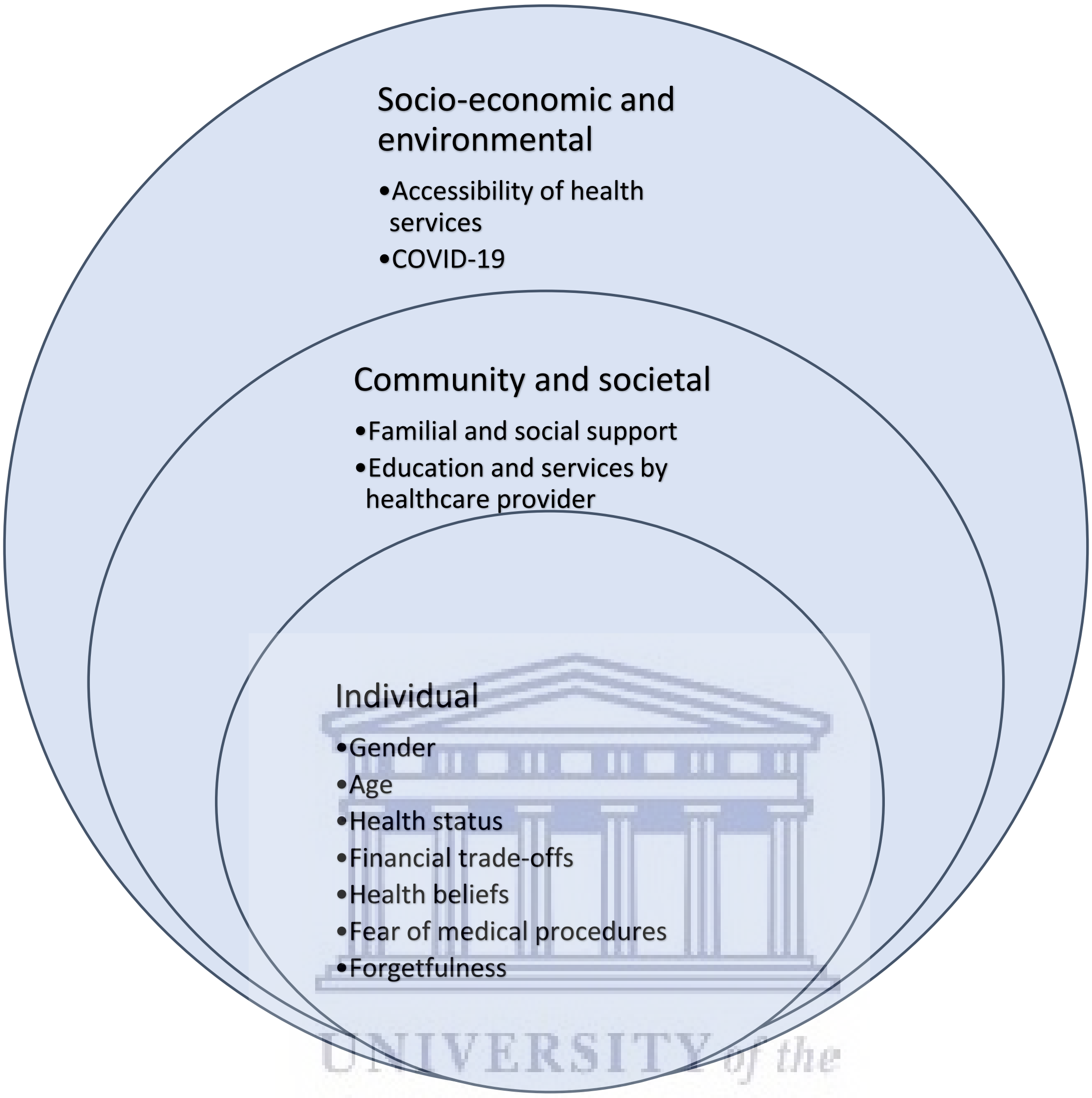

Figure 2.4.1: Factors that influence diabetic retinopathy treatment compliance behaviour among persons living with diabetes *(based on the Social Determinants of Health Model by Whitehead and Dahlgren, 1991)*

2.4.1 Patient / personal-related factors:

Comprehension of diabetic retinopathy and its consequences

Patients are not always aware of the large threat that DM poses to ocular health, especially if vision has not yet been affected (Lewis, 2015; Lewis *et al.*, 2007). In the study by Hua *et al.* (2017) 58.7% of patients who did not complete laser treatment for DR stated that they did not realise it was critical for ocular health and thus defaulted. Patients in this study were also more likely to be non-compliant in starting their laser treatment when they were not conscious of the threat untreated DR could hold for their vision. This indicates that informing patients living with diabetes of the potential consequences of DR is vital to guaranteeing high compliance rates (Hua *et al*., 2017). A study that was conducted in the US regarding diabetic eye care habits (including annual retinal screenings and DR treatment) in people aged 40 years and above found that 39.7% of the participants who did not comply with required ocular examinations did so because they did not understand the need for it (Chou *et al.*, 2014). Chou *et al.* (2014) also found that participants who were non-compliant due to not understanding the need for eye care tended to be over 65 years. They attributed this to patients not realising they are experiencing vision loss or patients accepting vision loss as a typical sign of aging. Chen *et al.* (2018) mentioned that in a previous study, even when compensating research participants for factors like cost, transport, and accessibility, a high non-compliance rate was still found. They attributed this to a lack of knowledge regarding DR among patients living with diabetes. Chua *et al.* (2018) noted that poor DR awareness was a major contributor to non-compliance in the high-, middle- and low-income Asia-Pacific communities. Mtuya *et al.* (2016) also found that 4.6% of patients who defaulted from DR treatment did so because they did not understand the necessity to comply. In one Southern Nigeria study, it was found that half of the participants were not compliant with DR care simply because they were not experiencing vision loss or any other ocular symptoms (Onakpoya, Adeoye and Kolawole, 2010). This, therefore, indicated acutely poor levels of DR knowledge among the participants in this study. Finally, even in a study done at a state hospital in Bloemfontein in SA, it was also found that while the majority of participants were aware that diabetes could cause vision loss; nearly half of these participants were not aware of what DR was (Kempen *et al.*, 2017).

Socio-economic status as a barrier to diabetic retinopathy treatment uptake

Socio-economic conditions are among the leading factors implicated in DR treatment access and uptake by the patient (Kashim, Newton and Ojo, 2018; Chou *et al.*, 2014; Chen *et al.*, 2018). A global systematic review of barriers related to compliance with DR care showed that socio-economic conditions were the mediators of non-compliance with DR treatment among patients living with diabetes (Kashim, Newton and Ojo, 2018). Among the lower-income group of participants, financial factors were strongly associated with non-compliance (Kashim, Newton and Ojo, 2018). Other similar studies showed a lack of funds or health insurance to be predictors of compliance to DR treatment uptake in various population settings (Chou *et al.*, 2014; Chen *et al.*, 2018). In fact, in a study by Chen *et al.* (2018), a statistically significant association was found between lower-income health scheme coverage and non-compliance to

DR treatment. In this case, the study participants on Medi-Cal (a health insurance scheme for lower-income patients in California) were found to be 5.01 times more likely to default treatment than the control patient covered by Medicare health insurance, after adjusting for factors such as age and gender. Participants on San Francisco Health Plan (a health insurance scheme for low-income patients in the San Francisco area) on the other hand were found to be 6.79 times more likely to be non-compliant, after adjusting for factors such as age and gender (Chen *et al.*, 2018). The authors of this study also noted that previous studies have found the strain of treatment costs to be a major deterring factor for DR patients seeking treatment (Chen *et al*., 2018). In an Asia-Pacific study by Chua *et al.* (2018) similar outcomes were found. The authors in this study found that participants from most of the Asian countries involved in the study mentioned medical costs as dominant factors in their non-compliance to DR treatment and showing up on follow-up appointments (Chua *et al.*, 2018).

In a Tanzanian setting, Mtuya *et al.* (2016) found indirect-costs to DR treatment to negatively affect compliance among the diabetic population of the Kilimanjaro Region. However, in this study, no significant correlation was found between financial earnings and compliance. In this study, there was also a division among participants who reported cost as the main cause of non-compliance. For instance, some indicated a 'lack of funds', and others who could afford the treatment showed 'reluctance to pay' for it (Mtuya *et al.*, 2016).

In addition to financial issues, international evidence also highlights a high education level to strongly associate with better DM and DR treatment compliance (Khan *et al*., 2012; Van Eijk *et al.*, 2011). In a Saudi-Arabian study done on the factors leading to the non-compliance of patients living with diabetes regarding general treatment for diabetes, education was found to play a significant role (Khan *et al.*, 2012). Seventy-two-point six percent of illiterate participants in this study were found to be non-adherent to DM treatment. The percentage dropped as the level of education increased. The non-compliance percentage was 61.6% among participants who finished primary school only. It was however 47.6% among participants who completed high school. Finally, it was 45.8% among participants who had achieved a higher education level than a matric (Khan *et al.*, 2012). In a study regarding the factors that influenced Dutch-speaking people living with diabetes to attend or neglect retinal screenings, higher levels of education were associated with better compliance (Van Eijk *et al.*, 2011). Similarly, in a United Kingdom study, Kashim, Newton and Ojo (2018) found that lower levels of education correlated to lower compliance with DR care.

Due to the lack of similar studies on DR treatment compliance in WCP, SA, we reviewed similar studies conducted in this province on other health issues not necessarily DR, from which parallels could be drawn. A few of these studies have shown permanent employment to positively influence medical compliance (Kendall *et al.*, 2013; Finlay *et al.*, 2012). However, in cases of non-compliance, time-constraints, and the inability to take time off from work were identified as barriers to the uptake of treatment. In this case, this was pronounced in the rural inhabitants of the WCP where the distance from health care facilities mediated non-compliance to treatment due to time constraints (Dudley *et al.*, 2018).

Transport constraints as a barrier to access diabetic retinopathy treatment

A couple of studies on DR compliance identified the distance to and from the health facilities as well as the cost of transportation to be among the main causes of non-compliance with the DR treatment. For instance, while Hua *et al.* (2017) found a small percentage (4.3%) of participants in their Chinese study that identified transport as the main cause for non-compliance with DR treatment, Chou *et al.* (2014) found poor availability of transport to be among the top five reasons for non-attendance of scheduled appointments for eye care among participants with DM in the United States (US). In this US study, this was most pronounced among patients living with diabetes aged 40 years and above. However, it is important to note that the study by Hua et al. (2017) was done in an affluent setting, while the Chou *et al.* (2014) study was done in a less affluent setting. Lewis *et al.* (2007) and Mtuya *et al.* (2016) corroborated these studies in that, they found strong associations between DR treatment non-compliance and increased distance concerning the cost of travelling to and from health facilities, especially in less affluent settings. Chua *et al.* (2018) further noted that among participants from rural China, the cost of transportation was a much bigger barrier to compliance than the cost of the required medical procedures.

Substance use as a barrier to access diabetic retinopathy treatment

Substance abuse is rampant in the WCP of SA. Frequent alcohol and drug use were found to be factors associated with non-compliance to tuberculosis (TB) and multidrug-resistant (MDR) TB treatment among participants in WCP, SA (Kendall *et al.*, 2013; Finlay *et al.*, 2012). This was thought to be due to alcohol's ability to negatively affect social behaviour, and due to alcohol amplifying the toxicity found in the treatment medication. Drug use was found to affect compliance in a similar manner to alcohol. While to our understanding there is no study done to assess the alcohol effect on the compliance behaviour with DR treatment in SA, we assume that it is possible to draw parallels from the aforementioned studies.

Family and peer support to access diabetic retinopathy treatment

Social and financial support from family and friends have also been identified as important factors that positively affect compliance behaviour regarding DR treatment (Hua *et al.*, 2017; Lewis *et al.*, 2007; Mtuya *et al.*, 2016; Duan *et al.*, 2017). Indeed, WCP inhabitants receiving medical treatment were also shown to be more likely to be compliant when they received support from family members and friends (Finlay *et al.*, 2012). Moreover, in a study conducted in Tanzania, a correlation was found between elderly patients who require a travelling companion and non-compliance to DR care (Mtuya *et al.*, 2016). In this study, 9% of participants stated that non-compliance was due to the unavailability of a travelling companion as well as the cost of travel that an extra person would induce.

Fear associated with laser treatment for diabetic retinopathy

Patients who are scared of laser treatment, or those who are afraid that it might harm their vision and thus alter their lives are significantly less likely to be compliant (Hua *et al.*, 2017; Mtuya *et al.*, 2016; Lewis, 2015). Similarly, Kashim, Newton and Ojo (2018) have found apprehension about the DR screening procedure to be a deterrent for compliance. Van Eijk *et al.* (2011) found that fear could also have a positive effect on compliance in that, those participants who understood the consequences of DR stated that the knowledge of potential vision loss, especially if DR treatment is not taken, had motivated them to comply with the DR screening. Hence, it is possible that fear stemming from the comprehension of the consequences of untreated DR could motivate individuals to comply with DR care, rather than individuals being demotivated by the fear of the treatment.

Effort and discomfort associated with diabetic retinopathy treatment uptake

The multitude of medical appointments that patients living with diabetes often have to schedule, sometimes end up hurting their attendance of retinal screenings and DR treatment (Lewis, 2015). Kashim, Newton and Ojo (2018) and Strutton *et al.* (2016) have found busy schedules and low prioritisation of DR care to be barriers to attending DR screenings. Other studies have identified the discomfort of a dilated pupil (necessary for a full fundal examination) and the discomfort of certain forms of laser treatments to also negatively affect eye care attendance (Lewis, 2015; Kashim, Newton and Ojo, 2018; Strutton *et al.*, 2016; Chua *et al.*, 2018).

Forgetfulness and confusion related to diabetic retinopathy care appointments

Khan *et al*. (2012) found forgetfulness to be a major cause for non-attendance of scheduled appointments among people living with diabetes. Mtuya *et al.* (2016), Chua *et al.* (2018), Kashim, Newton and Ojo (2018) and Strutton *et al.* (2016) have also found forgetfulness to be a notable factor associated with the non-compliance to DR screenings and treatment among patients living with diabetes.

Disabilities, also those that are brought about by diabetes disease progression

In a German study involving T2DM patients who were 50 years and older, Kreft *et al.* (2018) found that physical disabilities among participants were associated with a decrease in the compliance with DR care.

Sociodemographic factors (age, gender, and geographical location) as barriers to access diabetic retinopathy treatment

In a study involving a global systematic review of barriers to DR care, Kashim, Newton and Ojo (2018) noted a trend for compliance that increased with an increase in age, with the lowest compliance being among younger participants. A study conducted in Oxfordshire, in the United Kingdom, showed similar outcomes (Moreton *et al.*, 2017). In this study, it was found that compliance with prescribed DR care was the lowest among the youngest participants (those who were 12-39 years). Then it increased with age and thereafter decreased again in the oldest age group (>79 years). Kreft *et al.* (2018), who only included German type 2 DM participants over the age of 50 years, found that compliance with advised DR care decreased as age increased. Both Moreton *et al.* (2017) and Kreft *et al.* (2018) suggested that the decline in DR care compliance at more advanced ages could be associated with the increased mobility-related issues, comorbidities as well as disabilities at this advanced age. In contrast, a study conducted at a public health clinic in the US by Keenum *et al.* (2016) showed the opposite outcome. In this study, the researchers noted that older participants, as well as participants who were older when their diabetes was diagnosed, were more likely to comply with recommended DR care. Kendall *et al.* (2013) on the other hand found that participants from a rural area in the WCP were more likely to be compliant with MDR-TB treatment as age increased. The opposing results in the aforementioned studies may be a result of differences in geographical settings as well as socio-economic differences. Another notable factor could be the differing definitions of the term ‘older’ used in these studies. For instance, the studies by Kendall et al. (2013) and Keenum *et al.* (2016) did not clearly define age groups for terms like “older”.

In terms of gender, while both Keenum *et al.* (2016) and Hua *et al.* (2017) did not find gender to play a significant role in DR treatment compliance, Kreft *et al.* (2018) found that overall, men were less likely to comply with DR care. Interestingly, Kreft *et al.* (2018) added that having a disability, decreased the chances of compliance, especially in women. In yet another study by Chou *et al*. (2014), gender was found to influence compliance. Men living with diabetes tended to be unaware of the need for continual eye care, whereas their women counterparts tended to give cost as a reason for non-compliance (Chou *et al*., 2014).

Past studies have also found varying results where gender’s effect on DM treatment compliance was concerned (Khan *et al.*, 2012). These results were thought to be influenced by the geographical location, social gender norms as well as socio-economic differences between men and women (Khan *et al.*, 2012). While we couldn’t find similar studies that associated gender with DR treatment and screening compliance in SA, studies on other diseases showed gender to be among the main predictors of medical screening and treatment compliance (Moosa *et al.*, 2019; Barnighausen *et al.*, 2014; Johnson *et al.*, 2015; Pulerwitz *et al.*, 2019; Dennison *et al.*, 2007). With men less likely to seek health care when compared to women.

Diabetic retinopathy knowledge and suitable treatment beliefs

Chua *et al.* (2018) found a lack of faith in the medical professional’s training and ability to be an important factor of non-compliance to ocular care and DR measures in rural China. In SA, a large proportion of people still associate NCD conditions with supernatural forces. In this regard, their preferred source and first-line treatment are sought from traditional and faith healers (Finlay *et al.* 2012). As such, South Africans who opt for traditional healing for their ailments are often non-compliant with professional medical health care. The suspension of required medical treatment therefore often leads to severe consequences for the disease.

2.4.2 Service provider-related factors:

Poor education of patients by health care staff

As mentioned above, among the important factors that fuel non-compliance with DR treatment is the lack of optimum knowledge about the disease and the benefit of adhering to treatment.

Indeed, Hua *et al.* (2017) have shown that misinforming a patient with diabetes of the consequences of DR can lead to a severe decline in the initial and continual treatment attendance. Patients who do not receive an explanation regarding the process and protocol of DR treatment are more likely to default (Hua *et al*., 2017). Lewis *et al.* (2007), Kashim, Newton and Ojo (2018), Strutton *et al.* (2016), and Kreft *et al.* (2018) have also reported that inadequate quality of ophthalmic advice from medical professionals plays a role in poor attendance of ocular screenings and treatments among patients living with diabetes.

Both Khan *et al*. (2012) and Keenum *et al.* (2016) found that patients living with diabetes who had received adequate information regarding their disease, treatment, treatment dosage, treatment duration, and possible treatment side-effects were more compliant with their treatment. Van Eijk *et al.* (2011) had a similar finding, stating that patients who were better informed about DR complications and participants who were advised by medical professionals to have annual retinal screenings were more likely to be compliant with diabetic eye care requirements. While there is no available research on the current topic in SA, in a WCP study regarding TB treatment adherence participants were found to be more likely to default if they were not fully informed about the treatment procedures and especially the duration of the treatment program (Finlay *et al.*, 2012). We, therefore, have a reason to believe that the same outcome may be probable if individuals are not well informed about DR and its associated treatment.

Poor referral management

Inefficient referral structures prohibit patients living with diabetes from receiving the required attention (Lewis, 2015). In two separate American studies, both Kraft *et al.* (1997) and Rosenberg, Friedman and Gurland (2011) reported that the percentage of physicians that did not adhere to the recommended ophthalmological referral protocols for DR care ranged from 35% to 45%. This, therefore, affected the compliance of the patients to treatment care. A Nigerian study by Onakpoya, Adeoye and Kolawole (2010) also reported that 45.8% of participants were non-compliant to DR care due to a lack of referral by their physician.

In contrast, a Tanzanian study Mtuya *et al.* (2016) found that over 25% of the study participants did not understand all aspects of the referral they were given. However, no significant association between patients who comprehended all aspects of the referral and compliance with DR treatment was found. This implied that whether patients understood the referral or not, this did not significantly affect non-compliance rates found in this study (Mtuya *et al.*, 2016). No similar studies have been done in SA. Hence, the importance of the current study.

Staff attitudes towards patients

There is a dearth of data regarding this topic. The only available study that could be found highlighted negative and unpleasant medical staff attitudes to be the main deterrent to patient uptake for TB treatment in a WCP study (Finlay *et al.*, 2012).

Poor call-back systems

Inept notification systems at medical facilities can lead to poor attendance of scheduled appointments regarding ocular examinations and treatment in people suffering from DM (Lewis, 2015; Kashim, Newton and Ojo, 2018). Chou *et al*. (2014) stated that call-backs and reminders from medical professionals led to increased eye care appointments by patients, which also led to improved ocular health. They went on to say that improved call-back systems could be a way to combat non-compliance caused by a poor understanding of the consequences.

Waiting times

Increased waiting periods at medical facilities deter patients living with diabetes from attending treatments (Lewis *et al.*, 2007; Lewis, 2015; Kashim, Newton and Ojo, 2018). Haque *et al.* (2005) corroborated these studies in that, they found waiting times in primary healthcare facilities to negatively impact patient compliance with DM care in a CT study. In another CT study, Peer *et al.* (2020) noted that patients and healthcare providers alike have identified increased waiting times as a barrier to NCD management in primary healthcare facilities.

Accessibility of eye care services

Medical facilities that are deemed inaccessible or difficult to reach by patients living with diabetes greatly deter attendance (Lewis *et al.*, 2007; Chua *et al.*, 2018). Chou *et al.* (2014) found inaccessibility to be one of the top five reasons for non-compliance to eye care among people living with diabetes who are aged 40 years and above in the US. Van Eijk *et al.* (2011) reported that participants who found healthcare facilities to be more accessible were also more likely to be compliant with DR screenings.

Inconvenient clinic hours have been one of the most notable topics in SA. For instance, Bogart *et al.* (2013), Clouse *et al.* (2014) and Miller *et al.* (2010) all identified inconvenient clinic hours as an important barrier to patients receiving human immunodeficiency virus (HIV) care. Non-adherent participants in a study regarding TB treatment also singled out problematic and unsuitable clinic hours as a factor leading to non-compliance (Finlay *et al.*, 2012). To our knowledge, clinic hours as a barrier to DR treatment compliance has yet to be researched, further indicating a need for the current research.

2.4.3 Treatment-related factors

Fear, discomfort, and intolerance to treatment

Patients who cannot tolerate laser treatment and those that think it might harm their vision are significantly less likely to be compliant (Hua *et al.*, 2017; Mtuya *et al.*, 2016; Lewis, 2015; Duan *et al.*, 2017). Van Eijk *et al.* (2011) have shown that fear could also positively affect compliance, as participants who understood the consequences of DR, such as permanent vision loss, were more motivated to comply with DR care. The multitude of clinics and medical appointments that patients living with diabetes often have to schedule end up hurting their attendance of retinal screenings and DR treatment. The discomfort of a dilated pupil (necessary for a full fundal examination) and the discomfort of certain forms of laser treatment also negatively affect eye care attendance (Lewis *et al.*, 2007; Lewis, 2015). Moreover, discomfort caused by laser treatment procedures, as well as medication side-effects has been cited as reasons for non-compliance with DR and DM treatment, respectively (Lewis, 2015; Khan *et al.*, 2012).

2.4.4 Independent factors

Systemic diabetic end-organ damage (foot and kidney)

It was found that patients who were suffering from severe problems with feet or kidneys due to systemic diabetes were less likely to be compliant with DR treatment appointments (Chen *et al.*, 2018). It is thought that these patients are less likely to be responsive to medical advice, increasing their odds for DR and non-compliance. They are also more likely to be held up by their other diabetic-related problems, especially when not yet plagued by vision loss (Chen *et al.*, 2018).

