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**University of Southampton**

Faculty of Environmental and Life Sciences

School of Nursing

**How does the spirituality of a group of people with type 2 diabetes, living in England, influence their coping and self-management of their condition?**

by

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Thesis for the degree of Doctor of Clinical Practice

5 December 2019



**University of Southampton**

**Abstract**

Faculty of Environmental and Life Sciences

School of Nursing

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**How does the spirituality of a group of people with type 2 diabetes, living in England, influence their coping and self-management of their condition?**

**Natasha Duke**

Background: Type 2 Diabetes (T2D) is a lifelong condition mostly managed by people themselves through eating a healthy diet, taking exercise and medicines; many people find it difficult to follow this guidance. In the UK, the National Health Service advises clinicians to incorporate patients' religious, cultural and ethnic beliefs into individual healthcare plans. However, there is a paucity of research that identifies how the spiritual beliefs of British people may influence their coping and self-management of their T2D.

Study aims: The aim of this study was to explore how the spirituality of a group of people with T2D, living in England, influences their coping and self-management of their condition.

Design: The literature reviews led to the refinement of the research question. A constructivist approach using the biographic narrative interpretive method for interviews and thematic analysis for data interrogation were chosen. Eight participants who lived with T2D were recruited (five men and three women) from Hampshire GP Practices, and underwent two interviews focusing on T2D, spirituality and coping. Contextual data was obtained from their medical records including hba1c blood test results, living situation (e.g. alone/partner), age, length of time since T2D diagnosis, body mass index and medicines for T2D to triangulate with the interview data.

Findings: Participants described living with T2D alongside co-morbidities, their spirituality, health beliefs, coping and sense of responsibility for T2D self-management, which overlapped in complex layers. Through interpretive analysis, three themes were generated: (1) spirituality influences expectations in life; (2) beliefs influence coping styles of the self-management of T2D, and (3) responsibility influences the self-management of T2D. Implications for clinicians are to consider how their patients' spirituality, health beliefs, coping and sense of responsibility may influence their self-management of T2D. A model was created to assist clinicians addressing these aspects that may influence patients' self-management of T2D.



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## Research Thesis: Declaration of Authorship

Print name:       Natasha Duke

Title of            How does the spirituality of a group of people with type 2 diabetes,  
thesis:            living in England, influence their coping and self-management of  
                      their condition?

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. Parts of this work have been published as:  
Duke N and Wigley W (2016) Literature Review: The Self-Management of Diet, Exercise and Medicine Adherence of People with Type 2 Diabetes is Influenced by Their Spiritual Beliefs.  
*Journal of Diabetes Nursing* 20: 184–190

Signature:

Date: 5 December 2019



## Acknowledgements

I continue to be inspired and moved by people who live with the daily burden of managing T2D. I am indebted to the participants of this study, who shared their stories with me, some of which were deeply moving. Their struggles inspire me to be a better nurse, and my hope is that as other clinicians read their stories, they will endeavour to give personalised, holistic diabetes care to patients.

I am deeply grateful to my supervisors, Professor Andree Le May and Dr Wendy Wigley, for their guidance and support. Supervision sessions were always stimulating and encouraging, and I believe I was fortunate to have had them as my supervisors. I started out with one question, but the research has left me with many more, and has changed how I read research papers, analyse clinical situations and approach clinical care. I have found studying for this doctorate to be enlightening, rewarding and at times challenging. As I come to the end of this doctoral journey, I realise in fact it is only the beginning of learning about research, and developing research skills that have the possibility to influence clinical practice.

My special thanks go to my husband and my friends who always encouraged me. When times were tough, I drew upon my own spiritual resources to help me gain strength to keep going, and to tell the stories that I believe my participants wanted clinicians to understand.



## **Definitions and Abbreviations**

**BG** - Blood glucose levels

**BNIM** - Biographic narrative interpretive method

**CAMP** - Complementary and alternative medicines and practices

**RQ** - Research question

**DH** - Department of Health

**GP** - General practitioner doctor in a primary care setting in the United Kingdom

**Hba1c** - Glycated haemoglobin blood test, relating to the levels of glucose in the blood

**HP** - Health Professional

**HRA** - Health Research Authority

**NHS** - National Health Service

**NICE** - National Institute of Health and Care Excellence

**PIS** - Participant information sheet

**RC** – religious coping

**R & D** - Research and Development department

**SBNR** - ‘Spiritual but not religious’

**SMB** - SMB behaviours (e.g. diet, exercise and taking medicines)

**SQuIN** - Single question aimed at inductive narrative

**TA** – Thematic analysis

**T2D** - Type 2 diabetes

**UK** - United Kingdom

**US** - United States of America

For a Glossary of Terms, see (p277).





## Chapter 1 Introduction

This thesis is part of a Doctorate in Clinical Practice (DClinP), detailing the exploratory study of how the spirituality of a group of people with type 2 diabetes, living in England, influences their coping and self-management of their condition. In this study, religious beliefs and spiritual beliefs are combined into one term: 'spirituality'; this term is justified in Chapter 2. The impetus for the research arose from my clinical practice as an advanced nurse practitioner in the United Kingdom (UK), specialising in caring for patients with T2D. Managing T2D has been described as 'physically, intellectually, emotionally and socially demanding' (Kousoulis et al. 2014). Although in the UK people with T2D receive support and care from health professionals, the majority of managing their condition relies on them caring for this condition themselves. Everyday individuals must engage with tasks such as managing their diet and taking exercise. In this study, these are termed as self-management behaviours (SMB).

In clinical practice, I found that some patients struggle to manage their T2D well, despite being aware of the risk of complications, such as heart attacks and strokes. Patients may have attended diabetes education workshops and received counselling, received sustained support and advice from practice nurses, diabetes specialist nurses, doctors and dieticians. Usually patients with T2D have clinic appointments every 6-12 months to monitor this condition, and receive clinical advice about their diet, exercise and to have diabetes medication prescribed (NICE 2019a). In addition, monitoring involves assessment/discussion of nine 'care processes' (Box 1).

- Hba1c blood test check
- Blood pressure check to avoid/treat high blood pressure (hypertension)
- Body mass index check, to identify if normal, underweight or overweight
- Serum creatinine blood test, to measure kidney function
- Urine test, to check for protein, which occurs with kidney damage
- Cholesterol blood test, as high cholesterol can cause strokes and heart attacks
- 'Foot check' to examine for loss of sensation to the nerves or blood supply to the feet
- Smoking status check, as smoking increases cardiovascular risk
- Retinal eye screening, to check for damage to the vessels in the eyes, as this can lead to reduced vision and possibly blindness (Retinopathy: see Glossary p275)

(Diabetes UK 2017; NHS Digital 2018; NICE 2019a)

Box 1: T2D annual care processes in the UK

In a clinic, I met Jean (pseudonym) who had poorly controlled T2D. Diabetes control is identified by a high glycated haemoglobin blood test (hba1c). Good control would result in an hba1c near to 48 mmols/mol, but her hba1c was over 100. She commented:

'I don't really worry about my diet or exercise, as I know that God is looking after me. He won't let anything bad happen to me.'

The assessment of how patients' spirituality might influence their health beliefs are not within the diabetes care processes (Box 1)(p277) and does not usually occur in diabetes clinics unless the person uses insulin, and might fast for religious reasons (Peterson et al.2012; Warren 2016; Chabad.org 2019). Jean's comment led me to consider if the spirituality of people with T2D could influence some patients' lack of engagement with their SMB of T2D, even if they were not prescribed insulin. For one week, I selected patients whose hba1c test results showed poor diabetes control, and in an appointment asked them 'What is it that gives you the strength to cope with the challenges in life, such as having T2D?' Many of the patients told me about their spirituality, which included:

- Christians finding strength to cope with the challenges in life because of their belief in God's love and care for them

- Belief from a Wicca witch and one with New Age<sup>1</sup> practices that it is their 'fate' to have T2D, and nothing they can do will alter the outcome, therefore they do not eat a healthy diet or do exercise
- Belief that alternative practices such as hypnotherapy lower their stress levels. On the day of receiving hypnotherapy, they believe that they do not need to 'worry' about their diet, and may not take any of their diabetic medicines
- Belief that cinnamon is a valid alternative rather than diabetes medications. The patient believed this was a more 'natural' treatment for his T2D, rather than his prescribed diabetes medication. On checking, I found a Cochrane study (Leach & Kumar 2012) had shown insufficient evidence to support cinnamon use for T2D
- One Jewish patient not taking his insulin as prescribed due to concerns about the ritual purity of the insulin
- A Muslim patient fasting for Ramadan, but had not discussed this with health professionals, due to fears they would not understand him. He had not reduced his insulin doses sufficiently during his fast, which led to him having dangerously low blood glucose levels.

Following these comments, I performed a literature search regarding 'spirituality' and 'T2D' with a hospital librarian. I found most studies recruited Christian African-Americans, but there was a paucity of research about British patients. Research suggests that the religious beliefs may vary with ethnicity/race upon health beliefs and outcomes (Ford and Kadushin 2002; Franklin et al. 2007; Wallace et al. 2015). As little was known about how the spirituality of British people influences their approach to their SMB of T2D, I decided to commence a part-time self-funded DClInP to research this. I selected a doctorate rather than a PhD as this enabled me to conduct research while working clinically, and facilitate transition to becoming a non-medical prescriber through the Advanced Medicines Management & Pharmacology modules in the doctorate. In addition, I anticipated that completing a doctorate would open up new career opportunities.

As the majority of research regarding how peoples' spirituality influences their SMB of T2D has been conducted with African Americans, this study focused on patients living in England with T2D. A literature review was published with some clinical recommendations in 2016 (Duke and Wigley) and the findings of the present study will be published following DClInP completion to add to the body of knowledge regarding how the spirituality of people may influence their SMB of T2D. If

---

<sup>1</sup> According to Crabtree (2018) New Age practices include a varied collection and mix of practices and beliefs and not a structured belief system; it is not a religion.

clinicians in the UK are informed that patients' SMB of T2D may be influenced by their spirituality, they may choose to discuss this with patients in diabetes clinical appointments (NICE 2019a).

## 1.1 Aim and objectives

The aim of this study is to explore how the spirituality of a group of people with T2D, living in England, influences their coping and self-management of their condition. This aim will be met by the objectives in below (Box 2).

- Explore the condition of T2D and its complications
- Explore the terms 'spirituality' and 'religion' – jointly termed 'spirituality'
- Explore how participants' spirituality influences their coping with T2D
- Explore how participants' spirituality influences the self-management behaviours of following a healthy diet and taking exercise

Box 2: Objectives of the study

## 1.2 Drivers for the study

In the UK, the National Institute of Health and Care Excellence [NICE] advises clinicians regarding treatment and cost effective care of T2D (NICE 2011, 2012, 2015, 2017, 2018, 2019, 2019b; NHS Digital 2018). In England, having T2D entitles a person to free medicines (Diabetes UK no date) and 'exercise on prescription', i.e. clinicians can refer patients to exercise classes at no/low cost (GOV.UK 2017). The government funds these components to assist people to maintain their hba1c around 42-48 mmols/mol (Diabetes.co.uk 2019a; NHS Digital 2018), but individual targets are set for each patient, dependent on factors such as age. The hba1c measures an average of the blood glucose over the preceding 8-12 weeks. In addition to good hba1c control, patients' blood pressure should be less than 130/80 mmHg, and total cholesterol should be less than mmols/L (NICE 2019a). People with T2D who have poor SMB are likely to have these measurements above these parameters (i.e. they have 'poor diabetes control') and may experience the complications of diabetes such as heart attacks and strokes (UK Prospective Diabetes Study Group [UKPDSG] 1998; Huo et al. 2016; Chen et al. 2016; Song 2016; NICE 2019); kidney disease (Shiplack 2011; Diabetes.co.uk 2017) and blindness (UKPDSG 1998; Yau et al. 2012). These complications significantly impact peoples' quality of life (Quah et al. 2011) as well

as NHS resources due to the ongoing care subsequently required (Diabetes UK 2012; Hex et al. 2012; NICE 2012).

Although clinicians are advised to incorporate patients' religious, cultural and ethnic beliefs into individual healthcare plans (DH 2009; NHS 2019) clinicians may be unaware of how these may affect patients' SMB of T2D. This study sought to identify how patients' spiritual beliefs may influence their coping and SMB of T2D, and to publish the results in health-related journals. By having a fuller understanding of how patients' spirituality may influence their coping and SMB of T2D, clinicians will be able to incorporate these factors into patients' planned care, assisting them to have better diabetes control and reduce their risk of complications.

### 1.3 Structure of the thesis

This thesis has eight chapters. **Chapter Two** details the background of the study, outlining the condition of T2D and its management, and discusses T2D within the global and UK context. The potential complications of T2D, and the importance of reducing these through diet, exercise and taking medicines are detailed. The terms 'spirituality' and 'religion' show that a precise definition of the term 'spirituality' is elusive; therefore a definition of 'spirituality' is provided for this study (Figure 2). Finally, the relevance that spirituality has to healthcare is discussed.

**Chapter Three** details two literature reviews. The first review concerned 'type 2 diabetes and spirituality'. The review found that spirituality is a nebulous concept, and that the terms 'spirituality' and 'religion' were inter-related. With regards to T2D, spirituality included spiritual and religious beliefs, psychological aspects, coping styles, ethnicity, gender and complementary and alternative medicinal use and practices (CAMP). These factors overlapped in complex layers, influencing how participants approached their SMB of diet and exercise; CAMP affected adherence to T2D medicines and diet; and ethnicity, gender and coping had associations with spirituality. The second literature review concerned 'religious coping and T2D'. It found that religion and ethnicity influenced spiritual coping, and that positive and negative religious coping influenced the SMB of T2D.

**Chapter Four** details the study design. Firstly, philosophical assumptions and paradigms within healthcare research are outlined, and the choice of using the constructivist paradigm in this study is justified. The method for this study is detailed, namely the Biographic Narrative Interpretive Method [BNIM] (Wengraf 2001) and thematic analysis (Braun and Clarke 2006), with a discussion

## Chapter 1

of reflexivity and bias. The research process, recruitment, pilot interview, contextual data analysis and ethical considerations are also described.

**Chapter Five** discusses the analytic process and the findings of the study, alongside relevant literature. Firstly, the analytic process is detailed, including memo writing, and member checking. Secondly, participants are described in terms of their contextual data and their spirituality. Thirdly, three themes that were generated through interpretive analysis are explained : (1) spirituality influences expectations in life; (2) beliefs influence the coping styles in the self-management of T2D; and (3) responsibility influences the self-management of T2D.

**Chapter Six** is a discussion of how the findings sit within the existing body of literature regarding 'spirituality and T2D'. Unexpected findings, limitations of the study and the robustness of the study is evaluated against the model by Tracy (2010).

**Chapter Seven** is the conclusion of the study, where the key messages are summarised and the relevance and implications for clinical practice and future research are presented.

## Chapter 2 The research in context

### 2.1 Introduction

This chapter will address the first two objectives of the study: ‘to explore the condition of T2D and its complications’, and ‘to explore the terms “spirituality” and “religion”’ (Box 2). Firstly, the condition of T2D is explained, and the global and national prevalence and incidence of various forms of diabetes. The SMB of T2D are outlined, and two of these, namely a healthy diet and undertaking exercise are described within a UK context. Secondly, spirituality is discussed, with an explanation of the term ‘spiritual but not religious’. An outline of the global religious landscape is given, and the consideration of addressing patients’ spirituality within healthcare and nursing are discussed. Importantly, a definition of spirituality for this study is given (Figure 2).

### 2.2 Type 2 diabetes

Diabetes was first identified in ancient Egypt around 3,500 years ago (King and Donnelly 1999). Presently there are twelve types of diabetes recognised, with the most common forms being Type 1, T2D and gestational diabetes, but T2D accounts for 90% of the condition in the UK (Diabetes.co.uk 2019). Type 2 diabetes is a chronic, lifelong condition in which the hormone insulin is not being utilised efficiently. Insulin is necessary to convert the ingested food into blood glucose (BG) to be used for the body’s energy requirements. When insulin is not utilised efficiently, this results in rising BG levels, which damage the body. In the short term, symptoms of poorly controlled diabetes (i.e. high BG) include tiredness, increased urination and skin infections. In the long term, complications of poorly controlled diabetes may result in fatal and non-fatal strokes (UKPDSG 1998; Chen et al. 2016) and kidney disease (Shiplack 2011; Diabetes.co.uk 2017) with eleven percent of deaths in T2D being caused by failing kidneys (Morrish et al. 2001). In addition, sexual dysfunction (Malavige et al. 2009), reduced life expectancy (Leal et al. 2009), and painful nerve damage in the feet may occur, which can lead to lower limb and toe amputations (Boulton 2005; Alvarsson et al. 2012; Barker 2015). Diabetes can cause reduced vision and blindness (UKPDSG 1998; Yau et al. 2012) and is the leading cause of blindness of people of working age in the UK (Diabetes UK 2010). Perhaps unsurprisingly, depression in T2D is common, and is associated with poorer SMB of T2D. In summary, T2D needs to be managed well to prevent the complications of T2D occurring (Katon 2008).

T2D occurs in adults over the age of 40, but prevalence among ethnicities varies (King and Donnelly 1999). Whereas the prevalence among European populations is 2-10% in people over 70

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years old (Oldroyd et al. 2005), T2D is two to four times more common among 'South Asian and Black' people (Diabetes UK 2019g). Although in Europeans it is more common in middle-older ages, T2D may appear after the age of 25 years old in South Asian and African-Caribbean people (Diabetes UK 2010) due to the traditional diet that is high in fat and salt (Diabetes UK 2009).

### 2.2.1 Diabetes globally and nationally

Globally there are 422,000,000 people with T2D, with the prevalence doubling since 1980 to be 8.5% of the global adult population in 2017 (World Health Organization [WHO]). The WHO (2016) states that although diabetes was the 8th leading cause of death worldwide in 2012, it projects by 2030 it will be the 7th leading mortality cause. T2D prevalence has been rising more rapidly in low and middle income countries (Diabetes UK 2019a), and is likely to be caused by an increase in urbanization, increasingly sedentary lifestyles and the rise in obesity (Hu 2011). By 2040, Diabetes UK predicts that 642 million people will have diabetes (Diabetes UK 2019a). Diabetes UK (2018c) estimates that 1 in 11 of the world's adult population have diabetes, with up to 46% of the global population having undiagnosed diabetes. Countries with the highest rates of diabetes include oil-rich nations and the Pacific Islands; in 2017 over 17% of the population in Saudi Arabia had the condition (World Atlas 2019; International Diabetes Federation 2019).

In the UK, there 4.7 million people with all forms of diabetes (Diabetes UK 2019g) - the vast majority of whom will have T2D, with men accounting for 56% of UK adults with the condition (Diabetes UK 2019a). Diabetes UK however identifies that the real numbers are likely to be higher, as many people have the condition but have not been diagnosed (Diabetes UK 2018c). Public Health England [PHE] is the executive agency of the Department of Health and Social Care in the UK, and provides the government, the NHS and Parliament with relevant data to enable the distribution of resources to promote the nation's health. Clinical commissioning groups are clinically led statutory NHS bodies responsible for planning and commissioning the care of healthcare services for their local area and monitored by PHE. In 2016/2017, PHE identified that the Camden Clinical Commissioning Group (in the London area) had the lowest prevalence of diabetes at 4.0% of the population, whereas Bradford City (in the north Midlands) had the highest diabetes prevalence of the population at 10.4% (PHE 2017). Bradford has the largest proportion of Pakistani people in England at 20.3% (City of Bradford 2018) which is higher compared to the national average of 10.8% of Asian/Black/African/Caribbean British people (ONS 2011a). The higher percentage of this ethnicity grouping is likely to account for Bradford having the highest prevalence of T2D in the UK.



Previously, T2D mostly occurred in middle age Caucasians, but it is now occurring in children. Although T2D may occur in adults of South Asian and African-Caribbean people over the age of 25, the first cases of T2D in the UK were diagnosed in 2000. These occurred in overweight girls aged 9-16 years old living in the Midlands and Leicester, and were of Pakistani, Indian or Arabic origin (Ehtisham et al. 2000). Later in 2002, T2D was diagnosed in obese white adolescents (Drake et al. 2002), and in the US a morbidly obese three year old Hispanic girl has now been diagnosed with T2D (Boseley 2015). Consequently, the NHS Long Term Plan (NHS England 2019 p37) is planning ahead by developing services for children with T2D.

According to Diabetes UK (2012), the risk of developing T2D is 15% if either parent has the condition, but if both parents have diabetes, the risk rises to 75%. In the obese children diagnosed with T2D in the UK, parents had T2D or insulin resistance (which is a pre-diabetic condition). It may be that as the prevalence of T2D rises, the possibility of having a parent with diabetes increases. One of the middle-aged, male, white participants in this study developed T2D despite being lean, exercising daily and eating well - both his parents have diabetes. Whilst the likelihood of developing T2D increases with obesity and lack of exercise, it occurs in people of normal weight. This is highlighted by the Department of Health's comment: 'Diabetes is indiscriminate. Whilst the risk of developing diabetes increases with age, anyone can get it' (DH 2001 p2).

In 2006, it was estimated that although diabetes consumed 5% of the UK healthcare budget, the cost was predicted to rise (Kanavos & van de Aardweg 2012) and in 2019, the diabetes spend took 10% of the NHS budget (Diabetes UK 2019e). Diabetes is now predicted to consume 17% of the NHS budget in 2035/2036, with T2D expending approximately 8 times more than other types of diabetes (Hex et al. 2012). The medications for diabetes in the UK account for only a small amount of the diabetes costs (Kanavos and van de Aardweg 2012), but it is the complications of diabetes such as heart attacks and strokes that account for 79% of the NHS diabetes spend (Diabetes UK 2012b). For these reasons, diabetes has been referred to as a 'ticking time bomb' (NICE 2012) and the 'fastest growing health threat of our times and an urgent public health issue' (National Institute for Health Research 2015). The NHS recognises the necessity to prevent T2D, identify innovative ways to reduce disease complications and improve diabetic patients' quality of life (NHS England 2014) with The NHS Long Term Plan (Quilter-Pinner 2018; NHS England 2019) pledging to invest support in preventing T2D and its complications. Joint partnerships such as NHS England (2019), PHE and Diabetes UK are collaborating together to address these important concerns (NHS England 2016).

### 2.2.2 Management of T2D

T2D is a complex condition affecting multiple organs, and patients should attend regular clinical appointments to monitor for potential complications. In the UK, primary care nurses run diabetes clinics, only referring patients with complex needs to diabetes specialist nurses (RCN 2019). In addition to diabetes clinics, patients attend eye screening (PHE 2017) and require additional care if planning pregnancy (Diabetes.co.uk 2019d). Diabetes commonly co-exists with hypertension (Sun et al. 2019), and hypertensive patients will need additional medical appointments (Diabetes.co.uk 2019g). Clinicians advise patients of the SMB of T2D that include attention to diet, taking exercise, daily foot checks (reporting any signs of skin damage) and taking prescribed medicines (NICE 2019). Patients prescribed insulin will require daily multiple finger-prick blood tests to assess BG and adjust insulin doses (Diabetes.co.uk 2019b).

‘Medicines concordance’ is the planned agreement between a prescriber and the patient regarding the prescriber’s recommendation about drugs (Royal Pharmaceutical Society [RPS] 2019). ‘Medicines adherence’ refers to the medicine-taking behaviour of the patient (RPS 2019) and both adherence and concordance are important factors in patients’ medicines management, as between approximately 30-50% of all medicines prescribed for chronic conditions (such as T2D) ‘are not taken as recommended’ (NICE 2009 p4; RPS 2019). This has safety implications (Royal College of General Practitioners 2019), poorer health outcomes, and economic significance. It is estimated that around 45% of people with T2D have poor medicines adherence, with factors including patient-doctor relationships, medication beliefs and the complexity of medicine regimes that patients should adhere to (Polonsky and Henry 2016). Although medicines concordance and adherence is part of the SMB of T2D, it is a complex collaboration between clinician and patient (Cramer 2004; NICE 2009; García-Pérez et al. 2013; Capoccia et al. 2016). As outlined above, there are multiple SMB components to managing T2D. This doctoral study will only analyse the SMB of diet and exercise as these are under the control of the individual, and diabetes nurses spend a large proportion of the time advising patients about diet and exercise. (NICE 2014, 2015, 2017, 2019).

### 2.2.3 T2D and diet

Although all people are recommended to consume a healthy diet, for those with T2D it is essential. Ingested carbohydrate foods convert to glucose causing a rise in BG. The raised BG triggers the release of the pancreatic hormone insulin, enabling glucose to enter cells. For people with T2D, insulin production is reduced, and inefficient utilisation of insulin occurs. In addition, abdominal fat resists insulin. People with T2D are therefore encouraged to maintain a healthy

weight and consume foods that do not require large amounts of insulin utilisation, such as sugar-laden foods and refined carbohydrates. People with T2D are encouraged to learn about a healthy diet and to adapt this to their culture and lifestyle (WHO 2018; NICE 2019; NHS England 2019). There is no 'diabetic diet' to follow, and principles of a healthy diet are shown in Box 3.

- At least 5 fruits/vegetables a day
  - High fibre whole grains and pulses
  - Low fat dairy products and oily fish twice a week
  - Limited amounts of saturated fats, trans fatty acids, salt and glucose.
- (NICE 2015; NHS 2017, 2019b; Diabetes UK 2017)

Box 3: Healthy diet recommendations

#### 2.2.4 T2D and exercise

In the UK, the NHS defines 'regular exercise' as completing 150 minutes of moderate intense aerobic activity a week, which promotes cardiovascular benefits, assists BG control, strengthens bones, improves sleep and reduces stress (NHS Choices 2007; GOV.UK 2017; Diabetes UK 2018b). For people with T2D, exercise should be part of their SMB routine (NICE 2014; 2019, 2019b). Obesity and physical inactivity in Britain are rising, and both are modifiable risk factors in T2D (Gatineau et al. 2014). It is recognised that some people with diabetes lack motivation to exercise (Jenkins and Jenks 2017; Advika et al. 2017), and the NHS therefore offers 'exercise on prescription' (GOV.UK 2017; NICE 2019b). This enables healthcare professionals to refer people with T2D for low cost exercise classes/gym - as both aerobic and/or resistance exercise improves diabetes control (Sigal et al. 2007; Jorge et al. 2011).

Section 2.2 summarised the condition and context of T2D and the self-management of T2D including diet and exercise has been presented. The effects of poorly controlled T2D on individuals and the national economic burden of diabetic healthcare costs highlight the need to better understand the self-management of this condition.

### 2.3 Spirituality and religion

The following section will consider how spirituality and religion sit within healthcare. The terms 'spirituality' and 'religion' will be discussed, and the current global and national religious landscape will be outlined. The role of spirituality within nursing will be discussed, and a definition of spirituality given for this study.

### 2.3.1 The terms 'spirituality' and 'religion'

According to the Dictionary.com (2018e), the majority of words in the English language have a Latin or Greek root. The word 'spirituality' is a noun from the Latin root 'spir', meaning to 'breathe' (Lewis and Short 1879). 'The Vulgate' is a 4th century Latin translation of the Christian holy book, the Bible, which uses the word 'spiritus' to translate the ancient Hebrew word 'רוּחַ' (ruach) from the 'Old Testament' of the Bible and The Torah to mean 'wind, breath, mind, spirit, and the Spirit of God' (QBible 2018; Bereshis 1:2). The Torah is the Jewish sacred text, written in Hebrew around the 5th century B.C. (Finkelstein and Silberman 2001) and forms the first five books of the Bible. The 'New Testament' of the Bible was written in Greek around the 1<sup>st</sup> century A.D. (Cross and Livingstone 2005). The ancient Greek word 'πνεύμα' means 'air, breath, wind, breathing, life, spirit, soul and inspiration' and is also used to mean 'spirit' when referring to the 'Spirit of God' or the 'Holy Spirit' (Strong's Greek Lexicon 2018) found in the New Testament (Acts of the Apostles 2:4).

Historically in the UK, spirituality was part of religious belief. Julian of Norwich (2015) an anchorite<sup>2</sup> in 1373, describes her Christian spiritual experiences that concerned the love and compassion of God. Key historical Christian British figures such as Florence Nightingale, John Wesley and William Booth (Galli and Olsen 2000) instigated social change and new ideas that were born out of spiritual encounters with God. Until the early 20<sup>th</sup> century, the term 'spirituality' was part of religious belief, but has developed over time, continues to evolve, and is now considered separately from religion (Pargament 1999; King and Koenig 2009).

In the West, the last century has seen a rise in secularism, and a move away from religious organisations. Some have considered if religion is inherently 'dangerous' due to the divisions it has the potential to cause, and violent causes that may be associated with it (Ward 2006). Alongside the rise in secularism, interest in spirituality that is *disconnected* to organised religion has risen (Zinnbauer et al. 1997; Pew Research Center 2012; Bullivant 2017). As this has occurred, there has been a separation of the meanings of the terms 'spirituality' and 'religion'. The term 'religion' lacks a scholarly definition (Sandberg 2018) with disciplines emphasising various components, e.g. personal, social and transcendent aspects (Bowker 2000). The Lexico Dictionary (2018) defines it as 'the belief and worship of a superhuman controlling power, a personal God or gods'. According to Morreall (2013 p12), ancient and medieval societies used the term 'religion' to refer to the virtue of carrying out 'social obligations to family, neighbours, rulers and God.'

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<sup>2</sup> An anchorite was a religious recluse (Oxford Dictionaries 2018) who led an aesthetic life devoted to prayer.

Religion has organised elements, a social context, and the use of rituals such as is found in Christianity, Judaism, Islam, Buddhism and Hinduism (Jong 2015). These sets of values, rituals and practices (Tanyi 2002) are an ‘outward expression of the sacred’ (Cotton et al. 2006 p472). Religion has ‘organisational or institutional beliefs’, whereas spirituality might be described ‘in personal or experiential terms’ (Zinnbauer et al. 1997 p561; King and Koenig 2009; Koenig 2014; Hughes 2014). When asking people to define the words ‘spiritual’ and ‘religious’, Gillman (2007) noted the term ‘spirituality’ denoted a fluidity, a state of exploring and developing, whereas ‘religion’ was associated with rigidity, hierarchy and exclusivity. Carson (1989 p7) however connects religion with spirituality, perceiving that spirituality has both ‘vertical’ and ‘horizontal’ elements. The vertical is the transcendent relationship with Higher Being(s)/God(s), but the horizontal element is reflected in human relationships, and influences values, lifestyles, and interactions in the world.

The term ‘spirituality’ also lacks a single definition across academic disciplines (Kenneson 2015) with different perspectives in disciplines such as theology, philosophy and sociology. The Lexico Dictionary (2018) defines spirituality as ‘the quality of being concerned with the human spirit or soul as opposed to material or physical things’ and does not connect spirituality with religion. Although spirituality is connected to – it is not psychological, mental or emotional health - and ‘differs from other psychosocial concepts, such as psychological well-being’ (Koenig 2014 p9). Spirituality is understood to be a concept relating to being human; is subjective and experiential, and may have social and cultural elements (Janzen 2002; Cook 2011). Chuengsatiansup (2003 p10) states the challenges of defining spirituality is due to the ‘subjective and relational state of inner experience’ and partly due to its mystical element. McSherry and Smith state that spirituality is ‘deeply personal and individual’ (2012 p118), and due to its subjective nature means that an individual’s spirituality cannot be understood simply from looking at a ‘religious label’ or a ‘spiritual label’ that individuals or others may apply (McSherry et al. 2004). Crabtree states that individuals identifying as having New Age beliefs may have a ‘widely varied collection of practices and beliefs rather than a structured belief system, and as such is difficult to define’ including astrology, channelling, crystal work, divination amongst many others (2018 para. 1) combined in ways that are unique to the individual. Similarly, although a person may identify as Christian, there are many different expressions of that belief as evidenced by the numerous denominations of the Christian church relating to theology, traditions, rituals and spiritual practices, e.g. Anglican<sup>3</sup>, Roman Catholic and Messianic Judaism. Although some reasonable assumptions may

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<sup>3</sup> According to the Cambridge English Dictionary (2019a), ‘Anglican’ refers to The Church of England.

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be made as to their core doctrinal beliefs, e.g. a Christian is likely to believe in God and Jesus Christ, it may not be assumed how the individual interprets this in their own life. To take this further, if an individual identifies with a Christian denomination, their life experiences, their intellectual abilities to engage with their denominational doctrine, their individual commitment to their beliefs and their ability to experience God in their beliefs will influence the subjective interpretation of their religious beliefs and spirituality. Individuals identifying with the same Christian denomination will interpret and experience their faith differently. An example of this is a Christian who is drawn to the mystical elements within the religion and seeks a transformational encounter with God (so is 'spiritual and religious'), versus a Christian who attends their church regularly but does not expect any spiritual 'connection' with God (and may define themselves as 'religious' but not 'spiritual'). These elements suggest the inter-connectedness of the components of spirituality and religion that are unique to individuals.

### 2.3.2 'Spiritual but not religious'

Although the terms religion and spirituality are different concepts, they contain similar and different components. In their study of individuals from a range of religious backgrounds, Zinnbauer et al. (1997) found there was convergence and divergence between the two constructs of religion and spirituality. Swinton identifies that spirituality and religion, although being different concepts, are intricately linked (2010 p27), and it could be considered that there are broadly two categories: those who believe in God(s)/Higher Power and those who do not (Tanyi 2002; McSherry et al. 2004; Ammerman 2013). The terms spirituality and religion/religious are now being used to define groupings of people: 'religious', 'not religious', 'spiritual', 'not spiritual', 'spiritual and religious' and 'spiritual and not religious' (Saucier and Skrzypińska 2006; Pew Research Center 2012a; King et al. 2013; Kenneson 2015; The Woolf Institute 2015). Kenneson (2015 p5) states that these terms can be 'entangled with one another', with cultures that value individual autonomy having positive connotations with spirituality and being suspicious of religious institutional structures that may be seen to impose rigidity. It suggests that contemporary spirituality is a different construct to religion, and people may consider themselves spiritual whilst having no religious affiliation (Swinton 2010; The Woolf Institute 2015) as is evidenced by a humanist perspective (Elkins 2001) or the terms 'atheist spirituality' (Compte-Sponville 2014).

A recent term used is 'spiritual but not religious' (SBNR) (Ammerman 2013; Day et al. 2013; Mercadante 2014; Kenneson 2015; Nadal et al. 2018). Mercadante (2014) asserts the SBNR fall into five categories: (1) 'Dissenters', who consciously avoid institutional religion; (2) 'Casuals', who use spirituality therapeutically when required by life's stressors; (3) 'Explorers', who search for

novel experiences and enjoy a commitment-less freedom to spirituality that has no ultimate destination; (4) 'Seekers' who look for a spiritual home that they can commit to; and (5) 'Immigrants' who find a novel spirituality and have yet to settle in this new found identity. Research by Ammerman (2013 p268) with American participants from a range of religious and non-religious traditions found language used to describe spirituality clustered into four categories: 'Theistic Spirituality', 'Extra-Theistic Spirituality', 'Ethical Spirituality', and 'Belief and Belonging Spirituality'. Those with Extra-Theistic Spirituality focused on transcendence, community, awe of nature and seeking life's meanings, whilst 'Ethical' spirituality focused on compassion towards others. The non-religiously affiliated and the Neo-pagan<sup>4</sup> participants were in the 'Belief and Belonging' spoke of spirituality in terms of connectedness to others.

The terms spirituality and religion inter-link and overlap in ways that are complex and are likely to be unique to the individual, as is shown in Figure 1 below.

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<sup>4</sup> Neo-Paganism focuses on ancient polytheistic religions of Europe and the Middle East, with a close relationship to ritual magic and modern witchcraft. Often incorporated are celebration of nature with an emphasis on ecological concerns (Britannica.com 2019)

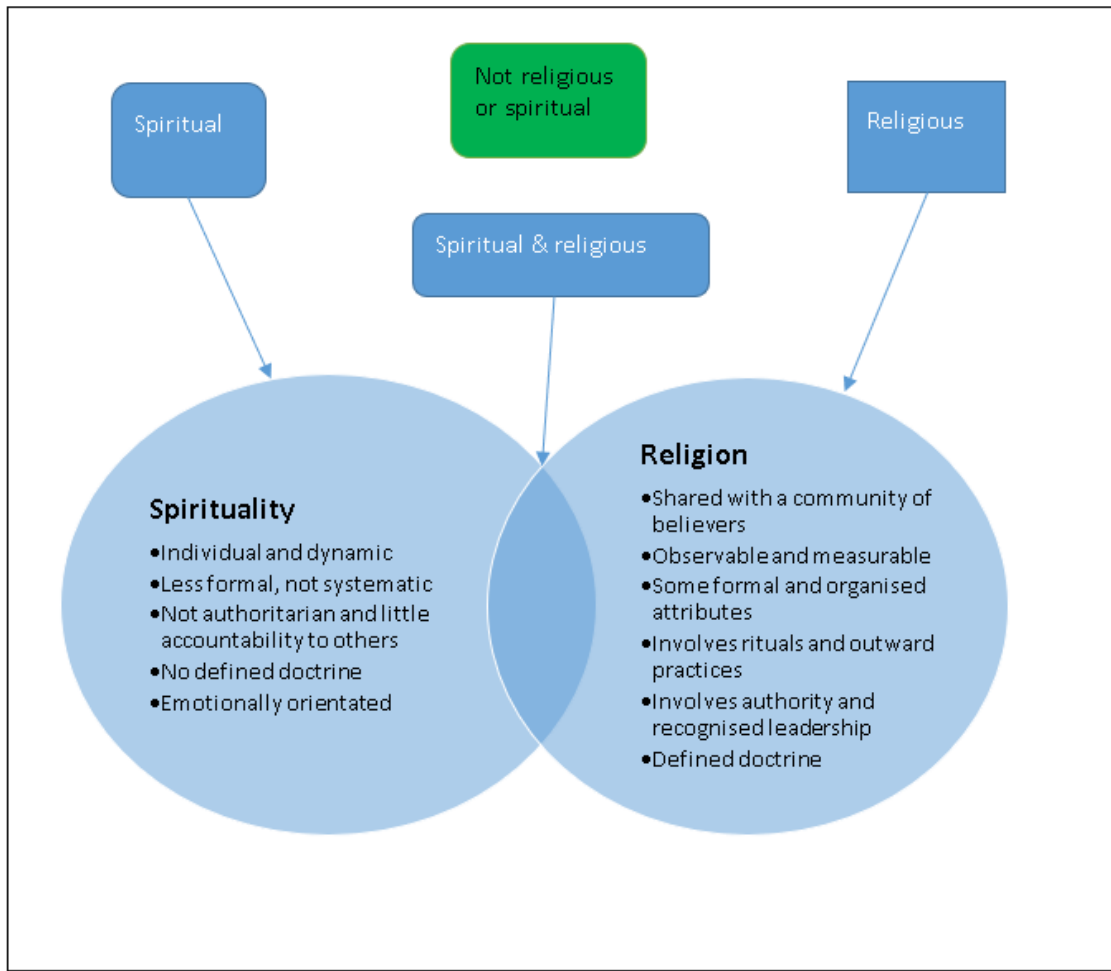


Figure 1: A spirituality and religion model

### 2.3.3 The global and national religious landscape

As this study discusses the religion and spirituality of people with T2D, the global and British religious landscape will be outlined. The Pew Research Center (2019b), an American based non-partisan fact tank, analyses attitudes and demographic trends shaping the world. In 2017, Christianity was the world’s largest religious group (Hacket and McClendon 2017) but by the year 2035, Pew predicts that Muslims will start to outnumber Christian births. Currently 16% of the global population are religiously unaffiliated (including those who profess atheism<sup>5</sup>, agnosticism<sup>6</sup>

<sup>5</sup> According to the Dictionary.com (2018b), ‘atheism’ is a lack of belief in God or gods or supreme being or beings.

<sup>6</sup> According to the Dictionary.com (2018a) ‘agnosticism’ affirms the doubt of the existence of ‘the ultimate cause, as God’ and that human nature is limited to experience.



and 'no particular religion'), but due to the declining birth rate of the religiously unaffiliated, Pew projects a decline of this group in future decades. Pew's current global predictions (2015) are that by 2050 Muslims will equal the number of Christians, and although India will have a Hindu majority, it will have the greatest Muslim population of any country. In the US, they predict that Christians will decline from three quarters of the population to just two thirds of Americans, and that Muslims will outnumber practising religious Jews. Pew research (2012) states that in the US religious belief is changing, with some people rejecting the main religions (i.e. Islam, Christianity, Judaism) and moving towards individual spirituality.

Similar to the US, there has been a move away from organised religion in the UK, with an increase in 'less formal, more personal, fragmented spiritualities and spiritually based practices, often drawing upon or connected to Eastern, mystical, esoteric, shamanic, and pagan traditions' (Coyle 2008 p57). Coyle posits that part of this move away from organised religion and its 'objective roles, duties and obligations' is to have the 'subjective' spiritual experience with an Eastern influence favoured towards the 'mystical'. It can be argued that Christian religious belief has always had mystical elements, as is shown by mystical visions encountered by people such as St Francis of Assisi in the 13<sup>th</sup> century (Sabatier 2007), Julian of Norwich in the 14<sup>th</sup> century (2015), and current Christian mystics such as Rik Joyner (Joyner 2006; Overstreet and Holcombe 2014). However, it is clear from the UK Census (ONS 2013) that there is a significant decline in religious affiliation in the UK. Christians are the largest religious population group at 59%, with non-religiously affiliated at 25%, Muslims at 5% and other religions combined at 11% (Sikh, Jewish, Hindu, Buddhist and other religions). The last decade in the UK has seen a move away from organised religion showing the number of Christians decreasing, whilst the number of people with 'no religion' has increased across all age groups to 25% of the population; this is particularly noticeable in the 'White' younger age groups (ONS 2013). This section has detailed the religious and spiritual global landscape, and now therefore spirituality within healthcare will now be considered.

#### **2.3.4 Spirituality in healthcare**

In 1998, the WHO developed a 'Spirituality, Religiousness and Personal Beliefs' questionnaire that recognised the importance of individuals' perceptions of their 'culture' and 'value systems' such as religious and spiritual beliefs. The concept of the connection between physical, mental and spiritual health is not new; ancient civilisations believed in the inter-connectedness between spirituality and health. According to Koenig (2000 p387), these beliefs were present among Egyptian, Hindu, Greek and Romans as far back as 6000 B.C. where thought was that physical and mental health were affected by spiritual forces such as demonic possession. Koenig cites Hindu

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beliefs in 2300 B.C. of priests' administration of spiritual practices to heal patients; and in Greek and Roman times, patients sought healing from either private physicians or the Asclepiad Temple, the Greek god of medicine. Ancient sacred texts from 6000 B.C. demonstrate the Hebrew belief in the healing power of Yahweh (God) in The Torah:

'If you listen carefully to the LORD your G-d <sup>7</sup> and do what is right in His eyes, if you pay attention to His commands and keep all His decrees, I will not bring on you any of the diseases I brought on the Egyptians, for I am the LORD, who heals you.' (Shemot. 15:26)

and Muslim belief in healing from Allah (God):

'And when I am ill, it is He [God] who cures me.' (Qur'an 26:80)

The early Christian church in the first century believed in the importance of helping the sick as part of their Christian duty, demonstrated in the text in the Bible (2019) in the Book of James (Chapter 5:14):

'Is anyone among you sick? Let them call the elders of the church to pray over them and anoint them with oil in the name of the Lord.'

In the West, healthcare started in religious communities where Christian nuns and monks believed caring for the sick was part of their worship to God. At the instruction of the Bishop of Caesarea, the early Christian church founded the first major hospital in Asia Minor in 370 A.D. (Friedlander et al. 1986). Caring for the sick is promoted within Christian religious texts where Jesus tells a parable<sup>8</sup>, in which the character of 'the King' is Jesus himself:

"Then the King will say to those on his right, 'Come, you who are blessed by my Father; take your inheritance, the kingdom prepared for you since the creation of the world. For I was hungry, and you gave me something to eat, I was thirsty, and you gave me something to drink, I was a stranger and you invited me in, I needed clothes and you clothed me, I was sick, and you looked after me, I was in prison and you came to visit me.'

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<sup>7</sup> According to the Collins English Dictionary (2019) the term 'LORD' is the tetragrammaton. It is composed of the four consonants of the ancient Hebrew name of God that is considered too holy to be spoken aloud; some modern Jewish texts omit the letter 'o' in the word 'God'. Modern reconstructions are Yahweh and Jehovah.

<sup>8</sup> A parable is a simple story used by Jesus to illustrate a moral or spiritual lesson (Oxford University Press 2018a).

“Then the righteous will answer him, ‘Lord, when did we see you hungry and feed you, or thirsty and give you something to drink? When did we see you a stranger and invite you in, or needing clothes and clothe you? When did we see you sick or in prison and go to visit you?’

“The King will reply, ‘Truly I tell you, whatever you did for one of the least of these brothers and sisters of mine, you did for me.’” (Matthew 25:36).

In the UK, St Thomas’ Hospital is one of the oldest hospitals in London. Originally founded as part of a Augustinian Priory of St Mary Overie to treat the poor and sick, in 1173 it was renamed as St Thomas’ Hospital following the canonisation of Thomas à Becket (Old Operating Theatre Museum 2018). Historically, the Christian church has led the religious landscape of Britain, and Koenig states that although the church oversaw hospitals for around 1000 years and granted ‘licences to physicians to practice medicine’ (2000 p37), the advent of the Renaissance period saw the state taking over the responsibility of medical licencing.

Although many religious orders continued to care for the sick, Sulmasy (2006) comments that between Enlightenment and the nineteenth century, the pathological approach to medicine caused medical practice to disconnect from their religious roots further. The wealthy could look to modern medicine with its scientific approach to cure illness and disease, while the poor who could not afford to pay for treatment turned to God for healing. Not only in the West, but according to Singh and Ajinkya (2012) in countries such as India the scientific and technical approach to treating patients faltered in addressing patients’ spiritual and holistic needs in medicine and psychiatry. Koenig (2012) however states the separation of religion, health and medicine has largely occurred in developed countries, with less developed countries still considering health and spirituality as inter-connected.

The result of this paradigm shift in the developed Western nations is shown by the definition of health by the WHO in 1948 – a definition of health that did not include spirituality. However, by 1998 the WHO definition had evolved, stating that incorporating patients’ spirituality was integral to good healthcare. In their report, they use Wright’s statement that ‘spirituality and health are bonded to each other’ and are ‘inseparable companions’ (Wright 2005 p15). In their document ‘Spiritual Care Matters’, NHS Education for Scotland (2009) cited The WHO:

“Until recently the health professions have largely followed a medical model, which seeks to treat patients by focussing on medicines and surgery and gives less importance to beliefs and to faith. This reductionism or mechanistic view of patients as being only a material body is no longer satisfactory. Patients and physicians have begun to realise the

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value of elements such as faith, hope and compassion in the healing process. The value of such 'spiritual' elements in health and quality of life has led to research in this field in an attempt to move towards a more holistic view of health" (1998 p7).

Nahardani et al. (2018) state that the modern WHO model of health focuses on the biological, mental, social and spiritual dimensions. This is similar to the New Zealand Māori health models 'Te Whare Tapa Whā' (New Zealand Ministry of Health no date; Durrie 2017) where indigenous Māoris have long held that well-being and health involve four aspects: psychological, spiritual, physical and family. There has been a growing interest in addressing spirituality within healthcare (Sulmasy 2006) and medical curricula in the US, Brazil, UK, New Zealand and Australia now incorporate spirituality in doctors' training (Rogério et al. 2016). Mirroring this is the increase in papers addressing spirituality, religion and health outcomes: in the 1960s there were just two papers; by 2010 there were 5,172 (Kharitonov 2012). In the UK, the Cochrane Collaboration (2019) who provide trusted evidence to healthcare professionals, have included studies regarding spirituality in healthcare.

In a recent qualitative study in Iran, Ghaderi et al. (2018) recruited twenty-two experts in the area of spiritual health from the disciplines of ethics, philosophy, theology, health and medical ethics, medicine, psychiatry and psychology to define spirituality and spiritual health, and to identify components and indicators of spiritual health. Participants were academics, authorities on healthcare in the Ministry of Health in Iran, researchers and authors in spiritual health and spirituality, and members of the Spiritual Health Department in the Academy of Medical Sciences of Iran. The study did not comment of the spiritual/religious beliefs of participants (e.g. if they were Muslim) and the study most frequently referred to 'God' as opposed to other references such as a Higher Power or other religious views of a deity/gods/God. In this aspect, it could be considered that 'God' in the study may have referred to the understanding of God in the Muslim faith, as the study was conducted in Iran, and 99.4% of Iranians identify with Islam (Central Intelligence Agency 2019). Although most participants considered that spirituality differed from spiritual health, they believed that spiritual health affected physical, mental and social health and it dominated over other aspects of health. Spiritual health incorporated connection with self, others, God, nature, transcendence and a 'proper lifestyle' – and these factors would lead to improved mental and physical health. They considered that spiritual health is a 'dynamic state, it can be promoted, its identities and patterns may change, and it can be hidden and invisible' (Ghaderi et al. 2018 p6). The dynamicity of spirituality and its effect on health is reflected in the statement by the Royal College of Nursing [RCN] (2011) who assert that spirituality of patients may be heightened at times of suffering or illness.

Although the NHS recognises the importance of addressing patients' spirituality when giving healthcare (WHO 2012), there is no clear consensus among the professionals of various healthcare disciplines as to what spirituality actually is (McSherry et al. 2004). This is unsurprising given the lack of consensus as to what constitutes spirituality. The difficulty in defining spirituality within healthcare reflects the challenges at a personal and organisational level 'to encapsulate an intangible essence which for many people gives the truest meaning of them and their lives' (Keighley 1997 p47). Most healthcare disciplines agree that spirituality and religion are phenomena that are important aspects of care, but each discipline may bring an additional focus.

To this end, Puchalski et al. (2014) detail the results of two international conferences, where experts from various disciplines such as clinical research, palliative care, healthcare, health economics, ethics, law, policy, insurance, workforce, and healthcare education discussed the application of spirituality within healthcare. The conferences formulated a definition for spirituality, alongside standards, strategies and recommendations that were focused within six themes: research, clinical care, education, policy/advocacy, communication, and community involvement. International multi-professional conferences such as these create opportunity for inter-professional dialogue regarding spirituality and application of this within healthcare.

### 2.3.5 Spirituality in nursing

Although religious orders established healthcare and hospitals in the UK, it was not until the 19th century that formalised nurse training was instituted. In 1860 Florence Nightingale followed what she believed was a calling by God, and established the first professional training for female nurses at St Thomas' Hospital (Florence Nightingale Museum London 2019). Nightingale asserted:

'If I could give you information of my life, it would be to show how a woman of very ordinary ability has been led by God in strange and unaccustomed paths to do in His service what He has done in her. And if I could tell you all, you would see how God has done all, and I nothing.' (Larson and Lowery 2009 p282).

Florence Nightingale was a devout Christian, but also believed other religions could give Divine revelation (Nightingale and Vallee 2003). Macrae (1995) stated that Nightingale's belief that spirituality is intrinsic to human nature and compatible with science guided the development of nursing practice. In 2011, the Department of Health [DH] stated that although 'nursing has been the catalyst for debate and reconnecting with the spiritual dimension of care for many healthcare professions' the phenomenon needed further research, with many studies lacking patient focus.

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The DH stated that most studies were quantitative, with no in-depth qualitative enquiry into the 'nature and perception and lived experience of spirituality' (2011 p14). The lack of critical analysis of spirituality within nursing is concerning (Swinton and Pattison 2010; Mcsherry and Jamieson 2013) because nursing policy and public expectations are being built upon a concept without clear definitions and boundaries (McSherry et al. 2004).

Reinert and Koenig (2013) state that definitions of spirituality in nursing have been influenced by mental health definitions, distancing themselves from religion, focusing more on meaning, purpose, hope and transcendence. Frankl (2004) was a neurologist psychiatrist whose experiences as a Holocaust survivor combines these, suggesting not only do people seek meaning in difficult circumstances, but those who have a strong faith fare better than those who lose faith - and consequently, hope. In times of ill health and crisis, patients' spirituality may become especially important as they seek to interpret the meaning of their illness, and may link this to their faith or beliefs (Royal College of Nursing [RCN] 2011).

Despite a lack of nursing consensus as to what spirituality is, nursing organisations such as the International Council of Nurses (ICN 2012; Stievano and Tschudin 2019), the Nursing and Midwifery Council [NMC] (2018b) and the RCN (2011) advocate addressing patients' spiritual needs. The RCN advised that nurses must attend to patients' spirituality, and it is 'not the sole responsibility of the chaplain' (RCN 2011 p5); indeed nurses should be 'treating spiritual needs with the same level of attention as physical needs' (p6) to ensure they give good quality care (NHS Education for Scotland 2009). Moreover, attending to the spiritual dimension is part of the basic '6 Cs' of nursing: care, compassion, competence, communication, commitment and courage (DH 2012; NHS England/Nursing Directorate 2013).

Following the creation the Equality Act in the UK (Great Britain 2010), the NMC stated that religious belief is a 'protected characteristic', and 'due regard' should be taken of this by its members (NMC 2017), yet the only reference to spirituality within the nursing Code is negative:

'make sure you do not express your personal beliefs (including political, religious or moral beliefs) to people in an inappropriate way' (NMC 2018 p18).

Although the NMC states nurses should assess 'spiritual factors' (2009) and 'spiritual needs' (2018b), it does not define what these are, or how they are to be assessed (NMC 2018). The lack of spirituality training within the nursing curriculum (Wigley 2013; McSherry and Jamieson 2013; Lewinson et al.2015) may result in nurses feeling confused, and asking for further guidance from professional organisations (McSherry 2010a). Some are fearful of negative reprisals (McSherry

and Jamieson 2013; Christian Concern 2017) especially if they are found to have expressed their religious beliefs inappropriately (Osbourne 2016). Despite the lack of critical analysis of spirituality within nursing, the perceived lack of training and minimal guidance from the NMC (McSherry and Ross 2015), British nurses appear to recognise the importance of spiritual care for patients (McSherry 2010a), with Ross et al. (2016) suggesting nurses' own spirituality is a strong predictor of perceived ability to provide spiritual care.

Swinton and Narayanasamy (2002) believe that those nurses lacking a spiritual worldview themselves may attempt to address the spiritual distress of patients with a psychological focus, and therefore concepts of spirituality and spiritual assessment tools would be beneficial in the nurse educational curriculum. Contrary to this, Paley (2009) strongly asserts that spiritual care has no place in nurse education or the NHS. Paley states that the movement of the term spirituality away from its Christian roots to an elastic universal phenomenon experienced by all renders its definition a 'giant conceptual sponge' (2008 p.5), emphasising that the spiritual components commonly referred to in the nursing literature would be better examined within scientific and naturalistic frameworks. Leget (2008) is critical of a reductionist approach to spirituality stating that it cannot be forced into a procrustean bed, and Swinton and Pattison argue that the term is necessarily emergent, contextual and evolving and that other terms such as 'healthcare' and 'care' are equally vague terms, but there 'is no inherent reason why a lack of clarity should necessarily denote a lack of significance' (2010 p.231). It appears that nursing scholars often fail to consider the influences of political, theological and social frameworks on spirituality but according to Clarke (2009) this may be driven by nurses striving to have their own body of knowledge.

### **2.3.6 Definitions of 'spirituality' and 'religion' in this study**

One of the weaknesses in papers concerning how spirituality influences the self-management of T2D was that many studies lacked definition of the terms 'spirituality' and 'religion'. It is imperative for this study to define the terms 'spirituality' and 'religion' to provide unambiguous meanings, which may otherwise be interpreted differently by disciplines (Foppe van Mil and Henman 2016), and enables the findings to be compared to those of other studies (Lincoln and Guba 1985). The definition given in Figure 2 below is the result of an amalgamation of the terms of 'spirituality', created from opinions and definitions from authors from various disciplines in nursing, theology, psychiatry and sociology. The definition of the term 'religion' is from the Lexico Dictionary (2019).

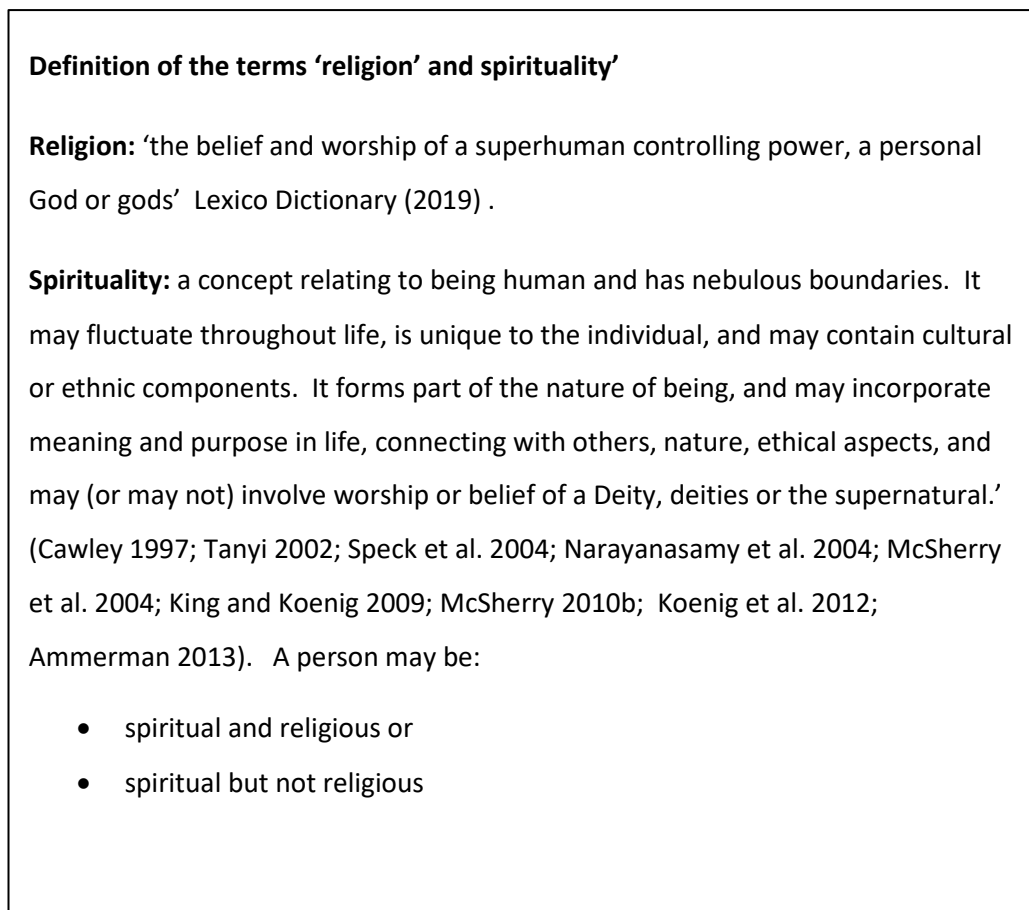


Figure 2: Definition of ‘religion’ and ‘spirituality’ in this study

## 2.4 Summary

This chapter has given an outline of the condition of T2D, and the disease burden of T2D both globally and nationally. The management of T2D is complex, but a brief outline has been given, with focus on individuals’ self-management of diet and exercise. The terms religion and spirituality have been discussed and a new term expressing a combination of these terms, i.e. ‘spiritual but not religious’ [SBNR] has been introduced. The global and UK religious landscapes have been considered, and how spirituality fits within healthcare and nursing. Importantly, a definition of ‘religion and spirituality’ for this study is given. It is important to note that in this study, the term ‘spirituality’ incorporates spiritual *and* religious belief; and in the remainder of this thesis, the term ‘spirituality’ will include both spiritual *and* religious belief. The next chapter details reviews of the literature, which led to a refinement of the research question and a better understanding of the results of the study.



## Chapter 3    Reviews of the literature

### 3.1    Introduction

The research process involves critical evaluation of existing evidence surrounding the topic in question. Literature reviews identify knowledge of specific subjects, resulting in a synthesis of knowledge, analysis of the strengths, limitations, bias, and identify gaps in the evidence base (Jesson & Lacey 2006). In this study, the internet and other sources identified published and unpublished data, websites, policy documents and reports. In addition, a manual search for University library books, and emails from experts in the field of spirituality and nursing was undertaken (Fink 2014). I subscribed to Duke University to access on publications on 'Spirituality, Theology & Health'; set up alerts relating to 'T2D' and 'spirituality' with databases, and followed key authors to identify new material, and during the first half of my candidature, subscribed to The British Association for the Study of Spirituality.

This study required two literature searches. As this study spanned six years, and the first literature search and review regarding 'T2D and spirituality' was undertaken in 2014 and published (Duke & Wigley 2016; Appendix A). In 2019, to identify new data, this literature search was reviewed and updated with some additional databases searched (Appendix B). Following collection and analysis of data in 2019, it was evident that participants used 'religious coping' to manage their T2D. Therefore, a second literature review was undertaken that identified literature regarding 'religious coping and T2D' (Appendix C).

#### 3.1.1    Review of 'T2D and spirituality'

The literature search of 'T2D and spirituality' was undertaken in June 2014 (Duke & Wigley 2016) and reviewed and repeated on 16.08.2019. Appendix A details the 2014 literature search across five databases and three other sources (Table 22-26) and Appendix B details the 16.08.2019 literature search across eight databases (Table 27-29) of peer reviewed, full text articles in English. The Boolean operator 'AND' connected the various search terms for T2D with the term 'spirituality'. Controlled vocabulary, 'suggested search term' and truncation enabled variations of words, e.g. 'spirit\*'. In the 2014 search, 57 papers were accessed, and 21 excluded. Following reading every abstract, 37 papers were considered relevant, and 13 were considered key papers (Appendix C). In the 2019 review, further literature was found: after reading every abstract, 71

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sources were accessed, with 25 papers excluded, and from the two reviews in 2014 and 2019 (Figure 3), fifteen papers were considered as key (Appendix F). The literature showed that the SMB of T2D included:

- attention to diet and exercise
- taking medicines for T2D
- complementary alternative medicine and practices (CAMP) that may affect participants' diet
- CAMP influencing medicine-taking

This study chose not to analyse prescribed T2D medicines management because it is a collaboration between clinicians and patients, not solely under participants' control. As the literature found participants' use of CAMP could be related to spirituality and influenced T2D self-management, CAMP was considered. The 71 sources were scrutinised for contexts; conceptual variations; findings; strengths and weaknesses of the research; designs and methodologies; bias; cultural differences; funding of projects; robustness; and areas identified requiring further research, and 46 papers were relevant to the SMB of T2D and spirituality. Most studies were from U.S., two from Australia; five from Britain; four from South-East Asia; three from Iran, one from Canada and one from Sweden. To refine the search, papers were scrutinised for components relating to SMB of T2D - diet, exercise, CAMP, or medicines; and fifteen papers selected. Sources highlighted the influence of spirituality, coping, gender, CAMP, ethnicity, religion, and the socio-cultural context in the SMB of T2D illustrated by a 'Mindmap' (Figure 4).

