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**Complementary and alternative medicine use in
diabetes: Prevalence, factors associated with use and
clinical implications.**

BY

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ABSTRACT

Diabetic patients require special care in terms of treatment, diet and/or lifestyle; the delicate balance of a treatment regimen can be influenced by several factors, including the use of complementary and alternative medicine (CAM). CAM includes herbal and dietary supplements, traditional medicine, body therapy, e.g. massage and yoga and mind therapy, e.g. meditation and reflexology. This research was carried out over five phases. The systematic review of prevalence offered an updated view of the magnitude of CAM use by diabetic patients and listed all CAM types used by diabetic patients available in previous literature. No previous study had synthesised factors associated with CAM use in diabetes using a systematic review methodology. The systematic review of factors associated with diabetic patients' CAM use synthesised factors reported in the literature for a comprehensive understanding of factors important to patients that drives them to use CAM. The subsequent study on patient online forums analysed discussions that diabetic patients have out with formal research or healthcare settings and hence offered novel insight into the factors associated with CAM use in diabetes.. The subsequent qualitative studies addressed the dearth of literature in Saudi Arabia regarding patient and healthcare professional perspectives on CAM use. The qualitative interviews with diabetic patients explored in-depth, their beliefs around CAMs. In particular, patient perspectives related to the cultural and religious significance of some CAM forms used in diabetes in Saudi Arabia were, to the researcher's knowledge not reported in such depth in previous literature compared to the findings of this study. A systematic review and meta-analysis of the available literature to identify the global prevalence of CAM use amongst diabetic patients was undertaken. This review also aimed to produce a comprehensive list of CAM types used by diabetic patients as reported in the peer-reviewed literature. The second phase involved a systematic review to identify the factors associated with CAM use by diabetic patients. The third phase studied diabetic patients' communications in patient online discussion forums. The fourth phase included qualitative semi-structured interviews with diabetic patients to explore their views and experiences regarding their CAM use. The fifth phase included qualitative semi-structured interviews with healthcare professionals involved in the care of diabetic patients to explore their perspectives on CAM use by their patients. The Theoretical Domains Framework (TDF) was used to design data collection materials and inform the analysis.

The first systematic review which included 38 studies, identified a pooled global prevalence of CAM use amongst diabetic patients of 51% (predictive interval 8%-93%), and listed a total of 37 types of CAM and 223 types of herbs that diabetic patients use. The review showed up to 2/3rd of users do not disclose CAM use to their healthcare providers.

From the second systematic review of 43 studies from 28 countries, a total of 84 factors associated with CAM use were identified and were mapped to the TDF. Key factors identified were related to treating and relieving symptoms, accessibility and affordability compared to physician visits and modern medicines, 'social influences' from family members, friends, religious and spiritual scholars. CAM users also reported lack of trust in modern medicines and perceived CAM to be safer and free from adverse effects.

Phase three of the study was not limited to specific country and identified and reviewed data from 22 diabetes online forums containing 77 threads with 1156 posts from patients. The study showed that diabetic patients seek other users' experience with using CAM for treatment of diabetes and offer instructions to one another on how to use CAM. Feeling stressed, frustrated or overwhelmed with the condition and prescribed medications was often linked to their decisions to use CAM. They described that healthcare professionals were often unaware or unable to help in regard to their queries around CAM. They sought and shared studies to support or refute claims around perceived benefits and harms.

Subsequent qualitative interviews with patients and healthcare professionals in Saudi Arabia identified barriers to effective communication between diabetic patients and their healthcare professionals regarding CAM use. These included lack of knowledge amongst both patients and healthcare professionals as well as cultural and regulatory barriers. Such limited discussion about CAM made diabetic patients vulnerable to financial exploitation by some CAM providers. Patients described substituting doses of prescribed treatments with CAM or resorting to CAM use as a standalone treatment often to avoid adverse events or due to perceptions that prescribed treatments contributed to disease chronicity. Both patients and healthcare professionals associated some CAM forms with cultural and religious significance. In conclusion, this study shows that CAM use in diabetes is widespread. However its consideration in clinical consultations remains limited and this research calls for acknowledgment of such widespread amongst patients by healthcare professionals, clinical guidelines and regulatory bodies. Healthcare professionals should be aware of their diabetic patients' use of CAM to ensure treatment optimization and medication adherence. The gap in communication between diabetic patients and healthcare professionals needs to be improved to optimise treatment outcomes through flexible consultation time, overcoming legal barriers, accommodating consultation protocols and culturally sensitive and evidence-based information provision to both diabetic patients and healthcare professionals. Alleviating patients' concerns and reluctance to use prescribed treatments is imperative to achieve therapeutic goals.

DEDICATION

I would like to dedicate this work to my parents, extraordinary people who had nothing and were able to accomplish everything for their family.

Everything I have accomplished and everything I will ever accomplish is because of them. Everything I am and everything I will ever be I owe to them.

I hope that my academic success would make them proud. May they rest in peace.

Mum, Dad, I love you and I miss you so much.

In memory of

Salihah (July 1941- 20 May 2013)

Saud (September 1936 - 9 November 2021)

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ABBREVIATIONS

CAM	Complementary and Alternative Medicine.
CI	Confidence Interval
COPD	Chronic Obstructive Pulmonary Disease.
COREQ	Consolidated Criteria for Reporting Qualitative Research.
COVID-19	Coronavirus Disease 2019
CPD	continuing professional development
CYP3A4	Cytochrome P450 3A4
DM	Diabetes Mellitus.
DMP	Data Management Plan
DSHEA	Dietary Supplement Health and Education Act
HDS	Herbal and Dietary Supplement
I ²	The percentage of variation across studies.
JBI	Joanna Briggs Institute
NICE	The National Institute for Health and Care Excellence in the UK
PrI	Prediction Intervals
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses.
PRs	Prevalence Ratios.
RoB 2	Cochrane risk-of-bias
SMBG	Self-Monitoring Blood Glucose
SRA	Social Research Association
T1D	Type 1 Diabetes Mellitus
T2D	Type 2 Diabetes Mellitus
TDF	Theoretical Domains Framework
WHO	World Health Organisation

CHAPTER 1: INTRODUCTION

1.1 Background

Diabetes Mellitus (DM) is a chronic metabolic disorder in which blood glucose levels are higher than normal for an extended period of time. These high blood glucose levels are attributed to disturbances in insulin production and function. Insulin is a hormone that regulates blood glucose levels.¹ Diabetes is caused by either lack of insulin production by the pancreas or the amount of insulin produced by the pancreas being insufficient to carry out all blood glucose regulation processes. Additionally, diabetes can occur even if the insulin is within normal levels because the body cells have decreased sensitivity to the insulin. Diabetes can also be caused by a combination of low insulin production and low insulin sensitivity.¹

1.2 Prevalence

Diabetes is one of the most prevalent diseases worldwide.² Globally, the estimated number of persons with diabetes increased from 382 million cases in 2013 to 463 million cases in 2019.³ Global diabetes prevalence is estimated to increase to reach 578 million cases by 2030 and 700 million cases by 2045.³

In 2017, it was estimated that 1.37 million deaths worldwide were directly caused by diabetes.⁴ The diabetes fatality rate is projected to reach 1.6 million deaths worldwide by 2025.⁴

1.3 Types of diabetes

Types of diabetes are classified based on the causes of high blood glucose levels. These include pre-diabetes, type 1 diabetes (T1D), type 2 diabetes (T2D) and gestational diabetes. T1D and T2D are the most common, most serious types and are

mainly associated with future long-term complications.⁵ Gestational diabetes is a form of diabetes that affects some pregnant women and usually subsides after giving birth.⁶

1.3.1 Pre-diabetes

Pre-diabetes is a condition in which the patient has a high blood glucose level but is not high enough to be classified as diabetes.⁶ People with pre-diabetes are at very high risk of developing diabetes. Pre-diabetes is usually easier to manage and reverse than diabetes.⁷ Therefore, diagnosing pre-diabetes through early detection and its management through primary prevention strategies such as diet and exercise is critical.⁷

1.3.2 T1D

T1D is caused by the pancreas' lack of insulin production due to the destruction of beta cells responsible for insulin production. The destruction of beta cells is usually caused by an autoimmune condition making the body's own immune system attack the beta cells. In some cases, the destruction of beta-cells is caused by external factors such as viral infection.⁸ Moreover, T1D can be described as idiopathic. i.e. diseases that occur spontaneously with no apparent and understandable cause.⁹ Regardless of the cause of beta cells destruction, the damage is irreversible and cannot be repaired. Patients with T1D cannot be cured and should be managed by external insulin in the form of injections to regulate blood glucose levels. All age groups can develop T1D, but it usually affects children and young people under the age of 30. T1D used to be called "juvenile diabetes" as most cases were among children.¹⁰ People with T1D often show no warning signs before developing diabetes.

