

HOW DO ILLNESS PERCEPTIONS INFLUENCE THE EFFECTIVENESS OF SELF-MANAGEMENT IN INDIVIDUALS LIVING IN BERMUDA WITH TYPE 2 DIABETES?

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Abstract

Diabetes is a chronic condition that occurs when blood glucose, or blood sugar, levels are too high in the body (NHS, 2016). Diabetes UK (2009) estimates that self-management is 95% of managing diabetes. Self-management refers to an individual's ability to identify and manage signs, symptoms, treatment, psychological, emotional, and physical factors, and lifestyle changes which are essential to living with a chronic condition (Barlow et al, 2012; WHO, 2018). Illness perceptions are the cognitive beliefs and emotional interpretations that an individual has about their illness which usually are the determining factors for health behaviours such as self-management (Leventhal et al, 1997; Chew et al, 2014). The effectiveness of self-management behaviours in diabetes is an interesting area of research, particularly in developed countries where prevalence is high, but the research is underdeveloped. There is no existing research that investigates the contributing factors or causal prevalence of Type 2 Diabetes (T2D) in Bermuda. The aim of this original research is to explore the lived experiences which contribute to illness perceptions, of patients within the Bermudian population, with type 2 diabetes; and to gain an understanding of how these illness perceptions impact the effectiveness of self-management. To address this gap in the literature, a qualitative method was designed to contribute to a richer quality of data by providing the opportunity for the participants to elaborate on their lived experiences which influence cognitive and emotional representations of type 2 diabetes. In-depth semi-structured interviews were carried out with twenty-five participants (fifteen women and 10 men) living with T2D in Bermuda. Using Deductive Thematic Analysis, three themes were generated, 1) Beyond my control; 2) Who I am vs. who I *should* be- [Sociocultural challenges] and 3) If you don't listen, you feel. These themes described how the participants' perceptions of the cause of T2D influenced self-management practices. Some participants identified as diabetics and others considered themselves as individuals living with diabetes. These self-described identities influenced how participants controlled T2D. To identify as a Bermudian from a traditional sociocultural perspective opposes what it means to

behaviourally identify as a “good” or healthy diabetic. Attitudes towards T2D self-management and health behaviours are seemingly lax if there are no overt physical consequences. The participants have engaged in some form of diabetes self-management education (DSME) but there was a perceived gap between knowledge, understanding and behaviour which ultimately impacted the effectiveness of T2D self-management. Based on the study’s finding, the researcher recommends modifying Leventhal et al (2016) CSMSR to gain insight into illness perceptions and how it influences the effectiveness of T2D self-management for individuals living with T2D in Bermuda. The centralised element of the modified CSMSR *control*, interrelated to the remaining 4 elements, *cause, consequence, identity, and timeline*. This reflected how effective T2D self-management and the interrelationship of the CSMSR elements influenced the participants’ causal beliefs, post-diagnosis self-identity and perception of the timeline to implement healthy self-management practices before experiencing overt physical consequences. Existing literature supports the findings in this study for future health psychology practice to address illness perceptions and their influence on effective self-management practices in a cultural context for individuals living with T2D in Bermuda. Therefore, practitioner psychologists could benefit from utilising elements of Leventhal et al (2016) CSMSR to address beliefs and illness perceptions with patients and reduce the gap between knowledge, understanding and behaviour as it related to effective T2D self-management.

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Preface

The Professional Doctorate in Health Psychology requires the completion of 5 competencies: 1) Teaching and Training, 2) Consultancy, 3) Psychological Interventions, 4) Professional Skills and 5) Research. The research competency is divided into 2 parts, the systematic review, and an empirical study. This thesis is in partial fulfilment of the research competency.

Prior to enrolling in the Professional Doctorate in Health Psychology, I worked under supervised practice in Bermuda within multidisciplinary teams of health professionals in Cardiac Rehabilitation and a Diabetes, Respiratory, Endocrinology and Metabolic Programme providing psychological support. Throughout my tenure, I developed a keen interest in clinical work within this patient population. As I engaged in clinical assessments and treatment plans, I was alarmed by the number of individuals who were living with type 2 diabetes (T2D) in Bermuda and struggled to effectively self-manage this chronic condition. As I developed an awareness of the prevalence of T2D in Bermuda, it piqued my curiosity about the cause. As I began researching, I discovered the scarcity in literature which led me to this study. The focus of this research is to explore how illness perceptions influence the effectiveness of self-management in individuals living in Bermuda with type 2 diabetes?

As part of the research competency requirement, I completed a systematic review entitled, “Are Psychosocial Interventions Effective in Decreasing Depression in Middle to Older Adults with Type 2 Diabetes: A systematic review”. As the systematic review did not inform this research it has been included in the appendices (See Appendices G).

1.0 Introduction

Diabetes is a chronic condition that occurs when blood glucose, or blood sugar, levels are too high in the body (NHS, 2016). Blood glucose is regulated by insulin which is a hormone produced by the pancreas. Type 1 diabetes occurs when the pancreas does not produce enough insulin (NHS, 2016). In Type 2 diabetes (T2D), the insulin produced by the pancreas cannot be effectively used in the body (NHS, 2016). Blood glucose is measured through blood tests, such as HbA1c, to diagnose T2D (Punthakee et al, 2018). The HbA1c blood test indicates glucose levels that are categorised as normal, prediabetes and diabetes (Diabetes UK, 2019). Normal blood glucose levels are less than 6.0% (Diabetes UK, 2019). T2D is diagnosed when blood glucose levels are above 6.5% (Punthakee et al, 2018). Prediabetes, or borderline diabetes, occurs when blood glucose levels are higher than normal levels but lower than diabetes diagnostic levels and range between 6.0-6.4% (Diabetes UK, 2018; Punthakee et al, 2018). When T2D is uncontrolled, insulin is not regulated, and an individual may experience persistent raised blood glucose levels, or hyperglycaemia, which can lead to serious complications in several of the body's systems over time (WHO, 2018).

According to the World Health Organisation (WHO, 2018), it is estimated that as of 2014, there are over 422 million people worldwide living with diabetes. This number has increased from 108 million in 1980. The significant rise has been predominantly due to the upsurge of T2D and obesity as its driving force. In 2016, diabetes was the 7th leading cause of death and approximately 1.6 million deaths were diabetes-related. In 2014 the prevalence of diabetes was 8.5% in adults over 18 years, a significant rise from 4.7% in 1980 (WHO, 2016).

Diabetes does not only have an impact on physical health but on emotional and psychological health. Emotional wellbeing is crucial to the overall management of health, particularly for people with long term conditions such as diabetes (Jena et al, 2018). Acceptance and understanding how diabetes effects the body, the impact it will have on daily life, implementing lifestyle changes and the ability to self-manage all have a psychological impact on people living with diabetes (Chew et al, 2014).

On average, people living with diabetes spend only a few hours annually with health professionals (Diabetes UK, 2009). Most of the responsibility for managing diabetes is placed with the individual. Diabetes UK (2009) estimates that self-management is 95% of managing diabetes. Self-management refers to an individual's ability to identify and manage signs, symptoms, treatment, psychological, emotional, and physical factors and lifestyle changes which are essential to living with a chronic condition (Barlow et al, 2012; WHO, 2018).

Self-management health behaviours of individuals living with T2D are often influenced by the behaviours of family members (Vongmany et al, 2018; Kang et al, 2010; Rosland et al, 2010). Family members are not limited to individuals who are connected by biology, adoption, or marriage but they include persons who are actively incorporated into one's life (Peyrot et al, 2015; National Council for Family Relations, 2014). Family members, in various capacities, are influential to health-related behaviours (Fadlon & Nielsen, 2019). It is important to consider the role of family members in the effectiveness of T2D self-management as T2D affects both the individual living with T2D and their family members (Mayberry et al, 2014; Rosland et al, 2010;2012).

Bennich et al (2017) conducted an integrated review which identified and assessed existing literature published between 2000-2016 on an intra-family perspective of supportive and non-supportive interaction within the families of individuals living with T2D. The inclusion criteria were 1. Families with a member living with T2D and 2. A focus on supportive and/or non-supportive intra-family interactions relating to life with T2D. The exclusion criteria were 1. Focus only on either the family or individual living with T2D perspective and 2. Non-western culture. The 5 studies included in the review were both quantitative and qualitative which comprised of questionnaires, diaries, and dyadic interviews (Bennich et al. 2017). The family members in all the studies were represented by either a spouse or a partner. Supportive interactions were defined as both the patient and family member collaborating to fulfil a shared goal. The common goal was either maintaining the psychological and physical wellbeing for the family and the patient; or maintaining the patient's adherence to the

lifestyle recommended for diabetes. The findings included 3 categories of interactions: 1. Impact of practical action - Supportive actions were collaborative activities such as maintaining cooking, food shopping, diet, meal planning and social events such as dining out. Non-supportive actions were considered destructive behaviour, for example, the deliberate preparation of unhealthy meals 2. Impact of emotional involvement – Having a positive attitude towards T2D, and persuasion and reminders were considered emotional involvement and supportive behaviours. In contrast, non-supportive behaviours included the lack of emotional involvement and a focus on the negative aspects of T2D and 3. Impact of communication content – Supportive communication was experienced when partners acted as sounding boards and provided emotional support when difficult T2D arose. This also included communication about meeting shared goals for T2D management such as medication adherence and glucose monitoring. The patients experienced non-supportive communication as nagging, verbal expressions of irritation or coercion to veer from their recommended diet. Additionally, lack of acknowledgement and conflict unrelated to T2D negatively impacted the patients' self-management. The study concluded that family function and supportive and non-supportive interactions within the family have implications for individuals living with T2D. Because the majority of T2D self-management occurs within the family environment, it was important to include both the patient and family in clinical practice to target effective T2D self-management. Supportive and Non-supportive interaction from the intra-family perspective should be addressed as the patient and family are affected by each other (Bennich, et al, 2017).

Comparable to Bennich et al (2017) supportive and non-supportive familial behaviours impact individuals living with T2D. Pesantes et al, (2018) conducted a qualitative study in Lima, Peru which explored the role of family members in providing support to their relatives who live with T2D and the perception of the role family support plays in implementing the efforts of T2D management for the individuals living T2D. Using a phenomenological approach, the researchers aimed to gain an understanding of how the experiences of patients living with T2D managed their condition.

Additionally, this study was a formative study to assess the feasibility randomised control trial. The inclusion criteria were 1. A diagnosis of T2D for at least one year 2. Aged 18 years and over, and 3. The ability to give consent to be interviewed. Individuals were excluded if they had visible serious T2D-related complications, such as blindness or amputated limbs. An interviewer on the research team conducted pilot interviews with 2 participants and the remaining 18 participants who met the inclusion criteria engaged in the semi-structured interviews to gain a better understanding of the participants self-management practices within the context of the social support they receive at home and their experiences with T2D. The 20 semi-structured interviews, which averaged 50 minutes in length, were transcribed and analysed deductively using a created codebook. The codebook assisting in shaping and identifying priori codes as patterns in the text became notable and were subsequently generated into themes. The study's findings revealed that individuals living with T2D received most of their familial support from their spouses and children. These family members provide motivation and encouragement to maintain and fight for their health. Additionally, they offered practical support such as healthy meal preparation, medication reminders and shared physical activities. However, these forms of support were also perceived as controlling or intrusive. Some participants shared that family members demonstrated non-supportive behaviours such as not adapting to their T2D-friendly eating habits. Participants expressed resentment towards relatives who did not make an effort to consider their dietary restrictions and described how family members' eating behaviours undermined their T2D self-management practices. However, there were limitations in the study. There was no data collected to gain insight from the family members' perspective about participatory behaviours for T2D management. This resulted in the inability to analyse the interaction between perceived and actual received support for both the participants and their family members. Additionally, this information would have provided an understanding about the family members' viewpoints about appropriately engaging in controlling behaviour. However, the study concluded that the implementation of interventions designed to target the supportive behaviours of key family member will improve overall T2D self-management practices (Pesantes et al, 2018).

As suggested in the previous studies, the self-management practices of individuals living with T2D are influenced by the behaviours of family members (Bennich et al, 2017; Pesantes et al, 2018). Routh et al (2019) conducted a cross-sectional study that explored the complexities of familial interactions, cultural norms, and experiences with T2D contributed to self-management behaviours throughout their lifespan. The 20 African American parent-adult child dyads comprised of 21 parents and 20 adult children met the following inclusion criteria. 1. The family had at least one parent or child participant who was living with T2D, 2. The parent had to have had at least one immediate biological relative such as a grandparent, parent, or sibling, either living or deceased, who was diagnosed with T2D and 3. This patient had an adult child who was both willing and available to participate in the study. Both the parent and adult child participants simultaneously engaged open-ended, semi-structured interviews with the principal investigator (PI) who shared the same racial background. Although the PI and the participants did not establish a rapport prior to the study, as the interview progressed, the PI shared personal connections to the study topics where relevant. The interviews explored the recollections or first experiences of T2D and T2D socialisation within the family; T2D diagnosis; the meaning of being diagnosed with T2D; food and nutrition; exercise; T2D management resources (individual, familial, social, medical, financial); coping resources; family support and intervention programming and adverse events that could exacerbate T2D. The researchers focused on data which described the experiences of intergeneration transmission of dietary and nutritional information, behaviours and understanding. Through inductive content analysis, Routh et al, (2019) generated two themes; 1. Family interactions characterised by T2D-related actions and communication patterns and 2. Intergenerational patterns of openness. The findings emphasised the importance of emotions and personal beliefs about T2D and how these factors shape familial interaction and how they were later perceived. The patterns that were identified related to how parents interacted with children across generations and wanting the future generations to be more informed about T2D. As the participants shared their experiences, often from childhood, as a part of their family's legacy of T2D, these interactions fuelled their beliefs, perceptions, and subsequent health behaviours. However, there

were limitations to the study. The researchers were able to recruit a sufficient number of parent-adult child dyads, the total number of participants was relatively small. Also, as this was a cross-sectional study, the researchers did not collect data to analyse the direct effects of family member beliefs, interactions or relationships. However, the qualitative approach allowed the researchers to emphasise on the experiences of individuals with strong family histories of T2D that are often unobserved or grouped together with other segments of the wider population. In this study, the participants acknowledged and considered the impact of multigenerational transmission and behaviours which can serve as a future incentive to organise family-level changes in behaviour (Routh et al, 2019).

Similarly, Mayberry et al (2014) conducted a study which examined the behaviours of family members and individuals living with T2D. Mayberry et al (2014) examined the association of obstructive family behaviours and glycaemic control among individuals living with T2D with limited health literacy compared to individuals living with T2D with adequate health literacy. This mixed-method study assessed whether support from family members of individual living with T2D and limited health literacy were associated with better glycaemic control. Additionally, the study assessed if supportive behaviours from family members protected individuals living with T2D with limited healthy literacy from obstructive behaviours and worse glycaemic control. The 53 participants of individuals living with T2D were recruited from a health centre in Nashville, USA. The participants either completed a telephone survey (N=38) and/or attended a focus group (N=13). The outcome measures for glycaemic control were a blood test administered by a clinical nurse and the participants' completed the Test of Functional Health Literacy in Adults and the Diabetes Family Behaviour Checklist II questionnaires. The differences between the participants who completed the survey only and participants who attended a focus group were assessed. The following four themes were generated based on the research question; 1) supportive family behaviours, 2) nagging/ arguing family behaviours, 3) sabotaging family behaviours and 4) suggestions and opinions about engaging family members in diabetes self-care (Mayberry et al. 2014). The participants with limited health literacy reported more supportive family

behaviours compared to participants with adequate health literacy. There was no association with health literacy status and obstructive family behaviours and glycaemic control. However, regarding low family supportive behaviours, there was an association with worse glycaemic control among participants with limited health literacy compared to participants with adequate health literacy. A limitation to this mixed-method study was the lower than desired number of participants in the focus group which in some instances, led to the inability to reach thematic saturation. Also, the researchers were unable to determine if differences in views on the role of family in adults' diabetes management were influenced by racial and/or cultural differences or if the findings reflected individual variability. However, the researchers suggest that family members involved in the self-care practices of individuals living with T2D should be taught to avoid obstructive behaviours. Otherwise, these obstructive behaviours can be exceptionally harmful to individuals living with T2D with limited health literacy (Mayberry et al, 2014). The behaviours of family members, whether supportive or obstructive directly impact the self-care practices of individuals living T2D with limited health literacy (Brahmantia et al, 2020; Mayberry, et al, 2014).

Health literacy is important to the self-management practices of individuals living with T2D.

Health professionals who care for individuals living with T2D play a key role in maintaining a practitioner-patient relationship which is inclusive of providing education and support that is significant to effective diabetes self-management (Bridges & Smith, 2016; Cubaka et al, 2016; Peimani et al, 2018). Diabetes Self-Management Education (DSME) are sessions usually conducted by a multi-disciplinary team of health professionals who educate patients on diabetes knowledge and provide them with the necessary skills and ability to effectively self-manage their disease (Wahowiak, 2017). For this reason, it is important to understand the attitudes of health professionals who implement DSME programs.

The primary role of HCPs is to identify, address and support psychosocial challenges associated with T2D which in turn promotes increased self-efficacy to improve self-management practices (Jena et al,

2018). A randomised control trial conducted by Azami et al (2018) examined the effectiveness of a nurse-led DSME 12-week program on HbA1c education. The participants were recruited in a primary and secondary outpatient endocrine clinic in Ilam, Iran, which is the only leading medical service available to Ilamian residents with T2D. Individual who met the following inclusion criteria were eligible to participate in the study; 1) Iranian adults aged ≥ 18 years, 2) clinically diagnosed with T2D for a minimum of 6 months and 3) lab results showing $HbA1C \geq 8\%$. Of the 142 participants, there were 72 participants randomised to the control group which received usual care and 72 participants to the intervention group who received both usual care and the intervention. The study primarily hypothesised that a nurse-led DSME would improve HbA1c levels in the intervention group compared to the control group. The secondary hypothesis was an improvement to psychosocial outcomes such as the self-management behaviours, social support, self-efficacy, and quality of life (QOL) in the intervention group. The outcomes were assessed at baseline, 12-week post intervention and 24-week follow up. At post intervention, the intervention group showed significant improvements to HbA1C levels and psychosocial outcomes compared to the control group. The intervention group maintained improvement in comparison to the control group at the 24-week follow up. Although, the 24-week follow up period of time was considered a limitation to the study as it may not provide sufficient time to evaluate the long-term effect of the intervention. However, the findings led to the study's conclusion that the nurse-led DSME intervention was effective (Azami et al, 2018).

DSME programs that focus illness perceptions and health beliefs offer the motivation to increase knowledge and the development of skillsets to maintain health behaviours, lifestyle changes and can effectively prevent diabetes-related complications (Jarvis et al, 2010; Solhi et al, 2014). Both Diabetes Self-Management Education (DSME) and Diabetes Self-Management Support (DSMS) are considered crucial components of care for people living with diabetes (Beck et al, 2017).

DSMS are designed for the required support which addresses the patient's psychological and emotional needs, ethnic and cultural factors, socioeconomic status, cultural influences, health beliefs,

illness perceptions and a host of other factors that have a role in an individual's ability to self-manage diabetes (Powers et al, 2015).

van Puffelen et al (2019) conducted a randomised control study to evaluate the effectiveness of a group-based T2D diabetes self-management support (DSMS) programme that focused on cognitions, diabetes distress and diabetes self-care.

The participants were recruited from General Practitioners'(GPs) offices across 6 regions of the Netherlands. Almost all the GPs in the Netherlands are organised in diabetes care groups who collectively agree upon a diabetes management program that is contracted by health insurers. Those GPs who were willing to participate in the study enrolled directly with the researchers. The eligible participants were included in the study based the following criteria: 1) diagnosed with T2D between 1 and 3 years prior to the study, 2) an electronic selection of all T2D individuals in participating GPs based on the T2D diagnosis code. From this point, all further data were manually extracted from electronic medical records. Individuals were excluded from the study if they met the following criteria: 1) aged over 85, 2) mentally or intellectually incapable to participate individuals were excluded and 3) if individuals were suffering from a severe, life-threatening condition or receiving current support from severe psychological or psychiatric problems. The participants were randomised into the intervention group which engaged in 4 group based interactive session or to the control group which received one educational lecture. The 82 intervention and 86 control group participants completed questionnaires on diabetes self-care, diabetes distress, diabetes-related attitudes, empowerment and partner support and illness perceptions. The outcomes were measures at baseline, immediately after the 3rd session and 6-months post intervention. The results showed that at baseline, the intervention group had slightly higher levels of diabetes self-care. Immediately after the 3rd session, the intervention group had a significantly higher increase in physical activity compared to the control group. However, at 6-months post intervention, this increase disappeared. Immediately after the program, with

relation to illness perceptions, the causal belief of T2D was bad luck or by chance in the intervention group who held significantly higher feelings of empowerment to self-manage T2D. The control group at 6-months post intervention had a significantly higher increase in perceiving T2D as having a long-term timeline. The researchers acknowledged the important role of partners in T2D management and noted that a limitation to the study was that half of the participants did not bring their partners to the course sessions. This could have had an implication on the effectiveness of the intervention (van Puffelen et al, 2019). However, the study concluded that increasing extensive support is necessary to achieve more maintainable behavioural changes. The researchers suggested that incorporating patients' illness perceptions and continuous DSMS to usual diabetes care (van Puffelen, et al 2019).

Evidence from systematic reviews, meta-analyses, cross-sectional and longitudinal studies confirm that illness representation directly correlates with physical and psychological health outcomes, specifically self-management behaviours in individual living with T2D (Asher et al, 2015; Baines, 2013; Breland, 2020; Broadbent et al, 2001, Hagger et al, 2003;2017; Mc Sharry et al, 2017).

Illness perceptions are the cognitive beliefs and emotional interpretation that an individual has about their illness which usually are the determining factors for health behaviours such as self-management. (Chew et al, 2014; Leventhal et al, 1997). In this context, one of the main goals of self-management is to acquire essential skills and resources, in particular the support of health professionals, which is necessary in informing decisions about diabetes treatment and management. An individual's ability to effectively self-manage diabetes is contingent on their knowledge about the disease, their illness perceptions and their self-regulatory behaviour (Baghbanian & Tol, 2012).

Leventhal and his colleagues developed the Common-Sense Model of Self-Regulation (CSMSR) which is the theory used to understand and predict an individual's responses, adaptation, coping strategies and inform self-management choices for chronic illnesses (Leventhal et al, 1980; Leventhal et al, 1992; McAndrew et al, 2008). The model emphasises the impact that an individual's lay, or common-sense perceptions to illness have in response to health threats which influences an individual's self-

management behaviour and overall health outcomes (Leventhal et al, 2016; Reynold et al, 2012; Shiyabola et al, 2018).

In the CSMSR framework there are interactions between two parallel processes; 1. Cognitive Process, which is an objective response, represents an individual's illness perceptions, coping mechanisms and evaluative processes and 2. Emotional Process, which is a subjective response, represents coping mechanisms and appraisals to assist with managing emotions associated with the illness (Leventhal et al, 1992; Martinez et al, 2017). (See Figure 1, Heffernan et al, 2016).

There are 5 core domains in the Cognitive Process. 1. Identity- the patient beliefs regarding the illness label and symptoms. 2. Timeline- the patient's beliefs around the duration of the illness; deciphering whether the illness is acute, short term or chronic, long term. 3. Consequences- the patient's beliefs about the emotional, psychological, financial effects of the illness. 4. Cause- the patient's belief about the possible causes of the illness such as lifestyle and genetic factors. 5. Perceived control- the patient's belief of the degree of control they will have over the illness. The Emotional Process of the CSM focuses on the patient's emotional response and the feelings that arise as a result of the illness. This can be related to cultural or social influences (Leventhal et al, 2005; Leventhal et al, 2016). (See Figure 1, Heffernan et al, 2016).

Both the cognitive and emotional processes of the CSM have 3 components; 1. Representation, 2. Coping and 3. Appraisal. Representation consists of an individual's perception of the illness symptoms. These perceptions are formed by information given from external influences such as the media, health professionals and significant others or previous experience with the illness. The parallel emotional process in the representation component of the CSM is the individual's emotional response to the illness (Leventhal et al, 1992; Leventhal et al, 2005). An individual's perceptions, which are developed and formed in the representation component, are directly influenced by the coping component. During this component, the individual processes information from internal and external influences in an attempt to control emotions such as fear in relation to the illness (Cameron & Leventhal, 2003;

Leventhal et al, 1992). In the appraisal component, the effectiveness of coping mechanisms outcomes and illness outcomes are evaluated in the cognitive process and the emotional process appraises coping mechanisms outcomes and emotional outcomes. During the feedback loop process the individual conducts an appraisal to determine whether their coping mechanisms and illness perceptions need to be maintained or modified (Cameron & Leventhal, 2003; Leventhal et al, 1992) (See Figure 1, Heffernan et al, 2016).

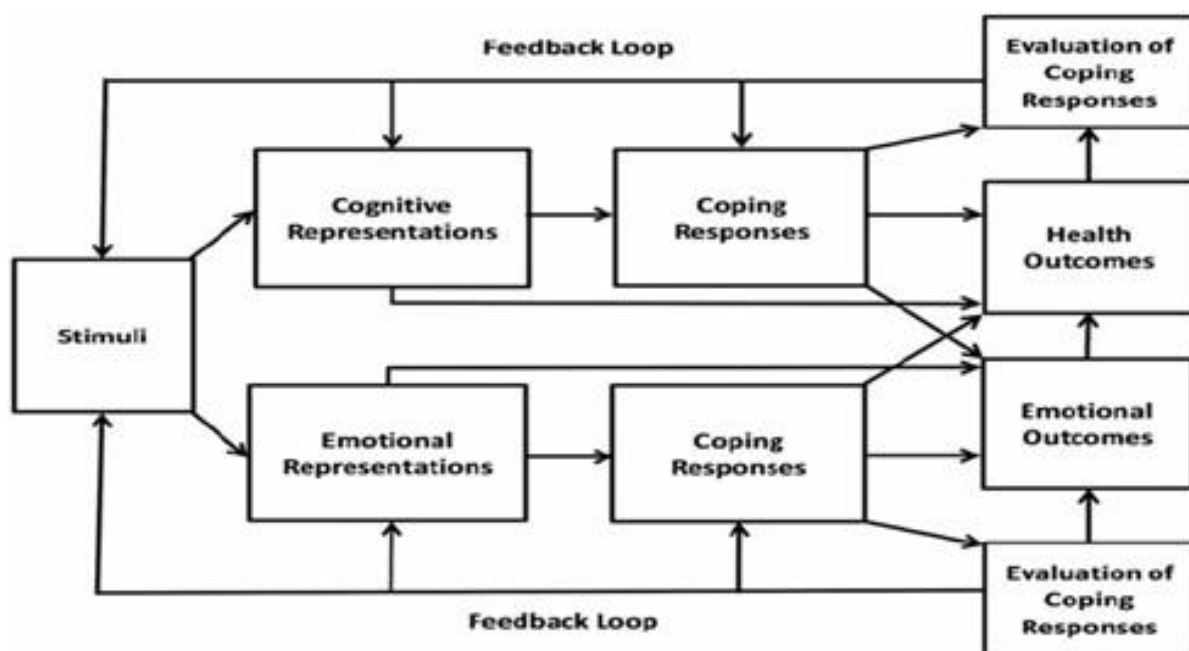


Figure 1 Leventhal's (1980) Self-regulatory model. This figure from Heffernan et al (2016) has been adapted from Hagger & Orbell (2003) with permissions in Appendices 5.4.

Kugbey et al (2017) conducted a cross sectional study that examined whether knowledge and illness perceptions predicted self-care behaviours in Ghanaian patients with type 2 diabetes. The participants were recruited from one of the largest healthcare facilities in Accra, Ghana. Individuals who met the following criteria were included in the study: (1) aged 30 years and above, (2) living with diabetes for one year or more, and (3) willing to give informed consent or assent to participate in the study. The

160 participants were given self-assessed or interviewer-assessed diabetes knowledge, diabetes self-care practices and illness perception questionnaires which were coded and analysed. Using the Statistical Package for the Social Sciences (SPSS), two data analyses were conducted to determine the best predictor of T2D self-care practices. Firstly, the relationship between illness perception and diabetes knowledge was examined using Pearson-moment correlation coefficient. Secondly, blood sugar testing, diet, exercise, footcare and medications and total self-care were analysed using regression fitted models as outcome variables. The results revealed that diabetes knowledge and illness perceptions significantly predicted patient's diet. Self-care practices such as testing blood sugar and diabetes footcare were solely predicted by diabetes knowledge, while illness perception solely predicted exercise. The study acknowledges limitations which included that the relationships examined did not reflect T2D control considering lab results such as HbA1c were not measured. Additionally, the impact of personal demographics characteristics was not considered regarding adherence to T2D self-care practices and the perceived cause of T2D was not assessed. However, the study concluded that the key determinants of patients' diabetes self-care practices were cognitive and emotional representations of diabetes and their diabetes knowledge (Kugbey et al, 2017).

Studies using the application of the CSMSR found that illness perceptions and health beliefs about diabetes play an integral role in facilitating self-management practices (Abraham et al, 2015; Broadbent et al, 2011; Jayne & Rankin, 2001; Lawson et al, 2013).

To understand how treatment and illness perceptions impact the self-management of chronic illnesses such as diabetes, health professionals seek to develop interventions based on the CSMSR (Eam & Surit, 2019; Nuong et al, 2020; Phillips et al, 2011). A qualitative study conducted by Quandt et al (2013) examined the fears about diabetes in older adults. The 74 ethnically diverse participants recruited across 3 counties in North Carolina, USA, engaged in comprehensive semi-structured interviews. The participants, who were living with T2D for a minimum of 2 years, answered interview questions which

focused on diabetes knowledge, beliefs, consequences, and symptom self-management. The researchers utilised the CSMSR framework in the analysis process which provided in-depth insight into the participants' information sources. Additionally, the CSMSR assisted with developing a broader understanding of the impact the information sources had on the participants' beliefs about T2D. The data from the transcribed interviews were analysed using a systematic, computer-assisted approach. Based on the interview schedule, the researchers developed a preliminary codebook and additional codes, and broad themes were used to characterise participants. The codes were categorised into nine domains: attitudes towards diabetes, causes, consequences, cure and control, diabetes physiology, how to control symptoms. The transcribed interviews were analysed, and the domains, consequences and symptoms were reviewed. The researchers conducted word searches to gather data on fears, diabetes management and family which developed into individual codes. The analysis was completed by returning to the original transcripts and searching for data that had not been generated in any of the previous attempts. The findings for the fear about diabetes included key consequences such as disease progression, amputation, blindness, and coma. The participants' beliefs about T2D and its consequences were founded on early life experiences before fully understanding the complexities of the chronic disease. These early life experiences were significant and the basis for individual health beliefs and ongoing self-management practices. The participants' self-management behaviours were directed toward the highest feared physical consequences than the overall control of T2D. The study concluded that addressing the fear of T2D consequences in older adults may improve diabetes self-management practices. The researchers suggested ensuring that older adults understand that day-to-day self-management practices to control glycaemic levels are key in preventing consequences (Quandt, et al 2013).

On a day-to-day basis, individuals living with T2D make self-management decisions such as monitoring their blood sugar, food choices, adhering to medication treatments and physical activity. It is important to acknowledge that managing T2D commands a large amount of time and attention and

includes lifestyle changes. These changes require self-efficacy to effectively maintain T2D care and adaptation to a new way of life and perhaps, a new identity as an individual living with T2D (Jarvis et al, 2010).

Using a CSMSR framework, Gois et al (2012) conducted a study in a hospital in Lisbon, Portugal and recruited 121 participants who were living with either type 1 or type 2 diabetes. The study investigated the distance between how participants viewed self and diabetes and the association of controlling for losses and benefits with diabetes. For example, it is better to “have diabetes” than “to be diabetic” (Gois et al, 2012; pg. 34). Additionally, the study hypothesised that participants with benefits with diabetes have higher levels of psychological adjustment compared to those with losses with diabetes regardless of the distance between self and diabetes. Lastly, Gois et al (2012) aimed to answer the question about identifying as being a diabetic or having diabetes by presenting a 2x2 combination with self-benefits or self-losses. The participants completed the Diabetes Psychological Adjustment scale (ATT39), a 39 item Likert Scale which measures the emotional adjustment to diabetes (Dunn et al, 1986). Also, written answers to open questions about benefits or anything positive and losses or anything negative about living with diabetes were submitted. There were no significant differences about identifying as a diabetic or having diabetes as the results were almost split in half. The participants who reported any benefits of living with diabetes had higher levels of psychological adjustment compared to participants reporting losses. Type 1 participants identified more as being diabetic whereas type 2 participants considered themselves as having diabetes. Those participants who identified as having diabetes and reported benefits of living with diabetes had higher levels of psychological adjustment. The study suggests future research with individuals who find benefits of living with the challenge of diabetes (Gois, et al, 2012).

Researchers have attempted to gain a better understanding about the self- management practices of individuals living with diabetes (Lai et al, 2007; Laranjo et al, 2015; Whittlemore et al, 2019; Wu et al, 2019). As aforementioned, Leventhal and his colleagues (1980) developed the CSMSR framework to

examine the influence of perceptions of illness, such as diabetes, intervention to improve health behaviours and self-management practices (Leventhal et al, 1997; 2008; 2016).

To summarise, illness perceptions are cognitive and emotional and are formed and guided by internal and external sources of information. Cultural and social factors, previous experience with the illness, information from health professionals, family members and significant others all guide and influence illness beliefs and perceptions (Hagger & Orbell, 2003; Cameron & Leventhal, 2003). The CSMSR suggests that individuals form illness perceptions about their condition and its treatment when they are confronted with a threat to their physical health in an attempt to understand and manage their illness (Leventhal, 1980;1992). The CSMSR considers an individual's past and current experiences and provides a theoretical basis to explore both cognitive and emotional representations of illness perceptions which influence individual coping mechanisms and health behaviour outcomes (Hagger & Orbell, 2003; Leventhal, 1980; 1992; 2008; 2016;). Health Psychology as a discipline implements a biopsychosocial approach to research to gain an understanding about individuals' health beliefs and behaviours in relation to health and illness which significantly impact health outcomes (Marks et al, 2018; Sarafino & Smith, 2016; Straub, 2019). In this context, an important aspect of Health Psychology research focuses on the application of theoretical frameworks to gain an understanding of the complexities of health behaviours. The CSMSR proposes the interaction between illness and cognitive representations and self-management which is useful when trying to understand health outcomes (Breland et al, 2020). The CSMSR is distinct from other health behaviours frameworks such as the Theory of Planned Behaviour and Health Belief Model because of its multidimensional concepts (Ajzen, 1991; Rosenstock, 1974; Leventhal, 1980; 2016). The CSMSR places emphasis on combining perception and abstract concepts of illness representations, whereas the aforementioned models tend to solely focus on abstract concepts (Leventhal et al, 2016).