Glycaemic levels

Chen *et al.* (2018) did not find a compelling correlation between glycaemic levels and non-compliance. However, Kashim, Newton and Ojo (2018) have noted that poor glycaemic control was associated with poor compliance to DR care in patients living with diabetes. The differences in findings between the two studies could be ascribed to their different definitions of non-compliance. Chen *et al.* (2018) defined non-compliance as failing to attend or re-schedule at least 80% of appointments throughout a year, or not re-scheduling appointments to within 1 month of the advised follow-up date. Kashim, Newton and Ojo (2018) on the other hand gave no clear definition of non-attendance and marked this as a study limitation. Other studies have also found that a patient’s awareness of their HbA1c (glycated haemoglobin) levels led to a higher compliance rate (Chen *et al.*, 2018; Keenum *et al.*, 2016). This was ascribed to patients being more aware of their health and health complications. Interestingly, Lewis (2015) and Van Eijk *et al.* (2011) stated that patients with generally high HbA1c levels felt guilt or shame due to their lack of glucose control, which led to their non-adherence to diabetic eye care.

Duration and type of diabetes mellitus

Van Eijk *et al.* (2011) did not find a significant difference between the non-compliance rates of people with type 1 and type 2 diabetes.

However, Van Eijk *et al.* (2011) found that DM sufferers with a longer duration of the disease (specified as >10 years) were more compliant with the annual retinal screening requirements than persons with diabetes who were diagnosed less than 10 years ago. Both Onakpoya, Adeoye and Kolawole (2010) and Kashim, Newton and Ojo (2018) also noted that more recent diagnoses of DM were associated with weaker compliance to DR care among diabetic participants.

Depression

According to Chen *et al.* (2018), previous studies have found that people living with diabetes are more likely to suffer from clinical depression, and that diabetic depression sufferers are more likely to be non-compliant with the general diabetic treatment. The authors have also found higher levels of non-compliance with DR treatment in participants suffering from clinical depression, especially participants in which PDR has been diagnosed (Chen *et al.*, 2018).

All the above independent factors still need to be researched in the South African context.

2.4.5 COVID-19-related factors:

Measures to reduce transmission and mortality rates

Finally, recently with the new global COVID-19 pandemic, countries have amended their procedures to manage patients diagnosed with NCDs. For instance, in many healthcare institutions perceived "non-urgent" appointments, health-promotive and preventive services had since been suspended during the hard lockdown in many countries (Palmer *et al.*, 2020; Kluge *et al.*, 2020). Palmer *et al.* (2020) also noted that various European countries have diverted funds meant for NCD research and management to COVID-19-related issues. South Africa, as a medium-income country that also depends on funding from Europe for its NCD research and management, had no choice but to follow suit, and suspend most of its NCD related services. All of these implementations and amendments, while deemed important for COVID-19 pandemic management, could have devastating effects on the long- and short-term management of NCD-related health problems, such as diabetes and DR (Palmer *et al.*, 2020; Kluge *et al.*, 2020). While there is still no evidence to support this aforementioned claim in SA, it becomes important therefore to conduct research that will investigate how patients receiving DR treatment have been affected by these current COVID-19 related changes.

Health behaviour changes as influenced by the COVIC-19 pandemic

Moreover, data from previous and current pandemics suggest that national and local pandemic-related measures, such as social distancing or isolation, often adversely affect NCD management due to changes in an individual's health behaviour (Kluge *et al.*, 2020). Health behaviour changes can lead to a delay in seeking treatment for NCD-related health problems (Kluge *et al.*, 2020).

2.5 Chapter Summary

The current chapter presents factors that could influence compliance with DR screening and treatment. Among these are studies that highlighted patient-, healthcare provider- and treatment-related factors to significantly influence DR compliance behaviour. Among the most important factors were patient awareness and knowledge of DR, patient socioeconomic status, and DR education given by healthcare providers. While these studies painted a clear picture of how DR compliance behaviour is affected worldwide, there seems to be a big gap in the South African literature regarding this topic. More importantly, data regarding COVID-19-related factors are still lacking. However, the impact of this disease in the country, especially in the WCP can never be underestimated. Hence, the need for the current research to bridge this gap in the scientific literature.

CHAPTER 3: METHODOLOGY

3.1 Chapter Overview

In the current chapter, the methodology used is being described in detail. In this case, the study design, study setting, sampling and data collection, data analysis, and the steps undertaken to improve rigour are being outlined. The chapter ends with the details of the ethical points that were considered before and during the data collection phase, as well as how the data obtained are being handled.

3.2 Study Design

To meet the study aim, a qualitative approach was used to explore the factors that influenced compliance behaviour among participants referred for DR treatment. As there is limited data concerning compliance behaviour towards DR treatment in the South African context and in lower-income settings internationally, the study sought to fill this research gap. A qualitative approach also helped in the exploration of factors that are unique among the people living with diabetes who make use of the WCP public health system to access treatment for DR. A qualitative approach was also deemed appropriate as it allowed the researcher to explore complex and diverse perspectives that included experiences and social realities lived by patients living with diabetes within the target setting (Cockburn *et al.*, 2012; Chen *et al.*, 2018; Pope, Ziebland and Mays, 2000; Baum, 1995; Creswell, 2014). The qualitative research methods further allowed the researcher to gain insight into the experiences of optometry specialists working within the target setting, as well as help in the detection of new findings due to the flexibility of these methods (Creswell, 2014; Pope, Ziebland and Mays, 2000; Baum, 1995).

3.3 Study Setting

The study was conducted in the NTSS of CT in SA. South Africa has a long history of inequality and oppression, and despite recent efforts to combat this, relative poverty has worsened and income disparities have widened (Mayosi and Benatar, 2014). This state of inequality also negatively impacts the social determinants of health in low socioeconomic communities (Ataguba, Akazili and McIntyre, 2011). Inequality figures for CT are higher than the figures for SA as a whole (City of Cape Town, 2016).

In 2018, the CTM population was estimated to be 4.14 million people, with a large ageing population (City of Cape Town, 2016; Western Cape Government, 2018). In 2018, the NTSS population consisted of an estimated 1.08 million people, the majority of whom (>80%) relied on the public healthcare system for medical services due to high private healthcare costs and the high prevalence of low-socioeconomic households (Western Cape Government, 2018; Mayosi and Benatar, 2014). Table 3.3.1, below, illustrates the sociodemographic indicators in the WCP population compared to SA.

Table 3.3.1: Sociodemographic information of the WCP compared to SA (Gray and Vawda, 2017)

Sociodemographic indicators	**WCP**	**SA**
Education (population %):		
Persons 20 years + with no schooling (2015)	1.5	5.1
Persons 20 years + who are literate (2014)	97.3	95.3
Housing type (household %):		
Formal (2016)	82.4	79.2
Informal (2016)	16.6	13.0
Traditional (2016)	4.9	7.0
Unemployment rate (2016, 4th quarter; working age population %)	20.5	26.5

*The researcher was unable to find relevant sociodemographic information of the NTSS area and thus used data of the wider WCP. Data might not be accurate for the NTSS as this area has a large urban population.

In the NTSS the Metro District Health Services (MDHS) provide primary health care to the majority of the population via primary healthcare centres within the NTSS. There is also one district hospital in this area (Western Cape Government, 2018). From the 13 primary healthcare centres approached to participate in the study, six approved research being conducted at their facilities. The primary eye care services and Retinal Screening Programme (RSP) running at these facilities refer DR cases to the Department of Ophthalmology at TBH for treatment.

3.4 Population and Sampling

3.4.1 Study population

The study population comprised patients living with diabetes who were identified as having RDR by the RSP running within the NTSS healthcare facilities and referred to the TBH ophthalmology department for diabetic retinopathy treatment. This population was chosen as it might contain a reasonable number of eligible participants with the required attributes for the proposed study (Ritchie, Lewis and Elam, 2003). Key informants included optometrists working within the RSP who refer patients from primary healthcare facilities to the tertiary hospitals within the CTM for DR.

3.4.2 Sampling

Purposive sampling was used to identify suitable candidates for the proposed study. Candidates identified for the study possessed distinct attributes that allowed for the collection of a wide variety of data regarding the study topic (Ritchie, Lewis and Elam, 2003; Robson and McCartan, 2016). The required attributes of participants include i) patients who have been diagnosed with DM; ii) those that have been screened for DR via the RSP programme at the participating day hospitals in the NTSS; iii) those that have been referred within the past 18 months to TBH for diagnosis and treatment of suspected RDR. These attributes ensured rich information regarding factors related to compliance behaviour in DR patients in a public health system (Robson and McCartan, 2016; Patton, 1990). Key informants included optometrists working within the CTM area RSP, since they have been regarded as good sources of valuable information relevant to the study topic, the population and the setting to be studied (Marshall, 1996).

Inclusion criteria: Participants who were included were conversant in English or Afrikaans, as these are the main languages spoken in the NTSS. This also allowed the researcher to be able to do the interviews independently and thoroughly since she was also fluent in both of these languages. Participants were 19 years or older and they were referred to TBH for diagnosis and treatment of suspected RDR within the past 18 months of the study.

Exclusion criteria: People who were not conversant in English or Afrikaans were excluded. Those who were referred longer than 18 months ago were also excluded, as the data for these people might not have been readily available at the time when the research was conducted (personal communication: Saib, 2018). Although DR could be present in children and adolescents living with diabetes (Kernell *et al.*, 1997), the participants chosen were aged 19 years and older for ethical reasons.

3.4.3 Sample size

A sample of 13 participants and 2 key informants (optometrists) were selected to participate in the qualitative interviews. In total, 15 participants were interviewed. According to Ritchie, Lewis and Elam (2003), for qualitative research methodology this smaller sample is believed to offer the variety of participants required that will encompass the reasonable homogeny of the sample population. Fugard and Potts (2015) also indicated that qualitative studies that make use of thematic analysis as a method of data analysis can reach data saturation within 12 interviews. Hence, we conducted a thematic data analysis in the current research. Finally, we used in-depth interviews as we were not concerned with making generalisations about a population, but rather we were concerned with researching complex and diverse perspectives and making sense of the experiences of non-compliant people living with diabetes within our setting. Thus, our smaller sample size of 13 participants is justified (Dworkin, 2012; Creswell, 2014).

3.5 Data Collection

Data collection was meant to commence from the 6th of March 2020. However, due to the delays that were motivated by COVID-19 related hard lockdown, data collection commenced mid-August 2020 and ended early September 2020. This was 3 weeks. The researcher sought access to review the files of the potential patients who were referred for vision-threatening DR in the NTSS from the non-governmental organisation (NGO) responsible for the RSP. Potential participants and key informants were then contacted telephonically between 8 AM and 5 PM during weekdays to recruit them to take part in the study. Once participants and key informants showed interest in the study and verbally agreed to participate, information sheets along with consent forms were sent to them electronically. Once participants and key informants read the information letter and sent back the signed electronic consent forms, interview times were scheduled with them. Telephone, semi-structured in-depth interviews were conducted individually with each of the 13 participants and 2 key informants. In-depth interviews were conducted to allow the researcher to gain a deeper understanding of the complex participants' behaviours and the rationale related to the compliance to DR treatment (Mack *et al.*, 2012; Creswell, 2014). The participant interviews explored their experiences relating to DR care as well as motivators and barriers related to attending treatment. The interviews with the key informants within the RSP explored their perceptions relating to patient compliance with DR care. The interviews were conducted using the pretested interview forms (see Appendices K-

N). The interview questions were guided by the conceptual framework (see Figure 2.4.1) to ensure the generation of data relating to the impact of socio-economic and environmental, community and societal, and individual factors on compliance behaviour. Questions were further informed by data found during the preliminary research stage as well as the study objectives. These interview forms were used to collect in-depth information from participants. Semi-structured interviews also allowed the researcher to discover new information by exploring diverse issues related to DR treatment compliance behaviour. This facilitated a less complicated analysis procedure and simplified comparison while maintaining flexibility (McIntosh and Morse, 2015).

Interviews were conducted one-on-one to allow the researcher to be more responsive towards participants (Robson and McCartan, 2016). Interviews were conducted telephonically to reduce the risk of COVID-19 transmission between the participants, the researcher, the health facility staff members, and the general public who used the facility. One participant elected to have her full-time caretaker, who lives with her and attends all appointments with her, to be part of the interview due to health issues. The participant and key informant interviews did not exceed 35 minutes and 40 minutes, respectively, to avoid 'respondent fatigue' (Robson and McCartan, 2016). Questions were kept short and simple to avoid confusion. In this case, double-barrelled questions were avoided (Robson and McCartan, 2016). The researcher was aware of noise interference from the participant's background and repeated questions for clarity where necessary. Interviews were conducted in either English or Afrikaans, depending on the preference of the participant, as these are the languages most frequently spoken in the Northern-Tygerberg district. The researcher was fluent in both English and Afrikaans. The researcher conducted the interviews from the privacy of her home. Telephone interviews were recorded. The researcher transcribed the audio data verbatim to convey cultural nuances. During transcription, the researcher replayed audio recordings multiple times to ensure accuracy. During the transcription process, the researcher translated data from Afrikaans to English where necessary. The researcher attempted to translate transcripts in such a way that the participants' meanings and nuances were accurately reflected. Transcriptions and audio data were sent to a third party to be reviewed for accuracy.

3.6 Data Analysis

For data analysis, thematic analysis was used. Thematic analysis requires that the researcher study all of the data and piece together themes developed from the data (Robson and McCartan, 2016). This approach is flexible to generate rich data, which lends itself to exploratory research

(Robson and McCartan, 2016). The steps taken during the data analysis process are illustrated below in Figure 3.6.1. The researcher studied all of the data and reflexively searched for recurring patterns; the researcher used taguette.org (https://app.taguette.org/, a free, web-based qualitative-research tool) to label information deemed relevant by highlighting and tagging bodies of text under the formulated codes (Braun and Clarke, 2006; Robson and McCartan, 2016). Relevant information (i.e., the information that is reiterated in various sections of the data; information deemed important by the interviewee; and information that the researcher deemed important or interesting) were grouped, and all rationale was fed into a journal for reflexivity (Robson and McCartan, 2016). This stage is termed "coding". All the developed codes were reviewed independently by the supervisor. After coding, the researcher pieced codes together to create categories and sub-themes that reflect how socioeconomic and environmental, community and societal, and individual factors affect compliance behaviour (Graneheim and Lundman, 2004). The researcher organised categories and sub-themes together to create a list of potential themes (Braun and Clarke, 2006). Themes were refined for coherence and accurate reflection of data by the supervisor (Braun and Clarke, 2006). The themes with their corresponding codes can be seen in Appendix O. Finally, the researcher wrote up an academic report describing the themes in detail and explained how themes were connected to the research problem. The researcher used text excerpts as examples and literature to solidify her interpretation (Attride-Stirling, 2001).

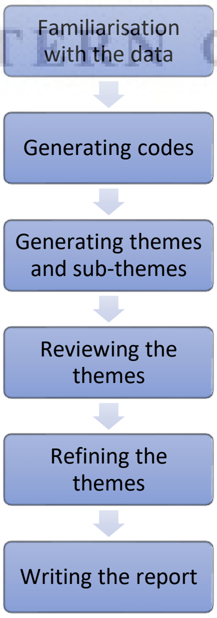

Figure 3.6.1: Steps taken during the data analysis process (*adapted from the Phases of Thematic Analysis by Braun and Clarke, 2006)*

3.7 Rigour

As noted by Seale and Silverman (1997) methods for data collection and analysis in qualitative research differs from methods used in quantitative research and can therefore not be evaluated using the same criteria. Instead, qualitative research relies on rigour to demonstrate the credibility and trustworthiness of the study's data and findings (Robson and McCartan, 2016; Mays and Pope, 2000). Although no set-in-stone, checklist exists to ensure trustworthiness (Barbour, 2001; Bradshaw and Stratford, 2010). This can be achieved by rigorous planning and the implementation of certain strategies at each step of the research process. Korstjens and Moser (2018) proposed that the following principles, adapted from Lincoln and Guba (1985), can serve as a measure of quality for qualitative research: credibility; dependability, confirmability, and transferability. The researcher set out to ensure rigour by applying the following strategies throughout the research process:

3.7.1 Credibility

Credibility demonstrates that the findings are an authentic reflection of participants' perceptions (Korstjens and Moser, 2018). Due to the researcher's occupation, she had spent extended time within the study setting before conducting this research. This prolonged engagement granted her a deeper insight into the participants' social context and an understanding of what to probe during interviews, which further demonstrated the credibility of this study's findings (Maher *et al.*, 2018). The researcher asked a simple identity verification question ('when is your birthday?') to participants during telephone interviews, prior to starting the audio-recording; their answers were cross-referenced with the RSP data. In that interviews were done telephonically and could not pick up on facial gestures, the researcher took care to repeat questions when participants sounded unsure. The researcher listened to segments of audio recordings multiple times during transcription to ensure the accuracy of transcripts. To further ensure the accuracy of data, transcripts, and audio data were sent to a third-party and the supervisor to be reviewed. Where translation was necessary, the researcher translated transcripts in such a way that the participants' meanings and nuances were accurately reflected to maintain the authenticity of the data. Furthermore, triangulation was used by comparing information collected from participants with information collected from key-informants; similar themes were forthcoming from the different sources, which increased the credibility of our findings (Creswell and Miller, 2000; Barbour, 2001).

3.7.2 Dependability

Dependability requires that thorough and accurate descriptions of all the research processes and elements are made which would enable another researcher to repeat the research (Maher *et al.*, 2018). To ensure dependability an audit trial was made available for review by external, independent parties (Korstjens and Moser, 2018). In the audit trail the researcher provided the following documents: i) rich descriptions of the study setting, ii) study context, methodology, iii) sampling strategies, iv) data collection and analysis processes; v) rationale for the chosen study methods and modifications made to the study design; vi) notes taken during meetings with the researcher's supervisor, vii) a study journal of the researcher's thoughts after participant interviews and notes taken during transcribing, and viii) the thought processes of how the researcher reached her findings from the data (Korstjens and Moser, 2018).

3.7.3 Confirmability

Confirmability refers to the extent to which the findings of a study could be confirmed by another researcher. This demonstrates that the participants' narratives were accurately represented in the findings (Korstjens and Moser, 2018). Hadi and José Closs (2016) suggested that confirmability could be improved by the disclosure of the researcher's preconceptions in to reduce researcher bias. The researcher kept a study journal in which she reflected on her thoughts and opinions after participant interviews, during coding, and during the synthesising of themes. The study journal was later used to evaluate how her perceptions have influenced the data collection, data interpretation, and the results (Creswell and Miller, 2000; Hadi and José Closs, 2016). To further improve reflexivity and to reduce bias, the researcher periodically discussed the progression of the data collection with her supervisor as a form of peer debriefing (Robson and McCartan, 2016).

3.7.4 Transferability

Transferability is used to check if the findings from one study could be applicable for a different study setting or context (Maher *et al.*, 2018). To allow for future transferability of this study's findings, detailed and accurate descriptions of the study setting as well as the context of the problem were outlined in the current report (Korstjens and Moser, 2018). Moreover, few of the characteristics such as the socio-economic and social history of participants within the participants' setting are briefly added in the current report to assist future researchers in determining whether the findings are applicable within their contexts (Malterud, 2001).

3.8 Ethics Considerations

Ethics approval to conduct face-to-face interviews was obtained from the Biomedical Research Ethics Committee of the University of the Western Cape before commencing with the study (Reference No: BM20/1/8, see Appendix A). Due to the COVID-19 lockdown, face-to-face interviews could not be conducted, and as such, an amendment to the protocol to conduct the interviews telephonically was done and the second ethics approval was sought from the same committee (Reference No: BM20/1/8, see Appendix A). Permission to access RSP referral files was gained from the NGO responsible for the RSP (see Appendices A and B). Permission to research at the preferred study settings was received from the Provincial Health Research Council (PHRC) (see Appendix A). The research followed the guidelines outlined in the Department of Health Ethics in Health Research Principles (2015). Participants were informed about the study aim and nature, as well as what would be expected from them before they could give consent (see Appendices C-J). The study detailed information was given verbally (in a telephone call) and sent in writing (electronically), in English or Afrikaans, depending on the participants' preferred language (see Appendices C-J). The telephone interview was only scheduled once the participant sent back written, signed informed consent, i.e., electronic confirmation that they understood the study information and therefore were giving consent to participate. Participants were advised that all their information was going to be kept confidential. To ensure anonymity, the participants' names were not recorded in the interview; instead, a code was used to link a participant's data with their identity. The researcher is the only person with access to the identification codes, which are being kept in a secure, lockable cabinet, separately from other paper-based data. Electronic consent forms are being stored in a secure, password-protected cloud-space, which only the researcher has access to. The audio recordings and typed interview notes are kept on a password-protected laptop. The laptop is kept in a secure location that only the researcher has access to. The paper-based participant information will be destroyed 5 years after concluding the study, while the electronic data will be also be deleted during the same time. The researcher was in a private environment during the conduction of telephone interviews. The participants were also encouraged to sit in private areas for their confidentiality. Participation was voluntary, and participants were informed of the potential risks prior to giving consent. Due to the subject of the study, the researcher anticipated that the participants could experience negative emotions regarding their DM diagnosis, their DR diagnosis, or their compliance behaviour. The researcher took precautions to avoid harm to participants, and they were allowed to quit the study at any point without fearing negative repercussions. Fortunately, none of the participants showed distress or any emotional disturbances before and during the interview. However, the researcher still informed them that they could access the appropriate health care professional at the health centres where they get their treatment for assistance when required. The researcher also advised the participants of the protocol they needed to follow to secure an appointment with the relevant day hospital psychiatric nurse in these facilities if needed. Participants were also given the toll-free numbers to get psychological counselling if they needed to.

3.9 Chapter Summary

In the current chapter, participants were sampled purposively from the RSP database of diabetic patients in the NTSS that have been referred for DR treatment. Thirteen participants and two key informants were sampled. Telephone interviews were conducted to reduce the risk of the respondents, the researcher, and the general public contracting COVID-19. Audio data were transcribed and translated by the researcher where necessary. These were checked by the independent party and the supervisor of the researcher. Thematic analysis was then used to code data and develop themes. In the next chapter, the outcomes of the current study will be presented based on these themes and narratives that were developed.

CHAPTER 4: RESULTS

4.1 Chapter Overview

This chapter presents the results of this study. Brief quantitative outcomes are presented. These outcomes outline selected socio-demographic factors of the study participants. A table presenting our definitions of different levels of compliance is also included, along with the extent of participant compliance in this study. The qualitative outcomes are presented in two main sections: themes developed from participant responses; and themes developed from key informant responses. The study themes were developed using thematic analysis, as outlined in the previous chapter, and are based on objectives 1 to 5 of this study.

4.2 Quantitative Outcomes:

Thirteen participants and two key informants were interviewed telephonically. One participant, an 87-year-old female, elected to have her full-time care-worker (noted as P1 carer) who lives with her and attends all appointments with her, to take part in the interview due to the participant’s health issues. Selected demographic information for the 13 participants can be found in Table 4.1.1

Table 4.2.1: Select demographic information for participants with diabetes mellitus

Participant no.	Gender	Age (years)	Diabetes Mellitus Type	Diabetes Mellitus Duration (years)	Diabetes Mellitus Treatment	Tygerberg Hospital diabetic retinopathy treatment compliance level
P1.	Female	87	Type 2	>5	Insulin	Did not attend any TBH appointments
P2.	Male	49	Type 2	3-4	Metformin	Did not attend any TBH appointments
P3.	Female	52	Type 2	10	Insulin	Attended all (excluding cancelled appointments due to COVID-19)
P4.	Male	55	Unconfirmed	30	Metformin	Attended all (excluding cancelled appointments due to COVID-19)
P5.	Female	68	Type 2	>10	Metformin and insulin	Attended all (excluding cancelled appointments due to COVID-19)
P6.	Female	51	Type 2	>20	Metformin and insulin	Attended all (excluding cancelled appointments due to COVID-19)
P7.	Female	53	Type 2	>4	Metformin	Attended all (excluding cancelled appointments due to COVID-19)
P8.	Male	65	Type 2	±30	Unconfirmed	Attended all (excluding cancelled appointments due to COVID-19)

P9.	Male	26	Type 1	10	Insulin	Possible referral error. Px was never referred/given a date for TBH, so did not attend. He has seen a private ophthalmologist after a being referred from a private optometrist in the past.
P10.	Male	60	Type 2	30	Insulin	Referred and a given date. On day P10 went to TBH but was told he did not have an appointment.
P11.	Female	62	Type 2	15	Metformin	Attended all (excluding cancelled appointments due to COVID-19)
P12.	Female	51	Type 2	15	Insulin	Attended all (excluding cancelled appointments due to COVID-19)
P13.	Female	54	Type 2	13	Insulin	Attended initial TBH consultation, but defaulted on follow-up treatments

Table 4.2.2: The mean values for select participant demographic information

Demographic factor	**Mean or Percentage**
Participants (n=13)	
Age	Mean = 56.38 years ± Standard Deviation = 13.34 years
Gender:	
Female	61.54%
Male	38.46
Diabetes mellitus type:	
Type 1	7.69%
Type 2	84.26%
Unconfirmed	7.69%
Diabetes mellitus duration:	
≤4	7.69%
>4	84.62%
Unconfirmed	7.69%
Diabetes mellitus treatment	
Metformin	30.77%
Insulin	46.15%
Metformin and insulin	15.38%
Unconfirmed	7.69%

According to Tables 4.2.1 and 4.2.2, 61.54% of participants were females and 38.46% were males. The mean age was 56.38 years with a standard deviation of 13.34. Eighty-four-point six two percent (84.62%) had T2DM, while 7.69% had type 1 DM (T1DM) and 7.69% were unconfirmed. Nearly eight percent (7.69%) of the participants had DM for 4 years or less, while the majority (84.62%) had DM for more than 4 years, and 7.69% had DM for an unconfirmed period. Forty-six-point one five percent (46.15%) of the participants used insulin exclusively to treat DM, while 30.77% used metformin exclusively, 15.38% used both insulin and metformin and 7.69% could not confirm their DM treatment.