1.3.3 T2D

Insufficient insulin level production or low sensitivity for the insulin by peripheral organs and tissue, sometimes referred to as insulin resistance are key factors leading to T2D.¹¹ A sedentary lifestyle is a significant risk factor for T2D. ¹² A less nutritious and unhealthy diet for example those including high sugar content and saturated fats are also other known risk factors.¹² Lack of enough physical activity and poor diet can result in increased body fat percentage and obesity.¹³ Accumulation of body fat, especially in the abdominal area, can cause insulin resistance, and as a result, patients develop T2D.¹⁴ The National Institute for Health and Care Excellence (NICE) in the UK provided guidelines on the management of diabetes and recommended that T2D can be managed by oral hypoglycaemic agents and, in severe cases, supplemental insulin.¹⁵ NICE is a UK public agency that develops treatments guidelines according to evidence-based recommendations made by independent professional committees.¹⁶

1.4 Clinical complications of diabetes

The World Health Organisation (WHO) most recent available estimate suggests diabetes to be the ninth leading cause of death worldwide in 2019 and projected to rank the seventh leading cause of death by 2030.² High blood glucose levels if poorly managed or left uncontrolled, can result in short- and long-term complications. Short term complications occur primarily as a result of a life-threatening condition known as diabetic ketoacidosis.¹¹ Lack of insulin leads to free fatty acid release into the bloodstream. The liver converts the free fatty acids to ketone bodies. Accumulation of ketone bodies in the blood lowers its PH resulting in diabetic ketoacidosis, which can be serious and fatal.¹¹ Short-term manifestations of ketoacidosis include nausea, vomiting, abdominal pain, dehydration, polyuria/polydipsia, weakness, hypotension

and abnormal breathing pattern.¹⁷ Long term complications of insufficiently-controlled diabetes are mainly due to the destruction of small as well as large blood vessels.⁵

Complications include but are not limited to:

- Cardiovascular diseases such as heart attacks, strokes and peripheral artery disease. The risk of developing cardiovascular diseases in diabetic patients is two to three times greater than in non-diabetic patients.⁵
- Diabetic nephropathy, damage to the terminal small blood vessels in the kidneys in which glomerular filtration takes place by high glucose level in the blood leading to renal failure.¹⁸
- Diabetes can affect small blood vessels in the eye leading to the destruction of the retina. This condition is called diabetic retinopathy and is characterised as a decrease in vision over time and then blindness. It is estimated that 2.6% of blindness cases globally are attributed to diabetes.¹⁹
- Nerve damage can be caused by high blood glucose levels, leading to an increased risk of wound infection in the feet and the development of ulceration (gangrene) that could spread to the rest of the body. As a result, and to prevent further complications, the affected foot gets amputated.²⁰

1.5 Management of diabetes

Self-management by patients for the prevention and self-management of diabetes includes but is not limited to adopting a healthy lifestyle, use of a balanced diet and adherence to prescribed treatments. A healthy, balanced diet that does not contain high levels of simple sugars or high quantities of starchy food is essential to managing blood glucose levels. In addition, regular exercise is recommended for diabetic patients, especially those with T2D, as obesity is considered one of the leading

causes.²¹ The risk of developing cardiovascular disease, one of the long-term comorbidities associated with diabetes can be decreased by regular exercise. A meta-analysis showed that the relative risk of cardiovascular diseases in diabetic patients increases by 1.18 (95% CI, 1.10 to 1.26) for T2D and 1.15 (95% CI, 0.92 to 1.43) for T1D for each 1% increase in the average blood glucose levels.²² In another meta-analysis, aerobic exercises and combination of resistance training was shown to have reduced average blood glucose levels by 0.6 (95% CI -0.98 to -0.27) ($P \leq 0.05$) and 0.67% (95% CI -0.93 to -0.40) ($P \leq 0.05$) respectively.²³ In addition, a balanced diet and regular exercise enables diabetic patients to keep body weight within acceptable limits allowing the regulation of body fat and blood glucose levels.²¹

Clinical guidelines inform the clinical management of diabetes. For example, The NICE guideline for the management of diabetes and other endocrinal, nutritional and metabolic conditions advises that prescribed medicines, including oral hypoglycaemic agents such as metformin and pioglitazone, as well as insulin therapy when used in appropriate patients following individual, tailored made treatment regimens should be beneficial for managing blood glucose levels and preventing future complications such as cardiovascular, neural and renal complications.¹⁵ Clinical guidelines state that diabetes complications, including those caused by diabetes, are treated as separate conditions regardless of the primary cause. For example, cardiovascular diseases should be treated following cardiovascular disorders treatment plans that are independent of diabetes management.²⁴

1.6 Medication adherence

Medication adherence refers to a patient following a healthcare professional's recommendations and taking the specified dose of medication for the prevention or the

management of health conditions such as diabetes.²⁵ Medication adherence is vital in order to achieve the desired results from the diabetes management plans, as non-adherence is a major barrier to successful management outcomes.²⁵ Poor medication adherence is considered a major contributor to poor management outcomes and higher financial costs of diabetes management.²⁶ Medication non-adherence can be unintentional and intentional.²⁷ Unintentional non-adherence happens spontaneously due to patients' ordinary behaviours such as carelessness or forgetfulness, while intentional non-adherence happens deliberately as patients chooses not to adhere to the prescribed medicine.²⁷ Factors that can influence medication adherence in diabetic patients include socioeconomic status, scheduling of the dosage of prescribed medicines, disease-related factors (e.g., duration of the condition), age (adherence is lower in very young and very old patients, the existence of mental and physical comorbidities and cost (co-payments)).²⁸ Other barriers to adherence include perceived lack of benefits of prescribed treatments, experiences or fear of adverse events, high cost of medications, and lack of trust between patients and healthcare professionals.²⁹

³⁰ As many diabetic patients are also known to use Complementary and Alternative Medicine (CAM), the use of CAM can also play a role in medication adherence.³¹

1.7 Medication adherence in diabetes

Existing literature reported diabetes estimated non-adherence at 43.4% (95% CI: 17.5-69.4; $P < 0.001$).^{32, 33} The cost of diabetes medication non-adherence is a financial burden on healthcare systems. The cost of non-adherence to diabetic medications in the US alone is estimated to be >\$5 billion ranging from \$2741 to \$9819 per patient per year.³⁴ Poor medication adherence is associated with early insulin use, older age and increased daily frequency of hypoglycaemic agents' dosage. Non-adherence to

insulin is also attributed to a fear of insulin injections and the embarrassment regarding their use in public.^{35, 36} Medication adherence to diabetes medications might be also influenced by the diabetic patient's decision to use CAM such as herbal products as an alternative treatments to prescribed medicines.³⁷

1.8 What is complementary and alternative medicine (CAM)?

WHO defines CAM as a "broad set of health care practices that are not part of that country's own tradition or conventional medicine and are not fully integrated into the dominant health-care system".³⁸ When describing these approaches, people often use "alternative" and "complementary" interchangeably, but the two terms refer to different concepts. "If a non-mainstream practice is used together with conventional medicine, it is considered 'complementary'. If a non-mainstream practice is used in place of conventional medicine, it is considered alternative".³⁹ CAM includes many different types. Examples of CAM types are acupuncture, homeopathy, mind–body therapies, religious and spiritual healing, Ayurveda, yoga, massage, chiropractic, meditation and herbal medicine.³⁹ Generating a comprehensive list of CAM types and herbs used by diabetic patients as reported in the peer reviewed literature is an objective of this PhD study will be provided in chapter 4.

1.9 Diabetes and CAM

The most recent available systematic review on CAM use by diabetic patients was conducted in 2007 and identified 18 studies from 9 countries published between 1990-2006. The review reported a prevalence of CAM use among diabetic patients ranging between 17%-72.8%.³¹ It reported that diabetic patients used various CAM forms, such as dietary supplements, herbal remedies, spiritual healing and relaxation techniques.³¹ However, up-to-date Information about the prevalence of CAM usage, types of CAM

used, beliefs and attitudes toward CAM among diabetic patients remains limited and there is a lack of up to date literature on the views and experiences of diabetic patients regarding their CAM use.

1.10 Evidence base on complementary and alternative medicine (CAM)

There is limited evidence in regards to the safety and effectiveness of CAM for the management of diabetes. However, CAM effectiveness, for example, the hypoglycaemic effects of cinnamon and yoga have been demonstrated in studies.^{40, 41} Therefore, adopting CAM as the only form of treatment is likely to increase the risk of developing diabetes complications. Moreover, the risks of interactions and adverse effects and the nature of benefits associated with concurrent CAM usage are not well-known.⁴²

1.11 Prevalence of diabetes and CAM use by diabetic patients in Saudi Arabia

Saudi Arabia is a country situated in south-west Asia. The population of Saudi Arabia was estimated to be around 35 million people in 2020.⁴³ It is estimated that 80% of the Saudi population live in urban metropolitan areas.⁴³ The dominant and the official religion of Saudi Arabia is Islam as Muslims comprise 97.1% of the total population in Saudi Arabia.⁴⁴



Figure 1.1: Map of Saudi Arabia. Source: [mapsopen.com](https://www.mapsofopen.com)

The healthcare system in Saudi Arabia is a national healthcare system and is provided free of charge for its citizens and is run by the government.⁴⁵ The government fund and run all levels of healthcare facilities, i.e. hospitals, outpatient clinics and general practices, and prescription medications are dispensed to Saudi patients free of charge.⁴⁵ There are parallel private healthcare systems run by private companies and supervised by the government. Patients can pay for treatment in the private sector or use medical insurance to cover expenses.⁴⁶

Diabetes mellitus is one of the biggest challenges facing Saudi Arabia's health care system. Saudi Arabia was ranked the seventh in the world in diabetes prevalence.⁴⁷ It was estimated that the prevalence of diabetes among adults was 18.5% in 2017, with 3,852,000 adults living with diabetes.⁴⁸

Limited previous literature exists on the use of CAM in diabetes in Saudi Arabia. A previous study conducted with diabetic patients in Mecca, Saudi Arabia showed 15.6% of participants believed that herbal remedies are safe and effective.⁴⁹ Another cross-sectional study conducted with diabetic patients at a diabetic centre in the capital city of Riyadh in 2014 reported that many type 2 diabetic patients were using some form of CAM.⁵⁰ Similarly, another cross-sectional study of diabetic patients in Jeddah, Saudi Arabia showed 61.6% of diabetic patients used CAM for diabetes-related complications, such as diabetic foot.⁵¹ However, there is a lack of qualitative studies exploring what and why diabetic patients use CAM for the management of diabetes. Qualitative studies are well placed to give patients the opportunity to express their views on this and allow researchers to further explore the subject.⁵² Understanding patient preferences around the use of CAM will enable healthcare professionals to

identify factors associated with use, identify and minimise drug related problems, drug interactions and offer opportunity to provide better counselling for diabetic patients.