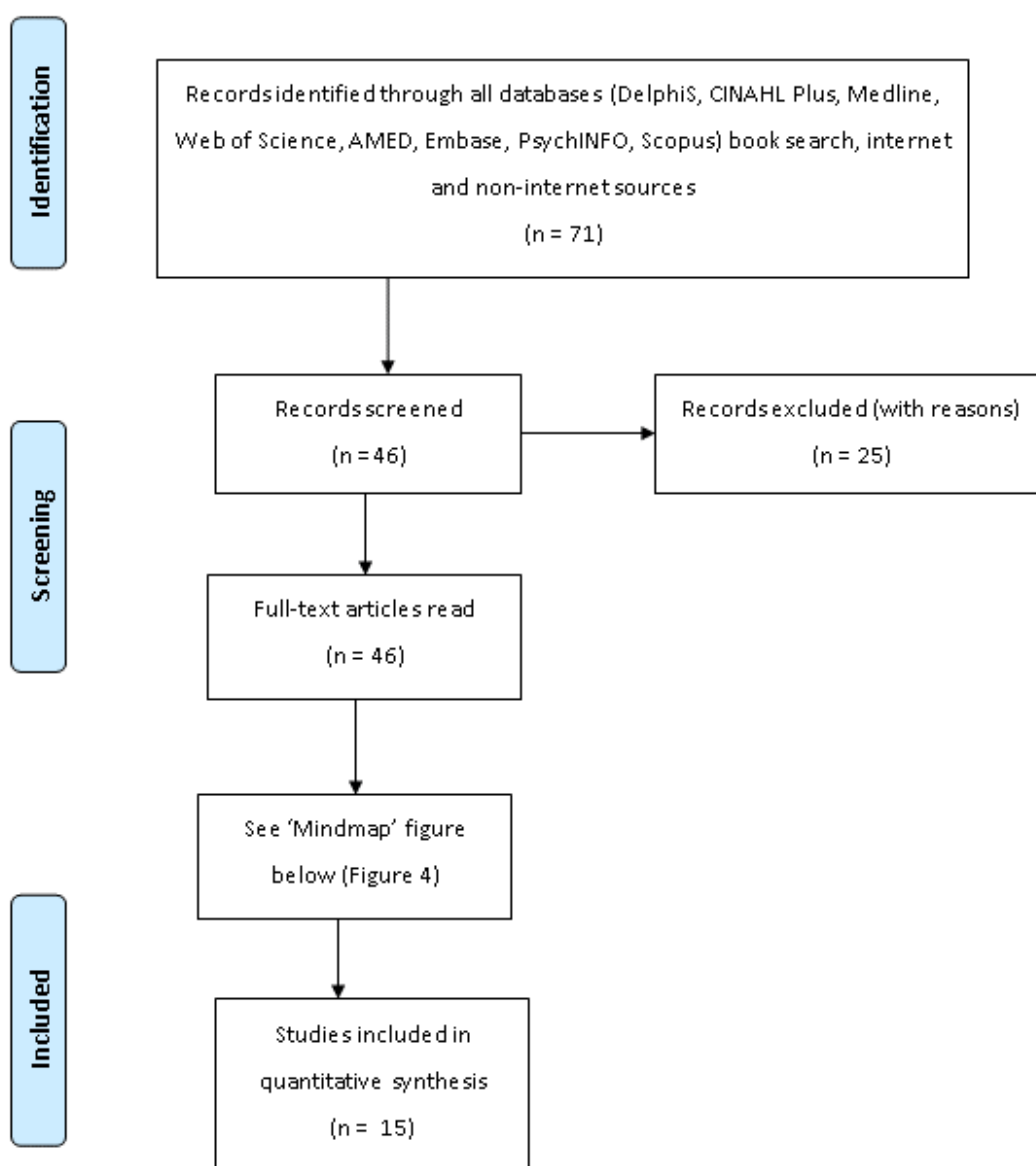


Figure 3: Adapted PRISMA 1: 'T2D and Spirituality' literature search in 2019

(Mohar et al. 2009)

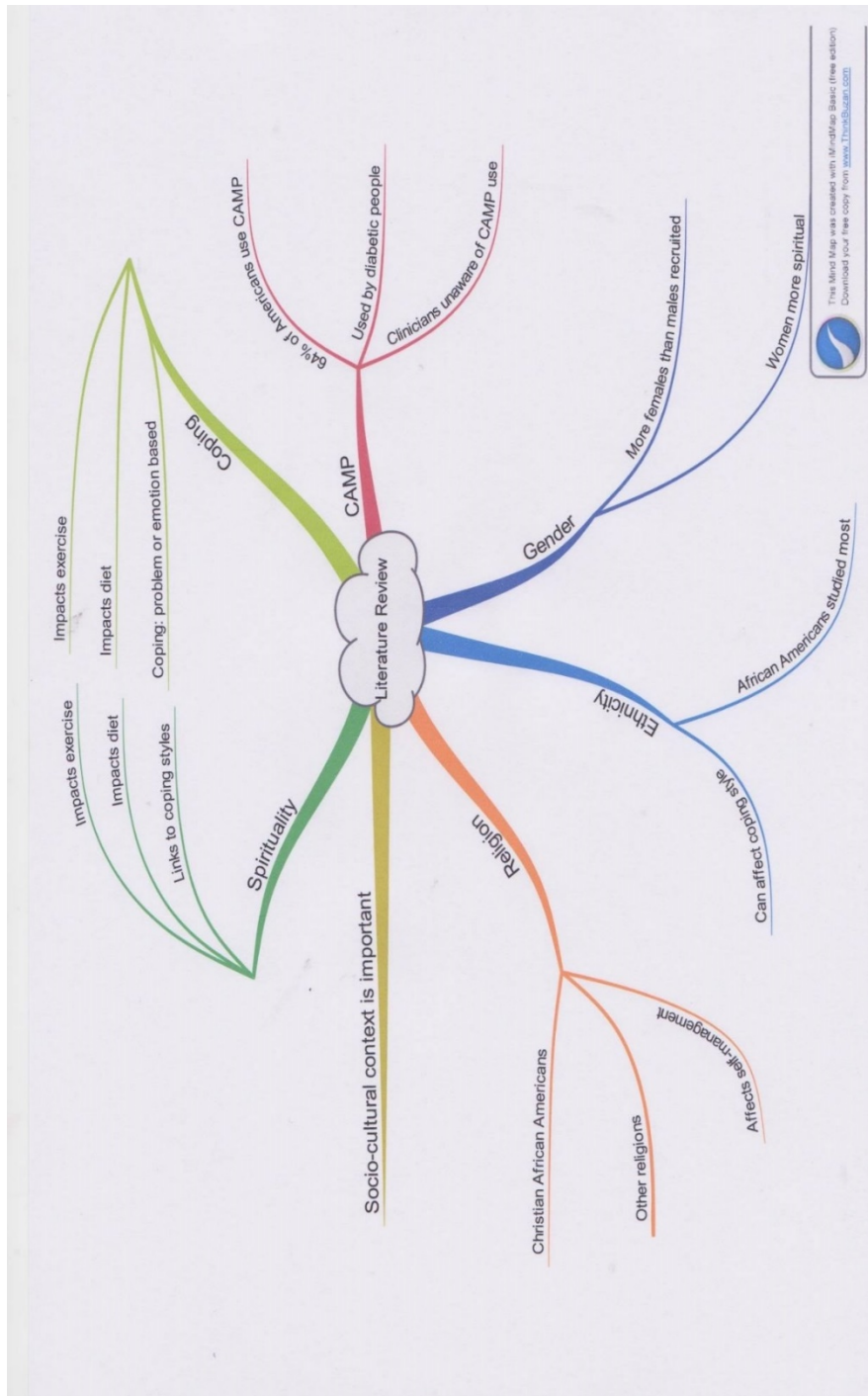


Figure 4: Mindmap of 'Spirituality and T2D' search

### 3.1.3 'Spirituality' and 'religion' within the literature

Chuengsatiansup stated 'health and policy experts lack common language in addressing spirituality' (2003 p4) which can be partly attributed to spirituality and biomedicine belonging to incommensurable scientific paradigms. Historically healthcare was dominated by Newtonian and Cartesian perspectives, characterised by reductionistic and materialistic worldviews. Spirituality however is a complex property of humans, with differing ontological and epistemological assumptions. In most studies the terms 'spirituality', 'religion', 'faith' and 'religious beliefs' were not discussed, raising issues of transferability of the research (Lincoln & Guba 1985) or the comparison of similar studies. Papers referring to spirituality often focused on one religion due to the participant sampling methods. Research on Thai immigrants by Thinganjana (2007) highlighted the term 'spirituality' does not even exist in Thai, although the concept is present (p95), and it cannot be guaranteed this word/concept exists in all languages. The papers reviewed were separated into concepts of spirituality and religion, but many papers showed while these concepts may differ, they are most often inter-related. Although being religious (religiosity) involved spirituality, spirituality may not involve religiosity (Swinton 2010). In the literature, spirituality/religion was broadly defined as the inner self being shaped by human experience and practice, often highlighted at times of difficulty, and often included awareness/worship of a Higher Power/God (Hjelm et al. 2005; Polzer & Miles 2007 (Appendix U); Harris 2008; Cordova 2011).

### 3.1.4 Spirituality may be influenced by ethnicity and gender

The majority of studies were American, where the prevalence of T2D in older African Americans is almost twice that of White Americans, with almost twice the rate of uncontrolled T2D, higher rates of diabetic complications and twice the mortality (Center for Disease Control and Prevention 2005; Polzer & Miles 2007; Rovner et al. 2013). African Americans are considered a spiritual people, and the socio-cultural-historical context key (Polzer & Miles 2007; Appendix U). This led to approximately half of American studies purposefully seeking African Americans, often from church/church programs (Polzer Casarez et al. 2010; Cater 2010). Around a quarter of studies had both Black American and White American participants. Other ethnicities studied included Native Americans, Mexican Americans, Latinos, Hispanics, Nigerians, Indians, Thai, Mohawk and Caucasians. Eight studies had mixed ethnicities, comparing outcomes of White versus Black Americans ( Popoola & Clinton 2004; Mayer-Davis et al. 2004; Harris 2008; Tang et al. 2008 Egede & Ellis 2010; Lynch et al. 2012; Hart & Grindel 2010; Aikens 2012). Research demonstrated that African Americans' propensity to use religion/spiritual practices to help diabetic control was not always true of non-Latinos and Caucasians (Landis 1996; Samuel-Hodge et al. 2000). Studies with

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Iranian Muslims varied with Zareipour et al. (2016) finding no association between hba1c and spiritual well-being, while Jafari et al. (2014) found good hba1c control was associated higher with scores in meaning, peace, and lower scores in depression in Muslim Iranians. Although Heidari et al. (2017) did not measure hba1c in Muslim Iranians, they found greater commitment to self-management of T2D.

American studies that did not focus on Black American participants were Hart & Grindel (2010) whose sample had 75% White Americans; Tang et al. (2008) had 64% White Americans, and the Swedish study by Hjelm et al. (2005) had 21 Caucasian and 14 Arabic participants. Hjelm et al. (2005) analysed contrasting beliefs of Swedish, Arabic, and Yugoslavian men: health centred on employment, financial independence and functioning sexually. The non-Swedes claimed supernatural factors and stress have negative health effects. Despite believing in Divine causality of T2D, some Arabs had healthy diets, exercised and avoided smoking. Although the Yugoslavians described health as 'the most important thing in life', their diet was poorer, they exercised less and smoked more than the Arabs and Swedes. When examining ethnic and gender differences in T2D, Misra and Lager (2009) found the difficulty in SMB of T2D varied by racial/ethnic groups: BG testing was considered the most difficult by Hispanics, dietary management the most difficult for non-Hispanic Whites, while exercise was the most difficult for African-Americans.

Eight studies recruited only females (Samuel-Hodge et al. 2000; Newlin et al. 2003; Whittemore et al. 2005; Newlin et al. 2008; Newlin et al. 2010; Hames 2010; Lundberg & Thrakul 2011; Wijesinghe & Mendelson 2013) and three studies only males (Hjelm et al. 2005; Cordova 2011; Namageyo-Funa et al. 2013). Often mixed studies had many more females to males; (Peyrot et al. 1999; Decoster & Cummings 2005; Jones et al. 2006; Thinganjana 2007; Polzer & Miles 2007; Harris 2008; Polzer Casarez et al. 2010; Amirehsani 2011; Rovner et al. 2013; Watkins et al. 2013) Some studies identified women as more likely to use spiritual practices (Decoster & Cummings 2005; Jones et al. 2006) or that gender was a specific predictor for diet (Watkins et al. 2013).

### **3.1.5 Complementary alternative medicine and practices (CAMP) linked to spirituality, and affects diet and medicines adherence**

Eleven papers specifically researched CAMP, including prayer, diet-based therapies, spiritual healings, massage, meditation and vitamin use (Jones et al. 2006). The American-based National Institutes of Health (2014) identifies around 40% of Americans use CAMP such as new age practices, meditation, acupuncture, chiropractic, naturopathy, herbs, diet, guided imagery,

hypnotherapy and many others. If prayer is included this rises to 62% (Jones et al. 2006; Barnes et al. 2004). Reasons for using CAMP are complex, but may involve cost, traditional beliefs, and mistrust of the medical system - a legacy of the 1932-1972 unethical Tuskegee Study (Thomas & Quinn 1991; Bhattacharya 2012). Egede et al. (2002) found CAMP were used more by diabetics than non-diabetics, with Jones et al. (2006) finding they were utilized more by women than men. Amirehsani (2011) found 50% of Latinos/Hispanics used herbs/plants alongside prescription medicines: 77% did not advise clinicians of use of herbs/plants (which may interact with medicines); and 72% did not advise clinicians they were using a combination of CAMP/prescription medicines. In addition, some patients altered their prescription medicines the days they took plants/herbs. Around 30% believed combinations of faith and medicines were effective; and 71% wanted doctors to use/prescribe prayer. Participants believed prayer helped prescribed/alternative medicines to work; assisted them coping; and influenced God guiding their doctors. Meetoo & Meetoo (2005) identified British patients not informing clinicians of CAMP use, but this was not related to spiritual beliefs.

### **3.1.6 Spirituality/religiosity affects self-management of diet and exercise**

Participants' perception of diabetes causality centred on the disease being hereditary, caused by stress, or the Divine will (Meetoo & Meetoo 2005; Hart & Grindel 2010; Lundberg & Thrakul 2013). For some participants, spirituality/religiosity resulted in lack of attention to self-management of diet and exercise (Polzer & Miles 2007; Polzer Casarez et al. 2010). However, others engaged well in self-management, despite believing it their fate or the Divine will to have diabetes (Hjelm et al. 2005; Lundberg & Thrakul 2013). Reasons for this were not apparent in the literature. Whilst religiosity/spirituality may give participants comfort, hope, meaning, and strength in adversity, the lack of self-management in others will lead to diabetic complications (Polzer & Miles 2005).

Polzer and Miles (2007; Appendix U) analysed how Christian African-Americans' spirituality influenced their SMB of T2D, finding three typologies: (1) participants take responsibility and work with God to care for their T2D; (2) participants are submissive to God's authority, and good outcomes in health are attributed to the Divine will, and (3) participants believed their faith was more important than self-management, as God could heal if they had enough faith. The study by Polzer Casarez et al. (2010) of Christian African-Americans identified spirituality may reduce efforts of self-management of attention to diet, doing exercise and taking medications for T2D.

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They defined spiritual practice in participants as patterns of behaviours, rituals, prayer or other religious disciplines. Group 1 used spiritual practices aiding self-management; Group 2 used spiritual practices and self-management towards healing; and Group 3 used spiritual practices as healing. In the study by Bhattacharya (2012) with African Americans, three themes were present: spirituality, religion and relationship with God; the role of the church in T2D; and health/illness beliefs and God. Jones et al. (2006) also found three typologies amongst Christian African-Americans with T2D using CAMP. Group 1 used prayer and faith; Group 2 believed God assists healthcare providers; Group 3 believed in links between faith and treatment, but none abandoned treatment and relied on God alone as in the study by Polzer et al. (2007). Research by Lundberg & Thrakul (2013) with Muslim/Buddhist women also found religion aided coping; spiritual practices aided diet and exercise; and support from family helped. However, medical advice could be ignored in favour spiritual practice, e.g. Muslims fasting during Ramadan without medical advice. Muslims see illness as atonement for sin, and Buddhists believe illness the result of behaviour in a previous life. They found whilst some endeavoured health-promoting behaviour despite these beliefs, other were resigned to their fate.

### 3.1.7 Coping

Coping has been described as a multi-layered, dynamic, contextual phenomenon employed uniquely by individuals to minimise or control stress (Pargament 1997; 2011; Folkman 2013). Lazarus (1966) defined stress as a relationship between an individual and their environment that is personally significant and overwhelms the person's ability to cope. It utilises cognitive and behavioural efforts to control or reduce internal and external demands on the individual. This forms the foundation of Lazarus and Folkman's 'stress and coping' theory (1984) that was developed by Folkman and Greer (2000). The theory framework is relevant to 'ordinary events of daily life, major life events and chronic stressful conditions' such as T2D and emphasises two processes – 'appraisal' and 'coping', as the 'mediators' between the person and their environment (Folkman 2013 p123). Two appraisals are made by people in relation to their beliefs, values and goals:

- 'Primary appraisals' of 'threat', 'harm'/'loss' or 'challenge'. Emotional responses to appraisals relate to individuals' evaluation of the personal significance of the stress and options available for solution. If the situations appraised are high in personal significance but low in controllability they are deemed 'threats', whereas those that have a high degree of controllability are viewed as 'challenges'.
- 'Secondary appraisals' of response options involves coping by seeking solutions: a higher number of potential solutions generates more options, whereas limited options raises



stress. Typically, 'threat' appraisals generate fear and anxiety, 'harm'/'loss' appraisals generate sadness, anger or guilt, and 'challenge' appraisals generate excitement tempered by mild threat. Although there are many coping strategies, research broadly categorises coping as adaptive or maladaptive (Jaeggi et al. 2010), where the context distinguishes whether the style is functional or dysfunctional (Moritz et al. 2016). Various coping methods are theorised, e.g. problem-based, emotion-based, meaning-based and religious coping.

Some studies discussed participants' coping styles. Active coping refers to steps taken to reduce the stressors negative impact and may involve problem-based and emotion-based coping.

Problem-based coping commonly involves seeking information and learning new skills/behaviours but may also include obtaining social support (associated with emotion-based coping). In this review, problem-based coping was more likely to be used by men and White Americans (Decoster & Cummings 2005) resulting in reduced hba1c (Newlin et al. 2003; Hart & Grindel 2010); better depression control (Lynch et al. 2012); increased exercise (Rovner et al. 2013) and reduced blood pressure (Newlin et al. 2003). Rovner et al. (2013) analysed African Americans' focus on the present-time or the future-orientation with religiosity, exercise, checking BG and reading food labels. Those who were future-oriented engaged in exercise, and had higher religiosity, although clear reasons for this were not known.

Emotion-based coping aims at minimising the distress caused by the stressor, and includes a very wide variety of strategies: e.g. self-soothing by relaxing or seeking social support, through to self-expression (e.g. crying) (Carver and Connor-Smith 2010). This review found some emotion-focused coping less successful than problem-focused coping, e.g. avoidance strategies, but other emotion-focused coping helpful, e.g. seeking instrumental support in managing T2D. Emotion-focused coping was often utilised by females and African Americans (Newlin et al. 2003, 2008; Decoster & Cummings 2005; Polzer and Miles 2005, 2007 (Appendix U)) and was linked to meaning-based and spiritual/religious coping (Newlin et al. 2003, 2008; Popoola & Clinton 2004; Polzer and Miles 2005, 2007; Cattich & Knudson-Martin 2009; Cordova 2011; Amirehsani 2011). Meaning-based coping identifies positive facets in every-day situations, and focuses on deeply held beliefs, values and goals (Folkman and Moskowitz 2000).

Meetoo & Meetoo (2005) found British Asian and Caucasians participants believed stress and hereditary factors were the main cause of T2D, and links to the belief of fatalism. Fatalism occurs when individuals believe that health outcomes are caused by chance, luck, fate or a Higher Power (Franklin et al. 2007). The diabetes fatalism scale (Egede & Ellis 2010) used with Black and White Americans found higher scores related to poorer spiritual coping. Spiritual coping related to a

belief of diabetic outcomes caused by of a Higher Power, and linked to decreased active coping, greater fatalism, and worse diabetes control. Fatalism has been studied in people with diabetes (Egede and Bonadonna 2003) resulting in both positive and negative coping strategies and linked to spiritual/religious coping (Egede and Ellis 2010; Berardi et al. 2016; Asuzu et al. 2017; Saidi et al. 2018). Pargament (2011) suggests that religious belief is a 'common coping source' (p270) and Newlin et al. (2010) suggest religiously grounded worldviews provide hope that can become prominent in times of stress, as individuals search for meanings and connection with the 'sacred'. In this review, religious/spiritual coping influenced T2D self-management in complex ways, and was used by American Christians, Thai Buddhists and Muslims.

### 3.2 Review of 'T2D and Religious Coping'

The findings in the present study demonstrated that some participants utilised meaning-based and/or religious coping in managing their T2D. Meaning-based coping links to the individuals beliefs, values and goals (Folkman and Moskowitz 2000), is likely to be utilised in chronic situations (e.g. serious illness) and Folkman (2011) posits that it becomes more likely when other coping mechanisms fail. One type of meaning-based coping is 'religious coping'. Lazarus and Folkman (1984) mention religion/spirituality in relation to coping resources (p157) but it was Pargament (1997) who provided a framework for religious coping. Pargament (2011 p270) suggests that religious belief is a 'common coping source' that can become prominent in times of stress as individuals search for the meaning and 'significance' in their lives, and connection with the 'sacred'. Religious coping has been defined by Wortmann (2013 107) as:

'religiously framed cognitive, emotional, or behavioural responses to stress, encompassing multiple methods and purposes as well as positive and negative dimensions'

A literature review was undertaken on 10.04.2019 regarding 'religious coping' and 'T2D'.

Table 30 Table 32 detail the searches across eight databases of peer reviewed, full text articles in English. The Boolean operator 'AND' connected the search terms 'religious coping' with search terms for 'T2D'. Controlled vocabulary, 'suggested search term' were also used resulting in 48 sources. All abstracts were read, and 21 articles selected that were relevant. 26 sources were excluded, and 13 sources were considered key as they focused on how religious coping influenced participants living with T2D (Figure 5).

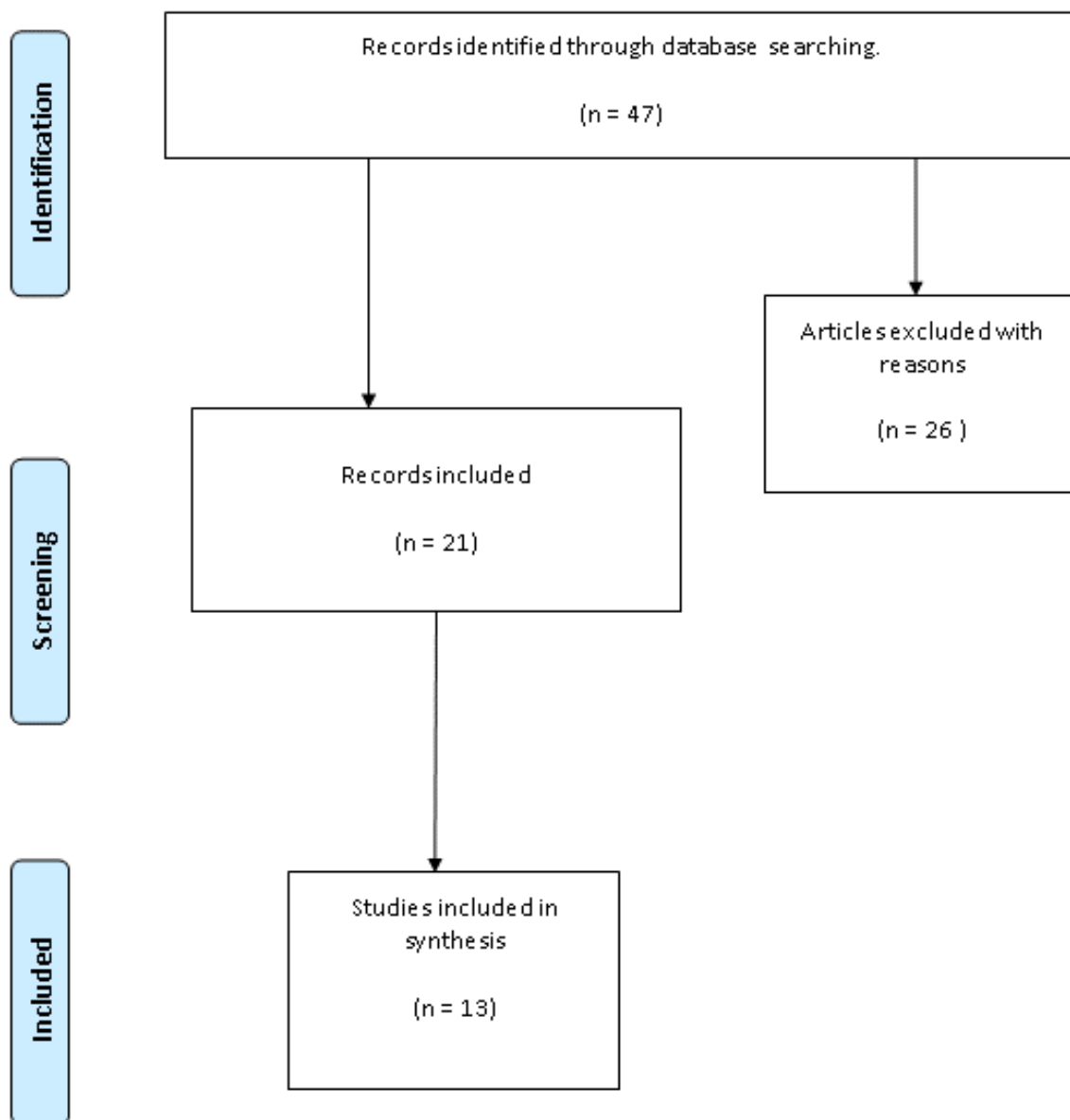


Figure 5: Adapted PRISMA 2. 'T2D and Religious Coping' search in 2019

(Moher et al. 2009)

### 3.2.1 Religion and ethnicity

This review identified three core religious groups (Buddhists, Muslims and Christians) and fourteen ethnicities ( Table 33-34). Some studies only referred to belief in God, or minimally detailed other religious beliefs, e.g. witchcraft (Rotheram-Borus et al. 2012). Ethnicity linked to religion, e.g. most African Americans identified as Christians, and those living in Iran and Jordan were Muslim. Spiritual practices included prayer, meditation, religious service attendance, spiritual healings, Bible readings, CAMP, pastoral support and church-supported education, the use of religious items (e.g. rosary beads) and the influence of nature (Table 35).

### 3.2.2 Religious coping influences self-management of T2D

The diagnosis of T2D was shocking for many. Muslims and Christians saw health as physical, emotional and spiritual (Hamadeh 1987; Egede and Bonadonna 2003; Popoola 2005; Newlin et al. 2010; Aghamohammadi-Kalkhoran et al. 2012; Lundberg and Thrakul 2012; Unantenne et al. 2013; Moridi et al. 2016), and attached meaning to their diagnosis (Egede and Bonadonna 2003; Newlin et al. 2010; Unantenne et al. 2013; Boonsatean et al. 2015).

Causality was attributed to be demonic, supernatural or God's will (Hamadeh 1987; Egede and Bonadonna 2003; Rotheram-Borus et al. 2012; Unantenne et al. 2013; Boonsatean et al. 2015; Moridi et al. 2016; Al-Amer et al. 2016; Newlin Lew et al. 2016). Although some African-American Christians coped by ignoring or denying the diagnosis (Egede and Bonadonna 2003), Cagle et al. (2000 p561) found women discussed 'not claiming' T2D as an illness, but this did not lead to denial. Rather it was refusal to consider themselves as 'sick which they stated many "White" women do'. Some Muslims (Aghamohammadi-Kalkhoran et al. 2012; Al-Amer et al. 2015) and Christians (Lager 2006; Unantenne et al. 2013; Boonsatean et al. 2015; Newlin Lew et al. 2016; Heidarzadeh and Amohammadi 2017) found their faith fostered hope. Hope is important as depression commonly co-exists with T2D (Popoola 2005; Rotheram-Borus et al. 2012; Al-Amer et al. 2015; Jafari et al. 2014; Al-Amer et al. 2016).

Family and community support (often religiously based) was valuable in assisting coping (Cagle et al. 2002; Lager 2006; Newlin et al. 2010; Lundberg and Thrakul 2012; Unantenne et al. 2013; Li et al. 2014; Shamsalinia et al. 2015; Boonsatean et al. 2015; Namageyo-Funa et al. 2015; Newlin Lew et al. 2016; Permana 2018). This support often occurred in and through American churches (Lager

2006; Popoola 2005; Namageyo-Funa et al. 2015; Newlin Lew et al. 2016; Permana 2018). Church connections were important with lower socio-economic communities who struggled to pay for T2D treatment (Cagle et al. 2002; Popoola 2005; Lundberg and Thrakul 2012; Boonsatean et al. 2015; Newlin Lew et al. 2016).

### 3.2.3 Positive and negative religious coping

Positive and negative religious coping was found in studies (Majeed-Ariss et al. 2013) and participants' dispositions influenced their coping styles (Samuel-Hodge et al. 2008). Passive, active and religious coping styles were noted in South African women using peer support through phone texting (Rotheram-Borus et al. 2012) whereas Black and African American women used cognitive reframing as a coping style (Newlin et al. 2010) and found church and community support significant (Cagle et al. 2002). Thankfulness and fostering hope was evident in religious coping with Muslims (Aghamohammadi-Kalkhoran et al. 2012; Moridi et al. 2016), and Christians and Buddhists who also expressed the importance of independence and self-management (Aghamohammadi-Kalkhoran et al. 2012; Unantenne et al. 2013; Boonsatean et al. 2015). Positive religious coping fostered hope and some studies found it linked to better diabetes control, with individuals taking responsibility for their diabetes (Popoola 2005; Egede and Bonadonna 2003; Newlin et al. 2010; Aghamohammadi-Kalkhoran et al. 2012; Unantenne et al. 2013; Stewart et al. 2013; Shamsalinia et al. 2015; Boonsatean et al. 2015; Namageyo-Funa et al. 2015). Thai female Buddhists believed their spirituality empowered them to manage T2D, despite low-income (Boonsatean et al. 2015). Even with karmic beliefs that illness is a result of misdeeds in past lives, Buddhists felt responsibility for self-management (Lundberg and Thrakul 2012). Permana's review of studies (2018) found cultural influences significantly affect interpretation of SMB of T2D, and was evident in Thai culture that included herbal remedies for T2D (Lundberg and Thrakul 2012). Some studies associated religious coping styles with hba1c results (Boles 2011; Al-Amer et al. 2016; Berardi et al. 2016) supporting claims of diabetes control, rather than those that just reported on coping styles (Lager 2006).

Religious fatalism, where belief that a Higher Power/supernatural/God(s) controlled their T2D resulted in poorer diabetes control in some Christians and Muslims (Hamadeh 1987; Egede and Bonadonna 2003; Samuel-Hodge et al. 2008; Newlin et al. 2010; Unantenne et al. 2013; Stewart et al. 2013; Shamsalinia et al. 2015; Namageyo-Funa et al. 2015; Newlin Lew et al. 2016; Permana

2018). Religious coping involved self-efficacy<sup>9</sup>, deferring and collaborative style (Boles 2011), with collaboration involving churches and supportive community/family members (Popoola 2005; Lager 2006; Namageyo-Funa et al. 2015; Newlin Lew et al. 2016; Permana 2018). Some religious coping led to distrust of doctors (Hamadeh 1987), or relying on doctors rather than focusing on self-management (Egede and Bonadonna 2003). Avoiding conflict with doctors was important with Thai female Buddhists (Lundberg and Thrakul 2012) and some Christians wanted prayer from their doctors (Stewart et al. 2013).

### 3.2.4 Limitations of studies

Definitions of spirituality and religion, and measures differentiating spirituality from religiosity are grossly lacking in the literature (Sessanna et al. 2011), affecting transferability of research (Lincoln & Guba 1985). In addition, whilst British healthcare is free at the point of access, American healthcare is funded by employers, individual insurance or the government (Rosenthal 2013), where patients/organisations are billed for individual services, medication or doctor's visits. Medicaid (US Government no date,a) is a government funded means tested program for American citizens of low income, and Medicare (US Government no date,b.) is a national insurance program paying for healthcare for those over 65 who have paid into the system. Participants from lower socio-economic groups may rely on spiritual beliefs more than those who can afford medical treatment (Cagle et al. 2002; Egede & Bonadonna 2003). Spiritual practices of poorer American communities become significant, as they are either free or low cost. Many poorer American diabetic people have no insurance, and CAMP was used alongside, or as an alternative to prescribed medicines. Although CAMP may be used by British diabetic people, this is unlikely that it is because they are cheaper alternatives to prescribed free medicines. Thus, the transferability of these studies to a British context is limited.

The validity of self-reported hba1cs by participants can be questioned, as participants may give inaccurate reports. Those studied including hba1cs taken from medical records gave validity to the claim that spirituality affected T2D control (Newlin et al. 2008; Hames 2010; Amirehsani 2011; Phelps et al. 2011; Egede & Ellis 2010; Cordova 2011; Boles 2011; Jafari et al. 2014; Amar et al. 2015; Al-Amer et al. 2016b; Albai et al. 2017). In addition, many studies were qualitative; therefore the findings were contextually specific.

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<sup>9</sup> According to the Cambridge English Dictionary (2019b), 'self-efficacy' refers to person's belief that they can be successful when carrying out a particular task.

### 3.3 Discussion

In both literature reviews, most of the studies were qualitative, but also included quantitative studies, systematic and literature reviews. Most studies involved African-American Christians; it appeared these participants were selected because they are considered a spiritual people (Polzer & Miles 2007) and the high prevalence of uncontrolled T2D of this group (Rovner et al. 2013). According to U.S. Census Bureau data, many African immigrants self-identify with their own ethnicity, and not as African American (Kusow 2014), therefore the term 'Black American' would benefit clarification. Frequently, other than being 'Christian', religious beliefs were not detailed, although some studies identified participants' church denominations. Except for some theses, authors did not declare their own biases, religious affiliations/beliefs, and only a few studies declared the ethnicity of the research team. Researchers' ethnicity may have influenced participants' interview responses, particularly if White-American researchers interviewed low-income African-American participants. Additionally, participants' perceptions of researchers' beliefs may have influenced their responses to religious/spiritual questions.

The systematic review of quantitative research between 1872-2010 by Koenig (2012) analysed the effect of religious belief and spirituality on mental and physical health, finding that religious belief and spirituality had psychological, social and behavioural processes that influenced health. Overall Koenig found that religious coping was associated with greater well-being and improved coping with stress. The positive psychological effects of religious belief/spirituality on mental health were improved ability to cope with adversity, positive emotions (e.g. optimism, forgiveness, gratitude, well-being), a positive world view, and appraisal of chronic conditions in such a way that made having T2D less distressing. In addition, positive social effects from religious social networks and behavioural effects were that religious beliefs/spirituality promote compassion, altruism and healthier lifestyles. Religious/spiritual people consumed a healthier diet – but more of it, therefore diet was not linked to healthier weight. While Koenig combined religion and spirituality, King et al. (2013) interviewed 7,403 individuals from the National Psychiatric Morbidity Study in England (NHS Digital 2009) and found that British people who were spiritual - but not religious - were vulnerable to 'mental disorder', therefore in their work spirituality separate from religious belief was associated with poorer mental health. Koenig (2012) found that negative effects of religious belief/spirituality could include depression, anxiety, fear, rigid thinking, avoidance and delay in seeking medical advice.

## Chapter 3

Pargament and Sweeney (2011) state that life's 'struggles represent a fork in the road' (p272) often leading individuals to utilise religious coping to interpret significant events in their lives. Positive religious coping strategies include re-interpreting stressors as beneficial and believing in God's care. These strategies may result in healthier choices, such as reduced alcohol due to belief that the body is holy (Quinn et al. 2001). Newlin et al. (2010) found diabetic participants' cognitive reappraisal mediated the relationship of well-being and diabetes stress. 'The fork in the road' may result in transformational forms of coping to search for significance, or individuals may temporarily disengage from seeking significance. Alternatively, it may include doubting God's care, being punished by God, or believing evil forces are connected to the stressor (Pargament et al. 2004; Permana 2018) resulting in decreased responsibility for health, favouring religious practices/beliefs over medical advice and poor treatment adherence (Gall et al. 2005; Permana 2018).

Some studies commented that clinicians should consider holistic assessment of diabetic patients that included their spiritual/religious beliefs, fatalism and health beliefs. Just as patients cope with disease processes individually, likewise a spiritual response to illness is multi-factorial (Holt et al. 2003). In the literature, the spiritual beliefs and bias of clinicians were generally not explored. Models to assess patients' health and spiritual beliefs assist clinicians (Kurtz & Silverman 1996; Anandarajah 2008; Saguil & Phelps 2012; Silverman et al. 2013), but patients' responses will always be subjectively interpreted by clinicians taking a spiritual history.

### 3.4 Summary

This review identified that psychological and social aspects, ethnicity and gender influence the spirituality/religiosity of people with T2D. In addition, individuals' dispositions influence dynamic coping styles that are contextually driven, and together all these factors influence individuals' self-management of diet, exercise, CAMP, and adherence to medicines. The literature found most research was with African Americans, with a paucity of evidence regarding how the spirituality of British people with T2D affects their self-management of their condition. The key themes of spirituality/religious belief, self-management, coping and ethnicity of people with T2D shaped the research question: 'How does the spirituality of a group of people with type 2 diabetes, living in England, influence their coping and self-management of their condition?' (Figure 6).



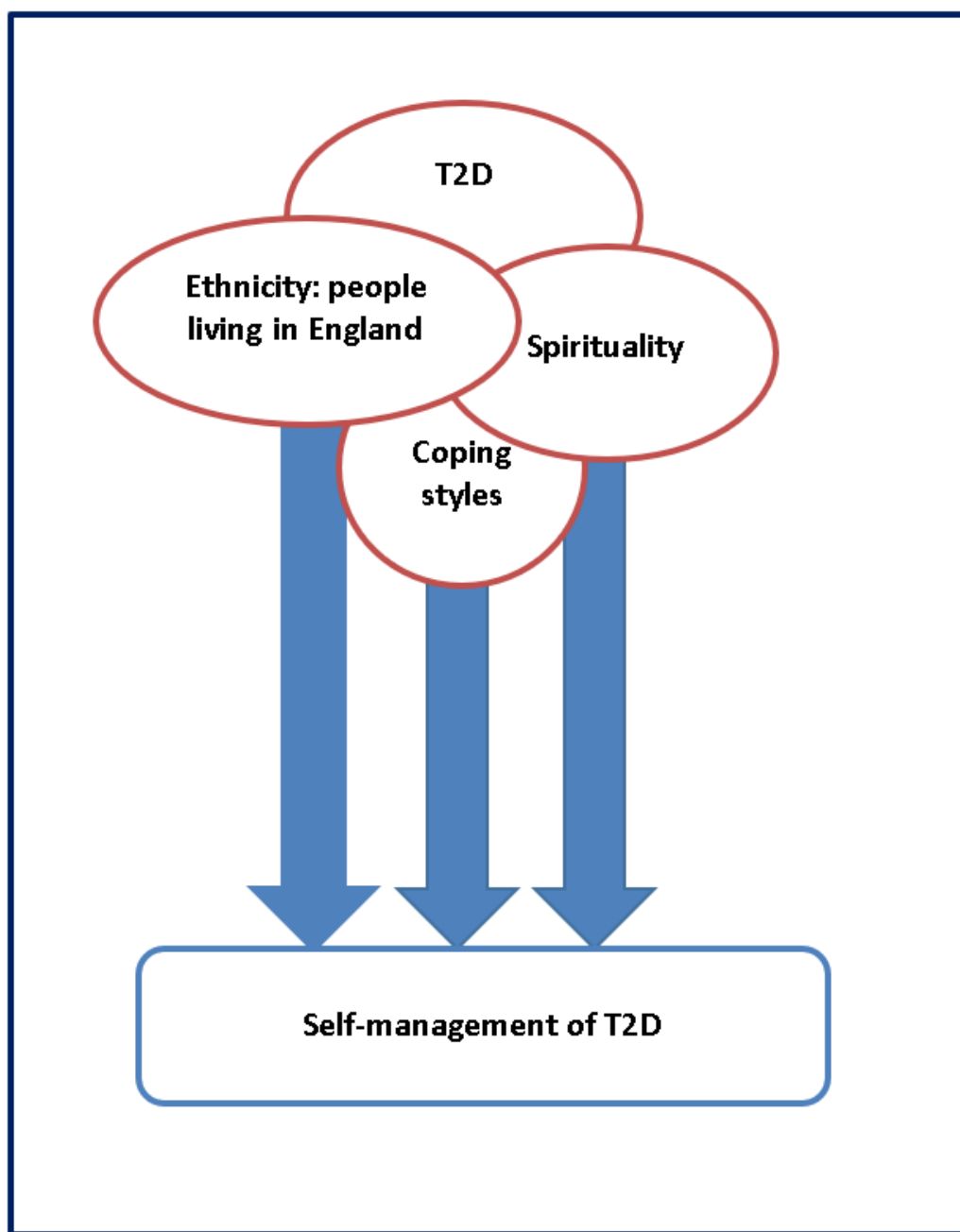


Figure 6: Refining the research question

As readers will see in Chapters 5 and 6, the interpretation and discussion of the findings in relation to spirituality and coping are linked for people with T2D living in England.



## Chapter 4 Study design

### 4.1 Introduction

The previous chapter discussed how the literature search led to the refinement of the research question; this chapter will provide a rationale for the study design, detailing selected methods. Once the research question is formulated, an appropriate study design must be selected, influenced by the type of information sought, what is already known about the subject, and the study's aim and objectives. 'Study design' refers to the entire research plan, including the philosophical assumptions, the paradigm and the methods chosen to collect and interpret the data (Creswell 2007), enabling assessment of the trustworthiness, transparency and rigor of the study.

The paradigm forms the base for the study design, with the method directing how data are collected and analysed. Theoretical frameworks are helpful in providing a coherent structure (Grant and Osanloo 2014) but were not utilised in this exploratory study, to avoid 'forcing' the data into a framework. This chapter will discuss the main paradigms used in healthcare research, and the choice to use the constructivist paradigm. My philosophical assumptions are presented, and how these led to the choice of methods: the biographic narrative interpretive method (BNIM) and thematic analysis (TA). Finally, the recruitment process, the contextual data and the interviews are presented with reference to ethical considerations of this study.

### 4.2 Paradigms in research

Paradigms refer to a set of beliefs and ways of thinking about the world that influence researchers' thinking and production of knowledge. Researchers need to disclose the philosophical assumptions that underlie their work, because these direct the choices made in answering the research question. In research, Patton (2002) asserts the main philosophical questions influencing the study design relate to ontology (the nature of reality), epistemology (ways of knowing about reality) and axiology (what is believed to be true). Guba and Lincoln (1994) however consider that the main questions relate to ontology, epistemology and methodology. Creswell (2007 p15) adds that rhetorical assumptions should also be considered as these influence the researcher's report-writing.

The ontological questions ask about the nature of reality; how the 'real' world is assumed and 'how things really work' (Guba and Lincoln 1994 p109); if there a verifiable truth or not, or if there

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are multiple realities. The epistemological questions relate to the relationship between the researcher and what can be known, what are the sources of knowledge, how to understand the new knowledge and the reliability of sources of knowledge (Creswell 2007). Axiological assumptions relate to the values, judgements and ethics that researchers bring, and relate to what the researcher values and will find of value to them in the findings (Aliyu 2015; Dudovskiy 2018). Methodological questions direct which approach will be appropriate, e.g. qualitative or quantitative. Differences in researchers' views on these philosophical assumptions have resulted in divergent paradigms and interpretive frameworks (Ormston et al. 2014), some of which are described below. Guba and Lincoln (1994) identify four major paradigms: positivism, postpositivism, critical realism and constructivism. An overview to the ontological, epistemological, axiological positions of these paradigms, and methods commonly used by them is shown in Table 1 overleaf.



Table 1: Common paradigms in healthcare research	<b>Ontology</b>	<b>Epistemology</b>	<b>Axiology</b>	<b>Methodology</b>
<b>Positivism</b>	<ul style="list-style-type: none"> <li>• 'Naïve realism'</li> <li>• Reality is true and apprehendable</li> </ul>	<ul style="list-style-type: none"> <li>• Objectivity essential</li> <li>• Strives to eliminate bias</li> </ul>	<ul style="list-style-type: none"> <li>• Research is undertaken in a value-free way</li> <li>• Researcher is independent from the data and maintains an objective stance</li> </ul>	<ul style="list-style-type: none"> <li>• Hypotheses subjected to empirical tests</li> <li>• Confounding variables accounted for</li> <li>• Mostly quantitative methods</li> </ul>
<b>Postpositivism</b>	<ul style="list-style-type: none"> <li>• 'Critical realism'</li> <li>• Objectivist</li> <li>• Reality is true, but the findings are 'probably apprehendable'</li> </ul>	<ul style="list-style-type: none"> <li>• Objectivity valued</li> <li>• Observation is fallible as influenced by externals</li> <li>• Findings influenced by critical community</li> </ul>	<ul style="list-style-type: none"> <li>• Research is value-laden</li> <li>• Researcher is biased by experiences</li> <li>• Biases affect research findings</li> </ul>	<ul style="list-style-type: none"> <li>• Modified experimental</li> <li>• Falsification of hypotheses</li> <li>• Quantitative and qualitative methods used</li> </ul>

Table 1: Common paradigms in healthcare research	<b>Ontology</b>	<b>Epistemology</b>	<b>Axiology</b>	<b>Methodology</b>
<b>Critical theory (postpositivistic)</b>	<ul style="list-style-type: none"> <li>• 'Historical realism'</li> <li>• Reality is shaped by external influences (such as politics, gender, etc) over time</li> </ul>	<ul style="list-style-type: none"> <li>• Subjectivist</li> <li>• Value-mediated findings</li> </ul>	<ul style="list-style-type: none"> <li>• Research is value-laden</li> <li>• Researcher is biased by world views and own cultural experiences</li> <li>• Biases affect research findings</li> </ul>	<ul style="list-style-type: none"> <li>• Methods chosen must fit the subject matter, quantitative or qualitative</li> <li>• Dialogical<sup>10</sup></li> <li>• Dialectical<sup>11</sup></li> </ul>
<b>Constructivism (postpositivistic)</b>	<ul style="list-style-type: none"> <li>• 'Relativism'</li> <li>• Constructed realities</li> </ul>	<ul style="list-style-type: none"> <li>• Subjectivist</li> <li>• Created findings</li> </ul>	<ul style="list-style-type: none"> <li>• Research is value-bound</li> <li>• Researcher is part of what is being researched</li> <li>• Findings are subjective</li> </ul>	<ul style="list-style-type: none"> <li>• Interpretive</li> <li>• Dialectical</li> <li>• Usually qualitative</li> </ul>

(Guba and Lincoln 1994; Weaver and Olson, 2006; Creswell 2007; Bunniss and Kelly, 2010; Dudovskiy 2018)

<sup>10</sup> Dialogical analysis is an interpretative methodology that analyses spoken/written utterances for their communicative significance (Frank 2005)

<sup>11</sup> Dialectical inquiry involves researchers identifying competing models emerging from participant responses (Berniker and and McNabb 2006)

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Positivism states that there is a single reality which can be known, 'when quantitative measured variables are manipulated in order to find relationships among them' (Hammersely and Atkinson 2005 p5). This view favours phenomena that are directly observable and measurable, and used to identify causal relationships and statistical differences, test hypotheses, or to explain the effects of an intervention (Howlett et al. 2014). Deductive reasoning develops a hypothesis regarding a phenomenon and seeks to prove or disprove it. Within medical research, this is the most commonly used paradigm, used for randomised controlled drug trials and structured social surveys (Broom and Willis 2007). In positivism, quantitative methods use data that are represented within numbers. Strict standardization is applied in the collection of data, to ensure minimal influence of the observer. Guba and Lincoln (1994) refer to positivism as 'naïve realism' where researchers assert that truth can be measured objectively.

According to Popper (1959) it is impossible to verify if beliefs about universals or unobservables are true. Postpositivism asserts that reality exists, but the findings are 'imperfectly apprehendable' (Guba and Lincoln 1994 p110). Cook and Campbell (1979) also suggested that the ontology of positivism required subjection to critical examination to apprehend reality – hence the term 'critical realism'. Postpositivists seek to understand the complexity of a specific phenomenon observed within a positivist framework, and to 'harness it within a complex research design' (Frane 2014 p5), with inquiry in naturalistic settings and qualitative methods. Findings should be based upon multiple sources (e.g. data, theories, methods) and fit within existing scholarly traditions, and be verified by the critical community (Guba 1990).

Critical theory is referred to by Guba and Lincoln (1994 p109) as 'historical realism' that includes several paradigms. Reality is considered to be shaped by political, social, cultural, economic, ethnic and gender values that become normalised over time to become 'real'. The ontological and epistemological assumptions become intertwined, as what can be known is value-mediated between the investigator and the object/group being investigated and can be emancipatory, e.g. participatory action research. The paradigm is oriented on critiquing society and challenging the status quo (Asghar 2013; Aliyu 2015) and in healthcare has been used in researching professional power structures (Witz 1992; Reeves et al. 2008). Emic views (i.e. subjective perspectives obtained from being part of a group) will influence findings (Kottak 2006) e.g. nurse researchers investigating healthcare power structures. Methods used are dialogic and dialectical due to the transactional nature of the inquiry.



### 4.2.1 Constructivism

Constructivism is the paradigm chosen for this study. According to Broom and Willis (2007 p24), the constructivist paradigm emerged in the 1920s and gathered momentum 1960s and 1970s, when social scientists looked to understand the way in which meanings were constructed and negotiated by individuals and groups. Rather than measuring or categorising behaviour and attitudes, constructivist researchers sought to understand what lay behind choices, patterns and meanings. Constructivism is referred to by Guba and Lincoln as 'relativism' (1994 p109). Constructivism may also relate to the interpretivist or naturalistic paradigm and uses qualitative methods (Broom and Willis 2007; Howlett et al. 2014). Knowledge is socially constructed, is experientially based at an individual and group level, and appears 'true' to those involved (Creswell 2007; Ormston et al. 2014). From an ontological perspective, the researcher accepts the idea of the multiple meanings and realities that the participants inhabit, and words and direct quotes from participants provide evidence of the different perspectives of participants (Kawulich and Chilisa 2015). Within an epistemological assumption, researchers' aims are to be as connected to their participants as possible, to see what their world is like, and conduct research where participants live or work to gain further insight to their world (Mertens 2010). The researcher does not seek to 'lessen the distance' between themselves and that which is being researched but to some extent is an 'insider' in the research (Creswell 2007 p17). Researchers and participants are interactively linked, causing the findings to 'be literally created as the investigation proceeds' and 'the conventional distinction between ontology and epistemology disappears' (Guba and Lincoln 1994 p111). Constructivist methods are dialectical and hermeneutic, involving interpretation. Sample sizes are often smaller than positivistic enquiry, and sampling may be purposeful (Howlett et al. 2014).

Whereas quantitative research relies on statistics, the data used by qualitative researchers includes interviews, artefacts, observations, visual data, field notes, audio recordings and social media, and can include data from the researcher as well as the participants (Denzin and Lincoln 2005). In qualitative research, language is personal and may involve narratives of the researcher as well as the participants. Constructivist researchers immerse themselves in the data, exploring it from multiple angles. Some qualitative methods, such as grounded theory (Glaser and Strauss 1967), ethnography and the BNIM (Chamberlayne et al 2000; Wengraf 2001) use memo-writing as an analytic tool (Given 2008). Memo-writing occurs through the study, aiding reflexivity, document the interpretive process and assist coding of the data (Birks and Francis 2008; Saldaña 2013). Glaser (1978 p83) insists that researchers 'stop and memo' as they are 'sparked' by thoughts during transcribing, coding, sorting and writing. All thoughts, reflections and ideas are recorded, as even seemingly inconsequential ones may prove significant in later analysis (Polit and

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Beck 2006). Memos vary from a sentence to a few pages, are the 'building blocks' that 'build the evolving process' of the researcher's reflection (Wengraf 2001 p211).

Creswell (2007) states that the rhetorical issues in qualitative research relate to the overall building of the final report and its embedded structures, i.e. the quotes, reflexivity, audience and encoding. The structure varies according to what authors believe will highlight the data, e.g. it could be chronologically focused, or theme focused. When quoting participants, researchers may use embedded quotes to illustrate a theme or significant aspect of the data. In inductive analysis, the findings are said to emerge out of the data (Patton 2002). However, the interpretation of the data will be influenced by the researcher's background, gender, social class, social, cultural and political beliefs, and as such the report is 'positioned' in a stance. The concepts, themes or models are created by the researcher(s) through data analysis (Thomas 2006), with the final construction taking into account the etic and emic approach of investigator(s). The etic approach 'realises that members of a culture are often too involved in what they are doing to interpret their cultures impartially' (Kottak 2006 p p47) whereas emic perspectives refer to an insider perspective (Willis et al. 2007). Some qualitative methods within the paradigm will generate a theory, such as grounded theory (Glaser and Strauss 1967) but this is not a focus in other methods, e.g. narrative, ethnographic or phenomenology (Creswell 2007).

### 4.2.2 Rigor

Rigor must be evident throughout the entire research design, as without it research has no value. Rigor is defined simply as the state of being 'thorough and accurate' (Cypress 2017 p254), and was termed as 'trustworthiness' by Lincoln and Guba (1985), to assess the quality and truthfulness of a study, and correct application of the methods. They asserted that the credibility of research is determined when the experience described resonates with the participants and other researchers. Lincoln and Guba replaced the positivist measures of rigor (internal and external validity, reliability and objectivity) with 'credibility', 'transferability', 'dependability' and 'confirmability', to address the trustworthiness of research.

#### 4.2.2.1 Credibility

'Credibility' addresses the internal validity of constructivist research. As reality is perceived as layers of constructions created by individuals or groups, constructivist research must clearly show these unique multiple constructions are interpreted and applied to participants' lives. The biases, assumptions, and relevant characteristics of researcher(s) must be stated, enabling assessment of

how these may have influenced the researchers' interpretation of participants' constructions of reality. These will vary according to the study, but in this present study, characteristics such as religion/spirituality, race, ethnicity, gender, age and diabetes-status could influence interrogation of data.

Rigor may be considered 'a more difficult task when dealing with narratives and people than with...statistics' (Cypress 2017 p254). Credibility can be addressed through peer debriefing to show how researchers are examining the data, ideas that are evolving, how the emerging themes are inter-linking (Nowell et al. 2017) and ensure proper application of methods. This enables challenge from others, and potential 'blind spots' of researchers to be questioned. In addition, the findings must be reviewed and agreed by the participants themselves (i.e. 'member checking') and is viewed by Lincoln and Guba as the 'single most crucial technique for establishing credibility' (1989 p239). It enables clarification and reactions from participants, to ensure that they have the opportunity to check for accuracy and that the research resonates with their experiences (Birt et al. 2016) opening the researcher's interpretation to scrutiny. Morse and Meadows (2001 p196) state that it 'may be difficult to imagine that the opinion of a single participant outweighs the expertise of a researcher/analyst', therefore, it is part of the overall strategy of checking and validation. Credibility is enhanced by prolonged engagement with the data, persistent observation, peer debriefing, negative case analysis, reflexivity, audit trails and triangulation (Morse and Meadows 2001; Morse 2015). Triangulation refers to the comparison between different methods of data collection (e.g. in this research: interviews and contextual data). Pope and Mays (2000 p51) assert this is a 'controversial' test of validity as it assumes that 'any weakness in one method will be compensated by another method' but it can aid reflexivity. Peer debriefing, discussion of the interpretive process, reflexive journals and audit trails assist triangulation.

#### **4.2.2.2 Generalisability and transferability**

Generalisability and transferability relate to the positivist term of external validity. In quantitative research, generalisability refers to the extension of the findings and conclusions on a sample studied to the population at large. However Leung (2015) suggests generalisability may become relevant in qualitative research if conducting meta-synthesis, meta-narrative or meta-ethnography. Transferability refers to the potential application of research to similar settings, times, situations and people; therefore, the research design of the study must be clearly stated, e.g. participant sampling and recruitment. If relevant, the socio-historical context and background that may influence the data should also be stated, e.g. the terrorist attacks in September 2001 in the US may be a significant aspect to consider with any research regarding

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Americans' spirituality undertaken around 2001 onwards (Schuster et al. 2001). Description of phenomena must be sufficient for readers to evaluate to what extent the conclusions drawn in the research are transferable to other contexts; the onus is on the reader to consider to what degree the salient conditions match. If multiple factors are not similar, transferability may be questioned. A major technique for establishing transferability is 'thick description', a term developed by the anthropologist Geertz (1973). Geertz posited it is not possible to understand phenomena unless the cultural components are clarified. For example, winking may be an unintentional twitch of the eyelid, or a conspiratorial gesture to a friend; it all depends on the context and culture. The description surrounding the phenomena allows readers to understand the implications, cultural significance and meaning of the gestures and actions. Although Lincoln and Guba stated that 'just what constitutes 'proper' thick description is...still not completely resolved' (1989 p241), it is understood in the constructivist paradigm to refer to the cultural contexts, conceptual contexts and meanings that occur with actions and words. By clarifying these, readers are enabled to make sense of and understand the behaviour and words of cultures, organisations and a variety of settings. It is anticipated that the descriptions of the process, the details of the analysis, the background information of Christianity (Appendix N) and the findings in this study provide evidence against which to determine transferability.

### **4.2.2.3 Dependability**

'Dependability' relates to the positivist term of reliability, and refers to the consistency of the inquiry process over time (Williams 2011). When assessing the dependability of a study, one must consider if the research design has been properly conceptualised, and the process rigorously followed. Due to the nature of narrative analysis and inherent bias in researchers, the interpretation of the data needs justification. According to (Williams 2011, ch5), 'the more consistent the researcher has been in this research process, the more dependable are the results.' Lincoln and Guba (1994) accept that as multiple realities are constructed by individuals and groups, inconsistencies within these realities will be present, but they must be analysed and resolved. Member checking and peer review address dependability, by confirming the researchers' observations (Cohen and Crabtree 2008), by identifying if techniques for meeting credibility and transferability can be applied. Lack of these casts doubt on the dependability of a study. Audit can also be undertaken to check for consistency. In this study, member checking enabled participants to verify themes, and details are given in Chapter 5. In addition, Williams (2011) states that qualitative inquiry should be under the most natural conditions possible, and participants not manipulated. The reported results should allow readers to have a sense of 'being there', enabling independent conclusions from the data. The conclusions should not be at odds with the participants' views, and findings should resonate with the research community.

#### 4.2.2.4 Confirmability

'Confirmability' relates to the positivist term 'objectivity' and refers to the 'quality of the results' where participants support the findings, peer review is in agreement and results are not at odds with other literature (Williams 2011, ch5). Guba and Lincoln (1989 p243) state it should be evident the findings are not 'figments of the [researcher's] imagination.' Interpretation of narrative data is subjective, therefore it must be clear it has not been distorted or misinterpreted by researchers' interpretations or beliefs. The field notes, memos written by researchers, sampling decisions, reflexive diaries, and records of peer-review conversations, developing emerging themes and consideration of ethical concerns, all assist to enable external verification of the interpretation of data. In this study, all of these were documented for audit purposes, but an audit was not undertaken.

### 4.3 Philosophical assumptions of this study

Both spirituality (Coyle 2008) and the self-management of T2D have been researched with positivist and constructivist paradigms (Gupta and Anandarajah 2014; Abolghasemi and Sedaghat 2015; Gainey et al. 2016; Heidari et al. 2017). As this study necessitates understanding the meanings that participants attached to their beliefs, a positivist approach was not chosen, as this would not reveal participants' subjective and at times unconscious choices in their lives. A positivist approach would not reveal how decisions that related to diabetes self-management were made, nor would it reveal *why* participants made certain choices about managing their diet and exercise, what were the influencing factors behind these choices, and *how* participants' spiritual beliefs influenced their self-management choices for T2D. The constructivist paradigm was selected as it has potential to source rich data about the lives of the participants, *how* these beliefs may *influence* their choices to manage their diabetes; and how participants interpreted their beliefs regarding their diabetes self-management. A constructivist approach would allow consideration of the complex layers of data that were likely to be present, and how these layers might interconnect with each other. As the investigators shape the research, their philosophical assumptions must be declared. I acknowledge that I am a middle-aged, White British female who is a non-diabetic nurse with an interest in T2D. My lived experience is shaped by living in different cultures and countries (Hong Kong, UK and New Zealand). I am a Christian of no particular denomination and accept participants' description of their spirituality at face value. The aim of this study was not to interpret participants' spiritual beliefs, but to understand *how* their spirituality relates to their self-management of T2D. My axiological influences relate to being a nurse-researcher, with my beliefs about healthcare and diabetes, and my views regarding

patients' responsibility influenced the questions I asked in participant interviews and in my interpretation of participant responses.

#### 4.4 Method

Different approaches were considered for participants to reveal their beliefs, reasons for actions and how they managed their T2D on a day-to-day basis. Phenomenology, grounded theory and the narrative method were all considered. Grounded theory was not chosen, as the aim was not to produce a theory (Strauss and Corbin 1999). The aim of the research is not to understand a phenomena as in phenomenological research (Moustakas 1994; van Manen 2016) but to explore how the participants' spirituality influences their coping and self-management of T2D. Therefore, it was considered that a narrative approach was most appropriate method for this research.

There is no clear agreement as to the definition of narrative and it does not fit into to one scholarly area (Reissman 1993 p17). In narrative research, Czarniawska (2004 p17) describes it as a 'spoken or written text giving an account of an event/action or series of events/actions, chronologically connected'. Creswell (2007 p76) states 'the inquirer focuses on the stories told from the individual and arranges these stories in chronological order'. Labov (1997) likewise agrees with chronological sequencing, and assumes all narratives are about past events.

Narratives are unique to time, place and person and evolve as the person transitions through life, and as such a story cannot be told exactly the same twice (Bailey and Tilley 2002). In most narrative research, the stories are influenced by the researchers' questions, which influence the telling of the story and the direction in which it flows. Pinnegar and Daynes (2007) state that 'narrative' can be used to describe both the method and the phenomena of the study, and has been used for nursing research (Casey et al. 2016). In describing qualitative inquiry methods Creswell states the narrative method is best for 'capturing the detailed stores of life experiences of a single life or the lives of a small number of people' (2007 p55). Illness narratives are useful for 'studying the world of biomedical reality, but also the illness experience and its social and cultural underpinnings' (Hyden 1997 p1) and the identity of being a person with an illness (Hyden 2010). Narrative research has been used to understand what it is like living with T2D (Gomersall et al. 2012; Bhattacharya 2013; Browne et al. 2013; Snow et al. 2013).

Wengraf (2015 per comm) states narrative methods are both psychodynamic and socio-biographic in approach, and concerned with the 'inner and outer worlds' that the participant inhabits. In telling their stories, participants express their conscious concerns and their unconscious cultural and societal beliefs within a historical social context. In this research, the

BNIM was considered appropriate for revealing how participants' spirituality may influence their approach to their diabetes self-management. In the BNIM, one or two interviews per participant are required. In this research, after university and NHS ethical approval, one participant was included in a pilot study, involving one interview that confirmed two interviews per participant would be necessary to obtain the data required for this study.

#### 4.4.1 The biographic narrative interpretive method (BNIM)

Participants recruited to the study underwent interviews using the BNIM (Chamberlayne and Wengraf 2000; Wengraf 2001; 2004; 2011). In healthcare, BNIM has been utilized to understand chronic conditions and illnesses (Curtin and Clarke 2005; Campbell-Green and Poland 2006; Sallinen et al. 2009; Thetford et al. 2013; Hughes 2014; Milne 2014) as well as the self-management of T2D (Gomersall et al. 2012). The BNIM has two components: the interview technique and the method of analysis. The interview technique can be used as a complete method for interviewing and data analysis by a research panel, or the unique interview technique may be used as a tool for the interviews alone, and a separate method used to analyse the data (Wengraf and Chamberlayne 2006; Gomersall et al. 2012; Corbally and O'Neill 2014; Casey et al. 2016).

The BNIM posits that to understand people's life stories, the historical, psychosocial and biographical aspects must be revealed. Wengraf states that the narratives of people express their conscious and unconscious biases that spring from cultural, societal and individual beliefs, and 'it is concerned with both the "inner" and the "outer" worlds of individuals' (2004 p4). The analytic strategy in the BNIM focuses on three components: (1) their biography: the life story of the individual; (2) their narrative: the way the story is told; and (3) the interpretation: the social interpretation by researchers. The biography reveals how historical aspects of society influences the choices people make and reveals how the decisions of the individual are set within a socio-historical context. The narrative is the way that individuals present themselves and their stories on an individual level, as well as socio-culturally. In the BNIM, thematic field analysis identifies two strands: the 'lived life' and the 'told story' (Wengraf 2001 p236). The 'objective knowledge' of the lived life is the important context, containing 'hard facts' (e.g. the year of birth). In the BNIM used for both interviews *and* analysis, a research panel uses a nine-stage analytic strategy to analyse the lived life and the told story of the participant. They look for emerging patterns of the lived life within the told narrative and create a 'case account', which is compared against other individual 'case accounts' (Wengraf 2001). As this study was a doctoral investigation and not suitable for data analysis by a panel, 'case accounts' were not created for panel analysis, and the

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BNIM was used for the interview technique *only* and TA (Braun and Clarke 2006) was chosen for data analysis.

In the BNIM interviews, up to three interviews for each participant are completed. The interviews, known as 'sub-sessions', are recorded and transcribed verbatim. The unique style of interviewing is non-directive that deliberately minimizes the researcher influencing the flow of the narrative, enabling participants to give an uninterrupted narrative. In the first sub-session of the first interview, the researcher asks a single question inducing narrative (SQuIN).

The SQuIN enables participants to choose which stories to tell, is significant in revealing their beliefs, systems and episodes of significance, their values, and their conscious and sub-conscious biases (Wengraf 2001 p69). Gestalt in the BNIM refers to adopting an interview style that minimises the interviewer's concerns, enables the participant to talk for as long as they wish to, with participants making it clear when they have finished their narratives (Wengraf 2004). The researcher does not ask any other questions, allowing the participant full expression of their narrative. Active listening skills are used by the researcher to enable spontaneous gestalt, whilst researcher notes are made on a specific notepad (Appendix G).

After the first sub-session, a short break occurs to allow the researcher to construct questions to ask in the second sub-session. These narrative-based-topic questions are created from the actual 'topic phrases' that were used by the participant; an example of a topic phrase could be 'I wept when I was diagnosed'. In the second sub-session, the researcher uses the topic phrases to encourage participants to amplify their stories, to produce 'particular incident narratives' (PINs). The topic phrases may only be asked in the order they were raised in the first sub-session. Asking this type of question is likely to trigger another narrative, revealing rich data with strong emotions, and often the participants are re-living the events: this is the aim of BNIM interviewing - to elicit deep PINs. Of the eight participants in this research, all gave PINs, and six experienced strong emotions or tears during interviews.

At the end of second sub-session, the first interview finishes. If after analysis of the two sub-sessions, further questions arise, participants are invited for a follow up interview (i.e. third sub-session). Here further narrative questions arising from the first interview, as well as questions that may not elicit a narrative may be asked that relate to the research question. Not all BNIM research utilises two interviews (Wengraf 2001; Ross and Moore 2014) but analysis of the pilot interview in this study indicated a follow-up interview would be required to identify sources of coping, spiritual practices, dietary and exercise details.



Although a criticism of the BNIM is that SQulNs might limit the dialogic possibilities (Bornat 2008) it can be equally argued that it facilitates greater freedom for participants to direct the flow of the interview. I attended a 5-day course on the BNIM research in London with Tom Wengraf, during which researchers practised the BNIM interviewing on each other. It was noted by all that, with skill, it was possible to obtain deep (and usually emotional) PINs from simple questions, such as ‘Tell me about starting school’ or ‘Tell me about leaving home.’ This convinced me that the BNIM for interviews would yield the rich data necessary for answering the research question.

#### 4.4.2 Reflexivity and bias

Bias occurs as data are filtered through the understanding of the researcher(s) (Stern 2004). Researchers must consider their identity and position and disclose their assumptions, values, prejudice, and influences. I considered my ethnicity, age, gender, nursing, life experience and Christian beliefs would influence the study and interpretation of the data (Anderson 2013; Mauthner and Doucet 2013). Morse (2015) identified two sources of bias. Firstly, it may occur from seeing what is already anticipated which may lead to a feature being unfairly emphasised during analysis. Although ‘bracketing’ will assist researchers to hold lightly the previous research, the literature reviews had influenced my expectations about what data may present (Morse and Meadows 2001). Not having T2D myself gave me an etic perspective: I do not live with a chronic condition that affects so many aspects of my life and am not part of the ‘community’ of people with diabetes. Yet to some degree, my nursing experience gave me an emic perspective: I appreciated participants’ descriptions of clinical scenarios, and that complex clinical relationships could influence adherence to treatment. My clinical experience found that some patients exhibited *decreased* responsibility for their own self-management of T2D due to their spiritual beliefs. Most of the narratives in my study however did *not* corroborate the phenomena of spirituality causing decreased responsibility. It was not possible to reflect during interviews, but this occurred immediately post interview and throughout transcription and analysis. My reflexive journal helped track my thoughts, questions, beliefs and biases and how this may affect interpretation of data, and to what level to interpret or accept the interview data at face value.

I did not wish to express my own views on spirituality with participants as this may influence interviews. However, many participants assumed that I was a nurse and some directly asked me about my spiritual beliefs. In her first interview, a participant stated:

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'You asked about spiritual. I'm a Christian, I go to church every Sunday. (2<sup>12</sup>) Uuum. Does God help me to cope? Maybe He does, I'm not aware of it. I can't say that spiritually (2) I'm encouraged by God. Full stop. I've run out of things to say.' (Sally: 1/89)

She appeared uncomfortable to discuss her spiritual beliefs further. After the first interview finished, Sally asked directly about my beliefs, and when I said that I was a Christian this changed her approach. She consented to a second interview (third sub-session), where she talked in detail her spiritual beliefs and diabetes. In this aspect, it appeared she considered I had an emic perspective, and used Christian jargon that I understood, e.g. feeling the presence of God. Some participants had specifically asked if I was a Christian before interviews, and it appeared that some shared spiritual experiences because they felt I would understand the meanings behind the narratives (Appendix O).