Table 4.2.3: Classification of compliance

Classification	**Definition**	**Participants**	
		Sample size (n)	**Percentage (%)**
Fully compliant	Being present for all TBH DR treatment appointments (excluding instances where appointments were cancelled by TBH due to the COVID-19 pandemic)	8	61.54
Partially compliant	Being present for the initial DR treatment consultation at TBH only	1	7.69
Not compliant	Did not attend any TBH DR treatment appointments	4	30.77

Based on Table 4.2.3, the majority (61.54%) of the participants were fully compliant with their DR treatment, while 7.69% and 30.77% were either partially compliant or non-compliant, respectively.

4.3 Qualitative Outcomes:

4.3.1 Participant responses

In this section, the important personal-, treatment-, healthcare provider- and COVID-19-related factors that influenced the compliance behaviour of participants to the DM and DR treatments are outlined. These are arranged based on objectives 1-3 and 5 of the current study. As such, the following 4 qualitative themes were developed from the transcribed data:

1. Knowledge about the aetiology and treatment of DM and DR and the need for information
2. Personal and sociodemographic factors that influenced compliance behaviour
3. Perceptions about the quality of health care provided at the tertiary and day hospitals
4. Perceptions of and experiences with care since the start of the COVID-19 pandemic

4.3.1.1 Knowledge about the aetiology and treatment of diabetes mellitus and diabetic retinopathy and the need for information

According to the data collected, the knowledge of DM and DR varied vastly among the participants. Along with insufficient knowledge of DR and its treatment, participants had low levels of awareness about how DM, specifically uncontrolled DM can negatively impact eye health.

For instance, while all the participants were aware that diabetes could have negative consequences on their vision; 12 out of the 13 participants (92.3%) could not give details on how this occurs. When asked about the knowledge of how diabetes may affect eye health, one participant responded by saying: *"…so diabetes can affect your eyes, your eye health, uhm … can cause blurry vision… In severe cases it could cause blindness… that's the extent I know about it"* (P9). This participant could not complete the explanation. Three other participants responded by saying: *"I understand that it affects the eyes, it makes your eyes weak"* (P1 carer); *"…he (the doctor at the day hospital) explains to me what the sugar can affect. It can affect my kidneys, my eyes, I can go blind."* (P13); *"But sometimes, after a time, I don't feel... It's a bit blurry in front of me then I know my sugar was a bit low"* (P10).

A 57-year-old female who had been diagnosed with T2DM over 10 years before the research was conducted was the only participant who showed some form of understanding of how diabetes affects the retina: When asked the same question, she responded by saying: *"So it's like they say, the sugar, it affects the veins in your eye. As I go along, and as I see the doctor for the 6-monthly script then we always speak. And like I said, the club, they explain to you"* (P3).

However, none of the participants mentioned that they were aware of DM leading to glaucoma, cataracts, ocular surface diseases, or papillopathy.

When participants were asked whether they were made aware that people living with diabetes generally require an annual retinal screening, five participants explicitly claimed that no one had informed them of the need for an annual retinal examination:

"I am not aware of that" (P8).

"No. Eye test, they never said we must go for an eye test, that was when I asked the doctor to see an eye specialist to get glasses (doctor at day hospital sent him for/booked him for retinal screening/eye test), it was the first time I got glasses since being at the day hospital. They won't tell you that you have to go for an eye test now" (P10).

"No one told me that. If I didn't ask them (day hospital staff) to make an appointment for me because my eyes are bad." (P11).

"No, they didn't say anything. Only when I ask, my glasses are lost, so I did tell the one nurse and she said November month (for the screening appointment date)" (P12).

"I didn't know… they didn't tell me that so for two years I didn't go for a screening" (P13).

Participants 7 and 9 were the only participants who said they were aware of the annual retinal screening required by persons living with diabetes: *"Correct yes, but I do do that every year, I do go to Specsavers"* (P9); *"Yes yes… I usually go every year (for a retinal screening) …Like I said, I also learned that from the Facebook group I belong to"* (P7).

The rest of the participants were not clear in their answers.

Finally, the correct utilisation of medication, along with lifestyle changes, are vital to diabetes control. However, despite this not being a widespread issue among the participants in the current study, one participant indicated that no one gave her instructions on how to use insulin: *Even when they put me on the… insulin, they didn't tell me how to do it, I had to go and google it"* (P7).

Participants generally indicated they would like to be better informed by day hospital and RSP staff regarding DR and how DM impacts ocular health. For instance, the participant 1 carer succinctly summarised the relevant information participants would like to receive as follows: *"What is happening to them, why they are losing their sight, why is the sight poor now and previously it was maybe a bit better, why is there a change of specs every two years? I would like for them to explain things more and give more information to patients and not just do a test and say 'go to the next room' but say what is happening"* (P1 carer).

4.3.1.2 Patient / personal and sociodemographic factors that influenced compliance behaviour

Concerns about health status

Among the important factors that motivate individuals to seek health care and take up treatment for DM (including retinal screenings and DR treatment appointments) is the concern about their ocular health and vision disturbances, and wanting to understand what is happening with their eyes. This has been observed in the current study where the majority of the participants communicated these concerns as follows: *"…if I don't do it then I'll eventually go blind"* (P3); *"I just want my eyes fixed"* (P4); *"…probably my fear that I'll go blind if I don't go"* (P7); *"For my own health, and now with me not seeing so well"* (P12); "*I went in order to know what I can do to prevent going blind"* (P13); *"I just expected that maybe they will tell me what's wrong, or if there's maybe something on my eye"* (P10); *"I just felt that I'm old now, and my age is counting against me and I have to do what's good for me in the long run"* (P11).

One participant thought that DR treatment might mean she won't need to wear glasses anymore: "*Because I thought if they said that once they remove the cataracts, I won't need to wear spectacles anymore. Because the glasses are a burden"* (P6).

While the fear of vision loss motivates screening and treatment compliance in some individuals, it is important to also note that some, who have a poor state of health could experience difficulties in complying with DR care. For instance, despite poor vision and a DR treatment referral, an elderly female (referred to as 'P1') did not comply with DR treatment as her family did not think she could endure the treatment due to her poor state of health (at that point P1's diabetes was not under control and she had had a light stroke at some point): *"…her grandson was here at the time and I discussed it with the family and they said no rather not because they don't want anyone poking around because* P1 *was quite sick at the time and they felt that she would not be able to handle much more"* (P1 carer).

Another participant had trouble complying with DR care such as retinal screenings due to non-ocular diabetes-related complications:

"…because I was in the hospitals for surgeries and other things, I never got around to it (eye examination)… I picked up an infection in my foot. A diabetic ulcer, and due to that I ended up in Karl Bremer Hospital. And eventually I had an operation on my left foot. And, uh, yes it took up a lot of time… I'll say a year.. 2018.. 2019.. I struggled with my foot to heal. I was bedridden for months, basically for my foot… I moved in between Karl Bremer and Tygerberg… when I was at Tygerberg Hospital… something strange happened with my heart. The enlarged valves that keep the blood from flowing (back) weren't closing properly. Then the blood flows back. For some reason this whole story that upset me so much, with my feet and all of that, caused the whole situation to develop in such a way that I have 28 and 50 percent function in my different valves" (P4).

One participant underwent a stressful situation at home during DR treatment at TBH: *"my right eye's vision is very poor… I had the eye surgery on 21 January (2020). The 27th of January I went for a follow up. And my husband was so sick then, because he had cancer. A week after my surgery my husband died. I went for all the appointments at Tygerberg. I didn't skip a single one"* (P11). Participant 11 complied with the DR treatment, despite enduring an emotionally stressful situation, as her vision had already been affected by DR.

Fear of the unknown, as well as the fear of screening and treatment procedures involved

Many participants experienced fear and anxiety over having DR treatment and attending the initial TBH consultation. Many said they did not know what to expect: *"I was scared. I didn't know what to expect"* (P8); *"I was a bit scared, but they, the doctor (ophthalmologist at TBH) said it isn't sore, they are only going to do some laser"* (P12); *"I'll be honest, I was scared of the laser. If I went for the other three appointments then we would have seen, and then they might have done the laser and I am a bit worried about that"* (P13).

However, most of these participants went through with the DR treatment regardless, as they were more concerned about their ocular health and vision. The fear of losing their vision, in this case, far outweighed the fear of the treatment: *"I know I'm a diabetic and they say it affects your eyes and so on. And in the long-term I will only gain from it (DR treatment), because if I don't do it then I'll eventually go blind"* (P3).

Although the majority of the participants claimed they have not experienced any unsubstantiated stories regarding eye treatments at TBH, a few claimed they have: *"I have heard that (rumours) from people, but they themselves didn't undergo it, I think they are trying to scare me… (examples) their own and some people's eyes weaken or there are some people who couldn't see through that eye again"* (P6); *"Look there are people who are negative 'yes, Tygerberg is this and that' and 'people just die there' and 'they just leave you there'… but for us, we've never had problems there"* (P8).

There were also instances of positive stories circulating: "*…she got to Tygerberg. They did her eyes. But she says she's so satisfied, she's back at work so satisfied, she can drive again and all of that"* (P8).

One participant experienced negative feedback about attending DR treatment at TBH from his spouse, due to unsubstantiated rumours: *"my wife was sceptical at the time… when the doctor said I required laser treatment, and when the appointment was made, that's when my wife started getting a bit sceptical… because the people hear things from other people, and then they follow their own minds"* (P4).

However, these participants said they did not pay heed to the rumours as they were worried about the condition of their eyes: *"We spoke and I decided to proceed. And my wife was sceptical and I told her that I needed to try something, it can't go on the way it's going now. I want to see a bit better, just like others"* (P4).

In the current study, some of the participants did not report fear, but rather elation when they were referred to TBH for DR treatment: *"I was actually so excited (about being referred for DR treatment) … I actually wanted to do it… because my mother went through the same process"* (P4); *"If I go to the day hospital now then I'll have to make an appointment. I don't know what I'll get for when. Their appointment book stays full… it was like that even before the COVID. That's why I was so happy when they referred me to Tygerberg. I was actually happy"* (P11).

Support from family and friends / social circles

Most participants informed their family members and/or friends that they required DR treatment at TBH, and the majority received support and positive feedback: *"they support all the way. And she'll (P6's daughter) never just drop me off, she goes in with me. She goes with everywhere and says she also wants to hear the discussions* (P6); *"And if they worked on my eyes, my daughter was at home at that time, then she would always come and pick me up with her car" (P11); "I tell my children at home, they care, and I tell my husband if I need to go to the hospital and what I need to go for… the oldest one (daughter), she's very… concerned… she said she thinks it's a good idea, so I can take care of my health, because I am also looking after the little ones (grandchildren) at home"* (P13).

Participant 5, who relied on a community member to take her to TBH and assist her inside, did not feel the need to tell her family, apart from her husband: *"No I don't think I should tell them. They have their own families and I have mine"* (P5).

Financial factors influencing diabetes mellitus self-care and diabetic retinopathy compliance behaviour

While not being a widespread problem reported by the participants, three participants brought up the issues regarding the financial problems related to DM control: *"to eat healthy, for a diabetic, is expensive… if the money isn't there… and you only have pap and bread and not even vegetables really... I mean households are struggling (financially)"* (P3); *"And sometimes, look we aren't rich, you can't select what you eat. Now because you have to take your diabetes medication you have to eat what you have in the house"* (P11); *"My wife and I are both diabetic… we eat our food that we buy… (It's) A bit expensive but… You can't not"* (P8).

Financial factors were not mentioned by participants attending DR screenings and treatment in a public health setting, most likely because the services are provided free of charge. However, one participant who wished to seek DR care in a private setting due to his negative experience in the public sector indicated that he had not yet sought care due to financial factors: *"…I'm waiting until I have money then I want to go privately again… If I go privately, and if they, if they do the laser it's going to be much more expensive"* (P10).

Time constraints including taking time off from work to attend appointments

Only one participant claimed he had missed a TBH appointment (although not eye-related) due to work-scheduling conflicts: *"I was not able to, to make it, because of work"* (P9). Furthermore, participant 6 had to take time off from work but justified that her health was more important than the wages: *"…look, you lose a day's wages, but you don't care, it's for your own health. I will never skip an appointment. Even if I have to lose a day's wages"* (P6).

Apart from participants 6 and 9, others did not have work-scheduling problems as they were either unemployed, whether by choice or inability to find work, or already on pension: "*No I'm a pensioner, I'm at home"* (P8); *"I'm not working anymore. It was easy for me, but it's time-consuming"* (P10); *"I'm not working at the moment. They retrenched me 10 years ago already*" (P12); *"No, luckily I don't work... I've stopped working 2 years, or a year and half before then"* (P7).

Perceptions influencing diabetes mellitus self-care

A 55-year-old male who was diagnosed with DM 30 years before, had interesting perceptions regarding DM that caused him to be non-compliant with DM care:

"Then eventually, to tell you the truth, I got fed up with having to struggle with the pills and so on. So, I decided to look at the pills that are important to me, in my life… So, the heart pills, which I will take, because I know I have a heart problem and I don't just want to get heart attacks… And… I just decided I'm only going to stick to things like that… then I decided, over a period of time, that I'm tired of the Metformin I'm drinking, because it makes me very constipated and so on. And then I left it and I've been off it for over two months now. And the same with the Insulin, I don't even use Insulin anymore... And my sugar is normal. (Now) My sugar is under 10… my sugar was always high, and then I just wondered if the pills were even worth taking? Are they even doing what they are supposed to be doing? I've been drinking cooldrink (sugar sweetened beverages) lately, now with the COVID when your throat is always

dry… I drink cooldrink and all of those things. I'm living normally, like how I used to live. And I check my sugar every now and then, when I think I'm feeling a bit strange, then it's not my sugar, then it must be something else… The day hospitals are very stubborn, when they start with a thing then they keep going with it, they don't want you to change things… I wondered whether the diabetes medication didn't maybe have a negative impact on my life, because my eyes weakened so much." (P4).

Accessibility and the services given at the health care centres

While getting to the day hospitals and tertiary hospitals seemed not to be an issue for most participants, getting the necessary treatment when they were at the health care centres seemed to be a challenge.

For instance, nine participants mentioned that they could easily access their day hospitals (pre-COVID-19) and indicated that they lived nearby: *"…it is within walking distance"* (P4); *"…it's easy because I don't live far from it"* (P10).

Moreover, none of the participants mentioned transport as a reason for not complying with TBH appointments. Participants had family, friends or community members who transported them to the tertiary hospital for treatment. For instance, some participants reported: *"No it wasn't difficult at all. When my husband went to work in the mornings then he just dropped me off where I needed to be"* (P3); *"…I had to ask someone to take me… I asked my daughter to take me"* (P6); *"my husband luckily has a car, so… That's not a problem"* (P7). *"my mom drove me there"* (P4); *"I have a car and my husband took me"* (P13).

One participant who had undergone bilateral leg amputation and uses a wheelchair said she did not have difficulty in getting to TBH for DR treatment: *"we just ask the pastor's wife to take me, because I can't walk"* (P5). These responses indicated a high dependency on other's for transport.

Three participants could reach TBH making use of public transportation services: *"…(I) just took an uber. It took me straight there, so I didn't have any difficulties"* (P9); *"I take the bus, right here in front. The Tygerberg bus comes past here, and then I just get on… getting there isn't a problem"* (P11); "…*there is a bus that goes to Tygerberg, but it rarely stops here and it's very early… I take a taxi to Bellville, and from Bellville to Tygerberg. But I always have to take someone with me because if they've done my eyes then I can't see when I'm walking"* (P12). When participant 12 was probed further on what happens when no one can assist her to

TBH on the day, she replied: *"then I struggle… I struggle to get to the taxi",* meaning she is motivated to still make the trip, but with more difficulty.

Two participants mentioned the option of driving themselves to TBH: *"I used my own transport"* (P10*); "I can drive during the day. I have my own transport but if I can't drive then here's always someone that can take me"* (P8).

Surprisingly, one participant had trouble contacting TBH eye clinic telephonically when she could not remember when her appointments were scheduled for, which led to her not attending: *"…I have Tygerberg's number, but when you phone them then they put you through to... that clinic (eye clinic) and you wait and the music plays in your ears and at the end of the day your airtime is finished"* (P13).

While transport to healthcare facilities was for the most part not an issue, some participants had difficulty getting retinal screening appointments at their day hospitals:

"Look, to get your retinal screening on a list at the day hospital (meaning to get an appointment-name on the list) is almost like… getting a rock out of water. They tell you, today, you must give your name in for a retinal screening on the 26th, then you go there (on the 26th) then they tell you it's full" (P8).

Another participant experienced the opposite of this: *"…when you're a diabetic, then you don't struggle… to get an appointment. But you wait quite a while, but it's much better when you're diabetic"* (P7).

Participants also mentioned having to wait for long periods before having a retinal screening: *"I waited so long before I could do a screening for my eyes. I probably waited more than 5 months before they did it"* (P11).

The waiting times and difficulty in getting retinal screening appointments at day hospitals could be problematic, as participants will often only seek care once vision has deteriorated, meaning the treatment is already overdue.

4.3.1.3 Perceptions about the quality of health care and information provided at the tertiary and day hospitals

Diabetes mellitus information received from healthcare service providers

In terms of the quality of health information, the participants' perceptions of the information they received regarding DM and DR and their state of health at the day hospital they attended varied a lot between participants and from different day hospitals.

For instance, a 26-year-old male living with T1DM was consistently satisfied with DM information he received from the health care providers: *"…so the doctors are very helpful there… (they) tell me how to control my diet, there's a dietician there… They also tell me if there's any questions, I can ask them"* (P9).

Similarly, two other participants only felt satisfied with the information received from the doctor:

"The information that the doctor gives me, I'm satisfied with that, and he explains to me what the sugar can affect. It can affect my kidneys, my eyes, I can go blind… I'm happy with what the doctor tells me" (P13).

"…well, my experiences so far, if it is with the doctor, seeing as I have some knowledge already, I can ask the questions then I get the answers. But I feel like if you don't really know much then they won't give you a lot of answers… when the doctor comes in during the afternoon, he will take all the monitoring sheets and he will have one-on-one conversations with everyone, which is a very beautiful thing to me" (P1 carer).

Participant 5, a 68-year -old female living with T2DM, who has had a double leg amputation, on the other hand, said she did not have any complaints; however, she did not elaborate in any detail what "no complaints" meant.

Two other participants (51-year-old female and 65-year-old male, both with T2DM) were satisfied with DM information given to them by the dietician. However, this information pertained to healthy eating habits. These two participants were unsatisfied with general DM information offered by doctors and most nurses:

"…only when I go see the dietician… I haven't seen the dietician in a long time" (P12). Then, about questions she might have regarding DM, she replied: *"There's only one nurse who you can ask, but I don't see her there anymore. I don't know if she's gone now"* (P12).

"At the dietician. She explains what I should eat and that is, that is all" (P8). When asked about the information given by the doctors, nurses and day hospital staff in general, he responded: *"…they don't give any information*" (P8).

When it comes to the information offered at the day hospital, six of the participants were unsatisfied with DM-related information. With the majority of the participants having feelings that the medical staff only re-write their prescriptions without offering relevant information:

"They've never really given (information) there. It's only sometimes when we have club then there's one who just comes there and 'blah blah blah you can't do this or that', but he looks worse than us. They usually talk about what is good, and what isn't good… they have nurses that sit there at the club, but they don't talk, they only ask you if everything is alright, then they look at the observation that the nurse did, that's all. Your urine, your 'Hgt' and your blood pressure, that's all. Then they just prescribe your pills again" (P10).

"to be honest with you, they don't give us information at all… every 6 months I see the doctor. So, they just rewrite my medication… A new prescription and then finished" (P6).

"… I have to take medication. They are going to give me this medication now… And further more nothing… If a person's sugar levels are a bit high then they only say 'go drink lots of water'. They don't ask what you ate the previous day, or what you ate that morning…" (P7).

Diabetic retinopathy information received from healthcare providers

In general, the participants were satisfied with the overall information they received from the tertiary health care centres they attended. Only one participant thought that the physicians at the TBH eye clinic did not supply sufficient explanations:

"The one doctor looked into my eyes and she was not happy with what she saw, and I felt a bit uncomfortable then. Then she called her superior. Then that one also came to have a look. So, then they spoke to each other, but they didn't tell me anything, what they saw or… It was actually my own fault; I should have asked. So, they spoke to each other but they didn't explain anything to me" (P6).

Participant 6 also could not say which procedures were performed on her: *"and the laser… is it a burning sensation? I wonder if they didn't perform that on me, I'm not sure, it did feel very strange…"* (P6). However, she was still satisfied with the overall care provided: *"…one thing… about Tygerberg, they are very kind… I was quite happy with them"* (P6).

On the contrary, most participants were not satisfied with the DR information being offered at day hospitals. Four participants explicitly claimed to have received no information regarding diabetes-related eye complications from the day hospital:

“No one (at the day hospital) mentioned that” (P7);

“Actually, you don’t get any treatment for eye at the hospital... at the day hospital. Zero, zero, zero. You just go there, you’re a diabetic, you sit there, the nurse doesn’t even ask you questions. She just writes your pills… and there you go. They don’t even touch you or anything! Nothing, nothing! So, there’s no information… for my eyes. We get ZERO information about eyes” (P8);

” … they have nurses that sit there at the club, but they don’t talk, they only ask you if everything is alright, then they look at the observation that the nurse did, that’s all… It’s not like you’re going for an examination where they tell you need to go for your eyes and this and that” (P10).

“…they (day hospital staff) always just told me to watch out for my organs, they... never told me about my eyes” (P11).

A 53-year-old female, diagnosed with T2DM more than 20 years before the research was conducted, claimed that she was only told about ocular complications from DM during her initial DM diagnosis:

“…when they found out I am a diabetic… further nothing. It’s very long, probably more than 20 years” (P6).

Moreover, when asked whether they are informed about DR during ‘workshops’ or educational sessions held at the diabetic club, the participants either were not aware of these workshops and not part of the diabetic club or offered that the workshops are mostly about what to eat:

“…it’s just a 2-hour workshop on a Thursday, I’m not sure if it’s still happening now (because of COVID-19 restrictions)” (P1 carer).

“No, never. Not at the day hospital I belong to” (P7).

The carer of participant 1, who is a registered full-time care worker and has general knowledge of certain medical conditions and their effects on the body, answered with a firm *“No”* when asked if health education related to ocular consequences of DM had ever been given when she attended ‘workshops’.

The carer for participant 1 also mentioned that she thought the information provided by the RSP staff regarding DR and the participant’s state of ocular health was generally insufficient.