Summary of the chapter

This chapter offered an overview of diabetes, its global prevalence and current burden in Saudi Arabia. This chapter also defined and introduced CAM and the context of use in diabetes. It briefly described Saudi Arabia's demography, culture, healthcare system, diabetes prevalence and use of CAM by Saudi diabetic patients. This chapter highlighted the gap in the literature regarding the extent and factors associated with the use of CAM by diabetic patients and how such study could help enable better health outcomes for patients. The rest of this PhD study will be focused address this gap in the literature.

CHAPTER 2: AIM AND OBJECTIVES

This chapter provides an overview of the aim and objectives of this research. The previous chapter introduced the research area and identified the dearth of research around prevalence and factors associated with the use of CAM by diabetic patients. This chapter will provide the overall aim of the PhD and objectives specific to different phases of the study.

2.1 Aim

This PhD research aims to investigate the prevalence and factors associated with the use of CAM among adult patients with diabetes through the use of systematic reviews and meta-analysis, analysis of patient conversation in online forums and qualitative studies with patients and healthcare professionals.

2.2 Objectives

1. To undertake a systematic review of literature to identify the previously reported estimates of prevalence and types of CAM that previous studies have reported that diabetic patients reported they used.
2. To undertake a systematic review to identify factors reported in previous studies that influence diabetic patients to use CAM.
3. To explore the perspectives of patients in relation to their use of CAM in diabetes through the use of conversation data from online patient forums.
4. To explore in-depth diabetic patients' beliefs, practices, and factors associated with CAM use through a qualitative study design.

5. To explore healthcare professionals' knowledge, perspective and views on their diabetic patients' CAM use through qualitative study design.
6. To describe implications for practice and research by triangulating the findings from different phases of this PhD study.

2.3 Research Questions

This research aims to answer the following research questions:

1. What is the up-to-date global prevalence of CAM use in diabetes?
2. What types of CAM are used by diabetic patients?
3. What are the factors that influence diabetic patients to use CAM?
4. What are patients' beliefs, practices, and factors CAM use for diabetes?
5. What is healthcare professionals' knowledge, perspective and view on their diabetic patients' CAM use?

CHAPTER 3: METHODOLOGY

Chapter overview: This chapter describes and provides an overview of the theoretical and methodological approaches used in this PhD. It also describes and justifies the choice of the study designs as well as the research tools used to answer the research questions. Ethical considerations relevant to different stages of the research are also presented.

3.1 Systematic reviews

The systematic review is a research design that helps researchers systematically and comprehensively examine all available literature.⁵³ The Cochrane Collaborations defines systematic reviews as “A systematic review attempts to identify, appraise and synthesize all the empirical evidence that meets pre-specified eligibility criteria to answer a specific research question”.⁵⁴ It allows researchers to identify, assess, summarise, and analyse the existing data available in the literature that are directly related to the research question.⁵³ Systematic review is a tool used to minimise bias and synthesise evidence to help researchers identify the gaps in the literature.⁵³ The quality of evidence provided by systematic reviews is considered the highest among other evidence synthesis approaches.⁵⁵ The evidence produced using systematic reviews is also considered the most reliable among other pieces of evidence produced using other research tools.⁵⁶ Systematic review is ranked at the top of the evidence hierarchy pyramid, followed by randomised controlled trials.⁵⁶

Systematic reviews help the development of management guidelines by offering evidence-based information through systematic examination and analysis of all available literature.¹⁶ These evidence-based recommendations are made through

interpreting, summarizing and prioritising those recommendations based on the current evidence. Guideline developing bodies use available systematic reviews to identify gaps in the literature to formulate research recommendations.¹⁶

Conducting a systematic review requires following set of stages to reach results and assess the quality of evidence. The key stages of conducting a systematic review consist of protocol development, literature searching, screening and selection, quality assessment, data extraction, synthesis and report writing.⁵⁷

Protocol development must precede the conduct of a systematic review. During this stage, the research question is formulated, search terms and databases are determined, inclusion and exclusion criteria are set, tools for quality assessment are chosen and the evidence synthesis approach is determined.⁵⁷ For the purpose of the systematic reviews conducted as part of this PhD, search terms included those related to CAM combined with terms related to diabetes. Databases were chosen based on their relevance to the subject being investigated. The systematic reviews undertaken as part of this PhD were informed by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines and checklist.⁵⁸ A protocol was developed as per the PRISMA-P protocol guideline and registered under (protocol ID CRD42019125036).⁵⁸ Search terms were guided by internet searches for all CAM types as well as by the House of Lords Committee on Science and Technology Sixth Report, and the US National Centre for Complementary and Integrative Health.^{59, 60}

The stage of screening and selection of studies starts with conducting database searches using the pre-determined key words. Search terms for this PhD were modified based on the individual settings of different databases. Truncated and

wildcard searches were used. Diabetes related MeSH terms related to diabetes were incorporated in the search strategy. For this PhD study, the search results are then screened by titles to determine eligibility for inclusion, followed by abstracts and full texts reviews. A final list of article is then selected for inclusion in the subsequent stages of the systematic review, i.e. quality assessment, data extraction, synthesis and reporting of the systematic review.⁵⁸

Quality assessment is a key stage in the conduct of a systematic review. Various tools are available for quality assessment such as the Joanna Briggs Institute Critical Appraisal tools (JBI) and Cochrane risk-of-bias (RoB 2).^{53, 61, 62} The choice of quality assessment tools is based on the types of included studies.^{54, 63} Validity of quality assessment tools can be measured in different ways, and many tests can aid researchers in determining the validity of a given instrument. For example, two or more reviewers can undergo quality assessment task and compare the outcomes produced by each reviewer.⁶⁴ The Critical Appraisal tool from the JBI checklists was adopted in the systematic review for this PhD study as most of the included studies were cross-sectional in design.^{62, 63} The quality assessment of included studies was focused on clarity of inclusion criteria and study setting and sampling, appropriateness of tests used for statistical analysis and dealing with confounding and validity and reliability of the measurement data. Questions listed in the JBI tools were answered either with Yes, No or Unclear.⁶⁵

Following quality assessment, relevant data from included studies are extracted and then analysed to report results. Both meta-analysis and narrative analysis are examples of data analysis methods used in systematic reviews. The choice of analysis

method depends on the type of data, meta-analysis is appropriate for homogeneous data, whereas narrative synthesis is more appropriate for heterogenic data.^{66, 67}

In this PhD study, two systematic reviews were conducted. The first systematic review was conducted to provide a comprehensive view and meta-analysis of the global prevalence of CAM use among diabetic patients and to identify the most popular CAM types among diabetic patients. Meta-analysis of prevalence is defined by the number of individuals that share a certain characteristic in a population pooled together from different studies.⁶⁸ In meta-analysis, results from various studies are weighted and averaged and can be used to pool effect sizes, as well as to estimate frequencies, i.e. incidence and prevalence.⁶⁹ Meta-analysis of prevalence can also be used to estimate subgroups' weight in that population.⁷⁰ Meta-analysis using quantitative synthesis of aggregate level data on prevalence was adopted for data analysis. Ninety-five percent predictive intervals i.e. predictions of what 95% of future studies would report, were reported to estimate prevalence of CAM use for population estimates.⁶⁹

The second systematic review was conducted to identify the factors that influence diabetic patients to use CAM. JBI tools for critical appraisal were used also for quality assessment as most of the included studies were cross-sectional in design, and the Theoretical Domains Framework (TDF) was adopted for analysis of results. TDF is explained below under the 'use of theory in research' section in this chapter. The findings of these systematic reviews served as a foundation on which the subsequent study designs and research objectives were decided.

