

TYPE TWO DIABETES AND EYE HEALTH

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ABSTRACT

This thesis contributes to the understanding of how people with Type 2 Diabetes (T2D) negotiate self-care and management of diabetes and eye health. The study aims to deliver an Enhanced Diabetic Optometric Practice (EDOP) which involves a graphic portrayal of diabetic retinopathy, as it manifests itself in the eye and in the patient's own eyes, whereby retinal images will be discussed within a normal optometric practice environment.

This PhD research study used the qualitative method of thematic and Foucauldian discourse analysis (FDA) to investigate if an EDOP is able to heighten the participant's concern of sight loss and thus lead to better diabetic control, and improved self-motivation and management. The research progressed in three stages; Study (1) A systematic review and meta-synthesis of qualitative research investigating the barriers to self-care for people with T2D, Study (2) A qualitative analysis of diabetes self-help literature and eye health, and Study (3) Evaluation of an Enhanced Diabetic Optometric Practice (EDOP).

A review of the literature evaluates research in the field of optometry and ophthalmology with regard to the use of retinal images for educating people with T2D about their diabetes and the ocular complications.

The findings of the three studies revealed, valuable insight into the barriers and constraints to self-care that people with T2D routinely face, enabling greater understanding of how to facilitate effective diabetes self-management Study (1). Study (2) discerned that self-help texts cannot facilitate the empowerment of people with diabetes who aspire to self-regulation, as they are constrained by the dominant compliant discourse of the expert-patient relationship. Finally, in Study (3) EDOP, optometrists can provide an enhanced optometric service, educating and motivating people with T2D to better self-care practices.

This thesis concludes that the optometrist, by way of the EDOP and the pertinent threat of sight loss can assist people with T2D to gain the confidence to apply the skills to effective self-management and so prevent blindness.

Key words:

T2D self-management education, Foucauldian discourse analysis, optometry, retinal images, diabetic eye disease, self-efficacy, motivation

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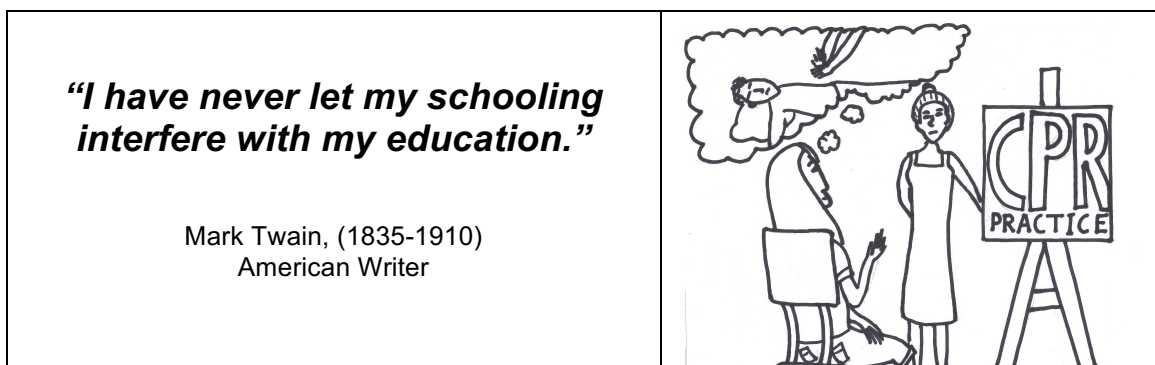
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At the beginning of each chapter the author has placed a renowned quotation with a remotely lateral link to the chapter content. Whilst these are of no consequence to, nor a direct reflection of, the narrative of this thesis, their insertion serves as a reminder to the reader that according to Foucault the only way of apprehending reality is through discourse, which determines our perception of reality. In an age of freely accessible and publishable raw information, this perhaps makes decisions harder rather than easier, an article from The Guardian summarised below, reflects on this;



‘Read This and Feel Better – How inspirational guff invaded our lives’

Paula Coccozza, The Guardian g2: (Wednesday November 19, 2014).

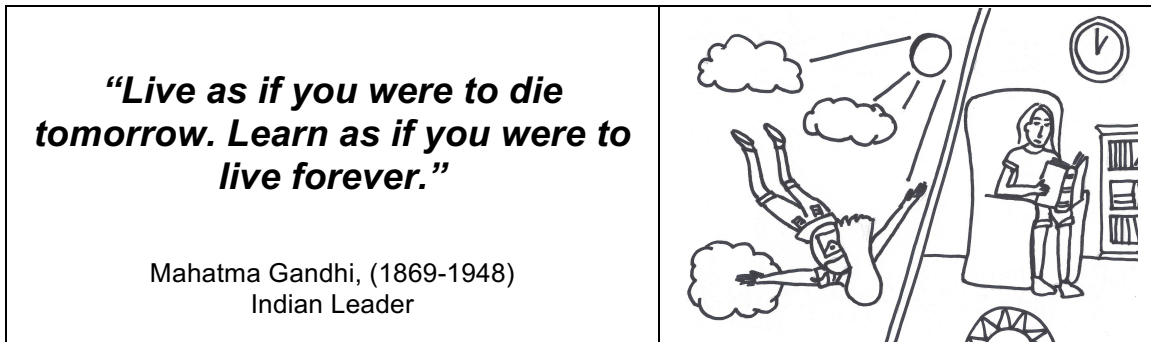




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1 INTRODUCTION



There are thought to be more than three million people with diabetes in England, with only 2.3 million having been diagnosed (Diabetes Health Intelligence, 2010). By 2020, 3.8 million people in England are expected to have diabetes, which is more than one in 12 of the total population (Right Care-NHS, undated). It is estimated that at diagnosis 50% of those with type 2 diabetes (T2D) may show signs of complications, and uncontrolled diabetes is the leading cause of blindness in people of working age in the UK (Diabetes U.K, 2010). If left untreated, 50% of those who develop proliferative diabetic retinopathy will lose their sight within two years (Kohner et al., 1996). Early detection and treatment of sight-threatening diabetic retinopathy can halve the risk of sight loss, (Arun et al., 2003); (DoH, undated).

This thesis is a report on the study of self-care and management of people with T2D and eye health. The study aims to deliver an Enhanced Diabetic Optometric Practice (EDOP) which involves a graphic portrayal of diabetic retinopathy, as it manifests itself in the eye and in the patient's own eyes, whereby retinal images will be discussed within a normal optometric practice environment. It is conjectured that the retinal images will result in a heightening of the participant's concern of sight loss and this will lead to better diabetic control, and improved self-motivation and management.

1.1 Diabetes Mellitus

Diabetes mellitus is a chronic disorder of sugar metabolism caused by the insufficient action of insulin in the body. The term '*mellitus*' is from the Latin for 'honey' and was first used by the 18th century Scottish physician (Rollo, 1797). The criterion for diagnosis of diabetes is based on blood plasma glucose concentrations established by the World Health

Organisation's International Diabetes Federation (IDF) in 2006 (WHO, 2006), which was later amended in 2011 (WHO, 2011).

1.1.1 Types of Diabetes

Diabetes is classified into two types; Type 1 diabetes (T1D) and Type 2 diabetes (T2D) (WHO, 1980). T1D previously known as insulin dependent diabetes mellitus (IDDM) is caused by the complete lack of insulin in the body, due to loss of beta-cells in the islets of Langerhans located in the pancreas which produces insulin. T1D is thought to occur via a complex mechanism involving aggressive autoimmune pathways and is often associated with other autoimmune conditions, (Delli and Kong, 2010).

Type 2 diabetes was previously known as non-insulin dependent diabetes mellitus (NIDDM) is a progressive disease, caused by a combination of genetic and acquired factors, of which obesity is the most predictive, (Alsahli and Gerich, 2010). T2D involves a combination of reduced beta-cell function and reduced sensitivity to insulin in the body tissues. It was considered that insulin resistance is the initiating factor, followed by a gradual loss of insulin secretion; however recent studies have shown that the leading element in T2D could be beta-cell dysfunction, (Alsahli and Gerich, 2010). As the disease progresses some patients may go on to require oral glucose-lowering agents and many will eventually require insulin therapy, (Stratton et al., 2000); (UKPDS Group, 1998c).

1.1.2 Epidemiology of Type 2 of Diabetes

The total number of people diagnosed with diabetes globally was 171 million in 2000 and is estimated to increase to 366 million by 2030, (Wild et al., 2004), with T2D accounting for approximately 90% of cases and the prevalence is increasing rapidly. In the UK since 1996 the number of people diagnosed with diabetes has increased from 1.4 million to 2.9 million in 2012. It is predicted that the prevalence of diabetes among adults will increase by 8.5% in 2020, and will rise further to 9.5% by 2030 (Diabetes Health Intelligence, 2010). However, according to Diabetes UK the figure is less conservative; by 2025 it is estimated that five million people in the UK will be diagnosed with diabetes and most of these people will have been diagnosed with T2D (Diabetes U.K, 2012a). T2D is usually diagnosed in people over the age of 40; however, more recently it has been diagnosed in children. The first cases of T2D in children living in the UK were diagnosed in 2000 and in 2012, 1.5% of children with diabetes aged 17 and under had T2D (Diabetes U.K, 2012a).

In the literature figures for the incidence rates of diabetes vary, this is because of the different models used, and the source of those figures. For example, the five million estimate from (Diabetes UK, 2012a) uses the AHOP Diabetes Prevalence Model (Public Health England, 2013) and the Quality Outcomes Framework (QOF). The QOF figures for diabetes incidence uses data provided by GP practices, but participation is voluntary and not all practices contribute. Some models use published research data on diabetes prevalence and apply them to population information like age, gender and ethnicity, which is then adjusted for various socio-economic factors. This information is gleaned from different sources, which may be based on outdated reference estimates, so comparison of predicted diabetes incidences is not always possible (YHPHO, 2010). In addition, the definition of diabetes used by the various models is not standardised.

1.1.3 Prevalence and Financial Burden of Type 2 Diabetes

In recent years, lifestyle and changes in diet have led to an increase in the incidence of T2D, and according to conservative estimates by 2036 the increase will be 20% which will present the NHS with serious clinical and financial challenges, (Bagust et al., 2002). In the UK in 2007, diabetes accounted for approximately 5% of healthcare expenditure, and T2D accounted for about 7% of the total NHS drugs budget, (Waugh et al., 2007). More recent estimates indicate the increased financial burden to be around £10 billion, which equates to approximately 10% of the NHS budget of £103 billion for 2010 to 2011. According to (Hex et al., 2012) the total cost to the UK of diabetes, both direct and indirect is currently estimated at approximately £23.7 billion and is expected to continue to rise in the future. In 2011, NHS spending on diabetes was £1 million per hour, (Hex et al., 2012), 80% of NHS spending on diabetes goes in to managing potentially preventable complications. However, according to (Turner et al., 1996), intensive treatment of T2D can substantially reduce the development and progression of disabling and costly complications.

1.1.4 Complications of Type 2 Diabetes

Diabetes is also a major contributor to kidney failure, amputations and cardiovascular disease, including heart attack and stroke (Diabetes U.K, 2011). The complications of diabetic disease are caused by high levels of glucose in the blood which damages tissues by altering proteins, the complications of diabetes can be acute or chronic, and chronic is divided into microvascular and macrovascular.

The microvascular complications occur in the smaller blood vessels, prolonged exposure of high levels of glucose results in progressive narrowing and occlusion of these small blood vessels, reducing perfusion, ischemia and damage to the tissues they supply. Microvascular complications include diabetic peripheral neuropathy; this begins in the extremities of the feet and hands; it is caused by progressive damage to the peripheral nerves as a result of sustained high blood glucose levels. Loss of peripheral sensation makes people with diabetes particularly susceptible to foot ulcers, which along with other complications of poor blood perfusion and peripheral arterial disease can lead to gangrene and the need for limb amputation. People with peripheral artery disease and diabetes have an eight times greater risk of amputation, (Johannesson et al., 2009). Diabetic nephropathy another microvascular complication of diabetes is the world's leading cause of end-stage renal disease in the developed world, (WHO, 2010).

The macrovascular complications of diabetes are related to the larger central and peripheral vessels, there is a two times increased risk factor for ischaemic stroke, (UKPDS Group, 1998c), and for cardiovascular disease when the coronary vessels are involved (Rodriguez and D'Agostino, 2002). As the development of atherosclerosis becomes more pronounced, the cardiac arteries narrow and arterial plaques develop, leading to angina and the increased possibility of a heart attack (Candido et al., 2010). The increased risk of cardiovascular complications is five times higher in men, and eight times higher in women, who have diabetes (Diabetes U.K, 2007).

Many of these complications are avoidable with good risk assessment and early diagnosis, patient education, support and good on-going services. It is estimated that there are more than 100 amputations carried out each week as a result of diabetes complications and of these 80% are preventable, (Right Care-NHS, undated). Research has shown an increase in complications of stroke, kidney failure, cardiac failure, amputations and retinopathy related to diabetes between 2006 and 2010, cases of retinopathy have increased by 118% between 2006 and 2010 (Health & Social Care Information Centre, undated) In addition to these physical complications there are psychological conditions also associated with diabetes, with anxiety and depression being the most common.

1.1.5 Diabetic Eye Disease

The microvascular complications of the eye are retinopathy, macular oedema, glaucoma, cataracts and neuropathies; diabetes alters the physical properties of the retinal vasculature, which leads to capillary leakage (Negi and Vernon, 2003). Diabetic retinopathy is a common secondary complication of T2D, (Stratton et al., 2001) and is the result of prolonged exposure to high levels of blood glucose causing loss of pericyte cells and endothelial cells in the retinal capillaries (Podesta et al., 2000). The capillaries leak and weaken, leading to microaneurysms, haemorrhages, areas of ischemia and hard exudate formation; as these progress, the retina becomes ischaemic and neovascularisation occurs. These new blood vessels are more prone to haemorrhage, which may lead to tractional retinal detachment resulting in severe loss of vision.

Diabetic eye disease is categorised into three distinct stages; background diabetic retinopathy (BDR), pre-proliferative diabetic retinopathy (pre-PDR) and proliferative diabetic retinopathy (PDR). Using the National Diabetic Eye Screening Programme (NDESP) classification, BDR is defined as grade 1 (R1) and is the earliest and least sight threatening change to occur. Although these background changes are not immediately sight threatening they can constitute referable retinopathy within the NDESP, as they are a warning that microvascular disease is present and indicate susceptibility to further retinal damage.

Microaneurysms, haemorrhages, exudation and cotton wool spots are features of Grade 1 (BDR). Microaneurysms are weakenings in the capillary wall, appearing as small red dots visible in the retina. Intra-retinal haemorrhages originate from ruptured capillaries within the retina; these haemorrhages appear round and are often described as dot or blot haemorrhages (Frank, 2004); (Kohner, 1993). Exudation occurs when lipoprotein residue accumulates in the retina, as a result of oedema and changes in the retina blood vessels. Exudate is yellow and waxy in appearance with defined edges forming a variety of circinate patterns, patches or tracking lines (Dobree, 1970). At the macula of the retina a star pattern can form, this is known as maculopathy. According to (Zander et al., 2000), maculopathy is the commonest cause of blindness due to diabetic retinopathy in 80% of cases. For those people with T2D, who have BDR there is a 53% probability of developing maculopathy. When diabetic retinopathy is noted within the macular area, the additional NDESP classification of maculopathy is given as grade M1. Diabetic retinopathy screening gives people with diabetes a retinopathy (R) grade and a maculopathy (M) grade.

Cotton wool spots appear as fluffy, greyish-white lesions on the retina and are the result of disruption in the normal axoplasmic flow within the nerve fibre layer of the retina, these ischaemic lesions which caused by a localised failure of the capillary network to supply

oxygen. (Kern, 2012); (Frank, 2004); (McLeon et al., 1977). Within the NDESP classification up to five cotton wool spots are allowed in Grade 1 (BDR). However, cotton wool spots are also a feature of pre-proliferative diabetic retinopathy and as the disease advances over a few months the lesions lose their feathery appearance and form pale areas on retina, and are then described clinically as focal ischaemic infarcts of the nerve fibre layer (Kern, 2012); (Osborne et al., 2004).

Grade 2, (pre-PDR) is referable and consists of; multiple cotton wool spots (as discussed above), venous beading and looping, multiple deep round and blot haemorrhages and intra-retinal microvascular abnormalities (IRMAs). Venous beading signifies serious retinal ischaemia, as the disease progresses the beading appears as venous loops indicating an imminently high risk of new vessel formation (Kern, 2012); (Hersh et al., 1981); (Kohner and Oakeley, 1975) . Venous beading is seen as irregular constriction and dilation of the lumen in the venules due to hypoxia arising from extensive capillary occlusion and ischaemia (Runkle et al., 2012). The deep round and blot haemorrhages are less regular and have indistinct borders; they occur in the deeper layer of the retina and indicate retinal ischaemia. IRMAs are areas of capillary dilation and are intra-retinal new vessels which form around or near to the occluded capillaries (Osborne, et al., 2004); (Hersh et al., 1981). As the disease progresses retinal blood vessels become increasingly damaged, the progressive endothelial cell loss results in occlusion of retinal capillaries and the formation of extensive chronic retinal ischaemic areas (Kern, 2012); (Osborne et al., 2004).

The most serious and sight threatening stage of diabetic eye disease is grade 3 (PDR), DR consists of new vessels at the disc and/or elsewhere on the retinal surface. These new vessels arise from retinal ischaemia as the hypoxic tissue attempts revascularisation. Vascular endothelial growth factor is stimulated by this hypoxia and is the primary mediator resulting in growth of new blood vessels from re-existing vasculature, known as of retinal angiogenesis (Rangasamy et al., 2012); (Adamis et al., 1994). These new vessel walls are fragile and have no support from surrounding structures as they grow in the vitreo-retinal interface, as such they can easily rupture which leads to pre-retinal or vitreous haemorrhages resulting in severe visual loss.

What is notable is that patients are often unclear about the relationship between diabetes and the secondary complications like retinopathy, as they lack information about their diabetes and its complications (Peel et al., 2004). Poor glycaemic control is associated with the development of retinopathy within six years, and 20% of patients have diabetic retinopathy at diagnosis and 60% after 15 years, (Stratton et al., 2001). Diabetic retinopathy

is the most common cause of blindness in working age people in the UK. Early detection of sight-threatening diabetic retinopathy and treatment halves the risk of sight loss, (DoH, undated).

1.1.6 Length of Diagnosis of Type 2 Diabetes

(Toljamo and Hentinen, 2001) found that there was no statistically significant association between adherence to self-care and duration of diabetes, whilst (Karter et al., 2000) found that age is correlated with worse diabetes self-management; they speculated that the high prevalence of coexistent chronic illness, depression and low social support among older adults represents an additional barrier to adherence to self-management activities. This is supported by (Svenningsson et al., 2011) who report that patients with T2D have more long term complications and poorer psychological well-being, which they found was indirectly link to length diagnosis. Women have a longer life expectancy than men and so have an increased risk of experiencing long-term complications and have more disability from the disease (Matthews et al., 2009).

In the study by (Dietrich, 1996) people with newly diagnosed diabetes were compared to those with established disease. The study found that the perceived seriousness of diabetes changed from very strong at point of diagnosis, weakening over the following years until diabetic complications started and/or anti-diabetic drugs were exchanged for insulin. These results were consistent with those found by (Massaki et al., 1990). When people are concerned that their illness is progressing, and when disease symptoms are present, they are more likely be motivated to change behaviour and lifestyle. Conversely, when they are well and appear symptom free, they are less likely to be concerned about the illness (Watkins et al., 2000). According to (Svenningsson et al., 2011) people's attitudes towards their disease influence how they manage everyday life in a practical way and negative well-being can prevent people with T2D from achieving improved glucose control. People with T2D admitted that when disease symptoms worsened, they took their condition more seriously and were more likely to adhere to treatment (Benyamini et al., 1999).

1.2 Detection of Diabetic Eye Disease

In the UK, the National Service Frameworks (NSF) set out guidance for healthcare in specific areas like diabetes care and is based on findings from outcome studies. The NSFs are long-term strategies concerned with improving care in the National Health Service

(NHS). The Diabetes NSF details standards relating to all aspects of diabetes care and prevention, covering; prevention of T2D, identification of people with diabetes, empowering people with diabetes, clinical care of adults, children and young people with diabetes, management of diabetic emergencies, care of people with diabetes during admission to hospital, diabetes and pregnancy and detection and management of long-term complications (DoH, 2001). These national standards identify key interventions for a defined service of care, with guidelines to support the implementation of care services, establishing ways in which progress in diabetes care can occur in a timely fashion.

In the delivery strategy for the Diabetes NSF, a national screening programme for England was announced. This was in response to the National Screening Committee's evaluation of the evidence, indicating that screening could significantly reduce the prevalence of sight loss through the prompt identification and effective treatment of diabetic eye disease. The programme was implemented across England between 2003 and early 2008, (Public Health England, undated). In Walsall where this study was undertaken, the retinopathy screening programme began in 2005.

Historically, screening for diabetic retinopathy was largely *ad hoc*; offered by some opticians, GPs and diabetes centres. In March 2005 only 13 programmes were undertaking systematic screening, by 2007 the NDESP had 101 screening programmes; of these 75 were undertaking systematic screening and 26 were screening, but not to fully systematic standards. The Priorities and Planning Framework (PPF) 2003-2006 and the Diabetes NSF Delivery Strategy set the targets for retinopathy screening. A minimum target of 80% of people with diabetes to be offered retinopathy screening as part of a systematic programme meeting national clinical standards by 2006, and by the end of 2007, 100% coverage was required. The minimum uptake rate target for retinopathy screening was set at 70%. Notably, in 2003 when these screening targets were set there were 1.3 million people with diagnosed diabetes, this figure increased to 2.06 million by December 2007, (DoH, undated).

1.2.1 National Diabetic Retinopathy Screening Programme

The Royal College of Ophthalmologists recommends that people with diabetes have their eyes screened for diabetic retinopathy annually (Royal College of Ophthalmologists, 2012). This recommendation requires the measurement of visual acuity and digital photographs after mydriasis, (dilation of the pupil). Visual acuity is recorded as a surrogate marker to detect clinically significant macular oedema. Macular oedema, a three-dimensional feature,

is not easily detected by inspection on a two-dimensional image, and required additional clinical information. In England and Wales the recommendation for retinal screening, to detect retinopathy early, is to photograph digitally two images per eye (NICE, 2002). The two field positions used are a macula-centred view and an optic disc-centred view for each eye. The macula centred view, shows the centre of the fovea within one-DD of the image centre, this image detects any maculopathy present. The disc centred view, shows the centre of the disc within one-disc-diameter (DD) of the image centre, this image is used to detect the presence of retinopathy.

The National Diabetic Eye Screening Programme is co-ordinated and led from the NHS Adult (non-cancer) Screening Programmes Centre in Gloucester, the aim is to reduce the risk of sight loss amongst people with diabetes by early detection and treatment of sight-threatening retinopathy. There are more than 80 local programmes currently deliver screening across England and Wales, these local programmes are accountable to the National Programme Team and submit an annual report containing general information about the service and information to support the service objectives and quality assurance standards. The local screening programmes inform GPs when people are invited for screening. GPs are also informed of their patients' screening results.

The earlier the retinopathy is detected, the easier it is to treat (Kohner et al., 1999); (DCCT, 1993), retinal images can be stored and used to follow the progression of the disease. However, these images require the use of a skilled grader or ophthalmologist to diagnose any disease; grading is expensive in terms of staff time and needs to be performed in a timely fashion. Grading is required by the NICE guidelines to be 80% sensitive and 95% specific for diagnosis of retinopathy (NICE, 2002). Sensitivity is the true positive result, which means that in the total population of people with diabetes, screening must pick up at least 80% of those with diabetic retinopathy. Specificity is the true negative result, which means that of those people with no diabetic retinopathy at least 95% need to be correctly identified. This means that the higher the specificity target, the higher the number of false positives, but conversely the number of false negatives will be lower, which means that fewer patients with disease will be missed.

Digital Healthcare is one of the companies offering software for diabetic retinopathy screening; the 'OptoMize' system is used currently by 41 schemes across England and Wales, which equates to approximately 1.2 million people with diabetes, (Digital Healthcare, undated). The Birmingham, Solihull and the Black Country, Diabetic Retinopathy Screening

Programme, of which Walsall is part, is currently one of those 41 schemes using the Digital Healthcare software.

The national target to screen 100% of people diagnosed with diabetes for diabetic retinopathy was not met by the end of 2007, only 85.7% or 1.67 million people in England diagnosed with diabetes were offered diabetic retinopathy screening. To prioritise and ensure the quality, coverage and safety of the NDESP, operating frameworks for the NHS in England from 2008 onwards included targets and guidelines for the programme.

A report published by the Department of Health in 2010 reviews the development and delivery of diabetes services and identifies the progress made over the past six years towards meeting the Diabetes NSF, (DoH, 2010). This Department of Health report draws on data from the National Diabetes Information Service (NDIS), including the National Diabetes Audit (NDA). The NDA is a valuable resource which allows for the scale of diabetes to be assessed, identifying where improvements are required and whether the changes implemented have worked. The NDIS is funded by the Healthcare Quality Improvement Partnership (HQIP) and has become one of the world's most extensive sources of a nation's diabetes data. The Diabetes NSF report: six years on, indicates that national screening figures have increased, in March 2008, 1.77 million people with diabetes in England were offered retinopathy screening and 1.32 million accepted the invitation, by September 2009 the number of invitations rose to just over 2 million, with 96.1% of the 1.54 million people with diabetes attending for screening, (DoH, 2010).

The operating frameworks for the NHS in England maintain the existing commitment to 100% of people with diabetes be offered screening for (DoH, 2010). The UK NDESP leads the world with this first large scale, population-based screening programme, the NDESP is expected to halve the rate of blindness from diabetic retinopathy in working adults. It is estimated that 4,200 people every year are at risk of blindness caused by diabetic retinopathy, and that screening could save more than 400 people per year from sight loss in England, (Public Health England, undated).

In 2010-2011, the service identified 2.47 million people with diabetes with 91.4% offered screening (The Health and Social Care Information Centre, 2012). However, in the report by Diabetes UK, State of the Nation (2012), concern over the accuracy of screening figures is raised; though 91.4% were offered retinopathy screening, only 79% of those invited were screened (Diabetes U.K, 2012b). This figure increased to 2.59 million people in England

over the age of 12 being identified with diabetes in 2011-2012, and 81% received screening, (The Health and Social Care Information Centre, 2013).

1.2.2 The Borough of Walsall

This study investigated people with T2D resident in Walsall. Walsall is a large industrial town, located in the West Midlands; eight miles north-west of Birmingham and six miles east of the City of Wolverhampton.

The 2011 Census estimated the resident population of the Metropolitan Borough to be 269,323 (Walsall Council, 2011), the demographic profile of Walsall shows a higher than national average population of children, and of over 65 year olds. With regard to the ethnicity and identity of Walsall, whilst White British is the highest population group at 76.9%, there has been an increase in the Asian population from 10.4% in 2001 to 15.2% in 2011.

Whilst levels of English language proficiency in Walsall are generally high (92.6% of residents speak English as their main language), some 3.3% of households in Walsall have no one who speaks English.

Health in Walsall is poorer than the national average, with one in five residents having a health condition which limits their daily activity, and just 77.3% of residents declaring their health to be good or very good, which is lower than the national average of 81.2%. A posting in the local media, the 'Walsall Advertiser' from 2013 highlighted that 'diabetes rates in Walsall are the seventh highest in England' (Walsall Advertiser, 2013). The article stated that analysis by Diabetes UK showed that 8.8% of people in Walsall have diabetes; the national average is 7.7%. Pete Shorrack, Diabetes UK's regional manager for the Midlands, is quoted as saying; 'It is alarming that Walsall has one of the highest diabetes rates in England and addressing this situation needs to be one of the top health priorities in the area'. Over the next five years, more people in Walsall are expected to develop diabetes, in line with national trends. In response to this, Mr Shorrack considers a vital step to addressing this situation is for people to 'realise how serious [diabetes] is and also that they understand their own personal risk, so that if they are at high risk they can make the lifestyle changes that can help prevent it' (Walsall Advertiser, 2013).

1.2.3 Birmingham, Solihull and the Black Country Diabetic Screening Programme

The Birmingham, Solihull and the Black Country Diabetic Screening Programme started in 2005, and is administered by the Retinal Screening Diabetes and Endocrinology Centre, Heartland Hospital, Birmingham which is a centre of clinical excellence. In 2011-2012 there were 138,000 people with diabetes (T1D and T2D) in the Birmingham, Solihull and the Black Country Diabetic Screening Programme, and of the 16,270 people in Walsall diagnosed with diabetes in 2011-2012, the actual screening figure for Walsall was 72.4%, compared to a national average of 81%, (unpublished data, Walsall Society for the Blind). This lower than average figure, is thought to relate to ease of access for some people to the retinopathy screening service, (unpublished data, Walsall Society for the Blind). In 2011-2012 figures indicate that there were 4,555 people diagnosed with background diabetic retinopathy, (NDESP grade 1) in Walsall, these figures are estimated to increase to 4,592 in 2015 and to 4,714 in 2020. There were 521 people in Walsall with diagnosed pre-proliferative and proliferative retinopathy (NDESP grade 2 and 3) and extrapolation of these figures showed a similar estimated rise to 525 people in 2015 and to 539 people in 2020, (unpublished data, Walsall Society for the Blind). In 2012-2013 the NDA showed an increase to 16,913 people diagnosed with T1D and T2D in Walsall; of which 15,499 have T2D, (these figures relate to data extracted from GP practices in Walsall, the practice inclusion rate was 93.5%).

1.3 Diabetes Education

Diabetes self-management education is recognised as essential for people with diabetes to achieve positive results from self-care, and people with diabetes require knowledge and skills to effectively manage their disease (Mensing et al., 2007). The American Diabetes Association (ADA), considers diabetes self-management education (DSME) programmes essential for improving health behaviours and preventing complications for individuals with diabetes (American Diabetes Association, 2001). Improved patient knowledge and behaviour has been shown to improve glycaemic control (Delahanty and Halford, 1993), and the effectiveness of diabetic education on patient outcomes has been summarised and reviewed in detail by (Norris et al., 2001); (Brown, 1990). Research shows that people with diabetes express a desire to live as normal and healthy a life as possible, the knowledge and problem solving skills obtained through diabetes education are vital in initiating the self-management process and empowering them, (Rayman and Ellison, 1998).

1.3.1 National Requirement for Diabetes Education

National Institute for Health and Clinical Excellence recommends that every person with diabetes should be offered structured education, (NICE, 2009). The NSF guidance on diabetes also advocates structured patient education as it has an important role in enabling people to manage their diabetes on a day-to-day basis, (DoH, 2001). The six-years-on report on the Diabetes NSF states that; 'the spread of the Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND), Dose Adjustment For Normal Eating (DAFNE) and the Expert Patient Education versus Routine Treatment (X-PERT) courses is encouraging' (DoH, 2010 p14). However, this statement is not supported by the Diabetes UK report, State of the Nation (Diabetes UK, 2012b), which comments; 'There has been NICE guidance since 2003, but courses are still not widely in place and not routinely offered to those newly diagnosed or with ongoing diabetes' (Diabetes U.K, 2012b p22). Dr Rowan Hillson, MBE and the National Clinical Director for Diabetes did concede that structured education and care-planning approaches need to be more widely adopted, to ensure that everyone with diabetes can benefit from enhanced quality of care and empowerment, and that cost-effectiveness for the NHS is proven (DoH, 2010).

Structured Education is a key component to enable people with diabetes to effectively self-manage and they should be offered the opportunity to attend an education course that meets specific national standards, enabling better understanding of their diabetes and to become successful self-managers. According to (Jarvis et al., 2010); 'education and self-management are pivotal if a person with T2D and their carers want to manage and understand the complexities in care that are demanded by this chronic disease', (Jarvis et al., 2010 p13). NICE devised guidance to standardise the way in which education courses are developed and run, which should be in either a group or on a one-to-one basis, and available in their local area (NICE, 2003). There are currently 110 primary care organisations and diabetes services that offer the DESMOND programme across the UK and Ireland. Since 2005, 860 educators have been trained to deliver DESMOND programmes, and are supported by a training team of 25 experienced trainers and assessors.

There is no data routinely collected at national levels to indicate performance against the provision and uptake of education for people with diabetes, and there is limited data on how many people with diabetes are actually offered and undertake education courses. Diabetes UK's 2009 Member Survey (Diabetes U.K, 2009) reported that only 36% of people had attended a course to help them manage their diabetes since diagnosis. Most of the Clinical Commissioning Groups (CCG) and Local Health Boards (LHB) are performing poorly with regard to structured education, which is fundamental to effective patient self-care. In England and Wales the figure for those people newly diagnosed with diabetes, who have

been offered and attended structured education is only 19.3% (The Health and Social Care Information Centre, 2014).

1.3.2 Structured Education

In 2003 the NICE published its guidance on the use of patient education models for diabetes, defining structured education as a planned and graded programme which is comprehensive, flexible, and is responsive to an individual's needs, as well as their educational and cultural background (NICE, 2003). Also recommended is that structured patient education should be available to all people with diabetes at the time of initial diagnosis, and then as required on an ongoing basis (NICE, 2003). In 2004, Diabetes UK and the Department of Health formed a Patient Education and Working Group to report on diabetes education. The group recommended that structured education needed to be of high-quality and evidence-based to have effectiveness, which would need to incorporate the key elements of a structured written curriculum with trained educators, and could be quality assured and audited (DoH, 2005).

In addition, for an education plan to have structure and be robust the issues of cost-effectiveness, accessibility, reproducibility and transferability need to be met. If the education plan is reproducible and repeatable then it is by virtue transferable, (International Diabetes Federation, 2007). According to (Jarvis et al., 2010) the required high-quality of the structured education programme can be ensured by evidence-based education, which is dynamic and flexible to the needs of the individual and able to support self-management attitudes, beliefs, knowledge and skills. Optometrists, as educators of people with T2D, are potentially able to fulfil and exceed all of the requirements for structured education This will be discussed further in the conclusion in Chapter 7.

1.3.3 Complex Interventions

Some studies recognise the complex nature of managing T2D, and although these multifactorial interventions demonstrate significant benefits, they are still very bio-medically orientated and do not necessarily address either lifestyle factors or the psychological issues that need to be considered as part of chronic disease management (Jarvis et al., 2010). Education interventions that do focus on these issues are complex with different component parts, making it difficult to isolate the 'active ingredient' that makes them successful (Deakin et al., 2006). For example, the successful ingredient could be the content of the programme,

the educator style or the setting. Due to these difficulties, research in structured T2D education requires complex intervention strategies, like those developed by the Medical Research Council (MRC) (Medical Research Council, 2008). Studies which follow this guidance are more rigorous and thus more likely to be replicable, and implemented as educational interventions. The issue of the 'active ingredient' becomes less important, because the programme is transferable into other contexts (Skinner, 2006).

In this PhD research study, the notion of an 'active ingredient' in the EDOP is considered advantageous, the aim is for the optometrist or the practice setting to be an 'active ingredient' which will enable people with T2D to make the connection between eye health, and the increased risk of sight loss due to poorly managed diabetes. This will be discussed further in Chapter 7.

The five step process in the UK complex intervention framework established by MRC is depicted below (Campbell et al., 2000). Step (1)-Preclinical stage involves exploration of theory to guide development of the intervention. Step (2)-Phase I requires modelling to predict outcome interactions. Step (3)-Phase II requires piloting of the intervention. Step (4)-Phase III requires definitive randomised controlled trials, using the standard protocols. Step (5)-Phase IV involves long-term implications of the robustness of the intervention. Figure 1, represents the continuum of increasing evidence from pre-clinical to Phase IV of the MRC complex intervention framework.

Figure 1: Medical Research Council Framework for the Evaluation of Complex Interventions, (Campbell et al., 2000)



1.3.4 Principles of Adult Learning Theory

(Lieb, 1991) established that to be an effective educator requires understanding how adults learn, which emphasises greater equality between the teacher and learner. T2D education is based on the principles of andragogy, which are problem-based and collaborative, rather than didactic. (Fidishun, 2000) defines andragogy as the art and science of helping adults learn, which originated in Europe in the 1950s and was established as a theory and model of adult learning from the 1970s by Malcolm Knowles, an American practitioner and theorist of adult education.

1.3.5 Individual and Group Learning

In the study by (Adolfsson et al., 2008) the researchers considered relationships, learning and ability to controlling T2D with regard to group and individual diabetes education. Authors, (Marton and Booth, 1997) defined learning as, 'a change in someone's capability for experiencing something in certain ways,' (Marton and Booth, 1997 p208). In the individual intervention the relationship between the patient and healthcare provider was vertical, with the healthcare provider having a superior role and the patient adopting a more passive one. Learning was by compliance and characterised by the healthcare provider giving advice and recommendations they expected the patients to follow. The individual participants experienced a sense of external control of the disease and did not understand the complexity of the disease and were dependent on the expert's knowledge. (Adolfsson et al., 2008) concludes that when patients followed advice, but with a lack of understanding, this contributes to their lack of self-confidence. The individual participants were aware of the need to make behavioural changes, but lacked self-discipline and when they did not follow the advice they felt guilty.

Whilst in the group intervention, the patient and healthcare provider had a partnership and the relationship was more horizontal and equal. Group discussion was found to have contributed to participatory learning, giving participants an opportunity to learn from each other's experiences. (Cooper et al., 2003) found that contributed to patients increased understanding of their disease. Participants reported feelings of support and encouragement from other participants and the facilitator and were able to evaluate and reflect on the complex associations between eating habits, physical activity and blood glucose in managing T2D. The group participants also reported that they had developed a degree of self-control, their self-esteem had increased and feelings of self-blame had diminished.

According to (Jarvis et al., 2010) group education offered many advantages, such as increased cost-effectiveness, also being in a group environment allowed individuals to draw on and learn from the experiences of other people within the group. (Brown, 1990) found that group education was beneficial to increasing learning and motivation, and when the education was behaviourally orientated (Mazzuca et al., 1986) found it to be 150-300% more effective. Although researchers recognise that the evidence for the effectiveness of group education is compelling, group approaches do not suit everyone it is down to personal preference of the participant (Brown, 1990).

In a study by (Rickheim et al., 2002) group and individual education for people with T2D was investigated. The education intervention was aimed at achieving successful self-management of T2D by empowering the patient, through increasing knowledge, facilitating self-management behaviour change, and modifying perceptions. The study found group and individual diabetes education to be equally effective, improvement in glucose control was reported in both populations, though a slightly greater reduction in glycated haemoglobin (Hb1Ac) within the group was reported. However, the researchers caution that it was not possible to determine if that indicated a significant advantage of group over individual education, due to a small sample size and a possible contributory factor of a higher rate of glucose lowering medication used by participants in the group compared with individuals.

The size of the group could be a factor in determining how effective group education is, (Rickheim et al., 2002) claim that before initiating this current study they found that educating more than eight participants in a group did not allow for appropriate individualisation when needed. Therefore, large group sizes may limit the opportunity for individual interaction and require a greater amount of didactic teaching, thereby reducing the effectiveness of the intervention. However, the researchers do not make reference to their previous research and cite any supporting literature. It is interesting to note that both the DESMOND and X-PERT programmes are based on groups of 10-15 participants.

1.3.6 Provision of Diabetes Education in Walsall

DESMOND is currently the only education offered to people with T2D in Walsall. Referral to the course is made by the diagnosing health care professional, who is the GP or practice nurse, and only those people newly diagnosed with T2D, within the previous 12 months are considered for referral, the current waiting time for DESMOND is four to eight weeks. The

course is run in Walsall over two half-day sessions, on two consecutive weeks. The course facilitators are usually a specialist diabetes dietician and a diabetes specialist nurse.

Figures from the NDA 2011-2012, (The Health and Social Care Information Centre, 2013), Summary for Walsall Clinical Commissioning Group (CCG)/Local Health Board (LHB) indicate that there were 1387 people newly diagnosed with T2D in 2012 in Walsall, of these, 192 were offered DESMOND structured education, and 200 people attended. The discrepancy in these figures is due to issues with data quality; as a patient may be recorded as attending structured education without it recorded as being offered to them. Notwithstanding, this number falls dramatically short of the NICE target, at only 14.4%, and is below the national value. Further to the noted discrepancy in the NDA figures, the author of this study made a freedom of information request to Walsall NHS Healthcare Trust with regard to referral and attendance figures for DESMOND. The information supplied indicated that in 2011-2012, 592 people with T2D were referred for DESMOND and 163 people attended. However, in 2012-2013, 518 people with T2D were referred and 180 people attended the course. These figures do not tally with those published in the NDA, Walsall NHS Healthcare Trust refers more people for DESMOND than is recorded in the NDA, whilst according to Walsall NHS Healthcare Trust, 20 less people actually attended in 2011-2012 than was recorded in the NDA.

At diagnosis people with T2D in Walsall are given a personal record diary, with useful information and a log to record blood glucose readings. However, at present this booklet is not available to patients, as it is in the process of being rewritten and updated. When enquiries were made by the researcher in this study to Walsall NHS Healthcare Trust via a freedom of information request regarding availability of the new booklet, the reply indicated that the new booklets will be available in summer 2015, as printing is scheduled after the end of the current financial year. However, the existing booklet was still available electronically for download by the GP practice.

The researcher attended a DESMOND course on the 10th and 17th February, 2011, an account and reflective comments can be seen in Appendix 2.

1.4 Diabetes Education Management

Patients' participation in managing T2D is viewed as especially important because of the multi-factorial nature of the disease; which requires a complex array of risk management

strategies, which are both bio-medically orientated and also address the psychological and life style factors associated with T2D, (Jarvis et al., 2010).

Management of T2D requires patients to increase their levels of physical activity, consume a healthy diet, and, in some cases, take tablets and/or insulin to improve and maintain their blood glucose control, (UKPDS Group, 1998c). The risk of macrovascular and microvascular complications is greatly reduced by controlling blood glucose levels and ideally this would be achieved without the need for oral agents or insulin, (Stratton et al., 2000). However, there are many treatment options available for managing T2D which are largely based around pharmaceutical interventions, such as blood glucose, lipid and BP control.

1.4.1 Key Studies and Research

Key studies have investigated a direct relationship between prolonged exposure to high blood glucose levels and the chronic microvascular and macrovascular complications of diabetes. These studies and trials have found that by keeping blood glucose levels as close to normal as possible, it is possible to prevent or delay the development of complications the UK Prospective Diabetes Study (UKPDS), (UKPDS, 1998); and the Diabetes Control and Complication Trial, (DCCT, 1993). Modern diabetes management and education is gleaned from these landmark studies.

1.4.1.1 United Kingdom Prospective Diabetes Study (UKPDS)

The UK Prospective Diabetes Study was a landmark randomised, multicentre trial of glycaemic therapies in 5102 patients with newly diagnosed T2D, the study lasted for 20 years, from 1977 to 1997 and was located at 23 different clinical sites in the UK. The UKPDS (1998) has shown conclusively that the complications of T2D, which were previously considered inevitable, could be reduced by improving control of blood glucose and/or blood pressure. When the intervention trial finished in September 1997, all surviving UKPDS patients were entered into a ten-year, post-trial monitoring programme. This was completed in December 2007 and results presented in 2008. The latest UKPDS report is UKPDS 84 (Alva et al., 2015).

UKPDS 38, (UKPDS Group, 1998c) reported an overall reduction in complications related to diabetes of 12% when there was a difference of 0.9% in Hb1Ac, between the strictly controlled and less well controlled groups, with a 25% reduction in the microvascular

complications like retinopathy (UKPDS Group, 1998c). The study also revealed that for every percentage point decrease in Hb1Ac there was a 40% reduction in the risk of complications such as retinopathy and nephropathy. This indicated that those who did not adhere to their diabetic regimes were at increased risk of developing complications and premature death, (UKPDS Group, 1998c). UKPDS 83 examined ethnicity and vascular outcomes (Davies et al., 2014) and UKPDS 32 investigated ethnicity, with regard to cardiovascular disease (UKPDS Group, 1998b).

UKPDS 38, (UKPDS Group, 1998c) also showed that a lowering of blood pressure (BP) by 10/5 mmHg in the intensive control group produced a reduction in microvascular complications of 24%, a 32% reduction in mortality rate and a 44% decrease in the number of individuals suffering stroke. This revealed that by reducing both blood glucose levels and BP there is a considerable beneficial effect of reduced risk of complications related to diabetes.

UKPDS reports which relate directly to diabetic eye disease are; UKPDS 30 which reported that baseline retinopathy levels indicated by microaneurysms or other lesions in at least one eye was present in 39% of men and 35% of women with newly-diagnosed T2D (UKPDS Group, 1998a), UKPDS 42 investigated microaneurysms and diabetic retinopathy (Kohner et al., 1999), UKPDS 50 (Stratton et al., 2001) and UKPDS 52 (Kohner et al., 2001) reported on the retinopathy progression, and UKPDS 69 examined the risk of visual loss in relation to retinopathy progression and blood pressure control (Matthews et al., 2004).

1.4.1.2 Diabetes Control and Complications Trial (DCCT)

The DCCT study involved 1441 participants aged 13 to 39 with T1D in the United States and Canada, the study compared the effects of standard control of blood glucose with intensive control on the complications of T1D, (DCCT, 1993). When the DCCT ended in 1993, researchers continued to study more than 90% of participants. The follow-up study, called Epidemiology of Diabetes Interventions and Complications (EDIC), assessed the incidence and predictors of cardiovascular disease events and diabetic complications related to the eye, kidney, and nerves (DCCT/EDIC, 2005).

1.4.2 Principles of Diabetes Education and Self-Management

The principals of diabetes self-management and control are derived from the key studies and research discussed above, by reducing these risk factors the chance of developing complications has been proven to be greatly reduced, (UKPDS 1998). Diabetes self-management education programmes will be discussed in Section 1.4.3 below.

The glycosylated haemoglobin test (HbA1c) is used to measure blood glucose levels over an eight to 12 week period, this is the length of time that red blood cells usually live for, which gives an indication of the level of diabetes self-management. Haemoglobin-A1c, is created when glucose in the blood sticks to haemoglobin in red blood cells, making glycosylated haemoglobin. Since 2009, HbA1c has been reported in millimoles per mol (mmol/mol) instead of percentage (%), making it easier for laboratories to compare HbA1c results and standardise the measurement internationally. The recommended HbA1c target for most people with diabetes is below 48 mmol/mol. evidence suggests that this level can reduce the risk of complications (UKPDS Group, 1998c).

Despite the clinical evidence of the benefits of decreasing HbA1c levels, studies indicate that most patients do not achieve acceptable glycaemic control (Gilmer et al., 1997). Self-management related to diabetes is complex with treatment recommendations difficult to incorporate into existing lifestyles (Whittemore et al., 2005). Self-management focuses on regulating carbohydrate and caloric intake and increasing physical activity, which are difficult lifestyle changes, encompassing a multitude of individual barriers. (Whittemore et al., 2005) describes living with diabetes as a difficult process, whereby individuals attempt to find balance between the self-management demands and their preferred lifestyle.

Type 2 diabetes is a progressive disease where the body becomes less sensitive and more resistant to the effects of insulin; regular physical activity reduces insulin resistance (Duncan et al., 2003). The recommendation is to do at least two-and-a-half hours of moderate intensity aerobic activity, such as cycling or fast walking, every week (Wallberg-Henriksson, 1992). Regular exercise also reduces BP and cholesterol, and increases the levels of HDL-C, which is the protective cholesterol. Mortality can be reduced by lowering cardiovascular risk (Christakos and Fields, 1995), a risk that is greater in women with T2D than men. In addition, physical exercise improves emotional wellbeing, as diabetic patients can be prone to depression. In addition, weight gain and difficulty in reducing weight can be a problem for people with T2D. Regular exercise and a healthier diet are important to help control weight, as obesity is a major factor contributing to complications in diabetes. Weight loss of 10% can significantly reduce blood glucose and BP and improve dyslipidaemia in diabetes (Diabetes U.K, undated-a).

Patient education with regard to healthy diet is focused on a balanced diet of eating plenty of fruit and vegetables, reducing salt, sugar and fat intake, and eating more fibre. Carbohydrates are broken down by the body into glucose and used by cells as fuel, and carbohydrates that are more slowly absorbed and have a lower glycaemic index do not affect blood glucose levels as much. People with T2D are advised to eat more whole grains and less processed foodstuffs. Reducing salt intake can help to reduce BP, it is generally the highly processed foods, which can have higher proportions of fats, sugars and salt (Diabetes U.K, undated-b). Smoking is also a major factor in the course of diabetic disease, as smoking is a contributing factor in the complications of diabetes, as the chemicals which occur in smoke accelerate atherosclerosis (NHS Choices, undated).

1.4.3 Diabetes Education Programmes

Education is available for people with T1D or T2D, people with T2D can attend the DESMOND (Diabetes Education and Self Management for Ongoing and Newly Diagnosed), or the X-PERT (Expert Patient Education versus Routine Treatment) courses. There is also the Diabetes Manual, which has a different approach to education for people with diabetes to DESMOND and X-PERT. The MRC complex Intervention framework was applied to these education programmes, which will be discussed in Sections 1.4.3.1, 1.4.3.2 and 1.4.3.3 respectively.

1.4.3.1 DESMOND

The aim of the DESMOND course is to deliver a structured education programme based on the principles of adult learning and is promoted by the Department of Health. DESMOND has been available nationally for around 10 years and promotes regular exercise and a healthy diet, by way of a six hour programme run over one day or two half days on consecutive weeks. The education is delivered in groups of about 10 people with diabetes and their partners; it is based on self-management and education on the correct life style choices. Family members are encouraged to attend to share the experience, this is particularly important with life style choices for the whole family to embrace the change.

The course is constructed to accommodate the individuals attending on that day, giving them information tailored to their own situations, needs and concerns. There is provision in the DESMOND course for people from different ethnic backgrounds, (DESMOND-BME), which

can be delivered in Gujarati, Punjabi, Urdu and Bengali. The content of DESMOND includes; thoughts and feelings of the participants around diabetes, understanding diabetes and glucose, what happens in the body, understanding the risk factors and complications associated with diabetes, understanding more about monitoring and medication, how to take control with food choices and physical activity, and planning for the future. The course uses visual aids to inform and educate participants, with emphasis on empowerment; DESMOND advocates self-care and management of diabetes through life style counselling, (Davis et al., 2008).

The theoretical pre-clinical stage of the MRC complex interventions framework for the DESMOND programme was explained in the paper by (Skinner et al., 2003). The philosophical principles of DESMOND were defined as 'informed choice', based on a 'humanistic view of the individual' (Skinner et al., 2003, p75), and were considered to be the key to empowerment (Skinner and Craddock, 2000); (Anderson, 1995). The theories under consideration in this paper were; Leventhal's Common Sense Theory of Self-Regulation (Leventhal et al., 1984), Dual Process Theory (Chaiken et al., 1996), Social Learning Theory (Bandura, 1977), and Self-Determination Theory (Deci and Ryan, 2000).

Leventhal's Common Sense Theory (Leventhal et al., 1984) applies to individuals' illness representation, which are key elements of the emotional responses to illness and self-care behaviour (Skinner et al., 2000). Dual Process Theory (Chaiken et al., 1996) makes a distinction between heuristic and systematic processing and is used to guide the education process and peoples understanding their illness. Social Learning Theory (Bandura, 1977) focuses on the individuals' perceptions of their ability to enact behaviour and follow through on action plans, which is referred to as self-efficacy, and similar to the concept of self-confidence. The focus of Self-Determination Theory (Deci and Ryan, 2000) is on the difference between controlled and autonomous motivation. Controlled motivation involves extrinsic or external factors; whilst autonomous motivation focuses on intrinsic or personal factors, which is predictive of successful diabetes self-care (Williams et al., 2004); (Williams et al., 1998a). Insight into potential risks is a necessary part of understanding the nature of diabetes and acts as a motivator for behaviour change. (Skinner et al., 2003) acknowledge this, commenting that if patients understand their personal health risks they are able to ask the question, 'What can I do about it?', (Skinner et al., 2003 p79).

The second modelling stage (phase II) and the pilot (phase III) of the complex intervention process for DESMOND are detailed in (Skinner, 2006) along with analysis of the pilot study. However, the final modelling of the DESMOND programme did not consider Dual Process

Theory (Chaiken et al., 1996) or Self-Determination Theory (Deci & Ryan, 2000) proposed by (Skinner et al., 2003); it was developed around the Common Sense Model of illness, (Leventhal et al., 2003); (Leventhal et al., 1984), Social Learning Theory (Bandura 1977), and an approach relating to the process of education/learning proposed by (Vygotsky, 1978). Vygotsky, (1978) emphasised the need for individuals to be actively involved in the learning process; the main idea being that learning needs to take place in the learner's Zone of Proximal Development (ZPD), with the educator's role being to provide an environmental framework for the learning process (Vygotsky, 1978).

(Davis et al., 2008) reports on the multi-center, cluster randomized controlled trial design of DESMOND in a primary care setting, (Phase IV of the complex intervention framework). The study found positive improvements in beliefs about illness and greatest improvements in weight loss and smoking cessation, but no difference in Hb1Ac levels up to 12 months after diagnosis. The long-term implementation of DESMOND, Phase V, is reported on by (Gillett et al., 2010).

1.4.3.2 X-PERT

The X-PERT Programme aims to increase knowledge, giving the people with diabetes the skills and confidence to make informed decisions regarding their diabetes self-management and is based on the work of Dr Trudi Deakin reported in her PhD thesis (Deakin, 2004). The course is aimed at anyone diagnosed with diabetes, their family and friends. The content of the X-PERT programme explains what diabetes is, advises on energy balancing with the 'eatwell' plate, there is carbohydrate awareness and explanations of glycaemic index. There is also a 'supermarket tour' for participants and understanding of food labelling and an interactive session with the 'X-PERT game'. Also the possible complications of diabetes and how they can be prevented are discussed, as well as the benefits of physical activity, with a final session addressing care planning.

X-PERT is a six-week programme based in the local community centred on the theories of patient empowerment and patient activation. X-PERT aims at a shared experience for the person with diabetes, so family and friends are invited along; the programme caters for a group of 16 participants and runs for two hours over six consecutive weeks. The final 20 minutes of each session is set aside for goal setting, as the aim of the X-PERT programme is to empower the person with T2D to self-manage. There is a patient manual which is given

at the beginning of the course; this covers background reading and additional material is added each week.

X-PERT structured diabetes education programme for adults with T2D, based on theories of patient empowerment, described as; 'helping people discover and use their innate ability to gain mastery over their diabetes' (Deakin et al., 2006 p945) and discovery learning where, the learner solves problems to gain knowledge through discovery (Brunner, 1966). The programme is designed to develop the skills and confidence required to improve diabetes self-management and enable sustained improvements in clinical, lifestyle and psychosocial outcomes for people with T2D. X-PERT encourages people with diabetes to be experts at living with their condition and to actively participate in the learning process. In addition, they were encouraged to have autonomy, by working in partnership with the healthcare professionals to implement effective self-management.

In her PhD thesis (Deakin, 2004) considered the theoretical pre-clinical stage, the second modelling stage (phase II) and the pilot (phase III) of the MRC complex interventions framework. The clinical trial of X-PERT, phase IV, MRC complex interventions framework was reported in (Deakin et al., 2006), and was conducted in Burnley, Pendle & Rossendale Primary Care Trust, East Lancashire, with 314 participants from White European and South Asian backgrounds who had been diagnosed with T2D for an average of 6.7 years. The programme was delivered by a single research dietician and consisted of six, two hour, weekly group sessions. (Skinner, 2006) warns against the possible 'active ingredient' effect in the delivery of this clinical trial.

Phase V, MRC complex interventions framework indicating the long term implications of the X-PERT was assessed through a continuous audit which found that the programme met with the standards identified in the published trial (Deakin, 2011). X-PERT was found to increase skills, knowledge and confidence for diabetes self-management, with improved glycaemic control and reduced cardiovascular disease risk factors in people with newly diagnosed and existing diabetes, (Deakin, 2011). The results found all outcomes had improved at one year; Hb1Ac reduced by 0.6%, body weight reduced by 3Kg, waist circumference reduced by 2.1cm, systolic BP reduced by 0.9mmHg and diastolic BP reduced by 2.2mmHg, LDL cholesterol reduced by 0.1mmol/L; triglycerides reduced by 0.2mmol/L, HDL cholesterol improved by 0.1mmol/L, and the requirement for prescribed diabetes medication was 23% less likely. Deakin (2011) concludes that X-PERT is a cost-effective approach that should be offered to all people with diabetes as an integral part of

their diabetes treatment and management, which would potentially save the NHS £367 million a year.

1.4.3.3 The Diabetes Manual

The Diabetes Manual is a one-to-one structured education programme for people with T2D. It has been developed in collaboration with the Heart Manual Team, (Sturt et al., 2008). The Diabetes Manual is aimed at people with established T2D and is designed to be delivered in primary and secondary care by health professionals experienced in providing routine diabetes care. The Manual uses cognitive behaviour therapy and self-efficacy theory to enhance both the health professionals' skills and the skills of the patient. This is achieved by 'confidently and progressively developing and valuing new behaviours' (Sturt et al., 2006 p7).

The Diabetes Manual is a 12 week patient-led programme, which incorporates educational and psychological diabetes intervention into a single programme, to include all aspects of diabetes self-management. The patient is given two CDs of frequently asked questions and relaxation techniques, and follows a 230 page workbook, with a nurse lead telephone support service. In addition, there is a two-day facilitators training course for the healthcare professionals who will be delivering the programme.

The Diabetes Manual uses teaching methods for practice nurses and people with diabetes; it is learner-centred and facilitates cognitive learning and behaviour change. The Pre-clinical stage and theoretical principal for the Diabetes Manual is detailed by (Sturt et al., 2006) and is based on Self-efficacy Theory (Bandura, 1977) and Experiential Learning Techniques (Kolb, 1984) to develop confidence, skills and knowledge in diabetes self-management, promote shared decision making with the diabetes team and provide theory-based structured education. The Diabetes Manual is modelled on the Heart Manual, a behaviour change programme with a strong evidence base (Dalal and Evans, 2003).

The researchers hypothesised from their work on the Heart Manual, a Diabetes Manual would be useful to people with established T2D and with HbA1c greater than 7% and for healthcare professionals in the field of T2D care. The Heart Manual was designed to promote psychological adjustment to chronic heart disease, but not measure biomedical outcomes. Whilst the Diabetes Manual is designed to promote increased self-efficacy (Bandura, 1977) and quality of life (Polonsky et al., 1995) for people with T2D, thus

improving HbA1c and reducing chronic heart disease risk factors. According to (Docherty and Dale, 2004), the Diabetes Manual phase I study had capitalised on the effectiveness of the Heart Manual in its entirety, questioning whether all the component parts of the Diabetes Manual were necessary. The Diabetes Manual is based on delivering one-to-one education and psychological components in a single programme, which is claimed offers the potential for people to learn about their diabetes in a psychologically motivating and confidence enhancing way.

(Sturt et al., 2008) reported on phase IV of the MRC complex interventions framework; the randomised, controlled trial was a delayed intervention with 245 participants delivered over 12-weeks, on a one-to-one basis. The control group received usual care for six months and then received the manual. In addition to the manual, participants received telephone support at week one, five and 11, from trained practice nurse educators, and participants were followed up at six and 12 months. However, the results did not show any biomedical differences between the groups, (Jarvis et al., 2010) suggested this may be due to the study being underpowered; though significantly reduced diabetes-related stress and increased confidence to self-care were reported.

1.4.3.4 Comparisons Between the Education Plans for Type 2 Diabetes

The principles for effective self-care and management of T2D are essentially the same for the three education programmes discussed, as they all use good practice based on evidence gleaned of the key diabetes studies, in particular the UKPDS (1998) discussed in Section 1.4.1.1. The philosophy for the three programmes is also the same, based around patient education, self-management strategies and empowerment. The DESMOND and X-PERT programmes focus on goal setting as the tool to empowerment (Funnell and Anderson, 2004); (Anderson and Funnell, 2000), whereas the Diabetes Manual has a much more psychological approach (Sturt et al., 2006). The goal setting for X-PERT occurs as the course progresses week-on-week, whereas DESMOND establishes goal setting at the end, to reinforce self-management as the take home message. Another major difference is that DESMOND and X-PERT are taught educational programmes, whereas the Diabetes Manual is patient-led, with telephone support.

The length of the individual courses and their structure varies considerably, X-PERT is 12 hours and DESMOND six hours, and the Diabetes Manual lasts for 12 weeks. DESMOND takes place over one or two weeks and X-PERT over six consecutive weeks. The

DESMOND and X-PERT programmes are community based and involve participants attending a venue for the course, whereas the Diabetes Manual remains within the GP practice, led by the practice nurse. X-PERT and DESMOND are group based interventions, where friends and family are welcomed along to share the experience and support the person with diabetes. Whilst the Diabetes Manual is undertaken on a one-to-one basis, support is provided for the individual by the facilitator. X-PERT and the Diabetes Manual use a course book from the outset, which is completed week-on-week by the patient as the course progresses, whereas the DESMOND programme gives the patient their course manual at the end.

There are similarities and significant differences in the psychological theories underpinning these interventions, and a comparison of structured education programmes, including DESMOND, X-PERT and the Diabetes Manual was conducted by (Jarvis et al., 2010). The DESMOND and X-PERT programmes are based on the idea of the ZPD proposed by Vygotsky (Vygotsky, 1978), and the DLT proposed by (Bruner, 1966). Bruner became increasingly influenced by Vygotsky as he became critical of the intrapersonal focus he had taken, and the lack of attention paid to social and political context. Bruner used the term 'scaffolding' in his DLT which he applied to various educational contexts, which he developed from Vygotsky's concept of the ZPD. The concepts in these theories are similar to those of learning by experience proposed by Kolb's Experiential Learning techniques (Kolb, 1984).

DESMOND and the Diabetes Manual use Bandura's Social Learning Theory and Self-efficacy Theory (Bandura, 1977), which is recognised as one of the strongest predictors of health behaviour change (Conner and Norman, 1998); (Gillis, 1993). Self-efficacy has been shown to be one of the most consistent predictors of successful self-care behaviour, and has been incorporated into most health psychology models, (Skinner et al., 2003). In addition, by enhancing self-efficacy in long-term disease management it has been shown to be associated with lower levels of healthcare consumption and improved psychosocial adjustment (Steed et al., 2003). Self-efficacy and behaviour change will be discussed further in Chapter 2, Section 2.3.1.1

X-PERT uses empowerment, which according to (Rodgers and Walker, 2002), cannot be given or taught, as it is a process that people can only enable for themselves. The basis of empowerment has elements of self-efficacy (Anderson and Funnell, 2000), and recognises that every person is an autonomous being enabling them to have knowledge and confidence to make informed choices about their own actions and behaviours (Walker, 1998).

1.4.4 Health Literacy

Health literacy within the context of diabetes education requires consideration, (Williams et al., 1998b) found that patients with lower literacy who had participated in educational programmes for diabetes had worse knowledge and self-management skills. Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services which are required to make appropriate health decisions, (Institute of Medicine, 2004) and is a measure of patients ability to read, comprehend and act on medical instructions. Poor health literacy is common amongst, racial and ethnic minorities, the elderly and those with chronic health conditions (Schillinger et al., 2002).

Studies indicate that patients with low health literacy skills and chronic diseases, like T2D have less knowledge of their disease and its treatment, and so have inadequate self-management skills (Williams et al., 1998b). According to (Schillinger et al., 2002) low health literacy is thought to independently contribute to the disproportionate burden of diabetes-related problems among disadvantaged populations. In a study by (Gazmararian et al., 2003) less than 50% of participants with inadequate health literacy knew that insulin and diabetes medication makes your blood sugar go down, compared with 68% in those with adequate health literacy. In addition, (Baker et al., 2002) found patients with inadequate health literacy were more likely to be hospitalised than those with adequate health literacy, even when the findings were adjusted for differences in demographics and health status.

According to (Osborn et al., 2010), the mechanisms linking health literacy to diabetes self-care and clinical outcomes are poorly understood. However, research has documented that the prevalence of diabetes is inversely related to educational status, and that difficulties in comprehension result in an incomplete understanding of the disease and its management for these people (Gazmararian et al., 2009). (Von Wagner et al., 2009), found that health literacy had an indirect effect on diabetes self-care and glycaemic control through social support, people with diabetes and limited health literacy may be obtaining support from healthcare providers, family, friends and caregivers.

(Rosal et al., 2004) suggested that people with a limited educational background lack understanding of the meaning of blood tests, and to understand tests such as Hb1Ac requires knowledge of complex mathematical concepts which are directly related to literacy and level of formal education. This is supported by (Gazmararian et al., 2009), who found

that most participants displayed significant knowledge gaps concerning appropriate diet for people with T2D, and though many seemed to understand there is an association between dietary intake and blood sugar levels, few followed the recommended dietary regimen.

1.4.5 Socio-economic Consideration

(Bains and Egede, 2011) found that health literacy was independently associated with diabetes knowledge and concluded that in a low-income, predominantly ethnic minority population, diabetes knowledge and perceived health status are the most important factors associated with glycaemic control. Limited health literacy seems to have an effect on diabetes knowledge, but was not directly related to diabetes self-care or medication adherence.

Health inequalities have been demonstrated with regard to the prevalence of T2D, which affects all socio-economic groups but is generally more frequent in lower socio economic categories (Connolly et al., 2000); (Evans et al., 2000). People from lower socio-economic groups are at greater risk from T2D, and are three-and-a-half times more likely to experience ill health as a result of their diabetes than those in more affluent groups, (DoH, 2001). The existence of a social gradient in health is notable and has been defined by (Marmot, 2004) as a stepwise or linear decrease in health with decreasing social position.

The modifiable risk factors for diabetes include; obesity, physical inactivity and cigarette smoking which are themselves related to socio-economic inequalities. Socio-economic disadvantage has been associated with high smoking rates (Nocon et al., 2007), low levels of leisure time physical activity (Popham and Mitchell, 2007) and a higher obesity prevalence has been reported for women of low socio-economic status (McLaren, 2007). However, according to (Maty et al., 2010), the association of T2D and socio-economic status is only partly explained by the known risk factors for diabetes.

(Imkampe and Gulliford, 2010) studied the socio-economic inequalities in diabetes prevalence with regard to gender, and found no significant inequalities in diabetes prevalence in men, but noted increasing inequalities over time in women. Several explanations for this have been proposed; T2D incidence could be increasing disproportionately among lower socio-economic groups, which may be related to an increasingly aging population. According to (Espelt et al., 2008), inequalities in diabetes prevail in both genders, but the degree of inequality was more severe in women.

1.5 Ethnic Populations and Type 2 Diabetes

South Asian peoples include those from India, Pakistan and Bangladesh they demonstrate an increased susceptibility to T2D. In the UK, people of South Asian origin are up to six times more likely to develop T2D than the white population (DoH, 2001), and up to 10 years earlier (Nicholl et al., 1986). (Nazroo, 2001) investigates migration to a country where immigrants encounter significant health inequalities because they are poorer and less well educated than the majority population.

This increased susceptibility of South Asian people to T2D is due in part to a genetic predisposition and individual risk factors linked to 'Westernisation' of lifestyle, (Greenhaulgh, 1997). (Garduño-Diaz and Khokhar, 2012) attributed the increased prevalence of T2D in migrant South Asians to an unhealthy diet and reduced physical activity, the incidence of T2D in Pakistan is 7.6%, in Indian 7.1% and in Bangladesh 6.1%, by comparison, the incidence of T2D in people from these ethnicities is 11 to 33% in the U.K. South Asians have an increased prevalence of T2D of three to six times that of White Europeans, (McKeigue et al., 1992); (Cruickshank et al., 1991) and according to (Tremblay and Hamet, 2008) South Asian people develop T2D at a significantly younger age of 45.9 years, compared to 57.3 years in Caucasians, which increases their risk of complications. Some studies also report that control of T2D to be poorer and with more complications in some ethnic groups compared to Whites (Garduño-Diaz and Khokhar, 2012); (Greenhaulgh, 1997). These risk factors are modifiable when culturally sensitive education is available, the aim for all people with T2D is to enhance self-motivation, and thus self-management and self-care (Garduño-Diaz and Khokhar, 2012); (Rhodes et al., 2003).

1.5.1 Prevalence of T2D in People of South Asian Ethnicity

Studies found that urbanisation and dietary changes bring about a higher consumption of foods of animal origin, more refined carbohydrates, more saturated fats and more processed foods and less fibre; which are associated with adverse health consequences such as obesity, insulin resistance and T2D, (Garduño-Diaz and Khokhar, 2012); (Ramachandran et al., 2010); (Mohan et al., 2008); (Dickinson et al., 2002). Dietary fat has an adverse effect on insulin sensitivity, which is heightened with obesity and low physical activity (Lovejoy and DiGirolamo, 1992).

The way in which fat is distributed is a factor which contributes to the complexity of the relationship between obesity and insulin. Several studies show when fat is distributed preferentially in the abdominal area, insulin-mediated glucose disposal is reduced, (Abate et al., 1996). Even without a significant accumulation of total body fat the preferential accumulation in the truncal or abdominal area may be associated with development of insulin resistance and T2D. South Asian people are more prone to develop abdominal obesity and have more insulin resistance; these ethnic differences in fat distribution have been considered to be a major contributor to the observed excessive prevalence of insulin resistance and diabetes in South Asians, which may be genetically determined (Raji et al., 2001); (Banerji et al., 1999).

Genetic factors also play a significant role in the onset of T2D in South Asians (Chandak et al., 2007); (Misra and Vikram, 2004); (Mohan et al., 1986) research shows a specific T2D gene to be repeatedly associated with the disease in some ethnic groups, including South Asians (Cauchi et al., 2007). South Asians are also predisposed to high risk lipid profiles, despite low total cholesterol levels (Zoratti et al., 2000). High LDL cholesterol, low HDL cholesterol, and high triglyceride concentrations are all recognised as risk factors for T2D (Jenum et al., 2005); (Raji et al., 2001).