This opinion was shared by four other participants when asked whether they had received an explanation of how diabetes affects the eyes from the RSP staff:

"My experience with the diabetes and the primary eyecare providers… they didn't provide a lot of info... look a lot of the people are uninformed… the people (patients) are uninformed and they (the medical professionals related to eyecare) have never made time to speak (to patients)." (P1 carer)

"No, they only test your eyes, and then they say you must come fetch your glasses there" (P11).

"Hm-mh (meaning no), they only told me about a pill I needed to buy at the pharmacy" (P6).

"They said nothing. They only prescribed spectacles for me, I had to look at glasses, and then I had to go to Tygerberg" (P10).

"Not so much. Not so much, no. They told me what I needed to know, just like the basics of what I needed to know and just rushed through the next patient" (P9).

The carer for participant 1 did however note that when she started asking questions, based on her knowledge and experience as a care worker, the optometrist with the RSP was more helpful and explained the current state of the patient's ocular health:

"…the person who helped us, he took his time because I asked the questions." (P1 carer). None of the other participants mentioned a similar experience.

Seven other participants also mentioned the feedback they were given by the RSP staff regarding their retinal screening:

"…and he told me there is bleeding at the back of P1's *eyes"* (P1 carer).

"They said I could go blind. That's what the lady said…" (P5).

"…they found out I have blood speckles in the back of my eye… And then they found out it's from the cataracts" (P6).

"*…and then they told me they think there is blood in the back of my eye or something like that"* (P2).

"…they didn't tell me why (regarding why he was being referred), because I thought that maybe there's something wrong with my eyes. Because they did, then I got the glasses, and then they said I must go to Tygerberg, and they just said I must go to Tygerberg. Ya, they didn't say why… They only gave me the date" (P10).

"And then they also… my left eye, at the back of the eye, when they took that photo for Tygerberg, they saw the eye is swollen" (P13).

"When I went for, for, for an eye test… What they found was blood behind the vessel, the blood vessels, behind my eye" (P7).

"They never called me. No feedback, no" (P9).

Six participants mentioned receiving DR information from sources other than the day hospital or RSP:

A 65-year-old male, diagnosed with T2DM nearly 30 years before the research was undertaken, explained that he resorts to asking a family member working within the medical field for DM-related advice: *"my sister-in-law, agh my daughter in law, she is a nurse at Somerset, one of the bigwigs there. I always ask her. I ask her if something's wrong with me, and then she tells me my sugar level is a bit high, I should do this and that. From her I get the most information"* (P8).

"…when I was still working, I had a medical aid, and then the doctor told me how it works… so I do have experience from when I was in private, that they, at uhh… N1 I saw the internist and they gave me a lot of information" (P10).

"If the sugar is maybe high, then it affects the eye or something like that. It's when I was lying in Tygerberg (for non-ocular related problems) that they told me that" (P12).

"But I knew it (that I needed an eye test) because I read up on it and I know that it (DM) affects your eyes and your organs and stuff… I read it in one of the Huisgenote" (P11). 'Huisgenoot' is a weekly Afrikaans-language general interest family magazine.

"…it's all things I learnt on… Facebook, the group I belong to, where I get the information" (P7).

"I do go to Specsavers... Yes, yes, they do explain in detail. The uhm, they sit me down, they do tell me ya, so like I said, last time I went through, the uhm, uh the… the doctor there, he did say that the back of my eye was a bit cloudy so I just have to, just watch out to see if there is any, uhm, any signs of that. Uhm, and then also he did say that uhm, if there's any blotches or any type of scarring on the eye if I can say that, say to come see him…" (P9).

Experiences with diabetic retinopathy-related service providers

In terms of the DR care services patients received, experiences varied, with most participants being satisfied with the services provided at TBH but unsatisfied with services provided at the RSP. Some participants were unhappy with RSP services because they were not given enough attention during their consultations.

"…to be honest it felt, it felt like, like I was a bit rushed, like they just want us to get to the next station. They told me what I needed to know, just like the basics of what I needed to know and just rushed through the next patient... so when I went there, there was [sic] a few people, quite a few people waiting to get their eye test and get their glasses and everything of that nature. Uhm, they did try to help as many people as they could. Uhm, sometimes two would go into a room at the same time, one would be helping one, the other would be helping another person. So, I kinda felt a little bit, it wasn't a very personal experience. So that's why I thought they were just trying to get through all the patients as quickly as possible… I think, I think they probably could have spent just a little bit more time on each patient if there was a, if there was [sic] less patients on that day… It only happens a wh... Once every, in a certain amount of time so like, one Friday in every three week or one Friday in every four weeks, so then once they do come they will always be full, so they will always rush through. So, I think there's a problem there" (P9).

"the staff that helped me there (retinal screening) were, they just started to work but they were listless, it looked like they've been working the whole day… they didn't make any extra effort" (P10).

Participants also experienced long waiting times on the day of the retinal screening: *"Because, the problem with going here (to the day hospital) for your eyes is, sometimes the people take so long. You get the feeling the people are like 'well I am here now, to work, so you just have to wait'"* (P10).

Some participants opted to go privately for the service in the future, even if it ends up being more costly: *"I'm waiting until I have money then I want to go privately again"* (P10).

One participant mentioned that she could not see with the glasses she was given by the retinal screening team: *"…the moment I read, then I'll see through them, but when I put the glasses on to see far then I don't really see far, because then when I take the glasses off, I see better at distance*" (P13).

One participant seemed to think the making of spectacles and retinal screenings were done by different organisations, and he was happy with the information given during the retinal screening, but not with the refraction:

"…they look into your eyes. What can you see on the board, 'ABCD', until there, then you get glasses… The retinal screening, the nurse, I can't remember her name now. She's very nice, a very nice woman. She called me back and said 'sir, we aren't going to make glasses now, come and see us at Tygerberg hospital.'… they give you information yes. And if they don't know then they ask the nurse that's there, from Karl Bremer, if perhaps they don't know something and so and so and so, then says 'no, do this and this and this'… Here (referring to the day hospital) you just get tested and get your glasses, and the glasses that they give you are bad" (P8).

Contrary to participants' experiences with the RSP, participants were overall satisfied with the care provided at the TBH eye clinic, despite waiting times and discomfort caused by certain procedures:

"That was also a whole process but… I'll tell you, I'm very impressed with the treatment... the whole day. Everything you get… it's quite long. I mean, I was there the morning… I got out of there at 4 in the afternoon, but I mean, there are so many people, and every test… they do so many different tests, and everything takes long, I mean that is understandable. For me it was the best. I was very impressed. At every person (testing station) they explained. My husband was allowed to ask questions" (P7).

"…they treated my eyes well. The doctor that saw me there at Tygerberg was a female, I can't remember her name, she treated me very well, (she was) very nice… the treatment they gave me there was very good. The laser that they gave me, I couldn't get out of the hospital for a while, because everything is blur [sic], but I just had to wait until it came right, then I go out… but I don't have a problem there (at Tygerberg)… like I experienced with the laser, it's only... your eye is very sensitive... you have to keep that eye open for very long. But they shoot it nicely. From one side to the other side then they check to see where they still need to shoot the blood… And the patients that were coming for that day, I could see, the people are satisfied. And also (you) don't wait that long, and you don't get discouraged and you know… you know which room is room A, B, C, E, F, G. You know how the system works. If you get there first don't think you're going to leave first, because it's a process that must be done… everything gets done well on that floor" (P8).

Experiences with referral protocol and scheduling of diabetic retinopathy treatment appointments

In the current research, there were more health service centre operation-related issues that cannot be ignored. Among these were appointment and patient referral issues that prevented the participants to be compliant with their appointments. For instance, one participant was referred for DR treatment in November 2019, but her appointment was postponed: *"…but at the time that doctor that I needed to see couldn't see me, so he gave me a date for March this year"* (P12).

Another participant encountered a problem with the referral from the RSP as well. This negative experience discouraged him from seeking further care for DR:

"When I got to Tygerberg, the uhm, the doctor who did this, or the person who did this eye test (RSP team) didn't refer me, they just said I must go (to Tygerberg eye clinic), the papers will be at the front… they just said I must go to Tygerberg… they didn't say why... my appointment was without a referral letter, they said the letter is at Tygerberg... when I got there, they told me that my name isn't anywhere on the list.… no one knew a thing about me… and that really upset me… I was worried, and I thought there could be something wrong with my eyes. And when I got there it was very disappointing" (P10).

When probed whether he had gone for another eye test since the negative experience, he did not seem to want to have an eye test at the day hospital through the RSP again: "*No not at all because I'm waiting until I have money then I want to go privately again"* (P10). He also had not sought to clarify the situation with the RSP due to the previous disappointment: *"I didn't phone them at all… because of the treatment I got there"* (P10).

Participants had experienced a lack of information given at the RSP regarding their TBH referral: *"They said nothing. They only prescribed spectacles for me, I had to look at glasses, and then I had to go to Tygerberg"* (P10).

Certainly, it is important to note that inefficient referral routes were found to greatly affect compliance with DR treatment. One participant was told he would be referred to TBH for DR treatment; however, he had a negative initial experienced:

"Well, when I originally finished the eye test (retinal screening) at the day hospital, the people told me there is bleeding and that they couldn't actually give me glasses because the bleeding in my eyes is caused by my diabetes. And then they referred me to Tygerberg the first year, and

then it never happened. But when I went for the second time to follow up about it someone eventually woke up and referred me to Tygerberg… I was upset, because the first time I went it (the referral) wasn't successful" (P4).

4.3.1.4 Perceptions of and experiences with care since the start of the COVID-19 pandemic

Attitudes and beliefs towards COVID-19

Participants had differing views regarding the seriousness of COVID-19, with perceptions ranging from concern, especially due to the DM diagnosis, to indifference:

"I am diabetic I am immune-compromised, so… (patient indicating fears about contracting the virus)" (P9).

"I am very scared of this COVID because I have lost many of my family members to this COVID. And my age… my age counts against me. I don't even go to the shops" (P11).

"…you know I tell the people every day, if I must get the germ (coronavirus) then I must get it… I'm not going to go look for it" (P6).

"I'm not (worried) at all because I know I will protect myself" (P10).

"I'm not scared… how can say, I'm not scared of the COVID. Because I don't have COVID, I'm not afraid of COVID" (P8).

Interestingly, two participants mentioned their religious beliefs when asked about their feelings towards COVID-19: *"if I get it, I get it. It's God's will"* (P5); *"And if you are a Christian and you believe, then you don't.. You are a religious person, you must believe in yourself, you must believe… I'm not going to let my health.. I'm not going to look for the disease, but I'm also not going to let my health (deteriorate as a consequence of fear for COVID-19)"* (P5).

Resolve to attend appointments

The COVID-19 pandemic had affected participants' resolve to access care. One elderly patient's family and caretaker decided that complying with DR treatment, which meant visiting the eye clinic at TBH, was not worth the risk as the patient was already struggling with health problems at the time: *"Yes she is at that age and she almost didn't make it, but because she is much better now we don't really want to expose her to anything unless it's really urgent for her to get to the hospital"* (P1).

Another participant, a 49-year-old male diagnosed with DM three to four years before the current research, defaulted on his DR treatment due to the pandemic: *"I didn't attend the treatment appointment because of COVID… I was just worried because I am a chronic patient, and now the COVID is so terrible and it will affect me. I did have an appointment with them (TBH). And I didn't go due to the whole COVID-19 business"* (P2).

However, as seen with the different attitudes showed towards COVID-19, not all participants were put off from attending TBH appointments due to the pandemic. Participants were keen to attend their DR treatment at TBH as they either believed they could take the necessary precautions, or that TBH would take the necessary precautions, or they viewed their vision as more important than the risk of contracting the virus: *"I move in between the people and I wear my mask, and it hasn't really bothered me yet. I know there's a risk but I try to be as safe as possible"* (P4); *"I will go (to TBH eye clinic). The reason is because if Tygerberg says 'listen, we are open' they will have things in place for the virus"* (P8); *"I would go (to TBH), because my eyes are very important"* (P11).

Participant 13 expressed that she would attend DR treatment at TBH during the pandemic only if it does not require her staying over due to a prior experience at the hospital:

"I'm just worried about having to lie there. But to go for my daily appointments then, then I go... in March, before the lockdown I was in the hospital... with the lung problem and the heart problem and to lie there, you can't go outside, you just have to lie in the room the whole time, it makes you a bit scared. If the family can come visit a bit then it stirs some hope, but to lie there so alone scared me. No one could come to you and you just had to lie there alone. And you couldn't really walk around, you just had to stay in the uhm, in the ward that you were in" (P13).

COVID-19 affecting access to diabetes mellitus care

Participants mentioned difficulty in gaining access to day hospitals with the strict measures implemented by day hospitals to limit the spread: *"We have to be very careful of COVID-19, so the people are standing outside by the gates. Even if you phone ahead and say you are coming in, you have to stand outside… to take anyone in to the day hospital now is terrible, especially for the high-risk diabetics"* (P1 carer).

Due to the limited amount of people allowed on the day-hospital premises, provision was made for chronic patients (including DM patients) to have their medication delivered to their homes.

This likely reduced the risk of non-compliance to DM treatment: *"…they have community service workers that bring the pills to you, then you don't have to go there" (P10).*

However, a possible administrative error led to participant 11 claiming she was without DM medication for a period: *"Because the nurses came around here, they asked for my… my details, wrote it down, and then left. But when I asked them, they said mine isn't made up (medication/prescription package). So, I was without medication for 2 months"* (P11). The same participant did not want to attend the day hospital during the pandemic: "*I am actually a bit scared, because I can see in the area where I live, the people aren't taking the COVID seriously. They probably feel like it hasn't touched them yet"* (P11).

All eight participants who were fully compliant with DR treatment noted that their DR treatment appointments had been cancelled by the TBH eye clinic due to the COVID-19 pandemic and subsequent restrictions:

"…she (nurse from TBH's eye clinic) phoned me to inform me that the appointment has been postponed until further notice…" (P3);

"I was supposed to go to Tygerberg hospital recently, for my eyes, because they would have done laser. But then the appointments got cancelled due to the COVID story… then they cancelled everything" (P4);

"with the corona the doctor cancelled my appointment" (P5);

"And now last time with my eye test, they found out there are cataracts on my eyes… which have to be removed. And just the week after, when I had to go, Corona came out. So, I couldn't go, but my eyes are getting weaker and weaker… And now I couldn't go for mine because Tygerberg is closed" (P6);

"…I was supposed to go for my first injection in April. Then June and July. But then COVID-19 happened. So, the clinics (eye clinic at TBH) were closed, only (open) for emergencies" (P7);

"It was just with the lockdown of March, my (TBH eye clinic) appointment was in that month, and so I phoned them before it (the appointment), and they told me unfortunately they aren't allowed to have anyone there… the appointment is on hold now" (P8);

"And then the doctor there also gave me a follow up date for the 5th of April, but then COVID-19 happened. And then everything was on hold… And in the meantime, my eyes have deteriorated" (P11);

"Because now I actually had to go for a surgery next month, but when I phoned, they told me they can't, they can't make an appointment for me now because... uhm… (COVID-19)" (P12).

Participant 4 expressed how he felt about his cancelled DR treatment appointment:

*"I know they cancelled all the (Tygerberg) appointments when the COVID-19 came around... And I can understand that they are worried about the high-risk people, but I am worried about my eyes. Where do you draw the line?... They said they would phone me, and that's why I want to phone them, because I thought maybe they've forgotten about me. To get an appointment at the eye specialist there is difficult because there is such a long waiting list. And when I eventually got an appointment there, it was like a breakthrough, and then the COVID-story happened and I'm just wondering if I'll get another chance" (*P4).

4.3.2 Key informant responses

This section outlines the responses given by the key informants. These responses are also based on objectives 4 to 5 of the current study. In this regard, the following 6 qualitative themes were developed from the data in the transcripts:

1. Perception about the patients' knowledge about the aetiology and treatment of DM and DR and the need for information
2. Experiences with patient referral at tertiary institutions (Tygerberg Hospital and Hospital 1)
3. Perceptions of patients' issues that influence compliance with DM and DR care
4. Recommendations to improve DR care compliance among patients
5. Perceptions of how COVID-19 affected access to DR care
6. Attitudes towards lack of DR care during the COVID-19 pandemic

4.3.2.1 Perception about the patients' knowledge about the aetiology and treatment of diabetes mellitus and diabetic retinopathy and the need for information

When the key informants were asked whether patients with diabetes are well-informed about DR, they offered different perceptions: *"No, the majority, from my experience is not, they are not well-informed"* (K2); *"so a lot of them are returning patients so they have a fair idea and the health promoters at the clinic also speak to them about the importance of it"* (K1). However, key informant 1 also commented the following regarding DM patients: "*A lot of them (patients) don't even know that, that the clinics offer a retinal screening programme. They just think they get the specs then they realise they are there for retinal screening*" (K1).

Both key informants were aware of educational sessions or 'workshops' that take place at the day hospitals' diabetic club's that the patients have to attend. They also were aware of the challenges that the health promoters at day hospitals are facing when imparting the diabetes-related information to the patients:

"…the way the health promoters offer their teaching… people don't really pay attention to the health promoters in general […] any time she is busy with diabetes and hypertension, they do not pay attention, based on body language and based on […] the way they are speaking back to the health promoter. They're not interested…" (K2)

Key informant 2 also highlighted the incomplete information given to the patients by the health promoters. *"I've listened to the health promoters passively mentioning that it can affect your eyes, what diabetes can do. So, the health promoter mentioned everything that can be affected by diabetes in the body, and they passingly said it can affect your eyes, and that's the only information I've ever heard... being given to the patients. The doctors may, may give information but I have not been inside the consulting room"* (K 2).

However, key informant 1 highlighted that not all the information is given in one consultation. The details of the information might be spread through different days; *"…well I know the health promoters sometimes have uhh days where they focus on diabetics and diabetic retinopathy alone… so then they will explain to them how it can affect the eye."* (K 1).

When key informant 1 was further asked whether she thought day hospitals supplied patients with enough DM and DR information, she had the following to say:

"Not all of them. Some do... I think some health promoters are more involved than others, and uh, so not all of them explain, no" (K1).

When the key informants were broached on the topics that are covered when educating the patient about DR by the RSP, they once again had differing perspectives. However, both seemed vague:

While key informant 1 responded like this, *"…a lot of them are returning patients so they have a fair idea and the health promoters at the clinic also speak to them… But I do speak to them while I'm testing their eyes about how sugar... because they ask me questions… and how diabetes can affect their eyes and why it's necessary because a lot of them come, you know, just for the specs"* (K1).

Key informant 2 highlighted that the information is personalised based on the severity of the condition.: *"…It depends patient by patient, but not all [sic] I am able to do as much as I would like to do… Because some have complicated refractions, and some have underlying pathology where the focus becomes the active pathology or trying to get the vision to become as good as possible"* (K2). He also identified time constraints and patients' impatience as barriers to giving detailed information about the patients' conditions: *"And in trying to get that done, we, we don't have time to go on about the uh the rest of the diabetic routine […] With time constraints and working conditions, and the rooms we get, the time we have with the people, just are not naturally conducive to testing…"* (K2).

He continued to say: *"The patients also themselves. Because they… have impatience issues and they differ, because we work over a wide spectrum of the network. People differ in personalities and differ in mentalities on different days with different outcomes. So […] it's more time consuming […] we might not have more time to spend on what we need to spend, because you're trying to calm them down and trying to get them to just do things the right way"* (K2).

4.3.2.2 Experiences with patient referral at tertiary institutions (Tygerberg Hospital and Hospital 1)

Key informant 2, an optometrist working within the RSP in the NTSS gave the following in response when asked whether there were any issues with referring patients to TBH for DR treatment: *"No… we have basically ironed out any issues, we try to.. to address them before they come through, if there are any. But in the past 6 months I cannot think of a, of a diabetic retinopathy issue with Tygerberg"* (K2).

Whereas key informant 1, an optometrist who works in the Southern-Western substructure, had the following to say about one of the tertiary institutions*: "we have a good relationship with hospital 1… they (referred patients) get seen very soon and then they come back quite happy […] when it comes to diabetic retinopathy if you go there.. you don't even have to make an appointment for them if it's non-urgent, the patient just goes there with a letter and they get screened initially on that day"* (K1).

She also highlighted the importance of good relationship with the hospitals: *"Hospital 1… is very good […] we've had meetings with them […] we know who each other is and it's just a much better relationship with… Even if they get 90 people they take every patient in. They don't turn people away anymore because they uh used to do that when they had a huge backlog, but … with our retinal screening programme […] that helped a lot to clear up their backlog… So, they are now able to take whoever is there on that day"* (K1).

The key informants were also asked about how patients usually react when they are informed of their DR referral. They thought overall, patients handle this news well, but also highlighted sociodemographic factors such as age, gender, social circles, language barrier, and other general fears that mitigate their referral responses.

"You get the one or two that uh might take the news a bit bad but usually they have other factors going on in their life […] (however the) majority of them are very understanding…" (K1).

"I think it's more of an age-group… mentality. I've cast, the younger the patient, the more positive [sic] they respond and the more likely they are to respond. The older the patient, and also gender, if they are male, the more they are likely to ignore or... or to not want to take it seriously… I find that women are more likely to seriously want to act on it… Men would be… try to avoid their... their appointment." (K2).

Key informant 2 also added: *"Also […] there are unfounded fears, because the… their source of knowledge is neighbours and family… and experience of others within their same social and socio-economic circle… So, someone will avoid an eye test if someone (that they know) went for an eye test and was referred for an operation… then the operation did not go the way they wanted it to go […] it's misinformation that happens at the patient (levels) whereby they don't get (understand) the explanations, the language barrier, semantics, of what really is going to happen and what's happening with them. […] this leads to fear, unfounded fear, for… keeping* *future appointments, […] they trust what happened to their neighbour more than what the professional says"* (K2).

When key informants were asked which difficulties they were likely to encounter when trying to refer a patient, they responded by saying:

"… sometimes they (patients) give you a phone number… there's a culture, of, ignoring phone calls. A culture of not returning a phone call... in most cases, if we don't give the date at the clinic, and we only pick it up later, we try to make an announcement that when you get a phone call between a certain time from a certain number, please answer it because it could be important for your life" (K2).

Key informant 1, on the other hand, said: *"Uhh I think one of the main problems is patients not going […] to hospital 1. Because they probably get a bit scared or they... So, a lot of the time they are scared and or … a lot of the time they don't take it seriously. They say […] something came up and they couldn't go or their son decided to take them for holiday that week or their daughter bought them tickets to go to Australia and they just leave it […] The main thing, I think they are scared"* (K1).

Key informant 1 continued to say: *"… sometimes they come back with their letter and they tell you "I missed it can you please give me another date?". Which we then, we rescreen them and we do. And then you get those that you pick up one year later […] If you look at them then some will honestly say 'I missed my appointment can I have another date?'… okay so a lot of the time they will say they were sick with the flu and they couldn't go. Or their spouse was sick and they had to take care of them, or the daughter took them on holiday"* (K1).

Key informant 1 then further added: *"Okay, so what would make them want to go (attend DR treatment) is obviously, they would not want their eyesight to deteriorate and they would not want to lose vision ...and I would think that most diabetics know now, that diabetes is a risk to their sight […] But then you do get those that don't want to go because they hear stories from other people […] maybe other people told them that they went and now they see worse than they did before and they say uhh that it didn't help them. But the thing is, maybe it didn't make it better but it stopped it from getting worse. So, you have to explain all of this to them"* (K1).

Further discussing difficulties often experienced when referring patients, Key informant 2 then stated:

"…10% of those (who were referred to TBH for DR treatment) don't show up, and (from) 8% of those we get a very good reason, like it was a family bereavement or something urgent, or lack of money […] we try to address the issues while setting the appointment. So, if the person tells us that on the date that we want to give them they will not have money, then we will not give them that date, so that we […] have good compliance. So, we try to... to remove any obstacles in the way of compliance" (K2).

Key informant 2 elaborated further: "*It's financial, the social issue whereby someone does not have someone to take them to... to the hospital. And they will always try to say 'there will be someone to take me', (we) give him the date, and then on the day, because of social situations, some of the children or the family that … our patients live with don't take their... family member's health seriously"* (K2).