3.2 Research philosophy

The two commonly adopted philosophies to understand human behaviours relate to positivism and interpretivism.⁷¹ Positivism refers to the researcher observing the phenomenon objectively and implies that only one reality exists to be observed.⁷¹ On the other hand, interpretivism means that the researcher observes the phenomenon subjectively, which means that the researcher plays a role in observing the phenomenon and interpretation of the phenomenon is unique to each researcher.⁷¹

Interpretivism examines the individual interpretations of behaviours.⁷² It is based upon trying to understand the meanings people give and the motivations people have to act in a specific manner in different contexts. Interpretivism focuses on gaining insight into the unique experiences of individuals and groups rather than approaching the phenomenon objectively.⁷³ Interpretivism suggests that different people will react in different ways due to individuals having free will and being able to act differently.⁷³ Interpretivism probes deeper than the surface of the phenomenon to uncover the meanings and motivations of peoples' behaviours. Adopting the interpretivism research philosophy enables the use of qualitative research design which in turn helps researchers to uncover hidden meanings they may not have been able to understand otherwise.⁷²

This research investigates the extent of use and factors associated with use of CAM among diabetic patients. As patients most likely use CAM outside of clinical settings, and patients probably use CAM based on their own beliefs and understanding about CAM use for diabetes, an interpretivism research philosophy is relevant for this research.

3.3 Research study design adopted in this study

Qualitative research generate data via direct or non-direct observations of social or medical circumstances in order to provide a deeper and more detailed understanding of the phenomenon.⁵² Qualitative research aims to address a given phenomenon and generates data to be analysed using words instead of numbers.⁵² Qualitative data can be obtained, for example, through interviews, focus groups, and voice or video recordings. The choice of interviews for this research over other qualitative approaches was based on the assumption that some of the anticipated responses might be considered personal and participants might be reluctant to share in focus groups. Moreover, the researcher involvement was essential to probe further on the reasoning behind diabetic patient's decisions to use CAM as it is often a sensitive topic and a subject people are wary of talking about particularly in term of disclosure to healthcare professionals and therefore an observational approach was deemed less appropriate. Unlike quantitative research (such as surveys, and experimental research designs), which uses fixed categories aiming to compute numbers aiming to test existing explanations and need enumeration to be meaningful, qualitative research, on the other hand, creates the categories and develops the explanations and does not need enumeration to be meaningful.⁷¹ This ability that qualitative research can offer in creating categories and developing explanations is applicable to study and understand how a phenomenon manifests and why it manifests the way it is rather than answering what the phenomenon is. Answering the questions 'how' and 'why' allows exploration of ideas, thoughts and feelings.^{52, 74}

A sequential mixed methods approach was adopted for this research.⁷⁵ The first stage of this research utilized quantitative data around prevalence estimates of CAM use in

diabetes as reported in previous literature and included quantitative synthesis of the data, i.e. meta-analysis. This was followed by a mixed methods systematic review involving data from qualitative and quantitative studies (i.e. surveys) regarding factors associated with use of CAM by diabetic patients. For the subsequent three stages of this research, a qualitative research design was adopted.

3.4 Conduct and reporting of qualitative research

3.4.1 Semi-structured interviews

Conducting and reporting of the findings in the semi-structured interviews were conducted in accordance with the consolidated criteria for reporting qualitative research (COREQ).⁷⁶ The reporting criteria include a checklist that focuses on three domains. The first domain addresses the research team and reflexivity, i.e. interviewer credentials, experience and training, the second domain addresses the study design including study setting, sampling and data collection, and the third domain focuses on analysis and findings in terms of consistency of findings and clarity of themes.⁷⁶

3.4.2 Online discussion forums

The study was conducted in accordance with the British Psychological Society's Ethics guidelines for internet-mediated research and the Association of Internet Researchers' Ethical guidelines.^{77, 78}

These guidelines offer recommendations on conducting research using data from online sources about or from human participants. The main focus of these guidelines relate to respecting privacy and dignity of participants, scientific integrity, maximising benefits and minimising harm.

3.5 Sampling strategy in qualitative research

There are two main classifications of sampling relevant to clinical research, probability and non-probability sampling.⁷⁹ Probability sampling is random and, therefore selects a representative selection of participants from a population, whereas non-probability sampling involves selecting participants in a non-randomised manner and is more often applicable in qualitative research.⁷⁹

There are four key sampling techniques that apply to qualitative studies and includes, convenience sampling, snowball sampling, quota sampling, and purposive sampling.⁸⁰

The *convenience sampling* technique involves selecting participants who are available or convenient for the study for the research. Samples are selected in a non-random fashion because not all subjects in the population have an equal chance of being selected. For example, this includes recruiting patients attending clinics. *Snowball sampling*, also called chain referral sampling, is when the participants are asked to refer the researcher to other people who could participate in or contribute to the study.⁸¹

This sampling technique is often used to find and recruit the hidden samples that are not easily accessible to researchers using the other sampling strategies,⁸¹ for example asking participants if they could suggest anyone to participate in the study who uses CAM for the management of diabetes⁸² *Quota sampling* is a sampling technique when groups are created based on each subgroup of the desired sample and the researcher decides how many participants to include from each subgroup.⁸³ *Purposive sampling* is a sampling technique used for choosing groups of participants according to pre-selected criteria relevant to a particular research question.⁸⁴ In purposive sampling, clear criteria and the rationale for inclusion must be established.⁸⁴ It is emphasised that the purposive sampling technique involves identifying and selecting individuals or

groups of individuals knowledgeable or experienced in the research interest or phenomenon.⁸²

In this research, a purposive sampling was adopted for the qualitative semi-structured interviews to ensure that the sample included as far as possible patients from different age groups, gender and length of time since diagnosis and healthcare professionals with different levels and scope of involvement with diabetic patients.⁸²

3.6 Data collection methods in qualitative research

Different approaches can be followed for collecting qualitative data. One approach is that of research interviews which can be structured, semi-structured or unstructured.⁸²

Structured interviews refer to the type of interview questions where the researchers ask questions about a very definite and precise topic and seek precise answers to those questions. On the contrary, *unstructured interviews* allow participants to freely provide their input and tell their stories without being constrained to pre-determined topics and mean in this type the researcher contributes and directs the interview less.⁸⁵

The nature of *semi-structured interviews* are somewhere between the previous two types. They allow researchers to steer the direction of the interview to a specific topic while at the same time allowing participants to express their thoughts and elaborate on their answers and also allowing the researcher to be interactive with the participant during the interview.⁸⁵

3.6.1 Semi-structured interviews

For this PhD study semi-structured interviews were conducted with patients and healthcare providers involved in the care of diabetic patients. As the reasons for CAM use by the diabetic patient could be extensive and varied, the choice of semi-structured

interviews is justified as it is essential to allow the participants to freely express their thoughts, feelings and experiences while giving the researcher some control throughout the interviews in order to minimise digression from the main subject of the study.⁷¹

3.6.2 Qualitative study using online discussion forums

Patients' health information seeking behaviours have changed during the digital age contributed to by the increased availability of health information online.⁸⁶ Health information sources online include but are not limited to websites, articles and online forums.⁸⁶ In fact, health information is one of the most searched topics online.⁸⁶ Patients tend to search for health information online due to accessibility, convenience and speed.⁸⁶

This research utilised patient conversations available in online discussion forums as the study data. This type of research collects data that is already posted by patients and available publicly online in its raw unstructured manner. Online discussion forums can be an important source of data, as it allows researchers to explore everyday conversations between patients about all sort of details regarding managing and dealing with their condition on which data can be challenging to obtain otherwise.⁸⁷

Patients exchange health information and share experiences and provide advice to one another through online forums and discussion boards.³⁵ Using online forums, patients write or post about their experiences in dealing with a medical condition including using traditional and untraditional means for disease management. These posts are also used by patients to share their concerns and thoughts regarding their

condition in more free and unrestricted settings that are not limited to a specific context.⁸⁷

In recent years, online forums and discussion boards have become a valuable data source in health services research. For example, a study aimed to understand the patient perspective of epilepsy treatment by analyzing what patients posted in three online support groups.⁸⁸ Further examples are available in the literature from diverse clinical areas such as patient experiences of cancer treatment,⁸⁹ barriers and facilitators of patient adherence to secondary stroke prevention medications after stroke⁹⁰ and experiences of people affected by cancer during the outbreak of the COVID-19 pandemic.⁹¹

3.7 Data analysis in qualitative research

Most commonly used analysis methods for qualitative research are narrative analysis, discourse analysis, interpretative phenomenological analysis, qualitative content analysis, and thematic analysis.⁹² *Narrative analysis* is conducted by listening to people telling stories and analysing the story and how it was told; since stories serve a functional purpose of helping researchers make sense of the subject being investigated. ⁹² *Discourse analysis* refers to analysing language within its social context, i.e. within the culture where it occurs, while grounded theory is a qualitative analysis method where the intention is to create a new theory or theories through a series of tests and revisions.⁹² Interpretative phenomenological analysis is a qualitative analysis technique designed to help researchers understand subjects' personal experiences concerning a significant life event and experience or a situation where this event or experience is the phenomenon.⁹² *Qualitative content analysis* is applied to

evaluate patterns in existing content. It is helpful to identify the frequency of which an idea is shared or mentioned. Content analysis provides a brief insight into quantitative thinking within a qualitative method.⁹³ *Thematic analysis* focuses on themes in a data set, e.g. set of interviews or focus group transcripts as thematic analysis takes bodies of data and groups them according to similarities into themes to help make sense of the context and derive meaning from it.⁹⁴ Thematic analysis can be applied to identify people's experiences, views and opinions as thematic analysis is an exploratory process.⁹⁴

3.7.1 Semi-structured interviews

For the analysis of the semi-structured interviews in this thesis, thematic analysis was applied to generate themes around patient perspectives on the use of CAM for the management of diabetes and healthcare professionals' perspectives on the use of CAM by diabetic patients. This technique was used as the objective of these studies was to explore experiences, views and opinions of stakeholders.