1.5.2 Theories for the Increased Prevalence of T2D in People of South Asian Ethnicity

There are various theories to account for this heightened prevalence of T2D in South Asian people, which are; central adiposity insulin resistance syndrome theory (Greenhalgh, 1997); (Dowse et al., 1993) and the thrifty genotype (Barker et al., 1993); (Neel, 1962), obesity and inactivity syndrome theory (Misra et al., 2008); (Hayes et al., 2002); (Tuomilehto et al., 2001); (Greenhalgh, 1997); (Dowse et al., 1991), Smoking (Rimm et al., 1995) and chewing Betel-nut (Boucher et al., 1994), vitamin D-deficiency (Greenhalgh, 1997), access to diabetes services (Rhodes et al., 2003); (Greenhalgh, 1997), and psychological stress and economic deprivation (Bradley and Gamsu, 1994).

1.6 Gender and Diabetes Self-management

Generally, women found their diabetes to be more of a burden and obstacle than men; they particularly felt that it restricted them in their social interactions which contributed to increased anxiety. (Enzlin et al., 2002) found that women reported greater difficulty in

adhering to diabetes regimens than men, despite having taken responsibility for their own care. Although men perceive diabetes self-management to be difficult, it has been less of a hindrance in their life and daily activities (Fitzgerald et al., 1995); (Gafvels et al., 1993). (Peel et al., 2005) found a gendered dimension to diet; women constructed their diets as something to be managed individually, which often in conflict with, and in addition to, what the rest of the family expected to eat. Whilst men constructed their diet as a broader family issue, which was not their concern alone. The women constructed accounts in which accommodating the family likes and dislikes which takes precedence over their own dietary requirements. Implying that their diet is a concern for them alone, warranting individual management in the context of the pre-existing family framework that was not amendable to modification.

In addition to issues surrounding diet and exercise, an increased risk for psychosocial distress and depression has been reported among people with diabetes in comparison with the general population, (Anderson et al., 2001); (Peyrot and Rubin, 1997). An estimated 25% of people with T2D have depression and the rate of depression in women with diabetes is double that of men (Whittemore et al., 2005). Psychosocial distress and depression have been associated with poor self-management and metabolic control, demonstrating a potential cyclical process of poor health outcomes (Ciechanowski et al., 2000). Women with diabetes have also been found to have an increased risk for psychosocial comorbidity compared with men with diabetes (Anderson et al., 2001).

Further to this, women with diabetes exhibit poorer diabetes self-care, glycaemic control, and quality of life (QoL) than men with T2D, which according to (Anderson et al., 2001) is further exacerbated by depression. (Svenningsson et al., 2011) compared perceptions of QoL and attitudes towards diabetes in obese and normal weight people with T2D from a gender perspective; they found that depression and anxiety was more common in women than men, and women experience poorer health and QoL than men (Svenningsson et al., 2011). According to (Whittemore et al., 2005) psychological stress may affect the ability to manage the disease and thus prevent women from achieving adequate metabolic control.

1.6.1 Social Support, Gender and Diabetes Self-management

With regard to gender and ethnicity, data from the study by (Anderson et al., 1995) suggested that disease management is not the result of a woman's ethnicity, but that it is positioned within the complexity of relationships. Whilst cultural categories do give specific

meanings to illness, the actual management of illness is more dependent on a woman's access to resources and the circumstances of everyday life, than in her cultural beliefs about illness. (Anderson et al., 1995) states; 'Diabetes management therefore becomes a multifaceted phenomenon, which has to be understood within the mediating circumstances of a woman's life' (Anderson et al., 1995 p191).

Successful diabetes management requires a combination of, knowledge of the disease along with behaviour and lifestyle modification (Misra and Lager, 2009). However, knowledge alone is not sufficient to establish healthy lifestyle choices (Simmons et al., 2004); whereas, knowledge in conjunction with social support and/or acceptance can significantly influence management behaviour, glycaemic control, and QoL (Speight and Bradely, 2001); (Coates and Boore, 1996). Social support has been studied by (Murphy et al., 1994) who found that family social support did not guarantee better metabolic control, even though it did promote better self-care. Support and confidence in living with diabetes was the most consistent factor associated with metabolic control, dietary self-management, and psychosocial adjustment (Whittemore et al., 2005). Previous research in diabetes and other chronic illness supports the positive effect of social support and self-confidence in performing specific health behaviours on a variety of health outcomes, such as QoL, adherence to treatment recommendations, metabolic control and well-being (Lenz and Shortridge-Baggett, 2002); (Kaplan and Toshima, 1990).

Social care and support is important for patients with chronic disease; as it promotes adherence to self-care, through which they are able to achieve better management and control (Toljamo and Hentinen, 2001). In their study, (Toljamo and Hentinen, 2001) categorise social support into four different types; (1) informational support, (2) emotional and instrumental support from family, friends and peers, (3) financial support, and (4) negative influence. These definitions of the types of support are in line with what other researchers have found (Tillotson and Smith, 1996); (Wang and Fenske, 1996).

Social support was found to have a positive association with exercise and diet management and was associated with better diabetes behaviours and was an enabling factor in health and illness management (Anderson et al., 1995). In addition, social support has been associated with better self-management (Toljamo and Hentinen 2001); (Glasgow and Toobert, 1988), better metabolic control (Trief et al., 2001); (Brown and Hedges, 1994), better psychosocial adjustment (White et al., 1992), and decreased risk of depression (Willoughby et al., 2000); (Connell et al., 1994); (Littlefield et al., 1990).

Studies examining gender differences with self-management in diabetes reported that men were more consistent with dietary and exercise behaviours than women, more confident in diabetes self-management, and had greater social support for making lifestyle changes related to diabetes self-management (Rubin and Peyrot, 1998); (Quackenbush et al., 1996); (Fitzgerald et al., 1995). (Trief et al., 2003) found that support from spouses assisted people with their diabetes self-management behaviours and problem solving, however, within marriage, men often report greater emotional support from their spouse than women (Kvam and Lyons, 1991). The health enhancing effects of social support may be contradicted in women living with diabetes by their traditional gender roles associated with being caretakers of others. (Misra and Lager, 2009) found that women's role as multi-caregivers act as a barrier to self-management especially with regard to diet and exercise. (Scott and Lyman, 1968) consider this with regard to mothers who have an obligation to put their children's interests first. Another factor that may contribute to these gender inequalities according to (Wood, 2002) is that employment reduces the amount of time women have to prepare meals.

Various patterns of family adaptation have been studied and documented; the families interactions in self-management choices provide descriptions of diabetes management within a social context, and indicate how including the family is beneficial to overcome barriers to self-care (Bumpas, 1990); (Nye, 1976). Findings by (Gerstle et al., 2001) support these earlier studies, indicating that family system measures are significant predictors of glycaemic control. Behaviour and lifestyle modification is easier with social support; wives and mothers are usually support givers, and it is evident that when they become support recipients, diabetes management improves (Gerstle et al., 2001).

1.7 Summary

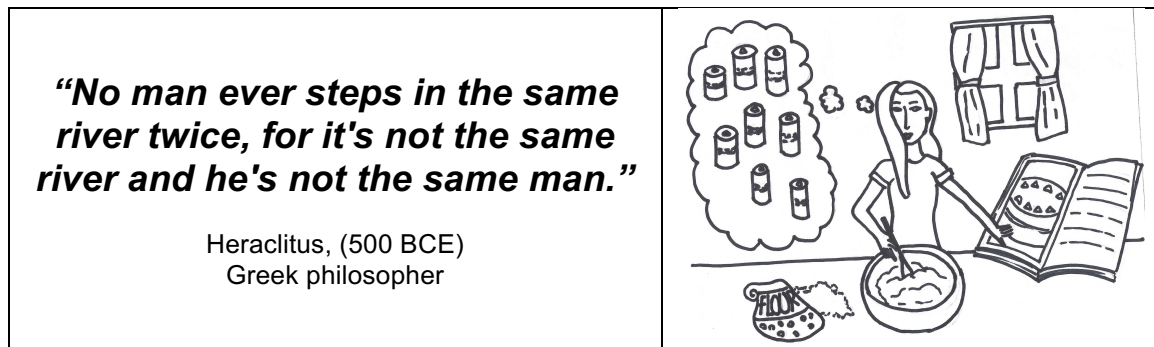
Despite the evidence presented of a positive relationship between better blood glucose control and lower risk of complications, indicated in the landmark studies and key research, many studies, including those with a strict clinical orientation have reported immense difficulty in attaining rigorous blood glucose control within day-to-day self-management, (Frewer et al., 2001); (Wolpert and Anderson, 2001). The UKPDS (UKPDS, 1998) long-term follow-up trial found that many participants were unable to maintain tight glucose targets, with blood glucose control steadily worsening over the nine years of the trial (Jarvis et al., 2010). This suggests that when strict blood glucose control is the main care criterion,

patients perceive it as inflexible, thus rendering their care choices to be limited and life to be controlled by the disease (Wolpert and Anderson, 2001).

People with diabetes need self-management education designed to promote informed decision-making, and care providers need to practice in ways that support patients to become effective self-managers (Funnell and Anderson, 2004). It is also noted that whilst health professionals are experts on diabetes care, it is the patient who is the expert on their own lives (Funnell and Anderson, 2004). Although people with diabetes generally know about and even fear the chronic complications of their disease, many have great difficulty in following recommendations and guidelines, because of the habits, choices and priorities that they have already established within their lives (Cyrino et al., 2009). Self-management care regimes need to be flexible, allowing people with diabetes to adapt treatment to the demands of their daily routines. According (Funnell et al., 2005), patients can then determine an approach to diabetes self-management that will work for them; having identifies and learned to solve their own problems. The person with diabetes must be responsible for, and in control of their daily diabetes self-management to succeed in effective self-care.

The research proposal for this PhD study and the rationale will be explored in the literature review, Chapter 2. The method and methodological reasoning will be discussed in Chapter 3. The research chapters are Chapters 4, 5, and 6; Study (1): (Chapter 4) Investigating the barriers to self-care for people with type 2 diabetes: A systematic review and meta-synthesis of qualitative research, Study (2): (Chapter 5) 'Can I See the Way?' A Qualitative Analysis of Diabetes Self-help Literature and Eye Health, and Study (3): (Chapter 6) Enhanced Diabetic Optometric Practice. Finally, the overall conclusions of this PhD study will be presented in Chapter 7.

2 LITERATURE REVIEW



2.1 Introduction

This PhD research study will investigate self-care and management of people with T2D and eye health, through the delivery of an EDOP; Study (3): Chapter 6, which involved a graphic portrayal of diabetic retinopathy, as it manifests itself in the eye and in the patient's own eyes. It is conjectured that the participant's concern for sight loss will be a driver towards better diabetic control, and the key to improved self-motivation and management. The purpose of this literature review is to evaluate research that has been undertaken within the field of optometry and ophthalmology with regard to the use of retinal photographs and the retinal screening episode for educating people with T2D about their diabetes and the ocular complications.

2.1.1 Interest in the Research Topic

Many optometrists undertake as a standard part of their daily optometry practice patient education on eye care. The optometrist is highly qualified to detect diabetic eye and is often employed as a screener and grader within the diabetic retinopathy screening programme. Literature in this area is deficient, highlighting the missed opportunity for meaningful and relevant education about eye health and general T2D self-management. As an optometrist and diabetic retinal screener the author of this PhD thesis has personal experience of people with diabetes wanting to learn more about the disease and its management; and is often asked about the retinal images, the significance of diabetic retinopathy on vision, and how to reduce the risks of diabetic eye disease and other complications of diabetes.

This missed opportunity for diabetes self-management education in the form of an additional optometric service is what gave the author and researcher of this PhD study the notion of

investigating the use of digital retinal images as an educational tool in the form of an enhanced optometric practice for people with diabetes. The rationale for focusing on diabetic eye disease in the form of an Enhanced Diabetic Optometric Practice (EDOP) will be discussed in Section 2.4

2.1.2 Scope and Organisation of the Literature Review

As discussed in Chapter 1, Section 1.1.3, the Incidence of T2D in all age groups and populations is increasing, and people with diabetes want more information about their disease and its complications (Peel et al., 2004). It is proposed that the diabetic retinopathy screening episode offers an already existing opportunity, which could be tailored to provide an EDOP and fulfil that role. Optometrists already undertake diabetic retinopathy screening, and use digital retinal images as an aid to early diagnosis and treatment of sight threatening diabetic eye disease. The notion of using the retinal screening appointment, not just as a means of detecting diabetic eye disease, but for education and empowerment of people with diabetes to enable more effective self-care may further help to reduce the risk of blindness. Digital retinal imaging is a relatively well established area of research with regard to detection, diagnosis and treatment of diabetic eye disease for clinicians (Niemeijer et al., 2007); (Olson et al., 2003). However, with regard to the use of retinal imaging as a patient educational tool to promote better health outcomes for people with T2D, this review found relatively little research.

The review of T2D self-care and management literature includes; chronic disease and illness representations, patient attitudes, beliefs and preferences, and appraises compliance, adherence and concordance in healthcare. The literature review explores the shift in T2D self-management and care, as the traditional diabetes care model of patients complying with instructions prescribed by healthcare providers is changing to one of a concordant mutual care relationship. Also considered is education and learning, motivation, empowerment, and behaviour change theories relating to optometry and T2D education. However, due to the lack of information available in the literature on T2D education delivered by optometrists, other professions were searched; dentists, podiatrists and pharmacists. As with optometrists, these health professionals practice within 'High Street professional service' environments. This defines them, particularly in terms of accessibility, from doctors, nurses, and dieticians who generally practice in 'institutional' environments, and so were not considered.

The literature review is organised into four main areas of research; (1) behaviour change models and theories, (2) medical imaging in healthcare, (3) T2D education delivered by healthcare professionals, and (4) compliance and concordance. The method used to search the literature will be explained in Section 2.2; the review will then be interpreted and synthesised, having considered the aims of the study, and deficiencies in the research field; finally, the rationale for this PhD research study will be presented along with the research questions, (Section 2.4).

2.2 Method

This literature review takes the form of a traditional 'narrative' as described by (Jesson et al., 2011). The method of critical reading of literature to be reviewed is based on (Fisher, 1993), and adapted by (Hart, 1998), who provided a systematic technique for reading analytically, which involves a process of searching the literature, appraising the identified literature and synthesising the content.

2.2.1 The Search Criteria

The databases searched were Science Direct, PubMed, PsycArticles and Web of Knowledge. The on-line search engine of Google Scholar was used to establish a wide range of literature, including grey literature. The use of Google Scholar was deemed particularly useful due to the limited number of published papers relating to the research topic. In addition, references quoted in the papers reviewed were followed-up as another source of possible data. The researcher of this study searched the data bases periodically between February 2011 and June 2015, and followed up research announcements and publications when information in the subject area was identified. An additional literature search was made in February 2016 into T2D education offered by the podiatrists, in response to a request by the examiners of this PhD thesis during the viva examination.

For each of the literature review search areas the following key words were used:

Key words for searching T2D self-management education;

Type 2 diabetes, diabetes self-care, diabetes self-management, diabetes education, health education, DESMOND, X-pert, Diabetes Manual, self-efficacy, empowerment, autonomy, motivation, fear

Key words for searching imaging in healthcare;

Type 2 diabetes, diabetic retinopathy, retinal imaging, teleretinal imaging, medical imaging, telehealth, telemedicine

Key words used to search for T2D education delivered by healthcare professionals;

Type 2 diabetes, diabetic retinopathy, diabetes self-management, health education, patient education

Optometry, optometrists, ophthalmology, ophthalmologists

Dentistry, dentist

Podiatry, podiatrist

Pharmacy, pharmacists

Key words used to explore compliance and concordance in healthcare;

Type 2 diabetes, compliance, adherence, concordance, diabetes management, diabetes education, non-compliance, strategic cheating

2.2.2 The Search Findings

Two relevant papers were already known to the author prior to beginning this literature search (MacDonald, 2010); (Rosberger et al., 1998) 16 different combinations of key words were used giving a maximum yield of 189 hits, which was reduced to 130 when the duplicates were removed. Five searches did not produce any hits, these were searches which used: retinal images, type 2 diabetes education and optometry/optometrists; diabetic retinal screening, patient education; and diabetic retinal screening, patient education and management.

When ophthalmology/ophthalmologists were included the search produced 386 hits when duplicates were removed. However, only one additional paper was found, all other articles retrieved related to education of ophthalmologists and detection of diabetic eye disease. As with the previous searches on optometry, comparisons of retinopathy detection using slit-lamp bio-microscopy compared with digital retinal screening were found.

With continued periodic searching of the data bases, using the key word combinations only two papers were found on the use of retinal images for diabetes education (Rees et al., 2013); (Salti et al., 2011) During these periodic searches, the researcher sought to find

published research articles and papers which had already been identified as research proposals from the previous searches.

When Google Scholar was initially searched in 2011, a research proposal was found that had been submitted to the US Army for medical research funding, based at Fort Detrick, (Peters and Connolly, 2010). This was further investigated by the researcher through personal correspondence with Dr Deborah Birkmire-Peters, principal researcher, as no research papers had been found during the searches. Dr Deborah Birkmire-Peters referred further correspondence to the author of a PhD thesis for which the funding was originally sought at the University of Hawaii, (Kihmm–Connolly, 2013). Dr Kathleen Kihmm-Connolly confirmed that no research papers associated with the thesis were published; however, Dr Kathleen Kihmm-Connolly kindly emailed a copy of the submitted thesis for this literature review.

Google Scholar also produced the protocol for a research study by the Diabetic Retinopathy Clinical Research Network (DRCR.net), to investigate the use of ophthalmology clinics as the specific location for diabetes education to occur. This research by the DRCR.net (Aiello et al., 2015) is of particular interest; as the idea of exposing patients with T2D to information about diabetic eye disease and exploiting the possibility of sight loss in an ophthalmology environment has similarities with this PhD research study.

2.3 The Literature Searches

This literature review on T2D self-care was conducted into behaviour change models and theories (Section 2.3.1), including self-efficacy, empowerment and motivation in people with T2D, (Sections 2.3.1.1, Section 2.3.1.2 and Section 2.3.1.3 respectively). Fear and motivation are discussed in Section 2.3.1.4, and the behaviour change models and theories are summarised in Section 2.3.1.5. Research literature was searched and reviewed in the area of medical imaging in healthcare, with regard to telemedicine and teleretinal imaging, (Section 2.3.2). In addition, T2D self-management education delivered by healthcare professionals, including optometrists, ophthalmologists, dentists, podiatrists, and pharmacists was reviewed (Section 2.3.3). Finally, the concepts of compliance, adherence and concordance in diabetes self-care were reviewed, with particular focus on healthcare practices, (Section 2.3.4.1) and deliberate non-compliance and strategic cheating, (Section 2.3.4.2).

2.3.1 Behaviour Change Models and Theories

Sufficient self-efficacy, empowerment and motivation are all qualities and responses required by people with T2D to be successful self-managers. (Steed et al., 2003) found that; the patient's ability to be involved in the daily routine of diabetes care is grounded in psychological and motivational factors, as well as educational factors. These elements collaborate together allowing people with diabetes to be adequately inspired and galvanised to employ the required self-confidence to achieve positive results from their self-care.

There are many behaviour change theories and models which focus on different factors to explain behavioural change; each having strengths and limitations. These theories were developed to enable clinicians, health care providers and researchers to appreciate the lived experience of people with chronic illnesses. They are effective in explaining health-related behaviours and provide insight into why people fail to adopt disease prevention regimes and enable the development of health education strategies, which may encourage individuals to develop and maintain healthy lifestyles. (Nouwen et al., 2011) consider that the motivational factors from SDT and SCT to account for behaviour change associated with adherence to dietary self-care in people with T2D. The self-regulation models like Leventhal's Common Sense Theory of Self-Regulation assume that an individual's personal model of an illness is an approximate determinant of both the emotional and behavioural response that a person has to a health threat (Leventhal and Nerenz, 1985); (Leventhal et al., 1980). According to (Glasgow et al., 2001) personal models of illness may affect the relationship between social support and behavioural outcomes, and must be factored into any educational programme plan.

2.3.1.1 Self-Efficacy and Type 2 Diabetes Self-Care

Self-efficacy and self-care agency are needed for diabetes self-management, (Sousa et al., 2005), self-care agency refers to the ability to perform specific behaviours, and includes the knowledge and skills necessary for effective self-care. (Po, 2000) described the relationship between self-efficacy and diabetes self-management in terms of the patient, who is usually not only the recipient of care but also the principle provider. People with diabetes need skills and knowledge to effectively self-manage, but also the confidence or self-efficacy to do so. Self-efficacy is influenced by a person's specific capabilities and other individual factors, as well as by environmental factors, which are the barriers and facilitators to self-care; these are discussed in Chapter 4. (Bandura, 1977) believed that the concept of self-efficacy was the link between knowing what to do and actually doing it. This notion is of fundamental

significance in this research study as research shows that although some people with diabetes are deficient in knowledge and skills regarding diabetes self-management and self-care practices; most do have sufficient self-management knowledge to enable an effective self-care regime, but do not implement it (Trief et al., 2009). Interventions that improve self-efficacy have been shown to improve self-care, (Anderson et al., 1995).

The primary goal of the diabetes educator is to improve a patient's self-efficacy, because according to (Glasgow et al., 1997) the strongest and most consistent psychological barrier to effective self-management of T2D is low self-esteem and the lack of family social support. Factors external to the patient such as receiving conflicting information or unclear goals from various healthcare providers, and having insufficient information and support from their healthcare team may also discourage patients and reduce their self-efficacy. When people with chronic disease are supported by healthcare professionals they are able to develop the capability and skills to recognise their own needs and solve their own problems, (Anderson, 1995).

(Hill-Briggs, 2003) suggest that in identifying individual perceived barriers to self-care it prepares people for negative emotional states, and provides people with chronic illness the problem solving strategies to enable them to confront the difficulties they face in their daily routine. In addition to problem solving strategies, the development of coping skills equips people to tackle the day-to-day problems of living with diabetes, as they become empowered (Funnell and Anderson, 2004). By simplifying self-care regimes and placing emphasis on patient's individual needs, the potential to be more successful is increased and self-efficacy improves. When the focus is on the patient and their environment, attention is drawn away from the disease process, improving self-efficacy (Funnell and Anderson, 2004).

2.3.1.2 Empowerment and Type 2 Diabetes Self-Care

(Funnell et al., 1991) defined empowerment as the discovery and development of one's inherent ability to be responsible for one's own diabetes. According to (Anderson and Funnell, 2000), the concept of patient empowerment has become an integral part of diabetes education; but embracing empowerment requires a paradigm shift that is often difficult because the traditional approach to care is embedded in the training and socialization of most health care professionals. For patients to be truly 'empowered' they need information to make informed decisions on a daily basis, be actively engaged in their treatment planning,

have skills for self-care and make behavioural changes with social and emotional support (Anderson and Funnell, 2010).

(Anderson et al., 2009) demonstrated improvement in self-efficacy using patient empowerment approaches helped people with T2D to feel more confident. They were better able to identify areas of satisfaction or dissatisfaction in living with diabetes, problem solve their own barriers, make cost/benefit decisions and achieve their personal goals. In addition, patients felt empowered to cope with emotional issues and manage their stress, which enabled them to remain motivated. Through an empowerment approach, people with diabetes are able to have an active role in their own care. Empowerment philosophy involves enabling the patient to make informed decisions and take an active role in planning and deciding on actions regarding their own health (Funnell and Anderson, 2004).

(Anderson and Funnell, 2000) states that empowerment is not something one does to patients; empowerment begins when care providers acknowledge that patients are in control of their daily diabetes care. Empowerment occurs when the health care professional's goal of increasing the capacity of the patients to think critically and make autonomous, informed decisions is achieved and when the patient actually makes autonomous, informed decisions about their own diabetes self-management. (Funnell and Anderson, 2003), considered empowerment to be the discovery and development of a person's inherent capacity to be responsible for their own life. This concept is termed by (Carvalho, 2004); in (Cyrino et al., 2009) as 'psychological empowerment', where individuals are able to experience greater control over their own lives. When individuals are empowered, they have sufficient knowledge to make rational decisions, sufficient control and resources to implement their decisions, and sufficient experience to evaluate the effectiveness of those choices, (Funnell and Anderson, 2003). According to (Anderson, 1995) support from healthcare professionals enables individuals to develop their own capacity and skills to recognise their own needs, and be able to solve their own problems. However, (Carvalho, 2004); (Anderson, 1995) have criticised the delivery of self-care education, because of the constraints imposed by social structure the quality and availability of the care services. (Funnell and Anderson, 2004), place great value on patient empowerment in research because while 'health professionals are experts on diabetes care, patients are the experts on their own lives', (Funnell, and Anderson, 2004, p124).

(Rossi et al., 2015) evaluated the BENCH-D study (Benchmarking Network for Clinical and Humanistic Outcomes in Diabetes), a model to monitor and improve clinical indicators for measuring person-centeredness and patient empowerment. The BENCH-D study used

validated questionnaires derived from the DAWN2 study (Diabetes attitudes, wishes and needs second study), (Nicolucci et al., 2013). The DAWN2 study reported in 2013 confirming a lack of self-management education, as well as a lack of critical resources, particularly skills, time and adequate referral sources among health care professionals for delivering appropriate self-management support. The BENCH-D study showed that higher levels of empowerment are associated with a better performance of self-care activities and better person-centred outcomes, (lower perceived diabetes burden such as diabetes-related distress and barriers to medications), higher satisfaction with diabetes treatment and diabetes care organisation, and higher perception of social support. In addition, the researchers found an association between higher levels of empowerment and better health and psychological well-being.

2.3.1.3 Motivation and Type 2 Diabetes Self-Care

Motivation is defined as the psychological process that initiates, guides, and maintains goal oriented behaviours. Motivation is what causes us to act; it involves the biological, emotional, social, and cognitive forces that activate behaviour. There are two types of motivation, extrinsic and intrinsic, they are not opposites, but the extrinsic can lead to intrinsic. Extrinsic motivation is based on activity for attaining separable outcomes, whilst intrinsic motivation occurs through satisfaction with the activity itself (Deci and Ryan, 1985).

However, according to (Williams et al., 1998a) autonomous-supportive motivation is the only type of motivation capable of delivering strict blood glucose control required for diabetes self-management over long periods. Autonomous-supportive motivation comprises of autonomous and controlled motivation and is situated within the principals of Self-Determination Theory (SDT). STD focuses on the outcomes of being more autonomous versus more controlled in one's motivation and on the environmental conditions that promote the different types of motivation. Autonomous motivation involves engaging in an activity willingly, with a sense of choice and eagerness, it is made up of two subtypes; intrinsic motivation and identified motivation. Intrinsic motivation refers to motivation that is driven by an interest or enjoyment in the task itself, and exists within the individual rather than relying on any external forces.

In contrast, controlled motivation is extrinsic and comes from a stimulus outside of the individual, which involves doing a task because of a sense of pressure, demand, or coercion, Extrinsic motivation comprises of two subtypes which are not well internalised; they are

external motivation and introjected motivation. External motivation is where the activity is undertaken in order to receive a reward or avoid a punishment; whilst introjected motivation, involves performing an activity because the person would feel approved of for doing it, or guilty and unworthy for not, and is partially internalised. (Koestner et al., 2008) indicated that autonomous motivation was substantially related to goal progress, whereas controlled motivation was not. In addition, autonomous motivation was shown to involve implementation planning; suggesting that when individuals pursue goals they should focus relatively greater attention on enhancing their autonomous motivation rather than reducing their controlled motivation (Koestner et al., 2008).

2.3.1.4 Fear and Motivation

When considering motivation elicited by fear, the fear-persuasion relationship is not as discernible as it may seem, prior to the classic Janis and Feshbach study of 1953 a belief that, more fear worked more effectively, regardless of other factors existed. However, (Janis and Feshbach, 1953) suggested that moderate fear would be a more effective persuader than high fear. However, this notion is refuted by other researchers, who have suggested that the bulk of the evidence indicates a positive relation between fear and persuasion and that (Janis and Feshbach, 1953) research results were the exception rather than the rule (Leventhal, 1970).

The fear-persuasion relationship was investigated by (Soames-Job, 1988), and considers punishment paradigms and reinforcement. (Soames-Job, 1988) discerned that the major disadvantage of punishment as a procedure is that it does not provide direction to a healthier behaviour, whereas reinforcement produces strengthening of specific behaviours. (Insko and Cialdini, 1969) provided some evidence that punishment is ineffective in producing attitude change. They found that verbal positive reinforcement alone (the use of 'good') was effective in producing self-reported attitude change, while verbal punishment alone (the use of a disapproving 'huh') was ineffective. The combined use of positive reinforcement and punishment had the same effect as the use of positive reinforcement alone, offering evidence for a direct reliable weakening effect of punishment.

(Soames-Job, 1988), considered how punishment affects behaviour, suggesting that the evidence by (Insko and Cialdini, 1969) has provided the 'sound basis' for persuasive communications upon which many health campaigns were based; quoting for example that, fast driving is followed by crashes, and smoking is followed by cancer, (Soames-Job, 1988

p164). In addition, high fear or anxiety provoking messages may be particularly ineffective in stopping behaviours which are themselves anxiety reducing, (Lovibond, 1970). The message may elicit the unwanted behaviour, like reaching for a cigarette or a drink for example. (Soames-Job, 1988), warned that despite the evidence, the tendency is to view most health promotions as the removal of unhealthy behaviour, which may lead many researchers and clinicians to see punishment as the appropriate approach. Health promotion, according to (Soames-Job, 1988) is better viewed as the increasing of healthy alternative behaviours. Considering the examples above, rather than promoting messages like 'don't smoke' or 'don't drink and drive', the messages should offer a set of skills for refusing cigarettes or alcohol, or for getting a ride with someone else instead of driving.

Further to this, and a consideration in this PhD study with regard to the fear of sight loss conveyed by the EDOP; if fear is used to elicit behaviour change, then it should be used in a way which allows fear offset reinforcement to follow an appropriate response, and must be explicitly stated. (Soames-Job, 1988) gives an example; a campaign aimed at increasing seat belt wearing by depicting a skeleton at the wheel of a car, with the caption 'Don't you feel naked driving without your seat belt?' (Avery, 1973), where perhaps the obvious response would be to wear your seat belt. However, the campaign was not successful, and the reasons for the failure of the campaign were proposed by (Soames-Job, 1988). (Soames-Job, 1988) suggests that within the punishment paradigm there was an inappropriate response-fear pairing, and that the event of death, on which the fear is based, was considered a very unlikely event.

In health promotion, pairing a conditioned stimulus, such as riding in a car without a seat belt, with a fear producing situation or unconditioned stimulus, such as injury or even death, relies on second order classical conditioning. However, in the above example, when this type of conditioned stimulus is presented without any effective unconditioned stimulus; the target audience observe that, despite continued not wearing a seat belt, injury, or death has not occurred, the fear response is diminished. This in turn eliminates the effectiveness of subsequent conditioning, as the warning regarding injury/death has only an unconditioned fear response, which is elicited by virtue of association with the event itself (Avery, 1973); (McGuire, 1962). For consequence as large as death, a very effective response is required to alleviate the fear, (Soames-Job, 1988). Notably, compulsory seat belt wearing in response to a fear of a fine was found to be sufficient, (Netterfield and Graham, 1987).

For the fear-persuasion relationship to be effective, the following are required; behaviour shaping, where specific responses are offered rather than naive advice. Fear levels should

be relatively low, so that inappropriate responses, such as denial, are not evoked to deal with the fear, and focus should be on the short-term effects, which allows for more immediate results from the behaviour change, (Lett, 1975). In addition, (Soames-Job, 1988) considered that ineffective use of fear in health promotion campaigns produced the opposite of the desired effects, making the target audience more likely to continue with the unhealthy behaviour, and thus desensitise the audience against the message they are aiming to deliver. This is a consideration in the study by (Aiello et al., 2015) discussed in Section 2.3.3.2 below.

(Evans et al., 1970) and (Janis and Feshbach, 1953) found that high fear communication was seen as more effective, in addition (Evans et al., 1970) found that subjects were more influenced by a positive reinforcement approach. In conclusion, (Soames-Job, 1988) considered that the use of fear is only likely to work under particular circumstances involving the identification of specific behaviours which successfully reduce the fear aroused; warning of the potential harm involved in fear-based campaigns, and that the tendency for health promotion to be seen as the removal of unhealthy behaviour to be resisted, presenting them instead as the shaping and reinforcement of healthy alternative behaviours.

Further to this, the meta-analysis by (Witte and Allen, 2000) suggested that strong fear appeals produce high levels of perceived severity and susceptibility, and are more persuasive than low or weak fear appeals. The results also indicated that fear appeals can motivate an adaptive danger control action such as message acceptance, and a maladaptive fear control action such as defensive avoidance or reactance. (Witte and Allen, 2000) found that strong fear appeals with high-efficacy messages produced the greatest behaviour change, whereas strong fear appeals with low-efficacy messages produced the greatest levels of defensive responses. In conclusion, fear is a great motivator as long as individuals believe they are able to protect themselves.

2.3.2 Medical Imaging in Healthcare and Telemedicine

Medical imaging is the technique and process of creating visual representations of the interior of a body for clinical analysis and medical intervention. Medical imaging comprises different imaging modalities and processes to image the human body for diagnostic and treatment purposes and therefore has an important role in the improvement of public health in all population groups. (WHO, undated). Medical imaging includes; X-ray technology, digital photography, ultrasonography (high frequency sound waves are used to create

images of the inside of the body), Computed Tomography (an imaging method that combines multiple X-ray projections, taken from different angles to produce detailed cross-sectional images of areas inside the body), Magnetic Resonance (radio waves in a magnetic field are used to create detailed images of organs and tissues), and Positron Emission Tomography (a nuclear imaging technique that provides information about how tissues and organs function). Clinical judgment is sufficient in the treatment of many conditions, the use of diagnostic imaging is significant for confirming, assessing and documenting the course of the disease.

In addition to clinical analysis and medical intervention for diagnostic and treatment purposes, medical imaging is a successful educational tool (Hollands et al., 2010). Medical imaging has been used in the field of preventative health as a means to behaviour change, and has produced significant beneficial health outcomes in a number of research studies, which are discussed in the following sections.

2.3.2.1 Medical Imaging as a Behaviour Change Tool

Medical imaging as a behaviour change tool is considered in a Cochrane review by (Hollands et al., 2010). The review reports health behaviour change, using visual feedback from individual's medical imaging results. The aim of the review was to assess the extent to which feedback, to adult, non-pregnant individuals of their own body images can affect a range of health behaviours. Nine trials were identified, involving 1371 participants. The studies included were; five studies with clinical populations, which used imaging techniques in patients receiving active treatment or disease assessment and four studies used imaging techniques in non-clinical populations.

Three of the five clinical studies assessed smoking cessation behaviours, (Shahab et al., 2007); (O'Malley et al., 2003); (Bovet et al., 2002), featuring arterial scanning procedures to assess cardiovascular risk, and reported a statistically significant effect favouring the intervention. A clinically significant result was noted in another of the clinical study which measured skin examination behaviour following a skin photography procedure for assessing moles (Oliveria et al., 2004). The fifth clinical study measured a range of dietary intake and medication usage behaviours featuring an arterial scanning procedure assessing cardiovascular risk, but reported no statistically significant effects (Lederman et al., 2007). All four of the non-clinical population trials featured ultraviolet (UV) photography to highlight UV-

related skin damage; however, only (Gibbons et al., 2005) reported a statistically significant result favouring the intervention.

The reviewers, (Hollands et al., 2010) concluded that targeted interventions using medical imaging technologies may be effective in certain contexts, or as applied to certain behaviours, but that this should be considered on an intervention by intervention basis, and not assumed as a general principle. Due to the low number of studies in the review methodological limitations were noted. In addition, there is considerable variation in how imaging information and risk or disease progression is communicated to patients, (Blaxter, 2009). Further to this review of medical imaging, a Cochrane review of biomedical risk assessment as an aid in smoking cessation, (Bize et al., 2005) found that a study which used the feedback of ultrasound images showing the presence of arterial plaques (Bovet et al., 2002) had the largest effect of any of the included interventions on smoking cessation.

(Hollands et al., 2010) noted that feedback of the images was not presented with accompanying comparison images in the studies reviewed. The researchers suggested that by explicitly showing study participants deviation from what is considered healthy or perhaps by using the patients past scans to reinforce behaviour change, to highlight an observed change in visualised risk may have an added beneficial effect. Research conducted by (Grogan et al., 2011) and (Williams et al., 2012a) discussed below supports this premise using evidence from facial morphing techniques. Further to this research, investigation in the field of teleretinal imaging discussed in Section 2.3.2.2 and Section 2.3.3.2, provides compelling evidence to suggest that visual feedback using comparative images may reinforce behaviour change in people with diabetes.

Facial morphing techniques are an application of medical imaging, and has been shown to be successful in health promotion. Facial morphing uses the 'APRIL' Age Progression Software to show people the likely impact on their faces of changing their behaviour. The technique allows males and females to see their own faces up to the age of 72 years with or without behaviour change, (Grogan et al., 2011); (Williams et al., 2012a). According to Grogan (Slides of 'Aston Uni Talk' May 2015), health-related campaigns fail to motivate many young people to change their behaviour, perhaps because they feel that health-related threats are too long-term to concern them and not relevant to them. (Grogan et al., 2010) found that smokers and non-smokers aged 17-24 years believed that smoking caused skin damage, but did not see this as a self-relevant risk; though many participants were highly motivated to maintain a youthful appearance.

(Grogan and et al., 2011) investigated smoking cessation and found four key themes from the thematic analysis of interview and focus group transcripts;

- (1) Shock at visible ageing, this key theme incorporated two sub-themes, shock at the difference between the photographs and shock at looking 'ugly'.
- (2) Concern about negative effects of UV exposure on appearance.
- (3) Motivation to change behaviour, the difference between the two photographs appeared to link to feelings of motivation to change behaviour.
- (4) Self-relevance of the intervention, a number of the participants reported that one of the most effective elements of the intervention was that it was personally relevant.

(Williams et al., 2012a) investigated sun protection use and found similar positive results to the above study from the facial morphing procedure. Eight themes were identified;

- (1) Fear of visible ageing, this was linked directly with emotional/visceral reactions to the visual images, and indirectly to issues of self-relevance such as personal risk, ownership, and motivation to quit.
- (2) Shock reaction to the images, was the most marked response.
- (3) Visual impact. The women explicitly linked this shock reaction with their intention to quit smoking, making the changes associated with smoking 'real'. Protection Motivation Theory would suggest that raising awareness of personal vulnerability will impact on threat appraisal and promote protection motivation and behaviour change (Rippetoe and Rogers, 1987).
- (4) Concern about skin wrinkling and sagging.
- (5) Concern about others' reactions. Participants reported feeling responsible for maintaining the look of their faces, and changing their behaviour to avoid unnecessary skin damage. yet they did not feel responsible for their health. (Williams et al., 2012a) explained this as being the result of not 'relating to' internal organs due to their invisibility, whereas their face was visible (to themselves and others).
- (6) Personal risk highlighted the importance of the self-relevance of the images shown.
- (7) Ownership and accountability.
- (8) Motivation to quit. The women felt able to take the next step, (Williams et al., 2012a) concluded that in showing young women how smoking will affect their skin in the future brings a long-term risk into the present, making it easier for them to believe that smoking will affect their own skin (Hall and Fong, 2007).

In summary, these studies on facial morphing according to the researchers (Williams et al., 2012a) and (Grogan et al., 2011) show promising qualitative findings, as appearance-focused information may be effective in changing attitudes and behavioural intentions towards smoking and sun tanning in young women. Thus quoting Grogan; 'Appearance-

related morphing interventions may be a useful adjunct to traditional health-focused programmes to encourage people to use sunscreen and to quit smoking' (Slides of Aston Uni Talk May 2015).

In this PhD study, although the images viewed in Study (3) the EDOP (Chapter 6) were not participants' own data, the digital retinal images showing the increasing severity of DR development were compared with normal, health eyes and the risk factors associated with diabetic eye disease were discussed simultaneously. Thus, feedback from the retinal images in the EDOP presentation delivered as part of a multi-component intervention produces a beneficial effect through biomedical risk assessment (Bovet et al., 2002).

2.3.2.2 Teleretinal Imaging

A more specialised field of ophthalmology applies medical imaging and telemedicine to the detection and diagnosis of diabetic eye disease, with regard to treatment and ultimately the preservation of sight; this has been discussed in Chapter 1 within the Diabetic Retinopathy Screening Programme. Within the field of teleretinal imaging, research investigates the use of digital retinal images as an aid to diabetes self-management education and behaviour change and is discussed below.

The literature review identified a retrospective study by (Fonda et al., 2007) based on the premise that; diabetes self-management training has been shown to impact lifestyle and behaviour beneficially, (Norris et al., 2002); (Norris et al., 2001). (Fonda, et al., 2007) investigated clinical outcomes in 13,752 participants on the Joslin Vision Network Telehealth Eye Care Programme (Cavallerano et al., 2005); (Cavallerano et al., 2003), and found improved HbA1c, LDL-cholesterol and systolic BP over two years, and an improved adherence to subsequent eye care for participants who had received the teleretinal imaging. The researchers concluded that the programmes was able to address the many aspects of care necessary to reduce the risk of visual loss due to DR and other complications of diabetes, as they are able to; 'remove barriers, and/or motivate people for the next steps in their eye care' (Fonda et al., 2007, p642). Barriers to self-care are discussed in Chapter 4.

Also identified was a review of telemedicine and ocular health in diabetes by (Bursell et al., 2012), who stated that; 'teleophthalmological studies indicate that the single act of patients viewing their own retinal images improves self-management behaviour and clinical outcomes' (Bursell et al., 2012 p311-abstract). In the review (Bursell et al., 2012) concluded

that appropriately designed and validated telehealth programs, which include telehealth eye care, are able to address the many issues necessary to improve clinical outcomes, and reduce visual loss and other complications in people with diabetes.

Further to these studies, the PhD study undertaken by (Kihmm–Connolly, 2013) was found which investigated a web-based diabetes eye care education programme using retinal images over the Internet. According to (Taylor et al., 2007) teleretinal imaging, combined with population-based strategies, have the potential to increase access to eye care and overcome the traditional barriers to diabetes self-care. (Kihmm-Connolly, 2013) used this premise and TTM (Prochaska et al., 2008) as the basis of her PhD study. The objective of which, was to understand the digital divide and relationship between technology and health outcomes, (Kihmm-Connolly, 2013).

All participants in the (Kihmm-Connolly, 2013) study were given the teleretinal intervention and assessment of behavioural measures including daily self-management, exercise, smoking, and carbohydrate counting. While other diabetes relevant data was obtained from the patient's electronic medical record, including HbA1c, BMI, and level of retinopathy. Participants were able access their personal retinal images and diabetic eye disease education via an on-line web portal. Overall, the study indicated a contribution to the 'digital divide in an underserved, predominately Native Hawaiian population in Hawaii' (Kihmm-Connolly, 2013 piv), and the findings demonstrated that a teleretinal imaging intervention could potentially improve health outcomes. A notable outcome in this study was participant access to technology; although the majority of participants stated that they had Internet access, the on-line patient portal and educational material had only been accessed six times, which equated to only 5% of the participant population. Participants not accessing their personal diabetes data and education material was also noted in (Aiello et al., 2015).

Notwithstanding, (Kihmm-Connolly, 2013), reported that participants during the focus group sessions expressed a willingness to learn and become more literate with computers and eHealth information, and were enthusiastic about the information that they have learned from the study. This is perhaps an obvious response from the participants who may be keen to please the researcher and so over play their participation and enthusiasm for the study, when asked by the researcher about their intended actions following an intervention designed to explore the 'digital divide'.

(Kihmm-Connolly, 2013), also reported that many participants commented that they were relieved that the results of the image showed no signs of eye disease. She concluded that

participating in digital retinal imaging was a form of empowerment; a way to take responsibility for their health and could be considered a form of taking charge and as such a positive step in diabetes management. A theme noted from the focus group discussions was that fear generated motivation for change. This included fear as a result of seeing family members who had died, or who had suffered debilitating health problems due to the complications of diabetes. This finding by (Kihmm-Connolly, 2013) is consistent with that reported by participants in Study (3) the EDOP of this PhD study, which will be discussed in Chapters 6 and 7.

2.3.3 Type 2 Diabetes Education Delivered by Healthcare Professionals

Investigation into this subject area of the literature review began by the researcher determining what 'point of contact' information and literature on T2D and eye health was available from the high street optometrist for patients. The researcher then considered sources of information available from other health care providers including ophthalmology, dentistry, podiatry and pharmacy.

2.3.3.1 Literature on Type 2 Diabetes and Eye Health Available at the Optometry Practice

Although the author of this study wished to investigate the literature on T2D and eye health available at the opticians practice, this resource was found to be considerably limited. The recruitment practices for the EDOP were surveyed; this included three independent practices, and Boots Opticians. One additional independent practice and three multiples were also surveyed, the multiples being; Specsavers in Walsall town centre and Brownhills, Vision Express in Walsall, and Scrivens Opticians in Willenhall. The only information available to people with T2D was the joint Royal National Institute for Blind People (RNIB) and the Royal College of Ophthalmology (RCOphth) 26 page booklet on 'Understanding eye conditions related to diabetes', (RNIB. and RCOphth., 2010). All of the independent optometric practices, other than the additional independent practice had this booklet available, no other information leaflets or publications were on offer. None of the multiples other than Boots Opticians had any information available on T2D and eye health. The researcher telephoned Specsavers and Vision Express head offices to enquire about the availability of patient information in their practices and was told that they did not publish any corporate eye health information.

This booklet is well presented, with little medical jargon, the print is large and the headings are clear and it is easy to access. 'Diabetes and your eye' is explained on page eight, with bullet points for; diabetic retinopathy, transient variations in vision due to poorly controlled diabetes, and cataracts. 'Temporary blurring' and 'Cataracts' are again discussed on page 22. The various stages of diabetic eye disease are discussed under sub-headings on page 9-11. 'Reducing the risk' of eye disease is a major section (p12-14), with annual retinal screening being given attention on page 13-14. There is also a comprehensive section on treatment for diabetic retinopathy (p15-21).

Boots Opticians was the only multiple which had any information on diabetes available to the public; this was in the form of their own publication. However, the advice offered in this A4 leaflet, 'Type 2 Diabetes – Let's keep things in balance' (Boots UK Limited, 2012) was found to be very limited; the message conveyed was hinged more on the pharmaceutical aspects of T2D management. The clear message being 'How can Boots help?' which is geared towards T2D medication compliance, which would perhaps be expected from an optometry practice within a pharmacy company.

The researcher noted the lack of available literature on diabetes and eye health at the patient-optometry interface and so surveyed the local GP practices. The GP surgeries surveyed were those located near to the opticians practices where recruitment occurred; this included; two town centre practices, Pleck Health Centre, Pinfold Health Centre in Bloxwich, and Park View Medical Centre in Brownhills, (the latter two practices, both have three GP surgeries).

There was a lack of information leaflets displayed or available within the reception/waiting area of a number of the practices. All the waiting areas had a display stand for patient information leaflets, but many were poorly stocked with any type of information literature. The only information available was for the diabetic retinopathy screening service. When the researcher made a request for information on T2D to the receptionist, none was, the researcher was told that when diabetes is diagnosed patients are given an information booklet by the practice nurse. No comment or assessment of the merits of this booklet on eye health and diabetes was possible, as the researcher was told that this booklet was only available for people with diabetes. The receptionist at a GP surgery in Park View Medical Centre suggested that the researcher 'google' the 'NHS Choices' website for information.

The local pharmacies were then investigated with regard to access to information on diabetes and eye health. Of the three multiples surveyed; Boots Pharmacy, Lloyds Chemist

and the Co-operative, all had information on T2D available to print on request. In addition, at Boots Pharmacy the researcher was offered the same leaflet which was available from Boots Opticians. This five page leaflet mentions only one sentence on eye health on the third page under 'long-term complications' the sentence states; 'Eye problems can affect vision (due to damage to the small arteries of the retina at the back of the eye)' (Kenny and Tidy, 2011). This comprehensive information leaflet on T2D management was lacking on any information regarding diabetes complications and eye health, and was found to be overly prescriptive regarding medication regimes.

In view of this disappointing and somewhat surprising lack of information on eye health and diabetic retinopathy available from the high street optician, the researcher of this PhD study considered information available from other health care professions, and self-help book as the most readily available source of information on eye health and diabetes self-care. Chapter 5 investigates eye health and self-help literature, and is study (2) of this PhD thesis; 'Can I See the Way?' A Qualitative Analysis of Diabetes Self-help Literature and Eye Health.

2.3.3.2 Optometry and Ophthalmology

There has been little investigation into optometric services and the role of the optometrist in education for people with diabetes, either within optometric practice or ophthalmology clinics. However, (MacDonald, 2010) advocates 'Optometrists as Educators' in her article in, 'Review of Optometry'; explaining that as essential health care providers for patients with diabetes, optometrists have the capacity and responsibility to increase patient awareness about diabetes. (MacDonald, 2010) continues to comment that as part of her day-to-day practice, and as a skilled clinician undertaking the task of healthcare provider for patients with diabetes, she was eligible to become a certified diabetes educator (CDE) and outlines for the reader a 'road map' of how to become certified.

The 'Certified Diabetes Educator' programme in the United States enables the educator to provide specialised training and care for people with diabetes. The educator becomes qualified to create individual self-management plans, deal with psychological issues and manage the various complications related to hypo- and hyperglycaemia. (MacDonald, 2010) also explains that being a certified diabetes educator has enhanced and benefited her own practice. She comments on how she feels integrated into the multidisciplinary team caring for her diabetic patients and urges every optometrist already undertaking the role of diabetes educator to become certified.

The role of ophthalmology was also considered; (Rosberger et al., 1998) found that when clinicians in ophthalmology departments had access to the retinal fundus images of patients from previous visits, the recommendations they made with regard to appropriate treatment and follow-up for those patients with diabetic retinopathy frequently changed. (Rosberger et al., 1998) found that in 21% of cases clinical recommendations were changed, which had implications for the quality and cost of care.

A recent research project by the Diabetic Retinopathy Clinical Research Network (DRCR.net) investigated ophthalmology clinics as the specific location for diabetes education to occur. The DRCR.net was established in 2002, is a collaborative network dedicated to facilitating multi-centre clinical research of diabetic eye disease in the United States. The DRCR.net is funded by the National Eye Institute, which is a part of the National Institutes of Health, a government organisation that funds medical research. The DRCR.net researchers proposed to use the patient's fear of sight loss as the key factor to achieving better compliance, and thus improved glycaemic control within the ophthalmology clinic setting.

The investigation procedure in the DRCR.net protocol appeared initially robust; having a randomised control trial paradigm, with randomisation of the site and/or the investigator (if it was a multi-investigator site). The sample size was 2000 participants for a period of 24 months. The intervention group received the intervention at the initial visit, and completed self-administered validated questionnaires at that visit, and at the 12 and 24 month follow up visits. The education intervention was targeted to create a 'personalised risk assessment report' associated with the patient's current Hb1Ac value, and their target goals. The participants would receive a written report, which included an 'easy to understand graph', showing the risk of worsening DR associated with their Hb1Ac level.

However, when the study findings were published on-line (Aiello et al., 2015) the results were somewhat disappointing, and the study abandoned after 12 months. The results showed there was no change in glycaemic control between participants who received the intervention and the control group. The researchers stated that this was the case 'even when the participant is motivated by fear of possible future ocular and renal complications' (Aiello et al., 2015 pE5). However, this is perhaps a simplified observation, as discussed above in Section 2.3.1.4, research shows that although fear is a motivational factor, it can also elicit a denial response which causes people to become desensitised to health behaviour change.

This aspect of fear as a motivational factor was not discussed by the researchers of this study (Aiello et al., 2015).

In addition to the the 'annual-follow-ups' group, there was a 'more-frequent-than-annual follow-ups' group, where a negative result was reported. Although the result in the annual intervention group was interpreted with caution by the researchers, as the sample size did not meet that required, they had expected that the 'more-frequent-than-annual-follow-ups' cohort may have had a greater potential effect. As this was not the case, the researchers proposed that this group may have become accustomed to the intervention over time, lessening the effect. However, an alternative to this explanation, not considered by (Aiello et al., 2015), is that people with diabetes often complain about the number of appointments they have in their diabetes care regime. This gives a feeling of being overwhelmed, causing them to deny their diabetes, which results in poorer self-management and worse glycaemic control (Russell et al., 2005). In the DRCR.net study the researchers also considered that the lack of expected results may lie in the possible variability of 'standard care' received by the control group. This however would indicate a possible flaw in the research methods and protocol for this study, in not having authority over this factor which may clearly affect the outcomes.

Notwithstanding, the overall failing of this research study is perhaps highlighted in the dissemination of the individualised findings for the participants in the form of the personalised report. The report was sent to the participant's primary care physician, who may not have shared it with the participant; or if the information was shared, then how it was discussed would not be consistent for all participants. Also at this stage, the information may have had less impact; as the initial location factor of the 'ophthalmologist's office' would have been lost. A notable outcome of this study was that only a small number of participants wished to receive a personal copy of the report, and surprisingly, of those who had requested the information 72% did not open the email. This finding of participants not accessing their personal diabetes data and education material is echoed in the PhD study by, (Kihmm-Connolly, 2013) discussed above.

Only two research papers were found on the use of retinal images and diabetes education (Rees et al., 2013) and (Salti et al., 2011). The research objectives in these studies was to evaluate the effect of discussing digital retinal imaging and diabetes self-management education with participants.

The intervention in the study undertaken by (Salti et al., 2011) involved non-mydratic retinal imaging performed by a technician following an endocrinologist examination. The images were then shown to the participant, with clinical features highlighted and a brief discussion by a single retina specialist given to the patient regarding the findings. The discussion included; (1) A presentation demonstrating a range of DR including a normal fundus, mild-moderate non-proliferative DR, active proliferative DR, (2) A brief summary of the results of the DCCT and UKPDS studies were given regarding HbA1c control and DR, and (3) The importance of blood glucose control to delay onset or slow progression of DR was emphasised. The control group did not undergo retinal imaging or discussion of the retinal findings by the clinician, and the clinician was masked as to whether the participant was assigned to the intervention or control group during care and follow-up.

The results showed a decrease in Hb1Ac for the intervention group of 1.35% and an increase of 0.26% for the control group, indicating that a better understanding of how diabetes affects the eye and vision may have a substantial impact on glycaemic control in the short term in patients with DR and poor glycaemic control. The researchers of this study, (Salti et al., 2011) suggest that perhaps the fear of visual loss was so compelling, as to alter their behaviour. Digital imaging allowed the participants to see any changes in their own retinas, thus personalising the experience and perhaps providing additional impetus for subsequent improvement in glycaemic control. The UKPDS showed a 35% reduction in the risk of onset or progression of DR in T2D when HbA1c decreased by one percentage point (Stratton et al., 2001). Interpretation of the results from this study, (Salti et al., 2011) indicated that the decrease of 1.35 % points in Hb1Ac found equates to a reduction of more than a 47% in the risk of onset or progression of DR. This research finding is particularly relevant to this PhD study, which is based on the same principles and hypothesis presented by (Salti et al., 2011), and will be discussed further in Chapters 6 and 7.

Similarly, (Rees et al., 2013) investigated the impact of personal retinal images on motivation in people with non-proliferative DR and suboptimal Hb1Ac. The research comprised of a pilot study measuring Hb1Ac and standard measures on beliefs, diabetes related distress and self-care activities. Participants in the intervention group were given visual feedback at baseline and three months on their own retinal images, which was contrasted with healthy retinas and images showing varying degrees of DR indicating the progression of DR. The participants own images were described as; 'mild', 'moderate' or 'severe' DR and the intervention involved explanation of the images, development of DR, the risk factors for diabetic eye disease, and target Hb1Ac levels. Findings of this study (Rees et al., 2013)

indicated that the intervention group showed significantly increased motivation to improve blood glucose control, foot care and eye health.

In conclusion the researchers found preliminary evidence that visual feedback of personal retinal images may offer a practical educational strategy for clinicians in eye care services to improve diabetes in some patients. However, the researchers of this study (Rees et al., 2013), caution that their findings indicate a need to supplement risk communication with effective behaviour change support, which must be combined with educational initiatives, (Funnell et al., 2009).

2.3.3.3 Dentistry

Due to the limited research in diabetes self-management education (DSME) by optometrists and ophthalmologists research literature regarding dentistry was considered. It is proposed that optometry and dentistry are comparable; people with diabetes visit their dentist and can present with oral manifestations of diabetes in a similar way to presenting with ocular complications when they visit their optometrist. The oral manifestations of diabetes are periodontitis, abscess, delayed healing, frequent infections and failure of treatment procedures (Esmeili et al., 2010). Oral signs and symptoms can be precursors to systemic diseases and conditions, and evidence suggests that periodontal disease predicts the development of end-stage kidney disease in diabetic patients, (Löe, 1993). Through health promotion practices, dental healthcare providers can address systemic and oral diseases, (Reznik, 2012); (Greenberg et al., 2010); (Vernillo, 2003) including diabetes (Esmeili et al., 2010); (Lamster et al., 2012). Health promotion practices can positively affect other health services, reduce treatment expenses, improve quality of life for the patients, their family and society; and has been shown to reduce health inequalities (Sheiham et al., 2011); (Watt, 2007).

Both optometry and dentistry in the UK have a similar organisational structure, were the practitioner has an optometry or dental practice undertaking private and NHS work outside of a hospital setting. According to (Kengne-Talla et al., 2014) in a Cochrane protocol for interventions to increasing health promotion practices in dental healthcare, 'dental healthcare settings offer a promising venue to perform general health promotion by dental healthcare providers and an opportunity to improve social costs related to oral diseases and systemic conditions' (Kengne-Talla et al., 2014, p4). (Fisher and Koerber, 2010) and (Wilder et al., 2009) both state that dental practitioners are uniquely positioned to be able to provide

diabetes education and counselling which will improve health behaviours and outcomes for people with diabetes. This consideration without doubt is transferable to optometry and the high street opticians practice.

Review of the literature regarding dentists and DSME revealed investigation into attitudes of, and response of dental practitioners offering diabetes education and counselling, rather than any actual educational interventions. (Fischer and Koerber, 2010) used the TPB model to assess the willingness of dental students and staff members to provide diabetes education and counselling to people with diabetes in the dental school. They found that there was interest, but a lack of knowledge and confidence was reported. This is supported by (Kunzal et al., 2005) who found that although dentists discussed metabolic control and oral complications with patients, they did not act proactively. This according to (Hema et al., 2014), was due to the dentists' belief that management of diabetes in a dental setting was peripheral to their role, along with a lack of knowledge about diabetes.

With the increasing evidence of a connection between oral health and general health, specifically with regard to diabetes and periodontal disease. Studies show that dentists are intervening, considering it an important part of their practice, (Esmeili et al., 2010); (Hema et al., 2014). (Hema et al., 2014) researched dentists' attitudes and practices related to patients with diabetes, finding over 95% of dentists had enough knowledge to assess and intervene with patients with diabetes in practice, and 73% felt effective in addressing diabetes issues with their patients. (Hema et al., 2014) consider their results to be encouraging, indicating that dentists are motivated to participate in addressing diabetes health issues. (Esmeili et al., 2010) investigated dentists' perceptions of the importance of diabetes management to their role, and found that dentists advised patients with diabetes about periodontal risks, but generally did not consult the patient's physician if complications were observed. However, only 30% of dentists felt effective in addressing diabetes with their patients, and less than half believed that they had enough knowledge to assess and intervene with patients. (Hema et al., 2014) proposes that this difference in attitude could be due to the varied medical curriculum in dental schools in different countries, (Hema et al., 2014) was conducted in India and (Esmeili et al., 2010) was carried out in the US.

2.3.3.4 Podiatry

In addition to dentistry, discussed above, there is the consideration of podiatry, which has a similar organisational structure, with the podiatrist undertaking private practice and NHS

work outside of the hospital setting. With regard to the complications of diabetes, eye health and foot health are comparable, the loss of a limb through amputation, like blindness, having severe and devastating results. People with diabetes are particularly fearful of these complications, as they cause a loss of self-esteem, and dependency on others (Al-Qazaz et al., 2011); (Gale et al., 2008); (Wong et al., 2005). Both these complications are preventable through early diagnosis and effective self-care.

The majority of podiatry based research and diabetes investigates wound management, while the scope of podiatry led T2D education interventions are aimed at educating patients on foot care and the risks of amputation (Diabetes U.K, 2013). In the Society of Chiropodists and Podiatrists booklet entitled, 'Diabetes and Your Feet', (The Society of Chiropodists and Podiatrists, 2009), the section on preventing foot problems explicitly states that; 'preventing problems starts with managing your diabetes well' (Society of Chiropodists and Podiatrist, 2009 p13). The multi-disciplinary approach to diabetes education programmes discussed in Chapter 1, (DESMOND, Section 1.4.3.1 and X-PERT, 1.4.3.2) have as part of the education team a NHS podiatrist. (Hendricks and Hendricks, 2001) considers research which supports the collaboration of the certified diabetes educator and the podiatrist working together.

A research poster presented at College of Podiatry Conference in November, 2014 (Hasting and Chandler, 2014), suggests that the delay in diagnosing T2D leads to an increase in the complications, including those associated with feet. This study highlighted the value of educational intervention which take a more holistic approach, and concluded that for education to be effectual and patients to be empowered, they require knowledge of their condition and the care they receive from their health professionals must be collaborative. No research papers by these authors were found during the literature searches, the researcher of this PhD research study contacted Lisa Chandler at the University of Northampton, who confirmed that this undergraduate dissertation research was not published.

A research proposal for a randomised controlled trial by (Dunphy and Thomson, 2010) from Queen Margaret University was found. This considers podiatrists as the most likely health care professional to have regular contact with people with T2D, and are best placed to implement long-term support and T2D self-management education. A further research proposal in this field, investigating podiatrists experiences of motivational interviewing for T2D self-management was presented at the NHS Education Scotland Conference, 2011 (Dunphy et al., 2011). However, no research papers were found during the searches relating to either research proposal. In conclusion, there appears a missed opportunity of educating people with diabetes about effective management within podiatry practice.

2.3.3.5 Pharmacy

According to (Berg et al., 2009) the pharmacist is one of few medical professionals to whom patients go for a consultation or advice without an appointment, they are easily accessed and knowledgeable about a number of issues concerning patients and their medication. Pharmacists are adopting a crucial role in the management of chronic illnesses like diabetes, providing care and advice and transferring their skills to diabetes self-management education, which the researchers claim establishes 'a good foundation for mutual trust and respect and for better patient compliance', (Berg et al., 2009 p148). This statement is somewhat contradictory as 'mutual trust and respect' should engender a concordant partnership, rather than a compliant one as stated. These and many of the pharmacy interventions reviewed in the literature are all prescriptive and rely on patient compliance to medication adherences; there were no research papers found that considered concordance issues with regard to medication and T2D management regimes. This prescriptive approach was notable in the information obtained from pharmacies during the initial phase of this literature review when the researcher wished to investigate information on T2D and eye health (Section 2.3.2.1). Compliance, adherence and concordance and its relevance in health care will be discussed further in Section 2.3.4 below and in Chapter 5.

(Lindenmeyer et al., 2006) reviewed the literature with the aim of demonstrating whether a range of diabetes care interventions delivered by pharmacists was successful in improving adherence to medication. Initially 21 papers on diabetes medication adherence were found, and five studies were reviewed. Two of the studies reviewed presented a reminder system of medication packaging (Matsuyama, 1993); (Skaer et al., 1993), and three investigated pharmacist led education programmes (Davidson, 2000); (Jaber, 1996); (Coast-Senior et al., 1988). (Lindenmeyer et al., 2006) found that there is evidence that pharmacists could play a role in improving diabetes care, by addressing the importance of medication adherence. This could be achieved by improving patient management with reminders and by supplying patient education, and facilitating communication between patients and healthcare professionals. In conclusion (Lindenmeyer et al., 2006) found that pharmacists could not only improve adherence, but also improve patient satisfaction and quality of life.

In the diabetes education study by (Song and Kim, 2009), a pharmacist and an ophthalmologist were part of the education team delivering individual complication monitoring. The intervention was composed of group education with individual education

elements; the group education session was delivered first, providing an overview of diabetes, self-care management, diabetes and obesity, foot care, and psychological support and stress management. The individual education session was structured to promote self-monitoring of blood glucose, insulin injection, and physical activity exercises. (Song and Kim, 2009) found participants in the intervention group decreased their mean HbA1c levels by 2.3%, compared with 0.4% in the control group. However, with regard to the contribution of the ophthalmologist or pharmacist there was no individual assessment, as they were part of the multidisciplinary care team.

With regard to this PhD study, the researcher was interested in how to facilitate an improvement in T2D self-management with an EDOP; through knowledge of diabetic eye disease and eye health to reduce the risks of sight loss. The scope of pharmacy led T2D education interventions are aimed at improving adherence to medication regimes, rather than enhancing self-care practices.

2.3.4 Compliance and Concordance

Within the patient-professional relationship the traditional view regards doctors and health care professionals as experts, with patients providing little other than their illness. To enable relative good health patients must comply with the medication and treatment regimens outlined by their care provider, compliance was defined by (Haynes et al., 1979) as the extent to which the patient's behaviour matches the prescriber's recommendations. This requires substantial patient involvement to achieve control over the complexities of a chronic illness like diabetes. (Vermeire et al., 2001) defines compliance to self-care regimes as; 'the extent to which a person's behaviour in terms of taking medication, following diets or executing lifestyle changes coincides with medical or health advice' (Vermeire et al., 2001 p332). However, the term compliance has been heavily criticised with regard to clinician-patient relationships, (Stimson, 1974), because of the negative connotations of following orders associated with patients not achieving goals and thus being labelled as difficult or unsuitable, especially when those orders are exclusively defined by clinical criteria.

(Chatterjee, 2006) critiqued compliance as it suggests 'submitting to' and 'obeying of' instructions, with the assumption in health care that patients should comply and that non-compliance is often the fault of the patient. Portraying non-compliance as deviant behaviour ensures that the blame is largely directed toward the patient, (Donovan and Blake, 1992). The term adherence was adopted by many as an alternative to compliance, in an attempt to

emphasise that the patient is free to decide whether to adhere to the doctor's recommendations, and is the extent to which the patient's behaviour matches agreed recommendations from the prescriber. This creates a subtle difference within the gradient of power and autonomy of this patient-professional relationship (Wishner and Lutfey, 2000); where the expression of medical power and patient submission is reduced, with a move from 'obedience to', towards 'acceptance of' the treatment. Nevertheless, there is continued criticism of this term, because adherence continues to reinforce the patients' submissive role (Glasgow and Anderson, 1999).

Challenges to the limitations of the traditional biomedical care model continued, and a new paradigm began to emerge; were people with chronic conditions are their own principle care givers, and the role of the health care professional is to support them, (Bodenheimer et al., 2002). In this patient-centred collaborative approach, (Cyrino et al., 2009) emphasis is placed on patients' experiences. This fundamentally different approach was defined in the Medicines Partnership (2001), as the 'Concordance Model' and was based on the tenet of agreement reached between the patient and the healthcare professional, in which responsibility is shared, giving the patient greater autonomy, (Bower and Mead, 2000). Essentially in this approach the nature of the agreement respects the beliefs, attitudes and preferences of the patient in determining when and how medicines are taken. In concordant consultations, the patient's beliefs and wishes were sought and considered to be of paramount importance, (Marinker, 1997).

(Bissell et al., 2004) reported on the limitations of the compliance model; some participants felt angry at not being understood by their health care provider, and had feelings of self-recrimination at not being able to meet the demands of a diabetic diet. The moral overtones of the compliance model are assimilated by people with diabetes in their attempts to accommodate medical advice and the demands of everyday life. According to (Horne, 1993) and (McGavrock et al., 1996) the concordance paradigm acknowledges that noncompliance is a rational response for many patients to their personal perceptions of the illness and treatment. Further to this, (Chatterjee, 2006) advocates concordance, as this encompasses the idea that the doctor and the patient are equals, and that the patient makes informed decisions. According to the concordance model there should be an open exchange of beliefs about medicines upon which both prescribing and medicine taking decisions are based, (RPSGB, 1997).

(Bodenheimer et al., 2002) proposed that a patient-centred collaborative paradigm within the concordance model embraces two components which are conceptually similar but clinically

separable, which are; collaborative care and self-management education. Collaborative care is concerned with collaborative care, where doctors and patients make health care decisions together, professionals are the experts about diseases and patients are the experts about their own lives. Patients accept responsibility to manage their own illness and are empowered to solve their own problems. While self-management education includes problem solving skills, which can enhance the lives of people with chronic illnesses (Bodenheimer et al., 2002). Self-management is concerned with self-efficacy, providing patients with the confidence to reach desired goals. Diabetes self-management education and self-efficacy has been discussed above in Section 2.3.1.1

2.3.4.1 Compliance and Concordance in Healthcare

The concept of concordance began to emerge in the mid-1990s, the UK Department of Health and the Royal Pharmaceutical Society of Great Britain started a collaborative project aimed to understand why patients did not take their medication, and to develop solutions to this problem. The resulting report, 'From Compliance to Concordance', was significant in the development of the concept of concordance, (RPSGB, 1997). The term concordance began to be used in academic literature following the definition in Medicines Partnership (2001).

The literature was searched in September 2013 using on-line data bases; PsycArticles, Science Direct, Scopus, and Web of Knowledge, between 1990 and 2013. The key words used were; *healthcare, compliance, adherence and concordance*; the search produced 895 hits relating to concordance in the consulting room and healthcare. Notable however, is that no papers were found prior to 2002, and from 2002 a steady increase in the number of articles was noted, peaking at 327 in 2007.

This change in terminology can be linked to changes in the socio-economic and political climate of the day. The new Labour government came to power in 1997, and published a White Paper, 'The New NHS: Modern, Dependable' (DoH, 1997) setting out its reforms for the NHS. The concept of concordance and personal responsibility appears to have emerged along with 'New Labour', 'New Labour' was coined in response to the controversial decision to rewrite Clause IV of the party constitution. The 1996 Labour Party Manifesto entitled; 'New Labour New Life for Britain' signalled this shift towards the right of the British political spectrum and some alignment with conservative values. 'New Labour's' economic policy of spending control and projecting fiscal responsibility facilitated the government's community health agenda of increasing NHS performance and enabling more targets to be met. The

concept of compliance and adherence are paternal, individuals are told what to do, thus absolving the individual from responsibility for their own health and becoming the responsibility of the state. This fits with the socialist concepts of a labour government; a national health service for all and it was under a labour government that in 1947 the National Health Service came into being. Yet conversely, this shift from the left enabled a 'New Labour' policy of target setting to ensure that spending departments delivered value in return for increased inputs. This was built on an audit culture, where meaningful performance indicators were developed and monitored, which in theory would, incentivise the 'producers' (teachers, doctors) and empower the 'consumers' (parents, patients), (Gorsky, 2011).