The CSMSR does not only describe the process of self-regulation, but it also focuses on several factors that impact how individuals adapt to illness (Benyamini & Karademas, 2019). Additionally, Leventhal

et al (2005) suggests that individuals undertake a psychological process, or memory schema when confronted with a health issue or illness. This memory schema is directly related to the illness and is based on individual lived experiences, beliefs and perceptions which form a collection of representations about the illness (Leventhal et al, 2005). The CSMSR suggests that this collection of illness representations and health behaviours are influenced by both the conscious and subconscious or habitual processes (Breland et al, 2012). Health professionals can develop interventions by identifying illness perceptions, which are often shaped by individual lived experiences, emotional and cognitive appraisals and sociocultural influences, to address health outcomes and self-management behaviours of individuals living with chronic conditions, such as T2D (Shiyanbola et al, 2018).

Illness perceptions as proposed by the CSMSR considers how individuals perceive their illness (Leventhal,1980). However, studies such as French et al (2013), conducted randomised, open, 3-arm parallel group trial to explore the role of beliefs in self-management health behaviours of individuals living with T2D. The study examined if self-management behaviours are influenced by the individuals' beliefs about self-management behaviours compared with their illness perceptions about T2D.

The 453 participants, with a mean age of 65.9 were recruited from GP offices in South Yorkshire and Oxfordshire, UK and completed questionnaires about medication adherence, beliefs about medication, diabetes self-care activities and illness perceptions. Each of the participants were allocated to one of three allocated interventions which were 1) standardised usual care, 2) use of a metre with clinician interpretation of results and 3) use of a metre with training in self-interpretation and the application of the results. The outcomes were measured at baseline and one year follow up. Baseline questionnaires were completed before the participants were randomised and the follow up questionnaires were completed by patients prior to the final assessments. Beliefs about illness were assessed using the Illness Perception Questionnaire (IPQ-R17) and beliefs about medication and perceived necessity and concerns about medications were assessed using the Beliefs about Medication Questionnaire (BMQ). The findings revealed that beliefs about diabetes did not had

significant variance to predict change in medical adherence behaviours. Also, beliefs about exercise predicted future change in physical activity, whereas beliefs about diabetes did not. A limitation to the study was the mean age of the population in relation to changes in diabetes health behaviours. The participants, with a mean age of 65.9 were living with diabetes for approximately 3 years. Therefore, the participants may have been less likely to pursue health behaviour changes compared to a younger population sample that was recently diagnosed with diabetes. However, the researchers concluded that beliefs about behaviours are as important as illness perceptions when predicting the health behaviours of individuals living with T2D (French et al, 2013). The study suggested that targeting beliefs about behaviour, rather than beliefs about illness behaviour change interventions with patient groups would be more effective (French et al, 2013).

Self-management behaviours are influenced by illness perceptions and health beliefs and differ across cultures and religions (Abubakari et al, 2013; Koenig, 2015; Nie et al, 2018; Permana, 2018; Sridhar, 2012). Ramadan is an obligatory observation in the ninth month in the Islamic calendar for individuals of the Muslim faith (BBC, 2020). During this 29-30-day period, strict fasting from eating, drinking and sexual relations is observed between dawn and sunset (Live Science, 2018). In addition to fasting, Ramadan is a time of prayer, reflection, family and community (National Geographic, 2020). A narrative review conducted by Ahmed (2020) explored current literature on clinical and scientific evidence of fasting during Ramadan for individuals of the Islamic faith who are living with diabetes. Regarding self-management practices, such as glycaemic control, there were reports of a 7.5-fold increase in T2D hypoglycaemic-related hospitalisations during Ramadan. The review highlighted the International Diabetes Federation Diabetes and Ramadan (DAR) Practical Guidelines (2016) which provided HCP with guidance to assist in caring for individuals living with T2D who participate in Ramadan. The guidance presented the consensus amongst health care professionals and religious leaders that individuals considered high-risk were advised to refrain from fasting. Those individuals considered low-risk could participate in their religious observations and self-manage T2D while

minimising the risk of diabetes-related complications. The review concluded with recommendations on diabetes managements during Ramadan (Ahmed, 2020).

The review emphasised the importance of religious sensitivities in relation to self-management practices (Ahmed, 2020). Like religion and spirituality, the self-management practices of individuals living with T2D are influenced by personal and cultural beliefs (Abubakari et al, 2013; Choi et al, 2019; Shahin et al, 2019). Research with a focus on the influence of cultural beliefs can help to bring insight into health behaviours and T2D self-management. For example, a mixed methods study conducted by Patel et al (2015) explored the influence of T2D self-management in a sociocultural context in a British South Asian population. For the quantitative measures, 67 participants, recruited from GP practices and the local community in the North West of England, were randomly selected to complete questionnaires which assessed illness beliefs, fatality and diabetes self-care activities. In the qualitative measures, using purposive sampling, 37 of the participants engaged in a social networks survey interview (SNSI) semi-structured interview which assess perceived and actual social support and explored beliefs about diabetes self-management. Regarding quantitative illness perceptions outcomes, most participants believed that T2D would last a lifetime and reported low levels of personal and treatment control and poor understanding. The highest ranked causal beliefs about T2D across the participants were genetics, stress, and diet and that T2D was dependent on chance or fate. Although most participants were relatively concerned about T2D consequences, they lacked personal control to improve their diabetes self-management. The participants reported that their social network provided higher levels of emotional support than illness work which related to perceived concern and emotional distress. Also, participants reported high levels of diabetes self-management. The 3 generated themes in the qualitative analysis were 1. Fatalism - cause and control, 2. The use of alternative therapies and 3. Diabetes management- a family affair. The analysis suggested that participants had fatalistic beliefs about T2D and parallel to the quantitative results, held genetics, diet and stress as T2D causal beliefs. The participants believed that alternative therapies such as ingesting

specific foods in combination with prescribed medication would improve T2D management. The most common food therapy discussed was Karella, or bitter melon. The participants shared the belief that bitterness from the Karella would regulate sugar levels and therefore improve T2D control. Lastly, diabetes management – a family affair revealed that the awareness of the high prevalence of diabetes in the British South Asian community led participants to normalise and downplay the seriousness of T2D. This normality of family members living with T2D seemingly reduced the emotional distress of the participants' own T2D diagnosis. This study concluded that the sociocultural context of T2D shaped the British South Asian participants' illness beliefs and T2D self-management practices (Patel, et al 2015).

The awareness of the influence of sociocultural aspects of T2D self-management resulted in current contextual research. Widayanti et al (2020) conducted a qualitative study using focus group discussions in a cultural context to gain an understanding about the lived experiences and lay perceptions of individuals living with diabetes. The participants were recruited from Eastern and Western developed provinces of Indonesia. Individuals living in the Western provinces are originally from a single, large ethnic group and Islam is the predominant religion. In contrast, individuals from the Eastern provinces have heritage from many, small ethnic groups and Catholicism is the predominant religion. The varying religions, ethnicities and provinces provided the researchers with the opportunity to gather rich data and insight about the participants perspectives from different sociocultural backgrounds. The individuals met the following inclusion criteria: 1) a diabetes diagnosis by healthcare professionals and 2) the ability to comprehend information and respond to the questions in Bahasa Indonesia or the local ethnic language. The 45 participants were asked to participate in focus groups of 6-10 members and the discussion questions were translated from English to Bahasa Indonesia, the national language. The main researcher was Indonesian and conducted all the focus group discussions in Bahasa Indonesia. The discussions were later transcribed verbatim from Bahasa Indonesia to English. The results reported environmental changes and culture

were barriers for implementing and maintaining a healthy diet in response to diabetes. Also, the analysis emphasised religious and spiritual leadership in the Indonesian culture could potentially offer support and encouragement to implement an overall healthier lifestyle. The study concluded that the participants' identified with diabetes from a cultural perspective which guided health behaviours and self-management practices (Widayanti et al, 2020).

The effectiveness of self-management behaviours in diabetes is an interesting area of research, particularly in developed countries where prevalence is high, but the research is underdeveloped. Within the International Federation of Diabetes (IDF) North American and Caribbean (NAC) region there are over 48 million people living with diabetes (IDF NAC, 2019). It is estimated that this number will rise to 62 million by 2045. Bermuda is one of 24 countries within NAC Region and in 2017 there were 6,600 reported cases of people living with diabetes within the adult population of 43,700. Among adults aged 20-79 in Bermuda, the prevalence of diabetes was estimated at 13.0% (IDF Diabetes Atlas, 2017; Parris, 2014). The diabetes rate was twice the Organisation for Economic Co-operation and Development (OECD) average rate of 6.3% and surpasses the prevalence when compared to all OECD countries (Bermuda Health Council [BheC] and Department of Health [DoH], 2011) (See Figure 2, BheC & DoH, 2011). The prevalence of diabetes in Bermuda has reached epidemic status (BheC & DoH, 2011).

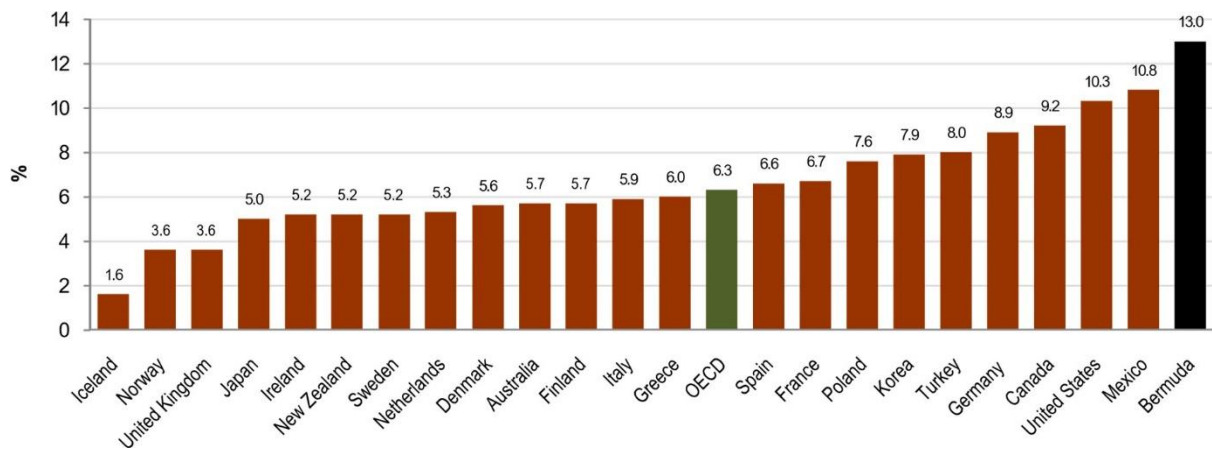


Figure 2 Prevalence estimates of diabetes, adults aged 20-79 years, 2010 from BheC & DoH (2011) with permissions in Appendices 5.4.

In the United Kingdom, healthcare is provided by a single payer, the British Government and is funded by the taxpayer (NHS England, 2015). Taxes are directly levied on individuals, households, and companies by the British Government (NHS England, 2015). Conversely, indirect taxes are applied to the manufacturing of goods and services (Kings Fund, 2020). All healthcare appointments and treatments are free to the patient and paid through taxes (NHS England, 2015). Most prescriptions are free or of little cost (Department of Health and Social Care, 2020; NHS Business Service Authority, 2015). Under this publicly funded healthcare system known as the National Health Services (NHS), all individuals living in the United Kingdom, including non-taxpayers have access to free healthcare (NHS England, 2015). Private health insurance is offered for a fee and residents are entitled to free NHS care which includes all treatments and visits to healthcare providers with the option to utilise both private and public healthcare (Department of Health, 2009).

Conversely, Bermuda arguably operates on a reverse healthcare system in comparison to the UK. Healthcare in Bermuda is not funded by a National Healthcare Service but it is categorised and funded based on employment status; the employed and unemployed or retired. Private-sector employers must provide insurance coverage for employees working more than 15 hours weekly; and are required

to provide the same coverage for their employee's unemployed spouse and children (Section 20 Bermuda Health insurance Act, 1970). The employers choose the insurance company and selects their employees' health insurance policy which must include the minimum requirements as directed by the Bermuda Government (Government of Bermuda, 2020; Health Insurance Act, 1970). Employees and employers share cost of the monthly premium of the health insurance policy. However, by law, the employers may not deduct more than half of the monthly premium from employees' salaries (Bermuda Health Council, 2017; Bermuda Health Insurance [Exemption] Regulations, 1971). All treatments, visits to healthcare services providers and prescription costs are not free to insured employees but are shared between the employee and the employer (Bermuda Health Council, 2017; Bermuda Health Insurance [Exemption] Regulations, 1971). Self-employed persons are responsible for 100% of the cost for an individual insurance plan (Bermuda Health Insurance [Exemption] Regulations, 1971). The Bermuda Government offers basic insurance plans, Future Care and the Hospital Insurance Plan (HIP), to unemployed and retired residents (Government of Bermuda, 2017; 2020). Annually, pensioners pay thousands of dollars to maintain the cost of healthcare (Government of Bermuda, 2017; 2020).

The Gross Domestic Product (GDP) is the measurement of a country's size and economic value during a specific period of time, which is usually one year (Bank of England, 2020). GDP is utilised to compare the size and economies of different countries at various points in time (Bank of England, 2020).

Bermuda's annual spending on healthcare coverage was approximately \$12,000 (£9,500) and the highest per capita worldwide (Mead, 2018; Government of Bermuda, 2014). At the time of this study the Government of Bermuda proposed healthcare reform. The Bermuda Health Strategy (BHS), a 5-year plan, with the goals of health financing reform and providing every resident, employed and unemployed, access to healthcare coverage (Government of Bermuda, 2019).

Although Bermuda and the UK operate within two different healthcare systems, the routine care for individuals living with T2D is quite similar. Individuals living with T2D in both the UK and Bermuda

consult their GP and/or other health professionals to develop the right treatment plan to suit their specific needs.

In the UK, individuals living with T2D are encouraged to attend regular check-ups reduce the risk of mismanagement which can lead to other health problems (NHS, 2020). During the check-ups, the GP or nurse checks the individual's average blood sugar levels to assess how close they are to normal. When newly diagnosed with T2D, the check-ups are scheduled every 3 months and then every 6 months once the individual living with T2D is stabilised (NHS, 2020). The difference in T2D check-ups within Bermuda and the UK is the cost. As previously mentioned, in the UK all healthcare treatment and appointments are funded by the NHS, a public healthcare system in comparison to Bermuda's privatised healthcare system.

Additionally, individuals living with T2D in the UK are encouraged to undergo an annual diabetes cares review which allows the GP to monitor their health. During the review, the individual's weight and body compositions are measured and blood pressure, blood glucose control, long-term HbA1c levels and cholesterol levels are assessed (Diabetes UK, 2020). This also provides an opportunity to discuss any issues regarding diabetes care with the health professionals and receive advice regarding any changes in lifestyle, medication, or self-management regimens. Additionally, the individual living with T2D will be asked about any potential psychological changes which include depression, anxiety, or physical changes such as sexual dysfunction (Diabetes UK, 2020; NHS, 2016). Lastly, the GP may refer the individual living with T2D for an annual diabetes retinopathy screening and feet examination (Diabetes UK, 2020).

In Bermuda, individuals living with T2D undergo a similar annual review. In addition to the examinations in the UK, Bermuda reviews include annual immunisations, kidney function test and bi-annual dental exam and cleaning.

In addition to medical care, the UK and Bermuda share similarities in T2D support services, which include DSME, nutrition, physical activity and talk therapy.

If an individual is uninsured and unable to afford the out-of-pocket cost of living T2D, they have the option to utilise the public services of the Government of Bermuda (GoB) Department of Health (DoH) or charities, such as the Bermuda Diabetes Association (BDA) without out-of-pocket costs.

The DoH encourages the uses of a diabetes care passport with the aim of assisting in effective T2D self-management. In the passport there is information about the T2D-related screenings, tests, and exams. It allows the individual living with T2D to record all medications, test appointments and results, and any other information to assist in tracking T2D care (GoB, 2016). The GoB offers weekly and bi-weekly services to assist with T2D care which include immunisations, blood sugar screenings, health education and promotion, nutrition assessments and counselling (GoB, 2016).

The Bermuda Diabetes Association is a charity which offers an extensive DSME programme including monthly nutrition education to improve health outcomes, and training sessions about implanted glucose monitoring systems and a 1:1 free session with a pharmacist to discuss all T2D-related medications (Bermuda Diabetes Association, 2021; 2019).

There are a number of different medications available in the UK for treating T2D include tablets and insulin which are prescribed by a GP. The medical costs associated with living with T2D in the UK include hospitalisation, doctor's visits, prescription medications, DSME, support programs all of which are funded under the NHS. Conversely, in Bermuda, in addition to the aforementioned medical cost of living with T2D, there are higher insurance premiums, potential loss of earnings, financial assistance programs and potentially the overall quality of life imposes a burden on all sectors of the community (BHC, 2011). However, in a press release, the Bermuda Government's Junior Minister of Health, Senator Richardson, expressed, "Bermuda's high cost of healthcare, the ageing population and increasing incidents of chronic diseases

such as diabetes, all contribute to the burden of healthcare” (Finighan, 2021, para 4). In Bermuda, health insurance typically covers approximately 80% of the cost of brand-name prescription medication (Argus Insurance Bermuda, 2021; Government of Bermuda, 2019; 2020). Senator Richardson presented the Bermuda Health Council Amendment Act (BHCAA), which enables the government to set maximum prices for commonly used medications in effort to decrease the out-of-pocket cost of medication (Bermuda Parliament, 2021; Finighan, 2021). The BHCAA act in its efforts to reduce cost will assist in increasing the effectiveness of self-management for individuals in living with T2D in Bermuda (Bermuda Parliament, 2021; Finighan, 2021).

There has been little research on this Bermudian population. In the Pan American Health Organisation (PAHO) Health in Americas report (2012) chronic, noncommunicable conditions, such as diabetes is amongst the leading causes of death in adults aged over 60 in Bermuda. These conditions are caused by poor lifestyle factors, which include physical inactivity and an unhealthy diet (PAHO, 2012). In conclusion, as individuals living with T2D spend only a few hours annually with health professionals, it is imperative to learn effective self-management practices. The ability to effectively self-manage T2D is dependent on the individual’s knowledge about this chronic condition and their illness perceptions which guide self-management behaviours. From this perspective, this original research will contribute to the field of health psychology by qualitatively exploring the illness perceptions of this specific, under-represented population whose prevalence of diabetes is amongst the highest rated worldwide. The findings from this study will contribute to the scarce existing literature on the impact of illness perception on diabetes self-management within a Bermudian context and potentially provide evidence that could be culturally relevant to Bermudians living with type 2 diabetes. Therefore, the aim of the study is to explore the lived experiences which contribute to illness perceptions, of patients within the Bermudian population, with type 2 diabetes; and to gain an understanding of how these illness perceptions impact the effectiveness of self-management.

2.0 Methodology

This chapter describes the methodology of the study. It includes the research design, the researcher's theoretical position, data collection, method of analysis and the interview design. Additionally, this chapter includes the recruitment process, the participants, procedure and concludes with data analysis.

2.1 Research Design

Exploratory qualitative research provides a method to gain a wealth of understanding about a particular subject. It is rich in description and designed to reveal the perceptions, views and behaviours of a study's population (Braun & Clark, 2009, 2013; Smith, 2015; Willig & Rogers, 2017). Comparatively, a quantitative research design is suitable for structurally obtaining numerical data to test a theory with a hypothesis which can be disseminated into usable statistics (Marks et al, 2018). Although, there is an abundance of existing data and knowledge on illness perceptions on a global scale, as previously stated, there is little to no data on this specific population. A qualitative approach was chosen to capture deeper insight and explore nuances directly relating to the relationship between illness perceptions and type 2 diabetes. (Hansen, 2020; Smith, 2015). Using a qualitative approach to this study provided an opportunity for the researcher to investigate the cultural significance of illness perceptions as it relates to the effectiveness of self-management in individuals living with T2D in Bermuda. Additionally, this qualitative design allowed for the flexibility to explore and obtain insight into the lived experiences and perspectives of an under-researched population (Hansen, 2020; Hammarberg et al, 2016). The qualitative method used in this study was designed to contribute to a richer quality of data by providing the opportunity for the participants to elaborate on their lived experiences which influence cognitive and emotional representations of type 2 diabetes.

2.2 Theoretical Position

The researcher carefully considered the epistemological theoretical position to research as it informs the methodology of this study (Edwards et al, 2014; Braun & Clark, 2013). Epistemology is the study of the nature of knowledge, and in the context of psychology, it focuses on how knowledge is obtained and justified (Fletcher, 2017; Slevitch, 2012; Willig, 2012). From an epistemological perspective, positivism is the relationship between our perception and the world (Killam, 2013). Data analysis is interpreted objectively, and knowledge is gained through observation (Killam, 2013). Conversely, in constructivism there is no one truth or no one reality, there are many knowledges and not just one knowledge. However, in contextualism, there is more than one way to obtain knowledge based on the context and it reflects the researcher's position (Raskin, 2011). It acknowledges that there is an element of truth so there is a dimension of realism (Braun & Clarke, 2013; Raskin, 2011). This study's analysis process utilised a contextualism epistemological method, which can be described as acquiring knowledge from the emergence of context and is subjectively analysed from the researcher's position (Ichikawa, 2017; Nagel & Smith, 2017; Baumann, 2016; Braun & Clark, 2013). During the analysis, the study/researcher acquired knowledge about the participants' illness perceptions and its influence on the effectiveness of T2D self-management. In this context, through the recursive process of thematic analysis, the data was subjectively analysed and interpreted by the sole researcher to generate themes. Therefore, the researcher's epistemological position as a contextualist is additionally reflected in this research during data collection from participants who all shared the same reality of living with T2D and through their individual lived experiences acquired knowledge to inform their illness perceptions which influenced their T2D self-management practices.

2.3 Data Collection

This section will provide the rationale for selecting interviews as the method for data collection for this study. In qualitative research designs, interviews provide the opportunity to obtain in-depth information about the experiences and perspectives about a particular topic from the viewpoint of

those participating in a study (Doody & Noonan, 2013). This form of data collection allows the researcher to collect an extensive amount of evidence for analysis to address the research question (Oltmann, 2016).

In this study, semi structured interviews were chosen to gain insight and detailed data about the influence of illness perceptions on the effectiveness of T2D self-management practices. Semi structured interviews are structured questions which use a flexible approach to gathering information (Galletta, 2013; Wilson, 2012). Whether in a group setting or in a one-to-one interview, the researcher uses the structured questions as guide and has the flexibility to explore relevant areas of interest that may arise during the interview (Galletta, 2013; Wilson, 2012)

The researcher chose to conduct the semi-structured interviews in person and face-to-face as this study's method of data collection rather than using telephone or virtual interview platforms such as Zoom, Microsoft Teams or Skype. In-person, face-to-face interviews are the most commonly used form of semi-structured interviews in health-related research (Kallio et al, 2016; Braun & Clark, 2013). The in-person interview enables the researcher to develop a rapport with the participant that may not be established whilst using other methods of communication (Dejonckheere & Vaughn, 2019). This approach to data collection is interactive and permits the researcher to observe non-verbal behaviours, such as body language, facial cues and mannerisms which broadens the opportunity to engage with the participants to gain further insight (Dejonckheere & Vaughn, 2019; Oltmann, 2016; Opendakker, 2006). In this study, semi structured, face-to-face, in-person interviews supported the researcher in gathering in-depth data which explored the participants experiences, thoughts and health beliefs about T2D which influenced the effectiveness of their self-management practices.

2.3.1 Interview Design

The Common-Sense Model of Self-Regulation (CSMSR) focuses on cognitive and emotional representations of illness perceptions. Using the CSMSR framework to inform the interview schedule, the researcher explored how self-management is influenced by patients' knowledge about the

aetiology and chronicity of diabetes, illness perceptions and health beliefs. The researcher constructed approximately 3 questions for each of the 5 dimensions (identity, consequence, timeline, control, and cause) in the CSMSR model. The study yielded 16 open-ended questions which required the participants to reply with more than a one-worded response (Yates et al, 2018). Each of the questions in the interview schedule included discretionary prompts to engage into a broader dialogue and provided the opportunity for participants to expand on their responses (See Appendices B, 6.1).

Often, the questions were not asked in the consecutive order outlined in the interview schedule (See Appendices B, 6.1). Instead, the researcher posed the questions based on the participants' previous responses. This guided flexibility allowed the researcher to obtain information to gain insight in a less interrogative manner while simultaneously developing a rapport with participants throughout the interview process.

2.4 Inclusion and Exclusion Criteria

An aim of qualitative research methods is to reach the point of saturation, which occurs when no new information is retrieved from the data (Nelson, 2016; Fusch & Ness, 2015; O'Reilly & Parker, 2012; Morse, 2010). The population sample size in qualitative research methods should be large enough to address the research question while adequately describing the phenomenon of interest without the risk of saturation (Rijnsoever, 2017; Boddy, 2016; Robinson, 2013; Mason, 2010; Patton, 2002; 1990). Researchers recommend that a sample size of 10-20 participants in inductive qualitative research methods, such as one to one interview, is appropriate when using Thematic Analysis (Fugard & Potts, 2014; Braun and Clarke, 2013, 2006). Braun and Clarke (2013) recommended selecting a sample population size categorised by small, medium and large projects for different data sets in qualitative research. Specifically, in a thematic analysis of interviews, the suggested sample size is 6-10 participants in smaller projects. In medium projects, the proposed sample size is 6-15 participants and in larger projects 15-20 participants are recommended (Clarke et al, 2015; Braun and Clarke, 2013). This study aimed to recruit 10-20 participants as recommended by Braun and Clarke (2013).

The inclusion criteria for participants in the study are as follows:

- a. over 18 years old; As aforementioned in Section 1.0, in 2017 there were 6,600 reported cases of people living in Bermuda with diabetes within the adult population of 43,700. Among adults aged 20-79 in Bermuda, the prevalence of diabetes was estimated at 13.0% (IDF Diabetes Atlas, 2017; Parris, 2014). The above-mentioned statistic provides the rationale for recruiting adult participant and demonstrates the potential participant numbers were not artificially limited.
- b. diagnosed with type 2 diabetes, which is the focus of this research
- c. living with type 2 diabetes for more than 2 years; Individuals with this length of experience living with diabetes would have developed illness perceptions and formed self-management routines (Quandt et al, 2013)
- d. fluent in the English language; Participants must have the ability to read the study materials, provide informed consent and participant in an interview conducted in English.

In contrast, participants with the following criteria will be excluded.

- e. under 18 years old (See inclusion criteria a)
- f. diagnosed with type 1 diabetes (or any form of diabetes other than type 2) (See inclusion criteria b)
- g. living with type 2 diabetes for less than 2 years (See inclusion criteria c)
- h. non-fluent in the English language (See inclusion criteria d)

2.5 Recruitment

Fountain Health is a primary care Endocrinology, Diabetes and Internal Medicine private clinic located in Bermuda. Their services include Diabetes Prevention, Diabetes Self-Management Education and Support, Obesity and Weight Management, Treatment of Thyroid and Bone Disorders and the treatment of additional Endocrine-related Disorders. As Fountain Health is a private clinic, all individuals who choose to become patients within this practice have health insurance or are willing to pay the out-of-pocket cost to utilise this service as described in Section 1.0. The participants involved in the study were recruited either through invitation by the Endocrinologist or by a recruitment flyer created by the researcher (See Appendices B, 6.2). The recruitment flyer included information about the study, the inclusion and exclusion criteria, the participant involvement, and the potential benefit of participation (See Appendices B, 6.2). Additionally, the recruitment flyer included a brief biography about the researcher and the contact details of Fountain Health for further information about the study (See Appendices B, 6.2). Recruitment flyers were posted at the reception area, in restroom stalls and on the office doors of each of the health professionals within the offices of Fountain Health (See Appendices B, 6.2). When eligible participants inquired about the study, the researcher was available in a private office for 20-30 minutes to discuss their potential role in the study and answer any additional questions. Once the participants agreed to take part in the study, they were given the option to be contacted by telephone or alternatively schedule their interviews at the time of their clinic visit. The Fountain Health administrative team assisted in arranging appointment dates and times with the participants according to their availability to participate in the one-to-one interview.

2.6 Participants

This study recruited 25 individuals who met the inclusion criteria and participated in one-to-one interviews conducted in a private office at Fountain Health from November 2019 to January 2020 (See Appendices A, 5.1; B, 6.2).

2.7 Procedure

2.7.1 Documentation

Prior to the start of the scheduled interview, each participant received a participation package, or written literature inclusive of an information sheet, informed consent form, privacy notice under the GDPR guidelines and debriefing form which included the details of additional diabetes support within the community (See Appendices B, 6.2-6.6). The participants were given approximately 20 minutes to read through the documents in a private office in Fountain Health before finalising their decision to take part in the study. Then, each participant had the opportunity to ask questions or raise any concerns after perusing the aforementioned documents.

2.7.2 Informed Consent

Each participant was required to sign a written informed consent document after verbally agreeing to participate in the study. Without the signed document the participant would not be allowed to engage in the study. The document reiterated that the participant's data would be anonymous and protected under the GDPR 2018 guidelines (See Appendices B, 6.5). Additionally, the document would outline the right to withdraw without reason at any time before the interview or during the interview and up to 2 weeks after the interview (See Appendices B, 6.5). *The researcher believed 2 weeks was sufficient time for the participants to process their interviews and decide to either continue or withdraw from the study.*

The informed consent form clearly stated that choosing not to participate or withdrawal from the study would not have a penalty and would not affect the standard or quality care in any way (See Appendices B, 6.5). If the participant was happy to proceed, they signed the informed consent form in my presence and receive a copy of said form and all documentation relating to their participation to the study for their records prior to the interview. (See Appendices B, 6.5).

2.7.3 Interviews

As previously stated, the researcher conducted in-person, face to face, audiotaped semi-structured, one to one interviews with the participants in the country of Bermuda. Each interview was conducted in a private room in Fountain Health. The participant and the researcher sat side by side at a round table. The patients were informed, verbally and through documentation about the audio-recording device which was placed on the table between the researcher and the participant during the interview. A laptop was positioned in front of the researcher and the participant was assured that the laptop would not be used for notetaking but only to refer to the interview questions. As aforementioned, the participants in this study were patients of Fountain Health and were familiar with the seating arrangement of the room and the use of a laptop from a health professional as it was common practice.

Piloting or testing an interview schedule is useful. However, there is a limited scope for formal piloting in smaller, qualitative research where interviews are conducted to test the schedule are not included as part of data collection (Braun & Clarke, 2013). With this consideration, it was not suitable to conduct a formal pilot study for this small, niche population. However, under the guidance of Braun & Clarke (2013) after conducting a few interviews, the researcher reviewed the guide and thoroughly reflected on the interviews, what could have been done differently and how to implement changes in the subsequent interviews (Braun & Clarke, 2013; Rolfe et al, 2021) which is further discussed in Section 9.0.

2.8 Data Analysis

2.8.1 Thematic Analysis

Data collected in this research was analysed using Thematic Analysis. Braun and Clarke (2006) described Thematic Analysis as “a method for identifying, analysing and reporting patterns within data.” (p. 79). Thematic Analysis provides a flexible approach to gain knowledge by systematically analysing data (Braun & Clarke, 2006, 2013). This flexibility and the ability to be utilised within most

theoretic frameworks separates thematic analysis from other forms of qualitative analysis (Willig & Rogers, 2017). In the process of Thematic Analysis, the researcher should firstly decide whether the themes should be identified using inductive or deductive analysis. Inductive Thematic Analysis has no predetermined theory or framework to analyse data, and the themes are driven by the research data (Braun & Clarke, 2006). Conversely, Deductive Thematic Analysis is theory-driven, and the researcher utilises a predetermined theory or framework in the analysis process. The themes are generated using the framework and research question and the data is analysed by looking for similarities and differences (Braun & Clarke, 2006). It was important to this study to analyse the data collectively because of the scarcity of existing research within this specific population in Bermuda. With this consideration, Deductive Thematic Analysis allowed the researcher to focus on the shared experiences of the participants to better represent the Bermudian population; in contrast, for example, to an Interpretative Phenomenological Analysis (IPA) approach which emphasises individual experiences (Braun & Clark, 2013; Smith, 2015).

Braun & Clarke (2006) clearly explained that the thematic analysis is not a linear process, completing one phase and moving from one phase to the next phase but rather it is a recursive process. The researcher shifts back and forth between the phases as needed. This study utilised Thematic Analysis to identify patterns across the qualitative data by following Braun & Clarke (2006) 6 step recursive process as follows:

- 1) Familiarisation with the data- the researcher should immerse themselves in the data by reading and rereading to become quite familiar with the content.
- 2) Generating initial codes- this phase involves initially producing codes that identify important themes may be relevant to answering the research question. The researcher should code the entire dataset for as many codes or themes as possible.

- 3) Searching for themes- during this phase there should be a long list of codes which are examined, and the data is organised to identify broader levels of significant patterns into potential themes.
- 4) Reviewing the themes – in this phase the researcher refines the themes. This may involve combining themes, splitting themes into smaller components, or discarding themes. The 2 processes in the phase are checking the proposed themes against the dataset to determining if the patterns are coherent at the level of coded data and to consider each theme as it relates to the research question at the level of the themes.
- 5) Defining and naming themes- the researcher should develop an overall detailed analysis of each theme and its individual narrative which includes deciding on an informative name for the theme and the scope and focus of each theme. In this phase, the themes should be clearly identified.
- 6) Producing the report –this phase involves the final analysis and write up of the report. The report should be concise, logical and coherently present an account of the data using a narrative analysis of each theme using detailed examples from the data.

2.8.2 Reflexive Thematic Analysis Process

Reflexive Thematic Analysis (RTA) differs from other approaches to Thematic Analysis because of the process and procedure of theme development (Braun & Clarke, 2019). RTA involves a significant amount of engagement and analytic work from the researcher to actively generate and develop themes (Braun & Clark, 2019;2020). During RTA process the researcher spends substantial time familiarising themselves with the data and rigorously searches to find shared meaning in the dataset (Braun & Clark, 2020). The researcher in RTA is to generate and subjectively interpret the theme which is supported by the researcher's theoretical assumptions, academic knowledge, and

sociocultural beliefs (Braun & Clark, 2020). In RTA, shared meanings are united by a central concept or idea (Braun & Clark, 2019). Below outlines the researcher's process of RTA in this study.

The audio-recorded interviews were transcribed verbatim and analysed by the researcher using a 2-column Microsoft Word table (See Appendices C, 7.1). The transcribed interviewed were inserted in the left column in black font. In the right column, the researcher used colour coded analysis. The blue font indicated coding, the red font represented cultural nuances, the green front denoted the researcher's initial thoughts, and the highlighted portions signified text incorporated into themes (See Appendices C, 7.1).