4.3.2.3 Perceptions of patients' issues that influence compliance with diabetes mellitus and diabetic retinopathy care

The two key informants highlighted some issues that hinder patients from complying with their medical care. For instance, based on their experience, they highlighted sociodemographic, familial, socioeconomic, social, and cultural issues as some of the mediators of DM and DR compliance.

For instance, key informant 2 talked about the social- and psychological-related issues: *"My (experience) with uh the social issues with diabetic retinopathy was on the Phelophepa train years ago. And the lady... could not keep the right food that was gonna [sic] assist her with her medication, because she lived with her grandkids, who were abusing her. So, they will be taking the food that she would buy herself with her social grant, that will assist her. So, they lived in the house and they were into drugs and all these things […] we did a holistic way of assisting her with the psychologists. And I was speaking with the psychologists there, and they said that it's actually true how they deal with other health issues as psychologists, that there's non-compliance and issues with health, but the problem is not with the health, the problem is the social situation that the person cannot control... that leads to the health problems there…"* (K2).

He further talked about the family- and household-related issues: *"We'll always find the […] same problems even now. The… family is not supportive, or […] does not want to understand their situation with diabetes […] when you live in a four roomed house, with one small lounge and one small kitchen, and the food that is cooked is nowhere close to what you need to eat, it* *becomes very difficult to say no, even if the food is wrong for you […] the person just gets worse and worse and they (the family) honestly say 'no we're not gonna stop eating the way we eat... because of you, and your diabetes'. And then without the family's support it's very difficult for a person to comply"* (K2).

Other issues he highlighted were socio-economically related. For instance, he highlighted issues related to extended family living together, with that affecting the psychology and the diet of patients with diabetes: *"... the nuclear family, the way that it was whereby it's parents and children only who live in the house, no longer applies within our communities. So, we have inter-generational… families. […] There's a support structure but it's not in a positive way. It's in a negative connotation because we are stuck together, because we don't have anywhere else to live… So those socio-economic situations add a lot to the... to the health crisis of diabetes and diabetic retinopathy… It's also prevalent (in the NTSS) […] Kids have kids and then […] leave them, the children, by the grandmothers, the grandfathers. And children always need chips, they always need these things that are not healthy to be cooked around for them"* (K2).

Finally, he highlighted social-related issues, where the community may be inconsiderate and not supportive of those with ill health: *"And they're smoking, because of societal pressures […] You might want to stop […] but if your neighbour is always smoking […] it becomes very difficult… There is no support structure when it comes to positive reinforcement, when it comes to health matters. It's always negative […] Now, in the community health centres, basically the people who come through there, it's a very difficult situation. There are some who, who have the support structure and those are the ones who never have problems in general. But the majority is people who don't have a support structure and as a result don't comply."* (K2).

4.3.2.4 Recommendations to improve diabetic retinopathy care compliance among patients

Both key informants 1 and 2 had similar ideas on how to improve patients' DR knowledge within day hospitals. Both key informants believe that improving patient education regarding DR would improve patient compliance with DR care:

"I think the main thing that you can do, or that you have to do is patient education. Because even though you get some help from doctors who talk about it, maybe once a year is not enough.

You can […] have it spoken about by doctors, nurses, health promoters, everyone and uh advising them (patients), as soon as they become diabetic they should know the consequences. So, the main thing is patient education should be increased" (K1).

"It… it needs… education… The... nurses at […] the diabetic clubs… all the nurses who work there, not just CNPs (clinical nurse practitioners), the auxiliary nurses who work there, and all the nurses, the ones who comes [sic] into contact with the diabetic patients in those specialised sections, needs to... send reminders (regularly educate regarding DR). Because that's when they pay attention, when the nurse speaks within the club, they take it seriously, because then they realise that's it's a matter of life and death" (K2).

Key informant 2 further explained how health promoters could be used to improve DR care compliance:

"I think there should be more health promoters […] health promoters actually play a big role in assisting the professional. I give anecdotal evidence, but I, I see in areas where the health promoter is, is more hands-on, and is more involved, community-based, goes out to old-age homes, goes out to clubs, to not only people coming to the clinic, the more community-based they are there seems to be better compliance and the clinics seem to cope better with the numbers and people not pitching up for their appointments…" (K2).

Key informant 2 also explained how community health workers could improve both DM and DR knowledge both in and outside of the day hospitals:

"…the community health workers are actually at the same social level as the community […] The community will trust what comes from someone they normally eat with, and go to a funeral with, and someone who takes a taxi like them, who lives... who they know, who (knows) their mother. They trust them with everything. They trust community health workers more than they trust the professionals" (K2).

Key informant 2 explained that to improve services they would need to have more teams visiting clinics, have an efficient booking system in place, and visit a smaller number of clinics more frequently (the retinal team responsible for Northern/Tygerberg and Eastern/Khayelitsha sub-structures sees on average 40 people per day, many of who also require refractions to be done, and visits each clinic about once a month, sometimes less):

"Ideally, we should be able to book 10 per hour. Let them come in 15 minutes before the hour when they are booked […] They know that between 9 and 10 they will be seen […] And it makes

people less impatient… it gets very difficult to work with impatient people […] but it needs the structures within the clinic to be top class, to implement that system […] It would be better to see less people and see them more frequently, to give them a fairer.. care. Fairer in the sense that we are able to educate them as well as we could […] or... if you could have more teams." (K2).

While data from participants lead you to think that service delivery at some day hospitals are poorer than others, when key informant 2 was broached on the subject, his response contrasted some of the participants' views and he brought up that there is a 'culture of dissatisfaction' among patients at certain day hospitals. This despite the medical staff trying their best to provide the service they can with the limited time they have per patient:

"…I've heard, uh, such unsubstantiated rumours. And I say unsubstantiated because from my experience it's the opposite […] So, the personalities of the people in the place sometimes means that they never can see something good. Like… they'll complain about everything and anything, the patients just do that. Yet they do not know how good they have it in terms of how […] the clinic tries to help them, and compensates and works within a time frame. Yet, they are the number one in complaining that it is not being done the way they want it to be done" (K2).

Key informant 2 then went on to discuss how he perceives the 'culture of dissatisfaction' to negatively impact service delivery, possibly leading to a vicious cycle:

"The more you complain the less the quality... the less inclined the staff is to… to want to help you. They just close out as it were, they get disinterested in what you have to do and ask for. Although they help you to the best of their abilities, they do it out of duty more than out of... love" (K2).

4.3.2.5 Perceptions of how COVID-19 affected access to diabetic retinopathy care

Key informants 1 and 2 noted that they were not allowed to perform retinal screenings for a prolonged period which started at the beginning of the national lockdown. At the time of the interviews (the last week in August 2020) retinal screenings had not yet commenced:

"due to the pandemic we've had to suspend our services completely because the clinics needed to reduce the number of patients visiting the clinic. So, we have not been running our services,

or our patients have not been getting retinal screenings or eye screenings for the past, how many months…" (K1).

"Well, we can't work and see diabetic patients because we are exposing them unnecessarily while they already have a… comorbidity […] And the clinics are full…" (K2).

Key informants were asked how many retinal screenings they perform daily, as well as on average how many patients require DR referral; they gave similar numbers: *"About 45"* screenings daily and *"maybe 2 or 3"* DR referrals daily (K1); *"Forty"* retinal screenings daily and *"per day it was 3*" DR referrals (K2).

Both key informants were asked whether he knew of any pathway available for patients with DM to get DR treatment:

"No, at the moment the public hospitals are only dealing with eh, emergencies when it comes to eyecare, so unless you are losing vision with an accident, they do not see routine cases… So there is no way to get help at the moment" (K2).

"The only other route, I think they could go directly to Hospital 1 […] So if they are going in without a referral letter or without any history of diabetic retinopathy then you would probably only get an appointment for next year… I've had patients […] telling me that Hospital 1 said they're are not doing cataract surgeries until 2021" (K1).

Interestingly, K1 also added the following regarding the lack of DR care: "*if they aren't experiencing vision loss, they wouldn't even know about it and if they wait until they do experience vision loss then it's already a bit late"* (K1).

4.3.2.6 Attitudes towards lack of diabetic retinopathy care during the COVID-19 pandemic

In this regard, the two key informants once again had differing views, although both seemed upset, one thought it was necessary while the other did not:

"Well it's upsetting because I understand the thing about regulation but I also don't think that eye care should have taken a backseat because it's so vital. It's so necessary. And, for all patients, not only the diabetic patients, there are other factors that could lead to blindness not only diabetic retinopathy… And I think this whole...for eye care to be out on the backburner for six months, I think it's ridiculous because there are so many people deprived of healthcare

and it's quite sad and ya, I really don't think eye care should be considered as a non-essential." (K1).

"Well, in terms of what's more important, my uh vision or being alive, so then I place life higher, I value life higher than being able to see [...] because of the real fact that diabetics who get, uh, COVID-19, are likely to end up in hospital and are likely to suffer severe.. severely. So I will rather wait 'til there is no COVID-19 or the COVID-19 is under control [...] a very low infection rate, before risking people's lives [...] It saves their lives, and it seem unfair, but it is only when they are alive and we can get back to trying to fix them, that we'll appreciate the the the reduced loss of lives" (K2).

He further added: *"It's sad… it's sad, and it's not anyone's doing, in terms of the health system in South Africa"* (K2).

4.4 Chapter Summary

In this study, 30.77% of participants were found to be non-compliant DR treatment, and 7.69% were found to be partially compliant based on the definitions used. Patient-related non-compliance and partial compliance to DR treatment and care resulted from a poor state of health and forgetfulness. Whereas institution-related factors stemmed from poor referral management by the RSP and TBH's inaccessibility via phone-call. Treatment fears were not found to be a barrier in this study. Mixed COVID-19 concerns were experienced by participants, however, COVD-19 fears were found to be a barrier to compliance.

Furthermore, all DR treatment appointments for fully compliant participants (61.54%) were cancelled by TBH at the start of the national COVID-19 lockdown as a result of restrictions. It was also found that the RSP had been suspended since the start of the lockdown, leaving people living with diabetes with no clear pathway to receiving DR care within the public health setting.

Importantly, most participants lacked vital DM and DR knowledge and were overall unsatisfied with services rendered at primary healthcare facilities. On the contrary, participants were satisfied with services rendered at tertiary healthcare facilities, despite also experiencing long waiting times at these facilities.

Despite a lack of in-depth knowledge about DR, all participants were aware that diabetes could negatively impact their eyes in some way. The fear of going blind proved to be a major motivator for participants to attend DR treatment, despite anxiety about the treatment procedure.

Finally, key informants commented that improved patient education regarding DM and DR, as well as increased health promotive services, could reduce patient's non-compliance with DR care. Poor socio-economic conditions were also identified as barriers to effective DM and DR care.

The next chapter will discuss these findings, taking the literature review into consideration.

CHAPTER 5: DISCUSSION

5.1 Chapter Overview

This study sought to explore patient-, institution-, treatment-, and COVID-19-related factors associated with compliance behaviour among patients living with diabetes in the NTSS of CT, SA. Non-compliance to the recommended annual retinal screening could lead to a missed diagnosis of DR. Untreated DR, or non-compliance with the prescribed treatment programme could lead to permanent vision loss (Duan *et al.*, 2017).

This chapter concentrates on the major findings of this study relating to factors influencing compliance behaviour. The findings are discussed in comparison with the findings from the literature view. Furthermore, key informant findings are used to either corroborate or contrast participant findings. The following participant themes are discussed, and the discussions are corroborated with the key informant responses and relevant, up-to-date literature:

- Knowledge about the aetiology and treatment of DM and DR and the need for information
- Personal and sociodemographic factors that influenced compliance behaviour
- Perceptions about the quality of health care provided at the tertiary and day hospitals
- Perceptions of and experiences with care since the start of the COVID-19 pandemic

5.2 Knowledge about the aetiology and treatment of diabetes mellitus and diabetic retinopathy and the need for information

In the current study we found that, overall, 100% of the participants had disadvantaged backgrounds and depended on the public health sector for treatment. However, it was encouraging to learn that they were privy to the information that diabetes could to some extent negatively affect their ocular health and/or vision. For instance, key informant 1 attested to this by saying that: "*…and I would think that most diabetics know now, that diabetes is a risk to their sight"* (K1). The high rate of awareness is further corroborated by two other South African studies. One study was done among female diabetic individuals in Khayelitsha, WCP, by Mkhombe (2015), and the other was done in Gauteng Province by Molapo (2011). The outcomes of these studies were that,79.20% of participants were aware that DM could lead to blindness (Mkhombe, 2015) and 96% of the diabetic participants were aware that diabetes could affect their eyes (Molapo, 2011). Despite these positive outcomes, a large majority (92.3%) of participants in this study were not aware of how DR manifests and could offer no specific definition on the mechanism between the onset of DM and the progression to DR. These outcomes were also confirmed by the key informants included in the current study, key informant 2 provided the following: *"No, the majority, from my experience is not, they are not well-informed"*.

When participants in the current study were asked about the DM-related information received from their day hospital, they often spoke about being advised about what to eat, with almost no information given on eye health. Similar outcomes had been presented by Mendenhall and Norris (2015), in their study to investigate the care received by women living with diabetes in Soweto, SA. In this study, the authors presented that the participants often received advice related to their diet, but very few were advised to exercise. In this study, it was also highlighted that this lack of information affected the DM literacy of the participants, such that they ended up having a poor understanding of DM itself and how to control it. Mash (2010) on the other hand previously noted these findings in primary care settings, particularly in the public health sector. This author highlighted that in the public health sector time constraints limit primary health providers to only briefly give advice and rewrite or amend prescriptions, with no extra time left to impart information about the disease presentation and/or progression (Mash, 2010).

Similar outcomes have been found in the current study when key informants were probed about the kind of information the patients are given by the health service providers. One of these professionals mentioned that he sometimes hears the health promoters touching on this topic "*… passingly said it can affect your eyes…"*. Moreover, the key informants indicated that the information that is imparted to the patients within the RSP is personalised based on the severity of the patient's condition and the patient's interest in the topic: *"…It depends patient by patient, but not all I am able to do as much as I would like to do [sic]"* (K2).

Some participants noted that they sometimes probe the health practitioners about their condition, especially those participants that have relatives who might not have enough knowledge about the disease and thus educate them about DM and its consequences. The key informants further talked about the issue of time, suggesting that they sometimes give their patients information depending on whether there is the time since most of their time is dedicated to treating the patients' presenting problems.

Another important outcome to the current study suggests a lack of knowledge that people living with diabetes require annual retinal screening. Only less than a fifth (15.38%) of the participants were aware that they needed to be screened for DR. Correspondingly, the key informants acknowledged that many patients are unaware of the central reason for attending retinal screenings and are under the impression that it is mainly done to receive new spectacles: "*They just think they get the specs then they realise they are there for retinal screening*". Similar findings have been presented in the studies of Chou *et al. (*2014), Chen et al. (2018), Chua *et al*. (2018), Duan *et al*. (2017), and Mtuya *et al*. (2016).

Kempen *et al.* (2017) also found a lack of knowledge regarding the requirement of an annual retinal exam to be insufficient. Also suggesting that only 41.4% of South Africans living with diabetes were informed about the requirement of periodic retinal screenings. Cook (2013) further highlighted that there is a lack of information among South Africans living with diabetes on why annual retinal screenings are required. This author further alluded that this often leads to patients only seeking care once visual symptoms present, at quite an advanced stage of DR, leading to a result of poor prognosis for these patients (Cook, 2013). However, it is important to note that only informing persons living with diabetes that they require an annual eye exam does not suffice.

For instance, Clarke-Farr, Nel and Wilkinson (2006) found that even though 96% of participants who had diabetes in a CT-based study knew that having regular eye examinations was important, only 30% went for annual retinal screenings. These authors attributed this to the poor understanding of the need for retinal screenings among DM patients, along with the insufficient mechanism of DR progression knowledge (Clarke-Farr, Nel and Wilkinson, 2006). Both Chua *et al*. (2018) and Bakkar, Haddad and Gammoh (2017) presented similar findings and attributed these findings, respectively, to participants believing retinal screenings are only required when visual symptoms present; and a lack of DR knowledge. These findings emphasise the need for health professionals to not only inform DM patients that they require an annual retinal screening but also explain why it is required even when visual symptoms are not present.

A low level of DR knowledge and poor understanding of the ocular complications of DM among participants in this study is consistent with international, national and regional literature (Chua *et al.*, 2018; Duan *et al.*, 2017; Hartnett *et al.*, 2005; Paksin-Hall *et al.*, 2013; Kempen *et al.*, 2017; Clarke-Farr, Nel and Wilkinson, 2006). Poor understanding of DR and ensuing ocular complications has previously been identified as an important barrier to DR treatment compliance as well as regular retinal screenings (Chou *et al.*, 2014; Chen et al., 2018; Chua *et al*., 2018; Duan *et al*., 2017; Mtuya *et al*., 2016). Patient education remains an important factor where compliance behaviour is concerned, and without adequate knowledge, patients will not be empowered to effectively self-manage or modify their DR risk factors (Cook, 2013).

To compensate for the lack of information, some participants in the current study made use of other sources of information that are outside of their health services. Among the sources mentioned are health professional family members, magazines, and *Facebook* groups. Mash (2010) and Mendenhall and Norris (2015) studies corroborate these findings in that, they suggested that community and patient health literacy remain the major barriers to the management of diabetes, especially among the lower-socioeconomic communities.

5.3 Personal and sociodemographic factors that influenced compliance behaviour

The current study has outlined 2 other important barriers to adequate DM control. The first one relating to financial constraints that result in difficulty with procuring a healthy diet, especially in less advantaged areas; as one participant duly stated: *"And sometimes, look we aren't rich, you can't select what you eat. Now because you have to take your diabetes medication you have to eat what you have in the house"* (P11). High and fluctuating glucose levels are a modifiable risk factor for DR. This barrier has been found to hinder the successful control of glucose levels by people living with diabetes. This barrier has not only been identified in global studies but nationally as well (Beaglehole and Yach, 2003; Stern, Puoane and Tsolekile, 2010).

The second barrier includes the perception that diabetes medication disrupts your daily life and could even worsen your state of health rather than improving it. In a global study, Nicolucci *et al.* (2013) have found that roughly 40% of participants who had diabetes felt that diabetes medication disrupts their lives, an outcome that corroborated our findings, which means that diabetic control is an important factor relating to DR (Chen *et al.*, 2018).

Concerns for ocular health and vision were important reasons for DR care compliance given by participants in the current study. Fear of going blind was the most important factor that positively influenced DR treatment compliance. Van Eijk *et al.* (2011) also found similar outcomes that fear of eyesight loss could have a positive effect on compliance, particularly when patients are aware that diabetes could lead to vision loss. Statements by key informant 1 further corroborate this finding: *"Okay, so what would make them want to go […] is obviously, they would not want their eyesight to deteriorate and they would not want to lose vision.*

Previous studies have also found that the apprehension of the retinal screening process and the fear of laser-treatments lead to non-compliance (Hua *et al.*, 2017; Mtuya *et al.*, 2016; Lewis *et al.*, 2007; Kashim, Newton and Ojo, 2018). Our results are in total contrast to this outcome; although many participants mentioned that they were anxious about attending the DR treatments, particularly the first scheduled treatment when they were unsure of what to expect. Despite key informant 1 believing this to be a reason for non-compliance among patients (“*Because they probably get a bit scared”),* the current study instead found that the fear of vision loss far outweighed the fear of the treatment, as the majority of participants attended their TBH eye clinic appointments regardless of expressing fear. Fear or apprehension of the treatment was not mentioned by any non-compliant participants. We learned that two participants in the current study were even happy about their referral to the TBH eye clinic. This happiness was thought to be motivated by the perceived difficulty in getting specialist care within the public health system. One of the participants stated that: “*Their appointment book stays full […] That’s why I was so happy when they referred me to Tygerberg”* (P11).

Relevant literature also suggested that the discomfort of certain required procedures, such as a dilated pupil or certain forms of laser, negatively affects eye care attendance (Lewis *et al.*, 2007; Kashim, Newton and Ojo, 2018; Strutton *et al.*, 2016; Chua *et al.*, 2018). Once again our findings did not corroborate this, as no participants mentioned this as a reason for non-compliance. Although some of the participants mentioned some level of discomfort after pupil dilation and during laser-treatment, this was not enough to cause non-compliance and participants were still satisfied with the procedures overall, as corroborated by key informant 1: “*…then they come back quite happy…”.*

Poor state of health in the current study was found to be among the important barriers to DR treatment compliance, despite severe vision loss. In this case, the cause of poor health was a multitude of factors including old age, the onset of dementia, uncontrolled diabetes and a previous cerebrovascular accident (stroke), thus the family speculated that the octogenarian would not be able to endure treatment at that time which led to non-compliance. This is similar to the findings of both Moreton *et al.* (2017) and Kreft *et al.* (2018) who suggested that the decline in DR care compliance at more advanced ages could be due to the increased chances of mobility issues, comorbidities, and disabilities.

Another determinant of compliance behaviour relating to participant health was non-ocular diabetes-related complications. A precarious foot ulcer that rendered a participant practically bed-ridden, required multiple hospital stays and surgery over a year. This led to non-compliance with DR care. This finding is corroborated by Chen *et al.* (2018) who found that patients with severe problems with feet or kidneys due to systemic diabetes were less likely to be compliant with DR treatment appointments. Both Chen *et al.* (2018) and Lewis (2015) suggested that the non-compliance could be due to a multitude of non-ocular diabetic appointments holding participants up, especially when vision has not yet been affected. Chen *et al.* (2018) also suggested that patients whose diabetes has progressed to end-organ damage are generally non-compliant to medical advice. We have found both reasons to be applicable in the current study. One of the participants had lost mobility due to his ulcerative foot and required multiple hospital visits. This specific participant was not compliant with DM medication and rejected the day hospital's findings regarding his condition.

Khan *et al.* (2012, Mtuya *et al.* (2016), Chua *et al.* (2018), Kashim, Newton and Ojo (2018) and Strutton *et al.* (2016) have found a strong link between forgetfulness and non-compliance among patients with diabetes, with DR screenings and treatment. The current findings corroborate this, as one participant stated that not knowing when her TBH eye clinic appointments were, led to non-compliance with her scheduled DR treatment.

In the current study, transport was not mentioned as a reason for non-compliance, and it was thus not found to be a significant barrier to DR care compliance among our participants. This is interesting, as multiple global and African studies contradicted this outcome. Chua *et al.* (2018), Lewis *et al.* (2007) and Mtuya *et al.* (2016) for instance found the cost of transport to be an important barrier to DR care compliance, especially in less affluent and rural settings; whereas Chou *et al.* (2014) and Khan *et al.* (2012) found a lack of transport as a barrier to DR care compliance. Although Hua *et al.* (2017) also found transport to be an insignificant barrier, their study was conducted in an affluent, urban Chinese setting where transport is not always an issue. We assume that the urban setting of our study led to this particular outcome (Gray and Vawda, 2018). Most of the study participants reported that they lived close to the health service centres where they regularly received treatment. Moreover, the heavy reliance on family, friends, and community members with private vehicles and drivers' licences who were always willing to take them for appointments. More than half of the participants reached the TBH eye clinic by relying on someone with a vehicle. Having a trusted person drive you home is usually advised by ophthalmologists when going for DR treatment as many of the procedures cause temporary blurred vision, which could explain the prevalence of this phenomenon (Kanski and Bowling, 2011). About a third of the participants used public transport to reach

TBH, which is in line with a national survey indicating that nearly 40% of workers in urban areas make use of public transport (StatsSA, 2014). Although financial problems could arise when requiring the use of public transport, key informant 2 pointed out that when referring patients for urgent care, the RSP would try to accommodate them with a suitable date: "*So, if the person tells us that on the date that we want to give them they will not have money, then we will not give them that date, so that we […] try to […] remove any obstacles in the way of compliance*". Less than one-fifth of participants indicated that they drove themselves to and from TBH. However, driving oneself home after DR treatment is usually warned against by ophthalmologists before the treatment date due to the blurred vision after procedures.