(Gorsky, 2011) reflected that the 'New Labour' government had broadly followed prior conservative government policy and that, 'the associated political rhetoric of localism, choice and patient empowerment of the previous labour government was therefore compatible with conservative discourse' (Gorsky, 2011 p1). The terms, 'producers' and 'consumers' quoted above are examples of this discourse. The Labour government continued its reforms of the NHS with the White Paper; 'Choosing Health: Making Healthy Choices Easier' (DoH, 2004), setting out its public health policy, detailing how government would provide more of the opportunities, support and information people want to enable them to choose health. The agenda was to promote individual responsibility with a focus on issues such as smoking, obesity, diet and nutrition, exercise and sexual health. In the foreword to this White Paper, Prime Minister Tony Blair stated; 'We are clear that Government cannot and should not pretend it can 'make' the population healthy. But it can and should support people in making better choices for their health', (DoH, 2004).

A further White Paper, 'Our Health, Our Care, Our Say: A New Direction for Community Services' (DoH, 2006), set a new direction for the whole health and social care system, with a radical and sustained shift in the way in which services were delivered, ensuring that they were more personalised and that they fitted into people's busy lives. Giving people a stronger voice ensured they were the major drivers of service improvement. In the foreword to this White Paper, Patricia Hewitt, Health Secretary stated; 'Services that are flexible, integrated and responsive to peoples' needs and wishes', with regard to encouraging patient choice, reiterating shared responsibility and concordance for health, (DoH, 2006).

(Lupton, 1993) analysed the socio-political function of health promotion rhetoric to determine why the ideal of maintaining health through personal endeavour was popular, concluding that this discourse is often used to blame the victim and to displace the real reasons for ill-

health on to the individual. Thus enabling an expression of outrage at behaviour deemed socially unacceptable, thereby exerting control over society and individuals.

2.3.4.2 Deliberate Non-Compliance and Strategic Cheating

Health care professionals direct their clinical practices predominantly towards blood glucose control and Hb1Ac, in-line with recommendations gleaned from the key research and landmark studies discussed in Chapter 1, Section 1.4.1. However, despite the evidence presented regarding the positive relationship between better blood glucose control and lower risk of complications, many studies have reported considerable problems with attaining rigorous blood glucose control within day-to-day self-management (Frewer et al., 2001); (Wolpert and Anderson, 2001). (Wolpert and Anderson, 2001) report that people with diabetes consider the implication that good control consists of control which is inflexible, and the choices within diabetes care they have, are redundant, and life is controlled by the disease. Notably, (Burns and Gavey, 2004) considered eating a normal, everyday necessity, yet within the lived context of 'being diabetic', everyday food intake is transformed into a 'treatment' of the condition (Burns and Garvey, 2004 p554). According to (Estupinan and Anderson, 1999); in (Cyrino et al., 2009) the problem of attaining strict blood glucose control causes health care professionals to regard non-observance of what was prescribed, as patients ignoring what is recommended. Considerable patient participation is required to achieve control over the complexities of chronic diseases like T2D, and when patients fail to achieve the results desired by the clinicians, they are considered difficult or incompetent, (Roter et al., 2001).

(Peel et al., 2005) found that participants in their study accounted for lapses and 'cheating' in various ways, with the aim of maximising and accomplishing a positive 'identity' (Broom and Whittaker, 2004). This is supported by (Cyrino et al., 2009), who investigated the complexity of T2D care and critiqued this traditional bio-medical view of obedience and compliance. They advocated a more 'person-centred approach' to the dissemination of T2D management information, considering the strategies that seek to value the experience and autonomy of patients as self-care agents need to be introduced as means for expanding patients' freedom and self-sufficiency within their daily lives. Diabetes self-care and self-management should be performed in a concordant fashion, with flexibility to enable people with diabetes to adapt treatment to the demands of their daily routines (Cyrino et al., 2009). The challenge for health care professionals and people with diabetes according to (Peel et al., 2005) is to create different ways to position diet within the lived context of attempting to manage and

control T2D. Interestingly, (Peel et al., 2005) present a paradox in this regard; if people with diabetes do not have to justify their food choices, this may increase their ability to share their concerns with their health care provider and receive appropriate advice. However, by alleviating the onus of accountability for food choice, this may reduce the impetus for people with T2D to eat healthily.

In the synthesis conducted by (Campbell et al., 2003) some participants were found to strategically adopted non-compliance, where they did not blindly adhere to medical advice in their daily lives but, instead, thoughtfully and selectively applied it. (Maclean, 1991) and (Kelleher, 1988) found that participants who reported to be in control of their diabetes had adopted an approach to diet which came from a conscious deliberation, taking into account their personal needs and preferences. (Campbell et al., 2003), considered people with diabetes to be on a 'continuum of control', and these participants were on the 'moderately flexible' part of the continuum which allowed certain 'indulgences' which they considered to be 'cheating', (Campbell et al., 2003 p678). They were distinguished from those at the 'very flexible' end of the scale because they did not feel guilty about this. Thus, this notion of being in control of the diabetes was linked across the studies synthesised, for example; 'strategic management' (Kelleher, 1988), 'conscious deliberation' and 'cheating without guilt' (Maclean, 1991). In addition, (Campbell et al., 2003) suggested that guilt was not an issue, because these participants were fully aware of what they were doing, and the reasons for it, given the amount of thought and reflection inherent in this approach.

(Campbell et al., 2003), also considered the concept 'cheating' in relation to people adjusting their treatment depending on observations of their symptoms and glucose levels, (O'Connor et al., 1997) and (Murphy and Kinmonth, 1995). These participants were termed 'Positive responders' and were found to deviate from the recommended medical advice strategically, and without guilt. Whereas, those 'negative responders' were found to cheat more, had more guilt and were less strategic in their cheating, (O'Connor et al., 1997). In conclusion, (Campbell et al., 2003) found that by departing from medical advice in a thoughtful and intelligent way, individuals were able to achieve a balance between the demands of diabetes control and the way they wanted to live their lives. The study showed that these individuals who 'strategically cheated,' were confident about how they were implementing their diabetes care, they had greater acceptance of their condition, had better blood glucose control, and felt less guilty.

Paradoxically, if 'strategic cheating' and non-compliance to the diabetes self-management regime recommended by health care providers, actually accounts for an improvement in

glycaemic control; then Hb1Ac is not an indicator of 'good' diabetes control, and compliance, but an indicator of that persons' self-management capabilities and 'good' diabetes management, *per se*. When people with diabetes have the confidence to effectively self-manage, with autonomy, the barriers to self-care are not insurmountable. By 'strategic cheating' people with diabetes felt in control of their disease, rather than the disease having control over them. Notwithstanding, although people with T2D know what to do to effectively self-manage, but, do not always do it, the issue is not as obvious as it would perhaps seem because of the complexities of the disease and issues like those discussed by (Peel et al., 2005) above. The consideration then would be, are people with diabetes 'strategically cheating' or just simply 'cheating'? This will be discussed further in Chapter 7.

2.4 Rationale for this Study

The rationale of this PhD research study will be discussed in this section; charting its evolution from the original research proposal, through progressive iterations adopted by the author. Synthesis of the literature review findings are presented in Section 2.4.2 this forms the premise and rationale for this PhD research study, which informs the research questions (Section 2.4.3).

2.4.1 The Research Proposal

The original research proposal was a mixed methods study to investigate optometry and diabetes education, considering whether optometrists could enhance patient self-management in T2D. The original concept was to acquire NHS ethics approval to recruit participants from diabetic retinopathy screening programme at the Heart of England Foundation Trust. Potential participants were to be recruited via the screening staff at the Trust. Baseline quantitative data was to include, Hb1Ac level and BP measurement; and qualitative data was to be gleaned from validated questionnaire on, diabetes quality of life (DQoL) and diabetes integration (DIQ). The intervention in the form of an enhanced optometric practice would make comparisons with normal standard optometric practice, and between newly diagnosed participants and those with established disease. It was also considered that participants of South Asian ethnicity should be included for comparison, as the incidence of T2D and severity of complication are greater in this population. The proposals for this PhD research study have been developed and modified to include only qualitative data, as it was considered that qualitative methods would give the most appropriate and richest research data reflecting the complexity T2D self-management.

This literature review has indicated the emerging nature of retinal imaging as an educational tool and motivational device; that has foundations within the established and extensively researched subject area of T2D self-management education. The research proposal thus evolved to consider how both male and female participants with either newly diagnosed T2D or established disease would respond to an EDOP. The intervention would also allow for comparison of male and female participants, of White and South Asian ethnicity; and consider the effectiveness of an individual EDOP presented on a one-to-one basis by the researcher, with that of a group of five participants.

2.4.2 Literature Review Synthesis

According to (Steed et al., 2003) support from education, along with psychological and motivational factors, determines how effectively people with diabetes self-manage. The person with diabetes is the recipient and also the principal provider of their own diabetes care, which requires confidence, or self-efficacy, as well as the skills and knowledge to effectively self-manage. According to (Witte and Allen 2000) fear appeals need to be strong with a high-efficacy message if they are able to produce the greatest behaviour change; however, if the message has a low-efficacy then a defensive response is produced. For a fear appeal to be an effective motivator, the individual must be confident in their belief that they are able to protect themselves. Interventions that improve self-efficacy also improve self-care, (Trief et al., 2009); (Anderson et al., 1995). (Bandura, 1977) believed that self-efficacy was the link between a person with diabetes knowing what to do and actually doing it; it is this premise which underpins this PhD research study.

Further to this, there is compelling evidence to suggest that this visual feedback using comparative images may reinforce behaviour change, when there is comparison of normal and healthy, with the abnormal and unhealthy, (Rees et al., 2013); (Williams et al., 2012a); (Grogan et al., 2011); (Salti et al., 2011). (Williams et al., 2012a) and (Grogan et al., 2011) considered the added element of successful behaviour change to be when the intervention has personal relevance; as with the shock reaction when participants saw their own faces during the facial morphing. This 'real' threat enabled participants to appraise their personal vulnerability, promoting a tangible intention for behaviour change. When long-term risks are positioned in the present, participants are able to consider the benefits of long-term objectives (Rippetoe and Rogers, 1987). This is of particular relevance in diabetes self-

management as the complications of poorly controlled T2D are long-term, and the risks not immediate.

(Salti et al., 2011) suggested that the participants in their study changed behaviour because the fear of visual loss was so compelling. However, in considering possible explanations for the successful outcomes of the (Salti et al., 2011) study, and lack of positive results from (Aiello et al., 2015); it is proposed that the use of retinal images in educating people about self-care may be the 'active ingredient' which enables them to make a significant behaviour change towards effective self-management of their diabetes. Both of these studies used personal information, making the intervention individual and personally tailored; both studies gave structured diabetes management education to the participant based on research from the landmark studies (UKPDS, 1998) and (DCCT, 1993); both were undertaken in an ophthalmology setting; and both used Hb1Ac measurements to assess quantitative outcomes. However, it is notable that participants in the (Salti et al., 2011) study viewed, and had explanation of their digital retinal images, along with the diabetes management education, whilst participants in the (Aiello et al., 2015) study did not.

A further consideration, as discussed above, people with diabetes often complain about the number of appointment they have in their diabetes care regime. This gives a feeling of being overwhelmed, causing them to deny their diabetes, resulting in poorer self-management and worse glycaemic control (Russell et al., 2005). If education was provided when they visit their optometrist for the annual diabetic retinopathy screening, in the form of an EDOP, then no extra appointment is created. In addition, erosion of motivation over time is avoided with this yearly event; and as people with diabetes become accustomed to this annual EDOP event of screening and education, then the comparison of the images they are able to make year-on-year is particularly personally relevant. This will bring the long-term threat of possible blindness, into the present, galvanising them into immediate action of behaviour change; these suggestions will be discussed further in Chapters 6 and 7.

2.4.3 Rationale for the Design of the EDOP Presentation

The focus of the EDOP presentation is supported by the research findings of (Salti et al., 2011) and (Rees et al., 2013), and is based on the same principles and notions. The EDOP presentation showed participants how the risk of blindness is increased with the progression of diabetic eye disease. During the EDOP participants were explicitly told that blindness was preventable and within their capabilities; and the way to preserve healthy eyes and good

vision was to follow the recommended self-care practices. The decision to focus on diabetic eye disease stems from the researchers own experience as an optometrist within the diabetic retinopathy screening programme, and patients requests for more information on eye health (Peel et al., 2004). Current diabetes self-management education delivers information to people with T2D, and the merits and limitations have been discussed in Section 1.3. Notwithstanding, people with diabetes know how to self-manage, but lack the confidence to so, (Trief et al., 2009); (Anderson et al., 1995); (Bandura, 1977).

Optometrists as part of the diabetic retinopathy screening service have at their disposal the tools, impetus and skill to implement an EDOP, which could educate and motivate the person with diabetes to better self-management through the use of retinal images showing diabetic eye disease. These considerations have been vital in the design and development of the EDOP, which presents a graphic portrayal of diabetic retinopathy as it manifests itself in the eye and in the patient's own eyes, along with discussion of the retinal images within a normal optometric practice environment. It is hypothesised that the EDOP will be the key to improved self-motivation and management through participant's concern of sight loss being a driver towards better diabetic control.

2.4.4 The Research Questions

Presenting the research questions for this study enables the researcher to define the limits of this study, plan for ethical issues, and identify the research method and analytical processes to be used. To determine the research questions, the 'Russian doll' principle and the 'Goldilocks test' described by (Clough and Nutbrown, 2012) were used. (Clough and Nutbrown, 2012) explains that by; 'breaking down the research question from the original statement to something which strips away the complication of layers and obscurities until the very essence - the heart - of the question can be expressed', (Clough and Nutbrown, 2012 p41). The 'Russian doll' principle enabled the research proposal and rationale of this PhD study to be simplified, generating the research questions; which were then subjected to the 'Goldilocks test', which is a metaphor for posing questions which are 'just right'.

The following research questions were proposed:

- 1) Are optometrists suitable people to provide education on T2D and eye health?
- 2) Can an EDOP be the key to effective T2D self-management education?
- 3) Do people with newly diagnosed T2D respond differently to the EDOP than those with established disease?

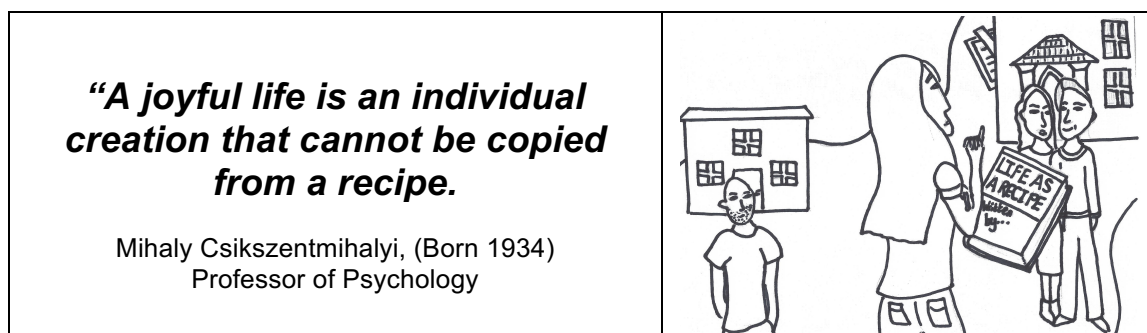
- 4) Do White people with T2D respond in the same way to an EDOP as those of South Asian ethnicity?
- 5) Do males and females with T2D respond differently to the EDOP?
- 6) Does individual basis or group delivery of the EDOP have a different impact?

2.5 Summary

When a long-term risk is situated in the present, people are able to believe in the benefit of long-term goals and enact a positive behaviour change (Hall and Fong, 2007), which is particularly relevant in diabetes self-management. The complications of poorly controlled T2D are long-term and the risks not immediate, and people with diabetes do not perceive the threat as relevant to them, (Soames-Job, 1988). The task for this PhD research study is to ensure that the EDOP is personally relevant to the participants, and although the threat of sight loss is long-term; it is a pertinent risk which requires immediate attention via protection motivation. However, because the risk of visual loss presented in the EDOP elicits a strong threat appeal, the message is one of high efficacy, delivered simultaneously with the visual representations. The EDOP will be explicit in allowing the participant to believe that the risks of sight loss are avoidable, desirable and relatively easy to achieve, to enable realistic and sustainable changes in T2D self-care practices.

Many optometrists participating in diabetic retinopathy screening routinely explain the digital retinal images to their patients, and (MacDonald, 2010) presented the compelling argument that many optometrists already provide some T2D self-management education as part of their ordinary practice. It is proposed that an optometric practice, enhanced for people with diabetes, in the form of an EDOP is a viable consideration in assisting people with T2D to improved self-care and management. In addition to advantages for the patient, when optometrists provide an EDOP their own clinical practice benefits, and the profile of the profession is raised.

3 METHOD



3.1 Introduction

Given the broad nature of this research project, which is located not only in optometry, education and health care, but also in the social sciences and psychology a flexible method was created to address the developing research questions (Robson, 2002). A pragmatic approach has directed this research, allowing for reflection on the focus of the research as it has progressed. Justification for the methodology and the particular research methods used are provided in this section. The particular stance taken with regard to the use of the terms method and methodology in this study is taken from, ‘A Student’s Guide to Methodology’, (Clough and Nutbrown, 2012). The methods are the ‘ingredients’ of the research, while methodology provides the reasons for using that particular research ‘recipe’ (Clough and Nutbrown, 2012 p25). To gain a better understanding of the richness and subtlety of the questions involved in self-care, researchers are placing value on individuals’ own experiences and notions about diabetes, and are turning towards qualitative methods to better understand the discourse produced (Anderson and Robins, 1998).

3.1.1 Aims

This PhD research study was designed to investigate how people with T2D receive education and perceive self-management and eye health. The aims are to investigate how people with T2D self-manage their diabetes and whether an Enhanced Diabetic Optometric Practice (EDOP) is able to provide the impetus to better self-care. Through analysis of the participant’s discussion of the EDOP, the challenges they face, and their motivation, an insight into the discursive terrain of what can be said about these topics can be gleaned. It is suggested that by using Foucauldian discourse analysis the discursive resources revealed will enable construction of advice and self-care recommendations which are more

empowering for people with T2D. The study begins by investigating the barriers to T2D self-care, Study (1), (Chapter 4), to facilitate an examination the power which exists between T2D education and self-management. Interest is in compliance and concordance relationships and the 'expert-patient' fashioned by the concordance models in healthcare.

3.1.2 Social Structuralism

Social constructionism (SC) has arisen from and been influenced by a variety of disciplines and intellectual traditions, dating back to the 1950s and 1960s. A major contribution to the development of SC was made by (Berger and Luckmann, 1966) who argued that human beings create, and then sustain all social phenomena through social practices. However, the origins of SC began with the philosophical developments of the 18th century. In psychology, a crystallisation of these ideas appeared in the paper by (Gergen, 1973), who declared that all knowledge is historically and culturally specific. The focus of enquiry being the social practices people engaged in during interaction with others. SC cautions researchers to be suspicious of assumptions about how the world appears to be; as descriptions or constructions of the world support some forms of social action, whilst excluding others.

3.1.3 Postmodernism and Post-structuralism

Postmodernism and post-structuralism describe theoretical movements in the late 20th century that focused on ideological structures of society and personal identity. Postmodernism is a philosophical movement that arose from wide-scale and far-reaching transformations in Western Society in the late 19th and early 20th centuries. The tenets of postmodernism are in art, architecture, literature and cultural studies and it emphasises the multiple and varied ways of life in society; whilst post-structuralism, is more associated with theory and philosophy, (Burr, 2003). Postmodernism is the cultural and intellectual background in which SC developed; it represents a questioning of and rejection of the fundamental assumptions of modernism, which include a belief in the supremacy of reason, the ideas of truth, self, meaning, and purpose to create a better society. The modernism premise emerged during the Renaissance period, in the 14th to 17th century, who promoted through educational ideas citizenship and civic consciousness, considering that man, rather than God, was the measure of all things.

Post-structuralism fits well with postmodernism, and poststructuralists like Michel Foucault, argue that meanings carried by language are never fixed, they are always open to question,

always contestable and always temporary. This concept is fundamental to post-structuralism and has major implications for the understanding of the person, their identity and the possibilities for personal and social change. Poststructuralist view language as a struggle where conflicting power relations are acted out and contested, the action orientation of language is that it constructs rather than represents. So if language constructs identities, maintains them and challenges them; then language provides both the personal and social impetus of change (Barker and Galasinski, 2001).

3.1.4 Discourse Analysis

Discourse is a specific pattern of language that tell us something about the person speaking the language, the culture that person belongs to and the network of social institutions that person is part of. Discourse analysis (DA) is an umbrella term used for the many ways in which written or vocal language, or semiotic events can be analysed. It developed from the 1970s onwards as a critique of cognitivism, and is concerned with the multiple versions of reality or multiple truths, which are constructed through texts. There is no defining description of people or society, because social life is continually changing. Language is more than just a way of describing things; it is a social resource for constructing different accounts of the world and events, (Harre et al., 1972). This 'turn to language' occurred in many of the social sciences with an interest in language, as a social performance, (Burr, 2003). Language is reconsidered as being productive, with language constructing versions of social reality and attaining social objectives.

At one end of the discursive spectrum is discursive psychology (DPsy), where discursive psychologists like Jonathan Potter, Derek Edwards and Margaret Wetherall in the UK (Potter and Wetherell, 1987) and Kenneth Gergen in the US (Gergen, 1973) consider that multiple versions of the world are potentially available through micro-social constructionism. At the opposing end of the spectrum is Foucault, who emphasises macro-social constructionism and the constructive power of language, which is related to social structure, social relations and institutionalised practices. Authors such as, (Ussher, 2000); (Rose, 1989) and (Hollway, 1984) have honed in on these ideas in their analyses, within a Foucauldian framework to highlight social inequalities, such as gender, ethnicity, disability and mental health.

Discourse analysis was selected for this study as it provides flexibility and drawing on social constructionism to address a range of research questions and is important as it enables language to be conceptualised as being productive (Willig, 2000). Language is viewed as a

social performance or action, as it creates and represents social phenomena. Social constructionism and discourse analysis consider that ways of talking do not neutrally reflect the world and social relationships; they play an active role in creating and changing the world. Social objectives are accomplished as discourse analysis constructs versions of social reality and assumes that there are multiple versions, rather than one exact way and investigates the consequences of that version over another. Particular versions of social reality are created according to the values and practices of some people in that society, whilst others less powerful groups have less influence in that society.

3.1.5 Michel Foucault and Foucauldian Discourse Analysis

Michel Foucault, was influenced by Nietzsches' idea of knowledge to be always possible by a 'will to power' (Porter, 2006). Nietzsche considered facts about the physiology and unconscious psychology of human beings to explain their conscious life, in particular, their moral and philosophical beliefs. Whilst Foucault took facts about human nature to be artefacts of particular discursive regimes; where human nature is a construct and the real cause of moral beliefs could only be understood within a certain discursive regime, (Britzman, 1995). Foucault's interest was in language and subjectivity, and the way in which discourse is regulated by procedures which can constrain it and which can produce it. Focusing on the way that discourse brings some aspects of our world into view as objects yet hides other aspects from us. Foucault's concern was more sociological, with the ways in which power is exercised over human beings and the ways of regulating individual behaviour and self-regulation.

Foucauldian discourse analysis (FDA) draws on the work of Foucault and is concerned with how the human subject becomes constructed through the structures of language and ideology. FDA considers what people say and write is not a route of access to their private world, they are not valid descriptions of beliefs or opinions, nor can they be taken to be manifestations of personality or attitude. They have their origin in the discursive culture that those people inhabit, bringing talk into being, by constructing the objects and/or subject that we know, and identifying the social understanding of discourse which enables or prevents possible ways of being in the world. Knowledge in the context of DA is constructed, brought into being through our social practices, and holds with the social constructionists premise that knowledge is not just a reflection of reality.

The structure of different regimes of knowledge is investigated by FDA, to determine what can and cannot be said and what is considered to be true and what is deemed false. FDA also focuses upon the historical and cultural specificity of knowledge and the relationship between such knowledge and the possibilities for social action and power. Foucault's primary focus was the 'archaeology of knowledge' which involved tracing back to uncover the conditions which allowed a certain discourse or knowledge to emerge. Foucault considered that by comprehending the origins of current ways of understanding and by questioning their legitimacy, people are able to resist them. For Foucault power and knowledge were inseparable and argued that in relatively recent history there has been a shift from 'sovereign power' to 'disciplinary power', in which the population is effectively controlled through self-monitoring processes (Rouse, 2007). In society in general, this form of power is particularly efficient, when people enter into the process willingly, they believe self-monitoring to be their own choice and for their own good.

The Foucauldian version of DA was chosen to analyse the data collected in this study because it considers the distinction between what is true and what is false. Truth is a discursive construction and one of the external constraints on discourse. Institutions work to exclude statements which they exemplify as false and keep in circulation those statements which they depict as true. (Foucault, 1972) states; 'it is always possible one could speak the truth in a void; one would only be "in the true" however if one obeyed the rules of some discursive "police" which would have to be reactivated every time one spoke', (Foucault, 1972 p224). Those in authority are seen as the experts who speak the truth; the doctors, diabetic nurses, dieticians, optometrist, and other health care professionals who practice in the realms of diabetes care. Truth is something which is supported materially by a whole range of practices and institutions, for example the NHS and Diabetes UK.

Truth is not as an irrefutable state of affairs, ultimately discoverable through the application of scientific method, but it is a fluid and unstable description of the world created through discourse. The absence of an ultimate truth is the foundation upon which the theoretical framework of SC is built and based in relativism, different constructions of the world can be judged only in relation to each other, and not by comparison with some ultimate truth. The consequence of which may appear to undermine attempts to morally ground actions and choices.

3.1.6 Epistemological Stance

According to (Wetherell, 2001), DA may be situated at any point along a continuum of epistemological positions, from realist to relativist. There are many competing traditions within DA that may be used according to the epistemological positioning of the researcher and also according to what research questions are being asked. FDA is considered to be a social constructionism at a macro level, and acknowledges the constructive power of language, but also sees it related to social structures, social relations and institutional practices. Macro SC takes a deconstructionist stance where the meaning of discourse extends beyond the immediate context in which language is being used incorporating practice by setting limits and channelling what can be said or thought, and what social interactions occur. The principles of macro SC lean towards relativism, which is the view that there can be no ultimate truth and that all perspectives are equally valid. However, with DA, caution should be exercised as the perspective which is valid, is that determined by the discourse to which the subjective positions are located.

Foucauldian discourse analysis defines discourse as a group of statements, objects or events that represent knowledge or construct a particular topic within a society. However, when considered ontologically the term SC refers to the way that real phenomena, our perceptions and experiences are brought into existence and take the particular form that they do because of the language that we share. Within a Foucauldian framework the tendency is towards relativism, (Parker, 1992) states 'discourse analysis needs to attend to the conditions which make the meaning of texts possible' (Parker, 1992 p28) advocating a critical realist stance. This PhD research study takes a pragmatic approach to the analysis, as the epistemological position varies between the different sub-studies siding with the critical realist viewpoint. Critical realists; consider that our knowledge of the world is constructed through language, which is epistemological relativism, whilst also acknowledging that there are structures and practices which create experiences, which we then construct versions of through language, which is ontological realism, (Willig, 2008).

3.2 Design and Study Procedures

The design of this PhD research project uses qualitative methods and proceeds in three stages; Study (1) A systematic review and meta-synthesis of qualitative research investigating the barriers to self-care for people with type 2 diabetes (Chapter 4), Study (2) A qualitative analysis of diabetes self-help literature and eye health (Chapter 5), and Study (3) Evaluation of an Enhanced Diabetic Optometric Practice (EDOP) (Chapter 6). The focus of the research was revised and reflected upon as the research progressed at each stage.

The systemic review and meta-synthesis (Study 1), and the investigation of T2D self-help literature (Study 2) were undertaken to enable the researcher to investigate the barriers to self-management, and to examine ways in which eye complications associated with diabetes are communicated. This facilitated the design and development of Study (3) EDOP, as possible strategies to overcome the obstacles to T2D self-care, and enhance successful self-management were gleaned.

3.2.1 Study (1): Investigating the Barriers to Self-care for People with Type 2 Diabetes: A Systemic Review and Meta-synthesis of Qualitative Research

This systemic review and meta-synthesis of qualitative studies investigating people's experiences of managing their diabetes will enable greater understanding of the barriers to self-care for people with T2D on a daily basis. By identifying the barriers to self-care and by drawing together the findings in this review, motivational factors to enable successful and effective diabetes self-management can be developed.

The design, procedure and method used in Study (1), the meta-synthesis will be described in Chapter 4, Section 4.2

3.2.2 Study (2): 'Can I See the Way?' A Qualitative Analysis of Diabetes Self-help Literature and Eye Health

Diabetes self-management education is recognised as essential for people with T2D to achieve positive results from self-care. According to (McCaul et al. 1987) knowledge is inconsistently related to adherence behaviour, better knowledge does not necessarily imply better adherence. Whilst knowledge does not predict diabetes self-management, it is a criterion for success. The purpose of this review is to examine how eye complications associated with diabetes are portrayed in self-help literature. The texts were analysed, using thematic and Foucauldian discourse analysis to examine the ways in which eye complications associated with diabetes are communicated.

The design and method used in Study (2), a qualitative analysis of T2D self-help literature will be detailed in Chapter 5, Section 5.2. While the analytical procedures will be described in this chapter, (Chapter 3, Section 3.6).

3.2.3 Study (3): Enhanced Diabetic Optometric Practice

Paradoxically many people with T2D know how to self-manage their diabetes, but do not always follow the recommendations. The findings from Study (1) The systemic review and meta-synthesis investigating the barriers to T2D self-care (Chapter 4), and Study (2) A qualitative analysis of self-help tests investigating how T2D self-care practices are communicated (Chapter 5) were used in the planning and development of Study (3) the EDOP.

Enhanced Diabetic Optometric Practice is an enriched procedure, of the normal diabetic screening service which already takes place in optometry practices participating in diabetic retinopathy screening. The aim of the EDOP is to educate and motivate people with T2D to better self-care, by enabling them to connect diabetes self-management and eye health, to reduce the risk of sight loss.

The design and method used in Study (3), EDOP, will be explained in Chapter 6, Section 6.2; while the ethical considerations, recruitment and the participants, the EDOP presentation, and the analytical procedures will be described in this chapter, (Chapter 3).

3.3 Study (3): The Ethics Process

The process began with an application for NHS Research Ethics Committee (REC) and Aston University ethical approval. A favourable opinion from NRES Committee West Midlands -The Black Country was obtained on 5/9/2012 and Aston University, Life and Health Sciences Research Ethics Committee approval was granted on 14/6/2012. (see Appendix 4). Research and Development (R&D) approval was also obtained from the Heart of England NHS Foundation Trust, and Walsall Healthcare NHS Trust was informed about this PhD research study. With regard to participant confidentiality, the EDOP presentations and interview data sets were anonymised for each participant, and pseudonyms were used to replace all personal identifiers.

3.4 Study (3): Recruitment and The Study Participants

In this section various aspects of Study (3) EDOP relating to the participants will be discussed.

3.4.1 Sample

The guidelines for sample size in qualitative research vary (Guest et al., 2006), and depends on how the data will be used or analysed (Johnson, 2014) Participants are commonly selected according to predetermined criteria relevant to the research objectives (Patton, 2002), and sampling continues until saturation is achieved (Braun and Clarke, 2013); (Guest et al., 2006); (Sandelowski, 1995). However, according to (Cheek, 2000), this approach can be problematic, as many research proposals require the number of participants in the study to be determined prior to the research commencing. In this PhD research study, a sample size of 40 participants was decided upon to ensure a homogenous sample with the desired inclusion criteria characteristics. The actual participant sample was 31; this was considered acceptable as an already rich level of data had been generated, and was in-line with recommendations on sample size for qualitative interviews and DA (Braun and Clark, 2013); (Guest et al., 2006). However, an interesting argument on sample size and saturation in PhD studies using qualitative interviews is proposed by (Mason, 2010). (Mason, 2010) found that studies which applied DA to the interview data had a sample size ranging from 5 to 65, with a mean of 25, and SD of 15.3, and concludes that; 'sample size becomes irrelevant as the quality of data is the measurement of its value' (Mason, 2010, p14).

Recruitment occurred between September 2012 and April 2013, initially the recruitment period was scheduled to last five months, however this was extended a further three months as recruitment in November and December was very slow as it was noted that fewer people with T2D were attending the practices for retinal screening. It was perhaps the case because during these months in 2010 the diabetic retinal screening programme was suspended for this time when the contract for provision of services was retendered and the system updated.

Initially 50 information packs were delivered to each practice in September 2012. When the recruitment period was finished the remaining information packs were collected; there were no participants recruited from Pleck, 17 packs were handed out at Brownhills and three participants recruited, 26 packs were handed out in Bloxwich and a total of five participants recruited. The researcher spent two separate days recruiting at this practice and had approached 24 of those potential participants personally, as only two packs had been previously offered to potential participants. The majority of participants were recruited personally by the researcher from the Walsall town centre practice, in addition to the initial 50 packs, a further 25 packs were left at this practice, which is a total of 75 packs handed out at this practice, and 21 participants recruited.

In summary, a total of 121 packs were handed out and 34 people were recruited through purposive sampling between September 2012 and April 2013. Three of the participants declined interviews and withdrew from the study. This was because of the ill health of one participant and so her daughter also declined further participation. The other participant was moving away from the area and felt unable to commit to an interview under the circumstances. This resulted in a sample size of 31 who had had the EDOP presentation and qualitative interview.

3.4.2 Recruitment

Participants were recruited for the EDOP from four optometry practices offering the diabetic retinal screening service in Walsall; these were located in Walsall town centre, the inner-urban location of Pleck and two separate local centres of Brownhills and Bloxwich.

Initial contact with potential participants was made by the retinal screener who had been instructed by the researcher on the inclusion and exclusion criteria required for the study. Those people with T2D who met the desired criteria were approached with a verbal request to participate in the study, if they showed an interest they were offered an information pack to take away and read and their contact telephone number was taken. The participant information packs contained a participant invitation letter, the volunteer information details and participant reply slip and pre-paid returns envelope, (the participant information sheet can be seen in Appendix 5).

The researcher then contacted those potential participants by telephone a few days later, they had had enough time to consider the invitation and if they would like to take part. Their particular preference for either an individual or group EDOP presentation was taken; if they did not express a particular preference then a group session was suggested as this session was considered to be the most difficult session to arrange logistically.

Those who expressed a preference for an individual presentation were offered a mutually convenient appointment at their own home or their optometry practice. Those participants who were willing to accept a group presentation were asked for their preference of a time and date to assist in arranging the sessions. Once a number of participants had been recruited who were agreeable to a group session this was arranged. These sessions proved to be more difficult to arrange logistically, so the participants were contacted with a choice of

two or three possible times and dates and after some further rearrangement and confirmation with all the group participants an agreeable date and time was arranged, and the participants were contacted again by telephone to confirm the arrangements.

3.4.2.1 Methodological Issue Study (3) - Sample Population

Initially during the planning stages of this study participants from the East Birmingham area were to be approached via a GP practice; this was to be arranged via a consultant diabetologist from the Heart of England NHS Foundation Trust based at Heartlands Hospital, Bordesley Green East, Birmingham. However, this did not occur as the consultant retired and due to rearrangement of roles within the screening programme it was not possible to receive active assistance from the Medical Innovation Development and Research Unit (MIDRU) based at Heartlands Hospital. The author of this study had previously been a diabetic retinal screener and grader within the NDESP for Birmingham, Solihull and the Black Country Diabetic Eye Screening Programme in Walsall, and used contacts within Walsall to recruit participants.

The majority of participants were recruited from the Walsall town centre opticians practice, where the researcher had been an optometrist for a number of years. Potential participants were willing to be recruited perhaps because they were familiar with the researcher, this will be discussed further in the reflexivity section (Section 3.7.6). The next largest numbers of participants were recruited from the Bloxwich optician practice, as the researcher attended the practice to personally recruit, as mentioned above. Three participants were recruited from Brownhills and none from Pleck. When the researcher investigated the reason for poor recruitment from these practices the screener admitted to neglecting to ask potential participants if they were interested, and at the Pleck practice the screener explained that many of their patients with T2D were of South Asian ethnicity, and did not meet the recruitment criteria due to their rather limited English language skills. With regard to recruitment of participants of South Asian ethnicity, the optician practices were selected with their demographic profiles in mind, to allow for an unbiased recruitment. Both the Brownhills and Bloxwich practices have mainly a White, Caucasian patient base; while the Pleck practice is mainly South Asian. The majority of participants (67.7%) were recruited from the town centre practice which has a 50:50 split of White and South Asian patients.

3.4.3 Participant Profile

In the sample there were 16 male and 15 female participants aged between 40 and 73 years old. Two of the participants did not have T2D, being the wife of two of the participants, all participants with diabetes were type 2, and had been diagnosed between 18 months and 28 years. Of the 31 participants, seven were of South Asian ethnicity, four males and three females. All the participants with T2D were categorised as having established disease, as no participants were recruited with a diagnosis of under six months.

3.4.4 The EDOP Presentation

The EDOP presentations were divided into group and individual sessions. All the group sessions were delivered at the Methodist Church Hall in Walsall Wood, which was a local venue easily accessed by all the participants. The sessions were scheduled for an afternoon or early evening and travelling time to the location was between 10 to 40 minutes for all participants. The individual sessions all took place at the participant's own home or their optician's practice, at a convenient time for the participant.

The individual sessions took around 25 minutes, with about five minutes to take informed consent and to explain the presentation format, the EDOP presentation itself lasted 20 minutes. The group session took a little longer as the administration took about 15 to 20 minutes.

Two of the individual sessions involved participants listening to the EDOP presentation as a couple, and one male and his daughter also received a joint presentation, otherwise all participants scheduled for an individual presentation received a one-to-one session with the researcher. During the group session the desired participant number for each session was four or five, however, this proved to be difficult to arrange and some participants did attend. The actual number of participants at each session was; Session (1) three participants, Session (2) three participants, Session (3) five participants, and Session (4) two participants.

3.4.4.1 Methodological Issues Study (3) - Study Location

Participants were given a choice of location for their individual EDOP and interview; all participants opted for their own homes or their opticians' practice. However, it is notable that when the EDOP was delivered at the opticians' practice there may be more potential for greater impact as discussed in Chapter 1, (Section 1.3.3) an 'active ingredient' of the EDOP is the location, then the opticians practice would be more potent.

The group sessions were initially to be conducted at Aston University, however, with recruitment being within Walsall this was considered to be an unnecessary distance for these participants to travel so a local venue was arranged. This location was chosen because of the contact the researcher had with the venue and its ease of access and facilities.

3.4.5 The Qualitative Interviews

Following the EDOP presentations the participants were interviewed, it was desirable to allow the participant some time to reflect on the presentation so interviews were arranged with participants at the presentation for one to two weeks following their EDOP. Four of the participants were willing to participate, but requested that the EDOP and interview take place at the same appointment as all gave time commitments as an issue. The interviews took place between one and three weeks after the presentation, though two of the interviews were conducted 11 and 14 weeks after the presentation. This was because both of these participants were away on holiday and gave difficulty scheduling as the reason; one of these participants was also unwell during this time and the other did not wish to be committed over the Christmas period.

3.5 Study (3): The EDOP Presentation

Visual media is becoming more common as a means to facilitate behavioural interventions, due to an increasing social preference for visual communication and advances in technology, (Williams et al., 2012b). Emotion and cognition are two key elements of behaviour which are influenced by visual images, (Bradley and Lang, 1999); (Ito et al., 1998), this forms the rationale for the use of visual images as potentially useful behaviour change tools, which has been discussed in the literature review (Chapter 2, Section 2.3.2). According to (Hagger and Orbell, 2003); (Leventhal et al., 1980), cognitive processes such as health, illness and risk representations influence health behaviours by and independently of emotion. Whilst cognitive representations, developed by patients of themselves and the disease process, are frequently embodied in non-verbal form (Harrow et al., 2008); (Mabeck and Olesen, 1997); suggesting that visual media may be an appropriate means by which these cognitions could be influenced (Lee et al., 2011).

Illness representations range from abstract or conceptual to concrete; representations that are increasingly concrete have the potential for greater impact (Leventhal et al., 1980). Visual images have greater ability to move representations from abstract knowledge to more concrete experiences, when the characteristics are closely matched to those of the viewer. This has been demonstrated in studies which have shown smokers ultrasound images of their own damaged arteries (Shahab et al., 2007). In addition, visual images have advantages over other forms of communication, as visual representations may be more memorable than those which are verbal or text based, and have a tendency for greater long term impact (Prabu, 1998); (Paivio et al., 1994). When the health message is promoted via visual imagery, rather than being mainly dependent on language or literacy skills, those with limited health literacy are not disadvantaged (DeWalt et al., 2004).

3.5.1 Development of the EDOP Presentation: Visual Intervention Model

(Williams et al., 2012b) developed a model for use with visually based healthcare interventions, as they caution that a failure to engage with theory which supports behaviour change may affect the effectiveness of the visual intervention based. The model is based on the UK Medical Research Council (MRC) Framework for the Development and Evaluation of Complex Interventions, which have already been discussed in Chapter 1, Section 1.3.3 (Craig et al., 2008). To develop visual based interventions that maximise the likelihood of being effective, (Williams et al., 2012b) suggest researchers must ensure; a narrative structure around which the intervention message can be organised and conveyed, with an appropriate theoretical and conceptual content through which it can be communicated. This model proposed by (Williams et al., 2012b) has been adopted for the development of the EDOP presentation in this PhD research study.

The model proposed by (Williams et al., 2012b) includes four steps; (1) The identification of a theoretical basis and associated concepts, (2) The development of visual narrative to establish structure, (3) The visual rendering of narrative and concepts, and (4) The assessment of interpretation and impact among the intended patient group.

3.5.1.1 Model-Stage 1: Establishing a Theoretical Basis

According to (Williams et al., 2012b) this stage requires knowledge of behavioural theory, lifestyle interventions and relevant clinical information. This may include; systematic reviews, meta-syntheses of studies that explore health and illness beliefs with regard to the particular

disease or behaviour, and review of literature that explores how these beliefs are already represented in visual form. In this PhD research study, the literature review, (Chapter 2, Section 2.3.2) investigates tele-retinal and medical imaging. The meta-synthesis (Chapter 4), and the qualitative review of diabetes self-help texts (Chapter 5) was employed in the development of the EDOP.

To embed theory for visual interventions to promote self-management the model proposed by (Williams et al., 2012b) incorporates various psychological theories, which include; Health Belief Model (Becker et al., 1977), Self-efficacy Theory (Bandura, 1977), Leventhal's Common Sense Model (Hagger and Orbell, 2003); (Leventhal and Nerenz, 1985); (Leventhal et al., 1980) and Kleinman's Explanatory Models (Kleinman et al., 1978).

Based on elements of the psychological theories discussed in the model presented by (Williams et al., 2012b), the theoretical basis of the EDOP presentation was devised. It was established that an EDOP presentation could be produced to create a visual message that would demonstrate the conceptual link between poor diabetes self-management, diabetic eye disease and the risk of sight loss. The EDOP visually conveyed to participants the risks of personal susceptibility to possible diabetic eye disease and blindness, when their diabetes self-management is poor. The visual imagery used would be able to increase the perceived benefits of good diabetes self-management and care, by raising participant's awareness of the potential health threat of poor diabetes self-control.

3.5.1.2 Model-Stage 2: Establishing Structure to Create a Visual Narrative

According to (Kulkofsky et al., 2008) an advantage of creating a visual narrative provide structures, retains attention, aids memory, and enhances the participant's ability to make causal links between sequential events, (Goncalves and Machado, 1999). Furthermore, according to (Krouse, 2001); (Healton and Messeri, 1993), visual narrative is able to project into the future and potentially increase self-efficacy through emphasising a range of possibilities and choices.

(Williams et al., 2012b) model uses a 'theory-embedded story board' to facilitate the development of the visual narrative, within a coherent and meaningful narrative structure. Evidence suggests that the development of these new coherent illness perceptions can contribute to the creation of behavioural intentions (Hall et al., 2004).

3.5.1.3 Model-Stage 3: Establishing the Aesthetics by Sensory Rendering of the Narrative and Concepts

The style of the narrative is defined once the narrative itself has been established; this involves determining how the theoretical concepts within the narrative are to be communicated. This depends on a wide range of parameters and sub-dimensions which may be used like colour, texture, and complexity.

According to (Williams et al., 2012b), this includes; sociology and medical anthropology with regard to common cultural metaphors (Helman, 2007), social semiotics (van Leeuwen, 2005), aesthetics and colour theory (Radley, 1999a). The most important parameter here relates to where images will lie on a continuum from 'metaphorical' to 'realist', where non-realist images may reduce complexity and thus enhance coherence and understanding, whereas, realist representations may enhance impact through concreteness, but be overly complex and so fail to deliver the message, thus reducing coherence.

(Williams et al., 2012b) advise to constantly check the meaning and clarity of the narrative at this stage, because members of the research team are acutely aware of the meaning the narrative is attempting to convey. Simultaneous feedback on the meaning and the impact of the visual message of the EDOP presentation was gathered from various people known to the researcher; they did not have diabetes and had no prior knowledge of eye health during the development stage to ensure clarity.

The EDOP presentation was developed using information already available to a person with T2D, the choice was made to use familiar images and use analogies which participants would be comfortable with. The 'key' analogy for insulin to unlock cell storage of glucose was used, as this is a common representation, which is not overly complex, taken from the DESMOND diabetes education course, (Chapter 1, Section 1.4.3.1). Medical jargon was kept to a minimum, and explained in lay terms where it could not be avoided. Information for the EDOP presentation was sourced from; the Diabetes UK website, (Diabetes UK, undated-a); (Diabetes UK, undated-b) and other internet sites explaining diabetes, T2D and T2D management. The animations of diabetic eye disease were accessed from 'my diabetes myway' (mydiabetes-myway, 2012) and a video detailing 'Tim's story' from NHS Choices (NHS choices, 2012).

3.5.1.4 Model-Stage 4: Establishing Interpretation and Likely Impact

The final stage in the model seeks to determine the views of the target audience, perhaps through focus group sessions or interviews with members of the target group and relevant health professionals.

The EDOP presentation was piloted on a small number of people with and without T2D, known to the researcher and feedback was given by; the researchers' supervising tutor, patients who attend Moores Opticians, Walsall, a recruiting practice for this research study and colleagues in the optometry profession. Some improvements and modifications were made to the EDOP at this stage from the feedback provided. In particular, the researcher was able to reflect on the overriding message of the EDOP; that diabetic eye disease and blindness was not inevitable and can be avoided, and considered that more repetition of this was required than had initially been considered.

With regard to this point, particularly valuable was the small group session conducted at Moores Opticians, which comprised an older couple, (the husband had T2D, his wife did not, though her brother had T2D) and the practice receptionist who was not diabetic and had limited knowledge of diabetes. Following the EDOP presentation when the pilot participants were asked how the presentation could be improved, they suggested a simple representation of earlier slides, with reiteration of the overriding message would be useful. They felt this would prevent an 'information overload', if new slides with more information were avoided, which would in turn would facilitate a greater reinforcement of cognitions brought about with familiarisation of the slides.

3.5.2 Practical and Ethical Considerations

(Williams et al., 2012b) caution that the context in which interventions are ethically and socially unacceptable must be considered, as the use of visual images and increased sensory engagement can have a powerful impact on experience, attitude, intention and behaviour. The potential dangers associated with the use of increasingly concrete imagery must be identified, as it is possible that such concreteness could be so powerful as to be considered harmful, promoting excessive rumination, intrusive images and ongoing anxiety (Olatunji et al., 2005); (Hackmann et al., 1998) images need to be tailored to suit particular social groups, personality types or cognitive styles.

The EDOP presentation is fundamentally significant to this PhD research study, as it is envisaged it may be able to provide the impetus for participants to change their behaviour.

With this consideration, the researcher has followed suggestions highlighted by (Williams et al., 2012b), in applying this model, and all guidance and precautions were followed to ensure maximum potential effectiveness. In addition, the technical inexperience of the researcher in preparing some material for inclusion in the EDOP presentation was addressed with the help of Nick Birch, Media Production Manager from the Marketing Strategy and Communications Department, Aston University.

3.5.3 The EDOP Slide Presentation

The 20 minute EDOP presentation consists of 23 slides; and can be seen in Appendix 3, with a print layout of the slides and a brief synopsis of the narrative accompanying each slide. The EDOP presentation was designed to provide participants with a baseline level of knowledge for about T2D, risk reduction for the complications of diabetes, and DR progression to vision loss. The researcher of this PhD study considered research by (McCaul et al. 1987), who found that better knowledge did not predict more successful diabetes self-management, it is a criterion for success. The presentation begins with an introduction to the PhD research study, the researchers, and a brief explanation of diabetes, along with the general complications associated with diabetes. The next slide introduces the diabetic eye complications, with a detailed explanation of how participants could reduce the risks of diabetic eye disease through better self-care and management. Before the stages of diabetic eye disease are covered by the presentation, participants will be shown a normal healthy fundal image and features of the digital retinal images taken during the diabetic screening process explained. For visual interventions, using fear appeals to be effective participants require comparative appraisal of unhealthy or abnormal with healthy and normal, (Rees et al., 2013); (Williams et al., 2012a); (Grogan et al., 2011); (Salti et al., 2011).

The stages of diabetic eye disease are then highlighted in the presentation, each stage of the disease was described in the same format, as to be consistent and avoid confusion. Explanation of the stages of diabetic eye disease begin with BDR, then PDR and finally maculopathy. With each stage a short animation will be presented showing the development of retinopathy. The animation is then followed by a series of slides of actual but generic retinal images, showing diabetic eye disease detected at a screening episode. During the presentation when the comparative images of diabetic eye disease are shown, the researcher explained the progression of DR leading to sight loss, and the preventative measures required to reduce the risk. It is envisaged that participants will make a connection between the images being presented on the screen and prevention of vision loss in their own

eyes. As discussed, by raising their self-efficacy, participants are able to believe they could act to reduce their personal risk of diabetic eye disease and sight loss. New illness perceptions will be created, enabling participants an understanding and sense of coherence in relation to the processes of connecting diabetic eye disease and blindness.

The important message of the presentation and the research itself is displayed on a slide stating that; 'diabetic retinopathy is progressive, but is avoidable'. It was deemed necessary to explicitly state that diabetic eye disease can be avoided following the previous slide selection, with representation of the slide listing how the risk of sight loss could be reduced and reiteration of the overriding message. A video clip entitled 'Tim's Story' was then shown to participants (NHS Choices, 2012). This was used to reinforce the message that the complications of diabetes including sight loss occur because of poorly controlled diabetes, and that to reduce the risk of complications a healthier lifestyle is advocated. The presentation concludes with some slides advertising where participants are able to access more information to better self-care, and the final slide thanks participants for their involvement and reminded them of the upcoming interview. A brief explanation of the focus of the interview was given to participants and reassurance that they would not be required to reiterate the information presented during the EDOP, as the information was for their benefit to demonstrate the necessity for diabetic retinal screening and to illustrate the importance of good diabetes control on eye health and vision.

3.5.3.1 Methodological Issue Study (3) - Design of the EDOP

For those participants of South Asian ethnicity, the researcher was mindful to ensure that the EDOP presentation was conveyed in a culturally appropriate manor to avoid misunderstanding. To ensure that the EDOP was relevant to a person of South Asian ethnicity with T2D, the information booklets offered to participants were available in the South Asian languages of Urdu, Punjabi, Gujarati and Bengali. The researcher is not of South Asian ethnicity and so was advised by an optometrist colleague whose mother had been diagnosed with T2D three years ago, and was a first generation Pakistani immigrant.

Although some researchers such as (Ahmad, 1993) argue that researchers from the same ethnic or 'racial' background are more likely to obtain a fuller picture, or a more nuanced description of the views of the group being researched. Other researchers argue that whilst there are very positive reasons to encourage people of the same ethnicity to research their own communities, there are also a number of arguments against matching researchers to

respondents, (Kelleher and Hillier, 1996); (Song and Parker, 1995). There are other important markers of identity between people besides ethnicity or race and these authors cast doubt on the need to match ethnicity, or any other characteristic of the researched group with that of the researcher. They also highlight the fact that there are likely to be multiple differences and commonality in the interaction between researcher and respondent. Researchers who are not from the same ethnic background are not precluded from having experience of discrimination in some way and may provoke discussion or the asking of both different and difficult questions. (Bissell et al., 2004) provide evidence to suggest that there are 'no a priori reasons which preclude White researchers (or those from any background) from researching the experiences of minority ethnic groups', (Bissell et al., 2004 p854).

3.6 Data Analysis Procedure

3.6.1 Data Coding

The transcripts were summarised as suggested by (Wiggins and Riley, 2010), with general impressions, arguments, subjects and objects being noted that construct particular realities. Key themes were identified as patterns in the data emerged. Coding was initially undertaken as an iterative process of interpreting and re-coding of the data, this process of summarising and identification was repeated on several times to allow for descriptive text summaries to formulate the conceptual themes within the data. To allow for this process to fully explore all the issues, the researcher was mindful to ensure that the coding was data-drive.

A series of extracts were then produced when the coded data was collated into themes, with oblique and overt instances included. Identification of the discourses were undertaken with some physical manipulation of the data extracts and colour coding strategies employed with Word and Excel in Microsoft Office. The process was repeated several times until the researcher was able to conceptualise the various ways in which different themes was discussed.

3.6.1.1 Methodological Issue – Coding

Initially it was considered that the coding process would be greatly assisted with the use of the NVivo package. 'NVivo' is a qualitative data analysis computer software package produced by QSR International. It has been designed for qualitative researchers working

with a large amount of text-and/or multimedia information, where deep levels of analysis on small or large volumes of data are required, allowing the researcher to organise the data to facilitate coding. However, the researcher considered that a more sensitive relationship with the data would be achieved without it, due to a lack of experience and expertise with this type of programme.

3.6.2 Thematic Analysis

Epistemology of thematic analysis looks at realist views and constructionist paradigms. With this realist approach, motives, experience and meanings can be theorised in a direct way, because of the simple relationship which is assumed in language. Although not within the tenant of FDA, (Potter and Wetherell, 1987), consider that language reflects and enables us to articulate meaning and experience. The constructionist analysis looks at meaning and experience as being socially produced and reproduced, rather than inherently within individuals. The socio-cultural context and structural conditions of thematic analysis are theorised, whilst the interpretive themes have constructionist tenancies.

There are two approaches to thematic analysis deduced by (Holloway and Todres, 2003); inductive and theoretical. An inductive approach means that themes identified are strongly linked to the data themselves, whereas a theoretical approach is analytical. Inductive analysis is a process of coding the data without trying to fit it into a pre-existing coding frame or the researcher's preconceptions. The analysis is driven by the data and not by the researcher's analytic interest. There are two levels at which themes can be teased out analytically, they are at a semantic level or an interpretive level; with semantic themes the researcher only codes what is said or written, whilst with interpretive analysis the underlying ideas or assumptions are examined. For the qualitative meta-synthesis both levels of analysis will be required.

The six step approach to thematic analysis set out by (Braun and Clarke, 2006) was be adopted; Step 1: Familiarisation with data: transcription of the data, Step 2: Generating initial codes: systematic coding of interesting features across the data set, Step 3: Searching for themes: collating codes into potential themes, Step 4: Reviewing themes: checking if themes work in relation to the coded extract and the entire data, Step 5: Defining and naming themes: on-going analysis to refine the specifics, and Step 6: Producing the report.

3.6.2.1 Methodological Issue - Justification for Using Thematic Analysis

The method outlined by (Braun and Clark, 2006) for thematic analysis of data was implemented in this study, justification for the use of Braun and Clarke's method centres on the formalised process of analytical steps in their approach, making the process of thematic analysis in this study transparent and allowing for a reflective process.

Thematic analysis was chosen as an analytical method in this study because it is independent of theory and epistemology, and able to give rich and detailed accounts of data; 'thematising meanings, is one of the few shared skills across qualitative analysis', (Hollaway and Todres, 2003 p347). In addition, thematic analysis is a useful and flexible method for qualitative research useful across different methods, (Braun and Clarke, 2006).

3.6.2.2 Methodological Issue - Critique of Thematic Analysis

Judgement is needed to determine what constitutes a theme, this may not always be the same for each data item, and a theme can be given a large space in some data items and little or none in others. (Braun and Clark, 2006) consider thematic analysis to be a method that works to reflect reality and to unpick or unravel the surface of reality. However, they caution that any theoretical framework holds a number of assumptions about the nature of the data and what that represents in terms of the 'the world' or 'reality'. To ensure a sound thematic analysis in this study the researcher will follow the recommendations made by (Braun and Clark, 2006) by making those assumptions clear. When considering the themes (Hollaway and Todres, 2003) warn that, it is not thematic analysis to simply use the questions posed to participants in interviews or focus group discussion as the themes identified. The researcher in this PhD research study was mindful of critique of thematic analysis and aimed to make the analytical process robust and transparent to ensure the quality in the choice of this qualitative method.

3.6.3 Foucauldian Discourse Analysis

Construction of the identified discourses and the consequences of using them were considered, the researcher explores what possible ways of being are facilitated or restricted by these discourses and the implication for subjectivity. Subjectivity is the term used to refer to individuality and self-awareness, and is always positioned in relation to particular discourses and practices produced by these, (Henriques et al., 1998). FDA attempts to make

connections between the discursive constructions used by the participants and their subjective experiences from various subject positions. According to (Parker, 1992) discourses are defined as, 'sets of statements that construct objects and an array of subject positions' (Parker, 1992 p245). This makes available, 'certain ways-of seeing and certain ways-of-being in the world', (Willig, 2008 p113). When these inferences are explored and located within their social and historical context FDA permits the analysis of knowledge and power.

The analytical process of FDA is based on the step-by-step guide suggested by (Willig, 2008); Step 1: Identify how the object is constructed in discourse, Step 2: Identify the different discourses involved, Step 3: Identify the action orientation of a particular discourse, Step 4: Identify the subject positions of people within a particular discourse, Step 5: Suggest the implications of the object constructions and subject positions for opening up and shutting down action, and finally Step 6: determine the consequences of the discourse for the subjective experience of the individual.

Identification of the object was aided by consideration of the research questions. The research questions propose that T2D self-management, eye health, the complications of diabetes, and digital retinal images, are the various objects under study. FDA examines the various features of T2D self-care and management, and eye health, and how they are constructed.

Discourse is defined by the Oxford English dictionary as 'written or spoken communication or debate, a formal discussion of a topic in speech or writing'. Various discourses were identified by the analysis; these discourses are related to the objects studied. Discourse produces subject positions, which in turn become subjected to the power and regulation of the discourse.

The action orientations of the various discourses are distinguished, enabling discussion of what could be gained from using that particular discourse, and what may be restricted. According to (Willig, 2008), 'A focus on action orientation allows us to gain a clearer understanding of what the various constructions of the discursive object are capable of achieving within the text', (Willig, 2008 p116).

The subject positions of the various subjects under study are, within particular discourses are identified, these are; the authors of the self-help texts, the study participants and the researcher of this PhD study.

The role of the object constructions and subject positions can then be investigated, allowing for determination of how action is created and limited by particular discourses. (Willig, 2008) states, that by identifying the subject positions of people within a particular discourse, they are defining their 'discursive locations from which to speak or act' (Willig, 2008 p116).

Finally, the consequences of the discourse for the subjective experience of the individual can be determined. (Willig, 2008) states; 'we are now concerned with what can be felt, though the experienced from various subject positions', (Willig, 2008 p117). (Howitt, 2010) considers the possible consequences of the discourses, for the individuals identified, drawing attention to how discourses; 'construct social and psychological realities for the individual in terms of (a) seeing the world and (b) being in the world', (Howitt, 2010 p231). Foucault's interest is in how text includes more than what is immediately apparent, beyond the immediate context in which the words are said. Further to this, (Parker, 1992) states that discourses analysed using FDA are able to 'facilitate and limit, enable and constrain, what can be said, by whom, where and when, (Parker, 1992 pxiii).

3.6.3.1 Methodological Issues - Justification for Using Foucauldian Discourse Analysis

It is considered that by applying FDA a thorough investigation is possible of the power relations within the various discourses identified. It was anticipated this would present richer findings, allowing for greater consideration and interpretation of the results. By considering how the various discourses are facilitated or constrained, the subject positions can be analysed to better understand the multi-faceted aspects of the participant's diabetes self-care practices, with regard to diabetic eye disease and the threat of sight loss.

This PhD research study investigates people with T2D and their self-management and self-care practices. Foucault's was interested in how the body is socially regulated by the practice of medicine, (Foucault, 1989). The justification for using FDA over other discourse analytical approaches centres on the concept of power relations, and focuses on subjectivity and the concept of knowledge/power which enables the role of institutions in supporting discourses to be regarded. (Willig, 2000) determines that through FDA, the role of discourse can be explored in terms of subjectivity, individuality and power relations, whilst highlighting the position of discourse in the wider social processes of legitimation of power.

The rationale for using FDA in the review was based on the following statement by (Parker et al., 1995); 'Foucault's work has been invaluable in drawing attention to the way language is organised around different systems of meaning which offer positions of power to certain categories of people and disempowers others', (Parker et al., 1995 p10).

With regard to power relations and knowledge, in an essay entitled 'Prison Talk' (Foucault, 1980) states that; 'it is not possible for power to be exerted without knowledge and it is impossible for knowledge not to engender power', (Foucault, 1980 p52). This is an important consideration in the discussion of knowledge, because it emphasises the way that knowledge is not separate but central to struggles over power, when knowledge is produced, a claim for power is also made, (Mills, 2003). Foucault was concerned with the notion that systems of knowledge and operations of power are mutually co-constitutive. From a Foucauldian perspective, all forms of knowledge are constructed through discourse and discursive practices, including scientific knowledge. This means that any research report, including this PhD research study is a discursive construction, which cannot be evaluated outside of a discursive framework. The researcher 'authors', rather than discovers knowledge; hence, a reflexive awareness of the researchers' own knowledge claims and the discourses used to construct them are an important element of discursive analytical research.

3.6.3.2 Methodological Issues - Critique of Foucauldian Discourse Analysis

Michel Foucault considered discourse to be a system of representations involving the production of power/knowledge through language. Cultural theorist Stuart Hall describes representation as the process by which meaning is produced and exchanged through the use of language, signs and images which embodies them (Hall et al., 2013). Foucault asserted that nothing has meaning outside of discourse, (Foucault, 1972); discursive constructions are real, and have tangible effects; a physical reality must exist to produce the discourse. The concepts of meaning and discourse go together; the notion of discourse is about where meaning comes from. According to (Mills, 1997) discourse produces, 'a narrowing of one's field of vision, to exclude a wide range of phenomena from being considered as real or as worthy of attention, or as even existing' (Mills, 1997 p51).

Within DA, discourse has the ability to construct the self and is implicated in subjectivity, but (Willig, 2008) suggests that it is debatable if discourse is the only requirement for the formation of personal identity through subject positions, because people sometimes position

themselves in ways that limit their opportunity for action, (Willig, 2000). (Burr, 2003) makes further criticism of FDA stating that when discourses are turned into objects, which have an existence independent of the people who use them and the contexts in which they are used, what the speaker is doing with their talk is neglected.

Critiques of FDA also considers that the lack of precise methodological principles has substantiated epistemological claims, that research undertaken in the Foucauldian framework is deficient in rigour and other discursive methods are thus superior. With regard to this PhD research study and the use of FDA, the author has considered (Graham, 2005) as an aid to those to critique Foucault, and assist in a clear justification for the use of this analytical method. (Graham, 2005) considers how many scholars using FDA have adopted a "*Foucauldianistic*" reticence to declare a method, as they are perhaps apprehensive of being considered prescriptive. She seeks explanation for the dilemma, stating; 'there is a very real danger in one's work being dismissed as "*unFoucauldian*", if one doesn't get it right. But how can one get it wrong when there are supposedly no rules to follow?' (Graham, 2005 p2 - authors own emphasis). To address the issues of quality in qualitative research the author considers aspects of; sensitivity to context, commitment and rigour, transparency and coherence, and the author has endeavoured to be clear with regard to all the aspects of reflexivity.

3.7 Quality in Qualitative Research

The following section will discuss how the researcher of this PhD research study ensured the quality of the qualitative research conducted, and the elements of best practice required to produce a robust method and sound understanding of the analytical process. (Burr, 2003) considers that reliability and validity are inappropriate for judging the quality of SC because there is no definite description of the world, and reality is inseparable from discourse, which is local and historically/culturally specific. According to (Yardley, 2000) qualitative methods are concerned with the particular circumstances and/or experiences of individuals and the interactive relationship between the researcher and the participant requires consideration, as this gives rise to personal and ethical issues derived from mutual influence. The dilemma for qualitative researchers is that the different methods of qualitative research have quite different practices and procedures depending on how the method has evolved or been developed, or from the philosophy from which it derives.

3.7.1 Characteristics of Good Qualitative Research

(Yardley, 2000) discusses the characteristics of good qualitative research which are; sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. To ensure good qualitative research, the researcher of this PhD study has been guided by these criteria and been mindful of the implications of such standards for quality in qualitative research.

Sensitivity to context has two contextual aspects, which are theoretical and socio-cultural. The theoretical context of the research considers previous research, which has employed similar methods or analysis. This has been discussed in the rationale for this PhD study within the literature review chapter (Section 2.4), insights and information obtained by previous research in the field of diabetes education and self-management, investigations using similar qualitative research methods and analytical techniques have been reviewed. Socio-cultural context is important, as language as social interaction and culture are regarded as being central to the meaning and function of all phenomena in qualitative research. It is vital to consider the social context of the relationship between the researcher and the study participants. With regard to discourse analysis (Yardley, 2000) states that; 'the listener contributes to what is said, not only by the moment-to-moment verbal and non-verbal input which prompts and completes the other's utterances, but also by actively or passively invoking the relative identities and shared understandings which provide the framework for speech', (Yardley, 2000 p221). The researcher is integral to the research and is not neutral, the study design must consider the effect of the researcher's interaction in the study, and the balance of power between the research and the participants during the study process (Karnieli-Miller et al., 2009). The challenge is to overcome the inevitable imbalance of power relations between the participants and the researcher who is seen as the 'expert'; this is of particular relevance when the study participants have an already established relationship with the researcher.

Commitment in qualitative research regards a prolonged engagement with the study topic, the researcher is an optometrist and screener/grader within the NDESP, and as such demonstrates commitment to diabetes care, management and education in this PhD research study.

Transparency and rigour in this PhD research study was achieved by detailing explicitly the process of data collection, the strategies employed in preparing the data. Data analysis was undertaken rigorously, with consideration given to all aspects of establishing quality in the

qualitative research. When information is transparent and available for inspection, all aspects of the research process can be examined and the reader is able to see how the investigation has progressed and how patterns in the data have emerged.

Qualitative researchers believe that the world can be overwhelmingly swayed by their own beliefs, objectives and behaviour that it is paramount to make clear and reflect on their position; this is reflexivity. The various aspects of reflexive practice will be discussed in detail as required and where appropriate, throughout this thesis. Coherence is related to the clarity and persuasiveness of the research argument, methodological coherence is required to ensure congruence between the research questions and the components of the method and analytical techniques. The methodological issues will be discussed as required and where appropriate.

The impact and significance of how research is judged is, according to (Yardley, 2000) critical; research findings must be useful, have practical impact, as well as adding value to the body of knowledge which it investigates. Particularly important is the socio-cultural impact of research (Yardley, 1997), all discourse arises from a specific social context, and serves a social purpose, or has a social effect. Discourse, ideas and beliefs are an intrinsic part of the health and illness experience, and can be substantially altered by research which contributes to a change in the way we think or talk about health (Yardley, 2000). It is hypothesised that the participants of this PhD study, through the EDOP experience, may be able to perceive their T2D differently and alter their self-management practices beneficially.

3.7.1.1 Methodological Issues – Quality of the Qualitative Research

Researchers and academics are accorded a greater claim to truth than the subjects of their studies, and the researcher's version of events has greater authority and is given more notability than that of the subject (Burr, 2003). The researcher of the PhD study has been mindful of the ethical issues to be considered in this situation, as most of the participants are patients of the researcher, who is their optometrist and has an already established and familiar relationship with them. (Yardley, 2000) warns of the prospect of possible exploitation and the need to be more vigilant on safeguarding participant anonymity and confidentiality. Notwithstanding, the researcher considers a personal relationship with most of the participants may guard against the possibility of excessive imbalances in power.

3.7.2 Reflexivity

An important part of the evolution of qualitative research is reflexivity, where researchers must examine how themselves and intersubjective elements impact on and transform research. According to (Finley and Gough, 2003), reflexivity requires researchers to turn a critical gaze towards themselves, to be aware of their own positions and interests and to explicitly situate themselves within the research. They argue that it is important for researchers to be continually reflexive about the research process to ensure against their own prejudgements becoming part of the research (Finlay, 2002). Reflexivity in research is imperative, as neither the researcher nor the participants have privileged access to the 'reality' of lived experience. It is important to acknowledge that data collection takes place within a specific context; for example, an interview is a formalised process which in most cases is structured and led by the researcher who is responsible for choosing the topic of the interview and the interview schedule (Kvale, 1996).

3.7.2.1 Reflexivity in Qualitative Research

Reflexivity is an invaluable tool in qualitative research which allows for the impact of the position, perspective and presence of the researcher to be examined. It also promotes a richer insight by examining personal responses and interpersonal dynamics, allows for evaluation of the research process, method and outcomes and enables public scrutiny of the integrity of the research through the methodology of research decisions, Finley (2002).

3.7.2.2 Personal Reflexivity

Given the importance of reflexivity in qualitative research it is necessary to identify my own pre-conceptions and assumptions with regards to this PhD research study. This is my position, and I accept that my prior-knowledge and professional status as an optometrist will inform and be challenged by this research. I began this research with an interest in diabetes and diabetic retinal screening as a screener/grader in the NDESP for Birmingham, Solihull and the Black Country Diabetic Eye Screening Programme in Walsall.