### 4.4.3 Pilot interview

Wengraf has previously advised it could not be known if three sub-sessions would be required in the study – it would depend on participants' responses to the first two sub-sessions. After hearing about the study via my husband, a middle-aged male approached me in the school playground, and asked to be in the study. As this informal mechanism of recruitment had not been included in the recruitment strategy, the supervision team decided that this participant's data should form a pilot interview. The pilot interview was at the university, lasted fifty-eight minutes and resulted in emotional PINs about spirituality significantly influencing his self-management of T2D. However, it did not reveal any specific data relating to diet and exercise. Therefore, it was anticipated this may occur in all first interviews, and that all participants would require a third sub-session; this proved correct. All participants spoke about living with T2D and spirituality in the first interview. The second interview yielded further information about spirituality but was focused towards diet and exercise.

### 4.4.4 Interviews using the BNIM

The SQuIN is the only planned question asked in the first sub-session interview. The SQuIN for this study is shown in Box 4. The first sub-sessions varied in length, commonly lasting ten to

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<sup>12</sup> In participants' quotations, the numbers in parentheses indicate the pause in narrative by the number of seconds.

twenty minutes. During this time, notes were recorded on a BNIM notepad (Appendix G) and used to formulate topic-based questions for the second sub-session.

“As you know I’m researching people’s stories of living with type 2 diabetes. Please could you tell me your story from when you first became aware that you might have diabetes up to now? You can start wherever you like. Please take all the time you need. I’ll listen first, I won’t interrupt. I’ll just take some notes in case I have any further questions for after you’ve finished telling me about it all.”

Box 4: SQuIN in first sub-session BNIM

In the second sub-session, three planned questions were asked (Box 5). The second sub-sessions varied from approximately forty minutes to two and a half hours.

- What is it that gives you strength to cope with the challenges in life?
- Have any particular spiritual practices or religious beliefs helped you cope with your diabetes?
- Can you tell me how having diabetes may have impacted your diet and exercise?

Box 5: Questions in second sub-session BNIM

In addition, after the second sub-session had finished, some participants went on to give further narratives for up to twenty minutes that they did not wish to be recorded but were happy for notes to be made. Participants showed me artefacts in their home that related to their diabetes, their spirituality or their family; these were recorded in a post-interview memo. In the second interview, all participants were asked to expand on comments made in the first interview, and were asked planned non-narrative questions relating to the central research question.

Interview times for all sub-sessions varied. One participant did not approach the interview reflexively, and his interviews consisted of a total time of 1 hour and 45 minutes. Others explored their emotions as they narrated, and their interviews were longer, up to 4 hours and 20 minutes. The average length of time was almost 3 hours per participant. All participants except one

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completed two interviews approximately one month apart. Participants chose the location of the interview: of the sixteen interviews, five were at the university and eleven in participants' homes. Five participants expressed deep emotions during the interviews. Wengraf states it must be ensured that the interview ends well (2001 p205). Interviews ended by asking participants if they wished for spiritual/emotional support to be arranged, and if they wished anything to be deleted from the interview. No participant requested post-interview support, and some said they found the interview cathartic.

### 4.4.5 Thematic analysis

It has been detailed in the section describing the BNIM (4.4.1) why the BNIM thematic field analysis was not used for data analysis. Discussion of the study with Tom Wengraf resulted in the selection of TA to analyse data. Boyatzis (1998) states that TA is a commonly used qualitative analytic tool that identifies analyses and describes patterns (named 'themes') within a data set. It enables management of large volumes of data generated from various sources, e.g. interviews, diaries, field notes, memos of the researcher, photographs, audio files, and organizes and enables analysis in relation to the research question or theory. This systematic approach involves 'coding' the data and classifying it according to themes, and then seeking common relationships and overarching themes that relate to the data. Analysis may be done manually, or using computer assisted qualitative data analysis software programs such as 'NVivo' (CAQDAS) (QRS International 2018), which can be helpful for organizing large amounts of data, and to show an audit trail of data analysis (Zamawe 2015). Software applications are merely tools, and it is the researcher who conceptualizes the process and transforms the data into themes. Theme creation is subjective, using the researcher's interpretation of the data to generate themes that relate to the research question. It may be used across many disciplines, and certain methods utilize it as a tool, such as the interpretive phenomenological analysis (Larkin et al. 2006) or grounded theory (Glaser and Strauss 1967).

TA has been criticized as being poorly defined, not being a specific method, and without a clear process (Attride-Stirling 2001). Roulston (2001) argues that underlying discourses may be glossed over, and fine-grained analysis of language is not possible as in methods such as discourse or content analysis (Vaismoradi et al. 2013). However, despite the disadvantages, TA was a suitable approach to analyse the data for this study. Braun and Clarke (2006 p78) state that although it may be used as a tool within qualitative analysis, it can also be considered as a method in its own right, utilizing six defined phases as shown in Box 6.

### Phases of thematic analysis

1. Familiarizing oneself with the data: transcribing, repeated re-reading, and noting initial ideas.
2. Generating initial codes: systematically coding the interesting features of the data across the entire data set, and collating data relevant to each code.
3. Searching for themes: collating codes into potential themes, then assembling data relevant to each potential theme.
4. Reviewing themes: checking if the themes work in relation to both the coded extracts, and with the entire data set. Generating a thematic 'map' of the analysis.
5. Defining and naming themes: analysis continues to refine the particulars of each theme, generating clear definitions, and the overall story that the analysis tells.
6. Writing a paper: in providing rich and vivid examples it enables final analysis of selected extracts, relating back of the analysis to the research.

(Braun and Clarke 2006 p87)

#### Box 6: Phases in thematic analysis

The six phases are followed systematically. In phase 1, 'immersion' in the data occurs by transcribing interviews, note-taking, and repeated re-reading of the data. Transcription is a complex part of qualitative research involving the writing down of the spoken discourse. It is acknowledged that the written account does not entirely capture the mental, social, and cultural components of the individual (Kowell and O'Connell 2013). In phase 2, initial codes are generated across the entire data set to identify specific interesting characteristics, and may be semantic in content or latent. In either case, codes will be affected whether the data are 'data-driven' or 'theory driven' (Braun and Clarke 2006 p88). Coding is cyclical, and will involve a minimum of 2 cycles as salient features of the meaning of the data become evident. Saldaña (2013) states that coding is a 'heuristic problem-solving technique...an initial step towards an evocative analysis' (2013 p8) enabling linking of the data parts. It is important to code across the entire data set, noting the patterns, and where there are inconsistencies within the data. Phase 3 commences when all the data are coded. The number of codes varies, but Saldaña (2013) asserts that it is helpful to have around 100 – 120 codes in analysis; more than this becomes difficult to manage, whilst Lichtman (2010 p164) considers in education research about 80-100 codes are organised into 15-20 categories, which will cumulate into 5-7 major concepts. Within this phase

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the codes are sorted into major and minor 'potential themes', potential 'sub-themes' and 'miscellaneous' themes (Braun and Clarke 2006 p89-90). Saldaña (2013 p13) defines a theme as a summarisation of connected codes, an 'outcome of coding, categorization, analytic reflection'. This initial analysis is helping the researcher consider how some of these potential themes may connect to form overarching themes later. No data are discarded yet, and all data are still relevant at this stage - even the 'miscellaneous' potential themes, as these potential themes are still a work in progress until phase 4.

Refinement of the potential themes begins in phase 4. Some potential themes may combine together, some may need to be expanded to form an additional theme, and some abandoned as it becomes clear there is either too little data to be relevant, or the data are 'too diverse' (Braun and Clarke 2006 p91). When re-reading all the extracted data within the theme, the data should clearly link together. At this stage, a thematic map can demonstrate the linkage between the main themes now present. The entire data set must be re-read to code any data that were missed in earlier phases, and to ensure that the main themes truthfully capture the data set in its entirety. If the thematic map does not work regarding the entire data set, the researcher returns to the earlier coding phases to identify potential themes. When the thematic map accurately reflects the entire data set, it should be clear how the main themes interlink.

Phase 5 involves defining and naming the themes. The researcher re-reads the collated data within the themes, organizes extracts into consistent sections and creates a detailed analysis and description of each theme. Within each theme, the researcher considers how the data within it relates to the research question, identifies the key aspects within it, how it links to other themes and the overall 'story' that is evident in the data. Braun and Clarke state the account must not 'just paraphrase the content of the data extracts presented but identify what is of interest about them and why' (2006 p92). This phase is creative and involves drawing together all the themes to ensure consistency. The theme names may need further refinement to ensure they accurately convey their content in a few words.

Phase 6 provides distinct themes that clearly link to the research question. Within themes, data extracts demonstrate the scope and diversity of the theme, moving from a descriptive to an interpretive and analytic level. The analysis considers the relevance of themes, the underlying assumptions and implications, and the 'overall story the themes reveal about the topic' (p94). Using a theoretical framework can assist anchoring TA, and various models were considered for this study. However, as this was an exploratory study with little known about British people's spirituality influencing diabetes self-management, it was considered that a theoretical framework may result in data being 'forced' into a framework. To address rigor in the study, the six phases

were systematically followed, and assisted by memo-writing, code-book development audit trail, keeping a reflexive journal and supervisory team reviews.

#### 4.4.6 Sampling and recruitment

Wengraf (2001) states in the BNIM purposeful sampling of participants is small, usually up to 'five or six' participants (p145). The BNIM often uses small sample sizes - examples of this are the study by Gomersall et al. (2012) with eight women regarding making sense of self-management of T2D; Stamm et al's (2008, 2009) study regarding living with a chronic condition with ten participants, and the study by Brown and Addington-Hall (2008) with thirteen people talking about motor neurone disease. For this study, a purposeful sample size of six to eight participants is sufficient (Gomersall et al. 2012) and was discussed with Tom Wengraf and advised to be sufficient due to the richness of the data likely to be collected (Wengraf 2015).

Following ethical approval from the university and Health Research Authority (Appendix I), recruitment occurred in Hampshire, England. GP Practices in Hampshire were contacted and consented to recruit patients via Recruitment Posters (Appendix J) displayed in their premises. In addition, practice nurses informed patients of the study. The Poster explained patients were sought who were willing to engage with interviews to talk about living and coping with T2D, and how spiritual practices may assist with this. Participants were recruited from seven GP Practices. Patients contacted me by their preferred method of contact, and those who fitted inclusion/exclusion criteria (Table 2) were sent Participant Information Sheets (PIS) (Appendix K) and a Consent form via the post (Appendix L). The PIS advised that their GP would be informed of their involvement in the study (Appendix M), and that contextual data relating to their T2D would be requested from their diabetes clinic records (e.g. hba1c).

Table 2: Inclusion/exclusion criteria for study

<b>Inclusion Criteria</b>
Speak English
Have had T2D at least 6 months*
Have read the Participant Information Sheet, explaining this study is regarding T2D, spirituality, coping and self-management
Gives consent to access their records stored on Clinic database
Gives consent to recorded interviews

Must be over 18 years old
<b>Exclusion Criteria</b>
Not speak English
Have had T2D less than 6 months*
Have read the Participant Information Sheet, and decided they are not comfortable talking about their T2D, or spirituality, or coping or their self-management
Not consenting to data collection from Clinic records
Clinic records have not been kept (e.g. is a new patient to their GP)
Consent is withdrawn from the study (which could be any stage)
Under 18 years old

\* Participants should not be newly diagnosed with T2D, or may still be in the phase of shock or denial (Peel et al. 2004), and not able to tell how they cope with the day to day management of their condition.

When I received participants' signed and dated consent forms by post, I contacted them by telephone to arrange interview dates. This was followed up for all (except one elderly participant) with a confirmatory email. Eight participants were recruited from five GP Practices: 5 men and 3 women. One male participant was included for a pilot interview only, and his contextual data were not sought. Participants consented to their GP being informed and in the event of any concerning information revealed during interviews (e.g. wrong use of insulin), their GP would be informed (Appendix M). Participants also consented to collection of contextual data from their diabetes clinic records.

#### 4.4.7 The process of research

In addition to the interviews, contextual data (such as BG readings) were obtained from GPs to aid triangulation of interview data. Participants were requested to read their interview transcripts



and check themes (member checking). After the thesis completion, participants will be contacted with the findings of the study, and offered a follow-up visit if they wished to discuss the research findings in person. The diagram below (Figure 7) summarises the research process.

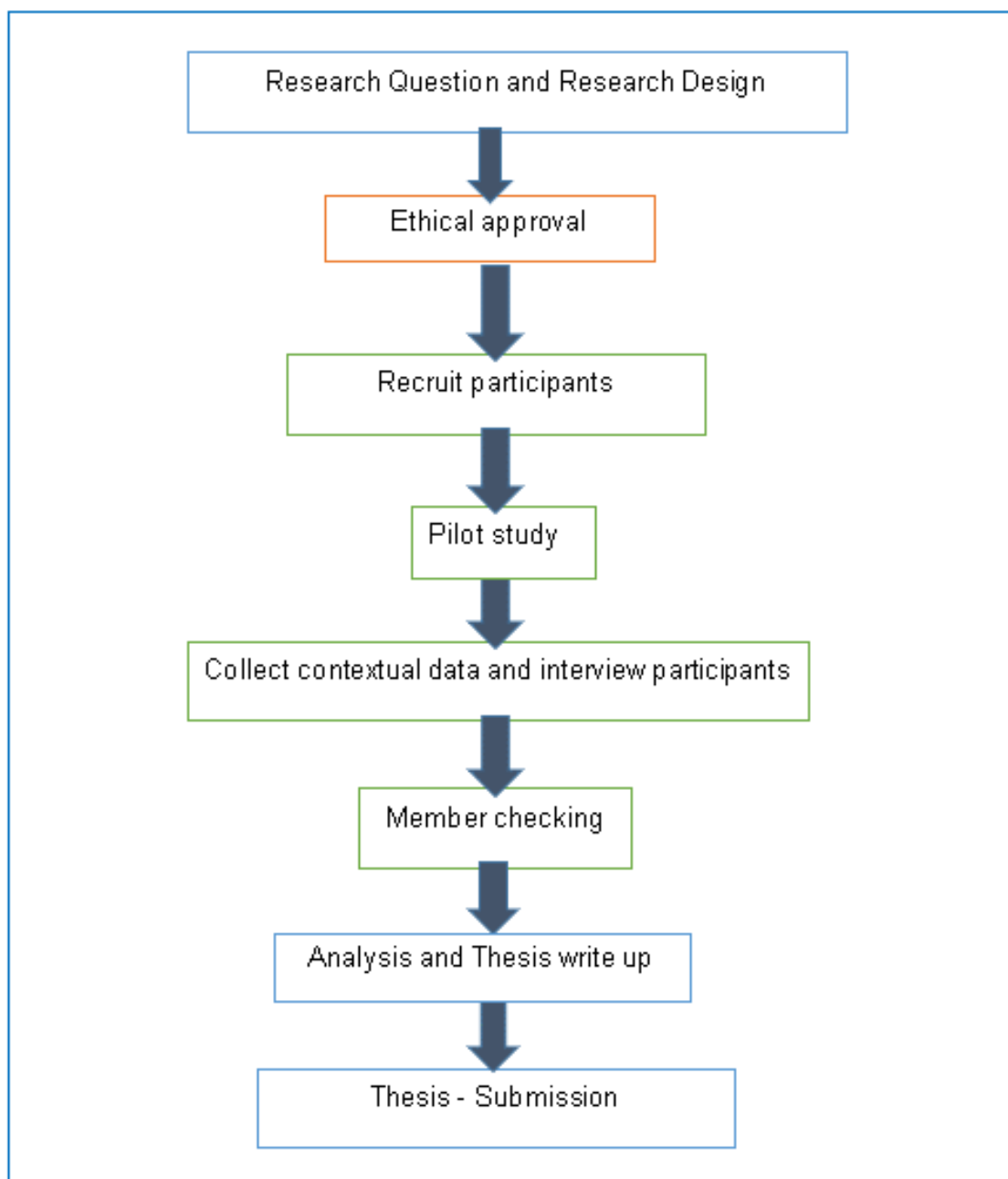


Figure 7: Research process

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### Contextual data

In this study, the 'objective knowledge' (Wengraf 2001) related to participants' diabetes related measurements, and were identified as 'contextual data'. Contextual data was required to give triangulation regarding their diabetes, factors that influenced their life, and aid analysis of their told story. For example, if a participant talked about following a healthy diet, this would be considered alongside their hba1c. The hba1c measures the BG levels over the preceding 12 weeks, and is a good indicator of how well a person's diabetes is controlled. Individuals with diabetes that is well controlled would usually have an hba1c near to 42-59 mmols/mol, but this target may be set higher for older people and is individualised (NICE 2019a). If participants had high hba1cs but believed their diet was healthy, this would raise questions about their understanding of a healthy diet. Contextual data were obtained for all participants, and its access is justified in Table 3.

Table 3: The 'objective knowledge' contextual data

<b>Contextual data sought</b>	<b>Justification</b>
Participant's name and address	The correct patient name and address was required as interviews were offered at participants' homes.
Age at T2D diagnosis, and age at the time of the study	Identify how long the participant had lived with T2D. The pancreas (which produces insulin) becomes less effective as diabetes progresses.
Living situation (e.g. living with partner)	Family members may participate in cooking. Likewise, a partner may participate in exercise with the participant (e.g. going for walks together) and this may influence how often the participant exercises.
Hba1c results over preceding two years	Hba1c identify how effective the participant's self-management has been, e.g. If participants have started a new exercise regime in the preceding six months, this may be reflected in hba1c reduction.
'Body mass index' (BMI) values in preceding two years	The BMI is a person's weight in kilograms divided by their height in metres squared. This identifies if they are normal weight, overweight, obese, or severely obese. Normal adult's BMI is 18.5-24.9. BMI results aided triangulation, when comparing the against diet descriptions, exercise activities and hba1c.

Medicines prescribed for T2D	As T2D progresses, additional prescribed medicines are usually required to maintain the hba1c within safe parameters. Medicines have different side effects, e.g. a sulphonylureas may cause weight gain, whereas a glucagon-like peptide-1 receptor agonist may cause weight loss. This is likely to be reflected in hba1c and BMI values.
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#### 4.4.8 Ethical considerations

The study ensured it followed ethical principles outlined in Table 4.

Table 4: Ethical Considerations

(adapted from Bryman and Bell 2007; University of Southampton 2015; Health Research Authority no date)

Principle	This Study
Justification for the research	<p>A literature review identified a paucity of research of <i>British</i> people regarding spirituality influencing T2D self-management.</p> <p>Permission and ethical approval to conduct the study was granted by the university and the HRA (Appendix I).</p>
Risks associated with this study	<p>A 'Risk Assessment Form' identified potential hazards to participants and the researcher. Key hazards were:</p> <ol style="list-style-type: none"> <li>1) lone interviewing. The 'Lone Interviewing' University guide was adhered to (University of Southampton 2010).</li> <li>2) Participants becoming emotionally or spiritually distressed during interviews.</li> </ol>
No harm should come to participants	<p>Participants had the potential to become emotionally or spiritually distressed when discussing their experience of living with T2D or spirituality. When this occurred, I offered to cease the interview. All participants chose to continue the interviews, although some required having a short break, to compose themselves. All participants declined further support from external sources (e.g. priest/GP or person that participant may identify). All participants were</p>

Principle	This Study
	composed when the interviews finished. All participants chose to have a second interview.
Credibility	The research process was systematically followed. Prolonged engagement with the data, peer debriefing, negative case analysis, reflexivity, records of supervision and triangulation were recorded.
Researchers should be competent in using selected methods	As the BNIM of interviewing is a skill that requires learning, I won funding to attend Tom Wengraf's five-day intensive training course on the BNIM. After the training, I conducted 'practice' interviews with colleagues and family members. I then conducted and analysed a pilot interview before commencing the interviewing of the 8 participants for the study.
Respect for participant's dignity	Should the participant wish anything to be deleted from the recorded interview, this would be done. This occurred with one interview (Sally).
Full consent should be obtained	Written consent was gained prior to the first interview via email or post. Verbal consent was gained before all three sub-sessions. During the interview, if participants became distressed, consent to continue was re-established. No consent was withdrawn.
The privacy of the individual must be protected	Participants were referred to as a pseudonym or number (e.g. PP1 Mary). No data were used to identify the individual.
Confidentiality of data should be ensured	Recorded interviews were uploaded to the University secure servers post interview. Files were stored on password protected computers, and encrypted University servers. Personal data were only stored on the University servers. Written data were kept locked in University offices. Data will be destroyed after the study in accordance with University Policy (usually 10 years).

Principle	This Study
Sources of funding, affiliations and conflicts of interest must be clear	Participants were advised that I am a doctoral student at the University of Southampton and sources of support disclosed in the PIS. Some participants made assumptions that I was a nurse. Some participants asked directly about my spiritual beliefs, and I stated that 'I am a Christian' but did not expand upon my beliefs.
Deception or exaggeration of the benefits of research must be avoided	Participants were advised that the research is taking place to assist clinicians to gain a broader understanding of patients' experiences of living with T2D. No financial benefits for being involved were offered.
Communication should ensure transparency	<ol style="list-style-type: none"> <li>1) The PIS advised participants that their GP would be informed of their involvement in the study, and their contextual data will be accessed.</li> <li>2) Participants were advised that their GP would be informed, if clinical concerns arose during their interview (e.g. wrong use of insulin).</li> <li>3) Participants were given University contacts if they have any concerns about the study. After the completion of the research, participants will be informed of the findings.</li> </ol>
Ethical consideration regarding publishing	It is an ethical imperative to publish this study, as the impetus of the research is to improve diabetes care for patients. The journal 'Religions' has invited me to publish the study findings. The literature review of this study has already been published (Duke and Wigley 2016).
Conflict of 'nurse' versus 'researcher' status	<ol style="list-style-type: none"> <li>1) If participants revealed harmful health behaviours, the PIS had explained that the researcher may contact their GP.</li> <li>2) Questions must be focused to satisfy the research question, and no other aspects related to nursing.</li> </ol>

## 4.5 Summary

This chapter has sought to explain key research paradigms and the underlying philosophical assumptions relating to this study. The constructivist paradigm and the importance of rigor have been discussed, and a description was given of the BNIM and TA. The sampling, recruitment, and access to contextual data has been justified, alongside evidence of ethical considerations and permissions. It is hoped that the description of data collection and analysis has demonstrated trustworthiness of the study design and methods. The next chapter will present the analytic process, a description of participants, and the findings of the sixteen interviews of eight participants.

## Chapter 5 The analytic process and findings

### 5.1 Introduction

The previous chapter has described the main paradigms used in healthcare research, and the methods used for the study. This chapter addresses the final objectives of the study, namely to:

- Explore how participants' spirituality influences their coping with T2D
- Explore how their spirituality influences the self-management behaviours of following a healthy diet and taking exercise

The chapter has three sections: (1) the 'analytic process' (2) a 'description of participants', and (3) the findings presented as three themes. To evidence rigor, the analytic process is described including the member-checking process, which was impacted by the introduction of new data protection regulations. A description of participants is given: their backgrounds, working life, their family and current living situation to give context to participants' spirituality. Due to individual interpretation of the terms religion and spirituality, participants were not asked to define themselves as 'religious' and/or 'spiritual', but to describe their use of spiritual/religious practices to identify if these affected their approach to diet or exercise. However, of the eight participants, six self-identified as Christians, therefore a brief description is given of Christian beliefs. To address the culture of Christianity, an outline of Christian history and participants' denominations is provided in Appendix N. Two participants self-identified as having no religious beliefs or spiritual rituals/practices. Justification is given regarding the two labels applied to participants: 'spiritual and religious' for the Christians, and 'spiritual but not religious' for the non-Christians.

Finally, three themes are detailed and discussed alongside relevant literature. The participants' spirituality and health beliefs influenced their coping in complex layers. Taking responsibility for their T2D was influenced by all these factors, which affected their SMB of T2D. Through interpretive analysis, three themes that met the research objectives were created:

1. Spirituality influences expectations in life
2. Beliefs influence coping styles of the self-management of T2D
3. Responsibility influences the self-management of T2D

The meanings attached to the beliefs of participants are analysed, detailing how these beliefs influenced their SMB of T2D. The 'care processes' previously shown Box 1 detailed the healthcare that people with T2D should receive (NHS Digital 2018; NICE 2019). Although

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participants briefly mentioned some other care processes (e.g. foot care), it is not within the remit of this study to explore all processes. However, additional findings regarding medicines are discussed at the end of this chapter.

### 5.2 Analytic process

The BNIM was used to conduct interviews, and TA to analyse data. An inductive approach (Polgar and Thomas 2008) that was data-driven was selected to generate meanings from the data, to identify patterns and relationships to formulate themes. Using Braun and Clarke's six-phase framework (2006), key data were analysed with reference to the research objectives. By using robust analysis alongside reflexivity, themes were identified that revealed how participants coped with living with T2D, and how spirituality influenced their approach to their SMB of T2D.

#### 5.2.1 Memo writing

Birks and Francis (2008) state that memo writing enhances all qualitative approaches. It aids analysis, maintains the productivity of the researcher (Charmaz 2006) and enables researchers to form an 'intense relationship with the data' (Birks and Francis 2008 p68) whilst supporting reflexivity and sensitivity to bias and as such, memos are part of the data (Ericsson and Simon 1980). Wengraf states memos must be written immediately after the first interview, where researchers should 'de-brief' (2001 p142) using free-associative flow to record interview experiences. Memos were written during literature reviewing, post-interviews, repeated re-listening and re-reading of interviews, during transcribing, throughout the analytic process and thesis write-up, and key memos were organised in Nvivo alongside codes and within a reflexive journal. Memos varied from a few lines Box 7 (below) to pages (Appendix O) including thoughts, questionings and speculation about the individual data and the data corpus.



*Mary (Code: Diet):* Doesn't seem like she pays a lot of attention to her diet much, except for avoiding a biscuit mid-morning. She eats cake, etc. However, at 89 I think this is reasonable, and it seems the diabetes specialist nurse does too. Wonder what her hba1c is like?

*Mary (Code: Complication of T2D):* She doesn't link her heart attack with diabetes (but it's the most common complication of T2D!)...perhaps it's never been explained to her (very likely) or is she in denial? I wonder if it is lack of communication by health professionals?

*Mary (Code: Responsibility):* She exhibits responsibility throughout the interview regarding her medicines, which leads to the question as to how well clinicians have communicated to her about diabetes symptoms, complications and good management. She hasn't had a recent hba1c, despite the last one being high, and her having a heart attack – poor care in my view. I spent time analysing my own view of clinicians' poor care: I am quite intolerant!

*Mary (Code: Spirituality):* She believes the outcome 'was going to be how it was meant to be'. Religious fatalism? Or resting in the peaceful knowledge that she can trust in her God?

Box 7: Short memo example

### 5.2.2 Reflexivity

Morse (2015) identified two sources of bias. Firstly, it may occur from seeing what is already anticipated leading to a feature being unfairly emphasised during analysis. I acknowledged that the literature search had influenced my expectations regarding what my data may present (Morse and Meadows 2001). My clinical experience was that spiritual beliefs of British patients had resulted in a decreased responsibility for their SMB of T2D, but on reflection I realised that in clinic I had only asked poorly controlled diabetics about their spirituality, and this had been biased.

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The research question focused on understanding *how* participants' spirituality may influence their coping and their approach to diet and exercise, it was not to interpret participants' beliefs. Prior to interviewing, I had considered the implications of how my spirituality could influence understanding data on participants' spirituality. However, I had not considered how my nursing beliefs, perspectives of patients taking responsibility for self-care, or attitudes towards responsible use of NHS resources could influence interrogation of data. My reflexive journal contained extracts of memos that were pages long, e.g. reflection of my own spirituality, views of nursing, and considering how my beliefs influenced data analysis. This added to discussion with the Supervision Team enhanced reflexivity, enabling holding in tension my interpretation of participants' responsibility of the self-management of T2D with my clinical experience. Audit trails were kept through documentation of coding book developments, memos, my reflexive diary, transcription, analytic strategies and theme development (e.g. figures created for main codes (Appendix S)), and Codebooks (Appendix H). These assisted in awareness of bias and ensuring the research criteria were met (Anderson 2008).

### 5.2.3 Phase 1

All interviews were conducted by me and transcribed verbatim. In the BNIM interviewing, the structuring principle is to allow the 'tacit and unconscious assumptions and norms' (Wengraf 2004 p115) and the 'fullest possible expression of the concerns, systems of value and significance, the life-world of the interviewee' to appear (p69). Interviews in some participants' homes (6/8 participants) revealed how their spirituality linked into their lives, e.g. a carved wooden cross ornament in the lounge. In the interviews, five participants became emotional when talking about their relationship with God, family bereavements or suicide attempts. These aspects were noted when transcribing interviews.

Phase 1 involved listening to interviews, transcribing, repeated re-reading and re-listening, memo-taking. Braun and Clarke (2006) do not specify transcription method, and as a novice researcher, I paid for university transcription for my first three interviews. I also transcribed them myself and compared my three against the university transcripts to ensure rigor. The university transcription utilised line numbering and identified the speaker. My transcripts denoted the speaker; used line numbering; notation to show pauses; used new lines denoting when a new unit of meaning occurred and included paralinguistic comments (Table 5Table 6).

Table 5: My transcription - units of meaning

Line number	Text
<b>LIAM</b>	
82	'Well you know, I'm so thin anyway, that must be the problem,
83	I must have so much fat on the inside of my body, (1) um so I thought

Table 6: My transcription notation

Symbol	Indication
(4)	Indicates the pause in seconds
[ ]	Used for paralinguistic comments and gestures of participants e.g. [quietly] [starts to cry] [laughs] [sighs] [rolls her eyes]
<i>italics</i>	Shows emphasis in speech

#### 5.2.4 Phase 2

Three cycles of coding identified salient features and meanings within the data. In TA, no transcription method is recommended. I chose to use one to create 'units of meaning' (Wengraf 2001 p214) as described above. I then converted all transcripts into 18 colours relating to potential codes, so that by scrolling down the transcript, it was possible to see where clear sections about specific topics occurred, e.g. a section on 'spirituality' (coloured light blue) had been preceded by a section on 'diabetes diagnosis' (coloured red) and expressing strong 'emotions' (coloured mid blue). Colour-coding the text enabled the transcript to be viewed panoramically to see where the interview shifted to specific topics, and how codes linked, e.g. 'Spirituality' and 'Decision making'. Occasionally paragraphs were just one colour (e.g. a holiday taken) but usually each paragraph had many colours, as shown in Box 8. Re-reading and re-listening to the interviews multiple times encouraged immersion in the data and connection to emotions expressed by participants by their tone of voice and expression.

<u>Line number</u>	<u>Text</u>
<b>LIAM</b>	
82.	'Well you know, I'm so thin anyway, that must be the problem,
83.	I must have so much fat on the inside of my body, (1) um so I thought, "Well I'm not -."
84.	You know, the book said "Consult your doctor". I thought 'Well I'm not going to do that [chuckles]
85.	because if I do that, they're going to say "Sorry, too thin, I wouldn't do that if I were you."
86.	and I thought, 'I've just got to try this' 'cause I was so desperate to – to reverse it.
87.	so I did a lot of research on diabetes. (Liam: 1/82-87)

Box 8: Colour coding of transcripts in Phase 1

Originally, manual coding was planned, but later I considered that learning to use CAQDAS would enhance rigor and should be part of my doctoral development. CAQDAS enables organisation of non-numerical data into categories (codes) enabling an efficient method to compare different data (Rodik & Primorac 2015). By assisting coding, storing, organising and retrieval of coded texts efficiently, it enables visual and panoramic viewing of data (García-Horta and Guerra-Ramos 2009). CAQDAS does not assist the interpretive process which is researcher initiated, but is a tool supporting the management of voluminous data. In Nvivo 12 (QRS International 2018), every piece of data is termed as a 'reference'. References are analysed and placed into named 'codes', which can be a broad 'parent code' or a 'child code' or sub-code'. An example of this in my research is below (Figure 8). Codes contained a description of the data included and excluded (Appendix H).

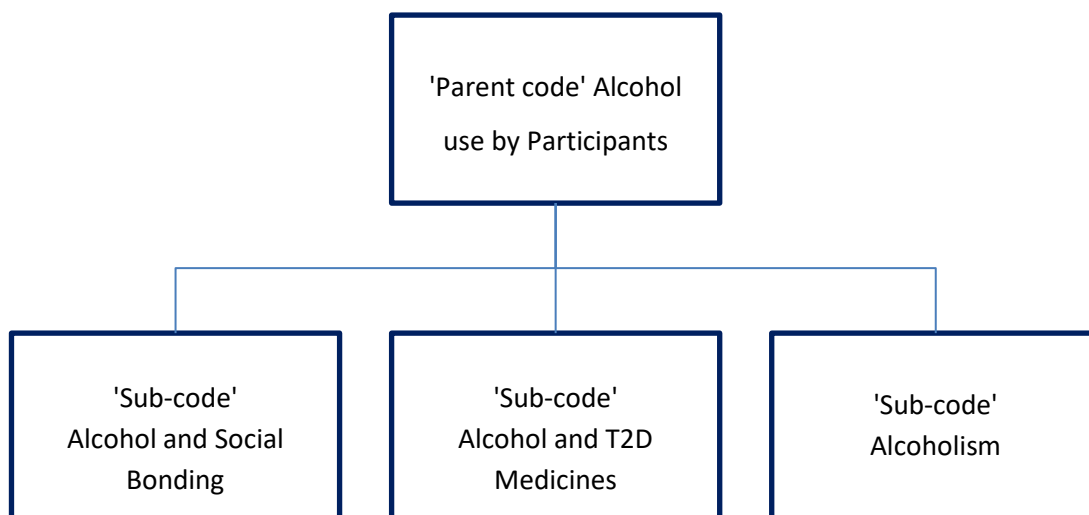


Figure 8: The alcohol code in Nvivo

### 5.2.5 Phase 3

Each entire interview was coded, as even seemingly irrelevant data might become pertinent as analysis progressed, linking to data from other participants. Names of codes related to the research objectives, e.g. 'Complications of T2D' but others did not, e.g. 'Holidays'. Memos were written as analysis progressed, and all Codebooks were submitted to the Supervision Team for scrutiny. References placed in codes could be a few words to a whole paragraph (e.g. a joke) varying from the lowest of 131 references for Steve, to the highest of 726 references for Liam's second interviews (Table 7). Phase 3 resulted in 18 'parent codes' and 91 'sub-codes' (Table 8).

Table 7: Codes and references of participants

<b>Name of participant</b>	<b>Number of codes</b>	<b>Number of references</b>
Mary 1 <sup>st</sup> interview	55	417
Mary 2 <sup>nd</sup> interview	52	399
Liam 1 <sup>st</sup> interview	70	588
Liam 2 <sup>nd</sup> interview	64	726
Ray 1 <sup>st</sup> interview	65	561
Ray 2 <sup>nd</sup> interview	45	213
Sally 1 <sup>st</sup> interview	55	305
Sally 2 <sup>nd</sup> interview	57	566
Will 1 <sup>st</sup> interview	65	556
Will 2 <sup>nd</sup> interview	60	452
Tim 1 <sup>st</sup> interview	61	602
Tim 2 <sup>nd</sup> interview	42	198
Ange 1 <sup>st</sup> interview	60	590
Ange 2 <sup>nd</sup> interview	55	428
Steve 1 <sup>st</sup> interview	46	276
Steve 2 <sup>nd</sup> interview	32	131

	<b>Parent Code</b>	<b>Number of files</b>	<b>Number of references</b>
1.	Alcohol	11	74
2.	Co-morbidities not part of T2D	14	154
3.	Communication	14	67
4.	Decision-making	17	480
5.	Diabetes	17	482
6.	Diabetes co-morbidity	13	35
7.	Diet	17	310
8.	Emotions of participants	17	568
9.	Exercise	16	147
10.	Family, friends and social	19	200
11.	Health beliefs	16	126
12.	Health professionals	17	243
13.	Politics	13	45
14.	Significant events	13	37
15.	Smoking	7	38
16.	Spirituality	16	507
17.	Weight	13	80
18.	Work of participants	13	65

Table 8: Codes and references in Nvivo

To facilitate understanding of narratives that were usually not chronologically constructed, I chose to compile 'Timelines'. This facilitated understanding of how life events connected to each other and how spirituality related to these events. Some timelines linked to participants' spirituality (Appendix P) but others did not. For some participants, a map would have been too complex, so a chart was drawn (Appendix Q), and for one participant, a family map was created to visualise familial relationships. Tables were created for all participants to analyse contextual data received from GPs (Appendix R).

### 5.2.6 Phase 4 and 5

Codes were reviewed and analysed alongside memos to understand how they related to the entire data set and research objectives with code 'maps' of the sequential analysis created. Nineteen individual 'maps' were created to evidence creation of main (parent) codes and sub-codes (or child codes). An example of one sub-code map is Figure 9 (the other 18 maps are in Appendix S). The 'spirituality theme' was the only code too complex for pictorial mapping, and a table was used instead (Table 9). In Phase 5, sequential 'Analysis Maps' were created, to assist theme creation. Map 1 was the initial map with broad codes, Map 2 analysed how the codes connected; Map 3 refined the codes further, Map 4 showed development towards creation of the final themes, and Map 5 reveals the final themes of the study shown below. Figure 10 shows the five maps.



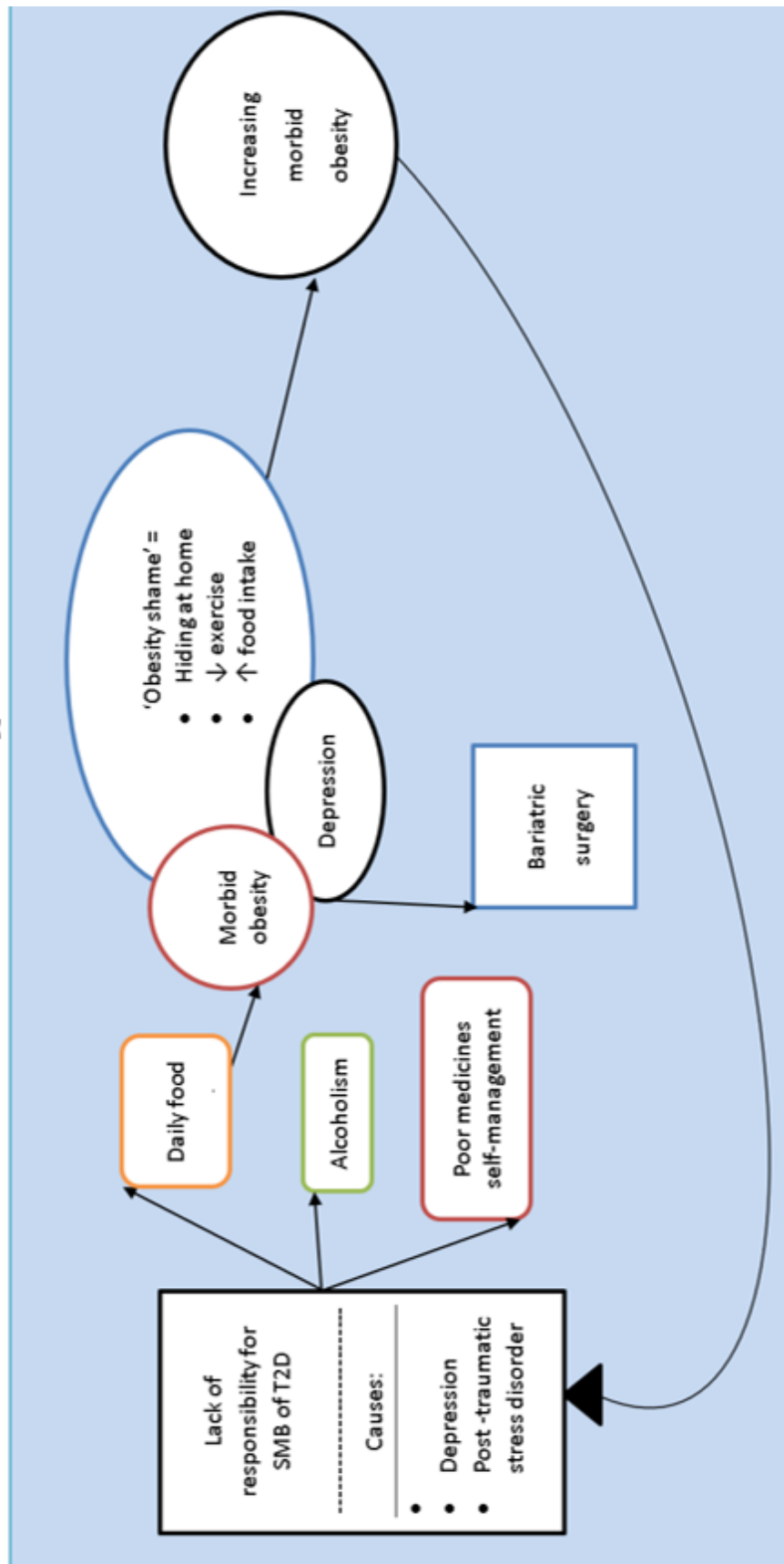


Figure 9: Child code: 'Lack of Responsibility'

(Child or sub-code of Parent 'Decision Making' Code)

Table 9: Spirituality code

Sub-code	'Spiritual and religious' (Christians)	'Spiritual but NOT religious'
<b>Christian faith of participant</b>	<ul style="list-style-type: none"> <li>i) Death</li> <li>ii) Resuscitation experience</li> <li>iii) Afterlife beliefs</li> <li>iv) Belief in 'allotted life' span by God</li> <li>v) God influencing events</li> <li>vi) God's 'plan' in my life</li> <li>vii) Hope</li> <li>viii) Repentance</li> <li>ix) 'Lucky' or 'fortunate'</li> </ul>	No belief in afterlife
<b>Christian rituals</b>	<ul style="list-style-type: none"> <li>i) Prayer; Communion; lighting candles</li> <li>ii) Connection with church</li> <li>iii) Reading the Bible</li> <li>iv) Listening to 'Evensong'</li> <li>v) Meditation</li> <li>vi) Fasting</li> <li>vii) Appreciation of nature</li> </ul>	Not applicable
<b>Gratitude</b>	<ul style="list-style-type: none"> <li>i) To God</li> <li>ii) To family and friends</li> <li>iii) To health professionals</li> <li>iv) For nature and beautiful world</li> </ul>	<ul style="list-style-type: none"> <li>i) For having type 2 diabetes, as it led to a healthier life</li> <li>ii) To family and friends</li> <li>iii) To health professionals</li> </ul>

Sub-code	'Spiritual and religious' (Christians)	'Spiritual but NOT religious'
<b>God's love</b>	No sub-codes	Not applicable
<b>Christian faith of other family and/or friends</b>	No sub-codes	Not mentioned
<b>Angry with God</b>	No sub-codes	Not mentioned
<b>Self-management of T2D linked to spirituality</b>	<ul style="list-style-type: none"> <li>i) Walking</li> <li>ii) Nature</li> <li>iii) Support from family and friends</li> <li>iv) Working with health professionals</li> <li>v) Managing diet</li> <li>vi) Managing medicines</li> </ul>	<ul style="list-style-type: none"> <li>i) Appreciation of nature (not associated with religious belief)</li> <li>ii) Allotment</li> <li>iii) Family</li> <li>iv) Managing diet</li> </ul>
<b>Depression, or low mood, or post-traumatic stress disorder</b>	No sub-codes	No sub-codes

**Analysis Maps 1-5.** Five analysis maps are presented below. This first one was created after analysing main codes (phase 3-5) and trying to get a broad idea of where they fit into the research question.

**Analysis map 1:** Eighteen codes created

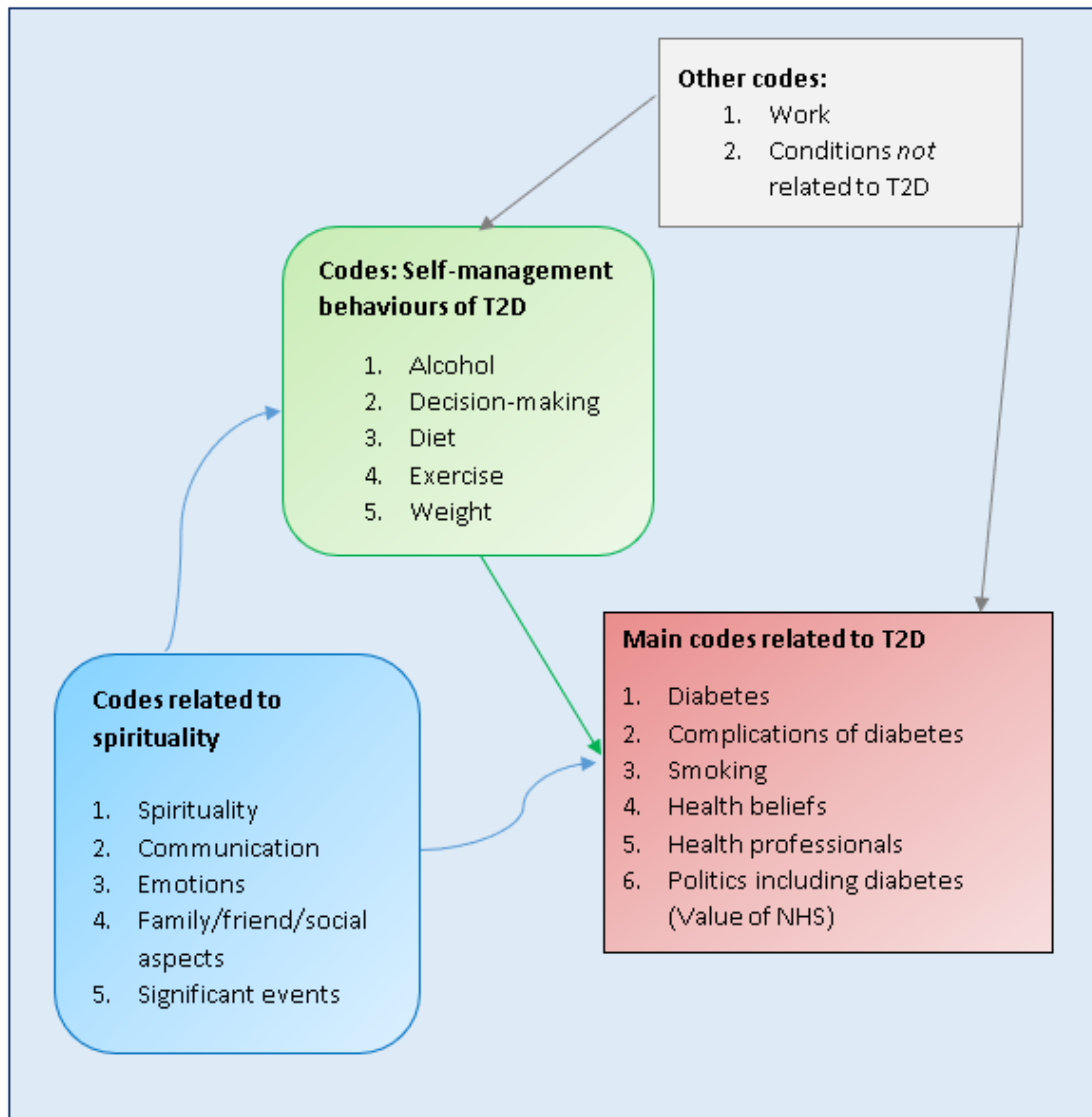
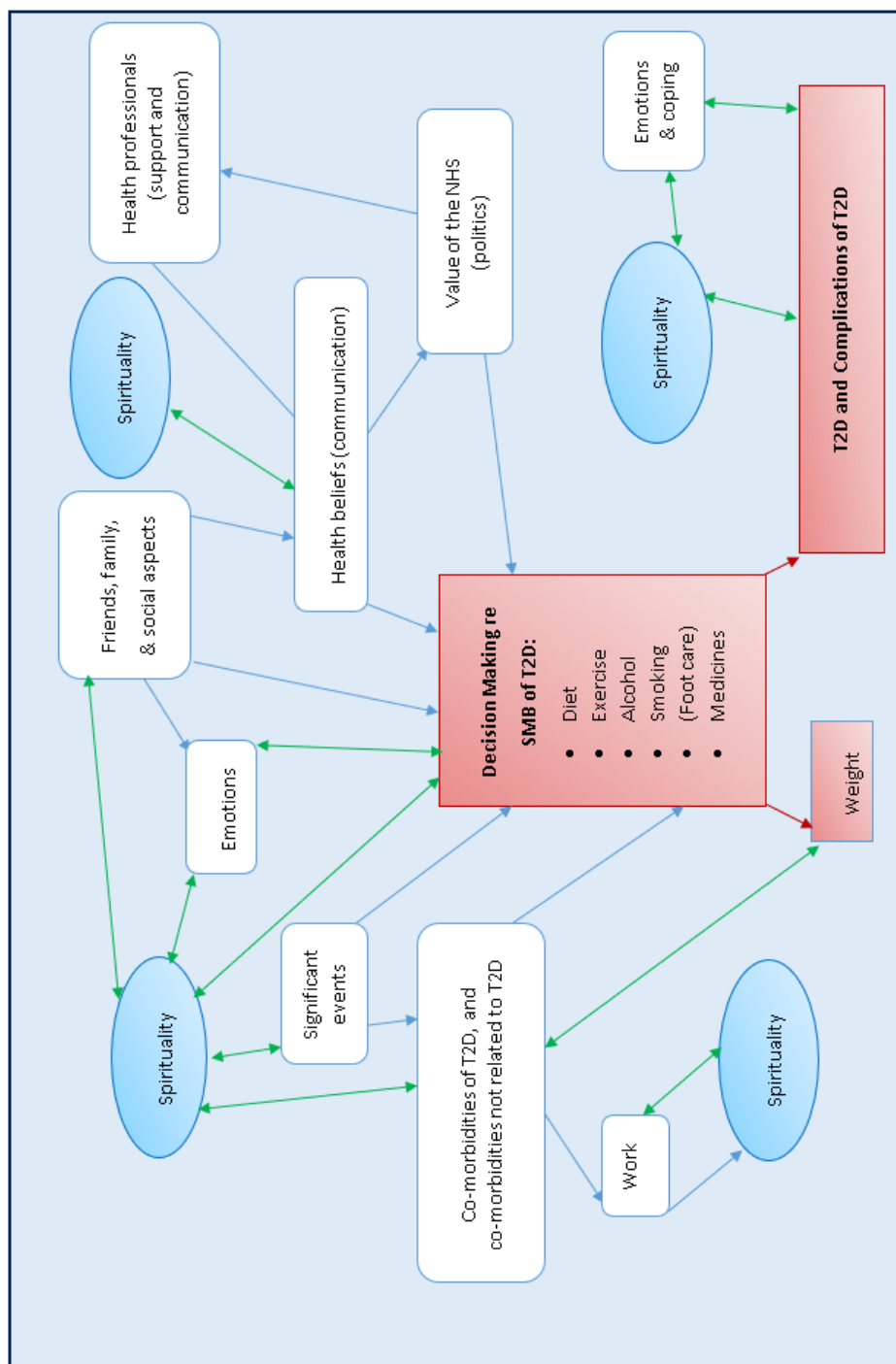
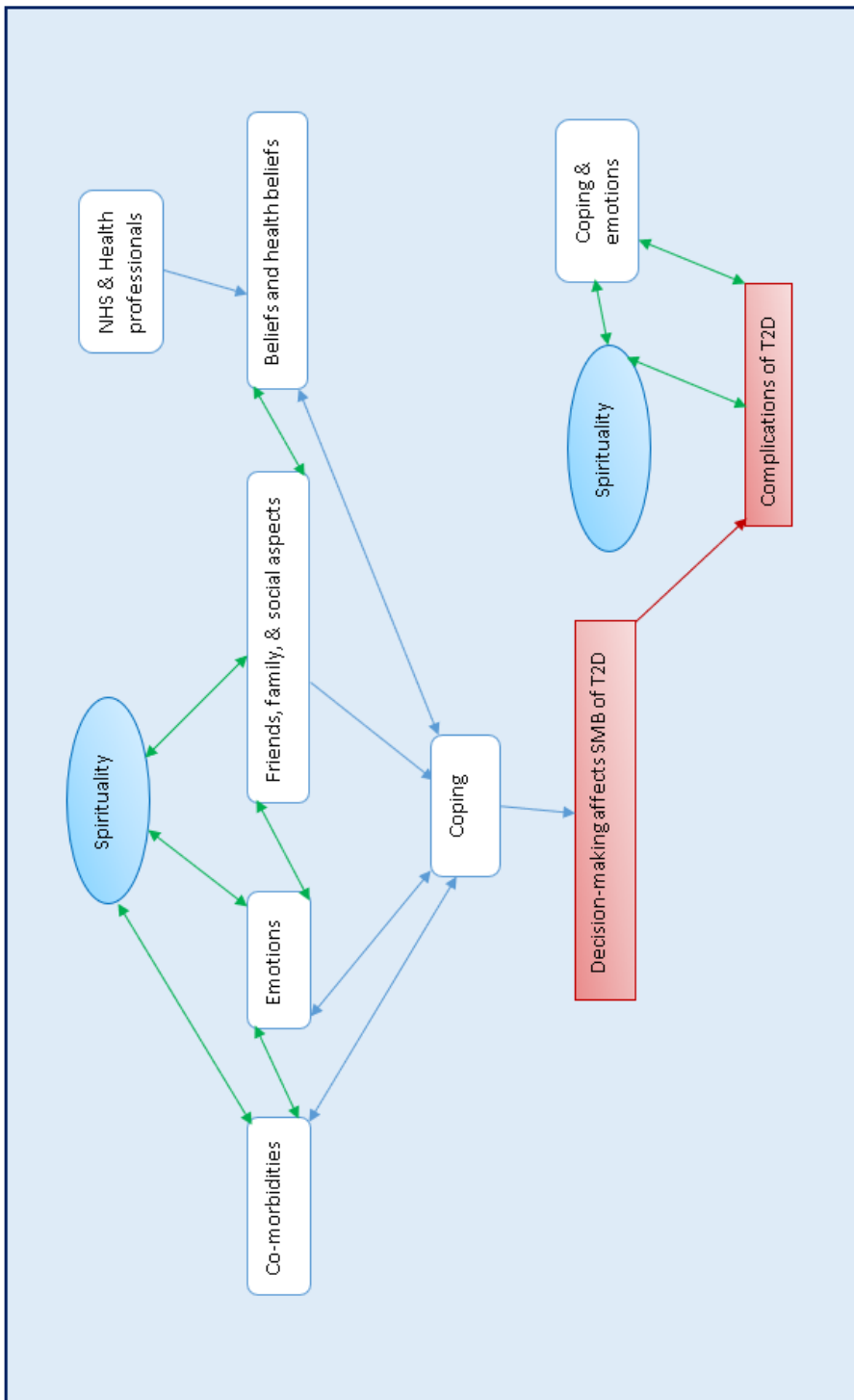


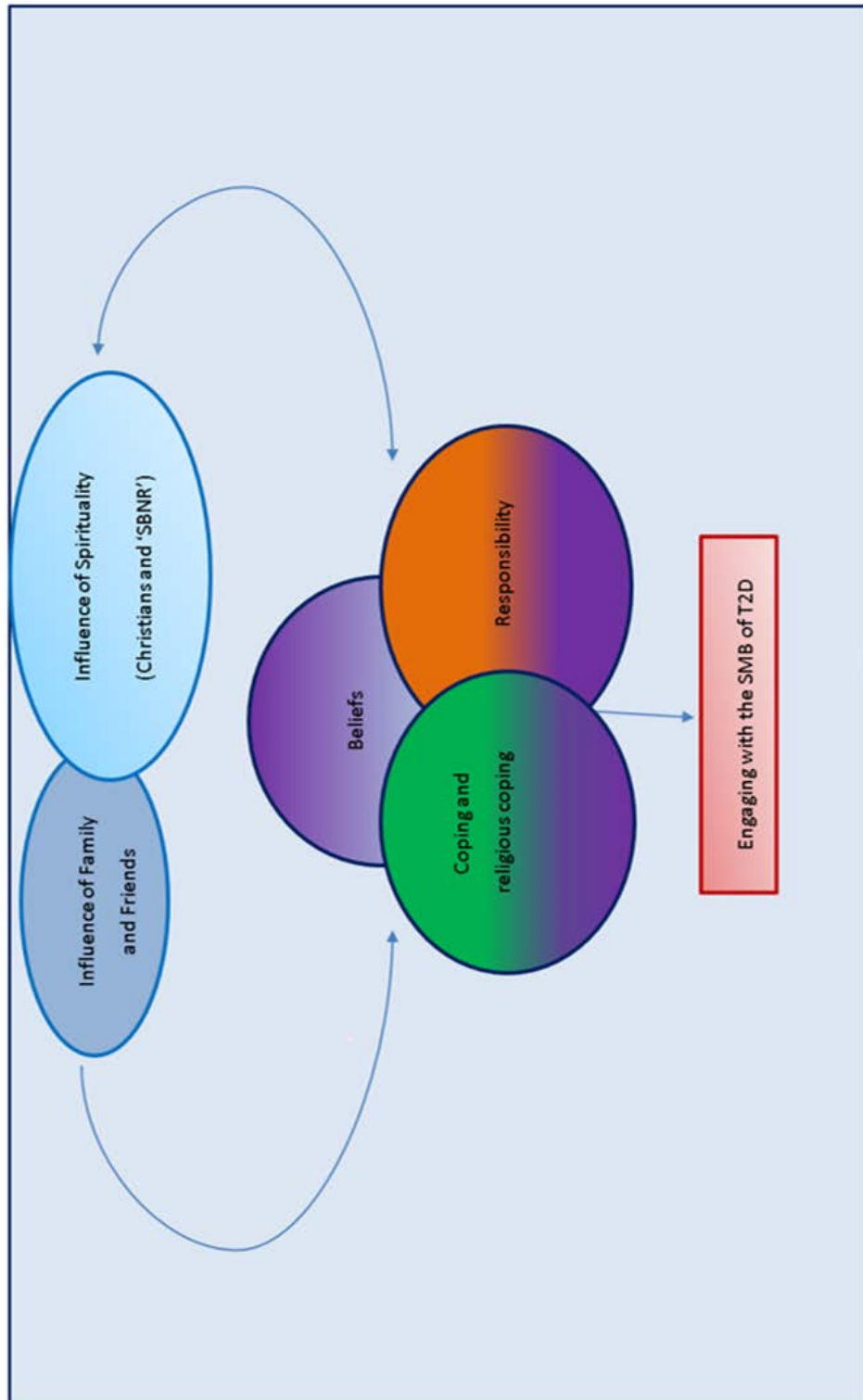
Figure 10: Analysis Maps 1-5



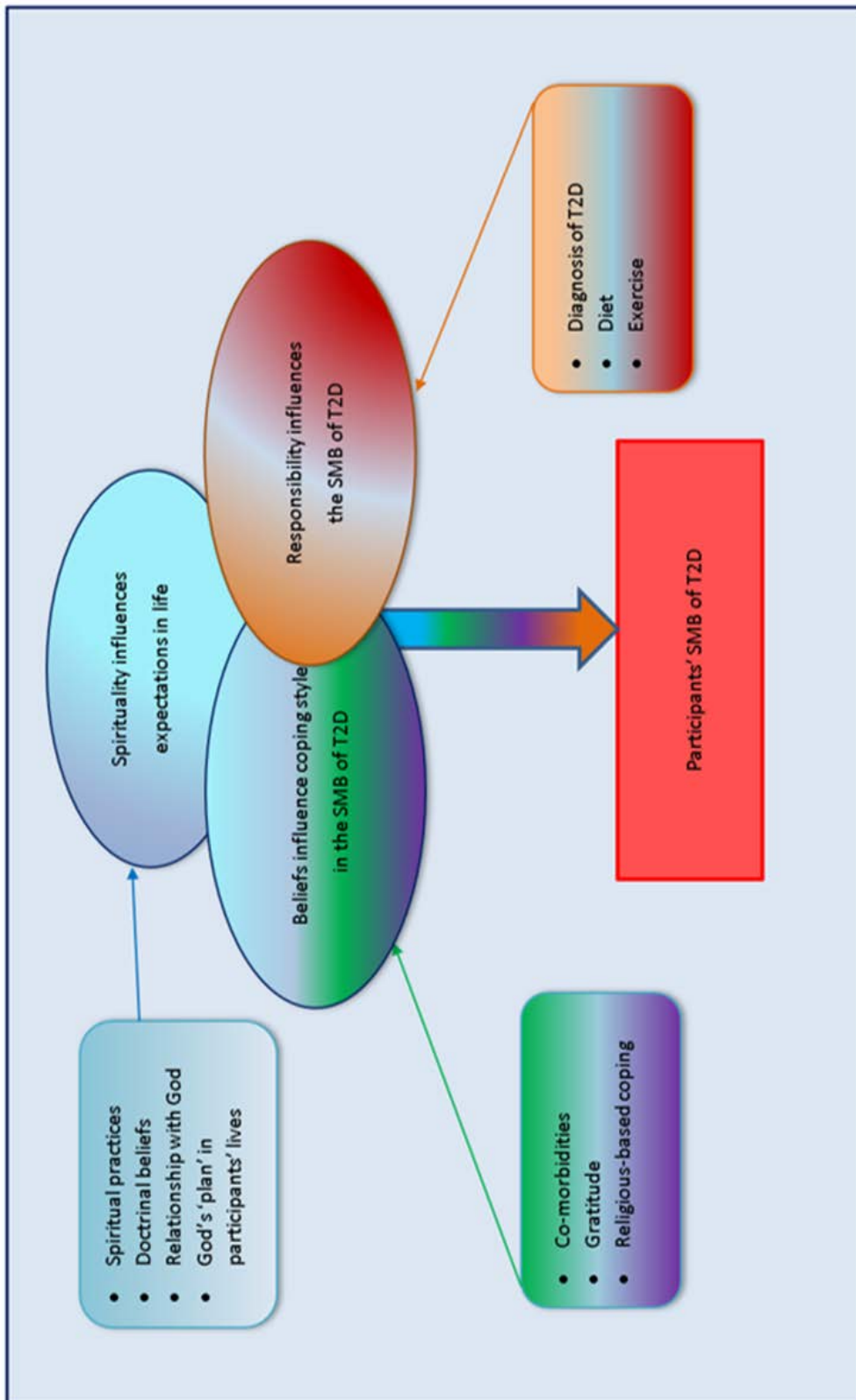
Analysis Map 2. How the 18 codes connect



**Analysis Map 3.** Refinement of the codes



**Analysis Map 4.** Codes moving into final themes



**Analysis Map 5.** Final three themes with sub-themes



### 5.2.7 Member checking

For the credibility of constructivist research, the multiple constructions adequately must be clearly demonstrated, and can be evidenced by prolonged engagement, persistent observation, triangulation, peer debriefing, negative case analysis and audit trails (Morse and Meadows 2001; Morse 2015). Lincoln and Guba considered 'member checking' as crucially important to establish credibility (1989 p239) by laying open the researcher's interpretation to scrutiny, enabling participants to check the accuracy, and if the research resonates with their experiences (Birt et al. 2016).

In this study, the second interviews enabled exploration of comments made in first interview, clarification of beliefs, and further questions (Box 5). In addition, discussion at the outset of the second interview centred on the transcripts and the individual codes generated from first interview analysis. All participants considered the transcripts a true record of the interview, and the codes resonated with their narratives. One participant requested certain remarks to be deleted from her transcript (and this was completed), as she felt they portrayed her husband in a negative light. During transcription of second interviews, new general data protection regulation (GDPR) came into effect (Information Commissioner's Office 2018). Although participants had given verbal agreement in the first interview for member checking, the PIS had not explicitly requested this, and the Supervision Team felt member checking may contravene GDPR rules. For this reason, after the second interview, the participants were not contacted with transcripts and codes. Of the second interviews, 2 of the 8 participants reviewed their transcripts/codes, 2 chose not to review them, and 4 participants did not have the opportunity to review their transcripts due to the GDPR. Additional codes from the second interviews that were not reviewed by participants are identified overleaf in Table 10.

Table 10: Member checking with 2<sup>nd</sup> interviews

	1 <sup>st</sup> transcript and codes member checked	2 <sup>nd</sup> transcript and codes member checked	Additional codes from 2 <sup>nd</sup> interview
<b>MARY</b>	✓	✓	No new codes
<b>LIAM</b>	✓	✓	No new codes
<b>RAY</b>	✓	X	No new codes
<b>SALLY</b>	✓	X	1. Family
<b>WILL</b>	✓	X	1. Health Professionals 2. Work
<b>TIM</b>	✓	Declined to review	1. NHS (politics) 2. Communication 3. Work 4. Bereavements
<b>ANGE</b>	✓	X	1. Alcohol 2. Finances 3. Communication 4. Hospital experiences 5. NHS (Politics) 6. Suicide attempt 7. Work
<b>STEVE</b>	✓	Declined to review	1. Overcoming difficulty

This section has detailed the analytic process of the data, and now a description of participants' living situations, lived lives and spiritual practices will lay a foundation for discussing how participants' spirituality influenced their coping in living with T2D.

### 5.3 Description of participants

Spirituality was an emergent property of participants lived lives and experiences and connected to their family's beliefs and health beliefs. Five of the participants had family members with T2D or Type 1 Diabetes, and 3 had family members who were health professionals (HPs). To understand their spirituality, this section describes their living situations and a brief history of their lived lives. Before interviews commenced, a label (e.g. PP1) identified participants. The term 'PP' referred to 'Patient Participant' and the number to the chronological order of recruitment of participants. During analysis, pseudonyms were considered more appropriate for qualitative research, and the identifier was changed to a pseudonym (Table 11).

Participants' analysis and presentation of data are generally presented in the order of PP1 – PP8, i.e. Mary's data is presented first, running through to Steve's data presented last. Participants were White, living in Hampshire, aged between 52-89 years old with a mean age of 67, and were currently married, widowed or single. The lived experience of T2D varied from 2 – 17 years. Table 12 shows participants' age, marital status, ethnicity, and years of living with T2D. It details if they exercised with family/friends or alone, if they cooked by themselves or with a partner, and how many other health conditions they discussed.