The researcher read the transcripts repeatedly to become familiarised with the data and used the recursive 6-step process of thematic analysis to generate themes (Braun and Clark, 2013). Reflexive thematic analysis allows the researcher to subjectively examine and interpret the data based on their live experiences from a sociocultural perspective (Braun & Clark, 2020). Throughout this process of familiarisation, it was apparent that each participant in the study and the researcher experienced cultural homophily, a relationship that develops when parties are bonded by similar attributes which stem from shared beliefs, attitudes or cultural characteristics (American Psychological Association, 2020; Haun & Over, 2015; Hofstede et al, 2010; McPherson et al, 2001). In this study, the participants and the researcher are Bermudian. This reflection on the researcher-participant homophilic relationship revealed cultural nuances that were expressed in the interviews which required additional interpretation in the analysis of the contextual significance as it applies to this study (See Appendices, E). The researcher, whose position is central to the study, acknowledged combining reflexive thematic analysis with features of a contextualist realist approach which yielded a Contextual Thematic Analysis. Themes did not emerge from the data, rather, they were generated by the researcher's recursive approach to data immersion and analysis using a contextualist theoretical position.

During the initial analysis each participant transcript was coded using a deductive approach to thematic analysis based on Leventhal's Common-Sense Model of Self-Regulation (CSMSR). Once the individual participant codes were finalised, the researcher progressed to investigating shared patterns and shared meaning across the dataset. As aforementioned, the CSMSR 5 beliefs included cause, consequence, control identity and timeline (Leventhal et al, 1980). The analysis of the dataset generated an initial list of codes. After multiple revisions, a final list of codes was created. These codes were then organised into 11 themes and after further analysis were collapsed into 6 themes. In the final analysis process, after reflectively immersing into the dataset to address the study's research question and aims, 3 main themes and subthemes were generated and will be discussed in the following chapter.

2.9 Ethical Considerations

2.9.1 Ethical Approval

This research received unconditional ethical approval from both the UWE Faculty Research Ethics Committee (FREC) and the Bermuda Hospital's Board Ethics Committee under the guidelines of the Bermuda Government Research Governance Framework (See Appendices A, 5.2, 5.3)

2.9.2 Confidentiality and Data Protection

The researcher recognised that confidentiality is a crucial ethical consideration, particularly within this small population. The interviews were conducted in a private office at Fountain Health to ensure the preservation of confidentiality and to offer a safe environment for individuals to participate in the study comfortably and securely. Additionally, a verbal explanation of the legal obligations of confidentiality was conveyed to the participants during the recruitment process, before and after the interview and at the conclusion of the study. Also, a document outlining the confidentiality agreement was provided to the participant for their records (See Appendices B, 6.4). The participants were notified that the study complies with the requirements of the General Data Protection Regulations

(GDPR) 2018, including specific information regarding the implications of GDPR for this research and their participation (See Appendices B, 6.4).

2.9.3 Data Storage/ Management

The audio recordings were stored in a secured password protected device and hard drive that was only assessable to the researcher. The recordings were transcribed verbatim by the researcher and the transcripts were stored on a password protected computer and password protected drive. After transcription, the audio recordings were deleted in accordance with the University of the West of England Guidelines (UWE, 2016; 2020). The participants were informed about data storage and management prior to the interview in the privacy notice, patient information sheet and provided a signed informed consent form located in the Participant Package (See Appendices B, 6.3-6.5).

2.9.4 Dissemination

Although the acceptance of mental health and psychological care has increase in recent years, there is still a lingering stigmatisation within Bermuda's small population. Regarding dissemination, the approach to anonymising quotations was carefully considered to decrease the risk of participants being exposed unknowingly. In the study's analytical process, the participants were given pseudonyms. In the transcripts, names of individuals, businesses, and or scenarios that were identifiable or potentially identifiable were redacted to further ensure confidentiality.

2.9.5. Publication

This final report of this study is available on the University of the West of England's open-access Research Repository. A hard copy of the report is available to research participants upon request. There are plans for publication to an academic journal and the findings will also be shared both within and outside the University of the West of England and the Bermuda Hospital's Board (See Appendices A, 5.2, 5.3).

3.0 Results and Discussion

3.1 Participant Demographics

This study recruited 25 individuals who met the inclusion criteria and participated in one-to-one interviews conducted in a private office at Fountain Health from November 2019 to January 2020 (See Appendices A, 5.1). The participants, who are identified by pseudonyms, offered demographic information which includes age, gender and race (See Table 1).

Of the 25 total participants, there were 15 (60.0%) women and 10 (40%) men who engaged in the study with a mean age of 63.0. The participants identified their race as Black, 19 (76.0%); White, 5 (20.0%) and Mixed-race, 1 (4.0%) (See Figure 3)

Taking into consideration that this qualitative study took place in Bermuda, with an adult population of 43,700 (IDF Diabetes Atlas, 2017; Parris, 2014), within the 21-square miles (56 kilometres) country of Bermuda. As the country yields a 21-square mile (56 kilometre) land mass and is divided into 9 parishes, or providences. Unlike larger countries, there are no varying religious, or ethnic-specific parishes. In this study, the participant demographics included mean age, gender, and race (see Table 1). Any additional demographic information could potentially jeopardise the preservation of participant confidentiality.

Mean Age and Gender

- Mean Age
 - 63.0
- Women
 - 15 (60.0%)
- Men
 - 10 (40.0%)

Race

- Black
 - 19 (76.0%)
- White
 - 5 (20%)
- Mixed Race
 - 1 (4.0%)

Race : Gender Ratio

- Black Women
 - 12 (48.0%)
- Black Men
 - 7 (28.0%)
- White Men
 - 3 (12.0%)
- White Women
 - 2 (8.0%)
- Mixed Race Women
 - 1 (4.0%)
- Mixed Race Men
 - 0 (0%)

Table 1

Participant Demographics Characteristics

Pseudonyms	Age	Gender	Race
Anna	79	Female	Black
Arthur	42	Male	Black
Barbara	59	Female	Black
Calvin	61	Male	Black
Caroline	61	Female	Black
Christine	35	Female	Black
Deborah	59	Female	Mixed Race
Elbert	48	Male	White
Eugene	69	Male	Black
Henry	82	Male	Black
Ida	73	Female	Black
James	57	Male	White
Jason	68	Male	White
Juliette	50	Female	White
Kenneth	60	Male	Black
Maria	56	Female	Black
Michelle	70	Female	White
Pamela	78	Female	Black
Philip	76	Male	Black
Rita	57	Female	Black
Rochelle	82	Female	Black
Sheila	58	Female	Black
Steven	56	Male	Black
Susan	67	Female	Black
Valerie	77	Female	Black

3.2 Summary of Findings

The research question for this study is *How do illness perceptions influence the effectiveness of self-management in individuals living in Bermuda with type 2 diabetes (T2D)*. To answer this question, the study aimed to explore the lived experiences, which contribute to illness perceptions, of patients within the Bermudian population, with type 2 diabetes; and to gain an understanding of how these illness perceptions impact the effectiveness of self-management. Twenty-five participants, fifteen women and ten men, engaged in semi-structured, audio-recorded interviews about their illness perceptions and experiences living with T2D. The interview schedule was based on the Leventhal et al (1980) Common-sense Model of Self-Regulation. The interviews were designed to obtain information from the participants about their perceptions of the cause, consequence, timeline, identity, and control of T2D. The transcribed interviews were analysed using Reflexive Thematic Analysis and the researcher generated three themes; 1) Beyond my control, 2) Who I am vs. Who I *should* be (Sociocultural challenges) and 3) If you don't listen, you feel. The findings presented in this chapter will be discussed in relation to the research question, the existing literature in chapter one and the practical implications for health psychology. Lastly, this section will reflectively review the strengths and limitations of the study and offer suggestions which could potentially direct future research and practice.

3.3 Themes

The themes and subthemes are mainly organised around the 5 main CSMSR representations: cause, control, consequence, identity, and timeline. Although the representations are intended to describe 5 distinct processes, this study generated the following 3 interrelated themes and subthemes; 1) Beyond my control; 1a. Perceived Control 1b. Who is in charge? Internal and external locus of control. 2) Who I am vs who I *should* be (Sociocultural challenges); 2a. Identifying as a diabetic vs. identifying as an individual living with diabetes, 2b. Interpersonal relationships and support, social expectations,

and cultural norms 2c. Socioeconomic status -The cost of living with T2D and 3) If you don't listen, you feel; 3a. Impact of Knowledge and Education 3b. The turning point (See Figure 4).

As aforementioned, the findings and discussion in this section are amalgamated. The findings, or themes, are presented with evidential quotes from the participants, who are identified by their pseudonyms (See Table 1) to support each theme and subtheme in relation to Leventhal et al (2016) CSMSR displayed in Figure 4 and will be discussed in relation to the existing literature outlined in Chapter 1.

Themes and subthemes	Beyond my control	Who I am vs who I <i>should</i> be (Sociocultural challenges)	If you don't listen you feel
	<p>1. Perceived Inevitability</p> <ul style="list-style-type: none"> a. Genetics, family history and family environment b. Living on the border - Prediabetes <p>2. Who is in charge? Internal and external locus of control</p>	<p>1. Identifying as a diabetic vs. identifying as an individual living with diabetes</p> <ul style="list-style-type: none"> a. The challenge of transition <p>2. Interpersonal relationships and support, social expectations, and cultural norms</p> <ul style="list-style-type: none"> a. The complex relationship with food <ul style="list-style-type: none"> i. Love and Loss ii. Moderation not deprivation iii. Cultural and Social dynamics b. Learned generational beliefs, attitudes & health behaviours. <ul style="list-style-type: none"> i. Traditions <p>3. Socioeconomic status -The cost of living with T2D</p>	<p>1. Impact of Knowledge and Education'</p> <ul style="list-style-type: none"> a. Underestimated timeline and severity b. DSME c. Knowledge without action d. There is not enough time e. No discernible consequences <p>2. The turning point</p>
Elements of Leventhal et al (2016) CSMSR	<p>CAUSE – the perceived causes of T2D (biological and internal susceptibilities, external factors, behaviour, social environment)</p> <p>CONTROL – the causal beliefs of T2D influences an individual's controllability and appraisal of their efforts to effectively self-manage T2D</p>	<p>IDENTITY – symptoms and labels to define T2D. The perceived label of T2D and the interrelationship of how that label directly connects to an individual's identity</p> <p>CONTROL – the individual's post-diagnosis self-identity influences the effectiveness of T2D controllability and self-management practices.</p>	<p>TIMELINE – beliefs regarding the development and duration of T2D. This is an individual's perception of a timeline to strategise to effectively control the threat of T2D</p> <p>CONSEQUENCE – the anticipated or experienced (physical, emotional, psychological, socioeconomic) consequences</p> <p>CONTROL – the interrelationship between the individual's delayed willingness to implement healthy behaviours to increase the effectiveness of T2D self-management is based on the perceived timeline of living without overt physical consequences</p>

3.3.1 Beyond my control

The following section will present and discuss the findings for the theme *Beyond my control* and its subthemes *Perceived inevitability* and *Who's in charge? Internal and external locus of control* as it relates to Leventhal et al, 2016 CSMSR and the existing literature.

The perceptions of the cause of T2D influenced how the participants controlled or self-managed their health behaviours. As aforementioned, there is a high prevalence of T2D in Bermuda (IDF Diabetes Atlas, 2017; BheC & DoH, 2011) and most of the participants shared that their immediate family members were also living with T2D.

3.3.1.1. *Perceived Inevitability*

Genetics, heredity, and family history

A few participants perceived genetics, heredity, and family history as the foundation of the causal belief that T2D was an inevitable diagnosis.

“Being that we are in Bermuda. And it’s not like a, you know, a big shock that people do have diabetes...just being black and all...we’re more predisposed towards it...and then it’s in my family. So, it wasn’t a shock”. (Steven)

“My mother was a diabetic, so I figured, you know, it sort of runs in the family. I've got two sisters who are diabetic. So, um...I just figured out...yep...I guess that's the way it's going... So, I think it's, it's mainly it's hereditary for me...” (Deborah)

“I wasn't blown away. Because I knew it was in my family. And I, I said it’s probably genetic...I used to hear folks say it skips a generation. But for me didn't because my mother had, had it and her mother had, had it. But I wasn't really...um, um, how can I put it? ...all that upset” (Valerie)

Additionally, two participants linked their causal perceptions of T2D with memories of their grandparents who experienced physical complications such as T2D-related lower limb amputation.

“Hereditary. My great grandfather...had it, he had lost both of his legs. And it seems like it skipped over various generation and it got me.” (Kenneth)

“Looking back um at family history, you know, watch my grandmother have both legs amputated and be the diabetic and so the, the roots in the family with diabetes is very strong, very predominant...so you can see the genetics also playing a role.” (Rita)

Another participant shared a similar recollection of relating the causal link to T2D with family history.

“Well, I have an aunt who has diabetes and lost her leg. And her son musta had diabetes, unless it was poor circulation, he lost his leg. And...it was a few other people in my family that has diabetes. So, you know it’s a family thing.” (Pamela)

Across the participants, there was a perception of the association/relationship between the cause of T2D and genetics, heredity, and family history. However, participants who held this belief and did not have a family history of T2D were not expecting their own diagnosis which left them uncertain about the cause of T2D.

“All my life... I have been low...And if I went too long meals, I would get shaky and headachy and the whole works. So, to be told that I had diabetes was a real shock. My mother was low sugar. So, I thought okay, I'm going to be like my mother and, and be low...[Doctor] put me on insulin right away” (Ida)

“I just didn't expect it. I didn't. Nobody in my family had it. I thought diabetes was something that you had to have had...not something that just occurs”. (Anna)

“I guess I had it in my head that I would never get diabetes because it’s not my family.” (Michelle)

A few participants expected a diagnosis based on the belief that a combination of genetics and lifestyle behaviours cause T2D.

"It's [T2D] definitely genetic and in my family, but I guess some my eating habits too...it was coming" (Barbara)

It's [T2D] all throughout my family so I have it too but it more likely has something to do with how I was eating" (Arthur)

"Didn't come as much of a surprise. Um...My mother's been type one ...my father's type two...um and diabetes being fairly prevalent in Bermuda, it was only really a matter of time given my lifestyle choices." (Elbert)

Another participant held an expectation of an eventual T2D diagnosis solely based on lifestyle.

"...my lifestyle and my, my health habits led me to having diabetes type two." (Steven)

Additional participants specified that lifestyle choices, particularly unhealthy eating habits led to weight gain which results in an inevitable T2D diagnosis.

"Probably lifestyle, I would think. I didn't get this is size, you know cause I don't eat. You know, junk food, yeah, I partake, took in junk food." (Jason)

"I was enjoying food, eating cake, starch, macaroni but you name it I ate it...pretty much everything...and then I wasn't drinking a lot. I was drinking water and not as much as I do now...So, I think that's what caused it." (Rochelle)

"I knew it was coming ...Yeah, absolutely. I was overweight...and I was eating and drinking whatever I felt like ... and just, just knew." (James)

Living on the border – Prediabetes

Participants shared their long-term awareness of the potential of a T2D diagnosis after living within the range of prediabetes. One participant shared their experience of initially learning about their prediabetes diagnosis.

"I was once told that I was prediabetic. I don't think that I was alerted sufficiently to take a corrective course of action that will delay or eliminate the possibility of diabetes" (Henry)

Similarly, another participant recalls their attitude after a prediabetes diagnoses and admits that lifestyle changes to avoid a T2D diagnosis was not taken under serious consideration.

"Got a pill for it? You know, yeah, I wouldn't say I didn't take it serious but I didn't take it really serious... Okay. The pill bought it [glucose] down to a level in a sense...I said it's acceptable... fine. I'll just go basically with my life. And that was for years going back and forth...[doctor] wanted to kill me half the time but that was just me" (Maria)

Additional participants shared their experiences of living with prediabetes for an extended period of time prior to receiving the diagnosis for T2D.

"it's not something that just popped up it's been a while and I... should have taken it under control and dealt with it but I didn't" (Eugene)

" I had been a couple of times to see other dietitians, you know your prediabetes that's gonna come up...Out of everything that I have going on that didn't seem like the most pressing thing; I'd been pre diabetic for years...maybe 30 years" (James)

“for years, the doctors kept saying I was prediabetic. And then so they said, exercise, try to do the right things, but I guess obviously I wasn't. So...maybe 6 years ago, that's when they said ...Okay, we're going to start putting you on medication.” (Susan)

Although one participant was uncertain about the definition prediabetes, they had an awareness about the term.

“I don't know what prediabetes is, but everybody seems to be prediabetic right now...so just makes you be aware...it seems like that's the new word, prediabetes, for people. Well, what is that? Are you gonna have it next week or next year?” (Caroline)

In contrast, another participant was not aware of the term prediabetes, but recognised the health behaviours that led to the T2D diagnosis.

“There are times in my experience...I was probably suffering from the early stages of diabetes... And it was over an extended period of time and not knowing that this could come back on me because not knowing the effects of overpowering your system with too much sugar or too much food period. That that fact was lost on me at that time. So therefore, I was doing things that was probably setting me up to be exactly where I am now as far as being diabetic” (Calvin)

3.3.1.2. Who is in charge? Internal and External Locus of Control

Locus of control significantly contributed to participants beliefs about their efficacy to manage and implement long-term effective self-management practices. Some participants believed that their health behaviours could change the outcome of their T2D diagnosis.

“and that’s another thing they say, oh if you lose weight your diabetes will like disappear, not disappear.... So, for me that hasn’t been the case because I’ve been sort of steadily, not losing dramatic amounts of weight” (Caroline)

“I know that it’s a possibility that I can overturn it... the fact that I knew that I had it gave me a sense of control” (Steven)

Conversely, others held a belief that any measures to manage T2D would be futile. They expressed feelings of hopelessness and emotional distress associated with the T2D which ultimately impacts the approach to behaviour change and beliefs about health outcomes.

“My body’s getting to the point where I can’t exercise like I wish I could... I’m 73 and I hope I’m not gonna live long... I don’t see any change in the future. I wish there was.” (Ida)

“And initially, I think like everybody else, you’re sort of ‘Oh my god, this is a death sentence, almost definitely’. I have not controlled it as good as I have it recent months and I think it’s, it’s a great deal of the both; coupled with feeling sorry for yourself, feeling like well, I’m not getting rid of it anyway, all of these things play a role in how you handle...Um...yourself.” (Rita)

One participant shared the feeling victimised when diagnosed with T2D after unsuccessful prevention efforts.

Interviewer: “What were your thoughts once they told you, yes, you have moved from pre diabetic to diabetes?”

Susan: I’m a victim (laughter)... “there were things I could have been doing, that I thought I was doing to prevent myself from becoming diabetic. Yeah, but obviously, I wasn’t.”

Other participants expressed anger and annoyance toward the self-management efforts of living with T2D.

"I get angry about it. I don't get weepy or anything like that, but I'm annoyed...And I never, it wasn't on my radar. And nobody ever...I'm certainly not blaming doctors or any medical people. But nobody ever told me, and I never knew that. My weight was an issue to getting diabetes. I just didn't know. And I'm sure that's probably why I did get diabetes ...so there's, there's definitely an anger there mostly at myself." (Michelle)

"I knew that my mother had been afflicted with diabetes and that, that influenced her health and led to a death. I wouldn't say that I was aware of a lot of people in the community who were diabetic. People just didn't talk about it...So, I guess I viewed it more as a nuisance factor which is, which meant having less sugar" (Philip)

Conversely, one participant describes feeling anxious and how the physical response affects her body.

"sometimes I'll just cry... then I get the shakes and I tell myself calm down, calm down, because when you get like this your diabetes your sugar goes up." (Sheila)

Another participant expressed worry about healthy food choices and concern about how sugar levels impact her body.

"... I'm constantly hungry and now they're starting to give out snacks around nine o'clock at night and it's like either a peanut butter and jelly sandwich or cookies ...that's sugar...so I'm constantly worried about that. And I'm constantly worrying about my feet" (Sheila)

In addition to the emotional impact of T2D, a participant considers both the physiological and psychological aspects of hunger to assist with eating behaviours.

"You know I remind myself...that's, that's the psychological hunger, it's not a physiological hunger...like you don't actually need food right now. You definitely have enough calories in

your system to burn and you got all this fat over her it'll, it'll eat up that so we could just... Yeah, it's, it's a mental thing a lot because...people go without eating all the time. It's just definitely a lot mental." (Christine)

Another participant describes the association of psychological and emotional T2D-related distress with physical consequences. According to the participant, diabetes-distress and negative thinking about health outcomes elevates blood glucose levels. Individuals living with T2D are encouraged to practice positive thinking as a self-management strategy.

"I think when people worry... I'm got sugar. I have a girlfriend says I can't eat that! I say stop that, stop it...See people get nervous about what they aren't supposed to eat ... I think if you relax about it ...I think by you being tight about it. I'm not really sure what tightness does but... pray, relax...holding stuff in and not having a free spirit that helps to bring up the sugar as well. It does...If something goes wrong and if you have a problem instead of you trying to release it, you wanna hold on it. I think that's the wrongest thing because it brings your pressure up, your sugar up and everything comes up. Enjoy life. You worry more... it kills you...and be positive, think positive things" (Rochelle)

Bermuda is considered a religious country (Association of Religion Data Archives [ARDA], 2015) . After diagnosis other participants adapted beliefs of how to manage their diabetes from a religious and spiritual perspective.

"God is good girl. That's who I depend on, I don't depend on nobody... Well sometimes, I have to talk to Him and say Lord (laughter) I'm not supposed to be eating all this sugar. Please help. And He helps... and then you know, I just don't eat it." (Pamela)

"If you keep your mind on the Lord, I think things will work out. And forget you have sugar. Ok you know you have it but put it behind you. And don't leave it up in front of you. ...have cake

and ice cream... yes, I would eat that, and I would come home and drink water and get myself together. So far it has worked because I'm relaxed about it. Everybody's so uptight, relax. So far it has worked. My doctor's quite pleased because the highest is like 125." (Rochelle)

Religion and Spirituality not only influences how some participants self-manage T2D, but it plays a significant role in how they manage daily life and perceive the future.

"I think it [religion] plays a role in how I manage my life period. You know, and, and how I cope with things." (Jason)

"I'm not looking too far down the road. I take one day at a time. And like I said, whatever comes...God is in control. I try not to stress myself out as to what's gonna happen". (Anna)

"Well, I put my future in the hand of God. Only He knows what the future is going to bring...um...I follow His Word and try to repent for all the sins I've done and try to live the way He wants me to live. Because I'm His child, I'm one of His children. So, I leave it in His hands and just try to do right by Him..." (Sheila)

There is a belief that individuals living with T2D have a responsibility to implement healthy behaviours which are supported by their religious and spiritual beliefs for effective T2D management.

"I'm a Jehovah Witness... it's impacted me in a way that I, I know I should do it, I should do it because being a witness, you got to live the truth and diabetes is a serious... it's a serious problem. And I need to come to grips with it...And being a Witness helps me because I'm out there doing the work of the Lord. But I'm not doing the work of controlling you know, my, my diabetes, and I need to do that." (Eugene)

"Well, I'm Rastafarian...really it's just the level of consciousness and the, the lifestyle encourages you to be healthy, eat healthy, live healthy. So, that within itself is motivation to

some degree...I heard recently that they've decided to classify it as a religion. Really, it's just a way of life.” (Calvin)

“I'm a Baha'i... we're not supposed to just let our health go. We're supposed to try to live as healthfully as we can.” (Ida)

The findings in this theme, *Beyond my control*, are based on the interrelationship of causal beliefs about T2D and the illness perceptions about controlling, or self-managing T2D in relation to Leventhal et al (2016) CSMSR (See Figure 4). When the participants expressed their beliefs about the cause, they recalled the witnessing their immediate family members experience the physical challenges of poorly controlled T2D. In Patel et al (2015) study, the highest ranked causal beliefs about T2D across 67 participants was genetics. Similarly, the majority of participants in this study perceived that a T2D diagnosis was inevitable based on family history and genetics. However, those participants with no family history of T2D who held the same T2D causal belief based on family history had no expectation of their own T2D diagnosis. There were participants in this study who attributed their T2D diagnosis to lifestyle choices, such as weight and prolonged unhealthy eating habits. Others shared that they knowingly lived within the range of prediabetes for long periods of time. Participants recalled health professionals providing information about healthy eating and physical activity. However, some participants did not grasp the prevention element of adapting healthy behaviours to avoid a T2D diagnosis. Others understood the prevention aspect and acknowledged the missed opportunity to make the necessary lifestyle changes to avoid a T2D diagnosis. All of the participants who lived with long-term prediabetes had the shared belief that their T2D diagnosis was inevitable.

The perception that T2D is caused by genetics or family history implies that an individual has no control over their diabetes. An individual's perceptions and causal beliefs about T2D, whether it was based on family history or lifestyle choices, directly impacts their approach to effectively control or self-manage T2D (See Figure 4). Participants who adapt the external locus of control shared the belief that their efforts to implementing healthy behaviours were futile. Although the language that these participants

used was seemingly dismissive, they expressed emotional distress and a sense of hopelessness which impacted their efforts to self-manage. The participants in this study shared feelings of anger, sadness, frustration and perceived T2D as a death sentence. Equally, Patel et al (2015) reported that participants held fatalistic beliefs about T2D and was dependent on chance or fate. However, participants who exercised internal locus of control, believed that adapting healthy behaviours would potentially reverse the T2D diagnosis. These participants acknowledge the emotional impact and diabetes distress associated with T2D self-care and encouraged other individuals to utilise positive thinking as a self-management strategy. The concept is negative thinking negatively impacts your physical body which results in elevated glucose levels. When an individual decides to think positively, in turn, they will implement positive health behaviours. French et al, (2013) reported that participants' beliefs about behaviours were just as important as illness perceptions when predicting the health behaviours of individuals living with T2D.

Existing literature from multiple researchers conducted between 2012 and 2018 corroborate that illness perceptions and health beliefs influence self-management behaviours across cultures and religions (Abubakari et al, 2013; Koenig, 2015; Nie et al, 2018; Permana, 2018; Sridhar, 2012) (See Figure 4). This study highlights the importance of religious beliefs to individuals living in Bermuda and its influence on T2D self-care. Those participants who rely on their religious and spiritual beliefs as a source to effectively manage their T2D implement a combination of external and internal control. On one hand, participants believe that their T2D self-management practices are effective because they rely on God.

"I have to talk to Him and say Lord...I'm not supposed to be eating all this sugar. Please help...And He helps...and then you know, I just don't eat it." (Pamela)

On the other hand, the participants hold themselves accountable to effectively self-manage T2D as it is a condition of their religious and spiritual beliefs to maintain a healthy lifestyle.

“Well I’m Rastafarian...really it’s just the level of consciousness and the, the lifestyle encourages you to be healthy, eat healthy, live healthy. So, that within itself is motivation to some degree” (Calvin)

In these instances, it is a combined effort of both internal and external locus of control to self-manage T2D. The participant utilised internal locus of control by making the effort to pray and recognised God as the external locus of control and source to help with healthful decisions. Other participants who practice in faith-based activities across Bahaism, Christianity, Jehovah’s Witness and Rastafarianism shared their responsibility to implement healthy behaviours which are supported by their religious and spiritual beliefs for effective T2D management. Similarly, Ahmed (2020), conducted a narrative review of current literature on clinical and scientific evidence of fasting for individual living with T2D and observe Ramadan. The review highlighted the guidance for health professionals from the International Federation Diabetes and Ramadan Practical Guidelines and emphasised the importance of considering religious and spiritual beliefs in relation to T2D self-management.

In summary, this theme, *Beyond my control* demonstrated the interrelationship between illness perceptions about T2D control and causal beliefs and was supported by the existing literature. *Beyond my control* can be seen to map onto the constructs in Figure 4 as Leventhal et al (2016) conceptualised *control* in the CSMSR as an individual’s perception about whether T2D can be cured or controlled and what role the individual, healthcare professionals, and others play in controlling T2D. This finding is important as it reflects that the participants perceived that a T2D diagnosis was inevitable based on their causal beliefs around family history, genetics, and lifestyle change. In turn, these causal beliefs determined how the participants controlled, or self-managed T2D through either internal, external or a combination of both locus of control.

3.3.2 Who I am vs who I *should* be (Sociocultural challenges)

In this theme, *Who I am vs who I should be (Sociocultural challenges)*, the participants talk about their self-perspective identities after the T2D diagnosis (See Figure 4). Some participants identify as

diabetics and others consider themselves as individuals living with diabetes. These self-described identities, which the participants shared in these findings, influenced how these individuals' control T2D. To identify as a Bermudian from a traditional sociocultural perspective opposes what it means to behaviourally identify as a "good" or healthy diabetic.

"Bermudians... we like our food, like alcohol and love our parties." (James)

3.3.2.1 Identifying as a diabetic vs. identifying as an individual with T2D

The following subtheme will present the findings regarding the participants' self-identity as it related to T2D. One participant, who also identified as diabetic, recognised the importance of effective T2D self-management.

"I knew what diabetes was. And I knew ...um...I knew that it was something... you have to self-manage. Really. I'm a much better diabetic now than I was then." (Caroline)

However, this participant acknowledged the emotional impact of living with T2D and how it impacts quality of life.

"It can make you feel like a little down sometimes. Just knowing that you have to do this every single day of your life. But I can't let that control my life either. Because if I was to just sit around worrying about having diabetes, and you know, and all that...I wouldn't be living. I would just be worried about having diabetes." (Caroline)

Another participant, who identified as diabetic, conveyed adhering to a standard of practice for living with T2D. The participant conveyed that their life is centred around T2D and the physical consequences of ineffective self-management practices to the extent that it has affected their interpersonal relationships.

"If you don't keep the standard practice, what does that mean? Right. High blood pressure, you're going to get, eye problems, you're going to get teeth problems, you're going to get limb problems, heart, heart, and kidney problems. Why? Because you're hanging around people

that are not used to living according to the rules and the standard practice of being a diabetic.”

(Kenneth)

Conversely, another participant who regarded T2D as an element of their lives rather than the centre of their lives, considered themselves as individuals living with T2D. They sought to incorporate T2D into their lives and the shared the impact their attitudes toward self-management practices have on their physical body.

“I don't want to be um having diabetes control me it should be the other way around... I don't want to be in that position, like one minute hopped in bed or doing dialysis or, or my life has been controlled, um...not being able to travel. And so, things like that, other than the health issues in itself...that are very negative impacts of not controlling diabetes.” (Eugene)

There are choices that individuals living with T2D make about the effort they are willing to put forth into self-management practices.

“People consciously decide that they're going to do a certain thing, or they know what they're doing is dangerous. But they make the conscious, conscious decision.” (Philip)

“I think the things I'm doing right now; they counter to what I should be doing.” (Steven)

A participant admitted to having an issue with acceptance of the T2D diagnosis.

“ You know, when, when I was doing this on my own, it was much easier to pretend it [T2D] didn't exist and ignored it.” (Elbert)

Another participant realised that ignoring the diagnosis would result in a decline in their health.

“You still have to manage yourself; you know what I mean, it’s no way out of it. You gotta do that or you’ll be...you’ll be really sick, you know?” (Caroline)

The Gois et al (2012) study assessed the association of controlling for losses and benefits with diabetes and the distance between how participants viewed self and diabetes. Gois et al (2012) reported two groups of people; those who considered themselves as having diabetes and other who identified as diabetics. There were higher levels of psychological adjustment in those participants who identified as having diabetes compared to those who considered themselves as diabetics. Also, these participants reported benefits of living with diabetes. Like Gois et al (2010), a participant in this study reported a positive outlook and describes the benefits of living with T2D.

“I think that diabetes at this point in my life has brought about very significant change...very much positive change, more so than taking away okay. As in, I am out in the garden...I use it as a form of movement I use it as um a form of relaxation, I use it as a form of being able to have healthy things in the house. I also use it as a tool for the grandchildren to see and learn. So the positive impact of that change is very significant...the benefits are really cool.” (Rita)

The challenge of transition

Regardless of how the participants identified, there was a shared conflict between the perception of how T2D *should* be managed and how it is *actually* managed. The participants expressed that transitioning to effective self-management practices was challenging.

“It’s a constant, conscious thing because it’s not just... that you have to manage the diseases as such...you have to change your lifestyle in order to really manage it effectively. And it’s not as easy for some...to just change their lifestyle. I find it...more difficult to keep it consistent and to really make it a lifestyle change. I try, um... but I’m not always successful” (Juliette)

A couple participants were concerned about the constant uncertainty of understanding which foods are considered healthy and how these choices affect their physical body.

"I never know what to put in my mouth. Okay, that's my biggest issue... that's how it affects me on a day-to-day basis is the constant...is this okay to eat?" (Michelle)

"I think the food is the thing you think about the most You're very conscious of the food you're eating. So, I think that's where it impacts you daily. Because what you put in your mouth every day is what affects your A1C" (Caroline)

Participants shared their understanding of integrating health behaviours to their daily lives to effectively manage T2D. However, they expressed resistance to their new lifestyle.

"You know, and I think it's more so that it's not a willing decision on your part as that person that's being diagnosed like any other health issues is something that is being forced upon you and hence, change...which is for I would think, for me personally, a great deal of resistance to that concept that...I have to." (Rita)

"anybody with just diabetes, it's an adjustment to your life. It's an adjustment to...everything and then with me... with my dairy and wheat allergies and gluten allergies, it's adds to it even harder...makes it even harder. Um...yeah, it's, it's not easy for anybody and I'm trying..." (Juliette)

Across the study, the participants shared the conflict between perception and reality of self-management practices. It was the perception of how T2D *should* be managed and the reality of how

it is *actually* managed. These differing viewpoints created a challenge for participants transition from unhealthy behaviours to healthy behaviours for T2D self-management.

A challenge that the participants had was spending a significant amount of time trying to avoid change. If the T2D diagnosis did not require lifestyle changes, the participant implies that there would be no desire to change. It was a challenge to choose to wholly change health behaviours. A participant recalls spending a significant amount of time in avoidance and resistance to implementing health behaviours.

“... I think it's a great portion um of time spent and on, how can I either manipulate, how can I maintain my bad habits? So, all of that plays a role.” (Rita)

Another participant agreed and shared the struggle to psychologically adjust to maintaining these lifelong changes.

“you have to change your lifestyle in order to really manage it effectively. And it's not as easy for some...to just change their lifestyle. I find it...more difficult to keep it consistent and to really make it a lifestyle change.” (Juliette)

The challenges of transition extend to others who are connected to the individual living with T2D through interpersonal relationships and support. A participant shared that their spouse who does the majority of food shopping and cooking found it equally challenging to adjust.

“A little frustrating. I like my groceries and being told what not to eat was a bit of a change...grocery shopping became a challenge. Cooking became a bit of a challenge...[partner] grew up on the USDA food pyramid so of course everything is wrong for a diabetic.” (Elbert)

To summarise this subtheme, Leventhal et al (2016) CSMSR, *identity* is described as the how an individual labels and perceives T2D (See Figure 4). In this study, the participants' illness perceptions about T2D had a direct influence on their post diagnosis self-identity. As outline in the findings, there was an interrelationship between identity and control as it related to CSMSR (See Figure 4).

Perceptions about self-identity informed the participants' approach to controllability of T2D self-management.