I do not have diabetes and have no personal experience of diabetes or other chronic illness; though as an optometrist and screener within the retinal screening programme I interact with people with diabetes on a daily basis. This has enabled me to observe how people living with diabetes self-manage and deal with the complex issues of diabetes self-care. I am

intrigued by the paradox that most people with diabetes know how to effectively self-manage, yet seem to choose not to. This is what interests me and is the reason I chose this research topic.

When speaking to patients attending for diabetic retinal screening I was aware of the lack of knowledge or misunderstanding of information that most people with diabetes have about their disease and wanted to investigate if this deficit could be addressed in the 'normal' optometric practice environment. My aim is to better understand how diabetes education could be better presented to people with T2D to enhance motivation enabling effective and lifelong self-care. I believe that diabetic retinal screening could not only be a tool to monitor and prevent vision loss, through the detection and timely treatment of diabetic eye disease, but could be a vital tool in diabetes education. I consider that the diabetic retinal screening episode is a missed opportunity for the early prevention of sight loss, through education and empowerment of people with T2D before DR occurs.

When I began this research I had no prior knowledge of qualitative methods, though I have experience of conducting quantitative research at Master's level. Having no preconceived ideas about the merits of the various qualitative methods I was drawn to the FDA, for the reasons I have already discussed in the previous section.

By outlining my position as researcher of this PhD study I hope to be transparent in the way my analysis has developed. Throughout my research I will continue to reflect on my own participation and impact on this study, how this has impacted on my participants and their diabetes management, and the influence they have had on my pre-conceived ideas about T2D education, management and self-care.

3.8 Summary

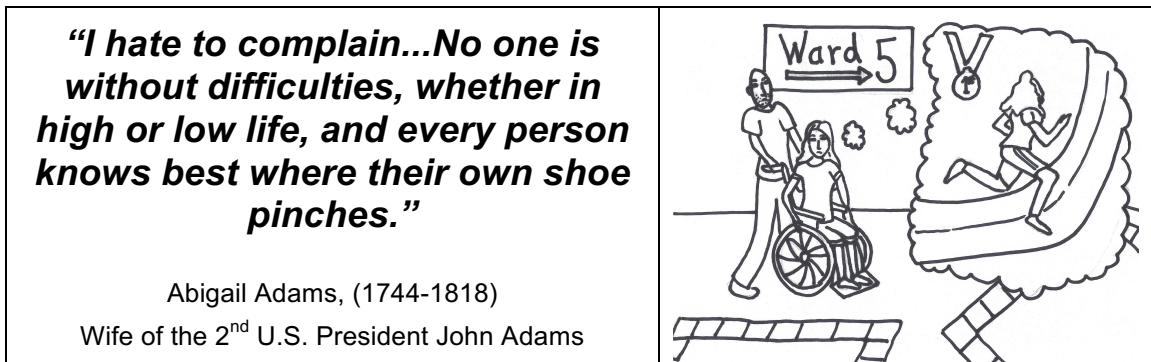
This chapter has explained the methods used and methodological considerations of how this PhD research study has been designed, and how the procedures have been implemented. Also discussed in this chapter has been how the quality of this qualitative research was initially assured, and how it has been maintained through considerations of good practice and reflexivity.

The next three chapters of this PhD study are the research chapters. Chapter 4, Study (1) A systemic review and meta-synthesis of qualitative research, investigating the barriers to self-

care for people with T2D, and Chapter 5, Study (2) The qualitative analysis of diabetes self-help literature and eye health have assisted the development of EDOP, Chapter 6, Study (6).

4 STUDY (1): SYSTEMATIC REVIEW AND META-SYNTHESIS

Investigating the barriers to self-care for people with type 2 diabetes: A systematic review and meta-synthesis of qualitative research



4.1 Introduction

Diabetes self-management education is recognised as essential for diabetic patients to achieve positive results from self-care, with responsibility placed upon patients to self-manage the disease (Cyrino et al., 2009). However, according to (Cyrino et al., 2009), people with diabetes often experience conflict between what is recommended by the clinician, their own needs and desires, and existing social or cultural circumstances. Living with diabetes has been described by (Whittemore et al., 2005) as ‘a difficult process whereby individuals attempt to find balance between the self-management demands and their preferred lifestyle’ (Whittemore et al., 2005 p196). Studies indicate that most people with T2D do not achieve acceptable glycaemic control, (Saaddine et al., 2002); (Gilmer et al., 1997) or accomplish effective self-management, people with diabetes find adhering to a healthy diet the most difficult aspect of their self-care regime (Sullivan and Joseph, 1998).

4.1.1 Aims

This systemic review and meta-synthesis of qualitative studies investigating people’s experiences of managing T2D will enable better understanding of their care needs, and to facilitate the development and implementation of the EDOP presentation in study (3), as discussed in Chapter 3. The wording and framing of the presentation was given careful regard in an attempt to create a positive approach to self-care and empower the participants to be effective self-managers.

Themes highlighted in this chapter relate to; patient lack of knowledge and understanding, provider lack of knowledge, provider-patient relationships, social support, external constraints and co-morbidity and internal constraints. Having identified the barriers to self-care and by drawing together the findings in this review, the motivational factors to enable successful and effective diabetes self-management can be understood; thus giving insight into strategies which can be employed by the patient and their providers to overcome these obstacles and facilitate effective self-care.

4.1.2 Type 2 Diabetes Education

According to (Snoek, 2002); (Coates and Boore, 1996); (Bloomgarden, 1987) knowledge is a prerequisite for successful management of T2D, but it does not ensure that people with T2D will implement care that results in strict blood glucose control. (Krichbaum et al., 2003) also found that knowledge of T2D is necessary, but not sufficient for improving glycaemic control, and it did not prepare people for managing the large amount of possible health consequences resulting from a lack of glycaemic control.

With regard to diabetes self-management education (Johnson, 1984) states that; 'if the patient does not know what to do, he cannot do it' (Johnson, 1984 p509). Though he adds, that while knowledge is a necessary condition for adequate health care, it is not a sufficient condition, stating that; 'the patient may know what to do, but not do it' (Johnson, 1984 p509). According to, (McCaul et al., 1987) knowledge is inconsistently related to adherence behaviour, better knowledge does not necessarily imply better adherence. While knowledge does not predict diabetes self-management, it is a criterion for success, (McCaul et al., 1987). Literature is ambiguous regarding the relationship between diabetes knowledge and outcomes (Norris et al., 2001), as diabetes knowledge is not necessarily a predictor of diabetes management.

There is evidence of poor compliance to education, (Duncan et al., 2010) and according to (Cleemput and Kesteloot, 2002), only 50% of the health professionals advice is likely to be taken up by patients. The complexity of what is to be learned, managed, and integrated with lifestyle explains the difficulties with adherence, (Goodall and Halford, 1991). Poor adherence of patients to medical advice has consequences, such as medical and psychological complications associated with disease, low quality of life, and wastage of health care resources. These issues have been discussed in Chapter 1.

Educators need to be realistic about what education can achieve, as various studies have shown that people may reject or fail to respond to health education messages if these do not strike a responsive chord with their own experiences, (Davison et al., 1991); (Blaxter, 1983). People's perceptions and understandings of their disease need to be situated and understood not only in terms of their individual experiences, but also within the broader social, cultural and historical context of their lives (Lawton et al., 2006). Personally relevant information has been used for improved health outcomes for many conditions with positive results. Studies have included; BP monitoring (Ahern et al., 2012), blood glucose self-management (Quinn et al., 2011) and cancer patients (McCorkle et al., 2011). For example, cancer patients in the intervention group of the (McCorkle et al., 2011) study compared computerised educational information, which incorporated data from their own electronic medical records with general information on cancer. The control group was given general information about cancer only. Results from this and other studies showed that more patients in the intervention groups felt educated; and they thought that the information was relevant. Patients also demonstrated a higher preference for personalised information and used the information more than those in the control groups (Jones and Pearson, 1999).

Although diabetes education is crucial to improving self-management, the positive effects of education declines over time (Denham et al., 2011) and (Norris, 2002), self-management education needs to be ongoing to obtain the best possible health outcomes, (Denham et al., 2011), Therefore, education requires continuous maintenance by individuals and health providers over time to obtain the best possible health outcomes (Rhee et al., 2005). An effective use of resources could be an annual EDOP at the yearly diabetic retinopathy screening appointment, which could effectively stop the erosion of positive beneficial effects of T2D self-management, which will be discussed in Chapter 7.

4.1.3 Type 2 Diabetes Self-Management

(Bains and Egede, 2011) found that diabetes knowledge influences self-management indirectly, and the level of self-management the patients can maintain daily depends largely on their perception of their ability to perform activities with an expected outcome. The assessment of one's own ability influences motivation, initiation, participation, and adherence to self-management, and therefore affects the control of diabetes. According to (Brown et al., 2002) the key to effective self-management is patient motivation and willingness to assume responsibility for their own care through a change in their attitude

towards the disease. Responsibility to self-manage T2D lies with the patient, who provide about 95% of their own care (Anderson et al., 1995). This requires confidence and motivation to enable them to make appropriate and permanent lifestyle changes, (Loveman et al., 2008). Aspects of motivation have been discussed in Chapter 2, Section 2.3.1.3 and Section 2.3.1.4

Patients must not only accept their disease but achieve extremely high levels of self-care, commitment, and attention to health promoting behaviours to control T2D and prevent possible complications, (Dietrich, 1996). According to (Schlundt et al., 2003), the patients responsibility to self-manage requires the daily decision to follow a regime of diet, exercise, and medication. Successful management is a combination of knowledge of the disease, along with behaviour and lifestyle modification, (Auerbach et al., 2001); (Funnell, 2000).

4.1.4 The Self in Self- Management of Type 2 Diabetes

Self-management of T2D is concerned with the patients themselves having responsibility for, and being active in, managing their illness. To control their diabetes individuals must manage their daily behaviour, and long-held habits often need to be changed.

(Gomersall et al., 2011) investigated the 'self' in self-management of T2D, and identified 38 articles in their review of contemporary qualitative research which considered the patient's perspectives. The researchers found self-management to imply an intrapersonal understanding of diabetes control, and that the management of diabetes appears to operate on multiple levels; not only internally, in terms of personal identity, but also externally, in terms of cultural resources and inter-subjective realities of medical consultations. (Gomersall et al., 2011) concluded that personal accountability is implicit in the terminology of self-management, where they found a strong moral component to self-management, indicating that failing health is linked to a failing self and in particular a failure to self-control.

4.1.5 Type 2 Diabetes Self-Care

Diabetes self-management education is recognised as essential for people with diabetes to achieve desirable results from self-care, (Cyrino et al., 2009). However, self-care *per se* is not a guarantee for better metabolic control, (Estey et al., 1990) and (Wilson et al., 1986), as self-care practices are influenced by a number of factors related to different life events, as

well as personal choices and preferences (Dean, 1989); (Levin, 1981). These are discussed in the following section of this chapter (Section 4.1.5).

(Misra and Lager, 2009) found that a minimum level of knowledge is required for good diabetes management, and diabetes knowledge is a prerequisite for good management, (Colleran et al., 2003); (Speight and Bradely, 2001). Although diabetes self-management education is essential to diabetes self-care; the most important aspect of modern diabetes management is that people with diabetes are actively involved in their own care, (van Dam et al., 2003). People with diabetes are responsible for the daily management of the disease, and it is necessary that they understand their condition and how to manage it (Funnell and Anderson, 2004). Social support improves self-care, with emotional support the most important type, as it leads to enhanced motivation (Toljamo and Hentinen, 2001). In their research, (Toljamo and Hentinen, 2001) use the term adherence, rather than compliance, as they found it to ensure self-care and improve self-management, as it is more holistic.

Limitations to compliance models, are considered by (Britten, 2001) and (Donovan and Blake, 1992), as they offer clear justifications for attributing blame when patient's actions do not meet the expectations placed on them by healthcare providers. (Blenkinsopp, 2001) draws attention to the growing awareness of these limitations in the application to health care relationships, and supports the concept of a concordance model. Patients must enact the management process (Cahill, 1996), and when they are encouraged to participate in medical decision making (Chatterjee, 2006), adherence is improved (Kaplan et al., 1989). The desired aim in disease management is now considered to be concordance; clinical interactions with patients should not be viewed as just opportunities to reinforce instructions around treatment. They should be seen as a space where the expertise of patients and health professionals can be pooled to arrive at mutually agreed goals, (Bissell et al., 2004). Flow of expert information occurs in both directions; patients rely on healthcare professionals for expert information, and patients provide expert self-information to their providers, (Golin et al., 1996). Compliance, adherence and concordance have been discussed in Chapter 2, section 2.3.4 and will be further considered in chapters 6 and 7.

In the early 1990s studies involving diabetes education were aimed at measuring the patients' knowledge and management of T2D before and after an educational intervention. However, from the mid-1990s educational interventions began to present strategies aimed at self-care, as well as focusing on the acquisition of knowledge about T2D. These studies included behavioural strategies involving patient empowerment, support, problem-solving (Brown, 1999), and autonomy-supportive motivation (Williams et al., 1998a), which have

their roots in cognitive psychology. Cognitive psychology is the branch of psychology that studies mental processes including how people think, perceive, remember, and learn. Research in the field of cognitive psychology involves improving memory, increasing decision-making accuracy, and structuring educational curricula to enhance learning.

4.1.6 Attitudes, Beliefs and Preferences of People with Type 2 Diabetes

People with diabetes generally know about and perhaps fear the complications, yet many have enormous difficulty in following recommendations and advice, in regard to the habits, choices and priorities that they have already instituted within their lives (Aljasem et al., 2001). Patients have primary responsibility for the day-to-day administration of the treatment regime, and the management of symptoms and their attitudes towards their disease influences how they manage everyday life in a practical way (Auerbach et al., 2001). Management of T2D must be examined from the patient's perspective, (Golin et al., 1996); (Hernandez, 1995), to understand the factors that enable people with diabetes to adhere to self-care, and to identify the barriers they face. When the barriers to self-management are not identified or underestimated adherence to self-care is affected, (Aljasem et al., 2001). Managing a chronic disease demands a huge amount of time, changes in lifestyle and confidence to do this. As well as improving knowledge and skills, self-management education can motivate a person to make and sustain lifestyle changes by addressing their health beliefs. The biomedical and psychosocial benefits have been shown to improve quality of life, reduce depression, reduce the need for medications, decrease body weight, improve glucose control and improve lipid profiles (Jarvis et al., 2010).

4.1.7 The Social Representations of Type 2 Diabetes

Social representations and care practices adopted by individuals are an expression of the meanings produced in relation to their identities and self-esteem, and in relation to their own ideas about their state of health and their own expression of the disease (Radley, 1999b). These expressions are established within a sociocultural context, and relate to becoming ill and being healthy (Herzlich, 1973). These representations provide a theoretical and practical understanding of the many dimensions and structures of meaning through which individuals acknowledge they have a chronic disease. According to (Cyrino et al., 2009), when applied to patient education social representations provide an important advancement over the dominant compliant approaches, where illness is reduced to disease. (Canguilhem, 1990); in (Cyrino et al., 2009) described 'clinical medicine' as the meeting place between the

healthcare provider and the patient, were the physician is in contact with the complete individual, and not with their organs and functions.

Within the traditional view of health and illness in western societies we see illness as something which may befall us if we are unlucky. However, we acknowledge the idea that our own lifestyle choices like diet, exercise and working practices can affect our chances of developing chronic illness. Biomedicine is not a universal concept and is a fairly recent development in our understanding of illness. The history of illness and the origins and treatment of disease can be understood through the application of concepts from physiology, anatomy, and biochemistry and the adoption of methods from the natural sciences, (Radley, 1999b). Our current understanding of illness is that we accept that psychological and social factors can influence our susceptibility to disease.

Other cultures have fundamentally different medical beliefs from biomedicine. Where the cures for diseases are often herbal remedies, and are not seen in terms of their effect on internal organs and systems, but take place to restore balance to the individual within the moral order of society (Radley, 1999b). (Radley, 1999b) describes the different ways of understanding the range of alternative medicines in our own society, up to the end of the 18th century doctors saw the patient's emotional and spiritual life as directly relevant to their state of health, and the illness they suffered was not conceptualised as independent of the sick person themselves.

Social constructionism views the body is either; disease-free and healthy, or there is a malfunction and we are ill. However, according to (Burr, 2003) it is not as obvious as this, (Burr, 2003 p36) asks, 'is the woman who is unable to conceive ill? Accepting that the presence of a disease is established, it is not as easy to make a judgement as to whether or not that person is ill. According to (Burr, 2003) this is because illness is dependent on social rather than biological criteria; illness depends on cultural issues affecting the persons' ability to perform their usual activities. 'Illness cannot be seen as a fixed entity but as something that necessarily varies according to the norms and values of the particular social group that one is studying', (Burr, 2003 p37).

(Radley, 1999b), gives an example of a person suffering from the flu or a cold, they have a variety of symptoms, such as headaches, sore throat, raised temperature. But are they suffering from a bad cold or the flu? The diagnosis according to (Radley, 1999b) is less of a physical issue and more moral. In our western society we see ourselves as partly responsible for catching a cold, however, in contrast the flu is unfortunate to catch. With

regard to diabetes, both T1D and T2D have the same complications and symptoms, but not the same aetiology; T1D it is perhaps viewed as unfortunate that a person has the disease, as it is caused by a virus (Delli and Kong, 2010), and no fault of the patient. In T2D the person is genetically predisposed to the condition (Alsahli and Gerich, 2010), which may then occur through poor lifestyle choices. This moral dimension has implications for the extent to which people claim sympathy and exempt ourselves from the usual responsibility. Participants in the study by (Hardey, 1998) considered the term illness to be reserved for serious conditions; and a person was not ill if they got on with life and did not focus on their symptoms. (Hardey, 1998) stated, 'illness was not so much the experience of symptoms as the reaction to symptoms (Hardey, 1998 p33).

According to (Cyrino et al., 2009), the social lives of people with chronic illness can be examined from two perspectives. Firstly, there are the consequences for individuals in their day-to-day routines, and for society, and the interrelations between them (Bury, 1991). This means that health-disease phenomenon may have cultural diversity of expression within different social settings (Laplantine, 1991); in (Cyrino et al., 2009), as individuals with chronic illnesses undergo changes in their daily lives, which are not directly related to their condition. Secondly, chronic diseases are manifest by the burden required to control it; while professionals prescribe medications, give advice and guide care, it is up to the patients to organise these care measures within their everyday lives. This requires an enormous amount of adaptive effort by patients for them to be able to manage their daily lives, which have already been structured through their established habits of family and social relationships. People with chronic illnesses are faced with new problems that require them to develop new skills for dealing with a variety of situations. In addition, (Laplantine, 1991) suggests that the representation of disease developed through subjective experiences of illness does not fit in with the idea of disease in bio-medicine, as practices within biomedicine have the effect of reducing illness to disease.

Research indicates that most individuals encounter barriers to self-care that pose major challenges in adhering to self-management programmes, (Aljasem et al., 2001); (Clark and Hampson, 2001); (Schoenberg and Drungle, 2001). The person with T2D needs motivation to enable appropriate and permanent lifestyle changes and the confidence to apply effective self-management, as the responsibility to self-manage the disease is placed upon them, (Loveman et al., 2008). (Sprague et al., 1999) found that barrier identification is critical in maximising adherence to self-management programmes, and is crucial in identifying facilitators of diabetes self-management, which can be used to implement important strategies for overcoming these barriers. In addition, (Song et al., 2010), concluded that

identifying the barriers to self-care experienced by individuals with diabetes, and developing education programmes that prepares them to overcoming these barriers, is vital for diabetes care providers and educators.

4.2 Method

The term 'qualitative meta-synthesis' was first developed by (Stern and Harris, 1985), the aim was to develop an explanatory model which could explain the findings of a group of similar qualitative studies. In their review (Walsh and Downe, 2005) summarise the process of meta-synthesis as; 'bringing together qualitative studies in a related area (which) enables the nuances, taken-for-granted assumptions, and textured milieu of varying accounts to be exposed, described and explained in ways that bring fresh insights', (Walsh and Downe, 2005 p205). Other researchers in this field include (Noblit and Hare, 1988) who presented a synthesis of linked ethnographies, describing their method as meta-ethnography. According to (Britten et al., 2002) and (Jensen and Allen, 1996), Noblit and Hare's work has become a template for subsequent studies.

4.2.1 Meta-synthesis: Analytical Procedure

The systemic review and meta-synthesis undertaken in this review proceeded in three stages. A systemic searching and screening strategy was developed to identify research papers which use qualitative methods to investigate the barriers to diabetes self-care and management; articles retrieved were evaluated for relevance, appraised and then synthesised, (Malpass et al., 2009); (Walsh and Downe, 2005). The research question; 'Investigating the barriers to self-care for people with type 2 diabetes' was formulated according to (Malpass et al., 2009) by identifying the parameters of the synthesis and aided by a modified version of the Setting Perspective Intervention Comparison Evaluation (SPICE) tool, (Booth, 2003).

4.2.1.1 Methodological Issue - Justification of a Meta-synthesis

A meta-synthesis was considered a sound approach to glean new information and insights into the barriers people with diabetes face on a daily basis. Meta-synthesis allows for a deeper appreciation of ideas which is not always possible with conventional reviews. Having identified the barriers to self-care and by drawing together the findings in this synthesis, the motivational factors to enable successful and effective diabetes self-management can be

better understood, so giving insight into the strategies and how they can be employed in the EDOP to reduce these obstacles.

The researcher consulted the paper by (Walsh and Downe, 2005) for their opinion on different methodological approaches, with regard to what to include for synthesis. They state that; 'In the qualitative paradigm, which sees truths as multiple and knowledge as constructed, it is legitimate to include a variety of approaches in a meta-synthesis', (Walsh and Downe, 2005 p207). However, opinion varies between researchers in this field, (Noblit and Hare, 1988) suggested the use of meta-synthesis in the context of ethnographic research, their argument being that it could only be applied to papers embracing the same method, whereas (Sandelowski et al., 1997) suggested an approach that could account for different methods through explicit recognition of them prior to and during the analytical stage. More recent meta-syntheses have included different qualitative methods, (Campbell et al., 2003) groups together papers for initial examination, before synthesis between methods was attempted and the analysis was conducted in a similar way to that used by (Sandelowski et al., 1997). The researcher has elected to use the approach advocated by (Campbell et al., 2003) as studies using different qualitative methods have been identified for synthesis in this PhD research study.

To judge the quality and credibility of qualitative meta-synthesis (Walsh and Downe, 2005) state that they must include descriptive tables of the studies under review (Campbell et al., 2003). These are essential, as they summarise the methodological and theoretical basis of individual studies, the criteria used to appraise the studies should also be included (Campbell et al., 2003).

4.2.1.2 Methodological Issue - Critique of a Meta-synthesis

With regard to locating the relevant papers (Walsh and Downe, 2005) quote (Barroso et al., 2003); 'for researchers conducting qualitative meta-synthesis projects, the ideal goal is to retrieve all of the relevant studies in a field, not simply a sample of them', (Barroso et al., 2003 p153); in (Walsh and Downe, 2005). (Walsh and Downe, 2005) continue to explain that for searches to be comprehensive they must employ search strategies which supplement electronic searches with more traditional methods of reviewing, including back-tracking of references for example, otherwise publications might be missed. With this in mind the researcher was careful to be thorough in the search for relevant papers.

4.2.2 Method-Stage 1: Systematic Search and Screening

Key search words included: *Type 2 diabetes, barriers, adherence, compliance, education, management, self-care and qualitative*. Terms were selected to include 'who' (people with T2D), 'what' (self-management) and 'how' (qualitative methods), (Malpass et al., 2009); (Walsh and Downe, 2005).

For inclusion in this review papers needed to be; qualitative research studies written in English and investigating barriers to self-care and self-management in adults with T2D only. Exclusion criteria were; children and adolescence, T1D, and articles which were not written in English. Searches of four major databases (Science Direct, PubMed, PsycArticles and Web of knowledge) were conducted by the author in August 2012. All studies meeting the inclusion criteria were identified in August and September 2012 from the literature searches, Grey literature was not included in this review.

4.2.3 Method-Stage 2: Critical Appraisal

Appraisal of the articles was based on a modified version of the Critical Appraisal Skills Programme (CASP, 1999), which was designed to be methodically neutral whilst encouraging critical assessment (Bennion et al., 2012); (Feder et al., 2006). Reviewed papers were then rated using the coding: KP (key paper which is conceptually rich); SAT (satisfactory paper); IRR (irrelevant paper); or FF (fatally flawed method), (Malpass et al., 2009); (Dixon-Woods et al., 2007).

4.2.4 Method-Stage 3: Synthesis of the Studies

The synthesis employed interpretative analysis following the principles of meta-synthesis (Bennion et al., 2012). Articles were read and re-read with details of the studies recorded, using data extraction forms to record details of findings coded as first and second order constructs (Malpass et al., 2009). First order constructs are study the participants' interpretations of their experience (direct quotes from participants); second order constructs are study authors interpretations of the participant accounts.

Thematic coding of extracted data involved a cyclical process of producing the synthesis; as a new theme was identified the author returned to the other papers to identify an occurrence of the theme. A data matrix was used to complete the analytic process and develop the third

order constructs, or the higher order themes (Malpass et al., 2009). This was achieved by taking the first and second order constructs as data and analysing them thematically following the principles set out by (Braun and Clarke, 2006).

4.3 Findings

This section explains the findings of study (1) The systemic review and meta-synthesis, under the three heading outlined below; Stage 1: Systematic Search and Screening, Stage 2: Quality Appraisal, and Stage 3: Synthesis Findings and Theoretical Standpoints.

4.3.1 Stage 1: Systematic Search and Screen

The review yielded 587 abstracts, which were read to assess the suitability for inclusion and to determine the reasons for exclusion, 48 articles were identified, the full text for 29 articles being obtained, as 19 were duplicates. After assessment of the full texts, 20 were rejected, the reasons for rejecting the articles were; quantitative methods (5), both quantitative and qualitative methods (3), participants not T2D, but at high risk of T2D (6), participants were not T2D, but health care professionals (4), participants were both health care professionals and T2D (1) and participants were both family members and T2D (1).

The author scanned the reference of the included articles to identify further articles which met the inclusion criteria, and one further article was identified. The final review was based on 10 articles. (Table 1)

Table 1 – Papers Table 1 – Papers Selected for Review and Meta-synthesis

Study	Are the research questions clear?	Are the research questions suited to qualitative inquiry?	Are the following clearly described?			Are the following appropriate to the research question?			Are the claims made supported by sufficient evidence?	Are the data, interpretations and conclusions clearly integrated?	Does the paper make a useful Contribution?	Rating
			Sampling	Data Collection	Analysis	Sampling	Data Collection	Analysis				
Rayman & Ellison, (1998)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	KP	
Vermeire et al., (2003)	Y	Y	Y	Y	Y	Y	Y	N	N	Y	SAT	
Bissell et al., (2004)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	KP	
Wong et al., (2005)	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	SAT	
Lawton et al., (2006)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	KP	
Nagelkerk et al., (2006)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	KP	
Casey et al. (2009)	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	SAT	
Gazmararian et al., (2009)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	KP	
Song et al., (2009)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	KP	
Al-Qazaz et al., (2011)	Y	Y	Y	Y	Y	N	Y	N	N	Y	SAT	

KEY:

KP – Key paper

SAT – Satisfactory paper

4.3.2 Stage 2: Quality Appraisal

The papers reviewed were judged to be of generally good quality. It is acknowledged that restrictions in journal word limits may cause problems for authors (Walsh and Downe, 2005). Appraisal was completed not as a basis for exclusion, but to highlight potential limitations with individual papers and the overall sample, allowing for the limitations in some studies to be offset by the strengths in others, (Dixon-Woods et al., 2006).

Six of the ten papers were found to provide adequate information to satisfy each of the quality prompt questions (Table 1). Common weaknesses included the lack of a clear description of analytic method, insufficient raw data to support interpretations, and limited contextual information about participants. Contextual information regarding the sample of each study is required to ensure transferability, (whether findings are applicable to other populations) and to create transparency, which is essential to achieve trustworthiness, (whether methods are sufficiently robust for findings to be used to inform practice or policy). The quality of the meta-synthesis was ensured by on-going self-critique and self-appraisal, (Rolfe, 2006).

4.3.3 Stage 3: Synthesis Findings and Theoretical Standpoints

The synthesis employed interpretative analysis following the principles of meta-synthesis (Bennion et al., 2012). Articles were read and re-read with details of the studies recorded (Table 2). To overcome the epistemological differences and to work with studies employing different methods the pragmatic approach proposed by (Yardley and Bishop, 2008) was used. The majority of studies reviewed employed thematic analysis: (Al-Qazaz et al., 2011); (Casey et al., 2009); (Gazmararian et al., 2009); (Nagelkerk et al., 2006); (Wong et al., 2005); (Vermeire et al., 2003). Two of the studies used grounded theory (Lawton et al., 2006) and (Bissell et al., 2004), whilst an inductive and interpretive approach was employed by (Song et al., 2010) and (Rayman and Ellison, 1998) the former using a constant comparative procedure, and the later, Krueger and Casey method, (Krueger and Casey, 2000). Some researchers have argued that the synthesis of research with different epistemological standpoints is not desirable as each individual study is theoretically and conceptually unique (Sandelowski et al., 1997). However, (Finfgeld et al., 2003) suggested that these concerns are unwarranted and that the combination of findings from multiple approaches can enhance the truthfulness of the synthesis.

Table 2 – Details of the Studies Selected for Review and Meta-synthesis

Study	Aim	Participants- Sampling Method	Participants- Age	Participants- Number and Gender	Participants Ethnic Mix	Participants- Length of Diagnosis of T2D	Data collection- Type	Data collection- Duration	Analysis
Rayman & Ellison, (1998)	To describe women's perspectives of provider and setting factors that support their ability to be affective self-managers of T2D	Participants nominated by education centre as exemplars in managing their own care	46 -69	17 F	13 Caucasian 2 Native American 1 African American 1 Hispanic	1-35 years	4 structured focus groups (3-7 in group)	2-3 hours	Inductive, interpretive approach- constant comparative method
Vermeire et al., (2003)	To report on the health beliefs of T2D patients in relation to their illness, their communication with caregivers and the problems encountered in adhering to treatment regimes	Purposive	40-80+ M 40-80 F	46 21 M 25 F	Not known	Less 5 years- more than 15 years	7 focus groups (male and females groups separated)	2 hours	Thematic
Bissell et al., (2004)	To empirically explore the relevance of a re-framed consultation through qualitative interviews with a small group of English speaking patients of Pakistani origin with T2	16 Purposive + 6 snowballing	Adults (age Unknown)	21 M+F	21 Pakistani	Length of diagnosis unknown	Individual interviews	X	Grounded theory
Wong et al., (2005)	To achieve better understanding of the perspectives and needs of indigenous people with diabetes and to identify ways to promote successful self-management	Purposive	30-70+M 30-70+F	67 26M 41F	Indigenous People of the Torres Straits Islands	Length of diagnosis unknown	11 focus groups (male and females groups separated) + 30 individual interviews	X	Thematic

Study	Aim	Participants-Sampling Method	Participants-Age	Participants-Number and Gender	Participants Ethnic Mix	Participants- Length of Diagnosis of T2D	Data collection-Type	Data collection-Duration	Analysis
Lawton et al., (2006)	To explore Pakistani and Indian patients' perceptions and experiences of undertaking physical activity as part of their diabetes care	Purposive and snowballing	30-70+	32 15M 17F	23 Pakistani 9 Indian	1-30years M 1-25 years F	Individual semi-structured interviews	Average 1 hour	Grounded theory
Nagelkerk et al., (2006)	To report the perceived barriers to and effective strategies for self-management of adults with T2D in a rural setting	Purposive	26-78	24 12M 12F	Caucasian	1-26 years	3 focus groups (2x6 + 1x12 in each group)	2 hours	Thematic
Casey et al., (2009)	To assess barriers and facilitators of participants in a supervised exercise programme, and adherence to exercise after programme completion	Sub-sample from a previous randomised control trial	39-65	42 participants enrolled in exercise programme 32 eligible for invitation to focus group sessions 16 attended 9	Not known	0.17-13 years	Semi-structured discussion with 3 focus groups (1x6 + 2x5 in each group)	~1.5 hours	Thematic

Study	Aim	Participants-Sampling Method	Participants-Age	Participants-Number and Gender	Participants-Ethnic Mix	Participants-Length of Diagnosis of T2D	Data collection-Type	Data collection-Duration	Analysis
Gazmararian et al., (2009)	To explore individual, educational and system barriers that limit low income diabetes patients' ability to achieve optimal diabetes self-care	Purposive	Mean age 48 new patient 58 current and frequent patient 54 infrequent patient	35 11 new patients 12 current and frequent patients 12 infrequent patient	31 African Americans 3 White 1 Latino	2 months–20 years	3 focus groups new, frequent and infrequent patients separated	1.5-2 hours	Thematic
Song et al., (2009)	To identify the barriers to and facilitators of self-management adherences in Korean older adults with T2D	Purposive	65+ Mean 69.9 years	24 14M 10F	Korean	Mean 12.8 years	3 focus groups 9 M+F 9M 6F	X	Interpretive, using Krueger & Casey, 2000
Al-Qazaz et al., (2011)	To explore diabetic patients' experience and knowledge about diabetes and its medication and to understand the factors contributing to medication adherence in Malaysian population	Purposive	48-61 years Mean 54 years	12 8 M 4F	8 Malay 2 Indian 2 Chinese	1-10 years Mean 4.16 years	Semi-structured interviews	20-35 minutes	Thematic

Table 2 (cont.) – Details of the Studies Selected for Review and Meta-synthesis

Study	Analysis / Themes	Additional Notes
Rayman & Ellison, (1998)	Identifiable turning points and barriers in learning to self-manage/ A culture of caring existed that enabled participants to learn to self-manage/ Significant patient-provider role shifts accompanied a phasic process of learning self-management/ A set of personal characteristics supported learning self-management within the context of the expert care setting	All women in this study had been nominated as exemplars in managing their care by experts from a diabetes treatment and research centre All participants wanted to actively seek out more information about T2D self-management Used to assess how effective this organisational culture is in facilitating effective T2D self-management
Vermeire et al., (2003)	Knowledge of the illness/ Information given by the physician/ Doctor-patient relationship/ Body awareness/ Adherence to treatment	Participants recruited by pharmacy treatment regime Investigating adherence to therapeutic regimes from the patient's perspective.
Bissell et al., (2004)	Integrating the diabetic regimen – constraints: financial, time co-morbidity / Respondents' experiences of health care interactions	Study is investigation health care interactions, compliance and adherence and the move towards the concordance model in respondents of Pakistani origin
Wong et al., (2005)	Going to the clinic regularly/ Following clinical instructions/ Taking care of feet	Analysis of diabetes self-care in remote communities
Lawton et al., (2006)	Roles, norms and responsibilities:- Lack of time (and/or) obligations to others/ Fear and shame External constraints:- Lack of culturally sensitive facilities/ Climatic conditions Perceptions and experiences of disease:- Co-morbidities/ Accounts of causation (and/or) perceptions of future health/ Diabetes triggers irreversible decline/ Physical activity can engender anxiety Activity and active respondents:- Short term goals/ I do enough already	Physical activity Data collected 2003/2004 (Same interviews as used in 2008 diet study)
Nagelkerk et al., (2006)	Perceived barriers: Lack of knowledge and understanding of a specific diet plan/ lack of individualised and co-ordinated care/ Helplessness and frustration from lack of glycaemic control despite adherence/ Limited resources to obtain recommended equipment, medicines, laboratory tests and provider services/ Inconvenient, costly, and non-specific group education sessions/ Difficulty in remembering to take medications, lack of knowledge about medication action, side effects, schedules and adjustments Effective strategies: Developing a collaborative relationship with a health care provider/ maintaining a positive attitude that promotes proactive learning/ Having a support person who gives encouragement and assistance and facilitates self-management/ Acquiring adequate resources for self-management/ Maintaining routine medication administration times and routines/ Participating in group education that encourages question and discussion of feelings and fears	Participants received a compensatory \$20.00 grocery voucher

Study	Analysis / Themes	Additional Notes
Casey et al., (2009)	Individual motivation/ The importance of supervision – support in exercise programme participation/ Difficulty of transitioning/ Derailment of exercise participation/ Programme characteristics Walking	Physical activity – supervised exercise programme. Participants offer this supervised exercise programme had participated in a previous randomised control trial with the same researchers
Gazmararian et al., (2009)	Knowledge of diabetes and self-care management/ Emotional impact and conflicts/ Understanding the numbers/ Medication adherence/ Lifestyle factors/ Nutrition and physical activity/ barriers/ Preferences for receiving health information/ Opportunities for improvement- implication	Low income
Song et al., (2009)	Barriers: Ageing-related physical and cognitive limitations/ Lack of self-discipline/ Restrictions related to specific cultural factors/ Poor understanding of self-management Facilitators: Knowing the benefits of and having a system to reinforce self-management/ reshaping historical life habits/ Family support	Participants were recruited from a population who had previously received a diabetes self-management education programme lasting 12 hours (2hours x weeks)
Al-Qazaz et al., (2011)	Knowledge about diabetes and its medication/ Experience about adverse effects of medication/ Issues related to adherence/ Impact of medical and family relationships on well-being	Malaysian population. Staff members of the diabetic clinic

4.4 Discussion of the Themes

Six themes were highlighted in the meta-synthesis which relate to; patient lack of knowledge or understanding, provider lack of knowledge, provider-patient relationships, social support, external constraints and co-morbidity, and internal constraints, and are discussed below.

4.4.1 Patient Lack of Knowledge and Understanding

Many of the studies synthesised found that lack of patient knowledge extends to all aspects of diabetes self-care, (Song et al., 2010); (Wong et al., 2005); (Rayman and Ellison, 1998), including medication (Al-Qazaz et al., 2011), (Vermeire et al., 2003), physical activity (Casey et al., 2009); (Lawton et al., 2006), and diet plans (Nagelkerk et al., 2006). These studies found that participants admitted to a poor knowledge of diabetes, and that they misunderstood the disease and its management, (Al-Qazaz et al., 2011); (Song et al., 2010); (Lawton et al., 2006); (Nagelkerk et al., 2006); (Wong et al., 2005); (Vermeire et al., 2003). However, in (Rayman and Ellison, 1998), the participants lack of knowledge was not discussed and in (Bissell et al., 2004) it was not found to be an issue.

In the following extract the participant's comments clearly demonstrate a lack of understanding of T2D;

'They say it's about sugar, but damn, I don't even eat sugar...' (Vermeire et al., 2003 p213).

Researchers in the (Wong et al., 2005) study discovered that most participants were unaware as to why adherence to care regimes was important in diabetes self-management, though they did understand the importance of taking medication regularly, but most did not know why. Interestingly however, in contrast to this lack of knowledge regarding medical regime, participants in this study (Wong et al., 2005), had a great deal of informed knowledge about how to look after their feet and the consequences of poor adherence to foot care and what complications could ensue. The researchers stated that;

'Losing a toe or foot is a common and highly visible complication of diabetes in the Torres Strait', (Wong et al., 2005 p175)

They found that while participants had different attitudes to and beliefs about foot care, their underlying motivation was fear of amputation. Nearly all participants said they wore shoes to protect their feet, clearly recognising the importance of taking care of their feet and they were aware of the added dangers that diabetes had to foot health. Participants in this study were acutely aware of the possibility and consequences of amputation;

'It's important to check your feet because if there is no pulse they may have to amputate' (Wong et al., 2005 p175)

This fear of losing a foot or leg through amputation stems from a possible loss of self-esteem, and dependency on others. This fear of foot complications was also demonstrated by participants in the (Al-Qazaz et al., 2011) study;

'Yes, because of complications, I'm scared of numbness; I'm scared when I walk, anything that pricks. I'm scared I cannot feel, I have to check my feet every night.' (Al-Qazaz et al., 2011 p183)

The barriers to physical exercise amongst people of Pakistani origin with T2D was investigated by (Lawton et al., 2006), who found that knowledge about the importance of physical activity was not communicated to the person with diabetes, which they concluded was due to the need for more patient education. However, (Lawton et al., 2006) highlight the importance of being realistic about what education can achieve, as various studies have shown that people may reject or fail to respond to the health education message if it does not echo their own experiences, (Hunt et al., 1998); (Davison et al., 1991). People's perceptions and understandings of their disease need to be located and understood in terms of their own personal situation and within their social and cultural environment, (Lawton, 2003). It is also necessary for care providers to understanding their patients from a cultural perspective, which can in turn nurture concordance (Bissell et al., 2004).

The participant's lack of knowledge about diet was ranked highest in the study undertaken by (Nagelkerk et al., 2006), this finding was particularly notable as all participants had received at least one dietician consultation, a participant makes the following comment;

'I would like a diet plan with some guidelines to it. I think that is the biggest problem that I have is not knowing what I can and can't eat.' (Nagelkerk et al., 2006 p154)

The researchers suggest that in their study the participants lack knowledge, but it could perhaps be a lack of understanding of the information, which may have been poorly communicated to them, as was reported in the other studies, (Lawton et al., 2006); (Wong et al., 2005). A participant in the (Wong et al., 2005) study states;

'They don't explain what it's for. Sometimes the doctor just checks the chart for obs and sends them away.' (Wong et al., 2005 p174)

In conclusion, (Nagelkerk et al., 2006) found their study to be consistent with others who report that diet is the most challenging aspect of diabetes care, (Whittemore et al., 2002); (Glasgow et al., 1984). Between 48-75% of respondents report inconsistent adherence to dietary recommendations and that revising eating habits to promote a healthier lifestyle is the most challenging aspect of diabetes self-care, (Anderson and Justafson, 1998).

Lack of participant knowledge about medication regime was investigated by (Al-Qazaz et al., 2011) and (Song et al., 2010). (Al-Qazaz et al., 2011) found that when participants were asked about the adverse effects of their medication they were not aware of the drug information leaflet enclosed with all their medication;

'No, so far no information given about the side-effects but I know every drug has side-effects.' (Al-Qazaz et al., 2011 p184)

(Al-Qazaz et al., 2011) proposed that participants were aware of the seriousness of the disease, but that this was not enough to ensure they adhered to the treatment regimes. They had transposed their own lack of awareness of information to being the sole responsibility of their healthcare provider, thus demonstrating a poor patient-provider relationship and lack of shared responsibility and concordance, discussed below. The dose of medication was also manipulated by participants in this study according to the beliefs they had about their own body's needs;

'Yes, I take it regularly, but sometimes if I eat a heavy meal or sweets, I take another big tablet (metformin) to control the sugar level.' (Al-Qazaz et al., 2011 p185)

In summary, the studies synthesised indicated that the majority of participants expressed a desire for greater understanding of their condition;

'... the medication, how it works when you take it. When you go to hospital they change the medication... they don't sit with you and explain it to you.' (Wong et al., 2005 p174)

4.4.2 Provider Lack of Knowledge

People with diabetes perceive provider lack of knowledge and experience as a major barrier to their self-management. This lack of provider knowledge creates mistrust and lack of patient confidence, particularly when they received incomplete and conflicting information from the provider. An example of care providers' lack of knowledge and expertise was noted by (Rayman and Ellison, 1998), one participant commented;

'I think I had been diabetic longer than I knew. Looking back, I had two bouts of yeast infection. Why this doctor that told me I was stupid (for gaining weight) didn't think to check me for diabetes.' (Rayman and Ellison, 1998 p614)

Examples of inconsistent and uncoordinated care were found by (Nagelkerk et al., 2006) and (Vermeire et al., 2003), and was commented on by a participant in the (Vermeire et al., 2003) study;

'Several doctors and nurses explained to me what to do or what not to do on different occasions. It seems to me as if everyone has their own diabetes theory.' (Vermeire et al., 2003 p213)

Another participant in the same study commented on the variety of care advice people with diabetes were receiving, which can lead to a lack of patient confidence;

'When I talk to other diabetics, it seems to me that there are so many different treatments... I should stick to mine.' (Vermeire et al., 2003 p213)

In summary, when people with diabetes receive inadequate or contradictory information regarding their diabetes management, they are unable to follow the advice given, and are considered to be non-compliant with the management regime prescribed by their care provider. This inevitably affects the provider-patient relationship, when the care provider fails to give adequate care advice or misunderstands the patient's situation, then the information

on self-management will be confusing and contradictory for the patient, resulting in a loss of confidence and they will be unable to attain effective self-care.

4.4.3 Provider-Patient Relationships

A number of comments by participants regarding their relationships with their provider were recorded. Whilst some of these comments were positive (Rayman and Ellison, 1998), the majority were negative, (Nagelkerk et al., 2006); (Bissell et al., 2004); (Vermeire et al., 2003). When the relationship between the patient and their care provider was not mutual, it was perceived as a barrier to self-management by the participants of the studies synthesised.

Participants commented on a sense of feeling 'welcomed' when the relationship with their care provider was positive, examples of this are commented on by participants on the managed diabetes education programme in the (Rayman and Ellison, 1998) study;

'Because they care (about you), you care enough to manage yourself.' (Rayman and Ellison, 1998 p615)

According to (Vermeire et al., 2003) and (Rayman and Ellison, 1998), when patients and their providers work collaboratively, management problems were resolved. (Rayman and Ellison, 1998) considered 'role reversal' or concordance, which they said took place when; care providers assumed the role of consultant and validators of patient's actions, and patients became experts in their own diabetes management, with provider taking a mentoring position.

However, in the (Bissell et al., 2004) study when the researchers explored the provider-patient relationship they found it was not beneficial to the concordance model because of their participants particular health beliefs linked to their cultural background. This is an important consideration; if the concordance model is to be applied effectively the patient must be willing to accept their own position and that of their providers within that paradigm.

When the participants relationship with the provider was less supportive negative feelings emerged, this is demonstrated in the (Bissell et al., 2004) study;

'Well it's like when I go to the doctor, she says I am overweight, that's what is causing everything... they are blaming me, it makes me feel bad and I get angry. All they say is you should lose weight and you are overweight, and they don't know it's hard (voice goes quiet) it's really hard being diabetic and there is nothing to look forward to.' (Bissell et al., 2004 p855)

The negative provider-patient relationship is further explored by (Nagelkerk et al., 2006), and (Vermeire et al., 2003). (Nagelkerk et al., 2006) found that barriers to self-management were established when, care providers not only lacked understanding, but when the information they provide was too generalised, or not specific enough to meet the participants individual social or cultural needs.

Poor attention to the participants' health beliefs was reported by (Vermeire et al., 2003) who found that doctors often decide on the medical actions to be undertaken, without enquiring about the patient's health beliefs, and these health care providers frequently demonstrated fluctuating tolerances, causing them to be overly severe or 'angry' with their patients;

'My doctor knows me, he is a good fellow... when I phone him to know my sugar (glycaemia), he usually says 'you're doing fine' even if the sugar is too high, but sometimes he sounds angry when he's saying that...' (Vermeire et al., 2003 p213)

This negative provider-patient relationship makes patients confused, because of the conflicting response they received from the doctor. The patient knows that they have had poor blood glucose control, yet the doctor said that their self-management is acceptable.

In summary, the provider-patient relationship should be seen as collaborative where the care provider offers advice as an expert in diabetes care and treatment, and the person with diabetes should be respected as the expert in their own diabetes management. However, when the relationship is not balanced and the care provider fails to acknowledge this, there is no mutual trust and the people with diabetes feel unsupported and their self-management becomes ineffective, as they lack confidence.

4.4.4 Social Support

Support provided by family, friends, peers, the community and the health care provider has a positive effect on self-management, (Song et al., 2010); (Casey et al., 2009); (Nagelkerk et

al., 2006). These beneficial effects of social support were investigated by (Nagelkerk et al., 2006), finding that participants who developed a supportive team of family, friends and health care providers had secured the resources necessary for self-management. They also had more positive attitudes and greater perceived success in integrating diabetes care into their daily lives, for example;

'My wife has helped me stay on my diet. She has made sure that we have had stuff in the house so I won't go off my diet; she asked me every day whether I walk or not...I have to answer to a higher authority.' (Nagelkerk et al., 2006 p155)

Positive provider support has a facilitator effect on patients. Participants in the Casey et al., (2009) study described how having a person support them through the exercise programme provided the encouragement and this motivation they needed;

'I needed them...they sat there and they watched, and they went and they checked you and they motivated me' (Casey et al., 2009 p81)

This support produced positive attitudes in the study participants who made extra effort to attend the programme. This facilitated motivation, enabling them to overcoming the external constraints of their work commitments to attend the programme, one participant commented;

'...I worked around my work schedule so that I would be there because I know that there are people that are taking their time to show us things, they are willing to do it and it was beneficial to me.' (Casey et al., 2009 p81)

Participants in the (Rayman and Ellison, 1998) study also reported similar motivational effects;

'Because they care (about you), you care enough to manage yourself.' (Rayman and Ellison, 1998 p615)

Peer support was discussed in the (Song et al., 2010) study, participants commented that being reminded of the importance and benefits of self-management through the self-help groups enabled them to gain encouragement; they felt more confident, and were as a result empowered.

Conversely, lack of social support was a major barrier to effective self-management, some participants in the (Lawton et al., 2006) and (Wong et al., 2005) studies commented on their absence of a supportive family. (Lawton et al., 2006) found participants were expected to undertake family obligations to which they were culturally bound. This lack of social support occurred, because the social care the participant delivered was not reciprocated by the patient's families, and their diabetes self-management suffered. This is highlighted by comments related to constraints on the participant's time;

'It's just the time you know. There's so many things in the day even though I am retired now. We're still y'know – my son has got a business, so I run errands for him, do his banking or this and that. It keeps me occupied.' (Lawton et al., 2006 p47)

In summary, when patients do not have adequate social support, external constraints, such as limitations on their time, work commitments, financial burdens and environmental factors, are seen as insurmountable. This is particularly the case when these constraints co-exist with current co-morbidities sometimes unrelated to diabetes. External constraints and co-morbidity are discussed below (Section 4.4.5).

4.4.5 External Constraints and Co-morbidity

A number of the studies, (Song et al., 2010); (Casey et al., 2009); (Lawton et al., 2006); (Nagelkerk et al., 2006); (Bissell et al., 2004) found there to be a number of external constraints and barriers to self-management of T2D, these were; financial, time constraints, work commitments, and co-morbidities.

Financial considerations can pose a major barrier to those of minority ethnic origin (Schillinger et al., 2002) and who have low socio-economic status (Casey et al., 2009), This is particularly notable with regard to the purchasing of food and medication, (Al-Qazaz et al., 2011); (Bissell et al., 2004), a participant in the (Bissell et al., 2004) study comments;

'Money is the main thing. I don't work, my husband is out of work now, for 6 weeks. When we get money in [from social security] then we have food for the family. After that, we don't, we live on what we have. And I have to eat whatever we have.' (Bissell et al., 2004 p855)

In the studies considering participants from ethnic minorities, (Song et al., 2010) and (Lawton et al., 2006) found women with T2D pointed out they prepared two separate meals; one that all the family would eat and a separate one for themselves. Other women commented that their children did not always want to eat the 'healthy' meals that were prepared for the diabetic member of the family (Lawton et al., 2006). This was time consuming and imposed additional financial burdens. (Casey et al., 2009) found that balancing competing responsibilities of work and families was a major barrier for the women in their study, with the most difficult aspect being time constraints associated with work and childcare. The following comment made by a participant in the (Casey et al., 2009) study highlights how one's own health is neglected with responsibility for caring for others;

'...All of us seem to be so conscientious about work, our families, our obligations to others that we put our health secondary.' (Casey et al., 2009 p82)

Participants in the (Lawton et al., 2006) study regarded their lives to be extremely busy, pointing to a strong work ethic amongst people of Indian and Pakistani ethnicity in Britain. It is common for people to work long anti-social hours often in shops, restaurants and taxi driving. This was also true for participants in the (Casey et al., 2009) study;

'I have my own business and sometimes I could not go because I'm busy. I have to prepare.' (Casey et al., 2009 p82)

Even participants of retirement age found it difficult to juggle their competing responsibilities;

'It's just the time you know. There's so many things in the day even though I am retired now.' (Lawton et al., 2006 p47)

(Song et al., 2010) also noted similar comments;

'I have to take care of my grandchildren because my daughter-in-law is working. They are 3 and 5 years old. It is very hard to have my own time to do anything except at the weekend. And I often have other chores to do in the weekend, such as getting my hair cut, attending a wedding, and so on.' (Song et al., 2010 p214)

It is generally considered that in retirement with the absence of dependent children and the completion of most of their life tasks older adults would have more spare time than their younger counterparts. However, research shows that older women are just as busy with the

role of grandparent, carer of an ill spouse as well as having to perform everyday house hold chores (Kim, 2006). Time constraints with regard to medication regime were mentioned by (Al-Qazaz et al., 2011);

'Most of the time regularly I take, but not at exact times, because in the morning I am very busy.' (Al-Qazaz et al., 2011 p185)

Several of the studies synthesised researched cultural issues, (Song et al., 2010); (Casey et al., 2009); (Lawton et al., 2006). A cultural barrier that arose in the Lawton et al., (2006) was that of being judged negatively by other members of the community. This is demonstrated by a Pakistani woman who had collapsed at the local shop, when she was exercising by walking, her family then refused to allow her to go out unaccompanied, she commented;

'My daughter said, 'people will wonder that your daughter can drive a car, yet her mother went out on her own'.' (Lawton et al., 2006 p47)

Another issue that arose was the lack of culturally sensitive facilities this was described as a barrier to self-management by several women, they were unable to go swimming or join a gym because of cultural prohibitions about exposing their bodies to members of the opposite sex and lack of availability of single sex classes with women instructors, (Lawton et al., 2006). A lack of suitable facilities were also mentioned by participants in the (Casey et al., 2009) study; once the programme had finished, some participants wanted follow-up sessions and referrals to gyms with expertise in catering for people with diabetes, to enable them to continue with their exercise regime, one participant comments;

'There's no physical check-up. Nothing. It's just selling membership, and that's not what we need.' (Casey et al., 2009 p81)

Culturally sensitive issues were also reported by (Song et al., 2010) which related to the difficulty men had in refusing alcohol while socialising. Accepting alcohol from another male is a sign of hospitality and a norm for older adults in Korean culture, a participant is quoted as saying;

'When I am out with my friends...my friends consume a little alcohol with meals. Sometimes it amounts to more than a couple of glasses. It is very hard for me to refuse because I have diabetes. And I feel that I am not a man when I am not able to drink...' (Song et al., 2010 p214)

Restrictions to socialising were also noted by a participant in the (Gazmararian et al., 2009) study;

'I can't enjoy family-style church dinner.' (Gazmararian et al., 2009 p783)

Participants in the studies synthesised discussed how the weather affected their exercise behaviour. Inclement weather for many was a considerable barrier to their physical activity and diabetes self-care regime;

'Last year I bought a dog and I walk the dog. But since the winter, I really stopped walking the dog. During the summer I walked a lot with the dog, in the winter... I am afraid of the ice.' (Casey et al., 2009 p82)

Another example is taken from (Lawton et al., 2006);

'The doctor told me to walk, and I used to go out a little but now the winter has come, I don't go out now, I don't like going out. I feel the cold.' (Lawton et al., 2006 p48)

Existing co-morbidity was also found to be a major a barrier to self-management, with particular regard to physical activity and was mentioned in the (Lawton et al., 2006) study. Many participants made comments regarding health complaints, such as asthma, breathlessness, heart problems, swollen joints and arthritis, which made even simple activities such as walking extremely difficult. The researchers concluded that this would leave participants feeling frustrated and despondent;

'They tell you to exercise a little, but I can't move around a lot because I have a problem with my leg (arthritis). If I walk a little then it swells up.' (Lawton et al., 2006 p48)

In other studies, (Song et al., 2010) and (Casey et al., 2009) co-morbidity was also reported as a barrier to exercise as participants noted that health concerns not related to their diabetes often impeded them;

'I have difficulty with my knees... that's the main reason that sometimes I don't go.' (Casey et al., 2009 p82), and;

'I used to exercise rigorously, but now my knee hurts too much...' (Song et al., 2010 p214)

(Song et al., 2010), reported memory decline was an issue which affected self-management;

'The doctor tells me I should take the pill 30 minutes before eating...I eat one spoon of food and then suddenly I remember. When the doctor tells me to take it 30 minutes after meals I sometimes...take it 1 or 2 hours later.' (Song et al., 2010 p214)

To summarise, the external constraints which produced barriers to self-management of T2D the studies synthesised found financial burdens, time constraints, work commitments, culturally sensitive issues, adverse weather and co-morbidities to be barriers to effective self-management. However, with social support and careful consideration to the personal circumstances of people with diabetes, these external barriers can be considerably reduced or modified.

4.4.6 Internal Constraints

Emotional issues relating to lifestyle changes and social adjustments to living with T2D were significant for most participants in the all studies synthesised.

Participants in the (Gazmararian et al., 2009) study acknowledge that the adoption and maintenance of effective self-management requires self-discipline and confidence. Notable are the comments made by a participant in this study regarding the added responsibility and stress of considering both internal constraints and personal feelings, and external constraints and the feelings of others;

'It's a nightmare. It is a total responsibility. Because you have to devote your time and attention to your diet, to your activities, to your feelings, and to the feelings of others... it's a lot of stress.' (Gazmararian et al., 2009 p783)

Participant in the same study also commented on the difficulty in maintaining self-care practices, and their lack of self-discipline;

'For 3 months I was ok, then I got back to eating what I want to eat.' (Gazmararian et al., 2009 p784)

This made them resolute about the situation, and although they accepted their illness, they felt isolated;

'I've resolved that this is my life.' (Gazmararian et al., 2009 p784)

This resolute stance is considered a barrier to self-care, as many of the participants who felt isolated were unable to become empowered to enact more effective self-management and be more proactive in their own care.

For many participants in this review and meta-synthesis the key factor that inhibits adherence to a healthy life style is denial, they disbelieve that the consequences of non-adherence will result in an increased risk of complications associated with diabetes. People with diabetes continued to eat desserts, sugary beverages, as well as fried and other foods detrimental to their health. This lack of self-discipline was commented on by a participant in the (Song et al., 2010) study;

'...but if it's food I like, it's too hard to resist...I think what the heck? I'll just eat less next time...then I'll go ahead...' (Song et al., 2010 p214)

According to (Vermeire et al., 2003) patients had difficulty in deciding to adhere to treatment when; they experienced minimal discomfort from the disease, when they lacked knowledge about the disease complications, or if the complications did not present for many years. They also found that knowledge about possible complications was considered by participants as rather regrettable and not something which they could or should do anything about, for example;

'I have had diabetes for almost 20 years. I take a pill in the morning and one in the evening. Food, well...less sugar. That's what they told me, and don't feel any trouble. I don't feel any difference, with or without treatment!' (Vermiere et al., 2003 p213)

Some study participants, (Al-Qazaz et al. 2011); (Casey et al., 2009); (Wong et al., 2005) refuted their diabetes, commenting that in denying their diabetes and its complications, they had control over the disease. A patient in the (Casey et al., 2009) study described their awareness of reduced motivation and denial. A participant in the (Wong et al., 2005) study described how not taking tablets helped her deny her illness;

'I feel that I make myself feel that I am not diabetic...when my tablets run out it takes me a long time before I will go and get my tablets.' (Wong et al., 2005 p174)

(Al-Qazaz et al., 2011) also found that a number of participants admitted to refuting their condition and not adhering to their medication regimen, for example;

'I usually do not take the drug, because I must control myself, not the drug control myself.' (Al-Qazaz et al., 2011 p184), and;

'For me, honestly, sometimes I stop the medication for few days, to give a "holiday" for my body.' (Al-Qazaz et al., 2011 p185)

The synthesis demonstrates serial deliberate non-adherence to dietary and medication regimes in a number of the studies, (Al-Qazaz et al., 2011); (Casey et al., 2009); (Gazmararian et al., 2009); (Wong et al., 2005); (Bissell et al., 2004); (Vermeire et al., 2003). These studies found that this non-adherence or 'cheating' resulted from the participants desire to maintain control over their own bodies, and not from poor knowledge about diabetes and its management. Participant considers that by not adhering to a dietary regime constantly they were able to maintain more control. Further to this deliberate non-adherence to dietary regimes or 'strategic cheating' was described by (Campbell et al., 2003), as discussed in Chapter 2, Section 2.3.4.2. When people with diabetes were found to deliberately cheat, choosing when not to adhere to a strict dietary regime, and when to make a conscious effort to have better than their 'normal' self-control; they not only had a sense of control over the disease, but also paradoxically facilitated better blood glucose management.

(Lawton et al., 2006) noted that when participants talked about why they thought that they had got diabetes, they almost universally attributed the causes to factors outside of their control, which enabled them to be absolved of individual responsibility as they consider the cause to be fatalistic, for example;

'God has given me this disease of sugar. Whatever happens, it happens because God wants it to happen.' (Lawton et al., 2006 p48)

This same fatalistic approach was reported by participants in the study by (Nagelkerk et al., 2006), which allows for a rather defeatist attitude from one particular participant who commented;

'It is a very discouraging disease. What happens, happens – I guess I have a bad attitude. It's as bad as cancer as far as I am concerned...you are either going to lose your eyesight, your kidneys, it does all your organs... (complications) are horrible.'
(Nagelkerk et al., 2006 p154)

These fatalistic beliefs have been shown to increase feelings of depression amongst people with diabetes, and contributes significantly to diabetes-related complications, (de Groot et al., 2001). Research has found that the incidence of depression is twice as high in people with diabetes, (Rubin et al., 2004); (Anderson et al., 2001).

To summaries the internal barriers to diabetes self-care described above, the patients' health beliefs were found to significantly affect their adherence to their self-care practices. A study by (Grant et al., 2003) showed that patients are more likely to adhere to treatment if they perceive it as helpful in maintaining their quality of life. According to (Vermeire et al., 2007), belief in the seriousness of the condition is important as a motivating factor for people with diabetes to make adaptations to their lifestyle and for maintaining them.

4.5 Discussion

Six key themes emerged from this review: Patient lack of knowledge or understanding, provider lack of knowledge, provider-patient relationships, social support, external constraints and co-morbidity, and internal constraints. The barriers identified have important implications for understanding the motivational factors to successful and effective diabetes self-care. When these barriers are explored, it gives insight as to the strategies which can be employed by the patient and their providers to overcome the obstacles.

When people with diabetes were equipped with adequate knowledge and understanding of their disease, and are fully aware of the consequences and seriousness of non-adherence, they achieved better self-care; because they were more confident and able to accept the disease and its complications. According to (Brown et al., 2002) the key to effective self-management is patient motivation and willingness to assume responsibility for their own care through a change in their attitude towards the disease. When people with T2D become effective self-managers, the complications of diabetes are reduced and their quality of life is enhanced. (Rayman and Ellison, 1998) found that the knowledge and problem solving skills obtained through diabetes self-management education are essential for initiating the self-

care process and empowering them, as patients express a desire to live as normal and healthy a life as possible.

The ability of the patient to succeed in self-management is not only affected by the multiple internal and external barriers they face, but also by their psychological state. The (WHO, 2003) report identified that implementation of self-management was often found to be compromised by multiple barriers. Acknowledgement that the adoption and maintenance of effective self-management requires self-discipline is demonstrated by participants in the (Song et al., 2010) and (Gazmararian et al., 2009) studies. Patients struggle to integrate their diabetes self-management regimes into everyday life, as situations demand daily assessment of biophysical needs, implementation of appropriate management strategies and evaluation of treatment effectiveness.

Researchers in the (Casey et al., 2009) study noted that when participants were part of the supervised exercise programme they had a reason to be organised. It is suggested that from the synthesis of these studies in this review, participants gave priority to being part of the programme over and above their normal constraints such as work commitments and their obligations to others. A time and place was arranged for the programme to be conducted to which they were obligated, rather than just being something that needed to be fitted into their daily life around their normal routine, and constraints. Patients acknowledge that they did not always put their health first, yet conversely, when they were part of the supervised education programme, (Casey et al., 2009) the normal obligations which constrained them are inverted. The obligatory feelings attached to being part of the programme took priority giving participants the intended health benefit, though on initial inspection this may seem unintentional. The negative constraint of being obligated was transformed into a benefit, as the obligation becomes positive, with desirable and tangible health benefits.

As discussed above some participants denied their diabetes and the associated complications; (Al-Qazaz et al., 2011); (Casey et al., 2009); (Gazmararian et al., 2009); (Wong et al., 2005); (Bissell et al., 2004); (Vermeire et al., 2003), claiming that in doing so it gives them control over their own bodies. This may allow people with diabetes to experience a sense of autonomy, but does not give them control over the disease; by patients denying their disease and ignoring the complications they will in the long term suffer greater consequences and complications. It is essential for people with T2D to accept their disease and the corollaries associated with it, enabling them to become successful and effective self-managers. Findings of this synthesis have established that some people with diabetes did not want to know about the complications of T2D, and wished to refute the disease. When

care providers are educated as to why patients do not adhere, their motives and disincentives; then the strategies devised to overcome these obstacles can be effectively employed. Sustainable life-long health changes within the concordance paradigm, through mutual education and understanding can be produced.

People with diabetes need confidence to create a positive change in their belief and attitude towards their illness, as it is a necessary precursor to their acceptance of the disease. This can be brought about by a change in psychological persona, through empowerment and continued motivation. The patient's mind-set needs to be in a similar zone to that of the participants discussed in the (Song et al., 2010) study. According to (Song et al., 2010) the patient's state of mind or psychological reasoning is a very significant factor in enabling them to be successful in self-management. These ideas were explored by (Song et al., 2010) who say that in Korean culture, Confucianism; the ethical and philosophical way of life developed from the teachings of the sixth century Chinese philosopher, Confucius, is an important belief among Koreans. They found this to be especially true for older adults who were taught that individuals are responsible for their own behaviours and consequences (Paik, 2008). Therefore, according to (Song et al., 2010) empowerment education for diabetes self-management (Mensing et al., 2007), can be very effective for Korean older adults. Perhaps these principles could be transferred to those patients who have a similar mind set and are able and willing to be empowered in that way, and thus motivated to achieve sustainable life-long self-care via this paradigm?

Considering the participants in the (Wong et al., 2005) study, they felt motivated to be adherent to a foot care regimen as they were fearful of amputation. The researchers refer to (Levin, 2002) who comments that the loss of a limb limits daily and leisure activities, social interactions and leads to loss of income, which are major considerations for people with T2D. A participant in the (Wong et al., 2005) study commented that; if his leg was amputated he would feel useless, revealing a non-desirable state of mind and psychological attitude that the physical limitation of amputation would bring, rather than there being just the actual physical constraint. Patients were highly motivated and empowered to adhere to effective life-long self-care, even when the demands placed upon them are complex, if the goals are highly desirable and tangible, or the consequences of non-adherence are costly. It is perhaps not the fear of amputation itself, which is the motivating factor, but a fear of the consequences that would ensue with amputation. This is the case with those studies that investigated smoking habits and macular disease, (Miller et al., 2011); (Klein et al., 1993). It may be that for patients living with the possibility of severe and life changing complications of disease like the loss of a limb or the loss of vision is more poignant than their own mortality.

According to results of a Seven-Country Survey presented at the International Diabetes Federation's 19th World Diabetes Congress in Cape Town, South Africa, adults with diabetes feared blindness or vision loss more than premature death, (IDF, 2006).

4.6 Summary

It is important for health care providers to understand the complexities of the barriers to self-care people with diabetes face on a daily basis and to take a holistic approach to the provision of education and support services for people with T2D. By identifying personal barriers and disincentives for patients that limit the effectiveness to self-management, the factors which enable and motivate can be established. Patient's beliefs, preferences and attitudes must to be considered when devising T2D self-management education programmes, allowing the barriers to self-management to be surmounted by people with diabetes and enabling them to make effective and sustained self-care changes.

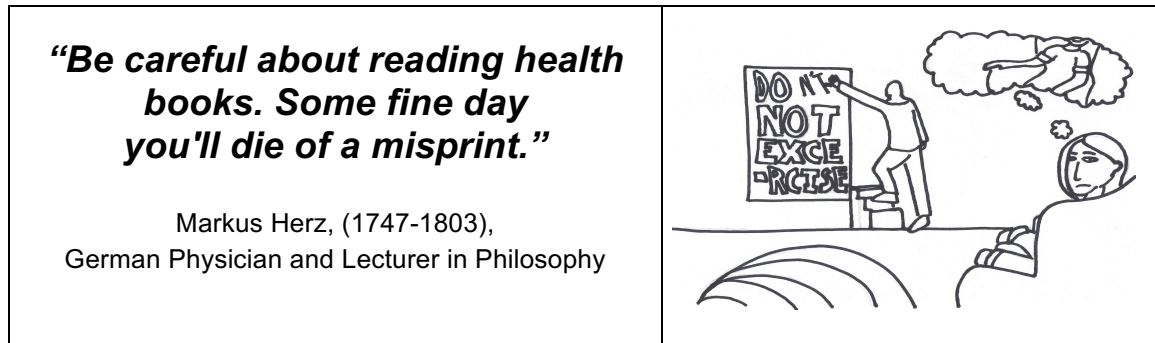
This systemic review and meta-synthesis has highlighted the barriers and constraints to self-care for people with T2D, and enabled the researcher of this PhD study to gain invaluable insights and have greater understanding of the complexities of diabetes self-care. Study (1) concludes that if the external factors and barriers to T2D self-care people face are to be surmounted, they need to be internalised, and transform into personal facilitators through improved self-confidence and motivation. It is postulated that the EDOP presentation in study (3) of this PhD research study may provide the impetus to self-change for participants, through enhanced self-efficacy and motivation, and support from the self-management education delivered in the presentation. Autonomous-supportive motivation is required to produce effective and sustained diabetes self-management, (Williams et al., 1998a), (Chapter 2, Section 2.3.1.3) and will be provided through a measured presentation of the possible, yet preventable consequence of sight loss associated with poor self-management of T2D. The autonomous, intrinsic element of motivation will be determined through the participant's personal desire to avoid the consequence of eye problems and live an enjoyable life free from visual impairment. The extrinsic, controlled component is provided by the fearfulness of living without sight, and the introjected motivation will be afforded by the possible feelings of guilty that they may experience for having not prevented their blindness.

The following chapter, Chapter 5 will investigate how diabetes self-management and eye health are communicated to people with T2D. The researcher of this PhD study will, in Study (2) Qualitative Analysis of Type 2 Diabetes Self-help Literature, investigate self-care and

management of T2D through FDA of the self-help texts. The notion of undertaking this research is to further understand how people with T2D receive and interpret information in preparation for Study (3) EDOP.