Table 11: Pseudonyms of participants

<b>Label</b>		<b>Pseudonym</b>
<b>PP0 (Pilot)</b>	Male	Jim
<b>PP1</b>	Female	Mary
<b>PP2</b>	Male	Liam
<b>PP3</b>	Male	Ray
<b>PP4</b>	Female	Sally
<b>PP5</b>	Male	Will
<b>PP6</b>	Male	Tim
<b>PP7</b>	Female	Ange
<b>PP8</b>	Male	Steve

Table 12: Description of participants

Pseudonym	Age (years)	Marital Status	Takes exercise	Cooks themselves = C Partner cooks = P	Years since diabetes diagnosis	Number of other health conditions discussed
Mary	89	Widowed	No*	C	17	5
Liam	52	Married	Yes: alone and with family/friends	C & P	2	2
Ray	79	Married	Not known	C & P	3	4
Sally	73	Married	<ul style="list-style-type: none"> <li>• Yes: not known if alone or with others</li> <li>• Sometimes with dog</li> </ul>	C	15	3
Will	56	Single	No*	C	8	4
Tim	68	Married	Yes: with family	C & P	10	2
Ange	59	Single	<ul style="list-style-type: none"> <li>• Yes: with friends, and alone</li> <li>• Sometimes with dog</li> </ul>	C	4	5
Steve	65	Married	Yes: with family, and alone	P	4	2

\*(unable due to health conditions)

Mary is a widow, retired and living alone in an old cottage. She was supported by a diabetes specialist nurse (whom she employed privately) and a gardener. She felt connection with the town she had lived in all her life, and had close relationships with her extended family living nearby. Mary and her husband did not have children, and had run a flower business together. Christians in Mary's family included parents, grandparents, her gardener and her niece. Recently her home had been flooded necessitating her living upstairs for a year. She had suffered bereavements of her husband, parents and friends. Mobilisation was difficult due to severe osteoarthritis<sup>13</sup>, necessitating using a walking frame and a stair-lift. She accepted this stoically and remained grateful for the good things in her life.

Liam is a self-employed successful musician, who lives with his wife (working as a nurse) and their two children in a house. He has mild neuropathy<sup>14</sup>, a diabetic complication. He was shaken by his T2D diagnosis, which led to a spiritual crisis, when he believed God chose not to heal him. In an unsuccessful attempt to 'reverse' his T2D, he had embarked upon a very low-calorie diet without medical knowledge. He was interested in curing diabetes, and sought involvement in research projects. He strongly believed people should take responsibility for their own health, and was motivated with regard to diet and exercise. He was shocked by those with T2D not performing good SMB. After overcoming low mood associated with his diabetes diagnosis, Liam actively pursued good mental health.

Ray is retired from the Navy and financial services sector, and lives with his second wife (a retired midwife and health visitor) in their house. He ran away from home at the age of 14, but did not explore reasons behind this, suggesting it was 'an adventure'. At age 17, he joined the Navy and started drinking. His first marriage failed due to poor communication, and he left his wife and two teenage boys. His second marriage was affected by his alcoholism and gambling, and their youngest son's autism. His first wife had been a Christian lay pastor, and he referred to one of his sons taking his faith 'very, very seriously' (2/889) and referred to him as a 'church geek' (1/961). Ray saw his children from both his marriages and referred to them as 'team one' and 'team two'. He described himself as having 'autistic traits' (1/374), and spoke in clipped tones. He did not usually reflect on life, but spoke in the interview about overcoming alcoholism, bereavements and family relationships. He believed the causality of his T2D was alcoholism. Consequently, he

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<sup>13</sup> Osteoarthritis is a painful condition causing joint pain and stiffness. Ref: <https://www.nhs.uk/conditions/osteoarthritis/>

<sup>14</sup> Diabetic neuropathy is a complication of T2D. Liam's symptoms of his peripheral neuropathy included numbness and tingling in his feet.

reduced his alcohol intake to healthy limits and his hba1c became normal. He lived with back and neck pain, and was awaiting cardiac surgery.

Sally is a retired nurse who lives in a house with her husband who has T2D. When working, she had completed diabetes-training modules. Her T2D diagnosis led to her re-commencing competitive ice-skating to lose weight, but the head injury risks associated with this high-risk sport caused her to swap instead to dog walking. She resented doctors who 'bullied' her about smoking, and she now vaped. She experienced sadness due to some of her family's mental health challenges. Despite living with anxiety all her life, her 'can do attitude' resulted in her seeking the positive aspects in challenging situations.

Will worked as a carer when younger, but due to health conditions is now unable to work. He rarely leaves his flat due to severe morbid obesity, but occasionally participates in council meetings. He severed relationships with his diabetic brothers, his parents have died, and he lives alone. His multiple health conditions have been negatively impacted by his weight. His reduced mobility is in part due to his stomach that reaches past his knees, but he fears losing weight. He previously considered suicide, and is receiving psychiatric support for chronic anxiety, depression and post-traumatic stress disorder from previously caring for his dying mother. He does not take responsibility for his health, and his friends remind him to take his medicines daily.

Tim is retired, and lives with his supportive second wife (a retired nurse) in a house. Tim was devastated when his first wife left him and his children, and became alcoholic. His suicide attempt failed when his children found him, but with psychiatric support he overcame his mental health 'breakdown' (1/894). Tim's mother had T2D, and his deceased parents' unhealthy lifestyles shocked him so that he now endeavours to pursue healthier dietary choices. He strongly believed in acting on health professionals' advice, following a good diet, and was concerned about diabetes 'bankrupting the NHS' (1/753).

Ange is unable to work due to health conditions, and lives alone in a flat; previously, she had worked as an NHS ward clerk. She had moved to England from another UK country in younger years. She did not discuss any family, other than her mother who had died from a stroke – a death that Ange wished to avoid. Ange's morbid obesity and low mood influenced her struggles with her weight. She expressed hope and humour, and although she yo-yoed with good and poor SMB of T2D, she was using the research to motivate her to live a healthier life.

Steve lives in a house with his wife, and is retired from investigating claims for medical insurance. As a child, he experienced bullying from a teacher due to talipes<sup>15</sup>, but made light of this. He used humour in interviews and avoided worrying about things that he could not alter, such as his benign acoustic neuroma<sup>16</sup>. After his T2D diagnosis, he swapped sedentary voluntary work to one that involved walking, swapped beach holidays to walking holidays, and started working an allotment, encouraged by his wife and daughter. He was motivated with diet and exercise, and strongly believed in listening to advice from health professionals.

### 5.3.1 'Spiritual but not religious' participants

Tim and Steve found difficulty to express an essence, which according to Keighley, gives many people 'truest meaning of them and their lives' (1997 p47). These two 'non religious' participants revealed spiritual elements such as meaning and purpose in life, connecting with others, nature, and ethical aspects, which have been included in the definition of spirituality in this study (Figure 2). For this reason, they are defined as 'spiritual but not religious' (SBNR).

Tim and Steve stated they had no religious beliefs, no belief in an afterlife, and no spiritual practices (Tim:2/49,53,167; Steve:1/468). In answer to why they expressed interest in this research about diabetes *and* spirituality, both had chosen the research to support the NHS and diabetes research. Steve said, 'Well I owe it' (1/464) due to the good care he had received. Tim emphasised that people with diabetes must take responsibility for their health, and involvement in this study was his contribution to diabetes research. In categorising the SBNR, Ammerman (2013 p272) describes 'ethical spirituality' where the main component is 'living a virtuous life, characterised by helping others'. She found this ethical aspect was present in both theist and extra-theistic spiritualities. Both Tim and Steve expressed altruistic motives to assist in diabetes research to help others, and desire to contribute to the NHS. Tim in particular expressed passion about education for people with diabetes, and hoped his contribution would help other people with T2D.

Neither Tim nor Steve referred to positive or negative childhood religious experiences, familial religious frameworks, societal religious influences or the supernatural in their lives. Steve expressed a negative view of religious belief, quoting Oscar Wilde 'I treat all religions with equal

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<sup>15</sup> Talipes is a non-painful birth defect that can affect one or both feet, causing the feet to point inwards. It inhibits walking and in the UK is corrected with surgery (Ref: <https://www.nhs.uk/conditions/club-foot/>).

<sup>16</sup> Acoustic neuromas are a type of localised and slow-growing benign brain tumour (Ref: <https://www.nhs.uk/conditions/acoustic-neuroma/>).



contempt' (1/471). He considered that participants' spiritual beliefs were more likely to 'interfere' with their self-management of T2D (1/473), inferring a negative view of the effects of religious/spiritual beliefs on self-management of health. He appeared surprised when I informed him that some participants had found their religious beliefs assisted them coping with T2D. After stating that he had no religious beliefs or spiritual practices, Steve went on to describe meanings in his life. He found fulfilment and pleasure from connections with nature and relationships, in caring for his family, growing his own vegetables and the joy of cooking with vegetables he had grown himself. He inferred a close relationship with his wife and children, and contentment in providing financially for his grandchildren. When asked about 'meaning and purpose' in his life, he replied:

'I can tell you (2) things that give me pride, if you will. Um, both my kids went to university. (2) Um. They've both got a better house than I have. Um, and things like that. Um [outbreath] (2) I get satisfaction in strange ways – you know, like um , if you have a Sunday roast and you have 5 vegetables with it and you've grown 4 of them (2) um – and I always thought it was garbage when people said, um "Home grown vegetables taste better!" They do!' (2/261)

Previously, Tim worked in management where money was his focus. He used religious language describing money:

'You must have money. You *must have money*...And it was my god for about 10 years I suppose. I'd always had money. [chuckles]' (2/548)

He was 'totally destroyed...absolutely for a whole year. I was totally destroyed' (2/138) when his first wife walked out on their marriage and children. His father died in the same year, resulting in Tim turning to alcohol. He spiralled into depression but was rescued from his attempted suicide when his daughter found him and took the tablets out his mouth. His family were unsupportive, but a psychiatrist helped him 'come out the hole' and realise the importance of talking about his problems (1/845). After recovering from his suicide attempt, he left his well-paid management job and became a butcher. Previously, his alcoholism put his children at risk (through drink driving), but in talking about recovering from alcoholism, he again used religious language:

'I can go 3 weeks, 4 weeks even. Without touching it – I can go to the Club, and just have Coke [i.e. no alcohol]. You know what I mean. It's not a case, it doesn't – it's not my god. It's not my god.' (2/443)

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When asked if he had any spiritual beliefs, Tim jokingly replied 'Malt whisky' (2/55). He expressed worry that drinking too much would lead to his death, but that death itself did not worry him, and he had no belief of an afterlife. Directly after declaring that alcohol was not 'his god', Tim described his family as the motivation and joy in life. Instead of acquiring money, his second wife, children and grandchildren were now the focus of his life:

'And we'll have – we'll sit down and – love it, I absolutely love. Just sit in the chair, get all the kids around me. And just watch them. And I love that. I love watching. I love cooking for them. Right, and I love the evening. Right. I'd love to just cook for them and sit back and watch them...And *that* takes me right away back to your very first question you said to me, "What's your motivation?" It is the kids. It is my kids.' (2/449)

Although he enjoyed the good relationships with most of his children, he was disconnected from one daughter in the preceding ten years, due to her opposition to his second marriage. He described putting on a tough exterior to most, but when with his wife and children, he was his true 'soft' self (2/561). He revealed this 'soft' self during the interview, and became emotional when recalling his relationship with his father, and his father's death, which had been due in part to alcohol. Although the Christian participants had some similarities, their relationships with God were unique. Conversely, Tim and Steve had similar beliefs regarding their 'motivation' (Tim:2/451) and 'pride'(Steve:2/261) in life: both identified enjoying time with their families, sourcing quality food and eating with their families.

Spirituality can be defined as 'privatised and experience-oriented' (Streib & Hood 2011) with Tanyi describing spirituality as a 'personal search for meaning and purpose in life' that involves connection to self-chosen values that inspire and motivate individuals (2002 p506). Tim and Steve, who self-identified as 'not religious' with no spiritual practices both went on to describe aspects of life and close family relationships that gave them 'pride', 'satisfaction' and 'motivation'.

### 5.3.2 Denominations of Christian participants

The Christian participants self-identified as Protestant. It is not possible to give a full description of Christianity here, but some details are given in Appendix N. The core beliefs of Christianity are:

- belief in a triune God - God the Father, God the son (i.e. Jesus Christ) and God the Holy Spirit
- that Jesus Christ atoned for the sins of the world by his sacrificial death
- that Jesus Christ was resurrected from the dead and ascended to heaven

- that Jesus Christ will return to earth on the Day of Judgement when the living and dead will be judged for their lives and sent to heaven or hell  
( Lewis 2012; Woodhead 2014; Westminster Abbey 2019)

Within Christianity, there are Catholic and Protestant church ‘denominations’. According to Oxford Dictionaries (2019a) a ‘denomination’ is a ‘recognised autonomous brand of the Christian church’. It should be noted that the term ‘the church’ originally meant groups of Christians meeting together, but over time this word evolved to also mean a building. The Christian participants self-identified with specific denominations as shown in Table 13. For some, their spiritual practices (described later) were linked to their denomination.

Table 13: Church denominations of participants

<b>Pseudonym</b>	<b>Spirituality</b>	<b>Christian church denomination</b>
<b>Mary</b>	Christian	Church of England (Anglican)
<b>Liam</b>	Christian	‘Traditional church’ (Anglican?)
<b>Ray</b>	Christian	Church of England (Anglican)
<b>Sally</b>	Christian	Church of England (Anglican)
<b>Will</b>	Christian	Not attending church, but interested in Salvation Army
<b>Tim</b>	Self-identifies as ‘not religious or spiritual’	Not applicable
<b>Ange</b>	Christian	Church of England (Anglican)
<b>Steve</b>	Self-identifies as ‘not religious or spiritual’	Not applicable

## 5.4 Spirituality influences expectations in life

The definition of spirituality for this study given in Chapter Two (2.3.6) is that spirituality is a

‘a concept relating to being human and has nebulous boundaries. It may fluctuate throughout life, is unique to the individual, and may contain cultural or ethnic components. It forms part of the nature of being, and may incorporate meaning and purpose in life, connecting with others, nature, ethical aspects, and may (or may not) involve worship or belief of a Deity, deities or the supernatural.’ (Cawley 1997; Tanyi 2002; Speck et al. 2004; Narayanasamy et al. 2004; McSherry et al. 2004; King and Koenig 2009; McSherry 2010b; Koenig et al. 2012; Ammerman 2013).’

Participants’ spirituality was integral to their lives, but had influence over more aspects of the lives of the Christians compared to the lives of the SBNR participants. It is impossible to analyse their spirituality as a distinct attribute and in isolation, as it influenced participants’ beliefs about themselves, their purpose in life, their health beliefs, challenges in their lives, their hopes and fears and influenced their coping strategies.

### 5.4.1 Spiritual practices

In this study, ‘spiritual practices’ are defined as any intentional activity that develops or nourishes an individual’s spiritual life. These activities may be regular or episodic, performed alone or in a community of believers. I have avoided the term ‘spiritual rituals’ due its limitations – a ‘ritual’ involves adhering to a ‘prescribed order’ of actions for a ceremony. (The only exception to this is The Eucharist<sup>17</sup>). The term ‘spiritual practices’ is chosen to incorporate any practice/ritual that individuals used, shown below (Table 14).

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<sup>17</sup> According to the Dictionary.com (2018b), ‘The Eucharist’ refers to the holy sacrament of consuming bread and wine, where the priest prays over the bread and wine, and the recipient receives them. It recalls the last meal that Jesus Christ had with his followers.

Table 14: Spiritual practices of all participants

<b>Spiritual practices</b>	
<b>Prayer</b>	Prayer for: <ul style="list-style-type: none"> <li>• Self</li> <li>• Others</li> <li>• Global affairs</li> </ul> Types of prayer: <ul style="list-style-type: none"> <li>• Conversational</li> <li>• Church led prayer</li> </ul> Prayer accompanied with: <ul style="list-style-type: none"> <li>• Lighting candles</li> <li>• Walking</li> </ul>
<b>Religious texts used</b>	The Bible Biblical theological commentaries Theological books Christian Bible study notes
<b>Church</b>	Attending church, and listening to sermons Taking 'The Eucharist' Reflection and quietness in church Fasting at Easter (fasting from smoking) Listening to 'Evensong <sup>18</sup> ' on radio Flower arranging in church with others
<b>Church</b>	Religious ceremonies/events: <ul style="list-style-type: none"> <li>• christening</li> <li>• baptism</li> <li>• marriage</li> <li>• burial</li> <li>• Christmas church attendance</li> </ul>

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<sup>18</sup> 'Evensong' is celebrated in the Anglican church, and is a traditional service in the late afternoon or early evening.

<b>Spiritual practices</b>	
<b>Relationships</b>	Family Friends Christian community God
<b>Nature</b>	Enjoying nature Keeping an allotment and eating home grown produce Walking Flower arranging in church
<b>Other</b>	Meditation Guitar playing Giving money to charity Participating in research with altruistic motives

#### 5.4.1.1 Prayer

Christian participants expressed that prayer enabled the possibility of changing the natural course of events or outcomes and increased their abilities to cope. Examples were Mary feeling it was Divine Providence<sup>19</sup> in meeting the Christian diabetes specialist nurse, Ray's belief of Divine healing of a leukemic boy and God communicating to Sally 'stop worrying' (2/179).

Prayer for self, others and the world were the most commonly used spiritual practices of the Christians; the SBNR participants did not pray. Participants used prayer to thank God, to ask for strength to cope, for healing, for protection and to repent from wrongdoing. The Christians found prayer gave peace, comfort and strength to cope with adversity. Prayer could be conversational, or through led prayers from a church service. Participants felt they communicated with God; it was a two-way practice that involved them talking to God and receiving communication from Him in the form of love, comfort and answers. Mary prayed at church and at home. Nightly prayer involved thanking God, but she did not 'keep on asking Him for things' (2/805); she also connected her prayers with lighting church candles. Liam, Sally and Ange prayed daily, and used

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<sup>19</sup> 'Divine Providence' can be understood to mean the planned and protective care of God regarding his creation, especially towards humans (Tiessen 2000 ; Elwell 2019)

conversational prayer. Prayer involved honest communication between themselves and God, which involved thankfulness, asking God questions, repenting from wrong-doing, and wrestling with God's intervention in their lives. These three participants felt that God answered their prayers in the form of perceived communication from God, feeling the Presence of God (Sally:2/178), being reminded of a pertinent Bible verse, and positive emotions experienced as a result of prayer. Ray found the vertical relationship with God (Carson 2001) gave him tranquillity, influencing his horizontal relationships and for him to be kinder in his relationships. The expression of this was that Ray took responsibility for his own life, but his Christian family prayed for his medical challenges – he did not pray for his medical concerns himself. In this way, his spirituality was circular – his faith influenced kindness towards family members, who in turn prayed for his health, and in turn, Ray believed that prayer 'worked'. In this way, Ray's health was being indirectly influenced by his spiritual beliefs.

Ray and Will prayed but not for themselves, but for others and the world. Will believed God influenced individuals' thoughts through prayer and through the Bible. Ray and Liam believed God could answer prayer for healing from illness. As a child, Ray's church had prayed for a leukemic boy who was survived (1/926) and consequently, Ray believed in the 'power of prayer' (1/930). He believed prayer was 'very important' and assisted him coping with life's challenges (2/464). Liam had prayed for healing from T2D, and when this prayer was not answered, it led to a crisis of faith that will be discussed later (p115). Will was inconsistent in his view on prayer: he prayed for global affairs or for others, but later stated that God chose not 'interfere with mankind' (1/322). Despite this view, he believed that God influenced him having an urgent GP appointment that led to his diagnosis. He could not identify why he avoided praying for himself, but it appeared to be related to his interpretation of God being powerful, but not benevolently disposed towards Will. Sally showed me 2 reed crosses in her kitchen, next to 2 written prayers. One prayer was called 'Share your disappointments with God' and the other was a poem about Jesus on the cross. She explained prayer was important in her life:

'and when I'm very down and I can't feel the presence of the Holy Spirit – that's when I really get down on my knees and pray and it all just comes back to me and I'll get a verse [from the Bible] or something, you know.' (Sally:2/183)

Ange prayed throughout the day, having a 'conversation with God' (2/679). Her friendly relationship with God enabled her to view God as supporting, comforting and protecting her. She believed God communicated with her in various ways, even throughout the interview process, when she joked that God was 'slapping' the back of her head (2/927) to help her pay attention to her diet.

### 5.4.1.2 Sacred texts

Three Christian participants found that reading the Bible and related religious material encouraged their faith. This varied from Liam who read the Bible occasionally; Will who read the Bible and Bible notes and Sally, who daily read the Bible and biblical commentaries. Sally's description of her early Christian life was linked to working as an Army nurse, where she mixed with Christians from all denominations, some of whom were still friends. Christian communities within the Army, such as the Nurses' Christian Fellowship fostered the growth of her Christian faith. These early experiences appeared to have shaped her attitude to her faith and her desire to understand it. She had numerous Christian books in her lounge, some regarding 'Theology'. Sally lived with anxiety and prayed for emotional strength with her diabetes:

'I just pray and ask God to help me [with diabetes] and often if I'm really, if I'm feeling really down, if I'm just down a little bit, I will take out my Bible and read a bit' (2/166)

Will also found 'comfort' from his Bible reading (1/850) and was the only participant who quoted from the Bible a number of times during the interview.

### 5.4.1.3 Church

Attending church was important for some participants. Mary's grandparents, parents and Mary had been christened<sup>20</sup> and married at her local Anglican church, and she wanted to be sure she would be buried there (1/276). Mary was the only one who talked about burial, stating her church was part of her (2/590) and 'her spiritual home' (2/588). It was a 'holy' place where she found 'peace' (1/248, 268; 2/653). Mary had previously worked with other women flower arranging for the church. Although 'The Eucharist' was important to her, her osteoarthritis impinged upon her mobility and she attended church infrequently. Liam also attended church infrequently, usually around Christmas, and was accompanied by his wife who had a quiet Christian faith. Ray had been brought up in a non-conformist church<sup>21</sup>, moved to a Methodist church<sup>22</sup> and from the age of 21 had settled in an Anglican church. The birth of his autistic son led to family pressures making church attendance difficult, but he

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<sup>20</sup> 'Christening' is an Anglican tradition where a child has water placed on the head, signifying their first step into Christianity (The Church of England n.d.)

<sup>21</sup> 'Non-conformist' churches are any churches that are Protestant, but not under the direction of the Church of England. They may also be referred to as 'free churches' (Britannica.com 2018b)

<sup>22</sup> According to the Collins English Dictionary (2018b), 'Methodists' are Protestant 'free churches' that follow the teachings of John Wesley from the 18<sup>th</sup> century. Similar to the Salvation Army church, they emphasise the work of the Holy Spirit in believers' lives (Christianity.com 2018).



found peace and tranquillity when he was able to attend church. During interviews, he reflected on his current infrequent attendance and expressed 'regret' at this (1/891). When he attends church now he appreciates the quietness with time for reflection and prayer. He found listening to sermons assisted his reflection on his relationships with others, which was a key focus of his faith. Before Easter, Ray would fast from smoking, which eventually led to him permanently quitting smoking. Like Mary, Sally 'loved' her Anglican church (1/401) and favoured Anglican services because they included what she considered the important aspects of her faith including 'confession [of sins], intercession [prayer]...and Bible reading' (2/156). Sally worked as a 'lay pastor' visiting sick people, and had previously been a secretary of the Mothers' Union. In addition to attending church, Sally enjoyed listening to Christian radio broadcasts and listening to Evensong.<sup>23</sup> Will was baptised<sup>24</sup> as an adult, and stated that if his health enabled it, he would attend the Salvation Church Army (Appendix N). He commented that he believed in 'Christianity not in churchianity' (1/876) indicating belief that denominational boundaries were less important than the principles of his faith.

#### **5.4.1.4 Relationships with others**

According to Carson and Stoll (2008), the horizontal aspect of spirituality 'fleshes out the many ways in which a personal relationship with the Divine influences...our interactions with others, and with nature' (2008 p7). Carson (1989) described vertical and horizontal elements of spirituality, where the vertically focused reaches upwards to the Divine, but horizontally focused reaches outwards to others or the self. Both Christian and SBNR participants expressed horizontal aspects when describing relationships to those around them with the meanings in their lives. In discussing atheist spirituality, Comte-Sponville (2014) considers community and good morals are vital to a well-lived life, and that relationships are interconnected, with people bearing responsibility for each other. He asserts that the virtue of love (which is the focus of the Biblical Gospels) transcends morality, and connects relationships (2002). Both the SBNR and Christian participants all saw good relationships as part of a full life, which assisted them in coping with life's challenges. The Christian participants found encouragement from family members or friends who shared their faith. Shared religious practices formed connections between them, such as Mary's

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<sup>23</sup> 'Evensong' is celebrated in the Anglican church, and is a traditional service in the late afternoon or early evening.

<sup>24</sup> 'Baptism' is a Christian ritual, referring to the use of water as a symbolic act of becoming a follower of Jesus Christ. It may occur as an adult, but in the Anglican church if performed on babies, is referred to as 'christening'.

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niece (who was like a daughter to her) lighting church candles and saying prayers on Mary's behalf, or participants going to church with family or friends. Sally was the only participant to express concern regarding a family member's lack of Christian faith.

Ray gave a frank account of his life, and how his negative relationships and actions had impacted others, such as his poor communication with his mother (who he now reflected may have also had autistic traits), walking out on his first wife and teenage boys, gambling and alcoholism, and the birth of his autistic son with his second wife. He believed his faith could inspire him to live a better life that was 'healthy' and to live a life that did not 'damage other people' (1/878) linking to Carson's view that spirituality is about a 'universal human dimension that expresses itself through relationships' (2008 p1). Whilst other participants spoke about their *relationship with God*, Ray was the only participant that specifically spoke about his faith influencing his actions towards his relationships. When Ray did attend church, he found the sermons<sup>25</sup> 'relevant' to his life, encouraging him to be 'nice to people' (2/348). Ray stated his faith helped him:

'in not shouting at A [his wife] and all sorts of things that I associate with the Christian faith such as helping me to be a good person to help other people. (1) Yes, yes, I find these sort of things really hard to put into words.' (Ray: 2/353)

Ray referred to himself as 'lucky' nine times in the interviews, nearly all in relation to how family members had 'stuck with [me] through thick and thin' despite his poor treatment of them. He did not pray for help with problems, but thought it possible that God may have given him 'strength to cope' (2/503). Carson (1989 p7) suggested the horizontal element influences our values, lifestyle and relationships that may be chosen consciously or unconsciously, and it appeared that Ray was evaluating his own life during the interview. Ray saw this vertical aspect as influencing him living his life in his relationships, encouraging him to be kinder to others.

Some participants described relationships that were associated with negative features such as bullying, marriage collapse and family stress. Tim revealed his choice to sever his relationship with his daughter due to her opposition to his second marriage, and Will chose not to forgive people for what appeared to be minor offences. Will commented that since childhood he had 'huge, huge problems with forgiveness' (1/970) stating:

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<sup>25</sup> According to the Cambridge English Dictionary (2018b), 'sermons' are part of the Christian church service, where the priest/lay person will give a talk based on religious or moral subjects, usually based on something from the Bible.

‘don’t cross me, because if you cross me, I’ll wipe you out of my life (6). And I have *always* (1) been like that’ (Will: 1/983)

Due to disagreements, Will would not speak to either of his brothers, but did have a few female ‘great friends’ (1/696). The first was an archdeacon of a church, the second was her parishioner aged 82 - ‘an angel in human form’ (1/700) who was the housemate of the archdeacon. The housemates believed they had a ‘ministry’ to help Will (1/710). Part of the ‘ministry’ involved cleaning his flat, reminding him to take medication, and encouraging him to see God at work in his life. The third friend was a female Christian work colleague who encouraged him in his faith, and her friendship was interpreted by Will as ‘the intervention of God’ (2/851).

#### 5.4.1.5 Connection with nature

Shelly and Miller (2006 p96) posit that spirituality is fundamentally relationally driven, whether with God or others, and relationally driven activities connect us to ourselves, others or God. Likewise Carson and Koenig (2004 p74) view that *any* activity (e.g. woodworking or sports) can be influenced by individuals’ connection with the Divine. Christian participants expressed joy at the beauty of nature, and connected this to their faith, the benevolence of God and feeling close to God. Both Mary and Liam were thankful for a ‘beautiful’ world (Liam1:802; Mary1:791), and Ange chatted to God when walking in the park. Liam expressed this appreciation of nature and connection to God:

‘I mean, especially if you go to like a nice historic town or something, where you stop for a minute, “This is just amazing” you know, “This is just um [sniffs] - wow!” Like a building that’s build brilliantly, you think “Yeah, that is just such a glorious thing!” [grins] um but the countryside particularly for me, you know, it’s – God [looks up and grins], that’s - it’s (1)... I – I love that you know. If I, um [sniffs] if I see a beautiful piece of nature, I find it awesome you know, I just - I can just sit there and just really - well I can’t take it in actually! [chuckles] (Liam:1/825)

The SBNR participants connected with nature; Steve through working his allotment and eating home-grown produce and Tim through walking with family. Both felt strongly about eating healthily and providing healthy food for their families, as was shown by Tim’s quote (p96). Other spiritual practices focused on relaxation, such as mediation and playing guitar. Some practices were altruistic, such as financial giving to charity, trying to improve healthcare by research participation and improving hospital access for learning disability nurses.

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This section has discussed participants' spiritual practices of prayer, sacred texts, church connection, relationships and enjoying nature. In the next section, the individual interpretation of the Christian participants' beliefs is discussed in relation to their doctrinal beliefs, their relationship with God and their interpretation of His power in their lives.

### 5.4.2 Doctrinal beliefs of Christian participants

Christian participants discussed some of the central beliefs of Christianity previously identified (p98) (Lewis 2012; Lane 2013 Woodhead 2014; Dean and Chapter of Westminster 2019; Appendix N). Ray articulated this belief: 'I'm a Christian and I believe in Jesus Christ and an afterlife' (1/873) and Will stated his belief in 'God the father, God the son and God the Holy Spirit' (1/886). Mary referred to having been 'born with the faith of Christ' (1/327) and saw God as the 'First Cause' (Britannica.com 2018) and 'The good Lord... the One that sets the ball in motion' (2/577). Will perceived God as a trinity<sup>26</sup>, and linked this to humans: 'Mind is God the Father, soul is God the Spirit, body is God the Son, so we are a trinity as much as God is a trinity' (1/887). Will described God as an 'all-enveloping source of light' and in contrast to the devil<sup>27</sup> who was an 'all-enveloping source of dark' (1/907). He believed the light would always win, and after death people would become part of that light, strengthening God's position. He saw Jesus Christ as the ultimate form of light who lived 'absolute pure socialism' (1/955) and died for the sins of others (1/921). He believed that to be a 'Messianic Jew'<sup>28</sup> was the highest form of Christianity (1/936) due to the historical Jewish element of Christianity (Appendix N).

Some participants' beliefs had been influenced by either growing up within a Christian family (Mary and Ray), going to a Catholic School (Mary), or from attending 'Sunday School'<sup>29</sup> in childhood (Mary, Ray, Ange). Ray had also been a Sunday school teacher when younger.

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<sup>26</sup> According to the Encyclopaedia Britannica (2019), the 'trinity' is 'the unity of Father, Son, and Holy Spirit as three persons in one Godhead'. (Ref: <https://www.britannica.com/topic/Trinity-Christianity>).

<sup>27</sup> In Judaism, Christianity and Islam, the devil is the prince of evil spirits and the arch adversary of God (Lewis and Short 1879; Britannica.com 2018c).

<sup>28</sup> Messianic Jew: a Jew who believes that Jesus is the fulfilment of Judaism and is the Messiah. (Reference: <https://jewsforjesus.org/jewish-resources/community/messianic-jews-a-brief-history/>)

<sup>29</sup> According to the Collins Dictionary (2018) 'Sunday School' is a British term used to describe a class organised by churches on a Sunday, for children to learn about Christianity.

Some participants talked of an afterlife, and Mary, Will and Ange believed that God was in control of the timing of their death, and death held no fear for them. Mary believed that life would be harder if you 'didn't know there was something better to come', referring to heaven (2/769). Mary expressed no fear of death, commenting that life on earth was brief, and that death was not 'the End...It's more like The Beginning' (1/216). She believed the 'soul' of people (2/714) would go to 'another dimension in some way' or 'heaven' where she would see 'loved ones' again, though not in 'bodily form' (2/711). After death, Will believed all physical suffering would cease, but was unsure if emotional suffering continued (1/432). He stated that at death, 'we become part of the light of God, so God's strength is continuing to grow' (1/927). Instead of connecting heaven with seeing friends or family, he linked this to other religions stating he believed in heaven he would be 'side by side' with people of other religions.

### 5.4.3 Relationship with God

Christian participants' relationship with God varied greatly from Mary's respectful awe, Ange's view of God as her 'best pal' (2/694) and Will's understanding of God as powerful but not personal. Christian participants described their understanding of God and how He worked in their lives, and how their faith influenced relationships with others. As relationships with God were subjective and unique, an outline is given of individual participant's beliefs.

Mary's attitude to God was one of 'respect' (2/608) and awe (2/653). She believed it that if it 'wasn't for the love of God' people would feel less 'safe' and 'happy' (2/581), and was grateful that God's love was expressed through the kind people God had placed around her (1/204). She referred to God as 'good', and trusted Him despite her belief that He 'allowed tragedies' as part of life (1/125). She felt connected to God and saw Him enabling her to cope with challenges, remaining thankful towards God. When hospitalised with a heart attack, Mary felt 'calm and peaceful' believing that God was looking after her. She had no fear of dying, stating that 'He [God] was holding my hand' (2/761).

Despite Liam's deep and emotional connection with God, he experienced a crisis of faith upon diagnosis. 'Diabetes distress' refers to challenges individuals experience concerning the emotional stress caused by diabetes and its management (Asuzu et al. 2017). Liam expressed emotions such as anger, despair, hope and love towards God, which are described later (p115), in

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the discussion regarding participants' views of the omnipotence<sup>30</sup> of God. Liam described God as caring for him deeply, that he was 'favoured' by God (2/675) and Jesus as the 'closest friend you're ever likely to have' (2/438).

Ray did not refer to God in any relational context as all the other participants did. Rather, he understood his faith as helping him to relate well to *others* saying it helped him with 'not being horrible to other people' (2/496) and in giving to charity. His relationship with God was focused horizontally and lacked the strong vertical element that other Christian participants discussed. It did not appear that he found understanding his own and others emotions easy.

Sally was formerly an atheist. On passing her psychiatric and then general nurse exams at aged 27 she felt 'so happy and so grateful' and asked 'but who could you be grateful to if you're an atheist?' (2/110). Around this time, a nursing colleague gave her a book about Christianity. She said that in the 1960s-70s 'intelligent well-bred people didn't believe in God' (2/122), yet she was inspired by the book thinking, 'If the Bible is true, I must get a copy of it, so I can read it and see if I think it's true' (2/124). Becoming convinced of the truth of the Bible, she knelt and prayed to God, and at that point 'became a Christian' (2/136). From this time onwards she had never doubted or 'questioned God' (2/198), and now thought atheism was a 'weak sad thing' (2/200). Sally felt that God 'speaks' to her (2/178), giving her comfort and strength saying:

'I can feel God's presence with me. I'm very lucky, 'cause some Christians have no feeling of God's presence with them, but ever since I became a Christian I've always felt the presence of the Holy Spirit' (2/180)

Will's relationship with God stood in contrast to the Christian participants, who all spoke of being aware of, or feeling God's presence, comfort or strength. Although Will believed that 'God wants us to love Him' (1/926) and described himself as a person who 'relied on God' and had a 'love of God' (1/868), he did not allude to God loving him. In a vignette about an affair with a married woman, Will felt that God highlighted to him the amount of people that would be harmed by this relationship, and believed God said, 'Sort yourself out [surname]!' (2/184). In using Will's surname and the harsh tone Will used to describe this, he implied that God was speaking to him sternly, issuing a directive. His description of God was not in terms of warm relationship, but that of power and omnipotence; he never referred to feeling comforted by God and the only other term he used for God was 'the Almighty' (2/331). Although he believed that

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<sup>30</sup> In the Cambridge English Dictionary (2018a), being 'omnipotent' refers to the unlimited power of God.

God had influenced him obtaining an emergency GP appointment that led to his diabetes diagnosis (2/260), and that God helped him quit smoking (2/279), his vignettes were not connected to gratitude or that God loved him. He expressed anger towards God for his mother's death and held God responsible for unkind comments from others towards him regarding his weight. He acknowledged that twice before when he had been suicidal, he did not perceive himself to 'be worthy...of anything, and that included God's love' (2/436). Yet on both occasions he believed God intervened to prevent his suicide, but did not link this to God caring for him, rather that God had work for him to accomplish on earth. If he had committed suicide, he was not sure of what God's response to him would be:

'But [chuckling] you don't know whether He's – if you pardon the expression – you don't know whether He's gonna give you a right bollocking! [laughs] And I ain't good at receiving them! [laughs]. And to receive one from the Almighty would be – whoa! [laughs].' (Will:2/329)

In quoting scripture, he sometimes questioned what a passage might mean, and then would answer this in the next sentence. The only section of the Bible that Will referred to reading was the Book of Job which is held by scholars to address theodicy<sup>31</sup> - God's relationship to human suffering and the justice of God (Biblica The International Bible Society 2018). The Book of Job seemed to encapsulate Will's approach to his relationship with God and why God allowed challenges in Will's life. He saw God as the major actor and himself as the minor actor in his own life, and he was powerless against the will of God. This is similar to one cohort in the study by Polzer and Miles 2007 (Appendix U), where some participants viewed God as the 'authority figure' and they were submissive to His will. Will's relationship with God appeared to be based on Will's perceived omnipotence of God, and his horizontal relationships with people (Carson 1989) did not appear easy for him either. Will was different from all the other participants who expressed hope, even in their struggles.

Ange had been to Sunday school as a child but had a period of non-attendance as a young adult. Like Sally, Ange had a spiritual experience that changed her life. After attempting suicide as a teenager, Ange believed she heard God say to her:

"But I love you; I carved you in the palm of My hand. So I've always got you by the hand." And I looked around and there was nobody there. And that's how I came to believe in God' (2/558)

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<sup>31</sup> Theodicy attempts to understand the complex nature of a good God who permits evil to occur in the world (Sherry 2018).

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This was the beginning of a relationship with God the Father as her friend (2/569) whom she referred to as her 'best pal' and 'confidante', and considered that God viewed her as a friend also (2/694). Although friends in her life may come and go, God was constant. She felt that God loved her 'unconditionally' (2/568), saying that she 'couldn't live without Him' (2/712) and expressed gratitude towards God. She believed that God was with her throughout the day and prayed conversationally with Him 'at least once a day' (2/701). On days when she felt low, Ange felt God's presence was like 'swans wings and a big duvet wrapping me up' (2/689). She felt that God gave her strength, believed God would provide for her 'material needs' (2/759) and He cared for her financial matters (2/594). Years previously, she believed that He had helped her through the loss of her house, job, mother, dog and car that all occurred within the same month. Ange's relationship with God was based in belief in His unconditional love for her. At times it involved conflict, when she felt that God wanted her to follow a course of action that she did not agree with. She believed God not only allowed events in her life but directed the course of it. She saw herself as being 'a little rebellious' at times but said 'every time' she was aware of this she apologised to God; although she might swear and shout at God, later she would say 'I've done it again, sorry!' (2/239). In describing herself as 'rebellious', she inferred there was a right way to behave, that she sometimes did not adhere to. Her descriptions of God were affectionate, and she felt that He understood her sense of humour. Even when she felt challenged by God, it was within a context of a friend facing her with a truth she was trying to avoid. When God faced her with uncomfortable issues, it was *because* He loved her and wanted to help her into freedom.

Ange relied on God daily to help her control sugar cravings that led to overeating, believing that God was 'teaching' her (2/770) to manage her T2D. She expressed that though the process of the second interview God was teaching her the importance of addressing her diet:

'He's slapping the back of my head, saying 'You've finally realised! [Ange grins and motions God slapping her head]' (2/925).

'I'd always be saying, "Oh stop me from doing this, stop me from doing this" [Makes an action of eating food, and raising her eyes upwards, and slaps her own hand]. [Chuckles with interviewer]. I'll be sitting there with God on one hand and a packet of Jaffa Cakes on the other!' (2/648)

She apologised to God when she 'pushed the boundaries' (2/237) regarding diet, and used various strategies when shopping, such as imaging God sitting on the freezer making access to unhealthy foods impossible. As her friend, God supported her dietary struggles. In a 'conversation' with God, she would say:



“Okay God, help me out here. I’ve done it again. Tie my hands behind my back when I go to the supermarket, please?” And then I feel quite good because I didn’t put one in the basket. Because He’s watching.’ (Ange:2/540)

Because of Ange’s benevolent view of God, God ‘watching’ her was a positive encouragement for her to make the right choices, because she felt loved and affirmed by Him. Individual Christian participant’s relationships with God were linked to belief in His intervention in their lives. Those who perceived God as compassionate and benevolent interpreted the challenges in their lives as something He ‘allowed’ but enabled them to cope with. Those who did not consider God as kindly disposed towards them or perceived Him as merely powerful, did not interpret Him as actively enabling them to cope with the complexity of challenges in their lives or their disease processes.

#### 5.4.4 God’s ‘plan’ in participants’ lives<sup>32</sup>

According to the Merriam-Webster Dictionary (2019), ‘fatalism’ is the ‘doctrine that events are fixed in advance so that human beings are powerless to change them’ and the outcomes dependent on chance, luck, fate or God (Franklin et al. 2007). Sally expressed certainty about the timing of her death due to chronic lung disease stating, ‘so I’ve got COPD<sup>33</sup> but I’m 73 and I’m going to die by the time I’m 85’ (2/70). All Christian participants except Ray spoke of God ‘allowing’ some events or ill health, whereas the SBNR participants did not imply fatalistic beliefs. Although there are positive benefits of religious beliefs (Koenig et al. 2001; 2007; 2012), fatalism may help or inhibit utilisation of healthcare or good healthcare behaviours (Gall et al. 2005). Fatalism has been studied in people with diabetes (Egede and Bonadonna 2003; Egede and Ellis 2010; Berardi et al. 2016; Asuzu et al. 2017; Saidi et al. 2018), can be linked with depressive symptoms, can motivate or inhibit SMB and can affect hba1c. In this study, participants’ belief in the causality of T2D was thought by some to be a combination of their choices and God ‘allowing’ this condition (Table 15).

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<sup>32</sup> Some participants spoke of God having a ‘plan’, or ‘allowing’ events in their lives.

<sup>33</sup> Chronic obstructive pulmonary (lung) disease is strongly associated with smoking (NHS 2016).

Table 15: Causal beliefs of T2D diagnosis

	<b>Spirituality</b>	<b>Belief of causal factors of T2D</b>	<b>God 'allowing' T2D</b>
<b>Mary</b>	Christian	Not commented	Yes
<b>Liam</b>	Christian	Not commented	Yes
<b>Ray</b>	Christian	Not commented	No
<b>Sally</b>	Christian	Obesity	Not commented
<b>Will</b>	Christian	Obesity Lifestyle	Yes
<b>Tim</b>	'SBNR'	Obesity and genes	No
<b>Ange</b>	Christian	Obesity and genes	Yes
<b>Steve</b>	'SBNR'	Not commented	No

Ange believed causes of her T2D were hereditary factors and her lifestyle (2/229), but like Will (2/631), she believed that God *could* intervene and change this:

'He's *allowed* me – He [God] doesn't give – He's allowed me to have these health problems... but whatever choice man makes, God will either do something or prevent it, if it's going to be the wrong choice.' (Ange:2/627)

Mary, Sally, Will and Ange believed the timing of their death was predetermined, believing that that nothing could alter the allotted time span God gave them. Will believed that God had prevented him fulfilling two of his planned suicide attempts because his 'time wasn't up' (1/453). Mary also expressed confidence in God giving her an allotted lifespan:

'but I think the day you're born, God knows the day you'll die. And I mean, it doesn't matter what you do, if you're meant to die, you're going to go. And that's your time.' (2/702)

Mary and Ange believed it was God's will for them to survive resuscitation. Ange survived resuscitation twice (2/722), stating God communicated to her 'You're not going yet – I've got

work for you to do' (2/725). Connected with her suicide attempt as a teenager was a spiritual encounter that enabled Ange to find strength. Later in life, she believed that God helped her address serious health issues saying:

'And I wouldn't be here if He wasn't. I'd be six feet under, long ago. Um, not suicide attempts, but health issues.' (2/714).

Some participants discussed yielding to or opposing the plans that God had for their life. Mary believed that God 'planned out' her life 'and it's not good fighting that, I mean just go along with it and do your best' (1/244). Ange stated that God 'mapped out' her life for her (2/203) which included her job, and relocation to England. Although God had 'a plan for her life' (2/177, 200) Ange could veer off this planned course, but she would ultimately come back to what God wanted (2/217). Unlike Mary, she resisted God's plan for her life sometimes:

'I've shouted, sworn, thrown things at God, and always come back and said, "Sorry, you were right." Um, yeah, it's – there's been conflict because I've wanted to do things that never worked out and then something else happened that was *better* outcome than probably the one I had thought would be the right one for me. And I've maybe resented it at first and then realised that it's a bit like being a child you know – 'Mummy knows best'! Only in this case – Dad [God] knows best! [chuckles] But yeah, I've done things I'm not proud of. I've gone off track a few times. But I've always come back because I've realised that going off track got to a point where it wasn't fun, or it didn't give me the (1) warm, cozy whatever feeling um, and realised that, "Oh alright, I've done it again. But I'm coming back okay." And then I come back [to God and His plan for her].' (2/219)

Liam's diabetes diagnosis led to a crisis of his faith. As he was slim and exercised, he was shocked to have developed T2D, resulting in a spiritual struggle to understand why God allowed this and confusion about his relationship with God. Liam spent most of the first interview weeping about his disconnect with God, and felt 'guilty' at his distress regarding the diagnosis (1/529). He embarked on a very low-calorie diet (without the doctor's knowledge) to 'reverse' his diabetes and 'cure' himself (1/86;959). This resulted in becoming underweight and did not reverse his diabetes. He prayed 'every day' that God would heal him (1/855), but as this had not occurred, he felt 'angry' and questioned did God love or 'favour' him? (1/877). He had asked several times 'Why have you [God] done this to me?' (1/897) He felt guilty expressing this, worrying that he was 'bad mouthing' God, and wrestled with this throughout the interview - he longed to believe that God still loved him and would somehow heal him (1/855).

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All participants underwent two interviews approximately one month apart. However, due a temporary halt in my doctoral studies, Liam's interviews were over fourteen months apart. A few months before the second interview, he experienced a renewed spiritual connection with God, when walking he had been 'bawling [his] eyes out' to God and 'crying and screaming' (2/381) about the frustration of living with T2D. He was the only participant who talked about Jesus rather than God, and he wept as he referred to a spiritual encounter, where he realised that Jesus is the 'closest friend you're ever likely to have' (2/434). In an emotional part of the second interview, he explained how God revealed His love for him:

'Jesus really did care [face shows a lot of emotion] and um [crying] (9). Excuse me, sorry [sniffs] um, and you know, God [cries again] (2) does care and um (1). He can't necessarily um (3) just make everything right, like that um, um, because we live in a world, the world that we live in, um, (2) um, you know it's not like, um - just cause things happen in this world. Excuse me; can I get a bit more? [Referring to tissues] Um, doesn't mean you've been abandoned, um (2). Because um, because of me being me, you kind of expect [sniffs] er, or me being the old me, you know - I always expected if you were a Christian that [sniffs] you were bullet-proof and you could always be saved, and um, miracles would just happen to you, you'd be alright, and you'll always be, you know (5). And the message [i.e. from God] I was getting was that "Things *aren't* going to be alright you know um." [Sniffs] (2) "That's not what I do um, I don't just, um [sniffs] um, um, I don't make things not happen, *because I can't do that* because um, that's the world, and I can't control that world, um, but I can *love you*." [Sounds very emotional] "And, um (3) help you and, um [crying] (2) you know, just be with you, um, while you um go through these things". [Crying]. (2/412)

Liam's spirit was 'regenerated' in this deep connection with God (2/878), which helped him to 'come to terms' with his diabetes (2/874). In the first interview fourteen months earlier, his questioning why God had 'allowed' him to have diabetes had led to 'confusion' and he had struggled with feelings of disloyalty to God just by expressing these thoughts (1/937, 970). Since then, his spiritual encounter had resolved his wrestling with God, enabling him to view God's power differently. Due to cognitive reappraisal, he now believed that God was *unable* to heal him, he no longer wrestled with feelings of confusion, abandonment and being 'unloved by God' (1/880). Although he had 'hope for healing' (2/642), he now felt the kindness of God towards him; God was with him as he suffered, and this restored their relationship.

Will held conflicted beliefs of God's power. He expressed frustration that God 'allowed' challenges in his life (e.g. his other co-morbidities) and held God responsible for a neighbour's unkind comment about his weight:

Will: 'Well, I thought – "Come on God, my life is hard enough as it is! (2) I struggle day to day just (1) to survive, or just to exist (1) and then You just threw that at me!" It was almost like the final straw that broke the camel's back. "Why do You?" [saying this to God]. I don't understand (1) why He allows people to be cruel to other people, I just don't understand, I don't get that. (2) Um. (2)'

Interviewer: 'And what would you prefer that God did in that situation?'

Will: 'That He made him not say it! [Laughs] (1) I mean [Sighs] (1). I mean God in His infinite wisdom can do whatever He wants! (2) Um, and I do find it strange that with - He could easily stop people from being cruel to each other I – I do believe that. But He chooses for some reason, not to. He seems to choose to, not to – not to interfere with mankind.' (2/303)

Later in the interview however, Will described how God *had* intervened to help him in other situations (e.g. preventing suicide) and therefore this comment regarding God not intervening in human relationships appeared to link to Will feeling that God *chose not to* help him at times. He was conflicted in his statements – he said that he did not believe that God was *responsible for* 'bad things', He did not *cause* 'bad things to happen', but he believed that God *did allow* 'bad things to happen' and felt there was a 'big chasm' between these two aspects (1/326). This seemed inconsistent with his statement that God was all-powerful and could 'move mountains' if he chose to (1/330); he believed in God's omnipotence but not that God had to be responsible for His actions. Will's statement that followed was:

'I do believe He could [move mountains]! But God chooses not to! Um (1) so but yes, He must have his reasons, I suppose. But He's never let me into it! [Raucous laugh](1/331)

That God 'never let me into it' seemed to encapsulate Will's understanding of God: God did not communicate His plan with him, and Will did not appear to find hope or comfort in his relationship with God. Will made conflicting statements about God's intervention in his life. He referred to himself directing God when he wanted to quit smoking after a heart attack: 'I actually said... to God, "I ain't gonna be able to do this on my own. You're going to have to help me"' (2/273) and he did successfully quit smoking. However, he held God responsible for some

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upsetting events in his life, e.g. having atrial fibrillation<sup>34</sup> and his mother's death. He believed that God 'did not put anything on you that you cannot bear' (1/419) which linked to God having responsibility, as it was Him that *put things* on Will, and Will had to accept them.

Although he had criticised God for 'allowing' 'bad things' to occur (1/329), he believed that God assisted in his financial and social situations, describing the housing officer as 'God-sent' when he needed to move his council accommodation (2/206,223). He believed God had intervened when twice Will had planned to overdose on paracetamol and insulin. As he sat contemplating suicide, he fell into a deep sleep for twelve hours; this was significant given his breathing difficulties<sup>35</sup> and that he usually only slept for two hours a night. He interpreted this deep sleep as God 'prevented me from doing that' as 'his time wasn't up' (1/450).

Will believed that God worked through 'prayer, through the scriptures...and everyday thinking' (2/164), that individuals had control over their thoughts, but also that that God could change a person's thinking. When I asked about his beliefs about being 'whole' physically but not 'emotionally' in an afterlife, he commented:

'Now why don't I believe that, that's interesting? (5) Maybe that's God's intervention again. (5). Maybe He's making me think like that to stop me from doing that [i.e. committing suicide]. He does work in mysterious ways....or maybe it's the Dark [i.e. the devil] making me think like that?' (2/130)

All Christian participants except Ray saw God's Providence in their lives. Providence is defined by the Oxford Dictionaries (2019) as 'the protective care of God or of nature as a spiritual power.' Positive connections with God, especially if linked with prayer, religious reading or human relationships influenced their emotions and participants' ability to take control and manage their T2D. When Mary needed additional support, she believed Providence connected her to the Christian diabetes specialist nurse. The nurse supported her emotionally and gave advice regarding diet and medicines. Although Will's view of God involved emotional and spiritual struggles, his female Christian friends called him nightly to ensure he had taken his medication and encouraged him to see God's Providence in his life. Will had a generally negative view of himself, life, and his relationship with God, which did not facilitate him using positive religious

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<sup>34</sup> Atrial fibrillation causes an abnormal irregular heartbeat, and may cause palpitations, shortness of breath, dizziness and feeling generally unwell (NHS 2018b).

<sup>35</sup> His morbid obesity caused obstruction to his airways, therefore Will had to use a mask and oxygen system called CPAP to help him breathe at night (Continuous Positive Airways Pressure)(NHS 2016b).

copied for his diabetes other than cognitive reappraisal of his suicide attempts. Some participants viewed religious coping as unhelpful. Ray stated those who abandoned diabetes self-management hoping God would heal them were 'idiots' (1/986) and Steve considered spirituality would be more likely to 'interfere' (1/477) with diabetes control.

## 5.5 Beliefs influence coping styles in the self-management of T2D

Christian and SBNR participants used problem-based, emotion-based and religious-based coping to manage living with T2D. Their health beliefs, emotions, spirituality and other people influenced their coping strategies. Participants' health beliefs included knowledge about causes, treatment and complications of T2D, and judicious use of NHS resources. Positive and negative emotions linked to their spirituality, influencing their coping styles. Most participants lived with other co-morbidities that sometimes influenced their management of T2D. Family, friends, HPs and diabetes knowledge linked with spirituality to influence participants' health beliefs, and religious coping both helped and hindered participants managing their diabetes.

The beliefs of individuals influenced appraisals of T2D, e.g. Liam's belief that God chose not to heal his diabetes led to a primary appraisal of 'loss'. Both of the SBNR participants appraised their diabetes as a 'challenge' for a healthier life; the Christian participants appraised it as a 'threat'. Secondary appraisals at diagnosis utilised problem-based coping, including strategies such as seeking health information (from HPs/Diabetes UK), altering diet, losing weight, doing exercise, reducing alcohol, taking medicines and attending appointments. Believing information given by HPs/Diabetes UK regarding the complications of T2D was key to encouraging participants to try to adopt these problem-based strategies:

'There must be a horrific number of amputations and other hospital admissions as a result of diabetes related problems. And I don't want to be one of those statistics. I certainly don't want to lose my feet, lose my toes' (Ange:2/923)

Participants also believed following medical advice would reduce their health risks, enhance energy and perceived positive benefits to weight loss. Easy access to clinicians, and good relationships with HPs resulted in participants being more likely to use these strategies for T2D as well as other co-morbidities, e.g. quitting smoking for COPD. Positive relationships with HPs involved clinicians listening, being sympathetic, supportive and planning care together.

Smoking negatively affects cardiovascular function and is a significant risk for diabetics. Sally felt 'bullied' by her GP to quit smoking (2/71) and resisted this pressure. A locum GP however persuaded her to try vaping, thereby reducing her microvascular and macrovascular risks.

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Supportive clinicians resulted in participants being more likely to try a problem-based strategy.

Ange's supportive GP listened sympathetically to her dietary struggles, saying:

“Don't beat yourself up about it, just don't eat anything beige.” And we had a laugh.’

(1/84)

Ray's 'autistic traits' (1/374) appeared to pre-dispose him to problem solving, and he utilised this to reduce alcohol consumption that he believed was connected to his diagnosis. He chose not to allow sciatic pain <sup>36</sup> to prevent him exercising, saying he would 'learn to live with it' (1/124).

Steve's problem-based coping towards health challenges was two-fold: follow medical advice for problems that could be treated (e.g. diabetes) but 'stop worrying' (1/403) about problems that he could not resolve, (e.g. acoustic neuroma).

Negative emotions of participants included shock, feeling unloved by God, anger, fear, guilt, loss and loneliness. Five of the eight participants had previously or currently experienced mental health conditions including depression, anxiety, low mood, post-traumatic stress disorder (PTSD) and suicide attempts. Poor mental health was associated with negative emotions and poor coping regarding the SMB of reduced exercise, increased alcohol intake, and not taking prescribed medicines. Negative emotions also were associated with a poor diet that was high in carbohydrates, leading to increasing obesity (which linked to increasing depression), 'obesity shame' and hiding at home. All of these led to an increasing risk of weight gain and further depression.

Maladaptive negative emotion-based coping strategies were comfort and binge eating, humour, distraction, alcoholism avoidance and adopting a very low-calorie diet without medical advice. Beliefs of participants acted like scaffolding in their lives, and when these beliefs conflicted with their lived experience, strong emotions followed. Tim was shocked that despite his high salary his wife left him, leading to depression and alcoholism. Will used mostly negative emotion-based coping, and 'catastrophised' (1/395) small difficulties in his life, e.g. his washing machine breakdown led to binge eating. He believed the cardiac surgeon was 'passing the buck' (1/250) by advising Will to lose weight before heart surgery and continued to binge eat. Liam was slim, and shocked by T2D diagnosis. In desperation to 'cure' diabetes and not require diabetes medication, he became underweight. Taking medicines for diabetes undermined his belief in his 'right to live':

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<sup>36</sup> Sciatica is pain in the back and side of the leg, running from the hip to the feet, caused by inflammation of the sciatic nerve (NHS 2017b)



‘my big issue is having to live on drugs for that part of my life, just makes me feel like a utter human failure... um, [tuts] I don’t deserve to be on this world, because – I don’t mean that; that sounds a bit hard, I don’t mean that literally but what I’m trying to say is, um, you know, my genes are not strong enough to survive [chuckles] therefore I shouldn’t be. Life is now a favour, rather than a right.’ (1/516)

Participants also used positive emotion-based coping such as emotional support, instrumental support (practical assistance offered by others), social support, positive cognitive reappraisal and fighting negative thinking. Emotional, instrumental and social support from family and friends influenced dietary choices: some participants shopped with, or enjoyed cooking with and for family members, resulting in healthier choices. These social connections could improve mood, and influenced the emotional well-being and mental health of participants. Will’s friends called nightly to check his medicine taking; Tim’s wife challenged unhealthy food choices; Ange valued friends’ support in healthier shopping and Steve’s family searched for healthy recipes. Participants felt gratitude for these social connections, and being grateful helped them cope with challenges in life. Spiritual and health beliefs influenced the choice to take exercise. Liam and Ange believed taking exercise improved their mood, and Ange combined it with prayer. Sally re-interpreted her diagnosis, turning ‘bad news’ into ‘good news’ (1/253), by seeing it as an opportunity for weight loss through restarting ice-skating that she enjoyed, and one of Liam’s coping strategies was to look for the joy in his life.

### 5.5.1 Co-morbidities of participants

Most participants had to cope not only with the diabetes diagnosis, but to incorporate the SMB of T2D into pre-existing self-management of their co-morbidities. Participants’ co-morbidities can broadly be categorised as conditions affecting the eyes, ears, heart, lungs, bladder and bowels, reproductive organs and the mind; most of these were chronic conditions ( Figure 11 below). Hypertension was the sole co-morbidity directly linked with T2D. Although other co-morbidities were un-related to T2D, some affected participants’ ability to manage their diabetes including:

- Ulcerative colitis (bowel condition) requiring a *low fibre diet* -rather than a high fibre diet that is recommended for T2D
- Poor mental health, linked with overeating and obesity
- Morbid obesity impeding exercise
- Osteoarthritis and spinal conditions impeding exercise
- Heart and lung conditions causing breathlessness and impeding exercise

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Participants used similar combinations of coping strategies in living with chronic conditions as they used to cope with T2D. These approaches inter-linked in complex ways that were unique to the individual.

Participants' attitudes to their co-morbidities varied from coping stoically to depression. Both Ray and Will were smokers, but their faith influenced them to quit. Mary, despite living with continual pain stated,

'And when I'm feeling a bit sorry for myself, if it's a bit painful I stop and think, "I've got nothing to grumble about!"' (2/881)

which contrasted with Ange's comment that 'life's shite when you get old' (1/30) and Will, who was depressed about his multiple co-morbidities. Ray alleged medical mismanagement of labyrinthitis led to him falling and subsequently requiring neck surgery, which now impeded his mobility. His coping strategy was to keep written notes of his medical appointments, which gave him a sense of control. His attitude contrasted with the approach taken by Will, who used avoidance strategies with his T2D and co-morbidities. When feeling low, Will avoided taking his medicines. Sometimes he lied to friends when they telephoned nightly to confirm he had taken them, and when offered bariatric surgery he said it 'took the weight off my shoulders' (2/555).

It is possible that co-morbidities may affect coping styles, such as Will's sleep apnoea that caused chronic sleep deprivation. Lack of sleep is linked with reduced utilisation of glucose and appetite regulation leading to obesity (Knutson 2007), reduced cognitive performance, and may affect motivation. Motivation is defined differently by researchers, but Herzberg (1968) defines it as satisfaction or dissatisfaction of an individual before he or she makes a decision. According to Chan et al. (2018) motivation is a factor on the choice of coping strategy. Based on Vroom's expectancy theory (1964), Chan states that individuals assess if the planned outcome is worth the effort required to attain this, then they will be motivated to work towards this. Will's fear of

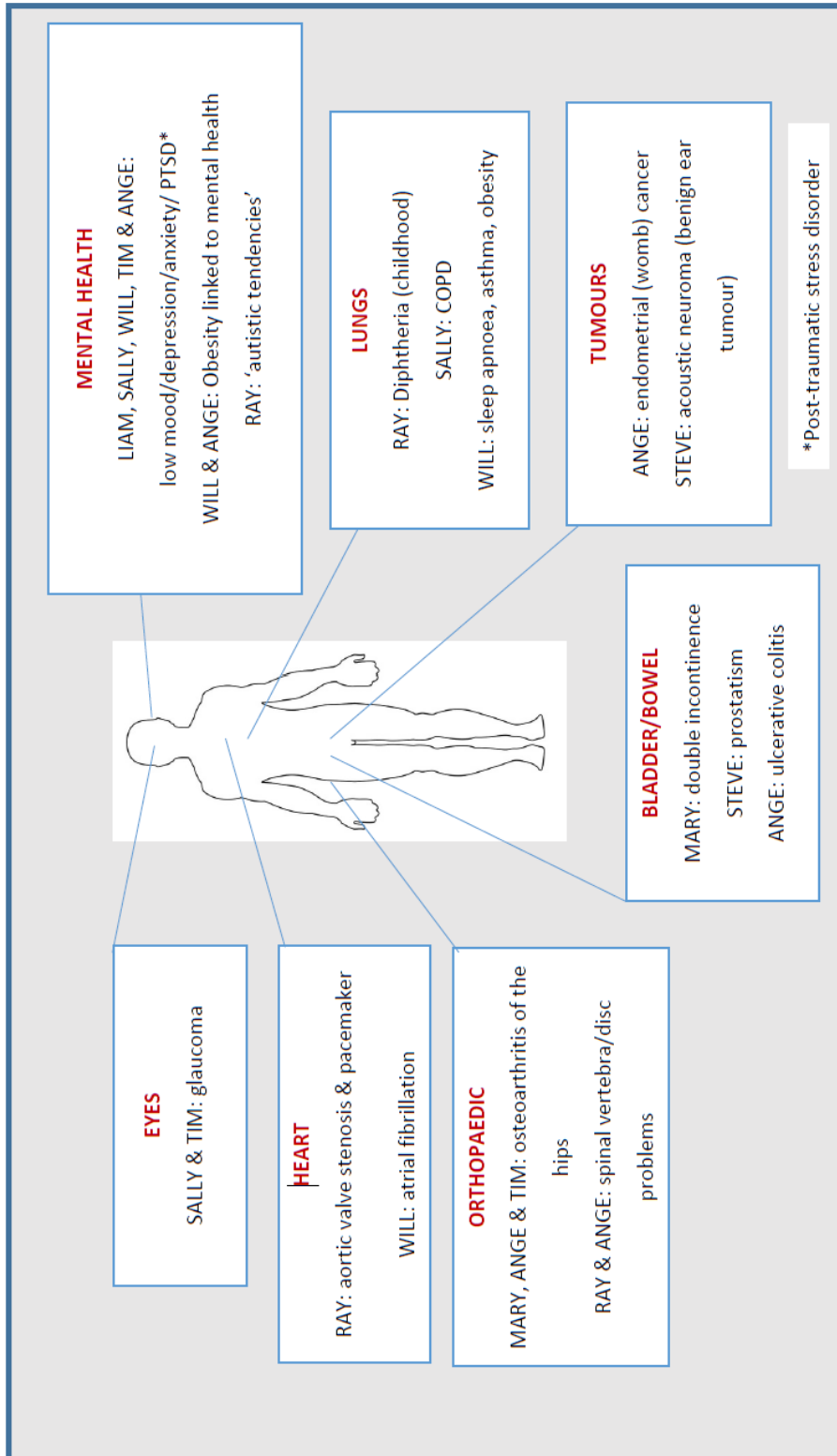


Figure 11: Co-morbidities of participants

losing weight coupled with sleep deprivation increased the likelihood of choosing negative emotion-based coping such as binge eating. Sleep apnoea is linked to poor mental health (Erman 1994; Lavie et al. 2009; Hashmi and Khawaja 2014; NHS 2016b) and Engle-Friedman (2014) states that sleep deprived adults have increased consumption of fast food/restaurant food, and are less likely to cook at home. Dingemans et al. (2017) found binge eating associated with anger, sadness and loneliness. Will's poor mental health may have been exacerbated by his sleep apnoea, and linked with his poor motivation and binge eating. Both Will and Ange' binge eating fuelled increasing obesity and 'obesity shame'.

### 5.5.2 Gratitude

Emmons and McCullough state that gratitude has been conceptualised as 'an emotion, an attitude, a moral virtue, a habit, a personality trait, or a coping response' (2003 p377) and is linked with good mental health (Emmons and Crumpler 2000; Emmons and McCullough 2003; Koenig 2018). Participants expressed gratitude for their lives, medical attention, family, jobs, nature, help of others, their independence, and some Christian participants felt thankful for the Providence of God. All participants except Will expressed positive psychological characteristics such as optimism and gratitude. Christian participants had a belief that they were either 'loved'/'favoured', 'looked after' by God or 'lucky'. Of the SBNR participants, Tim saw himself as 'fortunate' (Tim:1/626) and Steve expressed pleasure at his life. A positive focus enabled participants to interpret the challenges in life as something they were able to cope with. Mary expressed the most gratitude, and both Mary, Sally and Steve appeared the most stoic of all participants. When having to quit ice-skating that she loved, Sally focused on the benefits of saving money. Mary thanked God daily for her life 'as it is' (i.e. including the difficulties) (1/200). She minimised the pain caused by severe osteoarthritis, and believed that people were 'recompensed' in some way if you suffered (1/801). Her gratitude was directed vertically:

'Well, just thankful for all I have and all I've got I suppose really. It's all due to Him [God]' (2/699).