As the findings revealed, the perceptions of how T2D *should* be managed and how it is actually managed. Additionally, there were expressed concerns about transitioning from unhealthy behaviours to maintaining life-long self-management practices. For most participants, their post-diagnosis identity also shifted their interpersonal relationships.

3.3.2.2. Interpersonal relationships and support, social expectations, and cultural norms

Friends and family members of individuals living with T2D are also described as being impacted by the condition. From a Bermudian perspective, interpersonal relationship dynamics, social support, and cultural traditions influence individuals' ability to effectively implement self-management practices.

"You know...so [my partner] is just behind me 100% trying to clear off this terrible disease"
(Eugene)

Some differences in social support were observed according to gender. In the following text, a participant expresses the feeling of social isolation due to T2D-related lifestyle changes and comparatively describes the social support his wife received from her peer group.

"In Bermuda... a lot of the women that I know take much better care of themselves than most of the men do... I know my wife has changed her lifestyle as a result of this [T2D] and I know she's not gotten any flak from her friends. I caught hell when I wasn't drinking beer the other day. So...um...there's a fair amount of peer pressure here..." (Elbert)

"[Among women] It's much more socially accepted. In fact, I want to do it with her. Yeah, well, 'I'll go walking with you'...'I need to lose this, I'll have that diet too'. 'And what are you doing?' And then they share meal plans and then it's a whole thing...I can't go to my mates and say...guess what? I'm not eating sugar no more. They'll look at me like I'm lost. Yeah and the

drinking is, is a big thing...I got a raised eyebrow when I went for a gin and tonic, instead of the... you know, nice, big bespoke bottle of beer. Yeah, and when...I quit drinking for three months and no one knew what to do. Like suddenly we weren't invited anywhere...it was like 'oh my god, he's not gonna drink it. Is he going to die?' So, there's, there's a huge social stigma around it." (Elbert)

Other participants struggled to maintain boundaries with family members to avoid the temptation of eating unhealthily.

"Don't come home with chips and chocolate and don't offer me things." (James)

"Like, you know, we're going away [abroad], and my wife buys three packs of pastel... fruit pastels, and three chocolate bars and puts them in my carry bag. I said, what's that for? You know, just to eat on the airplane or whatever. I'm not supposed to be eating all that." (Jason)

The complex emotional relationship with food

The relationship with food for individuals living with T2D is complex. The participants expressed emotional connections to food. Some participants express their love for food, while others perceive food as an expression of love.

"I just I don't know why I just love...I was really bad with chocolate like I almost ate a chocolate every day" (Juliette)

"There might be a lot of peer pressure. So...yeah, especially around the holidays. Christmas, what! That's gonna be awful this year. Just because it's an adjustment to my wife's family. And they are, I love my in laws, but they express love through food." (Elbert)

One participant revealed that their relationship to food was seen as a necessity.

"Hey that's, that's my thing, my food you can't take my food away from me, you know"

(Eugene)

Another participant related to the sense of need or desire thinking about eating enjoyable unhealthy foods.

"I need this, I need Pizza.... There is like, you know...thinking what I'm gonna do before or after to get my blood sugar back down." (Christine)

Similarly, one participant recognised that conceding to their desire to eat unhealthy foods resulted in temporary gratification.

"I'm just drawn to sweets. And even though, when I go to have it... after I've had it, I'm not always satisfied that I really enjoyed it as much as I wanted, you know. I think it becomes a mental thing sometimes just becomes a cycle. Yeah, vicious cycle, psychologically" (Juliette)

Another participant became quite expressive about food when discussing their favourite recipe. emotional connection to food

"And then put two tablespoons of the sauce... salsa and then some cheese. Oh, it's great! I'm drooling thinking about it." (James)

A participant expressed that smaller portions of enjoyable foods would not satisfy their cravings and chose to deprive themselves completely by eliminating these foods from their diet. The participant admitted that it was challenging to adapt to new eating behaviours through elimination rather than selecting healthy food alternatives. When describing their new relationship to food, this participant conveyed a sense of loss caused by the T2D diagnosis.

"I miss apples, but I don't like a lot. I miss it" (James)

"Bananas I miss" (James)

"I miss pizza. I used to make it; I cook I don't mind. I miss pizza, real bread. Pizza. That's probably the biggest thing, I miss." (James)

God! I miss French fries!" (James) Get rid of that rice, potato, including French fries (I miss French fries) bread and pasta. If you just cut those out.." (James)

"but what's one potato chip [crisps] gonna do to you? It's gonna turn into a bag, which is then gonna turn into two bags and gonna to turn into a big bag of humpty dumpty barbecue chips that I really loved. (Laughter)." (James)

Most participants shared their challenges of creating a balanced modification to their eating behaviours without depriving themselves of enjoyable food choices.

"I think I'm successfully holding it at bay. I wouldn't go as far as saying I'm successful curing it. Um...I know I could do better with eating...I could starve myself of all candies and cookies and cakes and but it's Christmas time, am I going to eat some? Probably...yes" (Jason)

A few participants described their strategy to enjoy unhealthy foods in moderation.

"I'm a chocolate freak. So, I said, Okay, instead of having chocolate every day, try to have it once a month. [Doctor] says, try having dark chocolate instead of chocolate, chocolate. So, I tried that. And then I'll give into my weaknesses. So...I was trying not to eat any, um like desserts. I would um just stick to my chocolates and stuff" (Susan)

"When I eat anything that I shouldn't eat, I drink a lot of water. And it seems like or seem to keep my diabetes under control...When I'm out, then I enjoy...my dinner, my lunch. I enjoy it, but I know when I come back home, I should drink plenty of water." (Valerie)

Some participants admit to consuming unhealthy foods and are mindful about portion control while acknowledging that unhealthy eating behaviours on a consistent basis will harm the effectiveness of T2D self-management.

“Yes, I eat chocolate, yes sweet but I know how much to eat.” (Rochelle)

*“I know, look, if I haven't been out to eat in a while, but if I went ... I could have a hamburger. I can have a salad. And I'm going to take five onions rings from somebody and it's going to spike my sugar probably a little bit but by the morning it's going to be almost normal. But if I did that every. single. day... I'm gonna be back where I was before. So that's what I know.”
(James)*

One participant shares a self-management strategy of moderation to manage T2D without medication by incorporating regular intermittent fasting and maintaining a specific eating plan. The participant decided to research intermittent fasting after receiving unconventional advice from the first post-diagnosis general practitioner (GP).

“The doctor... was actually my mom's doctor. So, and they diagnosed me then... it was weird. The doctor was just like...just eat meat. (Laughter)...I stopped taking the insulin. And was doing intermittent fasting... which worked out for a while, but I think it worked out because I was...doing more activity than normal, so everything was fine for a while...so it was alright but then... they started going back up again.... Through my intermittent fasting research, I stumbled on keto.... And then probably about four months into keto got my A1C down again. And I was like below the diabetic level. And...yeah, so probably just do some version of keto, cause that seems to work...I don't really like medications anyway. And I feel like... type two... you shouldn't really need it. So, although, I think it is unrealistic to say I'm not any eating carbs anymore... I'll fast. I'll eat a day; I'll fast a day” (Christine)

Another participant implements a keto, or low carb diet on a short-term basis and found a variety of enjoyable, healthy alternatives.

“I didn't know what keto was, but...[doctor] said low carb.... You don't have to do keto. Keto is good to get the weight off quick. But you need to go back in eat again properly” (James)

“I can make [keto]cookies...I can make a keto pound cake.... So, what I've been doing is I've been introducing foods that I had cut out...But what I will have is pasta. I'm trying to make...(laughter) keto pasta which is good. That's hard to do.” (James)

One participant identifies as vegetarian and provided a description of their eating behaviours as it relates to T2D self-management. The Bermuda Cultural Context Guide describes the categories of vegetarianism (See Appendices E, 8.6).

Deborah: ... I am vegetarian.

Interviewer: Your whole your life?

Deborah: I started off as a vegetarian then I sort of tried meat. Um...and then I don't know what happened, but I just sort of didn't enjoy it anymore. I mean, I do eat [meat] occasionally.

I do eat... I, I do eat fish. And occasionally I might have a little piece of chicken, very small.

Yeah, you know, but I don't eat any red meat.

Aside from vegetarians, there are some Bermudians who may express that they do not eat meat and regularly consume fish and chicken. The Bermudians in this category do not consume beef and pork which are classified as unhealthy meats.

“I, I feel if have certain Christian beliefs you shouldn't be doing certain things, so I don't do that. Okay, there's certain foods I don't eat...pork. I only eat fish and chicken. Now and then I may have a little bit of a hamburger, but I don't make it a habit.” (Susan)

Eating habits or behaviours as it relates to effectively managing T2D, can be challenging for individuals living in Bermuda. Codfish and Potato, as described in the Bermudian Cultural Context Guide, is the quintessential traditional Sunday Breakfast (See Appendices E, 8.1). Below a participant shares a social interaction and their extensive thought processes as an individual living with T2D attempting to enjoy a cultural and traditional breakfast.

“He was saying ‘Yeah, man, let me buy you breakfast this morning’. It's me, ‘Yeah. Okay’ ...I told him before I already had fish and potatoes, you know I got something home to eat for breakfast. So yeah...we ended up at [takeaway restaurant]. While we were there, somebody came in and just wanted sauce. So, I thought about the sauce. And I said, you know what ‘the sauce has sugar in it’. I know their sauce has sugar in it because their sauce tastes a little sweet...the red sauce. Yes, it has sugar. I can tell because I'm sensitive to stuff [sugar] now, more so or I pay attention more. And I say ‘yeah, I do want red sauce.’ But this is two portions or maybe three... They load you up...We got, got the sauce as soon as I got home, divided in half. So, I took half the fish half the potatoes and half of the sauce and divided that portion up...They've given you the meal but not counted the calories, right? They're just piling your plate. Okay, I had to do my own counting. So, I was like ‘yeah, ok just give me about four or five potatoes.’ So like two and half potatoes that a lot...so I backed it down to...three halves which we would be one half potatoes and the fish...they gave trimming but they were scanty...”

“Yeah, it's a lot of things to consider like when you get fish and potatoes at home, I can regulate that because I know what I put in it.... So, it just makes you think about...how you can manage your portions and that's something that from being diagnosed that I've had to do. Most times I'm pretty good. But there's been times when I've been slacking.” (Calvin)

Participants agree that self-discipline is important for individuals living with T2D, but it remains a challenge to balance healthy behaviours with fitting in with the group in social settings.

“Peer pressure yeah. People don't want people to know that...they're suffering. You know, and they'll find a way to get over it by doing something stupid.” (Eugene)

Like we went out...And they said you want bread? And of course, everybody said, of course we want bread! (laughter)...And I'm saying, why did you say that? I'm gotta have a piece of bread! Yeah, so it's discipline, man. Really, it's the discipline that I'm lacking, right now I'm lacking it.” (Susan)

“...be strong willed. I mean it's, it's not impossible. But people tend to do things which gives them an immediate pleasure, that's where sweets come in. They tend not to like to do to delay gratification...Self-discipline. Well, it's true because diabetes is one of those chronic or long-term illnesses that requires the individual to self-manage.” (Philip)

Conversely, a participant was unaware of how undisciplined health behaviours impact the body. The participant admitted to excessive alcohol consumption which led to an unexpected T2D diagnosis.

"[I] had fluid around my liver because I used to drink a lot! Especially... I used to drink hard liquor but then I stop drinking hard liquor thinking wine would be better. And I started to drink the red wine which has a lot of sugar, which I didn't realise... [doctor] did some blood work and then said, 'oh, you have diabetes.' I'm like huh? That's all I need... diabetes... And that's how I found out I was diabetic. I had no idea." (Sheila)

Alcohol consumption is incorporated in sociocultural aspects of life in Bermuda. The participants shared how they adapted their behaviours and interactions to a new way of socialising as individuals living with T2D.

"that probably put a shock on me too because we were both fighting diabetes at the time... He would try to eat better foods, but he couldn't get rid of the carbs. And the beer, which is Bermuda's problem. It's the alcohol." (James)

"I'll have a drink, but I don't go out to drink. And even if I'm out that doesn't necessarily mean I'm gonna drink. That that's, that's been a major change because we used to go out every week. Not going out every week to get drunk, but I was definitely consuming quite a bit of liquor when we were just getting out and having a good time." (Calvin)

Cupmatch, as described in the Bermudian Cultural Context Guide, is the most celebrated national holiday (See Appendices E, [8.3](#)). During this 2-day holiday there is an abundance of food and alcohol consumption (See Appendices E, [8.3](#)- [8.5](#)). One participant shared the social pressures, and the challenges of effective T2D self-management practices during a cultural holiday.

“The social pressures, you know, it's accepted practice to Cupmatch. And you go up there you have all the food, you've got all the swizzle. I make my own swizzle for years; I've made it for years and I know what goes in there...it just seems wrong to not have swizzle. So I have a much more limited bit. But you know, conversely, I'll spend the whole day in the ocean swimming and trying to get as much exercise. I'll go for a walk in the morning to lower things down...even though I've written the recipe down for these people about a million times...if I don't make it, there's something wrong with it. (Laughter)” (Elbert)

Bermuda is a close-knit community and from this perspective interpersonal relationships and support, cultural norms and traditions directly influence an individual living with T2D self-management practices. The participants express their concern about the change in interpersonal relationship dynamics and discussed the importance of teaching others how to effectively support individuals living with T2D. One participant believes the most effective strategy is to separate yourself from others, including family members, who do not live with T2D.

“one of the worst things a diabetic could do is live with family members that are not diabetics, and they're prone to eat stuff the diabetic shouldn't have. It makes it too easy for the diabetic to skip off his diet...the family environment doesn't allow for diabetic living.” (Kenneth)

Although this participant's strategy may seem extreme, Mayberry et al (2014) conducted a study that assessed whether support from family members of individuals living with T2D and limited health literacy were associated with better glycaemic control. However, there no association with health literacy status and obstructive family behaviours and glycaemic control. The study's findings suggest that family members involved in the self-management practices of individuals living with T2D should be taught to avoid obstructive behaviours. Otherwise, these obstructive behaviours can be exceptionally harmful to individuals living with T2D with limited health literacy.

In contrast, other participants believe that family involvement, rather than separation has a positive influence on learning how to effectively support the self-management practice of individuals living with T2D.

"They're learned. I've told him. Oh, look you can eat this. NO! It says it's gluten free. No, it's gluten free, but what's the first ingredient? Sugar. So, people don't bring the stuff home like they used to, hey, here's a bag of chips, here's a chocolate bar for you know. Yeah. So that's positive." (James)

Food is an integral part of the Bermudian culture experience. It is an expression of love and represents family and community.

"...it's an adjustment to my wife's family. And they are, I love my in laws, but they express love through food." (Elbert)

There is an emotional connection to food and the participants shared how T2D changed their relationship with food. The participants conveyed feelings of love and loss. When talking about specific, enjoyable foods the participants demeanours shifted. They would smile with inflection in their voices and often relate these foods were attached to happy memories shared with loved ones. However, the participants would have the opposite reaction when relating those beloved foods with T2D. In turn, the joyous conversation about food quickly turned to an expression of loss. Participants chose to eliminate these foods from their diet as a self-management strategy. This speaks to an issue of self-control and the challenge of portion control and frequency of consuming these foods.

"I miss pizza. I used to make it; I cook I don't mind. I miss pizza, real bread. Pizza. That's probably the biggest thing, I miss." (James)

Other participants with higher levels of self-control implemented a strategy to reduce the intake of these through modification rather than deprivation.

"Yes, I eat chocolate, yes sweet but I know how much eat." (Rochelle)

“Don't just grab out of a container, try to measure it even if it's more than what you're supposed to, measure it out... so you know what you're getting. And then once you measure it out, once you get a little handle on you it. Then you can start saying well how many carbs are that?” (James)

Moderation can be quite challenging for individuals living with T2D as the emotional connections to food are associated with cultural norms and social dynamics within the Bermudian population. Bermudians have their own ideas on food categorisation and which foods are considered healthy as described in the Bermudian Cultural Context guide (See Appendices E). These classifications are culturally relevant to individuals living in Bermuda with T2D as beliefs about nutrition guide self-management practices such as eating behaviours.

Eating behaviours for the participants was challenging particularly during social events and celebrating Bermudian traditions (See Appendices E). Participants struggled to enjoy traditional dishes with ingredients that are not considered diabetes friendly. Additionally, Cupmatch, the national 2-day holiday as aforementioned, is celebrated with family, friends and community. Cultural events and traditions which include generous portions food and alcohol presented issues of peer pressure, challenges of self-discipline and potential social isolation. These cultural traditions impacted how the participants interacted with others in social environments in an attempt to maintain healthy behaviours and overall effective T2D self-management.

An Indonesian study conducted by Widayanti et al, (2020) explored the lived experiences and lay perceptions of individuals living with diabetes from a cultural context. The findings revealed that culture and environmental changes were barriers for the implementation and maintenance of a healthy diet for this population. The study concluded that participants' health behaviours and diabetes self-care practices were guided from an Indonesian cultural perspective.

Learned generational beliefs, attitudes, and health behaviours

The participants acknowledged their family history and experiences of T2D. The learned attitudes, beliefs, and perceptions about T2D were shared during the interviews. The following exchange demonstrates how a patient admits to initially ignoring warning signs before T2D diagnosis, then shifts to denying the warning signs and concluded by advising his young family member to pay attention to the warning signs.

“People talk about diabetes, but yeah, it's not a big thing I can get over it and that's it. You know, I never took heed to the warning signs...well no not really warning signs, but it's just that... I never took it on, you know, under serious consideration. Yeah, I just didn't worry about it... my mother had diabetes and my sister has it. And that's about it. So, it's all in my family, my nephews have heart trouble, you know, it's just one of those things... a family issue they need to pay attention to the warning signs of diabetes and uh...govern themselves accordingly” (Eugene)

Another participant with the belief that T2D is caused by family history or genetics shared concern about the health of the next generation.

“I wish I didn't have diabetes. And I'm trying to make sure that my two children, um...my son's a... big sort of big guy and I keep I don't want to nag him, but I keep encouraging him not to...to take better care of manages weight and um... and because I know men are terrible diabetics” (Caroline)

“But everywhere you look everybody is so big...and the kids...the little kids. And we see the parents have given them all kinds of goodies. Pizza, candy, chips so that's passing it on, down the line till somebody comes up with some kind of way to make it stop.” (Sheila)

One participant shares the generational differences in the perspective of healthy eating.

"everybody's [colleagues] into health and fitness and so but then again, their younger, you know. I don't know if it means anything but, in my generation, we were meat and potatoes. You know, we don't know, subscribe to the you know the lattes, not the lattes, the smoothies but it is, I think a generational thing as well" (Steven)

Below is an excerpt from an interview which displays a cultural homophilic moment between the interviewer and the participant regarding the buffet at traditional family gatherings.

Caroline: ... another thing I noticed is that we, you know, again, a family function. It's like the vegetables are way down the end. Even my own dinner at Christmas on Boxing Day. Yeah, you put all the time...worst choices first and the vegetables, they're like add on at the end.

Interviewer: Yeah, that that's interesting and relatable that

Interviewer and Caroline: Everybody seems to do that (laughter)

Caroline: Yes. Instead of the opposite way around get your vegetables on your plate first.

Another participant corroborates the variety of dishes at Bermudian family gatherings.

"Those in my generation has, each one, its own big issues with diabetes. And as you look over, not only will you predisposed, but your eating habits we are eating, you know. You can go to a picnic, and you see potato salad, peas and rice, Spanish rice, you don't see any salads...it's no type of green nothing and that's how we eat, but we expect something different...that's what you know, so that's what you come to expect. And it's habitual." (Rita)

There is an emotional attachment to maintaining culture and traditions that can be harmful to our health.

“Emotionally in the sense that you get those periods where you feel like you're doing a losing battle because I think that when you're grown up on food especially in Bermuda culture. You were raised on certain foods And I think do you have an emotional attachment to it. So, it's very hard to be cold turkey when you're suffering that because that's the way...this video out called “greasing” and it just tells you how ingrained that is in the Bermuda culture in terms of cooking macaroni and cheese.... I mean, you can't get away from that. Um, so, um I'm just trying to change my, my diet and juice. It's hard. I'm not gonna lie about that.” (Steven)

“The only problem with families that have a diabetic person that lives with them... is that those family members do not fully grasp...the importance of the quality of food around. And they will eat whatever cause they're not diabetic” (Kenneth)

“eating and drinking and certain extents of idleness are very accepted practices in our culture. And frankly, it's much easier to go with those.” (Elbert)

The inherited ways of cooking can be a challenge for Bermudians who are living with T2D.

“Bermudians like to put sugar in everything. Why would you put sugar and macaroni and cheese? So, they're, they're inherited diets, their inherited way of cooking is detrimental.” (Ida)
you've got generations, generations of this, this way of eating that um... how do you break it?
I don't know. Other than through education.” (Ida)

It can be difficult to limit or refrain from cultural and traditional dishes that are uniquely Bermudian but not considered diabetes friendly. For example, cassava pie is a traditional and essential Christmas

dish that has sociocultural meaning as described in the Bermuda Cultural Context Guide (See Appendices E, 8.2).

“I'm going to try to be vigilant leading up to Christmas because I know I'm going to have things like cassava pie. I have no idea what the nutritional value is of cassava pie. I don't know if anybody's ever done it. How many carbs are in there? I have no idea. (laughter)... Well, it's lots of eggs, butter and then the cassava itself, I don't know.... Yeah, we don't put a lot of sugar in ours... like a couple tablespoons...Not only that but we fry it and Crisco. So, we're bad. Yeah, but it's only once a year. We don't do it at Easter (laughter)...Once a year and um Christmas Eve or Christmas Day is usually when we have it in the morning...but last year we...started eating early and fry it with ham...Every day we're having it, you know, lunch, dinner (laughter) maybe not 3 times a day. Yeah, certainly until it's gone. We're eating it.” (Michelle)

One participant shared how they incorporate healthier alternative ingredients while enjoying cultural foods and traditions.

“I'll make cassava pie on Saturday. I use Splenda instead of sugar. I use eggbeaters instead of eggs. So, I try to make it as healthy as I can... I use butter. I used to Becel, but they don't sell anymore. And I've tried some of the other ones, but they don't work. They make it all mushy and it doesn't cook up right...I have used butter in the last few years to do the pies” (Jason).

One participant's strategy to control T2D was making a decision not to make or consume any pie.

“Nope. I didn't make any or have any [cassava] pie...when we had the Christmas dinner, well, I didn't take any carbohydrates. Well...I didn't have any, any...well those lot had macaroni and rice stuff. I didn't have any of that.” (Susan)

Another participant shared their strategy of intermittent fasting for T2D self-management after consuming traditional Christmas dishes.

“Christmas was... I ate so much [cassava] pie Christmas Eve and Christmas Day so then on Boxing Day I did...well I did like a 40 hour fast after, after Christmas. And then my blood sugar was back. Like I wasn't hungry though because my...I don't know...I think my body does use fuel more efficiently. So... I'm cooking food for people and I'm not eating it all that day. And they're like you're alright?” (Christine)

Other participants share the challenges of reducing the consumption of favourite condiments, beverages, and foods.

“I was at my dad's house and... I would cook something ...put my portion on the side without salt and pepper...because you know Bermudians, they like ketchup. Everything's about ketchup. You know, so, oh no I can't have ketchup! (Laughter) (Sheila)

It is usual practice to blend Bermuda Ginger Beer into the majority of alcoholic and non-alcoholic beverages as described in the Bermuda Cultural Context Guide (See Appendices E, 8.3).

“That wasn't really hard to do because it wasn't really a soda person, although do I like [Bermuda] ginger beer that that was that much of a challenge. You know? ... (Calvin)

Participants recall the health behaviours and attitudes towards T2D from their parents or older generations Bermudians.

“My father was the one that had the sweet candy...I remember as a kid...and he was diagnosed with diabetes, I remember that... He said I'm always thirsty and he was diagnosed probably... So, I'd say the mid-80s he lived till 1991 but he was taking insulin. He definitely didn't watch it; he didn't care at that point. He didn't. And that was the attitude most Bermudians still now have. ‘if Ima die, Ima die. I'm gonna eat what I want.” (James)

One participant conveyed that often the harsh reality of living with T2D and its physical consequences are not discussed.

“everyone knows someone with diabetes, you know my uncle, my grandfather, my mom's friend, you know, a colleague at work, and they got diabetes, but they don't see what goes into that. They don't see all the blood testing, we don't see the, the shakes at three o'clock in the morning or the restless leg and you know, I can't see properly or the sexual dysfunction that's never going to get discussed in Bermuda” (Elbert)

Another participant agreed that not only was T2D not explicitly discussed in the community but often it was stigmatised.

“I guess there's a bit of a stigma to being diabetic. They don't talk about it very much. My [family member] was diagnosed and...continued making Kool Aid with lots of sugar in it. Oh, I'm gonna water it down or but she just refused to accept the fact that she was harming herself.” (Ida)

However, most participants are not following the behaviours of previous generations. There is a concern with the historical attitudes and learned behaviours within their culture. Participants are making concerted efforts to change the narrative towards T2D by unlearning unhealthy behaviours and seeking to teach others about new healthy behaviours for effective T2D self-management and potentially T2D prevention.

“ And my children I try to tell them...ay watch it because I had it, your grandparents had it... they know they need to watch what they do what they eat because it sneaks up it didn't sneak up on me. I had plenty warning” (James)

“It effects the whole country. Yeah. Like something like this would be very useful. And I think looking at it from Bermuda level will be very helpful. If...if I could do more I would. And if I can, I will be happy to help.” (Elbert)

Participants shared the sense of isolation whilst living with T2D. One participant revealed that a family member expressed happiness about having a partner to share their knowledge and experiences of living with T2D with a loved one.

“My mother of course thought this is the best thing ever because she had a diabetes buddy. And um...she was able to share a lot of information with me. So that was very helpful.” (Elbert)

Another participant agreed with the feelings of isolation. However, the participant was willing to share their experiences to help other who are facing challenges of living with T2D.

“ Most times you think you're the only person that's going through this and it's so many more people out there that have the what, how and ifs, buts...Hopefully, one day I can help somebody else in the same position that I'm in... (whew) ”(Sheila)

Similarly, a participant recognises the generational influence of healthy behaviours. They have taken on the role of educator to teach their immediate family about gardening as a form of physical activity and encouragement to eat healthily to prevent the continuation of a T2D family history.

“I have to say, in my life at this point that diabetes has been a much positive impact on my family...for change...[gardening]...I use it as a form of movement. I use as um a form of relaxation; I use it as a form of being able to have healthy things in the house. I also use it as a tool for the grandchildren to see and learn.” (Rita)

Likewise, other participants took on the role of educator with their family to encourage healthy food choices and prevent T2D diagnosis in their lineage.

“my daughter and my grandson is to like kinda tell her say, ‘hey you’re getting candy, you know rethink about that...think about what you know what habits you’re forming now because that’s probably what would stick with him [grandson]as he goes on.” (Calvin)

“[daughter] has been told couple times that she’s pre diabetic...As far as, you know, weight and being a factor and you know, yeah, absolutely.... My [grand]kids eating a lot of pasta and stuff like that. It’s just don’t think it’s healthy and a lot of candy. Yeah so, they need to be more aware.” (Michelle)

Another participant took a hands-on approach to creating a healthier lifestyle for their family.

“I’m the shopper and I’m the cook. So, I basically decide what I want. And I try and keep everybody else intact as well...we don’t use sugar at home. Um...we use stevia, which, you know, is the natural, you know, sweetener... my husband doesn’t even use it.” (Deborah)

Bermudians are familiarised with T2D in the sense of prevalence and proximity and witnessed family members or adults from previous generations live with T2D. The learned generational beliefs, illness perceptions and attitudes towards T2D from the former generation influenced the health beliefs and self-management practices of the participants. Similarly, Bennich et al (2017) review on the intra-family perspective of supportive and non-supportive behaviours emphasised the importance of family in T2D self-management. A lack of familial support of patients’ self-care practices may impede the patients’ efforts to make the necessary behavioural changes for effective T2D self-management. also, support from family members who displayed a positive attitude towards T2D had a greater impact on T2D coping than support from professionals.

Low family supportive behaviours in Mayberry et al (2014) study found an association with worse glycaemic control among participants with limited health literacy compared to participants with adequate health literacy. The researchers suggest that family members involved in the self-care practices of individuals living with T2D should be taught to avoid obstructive or non-supportive

behaviours. Otherwise, these obstructive behaviours can be exceptionally harmful to individuals living with T2D with limited health literacy (Mayberry et al, 2014). The study concluded that behaviours of family members, whether supportive or obstructive directly impact the self-care practices of individuals living T2D with limited health literacy.

In this study, the participants recall the health behaviours and attitudes towards T2D from their previous generations Bermudians. Unhealthy behaviours, such as excessive food and alcohol consumption cloaked in culture and traditions informed the health behaviours of participants. Although the participants inherited ways of cooking, specifically for traditional recipes, they did not learn effective self-management through a practical example from family members living with T2D. There was a stigma about T2D, and a participant recalled that the health behaviours from the previous generations did not reflect an understanding of the relationship between nutrition and consistent self-care practices.

"I guess there's a bit of a stigma to being diabetic. They don't talk about it very much. My [family member] was diagnosed and...continued making Kool Aid with lots of sugar in it. Oh, I'm gonna water it down or but she just refused to accept the fact that she was harming herself." (Ida)

Vongmany and his colleagues (2018) conducted a systematic review and meta-analysis on family behaviours that were perceived as positively or negatively influencing the self-management practices of adults living with T2D. The study identified that adults living with T2D had diverse perceptions about family behaviours. The perceptions were 1) impeding negative T2D self-management behaviours, 2) facilitating positive T2D self-management behaviours or 3) 'equivocal behaviours' [pg. 188] had the potential to either impede or facilitate T2D self-management. The study suggested that family behaviours that are perceived as equivocal could be reframed as positive which would

encourage adults living with T2D facilitate positive T2D self-management practices (Vongmany et al, 2018).

A diverse range of family behaviours are perceived as positively or negatively influencing self-management across many domains of diabetes self-management. The identification that some family behaviours may be perceived as 'equivocal' warrants further exploration. If the concept of equivocal behaviours is confirmed, it may be possible to reframe these family behaviours so that they are perceived as being supportive to diabetes self-management. Reframing equivocal behaviours as positive, may deliver a two-tiered benefit by transforming a barrier to a facilitator. Considering how to harness positive family behaviours most effectively, and to minimise the impact of negative family behaviours is important for clinicians and researchers alike.

Like Vongmany et al (2018), participants in this study made efforts to change the narrative towards T2D by unlearning the unhealthy behaviours from previous generations and teaching the future generations to incorporate healthy, lifestyle behaviours for effective T2D self-management.

"the role that I play in the family as mother, grandmother, wife, is that they are actually looking to you to set the pace and you have the influential part of, of being very significant to them.... Whether it be financially, emotionally, they're the ones that have to be there to support. ...So, I mean, I have the *great* opportunity of redirecting the grandchildren even if they don't always make all the smart choices, yes they want the chicken nuggets, but we're trying to *relearn*, you know, and even say that you can make your own chicken nuggets...

(Rita)

"my daughter and my grandson ...'hey you're getting candy, you know rethink about that...think about what ... habits you're forming now because that's probably what would stick..." (Calvin)

To summarise, from a Bermudian standpoint, interpersonal relationships and support, social expectations, and cultural norms influenced the individual living with T2D ability to effectively self-manage. The participants shared their experiences of social support or lack of social support when transitioning to healthful behaviours. Additionally, the experiences of engaging within cultural and traditional settings often presented conflict. However, the participants shared strategies to balance effective T2D self-management practices.

3.3.2.3 Socioeconomic status – The cost of living with T2D

In this subtheme, the participants share the impact of finances and their socioeconomic status on their ability to self-manage T2D. The high cost of health insurance and medications were concerning for a few participants.

“We tend not to go to the doctor very much because it’s expensive. A lot of people don’t buy insurance because they think is a waste of money, they’re healthy. It’s illogical but that the way lot of people think. So, on that basis, our population is not as healthy as it should be. But we are very capitalist we are not a socialist society in anyway.” (Philip)

“People can’t afford health insurance. So, you know, in a way we have to be healthy just as a business decision.” (Steven)

“if I was still taking the insulin, I wouldn’t have been able to afford it...I wouldn’t have been able to afford it. If I was...if I needed to take the insulin. I definitely wouldn’t have been able to afford it. And the meters super cheap, but then the strips are like a million dollars.” (Christine)

Other participants express how expensive it is to financially maintain a healthy diet in the long term.

"it's like buying groceries, reading carbs, reading labels, buying healthy is more expensive."

(Juliette)

"the biggest problem is what am I going to eat? It's expensive buying food like that? It's expensive." (James)

"I started changing my eating habits...but money...that's what threw me back off because you know, vegetables, fresh vegetables and fruit is expensive" (Barbara)

Another participant agreed with high cost of living with T2D and the reality that financial restrictions often conflict with the desire to live a healthy lifestyle.

"So, you know, they know they have diabetes, they want to eat healthy, but you know, they've got X number of dollars, that can put one kid in college and one...they gotta take care of other two kids. And, you know, mortgage, utilities, you know, where else will they get the money to live it, live a healthy lifestyle." (Steven)

Although some participants live within high socioeconomic status, they acknowledge their privileges of affording the resources to effectively self-management.

"But I think my income is such where allows me to deal with that... Time wise, there is a cost to it; in addition to the financial costs of it, but it has it has negatively affected me financially. But I do think that over time, as I get older and my income gets less, that's when I'll see it." (Steven)

"I think I'm been lucky because the whole time I've had diabetes I've had insurance so I've been able to, to or whether someone's been sent me to what doctor or even the prescription I've been able to be on the things that I need to be to manage myself. But the weird thing is...my insurance pays for any drugs that are generic... But! the diabetes medicine is what I pay for,

so I think the drug companies sorta, they take advantage a little bit...but we have to... you know, you pay for the diabetes medicines and for the good ones, they're pretty expensive"
(Caroline)

"I don't have this issue, the cost because I have an excellent insurance plan... I have an excellent pension. So I have the money, to pay extra for prescriptions and things and to buy better quality food maybe? I think probably the cost of things for a lot of people might be, you know, an issue. I personally, like I said, I'm just very fortunate and grateful that I don't have that issue." (Michelle)

The cost of living with T2D is quite expensive in Bermuda. In chapter one, the private and public healthcare system was presented which included an explanation of insurance plans for individuals who are categorised as employed, unemployed or retired. The participants shared their concerns about the cost of self-managing T2D in Bermuda, which include the affordability of healthy foods, access to health professional services and medications.

Although all healthcare services and medication costs are shared between the individual and their employer (Bermuda Health Insurance [Exemption] Regulations, 1971). However, the co-pay is still quite expensive. The mean age of the participants was 63.8 and most are pensioners and are left to worry about their ability to afford living with T2D.