3.7.2 Online discussion forums

For the analysis of data for the study on online forums, two types of qualitative analysis were applied: qualitative content analysis and thematic analysis. Qualitative content analysis was used for this study for the purpose of identifying patterns and frequencies of quotes to analyse views and experiences within the content of the forums. Thematic analysis was adopted to explore the perspectives of patients on their beliefs, experiences and preferences in relation to their use of CAM in diabetes, and to identify factors that attract diabetic patients to use CAM or drive them away from conventional medicine to CAM.

3.8 Rigour in research

Systematic reviews were informed by (PRISMA-P) guidelines and checklist and the searches were performed using a comprehensive list of key words using several relevant databases.⁵⁸

The topic of judging quality in qualitative research has been controversial and little consensus is available on what constitutes valid, reliable and trustworthy qualitative research.⁹⁵ To ensure trustworthiness of qualitative findings, various strategies have been recommended.⁹⁶ A number of approaches were used to promote the rigour and trustworthiness of this research. Firstly triangulation, where researchers use two or more sources of related data, or two or more methods of collecting data, in an effort to reduce the bias associated with one source, method, or researcher was adopted.⁹⁵ In addition, a peer debriefing approach was adopted, as the supervisors independently reviewed qualitative data and agreed on themes. Thick description, by providing details in the study protocols and manuscripts on settings inclusion/exclusion criteria, sample characteristics, and data collection and analysis was also applied to this research.^{95, 96} The third approach was reflexivity. Reflexivity refers to how the researcher's own beliefs and previous experiences influence the outcome of the study.⁹⁶ The researcher is a native to the area where the study was conducted and had knowledge and experiences of cultural beliefs shared within that community. The researcher prior to enrolling in the PhD programme worked at Saudi the FDA as a pharmacist and had an extensive knowledge on CAM types preferred by the diabetic patients. Being a pharmacist might lead to bias against CAM. However, the researcher had no particular interests in favour or opposition of CAM and was simply investigating the prevalence and behavioural factors associated with CAM use which could offer pharmacists and

clinicians the opportunity to increase awareness and optimise treatment through better communication with patients.

The qualitative approach relies on the knowledge of the researcher. If a researcher has limited knowledge on the subject being investigated, the researcher would not be able to develop the interview questions appropriately or interpret the results efficiently.⁷¹ Moreover, qualitative research results can be influenced by the researcher's bias as qualitative data are subjective and need to be interpreted by the researcher.⁷¹ Therefore, results are difficult to replicate as different researchers can produce different interpretations for the same data set. To minimise the risk of bias that might occur during the interpretation of qualitative data and increase their validity, several measures were adopted. The researcher and the supervising team independently reviewed data and interview transcripts, discussed the results and agreed on themes.

Patient involvement and engagement in the research could have a positive impact on research. However, most of this research was conducted in 2020 and 2021 and due to restrictions set in place for the COVID 19 pandemic, it was difficult to arrange for such patients and public engagement for this research.

3.9 Use of theory in research

Theories can connect pieces of research data, resulting in findings that fit into a larger framework of other studies.⁹⁷ In addition to improving rigor and robustness, they can also enhance relevance and impact.⁹⁷ Theories can be applied at different stages of the research process, including data analysis and interpretation.⁹⁸

In qualitative research, a theoretical perspective can enable the design of data collection tools such as the interview schedules and focus group topic guides.⁹⁹ Rigour in research can be strengthened by ensuring that data analysis and interpretation are theory-based.

A wide range of theories have been used in health research. Examples of theories adopted in health services research include those applied in research around interpersonal communication (e.g., network theory), mass media (e.g., agenda setting theory), organisational communication (e.g., communities of practice), information technology (e.g., computer mediated communication), and health communication (e.g., social cognitive theory).¹⁰⁰ Because of the broad spectrum of theories, selecting one that is appropriate requires careful consideration of elements such as: the field of research; the nature of research; the theories available and their nature; and how were they previously applied in research.¹⁰⁰

Given the plethora of theories that often presents challenges to the researchers who are less acquainted with research paradigms, framework of theories has been developed for use in health services research.¹⁰¹ The TDF is a framework of theories of behaviour change that was developed by a panel of psychological theorists, health service researchers, and health psychologists.¹⁰¹ The TDF is derived from 33 psychological theories and 128 theoretical constructs organized under 14 overarching domains.¹⁰² The use of the TDF could enable data concerning a certain behaviour to be restructured and simplified into a set of theoretical domains that might be more appropriate for further use, including the development of behavioural interventions.¹⁰³ For example identifying behavioural determinants can enable the development of interventions to promote adherence to prescribed medicines in diabetes.¹⁰³

In this research, the TDF was applied to collect and analyse the data of the systematic review of factors influencing diabetic patients to use CAM. Using the TDF could help interpretation and also could allowed a diverse range of factors to be synthesised into a smaller number of meaningful constructs. Development of future interventions to optimise adherence to prescribed treatments while using CAM could be aided by basing the interventions on the key constructs.

This PhD study also used the TDF in the qualitative phases of the research. The development of the semi-structured topic guide (interview questions) for qualitative interviews was partially informed by the TDF. TDF-based qualitative studies have been shown to generate themes based on determinants of a particular behaviour and such findings could be beneficial for the design behavioural intervention studies.¹⁰¹

3.10 Ethical considerations

3.10.1 Conducting qualitative studies

3.10.1.1 Semi-structured interviews

This research involved patients as well as healthcare providers. Ethical considerations were applied in recruiting participants, obtaining informed consent, confidentiality and anonymity, participants' right to withdraw from the study as well as the storage, access and disposal of data. Participants' anonymity, confidentiality and data protection were maintained throughout this research. All data obtained during the conduct of this study were treated as confidential. A Data Management Plan (DMP)¹⁰⁴ was implemented to ensure the maximum data protection. Interviews were recorded using encrypted audio recording devices to protect records in case of lost or stolen devices. Transcripts of the interviews were organized and assigned codes instead of names or any other

information that might be linked to the participant. A coding system was implemented that could not be traced back to the participants by any person other than the researcher. Audio files were handled and processed by University of Birmingham computers that are covered by the university's network security systems.¹⁰⁵ Anonymity of the participants was maintained during coding, managing, processing and reporting of data. Access to data were limited to the research team.

An ethical approval application was submitted to the University of Birmingham Science, Technology, Engineering and Mathematics Ethical Review Committee and the Saudi Ministry of Health, since the studies involved interviews with patients and healthcare providers from Saudi Arabia.

During the ethical review process, the Ethics committee of the University of Birmingham advised adjustments around the risks of conducting face to face interviews during COVID-19 pandemic and suggested that the study should be switched to virtual interviews. The researcher and supervisors agreed to this suggestion. Suggestions were provided by the ethical review team with the University guidance on the key points to consider when switching from face-face interviews or focus groups to telephone or Skype formats.¹⁰⁶ The researcher strictly adhered to the guidance during the conduct of the studies.

Ethical approvals were granted by the Saudi Ministry of Health (AH1441-8-2) on 26 March 2020 and from the University of Birmingham Science, Technology, Engineering and Mathematics Ethical Review Committee (ERN_20-0637) on 17 June 2020.

The researcher strictly adhered to all the ethical requirements during all stages of this research, and the supervising team closely monitored the researcher's adherence to the ethical requirements throughout the conduct of this research.

3.10.1.2 Online discussion forums

For the study on patient online forums, only posts that were available in the public domain were included in this study. Forums that require subscription to access their content were not included as stated earlier in the inclusion criteria section as forum users in online forums that required subscriptions are communicating in some sort of exclusive online community and might not wish their posts to be available to public readers. Anonymity of the forum users was maintained during storing, managing, processing and reporting of data. Data were handled and processed by the University of Birmingham's computers that are covered by the university's network security systems.¹⁰⁵ Access to data were limited to the research team.

An ethical approval application was submitted to the University of Birmingham Science, Technology, Engineering and Mathematics Ethical Review Committee.

Ethical approval was granted by the University of Birmingham Science, Technology, Engineering and Mathematics Ethical Review Committee (ERN_20-1431) on 28 September 2020.

The researcher strictly adhered to all the ethical requirements stated above during all stages of this research, and the supervising team closely monitored the researcher's adherence to the ethical requirements throughout the conduct of this research.

3.10.2 Informed consent

3.10.2.1 Semi-structured interviews

Informed consent was obtained from all participants of the semi-structured interviews. The consent statements were read and consents were recorded over the telephone call approach adopted -using only encrypted recording devices- prior to the commencement of the interviews. Measures were set to be applied if a participant chose to withdraw from the study where all the materials obtained during the interview with that participant would be discarded, i.e. voice recordings deleted and paper copies of the interview transcript properly destroyed. Recordings of consent statements along with interview audios are stored in a University of Birmingham managed computer that is protected by the university's network security systems.

3.10.2.2 Online discussion forums

Informed consent for online forum users was not applicable as data were publicly available and forum users would be completely anonymous.⁷⁷ Personal details of forum users were kept anonymous to maintain confidentiality.

Summary of the chapter

This chapter described and summarized theoretical and methodological approaches used in this PhD are described and summarized in this chapter. It also explained and justified the study designs, research tools and ethical considerations related to this PhD. The next chapter will describe the aim and list the objectives and research questions for this PhD study.