Both Mary and Liam considered their suffering was less than others, and interpreted this as Providence. Liam overcame the 'grief' caused by his diabetes diagnosis, believing that one had to 'work towards happiness' (1/1213). He was thankful for diabetic medication, choosing to use the term 'medicine' instead of 'drugs' as he felt the word had healing connotations. Fostering gratitude has been used as a psychotherapeutic tool to improve mental health (Emmons and

Stern 2013), and Liam used this approach to see the beauty in his life. After his spiritual encounter, he cultivated gratitude:

‘I suppose it’s the fear of that, that, that kind of doom, that sense of –um [sniffs] negativity that I don’t want to go down that -I know so - I will - and also, um (1) since I’ve kind of um (1) - early days I suppose. But since I’ve started working, towards happiness, you know, realising I have to put an effort to make happiness, it makes me happier! [Chuckles] You know, it works! (1/1231). Yeah. I think that’s what motivates me: the fear of the doom and the joy of the happiness!’ (1/1242)

Steve stated he ‘was probably sleepwalking into a heart attack or stroke’ (1/372), but the T2D diagnosis combined with his problem-solving approach led to healthier lifestyle choices. Both the SBNR participants expressed thankfulness regarding the diagnosis of diabetes:

‘it sounds a *ridiculous thing to say*, but with hindsight, this [diagnosis of T2D] has been maybe a blessing in disguise.’ (Steve:1/187)

‘Thank you cholesterol; thank you diabetes, you’ve made me – you’ve made me a better person, in thinking that you know, I ain’t going to eat sausages with that much um saturated fats in it. I’m not going to eat whatever with half a ton of glucose – er – er salt in it.’ (Tim:1/695)

Tim described himself as being ‘fortunate’ many times in the first interview, mainly in relation to his T2D, and stated his healthier lifestyle had saved him money. The positive cognitive reappraisal of the diabetes diagnosis by the SBNR participants linked to both their primary stress appraisal of ‘challenge’. Although Liam’s stress appraisal was ‘loss’ at diagnosis, this appraisal changed to ‘challenge’ as he learnt to live with T2D. Having an optimistic approach to T2D assisted all participants to make dietary and exercise changes, but this did not help all participants to sustain the changes over time (e.g. Sally re-gained lost weight).

As participants progressed past diabetes diagnosis to adapting to living with T2D, coping strategies included being optimistic, seeing oneself as ‘lucky’/‘blessed’/‘fortunate’, focusing on joy, support from others, and for the Christians, feeling God’s love and believing God ‘allowed’ illness. In this study, gratitude was not measured. However, Will expressed low mood the most, was the least grateful, yet received the most instrumental support. The instrumental support was linked to spiritual relationships – care given by Christian friends who perceived it as part of their expression of faith, so appeared to be linked more to their faith, rather than Will’s faith.

### 5.5.3 Religious-based coping

According to Pargament et al. (2004 pp714) religious coping (RC) includes 'active, passive and interactive methods, encompassing emotion-based and problem-based coping, including cognitive, behavioural and spiritual approaches.' Positive RC strategies reflect a positive relationship with a benevolent transcendent force, others and a positive world view, whereas negative RC methods reflect the opposing view: spiritual tensions and struggles within oneself, others and the Divine (Koenig et al. 2001; Pargament et al. 2011; Koenig 2012 (Appendix V)).

In this study, secondary appraisals (Folkman 2013) resulted in Christian participants using positive RC. Participants used positive cognitive reappraisal to give strength and fortitude, e.g. Mary's comment that 'I thank the Lord every day, and I still do for my life as it is, because it could be a lot worse' (2/200). In addition, RC strategies such as prayer, meditation, music, quietness and reflection, connection with a church, seeing God as Providential and reading Christian texts increased their sense of well-being, hope and ability to cope. Most Christian participants found that God was a source of comfort and strength, especially if they experienced low mood. Exercise in the form of walking alongside prayer had positive benefits on mood. Some Christians found their faith helped them to quit smoking, cope with pain, cope with the complications of T2D, and accept the challenges in their life with a positive attitude. It influenced some participants to *choose* to cope, to choose joy with Liam's comment that 'laughter is good medicine' (1/1073). The key component of their religious coping was that they saw themselves as being in a dynamic relationship with God with themselves as the major actor. Although Mary expressed that it's 'all due to Him [God]' (2/699) this linked to her belief that God expected her to cope. All the Christian participants, including Will, echoed this. Her belief in God's plan for her life enabled her to 'accept' challenges in life (1/240). She saw herself as a co-partner with God in managing her diabetes:

'But I think all these things are sent to try us. And try our will power. I mean people say "Well why did He [God] let it happen?" Because God gave us will power. And it's your own will power that dictates whether you cope or you don't cope.' (1/225)

Liam's cognitive reappraisal that was borne out of his spiritual experience enabled him to accept that he could cope with T2D, because God was with him. There was a marked contrast between Liam's two interviews. In the first one, he struggled to believe God cared for him, but in his second interview, he explained that his spiritual experience rejuvenated him so that he felt 'favoured' by God (2/671) and felt God was with him:

'I guess the, the feeling [God communicating love to him] was that I was getting was that *no matter what happens*, um (2) whether it [T2D] reverses or whether it stays in me or gets worse, whatever is gonna happen from now on, I didn't have to feel so alone, you know.' (2/456)

Sally lived with anxiety, but found God helped her 'stop worrying', giving her strength to cope with managing her diabetes:

'but ever since I became a Christian I've always felt the presence of the Holy Spirit and when I'm very down and I can't feel the presence of the Holy Spirit – that's when I really get down on my knees and pray and it all just comes back to me and I'll get a verse or something, you know.' (2/182)

'Getting a verse' (2/185) referred to the Holy Spirit directing Sally to a Bible verse that would encourage her. Mary, Liam, Sally, Will and Ange believed that God influenced their thoughts through reading the Bible, or directly communicating with them, or through others to strengthen their ability to cope. Will held that God gave him a strategy to quit smoking, and Ange requested God's help daily as she battled with food choices:

'And I'll have the conversation, "Okay God, help me out here. I've done it again! [eaten unhealthily]. Tie my hands behind my back when I go to the supermarket, please?"' (2/538).

Although the Christian participants believed that God 'allowed' ill health, this did not result in negative RC but appeared to foster increased resilience and hope. Will was the only participant with significant maladaptive coping, which did not appear to be related to RC but his linked to his depression, co-morbidities, sleep apnoea and obesity.

## 5.6 Responsibility influences the self-management of T2D

Except for Will, all participants believed it was their responsibility to manage their T2D by eating healthily, exercising, monitoring alcohol intake, monitoring and managing blood sugars, foot care, and attending appointments. Assisted by family/friends, they sought information from HPs, internet sources/Diabetes UK and acted on advice. Their attitude towards responsibility of their diabetes was evident from diagnosis, and appeared to remain static from diagnosis through to learning to live with T2D, e.g. Liam exhibited responsibility for his SMB that remained constant,

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despite his spiritual struggle. Believing that the complications of T2D could affect *them* was a motivator to engage in self-management for participants. Ange stated:

‘there’s nobody else who will do my life for me. I don’t want to pop my clogs at sixty’  
(1/431)

Tim held that people were responsible for their healthcare choices, stating ‘You’re in control of your own destiny’ (1/68). He believed that ignoring medical advice could lead to serious complications:

‘Well, ok, it is your life, and you can do whatever you like with your life. But you’ve got to pay the consequences. Your decisions, right -? Your decisions, your decisions. You can decide.’ (1/149)

Some participants expressed strong opinions about those who ignored medical advice regarding the SMB of T2D. Liam expressed frustration about people failing to engage with treatment:

‘I discover more and more about people who, who have diabetes, and they don’t do anything about it! [Said in an incredulous voice]. And I completely get now why the medical profession has to deliver these horror stories, you know, because otherwise people just won’t understand, I mean they, they, ah! I’m constantly um, er, shocked I suppose by people who don’t take responsibility for this problem you know, and I, I, I’m thinking, ‘Wow, what’s *wrong with you?!* It’s not the doctor who’s gonna lose their feet – *it’s you!* You know, *you’re gonna* have your kidneys fail or you’re gonna have these issues happen unless you *do something about it!* (Liam:2/289)

‘I’m disgruntled about the fact that I’ve got diabetes but I’m not gonna *pretend it’s not there*, you know’ (2/301)

Tim was emotional, expressing frustration that his father ignored medical advice, resulting in an early death. He stressed the importance of listening and acting on medical advice, and the dire consequences if ignored. Problem-based coping resulted in his regular weight monitoring, and regulation of alcohol intake. Tim feared death if he drank too much, and Ange worried if she failed to address her diet, she risked death or toe amputation.

Some Christians believed God enabled them to take responsibility. Mary ‘relied’ on her faith (1/553) stating that it helped her cope with her heart attack. She held that people should be responsible to look after their health as God enabled people to cope by giving them ‘strength to carry on’ (1/297). This might occur through other people, such as the diabetes specialist



nurse being 'led' to her (1/402). Mary took responsibility in managing her diet and complex medicines regime stating:

'it's not good fighting that, I mean, just go along with it and do your best' (1/242).

Some reduced responsibility was evident in participants' behaviours. Although Sally immediately started dieting and exercising on diagnosis, she continued smoking despite the health risks. However, when the alternative of vaping was offered, she swapped smoking for vaping. Will's approach to his T2D was different to the other participants; he put most of the responsibility for his health and well-being on others. His multiple co-morbidities including anxiety, depression and PTSD appeared to influence his reduced responsibility towards his diet and medicines. He was too obese to exercise, or to bend down to care for his feet, or clean himself post bowel evacuation - the reason for which the council were installing an automatic toilet. Will appeared powerless to change his diet; his binge eating was triggered when he felt sadness regarding his mother's death. He was seeing therapists to prepare for bariatric surgery, yet feared losing weight. Rather than trying to lose weight, he commented 'I eat anything' (1/257) and felt no responsibility towards managing his diet. He described eating puddings:

'the cook, said to me "... it's - Um - apple crumble and custard for pudding, what are you going to have?" and I just looked at her and said, "Extra insulin!" [laughs loudly]' (1/255)

His morbid obesity resulted in difficulty in mobilising, depression, shame and avoiding going out, all of which became a cycle with Will avoiding responsibility for his health and asking, 'What's the point of my life?' (2/746).

### 5.6.1 Diagnosis of T2D

All participants described their response to the T2D diagnosis, and their approaches to taking responsibility for their T2D. Mary and Will were unwell, attended urgent GP appointments and commenced insulin; Will required hospitalisation but discharged himself to care for his mother. Neither participant appeared shocked about their diagnosis. The remaining six participants underwent routine health checks, and all were unprepared for a T2D diagnosis. Emotions were shock, surprise, upset, worry, poor understanding, guilt, fear of the condition and of passing this onto children, and wondering why this had occurred:

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'I can't put in words how shocked I was...I think for me, (1) [tuts](1) when I first got diagnosed, my um (1) I am surprised I can talk about this now without crying because er, I've got to a stage where I can now but before, every time I mentioned it to someone, I just, I just - in fact I'm a little bit on the edge now, actually um, I just cry, 'cause I'm just so devastated' [at this point he starts to weep] (Liam:1/46;137)

Due to her nursing training, Sally expressed surprise at not recognising her pre-diabetic symptoms:

'I was just so shocked. (1) Yeah. I thought 'It couldn't happen to me!' [laughs] (Sally:1/233)

Despite being an investigator for medical insurance claims, Steve had little T2D knowledge:

'He [the GP] completely bamboozled me and said, "I think you're diabetic."...Um (1). I was completely – not in shock – but taken aback um. I didn't know (1) anything at all about diabetes.' 'Christ, it's happened to me!' (Steve:1/15,140)

The manner that HPs conveyed the diagnosis was important - Liam and Ange's GPs did not grasp the impact of the diagnosis:

'The GP who sent me the letter wrote on it, 'we have to label you diabetic' and I totally resented being labelled.' (Ange:1/11)

Liam felt his GP delivered the news poorly, and swapped to a new GP who offered hope. Ange appreciated her new GP setting challenges for her to take responsibility, such setting three new health routines before her next appointment. HPs who offered emotional and informational support were highly valued:

'The nurses I spoke to at [healthcare provider] were brilliant– you know I was on the phone in tears and they were *so good*, you know they were just um, they were amazing' (Liam:2/1392)

HPs gave participants written and verbal information about the condition of T2D, encouraged participants to take responsibility for their diet and exercise, and some encouraged participants to discuss problems regarding their SMB. In addition, six participants researched diabetes related

information on the internet and Diabetes UK that were specific to their problems, e.g. Ange researched about diet drinks triggering sugar cravings (Wang et al. 2016).

### 5.6.2 Diet of participants

Details of a healthy diet were outlined previously (Box 3). There is no 'diabetic diet', other than one that is low in fat and sugar, and synergises with people's culture, lifestyle, beliefs, values and preferences (NICE 2019a). Five of the eight participants acted on information from nurses, dieticians or Diabetes UK and improved their diet post diagnosis. Married participants ate with their families, who influenced their diet choices. Participants' diets fell into six types; those who had:

- an excellent diet (Liam, Steve)
- a good diet (Ray)
- a moderate diet (Mary)
- a moderate/poor diet (Sally, Tim).
- an alternating diet: (Ange had two extremes: an excellent diet, or a poor diet – it depended on her mood/motivation)
- a poor diet: (Will)

For some participants, weight management linked to diet and was self-monitored. Perception of the causality of diabetes affected diet, e.g. Ray already had a good diet, and did not alter this due to his perception of alcoholism causing his diabetes. During interviews, participants detailed an average day's diet, which were analysed against recommended dietary guidance, their hba1c and weight (Table 16 below). An example of recording a participant's daily diet is in Table 17 (below).

Table 16: Diet analysis compared to contextual data

**Key** Red: poor/moderate. Brown: moderate. Green: good/excellent

	Age (years)	Last body mass index (BMI) (Aim for 18.5-24.9)	Hba1c (target for this group would be around 48-58 mmol/mol)	Cooks themselves = C Cooks with partner = CP Partner does cooking = P	Diet analysis
Mary	89	26.4	83	C	Moderate
Liam	52	23.4	60	CP	Excellent
Ray	79	22.5	41	CP	Good
Sally	73	32	48	C	Moderate/poor
Will	56	62.6	74	C	Poor
Tim	68	30.9	57	CP	Moderate/poor
Ange	59	47.8	58	C	Moderate/poor (good vs. bad days)
Steve	65	24.8	49	P	Excellent

Steve and Ray both had good/excellent diets, reflected by in-target-range BMI and hba1c. Those with moderate/poor diet had out-of-target range BMI and hba1c, except for Sally, whose hba1c was within target range. It would be expected that Liam's excellent diet and in-target-range BMI would result in a good hba1c, but this was not evidenced. Mary's out-of-range hba1c is likely due to insufficient insulin doses.

Table 17: Ray's diet

**Key** Red: unhealthy diet. Brown: moderate diet. Green: healthy diet

	Breakfast	Lunch	Evening meal	Snacks	Comments
<b>Ray</b>	Always 'cornflakes, toast and margarine, marmalade, fruit juice, coffee' (2/155).	Soups and brown bread or leftover casserole from dinner last night for lunch.	2 portions veg with dinner. Desserts at weekend.	Mid- afternoon: cake. No other snacks in the day.	Likes to eat regimented set diet. 'Autistic tendencies'. Sugar in his coffee. Made no change to diet since diagnosis, <i>but reduced alcohol significantly.</i> Fortunately, he ate a fairly healthy diet before diagnosis.

Mary, Ray and Sally followed a traditional British diet, whereas Liam and Steve aimed for high fibre and low carbohydrate diet; they were the only ones who had the 5+/day recommended of fruits/vegetables. Tim checked 'traffic lights labelling' on food nutritional labelling to check for sugar and salt. For six participants, moderate/poor diet was connected to insufficient nutritional knowledge, depression/low mood, sugar cravings and reduced motivation to eat healthily. Tim stated, 'we don't eat crap food, not like I used to' (1/220). He took responsibility for his diabetes, and favoured a healthy lifestyle, but was unaware his diet was high in fat, and linked to his poor understanding of a healthy diet.

Although both Will and Ange both ate unhealthily, Ange was struggling to maintain a healthy diet stating:

'Oh how do I stop this – stop eating and drinking all the things that I really enjoy?'  
(1/59).

She acknowledged that childhood eating habits, guilt regarding poor eating habits, sugar craving and low mood all led to her 'pigging out' (1/775). On 'good days' she ate healthily but 'bad days' led to poor diet (2/268). Chapman and Ogden (2009) suggest one mechanism for dietary change

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is a 'trigger to action.' Ange stated her interest in this research was to help trigger motivation to change her diet.

Will only ate in the evenings, consuming large volumes to ease his depression and anxiety:

'it's nothing for me to order a large pizza, a rack of ribs, and a Ben and Jerry's tub of ice cream and eat the lot. And then half an hour later have a bowl of cereal....I don't take any notice of what I eat (1) as far as diabetes is concerned; I'll be absolutely honest.'  
(1:230,254)

Will expressed fear regarding weight loss. Although he agreed to bariatric surgery, he was 'dreading' seeing a Food Behaviourist (2/454) stating:

'I don't know how to be a thin person. And I don't know if they can teach you that'  
(2/482).

His attitude to diet contrasted with Liam, who declared: 'every minute of every day I think about what I eat' (2/330) and Tim who was 'consistently looking at [his] diabetes' (2/211). Those who tried to follow a healthy diet also exercised more than those who had a poor diet. Will had the worst diet and exercised the least, whereas Liam and Steve had the best diet and exercised the most, inferring motivation and self-efficacy were key for both diet and exercise.

Ray and Tim believed that their T2D diagnosis linked to their previous alcoholism. Kim and Kim (2012) have posited that high alcohol consumption deteriorates BG tolerance, increases insulin resistance and may cause T2D. The recommended alcohol intake is a maximum of fourteen units/week (NHS Choices 2018). On diagnosis, Ray reduced his drinking from seventy-two units/week to twelve units/week, and his hba1c returned to within normal limits. Tim initially became teetotal, but now aims to avoid drinking heavily as he considers this increases his mortality risk.

### 5.6.3 Exercise of participants

Regularly exercising aids BG control (NICE 2014, 2017, 2019; Diabetes UK 2018b), reduces risk of cardiovascular diseases (Goit et al. 2018) and improves mental health (NHS 2018). The NHS recommends 150 minutes/week of moderate intensity aerobic activity; both resistance and aerobic exercise have benefits (Oliveira et al. 2012). In this study, taking exercise refers to actively pursuing an activity such as walking outside, ice-skating and working an allotment; it does not refer to daily walking around a home.

Promoters of exercise for participants were motivation, free time and pleasant walking areas. Inhibitors were lack of motivation and other health conditions impinging on exercise; three participants (Mary, Will, Ray) were not able to exercise due to health conditions. If a person is using insulin, their dose may need to be adjusted to prevent hypoglycaemia<sup>37</sup> (Diabetes.co.uk 2019f). Mary and Will both used insulin, but Mary's osteoarthritis prevented exercise and required her using a mobility frame, and Will's obesity and breathlessness prevented exercise other than walking from one room to another. Ray's exercise had become limited in the previous 2-3 months due to leg/neck pain, and breathlessness caused by a heart condition for which he was awaiting surgery. Before these symptoms, Ray regularly walked, but now it was just occasionally. Tim experienced mild hip pain, but ensured he walked regularly with his wife. The sciatica, back pain and foot drop<sup>38</sup> experienced by Ange could inhibit her from exercising at times, and she used a walking stick on these occasions. She stated she was 'bone idle by nature' (1/512) but pushed herself to get out. Both Liam and Ange noted that exercise could improve mood, and Ange identified her diet improved post exercise.

The diabetes diagnosis led to changes in exercise for some participants: Sally re-started ice-skating resulting in significant weight loss, but a head injury caused her to swap ice-skating to dog walking, and Steve swapped his voluntary work from driving to walking, and his beach holidays to active holidays. The five participants who exercised favoured walking with family/friends and dogs; Ange combined walking with prayer. Tim cycled sometimes, Sally gardened and Steve managed an allotment. Attitude to exercise varied, with Liam believing due his diagnosis, it was 'his duty' to do a minimum of thirty minutes walking daily (2/1268) through to Ray who was the least knowledgeable about T2D, and did not connect exercise with SMB of T2D.

In the study analysing daily activity of those aged 18-64 years old of people in 22 countries, Fisher et al. 2010 found those adults in the UK spent 59 minutes daily walking/housework/gardening for all participants. In this study aerobic and resistance exercise was analysed, therefore 59 minutes was not included. Minutes that participants spent on aerobic/resistance exercising varied from zero to one hundred minutes daily, and the combination of exercise and diet resulted in BMIs ranging from 22.5 for those active with a good diet, to a BMI of 62.6 for the least active and a poor diet (Table 18).

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<sup>37</sup> Hypoglycaemia is when the blood glucose level drops below 4, and is dangerous (NICE 2019a).

<sup>38</sup> Foot drop is a muscular weakness (or paralysis) making it difficult to lift the front part of the foot and toes; it may cause dragging of the foot on the ground when walking (NHS 2016).

Table 18: Exercise of participants

**Key:** Red: under target. Brown: not within target, but is exercising. Green: within and over target

	Age	Aerobic or resistance exercise daily. Approximate minutes (mins)	Aerobic or resistance exercise weekly. Approximate minutes (mins)	Approximate distance walked	Body Mass Index (BMI)
Mary	89	0	0	-	26.4
Liam	52	60 mins	360 mins	-	23.4
Ray	79	Leg pain (Sciatica?) prevents exercise.	?	300 yards	22.5
Sally	73	0	Slow dog walk (60 mins) 2 x week = 120 mins	One mile per walk	32
Will	56	0	0	-	62.6
Tim	68	0	160 mins	-	30.9
Ange	59	0	Slow dog walk, 4 x week. mins =?	?	47.8
Steve	65	12,000 steps 100 mins	700 mins	5 miles	24.8

#### 5.6.4 Additional information: diabetic medicines

Chapter Two outlined the complexities of medicines adherence and concordance, and how it is a partnership between patients and clinicians. Because it is not solely under the control of the patient, medicines management was excluded from the research process. In the participants' contextual data requested from the GP, details of diabetes medicines were requested only to



facilitate understanding of their SMB of diet and exercise (e.g. if injecting insulin, this could affect diet/exercise), and to consider how well their diabetes control. It was anticipated that hba1c results would be consistent with participant's diet, exercise, BMI and medicines. However, Liam's hba1c was high (60) despite excellent diet and exercise, and Sally's hba1c in-range (48) despite lower levels of exercise and a raised BMI. As this was unexpected, the side effects of their medicines were analysed - but this did not explain the anomalies (Table 19).

Table 19: Hba1c anomalies

Pseudonym	Hba1c	Diet	Exercise in minutes (mins)	Body Mass Index (BMI)	Years Since diabetes diagnosis	Diabetic medicines
Liam	60	Excellent	60 minutes daily	23.4	2	Gliclazide: causes weight gain  (but his BMI is good)
Sally	48	Moderate /Poor	Slow dog walk 2 x week. 60 mins weekly.	32	15	No side effect of weight gain from any medicine (so not causing ↑ BMI)

Following this, it was decided to analyse all participants' medicines against their diet, exercise, BMI and medicines to check for anomalies (Table 20 below).

Table 20: Diabetic medicines of participants

**Key.** Red: under/over target. Brown: not within target, but is exercising. Green: within and over target. Insulin is measured in international units (iu)

	Hba1c	BMI	Participants' medicines for T2D	Side effects of medication on weight
<b>Mary</b>	83	26.4	<ol style="list-style-type: none"> <li>1. Abasaglar insulin in morning (+/- 37 iu)</li> <li>2. Humalog BD (3 iu before breakfast and</li> <li>3. 2 iu before lunch)</li> <li>4. Statin (to reduce cholesterol)</li> </ol>	Insulin: causes weight gain
<b>Liam</b>	60	23.4	<ol style="list-style-type: none"> <li>1. Metformin</li> <li>2. Gliclazide</li> <li>3. Statin (to reduce cholesterol)</li> </ol>	Gliclazide: causes weight gain
<b>Ray</b>	41	22.5	<i>Diet controlled – no diabetes medicines</i> <ol style="list-style-type: none"> <li>1. Statin (to reduce cholesterol)</li> </ol>	N/A
<b>Sally</b>	48	32	<ol style="list-style-type: none"> <li>1. Metformin</li> <li>2. Saxagliptin</li> <li>3. Statin (to reduce cholesterol)</li> </ol>	No side effects on weight
<b>Will</b>	74	62.6	<ol style="list-style-type: none"> <li>1. Novorapid: 10-25iu when eats.</li> <li>2. Lantus: 76iu at night</li> <li>3. Metformin</li> </ol>	Insulin causes weight gain
<b>Tim</b>	57	30.9	<ol style="list-style-type: none"> <li>1. Metformin</li> <li>2. Statin (to reduce cholesterol)</li> </ol>	No side effects on weight
<b>Ange</b>	58	48.7	<i>Diet controlled – no diabetes medicines</i> <ol style="list-style-type: none"> <li>1. Statin (to reduce cholesterol)</li> </ol>	No side effects on weight
<b>Steve</b>	49	24.8	<ol style="list-style-type: none"> <li>1. Metformin</li> <li>2. Statin (to reduce cholesterol)</li> </ol>	No side effects on weight

Except for Liam and Sally, analysis of participants' hba1c correlated with their BMI, diet and exercise, and medicines adherence accounting for medicines that may cause weight gain/loss.

All participants evidenced a responsible focus towards managing their medicines, except for Will. Explanations he gave were low mood (1/375), being annoyed at having to take medicines (1/379) and 'catastrophising' (1/388). Other participants took medicines to be 'responsible' (Mary:1/442), to 'feel safe' (Liam:1/718) and used a system or 'dosette box' to ensure they remembered (Sally:1/133). Liam declared:

'it's absolutely up to me to make sure that I know, and take the medicines' (2/634).

In this regard, participants taking their medicines was linked to responsibility, but not spirituality.

## 5.7 Summary

This chapter has discussed the robust analytic strategy. The complex and unique spirituality of participants, including their spiritual practices has been described, and justification was given for labelling participants as 'Christian' or 'SBNR'. All participants used combinations of problem-based and emotion-based coping. Most Christian participants also used positive religious coping, despite their relationships with God linked to fatalistic beliefs. The spiritual and health beliefs of Christian and SBNR participants influenced their coping, and those who combined it with a positive approach exhibited positive coping strategies. Family and friends influenced all types of coping. Maladaptive coping was evident with one participant, which negatively affected taking responsibility leading to poor SMB. Most participants assumed responsibility for managing their diet, exercise and medicines, even when the management of other co-morbidities sometimes competed with self-management of their diabetes. The spirituality, health beliefs, coping styles and sense of taking responsibility all influenced participants' SMB of T2D. The next chapter will consider how these findings sit within the wider context of the relevant literature.



## Chapter 6 Discussion

### 6.1 Introduction

The aim of this study was to explore how the spirituality of a group of people with T2D, living in England, influenced their coping and self-management of their condition. The sample size was small compared to other studies regarding spirituality influencing the self-care of T2D (Jones et al. 2006; Thinganjana 2007; Polzer and Miles 2007 (Appendix U); Harris 2008; Polzer Casarez et al. 2010; Cordova 2011; Bhattacharya 2013; Lundberg and Thrakul 2013; Gupta and Anandarajah 2014). The sample size was chosen as this also matched the requirement of a clinical doctorate, and studies using the BNIM usually have smaller samples (See Sampling and recruitment).

Chapter 2 met the first two study objectives (Box 2), describing why T2D diabetes is a complex condition with multiple care processes, and that this study focused on analysing diet and exercise. Firstly, T2D was described within the global and national context. The self-management of diet (Box 3) and exercise were detailed, with a brief overview of the role of medicines for T2D. Secondly, the lack of consensus regarding the definitions of spirituality and religion was discussed. Various categories of spirituality, including 'spiritual but not religious' (SBNR) were outlined, and a model was created to demonstrate the overlap of spirituality and religion (Figure 1). After discussion of spirituality within the healthcare context, a definition of spirituality for this study was given (Figure 2).

Chapter 3 detailed two literature reviews. Firstly, the review of 'T2D and spirituality' found that many studies focused on African Americans, and that 'spirituality and T2D self-management' were influenced by ethnicity, gender, CAMP and coping styles (Figure 4). Secondly, a review of 'Religious coping and T2D', found all religions, ethnicities and genders utilised both positive and negative religious coping (RC), and RC influenced beliefs in the causality of T2D and the SMB of T2D. In both reviews, limitations of studies were the poor definition of some terms, transferability of research across healthcare organisations/countries due to variations of healthcare funding, and some studies not reporting hba1c values, giving limited validity that spirituality assisted T2D control. Chapter 4 discussed the study design, noting research paradigms. A rationale for using a constructivist approach was given, and the philosophical assumptions for this study were made explicit. The BNIM, TA and the research process were justified, and reflexivity, bias and ethical aspects addressed.

Chapter 5 met the last two study objectives (Box 2) describing the analytic process and results, revealing how participants' spirituality influences their coping with T2D, and their SMB of diet and

exercise. Three overarching themes that related to the research objectives were created: spirituality influences expectations in life; beliefs influence coping styles in the self-management of T2D, and responsibility influences the self-management of T2D.

This chapter will consider how the findings fit within the wider context of published literature, unexpected findings and limitations of this study. Finally, to ensure the study meets the criteria for quality research, the study is evaluated with the model by Tracy (2010).

### **6.2 Models of spirituality and type 2 diabetes**

There are various models to address spirituality and healthcare such as the FICA model (Puchalski and Romer 2000), the SPIRIT model (Maugans 1996) and the HOPE model (Anandarajah and Hight 2001) but a paucity of models addressing spirituality and self-management of T2D. As this was an exploratory study, it was not known how British participants' spirituality may influence their diabetic self-management and the data was not 'forced' into a theoretical model. However, some findings echoed with elements of Polzer and Miles (2007, Appendix U) model, which was conceptualised according to African Americans' culture, history and spirituality and the self-management of T2D. Findings also linked to Keonig's model (2012) regarding religion, spirituality and health (Appendix V) but specific attributes of Koenig's model such as mental health data were not specifically sought in the interviews. The findings as a whole however, did not fit neatly within any one model.

### **6.3 Spirituality influences expectations in life**

In this study, spirituality was significant for all participants, but had a wider influence over Christian participants lives, e.g. SBNR participants did not have a relationship with a Deity/deity/Higher Power/supernatural beliefs that influenced their interpretation of their challenges, and had fewer spiritual practices than the Christians had. In the literature, many studies recruited from religious settings, such as churches or an identified religious pool (e.g. practising Buddhists) resulting in all participants having the same religious affiliation. Similar to the findings of other studies, the main spiritual practices used by participants in this study included prayer, religious reading, the importance and significance of church, having good relationships and appreciation of nature. However, participants in the present study did not describe CAMP use, e.g. traditional /folk medicines , spiritual/alternative healers, plants/herbs/nutritional supplements, acupuncture, massage or hypnosis, as was found in other

studies (Egede et al. 2002; Meetoo & Meetoo 2005; Popoola 2005; Amirehsani 2011; Ben-Arye et al. 2011; Bhattacharya 2012; Unantenne et al. 2013).

### 6.3.1 Spiritual practices

To some degree, SBNR participants found their family relationships gave comfort and strength in similar ways that Christian participants enjoyed from their spiritual connections. Eating with and cooking for family was spiritually meaningful for the two SBNR participants, and nature was important for many participants. The study by Gupta and Anandarajah (2014) regarding spirituality and T2D with mostly Caucasian participants in New England included religious and non-spiritual participants: two-thirds were Christian, approximately a third had no religious affiliation and around 5% were Jewish. Themes were the effects of diabetes, motivators for self-management, sources of strength and hope, spirituality in illness, relationships, nature and relationship with God. The authors found the fear of complications was a bigger motivator for self-management rather than spirituality.

Consistent with other studies, the most commonly used practice for the Christians in this study was prayer, which gave comfort and strength; and religious reading also gave spiritual encouragement. Contrary to some studies (Jones et al. 2006; Polzer and Miles 2007 (Appendix U); Polzer Casarez et al. 2010; Lundberg and Thrakul 2011, 2013), participants did not forsake self-management believing prayer would heal their T2D. Christian participants were mostly Anglican, and although some Anglican churches offer prayer for healing (Jones 2016) generally Anglicanism promotes the healing ministry of the church in a supportive role (Dhas 2016; International Anglican Family Network 2017). Anglicanism appears not to promote God as a healer (Carson 2008) in the way some American churches were found to in the literature.

This study found participants' church connection was the least used to foster diabetes self-management, which contrasts with some studies that identified the church involvement was key for the SMB of T2D for African Americans (Hamadeh 1987; Cagle et al. 2002; Polzer and Miles 2005; Lager 2006; Popoola 2005; Harris 2008; Newlin Lew et al. 2016; Permana 2018). Namageyo-Funa et al. (2015) suggest that Black American men were less likely to seek church support than women. In their study regarding RC influencing health behaviours with British Christians, Brewer et al. (2015) found that religious coping and religious social support had positive effects on depression and belief, giving resistance to ill-health, but negative religious coping predicted higher alcohol consumption. Although participants in this study talked about the private and personal importance of church, the sense of community and support that was evident in studies with African Americans was lacking. The Pew Research Center (2019) states that African

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Americans are 'markedly more religious' than the American population as a whole, with 70% identifying with a church (Franklin et al. 2007). The spirituality and cultural identity of African Americans (Belgrave and Allison 2006; Amar et al. 2015), the sense of community within Black churches (Lew et al. 2015) and the distrust of the medical system (Bhattacharya 2012) are likely all contributors to the significance of the church supporting African Americans with self-management of T2D. In addition, those with no medical insurance may have no access to diabetes education. In their study with rural African Americans, Utz et al. (2006) found that 56% had not received diabetes education, which highlights the significant role of churches providing diabetes education.

In the UK, whilst some churches offer nursing support (Parish Nursing Ministries UK 2019), specific diabetes education resources are not offered as occurs with some African American churches. Ward commented in 2001 on the increase in private spirituality in the UK, and the British Census (ONS 2011b) confirmed this with a 13% fall in church attendance since 2001. Davie (1994) posits that over recent decades there has been a rise in 'believing without belonging', as was seen in this study by some participants who very occasionally attended church. It may be that the high prevalence of T2D in African Americans and their cultural identity fosters a greater sense of community, which contributes to the importance of the church in supporting diabetes self-management. In contrast, British people in this study did not discuss community connections encouraging their spirituality; it appeared to be more private than African Americans' experience. It has been commented that the British, especially the older generation (Khor and Marsh 2007) are emotionally reserved (Walter 1997) which may be associated with this finding.

African Americans also looked to the church due to distrust in their medical system. There is a paucity of evidence to suggest that British people with T2D distrust the NHS as noted with African Americans (Thomas & Quinn 1991; Bhattacharya 2012; Newlin et al. 2012; Lew et al. 2015) causing them to turn to the church. In contrast, this study found participants highly valued the NHS which is consistent with public opinion (King's Fund 2017), and they strongly promoted judicious use of its resources and valued HPs.

The literature revealed that many African Americans looked to God for healing due to the cost of American healthcare. Many studies either recruited Blacks of low income (Polzer and Miles 2007 (Appendix U); Cordova 2011; Namageyo-Funa et al. 2015b) or analysed income of African Americans (Newlin et al. 2003; Popoola 2005; Utz et al. 2006; Hart and Grindel 2010; Hames 2010; Newlin et al. 2010; Watkins et al. 2013). In this regard, the funding of healthcare between American studies and this study cannot be compared. It may be why these British participants, who receive free medicines did not use CAMP as other American-based studies have found, where cost of healthcare was cited as a factor. Participants did not use any



complementary/alternative medicines, and it may be that British Christians use CAMP less than other spiritual groups that promote alternative medicines such as New Agers (Crabtree 2018).

### 6.3.2 Relationship with God

In this study, participants' relationship with God was influenced by their belief of His character, which influenced their relationships with others. A benevolent view of God resulted in seeing Him as loving them and assisting them with life's challenges, including diabetes self-management. Positive reappraisal of negative events linked to participants' positive view of God. Likewise, the quantitative systematic review by Koenig (2012) of religion/spirituality on mental and physical health found religion/spirituality facilitated coping because negative events were imbued with meaning. Similar to other studies, participants in this study found that God provided strength, support, guidance and resources to cope with diabetes (Jones et al. 2006; Polzer and Miles 2007 (Appendix U); Cordova 2011; Namageyo-Funa et al. 2015; Heidari et al. 2017; Heidarzadeh and Amohammadi 2017; Saidi et al. 2018). Similar to some Muslims (Heidarzadeh and Amohammadi 2017; Saidi et al. 2018) Cordova found some Christians participants believed T2D was a 'test' – but this was not evidenced in this study. However, participants in Cordova's study believed that 'God does not put anything more than one can handle' (p82), which was echoed in this study. According to Koenig (2008), religious beliefs and practices in the Christian worldview provide a positive framework for individuals to interpret stressors. However, this is only likely if individuals believe God to be benevolent and responsive to individuals' needs.

With regard to God assisting with diabetes self-management, this study found participants saw God as an enabler, assisting them to manage their T2D; or God as the authority figure determining their life, or considered God was benevolent, but did not personally request His help. Polzer and Miles (2007; Appendix U) detailed some of these views with African Americans who managed their diabetes via 'a relationship with God'. With Group 1, participants believed that God helped them to perform good SMB related to T2D; self-management was emphasised rather than faith. In Group 2, participants believed that although God helped them with self-management they were submissive to His will, and any positive outcomes attributed to God. In Group 3, participants believed that if they had enough faith, self-management was not necessary because God would heal them. Aspects of Group 1 and 2 were echoed in this study, but no participants *abandoned* self-management believing that God would heal them as in Group 3. Due to the prevalence of T2D in African Americans and Asians, some studies found participants

anticipated a T2D diagnosis, and religious fatalism facilitated acceptance (Saidi et al. 2018) but in contrast, most participants in this study were surprised by their diagnosis.

## 6.4 Beliefs influence coping styles of the self-management of T2D

In this study, participants' health and spiritual beliefs influenced their coping strategies to manage their T2D, their co-morbidities and significant life occurrences (e.g. flooding of the home). Their health beliefs included knowledge of T2D and its self-management and beliefs about the NHS. These linked with their spiritual beliefs and the spirituality of family/friends. These beliefs overlapped and promoted various coping strategies.

Participants created meanings from their T2D experience, which influenced their coping strategies. Frank (2013) describes three narrative types that ill people use in creating illness stories, where stories may embody all or some of the narrative types:

- 'Quest', where the plot is a journey through ill health to something that is 'gained through the experience' (Frank 2013 p113)
- 'Restitution', where the plot focuses on having health, losing health and future health
- 'Chaos', where the 'plot imagines that life will never get better' (Frank 2013 p97)

Six participants' stories linked to Frank's types. The SBNR participants most strongly linked to 'Quest', as they created healthier identities for themselves through active coping. Liam, Sally and Ange's narratives related to 'Restitution', where they recognised current health problems but remained positive about their ability to cope and create future health. Will was entrenched in 'Chaos', where he could not find meaning in his suffering, and used maladaptive coping strategies. Meanings ascribed by Christian participants linked more clearly to their relationship with God and will be discussed within the Religious coping section (6.4.3).

### 6.4.1 Maladaptive coping

Maladaptive coping included comfort eating and binge eating and linked to depressive symptoms. Previous studies have shown that avoidant and negative emotion-based coping are less successful at controlling T2D (Peyrot et al. 1999; Garay-Sevilla et al.2011), has been linked with greater depressive symptoms, reduced emotional well-being (Al-Amer et al. 2015) and poorer T2D control. According to Diabetes.co.uk (2019c, 2019e), depression is the most common psychiatric disorder with T2D, and is present in 50% of binge eaters.

In this study, binge eating occurred with 2 participants who lived alone. It is recognised that eating disorders<sup>39</sup> are higher in those with T2D than the general population (Philpot 2013). Papelbaum et al. (2005) found that 10% of Brazilian T2D patients binge ate, and patients with eating disorders were more likely to be White, unmarried and have higher BMIs than those without eating disorders. Ryan et al. (2008) found that 27% of French men with T2D were binge eaters and Diabetes UK (2019b) state that 10% of people with T2D have an eating disorder. The systematic review by Abbott et al. (2018) found binge eating and night eating syndrome resulted in higher BMI, but no statistical difference with hba1c. In the meta-analysis of social support and patient adherence to medical treatment by DiMatteo (2004) greater success was seen in married individuals than those unmarried, which contrasted with the study by Gallant et al. (2007) which found for those with arthritis/T2D/heart disease, more negative influences occurred from family rather than friends. In this study, the 2 participants who described pathological eating also had similar factors of depression, high BMI, were not married and found friends rather than family were supportive.

#### 6.4.2 Active coping

Participants used emotion-based and problem-based coping to actively manage their T2D, e.g. supportive relationships with HPs increased their diabetes knowledge, and participants sought out additional T2D information that influenced healthier dietary choices. In the systematic review of diabetes related information seeking, Kuske et al. (2017) found that HPs and the internet were frequently used to source information regarding diet, exercise, medicines and complications, and other studies cited friends/family. They noted that although patients with T2D and other chronic diseases valued HPs highly as an information source, people with T2D and cancer often needed to search for additional information. Patients gathered information passively (e.g. a by-product of their activities, such as watching TV) or actively (e.g. searching on the internet) with more educated people seeking information from complex sources, e.g. using NICE websites.

In the study by Utz et al. involving rural African Americans with T2D, participants were 'working hard' (2006 p199) to address diet, exercise and taking medicines. They used combinations of problem-based, emotion-based and religious-based coping for the SMB of T2D, but believed

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<sup>39</sup> Eating disorders comprise binge eating disorder, anorexia nervosa, bulimia nervosa and unspecified eating disorders, e.g. purging disorder and night eating syndrome (Diabetes UK 2019b)

diabetes education was essential to achieve this. With regards to active coping with T1D and T2D in Ireland, Collins et al. (2009) found 3 coping styles and strategies that related to the value participants placed on their health. Group 1: placed high value on their health and used active coping. Group 2: were passive, but followed advice from HPs, and Group 3: who placed low value on their health, took minimal responsibility for their diabetes, and were in denial about the consequences of poor SMB. Most participants in the present study placed high value on their health and tried to motivate themselves towards SMB of T2D.

In this study, participants' emotion-based coping included seeking joy, using humour and fighting negative thinking. Participants' personality disposition linked with positive emotions such as optimism and feeling gratitude for strength to cope, healthcare, family life and material goods. Only SBNR participants expressed gratitude for the diagnosis itself. Studies demonstrate associations between gratitude and indicators of subjective well-being such as life satisfaction (Elosúa 2015; Lau and Cheng 2017). Gratitude is also inversely related to negative emotions (Lau and Cheng 2017) and depressive symptoms (Emmons and Shelton 2002; Emmons and McCullough 2003; Ruini and Vescovelli 2013). In their study regarding well-being, gratitude and coping styles, Wood et al. (2007) found grateful people were more likely to seek emotional and instrumental support, and use positive coping strategies such as planning and cognitive reappraisal, and less likely to use negative emotion-based coping such as self-blame, disengagement, substance abuse and denial. Depression commonly co-exists with T2D (The Lancet 2015; Diabetes UK 2019c) but in contrast positive affect<sup>40</sup> has been associated with superior medical outcomes for those with T2D (Massey et al. 2018). In the study by Papanas et al. (2010) those with T2D who scored higher on the WHO-5<sup>41</sup> well-being questionnaires had better diabetes control, and those with positive affect had lower mortality (Moskowitz et al. 2008).

In this study, the fear of diabetes-based complications was a powerful motivator to improve diet and reduce alcohol intake. Gupta and Anandarajah (2014) found that SMB motivators in African Americans included fear of diabetic complications, alongside desire to work and care for their family. The study by Albai et al. (2017) regarding coping with SMB of T2D found that emotion-based coping followed by social support-based coping was more successful than problem-based coping. Emotion-based coping was the most successful for patients taking exercise and having good BG control. Those with complications (e.g. neuropathy) were more likely to use problem-

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<sup>40</sup> Positive affect refers to the disposition to experience positive emotional states ([https://link.springer.com/referenceworkentry/10.1007%2F978-0-387-79061-9\\_2193](https://link.springer.com/referenceworkentry/10.1007%2F978-0-387-79061-9_2193))

<sup>41</sup> The WHO-5 well-being index is a short self-reported measure of current subjective well-being (Topp et al. 2015).

based and social support-based coping, but social support-based coping was associated with a significantly lower BMI. In this study, although exercise often was taken with family/friends, it did not link to lower BMI, and one patient with neuropathy (Liam) predominately used problem-based coping. The literature review of patient adherence to medical treatment plans by DiMatteo (2004) suggests that social support can buffer stress, increase self-efficacy and reduce negative health behaviours. Rosland et al. (2008) analysed the association of family/friends support with SMB of T2D with mostly female Latinos and African Americans, finding that physicians influenced 'medically related SMB' of checking feet, exercise and medicines for 67-84% of participants. However, for 'lifestyle SMB' of diet and exercise, full adherence occurred only 33-36% of the time, and was associated with family/friends. The review by Miller and DiMatteo (2013) found although family support can assist treatment adherence, negative effects may occur from being criticised by family, competing dietary demands of the family, or undermining individual's SMB of T2D. However, the study by Schiøtz et al. (2012) found that although social support is associated with better SMB of T2D, hba1c was likely to be higher for those co-habiting, indicating possible barriers with social support.

### 6.4.3 Religious coping

In this study, religious coping was mostly associated with motivation towards diabetes self-management. The literature shows both positive and negative effects of RC on health (Stauner et al. 2016). The systematic review of quantitative research between 1872-2010 by Koenig (2012) analysed the effect of religious belief/spirituality on mental and physical health. Of the 3,300 articles, 80% related to religion/spirituality and mental health. Positive effects are psychological, social and behavioural processes that influence health and coping, including positive emotions, a positive worldview, and appraisal of chronic conditions in a way that makes them less distressing. Koenig (2012) found that the negative effects of religious belief/spirituality could include depression, anxiety, fear, rigid thinking, avoidance and delay in seeking medical advice, but overall RC was associated with greater well-being and improved coping with stress. Similar to this study, Namageyo-Funa et al. (2015) found Black American men believed that God enabled coping, and prayer and Bible reading assisted taking responsibility and coping. Their faith empowered quitting smoking, trusting God instead of worrying and family/friends with similar spiritual beliefs supported them.

Pargament et al. (2004) suggests that negative RC may include doubting God's care, being punished by God and believing evil forces are connected to the stressor. Exline and Rose (2005) discuss that within Judeo-Christian frameworks, four spiritual types occur: 'suffering', 'virtuous

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striving', 'perception of supernatural evil' and 'social strain'. Decisions to attribute 'suffering' to God primarily occur when God is believed to be a relational being, and is held responsible for the suffering, which can lead to the individual's beliefs about God being undermined. Exline and Rose state that 'crying out to God' (2005 p318) may assist individuals – a strategy Liam used. Novotni and Petersen (2001) posit that anger towards God may be transient or sustained, and Liam resolved this through religious cognitive reappraisal. Although Liam's diagnosis led to a spiritual crisis, it did not result in reduced self-management of T2D. As Koenig's (2012) review found, religious cognitive reframing can enable acceptance of challenges.

In the present study, some RC arising from negative emotions such as worry resulted in turning to God and finding peace, comfort, feeling loved by God, and led to a 'can do' attitude, resulting in belief that participants could and *should* manage their diabetes. In the studies by Jones et al. (2006) and Utz et al. (2006), African Americans prayed for strength to cope with self-management, whereas others prayed for healing rather than taking responsibility for self-management. Similarly, the 3 types identified by Polzer and Miles (2007; Appendix U) showed African Americans management of their T2D via a relationship with God, which was perceived in terms of God's power in their lives. Group 1 who saw God as their collaborative supporter were American Episcopalian and Presbyterians, which have similar doctrines to Anglicanism (Encyclopaedia Britannica 2019; Casanova 2019; Christianity.com 2019). In the present study, the four participants who employed active coping were all Anglican, and the participants all expressed gratitude to God for both supporting and challenging them to enable good self-management. Denominational differences have been found to influence health; for example, in studying diabetes and obesity rates in American Black adults, Bentley-Edwards et al. (2019) found that Catholics and Presbyterians had lower odds of diabetes compared to Baptists. It may be that doctrine within the Anglican denominations influenced participants to consider their relationship with God as supportive and empowering their SMB, but not controlling them.

Other studies discuss the spiritual collaborative relationship between participants and God as enabling motivation and coping (Cordova 2011) and Aghamohammadi-Kalkhoran et al. (2012) found Muslims who had a God-centric life found strength to cope with the diagnosis and living with T2D. According to Heidari et al. (2017) Islam promotes a healthy lifestyle: eating in moderation, exercise, weight control and smoking avoidance, which assisted Muslim participants in their SMB of T2D. With Christian African-Americans, a motivating factor towards SMB was believing that their body was a temple of the Holy Spirit (Polzer and Miles 2007, Appendix U); Cordova 2011; Bhattacharya 2013) but this was not found in the present study for quitting smoking or the SMB of T2D.

## 6.5 Responsibility influences the self-management of T2D

In this study, most participants believed personal responsibility was key to diabetes control. They took responsibility for eating healthily, taking exercise, moderating alcohol, managing BGs, managing medicines, foot care and engagement with HPs. Most sought medical information from HPs, the internet and Diabetes UK. Baumeister et al. (2018) posit that people are information agents that can have socio-political values. Some participants believed their involvement in this research contributed to supporting the NHS, enabling reflection of their own SMB, and strongly believed that taking responsibility assisted beleaguered NHS resources.

The Medical dictionary (2019) defines 'responsibility' as 'accountability; the condition of being required to account for one's actions'. According to Hibbard and Gilbert (2014) 'patient activation' is a behavioural concept that refers to the responsibility, engagement and SMB that people adopt for their own health, where patients are 'activated' to have better health outcomes. It refers to 'individual's knowledge, skill and confidence for managing their health' (Greene et al. 2005). Penn et al. (2015) states that in the UK, health responsibility has gradually shifted from the state to the individual. The King's Fund (2017) asserts that the British public values the NHS, with 65% believing that individuals should be responsible for their health, with just 7% placing responsibility with the NHS. In the Netherlands, Hendriks et al. (2016) found no differences in patient activation between men and women with T2D in primary care. Well-being and macrovascular complications were associated with patient activation in women, whereas age, well-being and BMI were associated with patient activation in men. In Cornwall and the Scilly Isles, a patient activation intervention involved pharmacists completing motivational interviewing with 234 diabetic patients over 3 months to help them achieve their diabetes goals. Around 98% of patients who completed the intervention achieved (72%) or partially achieved (26%) their goals after 3 months, resulting in reducing the risks of T2D complications (NHS Clinical Networks 2018).

In this study, Will lived with anxiety, depression, PTSD and binge eating, and was the only participant who did not take responsibility for his T2D. Research suggests associations between depression, acute sad mood, and binge eating (Dingemans et al. 2017), and that most individuals with binge eating have at least one lifetime co-morbid psychiatric disorder, with mood and anxiety disorders amongst the most prevalent (Javaras et al. 2008; Grilo et al. 2009). The King's Fund (2014 p7) state that individuals who have low activation may feel 'overwhelmed' with the task of managing their health. They may have little confidence in their ability to do this; misunderstand their role in the process; have limited problem-solving skills; have a history in failing to manage their health; and use avoidance coping strategies when coping with managing their health. These all related to the findings of Will's lack of SMB of T2D, and he sat in the 7%

category of those who believe that the NHS shoulders responsibility for care, rather than the individual (King's Fund 2017). Conversely, high levels of patient activation are positively correlated with SMB and condition monitoring (Greene and Hibbard 2012; 2014; Rogvi et al. 2012) but although NHS England (no date) cites low levels of patient activation in 25-40% of the American population, it has yet to measure patient activation in the UK (Hibbard and Cunningham 2008).

### 6.5.1 Diet and exercise

Participants' T2D diagnosis varied from acceptance to shock, leading to changes in diet and exercise. In other studies, participants experienced similar emotions (Peel et al. 2004; Utz et al. 2006; Al-Amer et al. 2016b), with some ignoring obvious pre-diabetic symptoms (Utz et al. 2006) as occurred in this study. The primary appraisal of the T2D diagnosis being an opportunity to improve health (SBNR participants only) and has been found in other studies which did not specifically recruit religious/spiritual persons (Collins et al. 2009; Cordova 2011).

Most participants expressed the importance of having diabetes knowledge. In the UK, at diagnosis patients should be offered a Diabetes Education Programme referral (DEP) that incorporates patients' culture, lifestyle, beliefs, values and preferences and includes dietary advice (NICE 2019a). The National Diabetes Audit (NHS Digital 2018) shows that in 2016, although 74.5% of patients were offered DEPs, only 8.3% actually attended. Research in the Netherlands found 83% of participants preferred education to occur in their regular primary care check-ups, and only 3% attended DEPs (Gorter et al. 2010). Jager et al. (2019) found that the diets of ethnic minorities' in the Netherlands were influenced by culture, self-efficacy and social support, showing the significance of care delivered by primary care nurses, who know patients well and offer tailored diabetes advice.

The spirituality of some participants increased self-efficacy regarding dietary planning, the type and the quantity of food consumed. The quantitative systematic review by Koenig (2012) of religion/spirituality found 21 studies examining spirituality and diet, with 13 studies demonstrating a significant positive association between spirituality/religion and diet, and 1 study demonstrating a poorer diet. Although religious/spiritual people consumed a healthier diet, they ate larger portions, increasing the risk of ill health. Lower weight occurred in Amish, Jews and Buddhists, and in White, older and more highly educated individuals. Heidari et al. (2017) found that Muslim patients who reported more religious practices also participated in more self-management of their T2D, including diet and exercise, and Cordova (2011) found the spirituality



of Christian African-American veterans promoted self-efficacy and discipline regarding diet and taking medicines.

For the SBNR participants, family acted like the 'diabetes police', encouraging them to choose healthier foods, and challenging unhealthy food choices. Similar to findings by Samuel-Hodge et al. (2000), wives and daughters encouraged good diet. To identify information regarding the influence of family on diet, a brief literature scope was undertaken on 04.07.2019 with the terms 'T2D' OR 'T2D mellitus' OR 'diabetes mellitus type 2' AND 'family or family relationships' AND 'diet' in the DelphiS database (Appendix T). The 268 articles were refined by viewing British/Irish articles published in the last ten years, resulting in 12 articles of which 2 were relevant (Table 41). Lundberg and Thrakul (2011) found that family provided motivation for good diabetes control, including preparing healthy food. Jager et al. (2019) found that migrant diabetic patients' opinions about healthy food were determined by culturally influenced ideas, rather than by medical advice; this was similar to literature found in the previous searches showing that African Americans cultural practices can lead to unhealthy food choices (Utz et al. 2006; Hames 2010; Bhattacharya 2013). The articles showed that cultural, familial and spiritual aspects influenced dietary choices, which links to advice given in the NHS T2D guidance (NICE 2019a).

In this study, promoters of aerobic/resistance exercising were motivation, free time and pleasant walking areas, and inhibitors were reduced motivation and co-morbidities impinging on exercise/mobility. Spirituality linked to exercise for some participants. According to Watkins (2010), exercise appears to be the most underused lifestyle modification. Al-Amer et al. (2016b) found the least reported SMB was exercise with Jordanians with T2D. Lundberg and Thrakul (2013) found whilst the Buddhist women with T2D did not exercise, the Muslim women did aerobic exercise twice/week. Some studies commented that spirituality assisted exercise, but did not quantify type/duration of exercise (Utz et al. 2006; Heidari et al. 2017) whereas others measured this (Al-Amer et al. 2016b). The quantitative systematic review by Koenig (2012) of religion/spirituality found 37 studies linked to exercise. Of those, 25 reported significant positive relationships between religion/spirituality and greater exercise, whereas 6 found inverse relationships. In their systematic review of SMB of T2D in six European countries, Kousoulis et al. (2014) found consistent, multi-level approaches to long term education was required to address changes to diet and exercise, and was often focused in primary care. In the systematic review of randomised controlled trials of exercise in T2D by Avery et al. (2012), specific interventions regarding exercise had positive outcomes and reduced hba1c, with greater success for those using multiple behaviour change techniques. Currently in the UK, specific exercise interventions are yet to be promoted in diabetes care (NICE 2019a).

## 6.6 Unexpected findings

As discussed (in 5.6.4), Liam and Sally's hba1c values did not correlate with their BMI, diet and exercise regimes. Hba1c are influenced by multiple factors (e.g. truncal obesity, duration of T2D, BMI, diet, exercise, adherence to medication) and except for Liam and Sally, participants' hba1c correlated with these known factors.

Sally had a moderate/poor diet with a limited exercised regime, but her hba1c was 48 mmol/mol (in-target-range). It is likely her pancreas was working moderately well, evidenced by her hba1c returning to normal range when she initially lost weight at diagnosis. Liam had an excellent diet and exercise regime but his hba1c was 60 mmol/mol. Around diagnosis, he did not have typical T2D factors (e.g. truncal obesity that causes insulin resistance) and was slim. This indicated pancreatic failure without insulin resistance, and linked to his in-range BMI, excellent diet/exercise and strong genetic history (both parents had T2D) raises the possibility of misdiagnosis. Latent Autoimmune Diabetes of Adulthood (LADA) does not have a clear definition or treatment pathway, and is thought to straddle T1D and T2D (Diabetes UK 2019c). According to Professor Leslie, LADA is defined as:

‘initially non-insulin requiring diabetes diagnosed in people aged 30-50 years with antibodies to GAD - glutamic acid decarboxylase’ (Diabetes.co.uk 2019h).

There is the possibility that Liam may have LADA, and while I did not discuss this with him, in a post interview email I recommended him see his GP to discuss his hba1c, diet and prescribed medicines.

It was unexpected that religious participants in this study would all be Christian. Moreover, it was not anticipated that those with no self-identified spiritual practices would respond to recruitment posters, as occurred with the SBNR participants. The PIS (Appendix K) clearly stated the research was regarding T2D and spirituality, but did not specify in the ‘inclusion criteria’ that spiritual beliefs were essential. This was deliberate however: (1) due to the ambiguity surrounding the term spirituality, it enabled participants with diverse beliefs to be included e.g. Jedi knights (Crabtree 2012) and (2) other studies inclusion criteria generally did not specify having spiritual/religious beliefs.

## 6.7 Limitations

Limitations of this study are the small sample size and the age group of participants. A larger sample may have shown greater diversity of religious beliefs, and these findings may not apply to younger people. Due to the lack of consensus on the definition of spirituality in the literature, the

findings have limited transferability. Participants were not asked about diabetic complications, and it is possible that if complications were present, that these could have influenced coping styles. It is likely that knowledge of diet and exercise would have been influenced by diabetes education, but participants were not asked where/how/when/if they had attended a DEP, and T2D knowledge was not measured. Similarly, participants were not asked if they received any diabetes information from spiritual sources, e.g. church/church support programs such as parish nursing or other spiritual sources, which may have influenced motivation towards diet/exercise and coping. Motivations for joining the study were not explicitly explored, and these may have influenced the type of participant interested in the study, and the types of narratives shared. Although I presented myself as a researcher, some participants assumed I was a nurse, and some Christian participants asked about my spirituality, both of which may have influenced their self-presentation, their choice and style of narratives (Wengraf 2001a). These factors also influenced my data interrogation; it is possible other researchers would have identified different passages as more important to understanding diabetes self-management or spirituality. However, it is anticipated that the research method has been clearly described providing evidence that the study is rigorous and reproducible, with robust analysis.

## 6.8 Evaluation of healthcare research

This study met the nine principles identified by Greenhalgh and Wengraf (2008) that address the ethics of research, and evaluate the quality of narrative research in healthcare. Tracy's model (2010) recommends eight criteria to assess whether research is authentic, credible and robust, against which this study was examined (Table 21).

Table 21: Evaluation of this study with Tracy's model (2010)

	<b>How this was met in this study</b>
<b>Worthy topic</b>	The subject is relevant, as the NHS states that religious, cultural and ethnic beliefs should be incorporated into healthcare (DH 2009; NHS 2019). There is a paucity of research regarding British patients' spiritual beliefs influencing their self-management of T2D (Duke and Wigley 2016). This study adds to what is known about how spirituality influences people living in England, and their coping and

	self-management of T2D by patients. When published, it is anticipated that the findings will assist clinicians.
<b>Rich rigor (Study design)</b>	<ul style="list-style-type: none"> <li>• The philosophical assumptions of this study have been discussed and justified</li> <li>• My 'positioned stance', background, biases, etic and emic perspectives have been declared, and were reflexively considered throughout the study process</li> <li>• The study design was robust, using appropriate methods (BNIM &amp;TA) for research regarding spirituality and T2D</li> <li>• The sample size was sufficient for a study using the BNIM for interviews, with 2 interviews (three sub-sessions) for each participant</li> <li>• The recruitment strategy and context were clearly identified</li> <li>• The data collection and analysis were consistently applied</li> <li>• The analysis was clearly described and mapped</li> <li>• Regarding generalisability, the findings of the small sample size of this study are not suitable for comparison against larger populations</li> <li>• Regarding transferability, details have been given to assist researchers on the potential application of this research to other settings. A definition of spirituality has been given (Figure 2). Thick description should enable readers to understand the cultural and contextual settings of participants' narratives. The British context of T2D within the NHS has been outlined, assisting readers to understand participants' belief regarding taking responsibility for their health within the British healthcare system</li> <li>• Regarding dependability, the research process has been consistently followed. The realities constructed by individuals have been described, and negative case analysis was described (Will's relationship with God contrasted with most other participants). Participants expressed resonance with codes when member checking occurred</li> <li>• The results to a large degree echo research finding of Christians of other ethnicities with T2D. The unexpected</li> </ul>

	findings were analysed, and suggestions were given for the inconsistencies
<b>Credibility</b>	<ul style="list-style-type: none"> <li>• Thick description is evident</li> <li>• Peer debriefing occurred with the supervision team regarding application of methods</li> <li>• Peer debriefing occurred with the supervision team regarding evolving ideas and themes</li> <li>• Member checking (and transparency where this was incomplete on the 2<sup>nd</sup> interview transcripts) is described</li> <li>• Triangulation (artefacts noted in participants' homes; participants' narratives linked with their expressed emotions; contextual data were triangulated against interview data, e.g. hba1c and diet)</li> <li>• My nursing knowledge of T2D enabled understanding diabetic details of participants' narratives, and comparison of hba1c results against their diet and medicines</li> <li>• A reflexive diary was kept</li> <li>• A daily audit trail was kept demonstrating evidence of interviews, memos, transcribing, reflexive diary, developing codes, emerging themes, peer debriefing and thesis creation</li> </ul>
<b>Sincerity</b>	<ul style="list-style-type: none"> <li>• This study is clear regarding my interest in the topic (seeking to understand if patients' spiritual beliefs influence their SMB of T2D; seeking to add to knowledge-base of diabetes clinicians planning care with patients)</li> <li>• My subjective biases, values and inclinations are stated</li> <li>• I have been transparent regarding methods and challenges (e.g. introduction of GDPR)</li> </ul>
<b>Resonance</b>	<ul style="list-style-type: none"> <li>• Interview data is presented vividly, assisting readers to emotionally connect with participants' spirituality and the challenges they face in living with T2D, and their SMB of T2D</li> <li>• It is hoped clinicians will appreciate some of the anguish, challenges and triumphs that patients face, when tasked with daily management their T2D</li> </ul>

<b>Significant contribution</b>	<ul style="list-style-type: none"> <li>• Although the sample size is small, it adds to the knowledge base regarding what is known about how spirituality influences patients' SMB of T2D</li> <li>• This study extends knowledge about patients' experience of coping with living with T2D in England</li> <li>• This study will be published, thereby assisting clinicians to appreciate how spirituality may influence patients' coping with their SMB of T2D, and where appropriate, to incorporate this when planning patients' care</li> </ul>
<b>Ethical</b>	The ethical considerations of this study have been considered and met (Table 4).
<b>Meaningful coherence</b>	<p>The study has:</p> <ul style="list-style-type: none"> <li>• achieved its aim and objectives</li> <li>• justified the paradigm and methods</li> <li>• connected with relevant literature</li> <li>• collected appropriate data</li> <li>• and it is believed the analysis is credible</li> </ul> <p>The conclusions and recommendations interconnect with the data, the literature and the aim of the research.</p>

## 6.9 Summary

This chapter has discussed the findings and how they sit in relation to the wider literature. The findings did not sit neatly within one theoretical model, but this was anticipated due to the exploratory nature of the study. Some unexpected findings were outlined, and limitations of the study were made clear. Finally, the study was evaluated to ensure it met the criteria of robust research. The next chapter will conclude the study, detailing the key messages, the implications for clinical practice and recommendations for future research.

## Chapter 7 Conclusion

### 7.1 Introduction

This chapter will conclude the study by outlining the key messages, the implications for clinicians supporting patients, and future research considerations. In this study, interpretive analysis led to the creation of three themes to demonstrate how the spirituality of people with T2D living in England influences their coping and self-management of their condition:

- spirituality influences expectations in life
- beliefs influence coping styles of the self-management of T2D
- responsibility influences the self-management of T2D

Most of the research regarding spirituality influencing the self-management of T2D has been conducted with African Americans. To my knowledge, this study is the first to explore how the spirituality of people with T2D who live in England influences their coping and self-management of T2D, and builds on what is known about ethnicity, spirituality and T2D. Much of the existing research lacks a definition of spirituality, and it is hoped that the definition of spirituality given in this study (Figure 2) will assist future studies comparing their findings. As this was exploratory research, the data was not 'forced' into a model, but the findings did have some similarities with other models (Polzer and Miles 2007; Koenig 2012 (Appendix U-V)).

Eight participants were recruited from five GP Practices in Hampshire in the UK: 5 men and 3 women, with an age range of 52-89 years. Contextual data were collected from medical records including name, address, age at T2D diagnosis, living situation, hba1c blood test results, body mass index and medicines prescribed for T2D. The length of time participants had lived with T2D varied from 2-17 years. The biographic narrative interpretive method was used for conducting two in-depth unstructured interviews with each participant, and thematic analysis used to code the data corpus and generate themes, with CAQDAS assisting data management. Six of the participants (3 women, 3 men) self-identified as Christian; they were termed as 'spiritual and religious' and two male participants were termed as 'spiritual but not religious' (SBNR). Participants' spirituality and health beliefs influenced them living with T2D and coping in complex layers which affected their self-management behaviours of T2D. The multiple co-morbidities that participants lived with also influenced their diabetes self-management.

## 7.2 Key messages

Participants' spirituality, their relationships with family, friends and clinicians, and their approach to life all influenced them in coping with their self-management of T2D. In addition, Christian participants found prayer, religious reading and church connections valuable. Resonating with McSherry and Smith's view that spirituality is 'personal and individual' (2012 p118), this study found participants' spirituality was unique to individuals. However, for most Christian participants, their relationship with God particularly influenced their cognitive reappraisal of the stressors of their lives positively. Belief in a benevolent God provided benefits not found in human relationships. In addition to feeling loved and cared for, the belief that 'God allowed' challenges and was in control of the major events in their lives strengthened their coping. By interpreting stressors in life through the lens of their faith, most Christian participants were able to imbue positive meanings to difficult circumstances. One Christian without a loving relationship with God also believed that God was in control, but interpreted his life through a negative focus. The SBNR participants had a positive approach to life, appraised their T2D as a 'challenge' (Lazarus and Folkman 1984) and found meaning in pursuing healthier lifestyles, providing for and enjoying their families.