"I worry about the price of things... whether I'm going to be able to afford to be diabetic." (Ida)

"The drugs are very expensive. My insurance covers... what it covers and I have to pay the rest. So, yeah. And I worry about that, you know, as the funds that we've saved up for retirement as they come down slowly. I think am I going to get to the point where I'm going to have to decide whether or not to buy the insulin or not? Yeah. So it is worrisome." (Ida)

The ability to afford the cost of living with T2D in Bermuda influences the approach to self-management practices and adherence to treatment plans. A participant shared the inability to afford insulin as part of their treatment plan. Fortunately, the participant implements effective self-management practices that maintain blood glucose levels.

“if I was still taking the insulin, I wouldn't have been able to afford it...I wouldn't have been able to afford it...I definitely wouldn't have been able to afford it.” (Christine)

Interestingly, affordability does not automatically predict effective self-management practices for individuals living with T2D. Participants with insurance plans and the finances to afford the cost of living with T2D in Bermuda still have challenges with self-management. Participants who are considered middle class in Bermuda, still face financial challenges of maintaining the cost of living with T2D.

“So, you know, they know they have diabetes, they want to eat healthy, but you know, they've got X number of dollars, that can put one kid in college and one...they gotta take care of other two kids. And, you know, mortgage, utilities, you know, where else will they get the money to live it, live a healthy lifestyle.” (Steven)

In this subtheme, socioeconomic status is a significant factor in the effective management of T2D. Participants shared their concerns about the cost of health insurance, the expense of health food choices and their uneasiness about the ongoing financial expenses of living with T2D.

In summary, the theme, *Who I am vs. who I should be (Sociocultural challenges)* discusses the participants identity as either “diabetic” or “an individual living with diabetes” and the challenges of transitioning from unhealthy to healthy behaviours as it related to Leventhal et al, 2016 CSMSR (See Figure 4). How the participants self-identified post diagnosis influenced their efforts and ability to

effectively self-manage T2D (See Figure 4). There is an emotional response invoked by the relationship with food which is associated with interpersonal relationships, tradition, cultural and social norms. The participants' learned generational beliefs, attitudes and health behaviours were inherited from the previous generations and served as the foundation for T2D illness perceptions and self-management practices. However, the participants are keen to unlearn unhealthful behaviours from the previous generations and teach future generations about healthy T2D self-management practices.

3.3.3 If you don't listen, you feel

A common saying from older Bermudians is "if you don't listen, you feel" this serves as a warning about the consequences that will occur when you do not listen or pay attention to guidance. In this context, Bermudians' attitudes towards T2D self-management and health behaviours are seemingly lax if there are no overt physical consequences. This finding directly correlates with the interrelationship between the elements of Leventhal et al (2016) CSMSR *timeline and consequence* and how they influence the participants ability to effectively self-manage T2D (See Figure 4). The participants have engaged in some form of diabetes self-management education (DSME). However, there was a perceived gap between knowledge, understanding and behaviour that ultimately impacted the effectiveness of T2D self-management which will be discussed in the following findings.

3.3.3.1 *Impact of Knowledge and Education*

Underestimated timeline severity

The severity of T2D was not considered for some participants who had personal experiences with family members who lived with physical consequences of T2D.

"Laziness. Denial... I used to say no big deal ... I'm a diabetic. I've joined the club. My mom was diabetic. My daddy was diabetic. They managed it, but they died too." (Susan)

A few participants recalled family members who lived with a diabetes-related amputation.

“And like I said...people in my family had it. And me as a young child, I just envision my uncle had had his foot amputated. So, that, so I'm well aware of what the, the end result of not controlling diabetes can do to you”. (Steven)

“I should have been more careful. Because my mom had it. Her mother lost a leg from it... my mother's mother... lost a leg from it. My paternal grandmother, she had to get the needle. I remember the district and has coming up to the house when I was up there...And so, it's in my family. It's definitely in my family and, I, you know, I knew it, but you know, just don't pay attention all the time...I should have been more careful.” (Valerie)

“The long-term effect and I didn't want my legs amputated like my grandfather. I know I have to...I had a heart attack as well...four years ago. I just need to take a better care of my body.” (Juliette)

Diabetes Self-Management Education (DSME)

At initial T2D diagnosis, all the participants in this study confirmed receiving a form of DSME from health professionals. Additionally, the participants acknowledged that there are health professionals and local private and public health resources available for diabetes self-management education (DSME).

“yes, I've done the diabetes course... I used to see [health professional] on a regular basis.” (Jason)

“I was thinking the other day, maybe you need to go back to this [DSME] class. Because it's been a couple years. (Susan)

“I was listening to [a health professional] ... and she was announcing the radio. If by chance you have symptoms. Those are early onset signs of diabetes and you need to come in and see

your doctor and have them check it. I saw my doctor and found out my sugar level was 380"

(Kenneth)

A participant reported that the delivery of the DSME from the health professional was helpful and educational.

"I took the weeklong, well...course, which was like teaching you about different foods and what the repercussion are for your intake and how to crunch your calories and whatever. And I found that very informative." (Calvin)

One participant shared that they engaged in a helpful DSME programme.

"I took the weeklong, well...course, which was like teaching you about different foods and what the repercussion are for your intake and how to crunch your calories and whatever. And I found that very informative." (Calvin)

Another participant agreed that the DSME programs were useful and recognised that the information about self-management practices can be tailored to the individual.

"It's [DSME], very useful...to do the education but it's hard to eat what they're telling you to eat because if you're not used to eating that way, you know, it's like, never ate that stuff kind of thing. You know, or God I don't like that. So, you know, you have to just figure out for yourself what you like." (Deborah)

Since engaging in DSME, participants learned about nutrition and have adjusted their eating behaviours.

"I don't eat bread. I think the bread is something that really does...um increases your sugar very quickly. Yeah, you know, sugar rises very quickly, unfortunately, I'm not a brown bread

eater so white bread just goes to (animated noise) up there, uphill, you know, I think so. That affects it as well.” (Deborah)

“the starch is the killer, it’s just sugar as far as I’m concerned. I would have a big bowl of macaroni today and potato salad and all that. I realize now that’s a no-no... if you can help it.” (Rochelle)

A participant in treatment facility and began learning practical information about a diabetes-friendly diet. The participant made the choice to share the information about healthy food choices with members of staff and requested an amended diet.

“At the women's treatment centre, they knew I had diabetes, but they still were giving me food that was full of sugar. Because it was a group, you know facility and they only cooked one thing for everybody.... I got a pamphlet about diabetes and read it and it was saying what you can eat and what you should eat; and I cut out the sodas and drink juice... I liked tea and then they used to put Splenda in my tea.” (Sheila)

Another participant confirmed that although the DSME programmes were beneficial. There is seemingly a need for an increase in awareness and education about T2D.

“I think you can see that just by the percentage of Bermudians who have it...I mean it’s prevalent and, um...you know, whether or not they’re aware of that or not, there has to be some sort of avenue, if it’s possible, that has more information out there about you know, what exactly is diabetes. You know, because the thing about me, I’ve taken a couple of courses, I think each course like I took, I glean something out of it.” (Steven)

As the participants recalled, the health professionals who facilitated DSME programmes provided those individuals living with T2D with the practical knowledge about self-management. A nurse-led DSME intervention conducted by Azami et al (2018) reported significant improvements in HbA1c and T2D self-management behaviours in the intervention group compared to the control group. At follow up, the intervention group maintained improvement and Azami et al (2018) concluded that nurse-led DSME interventions were effective.

The majority of the participants as aforementioned have engaged in DSME programmes, however, there seems to be a gap between knowledge and understanding about the timeline and consequences of T2D which can lead to unknowingly maintaining unhelpful behaviours. One participant believes that T2D is not a chronic condition and is optimistic about reversing the T2D diagnosis.

"I didn't understand, I thought diabetes was a lifelong thing, but no, knowing the knowledge I have now is that is controllable...even possibly eliminated. Yeah, so given that...I, I am more optimistic to it and living with it more than anything else." (Steven)

Conversely, another participant believes that T2D is a lifelong condition and is sceptical about the possibility of reversing the diagnosis.

"I'll have it all my life and that's the way I view...people come up with the thing of curing diabetes. But then people say well you're not cured if you eat hamburger and order fries"
(James)

A couple participants are aware that obesity is a risk factor for developing T2D and noticed an increase in obesity within the Bermudian population.

"...I mean you hear commercial[s] about it on the radio about it and commercials on TV about diabetes about how Bermuda is top, one of the top per capita of people with diabetes. And if you look at it a lot of Bermudians are obese. I notice that the other day. I was in town and it

was like everywhere I looked people were just like...it was like how? You never saw that before...now everywhere you turn everybody is like huge" (Sheila)

"Yes and, and I never, in the past I never related those things [amputations] to diabetes ever. And but now I see people who are heavy [overweight], and my first thought is they need to be careful because they might, if they don't already have it, they might." (Michelle)

Knowledge without action

Participants share that they are informed about T2D. However, a few recognised that they either did not actively apply the knowledge to prevent a T2D diagnosis or obtaining knowledge about T2D did not significantly influence a change in their health behaviours.

"I knew a lot about diabetes. And I knew what it involved...I know a lot about diabetes, and I knew a lot of the things that could lead up to it. But I felt that I probably could have done more to prevent it." (Juliette)

"as soon as my local doctor confirmed it, he referred me to the diabetes education or whatever it is in the hospital. I attended that. I don't know how much it influenced any change in behavior." (Philip)

Another participant implied that effective T2D self-manage is based on choice. This participant acquired knowledge about T2D and choose not to apply their knowledge to their self-management behaviours.

"I've done the diabetes course... But I tend to eat what I feel like" (Jason)

This correlates with a participant who was willing to reenrol in a DSME programme but did not have a positive attitude towards behaviour change.

Anna: "I went to the hospital [classes]some years ago."

Interviewer: "Would you be open to a refresher?"

Anna: "Um...sighs...I'm not sure. It won't make any difference."

One participant agreed that he is informed about T2D and effective self-management practices but has struggled to apply these health behaviours to their lifestyle.

Steven: there's no excuse for me now because I have the knowledge, just a matter of me trying to fashion that lifestyle, work and fitness up into having that health regimen that I did back in the States..."

Interviewer: How long have you been back on Bermuda full time?

Steven: Been a while been like a good like 10 years.

There is not enough time.

One of the concerns about the Bermudian lifestyle, is the busyness of life and the challenge of time management to strategically incorporate time for self-care. Other participants express that effective T2D self-management is not just contingent on choice. External factors, such as time management, factor in an individual's living with T2D ability to prioritise healthful behaviours amongst other responsibilities.

"And I think that maybe that's what we're missing. Maybe we're missing more of the approach of um, can we slow down a little bit, but how can people? They can't afford the rents, they can't afford the electric light bill, they can't. It's our life here... is helping to cater to all of these

*illnesses. And until we can change that, that the, the numbers will keep skyrocketing... Why is Bermuda [prevalence] so high? It has **got** to be our lifestyle.” (Rita)*

The participants related the impact of busyness as a barrier to effective T2D self-management, particularly in relation to physical activity.

“Oh yeah, I should be exercising too, but I'm too busy” (Sheila)

*“So, I have a problem with doing exercise, I don't have a problem riding my bike or doing, doing the treadmill, just, just a matter of trying to fit that into my lifestyle.”
(Steven)*

A couple participants are making a conscious effort to incorporate exercise into their busy schedule.

*“So, I don't have that kind of time to walk. That's my problem, I don't have the time I'm gonna make time. I have the tapes, the DVDs. I have been doing them, but I haven't done them lately. I'm got all that, but it's me. So I know it's important to walk, I know”.
(Pamela)*

“I've exercised now, which I tried to try to do at least three times a week but it's hard to fit everything into your busy schedule... you know, kind of thing, and then do the work and all that” (Deborah)

Another participant recognised the important of self-care while maintaining a busy lifestyle and sought professional help.

“I just, I don't find I don't have enough time for myself to take care of myself. And I'm going to counselling to learn how to do that... so that I can become better.” (Juliette)

No discernible consequences

The consensus for the maintenance of T2D self-management behaviours is surrounded by consistency. Participants were challenged to adapt to long-term new health-related behaviours. Although the participants understood the concept of living with a life-long disease it was challenging to adapt and maintain life-long health behaviours, particularly if the changes were difficult to implement. For these reasons, the participants were hesitant to consistently sustain healthy behaviours without any discernible physical consequences.

“And again, if you don't, if there's no discernible consequence. You're just going to keep doing what you want to do...So unless there's something that gets your attention, it'll be like, you know what, I'll start tomorrow. You know, let me let me go out and get hot [drunk]... you can tell a Bermudian to eat less and walk more until you're blue in the face...unless there's a legitimate consequence it's not gonna to happen... unless you have that support, you know.” (Elbert)

Another participant conveyed that their perception of the seriousness of the T2D diagnosis and absence of overt consequences influenced their lack of urgency to effectively manage their health behaviours T2D.

“sometimes people need to be shocked and to do the right things for themselves. I did not have a full appreciation of what the full consequences of diabetes would be, had I had that information and knowledge I may have intervened and managed myself better... I don't blame the medical professionals... but sometimes you have to be frightened to do what's right for you” (Henry)

Another participant acknowledges that without apparent consequences individuals may not be motivated to implement lifestyle changes.

“People decide what they want to give up and what they want to continue. As long as they don't see any drastic effect on themselves, they will continue to do what they want to do.”

(Philip)

A few participants agree that without physical consequences, it is challenging to be mindful of the need to maintain healthful behaviours for effective T2D self-management.

“you probably didn't take it [T2D] as serious as you should. You know, then if you feel okay, you don't worry about it” (Anna)

“you know, people talk about diabetes, but yeah, it's no a big thing I can get over it and that's it. You know, I never took heed to the warning signs.” (Eugene)

Participant shared that their healthful self-management behaviours became lax over time.

I lost a lot of weight, did a lot of exercise and then...over [the years], I kinda...I wouldn't say slip right back, but I didn't pay as much attention because it wasn't right in my face, you know.”

(Jason)

“I used to measure it and be really, really strict. And I think once my levels got down, I said, Okay, I'm cool... I could relax a bit.” (Susan)

As aforementioned, the population of Bermuda has a high prevalence of T2D. Based on familiarity of T2D and observing the self-management behaviours of family members, participants may have misinterpreted information about the timeline and severity of T2D. The participants recall witnessing the long-term consequences of mismanaged T2D experiences with family members who lived with

physical consequences of T2D. However, the severity of the consequences as it relates to the participants own T2D was underestimated.

“Both parents are diabetic. And that's why I was trying my hardest to prevent from being medicated but all my siblings except I think one sister, I think, are diabetic...I've done the course, I think I'm okay. But now I'm having all these nicks and pains and you know, so maybe...I need to go to the course again, re-educate myself and take it more serious.” (Susan)

Similarly, in Patel et al, (2015) study, the British South Asian participants revealed that their community led them to normalise and downplay the seriousness of T2D. These communal attitudes seemingly decrease the levels of emotional related distress because of the normality of the family member living with T2D. The sociocultural context of T2D shaped the illness perceptions and self-management practices in the British South Asian living with T2D (Patel, et al 2015).

3.3.3.2. *The Turning Point*

Although some participants seemingly have a nonchalant attitude towards T2D, there is a fear about the consequences of ineffective self-management.

“I actually had a low that I sort of passed out...recently. And that's terrible...When you have a low, I know what it does. Like everything starts to... your brain, everything shuts down. That was very scary. (Caroline)

Often the fear of physical consequences leads to a turning point to implement healthy behaviours for effective T2D self-management.

“then next thing I did I woke up in the hospital. I was like where the devil am I? And apparently, I had a seizure...a diabetic seizure, went into a coma when I was in emergency, the ER for...they said I was in there for about three weeks! Well I don't remember nothing...I was just...it was

all because...when they checked my sugar levels it was 800...and I had no idea.... I felt fine.”

(Sheila)

A participant expressed that a cardiac episode caused an urgency to attend to the seriousness of living with T2D.

“What started me to pay attention was I had a heart attack...they put a stent in and that really made me pay attention” (Jason)

One participant shared experiencing a diabetes-related episode that affected eyesight which resulted in the turning point to implementing T2D self-care practices.

“My eyes start to blur. I couldn't, I couldn't see... I needed glasses...I went to my doctor, he said, No, you got sugar in your eyes. I think that really was like a wakeup call to me then. Because um...who's to say that that could affect my eyesight ... so that's I really took it seriously after that.” (Steven)

Some participants did not have personal experiences with the physical complications of unmanaged T2D. However, the lived experiences of others influenced the participants to heed to the warning signs of uncontrolled T2D.

“My girlfriend...I know she had a very bad [hypoglycaemic] experience, so I watch everything.”

(Rochelle)

A couple participants described witnessing how uncontrolled T2D affected their love one's eyesight and caused low limb amputations.

“my wife...she um... she’s familiar with diabetes because her mother went blind with it, and her father lost both limbs because of diabetes and she just keeps reminding me of the warning signs, you know. She said, it just hits you...One day, it could be everything could be fine, and all of a sudden, (pop) it attacks one of the organs. You know, it could be devastating.” (Eugene)

“I, I just don't want to be like how some other people I've seen and holes all on my feet, cutting a toe off, cutting a foot off... cut it below the knee, oh now we gotta go above the knee.” (James)

One participant shared that their turning point was seeing their co-worker hospitalised and undergoing dialysis treatment.

“The turning point? My co-worker, I heard she was sick, and I went to visit her... and I knew she was losing weight. I was shocked at how small she was. She can’t drive now because she can’t see properly and she’s going on dialysis. But I was like whoa! ...So, I said, Wow. So...seeing her like I said, you have to do something” (Susan)

Another participant expressed how the fear of amputation and the possibility of undergoing dialysis after observing other living with unmanaged T2D increased their efforts to effectively self-manage.

“what happens is, it does start to affect other parts of your body... I do know, and I've seen it in other people how I can affect you. So, you know, well, I don't want to be sitting up um...blind or on dialysis, those two things can scare you I think I just, you know, I need to start at least trying to manage my diabetes better.” (Caroline)

Quandt et al, (2013) reported that fear about diabetes consequences in older adults included disease progression, amputation, blindness, and coma. Additionally, the participants in Quandt et al, (2013) study revealed that their perceptions about T2D consequences was based on early life experiences prior to fully understanding the complexities of T2D. Quandt et al (2013) concluded that addressing the fear of T2D consequences may increase the effectiveness of self-management practices.

Similar to Quandt et al (2013), participants in this study reached a turning point when faced with the fear of long-term physical consequences, such as blindness, diabetic coma and dialysis, resulting from ineffective T2D self-management behaviours. When the participants reached this point, fear evolved into motivation to implement healthy behaviours for effective T2D self-management.

3.3.4 Summary of Themes

In Summary, there were 3 main themes; 1) Beyond my control, 2) Who I am vs. who I should be (Sociocultural challenges, and 3) If you listen, you feel (See Figure 4). The findings from *Beyond my control*, reflected that the participants' causal beliefs about T2D determined the ways in which they self-managed T2D. The participants shared their beliefs about lifestyle choices, family history and genetics as the cause for the T2D diagnosis. The perceptions about effective T2D self-management informed participants' beliefs about internal, external or a combination of both locus of control. For example, religious and spiritual beliefs influenced how the participants managed T2D with day-to-day activities and how they viewed their future living with T2D.

The results from the *Who I am vs who I should be (Sociocultural challenges)* illustrated the barriers to maintaining interpersonal relationships, engaging in cultural norms and traditions, balancing cultural identity whilst adapting a new T2D-related identity. To identify as an individual living with T2D directly opposes what it means to identify as a Bermudian. As a culture, Bermudians identify as family-orientated, social people who reside in close-knit communities. Cultural events, national holidays, family gatherings and the overall Bermudian lifestyle is immersed in food, alcohol and is the Bermudian way of displaying love. The question becomes how can I be Bermudian and participate in

sociocultural traditions without neglecting T2D self-management? Whether the participants in this study consider themselves as diabetic or identify as individuals living with diabetes, maintaining a dual identity presents a challenge. However, the individual has a choice about their new identity. Those who choose to identify as diabetics adapt the attitudes that diabetes controls all aspects of life. This perception about the timeline can discourage change and invoke thoughts of hopelessness towards T2D self-management. Conversely, those who choose to identify as individuals living with T2D recognise themselves as individuals firstly and decided to reframe their mindset to incorporate healthy T2D self-management practices into their lifestyle. Each person living with T2D has the control to reflectively create the new way of day-to-day self-management as they adapt to their new identity. These findings were imperative to gaining an understanding about the significance of culture and its impact on health behaviours such as T2D self-management. The learned behaviours from previous generations influenced the participants' illness perceptions about T2D and it equally informed their T2D behaviours. However, health behaviours were often determined by external factors such as socioeconomic status. As Bermuda is a privatised healthcare system and the participants acknowledged how finances control how T2D is managed. Monetary strain affected the participants decision regarding adherence to medicinal treatment, making healthy food choices and time management to incorporate physical activity.

The final theme, *If you don't listen, you feel* discussed the seemingly lax health behaviours when there are no discernible consequences to unmanaged T2D. It was interesting that the majority of the participants took part in DSME programmes yet there was a perceived gap between knowledge and understanding that impacted the participants ability to effectively self-manage T2D. The importance of this finding was understanding the significant role that cultural context plays in DSME. The participants shared that the turning point to begin lifelong healthful behaviours did not occur until there was a discernible physical consequence. Some participants personally experienced these physical consequences and others reached their turning point through the experiences of others.

Watching the experiences of others inspired some participants to change their health behaviours reveals the connection of the Bermudian community.

In the recursive data analysis process, outlined in chapter 2, self-management, or, controllability was the centralised common thread across the participants that maps onto Leventhal et al (2016) as displayed in Figure 4 and Figure 5 (Braun & Clark, 2019; 2020)

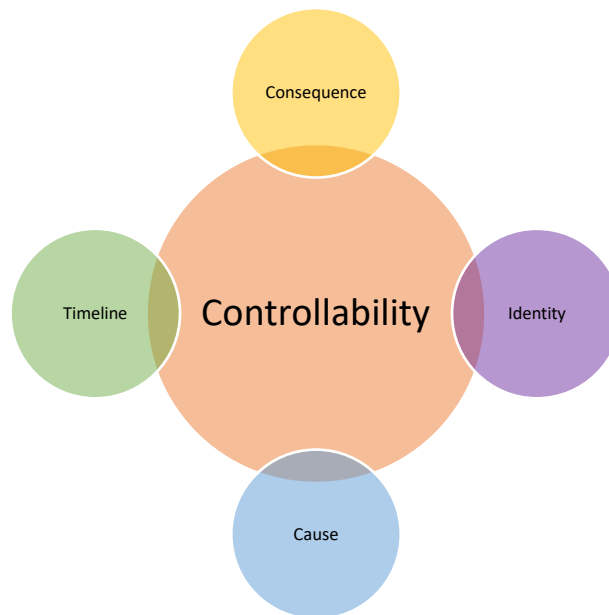


Figure 5

This study utilised Leventhal et al (2016) CSMSR as a framework to gain an understanding of how illness perceptions influence the effectiveness of T2D self-management. There is a centralised interrelationship between *controllability* and the additional elements of the CSMSR, *cause, identity, timeline, and consequence* in relation to of T2D self-management (See Figure 4 & 5) The participants' causal beliefs, post-diagnosis self-identity, perception of the timeline to implement healthy self-management practices before experiencing overt physical consequences, all influence the effectiveness of T2D controllability.

3.4 Strengths and Limitations of the study

This section will discuss the strengths and limitations of the study.

There were limitations to this study which included the age and the gender: race ratio of the participants, although this reflects the T2D population. The mean age of the participants in this study was 63.7. This represents the older population of adults living with T2D in Bermuda. However, it does not consider how illness perceptions influence self-management practices of younger adults living with T2D. Potentially age is a key factor to understanding the determinants of self-management practices based on illness perceptions of individuals who have a short span of life experiences compared to older adults who have a longer period of time to implement health behaviours. Also, there could be a difference between the attitudes, illness perceptions and readiness to change in younger adults living with T2D compared to older adults after practicing long-term unhealthy diabetes self-care. Although, the study population was racially diverse and represented different genders, women were overly represented and accounted for 60% of the total participants. Approximately 48% of the total participants were black women. Therefore, the findings should be considered within the context of the participants who were recruited, and the reader should consider the transferability of these findings to their own context (Braun & Clarke, 2013). There were limited demographics included in this qualitative study. As aforementioned, Bermuda's total land mass is 21- square miles (56 kilometres) across 9 parishes and there are no parish-specific ethnic or religious variations. The adult population is 43,700, therefore any additional demographic information could potentially risk disclosure and jeopardise the preservation of participant confidentiality.

It was important to establish and maintain a safe environment as the participants took part in the study. Although, the interview setting in Fountain Health did not present as a limitation, it was recognised that the setting is an influential factor on the data. There was a possibility that the participants may have reacted differently if the interviews were conducted in home setting opposed

to a clinical setting. However, the researcher may not have managed to recruit this population outside of this setting.

As a fellow Bermudian, the researcher was a member of the same Bermudian population as the participants, which can be considered as cultural homophilic relationship. The cultural homophilic relationship between the researcher and the participants was a strength during each stage of the study. Like cultural homophily, there is the concept of insider research, which occurs when a researcher identifies as a member of a community, organisation or sociocultural group that is being studied (Ross, 2017; Greene, 2014; Chavez, 2008). In this context, the strength of being a Bermudian researcher, or an insider researcher, was having an understanding of the participants motivation to take part in this research which informed the design of the recruitment flyer (See Appendices B, 6.2). The flyer was arranged in a question-and-answer format which provided key information about the study. There were 4 significant details aimed to pique the interest of Bermudian participants.; 1. A picture and brief biography about the researcher inclusive of the name and level of educational degree and work experience within Bermuda, 2. To clearly state that the researcher was a fellow Bermudian, 3. The researcher's future intentions to contribute to the community and 4. Participation could help to potentially provide evidence to improve the quality of life of Bermudians living with T2D.

However, the physical placement of the recruitment flyers created a limitation to recruitment. Individuals who were enrolled as patients but were disengaged with healthcare services, specifically Fountain Health, could not see the recruitment flyer as they were posted throughout the clinic. Additionally, the study would have excluded individuals who did not have health insurance or out of pocket costs. All participants were recruited from Fountain Health, a private endocrinology clinic and therefore individuals who do not have health insurance coverage or sufficient funds would not be patients of Fountain Health. However, as discussed in Section 1.0, the majority of Bermudians are insured, and these represent the majority of individuals living in Bermuda with T2D.

After the recruitment process and during the interviews the advantage of being an insider researcher was the shared understanding of Bermudian culture and traditions allowed both parties to build a rapport and develop a mutual trust in a short span of time. Whilst conducting the interviews there was a use of similar language, Bermudian colloquialisms, and an innate understanding of what the participants meant that did not require further interpretation which resulted in a rich dataset. Conversely, this cultural familiarity as an insider researcher could have been a potential limitation in this instance. A researcher who was not Bermudian and had no understanding of cultural references may have enquired further and requested expanded responses from the participants to gain deeper insight. However, this could possibly interrupt the researcher-participant rapport.

There are potential limitations as they relate to the community in which the study took place. As previously mentioned, the researcher is part of this close-knit community. There was a possibility that the size of the country of Bermuda and the researcher's insider affiliation with the community could possibly create a risk to confidentiality and disclosure. For this reason, participants may have felt reluctant to share the details of their lived experiences. However, the researcher reflected throughout the course of the research process and being part of the community was not felt as a risk to data collection.

As the researcher transcribed the audio-recorded interviews, it was noted that the researcher and participants spoke rather quickly with thick Bermudian accents. This may have presented a challenge for a Non-Bermudian researcher. The researcher simultaneously performed a dual role during data analysis. As a Bermudian, insider researcher, it was imperative to analyse and interpret the findings from an epistemological contextualist position. This allowed the researcher to identify and emphasise culturally relevant nuances so Non-Bermudian readers could understand the significance of the participants responses in relation to illness perceptions and self-management practices. Cultural homophilic relationships are considered a strength of qualitative research as evidenced by Widayanti

et al, (2020), whose primary researcher was Indonesian and facilitated focus groups in an Indonesian population using their national language.

Although the researcher was unknown to several participants, the researcher conducted this study as a recognised health professional. However, a limitation of a health professional in the role of a researcher conducting interviews was the prospect of participants' reluctance to reveal unhealthy behaviours. This could be considered a barrier to openly discuss T2D mismanagement. However, this did not appear to be an issue as reflected in the findings. Conversely, the recognition as a health professional was strength of the study. This role has a level of trust in the community which may have influenced obtaining a sample size of 25 participants which was beyond the recommended 15-20 sample for large, qualitative study (Clark, 2015; Braun & Clark, 2013).

Lastly, as mentioned in chapter one, there is scarce existing literature on the influence of illness perception on T2D self-management practices for individuals living in Bermuda. A strength of this original research is the contribution to health psychology that is culturally relevant to this under-represented population.

3.5 Practical implications for Health Psychology and Practice

This was an initial, qualitative, exploratory study within this population, both geographically and in population. It serves as a foundation study from an academic point of view for future research.

Based on this exploratory study's findings, in the following section are the practical implications for health psychology working with and supporting individuals living with T2D in Bermuda. Existing literature supports the findings in this study to address illness perceptions and their influence on effective self-management practices in a cultural context for individuals living with T2D in Bermuda.

Health psychologists have a role within several areas of T2D self-management which include conducting assessments, providing psychological support, psychoeducation, and facilitating practical

behavioural change interventions. It is the study's belief that a Health Psychologist can address the needs of the patient through an intervention at initial diagnosis and post-diagnosis to increase the effectiveness of self-management practices.

Using quantitative or qualitative assessment tools, health psychologists could investigate the patient's illness perceptions about T2D. In this study the participants' perception of an inevitable T2D diagnosis based on the causal beliefs of genetics and family history led to the development of fatalistic attitudes which is similar to the findings in Widayanti et al (2020) study. Bermudians have been told over the years that T2D is a chronic disease. Participants' responses were lax, which led to defeatist attitudes. These responses were not interpreted as lack of concern, rather, it presented as feelings of hopelessness. The emotional and psychological thinking shifts from causal beliefs of perceived inevitability to loss of control and feelings of hopelessness. These factors of causal beliefs and emotional distress inform illness perceptions which directly impact the self-management practices of individuals living with T2D. Health professionals should be mindful of this when presenting information about the causes of T2D and delivering DSME programmes. van Puffelen et al, (2019) study supports the view that encourages health professionals to incorporate patient illness perceptions and continuous DSME to usual T2D care (van Puffelen, et al 2019).

For this population, psychoeducation, such as DSME, is a key component to helping the patient make sense of their diagnosis in a Bermudian context. The 1:1 or group DSME could focus on moderation without deprivation during social events, teaching alternative healthy recipes for Bermudian dishes and facilitate support groups.

After analysing the results from the patient assessment, the health psychologist could implement a patient centred approach to psychological support using active listening and motivation interviewing to gain an understand of the patient's sociocultural background. At this point, the health psychologist could tailor an intervention based on the patient's needs and inform the health professions on the multidisciplinary teams (MDT) of the findings.

T2D does not have to be a death sentence as described by a participant, it is adapting to a new, healthier way of life. The participants in this study, although they initially implied that they accepted the diagnosis, wanted to find a way to manipulate T2D because the changes that are required are presented as unrealistic for lifelong maintenance. In a Bermudian context, new health behaviours and information about T2D and its prevalence could be taught to the new generation. There could be a new cultural shift and approach to being Bermudian. Sociocultural interventions could focus on the following:

- ✚ Reframing T2D illness perceptions from inevitability to possibility.
- ✚ Practical, strategic, and cost-effective behaviour change interventions.
- ✚ Active listening and motivational interviewing during psychological assessment to develop tailored interventions.
- ✚ Understanding the importance of the patient creating and implementing their own SMART goals.
- ✚ Diabetes Self-Management Education (DSME)- Bridging the gap between knowledge, understanding and behaviour to improve T2D self-management practices.

Although Bermuda does not have an equivalent organisation such as the National Institute for Health and Care Excellence (NICE), the recommendations from studies can be disseminated through healthcare networks. The researcher envisages the Health Psychologist having the most involvement based in private, community and hospital settings across two healthcare networks in Bermuda 1) Private Healthcare and 2) Public Health. Health Psychologists can provide their services either independently or within MDTs in privatised healthcare networks across GP offices, wellness programs and DSMEs. The provision for the majority of individuals accessing these services within privatised settings will be covered with health insurance. Additionally, the Health Psychologist can provide the aforementioned services within the public health networks such as community settings

in partnership with charities that specialise in provided MDT care for individuals living with T2D, government-funded public health initiatives and insurance companies who collaborate with health care professionals to provide public health initiatives. Those individuals who are not insured can assess these services without any individual out-of-pocket costs. Within the Bermuda healthcare systems patients are accessed through referral from GPs, specialists, and self-referral.

Based on the study's finding, the researcher recommends modifying Leventhal et al (2016) CSMSR to gain insight into illness perceptions and how it influences the effectiveness of T2D self-management for individuals living with T2D in Bermuda. In this study, the centralised element of the modified CSMSR *control*, interrelated with the remaining 4 elements, *cause*, *consequence*, *identity*, and *timeline* (See Figures 4 & 5). This reflected how effective T2D self-management and the interrelationship of the CSMSR elements influenced the participants' causal beliefs, post-diagnosis self-identity and perception of the timeline to implement healthy self-management practices before experiencing overt physical consequences (See Figures 4 & 5). Existing literature supports the findings in this study for future health psychology practice to address illness perceptions and their influence on effective self-management practices in a cultural context for individuals living with T2D in Bermuda. Therefore, practitioner psychologists could benefit from utilising elements of Leventhal et al (2016) CSMSR to address beliefs and illness perceptions with patients and reduce the gap between knowledge, understanding and behaviour as it related to effective T2D self-management.

The ultimate goal is to seek to change the systems of thinking by tailoring interventions that focus on addressing individual illness perceptions about T2D from a sociocultural perspective to implement lasting health behaviours and effective self-management practices.

3.6 Future research directions

This study was exploratory research and the broad inclusion criteria did not target a specific population of individuals living with T2D in Bermuda. As a recommendation for future research, this study suggests gender and age as primary targets for the inclusion & exclusion criteria for an evenly balanced race: gender ratio. Perhaps future research could target a younger population for similar results. The study recommends exploring how illness perceptions influence self-management behaviours of a younger population living with T2D in Bermuda.

Also, the researcher proposes investigating the effectiveness of self-management practices of Bermudians living with T2D outside of Bermuda. Would the same challenges with T2D self-management present in Bermudians residing in a different country? Would the participants have flexibility regarding their identity as Bermudian in a foreign company? Would this identity flexibility extend to maintaining cultural norms, such as preparing and eating traditional dishes within a different culture? Would the cost of living with T2D present a challenge for effective self-management for Bermudians living in a foreign country with a national healthcare service?

Lastly, it cannot be assumed that what works in one group works for another. With this in mind, the researcher recommends the use of this study for future research as a template for tailoring T2D self-management plans with the purpose of gaining an understanding of illness perceptions and T2D self-management practices in unique and unrepresented populations.