5 STUDY (2): QUALITATIVE ANALYSIS OF DIABETES SELF-HELP LITERATURE

‘Can I See The Way?’ A Qualitative Analysis of Diabetes Self-help Literature and Eye Health



5.1 Introduction

Successful management of diabetes occurs through the acquisition of knowledge, supported by behaviour and lifestyle modification. People affected by chronic illness, such as diabetes desire more information about their disease and its complications, so are turning to self-help genre. Self-help literature is often a first source of information for people experiencing a chronic life changing health condition (Rimke, 2000). The power relations and the power/knowledge concept of Foucault's ideas are of research interest in this PhD study, and the empowerment of people with diabetes Self-knowledge is about personal governance in society; according to (Rimke, 2000) the ability to know one's self involves behaviour which is governed by rules which can develop care of the self.

5.1.1 Aims

The purpose of this review is to investigate how diabetes self-management and eye health are communicated to people with T2D, and to examine how eye complications associated with diabetes are portrayed in self-help literature. Ten diverse self-help texts, with a range of differing formats were selected from an on-line bookstore. These texts were analysed, using thematic and Foucauldian discourse analysis to investigate if people with T2D are able to learn the rules of self-regulation, illustrated by the self-help texts, and reduce the risks of diabetic complications, to live a healthier, longer life.

5.1.2 Self-help Literature

According to (Wong et al., 2005) most participants in their study expressed a desire for greater understanding of their condition. People with chronic illness like diabetes are turning to self-help genre to acquire, or supplement their knowledge (Rimke, 2000). The increasing popularity of self-help literature was considered by (Covey, 1989), who found that many appealing rewards were promised to those prepared to engage in self-help projects. According to (Hamstra, 1996) the rewards and benefits of helping one's self can result in; good health, positive attitudes, a sense of inner fulfilment, and will make life more manageable and rewarding.

The genre of self-help continues to thrive, suggesting more and more people use self-help books to aid their understandings of specific conditions, life stages and relationships, as well as for advice on 'self-development and improvement'. A number of researchers have examined the growth of self-help texts on issues relating to health, personal growth and lifestyle, (Rimke, 2000); (Allwood, 1996). (Rimke, 2000), states that self-help literature has become within the past 25 years; 'an enduring, highly fashionable non-fiction genre', (Rimke, 2000 p62); having found that their relative low cost, ease of availability and accessibility, along with their relevance to everyday problems have all contributed to their increased popularity. (Allwood, 1996) found that self-help literature performs a number of related functions, which encouraged readers to regulate their bodies and themselves. The popularity and advocacy of self-help is associated with a change in socio-political mandates with regard to love of self, which is no longer discouraged. Historically self-love was viewed as pathological, egoistic or narcissist, because of religious long-standing prohibitions against selfishness where pride was considered a cardinal sin (Hazleden, 2003).

Bibliotherapy, or the 'treatment with books', is increasingly popular and is being promoted in many countries (Shechtman, 2008), in the U.S. self-help books account for two-and-a-half percent of the total number of books in print, which is worth \$2.5 billion a year. It is estimated that there are around 417,000 self-help titles available on the on-line Amazon site, and that one-third to a half of all adults in the U.S. have purchased a self-improvement book at least once in their lifetime (McGee, 2005). In June 2013 the 'Books on Prescription scheme' was launched in England. The national scheme, was already running in Wales and parts of Scotland, and was designed to help people to manage their mental wellbeing using cognitive behavioural therapy-based self-help books written by experts. The scheme is endorsed by health professionals and supported by public libraries. In January 2015 the 'reading well books on prescription for dementia' was launched, this scheme is run by The Reading

Agency, in partnership with the Society of Chief Librarians, and with funding from Arts Council England. However, at present there are no schemes available for T2D self-help books on prescription, though many local libraries do hold a selection of books on T2D self-management.

Self-help literature describes the self as; 'a unified centre of personal agency which can act upon itself, others, and the world. This idea presents the individual as the sole ontological pivot of experience', (Rimke, 2000 p64). Self-help relies upon the principle of individuality and entails self-modification and improvement. Self-help literature is considered to be a voluntary and individualistic activity, based on philosophies of choice, autonomy and freedom, with a clear socio-political mandate that responsible citizens are those with responsibility to themselves, not others, (Rimke, 2000). Individualism is the moral stance, political philosophy, ideology, or social outlook that emphasizes the moral worth of the individual. Citizens are advised by self-help literature to develop new forms of social responsibility, which is not however socially oriented, but is a form of hyper-individuality.

The self is considered to possess an inner reserve of power that can be accessed, thus suggesting an intense accountability, responsibility and sense of obligation that the individual can draw upon for choices and decisions. Through the concept of responsibility, popular self-help discourses provide an example of how the operations of power in everyday life can provoke governance of the self through morality. Personal power is generally viewed as integral to the self, and establishes the site of all self-regulation (Jeffers, 2005); (Moore, 1992); (Covey, 1989) (Peck, 1978). These cultural discourses contribute to the idea that individuals are predictable and uniform beings, capable of responsibility for their social conduct and experience in the world, where discipline is the key to responsibility.

Notwithstanding, (Rimke, 2000) points out that a fundamental flaw in self-help literature is that while the advice and techniques in self-help books appear to assist in the discovery of the 'real' self, it is 'an artificial discursive and extra-discursive construction of the self', which is actually created, (Rimke, 2000). (Rimke, 2000) warns that through the process of constructing one's identity, model citizens are produced, but, by the means of that self-fashioning, citizenship itself disappears.

5.2 Method

The review proceeded in four stages. A systemic searching and screening strategy was developed to identify the diabetes self-help texts which deal with diabetes self-care and management; texts identified were evaluated for relevance, appraised and reviewed, (Malpass et al., 2009); (Walsh and Downe, 2005). The research question, 'Can I See The Way? A Qualitative Analysis of Diabetes Self-help Literature and Eye Health', was formulated according to (Malpass et al., 2009) by identifying the parameters of the review (Booth, 2003). Finally thematic analysis of the texts was undertaken (Braun and Clarke, 2006), and texts relating to compliance and concordance were selected for FDA (Willig, 2008).

5.2.1 Method-Stage 1: Systematic Search and Screening

Key words in the searched included: *type 2 diabetes, eye health and diabetes, diabetic eye problems, eye problems and diabetes, and eye sight and diabetes*. Terms were selected to include 'who' (people with T2D), 'what' (self-management) and 'how' (self-help literature), (Malpass et al., 2009); (Walsh and Downe, 2005).

For inclusion in this review texts needed to be; widely available, written in English and of recent publication. The Amazon on-line book store was chosen because it can be easily accessed by a large population.

Excluded from the review were; medical textbooks, e-books, general self-help books, texts with a 'my diabetes journey' narrative, and those texts which made sensational claims. These texts were considered to be irrelevant to this review as the aim of the study was to discover how a person with diabetes can be informed through specific self-help texts relating to current diabetes self-care and management principles. The search was conducted and all texts meeting the inclusion criteria were identified by the author in February 2013 from the Amazon website, publication dates ranged from 2002 to 2011.

5.2.2 Method-Stage 2: Critical Appraisal

The searches produced 189 self-help publications available from Amazon with a potential 43 texts identified for review. Appraisal of the self-help texts was based on popularity and reading of the on-line book review or synopsis for content on eye complications or eye health, and checking the books on-line contents page where possible to identify chapters or sections on eye health, vision and complications after the irrelevant publications and kindle editions had been discounted.

Ten books were selected for the review from the initial 43, the reasons for rejecting texts were; textbooks and professional literature texts (17), self-help texts on general diabetes, where no direct reference to eye complications were given (12), 'my diabetes story' (3) and 'miracle cure' for diabetes (1). (Table 3)

Table 3 – Description of the Self-Help Texts Selected for Review

TITLE	COST	AUTHOR/EDITOR	YEAR	PUBLISHER	Country	TYPE OF DIABETES	PAGES
Prevent Diabetes Problems: Keep Your Eyes Healthy ISBN: N/A	£6.94	U.S. Department of Health and Human Services	?	NIDDK-national Diabetes Information Clearinghouse	US	T1D + T2D	1-16
Take Charge of Your Diabetes, 4 th Edition ISBN: N/A	£8.06	U.S. Department of Health and Human Services	2007	NIDDK-national Diabetes Information Clearinghouse	US	T1D + T2D	1-129
Know Your Numbers, Outlive Your Diabetes: 5 Essential Health Factors You Can Master to Enjoy a Long and Healthy Life ISBN: 978-1-56924-272-8	£10.99	Richard Jackson & Amy Tenderich	2007	Marlow & Company	US	T1D + T2D	1-289
Type 2 Diabetes Answers at Your Fingertips: 6 th edition ISBN: 978-1-85959-176-5	£12.74	Dr Charles Fox & Dr Anne Kilvert	2007	Class Publishing, London	UK	T2D	1-299
Type 2 Diabetes for Beginners: A Clear, Friendly Guide on Taking the Right Steps Toward a Healthy Life with Diabetes, 2 nd Edition ISBN: 978-1-58040-442-6	£14.20	Phyllis Barrier	2011	American Diabetes Association	US	T2D	1-203



TITLE	COST	AUTHOR/EDITOR	YEAR	PUBLISHER	Country	TYPE OF DIABETES	PAGES
The Uncomplicated Guide to Diabetes Complications. 2 nd Edition ISBN: 978-1-58040-133-3	£14.73	Editors by Michael A. Pfeifer & Marvin E. Levin	2002	American Diabetes Association	US	T1D + T2D	1-291
American Diabetes Association Complete Guide to Diabetes: The Ultimate Home Reference from the Diabetes Experts, 5 th Edition ISBN: 978-1-58040-330-6	£18.95	American Diabetes Association	2011	American Diabetes Association	US	T1D + T2D	1-480
Diabetes (When Your Doctor Says...) A Guide to Regaining Control Over Your Health and Well-being ISBN: 978-0-7808-1167-6	£19.50	Edited by David A Cooke	2010	Omnigraphics	US	T1D + T2D	1-407
Type 2 Diabetes in Adults of all Ages ISBN: 978-1-85959-166-6	£23.74	Charles Fox & Ragnar Hanas	2008	Class Publishing, London	UK	T2D	1-253
The Canadian Type 2 Diabetes Sourcebook. 3 rd edition ISBN: 978-0-470-15702-2	£27.11	M. Sara Rosenthal	2009	Wiley	CANADA	T2D	1-353



Illustration removed for copyright restrictions

5.2.3 Method-Stage 3: Thematic Analysis of the Texts

The review employed interpretative analysis, texts were read and re-read, and data extraction forms were used to record details of findings and codes. Using the thematic code extracted from all 10 texts, a matrix of shared themes was produced by the author including illustrative quotes from each theme. Themes are patterns across data sets which are important to the description of a phenomenon and are associated to a specific research question. These themes become the categories for analysis, (Braun and Clarke, 2006).

5.2.4 Method-Stage 4: Discourse Analysis of the Texts

The Foucauldian version of discourse analysis was used in this review, enabling a thorough investigation of the discourses of compliance and concordance presenting in Foucault's power/knowledge concepts. The analytical process undertaken is based on the step by step guide suggested by (Willig, 2008).

5.3 Findings of the Thematic Analysis

The aim of the review is to compare the books that have a more traditional 'biomedical' approach, with those of a more person centred stance. The texts with a biomedical position are: American Diabetes Association Complete Guide to Diabetes, (American Diabetes Association, 2011); Diabetes (When Your Doctor Says...), (Cooke, 2010); The Canadian Type 2 Diabetes Sourcebook, (Rosenthal, 2009); Type 2 Diabetes in Adults of All Ages, (Fox and Hanas, 2008); Take Charge of Your Diabetes, (Department of Health and Human Services, 2007); Type 2 Diabetes Answers at Your Fingertips, (Fox and Kilvert, 2007); The Uncomplicated Guide to Diabetes Complications, (Pfeifer and Levin, 2002); and Prevent Diabetes Problems: Keep Your Eyes Healthy, (Department of Health and Human Services, undated). The other books selected which take a more person-centred stance are: Type 2 Diabetes for Beginners, (Barrier, 2011) and Know Your Numbers-Outlive Your Diabetes, (Jackson and Tenderich, 2007). Though some of the texts selected took a 'biomedical' position and contain colloquial elements (Rosenthal, 2009); (Fox and Kilvert, 2007).

This review uses thematic analysis to examine how eye complications associated with diabetes are portrayed in self-help literature. Three major themes were identified;

- 1) Information on Eye Health;

Including six sub-themes: *Landmark Studies, Recommendations on Eye Checks, Explanation of the Signs and Symptoms of Diabetic Eye Disease, Advice on Diabetic Eye Disease, Smoking and Diabetic Eye Disease and Treatment of Diabetic Eye Disease and Low Vision*

2) Text Format and Style;

Including three sub-themes: *Question and Answer Format, Case Studies and Recording Personal Diabetes Data*

3) Motivational Elements;

Including three sub-themes: *Dissemination of Information on Diabetes and Eye Health, Offers of Encouragement, and Empowerment*

5.3.1 Information on Eye Health

The theme of eye health information is investigated with sub-themes relating to; the key diabetes research studies on diabetes control and management, the signs and symptoms of diabetic eye disease, the advice given on diabetic eye disease, recommendations made with regard to eye checks, the treatment of diabetic eye disease, and information on visual impairment resulting from eye disease.

5.3.1.1 Landmark Studies

The information conveyed in all these books stems from the landmark studies (UKPDS, 1998) and (DCCT, 1993) discussed in the Introduction, Chapter 1 (Section 1.4.1), though the references and citations vary, between the texts and within the same books.

In (Barrier, 2011) and (US Department of Health and Human Services, undated) the information from the key studies is used with no references or citations, whilst in (US Department of Health and Human Services, 2007) indirect references are made, but again not cited;

Research shows that keeping your blood glucose level as close to normal can prevent or delay the onset of diabetic eye disease...Finding and treating eye problems early can help save sight (US Department of Health and Human Services, 2007 p43)

Inconsistent referencing was the case in most of the books, in (Pfeifer and Levin, 2002) statistics are quoted from the landmark study, with no citations in some chapters, and full references in others. For example, Chapter 4 (Eye Disease) no reference is used;

With regular and lifelong eye examinations, more than 98% severe vision loss from diabetic retinopathy can be prevented (Pfeifer and Levin, 2002 p69)

Aa direct reference is, however, cited in Chapter 11 (Peripheral Neuropathy);

The DCCT showed that intensive insulin therapy lowered the risk of neuropathy by 60%. The Japanese (Kumamoto) study and the UKPDS of people with type 2 diabetes showed the same beneficial effects of good blood glucose control (Pfeifer and Levin, 2002 p158)

Direct cited references to the key diabetes research studies are made in; (ADA, 2011), (Fox and Hanas, 2008) and, (Fox and Kilvert, 2007), with recommendations on diabetes management supported with with evidence from the landmark studies. For example, (ADA, 2011);

Two landmark studies showed that keeping blood glucose levels as close to normal as possible can help prevent or slow the progression of many complications. (ADA, 2011 p228)

Stating that participants in the (DCCT, 1993) study (for T1D);

...reduced their risk for developing complications by more than 50% (ADA, 2011 p228),

and participants in the (UKPDS, 1998) study (for T2D);

...reduced their risk of complications such as eye disease and nerve disease by 25% (ADA, 2011 p229)

In this example, the reader is referred to the findings of these studies to justify the management strategy advocated in the texts, which the person with diabetes is expected to find empowering. The statistics quoted illustrate how the risks of the complications of diabetes can be reduced by following the recommended guidelines.

Another example is taken from (Fox and Hanas, 2008), the treatment of diabetic retinopathy is explained, stating statistics which are hard hitting;

Diabetes is the leading cause of new cases of blindness among adults aged 20-74 years. Diabetic retinopathy causes 12,000 to 24,000 new cases of blindness each year (Fox and Hanas, 2008 p213)

But hope and reassurance is offered as the text continues;

Detecting and treating diabetic eye disease with laser therapy can reduce the development of severe vision loss by an estimated 50-60% (Fox and Hanas, 2008 p213)

Interestingly, in (Jackson and Tenderich, 2007) both the (UKPDS, 1998) and (DCCT, 1993) studies are referred to, with the adage of saying that these recommendations are real;

Whilst we're in the midst of explaining the medical details, this is a good opportunity to point out that we're not making this stuff up. Over the last fifteen years, multiple, large, prospective, randomised, controlled, blinded clinical studies have explored the impact of these five tests and future diabetes related complications, (Jackson and Tenderich, 2007 p84)

In addition to how the books reviewed make reference to the information, or cite the references, there is variation between the texts as to the volume of information conveyed. Two books, (Cooke, 2010) and (Fox and Hanas, 2008) have a whole chapters dedicated to the key diabetes research studies. (Cooke, 2010), Chapter 35 p327-334, refers to the (DCCT, 1993) and (DCCT/EDIC, 2005); and (Fox and Hanas, 2008), Chapter 36, 'Outcome Studies in Type 2 Diabetes' p227-233, discusses a number of the key studies including (UKPDS, 1998) and (DCCT, 1993).

5.3.1.2 Recommendations on Eye Checks

With regard to eye examinations and checks, all the books reviewed state that some form of test is necessary, and most state that it is an annual dilated eye exam which is recommended to prevent sight loss, even when the vision is good, for example;

At first, you might not have any loss of sight from these changes. Have a dilated eye exam once a year even if your sight seems fine (US, Department of Health and Human Services, undated p5)

In (Barrier, 2011), (Cooke, 2010), (US, Department of Health and Human Services, 2007), and (Pfeifer and Levin, 2002) the recommendations for an eye exam is made and reiterated, examples of this reiteration are noted below;

Since diabetic eye disease may be developing even when your sight is good, regular dilated eye exams are important for finding problems early. (US, Department of Health and Human Services, 2007 p43), and as the section on eye problems continues;

Even if you are seeing fine, you need regular, complete dilated eye exams to protect your sight... you should have your eyes dilated and examined at least once a year. (US, Department of Health and Human Services, 2007 p45)

In (Cooke, 2010), eye problems are covered in two chapters; Chapter 22 (Preventing Diabetes Related Complications) and Chapter 24 (Preventing and Managing Eye Problems). In Chapter 22, under the heading; '*More Things You can Do*', the reader is advised about the recommended eye checks;

To keep your eyes health, visit an eye-care professional once a year for a complete eye examination that includes using drops in your eyes to dilate your pupils. (Cooke, 2010 p199)

The reader is further reminded of this information on page 201, and again the recommendation is reiterated in chapter 24, in the form of a list of the things that can be done to prevent diabetes-related eye problems, along with an explanation that this is necessary even if vision is good;

Retina damage happens slowly... At first, you may not have any loss of sight from these changes. Be sure to have a dilated eye exam once a year if your sight seems fine (Cooke, 2010 p211)

(Fox and Hanas, 2008) and (Fox and Kilvert, 2007) are both published in the UK, and eye checks in the form of retinal photography as part of the National Diabetic Screening Programme are discussed;

What are the complications and what should I keep a lookout for to ensure that they are picked up as soon as possible?

The complications specific to diabetes are known as diabetic retinopathy, neuropathy and nephropathy. You should have a check once a year...most areas now offer annual retinal photography to screen for diabetic eye changes (Fox and Kilvert, 2007 p219) and;

Who is the best person to check my eyes once a year?

Diabetes NSF recommends that every person with diabetes should be offered an annual eye check in the form of digital retinal photography (Fox and Kilvert, 2007 p224)

Interestingly though in (Fox and Hanas, 2008), diabetic retinal screening is discussed as a method of detecting diabetic eye disease, though an eye sight test is not. The sight test is mentioned in the text as something that is 'free', that the diabetic person is entitled to, and so perhaps by implication is of no value;

If you are diabetic you are entitled to free sight tests (Fox and Hanas, 2008 p225)

In addition, some of the texts highlight the necessity for eye checks by emphasising certain phrases, (Barrier, 2011) and (Rosenthal, 2009) taken as examples;

.... YOU CAN DELAY OR PREVENT EYE PROBLEMS BY HAVING AN EYE EXAM EVERY YEAR. Be sure your eye doctor uses eye drops to dilate your pupils, (Authors emphasis), (Barrier, 2011 p159)

However, it is noted that on the same page (Rosenthal, 2009) gives the reader conflicting information on the frequency of an eye check;

IT'S CRUCIAL TO HAVE FREQUENT EYE EXAMS....so as soon as you're diagnosed with Type 2 diabetes, get to an eye specialist for a complete exam and make it a yearly 'gig' from now on (authors emphasis), (Rosenthal, 2009 p274)

... In the early stages of diabetic eye disease, there are no symptoms. That's why you need to have a thorough eye exam every six months (Rosenthal, 2009 p275)

This ambiguity in frequency of the eye check was also noted in (ADA, 2011); though this book clearly states that diabetic retinopathy can begin without affecting vision, it falls short on advice, as it only recommends 'regular' eye exams, with no reference to a time interval;

Early detection is the key to keeping this disease from interfering with your vision. You can have retinopathy severe enough to threaten your vision without knowing it. Treatment can protect your vision this is the reason for having regular eye exams (ADA, 2011 p240)

5.3.1.3 Explanation of the Signs and Symptoms of Diabetic Eye Disease

This theme investigates how the signs and symptoms of diabetic eye disease are explained to the reader, which includes how the problems associated with retinopathy, macular oedema, neuropathy and red eye are conveyed. A number of the books reviewed give a wide range of signs and symptoms attributed to diabetic eye disease, but give the reader little or no explanation, for example;

At first there may not be any warning signs of diabetes eye problems. Later on, there may be changes in your eyesight, such as double vision, floating spots, or flashing lights or you may have trouble seeing (Barrier, 2011 p159), and;

Some people may notice signs of vision changes. If you're having trouble reading, if your vision is blurry, or if you're seeing rings around lights, dark spots, or flashing lights, you may have eye problems. (US. Department of Health and Human Services, 2007 p43), and;

How do I know if I have retina damage from diabetes?

You may not have any signs of diabetes retina damage, or you may have one or more signs: Blurry or double vision; Rings, flashing lights, or blank spots; Dark or floating spots; Pain or pressure in one or both of your eyes; Trouble seeing things out of the corners of your eyes (US. Department of Health and Human Services, undated p9)

The (ADA, 2011) offers a list the visual signs of diabetes complications and an explanation of retinopathy on page 239;

Vision problems, such as blurry or spotty vision or flashes (ADA, 2011 p228), and;

Unexplained visual problems, such as spots, floaters, cobwebs in your field of vision; blurring or distortion of vision; blind spots; eye pain; or persistent redness; Trouble reading books or traffic signs (ADA, 2011 p241)

The books in the above examples all list 'floating spots' and 'flashing lights' as symptoms of diabetic eye disease, which is however contradicted by (Fox and Kilvert, 2007), in the example below;

I get flashes and specs across my vision. Are they symptoms of serious eye trouble?

The reply clearly states;

Although people with diabetes do get eye problems, this does not normally cause flashing lights or specks across the vision. You should discuss it with your own doctor (Fox and Kilvert, 2007 p227)

Two of the other books reviewed, which provide the reader with an explanation of the signs and symptoms of diabetic eye disease are; (Cooke, 2010) and (Pfeifer and Levin, 2002). (Cooke, 2010) gives comprehensive information; there is a good diagram with detailed description of the structures of the eye and an easy to follow explanation of how diabetes can affect the retina (p209-12). In (Pfeifer and Levin, 2002), under the heading; '*How does diabetes affect the retina?*' (Pfeifer and Levin, 2002 p48). A comprehensive explanation of the progression of diabetic retinopathy, along with the symptoms of retinopathy and macular oedema are described. The following excerpt gives an example;

Symptoms of changes in your retinas may include blurred or fluctuating vision, floating spots, warping of straight lines or loss of vision (Pfeifer and Levin, 2002 p50)

Distortion of straight lines can be a serious symptom... This distortion is often a sign of macular oedema (Pfeifer and Levin, 2002 p50)

This book also indicates the possibility of other eye problems unrelated to diabetes, stating that whatever the symptom or its cause, it is advisable to get it checked out;

Floating spots may be the result of age-related changes, but they may also indicate vitreous haemorrhage (Pfeifer and Levin, 2002 p50)

Two of the books reviewed, (Fox and Kilvert, 2007) and (Rosenthal, 2009) give extended information on diabetic eye disease. The following example taken from (Fox and Kilvert, 2007) highlights the intended reassurance given by the author;

I have had diabetes for 20 years and seem to be quite well. Following my last eye photographs, I had a letter to say that I had some mild diabetic changes and would be referred to an eye specialist. Am I about to go blind?

There is no need for alarm. It would be surprising if there were no changes in your eyes after 20 years of diabetes. It is important to see an eye specialist at an early stage so that if treatment is required, it can be given before your vision is affected (Fox and Kilvert, 2007 p225)

(Rosenthal, 2009) also supplies excellent supportive clarification of eye disease, explaining retinopathy from non-proliferative (background) to proliferative retinopathy and advance diabetic eye disease in a coherent fashion, but remains elusive on the signs and symptoms of diabetic eye disease. This book disappointingly states only 'blurred vision' due to lens changes as a sign of diabetes related eye problems, rather than listing symptoms of the more serious complications. Blurred vision is a symptom of diabetes and can be due to lenses changes, though there are of course other more serious and potentially sight threatening causes of blurred vision, other than lens changes, which are not mentioned here;

As the eye damage progresses, you may notice blurred vision. The blurred vision is due to changes in the shape of the lens of the eye (Rosenthal, 2009 p275)

Diabetes eye disease affects both central and peripheral vision...often very gradual. The following are classic signs of failing or deteriorating vision; You sit closer and closer to the television, You're squinting in order to see, You need a stronger prescription for your glasses or contacts, You have difficulty reading the newspaper, You're bothered by bright lights, You're more accident-prone, You can't see well in the dark or at night; night driving is difficult (Rosenthal, 2009 p276)

This text continues to listing the signs of deteriorating vision, however, deterioration in vision can be caused by a number of issues, like diabetic retinopathy as well as old age. This explanation risks introducing the reader to a level of complacency, were vision could be lost.

Interestingly though, an important point regarding diabetic eye disease is highlighted in (Rosenthal, 2009), which was not noted in any of the other books reviewed, which is;

It is important to remember that the longer you have diabetes, the higher your risk of having diabetic retinopathy (Rosenthal, 2009 p275)

(Fox and Hanas, 2008) does not have a chapter which is solely dedicated to eye problems, information on eye health is discussed in Chapter 3, (Microvascular Complications p198-200) in a short section entitled; '*Complications affecting the eyes (retinopathy)*'. This contrasts with that of feet complications, to which a whole chapter is dedicated (Chapter 32 p204-7). The discussion on diabetes related eye problems worryingly states that '*blurred vision*' is the only symptom;

Blurred vision can be a symptom of a high blood glucose level. This is caused by a mismatch between the glucose content of the lens and that of the blood.... causing temporary short-sightedness (Fox and Hanas, 2008 p34), and that;

Blurred vision is a common symptom of unstable diabetes (Fox and Hanas, 2008 p199)

A further comprehensive search of (Fox and Hanas, 2008) found no mention of the signs or symptoms of diabetic retinopathy, the phrase '*double or blurred vision*' and '*disturbed colour vision*' were found on page 128 in relation to the symptoms of hypoglycaemia. The lack of an explanation of the signs and symptoms of diabetic eye disease was also noted in (Jackson and Tenderich, 2007), which states only;

In contrast to the other tests, there are no numerical results from an eye exam, no 'magic number'....Instead there are different grades of retinopathy, ranging from none to background to non-proliferative to pre-proliferative and further stages (Jackson and Tenderich, 2007 p30)

Another complication of diabetes is a difficulty in adjusting to lighting levels in dimmer or darker environments because of neuropathy. Only two of the books, (Cooke, 2010) and (Pfeifer and Levin, 2002) discuss this, for example;

If these nerves are damaged, the pupils respond more slowly to darkness, so it can take longer for your eyes to adjust when you enter a dark room. You may have more

difficulty driving at night because your eyes don't respond as quickly to the lights of an oncoming car (Pfeifer and Levin, 2002 p169)

In (Cooke, 2010) peripheral, autonomic and focal neuropathies are discussed in Chapter 28 (Preventing and Managing Nerve Problems);

Autonomic neuropathy can affect the pupils of the eyes, making them less responsive to changes in light. As a result, a person may not be able to see when a light is turned on in a dark room or may have trouble driving at night (Cooke, 2010 p259)

5.3.1.4 Advice on Diabetic Eye Disease

The texts vary enormously as to the urgency in which they advise the patient to have any eye symptoms investigated, the recommendations they make regarding those symptoms, and further explanations they give. The two books which offer the most urgent recommendations with regard to symptoms of eye disease are (US, Department of Health and Human Services, undated) and (Pfeifer and Levin, 2002), for example (Pfeifer and Levin, 2002) warn;

With any symptom, play it safe, and have your eyes examined (Pfeifer and Levin, 2002 p50), and;

Double vision may be the first sign of serious or life-threatening conditions ...immediate examination is critical (Pfeifer and Levin, 2002 p68)

In (US, Department of Health and Human Services, undated), the symptoms of eye problems associated with diabetes may be inconsistent in this text, as discussed earlier, but the advice it gives the reader is very clear;

Call your eye care professional right away if you are having any vision problems (US, Department of Health and Human Services, undated p6)

When to see your eye doctor is discussed in (ADA, 2011), which states; 'yearly', and when 'a sign or symptom of change in vision' is noted. The text continues with a description of

macula oedema, and states how it can lead to blindness. However, it is noted that instruction as to the urgency in which the reader should seek attention is lacking;

.... your vision becomes blurry, you have trouble reading, you see double, one or both of your eyes hurt, you feel pressure in your eye, you see spots or floaters, or you lose vision (ADA, 2011 p334)

Macular oedema can also occur in people with diabetes. Retinopathy causes swelling of the macula of the eye ...vision can be impaired and blindness can result (ADA, 2011 p240)

In addition, this lack of clear instruction is repeated on page 241 with the phrase '*distortion of vision*', (ADA, 2011); this symptom could be either, macular oedema associated with diabetes, or a symptom of wet macular degeneration, both of which are sight threatening and need to be investigated urgently.

As already mentioned earlier, (Fox and Kilvert, 2007) is the only text where the reader is told that '*flashes and specs*' in vision are not normally associated with diabetic retinopathy, However, the actual urgency to which these other symptoms should be investigated is not conveyed, the reader is simply told to; '*discuss it*' with their own doctor. Flashing lights and floaters may potentially be a sight threatening sign of retinal detachment, which needs urgent specialist attention by an optometrist or local eye casualty department, rather than GP.

I get flashes and specs across my vision. Are they symptoms of serious eye trouble? Although people with diabetes do get eye problems, this does not normally cause flashing lights or specks across the vision. You should discuss it with your own doctor (Fox and Kilvert, 2007 p227)

(Cooke, 2010) is another of the texts which advises on the need for further investigation of eye symptoms, pointing out early detection of eye problems is important to prevent more serious problems later;

Have an eye care professional examine your eyes once a year. Have this eye exam even if your vision is okay...Diagnosing eye problems early and getting treatment right away will help prevent more serious problems later on (Cooke, 2010 p210)

However, as with the other texts, (Cooke, 2010) is deficient in stating the urgency required to seek further medical attention for the more serious signs and symptoms of diabetes related problems. For example, 'double vision' is listed as, a diabetes related problem, but no warning is given that this potentially life threatening symptom should be checked out urgently, (Cooke, 2010 p213).

All the books reviewed mention physical activity and exercise as being one of the cornerstone management strategies for controlling diabetes, however only half of them; (ADA, 2011), (Cooke, 2010), (Rosenthal, 2009), (US. Department of Health and Human Services, 2007) and (Pfeifer and Levin, 2002) discuss diabetic eye disease and physical activity. (ADA, 2011) and (US. Department of Health and Human Services, 2007) advise caution when commencing physical activity if the patient has retinopathy, but give no explanation as to why, explanation is offered in (Cooke, 2010), (Rosenthal, 2009) and (Pfeifer and Levin, 2002). For example, (Pfeifer and Levin, 2002) give advice in Chapter 4 (Eye Disease) and Chapter 20 (Prevention);

In general, physical activity and exercise does not affect vision...In the case of active proliferative retinopathy, some types of physical activity might cause those new blood vessels to rupture (Pfeifer and Levin, 2002 p68)

What are your exercise options with retinopathy?

Very strenuous exercise of any kind can cause excessive increases in blood pressure. This in turn can increase the pressure in the eye and can cause haemorrhage, especially in the eyes that are already damaged. Keep your head UP! (Pfeifer and Levin, 2002 p285)

Interestingly, the 'keep your head UP!' comment in the example above is somewhat superfluous given the general tone of this text; no other similar comments were noted in this book.

(Cooke, 2010), Chapter 17 (Diabetes and Physical Activity), under the heading 'Types of physical exercise to avoid' clearly states in the following example;

Activities that increase pressure in the blood vessels of your eyes, such as lifting heavy weights, can make eye problems worse (Cooke, 2010 p163)

This same warning is given by (Rosenthal, 2009), under the heading;

EXERCISES THAT CAN BE HAZARDOUS. These are activities, such as wrestling or weightlifting, which can worsen diabetic eye disease (authors emphasis), (Rosenthal, 2009 p144)

5.3.1.5 Smoking and Diabetic Eye Disease

Smoking and diabetes is discussed (US Department of Health and Human Services, 2007) stating that smoking increases risk heart disease and stroke, but does no mention that it is a contributing factor in eye disease. Similarly, (Jackson and Tenderrich, 2007) mention heart disease and foot problems, but not eye problems;

Smoking is a particular risk factor for foot problems, not to mention your cardiovascular and pulmonary system (Jackson and Tenderrich, 2007 p237)

Smoking and eye disease are mentioned in five of the books reviewed; (ADA, 2011), (Barrier, 2011), (Rosenthal, 2009), (Fox and Hanas, 2008) and (US Department of Health and Human Services, undated). The (US Department of Health and Human Services, undated), states only that to prevent eye problems; '*don't smoke*', with no further comments. However, these other books do offer explanation of the increased risks of eye disease and smoking, for example;

The combination of smoking in conjunction with type 2 diabetes speeds up the rate at which complications may develop...There is plenty of evidence that smoking in conjunction with diabetes is linked to increased risk of stroke, heart attack, peripheral vascular disease, kidney failure and diabetic eye disease (Fox and Hanas, 2008 p156)

(Rosenthal, 2009) goes a little further on this topic, under the heading; '*Preventing diabetic eye disease*', the advice to; '*Stop Smoking*', continuing with the explanation;

Since smoking also damages blood vessels and diabetic eye disease is a vessel disease, smoking will certainly aggravate the problem (Rosenthal, 2009 p275)

A similar explanation is given in (ADA, 2011);

Retinopathy is caused by damage to the blood vessels that supply blood to the retina. High blood pressure, high blood glucose and smoking can all damage blood vessels (ADA, 2011 p239)

Under the headings; '*Causes of retinopathy*', (p239) and '*Tips for eye care*', (p241), the advice given by (ADA, 2011) is simply put; '*Quit Smoking*';

(Fox and Hanas, 2008), Chapter 23 (p156-159) and (Barrier, 2011), Chapter 16 (p139-141) both have a whole chapter on diabetes and smoking, giving the reader a lot of explanation as to the increased risk to other diabetes problems, not just the eyes.

You know that having diabetes means you're at risk for certain health problems. But smoking makes your risk even higher for heart disease and eye, kidney and nerve damage (Barrier, 2011 p139)

In addition, (Barrier, 2011) offers advice and guidance on smoking cessation, presenting an action plan to support and guide the reader;

5.3.1.6 Treatment of Diabetic Eye Disease and Low Vision

(US Department of Health and Human Services, 2007) and (US Department of Health and Human Services, undated) both convey the same information about the treatment of diabetic eye disease, as they are published by the same organisation; however, neither explain the procedures and there is no supporting information or prognosis for treatment. The similarities of the texts are noted below, (US Department of Health and Human Services, undated) states;

Treating eye problems can help save sight. Laser surgery may help people who have advanced diabetic eye disease, (US Department of Health and Human Services, 2007 p46), and;

An operation called vitrectomy may help those who have lost their sight from bleeding in the back of the eye. (US Department of Health and Human Services, 2007 p46)

Similarly, (US Department of Health and Human Services, undated) states that;

Your eye care professional may suggest laser treatment... Laser treatment may slow the loss of sight, (US Department of Health and Human Services, undated p8), and;

If a lot of blood has leaked...Your eye care professional might suggest you have surgery called a vitrectomy. The surgery can make your eye sight better (US Department of Health and Human Services, undated p8)

Brief information on laser treatment is given in three of the books reviewed; (ADA, 2011 p242), (Fox and Hanas, 2008 p199) and (Jackson and Tenderich, 2007, p31 and p54). (Jackson and Tenderich, 2007) uses the term '*photocoagulation*' for laser treatment and states it is a very effective for treating more advanced diabetic retinopathy, but does not offer any explanation or description of the procedure.

In contrast to the other books reviewed, (Pfeifer and Levin, 2002) is the most comprehensive of the texts with regard to treatment of diabetic retinopathy, discussing various procedures over ten pages, including those less commonly used procedure. The example below explains the treatment success of laser which is supported with statistics;

When diabetic eye disease is caught early, treatment can be successful. Current treatments such as laser surgery can prevent more than 95% of severe vision loss from proliferative diabetic retinopathy (disease of the retina) and more than 50% of moderate vision loss from diabetic macular oedema (swelling of the macula, a part of the retina) (Pfeifer and Levin, 2002 p46)

Two of the other books reviewed; (Cooke, 2010) and (Fox and Kilvert, 2007) discuss alternative treatments to laser photocoagulation, the latest research and future treatments for diabetic retinopathy.

For example, (Cooke, 2010) has information on laser treatment and the more recent research and treatment options in the same section;

If some damage has already occurred, your eye care professional may suggest laser treatment.... It may stop blood and fluid from leaking into the vitreous and may slow the loss of sight. (Cooke, 2010 p213)

recent small, short term studies have revealed the visual benefits of eye injections of medications that block a chemical signal, known as vascular endothelial growth factor (VEGF) that stimulates blood vessel growth...repeated doses of anti-VEGF medications may prevent blood vessels from leaking fluid and causing macular oedema (Cooke, 2010 p214)

This research information on anti-VEGF treatment is given along with citations of publications and research journals. However, it is perhaps difficult to know how this research information is of relevance to the average person with diabetes seeking self-help. Notwithstanding, this book is the only one which mentions this treatment for proliferative retinopathy (Cooke, 2010 p214-215);

The future treatments for diabetes are detailed in (Fox and Kilvert, 2007 p256-262), Chapter 9 (Research and the Future) and in (Cooke, 2010 p312-20), Chapter 33 '*What will the future Bring?*'.

With regard to low vision, only four of the books reviewed;(ADA, 2011), (Rosenthal, 2009), (Fox and Kilvert, 2007), (US. Department of Health and Human Services, 2007) mention or discuss visual impairment. (Fox and Kilvert, 2007 p230) makes reference to visual impairment with regard to talking book services, (ADA, 2011 p190 and p201) gives information on pre-filled syringes and visual aids for insulin doses, and (US. Department of Health and Human Services, 2007) does briefly mentions low vision services, but no additional information is provided;

If your sight is poor, an eye doctor who is an expert in low vision may be able to give you glasses or other devices that can help you use your limited vision (US. Department of Health and Human Services, 2007 p46)

In complete contrast however, (Rosenthal, 2009 p278-290) offers a large and very comprehensive section on low vision under the heading; '*All About Visual Aids*', with lots of practice advice and emotional support.

5.3.2 Text Formatting and Style

The theme of text format and style is subdivided into three areas; question and answer format, case studies and recording of personal diabetes information.

5.3.2.1 Question and Answer Format

A number of the books use this formatting style, (Fox and Kilvert, 2007); (Jackson and Tenderich, 2007), (Pfeifer and Levin, 2002) and (US. Department of Health and Human Services, undated), though some of these books employ this style simply as a technique only, with the subject title having a question mark. This was the case in (US. Department of Health and Human Services, undated) for example;

What can I do to prevent diabetes eye problems?

Keep blood glucose and blood pressure as close to normal as possible -Have a health care professional examine your eye annually, even if vision is ok (US. Department of Health and Human Services, undated p3), and;

How can diabetes hurt my eyes?

High blood glucose and high blood pressure from diabetes can hurt four parts of your eyes (US. Department of Health and Human Services, undated p4)

In (Pfeifer and Levin, 2002) the question answer format is inconsistent in the book, with information being offered with little or no further explanation, simply listed below a heading question, for example;

How does diabetes affect the retina? (Pfeifer and Levin, 2002 p48)

However, in other sections of the book, the questions are answered with a more complete narrative;

What are the symptoms of retinopathy?

YOU MAY HAVE SERIOUS, SIGHT-THREATENING RETINOPATHY EVEN THOUGH YOU HAVE NO SYMPTOMS, and vision can measure even better than 20/20 (normal vision). For this reason, annual eye examinations are so important, (authors emphasis), (Pfeifer and Levin, 2002 p49)

Conversely, only (Fox and Kilvert, 2007) fully embraced the question and answer format exploring actual questions posed, giving a fully comprehensive answer to the question and

offering reassurance to the reader, although, this is perhaps obvious, as the title states, 'Answers At Your Fingertips';

I have had blurred vision for a few weeks and have just been found to have diabetes. Why has this affected my vision?

Blurred vision is usually a temporary change, which can be corrected by wearing glasses. The lens becomes swollen when diabetes is out of control and this leads to long-sightedness. As the diabetes comes under control the lens of the eye returns to normal (Fox and Kilvert, 2007 p22)

Another example of this formatting style is given below, with an added emphasis on reassurance by the authors;

I have had diabetes for 20 years and seem to be quite well. Following my last eye photographs, I had a letter to say that I had some mild diabetic changes and would be referred to an eye specialist. Am I about to go blind?

There is no need for alarm. It would be surprising if there were no changes in your eyes after 20 years of diabetes. It is important to see an eye specialist at an early stage so that if treatment is required, it can be given before your vision is affected, (Fox and Kilvert, 2007 p225)

(Fox and Kilvert, 2007) present this text as 'an easy reference guide'; however, the researcher did not find this to be the case. The main disadvantage of this formatting style was that information on specific issues relating to diabetes were not easily located, as the information contained in answer to a question was not immediately apparent from the question posed. In addition, when the index was used to look up specific words or terms not all references were indexed. The following is an example;

Eye information was noted in Chapters 1 and 8; in Chapter 1, the information relates to; 'What is Diabetes?', 'Symptoms' and 'blurry vision' (Fox and Kilvert, 2007 p22), in Chapter 8 the information relates to; 'Long term Complications' and 'General questions, complications specific to diabetes' (Fox and Kilvert, 2007 p218) and 'Eye Questions' (Fox and Kilvert, 2007 p223-230). When the terms 'vision' and 'visual problems' was searched in the index, only pages 22, 172 and 227 were located as the phrases; 'blurry vision', 'field of vision' and 'flashing lights and specs across vision' were highlighted, and when the word 'sight' was searched, information was less easily located. This means that the reader would have to hit

on the specific key word, which would not be easy, as the novice patient may not know the appropriate terminology.

5.3.2.2 Case Studies

Case studies are used in (Barrier, 2011), (Fox and Kilvert, 2007) and (Pfeifer and Levin, 2002). In (Pfeifer and Levin, 2002) this technique is slightly abstract and inconsistent, not all chapters have the case studies and when they are included, there is a difference in format between them. This inconsistency may be the result of poor editing, as the chapters are authored by a large number of contributors (contributors list, p-vii). To illustrate these inconsistencies; Chapter 4 (Eye Disease, p45-69) includes case studies, but the following chapter on heart disease, Chapter 5 (Heart Disease, p70-88) does not, and the whole of Chapter 8 (Hypertension, p109-126) is a case study, with a long-running narrative.

In this example the case study is presented as a dialogue between a patient (Mr. LJ) and his doctor (Dr. JR). This dialog is somewhat pretentious, Mr. LJ asks; *'Once you have established that a patient with diabetes has hypertension, what next?'* Dr. JR answers with a list of questions that would perhaps be asked more generally asked and is clearly not specific to this patient, (Pfeifer and Levin, 2002 p111).

(Pfeifer and Levin, 2002) has two case studies in the eye chapter, Chapter 4 (Eye Disease, p45-69), which are presented at the beginning of the chapter, and as the text continues, there no direct reference to these case studies made as an illustrative example. This lack of using the case studies as illustrative examples seems to be the general position in this book, and it is tenuous to say what inclusion of case studies in this book adds to the actual narrative of the text. However, some of the chapters do explain the problems highlighted in the case study, though without a direct reference to them. For example;

Case study one, (Chapter 4, Eye Disease);

(A 36-year-old man). The ophthalmologist explains the sudden onset of floating specks may be a harmless change in the vitreous gel... However, in a diabetic patient, there is the possibility the floating specs may be caused by a haemorrhage (Pfeifer and Levin, 2002 p45)

Later, the text continues to give the reader further explanation of floating specs;

Floating spots may be the result of age-related changes, but they may also indicate vitreous haemorrhage (Pfeifer and Levin, 2002 p50)

Case study two, (Chapter 4, Eye Disease);

(A 60-year-old woman). reports the gradual onset of blurred vision.... Stronger reading glasses no longer helps. Examination of her macula with a special lens determines that she has macular swelling (Pfeifer and Levin, 2002 p45)

The text continues to explain what happens during an eye examination; (Pfeifer and Levin, 2002 p50), and the use of these special lenses to image the retina and macular are explained, along with macular swelling, under the heading; *'What is macular oedema?'* (Pfeifer and Levin, 2002 p49).

Conversely in (Fox and Kilvert, 2007), specific case studies *per se* are not used; however, these questions posed by patients are a type of 'case study', the questions are depicted as 'actual questions' asked by 'real patients' about specific problems or worried they have encountered. When the questions are answered by the author, explanation and reassurance is offered in a direct illustrative response, for example;

The last time I Was tested at the clinic, I was told that I had developed microaneurysms. What on earth are these? (Fox and Kilvert, 2007 p228), the answer provided explores the question;

Microaneurysms are little balloon-like swellings or dilations in the very small blood vessels (capillaries) supplying the retina...They are one of the earliest signs that the high blood glucose levels seen in poorly controlled diabetes have damaged the lining of these capillaries. They do not interfere with vision, they give an early warning that retinopathy has begun to develop. There is evidence to show that these can get better with the introduction of perfect control, whereas, at later stages of diabetic retinopathy, reversal is not usually possible (Fox and Kilvert, 2007 p228)

Case studies are also used as illustrative examples in (Barrier, 2011), for example in the chapter on smoking, Chapter 16 (Smoking and Diabetes p139-145);

Robert decided he wanted to quit smoking...His diabetes team help him make a plan by answering the questions below. Answer these questions will help you make a plan and take the first steps toward quitting smoking. (Barrier, 2011 p141)

Why Do I Want To Quit Smoking? Robert's answer: I know smoking means big trouble for people with diabetes

Your answer: _____ (Barrier, 2011 p142)

The reader is encouraged to follow the lead of the person in the case study, the message is, they succeeded so can you. In this eye related case study, the patient reports on his emotional state having lost his sight;

Carlos is sad about losing his eyesight from type 2 diabetes. Carlos says, 'do what your health care team tells you. I wouldn't be blind if I had taken care of my diabetes. I wish I had a second chance. I'd work with my diabetes team and take care of my diabetes' (Barrier, 2011 p159)

This example is used to make the reader examine their own thoughts and emotions about the possibility of losing their own sight, and to heed the warning given. Throughout the text in (Barrier, 2011), the author uses her personal interactions with clients and family members as illustrative examples.

5.3.2.3 Recording Personal Diabetes Data

One strategy used in some of the books to encourage the reader to self-manage is to record their personal information in a log, enabling the person with diabetes to look at their results and reflect on both the high and low readings, or the good and not so good results; the aim of which is to teach them to recognise their good and bad practices. The (US. Department of Health and Human Services, 2007) has a 50 page log at the rear of the book in which to record personal information including; record sick days, checks and goals for each visit, checks and goals for each year, glucose record sheet and details of the patients health care team. Record sheets are also available in (Barrier, 2011), (Cooke, 2010) and (Jackson and Tenderich, 2007) to record results. (Cooke, 2010) has a table in which to record daily blood glucose reading (p203), in (Barrier, 2011) the record sheets, also in the form of a log, are at the back of the book, with space is made available throughout the text for the reader to fill in as an on-going prompt and motivational tool, for example;

Making healthy food choices – this week I'll work on _____
(Barrier, 2011 p30)

(Barrier, 2011) combines case study with recording the readers own personal information in the log. However, using the example from above, the answer given here by Robert is considered to be the model answer, to which the reader should aspire;

Why Do I Want To Quit Smoking? Robert's answer: I know smoking means big trouble for people with diabetes

Your answer _____ (Barrier, 2011 p142)

(Jackson and Tenderich, 2007) also uses a log which is described as a personal 'health account', with the analogy of balancing it in a similar way to your bank account, for example;

DON'T THINK YOU HAVE TO TACKLE EVERYTHING AT ONCE - The risk table is designed to help you and your doctor pinpoint which one or two things you need to focus on improving in the coming months (authors emphasis), (Jackson and Tenderich, 2007 p38)

On page 53 the reader is encouraged to fill in their own 'Diabetes Health Account';

Once you have these results, place them into the chart provided here. At this point the most important factor is not so much what your numbers are, but the fact that you now know them (Jackson and Tenderich, 2007 p53)

The author continues with encouragement;

Once you have filled out the chart, step back, and pat yourself on the back. You have several reasons to be proud. You have just made the first step towards living a long and healthy life with diabetes (Jackson and Tenderich, 2007 p36)

The text continues to explain about the lack of information people have with regard to their diabetes, stating that;

....fewer than 10% of Americans in the USDA survey had even a general idea of their last A1c results, and what it meant (Jackson and Tenderich, 2007 p37)

The authors use this quote to emphasise the need for the reader to review their 'balance sheet' and keep on top of their personal diabetes risk issues.

5.3.3 Motivational Elements

The theme of motivational elements involves; dissemination of information on diabetes and eye health, how the narrative encourages and supports the reader, and then motivates them to be empowered to take action and become more effective self-managers.

5.3.3.1 Dissemination of Information on Diabetes and Eye Health

Being in possession of all relevant information about personal eye health, and how crucial that information is to managing and controlling your diabetes is noted in (Jackson and Tenderich, 2007) and (Pfeifer and Levin, 2002). For example, (Pfeifer and Levin, 2002) state;

Ask your doctor what level of retinopathy you have and to send a letter to your diabetes care provider. It is not enough to be told, 'You have some eye changes, come back in a few months' (Pfeifer and Levin, 2002 p53)

Similar comments are made in (Jackson and Tenderich, 2007) regarding eye checks, the author states;

Most ophthalmologists don't provide you with detailed information about your exam results. Sometimes your eyes may show non-proliferative retinopathy, and yet you will be told that your eyes are okay (Jackson and Tenderich, 2007 p31), but continues by qualifying this statement with;

What the ophthalmologist means in such a case is that there were no changes requiring immediate attention (Jackson and Tenderich, 2007 p31).

(Jackson and Tenderich, 2007) draw further emphasis to the importance of the knowing the results of the eye checks, highlighting the message in a text box, with capital letters;

YOU ARE THE ONE WITH DIABETES – These numbers belong to you, you knowing them is your right, as well as critical to your health – just like the numbers in your bank account (authors emphasis), (Jackson and Tenderich, 2007 p34)

5.3.4 Offers of Encouragement

There are four books which offer encouragement to the person with diabetes; (ADA, 2011), (Barrier, 2011), (Fox and Kilvert, 2007) and (Jackson and Tenderich, 2007). (ADA, 2011) states;

Even if you already have some complications, it's not too late to slow the progression. Lowering your blood glucose levels can help improve most complications – even if they've already developed, (ADA, 2011 p229)

In (Barrier, 2011) this encouragement makes use of the case studies to highlight issues, for example;

Mama was worried about diabetes problemshe knew all about diabetes problems from her sister, Carla. My patient Michael worried about diabetes problems too...THE GOOD NEWS IS THAT YOU CAN PUT OFF OR PREVENT DIABETES PROBLEMS (Author's emphasis), (Barrier, 2011 p157-8)

Whilst, in (Cooke, 2010) Chapter 2 under the heading, '*Diabetes Management Principles*', the emphasis is placed on 'must', this suggests compliance and not concordance, and is supported with evidence later in the text;

People with diabetes must take responsibility for their day-to-day care (Cooke, 2010 p23)

In general, every percentage point drop in A1c blood test results – for example, from 8% to 7% - can reduce the risk of microvascular complications – eye, kidney, and nerve disease – by 40% (Cooke, 2010 p197)

Highlighted in these excerpts, the phrase '*can reduce*' is less certain than the term '*must*', as outcomes are more probabilistic; there are multiple possible outcomes, each having varying degrees of certainty or uncertainty of occurring depending on how compliant the patient has

been in adhering to recommendations on reducing their blood glucose levels. By quoting statistics from the key research and the Landmark studies, as discussed earlier, the person with diabetes is provided with justification to adhere to their treatment regime and be indirectly empowered to be compliant. This personal responsibility is also noted in (Jackson and Tenderich, 2007), but the empowerment is much more transparent;

YOU ARE THE ONE WITH DIABETES – These numbers belong to you (authors emphasis),
(Jackson and Tenderich, 2007 p34)

In (Jackson and Tenderich, 2007) the author offers lots of information about diabetes which encourages and motivates the person to become empowered, to act upon the recommendations for good management and ‘outlive’ their diabetes. For example, this is explained right at the beginning of the book in Part 1 (Getting a Handle on Your Health), Chapter 1, under the heading; ‘*You have Diabetes – What now?*’ The ten things that the reader should know about diabetes are listed, examples below are the points related to eye health;

- *Diabetes is not itself a leading cause of blindness, but poorly managed diabetes is a leading cause of this and other serious health problems.* Jackson and Tenderich, 2007 p5)
- *Thanks to an ever-wider range of effective approaches and treatments for diabetes, the long range health complications such as heart disease, stroke, amputations, eye and kidney problems can be successfully avoided.* (Jackson and Tenderich, 2007 p5)
- *Your doctor doesn’t treat your diabetes – you do.* (Jackson and Tenderich, 2007 p6)

The phrase ‘*poorly managed*’ is an important qualifier, as diabetes *per se* does not cause blindness, but those probabilistic characteristics of how well the person with diabetes self-manages their condition, is what can ultimately lead to blindness.

5.3.4.1 Empowerment

In (Jackson and Tenderich, 2007) this encouragement continues with more phrases emphasised in text boxes, and capital letters. In the following example one of the five essential tests is an eye exam;

The good news in a nutshell, within the text box it states;

THE BOTTOM LINE is that, with the results of five essential tests and all the treatment choices available today, you can live well with diabetes in a way that no previous generation ever could. (Jackson and Tenderich, 2007 p10)

The writing style of this book, is very empowering, and the narrative is particularly well written and readable; *'What are your goals? ...be realistic'* (Jackson and Tenderich, 2007 p10). Encouragement flows throughout the text, advising the reader to be 'realistic', implying not to be over ambitious as this could lead to failure;

Find your present 'Diabetes Location' by learning the results of five specific tests– or magic numbers- for living a long and healthy life with diabetes. That makes them pretty darn important, (Jackson and Tenderich, 2007 p16)

This encouragement and reassurance is a constant theme throughout the book, in Part 1, Chapter 2 (What to do first: Discover your five magic Numbers), the author uses metaphors;

This chapter will walk you through understanding each test and show you how to create a personalised table of results – 'Your Diabetes health Account' (Jackson and Tenderich, 2007 p17)

The reader is given a sense of comfort, 'hand holding' and support. This support and warning not to be overambitious and thus avoid failure is reiterated later in this chapter, again in a text box entitled; *'Pinpoint your focus'*, to highlight the importance of the message offered;

DON'T THINK YOU HAVE TO TACKLE EVERYTHING AT ONCE – The risk table is designed to help you and your doctor pinpoint which one or two things you need to focus on improving in the coming months (authors emphasis), (Jackson and Tenderich, 2007 p38)

The author's authority, and thus credibility in (Jackson and Tenderich, 2007) is represented by the use of phrases such as;

People often refer to experience with a disease as a battle,we think this reference is wholly inappropriate for diabetes – one of the few chronic diseases with which patients have the power to both feel physically well day to day and to live a long and healthy life (Jackson and Tenderich, 2007 p71)

This statement, along with others forms the reassuring and encouraging vane, which is, as mentioned, very prominent in this book. In the preface the author explains that she is diabetic herself, giving the reader the sense that, if she can do it, so can I, which is also empowering.

5.3.5 Summary of the Thematic Analysis

Three main themes were established; information on eye health for the reader, formatting and style of the self-help texts, and the motivational and inspirational elements of the self-help texts conveyed to the reader. These main themes were then sub-divided;

Information on Eye Health: (1) Landmark Studies, (2) Recommendations on Eye Check, (3) Explanation of the Signs and Symptoms of Diabetic Eye Disease, (4) Advice on Diabetic Eye Disease, (5) Smoking and Diabetic Eye Disease, and (6) Treatment of Diabetic Eye Disease and Low Vision.

The reader is referred to the findings of the landmark studies and research (UKPDS, 1998); (DCCT, 1993), as the authors of the texts aim to provide justification for the management strategy they advocate, and which the person with diabetes should be expected to find empowering. Most of the information on eye health and diabetic eye disease and the risk factors was informative, but somewhat inconsistent and contradictory, with the signs and symptoms of diabetic eye disease being elusive. This is considered dangerous, because serious eye problems could be misinterpreted by the reader resulting in grave consequences and sight loss.

Formatting and Style: (1) Question and Answer Format, (2) Case Studies, and (3) Recording Personal Diabetes Data.

The formatting and style of the texts assist in strategies employed by many self-help texts to validate the author's authoritative stance as an 'expert' in their field, and as such, implying that their instruction should be complied with. However, by employing these strategies, and presenting the information in this prescriptive manor, sole responsibility for self-care is placed on the person with diabetes. The author is not accountable, and the issues and limitations of the compliance model are perpetuated.

Motivational Elements: (1) Dissemination of Information on Diabetes and Eye Health, (2) Offer of Encouragement, and (3) Empowerment.

The motivational elements presented in the texts exist but were found to be rather shallow, upon inspection the texts using the thematic analysis the message they convey appear to be motivational and inspiring.

5.4 Findings of the Foucauldian Discourse Analysis

Foucauldian discourse analysis of the themes highlighted in this book review on diabetes self-help texts will determine how; the reader, the person with diabetes, their care providers, the professionals, the experts and the authors all experience self-help through discourse. These discourses are those of; compliance and concordance, individualism and collectivism, patient and expert, illness and relative healthy, and model patients or deviant patients. The consequences for T2D management and eye health relating to diabetes self-care will be determined with regard to how they are constructed within the self-help texts.

5.4.1 Compliant and Concordant Discourses

The subject position of the authors and contributors to the self-help texts are those of experts in diabetes management and the reader takes the position of the patient, within the biomedical compliant discourse. It is noteworthy that the title of the book, '*Diabetes (When Your Doctor Says...)*', (Cooke, 2010) has a dominant compliant discourse connotation, which positions the patient as passive. It is somewhat alarming that this book implies, from its title, that it is able to interpret what the reader's doctor is saying, without possibly being able to know.

This prescriptive stance is noted in other texts with the biomedical discourses of; disease/diagnosis and relative health normality; (Barrier, 2011), (Fox and Kilvert, 2007) (Jackson and Tenderich, 2007) and (Pfeifer and Levin, 2002) although they were found to be less authoritative than in (Cooke, 2010), who uses the term '*must*'.

People with diabetes must take responsibility for their day-to-day care (Cooke, 2010 p23)

Within the concordance discourse the person with diabetes takes shared responsibility along with their care provider for their diabetes management. This shared responsibility of the concordance model is demonstrated by a more caring approach later in this text with the use of the phrase '*be sure*';

Retina damage happens slowly... At first, you may not have any loss of sight from these changes. Be sure to have a dilated eye exam once a year if your sight seems fine, (Cooke, 2010 p211)

Within the compliant biomedical discourses clinical interactions should not be viewed as mere opportunities to reinforce instructions to patients around treatment; they should be seen as a space where the expertise of patients and health professionals can be pooled to arrive at mutually agreed goals, (Bissell et al., 2004). Flow of expert information occurs in both directions; patients rely on healthcare professionals for expert information, and patients provide expert self-information to their providers, (Golin et al., 1996).

With regard to the discourses of compliance and concordance there is notable variability within the same section of text, for example, the person with diabetes is encouraged to discuss their diabetes management with their health care provider, within a concordant discourse;

If you are having trouble with your vision, talk with your health care team or eye doctor (US. Department of Health and Human Services, 2007 p43), and;

If you have diabetic eye disease, talk with your health care provider about the kind of physical activity that is best for you, (US. Department of Health and Human Services, 2007 p46)

Then conversely, within the same chapter on eye problems, Chapter 5, (Eye Problems, p43-46) the reader is told that they 'need' and 'should' have a dilated eye exam, within a complaint discourse;

Even if you are seeing fine, you need regular, complete dilated eye exams to protect your sight... you should have your eyes dilated and examined at least once a year, (US. Department of Health and Human Services, 2007 p45)

However, some texts do attempt to give a concordant message;

DON'T THINK YOU HAVE TO TACKLE EVERYTHING AT ONCE – The risk table is designed to help you and your doctor pinpoint which one or two things you need to focus on

improving in the coming months” (authors emphasis), (Jackson and Tenderich, 2007 p38)

The phrase, *‘you and your doctor’* is concordant terminology and by the author emphasizing that there isn’t an imperative to *‘have to’* tackle everything at once this implies a choice on behalf of the patient, fitting with the concordance model.

With regard to the FDA those in a position of authority are seen as ‘experts,’ who speak the ‘truth’. This creates a paradox within the concordance model as traditionally the ‘expert’ is considered to be the books author, the researcher or the professional contributor to the book. Truth is something which is supported by a whole range of practices and institutions, including; government departments, publishing houses, patient organizations and research institutions. All these institutions work to exclude statements which they characterise as ‘false’ and keep in circulation those statements which they characterize as ‘true’.

Notwithstanding, the self-help texts in this study are considered true when given authority by accreditation from government departments, publishing houses, and diabetes support organizations. For example; Diabetes UK supports; Type 2 Diabetes in Adults of all Ages (Fox and Hanas, 2008) and Type 2 Diabetes Answers at Your Fingertips (Fox and Kilvert, 2007), The American Diabetes Association promotes; American Diabetes Association Complete Guide to Diabetes (ADA, 2011), Type 2 Diabetes for Beginners (Barrier, 2011) and The Uncomplicated Guide to Diabetes Complications (Pfeifer and Levin, 2002), whilst the American National Institute of Diabetes and Digestive and Kidney Disease (NIDDK) publishes; Take Charge of Your Diabetes (US. Department of Health and Human Services, 2007) and Prevent Diabetes Problems: Keep Your Eyes Healthy (US. Department of Health and Human Services, undated).

To explain this with regard to the self-help texts reviewed, an example is taken from (Mills, 2003), ‘academic journals have editorial boards and referees who are responsible for evaluating whether articles sent to them “fit in” with the disciplinary rules for discussing a particular subject, and what it is possible to say within that discipline. They reject those articles that do not,’ (Mills, 2003 p60). It is in these academic journals that research data from the key studies discussed earlier is published, and which forms the basis of all recommendations made on diabetes self-management, to which these self-help books prescribe.

In addition, it is noted that The Marlowe Diabetes Library, which publishes (Jackson and Tenderich, 2007) lists their other publications in the appendix, which are; '*Titles available from on-line and bricks-and-mortar retailers nationally*', (Jackson and Tenderich, 2007 p-Appendix), thus, keeping this 'expert' knowledge in circulation. This validates the 'expert' position of the text, whilst at the same time excluding from being chosen other books which do not have this accredited status. Whereby, other just as informative, and perhaps superior self-help texts have been prevented from being read, these alternative versions of diabetes self-care are eliminated from becoming knowledge. The emphasis of diabetes management of T2D is clinical, with strict control over blood glucose levels, in response to key research and the landmark studies (UKPSD 1998); (DCCT, 1993).

5.4.2 Discourse of Individual Responsibility

The discourse of individual agency is constructed in the texts, indicating personal responsibility and ownership of one's diabetes, liberating the reader to deal with the responsibility of having diabetes and enabling self-management. However, this suggestion of individualism focuses on the consumer; where it can be considered that the patients' health care team are service providers, which fundamentally removes responsibility from the person with diabetes.

Considering the text by (Jackson and Tenderich, 2007), individual agency for T2D is repeatedly reflected in phrases and passages from the book;

You have Diabetes – What now? The author lists things that the reader should know about diabetes, one being; *Your doctor doesn't treat your diabetes – you do*, (Jackson and Tenderich, 2007 p6)

YOU ARE THE ONE WITH DIABETES – These numbers belong to you (authors emphasis), (Jackson and Tenderich, 2007 p34)

This indicates for the reader to take responsibility and ownership of their diabetes. The phrases, '*you do*' and '*You are the one*' creates a position for the person with diabetes as, them against the disease, within the individual citizen discourse, rather than the social citizen discourse. Thus, liberating the reader to deal with the responsibility of having diabetes and enabling self-management.

In addition, the phrase; *'You are the one'*, identifies the individual with diabetes as being at the centre of their disease, serving to isolate the individual to some extent by implying that they may be the only one with diabetes. The 'numbers' referred to in this text are representative of the level of their diabetic control, and thus indicate the potential for adverse effects or complications of the disease. Notwithstanding, the person with diabetes can gain control, by owning the 'numbers' and manipulating the figures, when they follow the advice recommended in this self-help texts. Having created more positive and beneficial outcomes by reducing the risk of diabetes complications.

The excerpt continues to state;

You knowing them is your right, as well as critical to your health – just like the numbers in your bank account, (Jackson and Tenderich, 2007 p34)

This analogy to the individual's bank account can be favourable depending on the balance in their account. Keeping a check on the person's health is likened to keeping an eye on their bank balance, as a prudent way of managing finances or diabetes. It is generally accepted that it is our own responsibility to monitor finances, so presumably the person with diabetes should similarly accept responsibility for these numbers and manage their disease. Furthermore, we not only have the right to know the numbers in our bank accounts, but it is of course something we have some degree of control over, either by spending more or by being thrifty. As such, the person with diabetes has the right to know the status of their health, by knowing the value of their 'diabetes numbers' and making the decision to control them better. The word *'critical'* is an extreme case formulation and serves to strengthen the statement made by the author that the reader, in knowing their own position with regard to diabetes control is of paramount importance.

The author then continues with encouragement;

Once you have filled out the chart, step back, and pat yourself on the back. You have several reasons to be proud. You have just made the first step towards living a long and healthy life with diabetes, (Jackson and Tenderich, 2007 p36)

Here journey metaphors are used to ask the patient to reflect on the values, by *'stepping back'* and give themselves credit for beginning the journey to diabetes self-management. The phrase, *'pat yourself on the back'*, encourages the reader to be *'proud'*, for several reasons it does not however actually define in the text. Though obviously a positive

statement, it positions the individual as being potentially required to obtain greater knowledge of their diabetes. The text continues by commending the reader with ‘congratulations’;

This is true no matter what your results – because the amazing fact is that most people with diabetes do not know what their numbers are, or what they mean. So congratulations, whatever your numbers are, you can feel good about the initial accomplishment of knowing them, (Jackson and Tenderich, 2007 p36)

The reader is told they should ‘feel good’, this phrase is used to instil a sense of well-being and is again used to encourage them, which can be empowering. However, in these excerpt empowerment is somewhat illusive; the reader is encouraged to be ‘proud’, though of what is not explicitly stated, yet they are given explicit permission to ‘feel good’, but of what value there is in feeling good is rendered doubtful. The numbers are representative of the level of diabetes control and fundamental to managing the disease. The author says that, by just knowing them is ‘the first step towards living a long and healthy life’; this is obviously not true, as managing them is actually the first step. The ‘initial accomplishment of knowing them’, is actually very restrictive. In the analysis of this excerpt, consideration is given to whether people with diabetes do not actually know their number, or perhaps they would rather not know them, or what they mean. In possessing this information people with diabetes are positioned into possible action, and thus compelled to take responsibility.

The suggestion of the individual against the disease focuses on the consumer; where it can be considered that; the patients doctor, diabetic nurse, chiropodist or dietician are service providers, this fundamentally it removes responsibility from the person with diabetes. The use of the phrase ‘what now’ indicates a possible sense of bewilderment or feeling of being lost. But also it serves to link other journey metaphors which occur throughout the text, the ‘what now’ alludes to the being the beginning of the journey to effective diabetes self-management and reduction of the risk of diabetes complication.

The contradiction with regard to the patient knowing the value of their vital numbers and just possessing them is again noted later in the text, the author states;

Once you have these results, place them into the chart provided here. At this point the most important factor is not so much what your numbers are, but the fact that you now know them (Jackson and Tenderich, 2007 p53)

From a health care point of view the 'numbers' matter greatly. Yet the author plays down knowing the value of these figures saying, just possessing them is considered sufficient having earlier emphasised the significance of knowing what they actually are. The author is facilitating the individual to record information which may be empowering; by the person with diabetes knowing their numbers it is a starting point at which they are able to change them. This phrase; *'At this point the most important factor is not so much what your numbers are, but the fact that you know them'*, alludes to the popular psychological idea that by a person admitting they have a problem, it is a step to finding a solution to that problem. The use of the word *'fact'* in this excerpt strongly suggests that by the reader possessing the numbers, there is truth or reality in knowing them. So then, the value of these number does indeed matter greatly, even though the reader is told it is not *'what your number are'* which is important. The significance of actually knowing the values of these numbers is further supported with the term *'not so much'* in this phrase.