Problem-based, emotion-based and religious-based coping strategies were used by participants in ways that were helpful (e.g. information seeking) or maladaptive (e.g. binge eating). Spiritual and health beliefs influenced their coping strategies in their self-management of T2D, their co-morbidities and challenges in life, with most believing that they must take responsibility for their health. In addition, most Christians believed that 'God helps those who help themselves' (Sidney 1698) and most aimed to address diet and exercise, even if this was a daily struggle. The Christian with a negative focus who was overwhelmed by his multiple co-morbidities did not take responsibility for his health, and mostly used maladaptive coping. All participants experienced instrumental, emotional and social support from family/friends, but Christian participants also valued the spiritual support from like-minded family/friends. Participants also engaged with clinicians and sought diabetic information from a variety of sources. They had various levels of skill and confidence in the SMB of T2D for eating healthily, taking exercise, moderating alcohol, managing blood glucose, managing their medicines and caring for their feet. For 6/8 participants, the hba1c was mostly reflected in their diet, exercise and BMI.

The findings in this study suggest that in this sample of people living in England, their spirituality influences their coping and SMB of T2D. Although spirituality and the lived experience of T2D is unique to the individual, themes in this research echoed with research regarding spirituality and T2D with other ethnicities and in other countries:



- the significant impact of a T2D diagnosis upon the individual
- that family and friends influence coping and self-management of T2D
- that spiritual beliefs, health beliefs and coping overlap in ways unique to the individual
- the sense of responsibility for self-management of their health influences coping
- the value placed on good relationships with clinicians.

### 7.3 Implications for clinical practice

Due the rapid rise in people with T2D, Diabetes UK (2019d) state that diabetes is ‘potentially the greatest health crisis facing our nation’, with joint partnerships such as NHS England, Public Health England and Diabetes UK collaborating to address the rising incidence, management and complications of the condition (Gatineau et al. 2014; PHE 2017a; NHS England 2016; 2019). People with diabetes should be referred to diabetes education classes, yet only 6% of newly T2D diagnosed people in the UK attend (NHS Digital 2019; Diabetes UK 2019). Although some localities have improved attendance (NHS Clinical Networks 2018) it mostly rests on primary care to deliver patient-focused, culturally relevant advice regarding diet and exercise that incorporates patients’ lifestyle, values, beliefs and co-morbidities (NICE 2019a). Primary care clinicians therefore need information regarding how spirituality influences their patients’ SMB of T2D. Clinicians should consider that the ability of patients to take responsibility for their T2D might be influenced by patients’ spirituality, health beliefs and coping because it directly affects their SMB of T2D and their diabetic outcomes. It is anticipated that publication of this study will inform clinicians how the complex interwoven layers of spirituality, beliefs, coping and responsibility influence patients’ spirituality when planning their diabetes care.

Clinicians need to ensure a good rapport with patients before opening discussions on spirituality and be careful to ensure their own spiritual beliefs do not influence patients. Within a diabetes clinic, clinicians may want to:

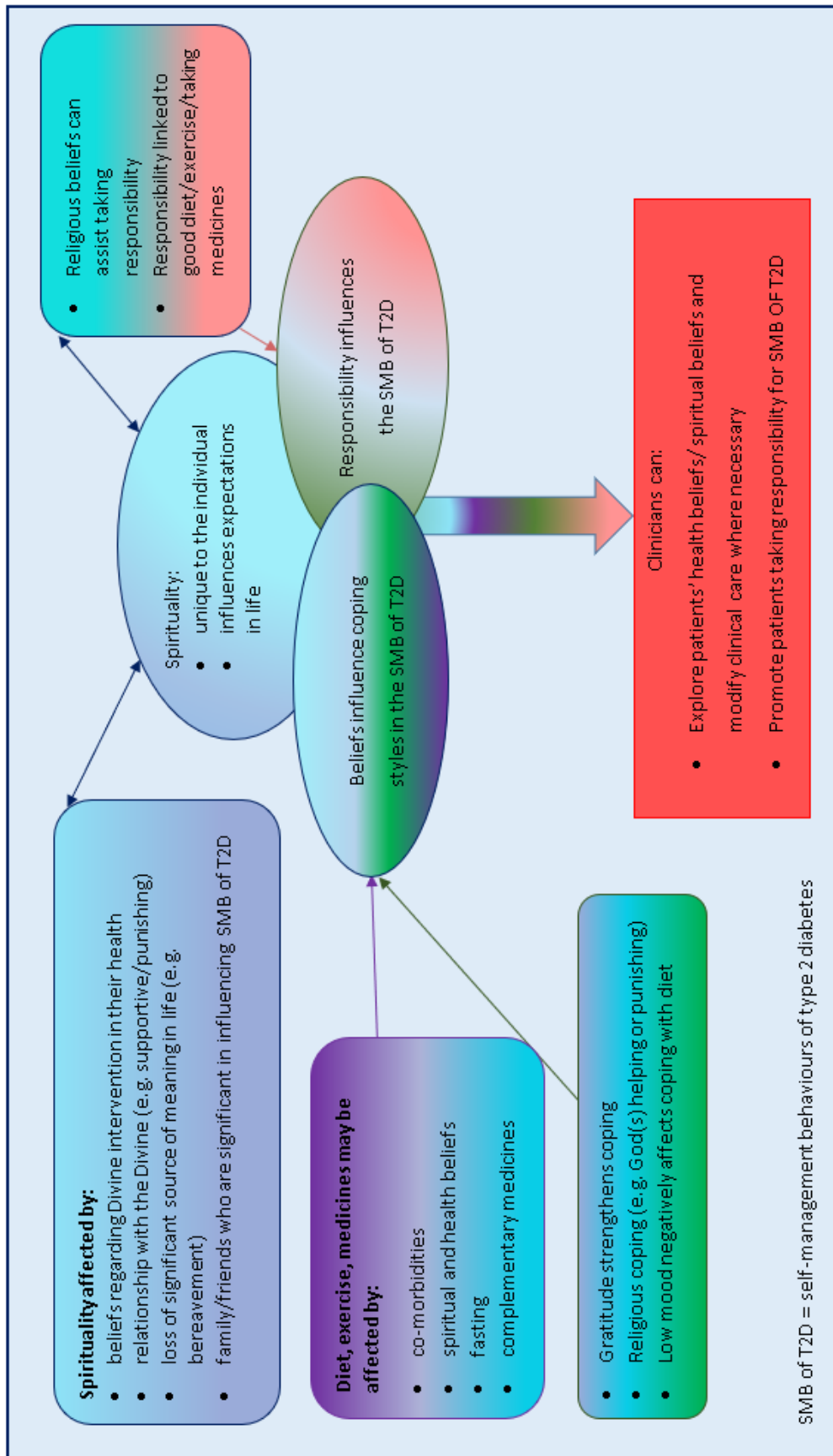
- explore if patients exhibit a positive or negative approach to life
- understand if patients’ spirituality links to a negative or positive interpretation of stressors (e.g. ‘My faith helps me cope’)
- explore patients’ motivation towards diet and exercise
- understand how patients’ spirituality may influence their diet, exercise or taking medicines

## Chapter 7

- consider that patients may be juggling the self-management of other co-morbidities or long-term conditions that may conflict with T2D management
- if appropriate, discuss ways to incorporate their spiritual beliefs into their diet, exercise or medicines
- work with patients to promote healthy coping, taking responsibility and be cognisant of how their spirituality may influence their self-management of T2D.

My own experience is that patients appreciate clinicians who seek to understand the complexity of their lives. By asking open-ended questions, and listening in a kind and compassionate manner, patients may feel comfortable sharing what may be ‘the truest meaning of them and their lives’ (Keighley 1997 p47). The findings in this study suggest that the components of spirituality, beliefs, coping and responsibility may be relevant for patients in their self-management of T2D, and a model is shown below to assist clinicians supporting patients managing their T2D (Figure 12).

Figure 12: Model for clinicians addressing spirituality in care of people with diabetes



## 7.4 Future research

The findings in this study suggest that in this sample of people living in England, their spirituality influences their health beliefs and coping strategies in complex interwoven layers, and the multiple co-morbidities that participants lived with were an additional factor influencing their diabetes self-management. This study found using the minimally structured BNIM for interviews yielded very rich narratives that revealed strongly held beliefs and deep emotions. This enabled participants to reveal beliefs of significance, which may not have occurred with structured interviewing. Without prompting, many participants finished their interviews by returning to the beliefs or convictions that were most important to them, and gave particular meaning to their lives. Future studies may find the BNIM of interviewing helpful in revealing the conscious and unconscious beliefs and biases that individuals hold.

The literature reviews identified that many studies focusing on spirituality and T2D did not define the term 'spirituality', 'religion' or clearly identify religious beliefs. Clear definition of these research terms would enhance future research. In addition, due to the subjective nature of spirituality, the biases and affiliations of author(s) should be transparent. Validity in studies would be enhanced by hba1c values accessed via patient records rather than self-reporting. In the literature, funding of care was a significant factor in coping strategies; therefore, it would be helpful if studies gave brief explanations of how healthcare is funded in the country of the research. Further exploration of how spirituality, responsibility and coping influences the SMB of T2D with larger samples, other ethnicities (e.g. Black British, Welsh, British Asian) and other religious groups will add to the understanding of how the spirituality of people with T2D influences the coping and self-management of their condition.

## Appendix A Literature search for ‘T2D and spirituality’

Table 22: Database search in June 2014 for ‘T2D and Spirituality’

Search in June 2014	DelphiS*	CINAHL Plus Full Text	MEDLINE ‘smart search’	Web of Science	AMED	EMBASE ‘Classic’	PsychINFO	SCOPUS	Total
Articles from original 2014 Search. (Removed duplicates or articles already accessed from other databases)	24	‘1	0	1	Not searched in 2014	Not searched in 2014	0	Not searched in 2014	
Total articles									<b>26</b>

\*DelphiS database searches: ERIC, RILM Abstracts of Music Literature, PsycINFO, Teacher Reference Center, PsycPAPERS, EconLit, MEDLINE, Textile Technology Index, SocINDEX with Full Text, American Bibliography of Slavic and East European Studies, CINAHL Plus with Full Text, Library, Information Science & Technology Abstracts, Computers & Applied Sciences Complete, RISM Series A/II: Music Manuscripts after 1600, GreenFILE, European Views of the Americas: 1493 to 1750, PsycCRITIQUES, PsycBOOKS, Arts & Humanities Citation Index, Science Citation Index, Social Sciences Citation Index, ScienceDirect, JSTOR Arts & Sciences I, JSTOR Arts & Sciences II, JSTOR Arts & Sciences III, JSTOR Ireland, JSTOR Arts & Sciences IX, JSTOR Arts & Sciences VI, JSTOR Arts & Sciences VII, JSTOR Arts & Sciences IV, JSTOR Arts & Sciences V, JSTOR Arts & Sciences VIII, JSTOR Life Sciences, MLA International Bibliography, OAlster, Oxford Scholarship Online, Oxford Handbooks Online, arXiv, Informit Business Collection, Informit Engineering Collection, Informit Health Collection, Informit Humanities & Social Sciences Collection, eBook Collection (EBSCOhost), Art Abstracts (H.W. Wilson), Newswires, Informit Literature & Culture Collection, Informit Indigenous Collection, Academic Search Index, Supplemental Index, Business Source Index, Publisher Provided Full Text Searching File, Grove Art Online, American National Biography Online, Grove Music Online, Directory of Open Access Journals, HeinOnline, OAPEN Library, British Library EThOS, JSTOR 19th Century British Pamphlets, JSTOR Arts & Sciences X, JSTOR Arts & Sciences XI, Oxford Dictionary of National Biography, University Press Scholarship Online, BioOne Online Journals, CogPrints, Naxos Music Library Jazz, Naxos Music Library, Naxos Spoken Word Library, Naxos Video Library, ACLS Humanities E-Book, Energy Citations Database, Oxford Reference, SciELO, University of Southampton Library Catalogue, British Standards Online, Project MUSE, Adam Matthew Digital, Rock's Backpages, Cochrane Database of Systematic Reviews

## Appendix A

Table 23: Books search in June 2014 for 'T2D and Spirituality'

<b>June 2014</b>	<b>Books searched for on UoS electronic database 'Webcat'</b>	<b>Number</b>	<b>Relevant</b>
<b>Search terms</b>	'spirituality' and 'healthcare'	2	0 (none specifically related to diabetes and spirituality)
	'spirituality' and 'diabetes'	0	0
	'spirituality' and 'health'	30	0 (none specifically related to diabetes and spirituality)
<b>Total</b>			<b>0</b>

Table 24: Other sources searched in June 2014 for 'T2D and Spirituality'

<b>Source</b>	<b>Details</b>	<b>Sources</b>	<b>Relevance</b>
Emailed 2 experts in the field in August 2014	Dr Wilfred McSherry Dr Linda Ross	0 (Experts not aware of any research currently being conducted in these areas)	0
Joined 'The British Association for the Study of Spirituality'	Search of Manley database	72	0
Manual Book search at University of Southampton Library	Search terms: 'T2D' and 'spirituality'	0	0
References from papers already sourced	9	9	9
<b>Total</b>			<b>9</b>

Table 25: Other internet sources searched in June 2014 for 'T2D and Spirituality'

<b>Other Internet Sources</b>	<b>Search Terms</b>	<b>Number of sources</b>	<b>Relevant</b>
Google Scholar search: title search only	'spirituality' 'type 2 diabetes'	8 (Already found in DelphiS: 7)	1
Cochrane database	'spirituality' 'meanings'	11	0
National Institute of Health and Clinical Excellence database	'spirituality'	34	0
Department of Health database	'spirituality'	1	0
Eprints University of Southampton (grey literature)	'spirituality'	147	1
Academia.edu. Group: Theory Development, Spirituality, Religion, Faith, Personality Theory, Mental Health, Physical Health, Disparity, Transdisciplinary Research, Ethnicity, Culture.	'spirituality'	71	0
<b>Total of other internet sources</b>			<b>2</b>

Table 26: Summary of 2014 literature search for 'T2D and Spirituality'

<b>2014 Literature Search Summary</b>	<b>Sources</b>
<b>Databases</b>	26
<b>Books</b>	0
<b>Other sources</b>	9
<b>Other internet sources</b>	2
<b>Total</b>	<b>37</b>

## Appendix B 2019 Literature search: Database search for 'T2D and Spirituality'

Building search for each database. Only full text, in English, peer reviewed accessible articles included:

1. 'Diabetes type 2' OR 'diabetes mellitus' OR 'diabetes mellitus type 2' with specific search terms identified for each database
2. 'Spirit\*' with specific search terms identified for each database
3. Combine titles 1 and 2 with Boolean operator 'AND'

Table 27: Database search in 2019 for 'T2D and Spirituality'

	<b>Search on 16 August 2019 Dates limits: 2014-2019</b>	<b>DelphiS</b>	<b>CINAHL Plus Full Text</b>	<b>MEDLINE 'smart search'</b>	<b>Web of Science</b>	<b>AMED</b>	<b>EMBASE 'Classic'</b>	<b>Psych INFO</b>	<b>SCOPUS</b>	<b>Total</b>
	<b>Search terms:</b>	'title'	'MM'	'MM'	'title'	'title'	'title'	'MW'	'title'	
1	<b>'diabetes type 2' OR 'diabetes mellitus' OR 'diabetes mellitus type 2'</b>	100,613	38,594	3,229,456	25,976	394	150,274	152,135	100,819	
2	<b>'spirit*'</b>	32,681	13,695	5,434	6,286	1,185	10,241	14,433	31,661	
3	<b>Combine Search 1 and 2</b>	16	38	1	2	2	12	1	13	
	<b>Articles (Removed duplicates and articles already accessed from first Search in 2014)</b>	<b>2</b>	<b>6</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>9</b>



Table 28: Summary of combined 2014 and 2019 literature search for 'T2D and Spirituality'

<b>2014 &amp; 2019 Literature Search Summary</b>	<b>Sources</b>
Sources found in 2014	37
Sources found in 2019	9
<b>Total</b>	<b>46</b>

Table 29: Excluded articles from 'T2D and Spirituality' 2014 and 2019 searches

Source	Reason for exclusion
Academic Journal (2011) <i>Nursing Times</i> Mar 22-28; 107 (11): 4. Available at: <a href="http://www.nursingtimes.net/nursingpractice/specialisms/diabetes/diabetes-raises-liver-disease-risk/5027989.article">http://www.nursingtimes.net/nursingpractice/specialisms/diabetes/diabetes-raises-liver-disease-risk/5027989.article</a> (Accessed 27 July 2014).	Not about spirituality, but diabetes and liver cancer risk.
Ahmedani B., Peterson E., Wells, K., and Williams, L. (2013) Asthma medication adherence: the role of God and other health locus-of-controls of control factors. <i>Annals of Allergy, Asthma &amp; Immunology: Official Publication of the American College of Allergy, Asthma, &amp; Immunology</i> , 110 (2): pp.75-79.	Asthma focus
Cater, G. (2010) <i>Faith Community Nursing: A Case Study of its Impact on African Americans with Type 2 Diabetes</i> . Unpublished PHD Thesis. University of Massachusetts.	About community nursing that is faith centred.
Cattich, J. & Knudson-Martin, C. (2009) 'Spirituality and Relationship: a Holistic Analysis of How Couples Cope with Diabetes', <i>Journal of Marital and Family Therapy</i> , 35 (1): pp. 111-24.	Family therapy
Cronjé J et al. (2015) 'Effect of a Faith-Based Education Program on Self-Assessed Physical, Mental and Spiritual (Religious) Health Parameters', <i>Journal of Religion and Health</i> , 56(1): pp. 89–108.	No mention of T2D
Deatcher, J. (2002) Tool chest. Use of Prayer in Diabetes Self-Management, <i>Diabetes Educator</i> , 28 (3): pp. 392-394.	Poorly designed
European Cancer Congress (2013) <i>European Journal of Cancer</i> , 49 (S2): pp.298-449.	Not about spirituality and diabetes, but cancer risks and diabetic drugs.
Haskell, W. (2003) 'Cardiovascular Disease Prevention and Lifestyle Interventions: Effectiveness and Efficacy', <i>Journal of Cardiovascular Nursing</i> , 18 (4): pp. 245-255.	Not about diabetes or spirituality, but diabetes has cardiovascular risk.
Hui, E, Bravis, V., Hassanein, M., Hanif, W., Malik, R., Chowdhury, T., Suliman, M., and Devendra, D. (2010) 'Management of People with Diabetes Wanting to Fast During Ramadan', <i>British Medical Journal</i> . Available	Medicines management during Ramadan

from: <a href="http://www.bmj.com/content/340/bmj.c3053">http://www.bmj.com/content/340/bmj.c3053</a> . (accessed on 20 August 2019)	
Jamalnia, S. (2018) 'The Relationship Between Spiritual Intelligence and Emotional Intelligence in Patients with Type 2 Diabetes', <i>Jundishapur Journal of Chronic Disease Care</i> , 7 (3). doi: 10.5812/jjcdc.79182	On reading the full article, this was concerning the relationship between the two types of intelligence, and not relating to self-management of T2D.
Kusnanto, K. (2015) 'Promoting Psycho-Social-Spiritual Response in Patients with Type 2 Diabetes Mellitus Through Application on Self- Care management Modul', <i>Jurnal Ners</i> , 8 (1):pp. 47-55.	Poorly translated from Indonesian to English.
Kadirvelu, A., Sadasivan, S. and Ng, S. (2012) 'Social support in type II diabetes care: a case of too little, too late', <i>Diabetes, Metabolic Syndrome And Obesity: Targets And Therapy</i> , 5: pp. 407-417.	Social support in diabetes
Larin, A., and Yuzvenko, T. (2015) 'The Results of Open-Label, Multicenter, Non-Randomized Study on the Efficacy and Safety of Insulins: Insuman Basal®, Insuman Comb 25®, Insuman Rapid® in Patients with Diabetes Mellitus Type 2 Who Underwent Basic Training in Diabetes Schools (SPIRIT)', <i>Mižnarodnij Endokrinologičnij Žurnal</i> 11(3.67): pp.67-81. DOI: 10.22141/2224-0721.3.67.2015.75276.	Not about spirituality, but just used the word SPIRIT for the name of the trial.
Malihe, I., et al. (2018) 'The Effect of Spiritual Care on the Body Image of Patients Undergoing Amputation due to Type 2 Diabetes: A randomized Clinical Trial', <i>Iranian Journal of Nursing and Midwifery Research</i> , 23(4):pp.322-326.	About amputations, and not about how spirituality influences the self-management of T2D
Misra, R., and Ranjita, J. (2009) 'Ethnic and Gender Differences in Psychosocial Factors, Glycemic Control, and Quality of Life Among Adult Type 2 Diabetic Patients', <i>Journal of Diabetes and Its Complications</i> , 23(1): pp.54-64.	Only gender and ethnic specific, and did not address spirituality.
O'Mathúna, D., and King, D. (2003) 'CRP Levels and Religious Attendance for Diabetics', <i>Focus on Alternative &amp; Complementary Therapies</i> , 8 (1): pp. 56-57.	Only about CRP blood levels in diabetics
Parsons, A., Kamat, N. (2006) Minerva. <i>British Medical Journal</i> (15) 332: p.922	Not about diabetes or spirituality.
Smith, L. (2011) <i>The Effects of Causal Attribution, Religiosity and Shared Beliefs On the Management of Type 2 Diabetes</i> . Unpublished PhD Thesis. Loma Linda University	Analysing couples relationship and coping

Appendix B

<p>Sukkarieh-Haraty, O. (2017) 'Diabetes Fatalism and its Emotional Distress Subscale are Independent Predictors of Glycemic Control among Lebanese patients with Type 2 Diabetes', <i>Ethnicity and Health</i>. DOI: <a href="https://www.tandfonline.com/doi/full/10.1080/13557858.2017.1373075">https://www.tandfonline.com/doi/full/10.1080/13557858.2017.1373075</a></p>	<p>Only small amount about RC, just states that 'Hopelessness is characterized by low spiritual coping, which is a rarity in our cohort given that the majority of Arabs are religious and are known to resort to spiritual coping to accept their chronic illnesses'.</p>
<p>Tanyi, R. (2006) 'Spirituality and Family Nursing: Spiritual Assessment and Interventions for Families', <i>Journal of Advanced Nursing</i>, 53 (3): pp.287-294.</p>	<p>Spiritual assessment of families; not about diabetes</p>
<p>Torres, E. (2009) '<i>Con el favor de Dios</i>: The role of Promotoras/Community Lay Health Workers as Spiritual Helpers in Supporting Diabetes Self-Management Among Mexican Americans', <i>Counselling and Spirituality / Counseling et spiritualité</i> Vol 28 (1): pp. 109-127.</p>	<p>Not about spirituality and diabetes of patients, but health lay workers.</p>
<p>Turner, R., Matthews, D., Neil, A., and McElroy, H. (1998) 'Tight Blood Pressure Control and Risk of Macrovascular and Microvascular Complications in Type 2 Diabetes: UKPDS 38', <i>British Medical Journal</i>, 317:pp.703-713.</p>	<p>About blood pressure control in diabetes</p>
<p>Whittemore, R., D'Eramo Melkus, G., and Grey, M. (2005) 'Metabolic Control, Self-Management and Psychosocial Adjustment in Women with Type 2 Diabetes', <i>Journal of Clinical Nursing</i>, 14 (2): pp. 195-203.</p>	<p>Nurse Coaching intervention</p>
<p>Yeongmi, H. (2008). 'Weight Perception and Diet Experience among Korean Adolescents', <i>Southern Online Journal of Nursing Research</i>, 8 (4): p.6 .</p>	<p>Not about diabetes or spirituality, and includes children</p>

## Appendix C Prisma 3: 'T2D &amp; spirituality' search in 2014

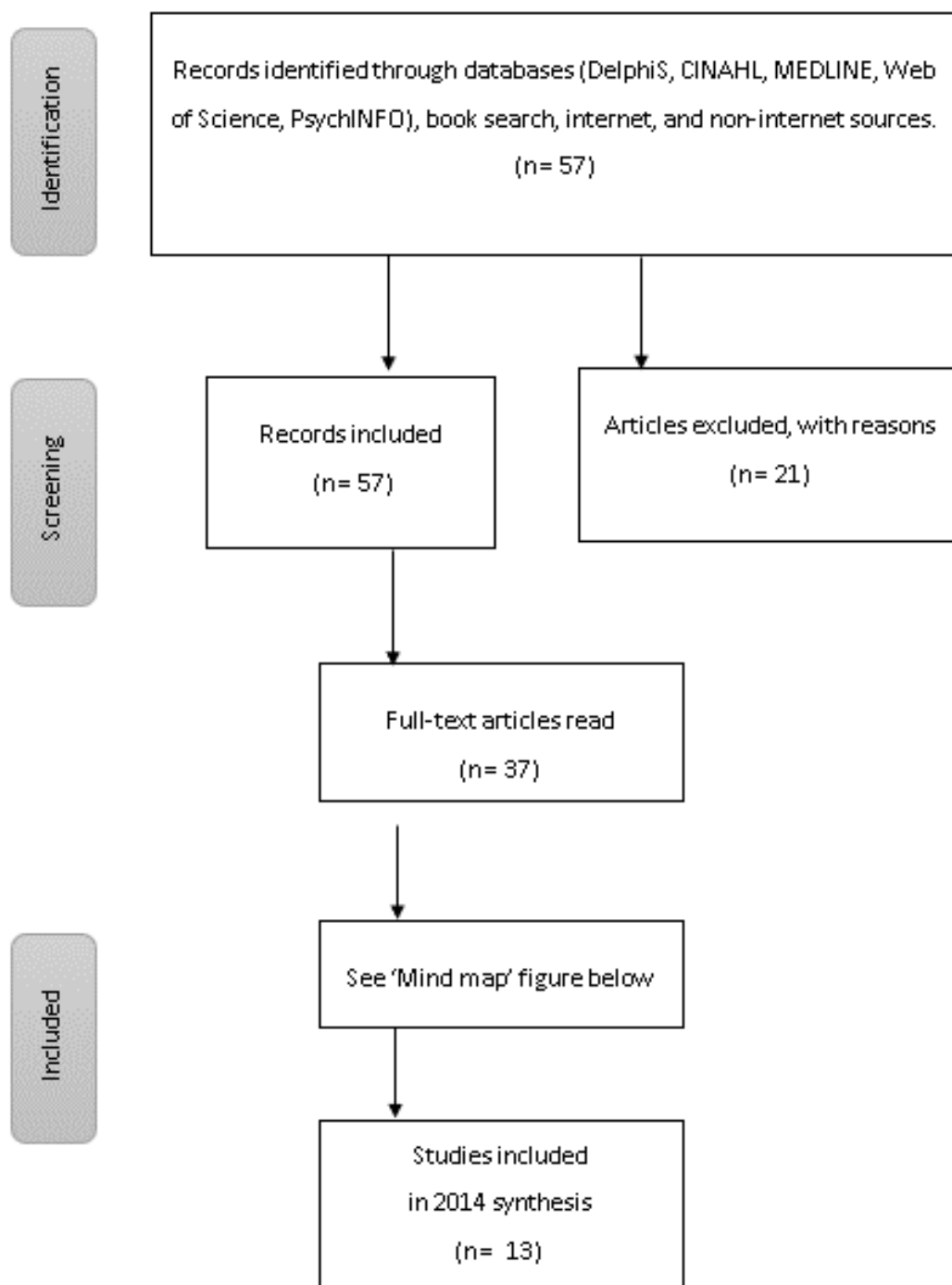


Figure 13: Prisma 3. 'T2D &amp; spirituality' search in 2014.

(Moher et al. 2009)

## Appendix D 'T2D and Religious Coping' Literature Search in 2019

Building search for each database:

1. Diabetes type 2 OR diabetes mellitus OR diabetes mellitus type 2 with search term 'title'
2. Religious coping OR religious or spiritual coping with search term 'title'
3. Diabetes type 2 OR diabetes mellitus OR diabetes mellitus type 2 with search term 'subject term'
4. Religious coping OR 'religious or spiritual coping' with search term 'subject term'
5. Combine titles 1 and 2 with search term 'title' for diabetes and coping
6. Combine subject terms 3 & 4 with search term 'subject term' for diabetes and coping

Table 30: Results from database searches for 'T2D and Religious Coping'

	Search on 8 April 2019	DelphiS*	CINAHL Plus Full Text	MEDLINE	Web of Science	AMED	EMBASE	PsychINFO	SCOPUS	Total
Search 1	'diabetes type 2' OR 'diabetes mellitus' OR 'diabetes mellitus type 2'	558,641	34,168	142,181	180,964	376	292,152	2,752	62,452	
Search 2	'religious coping'	4,287	397	1,694	824	26	1,601	866	596	

	Search on 8 April 2019	DelphiS*	CINAHL Plus Full Text	MEDLINE	Web of Science	AMED	EMBASE	PsychINFO	SCOPUS	Total
	'religious or spiritual coping'									
3	<b>(Combine Search 1 and 2)</b> <b>Duplicates removed:</b>	(10) 6	4	6	6	0	7	4 (none new)	74	115
	<b>Included</b>	6	(none new)	(none new)	(none new)	(none new)	(2 new)	(none new)		
4	'diabetes type 2' OR 'diabetes mellitus' OR 'diabetes mellitus type 2'	730,622	594,597	320,830	787,191	612	-	5,684	209,813	

	Search on 8 April 2019	DelphiS*	CINAHL Plus Full Text	MEDLINE	Web of Science	AMED	EMBASE	PsychINFO	SCOPUS	Total
5	'religious or spiritual coping'	450	9,637	568,170	4,811	0	-	1,525	3,124	
6	Combine Search 4 and 5	1	6 (1 new)	1	52	0	-	10 (3 new)	0	112
7	<b>Study relevant to research question</b>	7	0 (new studies)	0	13	0	1	0	0	<b>21</b>

Table 31: Databases for 'T2D and Religious Coping' literature search



Electronic Database search	Search terms (see separate table for 'search terms')	Name of database (Search for each database built in seven steps, exactly the same as for DelphiS database with same terms)
DelphiS* (UoS database)	'type 2 diabetes'  'subject terms'  And 'title'	DelphiS database searched: The Allied and Complementary Medicine Database, RILM Abstracts of Music Literature (1967 to present), PsycINFO, Teacher Reference Center, PsycARTICLES, Business Source Premier, EconLit, MEDLINE, SocINDEX with Full Text, American Bibliography of Slavic and East European Studies, CINAHL Plus with Full Text, Library, Information Science & Technology Abstracts, Computers & Applied Sciences Complete, RISM Series A/II: Music Manuscripts after 1600, GreenFILE, European Views of the Americas: 1493 to 1750, PsycBOOKS, Arts & Humanities Citation Index, Science Citation Index, Social Sciences Citation Index, ScienceDirect, MLA International Bibliography, Oxford Scholarship Online, Oxford Handbooks Online, arXiv, Informit Business Collection, Informit Engineering Collection, Informit Health Collection, Informit Humanities & Social Sciences Collection, eBook Collection (EBSCOhost), Art Abstracts (H.W. Wilson), Newswires, Informit Literature & Culture Collection, Research Starters, Scopus®, SciELO, Supplemental Index, Informit Indigenous Collection, Complementary Index, Grove Art Online, American National Biography Online, Grove Music Online, Directory of Open Access Journals, Public Information Online, eArticle, HeinOnline, OAPEN Library, British Library EThOS, 19th Century British Pamphlets, Henry Stewart Talks, Oxford Dictionary of National Biography, University Press Scholarship Online, Academic Search Index, BioOne Complete, CogPrints, Naxos Music Library Jazz, Naxos Music Library, Naxos Spoken Word Library, Oxford Reference, British Standards Online, ACLS Humanities E-Book, Adam Matthew Digital, Rock's Backpages, Oxford Bibliographies, ProjectMUSE, Cochrane Database of Systematic Reviews, SciTech Connect, Knovel, JSTOR Journals, Sustainable Organization Library (SOL), RePEc, MathSciNet via EBSCOhost, FT.com, Orlando: Women's Writing in the British Isles, from the

Electronic Database search	Search terms (see separate table for 'search terms')	Name of database (Search for each database built in seven steps, exactly the same as for DelphiS database with same terms)
		Beginnings to the Present, IEEE Xplore Digital Library, NASA Technical Reports, Routledge Handbooks Online, Emerald Insight, Times Digital Archive, Open Textbook Library.
CINHAL Plus with Full Text (Cumulative Index of Nursing and Allied Health Literature)	'major word in subject heading' and 'title'	
MEDLINE	'major word in subject heading' and 'title'	
Web of Science	'topic' and 'title'	Web of Science Core Collection, BIOSIS Citation Index, BICISIS previews, Current contents Connect, Data Citation Index, Derwent Innovations Index, Inspec, Korean Journal Database, MEDLINE, Russian Science Citation Index, SciELO CITATION Index.
AMED	'subject terms 'title'	
EMBASE	'title'	Books@Ovid, Yourjournals@Ovidfull tet, Embase, Embase Classic, Embase Classic + REmbase, Ovid MEDLINER, Journals@Ovid

<b>Electronic Database search</b>	<b>Search terms (see separate table for 'search terms')</b>	<b>Name of database</b> <b>(Search for each database built in seven steps, exactly the same as for DelphiS database with same terms)</b>
PsychINFO	'subject terms' 'title'	
SCOPUS	'keywords, abstracts' and 'title'	

Table 32: Studies excluded from 'T2D and Religious Coping' search

	<b>Source</b>	<b>Details of study</b>	<b>Reason for Exclusion</b>
Yazka E et al.	(2018) The Effect of Religious Belief and Forgiveness on Coping with	100 men and women with T2D: uses scales to investigate, forgiveness, religiosity, problems with diabetes, depression, anxiety and QoL, and BGs and hba1c. Investigated the relationship of religious beliefs and	Scores of the religious belief scale were not significantly

	Diabetes. <i>Journal of Religion and Health</i> 57 (3), pp.1010-1019.	forgiveness in diabetic patients with various sociodemographic characteristics, emotional problems and glycaemic control. Scores of the religious belief scale were not significantly related with the scores of depression, trait anxiety, PAID and QoL scales and the levels of the blood glucose and HbA1c. However, high levels of forgiveness lined to better QoL and lower depression.	related with the scores of depression, anxiety, QoL scales or HbA1c.
Amadi, K.	(2016) Relationship between religiosity, religious coping and socio-demographic variables among out-patients with depression or diabetes mellitus in Enugu, Nigeria. <i>African Health Science</i> . 16 (2), pp. 497-506.	Random sampling of 112 participants with diabetes and an equal number with depression. Religious coping used more with elderly & females with depression. Positive religious coping diabetic females with low socio-economic status. This paper had participants with T1D and T2D, and did not differentiate between them.	Not known which participants had which type of diabetes
Rao, K.	(2009) Recent research in stress, coping and women's health.	Review to highlight recent publications in the area of stress and coping, with specific reference to women's physical health status.	Not related to T2D

	<i>Current opinion in Psychiatry. 22</i> (2), pp.188-193.		
Amadi, K.	(2016) Religion, coping and outcome in outpatients with depression or diabetes mellitus. <i>Acta Pscychiatrica Scandinavica. 133</i> (6),pp.489-496.	This paper had participants with T1D and T2D, and did not differentiate between them. Igbo ethnic group and Christians. This paper had participants with T1D and T2D, and did not differentiate between them. Study compared the coping styles of patients with diabetes with those with depression.  224 patients, 112 with depression and an equal number with diabetes.	Not known which participants had which type of diabetes.
Amadi et al.	(2016) Illness coping behaviour of outpatients with depression or diabetes mellitus in two tertiary hospitals in Enugu state, southeast Nigeria. <i>Mental Health, Religion and Culture. 19</i> (4), pp. 371-378.	This paper had participants with T1D and T2D, and did not differentiate between them. Igbo ethnic group and Christians. Study compared the coping styles of patients with diabetes with those with depression. 224 patients, 112 with depression and an equal number with diabetes.	Not known which participants had which type of diabetes.

<p>Sukkarieh-Haraty, O. et al.</p>	<p>(2017) Diabetes fatalism and its emotional distress subscale are independent predictors of glycaemic control among Lebanese patients with type 2 diabetes. <i>Ethnicity and Health</i>. DOI: 10.1080/13557858.2017.1373075</p>	<p>280 adults with Muslim T2D in Lebanon. Four models identified which of the 3 subscales (emotional distress, spiritual coping and perceived self-efficacy) were associated with HbA1c.</p> <p>(1) Diabetes fatalism predicted poor glycaemic control (higher hba1C)</p> <p>(2) Emotional distress subscale of diabetes fatalism is the only significant correlate of poor diabetes control. <i>Spiritual coping and self-efficacy were not associated with Hba1c (as participants were Muslim, and utilised high spiritual coping, which is not associated with powerlessness or hopelessness. The absence of statistical significance in the sample could be due to the low variability in this subscale as most participants scored high on spiritual coping)</i></p> <p>(3) Age, female gender and diabetes education were significantly associated with lower HbA1c levels, whereas diabetes duration and a higher number of diabetes complications were associated with higher HbA1c levels.</p>	<p>Only one sentence about religious coping: 'Hopelessness is characterized by low spiritual coping, which is a rarity in our cohort given that the majority of Arabs are religious and are known to resort to spiritual coping to accept their chronic illnesses'.</p>

Fincham, F.	(2018) Religious Coping and Glycemic Control in Couples with Type 2 Diabetes. <i>Journal of Family Therapy</i> . 44 (1), pp.138-149.	Religious coping and shared glycaemic control activities appear integral to couples working together and managing type 2 diabetes (negative religious coping by the diabetic spouse, and positive religious coping by the nondiabetic spouse, related to lower levels and higher levels of shared glycaemic control activities)	Spouse could be a confounding factor
Hibberd, R.	(2011) Assumptive worldviews and religious coping with bereavement and type 2 diabetes. <i>International Journal for the Psychology of Religion</i> . 21 (3): pp.198-211.	Religious coping used for <i>comparing</i> the death of a child <i>compared to</i> RC of being diagnosed with diabetes	About death of child compared to diabetes.
	(2012) Spiritual coping and psychosocial adjustment of	Not adults.	Not adults

Reynolds, N., Mrug, S., and Guion, K.	adolescents with chronic illness: The role of cognitive attributions, age, and disease group. <i>Journal of Adolescent Health, 52(5),</i> pp.559-565.		
Reynolds N; Mrug S; Hensler M; Guion K; Madan-Swain A	(2014) Spiritual coping and adjustment in adolescents with chronic illness: a 2-year prospective study. <i>Journal Of Pediatric Psychology 39 (5),</i> pp.542-551.	Not adults.	Not adults
Yeongmi H.	(2008) <i>Southern Online Journal of Nursing Research 8 (4),p.6</i>	Not adults.	Related to weight in Korean children



Bockwoldt, D; Staffileno, B, Coke, L., and Quinn, L	(2016) Perceptions of Insulin Treatment Among African Americans With Uncontrolled Type 2 Diabetes. <i>Journal of Transcultural Nursing.</i> 27(2), pp172-180.	African Americans with T2D. Using Roy model to assess perception of insulin use. No spiritual assessment.	No inclusion of spiritual or religious coping
Amadi et al.	(2016) Illness coping behaviour of outpatients with depression or diabetes mellitus in two tertiary hospitals in Enugu state, southeast Nigeria. <i>Mental Health, Religion and Culture.</i> 19(4), pp.371-378.	This paper had participants with T1D and T2D, and did not differentiate between them.	Not known which participants had which type of diabetes
Martinez, Nelda C.;	(2011) Cross-cultural validation and psychometric evaluation of	Evaluation of a religious coping scale and not related to T2D.	Evaluation of a religious coping scale

Sousa, Valmi D.	the Spanish Brief Religious Coping Scale. <i>Journal of Transcultural Nursing</i> 22(3), pp.248-256.		
Whitney, Eric; Kindred, Elijah; Pratt, Abdullah; et al.	(2017) Culturally Tailoring a Patient Empowerment and Diabetes Education Curriculum for the African American Church. <i>Diabetes educator</i> 43 (5), pp. 441-448.	Diabetes education for African Americans.	Not about coping, but about education curriculum
Sukkarieh-Haraty, O, Egede, L, Karma J and Bassil, M.	Psychometric properties of the Arabic version of the 12-item diabetes fatalism scale. <i>PLoS ONE</i> . 13 (1) e0190719	This study describes the processes used to create an Arabic version of the Diabetes Fatalism Scale, and examine its psychometric properties.	Testing validity of scale.

Pisula, E. and Czaplinska, Z.	(2010) Coping with stress in adolescents with T1 diabetes and their mothers. <i>Eur J Med Res.</i> 15(Suppl 2), pp.115–11.	Not adults. T1D.	T1D adolescents.
Cattich, John; Knudson-Martin, Carmen	(2009) Spirituality and Relationship: A Holistic Analysis of How Couples Cope With Diabetes. <i>Journal of Marital Family Therapy.</i> 2009 Jan;35(1), pp.111-24.	Couples communication and problems solving patterns are related to family therapy.	Couples coping styles regarding illness and diabetes
Arnold, M; Butler, P; Anderson, R; et al.	(1995) Guidelines for facilitating a patient empowerment program. <i>Diabetes Educator</i> Jul-Aug;21(4), pp.308-12.	Evaluation of an empowerment program with diabetes.	Diabetes education and curriculum

Nishio, Ikuko; Chujo, Masami	(2017) Self-stigma of Patients with Type 1 Diabetes and Their Coping Strategies. <i>Yonago acta Medica</i> 60 (3), pp. 167-173	T1D diabetes patients and coping	T1D and not T2D
Vespa, A., Giulietti, M., Velia; Spatuzzi, R et al.	(2017) Validation of Brief Multidimensional Spirituality/Religiousness Inventory in Italian Adults Participants with Medical Diseases. <i>Journal of religion &amp; health</i> 56 (3), pp. 907-915 .	Assessed the reliability and construct validity of Brief Multidimensional Measure of Religiousness/Spirituality (BMMRS) on Italian sample.	Validation of scale.
Fitchett, G; Murphy,	(2001) Religious struggle: Prevalence, correlates and mental health risks in diabetic,	Examine the prevalence and correlates of religious struggle in three groups of medical patients: diabetes, heart failure and cancer. Did not state which type of diabetes.	Includes other diseases .e.g. cancer.

PE; Kim, J. et al.	congestive heart failure, and oncology patients. <i>Conference: Annual Meeting of the Society for the Scientific Study of Religion. Columbus: OCT 18-21,2001.</i>		
Dussart, F.	(2009) Diet, diabetes and relatedness in a central Australian Aboriginal settlement: some qualitative recommendations to facilitate the creation of culturally sensitive health promotion initiatives. <i>Health promotion Journal of Australia. 20 (3), pp.202-207.</i>	84 Aboriginals with diabetes, but not stated if T1D or T2D.	Not clear that it is T2D.

Vaccarino, V; Bremner, JO; Maisano, CA; et al.	(2004) Depressive symptoms are associated with insulin resistance. Conference: <i>77th Scientific Meeting of the American Heart Association</i> New Orleans, Nov 07-10 2004	Cannot locate any details about this paper	
Lewis, C. Gonçalves, B.	(2016) Intrinsic and extrinsic religious orientation in Portuguese Catholics. <i>Assessment of Mental Health, Religion and Culture</i> . 19 (8), pp. 155-168.	Intrinsic and extrinsic orientation coping scale, but not linked to T2D	Not about T2D.

Landis, B J	(1996) Uncertainty, spiritual well-being, and psychosocial adjustment to chronic illness.  <i>Issues in mental health nursing</i> . 17 (3), pp.217-31.	94 adults with T2D and T1D. Five instruments used to collect data. Findings suggest spiritual well-being may be important for people adjusting to T2D.	Includes T1D as well as T2D
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## Appendix E 'T2D and Religious Coping': religion, ethnicities & practices

Table 33: Religious groups in 'Religious coping and T2D' literature search

Religion	Author(s)
<b>Thai Buddhism</b>	(Lundberg and Thrakul 2012; Boonsatean et al. 2015)
<b>Muslim</b>	(Aghamohammadi-Kalkhoran et al. 2012; Shamsalinia et al. 2015; Moridi et al. 2016; Al-Amer et al. 2015; Al-Amer et al. 2016; Permana 2018)
<b>Christian</b>	(Hamadeh 1987; Popoola 2005; Egede and Bonadonna 2003; Lager 2006; Samuel-Hodge et al. 2008; Boles 2011; Unantenne et al. 2013; Namageyo-Funa et al. 2015; Newlin Lew et al. 2016)



Table 34: Ethnicities in ‘T2D and Religious Coping’ literature search

Ethnicity	Author(s)
Thai	(Lundberg and Thrakul 2012; Boonsatean et al. 2015;)
African Americans	(Hamadeh 1987; Cagle et al. 2002; Egede and Bonadonna 2003; Namageyo-Funa et al. 2015; Lager 2006; Boles 2011; Samuel-Hodge et al. 2008)
Black/African American, Non-Hispanic White & Hispanic	(Lager 2006)
Iranians	(Aghamohammadi-Kalkhoran et al. 2012; Shamsalinia et al. 2015; Moridi et al. 2016; Al-Amer et al. 2016)
Living in Israel (Jews, Christians, Druze)	(Berardi et al. 2016)
Anglo-Australians	(Unantenne et al. 2013)
South Africans	(Rotheram-Borus et al. 2012)
Indonesians	(Permana 2018)

Ethnicity	Author(s)
Jordanians	(Al-Amer et al. 2016)
Nigerians	(Popoola 2005)
Caucasian and African Americans	(Lager 2006)
Nicuraguan Miskito or Creole	(Newlin Lew et al. 2016)

The religions and ethnicities influenced the religious practices, e.g. prayer, reading sacred scriptures, and the importance of attending religious services was frequently identified by African-American Christians, but less so in Muslims (Table 35 below).

Table 35: Religious practices in literature search of 'T2D and Religious Coping'

Religious Practice	Author(s)
<b>Prayer</b>	(Hamadeh 1987; Cagle et al. 2002; Egede and Bonadonna 2003; Popoola 2005; Lager 2006; Rotheram-Borus et al. 2012; Stewart et al. 2013; Unantenne et al. 2013; Namageyo-Funa et al. 2015; Moridi et al. 2016)
<b>Meditation</b>	(Lundberg and Thrakul 2012; Egede and Bonadonna 2003; Boonsatean et al. 2015)
<b>Attending religious service or temple</b>	(Hamadeh 1987; Cagle et al. 2002; Egede and Bonadonna 2003; Lager 2006; Stewart et al. 2013; Boonsatean et al. 2015)
<b>Attending spiritual healing group</b>	(Hamadeh 1987; Unantenne et al. 2013)
<b>Bible reading</b>	(Cagle et al. 2002; Popoola 2005; Lager 2006; Unantenne et al. 2013; Stewart et al., 2013; Namageyo-Funa et al. 2015)
<b>CAMP<sup>42</sup></b>	(Popoola 2005; Unantenne et al. 2013)

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<sup>42</sup> Complementary and alternative medicine and practices

<b>Religious Practice</b>	<b>Author(s)</b>
<b>Pastoral support or church supporting education</b>	(Hamadeh 1987; Cagle et al. 2002; Lager 2006; Popoola 2005; Namageyo-Funa et al. 2015; Newlin Lew et al. 2016; Permana 2018)
<b>Holy water, rosary or talismans</b>	(Popoola 2005)
<b>Nature</b>	(Unantenne et al. 2013)

## Appendix F Key studies

Table 36: Key studies in 'T2D and spirituality' searches in (2014 & 2019)

Author and Title N= numbers	Method	Ethnicity, Gender and Religion	Key Findings	Limitations
<p>Amirehsani, K. (2011) (PhD Thesis) 'Self-Care Expressions, Patterns, and Practices of Latinos/Hispanics for the Management of Type 2 Diabetes' N=75</p>	<p>Cross sectional, correlational. Interviews. Leininger's culture care diversity and universality theory and sunrise enabler were used as the conceptual framework.</p>	<p>Male and female in new emerging Latino and Hispanic area in North Carolina, U.S.  67% female  64%: Catholic 28%: Christian 8%: Jehovah Witness, Seventh Day Adventist, or 'not religious'.</p>	<p>Poorer Latinos/Hispanics more likely to use CAMP and not inform doctor. Use CAMP because of belief in it; cheaper; difficulty with American healthcare system. Age and gender, and environmental context appear to impact cultural and social aspects; medical model of diabetes self-care, which all affect hba1c.  45% trusted CAMP <i>with</i> prescriptions; 44% trusted prescriptions; 5% trusted CAMP only.  Some participants adjusted prescription medicines the day they used CAMP. Participants wanted doctors to include faith-based remedies as part of their care.</p>	<p>Specific identity of people group means findings may not be same to other Latinos/Hispanics.  Participants may give limited answers to White researchers.  Hba1c only reported as either &gt; or &lt; than 7%.  As cross sectional, does not inform about changes over time, so cannot inform about how progressive nature of diabetes affects self-care.</p>

Author and Title N= numbers	Method	Ethnicity, Gender and Religion	Key Findings	Limitations
Bhattacharya, G. (2013) ‘Spirituality and Type 2 Diabetes Self-Management Among African Americans in the Arkansas Delta.’ N=31	Qualitative study using grounded theory. Perceptions of African Americans with T2D, about spiritual issues that may either hinder or promote their T2D self-management in the social-cultural contexts of the Arkansas Delta.	African Americans 15 males, 16 females Implied participants were Christian	Participants positioned spirituality within their community’s cultural and historical context of surviving great challenges. They saw God as healer and the role of church in T2D self-management. Churches guided their personal life goals. Their personal perceptions of health, illness, and health behaviours were tied to their spiritual practices and beliefs. African Americans may be fatalistic in their attitudes to chronic illness. Three themes (1) spirituality, religion, and relationship with God; (2) role of church in T2D contexts; and (3) health/illness beliefs and link to God.	Focused on African Americans only, and findings may not apply across other ethnicities. Findings relating to the significance of the church may not apply to churches not in the Arkansas Delta. Religion or spirituality was not specified - did not specifically state was Christian, but was implied throughout.

Author and Title N= numbers	Method	Ethnicity, Gender and Religion	Key Findings	Limitations
Cordova, C. (2011) (PhD thesis) 'The Lived Experience of Spirituality among Type 2 Diabetic Mellitus Patients with Macrovascular and/or Microvascular Complications' N=2	Giorgi's phenomenology method used to analyse interviews. Purposeful sampling of male veterans with faith in God, and having T2D with a micro and/or macrovascular complication.	100% Male = 25 military veterans 84% African Americans. 8% Pacific Islander/Asian 8% Caucasian. Christian: Catholic: N=11 Protestant: N=10 Jewish: N =1 Islam: N =2 Holiness (Christian evangelical) N = 1	Eight themes: (1) understanding the variations T2D complications, which was a precursor to the spirituality experience; (2) spirituality helps explain the "Why Me?" (3) relationship with God or a Higher Power in spirituality supports living with T2D (4) spirituality promotes self-efficacy in SMB (5) spirituality generates faith (6) spirituality encourages optimism (7) spirituality remains unchanged or enhanced (8) religiosity component of spirituality supplements adaptation or coping in living with T2D.	Findings may not apply to other groups – this group comprised only older male veterans (mean age was 64) with complications, with low education and low income. Low income could possibly influence participants' 'presentation bias' (p154) to researcher.

Author and Title N= numbers	Method	Ethnicity, Gender and Religion	Key Findings	Limitations
<p>Decoster &amp; Cummings (2005)</p> <p>'Coping with Type 2 Diabetes: Do Gender and Race Matter?'</p> <p>N=20</p>	<p>An exploratory research design using a mixed-methodological approach, and interviews.</p> <p>Explored coping methods of Americans with T2D.</p> <p>Ascertained if this was influenced by gender or race, and analyzed coping with relation to diabetes.</p>	<p>American Black, and American Non-Latino White.</p> <p>9 Black females, 5 Black males.</p> <p>15 White females, 5 White males.</p> <p>No religion specified, although religious questions asked were related to Christianity (e.g. questions related to Bible study, or gospel music).</p>	<p>Adults with T2D use different coping methods, influenced by race and gender. Participants used either problem-focused or emotion-focused methods to cope with diabetes. Problem based = better control, emotion focused = worse control.</p> <p>Most common coping strategies in Black Americans were prayer, faith in God and pre-occupy the mind.</p> <p>Most common coping strategies in Non-Latino Whites were determination, pre-occupy the mind; seek diabetes education; self-discipline; faith in God and prayer; and family encouragement.</p>	<p>Living in a large mid-South city in U.S., results may be different for other types (e.g. rural African Americans).</p> <p>Samples not even – large amounts of females.</p> <p>Religion or spirituality was not defined.</p>



Author and Title N= numbers	Method	Ethnicity, Gender and Religion	Key Findings	Limitations
<p>Gupta, P. and Anandarajah, G. (2014) 'The Role of Spirituality in Diabetes Self-Management in an Urban, Underserved Population: a Qualitative Exploratory Study' N = 18</p>	<p>Qualitative, focus group study of diabetic patients regarding spirituality in diabetes self-care, at an urban primary care practice in New England, U.S. (most other studies on diabetes and spirituality have been done in southern states in the US). Analysis by crystallisation/immersion.</p>	<p>Caucasian: N = 14 Native American: N = 1 Cape Verdean: N = 1 Hispanic: N = 1 African American: N = 1 Female = 11, male = 7. Christian: Catholic : N = 55% Other Christian: N = 11 % Jewish: N = 5 % No religious affiliation: N =28 %</p>	<p>Themes included: 1) significant impact of diabetes on daily life; 2) fear and family as prominent self-care motivators (3) relationships with self, others (4) nature and the Divine as major sources of hope and strength.</p>	<p>Findings may only apply to lower income individuals. No bio-statistical markers to contextualise qualitative data.</p>

Author and Title N= numbers	Method	Ethnicity, Gender and Religion	Key Findings	Limitations
<p>Harris, S. (2008) (PhD thesis) 'The Impact of Spirituality on Health Conditions of Persons with Diabetes in Eastern North Carolina' N=534</p>	<p>Mailed survey. Analysed using multiple regression and multiple logistic regression. Investigates the health outcomes of people with T2D using spirituality as a coping mechanism in U.S..</p>	<p>All were American: Black 69% White 28% Other 3% 63% female.  Christian 72% No religion 4% Other 14% No data 10%</p>	<p>Participants using spirituality as a coping mechanism for their diabetes have significantly lower current mean BG (hba1c).  Males have significantly lower hba1c than females.  African Americans have significantly lower mean hba1c levels than other races.  Higher educated have significantly lower mean hba1c levels (masters or doctoral degrees).  Older participants (62 years to 105 years) have significantly lower current mean Hba1c levels than younger.</p>	<p>Relied upon self-reporting of hba1c.  Data limited to 6 months, so longitudinal study would give greater validity.  Samples not even – large amounts of females, and African Americans.</p>

Author and Title N= numbers	Method	Ethnicity, Gender and Religion	Key Findings	Limitations
<p>Hart, P and Grindel, C. (2010)</p> <p>'Illness Representations, Emotional Distress, Coping Strategies, and Coping Efficacy as Predictors of Patient Outcomes in Type 2 Diabetes'</p> <p>N=119</p>	<p>Descriptive, cross sectional, correlational design. Used Self-Regulation Theory to analyse questionnaires.</p> <p>Hierarchical multiple linear regression analyses used</p> <p>Examined relationship of illness representations, emotional distress, coping strategies and coping efficacy as predictors of BG (hba1c) in people with T2D in U.S.</p>	<p>American White 75%</p> <p>American Black 21%</p> <p>Other ethnicity 4%.</p> <p>55 male, 64 female.</p> <p>Religion not specified</p>	<p>Found good coping efficacy resulted in better diabetes control.</p> <p>Participants perceived their diabetes to be a chronic, moderately cyclical condition with negative consequences and with moderate amounts of symptoms that influenced emotional status.</p> <p>Results showed (a) coping efficacy uniquely accounted for 9% of the variance in self-care behaviour and (b) illness representations, particularly timeline-cyclical, timeline-cyclical, and uniquely accounted for 12% of the variance in hba1c levels.</p> <p>Psychosocial factors influence self-management, hba1c values and therefore diabetes outcomes.</p>	<p>Recruited from diabetes health care programs, or health appointments, which may mean participants are more focused than non-attenders.</p> <p>As cross sectional, so cannot inform about how progressive nature of diabetes affects self-care.</p> <p>Samples not even: large amounts of American White people.</p> <p>Majority were white and well educated, which affects transferability.</p>

Author and Title N= numbers	Method	Ethnicity, Gender and Religion	Key Findings	Limitations
<p>Heidari, S. et al. (2017) 'Religious Practices and Self-Care in Iranian Patients with Type 2 Diabetes' N=154</p>	<p>Examined relationship between religious practices and self-care of patients with T2D. A descriptive cross-sectional survey with patients from teaching hospitals in Qom City, Iran.  Data analysed using descriptive statistics and statistical tests including independent t test, and Pearson correlation coefficient.</p>	<p>Iran Male: 59 Female: 95 100% Muslim</p>	<p>Significant positive correlations were observed between religious practices and self-care activities in diabetic patients. More religious practices was associated with more self-care diabetic activities (e.g. diet)  Participants believed God gave strength, support and guidance  Participants used:</p> <ul style="list-style-type: none"> <li>• Prayer</li> <li>• Mosque attendance</li> </ul>	<p>Implied was mostly Shiite Muslims, so findings may not apply to Sunni Muslims.  Large sample of females.  Cross sectional only, does not inform about changes over time, so cannot inform about how progressive nature of diabetes affects self-care.</p>

Author and Title N= numbers	Method	Ethnicity, Gender and Religion	Key Findings	Limitations
<p>Jones, S. et al. (2006)</p> <p>'Use of Complementary and Alternative Therapies by Rural African Americans with Type 2 Diabetes'</p> <p>N=68</p>	<p>Descriptive study in 2 rural communities in Central Virginia, U.S.</p> <p>Focus group sessions in community settings and described their use of CAMP.</p>	<p>100% Christian African-Americans</p> <p>39 women, 29 men</p> <p>Christian: Protestant or Baptist.</p>	<p>Explored the use of CAMP, religion and spirituality in African Americans with T2D. Most common alternative therapies are prayer, diet-based therapies and natural products.</p> <p>Women use CAMP more than men.</p> <p>These participants did not use CAMP as an alternative to prescription medicines.</p> <p>Three groups emerged:</p> <p>(1) Those who use prayer and faith</p> <p>(2) Those who believe God helps healthcare providers</p> <p>(3) Those who see a link between faith and treatment.</p>	<p>Results may only apply to these specific groups (Protestant and Baptist African-Americans).</p> <p>Rural participants may use CAMP more than those participants in the cities.</p>

Author and Title N= numbers	Method	Ethnicity, Gender and Religion	Key Findings	Limitations
<p>Jafari et al. (2014)</p> <p>'Spiritual Well-Being and Quality of Life of Iranian Adults with Type 2 Diabetes'</p> <p>N=203</p>	<p>Explore the spiritual well-being and its relationship with quality of life (QOL) in Iranian Muslim patients with diabetes and depression. Cross-sectional study with T2D patients Iran, using questionnaires. Used functional assessment of chronic illness therapy-spiritual well-being (FACIT-Sp) for QOL. Patient Health Questionnaire-2 (PHQ-2) used for depression..</p> <p>Descriptive analysis, Pearson's correlation, and multiple regression analysis</p>	<p>Isfahan, Iran</p> <p>69.5% female</p> <p>Not stated, but implied was 100% Muslim (as was in Iran).</p>	<p>64% had depressive disorders. There was a significant positive correlation between hba1c, QOL, meaning, peace, and total spiritual well-being score.</p> <p>Results showed poor QOL and spiritual well-being and high prevalence of depression in Iranian patients with T2D compared to other studies' findings especially western studies, indicating the need for psychosocial and spiritual support.</p>	<p>Did not state if they were Shiite or Sunni Muslims.</p> <p>Stated that sicker /older patients did not respond to questionnaires, so findings may only apply to younger Muslims.</p> <p>FACIT-Sp is not a diabetes specific tool to assess the quality of life and spiritual well-being.</p> <p>Hba1c was measured only as greater than 7 (indicating poor control) and less than 7 (indicating good control).</p>

Author and Title N= numbers	Method	Ethnicity, Gender and Religion	Key Findings	Limitations
<p>Lundberg &amp; Thrakul (2013)</p> <p>'Religion and Self-Management of Thai Buddhist and Muslim women with Type 2 Diabetes'</p> <p>N= 48</p>	<p>Exploratory study regarding how religion affects self-management of women with T2D in Thailand. Semi-structured interview and observation. Health Belief Model and Keonig's Theoretical Model analysed data.</p>	<p>100% Thai women in Bangkok.</p> <p>19 Buddhist</p> <p>29 Muslim</p>	<p>Religions can help and hinder self-management, but spiritual practices helped coping.</p> <p>Buddhists accept fate of illness due to previous sins. Buddhists did not exercise whilst Muslims did – but this seemed income related. Cultural factors affected diet – Buddhists eat lots of rice and found adaptation to a diabetic diet difficult. Muslims believe Allah controls people's health and He can heal.</p> <p>Family supported diet, exercise, medication, and doctor's visits.</p>	<p>BG data given by women was not accurate- so was not used, but raises concerns over other information given by participants.</p> <p>No previous data about religious practices before diagnosis. Study could have given further details of religion – e.g. Sunni or Shiite Muslim.</p>

Author and Title N= numbers	Method	Ethnicity, Gender and Religion	Key Findings	Limitations
Polzer & Miles (2007) 'Spirituality in African Americans with Diabetes: Self-Management Through a Relationship with God' N= 29	Grounded theory, using minimally structured interviews, and constant comparison.  Development of a theoretical model about how the self-management of T2D is influenced by the spirituality of African Americans.	African Americans from North Carolina in the U.S. 60% women  Protestant denominations: Apostolic, Church of God, Episcopal, Holiness, Methodist, Non-denominational, Resurrection and Power of Jesus Christ, Jehovah Witness, and one of no religious affiliation.  Included some Church Ministers.	Participants fell into one of three typologies: (1) Relationship and Responsibility: God Is in Background – participants work with God to care for their T2D. (2) Relationship and Responsibility: God Is in Forefront - participants are submissive to God's authority, and good outcomes in health are attributed to the Divine will. (3) Relationship and Relinquishing of Self-Management: God Is Healer – participants believed faith more important than self-management, as God could heal if they had enough faith. These typologies varied according to how participants viewed their relationship with God, and this impacted their self-management. Spirituality was linked to the denomination of church they attended.  Group 1 had mean educational level of Bachelor's degree.	Sample size only included Protestant African-Americans.  Age was older than 42 years, so findings may not apply to younger African Americans.



Author and Title N= numbers	Method	Ethnicity, Gender and Religion	Key Findings	Limitations
<p>Permana, I. (2018) 'How Religiosity and/or Spirituality Might Influence Self-Care in Diabetes Management : A Structured Review.' N=31 studies reviewed</p>	<p>Structured review to appraise and synthesise the best available evidence worldwide, including Indonesia, related to how people with diabetes perceives the role of religion and/or spirituality in managing daily self-care. Databases searched: CINAHL, Ovid MEDLINE and Garuda with age range 19-65.</p>	<p>Studies from U.S., Europe, Australasia, and Asia.  Latinos, African, Indonesian, Iranian and Maori ethnicities.  Muslims, Buddhists, Christians, and 'mixed religions'.</p>	<p>Qualitative and quantitative studies included. Several themes emerged from the evidence these included:</p> <ol style="list-style-type: none"> <li>1. Religiosity and self-care</li> <li>2. Religious belief</li> <li>3. Relationship with God or the transcendent</li> <li>4. Religion or spirituality as coping methods</li> <li>5. Religious practices and social support</li> </ol>	<p>Limited databases used.  Did not specify types of religion, e.g. Shiite Muslim.  Findings may not apply to older people with T2D.</p>

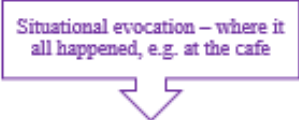
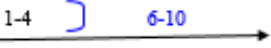
Author and Title N= numbers	Method	Ethnicity, Gender and Religion	Key Findings	Limitations
Polzer Casarez R., et al. (2010) 'Spiritual Practices in Self-Management of Diabetes in African Americans.' N=18	Qualitative descriptive approach with in-depth interviews, and TA used. Showed that African Americans use spiritual orientations to help manage or cure T2D.	100% Christian African-Americans 4 males, 14 females Christian: Baptist: N =8 Methodist: N = 6 Church of Christ: N = 2 Non-denominational: N =1. Not identified: N =1	Three cohorts found: (1): use spiritual practice aiding self-management; (2): spiritual practice and self-management towards healing; (3): spiritual practice as healing.	Samples not even – large amounts of females. Recruited only those greater than 40 years old, so limits transferability to younger diabetics. Recruited from Church, and senior citizens housing. Only persons interested in spirituality were likely to be recruited.

Author and Title N= numbers	Method	Ethnicity, Gender and Religion	Key Findings	Limitations
Rovner, B., et al. (2013) ‘Sociocultural Influences on Diabetes Self-Management Behaviours in Older African Americans’ N=110	Convenience sampling survey. X <sup>2</sup> analysis for categorical data, and one way analysis of variance for continuous data. Analysed African Americans with T2D, assessing present-time-orientation, and future-time-orientation with religiosity, as well as exercise, checking BG and reading food labels.	100% African Americans  80% female  Implied participants were Christian.	Time-orientation relates to participants’ focus on short or longer-term consequences. ‘Future-time-orientation’ participants relate current health behaviours with future disease progression. Participants engaging in exercise had significantly higher religiosity and future-time-orientation, although clear reasons for this were not identified.	Convenience sampling and older age group may influence findings. Samples not even – large amounts of females. Did not analyse type of religion, although it was implied it was Christian, as many participants attended church. Older participants future-time orientation could be influenced by other health concerns or impending mortality.

Author and Title N= numbers	Method	Ethnicity, Gender and Religion	Key Findings	Limitations
Thinganjana, W. (2007) ‘The Lived Experience Of Spirituality Among Thai Immigrants Who Are Living With Type 2 Diabetes.’ (PhD Thesis) N= 16	Descriptive phenomenological method. Open ended interviews. Analysed using Colaizzi's method. Describes the lived experience of spirituality of Thai immigrants with T2D living in the U.S.	Thai immigrants in living in the Richmond Metropolitan Statistical Area, other cities of the State of Virginia, and New York City. 4 male, 12 female. 100% Buddhists.	Five main themes: (1) Sequela of Diabetes (2) Coming to Terms (3) Managing Diabetes (4) Religion is Intertwined with Spirituality and (5) Cultural Patterns. Diet could be affected by spirituality. Some used CAMP to help with T2D. Spirituality affected coping mechanism and self-management of T2D. It helped to find meaning and purpose life, peace, security, hope and inner strength for coping with T2D.	Results only applied to this specific group (Thai immigrants in America). Samples not even – large amounts of females.