The most significant transport-related issue found was blurry vision after DR treatment procedures, which according to the results, negatively impacted participants who had to drive themselves or participants who made use of taxis unaccompanied. Although participants in the current study weren't deterred from going by a lack of a driving or travelling companion, this could affect compliance behaviour negatively. Mtuya *et al.* (2016) for instance, found that 9% of elderly participants were non-compliant to DR care due to the unavailability of a travelling companion as well as the cost of travel that an extra person would induce. These findings emphasise the importance of social support and understanding within our target population to minimise the potential barriers to compliance, as pointed out by key informant 2.

Along with the physical support participants received from family, friends, and community members with regards to transport, many participants who opted to open up about their health condition also received emotional support from family and friends which had positive influences on compliance. Social and financial support had been shown to positively affect compliance behaviour regarding DR treatment (Hua et al., 2017; Lewis, 2007; Mtuya *et al*., 2016; Duan *et al.,* 2017). Particularly, a study conducted in the WCP found that positive support from family and friends increased the chances of compliance among people receiving medical treatments (Finlay *et al.,* 2012). Key informant 2 has also encountered this: *"There are some who, who have the support structure and those are the ones who never have problems in general. But the majority is people who don't have a support structure and as a result don't comply".*

The current research likewise identified how social support could negatively affect DR compliance, as with participant 4 whose spouse was sceptical about DR treatment at TBH. His spouse was concerned about his health and urged him not to attend laser treatment at the TBH eye clinic as she had heard rumours about negative outcomes. Experiences by key informant 1 support this finding: "*But then you do get those that don't want to go because they hear stories from other people […] maybe other people told them that they went and now they see worse than they did before"*. This emphasises the importance of DM and DR education not only for individuals who are living with diabetes but also for their family members. Although Duan *et al.* (2017) noted how social support could negatively affect DM and DR compliance, this negative result was as a result of excessive care by family members which induced psychological burden.

A lack of familial support could have negative implications for both DM and DR compliance (Duan *et al.*, 2017). Participant 5, a senior female who had already undergone bilateral leg amputations, alluding to poor DM control, stated she did not think she should share the news about her condition with her children, indicating a possible correlation between DM compliance and familial support. Key informant 2 also noted that unsupportive social and familial situations could lead to DM and DR treatment non-compliance: *there's non-compliance and issues with health, but the problem is not with the health, the problem is the social situation that the person cannot control... that leads to the health problems there"* (K2). Duan *et al.* (2017) noted that with aging populations, a 'lonely elderly family' structure often develops, in which children are working and living some distance away and parents. The parents often do not wish to bother their children or become burdens.

Permanent employment has been found to influence medical appointment compliance both positively and negatively in WCP (Kendall *et al.*, 2013; Finlay *et al.*, 2012; Dudley *et al.*, 2018). Generally, non-compliance with medical care in the case of employed patients is related to time-constrains and difficulty in taking time off from work (Dudley *et al.*, 2018). The current study results show that only one participant needed to take time off from work to attend DR treatment appointments at the TBH eye clinic, as most participants were unemployed or retired. This participant mentioned losing out on a day's wages. However, she said she did not even consider not complying as her health took priority. The low significance of employment as an influencing factor on DR care compliance could be explained by the low rates of employment among the study's participants, possibly influenced by the socio-economically disadvantaged situation of the target population as well as the relatively high average age of study participants.

5.4 Perceptions about the quality of health care provided at the tertiary and day hospitals

Almost half (46%) of the participants in the current study were unhappy with the quality of information offered at their primary health care facilities. They alluded to the fact that, when they get chances to see medical staff at these healthcare facilities, they only get their medication prescription rewritten and no information about the diseases and their progression is given. According to Lewis (2015) and Chua *et al.* (2018), patients could be deterred from attending DR care appointments if the facilities are perceived as not useful and inaccessible.

The data in the current study also revealed that perceptions regarding the care received for DM at day hospitals were slightly more negative than positive. A study done among the patients with diabetes attending day hospitals in the CTM in 2014 corroborated our findings (Ibanez-Gonzalez, Mendenhall and Norris, 2014). The outcomes of this study suggested that slightly more than half of the participants in that study received poor quality of care. Findings by Setswe *et al.* (2016) contradicted the current findings and the findings in Ibanez-Gonzalez, Mendenhall and Norris (2014) in that, they found almost 70% of South Africans to have positive perceptions about the public health sector, with this based on their personal experience. It is however important to note that Setswe *et al.* (2016) study was a national study while the current study was a localised study.

In the current study, staff attitudes, waiting times, and access to a doctor were among the factors that were highlighted to impact the health service imparted to the patients. The two key informants included in the current study also mentioned time constraints, and further talked about the patient attitude to some of the staff as barriers to imparting quality information at health services. Similarly, in a study done among Soweto women with diabetes in 2015, Mendenhall and Norris (2015) highlighted long waiting times and poor treatment to be the major barriers to service provision in the public health sector. Many of these barriers could be ascribed to up-stream determinants such as an overburdened public healthcare system, as well as unbearable working-conditions experienced by healthcare staff employed within the public system (Pillay, 2009; Lehmann, 2009).

Barriers to attending retinal screening services were also found in the current study. Although the recommendations were made in the National Guideline: Prevention of blindness in South Africa Report (National Department of Health, 2002) that all people living with diabetes should have an annual retinal screening, Cook (2013) mentions the lack of a national registry/database and recall system for diabetic retinopathy screenings. This is also evident in the health system of current retarget used by day hospitals and the NGO responsible for retinal screenings. Within the RSP, each day hospital is responsible for booking their patients, whether newly diagnosed diabetic persons or returning patients. Appointments are usually made at reception or with the diabetic club nurse. The bookings are often on a first come first served basis for patients or with a recommendation from the doctor. According to a primary healthcare worker within the RSP if all the spots are full, the patients do not receive bookings (D Witlow, 2020, personal communications, 16 October). Participant 8 of the current study mentioned this, where he said: *"...you go there, then they tell you it's full".* Some day hospitals in WCP, SA, have a waiting list system. This assures appointments for all patients, even if they have a waiting period. This was noted by participant 11 where she mentioned that: "*I probably waited more than 5 months before they did it".* Certain day hospitals use a more efficient system whereby diabetic club members get rebooked annually, but then people living with diabetes who do not attend the club will not get booked or even know about the service. It often happens that there are not enough retinal screening dates per day hospital to ensure that each person living with diabetes will have their annual screening (D Witlow, 2020, personal communications, 16 October). On average, 38-40 people get a booking per retinal team visit per day hospital; one retinal screening team visits all the day hospitals within the Northern/Tygerberg and Eastern/Khayelitsha substructures on a monthly to two-monthly basis (D Witlow, 2020, personal communications, 16 October). In other words, there simply aren't enough retinal screening dates to accommodate all diabetic persons within the serviced area. This often leads to patient non-compliance with DR care in this region.

Inefficient call-back systems and the lack of a national database, as per Cook (2013), could further decrease the rate of DR care compliance as noted by Lewis (2015) and Kashim, Newton and Ojo (2018). In the current study, one participant mentioned that he was aware of, and compliant with the required annual retinal screenings, albeit at an optometry practice within the private sector, as he receives electronic reminders on his phone. This improvement in DR care compliance as a result of a reminder system is corroborated by Chou *et al*. (2014), who also found that call-backs and reminders from medical professionals lead to increased eye care appointments by patients. This could be used as a way to combat non-compliance caused by a poor understanding of consequences, although it would be dependent on accurate contact information (Chou *et al*., 2014).

Perceptions of service provision within the RSP were also somewhat negative. Participants in the current study complained of long waiting times on the day, only to have a "rushed" encounter with the retinal screening team, devoid of personal care or adequate DR information.

Pillay (2009) and Lehmann (2009) alluded to similar barriers, ascribing them to an overburdened public healthcare system, as well as unbearable working-conditions experienced by the retinal screening team within the public system, as confirmed by key informant 2: "*And the working conditions are not conducive… to being able... to do the best. With time constraints and working conditions, and the rooms we get, the time we have with the people, just are not naturally conducive to testing… the way we would love to test…"*. One participant aptly stated "*…I thought they were just trying to get through all the patients as quickly as possible… I think, I think they probably could have spent just a little bit more time on each patient if there was a, if there was (sic) less patients on that day"*. The lack of adequate ophthalmic and specifically DR advice by medical professionals could lead to poor DR care compliance which includes attendance of retinal screenings as well as attendance of DR treatments (Hua *et al.,* 2017; Lewis, 2015; Kashim, Newton and Ojo, 2018; Strutton *et al.,* 2016; Kreft *et al.*, 2018; Van Eijk *et al.,* 2011; Khan *et al*., 2012; Khan *et al*., 2012). Whereas, negative and unpleasant medical staff attitudes, as well as increased waiting periods, could deter patients from attending DR care appointments (Finlay *et al.*, 2012; Lewis, 2015; Kashim, Newton and Ojo, 2018).

Two participants in the current study experienced poor referral management which effectively prohibited compliance with DR treatment. In one case, the participant's resolve to seek ocular care was diminished after the negative experience, which led to complete non-compliance with DR care thereafter. Poor referral management by health professionals and inefficient systems have also been found to increase DR non-compliance in other African and global studies (Lewis, 2015; Kraft *et al.*, 1997; Rosenberg, Friedman and Gurland, 2011; Onakpoya, Adeoye and Kolawole, 2010). Although key informant 2 was aware of call-back system concerns ("*…there's a culture of ignoring phone calls. A culture of not returning a phone call…")*, we can assume that the RSP is not aware of referral pathway-related problems experienced by patients: *"No […] we have basically ironed out any issues".* This further emphasises the need for a DR database to be implemented. Interestingly, a study by Mtuya *et al.* (2016) found that whether the participant understood the need for a referral did not significantly improve DR treatment compliance.

As opposed to the somewhat negative care perceived at the day hospitals and the retinal screenings, participants were overall satisfied with the care provided at TBH eye clinic (prior to the COVID-19 lockdown) despite waiting times and discomfort caused by certain procedures. Participants often described their treating ophthalmologist as 'nice', indicating positive demeanours. Participants also noted that the procedures and findings were explained to them. These factors could be what caused the differences in participant perceptions of the primary vs tertiary institutions.

5.5 Perceptions of and experiences with care since the start of the COVID-19 pandemic (participants and key informants)

Participant attitudes towards COVID-19 varied significantly, ranging from very concerned to not concerned. The concerns varied from participants being alert not to contract the virus. These participants were alarmed by the circulating anecdotal evidence that people living with diabetes, the elderly or those with poor health have an increased chance of contracting COVID-19 and of suffering from serious COVID-19-related consequences. One highly concerned participant also mentioned that she had family members who succumbed to the disease. Other participants seemed to be moderately concerned about contracting COVID-19. Two participants mentioned that if they were to get COVID-19, *"…it would be 'God's will…"*. These participants seemed cautious, but not overly concerned. Two participants explicitly stated that they were not concerned about contracting the disease. Interestingly, both of these participants were male. A lack of concern regarding medical problems among males was also mentioned by key informant 2: "*if they are male, the more they are likely to ignore or... or to not want to take it seriously"*. Lower health-participation rates, particularly among older males, have been noted in previous South African studies, such as Johnson *et al.* (2015), Moosa *et al.* (2019) and Barnighausen *et al.* (2014) which relate to HIV-testing and treatment. The varied concern among participants was corroborated by Reddy *et al.* (2020). Reddy *et al.* (2020) conducted an online survey among South Africans regarding COVID-19 knowledge and perceptions and found that 23.1% of participants in the WCP perceived themselves to be at high risk of contracting the virus, 39.5% perceived themselves to be at moderate risk, and 37.4% perceived themselves to be at low risk. In the Reddy *et al.* (2020) study, the participants' reasons for perceiving themselves to be at high risk of contracting COVID-19 included increased age and comorbidities.

As with participants' attitudes towards COVID-19, participants' resolve to make and attend eye-related appointments were also unevenly affected. Many participants, even those who felt they were at high or moderate risk of contracting COVID-19 and suffering severe consequences, said they were willing to attend TBH eye clinic appointments throughout the COVID-19 pandemic lockdown period. There were three forthcoming reasons for this: i) trust that TBH would take all necessary precautions, ii) faith in their own ability to follow precautionary measures and avoid contracting the virus, and iii) their fear of vision loss outweighing their fear of contracting COVID-19. However, not all participants felt comfortable with attending TBH amidst the pandemic and the fear of contracting COVID-19 did lead to non-compliance with DR treatment. One participant indicated she would only attend TBH if she was not required to stay over, as the strict safety measures did not allow any visitors into the hospital. As inferred by Kluge *et al.* (2020), pandemic-induced safety measures can affect health and treatment-seeking behaviour in people with non-communicable diseases such as diabetes.

The eight participants who were fully compliant with DR treatment at TBH all stated that their appointments had been cancelled or postponed until further notice by the TBH eye clinic, with no participant having received a new appointment date at the time of the interview. The cancellation of appointments due to the coronavirus pandemic was one of the most important barriers to DR treatment encountered in the current study. One participant elaborated about how worried he was about his eyes and how difficult it was to get an appointment with an eye specialist at TBH; he aptly stated: "*... I can understand that they are worried about the high-risk people, but I am worried about my eyes. Where do you draw the line?"* (P4). This sentiment was echoed by key informant 1: *"...I understand the thing about regulation but I also don't think that eye care should have taken a backseat because it's so vital. It's so necessary".*

The RSP services were also suspended during the lockdown and had not resumed at the time of data collection. Both primary healthcare providers mentioned the lack of options for frequenters of the public health system who required retinal screenings or any form of eye care apart from emergencies. Although both optometrists were upset about the potential for vision loss, they had differing views regarding the halting of the RSP and eye care services. Key informant 1 was concerned about the number of people who were not receiving retinal screenings: "*…there are so many people deprived of healthcare";* and judged eyecare to be an essential service as sight is vital to most people's lives: "*I really don't think eye care should be considered as a non-essential"*. Key informant 1 felt that the halting of services was something that had to be done for the patients' safety considering diabetic persons' increased risk of suffering more severe consequences. He perceived that the halting of eye care services was done to save lives: *"...in terms of what's more important, my uh vision or being alive [...] I value life higher than being able to see while alive, because of the real fact that diabetics who get, uh, COVID-19, are likely to end up in hospital and are likely to suffer... severely'.*

The suspension of services that are vital to ocular health and NCD management as a result of the coronavirus pandemic has occurred globally (Palmer *et al.*, 2020; Kluge *et al.*, 2020). The results indicate that perceived non-urgent appointments, along with preventive and promotive services, have been suspended. As noted by Palmer *et al.* (2020) and Kluge *et al.* (2020), this could have devastating effects on the long- and short-term management of diabetes and more specifically DR. A large backlog of patients requiring retinal screenings and DR treatment is sure to follow once services are resumed, presenting another barrier to DR care.

5.5 Study Limitations

Although the study has brought forward a variety of important findings, it is not without limitations. The RSP information about patients with RDR was limited to patients who attend retinal screenings at the day hospitals, which therefore resulted in the study missing out on a group of the population who display non-compliant behaviour and who might have valuable information. However, it is important to note that this could not have been avoided since it is near impossible to find patients living with diabetes who have RDR but are not attending retinal screenings. Thus, it was justifiable to have excluded this group of participants.

The participants were limited in terms of age as all participants were 19 years and older due to ethical concerns. Given that children living with diabetes could also present with DR, a portion of the population who might have valuable information were excluded.

As interviews were done telephonically, the researcher could not pick up on non-verbal communication made by participants, such as facial expression and body language. This type of data is viewed as important for qualitative research (Robson and McCartan, 2016). The researcher was also unable to detect facial expressions indicating confusion, meaning participants might not have clearly understood some of the questions that were asked. The researcher did however take care to repeat questions when participants sounded unsure.

Although the researcher could ensure a quiet and private area within which to conduct telephone interviews, noise disturbances were experienced from the participants' side during some of the interviews which rendered some words inaudible. Despite the participants being encouraged to sit in a secure and private place during the interview, this could not be ensured, which could have led to participants not feeling comfortable to disclose certain information. However, judging from the satisfactory information obtained from this research, it seems as though the level of discomfort experienced by such participants was not too much to impact the responses given.

Finally, due to the qualitative nature of the study, the unique setting and study population, as well as the small sample size, the generalisability of findings were deemed to be limited to the setting and population from which the participants were sampled. It must also be noted that this study did not specifically seek to quantify the level of knowledge diabetic participants have regarding DR. A more specific inquiry is needed and could perhaps lead to different outcomes.

CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

This chapter presents the conclusions drawn from the research as well as recommendations to facilitate an environment conducive to positive DR care compliance among diabetic patients making use of public healthcare in the NTSS.

6.1 Conclusion

The focus of our study was to explore patient-, institution-, treatment-, and COVID-19-related factors associated with compliance behaviour among diabetic patients referred for vision-threatening DR within the NTSS. All of the study objectives have been met. For instance, the outcomes showed that 30.77% and 7.69% of participants were non-compliant and partially compliant to DR treatment, respectively. The study identified a range of patient-related factors negatively impacting compliance behaviour within the target setting, such as a poor state of health and forgetfulness. Furthermore, important motivating factors such as the fear of going blind were identified. It was also found that despite all participants being aware that DM could lead to vision loss, almost none of the participants could describe DR accurately. Our study also highlighted that not all international literature applied to this study setting in that a lack of transport and fear of treatment procedures were not found to be an important barrier to participant compliance, further justifying the need for the current research topic.

Institution-related barriers to DR included poor referral management and perceived poor service and information provision at primary healthcare facilities. Yet, it was found that participants were overall satisfied with treatment and information received at the tertiary healthcare facility, despite long waiting times and somewhat uncomfortable procedures.

Lastly, the COVID-19 pandemic was found to have caused a suspension in RSP and DR treatment services and despite concerns of contracting the virus among participants, most said they would still have attended eye treatment during the lockdown had it been an option. The suspension of services resulted in patients living with diabetes within the NTSS having no way of accessing retinal screening services or attaining treatment for vision-threatening DR. Whereas some healthcare workers felt that eyecare should not have been classified as non-essential due to the importance of sight, others saw this as a necessity to limit the loss of lives.

6.2 **Recommendations**

The efficacy of diabetes education programmes in primary health settings has been demonstrated by Lian *et al.* (2017). The authors found that an educational empowerment programme led to improved glucose control, decreased the incidence of DM complications, and decreased incidence of mortality among patients living with diabetes. Although a ‘diabetic workshop’ programme was identified during the research (the ‘workshops’ are based on the piloted sessions as described in Mash *et al.* [2012]), the outcomes suggest that it has not been evenly implemented throughout the entire NTSS primary healthcare network; many participants were not aware of this education programme. According to Mash *et al.* (2012), the sessions should be carried out with small groups (10-15 people), should be interactive, and should be accessible to all patients living with diabetes who are attending primary healthcare facilities. We recommend that specific, measurable, achievable, realistic and time-bound (SMART) objectives be set to monitor and evaluate the outcomes appropriately (Ogbeiwi, 2017).

Outcomes by Clarke-Farr, Nel and Wilkinson (2006) suggested that only informing patients living with diabetes that they require annual retinal screenings is not enough. The authors implied that patients who do not experience vision loss might not attend annual screenings. As suggested by the key informants working in this sector, it then becomes important to also periodically inform patients why retinal screenings are required. Seeing as diabetic retinopathy is a complex microvascular condition (Kanski and Bowling, 2011), and patients in this setting require interactive counselling (Mash, 2010), we recommend periodic training and educational sessions for all trained primary healthcare workers responsible for NCD management.

Health promoters are also responsible in part for patient education. As noted by key informants, a hands-on health promoter who is also community-based i.e., goes to old-age homes and collaborates with community stakeholders, improves the compliance rates within their designated primary healthcare facility. Although their content and communication style were sometimes questioned by key informants, the importance of health promoters remain. As advised by key informants, we recommend that an increased number of community-based health promoters be employed as well as that specialised training related to DR be provided to them (Ansari and Phillips, 2001).

A recent study by Tsolekile, Schneider and Puoane (2018) indicated that community health workers within the CTM have a poor overall knowledge of NCDs such as diabetes. We recommend continued training regarding diabetes care and education to enhance the auxiliary responsibilities of these primary healthcare workers in an overburdened healthcare system (Tsolekile, Schneider and Puoane, 2018).

According to findings by Chou *et al.* (2014), call-back systems and reminders from medical professionals lead to improved attendance of periodic retinal screenings, thereby improving identification rates of DR and reducing the burden of diabetes complications. We recommend that the RSP operating in the NTSS implement a call-back system as a way to combat non-compliance caused by a poor understanding of diabetes consequences, although it would be dependent on accurate contact information (Chou *et al*., 2014).

A large volume of work is expected from the RSP healthcare professionals in that they need to perform refractive, counselling, educational, and referral duties in sub-optimal working conditions. The findings of the current study indicate that the RSP has a backlog of up to 5 months at certain day hospitals. The findings also indicate that health professionals are not allotted enough time to effectively consult with patients, leading to perceived poor services. As suggested by key informant 2, to allow health professionals to spend more time with patients and increase retinal screening capacity, we recommend that more practitioners be employed to work within the RSP (Mubekapi, 2012). However, the feasibility of this solution would need to be assessed as it would require more financial resources from the NGO and increased coordination with day hospitals regarding working-space.

We recommend that the RSP and day hospitals collaborate with regards to the booking system (Hardy, Phillips and Lawrence, 2003). The outcomes of this study show that patients and health professionals alike are negatively impacted by increased patient waiting times. An optimal booking system, such as described by key informant 2 in which 10 patients are booked every hour, should ensure a shorter waiting time. Key informant 2 has also indicated that this implementation would be dependent on the efficiency of the day hospital, hence this implementation would first need to be piloted and assessed in various facilities for feasibility.

Anecdotal evidence by key informant 1 indicates that referral management may be improved by increased communication and collaboration between the RSP and TBH eye clinic. Communication in the form of brief, periodic treatment outcomes of patients that have been referred could be compiled by the THB eye clinic and sent to the RSP. This could then serve as a record of patients that were compliant and received the required treatment. Furthermore, this system could point out which participants have not received treatment and prompt the RSP to follow-up and manage. Collaboration between the two facilities to optimise the means of referral could thus improve compliance rates (Ansari and Phillips, 2001; Lewis *et al.*, 2007; Hardy, Phillips and Lawrence, 2003).