It is noted that in the excerpts which refer to the *'magic number'*, journey metaphors, such as *'diabetes location'* and *'walk you through'*, are frequently used in addition to extreme case formulations like, *'pretty darn important'* and *'life-saving'*, for example;

Find your present 'Diabetes Location' by learning the results of five specific tests– or magic numbers- for living a long and healthy life with diabetes. That makes them pretty darn important, (Jackson and Tenderich, 2007 p16)

The phrase *'pretty darn important'* is also quite colloquial, and is perhaps used by the author to create a scenario where the reader, being a person who is concerned about their diabetes health should also be greatly concerned about their *'magic number'* or values of their key indicators for good diabetes control. With regard to the use of the phrase *'magic numbers'* the author is alluding to these values as perhaps being less scary, and so not as vital as she has previously suggested they are. (Rimke, 2000) states, 'Healthy selves, according to self-help authors, are the result of a magic that can be located, harnessed and exercised only once the self-changer acknowledges its 'divine' presence, (Rimke, 2000 p64).

Perhaps the speciality of the *'magic numbers'* in the self-help text illustrates that for people with T2D to be healthy individuals, they must accept their diabetes. But in doing so, people with diabetes do need to know the value of their numbers, as they are the key to successful diabetes management. When the author uses the three elements of; *'magic numbers'*, extreme case formulations, and journey metaphors together, it perhaps serves to emphasis to the reader that even though these essential health indicators are made somewhat less

scary, (by calling them *'magic numbers'*), they are vitally important, (by the use of extreme case formulations). The journey metaphors serve to establish that, even though their diabetes health indicators may not be the optimum values desired for good control, they can be altered and improved in the process or 'journey' to self-help advocated in this text.

Journey metaphors are a narrative tradition which has historical roots to present day connotations; spanning ancient Greek literature to modern 'road movies' like *Thelma and Louise* (Scott, 1991). The protagonists embark on a process of self-discovery, with a series of challenges and complications along the way. Journey metaphors are commonly used in texts relating to chronic illness where it is inferred that people are expected to learn as they continue to attempt some degree of self-management. The analogy being that a journey has milestones along the way, as does a chronic condition where complications may occur. This then positions the person with the chronic disease of diabetes to actively manage their condition, by making the journey and taking advice along the way, so as not to take a wrong turning.

The journey metaphors in this text are typical of self-help literature 'hand holding', where the reader is guided, in a step-by-step fashion, to make the task seem less daunting; advocating self-discipline, restraint, and responsibility. This denotes that the readers' self-management and personal diabetes health indicators can be altered and improved in the 'journey' to self-help encouraged by these texts. In the classic by M Scott Peck, (*The Road Less Travelled: A New Psychology of Love, Traditional Values and Spiritual Growth*, 1978) Peck makes the statement; 'Life is difficult' (Peck, 1978 p13), arguing that life was never meant to be easy, and is essentially a series of problems which can either be solved or ignored. Peck considers discipline to be one of the basic tools required to solve life's problems, and instructs his reader to recognise, accept and revel their own 'immense personal power' (Peck, 1978 p43).

In (Jackson and Tenderich, 2007) the authors capitalise on the readers 'personal power' discussed above to better manage their diabetes;

This chapter will walk you through understanding each test and show you how to create a personalised table of results. We'll call this table 'Your Diabetes Health Account', because it clearly shows you which areas are your health 'assets' and which are your 'debts'....Although very simple, the table will track your most vital, life-saving information, (Jackson and Tenderich, 2007 p17)

The terms 'assets' and 'debts' are again banking metaphors, which are used to perhaps make the readers 'Diabetic Health Accounts' seem more ordinary and every-day, and so potentially more controllable.

5.4.3 Discourse of Camaraderie

Converse to the individualist discourse discussed above, a discourse of camaraderie can be identified, where the person with diabetes can be defined as perhaps a member of a 'club', where others in society, either known directly to them or not, have the same disease, so giving an amity;

Mama was worried about diabetes problems....she knew all about diabetes problems from her sister, Carla. My patient Michael worried about diabetes problems too. He knew about the problems his grandparents had from diabetes. Lots of people with diabetes feel this way....THE GOOD NEWS IS THAT YOU CAN PUT OFF OR PREVENT DIABETES PROBLEMS (Author's emphasis), (Barrier, 2011 p157-8)

In this excerpt, the implication for the person with diabetes is that they should be reassured to know other people in the same situation also worry; 'Mama was worried', the authors patient, 'Michael worried'. Concern over diabetes complications is to be expected; 'Lots of people with diabetes feel this way', but the 'good news' is, these problems can be prevented.

Although the author reassures the person with diabetes about their worries, she is perhaps also suggesting that they should to be concerned about the complications of diabetes. She says her mother was 'worried about diabetes problems' because 'she knew all about diabetes problems', as did her patient. They worried because they knew about diabetes complication, and implies that now the reader also knows, they too should worry. This text constrains the reader into the bio-medical discourse of illness from the position of being concerned about the possible complications of their disease.

In addition, in this excerpt the author initially refers to the people she knows in the past tense; 'Mama was worried' and 'Michael worried' then translates the reference into the present tense; 'Lots of people with diabetes feel this way', and to a future tense; 'you can put off or prevent diabetes problems'. By doing this, the author is emphasising that it is indeed 'good news' that these complications can be averted with lifestyles changes. This is representative of a 'journey', where the tense change, from past to present and into the

future suggests a passage to a healthier, longer, less complicated life, free from diabetic problems.

Notwithstanding with regard to the camaraderie discourse discussed, this tense transposition serves to create variation in the discourse and individualise the reader. Initially reference is made to people with diabetes unknown to the reader, implying diabetes problems may be of no concern to them. This then changes to '*Lots of people*' which could include the reader, and finally the change to a future tense, creating sole focus on the reader, to empower them. The author suggests that the reader can avoid complications, by following the advice offered in her book.

(Foucault, 1981) states that; 'any system of education is a political way of maintaining or modifying the appropriation of discourses, along with the knowledge and powers which they carry' (Foucault, 1981 p64). Self-help discourses are significant in advanced liberal democratic society, contributing to the formation of the self, producing citizens who are governable, predictable, calculable, classifiable, responsible, self-regulating and self-determined (Philip, 2009). (Rimke, 2000) and (Hazelden, 2003) have investigated the relationship between self-help and liberal government and argue that; self-help literature is the logical extension of cultural changes towards 'psy-disciplines', which bring the ideals and aspirations of individuals into alignment with wider political objectives. Foucault identified two major types of 'technology' relevant to government, which are 'technologies of power', the action that is applied over others and 'technologies of the self', the actions that individuals apply upon themselves, (Foucault, 1994 p225).

(Philip, 2009) explores self-help books with regard to 'technologies of self' explaining how the authors use devices to present a rational basis upon which to establish their self-help techniques. Examples of these devices are taken from (Jackson and Tenderich, 2007), which suggests a log to record blood glucose levels and other test results;

shows you how to create a personalised table of results – Your Diabetes health Account (Jackson and Tenderich, 2007 p17)

All the self-help texts studied represent T2D as a controllable, treatable illness;

with the results of five essential tests and all the treatment choices available today, you can live well with diabetes in a way that no previous generation ever could, (Jackson and Tenderich, 2007 p10)

Authors use their expertise to control what the key terms mean, creating contrasts between the; normal/deviant, realistic/unrealistic, rational/irrational, thought/feeling and objective/subjective. In these dualities, the first component is depicted as superior, further establishing legitimacy, (Philip, 2009). From (Fox and Kilvert, 2007) the patient asks for example;

I have had blurred vision for a few weeks and have just been found to have diabetes. Why has this affected my vision? The author replies; Blurred vision is usually a temporary change... As the diabetes comes under control the lens of the eye returns to normal (Fox and Kilvert, 2007 p22)

This demonstrates the shift from illness to relative good health, as obviously being more desirable for the person with diabetes.

With regard to society, and liberal modes of governance, the life of the individual is a private matter, free from state intervention. Citizens are encouraged to be the individual they wish to be as they are offered the opportunity for choice, autonomy and freedom. More specifically, governmental power is focused on 'the conduct of conduct', (Foucault, 1988), which is according to (Burchell et al., 1991), a generalised, widely dispersed activity that shapes, guides or affects the total lives of individuals. Thus, 'governmentality' defines all strategies and regimes which attempt to direct the practices of 'free' subjects in their relations to each other, (Foucault, 1988). Foucault is interested in how certain types of knowledge are used to 'rationalise' particular governmental practices. From this perspective, rationality is not a form of objective knowledge that simply represents reality, it is part of government itself, which creates a discursive domain in which exercising power is rational (Lemke, 2002).

(Rose, 1996) identified three problems of liberal governmentality; rationality, privacy and autonomy, and argued that in guarding against over-governing, liberalism is legitimised. Foucault was concerned with over governing and suggested that the legitimacy of government should always be questioned, stating; 'one always governs too much', (Foucault, 1994 p74). The challenge then for self-help is that of privacy and autonomy within liberal society. (Rose, 1996) further considered that liberalism depends on the creation of 'private' spaces such as the family, as they define what exists beyond the formal powers of the state. However, (Philip, 2009) claims that the problem for autonomy is ensuring that subjects act virtuously in private, as a threat to personal autonomy would be to run the risk of governing too much, creating a rather circular contention.

The dilemma for autonomy in self-help is represented in the following extract from (Barrier, 2011);

do what your health care team tells you. I wouldn't be blind if I had taken care of my diabetes. I wish I had a second chance. I'd work with my diabetes team and take care of my diabetes (Barrier, 2011 p159)

This excerpt serves to ensure the person with diabetes knows the consequences of deviant behaviour, especially in the private domain. Virtuous behaviour is ensured and autonomy maintained, as the onus is on the individual to self-govern. The excerpt above also demonstrates another device discussed in (Philip, 2009) where authors use quotations from reformed or regretful procrastinators, which is demonstrated with the phrase; '*I wish I had a second chance*', this suggests that the self-help methods revealed in the text have clinically proven results and thus validates the book itself.

Fundamental responsibility and unity with others is actively discouraged by the self-help text. Individual citizens are encouraged to become socially responsible to themselves, rather than being socially orientated in society, creating a paradox, where individual selves are produced, whilst individuality is constrained. Ayn Rand exploits this paradox with her version of extreme individualism, stating that the smallest minority on earth is the individual and those who deny the individual their rights, cannot claim to be defenders of minorities (Den Uyl and Rasmussen, 1987). An example of this paradox is noted in (Jackson and Tenderich, 2007);

With all the treatment choices available today, you can live well with diabetes, (Jackson and Tenderich, 2007 p10)

The early detection of eye problems allows you to achieve the maximum benefit from the many highly effective treatments available today, (Jackson and Tenderich, 2007 p29)

YOU ARE THE ONE WITH DIABETES (Authors emphasis), (Jackson and Tenderich, 2007 p34)

This produces the individual self with the word '*you*', but at the same time the individual is constrained by the proviso that, relative health is only obtainable because of the treatment

options which are available. Conversely though, (Philip, 2009) argues that self-help books can be read as a technology of liberal government, and quotes (Rose, 1996) as an example. (Rose, 1996) considers self-help provides a means for unifying how individuals conduct themselves as both 'subjects of freedom and subjects of society', (Rose, 1996 p98), thus overcoming the paradox. The person with diabetes is liberated from the constraint, as the responsibility for diabetes care is transferred from the self, to the health care professional. It is the professional who are required to detect any problems early enough for the patient to '*achieve the maximum benefit*'.

Further to this, (Rimke, 2000) explains this paradoxical enigma, stating that although the moral lesson in self-help texts is obvious, 'psychical and/or spiritual poverty will result from a lack of self-governance', (Rimke, 2000 p65). The excerpt from (Jackson and Tenderich, 2007) illustrates what is meant in relation to the diabetes self-help texts;

Frustration saps your positive energy, making you feel less able to care for yourself. If you think of your diabetes as a battle, you'll always be stuck in a miserable war. Make peace with your diabetes and you'll be at peace with yourself, (Jackson and Tenderich, 2007 p71)

This liberation/regulation paradox urges subjects to; 'sculpt a meaningful life without addressing or questioning the horizon of social relations and the contexts of social power', (Rimke, 2000 p65). Where self-help literature claims that, a greater pledge to personal and private needs leads to liberation and self-awareness, whilst at the same time it proclaims the rewards of self-regulation. With regard to the self, one needs knowledge or information about the self for purposes of assessment and judgement. The self-help texts provide this in the form of writing activities, questionnaires and sentence completions, for example;

Making healthy food choices – this week I'll work on _____ (Barrier, 2011 p30)

It's true that people with diabetes have a higher risk of heart, kidney and nerve damage than other people. However, you can take active, positive steps to reduce the risk of these problems, (ADA, 2011 p227)

In (ADA, 2011), patients are encouraged to record their test results in the, '*Diabetes Care Schedule*', for every visit, every 3 months and every year, (ADA, 2011 p327).

5.4.4 Medical Discourses

The medical discourses of disease/diagnosis and illness/relative health are particularly notable in (Fox and Kilvert, 2007), the patient asks;

I have had blurred vision for a few weeks and have just been found to have diabetes. Why has this affected my vision? The author replies;
Blurred vision is usually a temporary change... As the diabetes comes under control the lens of the eye returns to normal (Fox and Kilvert, 2007 p22)

This extract emphasises that changes in vision are temporary when diabetes is poorly managed, and normality is restored once the patient follows the recommended advice. The illness discourse of disease/diagnosis is transformed to one of relative health and normality, though with certain key lifestyle modifications and restrictions.

This disease/diagnosis discourse is further explored in the same text when another patient asks the question;

I have had diabetes for 20 years and seem to be quite well. Following my last eye photographs, I had a letter to say that I had some mild diabetic changes and would be referred to an eye specialist. Am I about to go blind? The author replies with;
There is no need for alarm. It would be surprising if there were no changes in your eyes after 20 years of diabetes. It is important to see an eye specialist at an early stage so that if treatment is required, it can be given before your vision is affected, (Fox and Kilvert, 2007 p225)

The patient's question of; '*Am I going to go blind?*' is not answered by the author, who replies with; '*There is no need for alarm*'. This could be interpreted as empathy on behalf of the author responding to the patient's possible panic, or infers that perhaps the person with diabetes should be alarmed. As panic is a necessary response to losing vision, particularly given that the author continues to advise that; '*it is important to see an eye specialist...early*'. The author then says; '*It would be surprising if there were no changes...after 20 years*', this phrase suggests that diabetic eye problems are normal, and as such, conveys a rather contradictory message. If the person with diabetes says that they have good control; '*seems to be quite well*', because they have perhaps followed recommended advice. Why then, one would ask is it normal to have some mild diabetic changes? Notwithstanding, how is the

patient able to assimilate this contradiction and continue to be adherent to their care regime, which is portrayed as not beneficial?

With regard to research into medication regimes, (Chatterjee, 2006) found that although a high percentage of patients believed that treatment would control their diabetes, most understood 'treatment' as being insulin therapy only, hence concluding that patient knowledge seemed to be lacking. (Al-Qazaz et al., 2011) proposed that patients are aware of the seriousness of diabetes, but did not adhere to their treatment regimes, having transposed their own lack of awareness of information to being the sole responsibility of their healthcare provider. (Al-Qazaz et al., 2011) also noted that participants in their study manipulated their medication dose according to the beliefs they had about their own body's needs, so took more medication to counter the effects of having raised blood sugar levels, as a consequence of poor diet management. Thus providing themselves with an excuse for lack of self-discipline in their diabetes management.

By the person with diabetes selecting a self-help text they have taken a step towards accepting their condition. However, according to self-help rhetoric, serious and committed self-helpers, first need to exercise honesty with themselves, to begin to initiate real self-transformation, (Prochaska et al., 2007); (Covey, 1989); (Peck, 1978). This highlights the controlling and regulatory mechanisms of self-discipline, which are supported by techniques based on self-monitoring. The author emphasises that by denying effective self-management, the person's medication will not be compensatory for their deviant behaviour. (Jackson and Tenderich, 2007) also warn of this lack of self-discipline;

What's also important is this: You cannot just have any unhealthy lifestyle you want and assume that your medication will 'take care of' the diabetes, (Jackson and Tenderich, 2007 p10)

With regard to eye health in (Jackson and Tenderich, 2007), the following excerpts state;

In contrast to the other tests, there are no numerical results from an eye exam, no 'magic number'....Instead there are different grades of retinopathy, ranging from none to background to non-proliferative to pre-proliferative and further stages (Jackson and Tenderich, 2007 p30)

THESE NUMBERS BELONG TO YOU, you knowing them is your right, as well as critical to your health (Authors emphasis) (Jackson and Tenderich, 2007 p34)

In these excerpts (Jackson and Tenderich, 2007) imply that there is nothing special about the results of an eye exam, there is '*no magic number*'. To compensate for this admission, it is noted throughout the text that there is explanation and reiteration of the importance of having accurate information from the healthcare professional on the outcome of their eye exam. In the next excerpt the author imagines a confrontation with the ophthalmologist in gaining personal information on eye health;

Ask your doctor what level of retinopathy you have and to send a letter to your diabetes care provider. It is not enough to be told, 'You have some eye changes, come back in a few months' (Jackson and Tenderich, 2007 p53)

This excerpt suggests that if the patient accepts being told they have '*some eye changes*', which the author has pointed out to be inadequate, then they cannot be taking full responsibility for their eye health and ultimately they risk being ineffective diabetes self-managers. Notable also is that this quotation uses the word, 'fight' which is a direct contradiction to the battle reference made in the following extract;

People often refer to experience with a disease as a battle ... we think this reference is wholly inappropriate for diabetes – one of the few chronic diseases with which patients have the power to both feel physically well day to day and to live a long and healthy life, (Jackson and Tenderich, 2007 p71)

With regard to authentication of the texts, the authors use various strategies, for example; in the following excerpt reference to the key diabetes studies are noted;

Whilst we're in the midst of explaining the medical details, this is a good opportunity to point out that we're not making this stuff up. Over the last fifteen years, multiple, large, prospective, randomised, controlled, blinded clinical studies have explored the impact of these five tests and future diabetes related complications, (Jackson and Tenderich, 2007 p84)

The reference to the landmark studies in this excerpt highlights their importance with the phrase, '*we're in the midst*', and also indicating that perhaps the medical details are confusing, but the reader will be guided by the author. In addition, this serves to disclaim any personal stake by the authors in explaining the medical details and proclaims mainstream scientific knowledge, their claims are positioned as 'scientifically valid' with the hyperbolic

disclaimer that *'we're not making it up'*. Where by suggesting that, what they say is not fictional, in contrast with the superfluous use of adjectives to describe the studies, *'multiple'*, *'large'*, *'prospective'*, *'randomised'*, *'controlled'* and *'blinded'*.

Indeed, the title of the book; *'Know Your Numbers, Outlive Your Diabetes'*, suggests that the reader could, by following the advice of the texts and knowing their numbers, live a healthier and thus longer life. Obviously they are not able to overcome their diabetes and be cured, as diabetes is a chronic life-long condition, so *'outliving'* it is the best alternative. But, in saying that the person can *'outlive'* their diabetes, it is perhaps implied by the author that they would then have the opportunity to die of something else instead and one would expect that to be old age, the same as anyone else who does not have diabetes.

The power reference in the following extract is perhaps referring to empowerment;

People often refer to experience with a disease as a battle ...we think this reference is wholly inappropriate for diabetes – diabetes is one of the few chronic diseases with which patients have the power to both feel physically well day to day and to live a long and healthy life. (Jackson and Tenderich, 2007 p71)

The person with diabetes is apprised that controlling diabetes is not a war to be fought or won on a battlefield; it should be controlled, managed and regulated within the social context of a civil society. Management of diabetes is concerned with policing the self-managers, which is both a proactive and reactive process. The person with diabetes is liberated to self-manage, yet is also restrained by following the self-care recommendations for diabetes advocated in the texts. Though according to Foucault's warning as discussed earlier, one must be cautious of governing too much (Foucault, 1994).

The following excerpt could be read with two different connotations;

*The good news in a nutshell, and within a text box which it states;
THE BOTTOM LINE IS THAT, with the results of five essential tests and all the treatment choices available today, you can live well with diabetes in a way that no previous generation ever could, (Jackson and Tenderich, 2007 p10)*

The first refers to the banking metaphors which run throughout this text, as *'the bottom line'* is the last line of an audit which shows profit or loss. The second is that of a decisive point, which is further highlighted in this excerpt with the author's emphasis and the preceding

comment; *'in a nutshell'*, which serves to sum up the 'good news'. Further to this the reader is asked; *'What are your goals?'* but they are warned to be *'realistic'*. This additional comment whilst encouraging the patient ensures they are not being over ambitious with regard to their diabetes management. The 'good news' is that the person with diabetes is able to be a successful self-manager by benefiting from the advances in modern technology.

Validation strategies used by the self-help authors are 'get out clauses'; the patient is encouraged in their diabetes management, whilst also being cautioned against over ambitiousness, as this excerpt demonstrates;

DON'T THINK YOU HAVE TO TACKLE EVERYTHING AT ONCE (Authors emphasis), (Jackson and Tenderich, 2007 p38)

If the management strategies set out by the author is not successful, it absolves them from accountability. The onus is on the person with diabetes to approach self-management responsibly, as they have been warned of failure by the 'expert' if they are not realistic and do not act conscientiously. This also adds vindication to the validity of the author's self-management style.

5.5 Discussion of the Foucauldian Discourse Analysis

There was a considerable variability and inconsistency noted in the texts, particularly within the compliance/concordance discourses, indicating limitations of the concordance model, as it is difficult within the confines of the self-help texts to maintain a more liberal-humanist discourse. FDA investigated this discourse variability and the strategies employed by the texts to motivationally support the reader beyond the mere acquisition of knowledge; to empower the person with diabetes to make sustainable and permanent life-style changes to their self-care regimes. The socio-political discourses lean towards individualism and concordance, where the social citizen is positioned with the socio-political considerations of self and 'governmentality'. Whilst the bio-medical discourse of patient and expert, illness and relative health tend towards compliance, where authoritarian and restrictive practices are advocated.

With regard to the research question proposed in this review; 'Can I See the Way?' The path to effective self-management and the reduction or elimination of diabetic eye problems, and blindness, is perhaps not as obvious as it would initially seem. The willing self-helpers, those

'good citizens', who wish to help themselves within the concordance ethos discussed. By initially choosing a self-help text people with diabetes are immediately constrained by the text itself into complying with the particular self-help strategy into which they have bought. The authors of the book are positioned in a place of authority as 'experts' and use the various strategies discussed to authenticate their position. These 'responsible' citizens, who purchase and read the self-help books, are willing to embrace that responsibility. However, if they are not successful in managing the disease, they can justify their absolution from responsibility by claiming to have done what they were instructed to do, but it didn't work. Responsibility is then negated from the reader to the author or contributor of the book.

It is noted throughout the texts with regard to the concordance discourse to which they endeavour, there is variability within the compliance/concordance discourse. This slippage indicates limitations in the concordance model. Foucault's interest in the analysis of discourse is the way that it is regulated, he states that; 'in every society the production of discourse is at once controlled, selected, organised and redistributed by a certain number of procedures whose role is to ward off its powers and dangers, to gain mastery over its chance events, to evade its ponderous, formidable materiality' (Foucault, 1981 p52). It is proposed that variability exists because health care professionals are aware of the proven benefits of particular care practices demonstrated in the landmark studies (UKPDS, 1998); (DCCT, 1993). All modern diabetes care and management is based on the various care systems, procedures, methods and treatments developed from this research, and have been proven to reduce the risk of diabetic eye disease and other complications of diabetes. The authors of the texts are therefore constrained into an authoritarian approach, by insisting that patients comply with these care regimes. Patients should feel encouraged, energised and inspired within the concordant discourse enabling them to be motivated and galvanized to become empowered. Yet what actually transpires is the possibility of disappointment, despondency and frustration within this dominant compliant discourse, thus creating ineffective self-managers, as they become disenfranchised.

(Foucault, 1972), in 'The Archaeology of Knowledge', asserts that discourse determines the reality that we perceive, and is associated with relations of power, of which it has both the means to oppress and the means to produce. A fundamental dilemma for liberal governmentality is thus created; citizens are encouraged to be socially responsible, and have personal governance. Foucault states in his work entitled 'Prison Talk' that 'it is not possible for power to be exerted without knowledge and it is impossible for knowledge not to engender power', (Foucault, 1980 p52). Thus Foucault concludes, rather than studying knowledge and power separately, they are intimately connected and it is 'knowledge/power'

couplet that needs to be described. (Prochaska et al., 2007) comments that knowledge is power, and it is this knowledge which is of vital importance and is the key to highly effective self-management. As such the authors and contributors to the texts wish to assert their powerful position as 'expert' because they have this knowledge, and this power is exerted when patients are required to conform.

It is conjectured that the contradiction between the compliant and concordant discourses is the result of the irrefutable scientific evidence gleaned from the landmark studies (UKPDS, 1998); (DCCT, 1993), to which the authors of the books and the health care professionals regard as 'true fact'. The notion of falsifiability, is connected with scientific evidence, Karl Popper proposed that; until 'scientific theory' can be expressed in a way that can be 'falsifiable', it will not reach the status of being scientific theory, (Popper, 2002). Popper's theory of demarcation is based upon his perception of the logical asymmetry which holds between verification and falsification, according to Popper, 'critical rationalism', of scientific progress cannot be achieved by verification of existing theories only by critique and falsification. The authors of the self-help texts regard research from the landmark studies as 'true fact' because of the strong evidence as such, so when knowledge is written and rewritten about, that particular version of 'truth' is reinforced as 'fact'. Foucault argues that rather than knowledge being a pure search for 'truth', power operates the processing of information which results in something being considered as a 'fact', whilst other knowledge is constrained or suppressed. However, as an optometrist it is apparent that incorrect information regarding the signs and symptoms of diabetic eye disease is claimed, so here false information emerges as true fact, of which the lay-reader would not be aware.

Self-help texts cannot actually promote the concordance model; the concept is aspirational. Obviously, there cannot be an exchange of dialog between the author and reader; the author can only make best guess assumptions as to how the person with diabetes may respond. Notwithstanding, this study has found that self-help texts reinforce the expert/patient relationship between the author and the reader with diabetes, and cannot facilitate empowerment of people with diabetes who seek self-regulation. The reader cannot be inspired into effective self-care action, as they are limited by regulatory forces external to the self which are exerted upon them by the texts. When the person with diabetes chooses a self-help text they enter into a concordant relationship with their health care provider, whilst having a compliant relationship with the author of the text. The person with diabetes is constrained by the dominant discourse of the self-help book. Particularly notable is the large amount of variation within the same text and between books within the compliance/concordance discourse. It is argued that this apparent concordance is just a

strategy on behalf of the author to be 'friendly' with their readership to perpetuate the text. The reader is not able to have a concordant relationship with the author, though the illusion is created, but breaks down, resulting in the noted contradiction and variation.

(Foucault, 1991) emphasises that power must not be thought of as something that is only negative or repressive, from a Foucauldian perspective, power itself is productive, producing 'regimes of truth'. Foucault determines power as an equally positive force capable of generating constructive and productive outcomes, and so it is conjectured that empowerment can be produced. Foucault expresses power and knowledge as elements of the same component, (Rayman and Ellison, 1998) found that the knowledge and problem solving skills obtained through diabetes education are essential for initiating the self-management process and empowering them. In addition, (Brown et al., 2002) argues that the key to effective self-management is patient motivation and willingness to assume responsibility for their own care, through a change in their attitude towards the disease. According to (Jeffers, 2005) empowerment techniques represent a mode of self-regulation which aims to govern subjects in terms of personal truths, like their inner strength, inner power and inner love. Where 'power' is assumed to be independent and internally located, thus available for possession. For the self-help 'experts', the more power we have, the more strength we possess. Notwithstanding, in this review it was found that these self-help books do not facilitate empowerment of people with diabetes who seek self-regulation. The reader is not galvanised into effective self-management of their T2D, as they are limited by regulatory forces placed upon them.

With regard to reflexivity, the author of this study is an optometrist with no personal experience of the disease and is constrained and placed in the position of 'expert'. From this expert position it is apparent and alarming that incorrect information regarding the signs and symptoms of diabetic eye disease conveyed by some of the texts could lead to blindness. From a Foucauldian perspective, has this misinformation occurred, not through poor quality of research, but from false information emerging as 'true fact', when knowledge is written and rewritten about, that particular version of 'truth' is reinforced as 'fact'.

It is proposed that optometrists as experts on eye health are best positioned to educate people with diabetes to self-regulate. Crucial to this suggestion is that people with diabetes often visit their doctor because they have a chronic illness, whereas they visit the optometrist for a routine eye check, not just as a person with diabetes, but as a responsible citizen. Optometrists are then positioned as partners in proactive management, where concordant consultations are an establish mode of optometry practice, so are not seen as responsive

service providers for the person with diabetes. It is postulated that role of the optometrist could be extended to encourage patients to take personal responsibility for self-care through a graphic portrayal of diabetic eye disease, where knowledge of their own disease status will be delivered via their retinal images within a normal optometric practice environment. It is hypothesized that the participant's concern of sight loss will be a driver towards sustainable and effective self-regulation, and the key to improved self-motivation and empowerment.

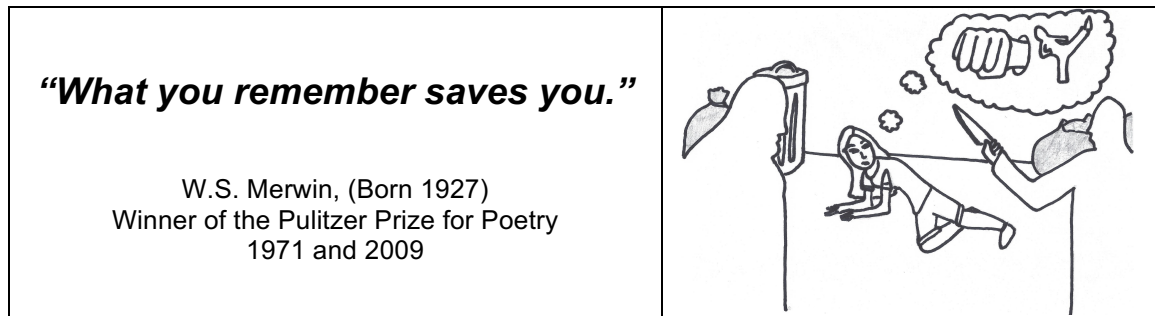
5.6 Summary

Self-knowledge is about personal governance in society and by learning the rules of self-regulation, illustrated in the self-help texts, people with T2D are able to reduce the risks of diabetic complications and live a healthier, longer life. Self-help literature illustrates the way in which discourses can create, invent, or establish people and their characters, (Rose, 1996); (Ward, 1996); (Hacking, 1986). This study found that self-help texts cannot facilitate the empowerment of people with diabetes who aspire to self-regulation, as they are constrained by the dominant compliant discourse of the expert-patient relationship. Self-help texts reinforce the expert/patient relationship where the author is positioned as the 'expert' and afforded power over the 'patient' with diabetes, as their illness is reduced to a disease, (Cyrino et al., 2009). When the reader accesses knowledge about diabetes self-management through the self-help texts, they cannot be inspired into effective self-care action, as they are constrained by regulatory forces external to the self which are exerted upon them by the texts.

From findings of this review, Study (3), the researcher was mindful of the ideas of 'governmentality', a mechanism for regulating and controlling populations (Burchell et al., 1991); and 'technologies of self', where people, as consumers create the kind of lifestyle they desire (Grace, 1991) in the design and development of the EDOP. According to (Turner, 1997), the coercive strategies of empowerment used by health professionals in the control of individuals and populations, improves the ability of the people to be governed, where empowerment is an illusion created for individuals to believe they are exercising their democratic freedom. Further to this, (Powers, 2003), found that the concept of empowerment is used by health care professionals as means to produce compliance, because patients are considered empowered only if they make the correct choice, as defined by the health care provider.

This PhD study proposes that the established relationship that people with diabetes have with their optometrist presents conditions for a be-spoke and concordant approach to diabetes management. The optometrist is uniquely positioned to educate and motivate the person with diabetes to self-regulate, which is a relationship which can be developed through the EDOP, thus avoiding the risks of 'governmentality' and encouraging 'technologies of self'.

6 STUDY (3): ENHANCED DIABETIC OPTOMETRIC PRACTICE



6.1 Introduction

Diseases have often been scaled according to the degree to which people are considered to be morally responsible for their illness (Sontag, 1978). Diabetes is frequently represented as a self-induced lifestyle condition, where blood sugar levels are explicitly understood to signifying a person health status and their compliance with the therapeutic regime. Failures of control imply not only poor health, but moral failings. Lay discourses in T2D management are commonly attributed to people’s lack self-control, eating to excess and being overweight. This view is reinforced by health promotion discourses which emphasise that T2D can be avoided through a sensible diet and exercise. People with diabetes are frequently blamed for their disease and for failing to take proper responsibility for their own health.

(Riessman, 1990) found that during research interviews participant’s used forms of narrative to present themselves and their illness strategically. (Becker, 1997), describes how metaphors are used by people with chronic illnesses to integrate their life experiences into identity. Metaphors operate as a mediator for change, enabling individuals to re-establish a social order, and at the same time, conceal the social paradoxes, simultaneously making changes to their lives and their identities. Diabetes is often represented as a ‘lifestyle’ disease for which people with the disease are blamed, lay explanatory notions propose to normalise the condition and minimise the moral implications.

The research by (Broom and Whittaker, 2004) considers how, through their discourse, people with diabetes both acknowledge and distance themselves from the potentially ‘discredited identity of diabetes’ (Broom and Whittaker, 2004 p2372). People with diabetes construct self-reflexive accounts that present their identities in positive terms, which include parodies of adults scolding children, such as being ‘good’ or ‘bad’, narratives of ‘guilt’ and ‘salvation’. This was found to be a common theme with the struggle between strict

compliance to a diabetic regime and the assertion of individual agency. (Broom, 2001) considers there to be a moral understandings of individual responsibility to be as healthy as possible, which is intimately related to the triumph of the rational self over the disorder of the physical body. Moral identity of people with T2D is negotiated through the often contradictory language of control, surveillance, discipline, and responsibility. (Broom and Whittaker, 2004) found that diabetes-related behaviour was frequently discussed by people with diabetes that positioned themselves or others as; disobedient children or as wicked or foolish. This erodes the very agency that health care providers recognise to be central to successful self-management.

(Broom and Whittaker, 2004) also noted that when people with diabetes discuss control, they employ two discourses at the same time. They use a biomedical discourse, used by clinicians and diabetes educators; and they also use metaphors to express their illness experience in an attempt to assert a positive identity and agency in the management of their disease. According to (Broom and Whittaker, 2004); 'the idiom expresses the subjective emotions of their relationships to the disorder and the changes in personal identity and lifestyle it entails', (Broom and Whittaker, 2004 p2381). The discourse of control is social and highly valued, being in control signifies personal agency and power, while being out of control implies chaos, madness, and moral failing.

6.1.1 Aims

The aim of the EDOP presentation is to educate and motivate people with T2D to better self-care, by enabling them to connect diabetes self-management and eye health to reduce the risks of sight loss. By using diabetic retinopathy screening to not only detect and treat diabetic eye disease, but also to prevent blindness by enhancing diabetes self-care practices. This chapter will investigate the participants' responses to the EDOP in the third study of this PhD project, using FDA. The researcher will consider how participants self-manage their diabetes, how they view the EDOP presentation, and whether the EDOP will make a difference to motivation and personal agency in regard to their diabetes self-management and care.

6.2 Method

The method chapter (Chapter 3) of this PhD thesis describes; the ethic process of the research (Section 3.3), sample size and participant recruitment (Section 3.4), the design and

development of the EDOP presentation (Section 3.5), and the principles of coding, thematic analysis and FDA used to analyse the data has been considered in Section 3.6. The data collection procedure and analysis for Study (3) EDOP discussed in the method below.

6.2.1 Method-Stage 1: Ethics Process

The process began with an application for NHS and Aston University ethical approval. A favourable opinion from NRES Committee West Midlands-The Black Country was obtained on 5/9/2012 and Aston University, Life and Health Sciences Research Ethics Committee approval was granted on 14/6/2012, (see Appendix 4).

6.2.2 Method-Stage 2: Participant Recruitment

Included in the study were people with T2D, who are due their annual diabetic screening appointment, it was expected that the participants would be able to relate the EDOP presentation to their recent experience of having had their retinal images taken for screening.

This PhD research study included male and female participants, of white and South Asian ethnicity, who had a good comprehension of the English language, as transcription of the interview data is diminished with translation. The participant's level of English language comprehension was established by the researcher prior to their recruitment. This was determined during their annual sight test conducted by the researcher who had the opportunity to assess their suitability.

The study also required participants with a new diagnosis of T2D, (less than six months) or with established disease, of more than two years.

In addition, it was desirable to have participants with a recent retinal screening grade of; R0 (no retinopathy) or R1 (background retinopathy), as per the National Diabetic Screening Programme. Those people with grade R2 (pre-proliferative retinopathy) or worse, at their last screening session were excluded, as it is hypothesised that if the screening grade is more severe the participant may not be as receptive to the EDOP.

Once ethical approval was granted and notification received, the process of participant recruitment began. Participant recruitment, EDOP presentations and the qualitative semi-structured interviews were undertaken concurrently; which allowed reflection and assessment of the research process as it progressed and modification of procedures when necessary.

6.2.3 Method-Stage 3: EDOP Presentation

Informed consent was taken from participants at the EDOP session, prior to the presentation, and participants were reminded that their participation was voluntary and they maintained their right to withdraw from the study, without prejudice at any time.

Following the presentation participants were offered the opportunity to discuss the presentation and asked if they required clarification on any part of the presentation or procedure for their involvement in the research study. Participants were also offered a selection of literature from Diabetes UK in the form of information booklets offering advice and explaining the complications of diabetes. The researcher also made arrangements with the participants for a convenient appointment to conduct the qualitative semi-structured interview.

6.2.4 Method-Stage 4: Data Collection

The interviews were conducted with participants two to three weeks after the EDOP presentation to allow time for participants to reflect, assimilate and formulate their thoughts on their own diabetes self- management and the EDOP presentation. It was considered that this period of reflection would allow for richer data. The interviews were semi-structured with the researcher referring to the interview schedule as a prompt. However, the researcher allowed the participant to lead the discussion adding probing questions such as ‘can you tell me more about that?’ when required. The semi-structured interview schedule can be seen in Appendix 6.

To begin the interview participants were asked to be truthful when answering questions about the EDOP presentation, and reminded that their comments, both positive and negative, were of interest to the study. The researcher felt it necessary to clarify this point as this could be an area of contention as the interviewer not only presented the EDOP but also created it; this raises reflexivity issues which will be discussed in Section 3.7.6

At the end of the interview participants were given the opportunity to add anything they felt had not been covered in the interview and ask questions about the research. The interviews were audio recorded for transcription and data collection occurred alongside data analysis which also allowed for reflection and flexibility.

6.2.4.1 Quality in Qualitative Interviewing

When undertaking qualitative interviewing, some interviewees will inevitably provide less than optimal data; however, the approach of the interviewer has a considerable contribution to the quality of data collected, (Howitt, 2010); (Kvale, 1996). outlines a number of considerations and the researcher was mindful to adhere to those recommendations to facilitate a good quality interview.

The researcher was careful to ensure that the interview questions were posed in a straightforward, jargon-free way and were comparatively shorter than the reply of the participant. This allows for relevant and extensive answers, the researcher was also cautious to follow up relevant aspects in the interview and seek clarification from the participant when necessary. Care was taken to summarise the participant's answers during the course of the interview, to verify interpretation of their responses. The researcher was aware of the need to ensure that the interviews were conducted in a sensitive way, allowing the participant to respond at their own pace, in their own words, avoid interruption, and to avoid steering the interview or digressing from the research topic.

Prior to the interview process the interview schedule was piloted on three individuals. Two of the pilot participants used Moores Opticians, (the town centre recruiting practice) and were known personally to the researcher. One of these participants in the pilot was female who had had T2D for nine years, the second participant was male and his mother was diagnosed with diabetes two years ago. The third participant was male and a diabetic screening colleague of the researcher. Informal feedback on the interview questions was reflected upon by the researcher, and amendments made to the interview questions as appropriate. This also gave the researcher a foresight as to how questions may be received and indicated where further probing might be necessary.

6.2.4.2 Methodological Issues - Qualitative Interviewing

Due to the researcher's hearing impairment a transcription service was used, as discussed in Chapter 3. The transcripts were checked for quality and completeness by the researcher listening to the audio file whilst reading the transcript.

A verbatim transcription without a full 'Jeffersonian' transcription was decided for the data in this study, this was a pragmatic decision matched to the skill level of the researcher, but with enough detail of how the participant spoke to address the research question. Whilst Jonathan Potter argues it should be done anyway, as what will be important is not known until the analysis begins, (Potter and Hepburn, undated). Pragmatists like Christine Griffin (Griffin, 2007) argue the time implications make it impractical. Although it can be reasoned that a full 'Jeffersonian' transcription is more authentic, it can also be an obstacle to analysis, as it becomes harder to read.

6.2.5 Method-Stage 5: Transcription and Coding

The audio recordings of the interview data were transcribed verbatim using a transcription service arranged by Student Finance England and The Disability Team at Aston University. The researcher has a hearing problem and was in receipt of a Disabled Student Award, which financed this service. The researcher listened to the audio recordings to check the authenticity of the supplied transcripts and began the process of reading and rereading to enable familiarity with the data.

The transcribed data was coded in a cyclical fashion, with reading and rereading of the transcripts enabling a more coherent and conceptual analysis, as described in Section 3.6.1

6.2.6 Method-Stage 6: Thematic Analysis of the Interview Transcripts

The analysis employed an interpretative technique, texts were read and re-read, and data extraction forms were used to record details of findings and coded. Using the thematic coding of the data extracted from the participants transcripts; a matrix of shared themes was produced by the researcher (Braun and Clarke, 2006). A cyclical process of producing the review occurred; as a new theme was identified the researcher returned to the other texts to check for occurrences of the theme. The procedure for thematic analysis has been described in Section 3.6.2

6.2.7 Method-Stage 7: Foucauldian Discourse Analysis of the Interview Transcripts

The Foucauldian version of discourse analysis was used in this review, enabling a thorough investigation of the various discourses presented in Foucault's power/knowledge concepts.

The analytical process undertaken is based on the step-by-step guide suggested by (Willig, 2008) and has been explained in Section 3.6.3

6.3 Findings

Six main themes emerged from the analysis which were; T2D education and self-management, the EDOP and eye health, diabetic retinal screening and optometric practice, individual and group EDOP presentation, ethnicity and partners.

The sub-themes identified were;

(Section 6.3.1) Type 2 Diabetes Education and Self-management;

(1) 6.3.1.1 *Lack of Knowledge and Misunderstanding of Type 2 Diabetes* (2) 6.3.1.2 *Sources of Type 2 Diabetes Knowledge*, and (3) 6.3.1.3 *Too Much Information on Type 2 Diabetes*

(Section 6.3.2) The EDOP and Eye Health;

(1) 6.3.2.1 *Education and Information on Eye Health and Diabetes*, (2) 6.3.2.2 *Lack of Understanding of Eye Health and Vision*, and (3) 6.3.2.3 *Responses to the EDOP Presentation*

(Section 6.3.3) Diabetic Retinal Screening and Optometric Practice;

(1) 6.3.3.1 *Screening Gives Reassurance*, (2) 6.3.3.2 *Confidence in the Optometrist*, (3) 6.3.3.3 *Participants Misunderstanding of Diabetic Retinal Screening and Eye Sight Testing*

(Section 6.3.4) Individual and Group EDOP Presentation;

(1) 6.3.4.1 *Preference for an Individual EDOP Presentation*, and (2) 6.3.4.2 *Preference for a Group EDOP Presentation*

(Section 6.3.5) Diabetes Self-management, Eye Health and Ethnicity;

(Section 6.3.6) Diabetes Self-management, Eye Health and Support from Partners;

(1) 6.3.6.1 *Wives Manage Their Spouse's Type 2 Diabetes*, and (2) 6.3.6.2 *Partners Share Responsibility for Type 2 Diabetes Management*

6.3.1 Type 2 Diabetes Education and Self-management

In a review article (McCaul et al., 1987) commented that although knowledge may be a necessary condition for adequate health care, it is not a sufficient condition. According to (Cyrino et al., 2009) diabetes self-management education is recognised as vital for people with diabetes to achieve positive results from self-care, though it does not ensure that people

with diabetes will implement these self-care practices which enable better blood glucose control (Snoek, 2002); (Coates and Boore, 1996); (Bloomgarden et al., 1987). Self-care *per se* is not a guarantee for better metabolic control (Estey et al., 1990); (Wilson et al., 1986); self-care practices are influenced by a number of factors related to different life events, as well as personal choices and preferences (Dean, 1989); (Levin, 1981). The following section will discuss participant's talk about their lack of diabetes knowledge and/or their misunderstanding of information on T2D.

6.3.1.1 Lack of Knowledge and Misunderstanding of Type 2 Diabetes

Some of the participants lacked a basic understanding of diabetes in general, perhaps through poor education and lack of information regarding the causes of T2D.

Teresa Interview 4

When asked about her diagnosis Teresa demonstrates her ignorance of diabetes and its causes, she states in lines 42-46 that the menopause had caused her T2D, which was what apparently also happened to her mother and aunt, which provides Teresa with 'evidence' for her belief. In line 43 when she states that; '*it was the menopause that caused it*', she is positioning herself from the potentially 'discredited identity of diabetes', (Broom and Whittaker, 2004 p2372) and constructs a positive, blame free identity, which is socially acceptable and has a historical context, as both her mother (line 42) and her Auntie (line 45) developed T2D during the menopause.

38 ***So did they tell you straight away,***
39 ***or did you have to go back?***
40 *They sort of give me a rough idea*
41 *but obviously til the er whatsit come back,*
42 *you see before that me mum was d...diagnosed as, as being diabetic*
43 *but it was the menopause that caused it*
44 *and I think it's what caused it with me*
45 *because me aunty was diagnosed diabetic*
46 *and once, once again I was in that,*

Teresa further admits to her lack of knowledge and understanding of diabetes, as she describes her insulin regime, (lines 196-201).

195 ***- increase and it stabilises on the same level?***

196 *Because what I can't understand,*
 197 *I, I set, I do va...vary me diet like with different things*
 198 *but it's usually the same diet I have,*
 199 *I've nothing different in it.*
 200 *In don't have sugar or anything that I know,*
 201 *that I know is going to affect me and so I don't.*
 202 **Right.**
 203 *And that's what makes me angry*
 204 *'cause I can't understand why.*

She explains how she tries to manage her diabetes with her diet, but that she does not understand how her blood sugar levels can be so variable, when she has a stable and unvarying diet, in line 199 she states; *'I've nothing different in it'*, Yet in line 197 she contradicts this. She adds that it is her lack of understanding which makes her feel angry, (lines 203-4), and at the same time Teresa also feels anger at her situation, she positions her T2D as unjust, because it does not follow the rules in a way that makes sense to her. She believes, her diabetes developed through the biomedical change in her body of the onset of menopause, and then her anger is reasonable as the cause is beyond her control.

Ghulam Interview 28

Similarly, to Teresa, Ghulam gives the reason for his diabetes to be due to an extenuating circumstance beyond his control, he describes the cause to be stress (line 165).

According to (Broom and Whittaker, 2004) a dominant model for the cause of T2D involves the effects of stress upon the body, also a very common theme in lay explanatory models of another chronic condition, (Whittaker, 2002); (Hunt et al., 1990). (Broom and Whittaker, 2004) describe stress as an external force which people with diabetes have little or no control over. The relationship between stress and diabetes reflects the ways in which people perceive their health within the larger context of their lives as social beings; stress discourse is therefore used to interpret a range of different life experiences, including work, family life, and outside pressures. Ghulam gives his examples of stress to be; *'family and stuff like that, a lot of issues as well with work'* (lines 168 and 169). His wife substantiates this, adding value to his claims, by agreeing that he did indeed suffer from all the adverse issues which were stressful (line 173).

165 *but the main one sticks in my mind could it be stress?*
 166 *I've had some issues,*
 167 *I've had to live in the UK and I've had a lot,*

168 *families and stuff like that,*
169 *a lot of issues as well with work and,*
170 *I've had four,*
171 *four five years of very, very, very stressful years so.*
172 *So now I think could it have started from then?*
173 *GAZALA: I think so definitely*

181 *My body's started to weaken and then straightaway*
182 *I got a cold and initially I was thinking that's scary*
183 *because then next effect is an absolute pattern,*
184 *every time I was stressed at work I get cold.*
185 *They say why do get a cold so often?*
186 *They say that,*
187 *it was always preceded by a stressful week.*

Ghulam continues to add evidence to his claims by giving a history in his narrative, in describing a cycle of repetitive colds and periods of stress at work, (lines 181-184) and by saying it is his work colleagues who say this; '*They say why do get a cold so often? They say that*' (lines 185-6). In addition, Ghulam further extenuates his claims by using extreme case formulations (ECF) with works like '*absolute*' (line 183) and '*every*' (line 184), According to (Edwards, 2000), the use these adjectives and adverbs in a narrative, when referring to an object or event invoke its maximal or minimal properties, thus limiting the questioning of the claims made.

Frank Interview 9

Frank is also an example of how the participants misunderstand their diabetes, which is highlighted by his rather simplified version of diabetes self-management. Frank explains about his initial naivety regarding diabetes management, (lines 17-22) he says he was simply being compliant, however he continues to lack understanding of diabetes self-care demonstrated in lines 66-69.

16 ***So how do you find controlling your diabetes?***
17 *Well in the beginning I...I felt erm,*
18 *I was taking tablets*
19 *and as far as I was concerned*
20 *I was told you take these tablets*
21 *and it...it...it controls your diabetes*
22 *so basically just get on with your life.*

66 *I'm always under the impression that*

67 *I'm taking the insulin*
68 *and I'm taking the tablets but...*
69 *I should really eat what I want.*
70 *Because it's not eating sugar that gives you the problem*
71 *is it when you're diabetic,*
72 *it's because you...you...you apparently just can't cope with the insulin.*
73 *And I try not to eat too much sugar and stuff*
74 *but it, it does happen.*

Frank says; '*...and I'm always under the impression*' (line 66) perhaps this is because he wants to believe that responsibility for management is not his. He perhaps would like the medication to do the hard work for him, (lines 67-69). In addition, the use of this phrase also implies that he is constantly aware of the responsibility of self-managing his diabetes, and so is compliant with the recommended regime. As discussed above, failures of control imply not only poor health, but moral failings (Sontag, 1978). When the researcher asks about his diabetes control Frank quotes in line 20 the imperative instruction, '*you take these tablets*', which he reiterates in lines 67 and 68. This is perhaps an attempt at individual agency to present a positive image of a 'good diabetic', because he is aware of the rules of compliance.

However, according to (Broom and Whittaker, 2004) discourse concerning diabetes control, surveillance, discipline, and responsibility is often contradictory, as people with T2D attempt to construct a positive moral identity. This is notable that Frank is confused about the cause of T2D, (lines 70-72), though he does know the amount of sugar he consumes needs to be reduced as he says; '*And I try not to eat too much sugar and stuff*', (line 73) though he does cheat, he states; '*but it, it does happen*' (line 74), with this phrase he is implying that it happens unwittingly, and so is not his fault. He positions himself as a victim rather than the perpetrator of this misdemeanour.

All participants had some information about T2D management, with a variable amount of knowledge of how to apply the self-care and management practices; they all however, lacked understanding of the disease and its management. The most significant area where participants said they lacked education and understanding was on diet issues, many participants felt they lacked information about foods and experienced poor confidence to address those issues.

George and Tina are typical exemplars of how many of the participants either lacked information about nutrition or misunderstood dietary advice. Basil was aware of the need for

a healthy diet, but did not know how much of a difference it could make to self-management of T2D prior to the EDOP, he states; '*I didn't realise quite the extent what the healthy diet can help*', (Basil, line 208). Peter is also aware of following a dietary advice, his wife comments on his choice of a very restrictive diet, '*I control it for him with the meals, I mean having chicken and fish, no alternatives and I think he gets bored quite honestly*' (Peter, lines 13-16).

In the excerpt below George describes how his blood sugar levels were high, even though he says he has never taken sugar (line 11), yet contradicts this in line 9. This contradiction is as mentioned above typical discourse of control, surveillance, discipline, and responsibility from people with diabetes in an attempt to construct a positive moral identity. This apparent confusion over food stuffs which contain sugar is quite notable (lines 7-9); George is a chief, and had training in the army catering corps, working in the officers mess. One would not expect someone with such a level of expertise to be ignorant of the basics composition of food and nutrition. Perhaps this confusion is designed to both acknowledge and distance himself from the potentially discredited identity of diabetes, (Battaglia, 1995). In line 15 when he states, '*I always used to have it over me cereal*', this shows evidence of some behaviour change.

George Interview 17

6 *But the thing is I couldn't understand that,*
7 *I know it comes out of food,*
8 *there's only sugar in some sort of food and you,*
9 *you know sometimes have an ice-cream*
10 *and different things erm.*
11 *But I've never took sugar,*
12 *I haven't took sugar since I was erm what about 11, 12 erm,*
13 *I stopped taking sugar er in, in me drinks,*
14 *all of me drinks naturally.*
15 *Erm I always used to have it over me cereal*

Tina Interview 27

Again in the following excerpt like George Tina equates sweet things with sweets, and does not understand how complex sugars are metabolised and broken down by the body to simple sugars like glucose. She states, '*I don't eat sweets*' (line 122).

120 ***And do you eat sweet things?***

121 *No, no I don't buy sweets,*
122 *I don't eat sweets anything like that.*
123 *It's got a piece of fruit*
124 *and a pot of whatshername, er yoghurt,*
125 *which I do have,*
126 *I have crackers,*
127 *cos them in the pound shop,*
128 *you get two big packets of them for £1*
129 *and I mean crackers there's no,*
130 *no calories in that,*
131 *it's just whatshername,*
132 *erm, I do have plain biscuits,*
133 *Rich Tea sometimes,*
134 *but it's only if I buy them*
135 *if I see 'em I buy 'em,*
136 *but other than that*
137 *I don't buy 'em you know.*
142 *I always buy me brown bread*
143 *and I do have that currant fruit bread whatshername,*
144 *I shop sometimes and I get the erm,*
145 *what they call 'em,*
146 *them that the birds eat?*
147 **Seeds?**
148 *What do you call them?*
149 **Trill? (laughter)**
150 *Oh dear yes, (laughs)*
151 *now what do you call them,*
152 *them sunflower seeds, yeah,*
153 *they are seeds aren't they, you know?*
154 *Yes they've got packets of all different kinds haven't they,*
155 *them green things?*
156 *Pumpkin seeds and things like that,*

Tina continues to explain her thriftiness with shopping at the pound shop, stating that there are no calories in the crackers she buys from there; she dismisses the suggestion that pound shop crackers have calories, (lines 126-131). She also admits to having a plain rich tea biscuit, but contradicts herself by saying that they are an impulse purchase and she only buys them when she sees them, (lines 133-137). In addition, Tina does demonstrate her knowledge of some aspects of diabetes management, by stating that she only buys brown bread with whole grains, which have a low glycaemic index, and so are metabolised at a steadier rate, which avoids the spikes in blood glucose levels. However, she does rather comically struggle to remember and articulate the name of the seeds in the brown bread she

claims to purchase, (line 145-156). This poses consideration to how often she actually buys this type of bread.

Cynthia Interview 1

Cynthia is very vocal in informing the researcher about how well informed about T2D self-care and management she is, (lines 151-155 and 190-199), however in the second example she simply echoes the researcher's comments and appears to be following the researchers lead. The researcher tells Cynthia that eye complications could lead to blindness (line 190-192), and she repeats this information in her own comment, '*because it does affect your eyes*' (line 198).

151 ***So what did you think of the presentation that I showed you?***

152 *I thought the presentation was very good er,*

153 *a lot of it I already knew from the,*

154 *from the classes that I went to,*

155 *the diabetes classes*

190 ***When I showed you the presentation, I showed you about the eye complication***

191 *That's right yes.*

192 ***That could lead to loss of sight, blindness...***

193 *That's right yes.*

194 ***...how does that make you feel***

195 ***about how well controlled you're able to be with your diabetes?***

196 *I think that's more important to be controlled,*

197 *the diabetes to be controlled*

198 *because it does affect your eyes,*

199 *but that I...I knew anyway.*

The following excerpt demonstrates Cynthia's position as knowledgeable about T2D, and salvation seeking discourse (line 304-307 and 387-391). She states that the EDOP presentation made no difference to her (line 388), though she is careful to be polite stating that she thought the presentation was very good (line 304), and in lines 390-391, and 395, she comments on the usefulness and helpfulness of the presentation, for other people with diabetes who are less knowledgeable than she is. In line 395 she uses the third person pronoun 'it' perhaps drawing parallels between the more general information conveyed in the presentation and her own personal knowledge and experiences.

304 *I think the presentation was very good*

305 *for someone who is erm just being diagnosed with er,*

306 *with erm diabetes,*
 307 *or doesn't know much about it.*

387 *Well I don't think it's made much difference to me*
 388 *because I was very knowledge about it*
 389 *But certainly*
 390 *I think that it was very useful to anyone*
 391 *who hadn't thought about that,*
 392 *and as I said,*
 393 *especially to er,*
 394 *and I...I think you did it,*
 395 *it was a very helpful presentation.*

Cynthia further presents herself as proactive in her T2D self-management, but what she may actually be doing is passively guarding against the disease; she seems to use information like a shield rather than a tool, almost insulating herself against the risk of complications. Cynthia tells the researcher that she collects the leaflets that the people doing the presentations '*nearly always*' bring with them, she says; '*you pick up those leaflets*' (line 447), however it is noted in this excerpt that she shifts pronouns. According to (Bakhtin, 1981) shifting pronouns portray a sense of an internal dialogue between the inner first person ('I') and a reflexive second person ('you'). Demonstrating the uncertain subjectivity of the speaker and their struggle to overcome habitual ways of being in the world, through the constant self-reflexivity and observation required to manage diabetes. Cynthia repeatedly tells the researcher about how well informed she is about T2D and its management, in performing this discourse she is perhaps seeking the possibility of salvation through compliance, (Broom and Whittaker, 2004), and uses the leaflets like trophies, as mementos of her diligence and commitment to diabetes self-care, (lines 447-448).

444 *the people who are doing the presentation*
 445 *they ne...nearly always bring leaflets with them*
 446 *about what they're talking about*
 447 *and you pick up those leaflets*
 448 *and those leaflets are very helpful as well.*

Some participants refer repeatedly to their diets as a means of controlling their diabetes, whilst others exhibit deviant behaviour in their diet regime and give elaborate descriptions of 'cheating' behaviour. Cynthia admits to cheating, as a '*lapse*', (lines 211-213) but excuses it because her diabetic nurse has condoned it, (lines 214-217). People with diabetes often describe ongoing struggles to manage their disease and their identities. (Stein, 1985) describes the 'contest for control', were health care providers consider this a compliance

problem, but for the person with diabetes it is a struggle for self-discipline. Cynthia is attempting to present a positive subjectivity, and although she admits to cheating behaviour, and thus non-compliance, she is paradoxically being compliant as these lapses are allowed by the expert, which further legitimises her behaviour as acceptable.

This inner struggle with diabetes control and self-management is further observed in the next excerpt, as she changes pronouns from the first person to the second. Perhaps in an attempt to distance herself from the deviant behaviour, for example; '*you can sort of lapse*' (line 211). Here parallels can perhaps be drawn between her struggles for self-control with those of a recovering alcoholic, where lapses are suggestive of slipping back into old habits and patterns of behaviour which are more comfortable and familiar. In line 213 for example Cynthia positions herself positively when being non-compliant as the occasion is; '*if you go out*' (line 213), here the exception and deviation in compliance is made on the event rather than herself. She further substantiates this with a discourse of moderation, by her comments in line 216 and 217; '*once, you know, in a while but you don't do it on a constant basis*'.

211 *Erm, well there are times when you can sort lapse*
212 *just a little bit, you know,*
213 *if you go out or anything like that you...*
214 *and my...my diabetic nurse has said that*
215 *it doesn't hurt, you know,*
216 *once, you know, in a while*
217 *but you don't do it on a constant basis she said.*

Cynthia has told the researcher on numerous occasions that she is quite well informed and has adequate knowledge of T2D management, but has misunderstood information regarding diet, which is demonstrated in the following excerpts. She states that she is careful what she eats (line 218), however when she says the word pastry, it is immediately followed by a rather convoluted description of the type, quality and quantity of the prohibited food, perhaps in an attempt to limit her admitted misdemeanour. She is quite aware of the reasons why pastry is not allowed, '*pastry increases your your er sugar levels*' (line 273-4). She describes having, '*just a tiny bit*', '*just a very small...*', '*a very small one*', and they are '*very small ones...*', '*very, very light*' (line 222-228). She also adds that the pastry is from '*Marks & Spencers*' (line 226), perhaps lessening her cheating by adding value to it. The brand of the pastry is somewhat irrelevant; as is the fact it is Cornish. But by emphasising the quality of the product, she is perhaps positioning herself as less deviant.

218 *So erm, I am careful with what I eat*

219 *and I try to have a lot of fruit and vegetables and erm,*
 220 *not so much cake, you know,*
 221 *and pastry,*
 222 *although I do sometimes have just a little tiny bit of pastry*
 223 *but I try to have just a very small...*
 224 *it's like a Cornish pasty I have*
 225 *a very small one.*
 226 *Marks & Spencers do some very,*
 227 *very small ones and their pastry is very,*
 228 *very light and it's er,*

273 *er but pastry increases your,*
 274 *your er sugar levels*
 275 *as do some of the other things that,*
 276 *that you would never think...*
 277 **Like what?**
 278 *Erm, cakes for instance you see*
 279 *and biscuits erm,*
 280 *you can have a plain biscuit,*
 281 *er I find that the erm Arrowroot biscuits are quite good*
 282 *because they're very,*
 283 *very thin, you know.*
 284 *Erm but Digestive,*
 285 *even the plain Digestives can be quite high in sugar, you know.*
 286 **Yes, yes**
 287 *Tea biscuits aren't so bad,*
 288 *but you know those are the things...*
 289 **Do you like biscuits?**
 290 *No...*
 291 *I don't, I don't have many,*
 292 *I always keep some in my biscuit barrel, you know,*
 293 *for visitors*

The above quotations give a rather interesting and humorous description of Cynthia's misunderstanding of some dietary issues and her 'biscuit habit', (lines 278-297). She likes to position herself as very knowledgeable and an expert in her own diabetes self-management, she is aware of the hidden or complex sugars in food stuff, and locates herself as a 'good diabetic', as she is aware of these dangers, which most people, including the researcher may not have knowledge of. She uses the word 'you' in this phrase to further legitimise her superior position of knowledge and thus power. When asked by the researcher to expand on this, she divulges that those foods are cakes and biscuits, (lines 278-279). This answer is curious because most people would associate cakes and biscuits as having a high sugar content. She tells the researcher that plain ones are allowed, and that some biscuits are

even 'good', as long as they are arrowroot, (line 281). She almost sees them as superior to mere digestive describing their thinness attribute, if they are thin then they will not contain as much sugar, or perhaps she is unconsciously likening the thinness of the biscuit to thinness in people. Diabetes is frequently represented as a self-induced 'lifestyle' condition, a disease of excess suffered by those who have overindulged. In lay discourses, it is commonly attributed to people who lack 'self-control', who eat to excess and are overweight, (Broom and Whittaker, 2004). Cynthia continues to describe other types of biscuits which are acceptable, she knows they are 'bad' *but 'not so bad'* as other varieties, (line 287), further legitimising the acceptability of her chosen biscuit over the others. By making reference to the 'badness' of biscuits generally, she is constructing her choice as being acceptable.

The researcher asks if she enjoys biscuits, her reply was notable; *'No...I don't, I don't, I always keep some in my biscuit barrel, you know, for visitors'* (line 290-293). However, if the biscuits are only for visitors as she claims, would it matter what variety of biscuit they were, the acceptable plain ones or indeed the high sugar and thus 'illegal' ones? It is difficult to equate her rather comprehensive knowledge of biscuits, with her claims to rarely eat them, though she admits to *'only very, very er occasionally'*, this admission is notable in her use of numerous qualifiers.

6.3.1.2 Sources of Information on T2D Management

Participant acquired knowledge of diabetes management through a variety of different avenues; all participants had read the information leaflet provided by their GP practices and chatted with other people with diabetes that they either knew socially or were family members. Others participants (Doreen, Tracey, Mike and Francis and Fay) had also accessed web sites on the internet to gain information, like the Diabetes UK web site, Tracey commented that she often entered chat rooms to discuss issues or ask for advice from her peers. Basil, had subscribed to the Independent Diabetes Trust and had gleaned information from the magazine which he received. Some of the participants had purchased recipe books or read self-help books (Doreen, Tracey, George, Joyce, Frank and Tina), and two participants had mentioned that they had received extra support for their diabetes, (Frank and Joyce). Mandy was the only participant who had been offered the DESMOND programme, but was unable to attend. Cynthia was the only participant who was a member of a diabetes support and social group; though Herminder did mention she attended a weekly over 60s exercise class for ladies at her temple. She said that most of the members had diabetes and they often had informal discussions on diabetes related issues.

The Internet

The internet is a values source of information for many of the participants, and was used as a tool to cross reference information and expand on their knowledge. This was aided by the availability and ease of access to information.

Tracey Interview 6

In the following excerpt Tracey describes how she and Trevor participate in a NHS health eating scheme, as part of a weight management programme. She accesses the internet to find information for them both, (lines 1-10). Her speech act is constructed very actively in line 5, when she tells the researcher that she is the one who talks on line.

In line 6 Tracey very precisely says that the programme is '*not a diet*', but as she continues her description in lines 7 and 8, she stumbles. Perhaps this is because as mentioned above, diabetes is frequently represented as a self-induced 'lifestyle' condition, a disease of excess and over indulgence and is commonly attributed to people who are overweight, as she tries to position herself positively to the researcher (Broom and Whittaker, 2004). She tells the researcher in line 9 and 10 that the diet is actually to '*eat more*', not less as in a calorie controlled diet, but a '*balanced diet*'. However, later in the interview Tracey states that the healthy eating programme is a '*weight loss thing*' (line 393).

1 ***Trevor said you're the one that gets online...***
2 *Oh yes...*
3 ***Tell me about that***
4 *...I talk to people,*
5 *yes I'm the one that goes onto the forums and talks to people.*
6 *Erm, I mean the main thing is what they try to emphasise is it's not a diet,*
7 *it's healthy eat...*
8 *it's some...*
9 *trying to get you to eat more,*
10 *a balanced diet and take more exercise.*

29 *Well when Tr...when Trevor was diagnosed*
30 *they gave him er a big pack full of leaflets*
31 *and you know er email address to go onto the Diabetes UK website*
32 *and things like that,*
33 *and we sort of looked up and erm, (laughs)*
34 *and er and I went out and bought a few recipe books*
35 *but didn't do much from them.*

166 *we've not really actually knowingly gone out to seek information,*
167 *erm, it's just stuff we've picked up from talking to other people*
168 *or watching stuff on television.*
169 *Erm, really we haven't gone out and,*
170 *and looked for it.*

390 *you don't want to be constantly thinking*
391 *oh I can't have this because of the diabetes,*
392 *can't have that cos of...*
393 *because the great thing about the Nutricheck weight loss thing that we're on*
394 *is that there are no forbidden foods,*
395 *you can have whatever you like,*
396 *but you moderate your portions,*
397 *do exercise if you go mad one day,*

In the interview Tracey also contradicts herself with regard to accessing information about T2D management. Initially in lines 30-33 she says they were given leaflets with contact details which they; '*sort of looked up*', yet in line 166 she makes a contradiction which is quite explicit; '*we've not really actually knowingly gone out to seek information*'. Considering the inconsistency of Tracey's narrative further; she says that they '*sort of*' looked the information up (line 33), which implies that they perhaps didn't, or that they didn't use the information. This is supported by her notable hesitation in the excerpts, and that she admits to buying recipe books but not using them (lines 34 and 35). In addition, when Tracey uses the phrase; '*not really actually knowingly*' (line 166), it seems to be slightly superfluous, perhaps implying that the only information they wanted, was that which they had look-up for themselves (line 148-9), which they would then be more comfortable with through self-censorship.

Mike Interview 11

Like Tracey and Trevor above, Mike's information on diabetes is sourced on the internet and is gleaned from other people with diabetes, it is noted that his responses in the extract below have a rather sarcastic tone, (lines 45 and 48-51). Mike uses 'I' the first person pronoun in his narrative and also 'we'; in using 'we' he is substantiating his statements and giving them authenticity. He also slips in the third person pronoun later in the excerpt (lines 65, 71, 72 and 74). In changing from the first person, in talking about his own experiences, he may be demonstrating the inner turmoil with his reflexive self; in addition, line 65 may also serve to

acknowledge the challenge to the traditional position of the expert he has presented in line 50.

40 **Okay.**
41 **So what sort of support and advice have you had**
42 **about controlling your diabetes?**
43 *Other than general knowledge,*
44 *talking to other diabetes,*
45 *because we talk too, you know,*
46 *we...we....we know.*
47 **You talk to each other?**
48 *Ooohhh yes,*
49 *we probably know more than the experts...*
50 *but I know we know more than the experts,*
51 *cos we look things up.*
65 *Cos obviously you research it don't you?*
66 **So where have you researched it?**
67 *Again talking to different people obviously with it*
68 *and they've got ideas*
69 *and they've done this*
70 *and they tell you that*
71 *and you do the same*
72 *and then you look it up on the internet don't you,*
73 *that magic thing.*
74 *And again you read all the government booklets*
75 *and ignore most of that.*
76 **So if this information that you've had sort of –**
77 *Probably all misinformation (laughs)*

Mikes confirms to the researcher that he would consider himself an expert patient (line 60), he is able to position himself as such because as he states, he has read all the information leaflets (line 74) and undertaken research on the internet, (line 65 and 72-73). However, he is not the embodiment of an expert patient from a concordance point of view, as he has a deep mistrust of the health care profession. Mike states that he has read all the patient information leaflets he has been given, implying he has been compliant, but dismisses the information, as he considers it to be propaganda, (lines 75-77). Perhaps Mike ignores 'most' of the government booklets because it is the government, or because he does not wish to know about diabetes, which may be the case as he states he ignores most, but not all the information. In addition, in line 74 he uses the words; 'and again' which is rather contradictory, if he considers the information to be 'misinformation' (line 77), why would he both to reread something he has already decided to ignore.