CHAPTER 4: Global prevalence and types of complementary and alternative medicines use amongst adults with diabetes: Systematic review and meta-analysis

Chapter overview: This chapter will present a systematic review and meta-analysis to identify the prevalence of CAM use amongst diabetic patients. It reports overall prevalence and data specific to subgroups such as gender and duration of diabetes. It also aim to list CAM types and herbs used by diabetic patients.

Citation: Alzahrani, A.S., Price, M.J., Greenfield, and Paudyal, V. Global prevalence and types of complementary and alternative medicines use amongst adults with diabetes: systematic review and meta-analysis. *Eur J Clin Pharmacol* **77**, 1259–1274 (2021). <https://doi.org/10.1007/s00228-021-03097-x>

Authors' contributions

Abdulaziz Alzahrani designed and conducted all the stages of the study.

Vibhu Paudyal and Sheila Greenfield supervised Abdulaziz Alzahrani's PhD.

Malcolm J. Price advised on the statistical analysis and presentation of quantitative results.

Abdulaziz Alzahrani led the drafting of the chapter to which all authors contributed through editing and revision.

All authors had access to the data sets and agreed to the final version of this chapter.

Ethics approval statement

Not applicable

Patient consent statement

Not applicable

4.1 Abstract

Aim

This study aimed to undertake a systematic review and meta-analysis of global prevalence and types of complementary and alternative medicine (CAM) use amongst adults with diabetes.

Methods

Nine databases including MEDLINE and EMBASE were searched for studies published between 2009 and 2019 which included extractable data for CAM use in adult diabetic patients. Study characteristics, types of CAM and overall and subgroup prevalence data in relation to CAM use were extracted. Meta-analysis of aggregate level data on prevalence and prevalence ratios (PRs) was performed using a random effects model.

Results

From the 38 studies included in the review, a total of 37 types of CAM and 223 types of herbs were identified. Pooled prevalence of CAM use was 51%. A wide variation in prevalence rates (predictive interval 8%-93%) was observed. In the context of high heterogeneity, we found no evidence that CAM use was associated with gender, chronicity, or type of diabetes. Approximately two third of patients did not disclose their use of CAM to healthcare professionals (95% PrI 25%,97%). Herbal medicines, acupuncture, homeopathy and spiritual healing were the common CAM types reported.

Conclusions

A wide variation in prevalence of CAM use by diabetic patients was identified. Healthcare professionals should be aware of their patients' use of CAM to ensure treatment optimization, avoid drug-herb interactions, and promote medication adherence in diabetes. Diabetic reviews and clinical guidelines should incorporate exploration of patient use of CAM as many patients do not proactively disclose the use of CAM to their healthcare professionals.

4.2 Introduction

The World Health Organization (WHO) estimates that over 400 million people are living with diabetes worldwide, and this is projected to increase to reach 592 million by the year 2035.¹⁰⁷ Poorly managed diabetes can lead to serious and possibly fatal complications such as cardiovascular disease, renal failure, nerve damage and blindness.^{5, 18, 19}

Diabetes Mellitus (DM) is a chronic metabolic disorder in which blood glucose levels are higher than normal for a long period of time. These high blood glucose levels are attributed to abnormal disturbances of insulin production and/or function.¹ Diabetes is caused by either lack of insulin production by the pancreas (type 1 diabetes, T1D) when the amount of insulin produced by the pancreas is insufficient to carry out all blood glucose regulation processes, or, by decreased sensitivity to the insulin by the body cells (type 2 diabetes, T2D). Diabetes can also be caused by a combination of low insulin production as well as low insulin sensitivity or be due to hormonal dysregulation in pregnancy.¹

Self-care practices relevant to self-management of diabetes include adherence to prescribed treatment and clinical management plans, adopting a healthy lifestyle and having a balanced diet.¹⁰⁸ In addition, many patients also use complementary and alternative medicine (CAM).³¹ The WHO defines CAM as a "broad set of health care practices that are not part of that country's own tradition or conventional medicine and are not fully integrated into the dominant health-care system".³⁸

CAM use is known to be prevalent in diabetic patients as a supplement to their existing orthodox diabetes treatments, as a replacement, or for reasons that might not be directly related to diabetes such as using CAM for energy and general wellbeing.³¹

Various factors may influence CAM use by diabetic patients. A study of 3,978 U.S. adults suggested that CAM use by patients who were diabetic for more than 10 years or patients who had a functional limitation caused by diabetes were more likely to use CAM compared to patients with less severe diabetes.¹⁰⁹ In addition, the study reported that 77% of patients who are using CAM for the treatment of diabetes were using CAM as a supplement to conventional treatment, while 23% used CAM as a replacement.¹⁰⁹

CAM users often perceive CAM to be an effective means of lowering blood glucose levels and treating side effects of prescribed diabetic medications.¹¹⁰⁻¹¹⁵ However, adverse outcomes of CAM use have also been reported. For example, CAM can affect the management of diabetes by either direct herb-drug interaction with the use of herbal remedies or indirectly by affecting medication adherence when using herbal or any other CAM types.¹⁰⁸

There is a lack of an up-to-date systematic review that investigates the prevalence of CAM use by diabetic patients. Patient sources of health-related information have changed immensely in the last decade.⁸⁶ In particular, increasing availability and use of web based information sources including social media and online health information in recent years may encourage and inhibit CAM use in long term health conditions.¹¹⁶ An up-to-date systematic review on the prevalence of CAM use by diabetic patients will help healthcare professionals to consider patient use of CAM when counselling patients, supporting adherence and identifying the risks of interactions and adverse effects when CAM are used in conjunction with prescribed treatments.

The aim of this study was to systematically review the global prevalence of CAM use amongst adults with diabetes. Specific objectives were to identify the types of CAM

that are used by the diabetic population and to identify differences in CAM use amongst different diabetic populations including types of diabetes, demographic characteristics, duration of diabetes and presence or absence of diabetic complications.

4.3 Methods

This systematic review was informed by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines and checklist.⁵⁸ A protocol was developed as per the PRISMA protocol guideline (protocol ID CRD42019125036).

4.3.1 Data Sources and Searches

Cochrane Library, MEDLINE, Embase, CINAHL, AMED, Web of Science, Google Scholar, and PROSPERO databases were searched for the last 10 years covering 2009 to June 2019. Open Grey was searched for grey literature. Search terms and an example search strategy are listed in Supplementary Table 4.1. The review was restricted to studies published in English. Studies that recruited participants who are adult diabetic patients, 18 years of age and older and reported partially or exclusively the prevalence and use of CAM amongst diabetic patients were included. Studies which either focused on CAM use in conjunction with conventional treatments or as a replacement were considered.

4.3.2 Study Selection

4.3.2.1 Inclusion criteria

- Studies that addressed the prevalence or types of CAM used by diabetic patients.
- Studies that recruited patients 18 years or older.
- Studies that were conducted between 2009 to 2019.

4.3.2.2 Exclusion criteria

- Studies discussing the effectiveness of one or more CAM types as an intervention.
- Studies that were conducted before the year 2009.

4.3.2.3 Screening and selection

Screening and selection were performed independently by two review authors (AA, VP) and were carried out in three phases. Titles and abstracts were screened for inclusion of possible relevant studies followed by assessment of full texts for eligibility. Reference lists of included studies were screened. If a title was considered relevant; the study was manually searched and the abstract examined.

4.3.3 Data Extraction and Quality Assessment

Data on study characteristics, prevalence of CAM use as well as types of CAM used by diabetic patients were extracted. Two review authors (AA, VP) independently assessed the quality of included studies using the critical appraisal tool from the Joanna Briggs Institute (JBI) checklist.⁶² Studies were classified into high, moderate and low quality based on the results of the JBI checklist (Supplementary Table S 4.1). The quality assessment in included studies was focused on three fields: clarity of inclusion criteria and study setting and sampling, appropriateness of approaches to data collection and analysis, and outcome measurement (i.e. use of CAM). Included studies included were judged to be of 'high quality' if quality criteria were satisfied by at least 7 items, 'moderate quality' for scores of 3-6 and 'low quality' for scores ≤ 2 .⁶⁵ All studies were included regardless of their quality.

4.3.4 Data Synthesis and Analysis

A quantitative synthesis of aggregate level data on prevalence was performed. Study specific results were reported as percentage prevalence with exact 95% confidence intervals (95%CI). When sufficient data were available for within-study comparisons of prevalence between dichotomous groups e.g. sex, then relative prevalence ratios (PRs) together with 95% confidence intervals were calculated. Meta-analyses of proportions and PRs were performed using a random effects model fit using the method of Der Simonian & Laird.⁶⁹ Heterogeneity was assessed using the I^2 statistic, the between study standard deviation and calculation of 95% prediction intervals (95%PrI) for the prevalence in a new study.^{67, 70} Data are presented in forest plots which include pooled estimates where appropriate. All analyses were performed using STATA version 15.

4.4 Results

A total of 2623 unique titles were screened of which 38 articles met the inclusion criteria (Figure 4.1). After applying quality assessment, studies fell into these categories (8 high quality studies, 30 moderate quality studies and no low quality studies). Details of critical appraisal results are available in Supplementary Table S 4.2.