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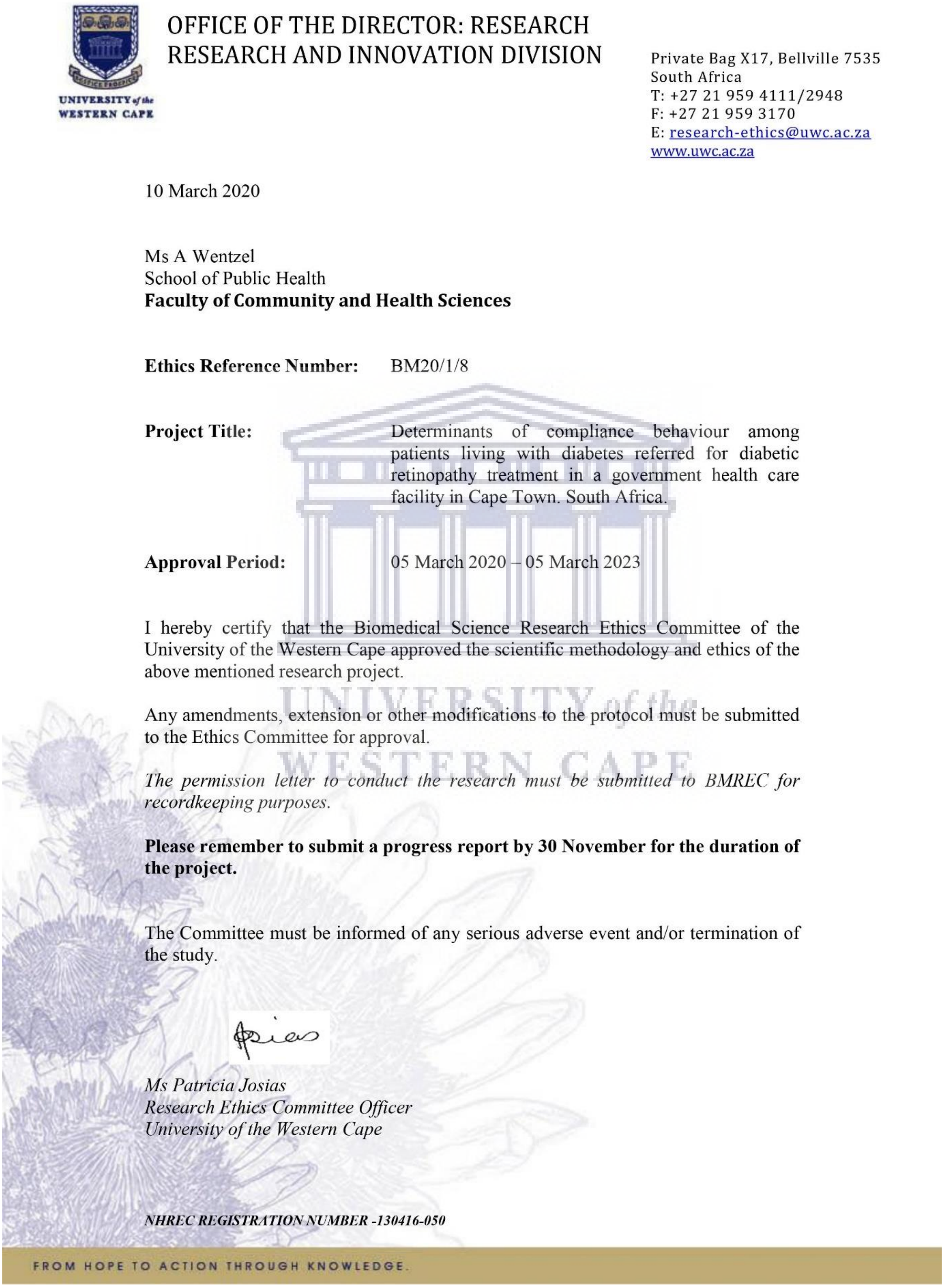
APPENDICES

Appendix A- Letters of Approval



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10 March 2020

Ms A Wentzel
School of Public Health
Faculty of Community and Health Sciences

Ethics Reference Number: BM20/1/8

Project Title: Determinants of compliance behaviour among patients living with diabetes referred for diabetic retinopathy treatment in a government health care facility in Cape Town. South Africa.

Approval Period: 05 March 2020 – 05 March 2023

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

The permission letter to conduct the research must be submitted to BMREC for recordkeeping purposes.

Please remember to submit a progress report by 30 November for the duration of the project.

The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

NHREC REGISTRATION NUMBER -130416-050

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02 October 2020

Ms A Wentzel
School of Public Health
Faculty of Community of Health Sciences

Ethics Reference Number: BM20/1/8

Project Title: Determinants of compliance behaviour among patients living with diabetes referred for diabetic retinopathy treatment in a government health care facility in Cape Town. South Africa.

Approval Period: 18 September 2020 – 18 September 2023

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report annually by 30 November for the duration of the project.

Permission to conduct the study must be submitted to BMREC for record-keeping.

The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

Director: Research Development
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REFERENCE: WC_202003_021
ENQUIRIES: Dr Sabela Petros

University of Western Cape
Robert Sobukwe Road
Bellville
Cape Town
7535

For attention: MS Annalie Wentzel

Re: Determinants of compliance behaviour among patients living with diabetes referred for diabetic retinopathy treatment at a government health care facility in Cape Town, South Africa.

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.

Please contact the following people to assist you with any further enquiries in accessing the following sites:

Bishop Lavis CDC	**Dr Mumtaz Abbas**	**021 927 1147**
Elsies River CHC	**Dr Muideen Bello**	**0 21 931 0211**

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
3. In the event where the research project goes beyond the *estimated completion* date which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
4. The reference number above should be quoted in all future correspondence.

Yours sincerely

DR M MOODLEY
DIRECTOR: HEALTH IMPACT ASSESSMENT
DATE: 28/08/2020

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REFERENCE: WC_202003_021
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University of Western Cape
Robert Sobukwe Road
Bellville
Cape Town
7535

For attention: MS Annalie Wentzel

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Please contact the following people to assist you with any further enquiries in accessing the following sites:

Delft CHC	**Dr Sheron Forgus**	**021 954 2237**
Parow CDC	**Ntombentle Mtshengu**	**021 444 0927**
Ruyterwacht CDC	**Liesel Rose**	**021 534 4361**

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
3. In the event where the research project goes beyond the *estimated completion* date which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
4. The reference number above should be quoted in all future correspondence.

Yours sincerely

DR M MOODLEY
DIRECTOR: HEALTH IMPACT ASSESSMENT
DATE: 1 October 2020

Western Cape Government
Health

STRATEGY & HEALTH SUPPORT
Health.Research@westerncape.gov.za
tel: +27 21 483 0866: fax: +27 21 483 6058
5th Floor, Norton Rose House,, 8 Riebeek Street, Cape Town, 8001
www.capegateway.gov.za)

REFERENCE: WC_202003_021
ENQUIRIES: Dr Sabela Petros

University of Western Cape
Robert Sobukwe Road
Bellville
Cape Town
7535

For attention: MS Annalie Wentzel

Re: Determinants of compliance behaviour among patients living with diabetes referred for diabetic retinopathy treatment at a government health care facility in Cape Town, South Africa.

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.
Please contact the following people to assist you with any further enquiries in accessing the following sites:

Reed Street CDC	**Murdock Home**	**021 946 2309**

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
3. In the event where the research project goes beyond the *estimated completion* date which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
4. The reference number above should be quoted in all future correspondence.

Yours sincerely

DR M MOODLEY
DIRECTOR: HEALTH IMPACT ASSESSMENT
DATE: 15/11/2020

16 March 2020

Permission Letter for Access to the Retinal Screening Programme Data

Research Project Title: Determinants of compliance behaviour in patients living with diabetes referred for diabetic retinopathy at a government health care facility in Cape Town, South Africa.

Dear Annalie Wentzel,

We hereby grant you access to our information pertaining to patients who have been referred for diabetic retinopathy in the Northern/Tygerberg sub-district by Carevision on the following conditions:

- Your research project has been approved by your university's governing ethics body
- The National Health Research Department or Provincial Health Research Department has approved your research project

Kind regards,

Ryan Sampson,

Manager

Carevision

ryan@carevision.co.za

CAREVISION
TEL / FAX: (021) 917 1841 | EMAIL: INFO@CAREVISION.CO.ZA
ADDRESS: KARL BREMER HOSPITAL, BUILDING M2, CNR OF FRANS CONRADIE DRIVE & MIKE PIENAAR BOULEVARD,
BELLVILLE, 7530
WWW.CAREVISION.CO.ZA

Appendix B

10 March 2020

Application Letter for Support by the Retinal Screening Programme

Director of Carevision:

Carevision: M2 Building, Karl Bremer Hospital, Bellville 7500
schoemanbv@gmail.com

Tel: 021 917 1841

REQUEST FOR PERMISSION TO ACCESS INFORMATION OF PATIENTS WHO HAVE BEEN REFERRED FOR DIABETIC RETINOPATHY BY THE RETINAL SCREENING PROGRAMME RUNNING IN THE NORTHERN/TYGERBERG SUB-DISTRICT

Research Project Title: Determinants of compliance behaviour in patients living with diabetes referred for diabetic retinopathy at a government health care facility in Cape Town, South Africa.

Dear Mr Schoeman,

We are currently planning a study to explore the determinants of compliance behaviour among patients on DR treatment in the Northern/Tygerberg substructure. This study is being done for the purpose of a mini-thesis at the School of Public Health of the University of the Western Cape.

We wish to apply for permission access information regarding adult patients who have been referred for diabetic retinopathy treatment via the Retinal Screening Programme in the Northern/Tygerberg Sub-structure.

This information will help inform strategic interventions to reduce the non-compliance among diabetic patients receiving treatment for diabetic retinopathy in the Cape Town Metropole area.

Attached is a copy of the full research proposal, as well as copies of the information sheet, consent form and interview guides. Upon completion of the study, we will provide your office with a copy of any research outputs that this project might result in.

If you require any further information, please do not hesitate to contact me on 0721040891 or

3814491@myuwc.ac.za. Thank you for your time and consideration in this matter.

I look forward to your favourable consideration.

Yours sincerely,

Annalie Wentzel

School of Public Health

University of the Western Cape

Email: 3814491@myuwc.ac.za

Tel: 0721040891

This research has been approved by the University of the Western Cape’s Biomedical Research Ethics Committee.

REFERENCE NUMBER: **BM20/1/8**

Biomedical Research Ethics Committee

University of the Western Cape

Private Bag X17

Bellville

7535

Tel: 021 959 4111

e-mail: research-ethics@uwc.ac.za

Appendix C

Information Sheet: Participant

Title of research project: Determinants of compliance behaviour among patients living with diabetes referred for diabetic retinopathy treatment in a government health care facility in Cape Town, South Africa.

What is this study about?

This is a research project being conducted by Annalie Wentzel, for the purpose of a mini-thesis at the University of the Western Cape. The purpose of this research is to explore the factors related to the compliance of diabetic persons that have been referred for diabetic retinopathy treatment. You are invited to participate in this research because you are a diabetic person who has been referred for diabetic retinopathy treatment and it is believed that your perceptions and experiences will help shed light on what motivates or demotivates diabetic persons to attend treatment for diabetic retinopathy.

What will I be asked to do if I agree to participate?

If you agree to participate in the study, you will be asked to sign a consent form. If you have agreed to participate in the study you will be given copies of the participant information sheet and consent form. You will be asked to participate in a telephone interview with the researcher. The interview will take place at a time that is convenient for you. The interview should not exceed 45 minutes. The interview will be recorded using an audio-recorder. It will be a once-off interview and no further action will be required on your part. You will be asked questions regarding your diabetic retinopathy treatment, as well as about your experiences and opinions regarding barriers in attending treatment appointments.

Would my participation in the study be kept confidential?

The researcher undertakes to protect your identity and the nature of your contributions. To ensure anonymity, your name will not be recorded in the interview; instead, a code will be used to link your data with your identity. The researcher will be the only person with access to the identification codes. The consent forms will be kept in a secure location that only the researcher has access to. The audio recordings and typed interview notes will be kept on a password protected computer. If we write a report or article about this research project, your identity will be protected. In accordance with legal requirements and/or professional standards, I will disclose to the appropriate individuals and/or authorities information that comes to my attention concerning child abuse or neglect or potential harm to you or others. In this event, I will inform you that I have to break confidentiality to fulfil my legal responsibility to report to the designated authorities.

What are the risks of this research?

Potential risks for participating in this study include discomfort or anxiety when speaking about diabetic retinopathy treatment. Similarly, speaking about barriers that demotivate treatment attendance can induce discomfort and stress. All human interactions and talking about self or others carry some risks. The researcher will minimise such risks and act promptly to assist you if you experience any emotional or physical distress during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

Contact details for referral resources:

Stikland Hospital:	0219404400
LOFOB:	0217053753
Helen Keller Society:	0215315311

Coronavirus hotline 0800029999

What are the benefits of this research?

The study might not help you personally; however, the findings may help the researcher learn more about the perspectives and experiences related to diabetic retinopathy treatment, as well as barriers experienced regarding the attendance of treatment appointments. It is hoped that people will benefit from the study through improved understanding of the needs of diabetic persons requiring treatment for diabetic retinopathy.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to participate. If you have agreed to participate, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalised or lose any benefits to which you otherwise qualify.

What if I have questions?

This research is being conducted by Annalie Wentzel through the School of Public Health at the University of the Western Cape. If you have any questions about the research study itself, please contact Annalie Wentzel at:

Tel: 072 104 0891

E-mail: 3814491@myuwc.ac.za

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Prof. Uta Lehmann

Director

School of Public Health

University of the Western Cape

Private Bag X17

Bellville 7535

ulehmann@uwc.ac.za

Prof Anthea Rhoda

Dean of the Faculty of Community and Health Sciences

University of the Western Cape

Private Bag X17

Bellville 7535

arhoda@uwc.ac.za

This research has been approved by the University of the Western Cape's Biomedical Research Ethics Committee.

REFERENCE NUMBER: **BM20/1/8**

Biomedical Research Ethics Committee

University of the Western Cape

Private Bag X17

Bellville

7535

Tel: 021 959 4111

e-mail: research-ethics@uwc.ac.za

Appendix D

Information Sheet: Key Informant

Title of research project: Determinants of compliance behaviour among patients living with diabetes referred for diabetic retinopathy treatment in a government health care facility in Cape Town, South Africa.

What is this study about?

This is a research project being conducted by Annalie Wentzel, for the purpose of a mini-thesis at the University of the Western Cape. The purpose of this research is to explore the factors related to the compliance of diabetic persons that have been referred for diabetic retinopathy treatment. You are invited to participate in this research because you are an optometrist working with and referring diabetic patients for diabetic retinopathy treatment in the Cape Town Metropole area. It is believed that your perceptions and experiences will help shed light on what motivates or demotivates diabetic persons to attend treatment for diabetic retinopathy.

What will I be asked to do if I agree to participate?

If you agree to participate in the study, you will be asked to sign a consent form or give written, electronic consent. If you have agreed to participate in the study you will be given copies of the participant information sheet and consent form. You will be asked to participate in a telephone interview with the researcher. The interview will take place at a time that is convenient for you. The interview should not exceed 45 minutes. The interview will be recorded. It will be a once-off interview and no further action will be required on your part. You will be asked questions regarding your diabetic retinopathy treatment, as well as about your experiences and opinions regarding barriers in attending treatment appointments.

Would my participation in the study be kept confidential?

The researcher undertakes to protect your identity and the nature of your contributions. To ensure anonymity, your name will not be recorded in the interview; instead a code will be used to link your data with your identity. The researcher will be the only person with access to the identification codes. The consent forms will be kept in a secure location that only the researcher has access to. The audio recordings and typed interview notes will be kept on a password protected computer.

If we write a report or article about this research project, your identity will be protected.

In accordance with legal requirements and/or professional standards, I will disclose to the appropriate individuals and/or authorities information that comes to my attention concerning child abuse or neglect or potential harm to you or others. In this event, I will inform you that I have to break confidentiality to fulfil my legal responsibility to report to the designated authorities.

What are the risks of this research?

Potential risks for participating in this study include discomfort or anxiety when speaking about diabetic retinopathy treatment. Similarly, speaking about barriers that demotivate treatment attendance can induce discomfort and stress. All human interactions and talking about self or others carry some risks. The researcher will minimise such risks and act promptly to assist you if you experience any emotional or physical distress during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

Contact details for referral resources:
Stikland Hospital: 0219404400

What are the benefits of this research?

The study might not help you personally; however, the findings may help the researcher learn more about the perspectives and experiences related to diabetic retinopathy treatment, as well as barriers experienced regarding the attendance of treatment appointments. It is hoped that people will benefit from the study through improved understanding of the needs of diabetic persons requiring treatment for diabetic retinopathy.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to participate. If you have agreed to participate, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalised or lose any benefits to which you otherwise qualify.

What if I have questions?

This research is being conducted by Annalie Wentzel through the School of Public Health at the University of the Western Cape. If you have any questions about the research study itself, please contact Annalie Wentzel at:

Tel: 072 104 0891

E-mail: 3814491@myuwc.ac.za

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Prof. Uta Lehmann
Director
School of Public Health
University of the Western Cape
Private Bag X17
Bellville 7535
ulehmann@uwc.ac.za

Prof Anthea Rhoda

Dean of the Faculty of Community and Health Sciences

University of the Western Cape

Private Bag X17

Bellville 7535

arhoda@uwc.ac.za

This research has been approved by the University of the Western Cape's Biomedical Research Ethics Committee.

REFERENCE NUMBER: **BM20/1/8**

Biomedical Research Ethics Committee

University of the Western Cape
Private Bag X17
Bellville
7535
Tel: 021 959 4111
e-mail: research-ethics@uwc.ac.za

Appendix E

Participant Consent Form

Title of research project: Determinants of compliance behaviour among patients living with diabetes referred for diabetic retinopathy treatment in a government health care facility in Cape Town, South Africa.

The study has been described to me in a language that I understand. My questions about the

study have been answered. I understand what my participation will involve and I agree to

participate of my own choice and free will. I understand that my identity will remain anonymous. I understand that I may withdraw from the study at any time without

giving a reason and without fear of negative consequences.

I agree to be recorded during my participation in this study: _____

I do not agree to be recorded during my participation in this study: _____

Participant's name …………………………

Participant's signature…………………………

Date …………………………

Biomedical Research Ethics Committee

University of the Western Cape

Private Bag X17

Bellville

7535

Tel: 021 959 4111

E-mail: research-ethics@uwc.ac.za

REFERENCE NUMBER: **BM20/1/8**

Appendix F

Key Informant Consent Form

Title of research project: Determinants of compliance behaviour among patients living with diabetes referred for diabetic retinopathy treatment in a government health care facility in Cape Town, South Africa.

The study has been described to me in a language that I understand. My questions about the

study have been answered. I understand what my participation will involve and I agree to

participate of my own choice and free will. I understand that my identity will remain anonymous. I understand that I may withdraw from the study at any time without

giving a reason and without fear of negative consequences.

I agree to be recorded during my participation in this study: _____

I do not agree to be recorded during my participation in this study: _____

Participant's name ....

Participant's signature..............................

Date ....

Biomedical Research Ethics Committee

University of the Western Cape

Private Bag X17

Bellville

7535

Tel: 021 959 4111

E-mail: research-ethics@uwc.ac.za

REFERENCE NUMBER: **BM20/1/8**

Appendix G

Inligtingsblad: Deelnemer

Titel van navorsingsprojek: Bepalers van nakomingsgedrag in pasiënte met diabetes wat verwys was vir diabetiese retinopatie vanaf 'n gesondheidsorginstelling in Kaapstad, Suid-Afrika.

Waaroor gaan hierdie studie?

Dit is 'n navorsingsprojek wat deur Annalie Wentzel gedoen word vir ‘n skripsie by die Universiteit van die Wes-Kaap. Die doel van hierdie navorsing is om die faktore te ondersoek wat verband hou met die nakoming van diabetiese persone wat verwys word na diabetiese retinopatie-behandeling. U word uitgenooi om aan hierdie navorsing deel te neem omdat u 'n diabeet is wat verwys was na diabetiese retinopatie-behandeling. Daar word geglo dat u persepsies en ervarings sal help om lig te werp op wat motiveer of demotiveer diabetiese persone om behandeling vir diabetiese retinopatie by te woon.

Wat sal ek gevra word om te doen as ek instem om deel te neem?

As u instem om aan die studie deel te neem, sal u gevra word om 'n toestemmingsvorm te onderteken. As u ingestem het om aan die studie deel te neem, kry u afskrifte van die deelnemer-inligtingsblad en toestemmingsvorm. U sal gevra word om deel te neem aan 'n telefoniese onderhoud met die navorser. Die onderhoud sal plaasvind op 'n tyd wat u goedkeur. Die onderhoud behoort nie langer as 45 minute te duur nie. Die onderhoud sal met behulp van 'n klankopnemer opgeneem word. Dit sal 'n eenmalige onderhoud wees en u hoef nie verder op te tree nie. Jy sal gevra word vrae oor jou diabetiese retinopatie behandeling, asook oor jou ervarings en menings oor hindernisse in die bywoning van behandeling.

Sal my deelname aan die studie vertroulik gehou word?

Die navorser onderneem om u identiteit en die aard van u bydraes te beskerm. Om anonimiteit te verseker, sal u naam nie in die onderhoud opgeneem word nie; in plaas daarvan word 'n kode gebruik om u data met u identiteit te koppel. Die navorser sal die enigste persoon wees met toegang tot die identifikasiekodes. Die toestemmingsvorms sal op 'n veilige plek bewaar word waartoe slegs die navorser toegang het. Die klankopnames en getikte onderhoudsnotas sal op 'n rekenaar met 'n wagwoordbeskerming gehou word.

As ons 'n verslag of artikel oor hierdie navorsingsprojek skryf, sal u identiteit beskerm word.

In ooreenstemming met wetlike vereistes en / of professionele standaarde, sal ek informasie rakende kindermishandeling of verwaarlosing, of moontlike skade aan u of ander persone onder die aandag van die toepaslike individue en / of owerheidsinligting bring. In hierdie geval sal ek u daarvan inlig dat ek vertroulikheid moet verbreek om my wetlike verantwoordelikheid aan die owerhede na te kom.

Wat is die risiko's van hierdie navorsing?

Potensiële risiko's vir deelname aan hierdie studie sluit in ongemak of angs as daar gepraat word oor die behandeling van u diabetiese retinopatie . Net so kan ongemak en stress veroorsaak word as 'n mens praat oor hindernisse wat die bywoning van behandeling demotiveer,. Alle menslike interaksies en om oor jouself of ander te praat hou 'n mate van risiko's in. Die navorser sal sulke risiko's verminder en sal dadelik optree om u te help as u emosionele of fisieke probleme ervaar tydens die deelname aan hierdie studie. Waar nodig, sal 'n toepaslike professionele persoon verwys word vir verdere hulp of ingryping.

Kontak inligting vir verwysings:

Stikland Hospitaal:	0219404400
LOFOB:	0217053753
Helen Keller Society:	0215315311
Koronavirus hulp-lyn	0800029999

Wat is die voordele van hierdie navorsing?

U sal miskien nie persoonlike voordeel uit die studie trek nie; die bevindinge kan die navorser egter help om meer te wete te kom oor die perspektiewe en ervarings wat verband hou met diabetiese retinopatiese behandeling, sowel as hindernisse wat met die behandeling van afsprake ervaar word. Daar word gehoop dat mense voordeel sal trek uit die studie deur 'n beter begrip van die behoeftes van diabetiese persone wat behandeling vir diabetiese retinopatie benodig.

Moet ek aan hierdie navorsing deelneem en mag ek op enige tyd ophou deelneem?

U deelname aan hierdie navorsing is heeltemal vrywillig. U kan kies om nie deel te neem nie. As u besluit om deel te neem, kan u op enige tyd ophou deelneem. As u besluit om nie aan hierdie studie deel te neem nie, of as u kies om op te hou met deelname, sal u nie gepenaliseer word of enige voordele waarop u anders kwalifiseer het verloor nie.

Wat gebeur as ek vrae het?

Hierdie navorsing word deur Annalie Wentzel deur die Skool van Openbare Gesondheid aan die Universiteit van die Wes-Kaap gedoen. As u enige vrae het oor die navorsingstudie, kontak Annalie Wentzel by:

Tel: 072 104 0891

E-pos: 3814491@myuwc.ac.za

As u enige vrae het rakende hierdie studie en u regte as navorsingsdeelnemer, of as u probleme wat u ondervind het rakende die studie wil rapporteer, kontak:

Prof. Uta Lehmann

Direkteur

School of Public Health

University of the Western Cape

Private Bag X17

Bellville 7535

ulehmann@uwc.ac.za

OF

Prof Anthea Rhoda

Dekaan van die Fakulteit Gemeenskaps- en Gesondheidswetenskappe

Universiteit van die Wes-Kaap

Privaatsak X17

Bellville 7535

arhoda@uwc.ac.za

Hierdie navorsing is goedgekeur deur die Universiteit van Wes-Kaapland se Biomediese Navorsingsetiekkomitee.

Verwysings nommer: **BM20/1/8**

Biomediese Navorsingsetiekkomitee

Universiteit van Wes-Kaapland

Privaatsak X17

Bellville

7535

Tel: 021 959 4111

e-pos: research-ethics@uwc.ac.za

Appendix H

Inligtingsblad: Belangrike informant

Titel van navorsingsprojek: Bepalers van nakomingsgedrag in pasiënte met diabetes wat verwys was vir diabetiese retinopatie vanaf 'n gesondheidsorginstelling in Kaapstad, Suid-Afrika.