However, by 'policing' the information in the government booklets, through his re-reading (line 74), he is being a 'good citizen' upholding moral values for society, or in this case, for other people with diabetes, in negating the information he considers to be cant. He has positioned himself earlier in the narrative to be an expert in diabetes, (lines 49- 50, 'we probably know more than the experts... but I know we know more than the experts'); he has given himself authority to perform this task legitimately; and positioned himself positively without moral failings, as he later admits to cheating.

Francis and Fay Interview 13

Francis and Fay, like Tracey and Trevor, have had no formal T2D education, other than the information they were given when Francis was first diagnosed. Both Francis and Fay make comments using extreme case formulations (ECF) to describe the complications of diabetes, (line 144 and 153). These ECFs are idioms, and as discussed above, they are used to express the subjective emotions of the person's relationship to their illness, and the changes in personal identity and lifestyle it entails. They express that they are acutely aware of the severity of T2D and its complications in using this ECF. Though interestingly, they chose to use the example of peripheral neuropathy and risk of amputation, rather than retinopathy and risk of blindness which is what this study is researching.

140 ***So you've had no formal education?***
141 *Not really,*
142 *other than the nurse, initially,*
143 *the diabetes nurse at the medical centre.*
144 *It frightened the life out of me.*

149 *to being told the extremes that diabetes can cause,*
150 *you know,*
151 *I thought, my goodness,*
152 *your feet dropping-*
153 *FAY: feet falling off and-*
154 *-things like this, you know,*
155 *which may seem comical,*
156 *but erm,*
157 *but that's probably the impression,*
158 *first impression erm,*
159 *but that is a reality,*
160 *probably not overnight,*
161 *but it is a reality of things happening.*

Fay comments that they had looked information up on the internet, (line 166-168), however she adds that the information they received from Francis's GP was lacking (line 169-172), She does not say this directly, she says; '*I'm not going to say that*' (line 169) thus allowing the researcher to interpret the implication of her criticism of the doctors and nurses. This phrase acts as a disclaimer, as Fay tells the researcher that they had not been given a lot of advice and support from their GP practice. As the interview continues Fay comments that she is the one who researches the information on the internet (line 181-182). Fay is positioning herself as the person in their relationship who manages his diabetes.

162 ***So do you think that the amount of information***
163 ***that you were given about diabetes education was sufficient,***
164 ***or have you gone away***
165 ***and supplemented knowledge yourself?***
166 *FAY: Yes, we've gone away,*
167 *read books on the internet*
168 *and done things like that.*
169 *Erm, I'm not going to say that*
170 *the doctors and the nurses at the practice haven't told us a lot,*
178 *FAY: if, I think we'd have had something like that sooner,*
179 *we may have understood it more.*
180 ***Right***
181 *Fay: but I go on the internet*
182 *and I look up and I read books*
183 *and I'm the one who asks all the questions at the doctor's*
184 *Yeah*
185 *FAY: Francis doesn't*

211 ***So you're the one that accesses the information?***
212 *FAY: We're a team, erm*
213 *I've always been the same as you can tell,*
214 *and (name) [daughter] is very much like me as you know,*
215 *erm and I always,*
216 *people say I shouldn't sort his medication out every day,*
217 *I should let him to it*

However, perhaps her criticism is not just against her GP practice, but also with Francis, she says; '*but I go on the internet and I look up and I read books and I'm the one who asks all the questions at the doctor's*'. In this excerpt the implication is that Francis does not face up to the responsibility of his diabetes, allowing Fay to control his diabetes, so that he doesn't need to. This is noted at the beginning of the interview, in lines 4-5, when she says that she does '*all the cooking obviously*' and it was put on her shoulders. Fay uses the word

'obviously' in an attempt to perhaps head-off a question from the researcher as to why she shoulders the burden of Francis's diabetes management.

- 1 ***So other than a surprise,***
- 2 ***how did it make you feel***
- 3 ***with regard to sort of lifestyle and things?***
- 4 *FAY: I think, because I do all the cooking obviously,*
- 5 *it was put onto my shoulders,*
- 6 *and I straightaway,*
- 7 *right, different diet.*

Fay possibly resents this responsibility and is enacting the position she wishes Francis to take when she says; '*I have to know*', and yet repeatedly uses 'we' when she actually talks about control, as she desires a joint responsibility, (lines 166, 179 and 212). According to (Broom & Whittaker, 2004) when people with diabetes speak of control, they simultaneously employ two discourses. They use the biomedicine discourse of the health care providers; and they talk about the illness experience and the desire to assert a positive identity and agency in the management of T2D.

She says that Francis, '*tends to sit there as much as to say, Fay shut up, you're asking too many questions*'. He doesn't actually say this; she is interpreting what other people are thinking. She admits to this later, lines 216-217 that there has been criticism. She excuses herself saying, '*I've always been the same as you can tell, and (name) [daughter] is very much like me as you know,*' The researcher is an acquaintance of Fays daughter, so Fay uses this to excuse herself. However, in line 213, with the phrase, '*I've always been the same*', she is clearly stating that she has no intention of change, and the researcher is invites to agree with her with the phrase '*as you can tell*'. The researcher however cannot really know if she has always been like that, therefore reality is not necessarily described but constructed for this purpose. Fay adds kudos to her statement by then saying, '*(name) [daughter] is very much like me as you know*' (line 214).

Independent Diabetes Trust (IDDT)

The Independent Diabetes Trust is a private charity delivering independent information to people with both T1 and T2 diabetes, based in Northampton. He asks the researcher if she has heard of the organisation in line 13, which serves to legitimise the information and the organisation. Basil says that he received '*quite a bit*' of information on diabetes from the IDDT. However, there is an implication in the narrative that the information has not been that informative, he says; '*I mean we've had plenty of magazines*' (line 10) and in lines 20 and 21

he excuses the poor quality of the information by say they're '*developing*' (line 21), he also makes prior reference to the IDDT as '*starting-up*', (lines 14 and 16) and '*starting*' (line 19).

Basil Interview 20

7 **So what education**
8 **or what information have you had about your diabetes?**
9 *Well quite a bit really*
10 *I mean we've had plenty of magazines,*
11 *the, the diabetes magazine*
12 *the IDDT one which is,*
13 *I don't know whether you know it,*
14 *it's for Northampton, that they've started up independent diabetes,*
15 *I think or, any, any, anyway it,*
16 *it started up,*
17 *it is fairly good erm*
18 *I did a subscription to them,*
19 *course that was start...starting*
20 *and I...I'm getting good information from them as they're,*
21 *as they're developing.*

Diabetes Self-help Books

All the participants had received the information booklets from their GP and a number of participants had said they had read self-help books, Tina is a typical example.

Tina Interview 27

Initially Tina tells the researcher that she was given a log book from her GP practice that they are supposed to fill in, but she comments in line 24-28 that the practice nurse '*doesn't bother*'. The implication would be that if her care provider doesn't bother, then why should she. Further to this Tina continues to give a narrative on the self-help books she has purchased and refers to, thus she is compliant with her diabetes management, and keeping to her side of the deal. Yet the expert, her GP practice nurse is not. Within the larger context of a moral society, and within this discourse Tina does not lack personal agency and is not failing, the responsibility is subjugated to the nurse who has let her down and thus is the one who has moral failings.

20 **So they give you an information booklet**
21 **from the doctor**
22 *yeah, from the doctor's.*

23 *Well no,*
 24 *they fill it in,*
 25 *she fills it in on the screen,*
 26 *she don't bother it,*
 27 *she don't bother filling it in.*
 28 *Just goes on the screen at the doctor's you know*
 29 ***and you've bought this other book from the library?***
 30 *Yeah,*

Tina had purchased self-help books, though they were second hand from the library; this is then not the most up to date source of information on diabetes self-management, which is noted when Tina appraises the books in line 46; '*because I mean if er the other one's even better than this*'. In being able to appraise and compare the content and quality of the information and advice in the self-help books, Tina has quite clearly accessed and assessed their content quite comprehensively. She is able to highlight inconsistencies and contradictions between the texts and compare this with the advice she has received from her GP, (lines 104-107). Tina continues to explain how she wants to improve her knowledge of diabetes management with particular regard to diet advice, but found the information difficult to understand. It is also noted in line 103 she says that all the information is '*gobbledygook*' and clearly finding it difficult to interpret.

100 ***So when you read these information books***
 101 ***that you've got from the library,***
 102 ***how easy do you find it is to understand what's in there?***
 103 *Well it's all gobbledygook*
 104 *because you read one book*
 105 *and then you read another one,*
 106 *it's entirely different, you know.*
 107 *Different things in it altogether*

Joyce Interview 26

Joyce also tells the researcher that she has had self-help books, then corrects herself as she still has them; '*I've had books, you know, I've got books, but*' (93-95), as they were given to her by a friend whose brother had diabetes. She does not like to have this extra source of information on diabetes which will be discussed below in Section 6.3.1.3

Additional Personal Support

Two participants Joyce and Frank had had additional personal support from their health care providers. Joyce received telephone calls from a 'diabetes buddy' (Section 6.3.1.3) and

Frank attended a support session at the diabetes centre linked to the hospital, both participants felt the additional support was of no value.

DESMOND

Mandy was the only participant who had been offered the DESMOND course, but she did not attend.

Mandy Interview 8

12 ***So have, have you been on any courses –***
13 *No.*
14 ***- or any diabetes education?***
15 *No, no.*
16 ***Okay,***
17 ***has that been offered to you***
18 ***or is it that -?***
19 *To be quite honest*
20 *when I was first diagnosed yes*
21 *and I think it was that DESMOND one and*
22 *(pause)*
23 *it was somewhere in Walsall,*
24 *me husband took me on the Sunday to go,*
25 *go and find it,*
26 *do you think we could find it,*
27 *anyway to cut a long story short*
28 *the day I was supposed to go,*
29 *which it,*
30 *I think it was in the winter,*
31 *that vomiting bug was about and I had that.*
32 *I rang up and cancelled and er,*
33 *they never sent me another appointment.*

She comments on her compliant approach to diabetes self-management, (line 10-11) and continues to give an excuse for not being compliant in failing to attend the course, (lines 24-33). She is positioning herself as the victim of circumstances which prevented her from attending, rather than having chosen not to go. This exonerates her from any moral failing in not taking individual responsibility for her diabetes.

Social Groups

Cynthia was the only participant who attended any form of formal diabetes education in the form of a social group, which she explains was very useful. However, she explained to the

researcher how the group would be finishing soon, because the lady who runs it will be retiring.

Cynthia Interview 1

- 15 ***You said erm to me when we did the presentation...***
16 *Yes, hm.*
17 ***...you go to a group about the...***
18 *Yes.*
19 ***...and do you learn about your diabetes there?***
20 *Erm, yes, yes, yes.*
21 ***Tell me a little bit about that.***
22 *Unfortunately that is finishing in December*
23 *which is a shame really*
24 *because the lady who runs it,*
25 *she's not getting any younger*
26 *and there's nobody else come forward, you know,*
27 *to take it on,*
28 *the group.*

Although Cynthia enjoyed the group and feels it is 'a shame' (line 23), that no one is going to take over its running. The use of the word 'shame' implies a moral responsibility for the group to continue, but Cynthia has not considered it her moral duty to offer. She says '*and there's nobody else come forward, you know*' (line 26), with the use of this phrase she dismisses herself as a candidate, by using the second person pronoun 'you'.

6.3.1.3 Too Much Information on Type 2 Diabetes

Most participants were happy to add to their diabetes education whilst Donald and Peter did not wish to have any more information because they felt subjugated or overpowered by the information they already had. Tracey and Joyce both comments that they have enough information, because they do not want to be constantly thinking about their diabetes.

Donald Interview 15

Donald explains to the researcher that he has too many appointments and there is too much interference in his diabetes management. In line 13 he said he previously received '*no back-up*', when the researcher asks if he has more support now he replies with the phrase, '*I believe there is too much back up now*' (line 16). It is notable that he uses the term '*back-up*'

again rather than support in replying to the researcher's question. Perhaps he considers the 'back-up' to be more low key and passive, were he only needs to assess the advice or information when he considers it necessary, whereas support is by implication more active and so too much and so wishes to 'get rid' of it, (line 36).

13 *No back up*
14 **there's more support now?**
15 *Oh yes,*
16 *I believe there is too much back up now*
17 **So why do say that?**
18 *Well, I'm a diabetic,*
19 *I may have to my eyes tested every twelve months*
20 *for glasses and everything,*
21 *and I have my feet tested, right?*

46 **So it's like lots of appointments?**
47 *Too any appointments*
48 *Yeah,*
49 *and they've all got different ideas,*

In addition, Donald's comments that he has too many appointments, there is too much advice, and too many ideas; the advice is inconsistent (lines 47-9). However, he does not consider the advice and recommendations to be wrong only the system, but does not offer a solution. Perhaps this is because he cannot imagine there to be one, or because he does not consider it to be his responsibility; he considers that the health care providers 'interfere' by being overly attentive, which is not welcomed, then by implication how can it be his responsibility to seek a solution?

Peter Interview 18

When Peter is asked if he has had any diabetes education or training he say he has not but that he would not want it, because he says he has, 'all the information I need' (line 127). Peter in this excerpt is perhaps suggesting that T2D is overpowering, and he normalises his autonomy by avoiding his diabetes, which is demonstrated in lines 130-132, 'I feel as though it was, was taking over me life, er if I went on any sort of –'. He uses the word 'no' on several occasions in his narrative (lines 119-26 and 133-5), as well as the word 'all' these are both qualifiers and the word 'definitely' used in line 138 is an adverb. According to (Edwards, 2000) these different grammatical categories, such as; extreme adjectives (total, absolute), the 'superlative' forms of adjectives (best, most, biggest, least), quantifiers (every, all, none),

and adverbs (always, never), are ways of referring to an object or event that invoke its maximal or minimal properties. They are used in ECF where no further explanation is needed, thus normalising it.

- 116 ***And have you been on any training,***
117 ***any education courses***
118 ***or anything?***
119 *No, no, no.*
120 ***And has anything like that ever been offered to you?***
121 *No.*
122 ***So do you think that would be useful for you,***
123 ***do you think –***
124 *No, no.*
125 ***- why do you say that?***
126 *I think no,*
127 *I think I get all the information I need*
128 *and I think it's,*
129 *if I've got to do that I'm....er,*
130 *I feel as though it was,*
131 *was taking over me life,*
132 *er if I went on any sort of –*
133 *no I don't think I'd like to do that,*
134 *not at all,*
135 *no.*
136 ***So do you think that that is an issue for diabetes,***
137 ***that it takes over your life?***
138 *It does take over your life yes definitely.*

Tracey Interview 6

The researcher asks Tracey about her lack of T2D education and enquires if she would like more, she replies; '*Well yes, but then I...I think I've...you've got to be careful of going too far the other way and becoming a bit too obsessed with it*' (lines 384-7).

- 384 *Well yes,*
385 *but then I...I think I've...*
386 *you've got to be careful of going too far the other way*
387 *and becoming a bit too obsessed with it.*

Joyce Interview 26

Joyce has self-help books, as they were given to her by a friend whose brother had diabetes. When asked by the researcher if she had read the books, she responds in lines 109-113, she hesitates and sighs (lines 109-110), saying; *'I have read them like'* (line 112), though she didn't like to; *'keep on reading them'* (line 113), this implies that she had perhaps not actually read them, which is further collaborated when she tells the researcher that she does not keep them on display, she keeps them in a drawer (line 107). Joyce may not wish to appear irresponsible, and perhaps does not like to be reminded about her diabetes. She did not actively seek information on diabetes, and perhaps feels overwhelmed with too much information.

96 **Who's given those?**
97 **Or have you got,**
98 **have sort of been and bought those yourself?**
99 *Well I haven't bought them,*
100 *but they've,*
101 *now where did I have the one,*
102 *oh I know a friend of mine,*
103 *erm, her brother in law had diabetes*
104 *and whoever he was in touch with gave him another set of books,*
105 *so he give the ones that he had.*
106 *You know,*
107 *so I've got them in the drawer. Erm*
108 **and do you read them?**
109 *but,*
110 *(sigh)*
111 *sometimes, not always.*
112 *I have read them like*
113 *but I don't like to keep on reading them you know. Erm*

Joyce's also describes how she had support from the 'diabetes buddy' which compounded her sense of subjugation, as the support was unwelcomed and completely useless, she refers to the 'diabetes buddy' as *'this woman'* (line 121), and says she was; *'supposed to talk about diabetes to her on the phone'* (line 122), implying that the suggestion was completely absurd. In line 121 Joyce implies that the arrangement was rather casual, and insignificant, later dismissing it by saying she couldn't *'remember anything about it'*, (line 124). Although she was quite pleased when she had an excuse to decline any further contact, (line 134-143), as her imminent holiday provided the exit. However, in lines 137-140 Joyce adds that her 'diabetes buddy' was not able to continue the arrangement anyway, due to ill health; with the addition of this further information, Joyce presents herself in a positive light, suggesting

that although she did not welcome the arrangement, it was through no fault of her own that it came to an end.

121 *but this woman used to ring me up every now and again,*
122 *supposed to talk about diabetes to her on the phone*
123 *and that like you know.*
124 *I can't remember anything about it.*
134 *I was going on holiday and all that*
135 *and I thought this is a waste of time (laughs).*
136 *It really was,*
137 *and anyway*
138 *and then she had trouble with her hip*
139 *and she had to go and have something done to her hip.*
140 *She had to go into a hospital,*
141 *she said,*
142 *do you want me to put you with another erm whatshername,*
143 *I said forget it.*
144 ***So you didn't find that useful?***
145 *I didn't find that useful at all,*
146 *No*

6.3.1.4 Summary of Type 2 Diabetes Education and Self-management

Many participants admitted to a lack of previous knowledge about diabetes following the EDOP presentation. All the participants had some knowledge of the complications of diabetes like amputations, though they lacked knowledge of the complications specific to eyes with regard to how eye complications occur and how vision is affected. Though many did know that blindness was a complication of diabetes, but did not know why that was.

6.3.2 The EDOP and Eye Health

The aim of the EDOP is to deliver a basic level of diabetes education, as many participants admitted to a lack of information regarding diabetes self-management particularly regarding diet and healthy eating issues, which is the cornerstone of T2D self-care. The EDOP was also designed to disseminate to participants the positive benefits of self-care to reducing the risk of eye complications. It is hypothesised that the EDOP could be the driver required to motivated participants into better T2D self-care through a graphic portrayal of diabetic eye disease and possible visual loss, as they connect poor T2D control with those complications.

6.3.2.1 Education and Information on Eye Health and Diabetes

Many participants are aware of diabetic complications like the loss of limbs and visual impairment due to poor diabetes control through personal experience of friends and family for example. All participants knew that a possible complication of diabetes was poor vision, but all participants were unaware of the connection between T2D control and eye health. None of the participants had any previous knowledge of how diabetes could affect the health of the eyes and how then vision could be lost.

Teresa is aware of diabetes complications following visits to the hospital diabetic clinic (line 517-28), but explains how she lacked knowledge of diabetic eye complications, of understanding of the T2D in general.

Teresa Interview 4

517 *I mean, as I say that day I went,*
518 *the first time I went up there and I seen 'em,*
519 *that really scared me to death.*
526 *and you've got people up with feet off*
527 *and legs off*
528 *and then started coming in with blind,*
529 *and I thought oh my God look at this,*
530 *I thought, don't tell me I've gotta come down to this*
531 *'cause there's no way.*
532 *'Cause when I used to go and see the doctor with different things with me legs and that*
533 *and I used to say to him,*
534 *when I do go up there or down there I want everything still attached to me.*
535 *It frightened me so I don't really much think about it now,*
536 *just trying, in me own little way.*

Teresa explains how a visit to the hospital diabetic clinic was her first experience of the complications of diabetes, she uses an ECF; '*really scared me to death*' (line 519) to express her alarm and fearfulness of the possible of these complications occurring to her. She comments to the researcher in lines 531-34 that she has no desire to suffer these complications, and tries the best she can to adhere to the recommended diabetic health guidelines, (line 536). (Edwards, 2000) points out that ECF are considered to have a 'nonliteral' use, clearly Teresa was not actually scared to death, ECF's are a sign of the speaker's involvement, as happens in hyperbolic constructions, where bold exaggerations are made. (Gibbs, 2000), defined Hyperbole as an, 'extravagant exaggeration by which something is represented as involving a greater intensity than in reality.' (Gibbs, 2000

p17). Thus, (Edwards, 2000) draws attention to the point that ECFs 'may be treated as index of the speaker's attitude (subjectivity) rather than as a straightforward description of the world' (Edwards, 2000 p352).

Teresa like many of the participants has knowledge of the general complications of diabetes like amputations and visual impairment, but lacks understanding of how these complications occur. The EDOP for all participants delivered a general knowledge of diabetes, with regard to the principles of T2D self-management. The following excerpts are typical examples of the participant's comments regarding dissemination of information on diabetes, T2D management and eye health following the EDOP.

551 *'cause I don't even know about,*
552 *well I call it that bleeding behind the eyes,*
553 *all that's crying that's behind your eyes,*
554 *I didn't know anything about that til you showed it to me.*
555 ***So, knowing about that now,***
556 ***does that make any difference to wanting to control your diabetes any better?***
557 *Well you, you can't,*
558 *it does in a way because you,*
559 *you want to control your diabetes*
560 *but until I can get it under control*
561 *and somebody might say*
562 *well come and see us and we'll see what we can do for you,*
563 *if we can get it under control.*
564 *But I can't do no more than what I'm doing now.*

Teresa, like some of the other participants, is not able to link the known complication of loss of vision to healthy lifestyle. She states; '*cause I don't even know*', (line 551). In lines 552-4 she recalls the graphic images, from the EDOP presentation showing the haemorrhages which can occur in the retina which lead to blindness. She uses the phrase; '*all that's crying that's behind your eyes*' (line 553), which conveys emotional upset or physical pain which causes a person to cry. She may have used this phrase because she found the possibility of sight loss to be very emotional.

The researcher asks Teresa if following the EDOP presentation, she is more motivated to have good diabetic control, she replies by saying; '*Well you, you can't*', (line 557). She uses shifting pronouns in her narrative, portraying a sense of an internal dialogue between the inner first person 'I' and a reflexive second person 'you' (Bakhtin, 1981). This inner dialogue communicates the ambivalent subjectivity of the speaker and the constant self-reflexivity and

surveillance required to manage diabetes, as the speaker struggles to overcome habitual ways of being in the world.

Teresa continues to explain in the excerpt that she wants to be better controlled, but feels unpowered, because she lacks the support she desires, (line 558-563), adding the comment; *'I can't do no more than what I'm doing now'* (line 564). This is perhaps because she lacks the knowledge required for empowerment, which is further demonstrated in the following excerpt when Teresa explains about her diabetes control.

172 *- it's like, it's on a wheel,*
173 *you keep going on this wheel,*
174 *you get off,*
175 *you get back on again,*
176 *you get off,*
177 *you get back on again,*
178 *and that's how it is to me.*

627 *But you seem to be,*
628 *as I say, on this wheel,*
629 *you get off,*
630 *you can get back on it,*
631 *you're just on a continuous wheel.*
632 *This is the most contradictory disease I've ever known,*
633 *have summat to eat else you're gonna be bad.*
634 *Don't test your blood before you've had summat to eat*
635 *'cause I've done that,*
636 *and it's...it's been sky high*
637 *and all I've had is about a piece a toast*
638 *and it's gone through the roof.*

It is this lack of understanding as discussed in Section 6.3.1.1 above which makes her angry; *'And that's what makes me angry 'cause I can't understand why'*, (lines 203-4). She also explains in lines 172-8 how frustrating she finds it to control her diabetes with insulin. Teresa describes the incessant routine of needing to increase her insulin dose in order to stabilise her blood sugar levels. Much later in the interview she again refers to this same endless routine (lines 627-631). It is notable again in these excerpts, the shift between the first person and her personal experience of diabetes, and the reflexive second person 'you'. This highlights Teresa struggle to understand her diabetes.

Teresa also proclaims that; *'This is the most contradictory disease I've ever known'* (line 632), however. She comments that it is the misnomer of being told to eat regularly to

manage the diabetes well, but summing that with the regulation of her blood sugar levels as they are high when she would expect them to be lower (line 633-8).

Cynthia Interview 1

Cynthia is aware of the complications associated with diabetic eye disease, but seems to simply reiterate the words of the presentation during the interview, '*small bleeds*', '*little haemorrhages*' (lines 126-127) and does not seem overly troubled by her diabetic eye problems. This may be because she is being monitored by the hospital, which she considers this to be the most exclusive and expert care she can receive, commenting that she receives all the '*essential*' checks (line 138). In lines 128-30 her acknowledgement of the diabetic retinopathy almost seems to be something she is glad about, as are the numerous eye conditions she suffers from; age related macular degeneration (line 134), glaucoma (line 136) and cataracts (line 142). She constructs her eye health status as superior, thus legitimising the extra attention and care. Notwithstanding, this is irrespective of the fact she has eye problems which are in effect considered severe enough to warrant hospital supervision. line 144 she adds; '*my sight is, is quite good,*' this statement perhaps for the benefit of the researcher, and is used to lessen the impact of the very fact she attends the hospital for serious eye conditions.

125 *if they look behind the eyes*
126 *they can then see whether you have got er small bleeds or any erm,*
127 *erm little haemorrhages at the back of your eyes*
128 *which I have,*
129 *and that's why I'm being monitored by the hospital*
130 *on a 6 monthly check up.*
131 **Yes.**
132 *At the moment I don't need any treatment*
133 *but they want to keep their eye on it.*
134 *Erm and er also for erm aging, you know*
135 *and erm, er any other*
136 *you know they test you for glaucoma as well,*
137 *you know and it, it's more er,*
138 *essential for anybody who's got glaucoma in the family.*
139 **Yes.**
140 *But erm,*
141 *er you know apart from that and apart from er*
142 *I've got er cataract on both eyes,*
143 *but at the moment that isn't bad enough to have those taken off.*
144 *And erm my sight is, is quite good,*

When the researcher enquires about her reaction to the EDOP presentation, she is rather dismissive of the educational content and motivational impact. She reiterates on a number of occasions that she was already very knowledgeable, (lines 153, 199, 205 and 248). In line 152 she tells the researcher that the presentation was 'very good', but she would appear impolite to say otherwise, even though she later implies it was of limited value compared to the diabetes social group classes she attended.

When she is asked about her diabetes control and the effect the EDOP presentation may have had, she states; '*I think that's more important to be controlled,*' (line 196). The question posed by this statement is, more important than what? Perhaps she is referring to how she presents herself in society, as a morally responsible person with diabetes. What is most important to her is her desire to present a positive subjectivity. She says that she does control her diabetes, because she is careful what she eats, (line 218). However, as already discussed in section 6.3.1 above Cynthia is not as careful as she claims, as she has a notable 'biscuit habit'. Similarly, when asked by the researcher again in lines 245-6 what difference the EDOP presentation made she ignores the question and reiterates her response, that she knows how to control her diabetes and was doing it already, she also adds a qualifier in line 250, '*And I...I...I already knew and realised*'.

151 **So what did you think of the presentation that I showed you?**

152 *I thought the presentation was very good er,*

153 *a lot of it I already knew from the,*

154 *from the classes that I went to,*

190 **When I showed you the presentation, I showed you about the eye complication**

191 *That's right yes.*

192 **That could lead to loss of sight, blindness...**

193 *That's right yes.*

194 **...how does that make you feel**

195 **about how well controlled you're able to be with your diabetes?**

196 *I think that's more important to be controlled,*

197 *the diabetes to be controlled*

198 *because it does affect your eyes,*

199 *but that I...I knew anyway.*

203 **And did it make you feel more motivated**

204 **to do the things that you should for controlling...**

205 *Oh yes I do do them,*

218 *So erm, I am careful with what I eat*

245 **does it...has it made any difference**
246 **by learning a little bit more about that aspect of the complications?**
247 *Erm, for me personally, erm,*
248 *I was already doing that anyway.*
249 **Yes.**
250 *And I...I...I already knew and realised*

She continues to state explicitly that because she is so knowledgeable it has made no difference to her at all, and that only people who were less well informed would benefit (line 387-391). It is notable in the excerpt that she struggles to articulate herself, she says '*er it...not ... doesn't make you more aware, but it brings you to something different*' (lines 377-379), and although the EDOP did not make her more aware of her diabetes self-control, she did register a change. She uses the second person pronoun 'you' to contemplate the reflexive self.

376 *I think that it makes you more erm,*
377 *er it...not...*
378 *doesn't make you more aware*
379 *but it brings you to something different.*
387 *Well I don't think it's made much difference to me*
388 *because I was very knowledge about it*
389 *But certainly*
390 *I think that it was very useful to anyone*
391 *who hadn't thought about that,*
392 *and as I said,*
393 *especially to er,*
394 *and I...I think you did it,*
395 *it was a very helpful presentation.*

6.3.2.2 Lack of Understanding of Eye Health and Vision

Most of the participants who commented on their visual ability considered it to be satisfactory, as they tended to equate it to their spectacle wear, which demonstrates this lack of understanding.

Richard Interview 16

Similarly, Richard demonstrates his lack of understanding eye health vision when he comments on the difficulty he is having in assimilating his diabetic related eye problem,

whilst continuing to enjoy good vision, (lines 63-66 and 126-127). He comments that he has 'been lucky' (line 65), but implies his luck is beginning to run out.

62 *But, it's hard to explain really*
63 *because they say I've got trouble with me eyes,*
64 *and I've always had,*
65 *I've been lucky*
66 *I've always had very good eyesight.*

120 *Well I tend to think,*
121 *I don't know if it's safe...safety valve*
122 *or what I think oh,*
123 *my ain't that bad yet, mine,*
124 *mine ain't that bad yet.*
125 *I mean well I was saying to meself*
126 *I've still got quite, quite good eyesight.*
127 *I only, I only wear glasses to read the paper*

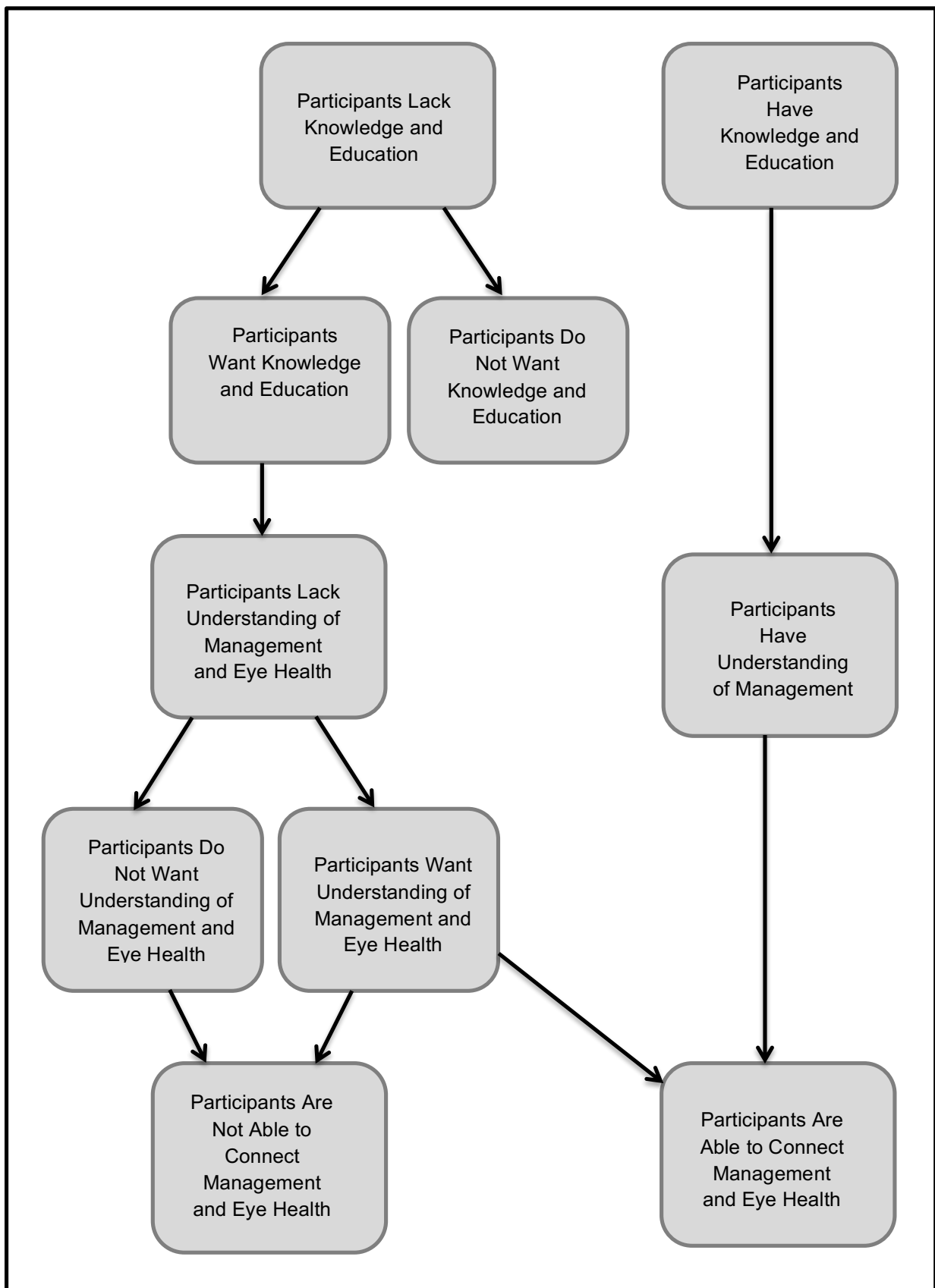
Richard uses a discourse of avoidance, because of his confusion over eye health and vision, he says, '*I don't know if it's safe...safety valve or what I think*' (line 121-2), the safety valve is perhaps a metaphor for his avoidance. Safety valves are switches on pipes that regulate the flow of fluid through them, allowing them to work more effectively; they can turn pipes on or off. Valves are often used to contain dangerous liquids or gases, so he uses avoidance to perhaps suppress the seriousness of his eye problems and/or his diabetes to regulate becoming overwhelmed.

6.3.2.3 Participants' Responses to the EDOP Presentation

The possible outcomes for participants following the EDOP presentation is that they are either able or not able to assimilate the information on eye health and diabetes self-management, which in turn may result in an enhanced motivational experience for those participants who are able to make the connection.

When considering diabetes education, and how knowledge and understanding of diabetes eye health and self-management are linked, the following diagram demonstrates the information processing mechanisms, (figure 2).

Figure 2 - Information Processing Mechanisms for Participants regarding Diabetes Knowledge and Education



Participants who were not able to make a connection and were not motivated

For this group of participants the EDOP did not have any tangible impact, the participants did not report any educational benefit and they were not able to connect eye health and diabetes self-management to become motivationally enhanced.

Donald Interview 15

- 60 ***So what did you think about the presentation***
61 ***that I showed you?***
62 *Well actually it was very good*
63 *all the way through er.*
64 *I didn't get bored with it.*
65 *It kept me focused all the way through it,*
66 *and you explained things as you went through*
67 *and I thought it was very good.*
68 ***So what did you like most about it?***
69 *What can I say? I don't really know, you know.*
70 ***So what about what did you like least about it?***
71 *I didn't like nothing least about it at all.*
72 ***So was there anything that you would change?***
73 *No, I don't think so,*
74 *because you went through all the subjects on it.*
75 ***So that's great,***
76 ***thank you very much***
77 *I've helped you?*

In lines 62-65 Donald states that '*actually*' it was very good (line 62), '*all the way through*' (line 63), he '*didn't get bored with it*' (line 64) and it kept him '*focused all the way through*' (line 65). This narrative constructs an overly positive response to the EDOP, the word '*actually*' perhaps suggests what he claims is not the case and he did find it boring and repetitive or tedious. He continues to be very none committal when the researcher asks for his opinion on various aspects, (lines 68-73). It is also notable from a reflexivity perspective that some participants wanted to please the researcher (line 77).

Doreen Interview 3

In a similar tone to Donald, Doreen has the same intangible experience of the EDOP, and willingness to please the researcher. This is demonstrated in lines 432-434, she tells the researcher what she feels is required and socially acceptable when she responds with the

phrase; 'Say, it's just yes' (line 436), but seeks reassurance that she is being helpful. When Doreen is reminded of the message presented in the EDOP, that she is able to reduce the risk of eye disease by effective self-management of her diabetes; and asked whether it has made a difference she responds with; 'Not at the moment' (line 452). Further to this, in lines 458 and 459 she says; 'So I've sort of found a level at the moment, erm my eyesight isn't altering'. She explains her excuse by saying she has 'found a level', because her eyesight is stable and by implication her diabetes must also be stable and so well controlled. This again demonstrates the participant's general lack of comprehension between eye health and vision. Doreen continues to qualify her position by telling the researcher she has her 'eyes checked;' (line 460), this constructs a compliant discourse; but is perhaps somewhat superfluous as she was recruited for the study by the researcher at the time of her retinopathy screening and 'eye check'.

432 *Not...not,*
433 *or can I say,*
434 *so hard to say.*
435 ***Don't...it doesn't matter what you say.***
436 *Say, it's just yes.*

451 ***– does it make any difference to how you would manage your diabetes?***
452 *Not at the moment,*
453 *erm, as I say*
454 *when I first had it and I read most of the things that they give you,*
455 *I read all of it and took it in,*
456 *erm and bought diabetes books for recipes*
457 *and different things like that.*
458 *So I've sort of found a level at the moment*
459 *erm my eyesight isn't altering*
460 *erm and I have my eyes checked*

Richard Interview 16

Richard similarly as noted in the narrative produced by Duncan and Doreen fails to make a connection between eye health and diabetes control, and is unable to make the step towards affirming how that may happen, (lines 99-106). He is obviously able to state that there is a connection, because the researcher would not be asking the question if it were not the case. But he is unable to explain what the issue is because he has not understood the distinction between eye health and vision. He tries to dismiss his lack of comprehension by stating that he is 'lucky' for his age (line 108). This statement may also serve present a positive identity, because he implies that his T2D is the result of extenuating circumstance,

in this case his age. This proposes a wider causality in an attempt to normalise the condition, and thus minimise the moral implications of the illness and his lack of understanding.

- 99 *I...I think...I think there is a connection somewhere.*
100 **So do you know anything about that?**
101 *No.*
102 **Right.**
103 **So, so it's not occurred to you that there's a connection?**
104 *Well I...I ain't sure really but er,*
105 *I think there must be,*
106 *there must be a c...connection somewhere.*
107 *I mean this is how I look at it,*
108 *I'm very lucky really I'm in my 70s now,*

Participants who were able to make a connection but were not motivated

For this group of participants the EDOP did have some tangible impact, the participants reported an educational benefit and they were able to connect eye health and diabetes self-management but they were not motivationally enhanced.

Duncan Interview 2

Duncan is able to make the connection between vision loss and diabetic eye disease without prompting from the interviewer, (lines 40-47), but misunderstand the connection between eye health and vision in lines 49-52. This is however not a true representation of his knowledge, because he later admits to understanding this connection when he says; '*so I think that lulls me in to a false sense of security, if you know what I mean*' (lines 53 and 54). By implication in the contradiction, he perhaps he doesn't want to know, which he admits to in line 55; '*but I don't think it*'. This is interesting because he appeared to be the participant who had the most denial about their T2D, (lines 30 and 35). In line 36, she says he is able to ignore his diabetes because it does not affect him, as he does not suffer any of the complications associated with diabetes, legitimising his position, notable in the phrase he uses of, '*so, therefore*' (line 37).

- 30 *I call myself borderline.*
31 **Yes.**
32 *And it's er,*
33 *and I don't really,*
34 *to be honest*
35 *I don't really take much notice of it,*

36 *because that's, it doesn't seem to affect me at all,*
37 *so therefore.*
38 *The only I do,*
39 *I like to think this is important because the,*
40 *the one thing you can lose in this life is your sight,*
41 *I think it's the most important thing*
42 *er cos it's the only thing that nature doesn't compensate for,*
43 *the others you can get artificial limbs,*
44 *you can get this that and the,*
45 *but you can't get an artificial eye at all,*
46 *all you can get is a guide dog,*
47 *which, which isn't the same thing.*
48 *So, it is important that er,*
49 *well the only thing I have is reading glasses,*
50 *that's all.*
51 *I can still the telly*
52 *and I can still see things at distance*
53 *so I think that lulls me in to a false sense of security*
54 *if you know what I mean,*
55 *but I don't think it.*

Participants who were able to make a connection and experienced enhanced motivation

Cynthia, Basil and Peter were able to connect eye health and diabetes management and then assimilate that to enhance their motivation to continue their self-care regime. However, it is assumed that the EDOP did not create motivation *per se*, as these participants were already quite motivated in their self-management, but both comment on how it was enhanced, perhaps by providing more self-efficacy.

Cynthia Interview 1

Cynthia describes how the presentation has enabled her to visualise the effects of diabetic eye disease and understand the significance of eye health and T2D management, in a similar way to Tracey and Trevor. She comments on how the presentation made her realise the effects of diabetic eye disease on vision which has made her more determined in her self-care (line 474-483).

459 *and the...the presentation was very good*
460 *because it gives you an insight into something*
461 *which you knew about*

462 *but actually seeing a presentation,*
 463 *seeing the eye*
 464 *and behind the eye*
 465 *and what actually happens behind the eye is helpful.*
 466 *Because although you've got it in your mind*
 467 *you can actually see it on the screen,*
 468 *you see...and er you can...*
 469 ***You can visualise it?***
 470 *...well you can...*
 471 *you can visualise it much better*
 472 *and you can see what actually happens as well you see.*
 473 *You can be...*
 474 *without the presentation*
 475 *you can only erm,*
 476 *surmise you know,*
 477 *well that's what happens behind the eye*
 478 *but when you actually see it,*
 479 *on the screen,*
 480 *and it makes you even more determined*
 481 *not to have it you see,*
 482 *when...once when you see it,*
 483 *see what it does.*
 484 ***So when you understand the consequences of it,***
 485 ***it makes you...***
 486 ***you're saying it makes you more determined.***
 487 *That's right,*
 488 *that's right yes.*

Cynthia uses the second person pronoun, 'you', in this excerpt, representing as discussed earlier ones reflexive self, (Bakhtin, 1981). Her discourse may indicate her struggle to overcome habitual ways of being in the world, as she reflects on the presentation; she is perhaps beginning the process of internalising and enacting the message of the EDOP presentation, which may lead to enhanced motivation. This use of the second person is notable because in previously analysed dialogue Cynthia has had a tendency to use the first person 'I' of her lived experiences with diabetes.

Further to this, the above narrative contains numerous eye and vision references such as; '*insight*' (line 460), '*seeing*' (lines 462, 463), '*eye*' (lines 463, 464, 465, 477), '*see it*' (lines 467, 478, 482), '*see*' (lines 468, 472, 483), '*visualise*' (line 471), and '*you see*' (lines 472, 481). This represents an extremely strong visual representation of eye health in diabetes and vision for Cynthia that is evidenced with her comment; '*without the presentation you can only erm, surmise you know*' (lines 474-476). This narrative provides some substantive

evidence that the EDOP presentation has delivered the desired impact for this study, and will be discussed further in Chapter 7.

Basil Interview 20

Like Cynthia, Basil says he was already aware of the complications with eye health and diabetes (lines 70-75), however, it was only after attending the EDOP that he realised that a healthy lifestyle was what reduced the risk of complications, (lines 76-80, 89 and 100-101). In lines 95-98, Basil says; *'but, I...I hadn't quite realised that the healthy living for to control diabetes would be all, is, is, also a major factor in in eyesight'*, he says the phrase *'healthy living for to control diabetes would be all'* the possibility is that he intended to say *'would be all that is required for good eyesight'*, but does not complete the sentence and makes a repair. This clearly demonstrates that he also understands the extent to which T2D self-management is complicated, and 'healthy living' is not that simple, when he begins to speak the phrase, he realises his error and makes the correction. Basil was already quite motivated to control his diabetes, and in line 104 he states that he is now *'more determined'* since this was explained in the presentation.

- 91 *I thought,*
92 *well I thought the eyes were something that...dete...*
93 *eye deterioration is something that you,*
94 *that you're more prone when you've got diabetes*
95 *but, I...I hadn't quite realised that*
96 *the healthy living for to control diabetes would be all,*
97 *is, is, also a major factor in,*
98 *in eyesight.*
99 **Right.**
100 *I do now since your,*
101 *since your presentation.*
102 **Right,**
103 ***so does that make a difference to you then knowing that information***
104 *It does, it, it makes you more determined.*
- 126 *I realised how lucky I was to not have the,*
127 *the severe diabetes that he had got –*
128 **Yes.**
128 *So that was,*
129 *that was a good motivation as well.*

He states in line 129 that his friend ill fortune was *'good motivation'*, perhaps this implies that good motivation is that which is strong and easy to adhere to. Though if there is good

motivation then the question would be what is 'bad' motivation? However, motivation is not value laden; one can be motivated to do something good or bad, motivation is only valuable, when it becomes a 'motivating factor'. The motivating factor is a personal phenomenon and if it is not personal to that individual, then it has no value and ceases to exist. People with diabetes have the knowledge to know what to do to self-care, but do not act, (Trief et al., 2009) this is perhaps one of the reason that some education programmes fail to be effective, all educators and participants accept that self-management for diabetes is important and valuable, but individuals with diabetes do not rank it of high enough value in their own lives, or other factors are equally or more important and so take precedence.

Other participants, (Leslie, Peter and Duncan) made similar comment to Basil about being lax over their diabetes management and the inner conflict of it. However, after the presentation they noted how they felt more empowered to be motivated to better self-care.

Peter Interview 18

143 *I was motivated before but,*
144 *but what you've done,*
145 *you know you,*
146 *you've jerked me back,*
147 *like you, you tend to get a little bit lethargic about it*
148 *and it, it's dragged me back*
149 *and I thought you, you've really got to*

Peter says he was already motivated to control his diabetes (line 143), but in a similar way to Basil he has been reminded of the need to control his diabetes (line 146 and 148). Perhaps with erosion of motivation which occurs and to which Peter admits (line 147) the EDOP can be a means of rejuvenating the motivational factor for people with T2D.

Basil's narrative, in a similar way to Cynthia's provides evidence that the EDOP may have produced the desired outcome, by enhancing the participant's awareness and motivation for T2D self-care practices. The visual representations of the EDOP presentation are echoed in his choice of vision related words, for example; '*eyesight*' (line 154), '*seen*' (line 154), '*insight*' (line 157) and '*eyes*' (line 159). Later in the excerpt Basil confirms this in line 161, he says that he '*hadn't really connected up before*', and '*so once again it's a, it's good motivation to continue*', (lines 163 and 164). In addition, he acknowledges the difficulty with T2D management, noting that he didn't want to slip back, because '*it is easy to -*' (line 166).

154 *from the eyesight I hadn't quite seen what you,*
155 *what you've showed me, the,*
156 *the different stages that, that can affect you.*
157 *And probably the biggest insight was*
158 *the fact that how important the diet is to,*
159 *to the eyes.*
160 **Yes.**
161 *Which I hadn't really connected up before.*
162 **Right, yes.**
163 *So once again it's a,*
164 *it's good motivation to continue.*
165 **Yes.**
166 *And, and not slip back because it is easy to –*

6.3.2.4 Summary of the EDOP and Eye Health

Many participants admitted to a lack of previous knowledge about diabetes following the EDOP presentation. Some participants were able to connect eye health with effective diabetes self-management; though only those participants who were already motivated experienced enhanced motivation from the EDOP. Those participants who did not already have a sustainable level of motivation were not empowered to better self-care this will be discussed further in Chapter 7.

6.3.3 Diabetic Retinal Screening and Optometric Practice

Participants were asked about their opinion of diabetic retinal screening and who they felt to be the most appropriate person to carry out screening.

6.3.3.1 Screening Gives Reassurance

All participants thought that diabetic retinopathy screening gave them reassurance about eye health and diabetes. They felt that this gave them security that eye problems associated with diabetes were being monitored, though some participants could only associate eye health with vision. All the participants knew the importance of having annual diabetic retinopathy screening, but not all understood its significance or the connotation to T2D management.

Cynthia Interview 1

Cynthia states that for her screening had a wonderful quality (line 119), and it is a 'fact' that it is recommended (line 119-122). Perhaps what she is trying to express is the significance of retinopathy screening for people with diabetes, which is designed to detect potentially sight threatening diabetic eye disease early and so prevent blindness. It is then the gift of sight which is wonderful, rather than screening.

117 ***What you think as well about***
118 ***actual annual screening for your eyes?***
119 *I think annual screening is wonderful and,*
120 *and definitely everybody who has got er diabetes should have it,*
121 *er with their erm,*
122 *in fact it's recommended.*

Peter Interview 18

Peter comments on how much he finds the screening reduces his anxiety about diabetic eye problems, which is typical of all of the participants interviewed. He articulates the value he places on his vision and how precious it is, (lines 34-43). He also like other participants praises the optometrist for undertaking the retinopathy screening, but also for giving advice and offering explanations (line 23 and 35). This perhaps makes Peter and the other participants feel that through the support of their optometrist the responsibility to self-manage their diabetes is shared. Eye health issues and their sight are negated to be the sole responsibility of the optometrist; they have only the responsibility to attend for the screening. Perhaps the off-loading of some responsibility for T2D management makes people feel less overwhelmed and underpowered, and so that is why they claim it to be such a 'wonderful thing', note Cynthia's comments above (line 119).

22 *yes it's been absolutely smashing really*
23 *and I mean very informative.*
24 *I think er, yes, yes, especially erm,*
25 *you see what worried me more than anything obviously*
26 *eyesight is the most precious thing I think anybody can have.*
27 *It's even more precious than life to me*
28 *because I think it's not life without eyesight*
34 *She was ever so good,*
35 *explained to me and,*
36 *and they,*
37 *that gives you peace of mind.*
38 ***So what having your screening gives you peace of mind?***
39 *I, it really does*

40 *er definitely gives you scre...I...*
41 *I look forward to it every year*
42 *because that gives me,*
43 *you know I think great, great.*

Further to the positioning of responsibility for T2D management and eye health, in lines 156-166 Peter links up the reassurance he gets from having the retinal screening with the optician who performs the screening. He describes how his experience of screening is '*not a chore*' (line 160), implying it is pleasurable, explaining to the researcher that he even '*loves*' to go for screening (lines 159 and 161). Again this affection for attending for screening is probably an emotion directed towards the alleviation of responsibility for his diabetes, rather than a love of actually attending the appointment. He perhaps '*loves*' the feeling of relief, empowerment, security, satisfaction, certainty and assurance that having retinopathy screening gives. Peter continues to explain how he had a preference for the optician carrying out the screening, because he feels they have the best experience and training with eye to be able to perform the task, which gives him confidence. Previously in the narrative Peter's uses ECF's to describe the optometrist expertise; '*it's flowing out of him, he knows everything that's going on*' (line 55 and 56). In addition, Peter explains the value of his screening experience, by offers the phrase, '*first hand*' (line 164), when the optician explains about the health of his eyes; the information he receives is not diminished in any way, because it is first hand, not second hand, and by implication better.

52 *the optician it's,*
53 *it's every day,*
54 *it's in him,*
55 *it's flowing out of him,*
56 *he knows everything that's going on.*

159 *Er, er I like, I love to go,*
160 *it's not a, it's not a chore for me to go,*
161 *I love to go because it's peace of mind*
162 *and you know that if there is any more information*
163 *you've got it,*
164 *but you've got it first hand,*
165 *you've got it from somebody as understands*
166 *and knows what's going on.*

6.3.3.2 Confidence in the Optometrist Undertaking Screening

Like Peter discussed above, any participants discuss how they have confidence in the screening because it is their optometrist, who undertakes it, and they trust his expertise. Many of the participants felt that the optometrist was the most qualified person to undertake screening as their training is more specific to eyes and specialised. All of the participants, who expressed a greater confidence in the optometrist as the screener, rather than their GP, gave the reason that, although the doctor was an expert, and so had the same authority as the optometrist it was the optometrist who brought a specialist quality to experience and so inferred as better.

Doreen Interview 3

632 *Because he only specialises in one thing*
633 *rather than the poor doctor who specialises in ha ha a heck of a lot,*

In the above quote Doreen refers to the doctor as 'poor', so then not as valued as the optometrist. However, in line 633 one would question if a person, even a doctor, could be an expert in a large number of specialities.

Mike Interview 11

147 ***Do you think it's a good thing?***
148 *Oh definitely, oh absolutely.*
149 ***Why?***
150 *Well I don't want me eyeballs to go, I don't want to be blind.*
151 ***Do you think it's good that you go to the opticians***
152 ***to have your screening done***
153 ***or do you think it's just,***
154 ***it'd be fine at your GPs practice?***
155 *Oh no definitely the optician.*
156 ***So why is that?***
157 *I wouldn't trust me doctor.*
158 ***Why would you trust the optician more?***
159 *Well I'd work on the theory that*
160 *the optician probably knows a little bit more about it,*
161 *if you want your car fixed you go to a mechanic,*
162 *not a plumber,*
163 *if you know what I mean.*

Even Mike who is noted to be rather cynical with regard to diabetes management from the analysis already undertaken considers screening to be particularly valuable in preventing blindness, (line 148), he adds an ECF in line 150 to further highlight the value of screening in

preventing sight loss. Mike also indicates a preference for the optician to perform the screening, because of his expert knowledge, (line 160-163). He uses an ECF again, but this time with the word '*little*' invoking a minimal property (Edwards, 2000), emphasising his claim that the optometrist is the better expert. He also qualifies his claim by saying; '*if you know what I mean*' (line 163), thus preventing the researcher from questioning his statement.

Richard Interview 16

Richard comments in a similar vein to Mike with regard to preferring the optician to perform the screening, explaining that if he had an eye problem, he would attend an eye clinic, not an '*earache clinic*' (line 73). He also adds the phrase '*ain't it?*' to line 72, implying that obviously for an eye problem; a person would visit the optician, thus preventing any challenge to his claim.

71 *but when you come down to er optician it,*
72 *it's your eyes, ain't it?*
73 *Er, you don't go to the earache clinic you know.*

6.3.3.3 Participants Misunderstanding Diabetic Retinal Screening and Eye Sight Testing

Doreen Interview 3

Many of the participants who misunderstood eye health and vision, discussed above in Section 6.3.2.2, also misunderstood the difference between screening for diabetic retinopathy and sight testing. Doreen is a typical example, and it is noted that the EDOP did not make any difference to her.

550 *and when you test my eyes.*
551 *As I say last time I came*
552 *you said there's a slight change*
553 *but didn't need to change my glasses.*
554 *If you said that is a vast change in my eyes*
555 *then I would think oh I'm doing something wrong*
556 *er or the diabetes is getting the better of me,*
557 *so I would probably need to rethink what I'm doing.*

Doreen is not able to distinguish between her routine eye sight check and the annual diabetic retinopathy screening. She continues to describe how her vision is very good and

she didn't need to change her glasses, but if there was a change the optician would note it on the retinal photographs taken during the screening and at her sight (lines 543-553). However, she says that she would only change her diabetes self-care practices if the optician noted a large change in her eyes (lines 554-557).

6.3.3.4 Summary of Diabetic Retinal Screening and Optometric Practice

All the participants considered that diabetic retinopathy screening was valuable in detecting diabetic eye disease and thus preventing blindness. However, not all of them were able to comprehend the distinction between vision and eye health, as they equated good vision to how well they saw and not why they were able to enjoy good vision. All the participants also thought that the optometrist was the best person to undertake the screening, because they considered the optometrist to be an expert in eyes, as it was their speciality. Whereas the GP was a 'general' specialist and so less qualified.

6.3.4 Individual and Group EDOP Presentation

Participants were asked whether they had a preferred for an individual or group EDOP presentation.

6.3.4.1 Preference for an Individual EDOP Presentation

There were 11 participants who indicated a preference for the individual presentation, though two of these were of South Asian ethnicity who said if the presentation was delivered in their native language of Urdu they would have no preference for either the individual or group session. Most of the participants who gave a preference for an individual session because they were private people and did not wish to discuss their diabetes with strangers, and/or they did not want other members of the group to and monopolise the session. Examples are given below.

Teresa Interview 4

Teresa says that she is a '*private person*' (line 542)

- 541 *I'd rather have the one-to-one basis*
542 *because I, in some ways I'm a private person,*

Peter Interview 18

Similarly to Teresa, he say; *'I think its better talking privately be, you know I think its better talking privately be, you know one to one'* (lines 77 and 78), adding a qualifier of that being more *'intimate'* (line 82), and so more friendly and so perhaps a more comfortable experience for him.

77 I think its better talking privately be, you know,
78 one to one,
79 not the other one.
80 **So why is that?**
81 I think it's,
82 it's more intimate,

Basil Interview 20

Basil comments that his preference for an individual presentation is because; *'you get a lot of stupid questions'* (line 197), which he feels would undervalue the experience, (line 195). In line 196, he substantiates his claim by drawing on past experience, so positioning himself with authority.

193 ***Do you think you might have gained anything***
194 ***from being in a group?***
195 *I, I don't think I'd have gained anything from being in a group,*
196 *having been in groups before*
197 *you get a lot of stupid questions,*
198 *so I think I definitely gained by an individual presentation.*

6.3.4.2 Preference for a Group EDOP Presentation

Twelve of the participants had a preference for the group presentation, though Herminder said she would only like to participate in the group if they were all ladies.

Tracey Interview 6

372 ***So you could like measure yourself against other people's experience?***
373 *Yes, I suppose it is in a way,*
374 *it's a purely selfish thing isn't it,*

375 *because you are measuring yourself against other people who...*
376 *oh I'm...I'm good I am compared to that...*
377 ***I'm just a little bit better than you, yes.***
378 *Yes (laughs)*

When asked why she would prefer the group session Tracey confirms that she compares herself to other people, she measures her own experiences against those of others (line 372-373). She says that this is a 'selfish' act (line 374-378), those this is perhaps what gives peoples the confidence to apply effective self-care, because they are able to compare themselves with their peers. The definition of selfish is; 'deficient in consideration of others, regarding chiefly personal profit or pleasure, (Stevenson, 2010) the connotation in society is to perhaps be amoral at others expense; however, by comparing herself to other people with diabetes she is not being selfish *per se*. She is acting with self-interest for her own gain, but if it does not affect those she compares herself with, because they wouldn't know that was happening, it is then not strictly a selfish act. The act of being selfish is perhaps lessened by Tracey who draws attention to her misdemeanour, as she draws attention on this egocentric discourse, and presents herself more positively.

Mike Interview 11

Mike preference was for group EDOP, as he felt that the opportunity to talk with his peers would be valuable, though he did acknowledge that perhaps he did not wish to speak to everyone, (line 182-184). He uses the words '*miserable buggers*' implying a wretched person not worthy enough to be considered with enough merit to be spoken to. Mike preferred the group presentation because he wanted to gain extra information from the other participants, which would then position him at an advantage over other people with diabetes, because with more knowledge comes power as Foucault discerns.

180 *No I think group was probably better.*
181 ***So why is that?***
182 *Well you could talk to other p...er*
183 *apart from them that was miserable buggers,*

198 ***Okay, why?***
199 *Because you learn things,*
200 *you know if,*
201 *if, if Mr Fred over there says*
202 *oh I've been naughty for the last 3 years*
203 *and me eyeballs are falling out now,*

204 *I'm going blind,*
205 *lah-di-dah,*
206 *you're going to think hang on a minute,*
207 *I could be there in 3 year's time,*

Mike comments rather astutely explain why he feels it is useful to talk with his peers, (lines 199-212), he comments that by learning about other people's diabetes self-management he is able to assess how complications like blindness may be the result of poor control, because of '*naughty*' behaviour. Mike terms deviant behaviour of poor diabetes self-control as '*naughty*', naughty behaviour is seen as behaviour which can be considered more mischievous than bad, and is also a word considered generally to describe something which is improper or tantalising. Mike may consider that not adhering to good diabetes self-control is disobedient but also exciting. However, according to (Broom and Whittaker, 2004) the word '*naughty*' evokes rhetoric which positioning people with diabetes as children, which considers the power differences which are implicit in relationships with health care providers. This child parody simultaneously evokes images of children as blameless innocents who are not responsible for their condition, and also ways in which children are taught to become responsible for their own actions. People with diabetes have their agency as adults reduced by the health services who reproach them to change their ways and by being required to learn new ways of being responsible for themselves.

In lines 182-, Mike says; '*Well you could talk to other p...er apart from them that was miserable buggers*', he may be referring to people with diabetes who are hyper-compliant. According to (Broom and Whittaker, 2004), hyper-compliance might please service providers and protect against one kind of 'spoiled identity', however it makes people vulnerable to negative judgements from fellow diabetic or friends who do not have diabetes. In addition, the phrase '*lah-di-dah*' is used to denote the disingenuous attitude of people pretending to belonging to a higher social class. Mike perhaps sees his '*Mr Fred*', with his diabetic eye disease as belonging to a group in society to which he does not wish to affiliate.

6.3.4.3 Summary of Individual and Group EDOP Presentation

There were six participants who expressed no preference for either an individual or group session and two participants were not asked by the researcher to express a preference. Of the participants who expressed a preference, it is noted that it there was an equal split as participants in this study demonstrated personal preference for the session they favoured. According to a study by (Rickheim et al., 2002) group and individual diabetes education are

equally effective. Education in either setting resulted in similar improvement in learning, behavioural and clinical outcomes. (Adolfsson et al., 2008) explored the relationship in group and individual learning, with vertical relationships being the characteristic of individual learning and horizontal relationships being the former. With vertical relationships the educator is seen as having the superior role and the learner a subordinate one, whilst in group sessions the relationship for all is more mutual, as group discussion contributes to participatory learning, giving them an opportunity to learn from other group members experiences.

6.3.5 Diabetes Self-management, Eye Health and Ethnicity

It was difficult to fully explore the complex ethnicity issues discussed in Chapter 1 Section 1.5, because of the limitation and difficulties experienced in recruiting participants of South Asian origin (see Chapter 3 Section 3.4.2). However, Memuna gives some insight into the issues of exercise and diet in her culture.

Memuna Interview 30

- 10 *I think for Asian people...*
11 *I think it's a big thing*
12 *if an English person is telling them about diabetes*
13 *because they're thinking it doesn't relate to their diet,*
14 *their way of life.*
15 *The way they live their life,*
16 *you know what I mean?*
21 *For an Asian person that wouldn't relate to them*
22 *because they don't relate exercise to do with diabetes,*
23 *so I would advise to use an Asian person*
24 *to show that how exercising actually lowers the blood glucose level*
25 *because they think that exercise is to keep fit,*
26 *not to do with diabetes.*
- 37 *They just think it's all think it's all to do with food,*
38 *which it is, obviously,*
39 *but it's also to do with exercise*
40 *or lack of exercise.*
41 *But a lot of Asians think that it's all to do with food,*
42 *nothing to with exercise.*

In lines 10-16 Memuna explains that for Asian people to act then it must be relevant to them, and the person delivering the presentation needed to be Asian. However, this is not just of significance culturally as noted by this participant; it is also resonant of lifestyle, gender, age, socio-economic status and possibly even severity of the disease. She also explained how most Asian people with diabetes consider self-management to be related to diet alone and do not consider exercise to be a way of managing their diabetes (lines 21-26 and 37-42).

Memuna continues in her narrative to explain from the perspective of her elderly father, also a participant in this study. She describes how alien exercising for pleasure and health would be to him; she says he would say *'have you gone mad?'* if she were to suggested a walk in the park (lines 72-77). She says that for him and many Asian people like him, the way he would lower his blood glucose level is to eat less, because he see his glucose levels are high because he has excess energy, rather than utilising the excess energy by doing more exercise (lines 80-85).

71 *but if I said him, okay Dad,*
72 *we're going to go the park,*
73 *you and me,*
74 *and we're going to walk around the park.*
75 *And he's going say,*
76 *why, are you mad?*
77 *Because he won't relate the walking the park,*
78 *walking somewhere is actually using his energy*
79 *which is going to lower his,*
80 *he would say, let's not eat.*
81 *And that's what he has done,*
82 *he's cut out his meal*
83 *because he wasn't utilising that food,*
84 *so he said let's not eat at all,*
85 *so he's cut down on his food*

113 *we're not taught that exercise is something that we are supposed to do,*
114 *we just feel exercise is there to keep us fit.*
115 *You know to er, not fit,*
116 *I shouldn't say fit,*
117 *but to have yeah, muscles,*
118 *to have a toned body,*
119 *because they don't relate health with exercise.*

In this narrative Memuna adds that exercising for health benefits is not part of the Asian culture, so would associate exercise with developing muscles and to tone the body (lines

117-119). However, it is notable that she understands the concept of exercise to regulate blood glucose levels, as part of a healthy lifestyle to better manage T2D, yet she is quite insistent that it is not what people of Asian ethnicity do, because it is cultural, and so perhaps beyond reproach. In line 113 she says; '*we're not taught that exercise is something that we are supposed to do*'. If exercise is not taught, then they are not supposed to do it, because by implication they do not know any difference. Thus responsibility to manage their diabetes through exercise is negated from Asian people with diabetes without loss of agency within this moral, cultural discourse.

6.3.5.1 Summary of Diabetes Self-management, Eye Health and Ethnicity

Memuna discusses a discourse of compliance to her Asian culture, when she explains how exercising for health benefits is not embedded. However, converse to this Herminder an elderly lady of South Asian ethnicity described how she attended ladies only keep fit exercise class at her temple, this demonstrates that not all Asian people consider exercise to be 'body building' and they do relate health with exercise. Perhaps Memuna is constructing a plausible claim for her own lack of exercise, which thus negates her own poor compliance to diabetes self-care. She presents herself as a model citizen in Asian and Western society, by presenting both perspectives with her narrative, according to (Mattingly, 1998) people construct; 'a dialogue of moral codes about how one ought to live or who one ought to become' (Mattingly, 1998 p118).

6.3.6 Diabetes Self-management, Eye Health and Support from Partners

In the following section partner and married couples describe how they receive support from each other, in particular it is noted that the husbands comment that it is their spouses who actually manage their diabetes.

6.3.6.1 Wives Manage Their Spouse's Type 2 Diabetes

Most participants claimed that their families and spouses were supportive in their T2D management and self-care, and some wives actually took the lead in managing their husband's diabetes. Peter, Basil, Donald, Duncan and Khalid are typical examples of this, so effectively the husbands have little or no responsibility to self-manage their own diabetes.

Peter Interview 18

In line 12 Peter says that he does not find controlling his diabetes difficult, '*sometimes*', so presumably, on occasion he does find it difficult to control. In line 13 Peter's wife says that she controls his diabetes for him with the meals she prepares. Perhaps then it is on the occasions that he has to manage his diabetes himself that he finds difficult.

12 *It's erm, it's not difficult, sometimes –*
13 *WIFE: I control it for him with the meals,*
14 *I mean having chicken and fish,*
15 *no alternatives*
16 *and I think he gets bored quite honestly*

Basil also makes similar comments to those made by Peter, his wife controls his diabetes, by governing what he eats, negating personal responsibility and accountability, which is perhaps why he says he considers himself to be lucky (line 67).

Basil Interview 20

63 *My wife is very, very good*
64 *and really erm controls it for me, b...on the,*
65 *on the diet that she gives me.*
66 ***Right.***
67 *So I'm, I'm very lucky.*

Duncan Interview 2

Doreen Duncan's wife manages his diabetes; and she has a routine that he is compliant with, (line 141-5). Perhaps he is able to so easily deny his diabetes because he has no responsibility for self-care (line 162-163). In line 145, he says he '*never argues about it*', the word '*never*' is an ECF according to (Edwards, 2000), which is used to describe some state of affair as a common practice, not needing further explanation, thus normalising it. He then contradicts this in the next line, as he does not take them when he going out

140 ***So how do you find controlling your diabetes then?***
141 *The missus makes sure I get my tablets,*
142 *er she comes er at times,*
143 *she's got it all timed*
144 *and she brings me me tablet and I take it,*
145 *I never argue about taking it.*
146 *The only time I will not take them is when I'm going out*

159 **So how motivated are you at controlling your diabetes?**
160 *Well I'm...*
161 *to be honest I'm not really,*
162 *I only take me tablet because she gives them to me*
163 *and it doesn't bother me one iota.*
164 **So why is that?**

When the researcher asks how motivated he is to control his diabetes, he says he is not, and that he; '*only take me tablet because she gives them to me*' (line 162), and that it '*doesn't bother him one iota*' (line 163). Obviously he will not be motivated to control his diabetes when his wife takes responsibility, and similarly it is obvious that he would not be bothered.

6.3.6.2 Partners Share Responsibility for Type 2 Diabetes Management

Francis and Fay, Trevor and Tracey and Mike and Mary are typical exemplars of the participants shared responsibility for T2D management.

Francis and Fay Interview 13

During the interview with Francis, Fay would answer the majority of the questions, seeming to take on the persona of having diabetes herself. Fay comments in the narrative on how they had found the EDOP presentation very informative and educational, she says she can remember saying that to Francis (line 132). However, she tells the researcher not to ask her; '*what it was now*' (line 133). This is somewhat absurd, though it is probably a strategy to divert further questioning, where she or Francis may be asked to recall information from the presentation. Perhaps this is because the presentation was not a memorable experience for them. However, within social norms, they may feel compelled to comment on the effectiveness and good quality of the presentation, which has reflexivity issues already discussed in Chapter 3.

In addition to this, Francis and Fay are known to the researcher, because she is acquainted with their daughter, Francis has early onset dementia and Fay often 'covers-up' for his slips of memory, perhaps Fay is anticipating that he will not be able to recall the presentation and so instructs the researcher not to ask about it. This is evidence in line 137 as Francis begins to make an agreement noise in line 136; she seems almost constantly poised to make a repair in the narrative should Francis make a mistake.