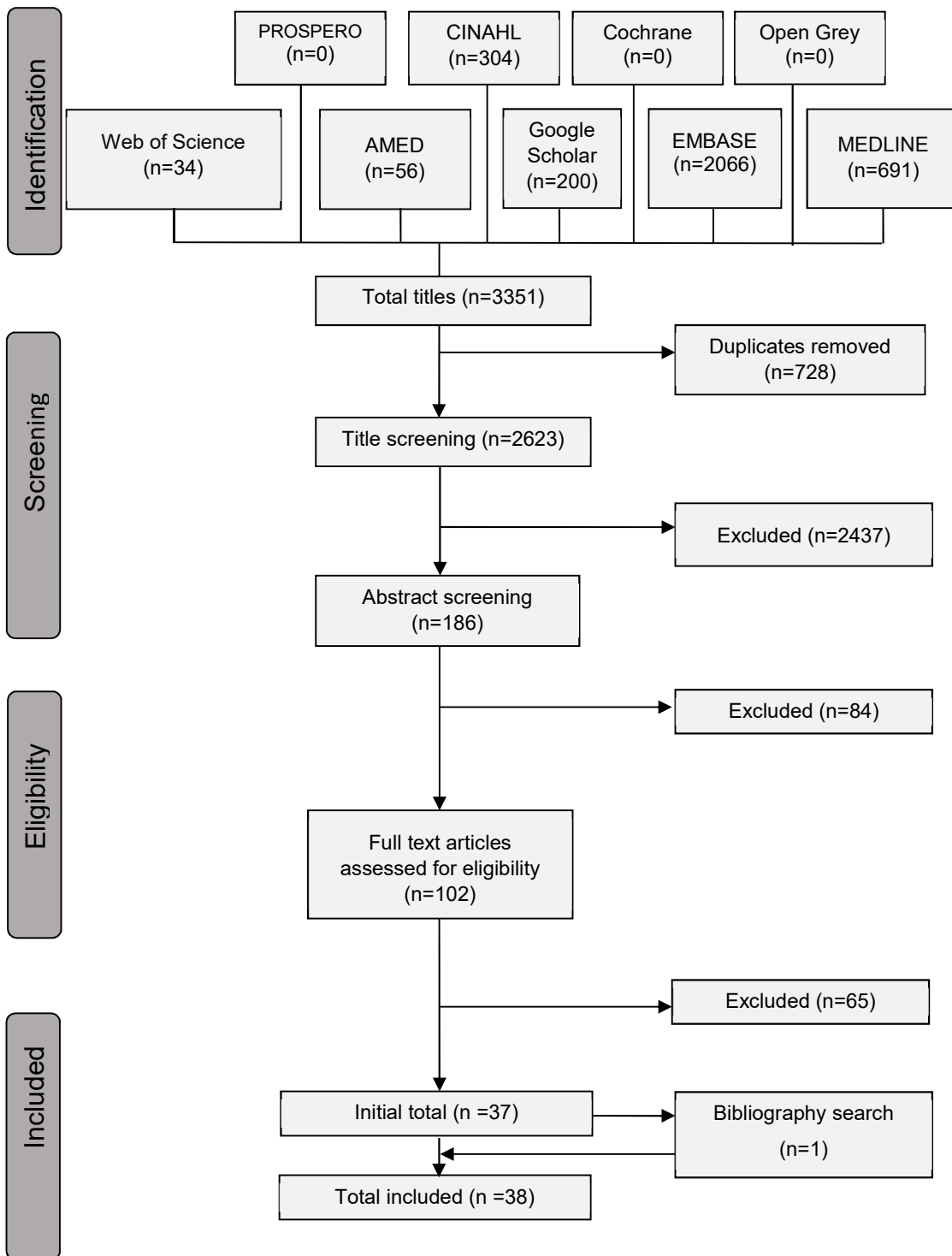


Figure 4.1: PRISMA flow diagram

4.4.1 Study characteristics

Included studies originated from 25 different countries. Participants were mostly recruited from diabetes clinics and healthcare centres (Table 4.1). Fifteen of the studies enrolled participants with either T1D or T2D, and 23 studies only included patients with T2D. Out of the included 38 studies, 37 were cross-sectional surveys, and one analysed data from another cohort study (Table 4.1).

Table 4.1: Study characteristics

Author and Year	Country of study	Focus of the study	Study settings and recruitment of participants	Study design	Data collection method	Study participants
Alami et al., 2015 ¹¹⁷	Morocco	Herbal supplements only	Mohammad VI university hospital ,Oujda	cross-sectional	Face-to-face interview using a Semi-structured questionnaire	T1D and T2D patients
Al-Eidi et al., 2016 ⁵⁰	Saudi	Any CAM type	Diabetic Centre of King Salman bin Abdul-Aziz Hospital, in Riyadh city	cross-sectional	Face-to-face interview using a structured questionnaire	T2D patients
Al-garni, Al-Raddadi & Al-Amri, 2017 ¹¹⁸	Saudi	Herbal supplements only	Jeddah Diabetic Centre	cross-sectional	Interviewer-administered semi-structured questionnaire	T2D patients
Ali-Shtayehet et al., 2012 ¹¹⁴	Palestine	Any CAM type	Patients attending outpatient departments at Governmental Hospitals in 7 towns in the Palestinian territories (Jenin, Nablus, Tulkarm, Qalqilia, Tubas, Ramalla, and Hebron)	cross-sectional	structured questionnaires	T1D and T2D patients
Amazeze et al., 2018 ¹¹⁹	Nigeria	Herbal supplements only	5 secondary health care facilities across Lagos State	cross-sectional	Interviewer-administered questionnaires	T2D patients
Andrews, Wyne, & Svenson, 2018 ¹²⁰	Guatemala	Any CAM type	Interview three groups in the San Lucas Tolimán area	cross-sectional	Semi-structured questionnaires	T2D patients Health promoters Traditional healers
Ashur et al., 2017 ¹²¹	Libya	Any CAM type	National Centre for Diabetes and Endocrinology in Tripoli	cross-sectional	self-administered structured questionnaire	T2D patients
Avci et al., 2018 ¹²²	Turkey	Any CAM type	Van Yuzuncu Yil University, Van	cross-sectional	Semi-structured questionnaires	T1D and T2Dpatients

Azizi-Fini, Adib-Hajbaghery & Gharehbohlou, 2016 ¹¹¹	Iran	Herbal supplements only	Golabchi and Naqavi diabetes clinics in the Kashan city	cross-sectional	Interviewer-administered structured questionnaires	T2D patients
Baharom, Shamsul & Rotina, 2016 ¹²³	Malaysia	Any CAM type	45 government health clinics across Nigeria Sembilan	cross-sectional	Interviewer-administered structured questionnaires	T2D patients
Bradley et al., 2011 ¹¹³	USA	Any CAM type	Patients with moderately to poorly controlled T2D who receive care from Group Health Cooperative, a large non-profit, integrated health care system in Washington State.	cross-sectional	Telephone-administered questionnaires.	T2D patients
Candar et al., 2018 ¹²⁴	Turkey	Any CAM type	Patients registered with the Bursa Yuksek Ihtisas Training and Research Hospital Education Family Health Centre	cross-sectional	questionnaires	T1D and T2D patients
Chao et al., 2014 ¹²⁵	USA	Any CAM type	Patients who received primary care at one of four publicly funded clinics in the Community Health Network of San Francisco	cross-sectional	Data collected for the Self-Management Automated and Real-Time Telephonic Support (SMART Steps) Study	T2D patients
Ching et al., 2013 ¹²⁶	Malaysia	Any CAM type	Primary health care clinic at Salak in Sepang	cross-sectional	Face-to-face interview using a structured questionnaire	T2D patients
Damnjanovic et al., 2015 ¹²⁷	Serbia	Herbal supplements only	6 Remedia Pharmacy Health Facilities in the territory of Nis	cross-sectional	structured questionnaires	T2D patients
Devi et al., 2015 ¹²⁸	India	Any CAM type	Diabetes Health camp conducted by VS micro lab, Madurai	cross-sectional	structured questionnaires	T2D patients
Fabian et al., 2011 ¹²⁹	Austria	Herbal supplements only	Diabetes Centre of the Division of Endocrinology and Metabolism,	cross-sectional	Face-to-face interview using a structured questionnaire	T1D and T2D patients

Department of Internal Medicine, Medical University of Graz						
Fan et al., 2013 ¹³⁰	Singapore	Any CAM type	Single centre study conducted in an outpatient diabetes Centre with an average load of 2500 patients a month	cross-sectional	Self-administered questionnaires.	T2D patients
Hashempur et al., 2015 ¹³¹	Iran	Any CAM type	Two outpatient diabetes clinics affiliated with the Shiraz University of Medical Sciences, Shiraz	cross-sectional	Face-to-face interview using semi-structured questionnaire	T1D and T2D patients
Kamel et al., 2017 ¹³²	Saudi	Herbal supplements only	King Abdul-Aziz University and King Fahad General Hospitals in Jeddah	cross-sectional	Interviewer-administered structured questionnaires	T1D and T2D patients
Karaman et al., 2018 ¹¹⁰	Turkey	Herbal supplements only	Endocrinology clinics of two hospitals in Izmir	cross-sectional	Face-to-face interview using a structured questionnaire	T1D and T2D patients
Khalaf & Whitford, 2010 ¹³³	Bahrain	Any CAM type	Patients attending two hospital diabetes clinics	cross-sectional	Questionnaires (administration not detailed)	T1D and T2D patients
Khalil et al., 2013 ¹³⁴	Egypt	Herbal supplements only	Outpatient clinics of Alexandria University Hospital, from seven health insurance centres, six MOH hospitals, and one private healthcare facility.	cross-sectional	Questionnaires (administration method not reported)	T2D patients
Koren et al., 2015 ¹³⁵	Israel	Herbal supplements only	Internal medicine department at Assaf Harofeh Medical Centre, Zerifin	cross-sectional	Interviewer-administered structured questionnaires	T2D patients
Lui et al., 2012 ¹³⁶	Australia	Any CAM type	Data reported here are taken from the Living with Diabetes Study, a five-year, prospective cohort study being conducted in the State of Queensland	Data from cohort study	Questionnaires (administration not detailed)	T1D and T2D patients