3.7 Conclusion

This study concluded that illness perceptions are based on sociocultural lived experiences for individuals living with T2D in Bermuda. The causal belief about T2D controlled diabetes self-management behaviours which is interrelated with how individuals living T2D identify. The sociocultural aspect and quality of Bermudian life enriched with culture and tradition challenged

individuals living with T2D to implement healthy self-management behaviours. Bermuda has one of the highest rates of T2D prevalence worldwide and most Bermudians have knowledge about this chronic disease, usually through experiences with family members living with T2D. There is a gap between knowledge and understanding. The perception that T2D is inevitable can cause a level of distress and hopelessness which is often misconstrued as a laxed. However, as the participants shared, they are opposed to living with consequences of mismanaged T2D. They are willing to unlearn generational beliefs and behaviours to teach the future generations about implementing a healthy lifestyle. Culturally relevant efforts from health professionals will allow individuals living with T2D to make conscious, informed choices about their T2D self-management health behaviours. Health professionals, particularly Health Psychologists, could minimise the gap using motivational interviewing to increase patient self-efficacy, behaviour change approaches, patient centred care and the implementation of SMART goals to increase effective T2D self-management and create a balanced quality of life for individuals living with T2D in Bermuda.

4.0 References

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5.0 Appendices A - Permissions

5.1 Permission from Fountain Health

This portion of the appendices has been removed as it contains personal information.

5.2 UWE Graduate School Approval

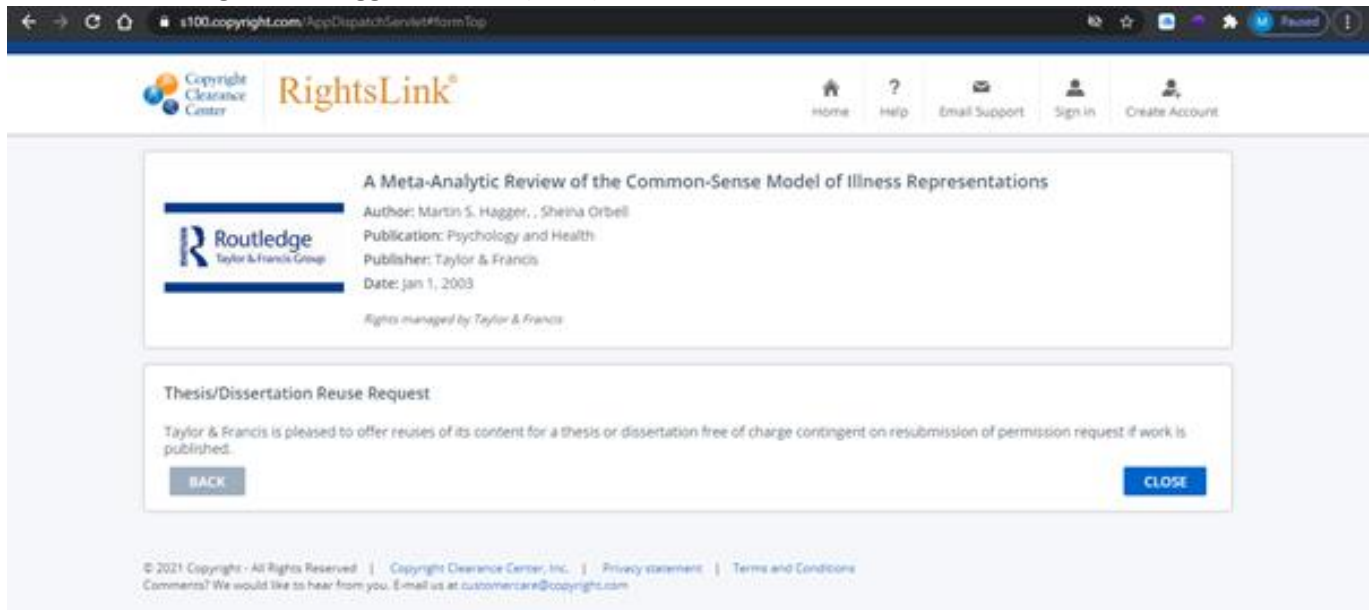
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5.3 BHB- the Bermuda Hospital's Board Ethics Committee approval letter

This portion of the appendices has been removed as it contains personal information.

5.4 Permissions for use of Figures and Tables

Permission for Figure 1 – Haggard & Orbell (2003)



The screenshot shows the RightsLink interface for a request. At the top, there are navigation links for Home, Help, Email Support, Sign In, and Create Account. The main content area displays the following information:

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- Author:** Martin S. Haggard, Sheina Orbell
- Publication:** Psychology and Health
- Publisher:** Taylor & Francis
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Permission for Figure 1 – Heffernan et al (2016)



The screenshot shows the article page for "Understanding the psychosocial experiences of adults with mild-moderate hearing loss: An application of Leventhal's self-regulatory model" by Eithne Heffernan et al. (2016). The article is open access. The "Reprints and Permissions" section states: "This is an open access article distributed under the terms of the Creative Commons CC BY license, which permits unrestricted use, distribution, reproduction in any medium, provided the original work is properly cited. You are not required to obtain permission to reuse this article in part or whole." There are also buttons for "Sign in here to start your access" and "Select Language".

Article statistics shown on the left:

- 3,936 Views
- 51 CrossRef citations to date
- 13 Abstracts

Navigation links at the bottom of the article page include: Full Article, Figures & data, References, Supplemental, Citations, Metrics, Licensing, Reprints & Permissions, and PDF.

Related articles section:

- People also read
- Recommended articles
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One related article is listed: "Coping together with hearing loss: a qualitative meta-synthesis of the psychosocial experiences of people with hearing loss and their communication partners".

Permission for Figure 2 - BheC & DoH (2011)

Health in Review

*An International Comparative Analysis of Bermuda
Health System Indicators*

Contact us

If you would like any further information about the Bermuda Health Council, or if you would like to bring a healthcare matter to our attention, we look forward to hearing from you.

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6.0 Appendices B – Participation Package

6.1 Participant Interview Schedule



University of the West of England (UWE)
Department of Psychology
Frenchay Campus
Coldharbour Lane
Bristol
BS16 1QY

Study Title: How do illness perceptions influence the effectiveness of self-management in patients living in Bermuda with type 2 diabetes?

Interview Schedule

The interview schedule comprises of open-ended question, which will be used flexibly and appropriately depending on the interview participant and their individual responses. Discretionary prompts are included to engage the participant into a broader dialogue.

1. Could you tell me about when you were first diagnosed?
 - a. Prompt- What symptoms were you experiencing before diagnosis?
 - b. Prompt - What were your thoughts after diagnosis?
2. How has diabetes impacted your daily life?
 - a. Prompt- How has diabetes affected you emotionally...financially?
3. What do you think caused the type 2 diabetes?
 - a. Prompt- Do you think lifestyle impacted your diagnosis? Could you tell me more about that?
 - b. Prompt-Do you think your family history played a role in the cause of type 2 diabetes?
4. What was it that encouraged you to take action in managing diabetes?

5. How do you manage diabetes?
 - a. Prompt- What steps do you take to regulate your blood sugar after it has been low/high?
6. Have you made changes to your lifestyle as a result of your diagnosis?
 - a. Prompt – (if no) How did you come to that decision?
 - b. Prompt- (if yes) What changes have you made to your diet...physical activity?
7. How did you cope with these changes? Or How did these changes make you feel/ how did these changes impact you emotionally?
 - a. Prompt- Where these changes difficult to maintain?
8. What do you find most difficult/challenging about managing diabetes?
9. Do you think that you are successfully managing diabetes?
 - a. Prompt –(Yes) how so? (No) Why do you think that is?
 - b. Prompt- What keeps you on track (with self-management)?
 - c. Prompt -What happens when you get off track?
10. How would you describe your religious or spiritual beliefs?

Prompt- what role does your religious or spiritual beliefs play in how you self-manage your diabetes? Please tell me more
11. How do the health professionals address your needs or preference for care?
 - a. Prompt - How often do you rely on health professionals to help manage your diabetes?

- b. Prompt - If applicable. what are the barriers/what makes it difficult to accessing your local diabetes services?
- 12. What is most important to you in your diabetes care?
 - a. If you could, what would you change about your diabetes care?
- 13. What strategies do you find most useful for managing type 2 diabetes?
- 14. What do you think stops people from diabetes self-care practices?
- 15. What would you like to suggest to improve diabetes management behaviour among other diabetes patients?
- 16. How do you see your future living with diabetes?

6.2 Recruitment Flyer



BERMUDIAN PARTICIPANTS NEEDED FOR DIABETES RESEARCH!

What is the study about?

Bermuda has one of the highest ratings of prevalence of diabetes worldwide. Diabetes is a long-term condition that requires the individual to play an active role in managing the condition themselves. Self-management refers to an individual's ability to identify and manage signs, symptoms, treatment, psychological, emotional and physical factors and lifestyle changes which are essential to living with diabetes. The goal of the study is to explore the personal beliefs and perceptions about diabetes in individuals living with type 2 diabetes and how their experiences influence diabetes self-management.

Who can participate?

- Bermudian
- Over the age of 18
- Lived with type 2 diabetes for over 2 years

What does participation in the study involve?

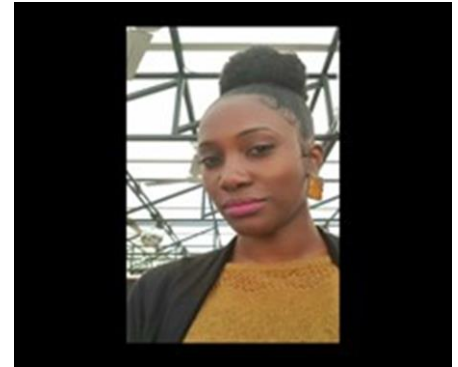
If you agree to take part, you will be asked to participate in a one to one interview. This will be conducted by Tameisha Matthew. The focus of the interview will be to gain information about your individual experience of living with and managing diabetes. The interview will take approximately 45-60 minutes and take place in a private office at the Fountain Health clinic. The interview will be recorded on a voice recorder. The answers you give in the interview will be confidential and pseudonymised. This means that the recording will not include your real name, instead you will be referred to by a fictitious name.

What are the benefits of participating in the study?

If you participate, you will be helping us to potentially provide evidence that could be culturally relevant and improve the quality of life of Bermudians living with type 2 diabetes. Additionally, the findings from this study will contribute to the scarce existing literature on the impact of beliefs and perceptions of diabetes self-management in Bermuda.

If you are interested or would like further information, please contact Fountain Health (441) 232 2027 or alternatively info@fmg.bm

Tameisha N. Matthew, MBPsS



I am a Bermudian Trainee Health Psychologist and this study contributes to my Professional Doctorate in Health Psychology at the University of the West of England.

I have over 7 years of experience providing individual and group psychological support within multidisciplinary teams of health professionals who care for people living with long-term illnesses such as diabetes and cardiac-related diseases.

Currently, I am working within the NHS in the Department of Clinical Health Psychology at St Mary's Hospital in London, United Kingdom.

Additionally, I co-designed and co-lead the *Professional Issues in Health Psychology* module within the MSc Health Psychology programme at the University of Buckingham.

After the expected completion of my degree in 2021, I will return to Bermuda and continue contributing to improving the health outcomes of people living with long-term illnesses.

6.3 Participant Information Sheet



University of the West of England (UWE)

Department of Psychology

Frenchay Campus

Coldharbour Lane

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BS16 1QY

Tel: +44 (0)117 965 6261

Study Title: How do illness perceptions influence the effectiveness of self-management in patients living in Bermuda with type 2 diabetes?

Patient Information Sheet

You are invited to take part in this study which contributes to my Professional Doctorate in Health Psychology from the University of the West of England, Bristol. Before you decide whether to take part, it is important for you to understand why the study is being done and what it will involve. Please read the following information carefully and if you have any queries or would like more information please contact Tameisha Matthew of the University of the West of England, Bristol tameisha2.matthew@live.uwe.ac.uk

The aim of the research

Bermuda has one of the highest ratings of prevalence of diabetes worldwide. Diabetes is a chronic, or long-term condition that requires the individual to play an active role in managing the condition themselves. Self-management refers to an individual's ability to identify and manage signs, symptoms, treatment, psychological, emotional and physical factors and lifestyle changes which are essential to living with diabetes. The aim of the study is to explore the personal beliefs and perceptions about diabetes in individuals living with type 2 diabetes and how their lived experiences influence diabetes self-management.

Why have I been Invited to take part?

As an individual living with diabetes, we are interested in gaining information about your views so the interview will ask you about these things. The purpose of the questions will be to gain information about your experience living with and self-managing type 2 diabetes.

Do I have to take part?

Your participation in this study is entirely on a voluntary basis. It is up to you to decide whether or not you want to be involved. If you decide to participate, you will be given a copy of this information sheet to keep for your records and will be asked to sign a consent form. If you do decide to take part

in this study, you are able to withdraw without reason at any time before the interview or during the interview and up to 2 weeks after the interview. If you want to withdraw from the study with these time periods, please write to Leigh Taylor, Senior Research Officer (Research Ethics), University of the West of England, Bristol via email leigh.taylor@live.uwe.ac.uk. Deciding not to participate or withdrawing from the study does not have a penalty and will not affect the standard or quality care you will receive in any way.

What will happen to me if I take part and what do I have to do?

If you agree to take part, you will be asked to participate in a one to one interview. This will be conducted by Tameisha Matthew. The interview will take approximately one hour and take place in a private office at the Fountain Health clinic. The focus of the interview will be to gain information about your beliefs and perceptions about diabetes and your individual experience of living with and managing diabetes. The answers you give in the interview will be confidential and pseudonymised. Your interview will be recorded on a voice recorder, but the recording will not include your name. A unique identifying will be used to re-identify you if you choose to withdraw from the study within the time periods stated above. After your interview has been transcribed, your voice recording will be deleted. Your data will be pseudonymised at this point, meaning that you will be referred to by a fictitious name and will be analysed with interview data from other pseudonymised participants.

What are the benefits of taking part?

If you take part, you will be helping us to potentially provide evidence that could be culturally relevant to the Bermudian population living with type 2 diabetes. Additionally, the findings from this study will contribute to the scarce existing literature on the impact of beliefs and perceptions of diabetes self-management within a Bermudian context.

What are the possible risks of taking part?

We do not foresee or anticipate any significant risk to you in taking part in this study. If, however, you feel uncomfortable at any time you can ask for interview to stop. If you need any support during or after interview, then the researchers will be able to put you in touch with suitable support agencies. Tameisha Matthew is experienced in conducting one to one interview and is sensitive to the subject area. The interviews have been designed with these considerations in mind. The interviews will take place at Fountain Health and in the event of a physical risk to your well-being, medical professionals will be readily available.

What will happen to your information?

All of your information will be treated in the strictest confidence. All the information that you give will be kept confidential and pseudonymised during the interview and write up of the study. The pseudonymised transcription of the voice recordings will be kept on a secure password protected laptop and password protected drive in accordance with the University's and the Data Protection Act

2018 and General Data Protection Regulation requirements. The voice recordings will be destroyed securely immediately after the pseudonymised transcription. Your pseudonymised data will be analysed together with other interview and file data and there is no possibility of identification from this point.

Where were the results of the research study be published?

A report will be written containing the study's findings. This report will be available on the University of the West of England's open-access Research Repository. A hard copy of the Report will be made available to research participants upon request. Key findings will also be shared both within and outside the University of the West of England, the Bermuda Government Department of Health and The Bermuda Hospital's Board. Anonymous and non-identifying direct quotes may be used for publication and presentation purposes.

Who has ethically approved this research?

The project has been reviewed and approved by [the Faculty/University of the West of England University Research Ethics Committee and The Bermuda Hospital's Board. Any comments, questions or complaints about the ethical conduct of this study can be addressed to the Research Ethics Committee at the University of the West of England at: *Researchethics@uwe.ac.uk* or The Bermuda Hospital's Board Ethics Committee at: *ethics@bhb.bm*

What if I have more questions or do not understand something?

If there are any further queries about this study, please do not hesitate to contact me via email *tameisha2.matthew@live.uwe.ac.uk* or telephone 441 599 3131 (Bermuda) or +4477 8518 6548 (UK). If you have any concerns or issues with the study, please contact my UWE supervisor, Dr. Julian Bath via email *julian.bath@uwe.ac.uk*.

Thank you for agreeing to take part in this study. You will be given a copy of this Participant Information Sheet and your signed Consent Form to keep.

6.4 Privacy Notice



University of the West of England (UWE)

Department of Psychology

Frenchay Campus

Coldharbour Lane

Bristol

BS16 1QY

Tel: +44 (0)117 965 6261

Study Title: How do illness perceptions influence the effectiveness of self-management in patients living in Bermuda with type 2 diabetes?

Privacy Notice for Research Participants

Purpose of the Privacy Notice

This privacy notice explains how the University of the West of England, Bristol (UWE) collects, manages and uses your personal data before, during and after you participate in *How do illness perceptions influence the effectiveness of self-management in patients living in Bermuda with type 2 diabetes?* 'Personal data' means any information relating to an identified or identifiable natural person (the data subject). An 'identifiable natural person' is one who can be identified, directly or indirectly, including by reference to an identifier such as a name, an identification number, location data, an online identifier, or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person.

This privacy notice adheres to the General Data Protection Regulation (GDPR) principle of transparency. This means it gives information about:

- How and why your data will be used for the research;
- What your rights are under GDPR; and
- How to contact UWE Bristol and the project lead in relation to questions, concerns or exercising your rights regarding the use of your personal data.

This Privacy Notice should be read in conjunction with the Participant Information Sheet and Consent Form provided to you before you agree to take part in the research.

Why are we processing your personal data?

UWE Bristol undertakes research under its public function to provide research for the benefit of society. As a data controller we are committed to protecting the privacy and security of your personal data in accordance with the (EU) 2016/679 the General Data Protection Regulation (GDPR), the Data Protection Act 2018 (or any successor legislation) and any other legislation directly relating to privacy laws that apply (together “the Data Protection Legislation”). General information on Data Protection law is available from the Information Commissioner’s Office (<https://ico.org.uk/>).

How do we use your personal data?

We use your personal data for research with appropriate safeguards in place on the lawful bases of fulfilling tasks in the public interest, and for archiving purposes in the public interest, for scientific or historical research purposes. We will always tell you about the information we wish to collect from you and how we will use it.

We will not use your personal data for automated decision making about you or for profiling purposes.

Our research is governed by robust policies and procedures and, where human participants are involved, is subject to ethical approval from either UWE Bristol’s Faculty or University Research Ethics Committees. This research has been approved by Faculty Research Ethics Committee, Ethics application reference number and the email contact of the research committee is researchethics@uwe.ac.uk for queries, comments or complaints. This research project adheres to the Ethical guidelines of the British Educational Research Association (and/or the principles of the Declaration of Helsinki, 2013) and the principles of the General Data Protection Regulation (GDPR).

For more information about UWE Bristol’s research ethics approval process please see our Research Ethics webpages at: www1.uwe.ac.uk/research/researchethics. We will only share your personal data in accordance with the attached Participant Information Sheet and your Consent.

What Data do we collect?

The data we collect will vary from project to project. Researchers will only collect data that is essential for their project. The specific categories of personal data processed are described in the Participant Information Sheet provided to you with this Privacy Notice.

Who do we share your data with?

We will only share your personal data in accordance with the attached Participant Information Sheet and your Consent.

How do we keep your data secured?

We take a robust approach to protecting your information with secure electronic and physical storage areas for research data with controlled access. If you are participating in a particularly sensitive project UWE Bristol puts into place additional layers of security. UWE Bristol has Cyber Essentials information security certification.

Alongside these technical measures there are comprehensive and effective policies and processes in place to ensure that users and administrators of information are aware of their obligations and responsibilities for the data they have access to. By default, people are only granted access to the information they require to perform their duties. Mandatory data protection and information security training is provided to staff and expert advice available if needed.

How long do we keep your data for?

Your personal data will only be retained for as long as is necessary to fulfil the cited purpose of the research. The length of time we keep your personal data will depend on several factors including the significance of the data, funder requirements, and the nature of the study. Specific details are provided in the attached Participant Information Sheet. Anonymised data that falls outside the scope of data protection legislation as it contains no identifying or identifiable information may be stored in UWE Bristol's research data archive or another carefully selected appropriate data archive.

Your rights and how to exercise them

Under the Data Protection legislation, you have the following **qualified** rights:

- (1) The right to access your personal data held by or on behalf of the University;
- (2) The right to rectification if the information is inaccurate or incomplete;
- (3) The right to restrict processing and/or erasure of your personal data;
- (4) The right to data portability;
- (5) The right to object to processing;
- (6) The right to object to automated decision making and profiling;
- (7) The right to complain to the Information Commissioner's Office (ICO).

Please note, however, that some of these rights do not apply when the data is being used for research purposes if appropriate safeguards have been put in place.

We will always respond to concerns or queries you may have. If you wish to exercise your rights or have any other general data protection queries, please contact UWE Bristol's Data Protection Officer (dataprotection@uwe.ac.uk).

If you have any complaints or queries relating to the research in which you are taking part please contact either the research project lead, whose details are in the attached Participant Information Sheet, UWE Bristol's Research Ethics Committees (research.ethics@uwe.ac.uk) or UWE Bristol's research governance manager (Ros.Rouse@uwe.ac.uk)

6.5 Participant Informed Consent Form



University of the West of England (UWE)

Department of Psychology

Frenchay Campus

Coldharbour Lane

Bristol

BS16 1QY

Tel: +44 (0)117 965 6261

Study Title: How do illness perceptions influence the effectiveness of self-management in patients living in Bermuda with type 2 diabetes?

Informed Consent Form (please complete and return)

This consent form will have been given to you with the Participant Information Sheet. Please ensure that you have read and understood the information contained in the Participant Information Sheet and asked any questions before you sign this form. If you have any questions please contact a member of the research team, whose details are set out on the Participant Information Sheet

If you are happy to take part in the interview, please sign and date the form. You will be given a copy to keep for your records.

- I have read and understood the information in the Participant Information Sheet which I have been given to read before asked to sign this form;
- I have been given the opportunity to ask questions about the study;
- I have had my questions answered satisfactorily by the research team;
- I agree that anonymised quotes may be used in the final Report of this study;
- I understand that my participation is voluntary and that I am free to withdraw at any time until the data has been anonymised, without giving a reason;
- I agree to take part in the research

Name (Printed)

Signature.....Date.....

6.6 Participant Debriefing Form



University of the West of England (UWE)

Department of Psychology

Frenchay Campus

Coldharbour Lane

Bristol

BS16 1QY

Tel: +44 (0)117 965 6261

Debriefing Form

Thank you for your participation in this study.

This study will explore how do illness perceptions influence the effectiveness of self-management in patients living in Bermuda with type 2 diabetes?

Your participation in its entirety, inclusive of the audio recorded interview and the report will remain completely confidential. However, if you subsequently decide that you would not like your interview to be included in the study, you have a withdrawal period of two weeks after the completion of the interview to contact me via email tameisha2.matthew@live.uwe.ac.uk or telephone 441 599 3131 (Bermuda) or +4477 8518 6548 (UK).

If you would like to participate in a diabetes education program or would like assistance with the treatment of physical challenges relating to your diabetes care such as managing eye, foot, kidney, dietary issues or weight management please contact the team at Fountain Health located at 63 Victoria Street, Hamilton, HM 12. Please call 441-232-2027 or visit their website www.fountainhealth.bm

If you would like to seek counselling, additional support, advice or encouragement please contact the Bermuda Diabetes Association Resource Centre *located at* 2 Beacon Street, Hamilton, HM12 on the Corner of Dundonald and Cedar Avenue. For further information call 441-297-8427 or visit their website www.bermudadiabetes.org

Additionally, the Bermuda Hospital's Board DREAM Centre offers a week-long diabetes self-management education program located at the Mid-Atlantic Wellness Institute, 44 Devon Springs Road, Devonshire, FL01. For additional information regarding this program, please call 441-239-2027 or email diabetes.centre@bhb.bm

If you have any further questions about this study, you may contact my UWE Supervisor Dr. Julian Bath via email julian.bath@uwe.ac.uk.

7.0 Appendices C -Example of annotated transcript

Annotated Transcript

As aforementioned, the country of Bermuda has a small adult population of 43,700 (IDF Diabetes Atlas, 2017). With this consideration, coupled with the awareness to maintain participant anonymity, the researcher refrained from including a full transcript. However, the following is an excerpt from a participant transcript to illustrate the method of coding during the reflexive thematic analysis process.

<p>Interviewer</p> <p>Do you find that diabetes has had an impact on your finances?</p> <p>James</p> <p>Yes, and not as...like I said, I'm eating less junk food. I'm not eating the junk food so bag of chips will cost you two bucks. I do drink diet sodas sighs... I do use um...I'll make a drink more water. So, I take 40 ounces today during work, in the winter I'll probably drink 20. I might have two diet sodas a day. Yeah, I know it's no good for you, but sorry. It's um... I keep saying I'm sorry. I'm not sorry. That's what I drink. That's it. Finances, cooking.... almond flour, cheesh...yeah, that's expensive. Anything you get like that. I'm looking for food oat fibre right now to try to make bread. Not the keto bread, but oat fibre is that the fibre good and it's new carb it in. it's just it's psyllium husk. I haven't got the...maybe, I can find something to</p>	<p>Chips = crisps</p> <p>Gap between knowledge and implementing knowledge with behaviour.</p> <p>Taking accountability unapologetically for still partaking in enjoyable foods</p> <p>Expensive healthy foods /ingredients costs</p> <p>Oat fibre- no gluten, no carbs, does not raise sugar levels.</p>
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put it in. It's gonna be the same way. It's just it's the outside. So, the oat fibre is the outside of the ...what everybody else would eat. It's the throw away part. They want too much money for that stuff. Yeah, it's expensive. So, but if you buy it I mean I got a freezer, it's full on everything I use. And it's... eggs I probably eat three times more eggs than I used to. It's not I'm not eating eggs every day. But I never used to eat them at all. It's...yeah, it's more expensive. I eat the head of lettuce every day. Yeah, yeah, you go through... you get 3 romaines, I can do one and a half for a meal of romaine. I'll put tomatoes on there again you're looking for organic. Just because you're eating so much of it so if you try it if I can get organic, I do if I can't I can't. I'm not gonna lose sleep over it. I miss apples but I don't like a lot. I miss it and I can do that. So, if somebody is making an apple, I just want a quarter I'll make a chicken salad sandwich... chicken salad and I can take that for lunch, just eat that by itself for lunch. That will have celery and you have to put some...apple...and you can put some raisins in and even again half that box...that little tiny box. And you can you use the cans, you get cans of two cans of it and you make enough there for two meals or three, if you can. If you have a salad with it, then you can make more. It does. It decreases the finances, it... it's more expensive to eat, I guess. Long story short.

Expensive healthy food

Expensive foods

Increase in specific food to balance out

Increase in uptake of specific healthy foods

Is organic the healthier choice? Or does more expensive translate as healthier?

Relationship to food – loss

Healthier eating decreases the finances

Healthier eating = financial strain

Interviewer

How do you see your future living with diabetes?

James

Positive. I can have a normal...my last two A1C were normal but I still got diabetes. I'll have it all my life and that's the way I view...people come up with the thing of curing diabetes. But then people say well you're not cured if you eat hamburger and order fries and everything you know your sugars go, Yeah, cool, that's not a normal meal. So, the, for me, the hardest thing is figuring out what can I eat? That's good. I know, look, if I haven't been out to eat in a while, but if I went Swizzle Inn tonight, I could have a hamburger. I can have a salad. And I'm going to take five onions rings from somebody and it's going to spike my sugar probably a little bit but by the morning it's going to be almost normal. But if I did that every. single. day... I'm gonna be back where I was before. So that's what I know. In other words, you got to think, if I go on a cruise, what can I eat? Do it is

Acceptance – T2D chronic condition

Perception about T2D

IP Timeline (CSMSR)

DSME – knowledge about T2D timeline

Hardest challenge- figuring out what to eat

With DSME knowledge about nutrition there's still questions around food choices

Swizzle Inn – a restaurant (similar to a family pub setting) & home of Bermuda's national alcoholic beverage

Onion rings - No deprivation of enjoyable foods self- control- knowing limitations & understanding how their individual body processes foods

before you do the cruise? Research it. Think about what you're going to eat today, tomorrow. What can you have? So, you can have this stuff...and if I go to work and I don't have the food with me, what's gonna happen when you're hungry? Where you gonna go? Take... Dr. [name] used to tell me that [they] took on quite a few years now. So, Dr. [name] was the first dietitian and so twice, [they] always told me, and I didn't do what [they] said for the first time. And when I was probably pre diabetic and getting big. [They] says take your lunch to work. So, I started taking...and people used to tease me I had a big bag, this big, (hand gestures for sizing) it's in the car. It's cold. I got two ice packs in there. I have food in there I don't worry about it because it can be in there all day long. It's...got ice packs. It's got my food, it's got my water, it's probably got a Diet Pepsi in there right now because I haven't drank it today so I just had water and um...some piece of cheese like I said for my snack and some walnuts. That's why I didn't worry about lunch today so much. I have macadamias. Try to measure things out too. Don't just grab out of a

Strategies for a balanced lifestyle – travel & cuisine. Research – Informed decision making

Meal planning

The thought process of daily eating/food choices

Gender neutral pronoun [they]

Didn't listen to the health professional's advice the first time it was offered.

Social aspects of healthy behaviour changes

Bringing vs. buying lunch warranted teasing?

Pack your lunch –you know what you're eating if you prepare it yourself

Awareness of portion control

Practicing portions

Strategy to monitor sugar intake

Measuring portions

Practice measuring portions for a period of time for T2D self-management

container, try to measure it even if it's more than what you're supposed to, measure it out.

And they have a little time those little tiny packs on pour in there. Just measured it out and maybe more than you're supposed to have...measure it out so you know what you're getting. And then once you measure it out, once you get a little handle on you it. Then you can start saying well how many carbs are that?

Oh wow, that's 20 cut back. When I was first diagnosed, I would count 15 corn chips, which is a serving, or I'll weight them as well. And then put two tablespoons of the sauce... salsa and then some cheese. Oh, it's great! I'm drooling thinking about it. That's also 25 grams of carbs. By the time you have everything on it. See what I mean? 50 grams of carbs.

Gain an understanding about portion control and relate it to a T2D self-management practice of counting carbs.

Prochaska -TTM -action & maintenance stage

Measure it out so you know what you're getting

Expressive emotional connection to food

Relationship to food – enjoyment

Progressive application of DSME

8.0 Appendices E - Cultural Context Guide

Bermuda is located in the Western North Atlantic Ocean (World Atlas, 2021). The country of Bermuda has a total land area of approximately 21 square miles (56 kilometres) and is 1.75 miles (2.8 kilometres) at its widest point (Bermuda, 2019). Contrary to popular belief, Bermuda is neither spatially or geographically part of the Caribbean (West Indies) islands. Bermuda, a self-governing British Overseas Territory, is approximately 900 miles (1500 kilometres) north of the Caribbean and approximately 700 miles (1127 kilometres) east of North Carolina, United States (Rushe & Heaton, 2021). (See picture below).



Bermuda has its own culture and is a community-oriented country that practices cultural traditions of family gatherings, passing down family recipes, sharing food and events where there is copious amounts of food and drink as described below.

8.1 Codfish & Potatoes

Bermuda's quintessential traditional Sunday breakfast is codfish and potatoes. The packaged codfish is heavily salted for preservation. On Saturday, the fish is soaked in cold water to desalt the meat. On Sunday morning the fish and potatoes are boiled in fresh water. It is served with fresh avocado, banana, boiled eggs and topped with a sweet, tomato and onion sauce or a butter and onion sauce. Also, Bermuda Johnny Bread or Cornbread is served on the side of Codfish and Potatoes. Johnny bread can be described as a simple, sweet bread and its main ingredients are flour, sugar and a generous amount of butter. Similarly, cornbread is a sweet bread, and the main ingredient is cornmeal. If any of the abovementioned ingredients are missing, Bermudians will not eat the meal because the breakfast will be considered incomplete. This traditional breakfast is not considered diabetes-friendly because of usual portion size, the breakdown of sugar from the starches and the quantity of sugar in the tomato, or red sauce. However, individuals living with T2D in Bermuda, are mindful of the ingredients and often struggle to enjoy this tradition.



CODFISH AND POTATO



JOHNNY BREAD



CORNBREAD

8.2 Christmas and Cassava Pie

It can be difficult to limit or refrain from cultural and traditional dishes that are uniquely Bermudian but not considered diabetes-friendly. For example, cassava pie is a traditional and essential Christmas dish in Bermuda and is often enjoyed at Easter. The pie customarily incorporates tender, boiled herb chicken and is flavoured with spices such as nutmeg and cinnamon. The recipe, which is usually made in large quantities, calls for approximately 5-6lbs of cassava, 14-18 eggs, 2lbs butter, 1-2 cups of sugar and vanilla extract to taste. Although the pie is a unique mix of sweet and savoury, it is not a dessert; it is served as a side dish for the main Christmas dinner. Cassava pie is consumed all throughout Christmas week and is served hot and usually reheated by pan-frying with a little butter. Bermudians consume, share, and exchange their pies when visiting family and friends across the island throughout the Christmas holidays. Every Bermudian has their own family recipe for cassava pie. The older family members usually do not write their recipes down or use measuring tools. The younger generation learn measuring and baking techniques that can only be taught by engaging in the 3.5 hours process. The quantity of ingredients in the pies can be considered unhealthy,

particularly for individuals living with T2D. Some participants share their challenges of maintaining Bermudian tradition and their efforts to modify recipes and choose healthy alternatives.



CASSAVA PIE SLICES

8.3 Bermuda Ginger Beer

Bermuda Ginger beer can be described as a staple beverage in Bermuda. It is usual practice to blend Bermuda Ginger Beer into the majority of alcoholic and non-alcoholic beverages. It is important to note that there are 49g of sugar per 8oz can of Bermuda Ginger beer. However, in recent years, a sugar-free version of Ginger Beer was produced.



Bermuda GINGER BEER ORIGINAL



Bermuda GINGER BEER ORIGINAL

Nutritional Information



Bermuda GINGER BEER SUGAR FREE

8.4 Bermuda Rum Swizzle & Dark & Stormy

Bermuda Rum Swizzle is considered the unofficial national alcoholic beverage. Although there is a generic recipe, most Bermudians make their own unique blend. The ingredients include a variety of unmeasured alcohols such as 2 types of rums- Bermuda's Gosling's Black Seal Rum and Gold rum, triple sec liqueur, sugar syrup, grenadine, bitters and pineapple and orange juices.

The Dark 'n Stormy cocktail is regarded as the unofficial national alcoholic beverage. Its ingredients are Bermuda's Gosling's Black Seal Rum and Bermuda Ginger beer garnished with a wedge of lime.