123 **So tell me about what sort of education you've had**
124 **for controlling your diabetes.**
125 **Have you had any?**
126 *FAY: Now can I answer this one*
127 *because I know it's exactly the same as what Francis would say?*
128 *We came on that night*
129 *and I only came as spectator as you know,*
130 *but we know learned,*
131 *you told us a lot of things that we'd never been told before.*
132 *I remember coming out saying that,*
133 *but don't ask me what it was now,*
134 *but you explained things more about the back of the eye,*
135 *and we both came out and said that.*
136 **Hm hm.**
137 *FAY: but don't ask me to say exactly what it was,*
138 *because it's a bit too..*
139 *...It was very informative*

6.3.6.3 Summary of Diabetes Self-management, Eye Health and Support from Partners

With regard to the married couples and diabetes self-management, responsibility is either shared, or was the sole responsibility of their wife. In these cases, the husbands comment on how easy they find it to control their T2D, and how compliant they are with their care regime, which is a misnomer. They may be passively compliant, but they are not responsible; the wives take on that responsibility, and the husbands reap the benefits. The husbands with diabetes have reduced risk of complications, through the hard work of their spouse, and they have ensured a positive identity and agency in the management of their disease.

6.4 Discussion of the Themes and Summary of the EDOP

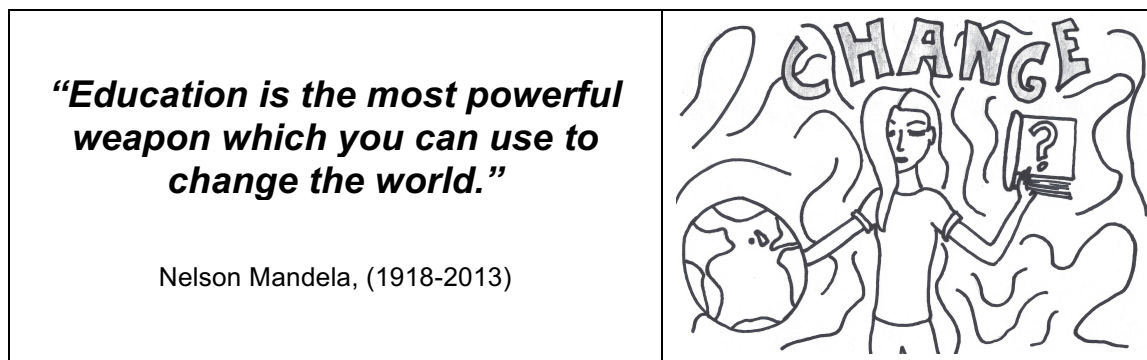
The objective of this study, study (3): Enhanced Diabetic Optometric Practice was to investigate using FDA, the participant's responses to the EDOP presentation. To establish whether an enhanced optometric practice for people with T2D would enable them to become more motivated to self-care practices. Could an EDOP be the mediator to improved personal agency and better self-management of diabetes, significantly reducing the risks of developing complications associated with poor diabetes control, and preventing the loss of vision through diabetic eye disease.

Participants were generally very receptive to the EDOP presentation and all felt it delivered valuable knowledge about T2D self-management and the risk of complications; many participants commented that their diabetes self-management education was lacking. In particular, many participants found the explanation of the mechanisms by which complications occur informative, and commented on how the visual representations greatly enhanced their ability to better understand the sequence of these events. They were able to appreciate that by making seemingly small changes to their diabetes care regime it would significantly reduce their risk of visual impairment.

Some participants had already connected sight loss with diabetes self-management, but for other they were able to do so after the EDOP presentation. All of participants said that they knew eye problems and loss of vision was a possibility of having diabetes; however, after the EDOP presentation they were able to appreciate that it was not inevitable, and that they had the power to prevent blindness by effective self-care and management.

The analysis of these findings relating to; T2D education and self-management, the EDOP and eye health, diabetic retinal screening and optometric practice, individual and group EDOP presentation, ethnicity and support from partners will be discussed in Chapter 7, in relation to the research questions of this PhD study. Also considered in Chapter 7 will be the research question and role of the optometrist in the high street practice to deliver the enhanced optometric practice to people with T2D.

7 DISCUSSION AND CONCLUSION



7.1 Introduction

This chapter considers the findings this thesis as a whole and its implications for people with T2D, eye health and optometry. Firstly, the key findings from each of the three research study chapters will be summarised; Study (1) Investigating the barriers to self-care for people with type 2 diabetes: A systemic review and meta-synthesis of qualitative research (Chapter 4), Study (2) A Qualitative Analysis of Diabetes Self-help Literature and Eye Health (Chapter 5), and Study (3) The Enhanced Diabetic Optometric Practice (Chapter 6). Secondly, the practical implications of the research outcomes will be discussed and each of the research questions will be considered. Finally, the limitations and contribution of this thesis, along with a personal account of reflexivity by the author, and the possibilities for further research in this subject will be presented.

The main research questions for this PhD thesis were;

- 1) Are optometrists suitable people to provide education on T2D and eye health?
- 2) Can an EDOP be the key to effective T2D self-management education?
- 3) Do people with newly diagnosed T2D respond differently to the EDOP than those with established disease?
- 4) Do White people with T2D respond in the same way to an EDOP as those of South Asian ethnicity?
- 5) Do males and females with T2D respond differently to the EDOP?
- 6) Does individual or group delivery of the EDOP have a different impact?

7.2 Summary of the Research Findings

The findings and outcomes of each of the three research studies; Study (1) Investigating the barriers to self-care for people with type 2 diabetes: A systemic review and meta-synthesis of qualitative research, Study (2) 'Can I See the Way?' A Qualitative Analysis of Diabetes Self-help Literature and Eye Health, and Study (3) EDOP are summarised below.

7.2.1 Study (1): Investigating the Barriers to Self-care for People with Type 2 Diabetes: A Systemic Review and Meta-synthesis of Qualitative Research

This review and meta-synthesis was undertaken to enable the researcher of this PhD study to investigate the barriers to self-management and understand what factors prevent effective self-management of T2D. This knowledge was then used in the design of the EDOP to incorporate strategies to overcome these obstacles and enhance successful self-care.

Six themes were found in the meta-synthesis which relate to; patient lack of knowledge or understanding, provider lack of knowledge, provider-patient relationships, social support, external constraints and co-morbidity, and internal constraints. Valuable insight into the barriers and facilitators to T2D self-care has been provided by this review and meta-synthesis, which serves to emphasis the usefulness of undertaking this study, as the themes highlighted were echoed by many of the participant in, Study (3) EDOP (Chapter 6).

7.2.2 Study (2): 'Can I See the Way?' A Qualitative Analysis of Diabetes Self-help Literature and Eye Health

Self-knowledge is about personal governance in society (Philip, 2009) and by learning the rules of self-regulation, illustrated in the self-help texts, people with T2D are able to reduce the risks of diabetic complications and live a healthier, longer life. Self-help literature illustrates the way in which discourses can create, invent, or establish people and their characters, (Rose, 1996); (Ward, 1996); (Hacking, 1986). This study found that self-help texts cannot facilitate the empowerment of people with diabetes who aspire to self-regulation, as they are constrained by the dominant compliant discourse of the expert/patient relationship. Self-help texts reinforce the expert/patient relationship where the author is positioned as the 'expert' and afforded power over the 'patient' with diabetes, as their illness is reduced to a disease, (Cyrino et al., 2009).

When the reader accesses knowledge about diabetes self-management through the self-help texts, they cannot be inspired into effective self-care action. Self-helpers with T2D are

limited by regulatory forces external to the self which are exerted upon them by the texts, and the illusion of concordance is created. Qualitative analysis of the self-help texts and interpretation of these findings along with those of Study (3) EDOP, proposes that the established relationship people with diabetes have with their optometrist presents the conditions for a be-spoke and concordant approach to diabetes management. The optometrist is uniquely positioned to educate and motivate the person with T2D to self-regulate. This is considered further in relation to the research questions in Section 7.3.1

7.2.3 Study (3): Enhanced Diabetic Optometric Practice

Participants felt that the optometrist was the most appropriate health care professional to provide T2D self-management education and information on eye health. Some participants had already connected sight loss with diabetes self-management, whilst others were able to do so after the EDOP presentation. All of participants said that they knew eye problems and loss of vision was a possible complication of diabetes. However, after the EDOP presentation they all knew that it was not an inevitable consequence of having diabetes and that they had the power and capability to prevent blindness by effective self-care and management.

7.3 Discussion and Conclusion of the Research Findings

The research questions posed in Chapter 2 will be addressed, answers to these questions will be proffer, along with the additional questions that will be raised, and the opportunities for further research posed, which will be considered in Section 7.7

7.3.1 Are Optometrists Suitable People to Provide Education on Type 2 Diabetes and Eye Health?

It was considered that the established relationship that people with diabetes have with their optometrist presents the conditions for a be-spoke and concordant approach to diabetes management, the optometrist being uniquely positioned to educate and motivate the person with diabetes to self-regulate. Optometrists, unlike other health care providers are not seen as responsive service providers. It is proposed that the role of the optometrist could be extended via an enhanced diabetic optometric practice, to encourage patients to take personal responsibility for self-care.

Optometrists, as educators of people with T2D, are able to fulfil and exceed all of the requirements for structured education, explained in Chapter 1, Section 1.3. The high street optometry practice, located in the community is readily accessible and a cost-effective opportunity of providing this service and it is familiar to people with diabetes, as the optometrist already provides a role within the NDESP. All the participants of Study (3) EDOP, thought that diabetic retinopathy screening was valuable in detecting diabetic eye disease and thus preventing blindness, and they all considered the optometrist to be the best person to undertake the screening. Whereas many felt that the GP was a 'general specialist', and so less qualified to undertake diabetic retinopathy screening. All participants were more confident in the optometrists ability, because of their specialist knowledge and expertise; and in the opinion of all participants in Study (3) EDOP, the optometrist would be the best person to offer education on T2D and eye health. As mentioned in Chapter 6, this is considered with some caution due to reflexivity issues of participants in the study wishing to please the researcher, and offer what they feel are desirable outcomes.

Further support for the optometrist and the optometry practice being an optimal location for the EDOP is discerned from the study by (Aiellio et al., 2015). The personalised reports were sent to the participant's primary care physician for dissemination; however, at this venue, the information may have had less impact, because the initial location factor of 'the ophthalmologist's office' will have been lost.

It was proposed that the optometrist and optometry practice would provide an 'active ingredient' in this EDOP intervention. It was conjectured that this would facilitate the beneficial outcomes, enabling people with diabetes to make a significant behaviour change towards effective self-control and management; thus reducing the risks of complications associated with diabetes like sight loss. The optometrist delivering the EDOP was for some participants the same optometrist who performed their annual diabetic retinopathy screening and/or their yearly sight test. (Jarvis et al., 2010) warns about the notion of an 'active ingredient' in an education intervention, such as the location, a specific educator or educator style. However, converse to this caution, the researcher of this PhD study has targeted the optometrist and the optometry practice to specifically provide this as an 'active ingredient', which it is proposed will make a difference to people with T2D. The use of digital retinal images as an 'active ingredient' is discussed in response to the next research question, Section 7.3.2 below.

With regard to reflexivity issues, this would certainly add bias to the intervention, though this was considered a positive and desirable effect. This PhD study has intentionally used the

EDOP as an enhancement of the already established ordinary optometric practice which the patient receives from their optometrist; and as such it is improbable to separate the optometrist from the optometry practice, delivering optometry care.

7.3.2 Can an EDOP be the key to Effective Type 2 Diabetes Self-Management Education?

Research has shown that most people with diabetes have sufficient self-management knowledge to successfully self-care, but do not implement it (Trief et al., 2009). (Bandura, 1966) believed that adequate self-care was not applied because they lacked self-efficacy and the confidence to enact effective T2D self-care. With this in mind, the motivational factor presented in the EDOP was one of fear for the loss of sight and possible permanent blindness. However, for fear appeals to deliver the desired impact they need to have a strong, high-efficacy message, (Witte and Allen, 2000), and the recipient must be confident in their belief that they can protect themselves from the threat. However, if the message has a low-efficacy and strong fear component, then a defensive response will be produced, and the desired effect will not be achieved.

In the study by (Wong et al., 2005), from the meta-synthesis undertaken in Study (1), the researchers concluded that the participants felt motivated to be adherent to a foot care regimen as they were fearful of amputation. Perhaps however, it was not the fear of amputation itself, that was the motivating factor; but a fear of the consequences that would ensue after amputation. This would be the case for most people living with the possibility of severe and life changing complications of disease like the loss of a limb or the loss of vision, making this perhaps more poignant than their own mortality. The consideration of living with such a disability is supported by research from the U.S results of the Seven-Countries Survey, (IDF, 2006). Diabetes is the leading cause of blindness in working-age adults and many U.S. adults with diabetes who had not yet experienced vision loss or blindness reported that they were worried about losing the ability to conduct certain daily life activities, such as driving (65%), reading (61%) and continuing hobbies or interests (43%), they also reported the emotional issues of blindness like frustration (44%), depression (34%) and loss of independence (34%).

To ensure the fear appeal of the EDOP would produce a positive outcome and the greatest behaviour change, the message needs to be relevant and 'real' for the participants, thus a threat worth avoiding. When participants in Study (3) appraised their personal vulnerability to the threat of sight loss presented in the EDOP, a tangible intention for behaviour change

based on Protection Motivation Theory was the intended goal (Rippetoe and Rogers, 1987). By ensuring relevance in making the threat 'real' this positioned the long-term risk of diabetic eye disease in the present; allowing participants to consider the benefits of their long-term objectives. Although the participants were not shown their own retinal images and generic images were used, the presentation did have relevance to the screening episode they had received recently, and it was made clear to them that the images they were viewing, although generic were comparable to their own eyes.

The fear appeal contained healthy and normal images, and unhealthy and abnormal images, for participant to make the comparative appraisal for positive behaviour change (Rees et al., 2013); (Williams et al., 2012a); (Grogan et al., 2011); (Salti et al., 2011). The EDOP presentation provided the participants with the means of comparing healthy eyes with abnormal images showing the worsening stages of DR. Animations were also presented and simultaneously equated to poor diabetes self-control and management over time. Animations also portrayed a worsening of diabetic eye disease from mild and non-sight threatening, to severe and the possibility of certain blindness. As discussed in the literature review, Chapter 2, Section 2.3.3.2, the research by (Salti et al., 2011) is particularly relevant to this study, as similar principles were presented as have been used in Study (3) EDOP of this PhD research study.

All the participants were receptive to the EDOP presentation and all felt it delivered valuable knowledge about T2D self-management and the risk of complications. Most participants found the presentation of visual images, which explained the mechanisms by which complications occur particularly memorable; commenting that this had greatly enhanced their understanding of how blindness is a serious and pertinent threat. This suggests that the EDOP had produced the desired strong fear appeal presenting the loss of sight as a real threat, and that the message to the threat had a high-efficacy. Participants had understood from the EDOP that the risk of blindness was a very real possibility for anyone with diabetes, including themselves, but could be avoided. Those participants who were particularly receptive to the EDOP were able to appreciate that, by making seemingly small and easily available changes, they could significantly reduce their risk of visual impairment, by avoiding the threat and controlling their fear. In addition, the high efficacy message conveyed by the EDOP, that sight loss was avoidable, address the issues of fatalism regarding the development of diabetes and the assumption that illness is inevitable which is raised in the NICE guidelines (NICE, 2009).

A further consideration is the participant's psychological persona, which requires a mind-set which is more receptive to positive behaviour change. This was achieved through the EDOP presentation and the strong fear appeal with the high-efficacy message as discussed above. However, this was more easily achieved with some participants than others. Those participants who were more responsive to the message of the EDOP were perhaps those who already took their self-care seriously. Exemplars of this were, Cynthia, Basil and Peter were able to connect eye health and diabetes management, which allowed them to gain enhanced motivation to continue with their self-care regime in a more determined fashion, as these participants were already quite motivated in their self-management. Cynthia described how the presentation has enabled her to visualise the effects of diabetic eye disease and understand the significance of eye health and T2D management. She commented that the presentation made her realise the effects of diabetic eye disease on vision, which made her more determined in her self-care.

According to (Mensing et al., 2007) the patient's psychological reasoning is a very significant factor in enabling successful self-management and empowerment education for diabetes self-management . A desirable state of mind to facilitate a positive behaviour change for the participants of the EDOP would be similar to that of the participants in the (Song et al., 2010) study, reviewed in Study (1) the meta-synthesis. (Song et al., 2010) found that the older Korean participants had a firm belief in Confucianism, the foundations of Confucianism is based on the belief that human beings are fundamentally good, and teachable, improvable, and perfectible through personal and communal endeavor especially self-cultivation and self-creation. This renders a greater willingness to embrace a positive personal behaviour change. It was considered that these principles could be translated to those participants of the EDOP who have a similar mind set and are able and willing to be empowered in this way, and thus motivated to achieve sustainable life-long self-care via this paradigm.

7.3.3 Do People with Newly Diagnosed Type 2 Diabetes Respond Differently to the EDOP Than Those with Established Disease?

Due to the difficulties encountered in recruitment of participants for this study, it was not possible to determine an outcome for this research question. As mentioned in the introduction (Chapter 1), the perceived seriousness of diabetes changed from very strong when people were first diagnosed, weakening over the following years, until the complications of diabetes started (Dietrich, 1996). People became more concerned and thus more motivated towards behaviour change as their illness progresses and symptoms develop (Benyamini et al., 1999); (Massaki, 1990). Converse to this, (Matthews et al., 2009)

found that when patients appeared symptom free, they are less likely to be concerned about their illness. With this in mind, the EDOP presented comparative images of the progression of diabetic eye disease; from mild and relatively non-sight threatening, through pre-proliferative DR as the severity and seriousness increases, to proliferative DR and maculopathy with the gravest consequence of blindness. The message conveyed by the EDOP was one of a progressive disease, which can be delayed or even halted and the loss of sight prevented with appropriate self-care.

This message is of relevance for people with T2D who may currently not suffer any symptoms of diabetic eye disease. That is to say, perhaps the length of time a person has been diagnosed with T2D is superfluous; by implication, the length of time since diagnosis determines the severity of a person's eye disease, as T2D is a chronic progressive condition. However, this is perhaps an overly simplified stance, because how well the individual self-manages is what actually determines their risk of sight loss. Notwithstanding, this is also perhaps too simple, as has been discussed on the issues of strategic cheating, (Chapter 2, Section 2.3.4.2). Perhaps the research question of greater value would be; 'What difference does the severity of a person's diabetic eye disease make to how they respond to the EDOP?' A further opportunity for research to understand this question could be proposed, and will be discussed in Section 7.7 below.

7.3.4 Do White People with Type 2 Diabetes Respond in the Same Way to an EDOP as Those of South Asian Ethnicity?

Due to the difficulties encountered in recruitment of participants for this study, it was not possible to establish an outcome to this research with any confidence. However, two of the participants who indicated a preference for the individual presentation where of South Asian ethnicity, and said if the presentation was delivered in their native language of Urdu they would have no preference for either the individual or group session.

In addition, Memuna, a middle aged lady of South Asian ethnicity, who attended the EDOP presentation with her very elderly father, Akeel, commented that because of his strong cultural identity he was particularly unreceptive to the presentation. When the researcher asked her to expand on this, she explained that he did not find any of the presentation relevant to his personal circumstances, or cultural background. Akeel was particularly embedded in his cultural beliefs, due to his advanced years, life-long habits and values, mobility and co-morbidity issues. Research into how people from different cultures and ethnicities relate to an EDOP would provide the opportunity for further research.

7.3.5 Do Males and Females with Type 2 Diabetes Respond Differently to the EDOP?

The research data did not allow for this question to be addressed *per se*, FDA allowed analysis which presented married couples providing shared responsibility for their spouses T2D management. With regard to gender and T2D self-management, discussed in Chapter 1 (Section 1.6), social care and support is important for patients with chronic disease; as it promotes adherence to self-care, through which they are able to achieve better management and control (Toljamo and Hentinen, 2001). In the case of some male participants, their wife took full responsibility, making T2D management their own personal responsibility, particularly notable in this discourse was the interview with Francis and Fay. When sole responsibility was that of the wife, the husbands comment on how easy they found it to control their T2D, and how compliant they are with their care regime, which is a misnomer. A discourse of passive compliance was constructed, where the husbands were able to reap the benefits of their wives hard work. Essentially, they gained autonomy through lack of personal accountability and responsibility for their diabetes, ensuring a positive identity and agency.

Typical gender roles and expectations are; caregiving for wives and autonomy for husbands. However, perhaps a more appropriate comparison for this PhD research study would be between a married partner and those who were single, like a widower for example. (Rook et al., 2011) investigated spousal social control in the context of chronic illness, and referred to research by (Wrubel et al., 2010), who found gender roles in same sex couples, who were in a stable co-habiting relationship, to be less strongly linked to expectations for a partner's involvement in disease management.

In addition, (Beverly et al., 2007) investigated dietary behaviour in married couples and found supporting the couple as well as the individual led to more successful diabetes control. Interestingly, DESMOND invited partners and care givers to attend the course, on the premise of social support discussed in Section 1.6. However, (Wrubel et al., 2010) caution that their analysis demonstrated that a couples-based adherence intervention may be more complex than simply inviting partners to participate; as is the case with DESMOND and other T2D self-management education.

7.3.6 Does Individual or Group Delivery of the EDOP Have a Different Impact?

The participants in Study (3) EDOP were given a choice of a group or individual EDOP presentation. Only six participants did not express a preference, of the participants who expressed a preference, there was an equal split between those who chose an individual or group session. When questioned about their choice in the semi-structured interviews, which took place after the presentation, all the participants concurred that they were happy with session they had opted for. No one said in hindsight they wished they had chosen the alternative session.

Whilst two of the 11 participants who indicated a preference for the individual presentation where of South Asian ethnicity and said if the presentation was delivered in their native language of Urdu they would have no preference for either the individual or group session. Most participants gave reasons of privacy for opting for the individual session, other participants like Basil commented on a dislike of other people's opinions when in a group.

The twelve participants who had a preference for the group presentation, gave reasons of peer comparison and knowledge acquisition as their reason for preferring the group sessions. Mike was an example of a participant who wanted to gain extra information from the other, which he felt would position him at an advantage over other people with diabetes, because with more knowledge comes power as Foucault discerns. In his essay entitled 'Prison Talk' (Foucault, 1980) states that, 'it is not possible for power to be exerted without knowledge and it is impossible for knowledge not to engender power', (Foucault, 1980 p52).

As discussed in Chapter 2, Section 1.3.5, there is some debate as to whether group or individual education is superior. From findings in Study (3) EDOP, those participants who experienced the group EDOP felt they had the advantage of peer comparison. To compare their T2D self-management behaviour, with that of others in the group lead to improved self-confidence, and self-efficacy; with improved self-efficacy comes empowerment, and better self-care becomes less elusive and more attainable.

7.4 Limitations to the Study

Recruitment of participants for this study proved to be more difficult than had been expected, presenting a limitation to the study. This imitation was due to both an ethical consideration and logistical problems; hence the proposal of comparing people with newly diagnosed T2D and established disease was not possible, as discussed above in Section 7.3.3. In addition, a comparison between South Asian and White populations was not as effective as the

researcher had wished, because of the lack of willingness of people of South Asian ethnicity to participate, discussed in Section 7.3.4 above.

With regard to data collection and the participants of South Asian ethnicity, the researcher is White British, this may present a possible limitation in this PhD research study. Although some researchers such as (Ahmad 1993), argue that researchers from the same ethnic or 'racial' background are more likely to obtain a fuller picture, or a more nuanced description of the views of the group being researched, others suggest that whilst there are very positive reasons to encourage people of the same ethnicity to research their own communities, there are also a number of arguments against matching researchers to respondents, (Kelleher, 1996); (Song and Parker, 1995). There are other important markers of identity between people besides ethnicity or race and these authors cast doubt on the need to match ethnicity, or any other characteristic of the researched group with that of the researcher. They also highlight the fact that there are likely to be multiple differences and commonality in the interaction between researcher and respondent. Researchers who are not from the same ethnic background are not precluded from having experience of discrimination in some way and may provoke discussion or the asking of both different and difficult questions. (Bissell et al., 2004) provide evidence to suggest that there are 'no a priori reasons which preclude White researchers (or those from any background) from researching the experiences of minority ethnic groups', (Bissell et al., 2004 p854).

The main limitation to this PhD research study was in not using the participants own digital retinal images. However, care was taken to ensure that participants are able to appreciate that the generic images were comparable to their own. Guidance on applying the model, and its limitations highlighted by (Williams et al., 2012b) were followed and all precautions were taken to achieve maximum effectiveness.

The researcher of this PhD study is also the designer, facilitator and analyst for the study, which for some researchers presents a limitation to the interventions or research (Jarvis et al., 2010). However, these issues have been considered throughout the study and reflected upon to aid transparency and ensure the quality of the research through reflexivity. Notwithstanding, as discussed above in Section 7.3.1, the researcher of this PhD study is uniquely positioned as; an optometrist, the designer, facilitator and analyst are considered to be an advantage.

7.5 Contribution of the Thesis

This thesis has contributed to existing body of qualitative research into people with chronic illness and T2D, suggesting how people with T2D can be motivated towards better self-care and management of their disease. Through an enhancement of ordinary optometric practice, the optometrist, by way of the EDOP, enables people with T2D to gain the confidence to apply the skills required for effective self-management, and the prevention of blindness. This PhD research study provides a major contribution to the profession of optometry, affording practitioners a means of developing their clinical skills to deliver T2D education on eye health, to reduce the risks of sight loss.

7.5.1 Clinical Application of the EDOP Presentation

For research purposes the EDOP presentation has a duration of about 20 minutes, this however, in a busy high street optometry practice is not practical or logistical and would be ineffective. For the EDOP to have relevant practical applications and a clinical benefit for patients and practitioners it would be shorted to 5-6 minutes and be presented in two parts. The clinical EDOP will give patients a baseline level of knowledge about T2D self-management and the risk factors for complications, eye health and DR.

The initial part of this clinical EDOP will take place when the optometrist undertakes the pre-photography procedures of instilling the dilating drops. At this point the patient would not be suffering any blurring of vision from the effects of mydriasis. The clinical EDOP would last for about 3 minutes be presented in the form of a short computer presentation (Step 1-5), which will include images and a narrative, step 6 will be presented by the optometrist.

- 1) Title slide (duration 5 seconds)
- 2) Slide: What is diabetes? and What are the complications - focusing on eye health? (Study (3) EDOP - combination of slides 3 and 4), (duration 30 seconds)
- 3) Slide: Advice on T2D self-management and how to reduce the risk of complications (Study 3 EDOP - slide 5), (duration 40 seconds)
- 4) Slide: Reminder of the features of the retinal image (Study 3 EDOP - slide 6) (duration 10 seconds)
- 5) Animation: Video clip showing the stages of progression of DR, from a health 'normal' eye to advanced DR and blindness. (duration 40 seconds based on Study 3 EDOP - slides 7, 11 and 15)

6) Presentation of the patient's previous retinal image, taken at the last screening session one year ago and discussion of the previous grade (duration 60 seconds)

Whilst the dilating drop are working it is envisaged that this will afford the patient some time for reflection before the second part of the clinical EDOP, when the current diabetic retinopathy images will be taken. Once the current images are captured the optometrist will take 2 minutes or so to draw together the patients current eye health status, previous retinopathy grade and implications for their self-management. The optometrist will explicitly state to the patient that their eye health is stable or has changed, indicating it has increased from X% to Y%. Further to this, for the EDOP to have real clinical relevance when an increase in DR has been noted, the patient can then be referred for assistance with their diabetes self-management. A possible suggestion is the Diabetes Manual, which has been shown to improve participant self-efficacy and confidence (Section.1.4.3.3); as this PhD study has highlighted, it is these factors which are key in improved self-care for people with T2D.

7.6 Reflexivity

Throughout this PhD research study, I have been conscious of my personal involvement in this research; as author, researcher, interviewer, and analyst and how that has shaped the direction and the outcomes of this thesis. I have endeavoured to be transparent in the presentation of and explanation of my research proposal, rationale, research methods, in the analytical approach taken, and in the interpretation of the findings; making a deliberate effort to explain the methodological issues throughout.

The focus of this PhD research study has been on T2D self-management education and eye health, and I have tried to be consistent in my presentation of the EDOP and interview technique. Notwithstanding my position as an experienced clinical optometrist, and also my relationship with the participants, as their own optometrist in many cases, has inevitably meant that I may have provided, a more personal interpretation of their diabetic retinopathy screening than might otherwise have been the case. Whilst this has raised important ethical questions regarding my relationship with the participants, my position as a professional optometrist, and with the standards in professional practice, it has meant I have been able to maintained a separation between the two.

I do not, however, believe that these reflexivity issues are of overly significant consequence, as they are the same as any optometrist would encounter in providing an EDOP to their

patients with T2D. In addition, as stated above, this can be translated as an advantage in this PhD study, as the optometrist and optometry practice provided the 'active ingredient' to this intervention. I am particularly pleased that when I have subsequently seen my participants in a professional capacity for their sight test and/or diabetic retinopathy screening, all have enquired as to the outcomes of this research and most expressed their gratitude at being involved in the project and having benefited of this unique T2D self-management education.

I have found undertaking this qualitative research to be a challenging aspect of this thesis due to my lack of prior experience in this methodological field. The many hours of effort in understanding these methods, starting from the position of novice have however, been rewarded by a tremendous sense of achievement in gaining such a rich understanding of the data through FDA. This has brought a critical perspective to my research in a field where patient behaviour is often tangential to what a strictly quantitative or physiological analysis might suggest. I feel privileged to have been able to offer interpretation on the contradictions and variation I have discovered exists within the discourses I have studied in researching this PhD thesis.

In summary, and keeping to my theme of quotations, both within and additional to this research, I quote Prof. Johnny Ludvigsson; (T2D in Adults of All Ages, Fox and Hanas, 2008 p9), one of the self-help books reviewed in chapter 5

'It is no fun getting diabetes, but you must be able to have fun even if you have diabetes'.

Prof. Johnny Ludvigsson, (Sweden)

7.7 Further Research

This PhD research study has shown that an EDOP is effective in giving people with T2D the confidence to more effectively self-manage. However, if it were tailored to use personal data, and peoples own retinal images, research has shown that the outcomes can have a greater impact on the patient, and is more effective (Williams et al., 2012a); (Grogan et al., 2011). Perhaps a further research project would be to compare participant responses to images of generic diabetic eye disease, with those from their own eyes. An interesting addition to this suggested further research study would be to determine if the response was different for different degrees of DR, and thus different levels of threat provided by the increasing fear

appeal. The research proposal could offer insight into the response to an EDOP, with participants whose eye health status provides three different categories of DR severity; participants without DR, participants with mild non-sight threatening complications, and participants with serious diabetic eye disease.

The effects of an annual, on-going EDOP programme were not investigated in this PhD research study, but this proposal could perhaps form the basis of further research. Various avenues of investigation are possible using this annual event which could take place simultaneously with the patient's yearly diabetic retinopathy screening appointment. Drawing on the findings of the Study (1) the meta-synthesis, participants in the (Casey et al., 2009) study acknowledged that they did not always put their health first. The normal obligations which constrained them are inverted when they were part of an organised diabetes self-management exercise programme. Perhaps the EDOP could offer similar benefits with regard to T2D self-management education and eye health, with an annual refresher course to reminding them of the benefits of effective self-care.

The positive effects of education decline over time, (Norris, 2002) and needs continual maintenance to obtain the best possible health outcomes (Rhee et al., 2005). As mentioned above, a key factor of the EDOP, is that it could be repeated annually. When people with diabetes become accustomed the annual EDOP event of screening and education, with the adage of being able to compare their own images year on year; this would bring the long-term threat of possible blindness, into the present, galvanising them into immediate behaviour change. This is supported by a suggestions made by (Aiello et al., 2015), as the researchers considered a possible reason for the negative outcomes of the study was the lack of participants follow up after the initial intervention, and that improved communication may reinforce participant behaviour and improved outcomes. This suggestion presents another avenue for research into the longitudinal effects of the EDOP.

7.8 Concluding Comments

The researcher of this PhD study has drawn on the work of Foucault, who considered power and knowledge to be inseparable and argued that in relatively recent history there has been a shift from 'sovereign power' to 'disciplinary power' in which the population is effectively controlled through self-monitoring processes, (Foucault, 1980). People with T2D are expected to be effective self-managers; personal accountability is implicit in the terminology of self-management, because of the strong moral component of self-care. Failing health, as

in T2D, is intimately linked to failing self, and in particular a failure to self-control (Gomersall et al., 2011); (Rimke, 2000).

Yet a paradox exists, people with T2D have been shown to have improved Hb1Ac levels and good T2D control when they strategically cheated, (Chapter 2, Section 2.3.4.2). Perhaps this paradox can be accounted for by (Willig, 1999) who considered individuals to be constrained by available discourses, because of pre-existing discursive positions, and how the self is limited by the discourses which are available. This PhD study has presented evidence of this fundamental flaw in self-help, self-care and self-management.

People with T2D have personal agency, and mutual respect with their health care providers within the concordance model, a position is achieved where the health care providers and 'experts' in diabetes accept the person with T2D as an expert in their own disease. The EDOP presents an opportunity for optometrists to assist in this process, by facilitating the empowerment and self-efficacy of people with T2D towards better self-care, enabling them to confidently apply the skills to effective self-management and reduce the risk of sight loss. This in turn reduces other complications of diabetes, and will ultimately alleviate some of the financial burden of managing and treating T2D and its complications.

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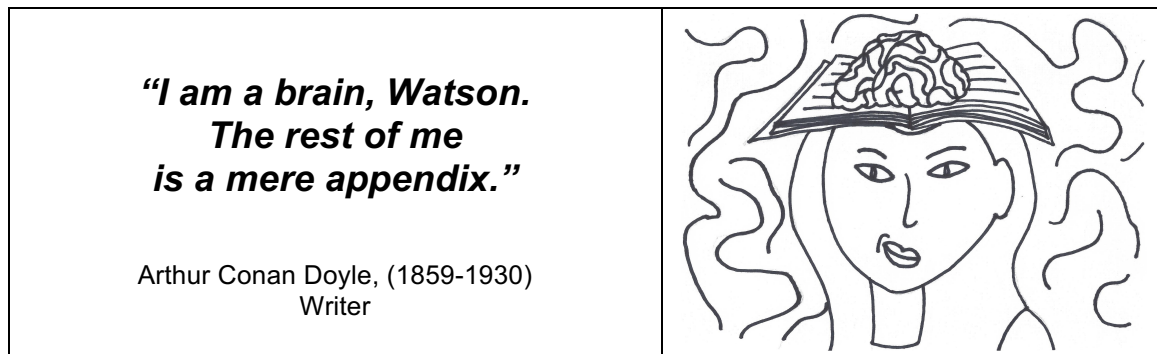
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APPENDICES



APPENDIX 1

List of Abbreviations

ADA	The American Diabetes Association
BDR	Background diabetic retinopathy
BENCH-D	Benchmarking Network for Clinical and Humanistic Outcomes in Diabetes
BM	Measurement of blood glucose level
BMI	Body mass index
BP	Blood pressure
CASP	Critical Appraisal Skills Programme
CCG	Clinical Commissioning Group
CSM	Common-Sense Model
DA	Discourse analysis
DAFNE	Dose Adjustment For Normal Eating
DAWN-2	Diabetes attitudes, wishes and needs second study
DCCT	Diabetes Control and Complications Trial
DD	Disc diameter
DECODA	Diabetes Epidemiology: Collaborative Analysis Of Diagnostic Criteria in Asia
DESMOND	Diabetes Education and Self-Management for Ongoing and Newly Diagnosed
DIQ	Diabetes Integration Questionnaire
DLT	Discovery Learning Theory
DoH	Department of Health
DPsy	Discursive Psychology
DQoL	Diabetes Quality of Life Questionnaire

DR	Diabetic retinopathy
DRCR.net	Diabetic Retinopathy Clinical Research Network
DSME	Diabetes Self-Management Education
EDIC	Epidemiology of Diabetes Interventions and Complications
EDOP	Enhance Diabetic Optometric Practice
ECF	Extreme case formulation
ELM	Experiential Learning Model
FDA	Foucauldian discourse analysis
FF	Fatally flawed method
GP	General practitioner
HbA1c	Glycosylated haemoglobin
HBM	Health Belief Model
HDL	High density lipoprotein
HQIP	Healthcare Quality Improvement Partnership
HSCIC	Health and Social Care Information Centre
IDDM	Insulin dependent diabetes mellitus
IFG	Impaired fasting glucose
IGT	Impaired glucose tolerance
IRMA	Intra-retinal microvascular abnormality
IRR	Irrelevant paper
JDC	Joslin Diabetes Centre
JVN	Joslin Vision Network
KP	Key paper
LDL	Low density lipoprotein
LHB	Local Health Board
MIDRU	Medical Innovation Development and Research Unit
MRC	Medical Research Council
NCA	National Clinical Audit Programme
NDA	National Diabetes Audit
NDESP	National Diabetic Eye Screening Programme
NDIS	National Diabetes Information Service
NHS	National Health Service
NICE	National Institute for Clinical Excellence
NIDDKD	National Institute of Diabetes and Digestive and Kidney Diseases
NIDDM	Non-insulin dependent diabetes mellitus
NSF	National Service Frameworks
PDR	Proliferative diabetic retinopathy

PPF	Priorities and Planning Framework
Pre-PDR	Pre-proliferative diabetic retinopathy
QoL	Quality of Life
SAT	Satisfactory paper
SC	Social constructionism
SCT	Social Cognitive Theory
SD	Standard deviation
SDT	Self-Determination Theory
SLT	Social Learning Theory
SPICE	Setting Perspective Intervention Comparison Evaluation
TA	Thematic analysis
T1D	Type 1 diabetes
T2D	Type 2 diabetes
TPB	Theory of Planned Behavior
TRA	Theory of Reasoned Action
TTM	Trans-theoretical Model
UK	United Kingdom
UKMRC	United Kingdom Medical Research Council
UKPDS	United Kingdom Prospective Diabetes Study
UV	Ultraviolet
X-PERT	Expert Patient Education versus Routine Treatment
ZPD	Zone of Proximal Development

APPENDIX 2

The Authors Account of a DESMOND Course

The author attended a two day DESMOND course on the 10th and 17th February, 2011, the evaluation is derived from a blend of observations made on the day, interviews with the course co-ordinators and other published facts.

DESMOND is run by Walsall Healthcare NHS Trust, and it has been available in Walsall for about eight years. The course is available for diabetic patients and their families.

Day 1: (10th February, 2011)

The course is run by two staff, a dietician and a podiatrist.

The opening session is very much an open discussion and the participants encouraged to 'tell their own story', including details such length of diagnosis and any symptoms they had experienced. Participants are encouraged to raise issues and questions they wish to be addressed or answered, which are then written down and displayed. As the session continues and a particular issue is addressed or question answered, it is then recorded next to the respective question or issues posed.

The individual courses are geared to the specific needs of those attending on the day. The group of patients attending on the day the author attended were on diet control and oral glucose lowering agents. However, none of the participants were on sulphonylurea medication (gliclazide), so the risk of a hypoglycaemic attack for these patients was not an issue, and so not discussed.

The question of 'what is diabetes?' was discussed, using the analogy of insulin as the 'key' needed to unlock the cells to let the glucose in. A visual aid of magnetic organs and insulin keys was used to demonstrate this, showing that when insulin is not available the glucose is unable to gain access to the cells and accumulates in the blood. Participants were told that prior to a meal their blood glucose levels were 4-5m.mol/l, and after a meal 6-7m.mol/l; normal blood glucose levels should be between 4-7m.mol/l.¹ The nature of diabetes as a progressive disease was also stressed, with the effects of insulin resistance mentioned.

The secondary complications of diabetes were then discussed, along with the Hb1Ac test, (which is due to change from m.mol/l to %, in May 2011), and the beneficial effects of

exercise and diet were extensively covered. The possibility of eye problems was covered in under 3 minutes and was not discussed in any detail. This may have been because in the initial introduction it was not mentioned by any of the participants as being a concern.

Finally, the participants were asked to put a variety of plastic models of food stuffs, (like bread, pasta, potatoes, crisps, biscuits, fish both oily and white, ham, jams; full sugar and reduced sugar and different fruits) into order of what would contain the most sugar. The exercise required the participants to think about how starches turn to sugar in the body. After they had completed the task the glycaemic index (GI) of food stuffs and the requirement for diabetic patients to have foods with a low GI, like whole grains was discussed. A list of foods was then drawn up for carbohydrates, and the participants were asked to categorise them into starches and sugar, using the knowledge they had just acquired. It was explained that knowing what potential sugars food stuffs contain can be very confusing for diabetic patients and DESMOND was educating them to make the right choices.

Day 2: (17th February, 2011)

This session is run by the same dietician and a diabetic nurse.

The nature of diabetes as a progressive disease was discussed further this week, participants were told that to maintain control of their diabetes they would go from being diet-control only, to needing medication and then finally most of them will end up requiring insulin. Blood glucose targets were also looked at, along with ways of reducing the complications of diabetes.

The patient individual data concerning their latest Hb1Ac level, other blood test results (like liver function), blood pressure readings, and weight are available to the staff. This information is not discussed openly, but the participants are told that they can ask about the information privately if they wish.

The various secondary complications of diabetes were covered, and the sheets of notes from the previous week had been again displayed, and the exercise of addressing the 'real issues' of the participants continued with previous questions posed being answered.

When the eye complications were mentioned it was the cataract and changes in prescription that were discussed more, and with retinopathy tending to be glossed over, by other issues to do with feet, depression and risk of stroke. This is perhaps consistent with the focus of DESMOND, which is very much on diet and exercise, the emphasis on the sessions

attended by the author was on a healthy balanced diet, good blood pressure control, physical exercise, and smoking cessation.

Finally, the participants were asked to do a couple of exercises; firstly matching the number of cubes of sugar to various food stuffs by looking at the food labelling (food stuffs included; bread, pasta, jelly and jams (both standard and reduced sugar varieties), potatoes, tinned custard, soups, yogurts, fish, meats and various biscuits and cakes). This exercise was used to reinforce the message of thinking about the sugar in food stuffs. Participants were then asked to complete the second exercise using the same food stuffs, this time thinking about fat content and how foods may be cooked.

The message implied by the exercise was for participants to go for the reduced sugar or fat varieties when shopping, cooking and generally making food choices, though it was notable that many of the male participants stated that they were not responsible for these activities, which makes participation of the appropriate family members at the course critical to success in these cases.

Patients are given a DESMOND folder pack to take away, and refer to, and they are asked to complete the task set out in the pack at periodic intervals, requiring them to 'set themselves goals' in order to keep their diabetic control in check.

The DESMOND message to the patient is:

- To reduce cholesterol by participating in physical exercise.
- Reduce fat intake and embrace the '5 a-day' message.
- That physical activity will increase wellbeing and reduce depression, lower blood pressure and aid weight loss.
- A way to lower blood pressure is to reduce the amount of salt consumption, and by the weight reduction advocated.
- Weight loss can be achieved by reducing calorie intake by consuming less carbohydrates in the diet, this will also reduce blood glucose levels.
- That all these recommendations encompass improved diabetic control.

The message of DESMOND is for the patient to assume responsibility for the control of their diabetes, and thus reduce the complications of the disease, and by implication, the likelihood of requiring insulin therapy.

The Authors Personal reflection of the DESMOND Course

Overall, the course is informative, well organised and relevant, with the sessions attended being particularly well delivered, and focused at a level easily assessable to all age groups and to all patients, with obviously different levels of health literacy. The course made good and effective use of simple visual aids.

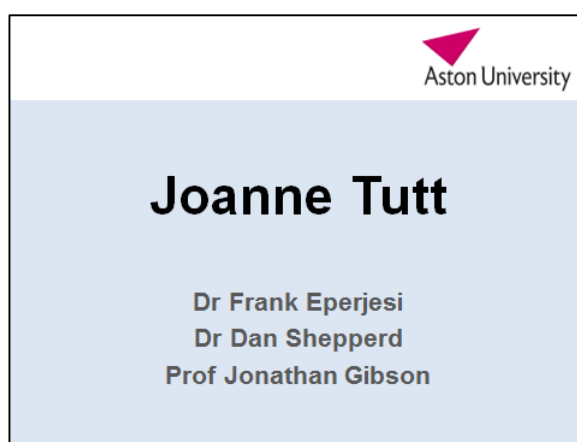
Notwithstanding given the apparent quality of the course, the attendance over the two days was very poor. The course is designed for around 10 participants, at the sessions the author attended there were only 4 participants, at the first session and 5 on the second. Given that the sessions are resourced by 3 healthcare professionals, and with delivery expenses also to cover, there is a clear value for money issue if the attendance at that particular set of course sessions is representative of the programme as a whole.

APPENDIX 3

The Enhanced Diabetic Optometric Practice (EDOP) Presentation

The following slides document the EDOP presentation given to the Participants in Study (3):

SLIDE 1 Introduction to myself and the individuals involved in the study



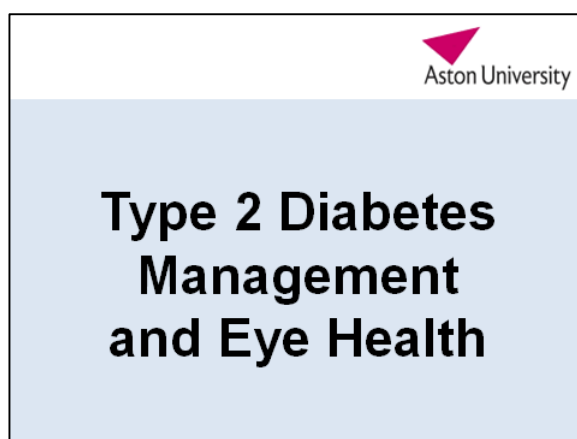
Thank you for coming today, and giving your time.

My name is Joanne Tutt, and this is my PhD study, I am an optometrist and am very interested in the effects of diabetes in the eye and on vision.

The other researchers on the project are: Drs. Frank Eperjesi, Dan Shepperd and Prof. Jonathan Gibson.

It will be my-self who will be presenting this short presentation, and I will be the person who will be conducting the interviews with you in the next few weeks.

SLIDE 2 Introduction to the study - PhD at Aston University



This short presentation will explain diabetic retinopathy and diabetic eye disease, which is damage to the seeing part at the back of your eye, and is a complication that can affect anyone who has diabetes.

My aim is to explain to you what it is, and the positive actions that you can take to prevent the damage caused by diabetes and loss of vision.

You would tend to only notice the signs of retinopathy when it is quite advanced, annual retinal screening detects retinopathy in the early stages and increases the chances of minimal and effective treatment.

I want to investigate your attitudes to this EDOP, I am interested in your thoughts and ideas about how motivated, or not you may be about managing your diabetes after this presentation, which I will ask you about at the interview.

Firstly, What is diabetes?

Diabetes is a common life-long condition, where the amount of glucose or sugar in the blood is too high.

Diabetes happens because an organ called the pancreas does not produce enough insulin, or the insulin that is produced doesn't work properly.

Insulin helps the body store glucose (or sugar) for energy.

There are 2 types of diabetes; type 1 and type 2;

SLIDE 3 What is diabetes?



Diabetes is a common life-long condition, where the amount of glucose or sugar in the blood is too high.

This is because an organ called the pancreas does not produce enough insulin, or the insulin that is produced doesn't work properly.

(Insulin is represented by the key on this picture) Insulin helps the body store the glucose for energy.

There are 2 types of diabetes; type 1 and type 2;

T1D develops before the age of 40 or especially in childhood and is treated with insulin injection, as the body no longer produces insulin. (Diagram type 1 diabetes)

T2D usually develops after the age of 40, though in south Asian people it can appear from the age of 25, the insulin the body produces is damaged, so is not as effective in helping the body store the glucose. (Diagram type 2 diabetes)

Some people are treated with a healthy diet and regular physical activity, but medication and/or insulin is often required.

SLIDE 4 The complications of diabetes



These are the complications of diabetes.

Click to introduce each of the items on the list as they appear:

Heart disease or cardiovascular disease.

Stroke.

Nerve damage or neuropathy can cause problems with your feet.

Kidney disease or nephropathy.

Eye disease or retinopathy is what we are going to concentrate on today.

How do these complications happen?

Persistent high levels of glucose or sugar can lead to damage in the body and in the eyes, and I am going to show you how this occurs.

To reduce the risk of eye problems blood glucose, blood pressure and blood fats need to be kept within a target range, which are advised to you by your GP and monitored by your practice nurse.

SLIDE 5 Reducing the risk of complications

How to reduce the risk of eye disease ?

- Have your annual diabetic screening.
- If you notice a change in your vision, see your GP or optician straight away.
- Talk to your GP or diabetic nurse if you are having trouble achieving your targets for blood glucose, cholesterol and blood pressure.
- Take your medication as prescribed.
- Lose weight (if you are overweight), keep to a healthy diet, high in fruit & vegetables, and low in fat, sugar and salt.
- Increase your levels of physical activity.
- Stop smoking.

How can you reduce the risk of eye disease?

Click to introduce each of the items on the list as they appear:

Attend for annual retinal screening; this will detect any potentially sight threatening eye disease.

Any change in your vision should be reported to your GP or optician immediately.

If you are having problems with controlling your diabetes, you should discuss it with your GP or practice nurse.

Take your medication as prescribed, and do not miss any.

Eat a healthy diet high in fruit, vegetables and fibre; it is the wholemeal and whole grains that are recommended.

Reduce the amount of fat, sugar and salt in your diet.

Live a healthier life style by increasing your physical activity. What is recommended is to do 20 minutes moderate exercise 3x a week, where you get slightly out of breath.

And, give up smoking.

What is the message?

Retinopathy or diabetic eye disease is a complication of diabetes, so the chances of developing retinopathy and vision problems will be reduced by acting on these recommendations.

SLIDE 6 A healthy eye



Illustration removed for copyright restrictions

This slide shows the features of a normal healthy eye.

This is the retinal images, or pictures of the back of your eyes that the optician or doctor looks at to assess the healthiness and to check if there is any damage.

Click to explain each of the features as they appear:

These are the blood vessels on the surface of the retina (seeing part of the back of the eye), there is also a delicate network of tiny blood vessels which supplies the retina with blood.

It is these blood vessels that become blocked, leaky or grow unevenly which damages the retina and prevents it from working properly.

This is the optic disc, where all the blood vessels and nerves enter the eye ball. This picture shows a left eye, because the optic disc is on the left of the image.

Macula area this is the most used part of the retina, it provides us with the most detailed vision and is essential for clear detailed vision.

This is a photograph orientation mark, which is just a feature of the photograph made by the camera.

Firstly, there is early or background retinopathy which can then advance or spread, this is called proliferative retinopathy and there is maculopathy which is eye disease affecting the macula area, and can have the most devastating effect on vision.

SLIDE 7 Video clip - Background retinopathy



Background retinopathy is the earliest damage which can occur in the retina.

Start the video clip: (31 sec)

At this stage, blood vessels in the retina are weakened, this leads to tiny dot-like bleeds.

In the next slides I will explain the features of background retinopathy in more detail.

SLIDE 8 Background retinopathy 1



This slide shows this earliest damage which is visible in the retina. This is a picture of the left eye.

Start the animation:

The small blood vessels in the retina become blocked.

And begin to bulge slightly and look like tiny dots, these are called microaneurysms.

As the tiny blood vessels become leakier, small dot-like haemorrhage or bleeds appear.

SLIDE 9 Background retinopathy 2



This is a picture of a right eye.

Start the animation:

As the tiny blood vessels become even more leaky, the small dot haemorrhage or bleeds become larger forming a blot shaped haemorrhage, within the retina.

This type of retinopathy does not affect your vision, but will need monitoring at the annual screening appointment.

SLIDE 10 Background retinopathy 3



As the blood vessels continue to leak and haemorrhage, a watery fluid, rich in fat and cholesterol is noticed.

Start the animation:

Although the body absorbs the water easily, the fat and cholesterol is left behind in a residue called exudate, which you can see on the picture of a right eye.

I will explain more about the effects of this leaking fluid on your vision a little later.

SLIDE 11 Video clip – proliferative retinopathy



As the diabetic eye disease becomes more advanced, the next stage of diabetic eye disease is called proliferative or spreading retinopathy.

Start the video clip: (25 sec)

As the tiny blood vessels become blocked they burst or haemorrhage, leaking more blood into the retina, at this stage you may notice some deterioration in your vision.

You may notice floaters or blurred patches, which diminish the clarity of your vision.

SLIDE 12 Proliferative retinopathy 1



More bleeds or haemorrhages occur and the degree of retinopathy progresses, having greater and greater effect on the quality of your vision.

Start the animation:

With these circulatory problems with the blood vessels of the retina it means that some areas of the retina don't get enough oxygen.

The following slide shows what happens next.

SLIDE 13 Proliferative retinopathy 2



This lack of oxygen in the retina causes new fragile blood vessels to form to bring this missing oxygen.

Start the animation:

This begins with the blood vessels starting to grow unevenly, and this is noticed as small changes in the blood vessels.

At this point treatment at the hospital may be required.

SLIDE 14 Proliferative retinopathy 2



These new blood vessels will continue to grow, without treatment, especially around the optic disc.

Start the animation:

Since these new blood vessels are so delicate, they could haemorrhage easily leading to blood leaking into the retina and the jelly of the eye.

This is a serious complication of advanced diabetic eye disease.

Vision would be reduced considerably, possibly leading to a permanent loss of vision.

SLIDE 15 Video clip – Maculopathy



The macula is the most used part of the retina; it provides us with the most detailed vision and is essential for clear detailed vision.

Macula eye disease or maculopathy affects the central part of the retina called the macula.

Start the video clip: (1 min 11 sec)

The video clip is showing the macula area.

Fluid begins to leak out of the tiny blood vessels surrounding the macula area, more fluid leaks into the retina. Slowly then the body begins to absorb and soaks up the fluid.

This leaves behind a residue or exudate. These are the fat and cholesterol deposits left behind from the fluid.

(Digital image of the retina appears- 38 sec) You can see this on this photograph of the retina.

As this fluid leaks into the macula area closer to the centre of vision this can cause swelling or macula oedema it is caused by the build-up of fluid at the centre of the macular and it is known as maculopathy.

This watery fluid leaks through damaged blood vessels into the centre of the vision causing swelling of the macula, and damage to the delicate structures that give us our detailed vision. If the fluid accumulates too close to the centre of vision this will lead to vision loss, especially for reading or for seeing finer detail.

The fat and cholesterol deposits or exudates are left behind as I have already mentioned, causing further damage to vision and possibly blindness.

SLIDE 16 Diabetic maculopathy



Here we can see the retinal photographs showing the exudates.

Start the animation:

As the fluid leaks close to the macula, a circular pattern appears around it.

If maculopathy is left untreated it will cause permanent loss of vision and blindness, this is a serious complication of diabetic eye disease.

SLIDE 17 The message

What is the message?

Diabetic retinopathy
can be progressive,
but is avoidable

Diabetic eye disease can be progressive for some people, **BUT** it is preventable for all when the targets of good control and management are achieved, as mentioned on one of the earlier slides.

SLIDE 18 Reducing the risk of complications

How to reduce the risk of eye disease ?

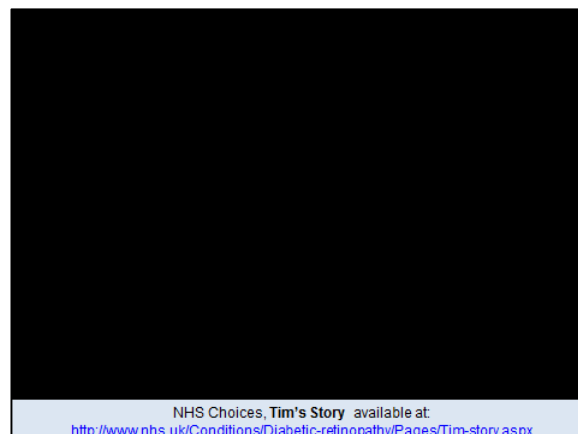
- Have your annual diabetic screening.
- If you notice a change in your vision, see your GP or optician straight away.
- Talk to your GP or diabetic nurse if you are having trouble achieving your targets for blood glucose, cholesterol and blood pressure.
- Take your medication as prescribed.
- Lose weight (if you are overweight), keep to a healthy diet, high in fruit & vegetables, and low in fat, sugar and salt.
- Increase your levels of physical activity.
- Stop smoking.

I would like to reiterate that diabetic eye disease can be progressive for some people, **BUT** it is preventable for all when the targets of good control and management are achieved.

This is the earlier slide indicating how you can you reduce the risk of eye disease?

Retinopathy or diabetic eye disease is a complication of diabetes, so the chances of developing retinopathy and vision problems will be reduced by acting on these recommendations.

SLIDE 19 This is the Message



Diabetic retinopathy is controllable and that sight loss is avoidable.

I want to show you this short video clip about Tim's experience of diabetic retinal screening, and his experience of having diabetic retinopathy.

Also this video clip will explain the purpose and importance of screening from the perspective of someone with diabetes like your selves.

Start the video clip: (2 mins 50 sec) - Tim's dialogue

Tim had eye problems and managed them by living a healthier lifestyle; maintaining good blood glucose (sugar) control, and keeping his blood fats (cholesterol) and blood pressure at the levels recommended by his doctor. The message is that diabetic retinopathy and sight loss are avoidable, and it is down to you.

SLIDE 20 Information on diabetes

Where can you find more information?

- GP / Practice Nurse / Specialist Diabetic Nurse
- Diabetes UK
- Optometrist / Pharmacist
- Internet
- Information Booklets
- Self-help Books
- Educational Courses – DESMOND

Various leaflets and booklets are available on diabetes care.

Please feel free to take a pack.

Remember in the video clip I showed you, Tim had eye problems and managed them by living a healthier lifestyle; maintaining good blood glucose (sugar) control, and keeping his blood fats (cholesterol) and blood pressure at the levels recommended by his doctor. Tim did not do anything other than what was recommended to him by his doctor.

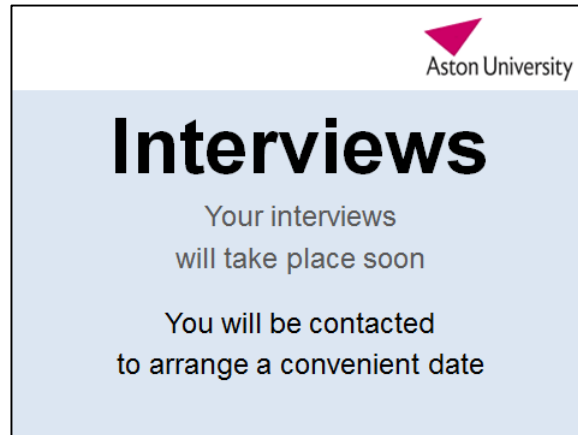
SLIDE 21 Resources available and information



Aston University

Illustration removed for copyright restrictions

SLIDE 22 Interview reminder



Aston University

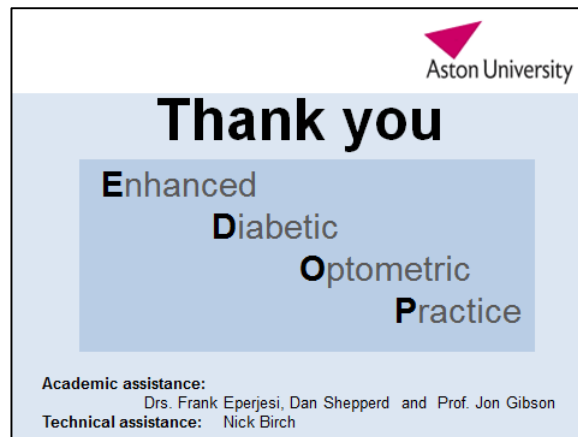
Interviews

Your interviews
will take place soon

You will be contacted
to arrange a convenient date

Just to remind you that you have agreed to be interviewed and I will contact you all in due course to arrange a convenient time.

SLIDE 23 Thank you



Aston University

Thank you

Enhanced
Diabetic
Optometric
Practice

Academic assistance:
Drs. Frank Eperjesi, Dan Shepperd and Prof. Jon Gibson
Technical assistance: Nick Birch

I would like to thank you all for listening and for agreeing to participate in this study, and I look forward to speaking to you again at the interview.
I would also like to acknowledge the assistance I have had and the use of the education material and video clips.
Do you / Does anyone have any questions?

APPENDIX 4

Ethics information

NHS Ethics Approval

Aston University Ethics Approval



Health Research Authority

National Research Ethics Service

NRES Committee West Midlands - The Black Country

HRA NRES Centre Manchester
3rd Floor, Barlow House
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7832
Facsimile: 0161 625 7299

14 June 2012

Mrs Joanne M Tutt
School of Life & Health Sciences,
Vision Science Building,
Aston University,
Birmingham
B4 7ET

Dear Mrs Tutt

Study title: Investigation of the attitudes of people with type 2 diabetes to an Enhanced Diabetic Optometric Practice (EDOP) education intervention, based on retinal images of diabetic retinopathy to focus the patient's emotional reaction to the reality of their condition, in an attempt to improve their self-motivation and management of their diabetes.

REC reference: 12/WM/0134
Protocol number: JMT001

Thank you for your letter of 10 June 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Alternate Vice-Chair and Mrs Jennifer Walton.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

A Research Ethics Committee established by the Health Research Authority

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter from Mrs Joanne Tutt		13 April 2012
REC application 93044/318893/1/150		18 April 2012
Protocol	1	01 February 2012
Investigator CV: Frank Eperjesi		
Investigator CV: Dr Elizabeth Peel		
Investigator CV: Mrs Joanne Tutt		
GP/Consultant Information Sheets	1	18 April 2012
Participant Information Sheet: Volunteer Information Sheet	2	11 June 2012
Participant Consent Form: Volunteer Consent Form	2	11 June 2012
Letter of invitation to participant	2	11 June 2012
Interview Schedules/Topic Guides	1	18 April 2012
Evidence of insurance or indemnity		29 June 2011
Response to Request for Further Information from Joanne Tutt		10 June 2012

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

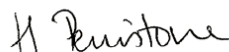
Further information is available at National Research Ethics Service website > After Review

12/WM/0134

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



**Dr Jeff Neilson
Chair**

Email: helen.penistone@northwest.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: Dr Nichola Seare
Aston University
Aston Triangle
Birmingham
B4 7ET

Miss Elizabeth Adey
Heart of England NHS Foundation Trust
MIDRU
Birmingham Heartlands Hospital
Bordesley Green East
Birmingham
B9 5SS

Memo

Life and Health Sciences Research Ethics Committee's Decision Letter

To: *Dr Frank Eperjesi*

Cc: Rachel Giles, administrator to the Life and Health Sciences Research Ethics Committee

From: Dr Doina Gherghel

Chair of the Life and Health Sciences Research Ethics Committee

Date: 5/9/2012

Subject: Project : # 404: Attitudes of people with type 2 diabetes to an emotive education plan

The documentation and additional information for the above proposal has been considered by the Chair LHS Research Ethics Committee.

Please see below for details of the decision and the approved documents:

Reviewer's recommendation: Approved.

Reviewer's comments: This study may now proceed.

Please see the tabled list below of approved documents:

Documentation	Version/s	Approved
Consent Form	1	✓
Participant Information Sheet (PIS)	1	✓
Protocol	1	✓
Risk Assessment	1	✓
Questionnaires	1	✓
Other (please detail)		

[After starting your research please notify the LHS Research Ethics Committee at lhs_ethics@aston.ac.uk of any of the following, quoting the original project reference number:](mailto:lhs_ethics@aston.ac.uk)

- Substantial amendments – any amendment should be sent as a Word document, with the amendment highlighted. Please include a version number and amended date to the file name of any amended documentation (e.g. Ethics Application #100 Protocol v2 amended 17/02/12).
- New Investigators
- The end of the study

Please note that all the necessary documents are available to download from <http://www.ethics.aston.ac.uk/documents-all> Please note that these documents can ONLY be opened using Firefox or the latest IE version.

Yours sincerely



Dr Doina Gherghel
Chair of the LHS Research Ethics Committee

APPENDIX 5

5.1 Participant Information Sheet



Optometry
Vision Sciences Building
School of Life and Health Sciences
Aston University
Birmingham B4 7ET, UK
Tel: +44 (0)121 204 4114

VOLUNTEER INFORMATION SHEET

Project Title

Attitudes of people with type 2 diabetes, to an emotive education plan based on retinal images of diabetic retinopathy

Invitation

You are invited to take part in this research study. Before you decide whether to take part, it is important that you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

The purpose of this study is to assess the effect an Enhanced Diabetic Optometric Practice (EDOP) education plan, focusing on the exploration of diabetic eye problems might have on the patient's emotional reaction to the reality of their condition, and their motivational attitude towards and management of their type 2 diabetes.

The EDOP presentation involves a graphic portrayal of eye changes due to diabetes, where eye photographs taken during annual diabetic screening will be explained. We are seeking to find out whether better knowledge of their eye problems caused by type 2 diabetes may

encourage people to take better control of their diabetic condition, and be the key to improved self-motivation and management.

The assessment of your self-motivation and control of your type 2 diabetes will be determined by way of observation and interpretation of your responses to the interview questions.

Why have I been chosen?

You have been asked to take part because you have shown an interest in the study and because you fit the criteria required. We are aiming to recruit about 40 volunteers in total.

Do I meet the selection criteria?

To meet the criteria you must have type 2 diabetes and describe yourself as either White or South Asian in ethnicity. You must also have a good comprehension of the English language and be able to understand and speak English well.

What will happen to me if I take part?

You will be asked to attend your optician's practice if you have been selected for an individual education presentation, or, if you have been selected for a group presentation, you will be asked to attend Walsall Wood Methodist Hall, Lichfield Road, Walsall Wood WS9 9NP. This session will last for about 30–45 minutes and will take place within 3 months of your selection for the study. The presentation will be video recorded.

Some 4 to 8 weeks after the education presentation you will be asked to participate in an audio taped, semi-structured interview, which will last about an hour. You will be given the choice of interview location which can be; Aston University, your own home, or any other location you are familiar and comfortable with.

The interview schedule will include questions on your diabetes and how you control it. The interviewer will also ask you about any support, advice or education you have received, or would like to receive, regarding your diabetes. We would also like to know about your experience of attending the annual diabetic screening at your optician's practice. Finally, the interviewer will ask you about the presentation, and about your self-motivation before and after.

What do I have to do?

You need to be willing to participate in both a video recorded education presentation, and the follow up semi-structured interview, which will be audio recorded only.

You will be informed prior to the presentation if you have been selected for an individual or group session.

Are there any potential risks in taking part in the study?

Eye problems sometimes associated with diabetes will be discussed during the presentation and the interview, and it is possible that this might make you anxious. The interviewer will be available to answer your questions and help with any concerns you have.

You will be reminded of your right to withdraw from the study, and that you can choose not to answer any of the questions.

What are the possible benefits in taking part in the study?

The benefits of your taking part in the study will be an improved knowledge of your condition, and an increased awareness of the possible problems of diabetes, especially in the eye. We hope that by taking part in the study you will have better self-motivation and better control of your diabetes.

Do I have to take part?

No, participation is entirely voluntary and it is up to you whether you take part or not, you will be given time to consider your decision.

What happens if I change my mind?

You are free to withdraw at any time and without giving a reason, and your standard of care will not be affected.

Will my taking part in this study be kept confidential?

Your anonymity and any personal information will be protected. All data will be stored in a secure area and on a password-protected computer. It will only be accessible to the researchers. Your personal information will remain strictly confidential.

With your permission, your GP will be informed that you have agreed to participate in this research study.

What will happen to the results of the research study?

The data collected will be analysed and the results will be included in Joanne Tutt's PhD thesis. The results may also be published as a research paper in a scientific journal or presented at a conference. The confidentiality of all participants will be preserved. No one will be able to identify you or your comments.

If you would like to receive an information letter summarising the findings at the end of the study, this will be posted or emailed to you. If you wish to receive a copy of any published research paper, please let one of the researchers know.

Who is organising and funding the research?

The researchers involved in the study are Mrs Joanne Tutt, Dr Frank Eperjesi, Dr Elizabeth Peel and Professor Jonathan Gibson. They work in the Vision Sciences Building (Optometry) at Aston University (School of Life and Health Sciences). Professor Jonathan Gibson also works at Heartlands Hospital for the Heart of England NHS Foundation Trust.

Aston University is funding this project.

Expenses and payments

There will be no monetary payment for participation but we will be pleased to reimburse all reasonable travel expenses.

Who has reviewed the study?

The NHS Ethics Committee, NRES Committee West Midlands – The Black Country, and Aston University Ethics Committee have reviewed the study and approved this research.

Who do I contact if I have more questions or haven't understood something?

Please contact Mrs Joanne Tutt, Ophthalmic Research Group, Vision Sciences Building, Aston Triangle, Aston University, Birmingham, B4 7ET or email j.m.tutt@aston.ac.uk or telephone 0121 204 4091. Alternatively, contact Dr Frank Eperjesi at the same address or email f.eperjesi@aston.ac.uk or telephone 0121 204 4114

Independent advice and information on participating in research is available from; Professor Jonathan Gibson, School of Life and Health Sciences, Aston University, Aston Triangle B4 7ET or email j.m.gibson@aston.ac.uk or telephone 0121 204 3848

Who do I contact if I wish to make a complaint about the way in which the research is conducted?

If you have any concerns about the way in which this study has been conducted, you should contact:

The Secretary of the University Research Ethics Committee on,

j.g.walter@aston.ac.uk or telephone 0121 204 4665

APPENDIX 6

Interview Schedule

- 1. Can you tell me how you came to be diagnosed with diabetes?**
How were you told, and by whom?
- 2. How did you feel when you found out that you had diabetes?**
(Relieved / scared / isolated etc.)
How have other people reacted to your diagnosis?
- 3. How do you find controlling your diabetes?**
Do you find it easy/ difficult/ do not really think about it?
How motivated are you to control it?
- 4. What sort of support, advice or education have you had or want?**
Informal information and support from family, friends
Diabetes UK
Books, information leaflets and the internet
Additional input from medical profession/ GP/ Diabetic nurse
Education programmes such as DESMOND, X-PERT, other?
- 5. How have you found the advice / information / support you've been given (by various professionals)?**
(Easy / straight forward / difficult / too complicated / motivational etc.)
- 6. What has been your experience of attending the optometrists practice for your annual diabetic screening?**
Informative / helpful with regard to understanding diabetes and eye complications?
- 7. What do you think about the education presentation?**
Was it informative/ easy to understand/ too complicated?
How did you find your individual/ group session/ would you have preferred an individual or group session?
- 8. Was there anything else you'd like to have been covered in the education presentation?**
What else would you like to see from diabetes education in the future?
- 9. What effect, if any did the education presentation have on you?**
Do you feel more or less motivated / more or less able to control your diabetes?
- 10. Is there anything you want to bring up that we haven't talked about already?**