# Appendix G BNIM 'Notepad'

## THE BNIM NOTEPAD: Natasha Duke

Standard question	Topic Key-phrase	Nudge towards narrative Q- only if necessary	Beta n-pointed Question	Alpha n-pointed Question "IT ALL" "ALL THAT"
"You said...."		<p>PURPLE</p> <p>Situational evocation – where it all happened, e.g. at the cafe</p>  <p>Images or feelings about that, that struck you at the time [or only if necessary, "strike you now?"] Or any thoughts? [Then go back to 'images' as above]</p>	<p>YELLOW      RED</p> <p>Do you remember [any more about] that particular</p> <p>1-4      6-10</p>  <p>1. situation      5. day 2. time      6. occasion 3. phase      7. happening 4. example      8. event                     9. incident                     10. moment</p> <p>How it all happened?</p>	<p>BLUE</p> <p>Do you remember any more details about how</p> <ul style="list-style-type: none"> <li>• all that happened?</li> <li>• it all happened?</li> <li>• all that occurred?</li> </ul>

## Appendix H Nvivo Codebook

Table 37: Nvivo codebook

<b>Name of Code</b> <b>(18 Parent code in bold)</b> <b>(91 Sub-code in normal font)</b>	<b>Description</b>
<b>Alcohol use by Participants</b>	Participants' use of alcohol; not family or friends use of alcohol
Alcohol and social bonding	How alcohol aids social bonding, or facilitates relationships
Alcohol and T2D medicines	Any interactions of medicines with any alcohol
Alcoholism (RAY, TIM)	Of participant (not family member or friends). Does not have to have analysed units per week, but is defined by the participant themselves as having a problem with alcohol.
<b>All Co-morbidities NOT related to T2D</b>	Only of participants, not relatives/others
Acoustic neuroma (Steve)	
Aortic Stenosis (Ray)	
Atrial Fibrillation (WILL)	
Bariatric Surgery (WILL)	
Bladder or bowel problems (Mary)	
Cancer & Gynaecology (Ange)	Recent Cancer & hysterectomy, and also Fibroid removal at age 27/28
Club Foot (STEVE)	
COPD and Glaucoma (SALLY)	
Diphtheria (Ray)	
Glaucoma (TIM)	

<b>Name of Code</b> <b>(18 Parent code in bold)</b> <b>(91 Sub-code in normal font)</b>	<b>Description</b>
Minor Surgery (not T2D) (SALLY)	
Osteoarthritis (Mary & Ange)	
Sleep Apnoea (WILL)	
Spinal or Back problems (RAY, ANGE)	
Ulcerative colitis (Ange)	
<b>Communication</b>	Between participants and family/friends
<b>Decision Making</b>	
Lack of responsibility	Regarding SMB of T2D
Problem solving	Ways in which Participants solve their problems: can be a method, or vignette about how they solved a situation, e.g. LIAM stopped having alcohol with metformin as it caused diarrhoea. For RAY, it will include his 'autistic tendencies'.
Responsibility of Participants	for SMB of T2D
<b>Type 2 Diabetes</b>	This is a broad node, and will be used to code for ALL mentions of diabetes
BG testing & Insulin Given by Participant	Any BG (blood glucose) testing by participant and also any giving insulin injections, as they are linked to the BG testing. However, also code giving injections in a separate node, in case this is needed to analyse further
Blood test at GPs or Hospital	Only hba1c or diabetes related blood tests
Cholesterol	Includes cholesterol results; mentions about diet to address cholesterol; or alcohol which can impact cholesterol

## Appendix H

<b>Name of Code</b> <b>(18 Parent code in bold)</b> <b>(91 Sub-code in normal font)</b>	<b>Description</b>
Community of T2D people	Belonging to a group of people who have diabetes
Diagnosis	This will code ALL references to the patient's diagnosis, whether good or bad
Eyes of Participants (risk of retinopathy)	
Feet (not Neuropathy-see Diabetes co-morbidity)	
Hba1c	Results only, not experiences of having the blood test
Hyperglycaemia or diabetic ketoacidosis	Any reference relating to high BGs, or effects of high BGs
Hypos	Any datum related to hypoglycaemic episodes, whether at hospital or home, monitored by Participants or by health professionals.
Knowledge of diabetes by Participant	Anything related to knowledge about any type of diabetes, and can include everything (diet, exercise, disease process, complications, research, etc.) that is known by participants or facts about diabetes
Medication	Use of any medication related to diabetes only
Medication NOT diabetes related	e.g. medicines for osteoarthritis
Testing BGs by Others	Testing in hospital/home/elsewhere by any other person, whether health professional or family member
<b>Diabetes co-morbidity</b>	Any co-morbidity that is linked to, or caused by diabetes
Hypertension (MARY, RAY, TIM)	Any reference to raised blood pressure.



<b>Name of Code (18 Parent code in bold) (91 Sub-code in normal font)</b>	<b>Description</b>
Myocardial infarction (MI) (heart attack) linked to diabetes (MARY, WILL)	Only include experiences or feelings or spirituality related to MI. If it is knowledge about MI and relates to others family or friends' MI, do not include here (include that under Family, Friends, Social code).
Neuropathy (Liam)	Any reference to foot symptoms, treatment or pain
Renal (ANGE)	Any comments, beliefs or experiences related to kidney function
<b>Diet</b>	
Attention to diet by Participants	All mentions of diet. Does NOT include referral to dietician - separate node for this under Health Professionals
Eating out	In restaurants or at friends/family's homes
Lack of attention to diet	References to poor diet - this will be an interpretive process as I will be using my medical knowledge to make a judgement on this. The Participant may not perceive their diet to be poor, but I may interpret it to be so. e.g. TIM having sausage and chips.
'Reversing Diet' or 5:2 diet	Or any other 'special diet' to reverse diabetes in its early stages, such as the Michael Mosely [MM] or BG Diet or fasting diet
<b>Emotions of Participant</b>	
Anger of Participants	Related to anything, not just T2D
Attitude to T2D	How Participants approach their SMB of diet/exercise/meds/ alcohol /lifestyle
Coping of Participants	Any reference to coping, whether it is diabetes or challenges in life. Don't include coping of others.
Emotions of Others	Negative and positive emotions of Participants
Loss affecting Participants	This could be bereavement, health, possessions that Participants have felt they have lost

<b>Name of Code</b> <b>(18 Parent code in bold)</b> <b>(91 Sub-code in normal font)</b>	<b>Description</b>
Bereavement of Participants	Of friends or family members
Low mood (LIAM, SALLY, WILL, TIM, ANGE)	Of participants. Relates to any depression, not just diabetes related
Diabetes distress	Diabetes distress refers to the unique, often hidden emotional burdens and worries that are part of the spectrum of patient experience when managing a severe, demanding chronic disease like diabetes (Fisher 2012). Include Participants feeling guilty about being upset about having diabetes or being a burden
Suicide	Related to participants only
Positive Emotions of Participant	Any positive emotion about anything, and consider putting in Coping code also.
Diagnosis has benefits	Perceived benefits of having diabetes by Participants. e.g. ANGE: 'God's given me the health problems, but made me sick enough to be supported by state benefit, but well enough to enjoy it.'
<b>Exercise</b>	
Factors aiding exercise	Anything that help participants exercise
Factors inhibiting exercise	e.g. pain, lack of time, confidence.
<b>Family, Friends, social</b>	Any reference to family or friends or social events or social aspects
Family or friends with diabetes	This will code all references to family members or friends who have any type of diabetes
Holidays	Participant's holidays only (not those taken by other family members)
<b>Health beliefs</b>	Of participants
About diabetes	All types of diabetes

<b>Name of Code</b> <b>(18 Parent code in bold)</b> <b>(91 Sub-code in normal font)</b>	<b>Description</b>
About other diabetics	Participants views of people with diabetes - can be positive or negative
NON-T2D health issues of Participants	Could be anything. e.g. belief that hypertension is only hereditary and does not have links to obesity or alcohol.
<b>Health Professionals</b>	Any interaction by participant or family members or friends
Changing doctor	Related to T2D only
Dietician	Referral to dietician with regard to diabetes
Given diagnosis of T2D	By any health professional
Hospital- diabetes experiences	Of participants, that only relate to diabetes care
Hospital experiences NOT T2D related	Not related to diabetes, e.g. MI.
Negative experience of Health Professionals (HPs)	By Participants - or their significant others, as this may influence the Participant to not trust the HP or NHS too.
Positive experience of HPs or medicine	Any good experience of positive comment about HPs or the NHS
<b>Politics including healthcare</b>	Participants' views only. Thoughts on NHS, and government of NHS, and diabetes resources
<b>Significant event</b>	
Challenges in life	Any reference mentioned by Participants to challenges faced by them, that are NOT included in other specific nodes, e.g. bereavement or suicide. Will include data like MARY's flood and TIMs divorce.
<b>Smoking</b>	
<b>Spirituality</b>	

## Appendix H

Name of Code (18 Parent code in bold) (91 Sub-code in normal font)	Description
Acceptance of NON-T2D challenges	Belief that God or fate has allowed non diabetes related challenges faced by the Participants
Acceptance of T2D	Belief that God or fate has allowed it
Afterlife	Any reference to afterlife
Angry or disappointed with God	About anything
Beautiful world or Good Life	Datum mentioning nature, beauty, lovely surroundings that bring peace/joy to Participants, animals, etc. that bring comfort, serenity, joy to the Participants. Or a good life, that they appreciate their good fortune.
'Blessed' 'cared for' 'lucky' 'loved' 'favoured' 'looked after by God'	External force caring for them, or shielding them from harm
Christian Faith of Others	Any narratives around faith of friends/family of participants
Christian Faith of Participants	Any reference to their beliefs in God
Church or Sacred spaces	Any mention of church or a sacred space by Participants
Death or dying	The actual process, not belief in an afterlife - code this separately
Decision to choose joy or hope	Of participant
God helping me (with T2D) (Theoretical model Polzer & Miles)	Diabetes related narrative of participants
God helping me (non-T2D related)	Narratives that are non-diabetes related, only of participant

<b>Name of Code</b> <b>(18 Parent code in bold)</b> <b>(91 Sub-code in normal font)</b>	<b>Description</b>
God influencing occurrences or thoughts	This can include any fatalistic comments, implying 'it was meant to be' or a power outside of themselves was directing events/actions/thoughts of the Participants
Not spiritual	Any data regarding viewing themselves or their beliefs as not spiritual or religious
Prayer hope for healing of T2D co-morbidities	By Participants only
Rituals of spirituality of Participants	Any ritual of the Participants: prayer, communion, going to church, fasting, reading the Bible
Thankfulness	Participants being thankful about anything in their life (and this may aid coping?)
<b>Weight</b>	
Healthy weight of Participants	That is, BMI 18- 24.9
Overweight (MARY, SALLY, WILL, TIM, ANGE)	If BMI is greater than 30. NHS definition of BMI of: 18.5 to 24.9 means - healthy weight (LIAM, RAY, STEVE) 25 to 29.9 means - overweight (MARY) 30 to 39.9 means - obese (SALLY, TIM) 40 or above means - Morbidly or severely obese (ANGE, WILL)
Underweight (LIAM)	
Weight loss as self-management	Intentional weight loss for T2D control
<b>Work, retirement or study of Participants</b>	Retired: MARY, RAY, SALLY, TIM, STEVE. Not working due to obesity/ill health: ANGE, WILL. Working: LIAM (musician)

## Appendix I Health Research Authority Approval



**Health Research Authority**

Mrs Natasha Duke  
Doctoral Student University  
Postgraduate Research Student (DClinP) Faculty of  
Health Sciences, Building 45 University of Southampton,  
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SO17 1BJ

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

### HRA Approval Letter

06 June 2016 Dear Mrs Duke,

<b>Study title:</b>	<b>'How does the spirituality of a group of people with type 2 diabetes, living in England, influence their coping and self-management of their condition?'</b>
<b>IRAS project ID:</b>	<b>168308</b>
<b>REC reference:</b>	<b>16/NI/0089</b>
<b>Sponsor</b>	<b>University Of Southampton</b>

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

### Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

*Appendix B* provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read *Appendix B* carefully, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt

## Appendix I

out of the study, or request additional time, before their participation is assumed.

- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from [www.hra.nhs.uk/hra-approval](http://www.hra.nhs.uk/hra-approval).

## Appendices:

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

## After HRA Approval:

The document “*After Ethical Review – guidance for sponsors and investigators*”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to [hra.amendments@nhs.net](mailto:hra.amendments@nhs.net).
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

## Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

## Appendix I

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>. If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at [hra.approval@nhs.net](mailto:hra.approval@nhs.net).

Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

### HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is **168308**. Please quote this on all correspondence.

Yours sincerely

Miss Lauren Allen

Assessor

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

(N.B. For the sake of brevity, all the Appendices of HRA Approval letter are not attached.)



## Appendix J Recruitment poster



Site:[Name of Surgery]. Start date: June 2016. End date: 30.04.2018. ERGO#:18602. IRAS#:168308  
Date: 18 May 2016 Version V2

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### **Do you have Type 2 Diabetes? Would you like to tell us what it is like living with this condition?**

A lot of research focuses on the physical aspects of diabetes, but this study wants to listen to how diabetes affects people on a day to day basis, and what gives them strength and helps them cope with this condition. I am a doctoral student from the University of Southampton, and would like to hear from you if you would like to be involved in this study.

I will listen to you telling me what it is like living with diabetes, and ask you some questions to understand if any particular beliefs (such as spiritual or religious beliefs) help you to manage your diabetes. If you are happy, I will also conduct a second interview with you about one month later.

You can decide where you would like to meet. I can come to your home, but if you prefer we can meet at the University. If you are interested, please contact Natasha Duke. You can email me at: XXXXX or call me on XXXXXXXX. There are 'tear off slips' below with details that you can rip off to take the details home.

## Appendix K Participant information sheet



### Participant Information Sheet

**Study Title:** 'How does the spirituality of a group of people with type 2 diabetes, living in England, influence their coping and self-management of their condition?' Student: Natasha Duke. Supervisors: Professor A Le May; Dr W Wigley. Version: v4. ERGO No:18602.IRAS No: 168308. Date: XXXX

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**1. Please read this information carefully before deciding to take part in this research.** If you are happy to participate, *please sign and date the consent form enclosed in this pack.* If you have received this Recruitment Pack from your GP or Diabetes Clinic, please give the signed Consent Form to Reception. If you have received this in the post, please return the signed Consent Form in the stamped, addressed envelope to the Researcher, Natasha Duke.

#### **2. What is the research about?**

I am a doctoral student at the University of Southampton, researching how people cope with managing their type 2 diabetes on a day to day basis. This research is supported by the Royal College of Nursing, and the Florence Nightingale Foundation.

People with type 2 diabetes have to cope with managing their diabetes in a number of ways, e.g. managing their diet and exercise. This study would like to explore what gives people the strength to do this, and helps them cope with this in day to day life. Research so far has shown that people use all sorts of ways to help them cope, and some people have found that spiritual practices help them to cope with having diabetes.

Spiritual practices are unique to each person. They could include prayer, meditation, complementary medicines or vitamin use, new age practices, spiritual healings, massage,

acupuncture, naturopathy, herbs, guided imagery, hypnotherapy and many others. Some people find their belief in God (or gods) helpful, and this gives them comfort and strength.

### **3. Why have I been chosen?**

You have been invited to take part because you have type 2 diabetes. Anyone can take part as long as they:

- have had type 2 diabetes for at least 6 months
- are over 18 years old
- speak English
- are happy for details about their diabetes to be obtained from their GP's or Diabetes Clinic computer records (e.g. their blood test results)
- are happy to have a recorded interview (at a location of their choice)
- and have signed and dated a Consent Form.

### **4. What will happen to me if I take part?**

I will contact you to find a time that is convenient for you to talk to me about what it is like living with type 2 diabetes. Most people would like to talk about this in their own home, but if you prefer it can take place at the University of Southampton.

The interview is recorded on a small tape recorder, and I will also take some notes. There are 2 parts to the first interview, with a break of around 15 minutes in the middle. The interview can last for as long or as short as you like; the usual time is anything from around 30 minutes to 2 hours. I may ask to have a follow up interview with you, about one month later.

If you decided not to continue with any interview at any stage, you can simply tell me, and the interview will end and all information about you, and any recording will be deleted.

### **5. What information will you be collecting about me?**

In order to provide background information about your type 2 diabetes, I will need to collect some information about your diabetes from your GP or Diabetes Clinic database. These will include:

- your living situation, i.e. if you are living alone or with a family/partner. It will help this study to understand if you manage your diabetes alone, or if your family/partner help you with this, for example, shopping or cooking meals.
- your date of diagnosis of type 2 diabetes
- your age
- your diabetes BG test (called an 'hba1c' test)

## Appendix K

- your body mass index
- medicines you are taking for type 2 diabetes
- your address and phone number so that that I can contact you

### **6. Are there any benefits in my taking part?**

There are no payments given for taking part in this research. Most people take part in diabetes research because they would like to contribute to improving the lives of people with this condition.

### **7. Are there any risks involved?**

This study has already been examined internally by the Research and Governance Office at the University of Southampton, and externally examined by the NHS Research Ethics Committee, and has been deemed safe. Your usual diabetes treatment will not be affected in any way by taking part in this study. However, some people may feel emotional discussing their experience of living with diabetes. If you wish to stop the interview at any stage, I will finish the interview. If you wished for me to delete anything from the record, I will do this.

### **8. Will my participation be confidential?**

Yes. This study complies with the University of Southampton's ethical guidelines for confidentiality. Patients' identity will be protected, and personal data will comply with the Data Protection Act 1998, and the Research Data Management Policy of the University. In accordance with the University's Policy, all research data are kept for up to ten years. After the ten years, all data involved with the study will be deleted. During the research, personal data, such as your name, address and phone number will only be stored on the University's secure server. Other data, such as written transcripts will be stored in a locked filing cabinet within my home office. My home computer is linked to the University, and is password protected with antivirus software installed.

No details in the study will refer to any person by name. All the participants' names will be anonymised by the substitution of a Participant Number (e.g. P1). This will apply to any direct or indirect quotes in the study – they will only refer to a Participant Number.

Although it is unlikely, if something you said caused me to be seriously concerned that your health was in danger, I would discuss this with you, and I would need to contact your GP/Diabetes Clinic.

### **9. What happens if I change my mind?**

If you change your mind about being involved, you can withdraw from the study at any time without giving a reason, and all information about you will be deleted. You may stop an interview at any time if you don't wish to continue, and the interview will be deleted. This will not affect your diabetes care with your Doctor or Nurse in any way. Also, your legal rights will not be affected in any way.

If you wish to withdraw from the study, you can contact me or one of the Supervisors of the study. You can:

- email me (Natasha Duke): xxxxxxxxxxxx
- email Dr Wigley: xxxxxxxxxxxx
- or write to: Dr Wigley at xxxxxxxxxxxx.

### **10. What happens if something goes wrong?**

If you have a concern or complaint about the study, you could contact someone who is independent and not involved with the research. You could:

- write to the Research Integrity and Governance Manager xxxxxxxxxxxx at: The University of Southampton. Address is: xxxxxxxxxxxx.
- or email the Research Integrity and Governance Manager xxxxxxxx at xxxxxxxxxxxx
- or call the Research Governance Office on xxxxxxxx

The Research Governance Office have a complaints procedure that will be followed.

### **11. What will happen to the findings of this study?**

The results of this study will be published in health professional journals, discussed at health conferences, and used in the education of health professionals. The aim of this is so that health professionals can give better, more holistic care to people with type 2 diabetes. No identifiable data will be used that will link the information directly to you.

### **12. Will I be told about the results of the research afterwards?**

Yes. I will arrange for a letter to be sent to you, to inform you of the outcomes of this research. If you choose to participate in this research, but you do not wish to know about the results of the research (when it's completed in around 2-3 years), please let me know this.

**13. What are the benefits of this research?**

The aim of this study is for health professionals to have a greater understanding of the complexities of living with type 2 diabetes, and to be able to offer better diabetes consultations when you have your diabetes clinic appointments.

**14. Where can I get more information?**

I would welcome any questions you would like to ask about this study. You can contact me, Natasha Duke by email or phone.

- email me - xxxxxxxxxxxx
- call me – xxxxxxxxxxxx

**15. Can I get information that is independent?**

If you would like to speak to someone independent of this study, and not involved with the research. You could:

- write to the Research Integrity and Governance Manager, xxxxxxxx, at: xxxxxxxxxxxx
- or email the Research Integrity and Governance Manager, xxxxxxxx, at xxxxxxxxxxxx
- or call the Research Governance Office on xxxxxxxx,

**16. Thank you for taking time to read this information sheet.**

If you are happy to participate, *please sign and date the consent form enclosed in this pack*. If you have received this Recruitment Pack from your GP or Diabetes Clinic, please give the signed Consent Form to Reception. If you have received this in the post, please return the signed Consent Form in the stamped envelope to the researcher.

## Appendix L Consent form

**Study Title:** 'How does the spirituality of a group of people with type 2 diabetes, living in England, influence their coping and self-management of their condition?' Student: Natasha Duke. Supervisors: Professor A Le May; Dr W Wigley. Version: v4. ERGO No: 18602 IRAS No: 168308. Date: xxxxx

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**Please initial each box, if you agree with the statements below.**

1. I have read and understood the Participant Information Sheet (V3, 18 May 2016).

2. I consent to interviews that will be recorded.  
I have opportunity to ask questions about the study.

3. I agree to take part in this research, and agree for information about me to be used for the purpose of this and future research only.

4. I understand my involvement is voluntary, and I can withdraw my consent at any time, and stop my involvement, and all information about me will be deleted. My legal rights will not be affected.

5. I understand if I am unhappy with any aspect of this study I may contact the University.

6. I understand that relevant sections of my medical notes and data

Appendix L

collected during the study, may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.



**Data Protection**

I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study. All files containing any personal data will be made anonymous.

Name of Participant.....

Signature of Participant.....

Date signed by Participant.....

Name of Researcher: Natasha Duke. Signature of researcher.....

Date signed by Researcher.....

**What to do with this form: see the Participant Information Sheet, page 1, paragraph 1 about what to do if you wish to take part in the research, and have signed this form.**

1 copy for participant. 1 for investigator. 1 copy for GP Practice



## Appendix M GP Letter

Version: v2

My University Address

GP Name and address

Date

### **Your Patient is Involved in a Diabetes Research Study**

ERGO No: 18602 IRAS No: 168308 Date: xxxxxx Version V2

Dear Dr .....

#### **Patient Name and Address**

This letter is to inform you that the above patient, who has type 2 diabetes, has consented to be involved in a qualitative study that is researching how patients' beliefs may influence their approach to the self-management of their diabetes.

This is not a clinical trial, and their usual care will not be affected in any way. However, in the unlikely event that your patient revealed dangerous healthcare practices (such as incorrect use of insulin), your Surgery would be informed. A Patient Information Sheet is included for your information.

If you wish to know more about this study, please feel free to contact me.

Yours faithfully

Natasha Duke

Chief Investigator, Doctoral Student and Advanced Nurse Practitioner

Incl: Patient Information Sheet

## Appendix N Christianity

Christianity is a monotheistic religion that emerged around the 1 century A.D. initially as a sect of Judaism (Acts of the Apostles 24:14). Abraham founded Judaism around 1800 B.C. as an ancient monotheistic religion that incorporates the religion, philosophy and culture of the Jewish people (Chabad.org 2018). The sacred text is the Torah, accompanied by the Talmud, which are rabbinic commentaries and interpretations of the Torah (Neusner 2014; Steinsaltz 2006). Within Judaism is the promise by Yahweh (God) of a future 'King Messiah' (מל משיח), who will be a saviour and prophet for the Jewish people (Devarim 18:18). In the 1<sup>st</sup> century A.D., an itinerant Jewish rabbi named Jesus who was from Nazareth was the focus of the fulfilment of the King Messiah. Jewish religious leadership rejected this belief stating Jesus was a false Messiah, and persuaded the Roman authorities that he was a threat to the kingship of Caesar, resulting in the execution of Jesus by Roman crucifixion. His Jewish followers asserted that three days later he was resurrected from death, and that this was in fulfilment to Jewish prophetic writings in the Book of Isaiah that predicted that God would allow the King Messiah to suffer death as an atoning sacrifice for the world's sin (Yeshayah 53). A new movement sprang out of Judaism that held that Jesus is the King Messiah, and that he will return to earth at a future time to bring in an age of peace (Acts of the Apostles 1:11). Over time, the followers of this movement were called 'Christians' (Acts of the Apostles 11:26). Initially the followers of the new Christian movement were Jewish, but within a short time, non-Jewish people also became Christians. As this occurred, the term 'Christ' (meaning 'anointed one' – 'Χριστός' in Greek) (Luke 2:26) was used instead of King Messiah by non-Jewish believers, and Jesus is frequently referred to as 'Jesus Christ' in the Bible (1 Timothy 2:5).

### Doctrine

Core beliefs of Christianity are:

- belief in a triune God - God the Father, God the son (i.e. Jesus Christ) and God the Holy Spirit
  - that Jesus Christ atoned for the sins of the world by his sacrificial death
  - that Jesus Christ was resurrected from the dead and ascended to heaven
  - that Jesus Christ will return to earth, and on the Day of Judgement when the living and dead will be judged for their lives and sent to heaven or hell
- ( Lewis 2012; Woodhead 2014; Dean and Chapter of Westminster 2019)

## **The Christian Church**

The church in the 1<sup>st</sup> century in Israel had only one 'church', and as this spread it gradually became known as the Catholic church - the term 'catholic' meaning universal (Collins English Dictionary 2018). The Catholic church gradually became known as the Roman Catholic church because of the Italian based church based in Rome. In Germany in 1517, a professor and monk named Martin Luther, protested against corruption within the Roman Catholic church. His production of the 'Ninety-Five Theses' (Luther 1997) led to breaking from the Roman Catholic church and the beginnings of the Protestant Reformation. In England, King Henry VIII removed the church from the Roman Catholic church leading to the creation of the Protestant Church of England (Pettegree 2011). From the 16<sup>th</sup> century onwards, different interpretations of Protestantism have resulted in many Protestant denominations such as Anglicans, Methodists and Baptists across the globe. Christianity is also expressed differently according to ethnicity, e.g. it is noted that Black-American churches may have a stronger community focus than White-American churches (Cagle et al. 2002). Christian denominations vary in their expression of their liturgy, e.g. Pentecostal and charismatic churches are more likely to offer unstructured worship than Anglican churches (Emmons and Kneezel 2005). In this study, the majority of Christians were Anglicans, and one cited the Salvation Army was a denomination he would attend, if his mobility enabled.

## **Anglicanism**

The central belief in Anglicanism (i.e. beliefs of Anglican members of the Church of England) is that God is a triune being including the Father, the son Jesus Christ and the Holy Spirit (i.e. the Trinity) and reveals Himself to humans. In addition, Anglicans believe in the truth contained in the Bible, in becoming a follower of Jesus Christ and being baptised, in prayer, in attending a church and in Holy Communion (The Church of England n.d.). The celebration of Holy Communion or 'The Eucharist'<sup>43</sup> is a commemoration of the last meal that Jesus had with his disciples before his crucifixion, and involves Anglicans having symbolic bread and wine together as a community of believers. The Apostles' Creed is a verbal declaration made regularly by Anglicans containing the important components of faith, e.g. belief in the triune God; the virgin birth of Jesus and the salvation brought through the death and resurrection of Jesus. It also declares that Jesus will return to the earth to judge all people, in heaven and hell, in the resurrection of Christians, and that when Jesus returns to earth, his kingdom will be endless (The Church of England n.d.).

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<sup>43</sup> The Eucharist (Dictionary.com 2018d) refers to the holy sacrament of consuming bread and wine, in memory of the last meal that Jesus Christ had with his disciples before crucifixion.

### **Salvation Army**

The Salvation Army church also believes in the Trinity; the truth contained in the Bible; in becoming a follower of Jesus Christ and being 'regenerated by the Holy Spirit'. The Salvation Army church believes in the judgment at the end of the world, and in heaven and hell. It does not however observe water baptism or The Eucharist (The Salvation Army 2010). In addition, a large focus of The Salvation Army is 'missional zeal' of social action and justice that help to fulfil God's mission of transforming the world (Field 2010; The Salvation Army 2010 p247, p253; 2018).

## Appendix O Long Memo example

### Memo: Self as a Christian

December 2017

I have decided to disclose to participants before I interview them that I am a Christian before the interview starts. I am aware I am asking them to be vulnerable, and expose some beliefs that they will hold sacred, and there may be anxiety within them that I may question their beliefs.

Why do I feel this? When I underwent the BNIM training, all the trainees had to undergo BNIM interviews themselves. Due to my research question, I chose to talk about my spirituality – I felt this would help me appreciate how it may feel to participants when they are interviewed for this research. Other BNIM trainees chose various subjects – going to school, getting married, starting university – all normal life events, and nothing particularly deep. And yet, at some point, due to the BNIM interview method of ‘going deep’, every single one of us shed tears. The method just keeps taking you - like Alice – down, down, down the rabbit hole until you are reliving the experience! And it’s so personal!

For this study, in disclosing my spiritual beliefs before the interview, I am hoping this will enable them to feel more comfortable. I think if as a Christian/Buddhist/Pagan or whatever you are, you are sharing deeply personal things to someone – perhaps who doesn’t hold your beliefs – there is the fear you will not be believed – or at worse – silently mocked. So I am hoping if I say that I hold spiritual beliefs that are sacred to me, and I am hoping to understand *their life, their meanings, their understanding of the world, how (awful!) it is to live with diabetes, and I will treat everything they say with respect*, that it will hopefully help them to feel less anxious about sharing with me.

Before the interview, I have made a decision that I will accept at face value whatever participants say. I am not a psychologist, psychiatrist, counsellor or minister. Therefore I am not seeking so much as to understand *why* they believe what they do (although that may shed some interesting light in understanding their behaviours) or interpret it, but I do want to know *how* it influences their self-management behaviours of diabetes.

In my diabetes clinics, a patient said to me ‘I just believe I am so peaceful after this complementary therapy, that I don’t need to worry about my diabetes that day’ I want to understand *how* they come to this conclusion, and how it then affects the rest of their diabetes care – how long do they not take their medicines for? Or does that mean they just consume loads of sugar after having a complementary therapy? Or not do any exercise, and if so, for how long? And does that mean that they *worry* about their diabetes usually, or does that worry translate into good diabetes self-management behaviours on other days?

## Appendix O

So, in the research interview, if a participant tells me for example, 'God told me to eat healthily' I want to understand *how* that translates into normal life – what does that mean to eat healthily? Do they look at information labels on tins? Count their carbohydrates? Not drink alcohol? And has God 'spoken to them' before about their diabetes? Does he normally 'speak to them' about other stuff?

So I don't want participants to feel 'judged' by me in any way. I don't want for them to feel 'If I say such and such, she's going to think I'm crazy...or not believe me.' I really want to be able to accept that what they believe is true for them, is true! So even if it is not my belief or understanding of the world, it is *their belief*, and it is part of what makes them tick, why they think they way they do, and part of the meanings they attach to the world, and how they make sense of the world and the things that happen to them.

### **May 2018: complete change of view on disclosing my spirituality**

I've been thinking about this a great deal, and have completely changed my mind! I think if I tell participants what I believe, it could influence the stories *they chose* to tell me. Or maybe it will completely be *at odds* with what they believe, and might cause them to shut down? Or what if this causes them to try to start justifying what they believe?

I guess that I don't really know how it might influence them. It could be good or bad! I think on balance it is probably safer *not* to discuss my beliefs (but then what if they ask directly about them!?)

I think I will *avoid* talking about my beliefs, but have to play it by ear a bit, because who knows, it might be relevant. Maybe participants will ask if I understand what they're referring to, which will in some way give the game away about what I believe? E.g., if they say, "I find going to Mass brings me peace, do you know what I mean?" I might say 'yes' – actually referring to the fact that I understand that certain rituals/actions/behaviours can bring peace – but then they might assume I'm Catholic (which I'm not)! Oh this is confusing!! Think I need to talk further with this at Supervision.

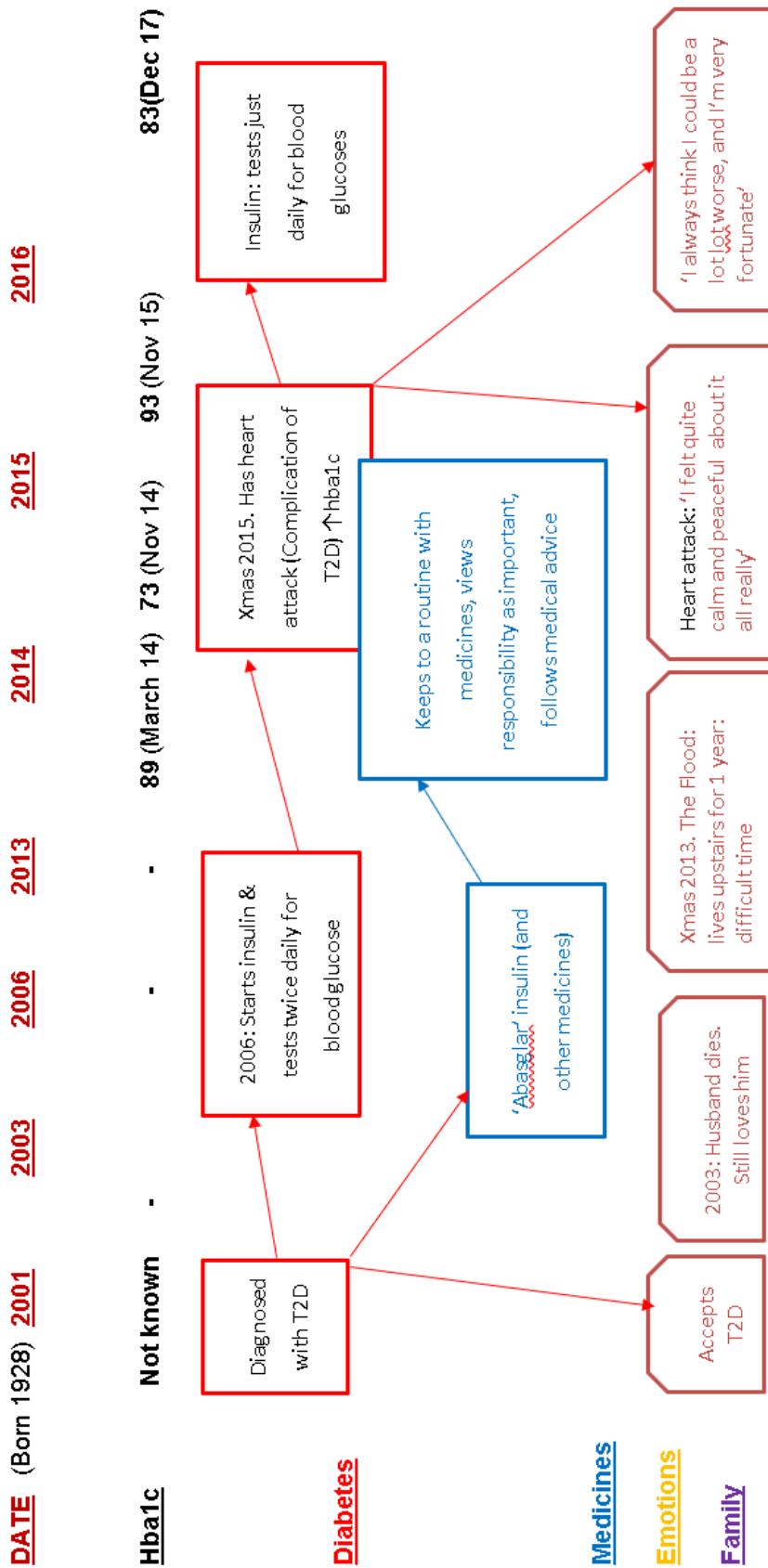
### **October 2019: what happened in interviews**

Really interesting reading this back, as I'm writing up! Quite a few of them just asked if I went to church either before or after the 1<sup>st</sup> interview, and I didn't feel that I could *avoid* the question – I thought if I don't share with them, then they may feel I'm hiding something. Anyway, some seemed to make an assumption from me saying 'Yes' that I was a Christian. Interestingly, it was only the Christians that asked me, and Tim and Steve did *not* ask me.

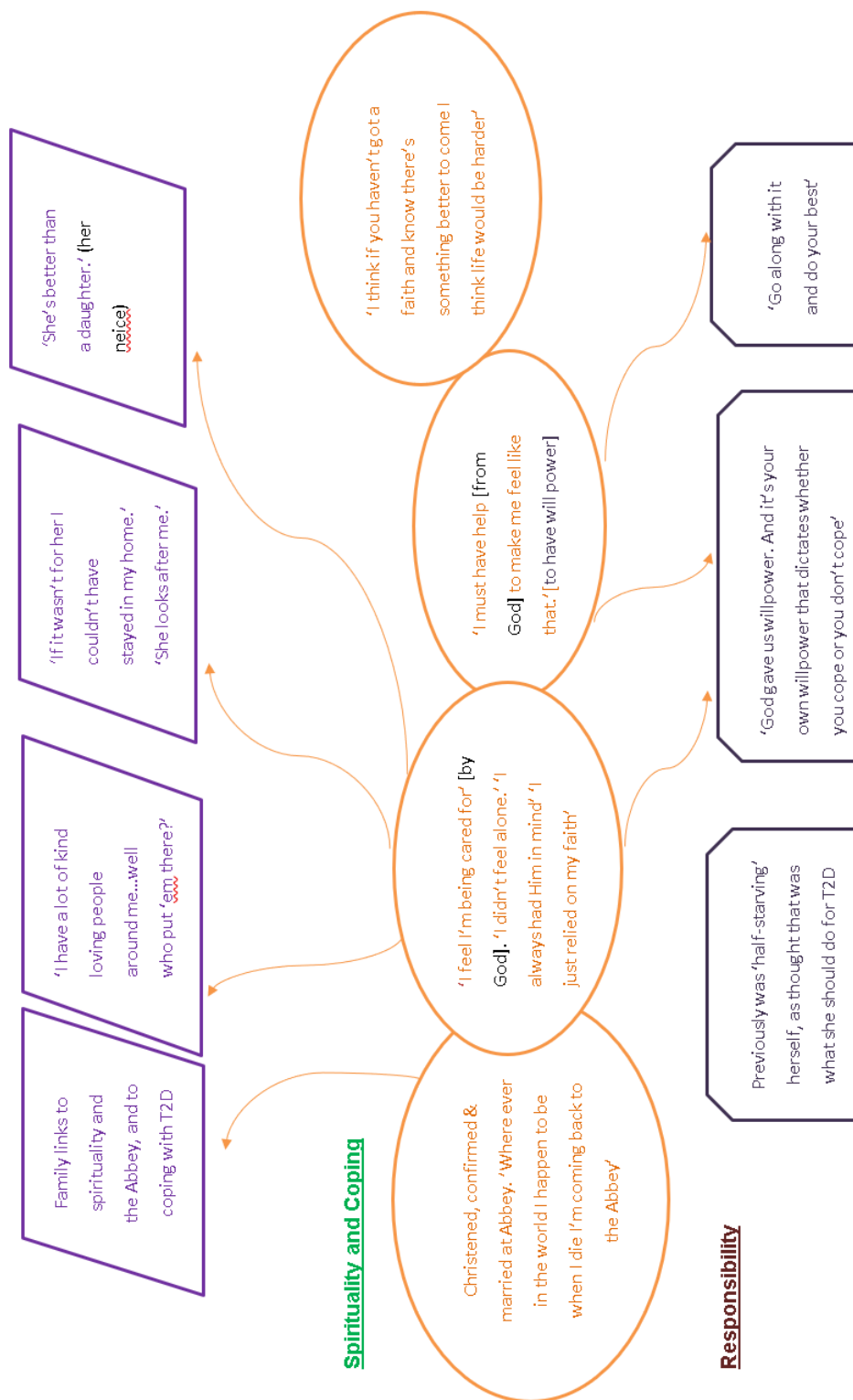
Table 38: Participants asking about my spiritual beliefs

	<b>Did they ask about my beliefs?</b>	<b>Did I reveal that I was a Christian?</b>
<b>Mary</b>	Yes	Yes
<b>Liam</b>	No	Yes
<b>Ray</b>	No	No
<b>Sally</b>	Yes	Yes
<b>Will</b>	No	No
<b>Tim</b>	No	No
<b>Ange</b>	Yes	Yes
<b>Steve</b>	No	No

# Appendix P Mary: Biographical data chronology







## Appendix Q Ray: Biographical data chronology

Age	or Date	Event	Occurrence (Colour coded)	Spirituality
1938		Born	Near Norfolk/Suffolk border	
Age 6?			Goes to church as a boy. Prays for others then and throughout his life	'Yes. I do [pray for others' health problems]. Quietly and to myself.'
Age 7?	1949?	Death	Grandfather dies	
Age 7	1949?	Death	Uncle dies	
Age 7	1949?	Death	Father dies, but mother does not tell him – he just eventually realises	
Age 7	1949?	Sister returns	Sister (who was working in Australia in Intelligence during the War) flies home due to father's death	
Age 8	1949	Hospitalisation alone	Has diphtheria and is in hospital for 100 days	
Age 12		Prays for boy with leukaemia	Boy lives and does not die. Implies this is a miracle. Believes that prayer 'works'	'yes I do – I believe in prayer....had leukaemia and he was gonna die and we all prayed like fury, the whole church (2) and he lived [looks emotional]
Age 13/14		Runs away	Runs away from home. Found and brought back.	

<b>Age</b>	<b>or Date</b>	<b>Event</b>	<b>Occurrence (Colour coded)</b>	<b>Spirituality</b>
Age 17		Starts work and smoking		
Age 20		Joins Navy		
	1959	Hospital	Varicose veins stripped	
	1986	ECG	Right bundle branch block	
	1999	Hospital	Transient ischaemic attack	
	2000	Hospital	Endarterectomy	
		1 <sup>st</sup> marriage	Poor communication, so 'walked out' on 1 <sup>st</sup> wife, and teenage boys (14 and 16)	
			Has a girlfriend	
		2nd marriage, in London		
		R born	R was born (who has 'severe learning difficulties')	
			Left the Navy	
			Worked at The Savoy Hotel as 'security man'	
			ST born	
			Leaves The Savoy due to long work hours	
			Worked in Financial services – is ok due to Navy pension	
	2005	Stops smoking	Reasons: cough, wife does not like it, and concerns re potential lung cancer	
	2007		Dysentery	

## Appendix Q

Age	or Date	Event	Occurrence (Colour coded)	Spirituality
	2008		Dislocated shoulder	
	2010		Right hip replaced	
	2013		Diagnosed with T2D	'I don't think my faith makes a lot of difference to my diabetes.'
	2015		Calcification in the gluteus median tendon insertion into the trochanter	
	Before his fall		Saw physiotherapist	
	2017	?Misdiagnosed by GP	GP diagnoses labyrinthitis, but in fact it sounds like it was cardiac, and he went on to have a fall	
	17 November 2016	Pacemaker insertion	Had a fall (syncope caused by a trifascicular block)	
	2017	C6/C7 surgery	Discectomy: Fusion and plating	
	2017	C3/C4	Discectomy: Fusion	
	April 2018	80 <sup>th</sup> birthday		

## Appendix R Contextual data

<b>Name</b>	MARY							
<b>Age</b>	89							
<b>Diagnosed in</b>	2001							
<b>Living alone?</b>	Yes							
<b>Date</b>	March 2014	Dec 2014	Jan 2015	Dec 2015	Nov 2015	Jan 2017	May 2017	Dec 2017
<b>Hba1c</b>	89	73	NK*	NK	93	102	67	83
<b>Body mass index (see chart below)</b>	NK	NK	26.6	26.4	NK	NK	NK	NK
<b>Medicines for T2D</b>	Abasglar insulin Kwikpen							

NK – not known

### Classification of overweight and obesity

#### Adults

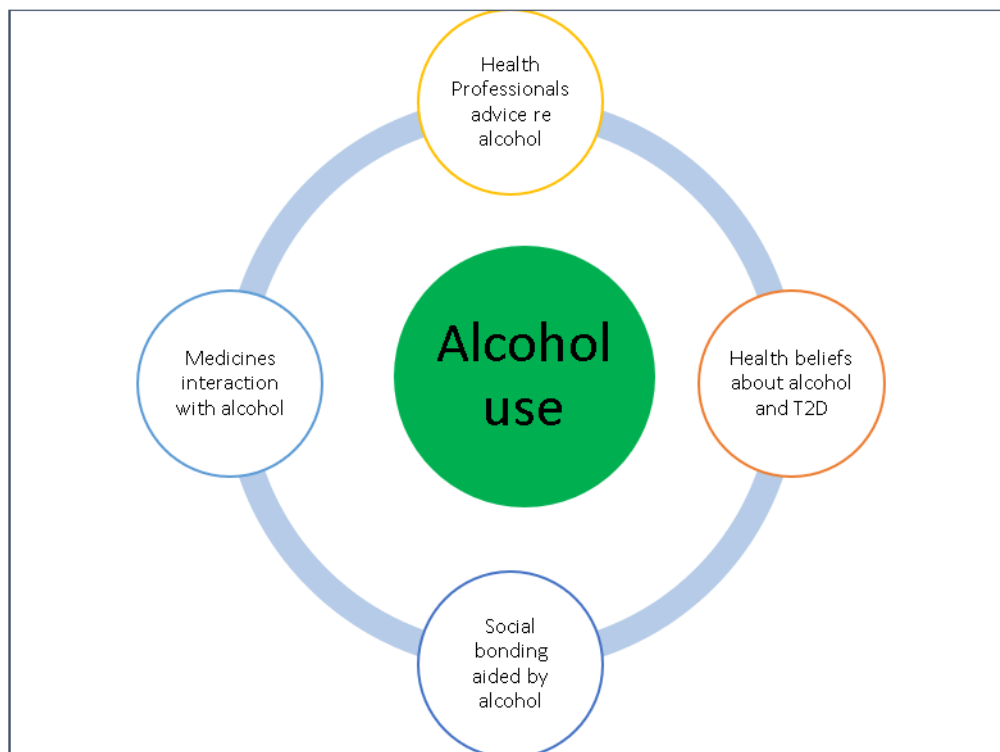
1.2.7 Define the degree of overweight or obesity in adults using the following table:

Classification	BMI (kg/m <sup>2</sup> )
Healthy weight	18.5–24.9
Overweight	25–29.9
Obesity I	30–34.9
Obesity II	35–39.9
Obesity III	40 or more

Reference: <https://www.nice.org.uk/guidance/cg189/chapter/1-recommendations> (Accessed 1 October 2019)

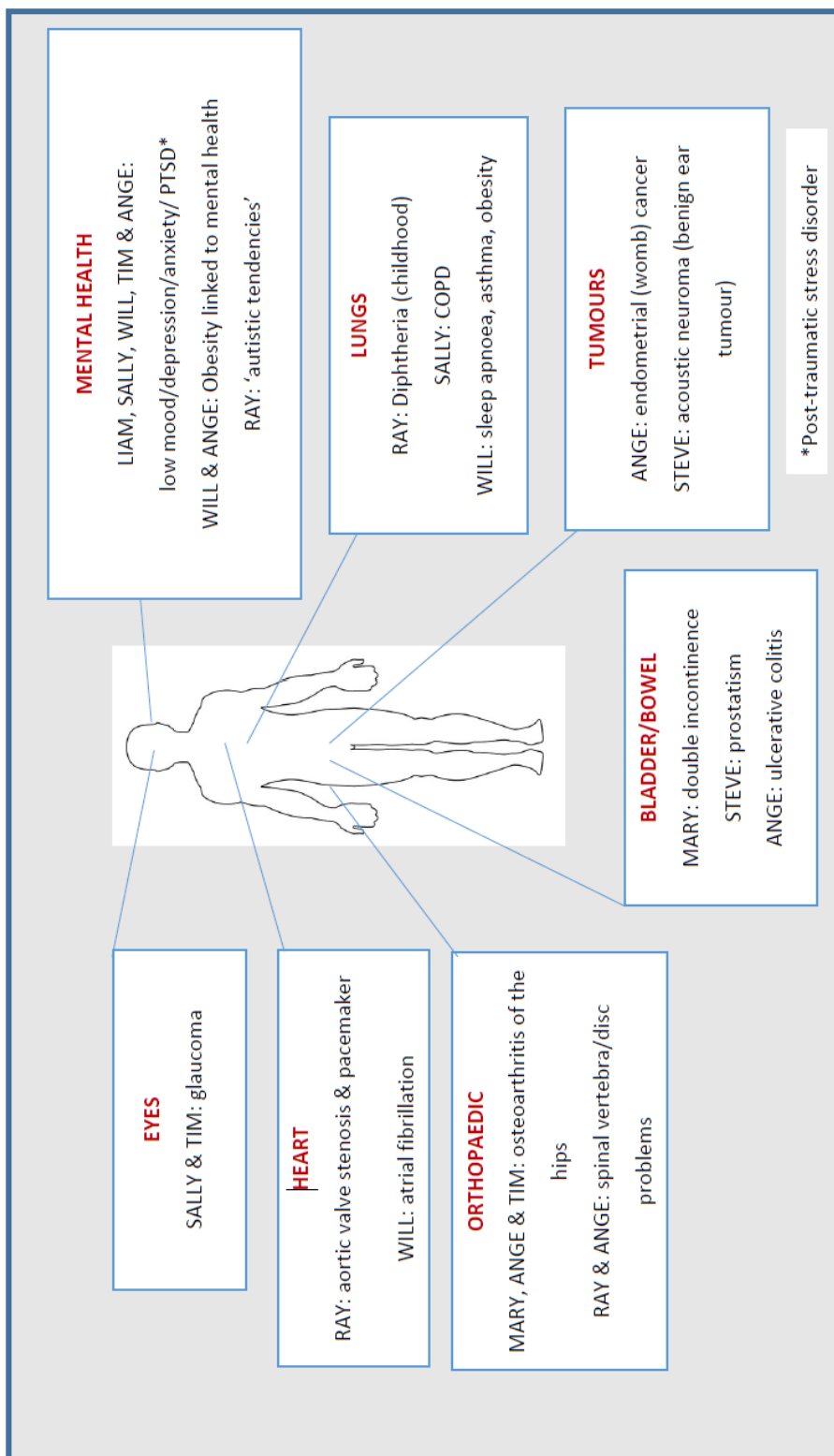
## Appendix S Code maps

(It is notes that the quality of some of the 18 Code maps could be better. The more complex maps have been inserted as PDFs, as when they were created individually in the thesis, this had significance with formatting with regard to making the Maps 'accessible' for those with impaired vision).

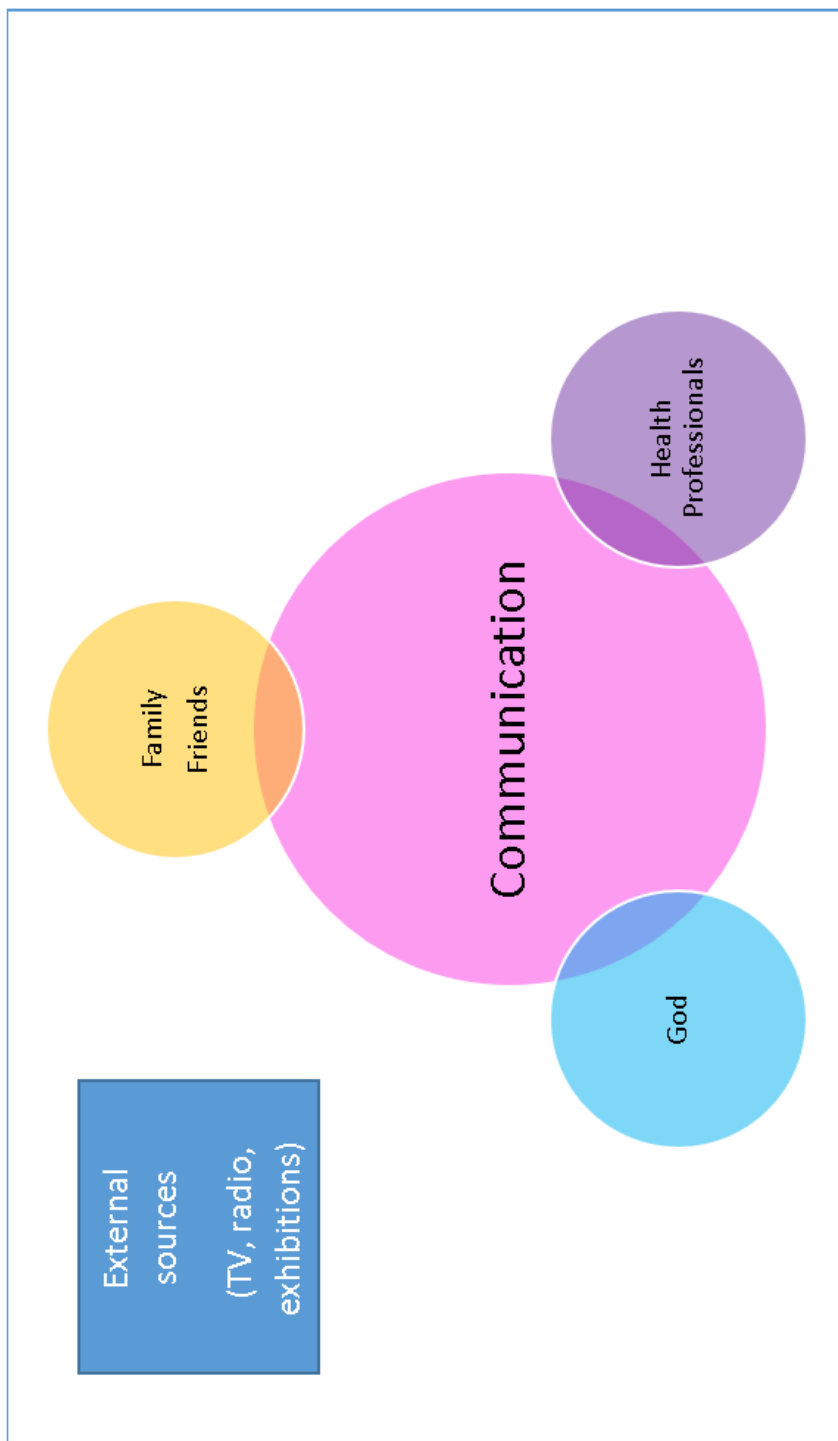


### 1 'Alcohol' code

(Parent and child nodes combined)

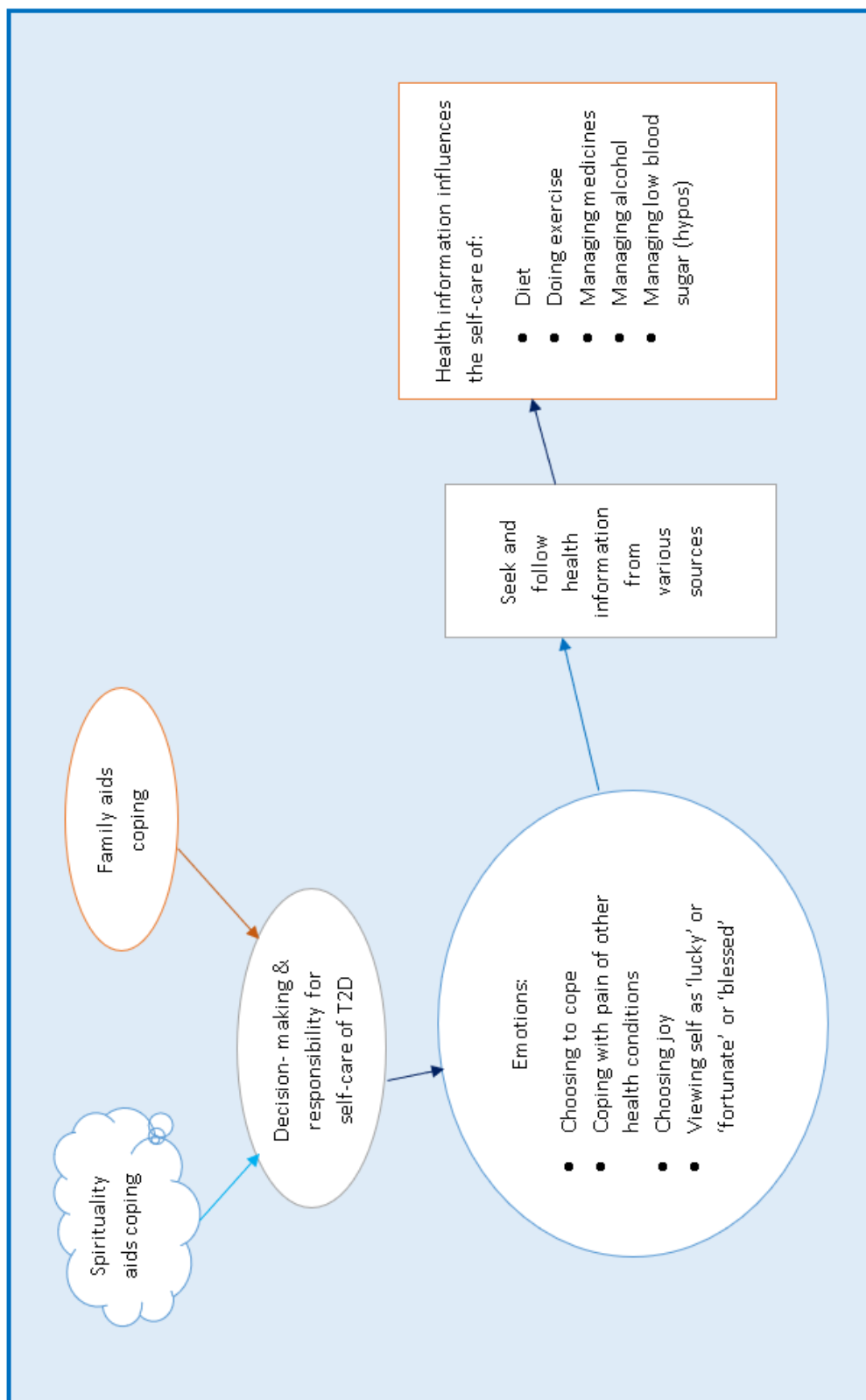


2 'Health conditions not related to T2D' code

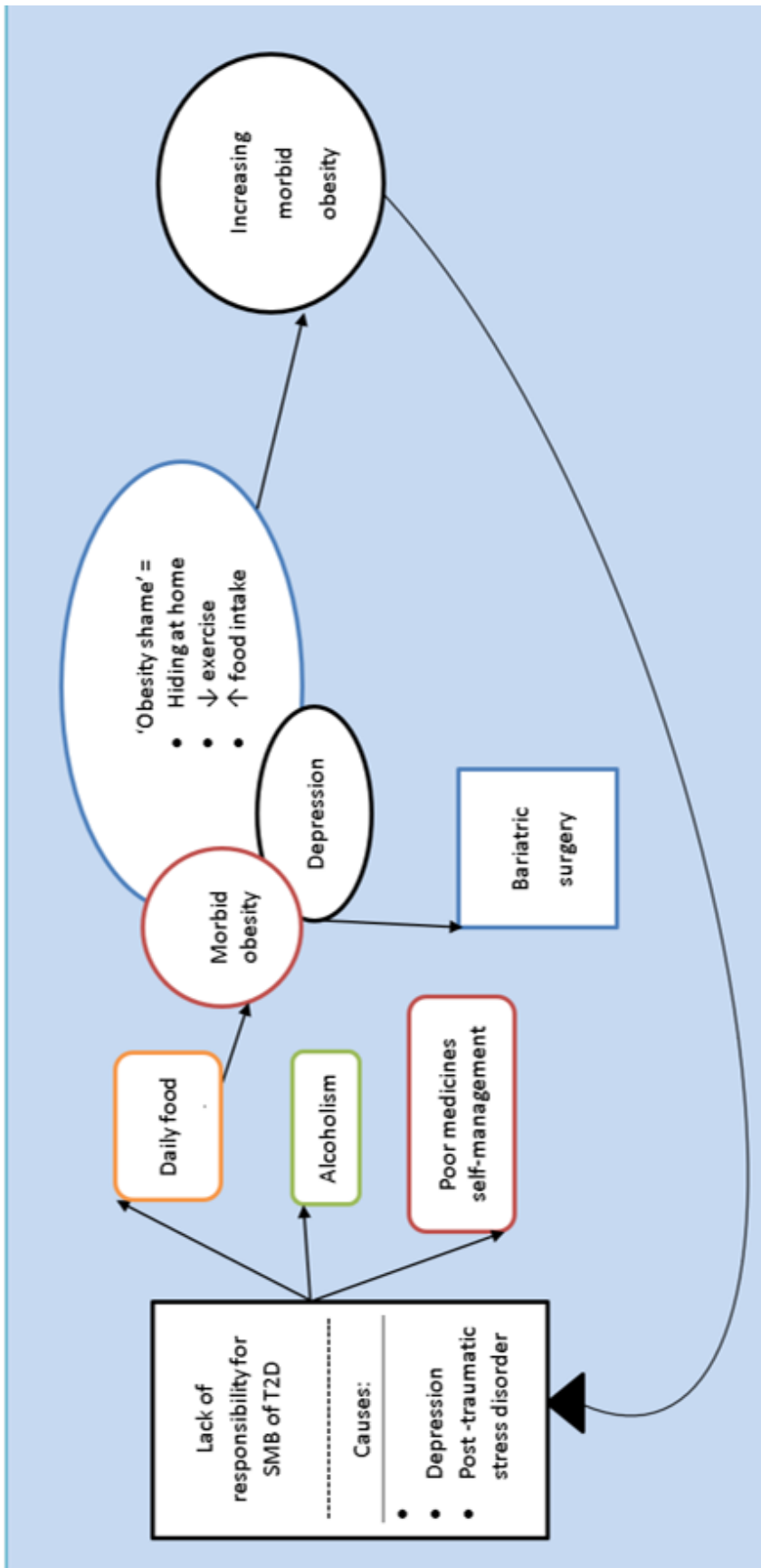


**3 'Communication' code**

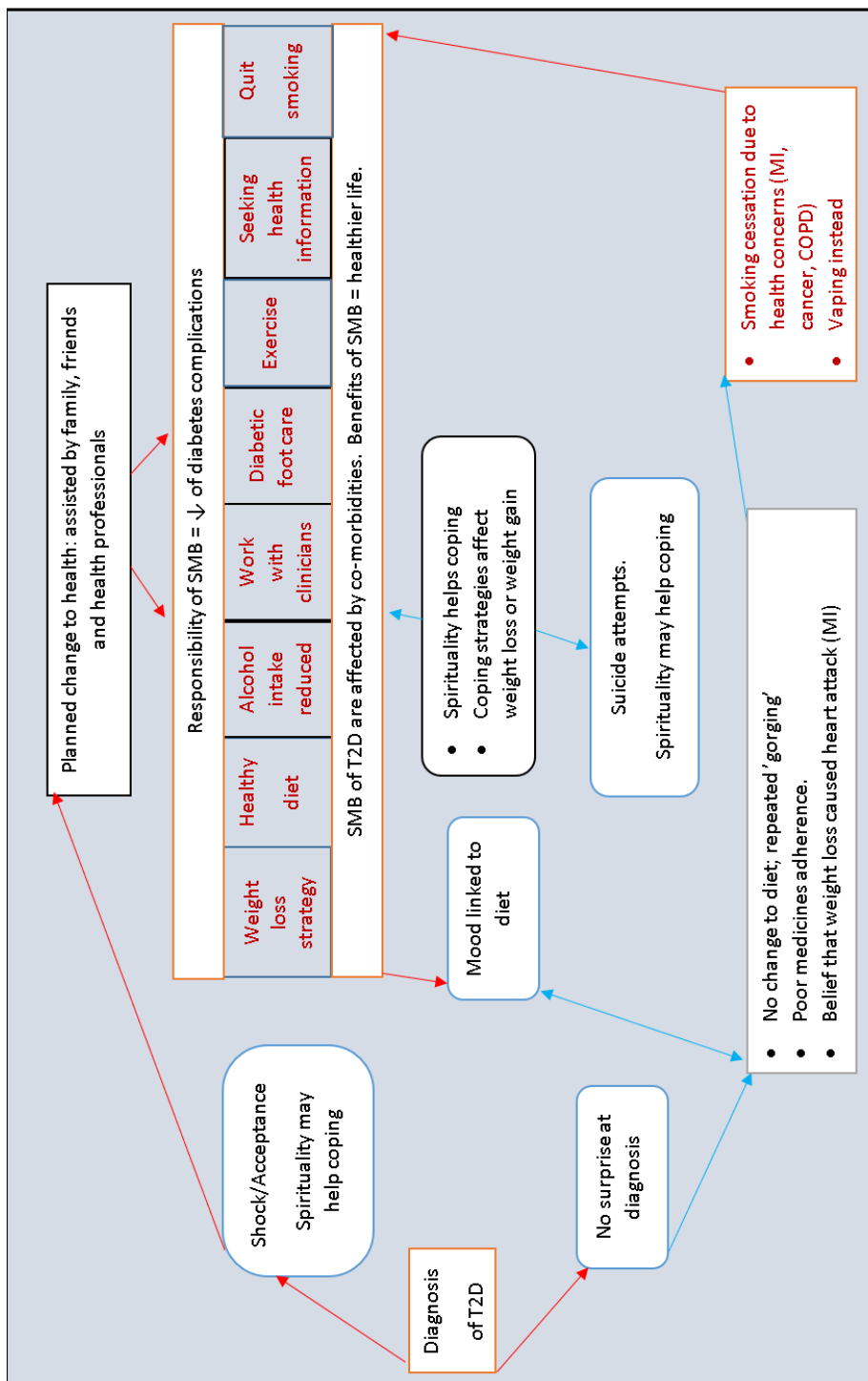




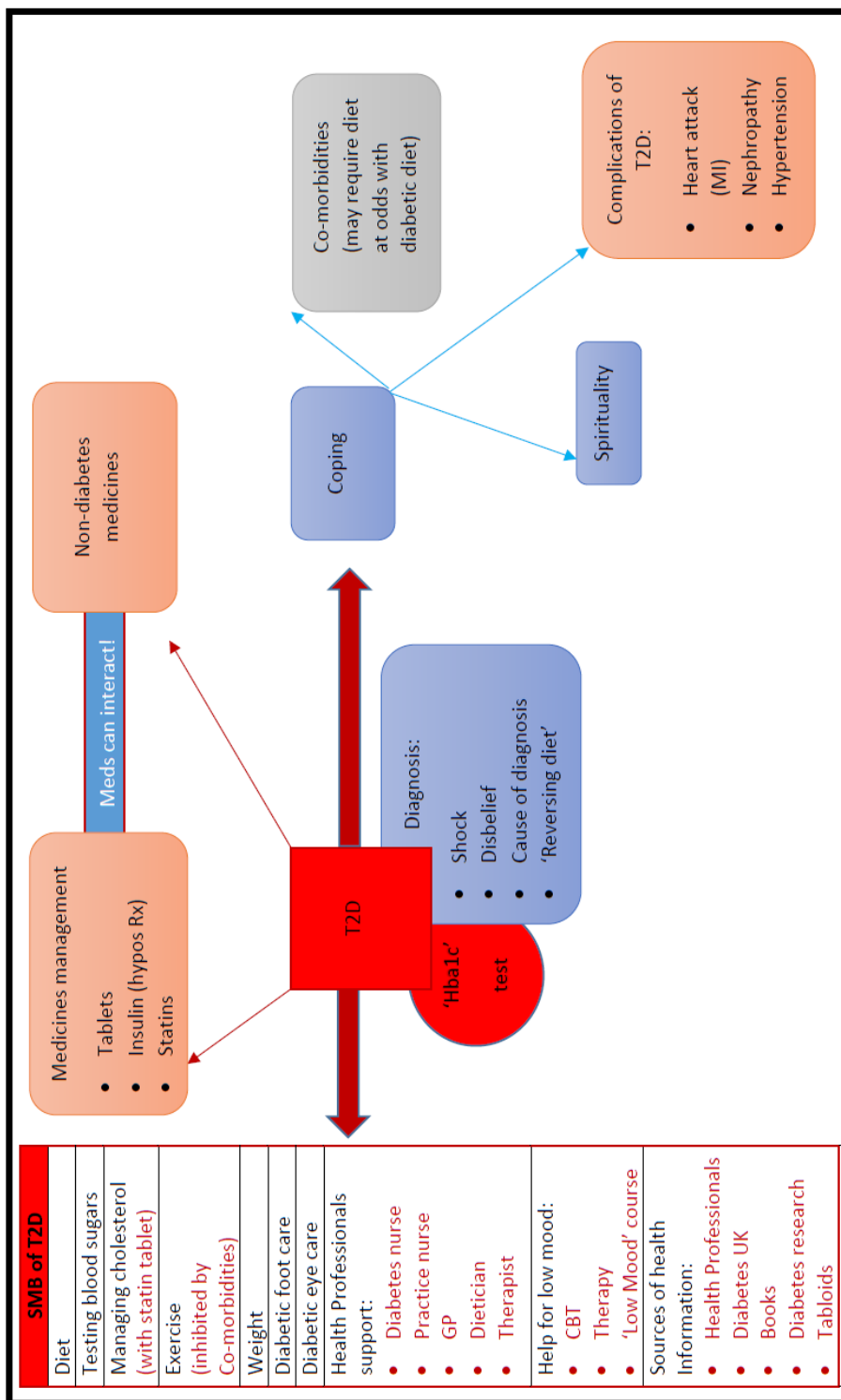
4 'Decision-making' code



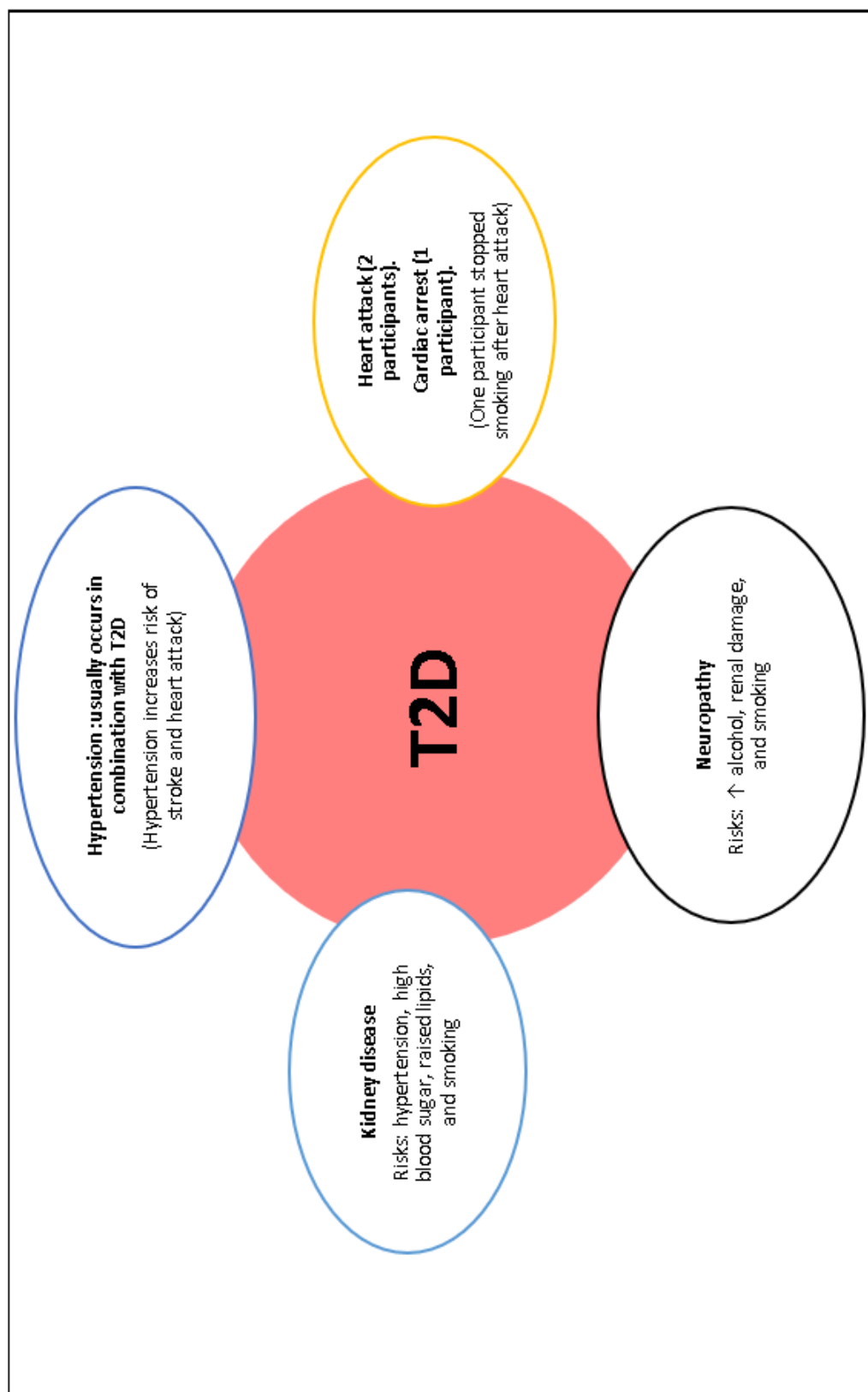
4a. 'Lack of responsibility' code. Child node of 'Decision Making' code