Waaroor gaan hierdie studie?

Dit is 'n navorsingsprojek wat deur Annalie Wentzel gedoen word met die oog op 'n skripsie aan die Universiteit van die Wes-Kaap. Die doel van hierdie navorsing is om die faktore te ondersoek wat verband hou met die nakoming van diabetiese persone wat verwys word na diabetiese retinopatie-behandeling. U word uitgenooi om aan hierdie navorsing deel te neem omdat u 'n oogkundige is wat met diabeetpasiënte saamwerk en hulle verwys vir diabetiese retinopatie in die Kaapstadse metropool. Dit word geglo dat jou persepsies en ervarings sal help lig werp op wat motiveer of demotivates diabeet persone om behandeling vir diabetiese retinopatie by te woon.

Wat sal ek gevra word om te doen as ek instem om deel te neem?

As u instem om aan die studie deel te neem, sal u gevra word om 'n toestemmingsvorm te onderteken. As u ingestem het om aan die studie deel te neem, kry u afskrifte van die deelnemer-inligtingsblad en toestemmingsvorm. U sal gevra word om deel te neem aan 'n telefoniese onderhoud met die navorser. Die onderhoud sal plaasvind op 'n tyd wat u goedkeur. Die onderhoud behoort nie langer as 45 minute te duur nie. Die onderhoud sal met behulp van 'n klankopnemer opgeneem word. Dit sal 'n eenmalige onderhoud wees en u hoef nie verder op te tree nie. Jy sal gevra word vrae oor jou diabetiese retinopatie behandeling, asook oor jou ervarings en menings oor hindernisse in die bywoning van behandeling.

Sal my deelname aan die studie vertroulik gehou word?

Die navorser onderneem om u identiteit en die aard van u bydraes te beskerm. Om anonimiteit te verseker, sal u naam nie in die onderhoud opgeneem word nie; in plaas daarvan word 'n kode gebruik om u data met u identiteit te koppel. Die navorser sal die enigste persoon wees met toegang tot die identifikasiekodes. Die toestemmingsvorms sal op 'n veilige plek bewaar word waartoe slegs die navorser toegang het. Die klankopnames en getikte onderhoudsnotas sal op 'n rekenaar met 'n wagwoordbeskerming gehou word.

As ons 'n verslag of artikel oor hierdie navorsingsprojek skryf, sal u identiteit beskerm word.

In ooreenstemming met wetlike vereistes en / of professionele standaarde, sal ek informasie rakende kindermishandeling of verwaarlosing, of moontlike skade aan u of ander persone onder die aandag van die toepaslike individue en / of owerheidsinligting bring. In hierdie geval sal ek u daarvan inlig dat ek vertroulikheid moet verbreek om my wetlike verantwoordelikheid aan die owerhede na te kom.

Wat is die risiko's van hierdie navorsing?

Potensiële risiko's vir deelname aan hierdie studie sluit in ongemak of angs as daar gepraat word oor die behandeling van u diabetiese retinopatie . Net so kan ongemak en stress veroorsaak word as 'n mens praat oor hindernisse wat die bywoning van behandeling demotiveer,. Alle menslike interaksies en om oor jouself of ander te praat hou 'n mate van risiko's in. Die navorser sal sulke risiko's verminder en sal dadelik optree om u te help as u emosionele of fisieke probleme ervaar tydens die deelname aan hierdie studie. Waar nodig, sal 'n toepaslike professionele persoon verwys word vir verdere hulp of ingryping.

Kontak inligting vir verwysings:

Stikland Hospital: 0219404400

Wat is die voordele van hierdie navorsing?

U sal miskien nie persoonlike voordeel uit die studie trek nie; die bevindinge kan die navorser egter help om meer te wete te kom oor die perspektiewe en ervarings wat verband hou met diabetiese retinopatiese behandeling, sowel as hindernisse wat met die behandeling van afsprake ervaar word. Daar word gehoop dat mense voordeel sal trek uit die studie deur 'n beter begrip van die behoeftes van diabetiese persone wat behandeling vir diabetiese retinopatie benodig.

Moet ek aan hierdie navorsing deelneem en mag ek op enige tyd ophou deelneem?

U deelname aan hierdie navorsing is heeltemal vrywillig. U kan kies om nie deel te neem nie. As u besluit om deel te neem, kan u op enige tyd ophou deelneem. As u besluit om nie aan hierdie studie deel te neem nie, of as u kies om op te hou met deelname, sal u nie gepenaliseer word of enige voordele waarop u anders kwalifiseer het verloor nie.

Wat gebeur as ek vrae het?

Hierdie navorsing word deur Annalie Wentzel deur die Skool van Openbare Gesondheid aan die Universiteit van die Wes-Kaap gedoen. As u enige vrae het oor die navorsingstudie, kontak Annalie Wentzel by:

Tel: 072 104 0891

E-pos: 3814491@myuwc.ac.za

As u enige vrae het rakende hierdie studie en u regte as navorsingsdeelnemer, of as u probleme wat u ondervind het rakende die studie wil rapporteer, kontak:

Prof. Uta Lehmann

Direkteur

School of Public Health

University of the Western Cape

Private Bag X17

Bellville 7535

ulehmann@uwc.ac.za

OF

Prof Anthea Rhoda

Dekaan van die Fakulteit Gemeenskaps- en Gesondheidswetenskappe

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Privaatsak X17

Bellville 7535

arhoda@uwc.ac.za

Hierdie navorsing is goedgekeur deur die Universiteit van Wes-Kaapland se Biomediese Navorsingsetiekkomitee.

Verwysings nommer: **BM20/1/8**

Biomediese Navorsingsetiekkomitee

Universiteit van Wes-Kaapland

Privaatsak X17

Bellville

7535

Tel: 021 959 4111

e-pos: research-ethics@uwc.ac.za

Appendix I

DEELNEMER INSTEMMING VORM

Titel van navorsingsprojek: Bepalers van nakomingsgedrag in pasiënte met diabetes wat verwys was vir diabetiese retinopatie vanaf 'n gesondheidsorginstelling in Kaapstad, Suid-Afrika.

Die studie is vir my beskryf in 'n taal wat ek verstaan. My vrae oor die studie was beantwoord. Ek verstaan wat my deelname sal betrek en ek stem saam om deel te neem van my eie keuse en vrye wil. Ek verstaan dat my identiteit nie aan enigiemand bekend gemaak sal word nie. Ek verstaan dat ek kan besluit om nie meer deel te neem aan die studie te eniger tyd sonder om 'n rede en sonder vrees vir negatiewe gevolge of verlies van voordele vir my.

Deelnemer se naam ………………………….

Deelnemer se handtekening ………………………….

Datum ………………………….

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Verwysings Nommer: **BM20/1/8**

Appendix J

BELANGRIKE INFORMANT INSTEMMING VORM

Titel van navorsingsprojek: Bepalers van nakomingsgedrag in pasiënte met diabetes wat verwys was vir diabetiese retinopatie vanaf 'n gesondheidsorginstelling in Kaapstad, Suid-Afrika.

Die studie is vir my beskryf in 'n taal wat ek verstaan. My vrae oor die studie was beantwoord. Ek verstaan wat my deelname sal betrek en ek stem saam om deel te neem van my eie keuse en vrye wil. Ek verstaan dat my identiteit nie aan enigiemand bekend gemaak sal word nie. Ek verstaan dat ek kan besluit om nie meer deel te neem aan die studie te eniger tyd sonder om 'n rede en sonder vrees vir negatiewe gevolge of verlies van voordele vir my.

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Appendix K

Semi-structured interview guide: participants

1. Can you tell me about the day hospital that you visit for treatment and information (for diabetes)?
   Prompts
   - Is it easily accessible?
   - How do you feel about the services?
   - How do you feel about the staff?
   - How do you feel about the information they give you?
2. How long have been living with diabetes?
3. Can you tell me what you know about diabetes and eye health?
   Prompts
   - Can you elaborate?
   - Where did you get this information from?
   - What information has the day hospital provided regarding eyecare for diabetic patients?
   - Do you ever get your information from friends, family or the internet (google)?
4. Are you aware that you require an eye examination every year due to your diabetic condition?
5. Can you tell me what you were told about diabetic retinopathy treatment?
   Prompts
   - Who told you?
6. Is there anything related to diabetic retinopathy you wish medical staff explained better?
7. Did the person who referred you for treatment tell you what to expect when going for treatment?
8. Can you tell me about finding out that you have diabetic retinopathy?
   Prompts
   - Who informed you?
   - What did they say?
   - Can you explain how you felt?
   - Why?
9. Did you attend the eye treatment?
10. Was it easy for you to get to Tygerberg Hospital?
    - Did you have to rely on someone for transport?
    - Was the distance to travel or cost of travelling a problem?
11. Did you have to take time off of work?
12. Can you tell me about the experience you had when you went for diabetic retinopathy treatment?
    Prompts
    - Was the procedure comfortable or uncomfortable?
    - Did anyone explain to you what they were doing and why?
    - Would you go for another treatment if it was required?
13. Can you tell me about some times when you missed your treatment appointments?
14. What made it difficult for you to attend appointments?
    Prompts
    - What was going on in your life?
    - Did you tell friends and family about needing the treatment?

- Were your family and friends supportive?
- What were your experiences with Tygerberg Hospital and its staff members?

15. What were the main factors that motivated you to attend appointments?
16. Has it been easier or more difficult to get the required diabetic retinopathy treatment since the coronavirus lockdown?
    Prompts
    - Can you explain what process you went through?
17. Did you forgo eye appointments due to corona-virus concerns?
18. Has the coronavirus pandemic stopped you from seeking medical care for diabetic retinopathy?
    Prompts
    - In what way?
    - Are you worried about going to a hospital during this time?
    - Why are you worried?
    - Were your treatment or follow-up dates changed as a result of COVID-19 related problems?

Appendix L

Semi-structured interview guide: key informants

1. Please describe your role within the Retinal Screening Programme
   Prompts
   - Can you elaborate on your duties relating to the retinal screenings?
   - Are there more people in your team?
2. What information regarding diabetic retinopathy do you provide to diabetic patients during their retinal screening?
   Prompts:
   - Do the patients seem well informed regarding diabetic retinopathy?
   - Are you aware of any other medical professionals that inform them of diabetic retinopathy?
   - Do you think the day hospital provides enough information regarding diabetic retinopathy?
3. Do the other members of your team offer patients information regarding diabetic retinopathy?
   Prompts:
   - What information do they offer patients?
   - How is it different from the information you offer patients?
4. Do you know if the day hospital provides them with any info?
   - Do you think it would help if health promoters take on some of those education responsibilities?
5. What information regarding the **treatment** of diabetic retinopathy is provided to diabetic patients when they are referred?
   Prompts:
   - Are patients informed of the available treatments?
   - Are patients informed about what they can expect regarding treatment?
6. How do diabetic patients react when you inform them that they need to be referred for diabetic retinopathy and require treatment?
7. What support is provided by the Retinal Screening Programme/your NGO for patients who need treatment?
8. What are some of the challenges you have faced when referring participants for diabetic retinopathy treatment?
   Prompts
   - Were there challenges relating to the patient/ patient compliance?
   - Were the challenges related to the referral protocol with the tertiary/treating institution?
   - What were the challenges related to the diabetic retinopathy treatment facility or its staff members?
9. How would you address challenges brought up in the previous question?
10. Have any patients informed you that they have missed their scheduled treatment appointments?
    Prompts:
    - Did they give a reason?
    - What were the reasons?
    - To your knowledge, did they receive a new date for treatment?
    - Was it relatively easy for them to get another date?
11. What, in your opinion, are the main barriers to compliance among your patients?

12. How does the health care facility (day hospital AND Tertiary Hospital sides) help address these problems?
13. What steps/implementations/measures do you think can be taken by day hospitals or your NGO/retinal screening programme to reduce the non-compliance rates regarding DR treatment?
14. Has the coronavirus pandemic affected your ability to perform retinal screenings and refer patients for diabetic retinopathy treatment?
    Prompts
    - How has it affected your ability to perform at work?
    - How do you feel about this?
15. If you are unable to provide the retinal screening services during this time, are you aware of any other routes that patients within the public health system can take to access primary eyecare services and retinal screenings?
    Prompts
    - Can you describe the routes?
    - If there aren't any other routes, what do you think will happen with patients who urgently require diabetic retinopathy treatment?
    - Do you think urgent cases will receive timeous treatment?

Appendix M

Semi-gestruktureerde onderhoudsgids: deelnemers

1. Kan u my vertel van die daghospitaal waar u behandeling en inligting ontvang vir u diabetes?

aanwysings

- Is die daghospitaal maklik bereikbaar?
- Hoe voel u oor die dienste?
- Hoe voel u or die personeel?
- Hoe voel u oor die inligting wat hulle vir u gee?

2. Hoe lank is u al ‘n diabeet?

3. Kan u my vertel wat u weet van hoe diabetes die ooggesondheid beinvloed?

aanwysings

- Kan u uitbrei?
- Waar het u hierdie inligting ontvang? (wie het die inligting aan u oorgedra?)
- Watter inligting het die daghospitaal aan u verskaf rakende oogversorging vir diabetiese pasiënte?
- Kry u ooit u informasie by vriende, familie of die internet (google)?

3. Is u bewus dat diabete elke jaar ‘n retinale/oog toets behoort te kry?

4. Weet u dat u elke jaar 'n oogondersoek benodig as gevolg van u diabetiese toestand?

5. Wat weet u rakende die **behandeling** van die oogprobleme wat versoorsaak is deur diabetes?

aanwysings

- Wie het jou vertel?

5. Het die person wat jou verwys het vir oogbehandeling jou vertel wat jy kan verwag?

6. Dink u die mediese personeel behoort meer oor die ooggesondheid en diabetes verduidelik?

7. Het die persoon wat u vir behandeling verwys het, vir u gesê wat u kan verwag wanneer u vir behandeling gaan?

8. Kan u uitbrei oor hoe u gevoel het toe u vertel is dat u diabetiese retinopatie het?

aanwysings

- Wie het u ingelig?
- Wat het hulle gesê?
- Kan u verduidelik hoe u gevoel het?

- Hoekom?

9. Het u die oogbehandeling bygewoon?

10. Was die Tygerberg Hospitaal vir u maklik bereikbaar?

- Moes u iemand vra om u daarheen te neem?
- Was die reisafstand of die koste van die reis 'n probleem?

11. Moes u tyd by die werk afgevat het?

12. Kan u my vertel van die ervaring wat u gehad het toe u vir die oogbehandeling gegaan het?

aanwysings

- Was die prosedure gemaklik of ongemaklik?

- Het iemand aan u verduidelik wat hulle doen en waarom?

- Hoe het u die personeel ervaar? Was hulle vriendelik etc.

- Sal u vir verdere behandeling gaan as dit nodig is?

13. Kan u my vertel van die kere wat u die afsprake misgeloop het?

14. Wat het dit vir u moeilik gemaak om afsprake by te woon?

Aanwysing

- Wat het in jou lewe aangegaan toe jy afsprake gemis het?
- Het u vriende en familie vertel dat u die behandeling benodig?
- Was u familie en vriende ondersteunend?
- Wat was u ervarings met Tygerberg Hospitaal se oogkliniek en sy personeellede?

15. Wat het u gemotiveer maak om oogafsprake by te woon?

16. Was dit makliker of moeiliker om die nodige behandeling met diabetiese retinopatie te kry sedert die pandemie-maatreëls van die Coronavirus in werking getree het?

aanwysings

- Kan u verduidelik watter proses u deurgemaak het?

17. Het u oogafsprake gemis weens korona-virus?

18. Het die koronaviruspandemie u verhinder om mediese behandeling vir diabetiese retinopatie te soek?

aanwysings

- Op watter manier?

- Is u bekommerd om in hierdie tyd hospitaal toe te gaan?

- Waarom is u bekommerd?

- Is u behandelings- of opvolgdatums verander as gevolg van COVID-19 verwante probleme?

Appendix N

Semi-gestruktureerde onderhoudsgids - Belangrike informante

1. Beskryf u rol in die Retinal Screening Program

   Aanwysings
   - Kan u meer verduidelik oor u pligte rakende die retinale ondersoeke
   - Is daar ander mense in u span?

2. Watter inligting word rakende diabetiese retinopatie gegee aan pasiënte gedurende die oogondersoek?

   Aanwysings
   - Lyk die pasiënte goed ingelig rakende diabetiese retinopatie?
   - Is u bewus van enige ander mediese beroepslui wat hulle inlig oor diabetiese retinopatie?
   - Dink u die daghospitaal verskaf genoeg inligting rakende diabetiese retinopatie?

3. Bied die ander lede van u span pasiënte inligting rakende diabetiese retinopatie?

   Aanwysings:
   - Watter inligting bied hulle aan pasiënte?
   - Hoe verskil dit van die inligting wat u aan pasiënte bied?

4. Weet u of die daghospitaal inligting aan hulle verskaf?
   - Dink u dit sal help as gesondheidsbevorderaars sommige van die verantwoordelikhede / opvoedingsprogram aanvaar?

5. Watter inligting wat handel oor diabetiese retinopatie **behandeling** word aan diabetiese pasiënte gegee wanneer hulle verwys word?
   - Word pasiënte ingelig oor die beskikbare behandelings?
   - Word pasiënte ingelig oor wat hulle kan verwag?

6. Hoe reageer diabetiese pasiënte as u sê dat hulle na diabetiese retinopatie behandeling verwys moet word?

7. Hoeveel steun word deur die Retinal Screening Programme gebied vir pasiënte wat behandeling benodig?

8. Wat is 'n paar van die uitdagings wat u in die gesig gestaar het toe u pasiënte moes verwys vir diabetiese retinopatie behandeling?

   Aanwysing
   - Was daar uitdagings wat verband hou met die nakomingsgedrag van die pasiënt
   - Hou die uitdagings verband met die verwysingsprotokol na die tersiêre / behandelende instansie?
   - Wat was die uitdagings wat verband hou met die behandelingsinstansie vir diabetiese retinopatie of sy personeellede?

9. Hoe sou u hierdie uitdagings aanpak?

10. Het enige pasiënte u in kennis gestel dat hulle hul geskeduleerde behandelingsafsprake misgeloop het?

    Aanwysings
    - Het hulle ‘n rede gegee?
    - Wat was die redes?

    - Het hulle, volgens u wete, 'n nuwe datum vir behandeling ontvang?
    - Was dit relatief maklik vir hulle om 'n ander afspraak te kry?

11. Wat is volgens u die belangrikste hindernisse vir die nakoming van afpsrake vir u pasiënte?
12. Hoe help die gesondheidsorgfasiliteit (daghospitaal EN Tersiêre hospitaal) om hierdie probleme aan te spreek?
13. Watter stappe / implementerings / maatreëls dink u kan deur daghospitale of u NRO / retinale siftingsprogram geneem word om die nie-nakomingsyfers rakende DR-behandeling te verlaag?
14. Het die koronaviruspandemie u vermoë beïnvloed om retinale siftings uit te voer en pasiënte na diabetiese retinopatie behandeling te verwys?
    Aanwysings
    - Hoe het dit u vermoë om te presteer by die werk beïnvloed?
    - Hoe voel u hieroor?
15. Is u bewus van enige ander roetes wat pasiënte binne die openbare gesondheidsorgstelsel kan gebruik om toegang tot primêre oogversorgingsdienste en retinale siftings te verkry, as u nie in staat is om die retinasiftingsdienste gedurende hierdie tyd te lewer nie?
    Aanwysings
    - Kan u die roete beskryf?
    - As daar geen ander roetes is nie, wat dink u sal dan met gebeur met pasiënte wat dringend retinopatiese behandeling benodig?
    - Dink u dringende gevalle sal tydig behandel word?

Appendix O

Table 5: Themes and corresponding codes used for tagging participant data

Themes	**Codes and frequency**
1. Knowledge about the aetiology and treatment of DM and DR and the need for information	• Annual retinal screening awareness (9) • DR and eye info participants want (10) • DR info given at day hospitals (37) • Diabetes-related information given at day hospitals (36) • Eye test purpose as per participant (specs>retinal screening) (4) • Info from community members/non-treating medical professionals/internet (15) • Info given at retinal screening (18) • Info given at Tygerberg ophthalmology regarding DR (2) • Participant knowledge or explanation of DR and other related info (30) • Explanation for DR referral (7)
2. Personal and sociodemographic factors that influenced compliance behaviour	• Barriers to receiving DR treatment and care (Tygerberg and retinal screenings) (58) • DR treatment compliance (12) • General accessibility of day hospitals (3) • Financial problems relating to diabetes control (3) • Barriers to attending TBH in general (4) • How participants felt when told they have DR (11) • Motivations to comply with DR treatment and care (28) • Negative experiences with DR care (2) • Participant access to TBH (19) • Reasons for non-compliance to DR treatment (9) • State of vision and experiences with vision loss (12) • Diabetes control (25) • Familial support (21)

3. Perceptions about the quality of health care provided at the tertiary and day hospitals	• Experience at Tygerberg ophthalmologist (36) • Experiences at Tygerberg in general (7) • One on one at day hospitals to improve patient relationships (and compliance) (2) • Participant experience of care at day hospital (61) • Participant perceptions (interesting) (19) • Participant problems with Tygerberg (2) • Positive stories about Tygerberg Ophthalmology (1) • Referral issues after retinal screening (8) • Unfounded stories regarding TBH/eye problems (9) • Participant experience at retinal screening (27)
4. Perceptions of and experiences with care since the start of the COVID-19 pandemic	• Attitude towards COVID-19 (17) • COVID-19 affecting access to care (33) • COVID-19 affecting participant resolve to get DR treatment and care (21)

Table 6: Themes and corresponding codes used for tagging key informant data

Themes	**Codes**
1. Perception about the patients' knowledge about the aetiology and treatment of DM and DR and the need for information	• Retinal screening duties/purpose (2) • Key informant- information given at retinal screening (6)
2. Experiences with patient referral at tertiary institutions (Tygerberg Hospital and Hospital 1)	• Key informant experience with TBH (1) • Key informant experience with Hospital 1 (5) • Referral procedure (6)
3. Perceptions of patients' issues that influence compliance with DM and DR care	• Perceptions of barriers to DR care compliance (18) • Key informants- interesting perceptions (13)
4. Recommendations to improve DR care compliance among patients	• Health promoter and community health workers (7) • How to improve DR care compliance (7)
5. Perceptions of how COVID-19 affected access to DR care	• COVID-19 affecting access to care (33)

	• COVID-19 affecting px resolve to get DR treatment and care (21)
6. Attitudes towards lack of DR care during the COVID-19 pandemic	• Attitude towards COVID-19 (17)

Appendix P

Table 7: The Scottish diabetic retinopathy grading system (Zachariah, Wykes and Yorston, 2015)

Retinopathy grade	**Retinopathy description**	**Outcome**
R0	No diabetic retinopathy present	Rescreen in 12 months
R1	Non-proliferative diabetic retinopathy – mild *The presence of at least one of any of the following features anywhere* • *dot haemorrhages* • *microaneurysms* • *hard exudates* • *cotton wool spots* • *blot haemorrhages* • *superficial/ flame shaped haemorrhages*	Rescreen in 12 months
R2	Non-proliferative diabetic retinopathy – moderate *Four or more blot haemorrhages in one hemi-field only*	Rescreen in 6 months
R3	Non-proliferative diabetic retinopathy – severe *Four or more blot haemorrhages in both inferior and superior hemi-fields* • *Venous beading* • *Intraretinal microvascular abnormalities*	Refer to an ophthalmologist
R4	Proliferative diabetic retinopathy • *Neovascularisation* • *Vitreous haemorrhage* • *Pre-retinal haemorrhage*	Refer to an ophthalmologist urgently
R6	Retina not adequately visualised	Arrange an alternative screening
M1	Hard exudates within 2 disc-diameters of the fovea but further than 1 disc diameter from the fovea	Rescreen in 6 months
M2	Lesions as specified below within 1 disc-diameter of the centre of the fovea • *Any blot haemorrhages* • *Any hard exudates*	Refer to an ophthalmologist