GOSLING BLACK SEAL AND GOLD RUMS

8.5 Cupmatch

Cupmatch, a celebration of the emancipation of slavery, is Bermuda's biggest annual event. This 2-day national holiday is held on the Thursday and Friday closest to 1st August. The event is centred around the 2-day cricket match between the island's eastern and western teams. This is a fun filled, family and friend-oriented time in Bermuda which continues all weekend. Cupmatch activities include swimming, boating, camping, concerts, beach parties and locals are quite generous with the consumption and sharing of food and alcohol, particularly Bermuda Rum Swizzle and Dark 'n Stormy®. It can be challenging to fully enjoy the holiday and other social events individuals living with T2D.



CUPMATCH CRICKET MATCH



CUPMATCH BOATING

8.6 Bermudian Food Classification

Non-Bermudians may define “vegetarianism” as the practice of abstaining from meat consumption. Culturally, it is not uncommon for Bermudians to identify as vegetarians whilst incorporating meat into their diets. There are a few categories of vegetarians in Bermudian culture that are based on the frequency of meat consumption. A category of vegetarians are individuals who adhere to a traditional vegetarian diet and refrain from consuming all classifications of meat. Another category of vegetarians are individuals that regularly consume fish and refrain from eating any other classification of meat. Most Bermudians do not consider fish a meat. There is a category were individuals who identify as vegetarians and regularly consume fish but on rare occasions eat chicken.

Moderation can be quite challenging for individuals living with T2D as the emotional connections to food are associated with cultural norms and social dynamics withing the Bermudian population. Bermudians have their own ideations on food categorisation and which foods are considered healthy. For example, vegetarianism has its own culturally relevant classification which is divided into categories based on the frequency of meat consumption. The term vegetarian in the Bermudian context is interpreted as ‘non-meat eater’. Meat is categorised and divided into healthy and unhealthy

meats. Fish is not considered a meat; all poultry is considered healthy meat and pork and beef (red meat) is regarded as an unhealthy meat. One classification of vegetarians are Bermudians who do not consume pork or beef (red meat) and identify themselves as non-meat eaters whilst regularly consuming poultry and fish.

As reflected in the findings, in terms of self-identity and self-management practices such as eating behaviours, like any other culture, Bermudian culture and tradition impacts the everyday dietary habits of individuals living in Bermuda. Food has a number of significant sociocultural meanings and is an “indicator of social identity, from region to ethnicity from class to age or gender...” (Leeds-Hurwitz, 1993, pg. 90). Cultural food practices refer to material and cognitive elements that give rise to specific eating behaviours and dietary patterns within a geographical region or sociocultural group (de Garine, 1972; Balirano & Guzzo, 2019). Culture and cultural beliefs can influence attitudes, beliefs, practices, traditions, value systems and daily dietary practices which in turn, can affect food selections (Collins et al, 2009; Drago & Goody, 2010). An individual’s level of commitment to their culture and religion may affect whether they adopt the dietary practices of that religion and/or culture (Collins et al, 2009; Drago & Goody, 2010). Also, individuals who have been raised in a specific ethnic group or culture will choose and make food selections based on their background. This means that their self-identity, attitudes, and perspectives towards health will be greatly influenced by ethnicity and/or culture. Different values which influence factors, such as eating behaviours, derive from an individual’s country of origin (Asamane et al, 2019; Dindya; & Dindyal, 2004;).

Culturally-specific eating patterns or dietary habits are maintained because they are considered practical or representational meaningful behaviours with a specific culture that may not be apparent to those outside of the culture (Fieldhouse, 2014). Culture is complex and is not something that is readily taught. It can be described as the sum total of a group’s learned experiences and behaviours as they live their daily lives (Fieldhouse, 2014). However, cultural behaviours can be modified and unlearned as reflected in this study’s findings. Although individuals learn about the traditions and

behaviours of the culture they are born into, it changes within each generation and is never exactly the same as the previous generation (Fieldhouse, 2014). This also is reflected in the findings of this study.

For example, an individual who practices Islam may describe their religion as part of their identity. Although there are traditional and religious festivals, such as Eid, which include an abundance of food does not mean that religion does not influence their food choices and/or daily dietary habits. The religious influence of an individual who practices Catholicism will extend further than attending mass on Sundays and will guide the individual's decisions throughout the week as their religion is part of their identity. From an influential cultural perspective, individuals who identify as Italian who have been raised by Italian families in Italy consuming traditional Italian cuisine daily will impact on their everyday dietary habits. Likewise, individuals who identify as Bermudian who have been raised by Bermudian families in Bermuda consuming traditional Bermudian cuisine on a daily basis, just as any other culture, will be influenced in their daily dietary habits.

8.7 References

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9.0 Appendices F - Reflection

The following section is a reflection about the preparation for this study and the researcher's role in the methodology of the research design, data collection and analysis.

Background

As mentioned in the preface, through clinical practice working with individuals living with chronic conditions in Bermuda, I was disturbed by the high prevalence of T2D and the significant amount of people who found it challenging to effectively self-manage T2D. However, through research, it became apparent that there was little to no literature on the cause for this rate of prevalence, one of the highest globally. From a Health Psychology standpoint, I began thinking about the best methodology to answering the question, *how do illness perception influence the effectiveness of self-management for individuals living in Bermuda with T2D*. With this in mind, it was important to focus on qualitatively approaching the question by directly obtaining information from those living with T2D by exploring their experiences.

Methodology

Research Design

Interviews were chosen as the appropriate methodology for data collection. The Common-Sense Model of Self-Regulation (CSMSR) informed the design of the interview schedule. Initially, I struggled to develop the semi-structured questions, so I began to organise the questions into headings as it related to elements of CSMSR. For example, one element of the CSMSR is *cause*, which refers to an individual's perception about the cause of the illness. This led to the development of the question, *"What do you think caused the type 2 diabetes?"* (See Appendices 6.1). As I followed this strategy and continued to develop the questions, the first draft of the interview schedule yielded approximately 30 questions. The large number of questions was unrealistic for completing the

interview within the timeframe of an hour. I re-strategised to decrease the number of questions. Firstly, I eliminated the closed questions, or questions that only required a yes or no response. I would be unable to achieve the desired outcome of acquiring in-depth information and understanding the participants' experiences with one-worded responses. Secondly, I amalgamated duplicates of questions that were worded differently but had similar meaning. Lastly, I included probes, or follow up questions, to provide the opportunity for the participants to expand their answers or to clarify any potentially vague responses. After a few amendments, I was happy that the final interview scheduled was narrowed down to 16 questions (See Appendices B, 6.1)

Recruitment

I strategised to implement my nationality and awareness of cultural norms as an advantage for participant recruitment. Once I obtained permission to recruit and conduct the study from Fountain Health, I began designing a recruitment flyer with the participant inclusion criteria in mind (Appendices A, 5.1; Appendices B, 6.2; Methodology, 2.4).

As detailed in Chapter 3.4, the recruitment flyer was designed to provide key information about the study which included a detailed biography which emphasised that the researcher is a fellow Bermudian. Retrospectively, I recognise that utilising my cultural advantage may have had a negative impact on the recruitment process. The participants potentially could have chosen not to share openly about their experiences living with T2D with a "local". As aforementioned, Bermuda is a small country with a close-knit community. Issues surrounding confidentiality and anonymity may have caused concern and an unwillingness or uninterest to participate in the study. Also, highlighting my work experience as a Trainee Health Psychologist within Bermuda was initially viewed as a strength, I recognise that it could have easily become a weakness. Potential participants may have viewed on the title of *psychologist* as a deterrent or off-putting. Others, as I experienced whilst conducting the

interviews, noted the title of *psychologist* and had an expectation about the format of the interviews as I will further discuss in the following section.

Conducting Interviews

The interviews were conducted in Fountain Health (See Appendices A, 5.1). In reflection, I acknowledge I relied on the title of *Trainee Health Psychologist* as a strength, however, it became a barrier during a few interviews. It was challenging to maintain a research-focused interview whilst these participants often tried to redirect our interactions into a therapy-based session. However, after the first instance, I quickly identified the attempts to redirect the interview format and developed a strategy. The strategy to implement active listening and repeat the participant's phrase that related to a question was often successful.

The recruitment flyer was well-received; however, I became overwhelmed during the first day of interviews. Initially, I allotted one hour for the participant interviews with a 10–15-minute break. For example, the first interview was scheduled for 11:00am and second interview was arranged for 12:30pm. I had not considered that the interviews may run longer than expected. I completed the first interview at 12:30pm and in turn, I was a few minutes late starting the second interview. This was upsetting and I felt rushed. Fortunately, the second participant was gracious, and the interview did not reflect how I felt internally. Although, it may seem trivial, but by the end of the interviews, I was famished. I decided to change the way I arranged the interview schedule based on what I learned on the first day. Interviewing provides the opportunity to engage with participants and is personally the most enjoyable part of research. However, it can be quite taxing if multiple interviews are conducted in one day. From that point onwards, according to the participants' availability, I planned to schedule no more than 2 interviews per day with a minimum of 2 hours between them. This provided time to decompress, reflect on previous interviews and have tea.

As mentioned in Chapter 2.82, the researcher and the participants shared a cultural homophilic relationship. This provided a familiarity between both parties as cultural nuances did not need to be explained and it significantly eased the challenge of building the researcher-participant rapport.

Transcription

I did not meet the personal deadline I set to manually transcribe the interviews. Although, I am a Bermudian with a Bermudian accent, I was reminded of our speech patterns which can include inflections and variations of speed. Frequently, I laughed at how often the participants shared a story within a story, all of which was relevant to the study.

Analysis

During transcription I did not notice the odd Bermudian phrase. However, through the familiarisation process of Reflective Thematic Analysis I realised that context would be needed to fully grasp the participants' responses. Initially, I began including context within the coded transcripts. At the suggestion of a reviewer, I created a cultural context guide (See Appendices E). Originally, I planned to utilise qualitative software to assist with analysis. Ultimately, I chose to manually conduct a thematic analysis. I wanted to incorporate some form of technology for organisational purposes. After a YouTube tutorial, I conducted the analysis using Microsoft Word (See Appendices C).

In the proposal stage of this research, I was hesitant about selecting thematic analysis as this is my first time conducting this form of analysis. As I carried out the stages of thematic analysis, I experienced bouts of Imposter's Syndrome and often felt anxious about my capability to analyse correctly. Fortunately, Braun & Clark (2019, 2020) published a current paper that provided clarity about conducting Reflexive Thematic Analysis. As I continued to refer to the papers, my confidence increased. The Braun & Clark (2020) emphasised my role as the researcher to subjectively generate and interpret the theme based on my own knowledge, sociocultural beliefs and theoretical

assumptions. Throughout the analysis, I interpreted the data from different perspectives and roles. As the researcher, I interpreted the data from a Health Psychology theoretical standpoint informed by the Common-Sense Model of Self-Regulation (CSMSR). Also, I analysed and interpreted the data as a Bermudian with the consideration that the readers need sociocultural context to gain an understanding of the significant culturally-relevant findings. Lastly, I interpreted with the awareness that there is little no research on this population. It was important to extract rich data and develop themes that provided a representation of the shared meaning and shared experiences of Bermudians living with T2D.

The findings from the study provided a holistic view of the experiences of individuals living with T2D. I learned more about the challenges the participants' encounter daily. The shared experiences provided insight about the struggles to effectively self-manage T2D but it was a step in the direction of developing tailored interventions and public health initiatives to increase efficient self-management practices and improve overall quality of life.

10.0 Appendices G - Systematic Review

Are Psychosocial Interventions Effective in Decreasing Depression in Middle to Older Adults with Type 2 Diabetes: A Systematic Review

10.1 ABSTRACT

In recent years there has been recognition of the relationship between diabetes and depression. Middle to older adults with diabetes have the highest prevalence of comorbid diabetes and depression. The purpose of the current review is to identify if there is evidence that psychosocial interventions are effective in decreasing depression in middle to older adults with type 2 diabetes. A review of current studies conducted over the last ten years was assessed. A search was organised for potential studies using the following electronic databases: British Nursing Index (BNI), Cumulative Index of Nursing and Allied Health Literature (CINAHL), Cochrane Library, MEDLINE via EBSCO, PsychARTICLES via EBSCO, PsycINFO via EBSCO, PUBMED via EBSCO and Scopus. 10 studies were identified using disparate designs including, Cognitive Behavioural Therapy, Self-Management, Psychoeducation and Mindful Self-Compassion Therapy. Since the variability was significantly high across the studies and the measures in each intervention were disparate, it was inappropriate to conduct a meta-analysis. Across the studies, results showed significant differences in depression scores between the intervention and control groups from baseline, post intervention and follow up. The quality of the 10 included studies were assessed and given a global rating (2 strong, 7 moderate and 1 weak) using the Effective Public Health Practice Project (*EPHPP*) tool. The review concluded that there are moderate to strong psychosocial interventions reduced depression scores in middle to older adults with type 2 diabetes. These evidence-based findings will be useful to healthcare professionals when designing psychosocial interventions to reduce depression for patients with diabetes and beneficial for patients experiencing these comorbidities.

10.2 INTRODUCTION

In the UK there are an estimated 4.5 million living with diabetes (Diabetes UK, 2016) 90% of these people have type 2 diabetes.(Diabetes, UK, 2018) The number of people diagnosed with diabetes in the UK has more than doubled from 1.4 million to 3.5 million since 1996 (Diabetes UK, 2014).

According to the International Diabetes Federation (2017), globally there are approximately 425 million adults living with diabetes and those aged 40-59 were among the greatest number. Life expectancy is reduced by 6 years for patients with diabetes when compared to patient without.

Diabetes does not only have an impact on physical health but on emotional and psychological health. Emotional wellbeing is crucial to the overall management of health, particularly for people with long term conditions such as diabetes (Bajracharya, 2010).

In recent years there has been recognition of the relationship between diabetes and depression. According to the World Health Organisation (WHO, 2017), people with diabetes are twice as likely to suffer from a form of depressive disorder as people without diabetes. Between 2005 and 2015 there has been an increase of over 18% of people living with diabetes. It is estimated that over 300 million people worldwide are living with depression. The prevalence of diabetes within the general population ranges from 3% to 10% which is significantly lower compared to other groups living with chronic diseases. For example, comorbid depression and diabetes account for 27%, stroke 31% and cancer 33% (WHO, 2003).

Studies suggest that people with diabetes are twice as likely to suffer an episode of depression (Mommersteeg et al, 2013) and have longer periods of depressive episodes which occur more frequently compared to those without diabetes (Mezuk et al, 2008). The outcome of both conditions is worsened by the presence of the other (Holt et al, 2012; Lloyd et al, 2010).

Acceptance and understanding how diabetes effects the body, the impact it will have on daily life, implementing lifestyle changes and the ability to self-manage all have a psychological impact on person with diabetes. This often leads to some form of emotional distress, such as depression and

anxiety (Chew et al, 2014). Diabetic patients with depression are less likely to adhere to treatment than patients who are not depressed. Patients who experience comorbid diabetes and depression often find it challenging to cope and manage both chronic illnesses (Badescu et al, 2016). Kilbourne et al (2005) measured depression and adherence in patients with diabetes. The self-report results showed that patients with depression were less likely to adhere to medications. Older patients with depression have greater difficulty with diabetes management; this can be attributed to living with other chronic diseases and additional medicinal treatment (Lorenc et al, 1993; Kilbourne et al, 2005) Self-management is even less adequate among diabetic patients with depression than those without it. The clear association between depression, inadequate self-management, and adverse outcomes has led many to advocate for better identification and treatment of depression among diabetic patients. Thus far, cross-sectional studies have provided most of the evidence regarding the association of depression with poor diabetes self-management and adverse outcomes. (Lin et al, 2006). The implications of unaddressed depression can affect a person's ability to effectively manage diabetes. Lustman et al, 2005 study reported that patients with diabetes and depression had poor glycaemic control which results in increased symptoms of depression. When the depression was addressed in patients with diabetes there was an increase in glycaemic control and a significant improvement in quality of life and mood. As a result of the current studies, healthcare professionals develop psychosocial interventions to support depression treatment and diabetes management (Sabourin et al 2013).

Recent systematic reviews have investigated the efficacy of psychosocial interventions, such as Cognitive Behavioural Therapy (CBT), Mindfulness Based Cognitive Therapy (MBCT), Self-Management and Psychoeducation to decrease depression. Chen Li et al, (2017) examined 10 randomised control trials (RCTs) studies for the effectiveness of CBT with the aim of reducing depression in middle-aged patients with diabetes. The results showed a significant decrease in depression when compared to the

control groups, (SMD -0.65, 95% confidence interval). The study concluded that short-term CBT is more effective in decreasing depression symptoms compared to long term CBT.

Markowitz et al (2011) conducted a systematic review that investigated treatments for depression in patients with diabetes. The search yielded 17 studies, 6 of which were randomised control trials psychosocial interventions. Of the 6 psychosocial interventions, 5 were CBT-based. Markowitz et al, (2011) evaluated these individual and group-based interventions that ranged between 5 and 14 weeks. The CBT group had a significant reduction in depression scores compared the control group. Additionally, the CBT group scores remained consistent at 6-month follow up. The study concluded that CBT was effective in improving depression scores; there is no evidence that lessening depressive symptoms will inevitably improve adherence and self-management.

Self-management interventions include approaches to behaviour, problem solving and addresses diabetic-health beliefs which influence adherence. Steed et al (2003) conducted a systematic review which examined the impact of psychosocial outcomes in patients aged 50-60 with diabetes post intervention. 15 of the 30 studies focused on the effect self-management, education or psychological intervention have on depression. Results show that psychosocial interventions improve depression scores and self-management interventions quality of life. The study concluded that psychological interventions were more effective in decreasing depression than self-management interventions (Steed et al, 2003).

Skurt et al (2015) systematic review explored RCTs that identified interventions that were effective in reducing diabetes distress. 41 studies included 6650 patients with a \bar{x} age of 56.5 years. The psychosocial interventions included motivational interviewing, generalist intervention and psychoeducation. The results revealed that psychoeducation (-0.21 [-0.33, -0.09]), was the most effective intervention in reducing diabetes distress. Moreover, it concluded that at follow up, diabetes-related psychoeducation interventions, delivered in any design, was significantly correlated with decreasing diabetes distress.

Most middle to older adults with diabetes have psychosocial and diabetes-related comorbidities that may inhibit effective self-care and diabetes management. (Kirkman et al, 2012). The key difference in this systematic review is based on age group. Middle to older adults represent the fastest growing population of adults living with diabetes (Kalyani et al, 2017). This is the key time for the emergence of diabetes-related comorbidities. These comorbidities often include psychological issues such as depression. Identifying psychosocial interventions are an essential aspect of diabetes care for this population (Beverly et al, 2016). The purpose of the current review is to identify if psychosocial interventions are effective in decreasing depression in middle to older adults with type 2 diabetes.

10.3. METHODS

10.3.1 Search Strategy

A systematic review was conducted to identify published literature on the effectiveness of psychosocial intervention for middle to older adults with type 2 diabetes. To identify relevant literature, a search using grey's literature and electronic databases was conducted. The process of the grey's literature involved a hand search through references and contact with an author. Although, the author responded, the article was not included in the review as it did not meet the inclusion criteria. Potential studies were searched using the following electronic databases: British Nursing Index (BNI), Cumulative Index of Nursing and Allied Health Literature (CINAHL), Cochrane Library, MEDLINE via EBSCO, PsychARTICLES via EBSCO, PsycINFO via EBSCO, PUBMED via EBSCO and Scopus. In order to review evidence on up-to-date knowledge of recent research and innovations in care literature searches for the last ten years (April 2008–April 2018) were conducted. Combinations of three concepts: diabetes, psychosocial intervention and depression were used to conduct the searches, including “diabetes”, “diabetes mellitus”, “type 2 diabetes”, “type 2 diabetes mellitus”, “diabetic”, “diabet*”, “psychosocial interventions”, “psycho* intervention”, “support”, “psychosocial care”, “psychological interventions”, “behaviour therapy”, “behaviour therapy”, “acceptance and commitment therapy”, “problem solving therapy”, “counselling”, “counseling”, “cognitive

behavioural therapy” , “psychoeducation” , “behaviour change” , “behaviour change” , “mindfulness” , “mindfulness based” , “mindfulness-based” , “mindfulness based cognitive therapy” , “mindfulness-based cognitive therapy” , “motivational interviewing” , “group therapy” , “co-morbid depression” , “comorbid depression” , “depressive” , “low mood” and “depress*”.

10.3.2 Inclusion and Exclusion Eligibility Criteria

A set of inclusion and exclusion criteria was created with the aim of identifying eligible primary care psychosocial interventions that focus on decreasing depression in older adults with type 2 diabetes.

10.3.2.1 Inclusion

The articles were published in English within 10 years, 2008-2018, in order to provide a current review. The studies which met the following inclusion criteria were selected for the subsequent analysis: a) participants over 50 years old diagnosed both type 2 diabetes and established depressive symptoms, b) a psychosocial intervention with a primary aim to decrease depression, c) primary care setting with an intervention and control group. Randomised control trials and non-randomised control trial were included Studies were excluded if they met the subsequent criteria: a) participants under 50 years old, b) with other forms of diabetes, c) community-based setting and d) additional mental and/or physical comorbidities

2.2.2 Exclusion

Studies with participants who had comorbidities including mental illness and other health conditions (e.g. schizophrenia, heart disease) were excluded, given that the focus of the review was to identify psychosocial interventions to decrease depression among type 2 diabetics. Interventions could include any kind of psychosocial and/or psychoeducation approach and could be delivered in a variety of approaches (e.g. face to face, group-based, one to one, web-based etc.). However, only the interventions conducted in primary care settings were included. Systematic review, literature reviews and meta-analysis were also excluded. The studies had to be controlled, the intervention group had to be compared with either an alternate intervention or usual care or control group. Studies that used

mixed methods were included in this review and the qualitative methods and results were excluded. The studies had to measure depression as a primary outcome variable at baseline and post-intervention. Abstracts were initially read and review by the primary author.

10.3.3 Outcome Indexes

The changes in depressive symptoms were used as the primary outcome and were assessed and quantified by the established depression questionnaires; Beck's Depression Inventory (BDI), Center for Epidemiologic Studies Depression (CES-D) Scale, Diabetes Distress Scale (DDS) Diabetic Inpatient's Depressive Symptoms Observation Checklist (DIDSOC), Physical Health Questionnaire (PHQ-9) and Problem Areas in Diabetes (PAID). The data about glycaemic control including Haemoglobin A1c (HbA1c) were secondary outcomes and measured at baseline and post intervention at different intervals.

10.3.4 Data Extraction

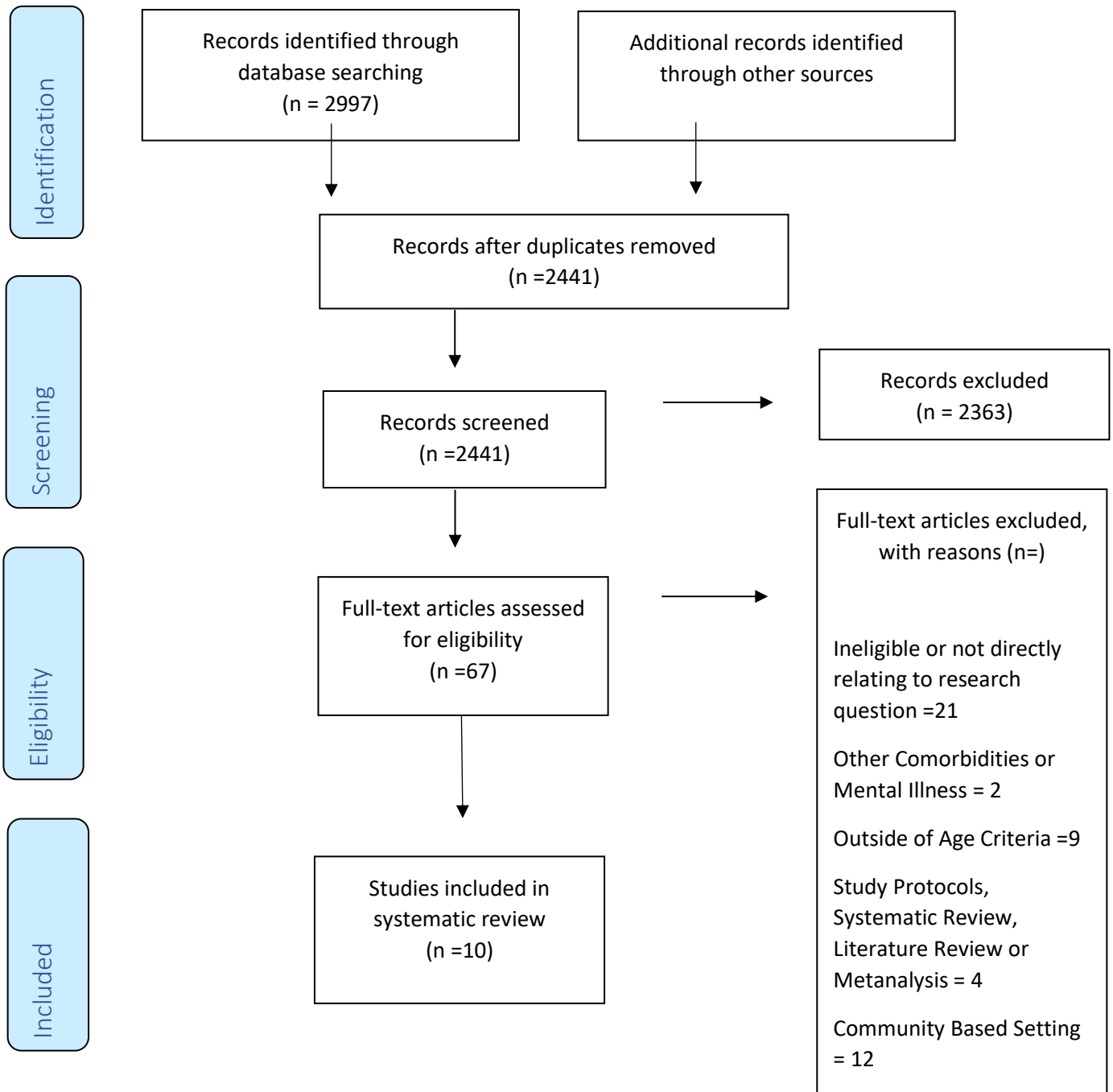
The primary reviewer independently reviewed the potential studies according to the above-mentioned inclusion and exclusion criteria and identified the included studies. Relevant data from these included studies were extracted using a tailored, Cochrane data extraction template. The data extraction procedure was also independently completed by the primary reviewer. The following data were retrieved from the included studies: 1) demographic data- including mean age, sex ratio for both the intervention and control group 2) data about depressive symptoms, including scores at baseline and post intervention intervals 3) data about glycaemic control at baseline and post intervention intervals where applicable 4) type and method of psychosocial intervention and control group and 5) setting and location of intervention. Data extraction from the final sample of studies is presented in Table 1.

10.3.5 Appraisal of Study Quality

The quality of the final studies was evaluated by two reviewers that independently assessed risk of bias in the individual studies using the Effective Public Health Practice Project (*EPHPP*) Quality Assessment Tool. The following 10 studies were assessed for risk of bias: 1) selection bias; 2) study design; 3) cofounders; 4) blinding; 5) data method collection; 6) withdrawals and drop outs. The studies were given a global rating of either strong, moderate or weak (See Table 2). Any disagreements between the reviewers were resolved through discussion. These findings were used in data synthesis during the evaluation of the studies.

PRISMA Flow Diagram

Figure 1



10.3.6 Data Synthesis

The ten studies were assessed for clinical and methodological heterogeneity. Since the variability was significantly high across the studies and the measures in each intervention were disparate, it was inappropriate to conduct a meta-analysis and a narrative synthesis was used to highlight findings in each intervention type. The interventions were group according to design, Cognitive Behavioural Therapy (CBT) Psychoeducation, Self-Management and Mindful Self-Compassion.

10.4 RESULTS

This section will present the search results, the study characteristics, outcome measures. The studies in this review are heterogeneous and will be grouped and assessed according to intervention type.

10.4.1 Search Results

The search was conducted according to the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) guidelines. First, 2997 potentially relevant studies were obtained. After duplicates were removed (n=556) and the records were screened, the remaining full text articles were assessed for eligibility (n=67). Then, 57 studies were excluded due to the following reasons: i) ineligible or not directly related to the research question (n=21); ii) other comorbidities or mental illness (n=3); iii) outside of the age criteria (n=8); iv) the studies were systematic reviews or meta-analysis (n=5); v) community based settings (n=11) and vi) the primary outcome was not depression. (Figure 1). Finally, the search identified 10 articles that met the inclusion criteria and were consequently included in the final review (See Figure 1).

10.4.2 Study Characteristics

There were 1,349 participants with T2DM and depression included in these studies. The mean age of patients in the intervention group was approximately 57.14 years. Within both the intervention and

control groups across the studies females accounted for (63.9%) of the participants. The studies were conducted worldwide, 2 in the United States of America, 2, in Taiwan, 2 in Croatia and Nigeria, New Zealand, Hawaii and The Netherlands respectively. As required by the inclusion criteria all ten of the studies were written in English. The duration of the interventions ranged from 4 weeks to 12 months. The study characteristics such as age, gender and location are applicable to the findings. This systematic review focuses on a middle to older aged population. Female participants significantly outnumbered the males and none of the included studies were UK-based. These characteristics imply that the results may differ when applied to diverse populations based on age range, gender ratios and location.

10.4.3 Outcome Measures

The changes in depressive symptoms were assessed by depression questionnaires and diabetes-related depression questionnaires and were used as the primary outcome. 5 of the studies solely used the Center for epidemiologic Studies Depression Scale (CED-S), 1 study used the Problem Areas in Diabetes (PAID) Scale and 1 study used Beck's Depression Inventory (BDI) as the primary measure of depression. The remaining studies used more than one questionnaire to assess depression and diabetes-related depressive symptoms; 2 studies used both the CED-S and PAID Scales and 1 study used the Patient Health Questionnaire (PHQ-9) and Diabetes Distress Scale (DDS). 7 studies reported data about glycaemic control as a secondary outcome. Laboratory blood testing haemoglobin (HbA1C) was measured at baseline, post-intervention and follow up.