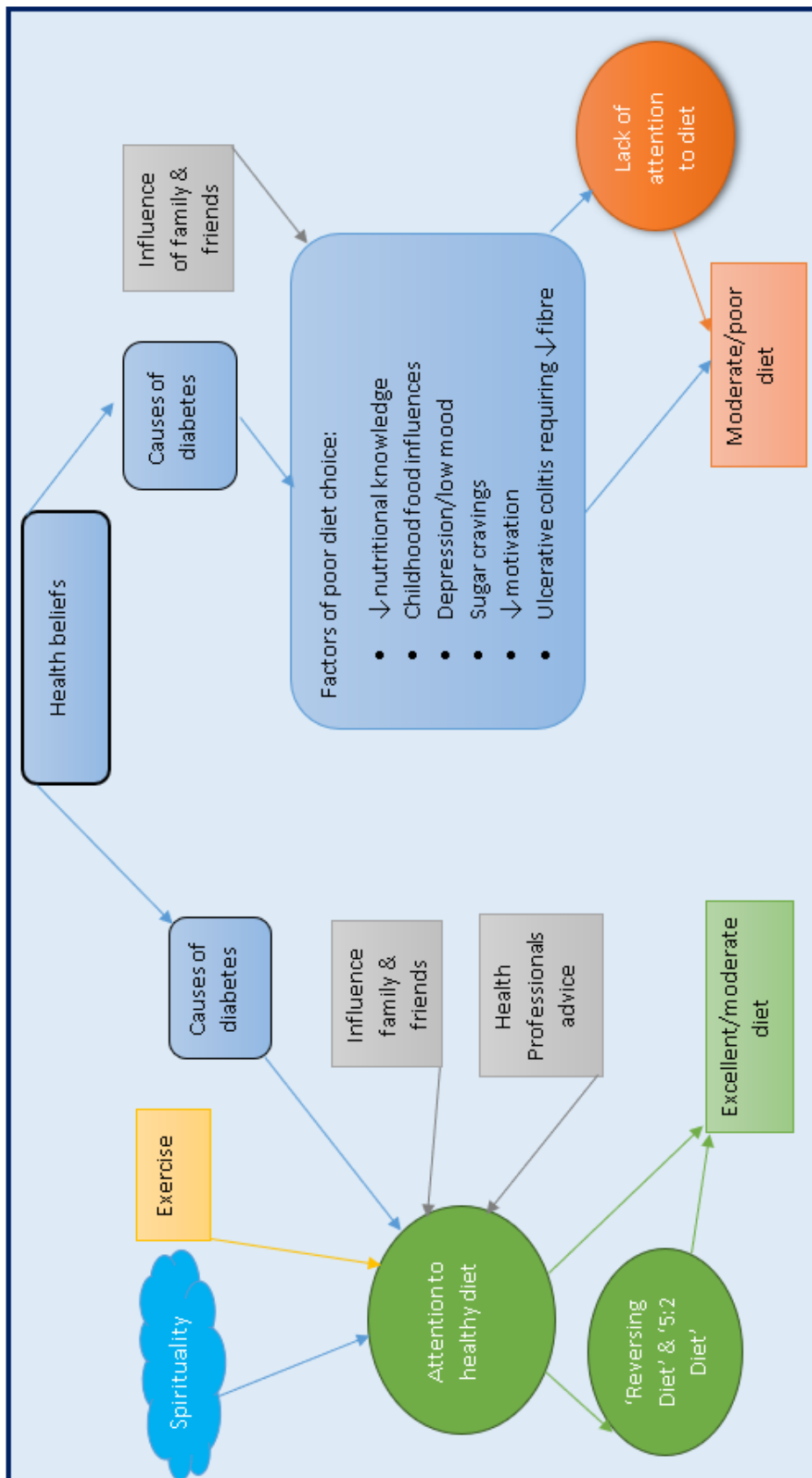
4a-b Combination of the Codes of 4b 'Problem solving' and 4c 'Responsibility' codes



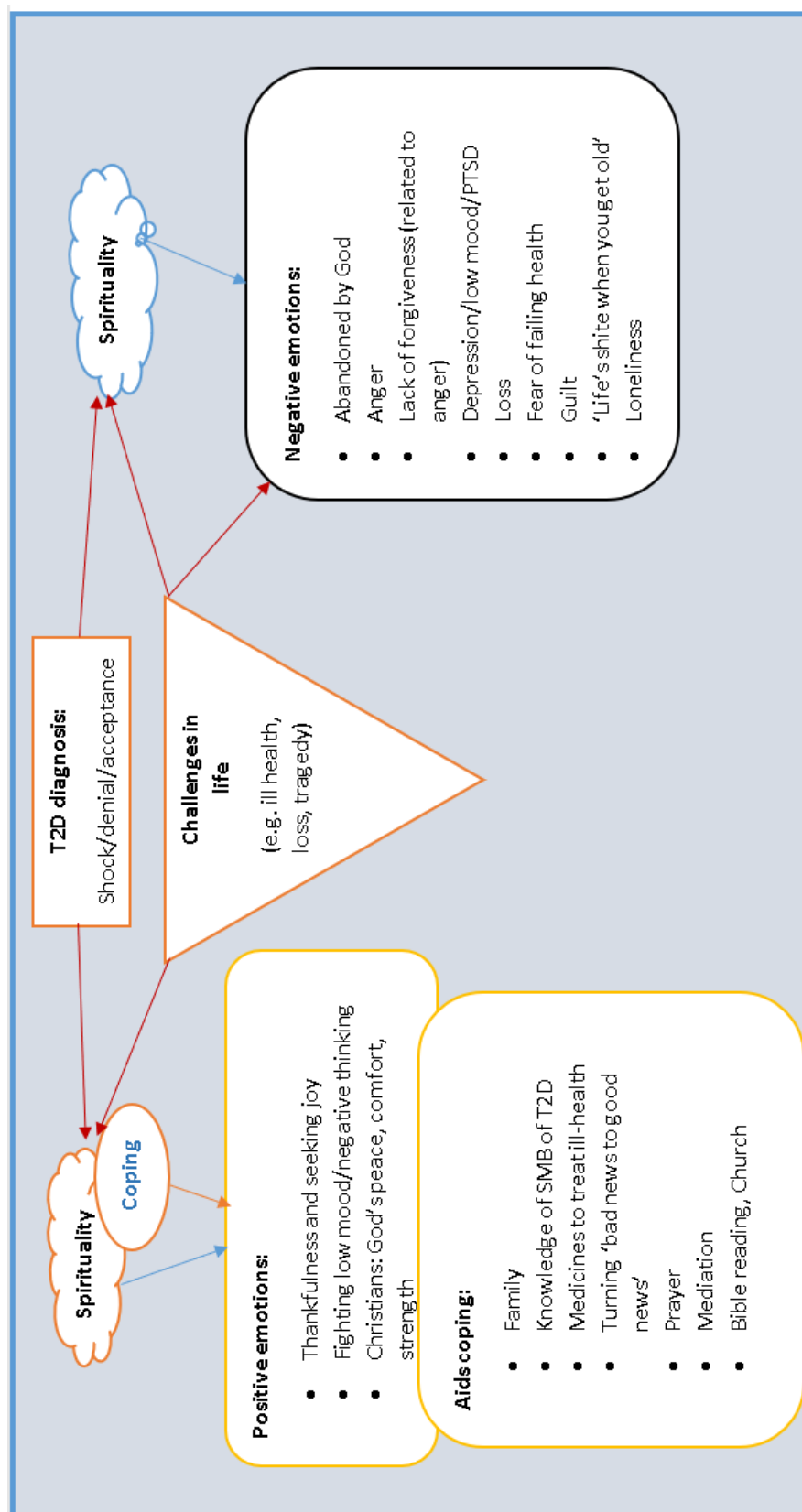
5 'Diabetes' code (Parent and Child codes)



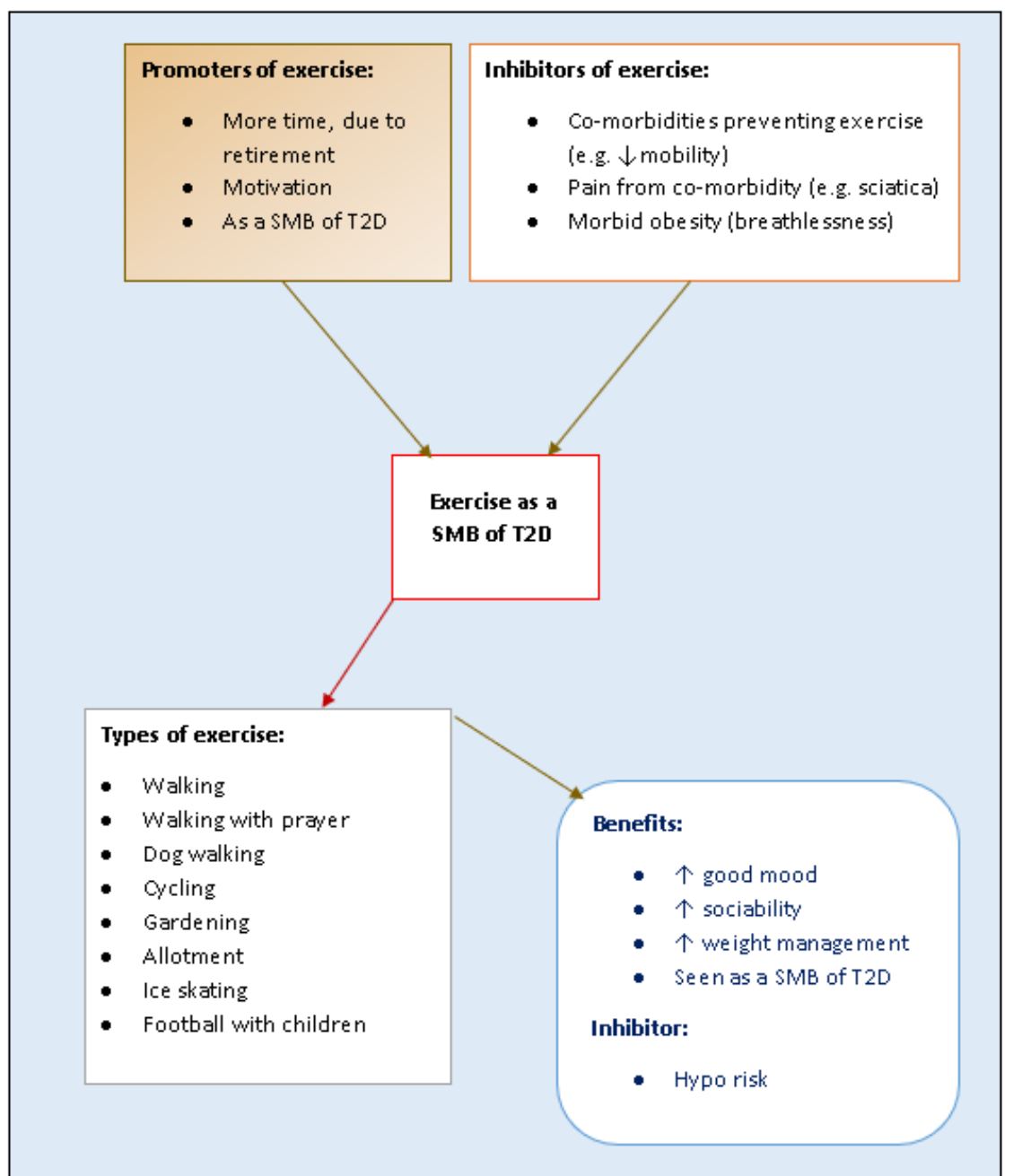
## 6 'Diabetes complications' code



7 'Diet' code

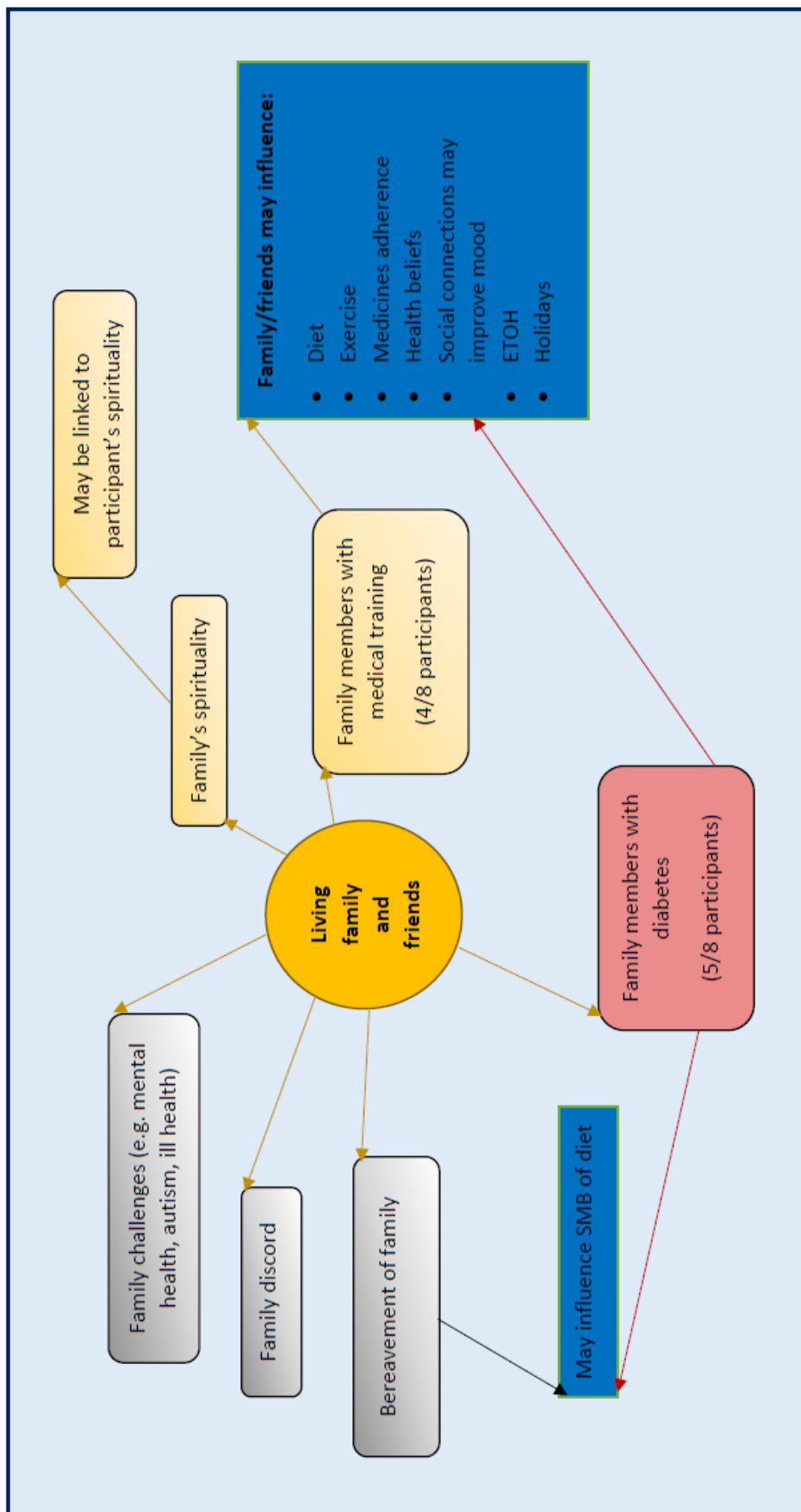


8 'Emotions' code

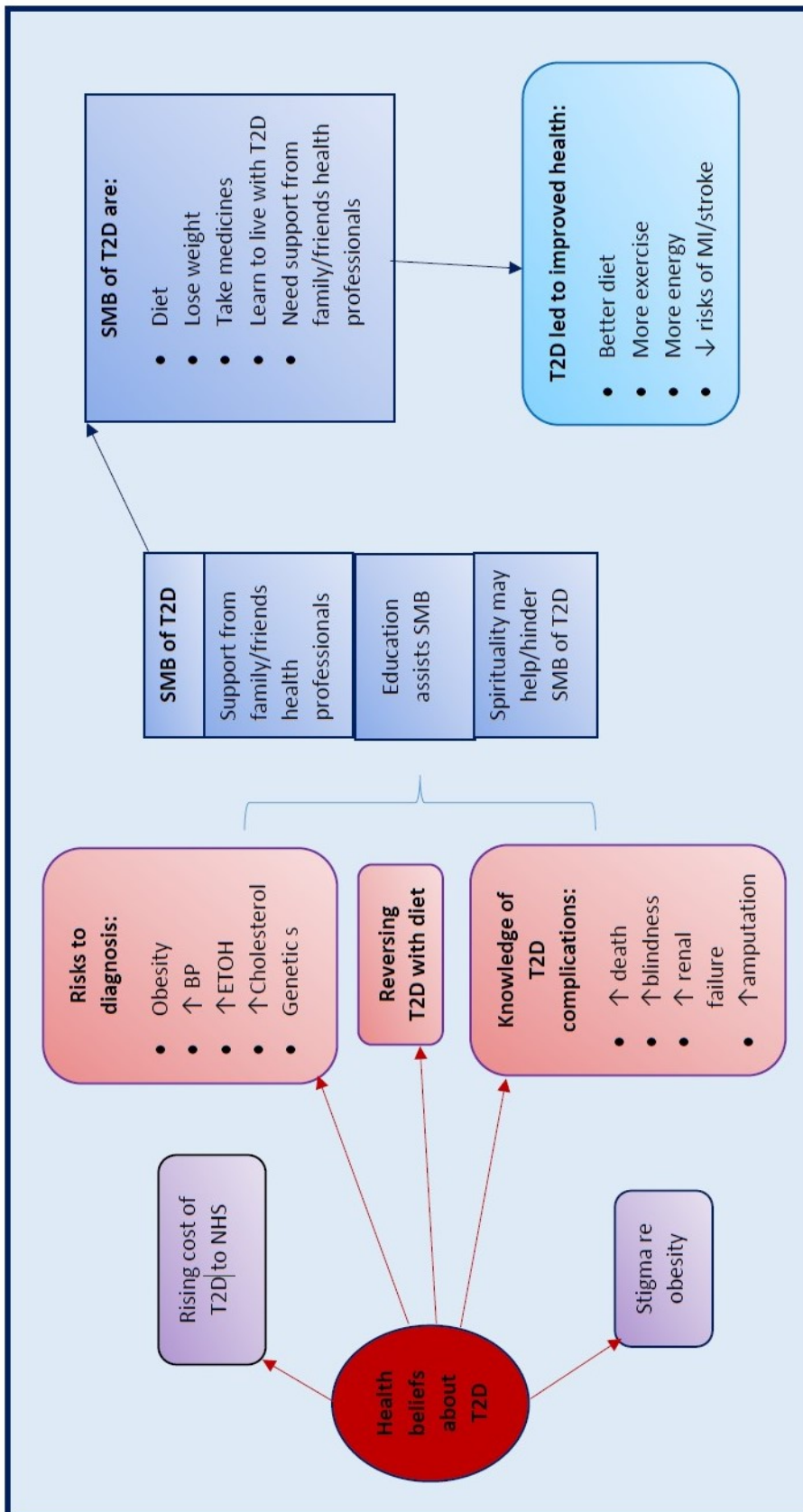


## 9 'Exercise' code

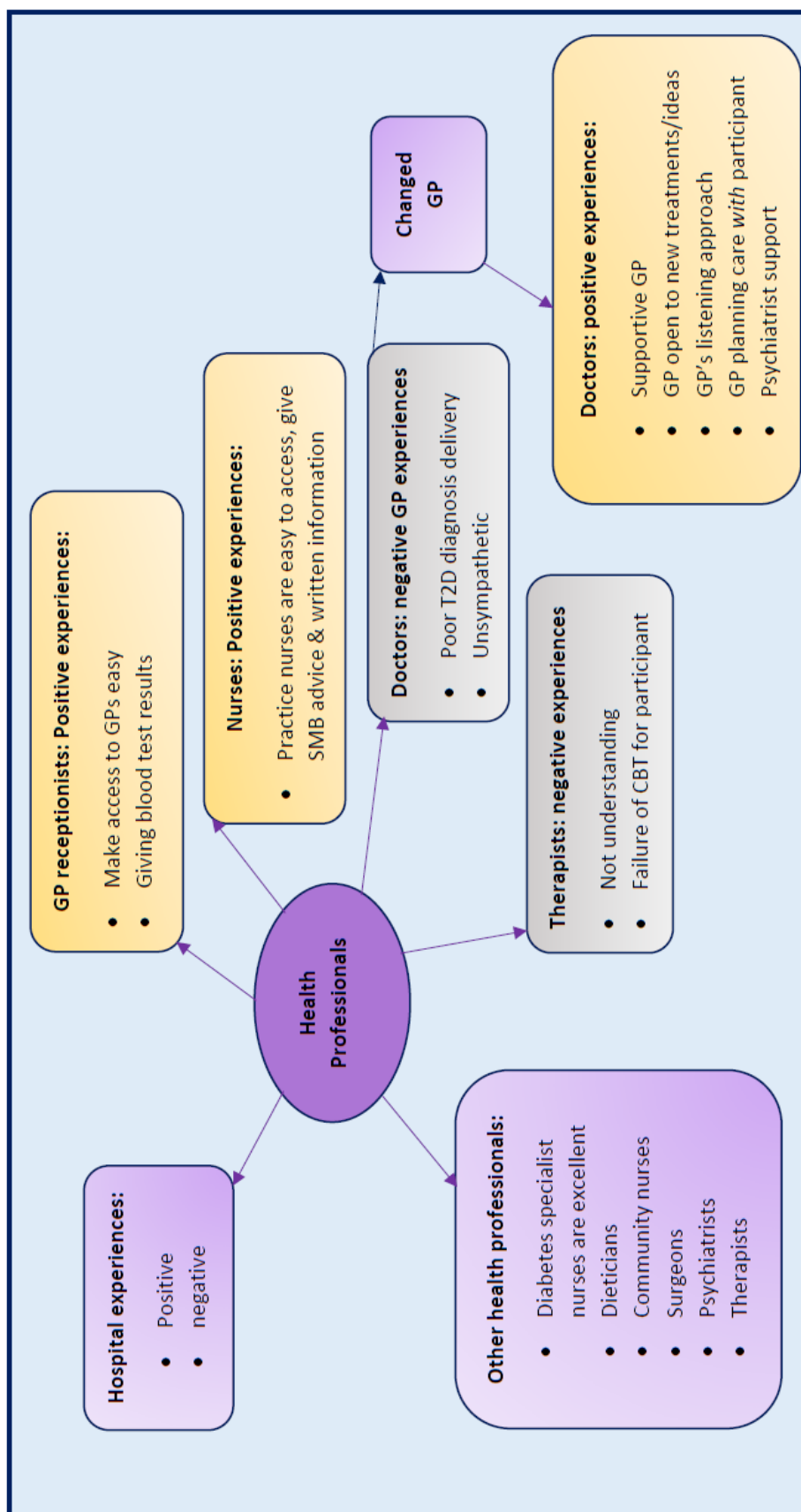




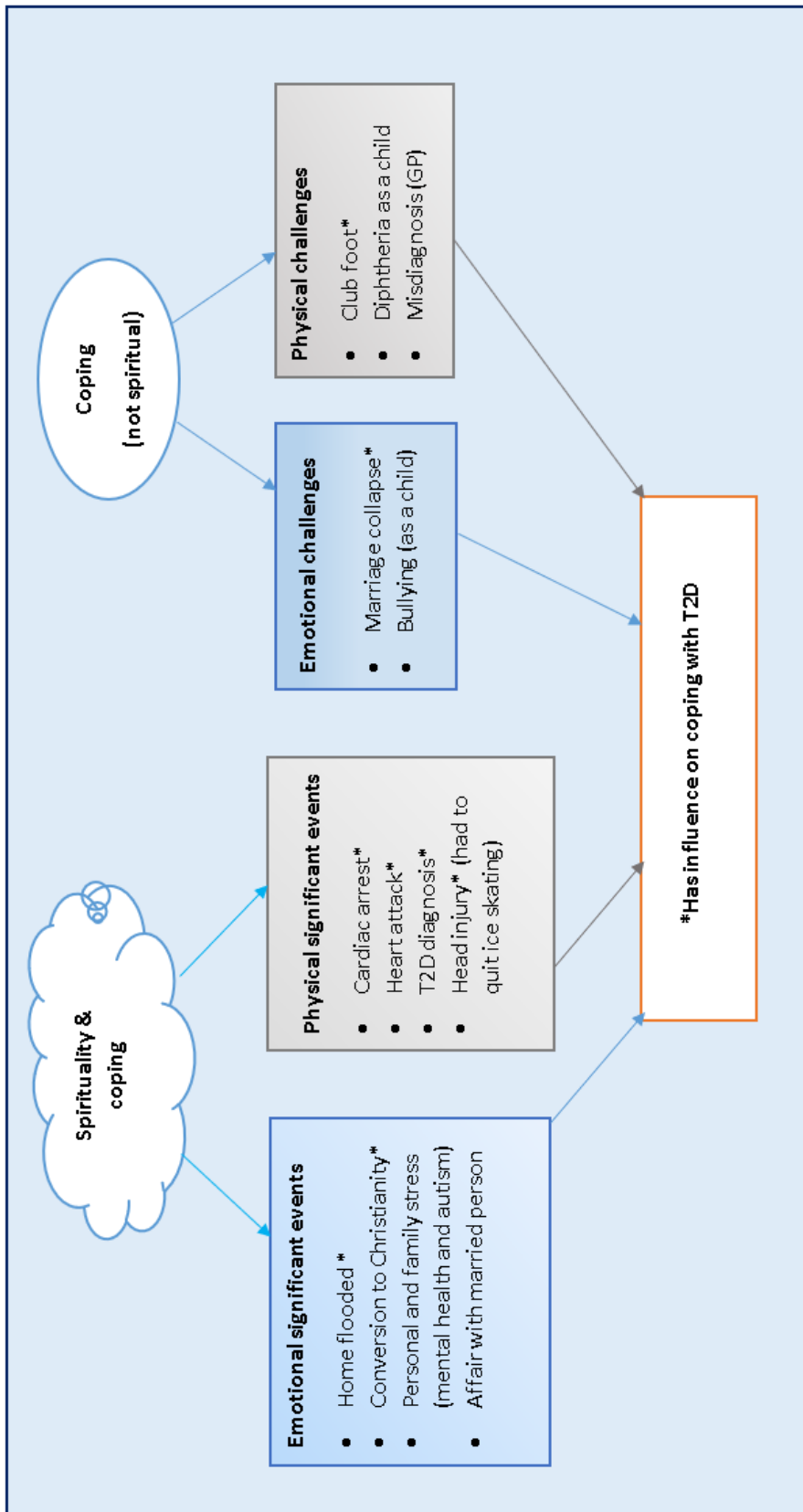
10 'Family/friends/social' code



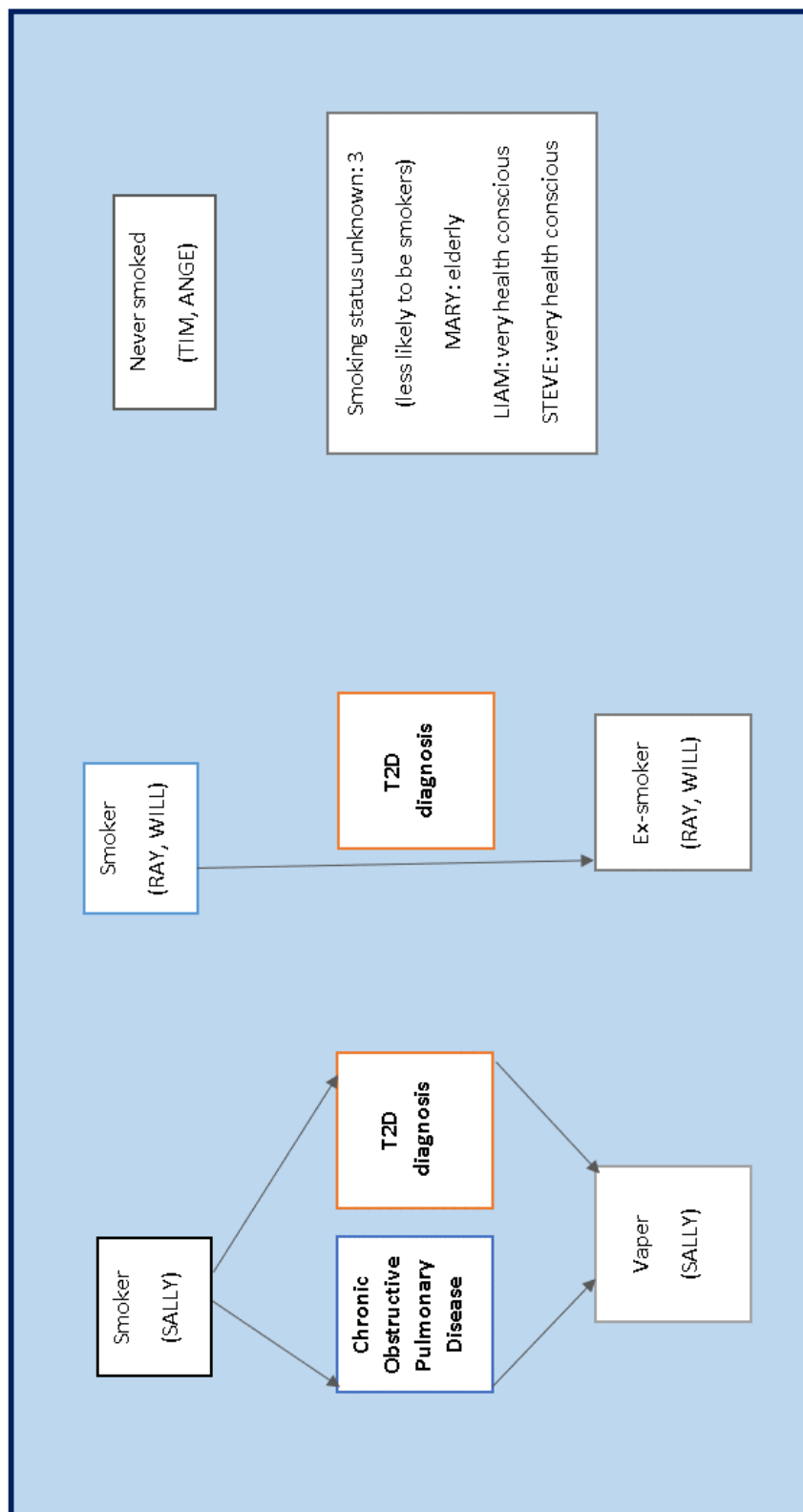
11 'Health beliefs' code



12 'Health professionals' code. (No map was created for the 13<sup>th</sup> sub-theme Politics, as it was not related to the research question)



14 'Significant events' code

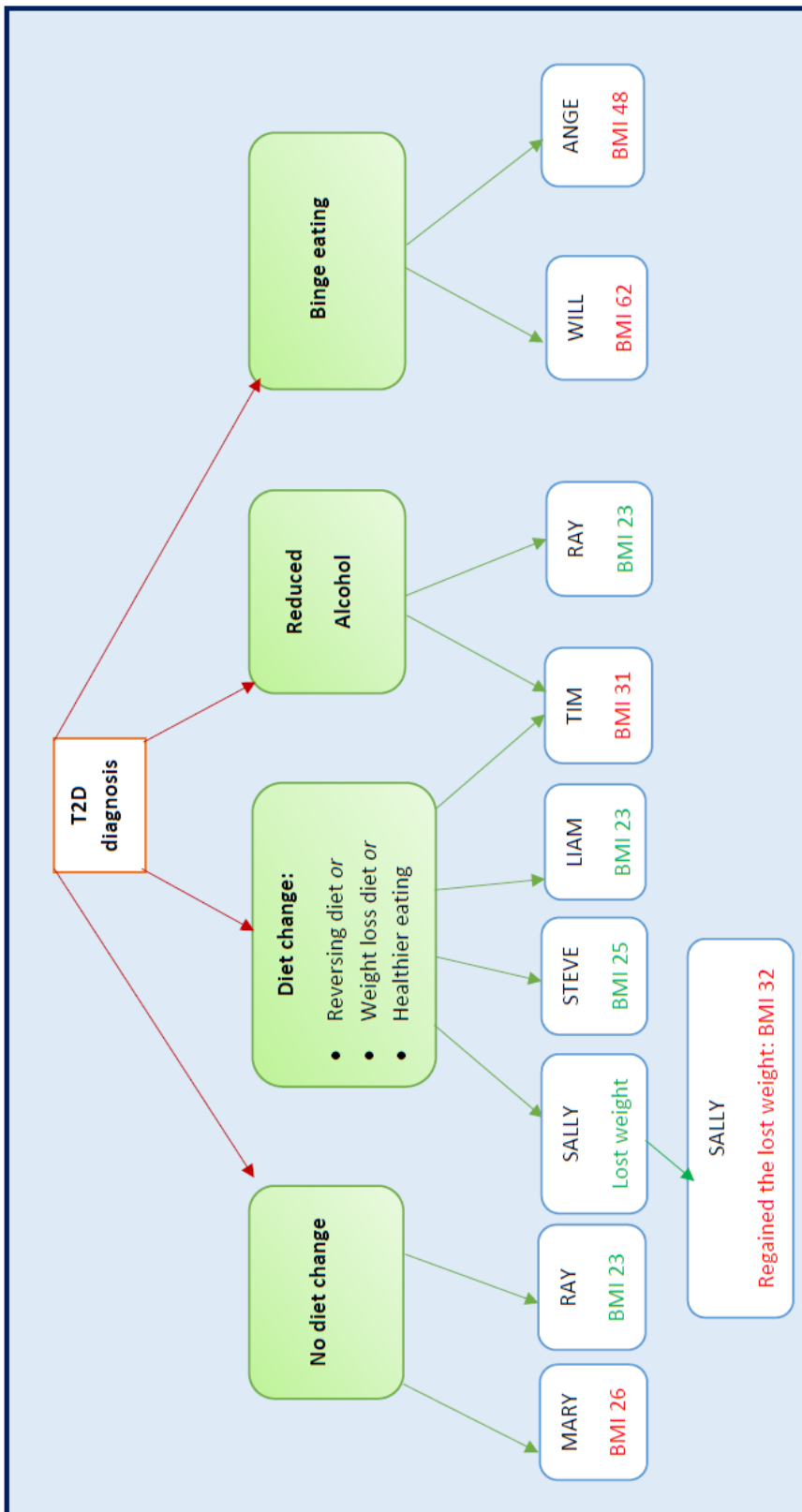


15 'Smoking' code

## 16. 'Spirituality' code

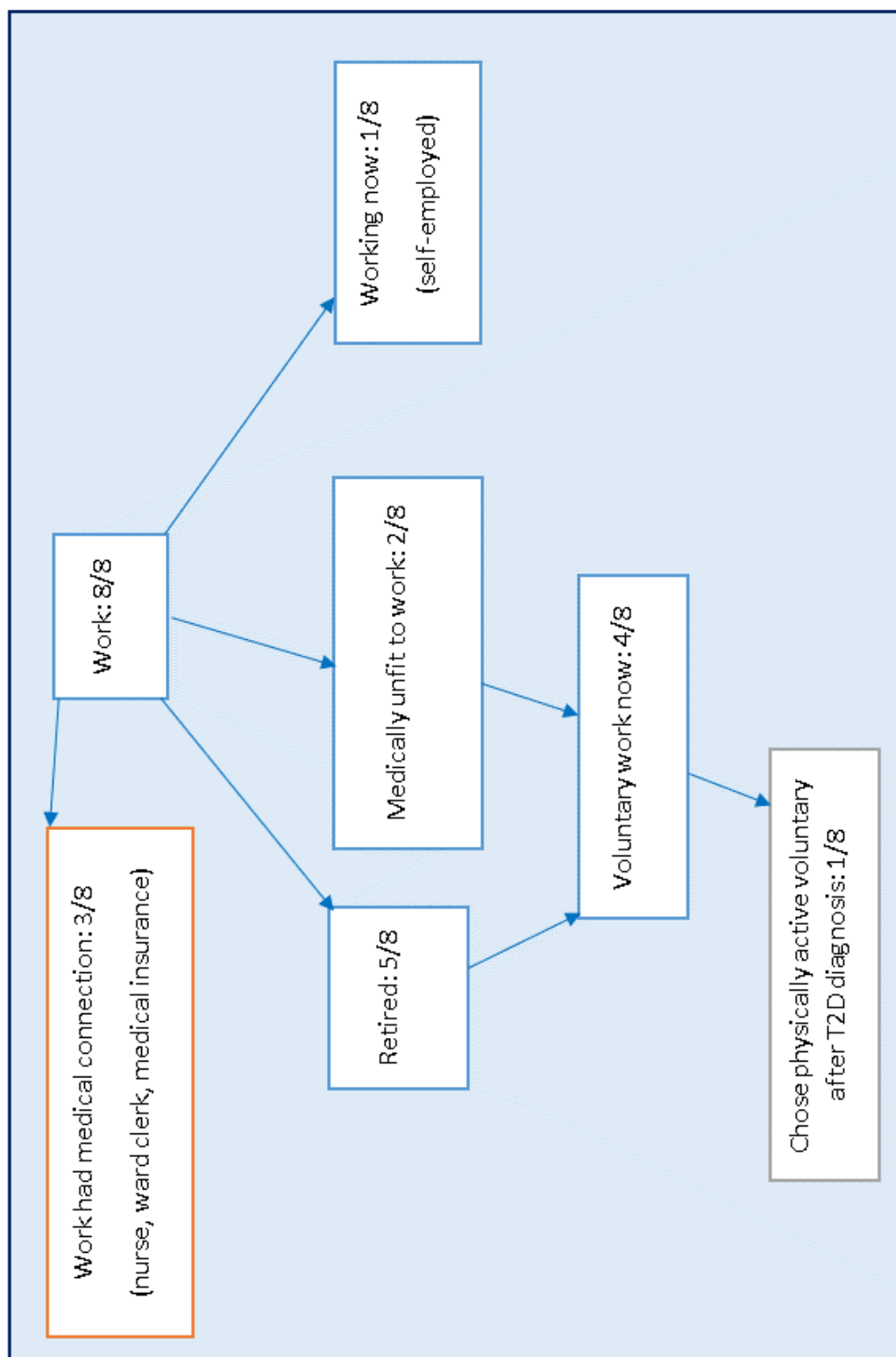
'SPIRITUALITY' Sub-themes	'Spiritual and religious' (Christians)	'Spiritual and NOT religious'
<b>Christian faith of participant</b>	<ul style="list-style-type: none"> <li>i) Death</li> <li>ii) Resuscitation experience</li> <li>iii) Afterlife beliefs</li> <li>iv) Belief in 'allotted life' span by God</li> <li>v) God influencing events</li> <li>vi) God's 'plan' in my life</li> <li>vii) Hope</li> <li>viii) Repentance</li> <li>ix) 'Lucky' or 'fortunate'</li> </ul>	<ul style="list-style-type: none"> <li>i) No belief in afterlife</li> </ul>
<b>Christian rituals</b>	<ul style="list-style-type: none"> <li>i) Prayer, communion and lighting candles</li> <li>ii) Connection with church</li> <li>iii) Reading the Bible</li> <li>iv) Listening to 'Evensong'</li> <li>v) Meditation</li> <li>vi) Fasting</li> <li>vii) Appreciation of nature</li> </ul>	Not applicable

'SPIRITUALITY' Sub-themes	'Spiritual and religious' (Christians)	'Spiritual and NOT religious'
<b>Gratitude</b>	i) To God ii) To family and friends iii) To health professionals iv) For nature and beautiful world	i) For having type 2 diabetes, as it led to a healthier life ii) To family and friends iii) To health professionals
<b>God's love</b>	No sub-codes	Not applicable
<b>Christian faith of other family members/friends/colleagues</b>	No sub-codes	Not mentioned
<b>Angry with God</b>	No sub-codes	Not mentioned
<b>Coping <i>not</i> faith based</b>	i) Walking ii) Friends and family iii) Working with health professionals iv) Managing diet v) Managing medicines	i) Appreciation of nature (not associated with religious belief) ii) Allotment iii) Family
<b>Depression/low mood/ Post-traumatic stress disorder</b>	No sub-codes	No sub-codes



17 'Weight' code





18 'Work' code

## Appendix T Scoping of database for 'Diet, family and T2D' search

Building search from the DelphiS (UoS) database only in 2019 (See below for databases included in a DelphiS search):

1. Diabetes type 2 OR diabetes mellitus OR diabetes mellitus type 2 with search term 'subject terms'
2. 'Family' OR 'family relationships' with search term 'subject terms'
3. Combine titles 1, 2 and 3 for diabetes, family, and diet
4. Refined the 268 articles by only including articles from UK/Ireland, published 2009-2019, available at UoS.

Table 39: Results from DelphiS search for 'diabetes, family and diet' scoping

	Search on 4 July 2019	DelphiS Database (UoS)	Articles published in UK/Ireland in 2009-2019	Total
<b>Search number</b>	'Subject terms'			
<b>1.</b>	'diabetes type 2' OR 'diabetes mellitus' OR 'diabetes mellitus type 2'	278,683		

	<b>Search on 4 July 2019</b>	<b>DelphiS Database (UoS)</b>	<b>Articles published in UK/Ireland in 2009-2019</b>	<b>Total</b>
<b>2.</b>	'Family' OR 'family relationships'	2,168,451		
<b>3.</b>	'Diet'	765,940		
<b>4.</b>	Combine search 1, 2 and 3	289		
<b>5.</b>	<b>Combine search 1, 2 and 3 (UK/Irish: 2009-2019)</b>		<b>12</b>	<b>12</b>

Table 40: Electronic database DelphiS for Diabetes, Family &amp; Diet scoping

Database search	Search terms	Name of database
DelphiS (University Of Southampton database)	'type 2 diabetes'  'family' OR 'family relationship'  'diet'	ERIC, AMED - The Allied and Complementary Medicine Database, RILM Abstracts of Music Literature (1967 to present), PsycINFO, Teacher Reference Center, PsycARTICLES, Business Source Premier, EconLit, MEDLINE, SocINDEX with Full Text, American Bibliography of Slavic and East European Studies, CINAHL Plus with Full Text, Library, Information Science & Technology Abstracts, Computers & Applied Sciences Complete, RISM Series A/II: Music Manuscripts after 1600, GreenFILE, European Views of the Americas: 1493 to 1750, PsycBOOKS, Arts & Humanities Citation Index, Science Citation Index, Social Sciences Citation Index, ScienceDirect, MLA International Bibliography, Oxford Scholarship Online, Oxford Handbooks Online, arXiv, Informit Business Collection, Informit Engineering Collection, Informit Health Collection, Informit Humanities & Social Sciences Collection, eBook Collection (EBSCOhost), Art Abstracts (H.W. Wilson), Newswires, Informit Literature & Culture Collection, Research Starters, SciELO, BioOne Complete, CogPrints, Naxos Music Library Jazz, Naxos Music Library, Naxos Spoken Word Library, Oxford Reference, Informit Indigenous Collection, Academic Search Index, Supplemental Index, Complementary Index, Grove Art Online, American National Biography Online, Grove Music Online, Directory of Open Access Journals, Public Information Online, eArticle, HeinOnline, OAPEN Library, British Library ETHOS, 19th Century British Pamphlets, Henry Stewart Talks, Oxford Dictionary of National Biography, University Press Scholarship Online, Scopus®, British Standards Online, ACLS Humanities E-Book, Adam Matthew Digital, Rock's Backpages, ProjectMUSE, Cochrane Database of Systematic Reviews, Oxford Bibliographies, JSTOR Journals, Knovel, SciTech Connect, Sustainable Organization Library (SOL), MathSciNet via EBSCOhost, FT.com, RePEc, Orlando: Women's Writing in the British Isles, from the Beginnings to the Present, NASA Technical Reports, Routledge Handbooks Online, IEEE Xplore Digital Library, Emerald Insight, Times Digital Archive, Open Textbook Library

Table 41: Articles excluded from Diet, Family and T2D literature scoping

Author	Title	Details	Reason for exclusion
Ahmadi-Abhari S., et al.	'Dietary Intake of Carbohydrates and Risk of Type 2 Diabetes: the European Prospective Investigation into Cancer-Norfolk Study', <i>British Journal of Nutrition</i> , 111(2): pp. 342-352.	Investigated association between dietary intake of carbohydrates and T2D risk. N= 749. Method: Food diaries analysed. Findings: fructose and glucose are inversely associated with T2D risk.	Excluded. Not about family effect on diet.
Lee et al.	(2018) 'The Associations of Illness Perception with Metabolic Control (HbA1c) Among Type 2 Diabetes Mellitus Patients in a District Hospital, <i>International Journal of Pharmacy Practice</i> , 26(5): pp.442-449.	N=749 people with T2D, aged 40-79 years old. Method: Food diaries. Analysed using Cox hazard regression. Findings: fructose was inversely related to diabetes risk.	Excluded. Not about family effect on diet.
Cox and Bostock, B.	(2018) 'Curing type 2 diabetes?', <i>Practice Nurse</i> , 48(2): pp.16-19	N=149, aged 20-65 years old. British patients with T2D. Method: very low calorie diet with exercise. Findings: 24% of patients lost 15kg or more.	Excluded. Not about family effect on diet.
Shi, L et al.	(2011) 'Healthy Lifestyle Factors Associated with Reduced Cardio-metabolic Risk, <i>British Journal of Nutrition</i> , 2011 Supplement 3; 105: pp.747-754.	Part of multi-centre multi-stage epidemiological study. Examined the combination of healthy lifestyle behaviours and cardio-metabolic risk. N=1,454. Method: Cross sectional study.	Excluded, as did not include family influence on lifestyle factors of diet.

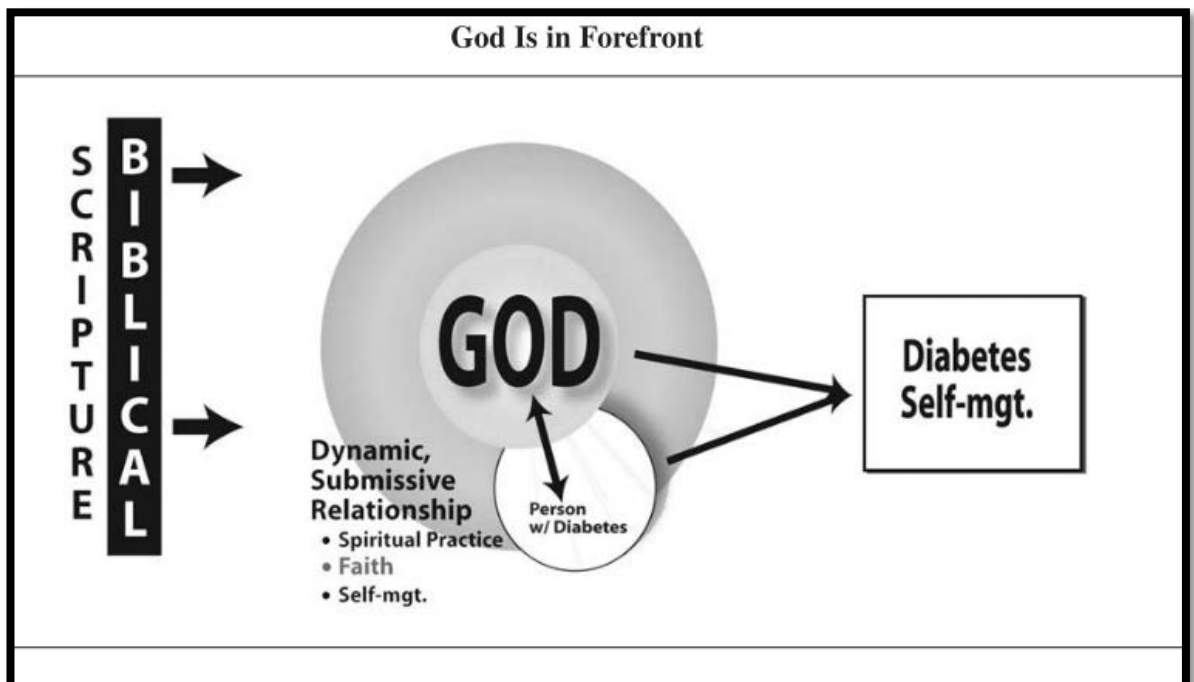
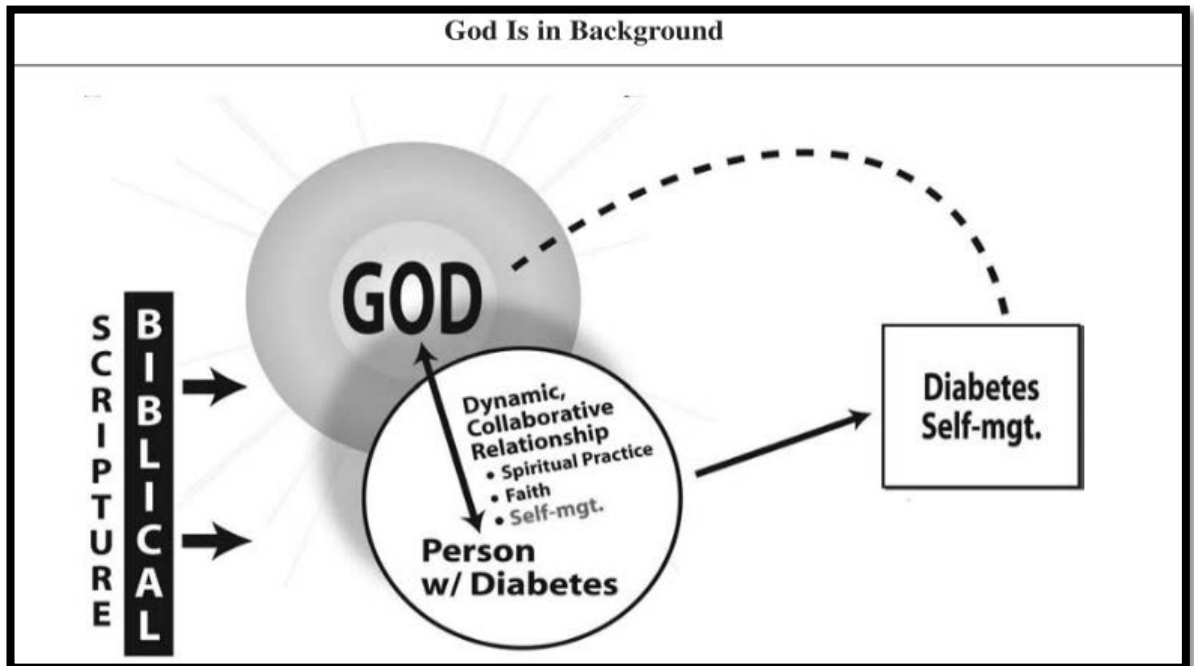
		Findings: Higher healthy lifestyle score associated with lower prevalence of cardio-metabolic risk.	
Gorter, K et al.	(2010) 'Preferences and Opinions of Patients with Type 2 Diabetes on Education and Self-care: a Cross-sectional Survey', <i>Diabetic Medicine</i> , 27(1): pp.85-91.	Assessed preferences of people with T2D regarding self-care activities and diabetes education. N = 994. Method: Questionnaire in Netherlands; analysed using SPSS for Windows. Findings: 19% thought they had poor/average diabetes control; 61% thought they were overweight; 32% thought they took too little exercise. Some preferred education by nurses, some by doctors, and mobility affected exercise.	Excluded, as did not include family influence on lifestyle factors of diet.
Ball, L., et al.	(2012) 'Patients' Perceptions of Nutrition Care Provided by General Practitioners: Focus on Type 2 Diabetes', <i>Family Practice</i> , 29(6): pp.719-725	Examined people with T2D in Australia regarding information received about diet from GPs. N=939. Method: cross sectional online survey. Findings: 43% received advice from GPs. 91% were satisfied regarding nutrition information from GPs, but only 34% thought it improved their personal effectiveness regarding nutrition.	Excluded, as did not include family influence on lifestyle factors of diet.
Griffen , S., et al.	(2011) 'Protocol for the ADDITION-Plus Study: a Randomised Controlled Trial of an Individually-Tailored Behaviour Change Intervention Among People with Recently Diagnosed Type 2 Diabetes under Intensive UK	Explanatory RCT behaviour change intervention for newly diagnosed people with T2D. N=478. Method: patients randomised to receive intensive treatment alone or this plus behaviour change intervention. Findings: had not yet been reported.	Excluded – no results from trial included.

	General Practice Care', <i>BMC Public Health</i> , 11(1): pp.211-211.		
Maindal, H., et al.	(2011) 'Effect on Motivation, Perceived Competence, and Activation after Participation in the "Ready to Act" Programme for People with Screen-detected Dysglycaemia: A 1-year randomised controlled trial Addition-DK', <i>Scandinavian Journal of Public Health</i> , 39(3): pp. 262-271.	Investigated the effects of the 'Ready to Act' Programme, and was part of a larger trial (Addition-Cambridge trial). N =509 with dysglycaemia (not diabetes) – a diabetes screening programme. Method: Used group sessions and questionnaires. Findings: men benefited more than women from programme.	Excluded – not regarding T2D.
Duijzer, G., et al.	(2012) 'Translating the SLIM diabetes prevention intervention into SLIMMER: implications for the Dutch primary health care', <i>Family Practice</i> , Suppl 1; 29 i145-i152	Overview of the SLIM diabetes 1 year pilot prevention Dutch programme. No findings reported.	Excluded. Not regarding family and diet with T2D.
Nursing Standard 'In Brief News'	'In Brief: People with Type 2 Diabetes can Improve Blood Glucose Control with as little as 6.5 Hours of Specialist Dietary Advice, According to Research', <i>Nursing Standard</i> , 25(45): p.8.	"The findings, presented at the American Diabetes Association conference in San Diego this month, show that the government could save more than £360 million a year on medication if everyone with type 2 diabetes in England attended a self-management course. See <a href="http://www.experthealth.org.uk">www.experthealth.org.uk</a> for more information."	Excluded. Cannot access original article (no details on author or title, and internet address not linking to article)





Appendix U **Model of self-management through a relationship with God (Polzer & Miles 2007)**



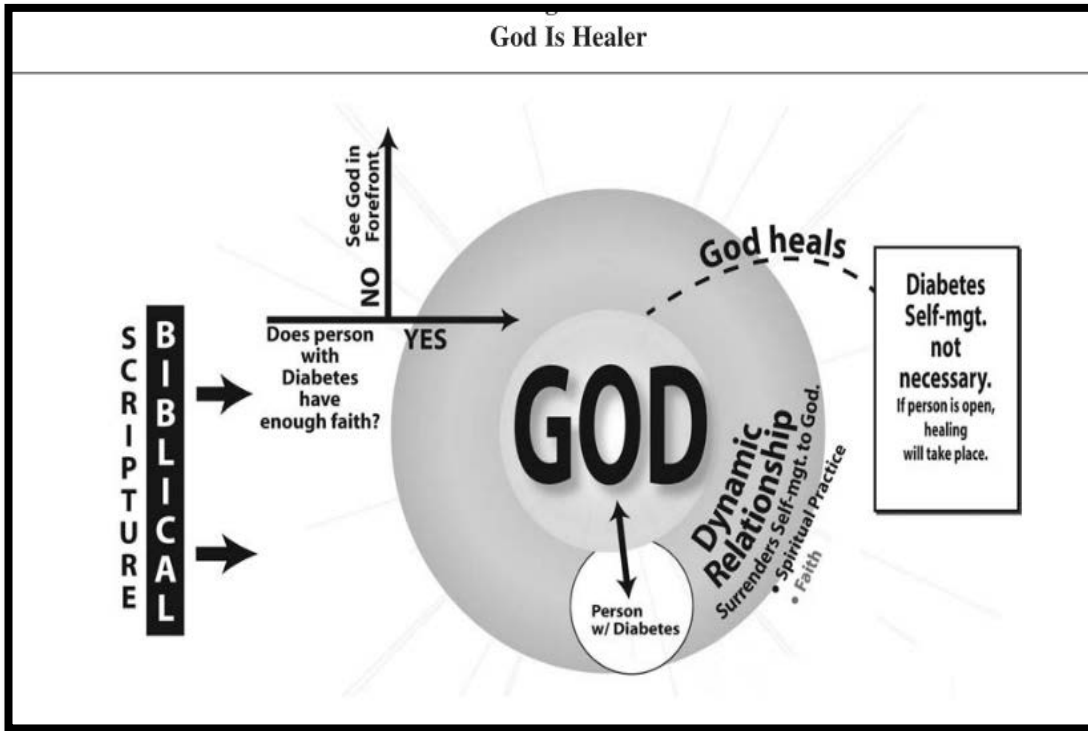


Figure 14: Model of self-management through a relationship with God (Polzer & Miles 2007)

Used with permission

## Appendix V Theoretical model (Koenig 2012)

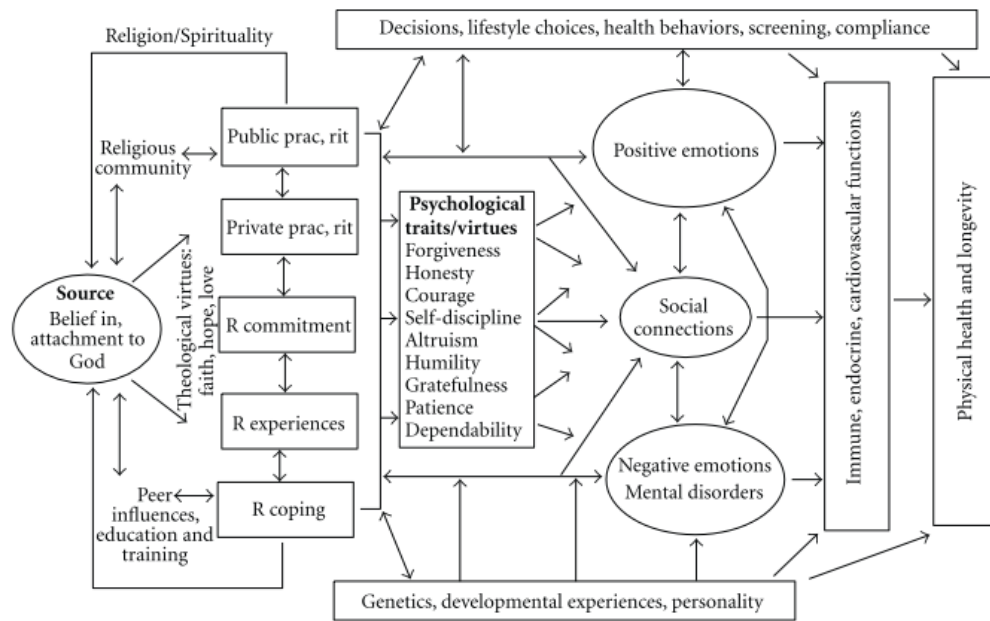


Figure 15: Theoretical model of causal pathways for mental health (Koenig 2012)

Used with permission



## Glossary of Terms

**Hypoglycaemia:** Occurs when blood glucose (BG) levels fall below the safe level of 4 mmol/L. The normal range of BG is 4-7 mmol/L.

**Hyperglycaemia:** When BG levels are greater than 8 mmol/L, taken at least 2 hours after a meal, or greater than 7 mmol/L when fasted. Various factors can cause this (such as eating a lot of carbohydrate, missing diabetic medication, or being ill).

**Morbid obesity:** a person's body mass index (BMI) is calculated from their weight and height. A normal BMI is in the range of 18.5-24.9. Morbid obesity is classed as having a BMI > 40.

**Neuropathy:** is a nerve disorder which has different categorisations. It may affect:

- the nerves which detect touch and temperature (sensory neuropathy)
- the nerves that control muscle movement (motor neuropathy)
- or nerves that control involuntary actions, such as digestion (autonomic neuropathy)

**Retinopathy:** Diabetic retinopathy is the most common form of diabetic eye disease. Diabetic retinopathy usually only affects people who have had diabetes (diagnosed or undiagnosed) for a significant number of years. Retinopathy can affect all diabetics and becomes particularly dangerous, increasing the risk of blindness, if it is left untreated.

(Diabetes UK 2017a)



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