AUTHORS (YEAR)	STUDY DESIGN, SETTING AND LOCATION	PARTICIPANTS (N) (Gender, \bar{x} Age)	PSYCHOSOCIAL INTERVENTION AND CONTROL CARE	DEPRESSIVE MEASURES AND DEPRESSIVE OUTCOMES (Baseline, Post Intervention, Follow Up)	GLYCAEMIC CONTROL MEASURE AND OUTCOME (Baseline, Post Intervention, Follow Up)	EPHPP GLOBAL OUTCOME
Friis, A et al. (2016)	Randomised Control Trial University of Auckland	N = 63 (43 Female. 20 Male) Intervention = 32 Control = 31 \bar{x} age Intervention =42.87±14.30 Control = 46.65±16.44 T2D= Intervention = 6 Control =11	INTERVENTION Mindful self-compassion (MSC) program, Groups of 8-12 patients in 8- weekly sessions each lasting 2.5 hours. Each patient received an email 2 days after each session with summaries of the week's teaching and encouraged to practice what they had learned CONTROL CARE The wait-listed patients received usual care	MEASURES: Patient Health Questionnaire (PHQ- 9) Diabetes Distress Scale (DDS) MEASURES Patient Health Questionnaire (PHQ- 9) Diabetes Distress Scale (DDS) OUTCOMES Baseline (Time 1): PHQ9 MSC = 14.01±4.52 Control =9.74±6.06 DDS MSC = 3.16±0.88 Control = 2.35±0.63 <i>Scores were greater in the intervention group than in the control group.</i> 8 Weeks (Time 2) PHQ9 MSC = 9.16±6.50 Control = 7.30±5.02 (C)	MEASURE HbA _{1c} MEASURE HbA _{1c} OUTCOMES Baseline (Time 1) Intervention = .94±1.38 Control = 8.01±1.22 <i>The scores were greater in the intervention group than the control group</i> 8 Weeks (Time 2) Intervention 8.69±1.68 Control = 8.19±1.14 3 Months (Time 3)	1, Strong

				<p>DDS MSC = 2.33±0.86 Control = 2.29±0.85</p> <p>3 Months (Time 3) PHQ9 MSC = 7.88±4.6 Control = 9.32±6.50</p> <p>DDS MSC = 2.10±0.84 Control = 2.10±0.89</p> <p><i>The intervention reduced depression scores between Time 1 and Time 2 and the results were maintained at Time 3 ANOVA measures effects for both time (F[2,60] = 27.30, P, 0.001, hp2 =0.48) and group (F[1,61] = 3.92, P = 0.05, hp2 = 0.06) and interaction between time and group (F[2,60] = 12.24,P , 0.001, hp2 = 0.29). MSC reported a significant decrease in PHQ-9 scores compared the control group. (x2 [1, n = 63] = 12.28, P= 0.001, w = 20.47). MSC decreased depression scores on DDS compared to the control group (x2 [1, n = 63] = 8.93, P ,0.05, w = 20.41).</i></p>	<p>Intervention = 8.0±1.49 Control = 7.85±1.36</p> <p><i>Results showed an effect for time but not group. Overall in HbA1c reduction over time was qualified by an interaction between time and group (x2 [1, n = 63] = 7.05, P,0.05, w =20.37)</i></p>	
Huang, C.Y et al (2016)	Randomised Control Trial	N = 61 (32 Female, 29 Male)	INTERVENTION Usual care, 4 sessions of Motivational Enhancement	MEASURE Center for Epidemiologic Studies Depression (CES-D) Scale	MEASURE HbA _{1c}	2, Moderate

	Hospital-based endocrinology outpatient department in Taiwan	<p>Intervention = 31 Control = 30</p> <p>Age \bar{x}</p> <p>Intervention=55.06 ±10.44</p> <p>Control = 57.83 ± 10.38</p>	<p>Therapy (MET) over a period of 1 month</p> <p>Followed by 8 sessions of CBT for two additional months.</p> <p>Totalling 12 weekly group sessions, each lasting 80 minutes, in two 15–16 patient groups.</p> <p>CONTROL CARE Usual Care- medical nutritional therapy and diabetes self-management education and support</p>	<p>OUTCOMES</p> <p>Base Line (Time 1) MET - 21.81(5.68); Control - 21.97(3.37) T test (p) - 0.13 (0.89) <i>There were no differences in depression symptoms among both groups</i></p> <p>Post Intervention (Time 2) MET - 15.51(3.96) Control - 23.03(3.63) T test (p) - 7.73 (\0.01) <i>Depressive symptoms in the intervention group were significantly lower compared to control group</i></p> <p>90 Days After (Time 3) MET - 13.99(3.68) Control - 22.42(3.56) T Test (p) - 9.09 (\0.01) <i>Depressive symptoms in the intervention group remained significantly lower in comparison to the control group</i></p>	<p>OUTCOMES</p> <p>Base Line (Time 1) MET - 7.68(1.44) Control - 7.84(1.95) T test (p) - 0.36 (0.72)</p> <p><i>There were no differences in HbA1C among both groups</i></p> <p>Post Intervention (Time 2) MET - 6.61(1.17) Control - 6.91(1.81) T test (p) - 0.76 (0.45)</p> <p>90 Days After (Time 3) MET - 6.16(0.92) Control - 7.49(1.82) T test (p) - 3.49 (\0.01)</p> <p><i>HbA1C in the intervention group were significantly lower than in the control group</i></p>	
Inouye, J. et al (2015)	Randomised Control Trial University of Hawaii School	N = 207 (113 Female, 94 Male)	<p>INTERVENTION</p> <p>CBT group session with 2-6 participants per group</p>	<p>MEASURE:</p> <p>Center for Epidemiologic Studies Depression (CES-D) Scale</p>	<p>MEASURE</p> <p>HbA_{1c}</p> <p>OUTCOMES</p>	1, Strong

	of Nursing & Dental Hygiene	<p>Intervention = 104 Control - 103</p> <p>\bar{x} age 57.0±11.1 (I); 57.8±10.8 (C)</p> <p>72% Asians and the remaining 28% Hawaiians or other Pacific Islanders.</p>	<p>6 weekly sessions that averaged 1–2 hours per session</p> <p>Focused on behavioural practice that included modules on stress management, biofeedback assisted relaxation, mood management, cognitive restructuring, empowerment, values clarification, problem solving, and decision making</p> <p>CONTROL CARE Diabetes education and support (DES) primarily focused on sharing personal experiences and receiving a review of diabetes education. 6 weekly sessions that averaged 1–2 hours per session</p>	<p>OUTCOMES</p> <p>Pre-Session CBT - 10.48(0.83) DES - 9.68 (0.83) <i>No significant differences were observed by gender (P = .53)</i></p> <p>End Session CBT - 8.03(0.88) DES - 9.37(0.85) <i>A significant difference between groups was found for depressive symptoms via the CES-D from Pre-Session to End-Session (P = .03) The \bar{x} decrease in CES-D score for the CBT group was greater (-2.45) in contrast to the DES, which was almost unchanged (-0.31).</i></p> <p>12 Months Post-Session CBT - 9.33(0.90) DES - 10.21(0.86) <i>No significant change in CES-D score from Pre-Session to 12 months Post-Session was found between the both groups (P = .09)</i></p>	<p>Pre-Session CBT - 7.93 (75) DES - 7.79 (84)</p> <p>End Session CBT - 7.64(58) DES- 7.61 (61)</p> <p>12 Months CBT - 7.84, 71 DES - 7.64(58) <i>There was minimal change with CBT and DES from Pre-Session to End-Session and 12 months Post-Session</i></p>	
Lamers, F. et al (2011)	Randomised Control Trial	N= 208 (106 Female, 103 Male)	<p>INTERVENTION 4 sessions of nurse-led Minimal Psychological Intervention (MPI) based</p>	<p>MEASURE: Problem Areas in Diabetes (PAID)</p> <p>OUTCOME</p>	<p>MEASURE HbA_{1c}</p>	2, Moderate

	<p>Department of Social Medicine, School for Public Health and Primary Care (CAPHRI), Maastricht University, The Netherlands</p>	<p>Intervention = 105 Control = 103</p> <p>\bar{x} age</p> <p>Intervention = 70.7±6.6 Control = 69.7±6.6</p>	<p>on Cognitive Behavioural Therapy (CBT) and self-management</p> <p>5 Steps</p> <ol style="list-style-type: none"> 1. Nurse explores the participant's feelings, cognitions and behaviours. 2. The participant keeps a diary, where he or she records symptoms, complaints, thoughts, worries, related feelings and behaviour. 3. The participants are challenged to link his or her mood to the consequent behaviour, using information from the diary 4. Self-management approach is introduced and the participant explores possibilities to alter his or her behaviour and 	<p>Baseline MPI – 22.6 (20.5) UC - 23.4 (19.5)</p> <p>1 week MPI - 23.42(1.73) UC - 24.00 (1.62) <i>PAID scores increase between baseline and 1 week between both groups</i></p> <p>3months MPI - 21.49(1.79) UC - 23.56(1.63)</p> <p>9months MPI - 18.49(1.76) UC - 22.89(1.72)</p> <p><i>A minimal significant difference after 9 months (group difference = 4.4, P =0.06).</i></p>	<p>OUTCOME</p> <p>Baseline MPI – 7.5(1.2) UC – 7.2(1.4)</p> <p>1week MPI - 7.8(0.2) UC - 7.4(0.2)</p> <p>3months MPI - 7.4(0.2) UC - 7.5(0.2)</p> <p>9months MPI - 7.3(0.2) UC - 7.8(0.2)</p> <p><i>Over time there was a decrease in HbA1c in the MPI, whereas UC increased. The difference between groups after 9 months was significant in favour of the MPI. (the group difference = 0.5%, P = 0.02).</i></p>	
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			<p>draws up an action plan. By changing the behaviour that is linked to the depressed mood, mood itself can be altered.</p> <p>5. The progress in achieving the goals of the action plan is evaluated</p> <p>CONTROL CARE Usual care (UC) included regular follow-up of somatic symptoms, but did not involve the detection and treatment of depressive symptoms. Co-interventions-pharmacological depression treatments were allowed, and considered nondifferential between groups.</p>			
Onyechi, K.C.N., et al (2016)	<p>Randomised Control Group Design</p> <p>Public hospitals in Onitsha metropolis of</p>	<p>N = 80; (55 Female, 25 Male)</p> <p>Intervention = 40 Control = 40</p>	<p>INTERVENTION</p> <p>Cognitive Behavioural Coaching</p> <p>Cognitive Behavioural Coaching (CBC) is group focused face to face</p>	<p>MEASURES:</p> <p>Becks' Depression Inventory II (BDI-II)</p> <p>Diabetic Inpatients' Depressive Symptoms Observation Checklist (DIDSOC) developed by the researchers</p>	-	1, Strong

	Anambra State, Nigeria	Age = 48-60 yr. \bar{x} 52.89 \pm 21.89	<p>psychological treatment for managing depression.</p> <p>18 sessions, lasting 50 minutes each, twice weekly for 9 consecutive weeks</p> <p>Focused on 6 key areas of intervention- enhancing participants' motivation to change; goal setting; monitoring progress; dietary management; disputing unrealistic beliefs; and relapse prevention</p> <p>CONTROL CARE Conventional counselling approach – advice and instruction as a guide to make autonomous decisions about managing their diabetes-related depression</p> <p>18 sessions, lasting 50 minutes each, twice weekly for 9 consecutive weeks</p>	<p>OUTCOMES</p> <p>Baseline (Time 1) <i>BDI-II</i> CBC - 60.03 (2.99) Control - 59.40 (3.44)</p> <p><i>DISDOC</i> CBC - 21.62 (0.67) Control - 21.65 (0.53) <i>Depressive symptoms were severe for all participants but did not show a significant difference between the groups. P=0.05</i></p> <p>Post Intervention (Time 2) <i>BDI -II</i> CBC - 16.88 (1.56) Control - 59.10 (3.36)</p> <p><i>DISDOC</i> CBC - 21.62 (0.67) Control - 21.65 (0.53)</p> <p><i>CBC significantly reduced depression in the intervention group compared to the control group. P=0.0001</i></p> <p>6 Month Follow Up (Time 3): <i>BDI-II</i> CBC- 9.58 (2.62) Control - 59.28 (3.24)</p>	-	
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				<p><i>DISDOC</i> CBC - 6.13 (1.02) Control - 21.85 (0.36) <i>CBC significantly reduced depression and remained consistent in the intervention group compared to the control group. P=0.0001</i></p>		
Penckofer, S. et al (2012)	<p>Randomized, repeated measures, experimental design</p> <p>A major midwestern medical center in the USA</p>	<p>N= 74 (Female only)</p> <p>Intervention – 38 Control - 36</p> <p>\bar{x} age: 54yo T2D \geq10yrs</p>	<p>INTERVENTION</p> <p>SWEEP- psycho-educational intervention which focused on 3 key areas. (1) identifying the signs and symptoms of depression and other emotions. (2) recognizing the relationship between moods, metabolic control and self-care behaviours, and (3) using CBT to manage depression, anxiety, and anger.</p> <p>SWEEP included practical skills to change mood-related thoughts or behaviours in the group CBT sessions. In addition to homework such as personal projects as to reinforce skill development</p>	<p>MEASURE</p> <p>Center for Epidemiologic Studies Depression (CES-D) Scale</p> <p>OUTCOMES</p> <p>Baseline SWEEP - 27.7(9.3) UC - 28.9(9.5)</p> <p>12 Weeks SWEEP - 15.2(7.9) UC - 23.1(11.4) (<i>p=0.003</i>)</p> <p>24 Weeks SWEEP - 12.6(8.0) UC - 21.5(10.2) (<i>p=0.001</i>)</p> <p><i>post hoc tests indicated, that at 3 and 6 months, those in SWEEP had significantly</i></p>	<p>MEASURE</p> <p>HbA_{1c}</p> <p>OUTCOMES</p> <p>Baseline SWEEP - 7.8(1.8) UC - 7.9(2.0)</p> <p>12 Weeks SWEEP - 7.4(1.3) UC – 7.8(1.8)</p> <p>24 Weeks SWEEP - 7.4(1.3) UC - 7.8(1.6)</p>	2, Moderate

			<p>8 weeks of 1 hr CBT-based program with homework. 2 post intervention booster sessions at 14 and 22 weeks</p> <p>CONTROL CARE Usual care women received diabetes and depression treatment outside of the study as needed. If patients met the criteria after the completion of the study, they were offered the SWEEP Program.</p>	<p><i>lower levels of depression compared to UC (p0.003 ,p0.001, respectively</i></p> <p><i>ANOVA measured a significant interaction between time and SWEEP [F (2, 116)03.78, p<.05]. There was a significant decrease in depression in SWEEP patients compared to UC patient between baseline and 24 weeks post intervention. (p<.001] and week 24</i></p>		
Pibernik-Okanović M. et al (2009)	<p>Randomised Control Trial</p> <p>A tertiary clinic- Vuk Vrhovac University Clinic in Croati</p>	<p>N = 50 (37 Female, 13 Male)</p> <p>\bar{x} age</p> <p>Intervention 55 Control - 58</p> <p>T2D \leq</p> <p>Intervention - 10 Control - 10.5</p>	<p>INTERVENTION</p> <p>Psycho-educational programme (PEP)</p> <p>(4) 90 mins interactive group sessions inclusive of a manual, self-report and homework exercises</p> <p>First 2 session weekly; last 2 sessions biweekly</p> <p>Contacted via telephone in 2-3-month intervals with a 6 and 12 month follow up.</p>	<p>MEASURES:</p> <p>Center for Epidemiologic Studies Depression (CES-D) Scale</p> <p>Problem Areas In Diabetes (PAID)</p> <p>OUTCOMES</p> <p>Baseline</p> <p>CED-S PEP - 26 UC - 24</p> <p>PAID PEP - 51 UC - 45</p> <p>6 Month Follow up</p> <p>CED-S</p>	<p>MEASURE</p> <p>HbA_{1c}</p> <p>OUTCOMES</p> <p>Baseline</p> <p>PEP – 7.5 ET – 7.7</p> <p>6 Month Follow Up</p> <p>PEP – 7.3 ET – 6.9</p> <p>12 Month Follow Up</p> <p>PEP – 7.0 ET – 7.0</p>	1, Weak

			<p>CONTROL CARE Usual care (UC). Only patients with elevated scores were given an explanation were offered information about available treatment options. The participants were contacted via phone at the same intervals as the intervention. After 6 and 12 months were re-assessed for psychological variables.</p>	<p>PEP - 18 UC - 20 12 Month Follow up CED-S PEP - 19 UC - 19 <i>ANOVA measures denote that individuals treated with PEP reported improved depressive symptoms at the 6-month assessment and remained so after 12 months (p = 0.004).</i></p>		
Pibernik-Okanovic M. et al (2015)	<p>An experimental design using randomised, repeated measures</p> <p>A tertiary clinic- Vuk Vrhovac University Clinic for Diabetes in Zagreb</p>	<p>N = 209 (113 Female, 96 Male)</p> <p>Psychoeducation Group N=74 (40 Women, 34 Men) x̄ age - 57.7(6.2) T2D ≥ 11.4(9.1)</p> <p>Physical Exercise Group N=66 (37 Women, 29 Men) x̄ age - 58.5(4.8)</p>	<p>INTERVENTION This group-based psychoeducation intervention consisted of a 90-minute session with a small number of participants who met weekly over 6 weeks.</p> <p>The first 10-15 minutes of each session was reserved for Psychoeducational (PE) topics. During this session participants had an opportunity to share and exchange personal</p>	<p>MEASURES: Problem Areas In Diabetes (PAID) Center for Epidemiologic Studies Depression (CES-D) Scale</p> <p>OUTCOMES Baseline CES-D PE - 19.7(9.1) PHE - 20.5(8.6) RE - 19.7(8.7) PAID PE - 37.9(19.7) PHE - 42.6(20.5) RE - 39.1(19.6)</p>	<p>MEASURE HbA_{1c}</p> <p>OUTCOMES Baseline PE -7.4(1.2) PHE - 7.2(1.1) RE - 7.2(1.1)</p> <p>12 Month Follow Up PE -7.2(0.9) PHE -7.2(1.0) RE - 7.0(1.0)</p>	1, Strong

		<p>T2D ≥ 12.9(2.8)</p> <p>Diabetes Re-education Group N=69 (36 Women, 33 Men)</p> <p>\bar{x} age - 58.2(5.6)</p> <p>T2D ≥ 10.5(6.9)</p>	<p>experiences with the group.</p> <p>Physical Exercise (PHE)Activity 6 weekly 90-minute small-group sessions interaction between physical activity, mood and diabetes etc</p> <p>CONTROL CARE The researchers in this study did not include a control group because wanted to offer professional help to the patients who were experiencing depressive symptoms. As an alternative, an enhanced treatment as usual which consisted of one 90min small group Re-Education (RE) intervention was offered.</p>	<p><i>The significance between the scores at baseline 0.358</i></p> <p>12 Month Follow Up</p> <p>CES-D</p> <p>PE - 16.7(7.9)</p> <p>PHE - 18.1(9.8)</p> <p>RE - 17.4(9)</p> <p>PAID</p> <p>PE - 16.7(7.9)</p> <p>PHE – 18.1(9.8)</p> <p>RE – 17.4(9.0)</p> <p><i>Significant reductions in depression across all 3 groups compared to baseline</i></p> <p><i>There were significant reductions in depressive symptoms from baseline to the 12-month follow up</i></p>	<p><i>There was borderline significance in HbA_{1c} changes across time (F = 2.70, p = 0.078)</i></p>	
Wang, M. et al. (2014)	<p>Randomised Trial</p> <p>University of Massachusetts Medical School</p>	<p>N= 252 (193 Female, 59, Male)</p> <p>Intervention - 124</p> <p>Control – 128</p>	<p>INTERVENTION 12-month group-based self-management intervention concentrating on diabetes self-management knowledge,</p>	<p>MEASURE: Center for Epidemiologic Studies Depression (CES-D) Scale</p> <p>OUTCOME</p> <p>Baseline (Time 1) Intervention - 20.8(12.2)</p>	<p>MEASURE</p> <p>HbA_{1c}</p> <p>OUTCOMES</p>	2, Moderate

	Massachusetts , USA		<p>self-efficacy, and behaviours.</p> <p>12 intensive weekly sessions followed by 8-monthly sessions. Using social cognitive theory with a targets diabetes knowledge, self-efficacy for diabetes self-management-related changes, and self-management behaviours.</p> <p>CONTROL CARE</p> <p>Laboratory results (HbA1c, fasting blood glucose, and lipid profiles at baseline and at 4 and 12 months) sent to their providers, who provided care deemed as appropriate or as routinely delivered for all study participants.</p>	<p>Control - 22.3(15.5)</p> <p>4 months follow up (Time2) Intervention - 17.5(13.0) Control - 21.8(12.4)</p> <p>12 months follow up (Time 3) Intervention -18.5(13.0) Control - 22.6(13.4)</p> <p><i>T tests indicated that intervention participants had lower mean CES-D scores at 4 months (p= 0.011) and 12 months (p=0.021) compared to usual care participants.</i></p> <p>Linear mixed effects regression models examining change in CES-D scores indicated significant group by time effects at 4 months ($\beta=-2.63$; $p=0.04$) but not at 12 months ($\beta=-2.05$; $p=0.13$). With respect to rate of change, intervention participants had reduced CES-D scores (compared to baseline) at 4 months ($\beta=-3.39$; $p= 0.0004$) and 12 months ($\beta=-1.97$; $p=0.041$). No significant changes in CES-D scores were observed among usual care participants at 4 months ($\beta=-0.77$; $p=0.4$) or 12 months ($\beta= 0.08$; $p=0.93$).</p>	-	
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Wu, S.F., et al (2011)	<p>Quasi-experimental design</p> <p>An outpatient clinic in a municipal hospital in Taipei</p>	<p>N = 145 (93 Female, 52 Male)</p> <p>Intervention - 72 Control - 73</p> <p>\bar{x} age: 64</p> <p>78% Fukien province</p>	<p>INTERVENTION</p> <p>A self-management intervention programme, Self-Efficacy Enhancing Intervention Programme (SEEIP).</p> <p>4 weekly self-efficacy enhancing sessions with a focus to improve psychosocial skills or address attitudes and beliefs specific to diabetes or the regimen behaviour. Participants also received the standard diabetes education</p> <p>Telephone follow up at 3- and 6-months post intervention</p> <p>CONTROL CARE</p> <p>Standard diabetes education in the outpatient clinic which consisted of a 1:1 consultation with a diabetic nurse and a 15-20-minute consultation with a nutritionist.</p>	<p>MEASURE:</p> <p>Center for Epidemiologic Studies Depression (CES-D) Scale</p> <p>OUTCOMES:</p> <p>Baseline (Time 1) SEEIP - 9.64(4.7) Control - 9.29(3.88)</p> <p>3 Month follow up (Time 2) SEEIP - 9.33(4.97) Control - 9.45(3.95)</p> <p>6 Month Follow Up (Time 3) SEEIP - 9.34(4.65) Control - 9.50(3.88)</p> <p><i>SEEIP reduced depression in the intervention group from Time 1 to Time 3, whilst the control group increased depression from Time 1 to Time 3. However, depression scores did not significantly change over time in the two groups</i></p>	<p>-</p> <p>-</p> <p>-</p>	<p>2, Moderate</p>
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10.4.4 Interventions

The psychosocial interventions in these studies were disparate. Four of the interventions used Cognitive Behavioural Therapy (CBT) or CBT combined with an additional Psychological Therapy. There were three Psychoeducation Interventions, Two Self-Management and one Mindful Self-Compassion Intervention. Therefore, the narrative synthesis will be structure by intervention design and will include outcomes and quality appraisals.

10.4.4.1 Cognitive Behavioural Therapy (CBT)

4 studies, (Huang et al, C.Y. 2016; Inouye et al, 2015; Lamers et al, 2011 and Onyechi et al 2016) used CBT or CBT combined with other psychosocial interventions with the aim of decreasing depression in middle to older adults with type 2 diabetes. The intervention duration across the studies were between 6-9 weeks with a follow up of 3-12 months. 2 studies were of strong quality, Inouye et al (2015) used traditional CBT and Onyechi et al (2016) used Cognitive Behavioural Coaching (CBC). The remaining 2 studies were of moderate quality, Huang et al, (2016) used a combination of Motivational Enhancement Therapy (MET) and CBT and Lamers et al (2011) combined a Minimal Psychological Intervention (MPI) with CBT. CBC used BDI and the researchers developed the Diabetes Inpatients' Depressive Symptoms Observation Checklist to measure the severity of depression, while Lamers, et al (2011) used the PAID Scale.

The remaining studies (Huang, et al 2016 and Inouye, et al 2015) measured depression using CES-D. The control groups varied across the studies. Lamers et al (2011) did not have a control group. The patients who participated in the intervention had usual care, but it did not include depression-related assessments or treatment. A co-intervention of prescribed medication was offered and the outcome was non- differential between the groups. However, the remaining 3 studies had a control group who received varied diabetes education and support. 3 of the studies had group-based interventions in contrast to Lamer et al (2011) individual intervention.

Both CBC and MET found no differences in depression severity between the intervention and control groups, sequentially ($p=0.5$, t test=.013). Between Time 1 (baseline) and Time 2 (post intervention) CBC significantly reduced depression in the intervention group compared to the control group ($P=0.0001$). MET significantly reduced levels of depression between Time 1 and Time 2. Both CBC and MET intervention groups significantly reduced depression between Time 2 and Time 3 (follow up) and remained consistent compared to the control group $P=0.0001$

Although, Inouye et al (2015) results reported improvements in the CBT group in comparison to the DES group at End-Session (Time 2), the differences did not remain consistent at Post-Session. Throughout the study from Pre-Session (Time 1), End-Session (Time 2) and Post-Session (Time 3) there were minimal glycaemic changes between the groups.

The CBT interventions in these studies decreased depression between baseline and post intervention. However, the results are not consistent during follow up as evidenced by 3 of the 4 studies.

All of the studies had a form of blinding. Onyechi et al (2016) and Inouye et al, (2015) were double blinded design to reduce the risk of bias. The researchers in Lamers et al (2011) were blinded, whereas Huang et al (2016) participants were blinded. 3 of the 4 studies upheld intervention integrity and reported at least 80% of the participants received the completed intervention. Conversely, the effect of Lamers et al (2011) may be overestimated due to compromise of the control group receiving a co-intervention. Overall, based on the significant outcomes of these moderate to strong quality studies, using CBT or CBT combined with additional psychological therapies results in decreased depression in patients with comorbid diabetes and depression.

10.4.4.2 Psychoeducation

Three of the ten studies explored the effectiveness of psycho-education interventions (Penckofer et al, 2012, Pibernik-Okanović, et al 2009 and Pibernik-Okanović, et al 2015). The durations of the interventions ranged from 6-12 weeks with follow up between 6-12 months. Penckofer et al (2012)

measured depression using CES-D, while Pibernik-Okanović, et al (2009) and Pibernik-Okanović, et al (2015) used both the PAID and CES-D. Across the three studies, there were no significant differences in depression scores between the intervention and control group at baseline. Pibernik-Okanović, et al (2015) was of strong quality and Penckofer et al (2012) was of moderate quality. Penckofer et al, (2012) intervention was more effective than usual care in reducing depression in patients with type 2 diabetes compared to Pibernik-Okanović, et al (2009) and Pibernik-Okanović, et al (2015). (mean difference of -15 vs. -7, $p < .01$)

ANOVA results yielded a significant main effect of time ($p < .001$), for the women who completed the Penckofer et al (2012) study. This suggests, that on average, there was a decrease in depression over the course of the study. More notably, was the significant interaction between time and SWEEP [$F(2, 116) = 3.78, p < .05$]. Additionally, Penckofer et al (2012) had significant lower levels of depression when compared to the usual care group between week 12 and week 24.

Across all three studies the control group showed a notable decrease in depression scores from baseline to post intervention at different intervals. Penckofer et al (2012), a strong quality intervention, not only produced a reduction in depression symptoms over time that was significantly greater than usual care, but also the percentage of patients who were depressed by 6 months was substantially less than those who had received usual care (35 vs. 85 %).

The results of Pibernik-Okanović et al (2015) moderate quality intervention resulted in no significant effect at baseline between groups in relation to depressive symptoms ($p = 0.656$). These outcomes indicate comparable efficacy of psychoeducation, physical exercise and diabetes re-education. There were significant reductions in depressive symptoms from baseline to the 12-month follow up. The participants and researchers were not blinded in Pibernik-Okanović et al (2009) study. Both the intervention and control group reported a reduction in depressive symptoms between baseline, 6 months ($p = 0.63$) and 12 months follow ($p = 0.74$). However, there was no significance between both groups either at 6 or 12 months follow ups. In addition to the issue of blinding, Pibernik-Okanović et

al (2009) did not report withdrawal and drop outs which led to a weak quality score on the EPHPP global rating.

Due to the inconsistent quality rating across the 3 studies (strong, moderate, and weak) a firm conclusion cannot be drawn. However, based on the evidence, psychoeducation interventions reduce depression in middle to older adults with type 2 diabetes. Therefore, evidence suggests that psychoeducation interventions reduce depression in patients with type 2 diabetes.

10.4.4.3 Self-Management

Diabetes is a chronic condition which requires a considerable commitment to daily self-management (Harvey, 2015). These interventions aimed on the self-management of comorbid diabetes and depression. There was significance in duration of the intervention between both studies, Wu et al (2011) lasted 4 weeks while Wang et al, (2014) continued for 12 months. While the means of the depression scores for Wu et al (2011) were not significant at different times, there was a reduction in scores in the intervention group at Time 1 (9.64), Time 2 (9.33) and Time 3 (9.34). There was no significance on the mean of different times on depression ($p=0.97$), the mean between groups ($p=1.00$) or on the interaction effect of the group by time ($p=0.64$). The depression scores in the intervention decreased between Time 1 and Time 2 and remained consistent at Time 3. However, in the control group there is an increase in depression between Time 1 (9.29) and Time 2 (9.45) and continued to increase in Time 3 (9.50).

Using a two-sample t-test, the participants in Wang et al (2014) intervention had lower mean scores at 4 months ($p=.0011$) and 12 months ($p=0.021$) compared to the usual care. The intervention group has a decreased in CES-D score from baseline and 12 months. However, there were no changes in CES-D among the control group at months or 12 months. Linear regression models tested changes in CES-D scores revealed significant group by time effects at 4 months but no effects at 12 months.

At follow up, results indicate that Wang et al (2014) self-management intervention was associated with the decrease in depressive symptoms. The results indicated that an increase in depression score between Time 2 (4 months) and Time 3 (12 months).. The depression scores for Wu et al, (2011) control group continued to increase overtime. Although, the decrease in depression scores for the intervention group was not significant, the results show that the self-management intervention was more effective than usual care.

Although both self-management studies were of moderate quality, Wu et al (2011) attributed the self-report as a potential response bias as a limitation to the study. Wang et al (2014) had a moderate quality rating because it was doubled blinded; however, the study appeared bias as there were significantly more women participants than men.

Overall, evidence suggests that self-management psychosocial intervention decrease depression scores in patients with type 2 diabetes but do not remain consistent at follow up

10.4.4.4. Mindful Self-Compassion

Mindfulness self-compassion (MSC) is aimed at reducing suffering associated with avoidance. Friis, et al (2016) designed to their MSC intervention to reduce the depression in diabetics. At baseline, although the scores were greater in the intervention group than the control group, there were no diabetes-specific differences between the two groups. There was an effect for changes in depressive symptoms for the t-test showed the MSC intervention reduced depression scores between Time 1 and Time 2 in the intervention group and the improved results were maintained in Time 3.

Mindfulness is the foundation of Mindful Self-Compassion. Friis et al (2016), showed significant improvement in group difference between the Time 1 and Time 3. In the intervention group, 20 of 32 participants reported a significant decrease in PHQ-9 scores compared to 5 of 31 participants in the control group. There was a decrease in depression recorded on the DDS for 15 of 32 participants

compared to 3 of 31 in the control group. Additionally, HbA1c scores significantly decreased for 21 of 32 participants in the intervention group compared to 9 of 31 patients in the control group. Although, the evidence suggests that the impact of MSC is significantly effective in decreasing depression in type 2 diabetics it is the only mindfulness-based study within this review. Friis et al, (2016) intervention was a randomised control blinded design study of strong quality and had a withdrawal rate of less than 6%.

10.5 DISCUSSION

10 studies examining the effectiveness of psychosocial interventions for decreasing depression in middle to older adults with type 2 diabetes were identified and included in this review. Psychosocial intervention types included psychoeducation, self-management, mindful self-compassion and CBT.

10.5.1 CBT

CBT is acknowledged as an effective intervention for depression with a lower relapse rate when compared to antidepressant treatment (Beck et al, 2010). In this review, all four of the CBT interventions were effective quality. The evidence suggests that health professionals can use CBT or a combination of CBT with usual care to reduce depression in diabetes. A combination of MET and CBT was found to improve depressive symptoms (Lamers et al, 2011). The CBC group, Onyechi et al, (2016) resulted in a significant reduction in depression scores compared to the control group between baseline and post-intervention. 3 of the 4 CBT interventions had maintained decrease depression scores at follow up (Onyechi et al, 2016; Huang et al, 2016; Lamers et al, 2011). The remaining study, Inouye et al (2015), depression scores increased at follow up. However, this can be attributed to the 12 month post-intervention lapse. The evidence is reliable and CBT interventions are effective in decreasing depression based on the significant outcomes.

10.5.2 Psychoeducation

Recent studies have suggested that psychoeducation has a significant effect on decreasing depression in patients with type 2 diabetes (Yuniartika, et al 2016). Although, there was a significant decrease in depression outcomes in the psychoeducation group studies across baseline and post intervention interval, this review suggests that we cannot rely on this evidence. All three studies did not have a strong control group to accurately test the efficiency the intervention. The participants in each of the studies received usual care with additional depression-related treatment. The care the control group received in Pibernik-Okanović (2009) could arguably be considered as a smaller scale intervention. The participants were screened for depression, discussed the results with the researchers in a one to one session and followed for one year, which is a therapeutic approach that patients in usual care do not receive. Similarly, the control group in Penckofer et al, (2012) study received depression treatment as needed outside of the study. Additionally, Pibernik-Okanović (2015) replaced a control group with an enhanced treatment diabetes re-education group. Presently, this evidence supports the importance for a strong control arm of a study with the aim of evaluating the efficiency of the intervention.

10.5.3 Self-Management

The self-management interventions decreased depression across the two studies. However, based on the evidence of this review, considering a longer duration for the interventions may produce a greater significant effect. In particular, Wang et al, (2011) increase in depression score from Time 2 (4months) and Time 3 (12 months) could be attributed to the length of time between post-intervention and follow up. Booster sessions could possibly contribute to a consistent decrease in depression score.

10.5.4 Mindful Self-Compassion

The MSC intervention reduced depression in patients with type 2 diabetes. Mindfulness serves as the foundation for MSC and this study is evidence that self-compassion is an effective psychosocial intervention on its own. The MSC training showed a decrease in depression and is consistent with previous mindfulness-based studies such as Tovote et al (2014), a randomised control study that

resulted in greater reduction in depression among patients that received MBCT and CBT compared to patients in the waitlist control group.

10.5.5 Effectiveness of Psychosocial Interventions

There were similarities and differences between the interventions. 7 of the 10 studies remained effective from baseline to follow up and this evidenced by the consistent decreased in depression outcomes. In contrast, 3 studies (Wu et al, 2011; Pibernik-Okanović et al, 2009; Wang et al, 2014) had an increase in depression scores from post-intervention to follow up, however the results were not statistically significant. There were 2 individual interventions (Wu et al, 2011; Lamers et al, 2011) and 8 group-based interventions. The individual-based study designs were CBT and Self-Management and both interventions were conducted over 4 weeks. 3 of the 4 studies (CBT, Self-Management, Psychoeducation) with a 12 month follow up did not remain consistent in decreasing depression post-intervention, the remaining psychoeducation (Pibernik-Okanović et al, 2015) intervention produced a significant effect on reducing depression scores at 12 months follow up.

2 of the 10 studies were of strong quality, 7 were moderate and 1 was of weak (Pibernik-Okanović, M. et al 2009) quality due to lack of blinding and withholding withdrawals or drop out statistics as assessed by the EPHPP. 4 of 7 studies were CBT interventions that reduced depression from baseline to follow up.

Therefore, it cannot be definitively said that CBT is effective in decreasing depression in type 2 diabetes, because the only 2 of the 4 CBT studies were of strong quality.

10.5.6 Limitations of the studies

The limitations across the 10 studies were based on duration and time span between post intervention and follow. Across the 10 studies are the length of time without interaction between post intervention

and follow up (Inouye et al, 2015; Pibernik-Okanović et al, 2015; Wang et al, 2014). Future studies may consider additional booster sessions to increase outcomes and long-term benefits for the patients.

Throughout the studies there were similarities in usual care for the control groups. The usual care in the control group and some studies did not included a control group in traditional sense (Pibernik-Okanović, et al 2015; Onyechi et al, 2016) but offered a smaller scale intervention that consisted a form of counselling. In terms of group-based studies, the control group were offered psychological or therapeutic services for the same duration and time intervals (Inouye et al, 2015, Onyechi et al, 2016; Pibernik-Okanović et al 2009). Group based psychological service can serve as an intervention. Research has shown that group support serves as motivation to improve self-management and overall well-being in middle to older adults with diabetes (Nicklett et al, 2013).

10.5.7 Limitations of current review

The limitation to this systematic review included studies that were not double blinded. This could have resulted in potential bias in that participants may have exaggerated score in self-reports. The criteria for this review included interventions primary care settings and excluded community-based setting. Perhaps other settings would be useful in expanding the data and outcome. Additionally, an emphasis on session attendance may have a significant impact on the outcomes of the interventions. Lastly, the impact could have been taken into consideration as the interventions included in this study were conducted in various countries worldwide. The limitations to this review could change the interpretations of these results.

10.6 CONCLUSION

It will be beneficial for health Professional to choose CBT design when developing interventions aimed at decreasing diabetes-related depression because of the significant results in this study (Onyechi et al, 2015). Whereas, psycho-educational treatment appears to be beneficial in diabetic patients with mild to moderate depressive symptoms, (Pibernik-Okanović, et al 2009) but its effects are comparable with the additional support given to the participants in the control group.

Future research would benefit from comparing the effectiveness of an intervention to a control group who solely receives usual care. These evidence-based findings will be useful to healthcare professionals when designing psychosocial interventions and beneficial for patients experiencing comorbid depression and diabetes.

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Appendix

Are Psychosocial Interventions effective in decreasing depression in middle to older adults with Type 2 Diabetes?: A Systematic Review

Table 2

Authors	Selection Bias	Study Design	Confounders	Blinding	Data Collection	Withdrawals	Global rating
Friis et al, (2016)	Moderate	Strong	Strong	Moderate	Strong	Weak	Moderate
Huang et al, (2016)	Weak	Strong	Strong	Moderate	Strong	Strong	Moderate
Inouye et al, (2015)	Moderate	Strong	Moderate	Strong	Strong	Weak	Moderate
Lamers et al, (2011)	Strong	Strong	Strong	Moderate	Strong	Moderate	Strong
Onyechi et al, (2016)	Strong	Strong	Strong	Strong	Strong	Strong	Strong
Penckofer et al, (2012)	Moderate	Strong	Strong	Weak	Strong	Strong	Moderate
Pibernik-Okanović et al, (2009)	Moderate	Strong	Strong	Weak	Strong	Weak	Weak
Pibernik-Okanović et al, (2015)	Weak	Strong	Strong	Moderate	Strong	Strong	Moderate
Wang et al, (2014)	Weak	Strong	Strong	Moderate	Weak	Strong	Moderate
Wu et al, (2011)	Strong	Strong	Strong	Moderate	Strong	Strong	Moderate

EPHPP Quality Appraisal Scores