Lunyera et al., 2016 ¹³⁷	Tanzania	Herbal supplements only	Kilimanjaro Region of Tanzania	cross-sectional	Verbally administered structured questionnaire	T1D and T2D patients
Medagama et al., 2014 ¹³⁸	Sri Lanka	Herbal supplements only	Diabetes clinic at Teaching Hospital Peradeniya	cross-sectional	Face-to-face interview using a structured questionnaire	T2D patients
Mekuria et al., 2018 ¹³⁹	Ethiopia	Herbal supplements only	Diabetes care clinic of University of Gondar comprehensive specialized hospital	cross-sectional	Interviewer-administered questionnaires	T2D patients
Mohamed Ali, & Mahfouz, 2014 ¹⁴⁰	Sudan	Herbal supplements only	125 primary health care centres in Khartoum	cross-sectional	Interviewer-administered questionnaires	T2D patients
Naja et al., 2014 ¹⁴¹	Lebanon	Any CAM type	Patients recruited from two major referral centres in Beirut- a public hospital and a private academic medical Centre	cross-sectional	Face-to-face interview using a structured questionnaire	T2D patients
Nguyen et al., 2014 ¹⁴²	USA	Any CAM type	Patients recruited from seven primary care or endocrinology clinics affiliated with an academic medical centre in Southern California	cross-sectional	self-administered structured questionnaire	T2D patients
Putthapiban, Sukhumthammarat & Sriphrapadang, 2017 ¹⁴³	Thailand	Herbal supplements only	At the Endocrine Clinic in Ramathibodi Hospital, Bangkok	cross-sectional	Face-to-face interview using a structured questionnaire	T2D patients
Rhee, Westberg, & Harris, 2018 ¹⁴⁴	USA	Any CAM type	Non-institutionalized civilians in US	cross-sectional	Data were from the 2012 NHIS, which was administered by the National Centre for Health Statistics of the Centers for Disease Control and Prevention	T1D and T2D patients

Sethi, Srivastava & Madhu, 2011 ¹¹²	India	Any CAM type	Tertiary care Centre in Delhi	cross-sectional	Face-to-face interview using a Semi-structured questionnaire	T1D and T2D patients
Vishnu, Mini & Thankappan, 2017 ¹⁴⁵	India	Any CAM type	Rural Kollam district of the Indian state of Kerala (community based)	cross-sectional	Interviewer-administered structured questionnaires	T1D and T2D patients
Wanchai & Phrompayak, 2016 ¹⁴⁶	Thailand	Any CAM type	Four primary healthcare units and two secondary hospitals in the north of Thailand	cross-sectional	Semi-structured questionnaire	T2D patients
Wazaify et al., 2011 ¹¹⁵	Jordan	Herbal supplements only	Outpatient departments at The National Centre for Diabetes, Endocrine and Genetics.	cross-sectional	Face-to-face interview using a Semi-structured questionnaire	T1D and T2D patients
Yildirim & Marakoglu, 2018 ¹⁴⁷	Turkey	Any CAM type	Outpatient diabetes from Selçuk University Family Medicine Diabetes Education Clinic	cross-sectional	Face-to-face interview using a structured questionnaire	T2D patients

CAM: Complementary and Alternative Medicine

4.4.2 Types of CAM

Sixteen studies focused exclusively on herbal and nutritional supplement use by diabetic patients (Table 4.1). The remaining 22 studies discussed other CAM types. Fourteen of those 22 studies that investigated other CAM types also reported the use of herbal and nutritional supplements as a form of CAM.^{50, 112-114, 124, 126, 128, 130, 131, 133, 141, 144-146} A total of 35 different CAM types were reported in at least one study. The names of various CAM forms were reported exactly as they were mentioned in the included studies. CAM types used by diabetic patients and mentioned in the most studies were acupuncture (n=6 studies), Mind–body therapies (n=6 studies) religious and spiritual healing (n=5 studies) and homeopathy (n=4 studies) (Table 4.2).

Within the 31 studies which reported the use of herbal and nutritional supplements by diabetic patients, a total of 223 different herbal and nutritional supplements were reported (Supplementary Table S 4.3). The five herbs that were mentioned in the most studies were, Cinnamon (*Cinnamomum verum*) and Fenugreek (*Trigonella foenum-graecum*) each reported in 18 different studies, Garlic (*Allium sativum*) reported in 17 studies, Aloe Vera (*Aloe Vera*) reported in 14 studies and Black seed (*Nigella sativa*) reported in 12 studies.

Table 4.2: List of complementary and alternative medicine types as cited by included studies.

CAM forms (other than herbal supplements)	Studies cited the CAM form	CAM forms (other than herbal supplements)	Studies cited the CAM form
Acupuncture	50, 121, 128, 131, 142, 144	Ruqyah (recitation) with the Quran	50, 121
Mind–body therapies	124, 126, 128, 131, 133, 144	Ruqyah water or oil	50, 121
Religious and spiritual healing	121, 124, 141, 142, 146	Balneotherapy	124
Homeopathy	112, 128, 144, 145	Biofeedback	144
Meditation	113, 128, 144, 146	Chelation	144
Massage	50, 113, 130, 141	Chinese medicine	141
Ayurveda	128, 144, 145	Curandero	142
Chiropractic Massage	113, 142, 144	Daode Xinxi,	146
Energy therapies	126, 133, 144	Deep breathing exercises	113

Specific diet	50, 113, 128	Leech (Hirudotherapy)	124
Yoga	113, 128, 144	Music therapy	128
Al-hijama (wet cupping)	50, 121	Prayer by religion person (imam)	122
Biologically based therapies	128, 144	Progressive Muscle Relaxation	113
Cupping	124, 131	Qi gong	144
Folk medicine	113, 141	Sugar therapy	145
Honey	50, 114	Tai chi	144
Movement therapies	128, 144	Traditional healers	144
Naturopathy	142, 144		

CAM: Complementary and Alternative Medicine

4.4.3 Prevalence of CAM use

The highest prevalence of CAM (all types) use was reported at 89% by two studies, one each from India and Jordan followed by studies in Tanzania (78%), Sri Lanka (76%) and Iran (75%) (Table 4.3).^{112, 127, 131, 137, 138} The lowest prevalence of CAM use was 17% as reported by a study conducted in Jordan.¹¹⁵ A study in Australia reported a prevalence of 8%, but the study gathered data from patients about their visits to CAM practitioners only and did not include data on CAM use in general by diabetic patients¹³⁶. Other studies reporting the lowest prevalence of CAM use included studies in Libya (29%), Saudi Arabia (26%), USA (26%), Israel (23%) and Jordan (17%).^{115, 118, 121, 135, 144} Pooled prevalence of CAM use was 51% (95%CI 43%,59%). However, heterogeneity was very high ($I^2 = 99\%$) with the predictive interval ranging from 8% to 93%. (Figure 4.2)

Table 4.3: Included studies overall and subgroups prevalence of CAM use

Country	Study	Sample Size	Prevalence of CAM use	All Participants		Female			Male			T1D diabetes				T2D diabetes				Had diabetes for ≤5y				Had diabetes for >5y			
				users	non users	users	non users	%	users	non users	%	users	non users	%	users	non users	%	users	non users	%	users	non users	%	users	non users	%	
India	Sethi, Srivastava & Madhu, 2011	113	89.38%	101	12	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR			
Serbia	Damjanovic et al., 2015	519	88.82%	461	58	261	15	95%	200	43	82%	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR			
Tanzania	Lunyera et al., 2016	45	77.78%	35	10	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR			
Sri Lanka	Medagama et al., 2014	252	76.19%	192	60	139	28	83%	53	32	62%	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR			
Iran	Hashempur et al., 2015	239	75.31%	180	59	124	37	77%	56	22	72%	10	7	59%	170	52	77%	80	25	76%	100	34	75%				
Thailand	Wanchai & Phrompayak, 2016	508	70.87%	360	148	282	102	73%	78	46	63%	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR			
Nigeria	Amaeze et al., 2018	453	67.33%	305	148	98	45	69%	207	103	67%	NR	NR	NR	NR	NR	NR	96	66	59%	209	82	72%				
India	Devi et al., 2015	252	64.29%	162	90	98	41	71%	64	49	57%	NR	NR	NR	NR	NR	NR	55	40	58%	107	50	68%				
Saudi	Kamel et al., 2017	214	64.02%	137	77	84	44	66%	53	33	62%	50	20	71%	87	57	60%	NR	NR	NR	NR	NR	NR				

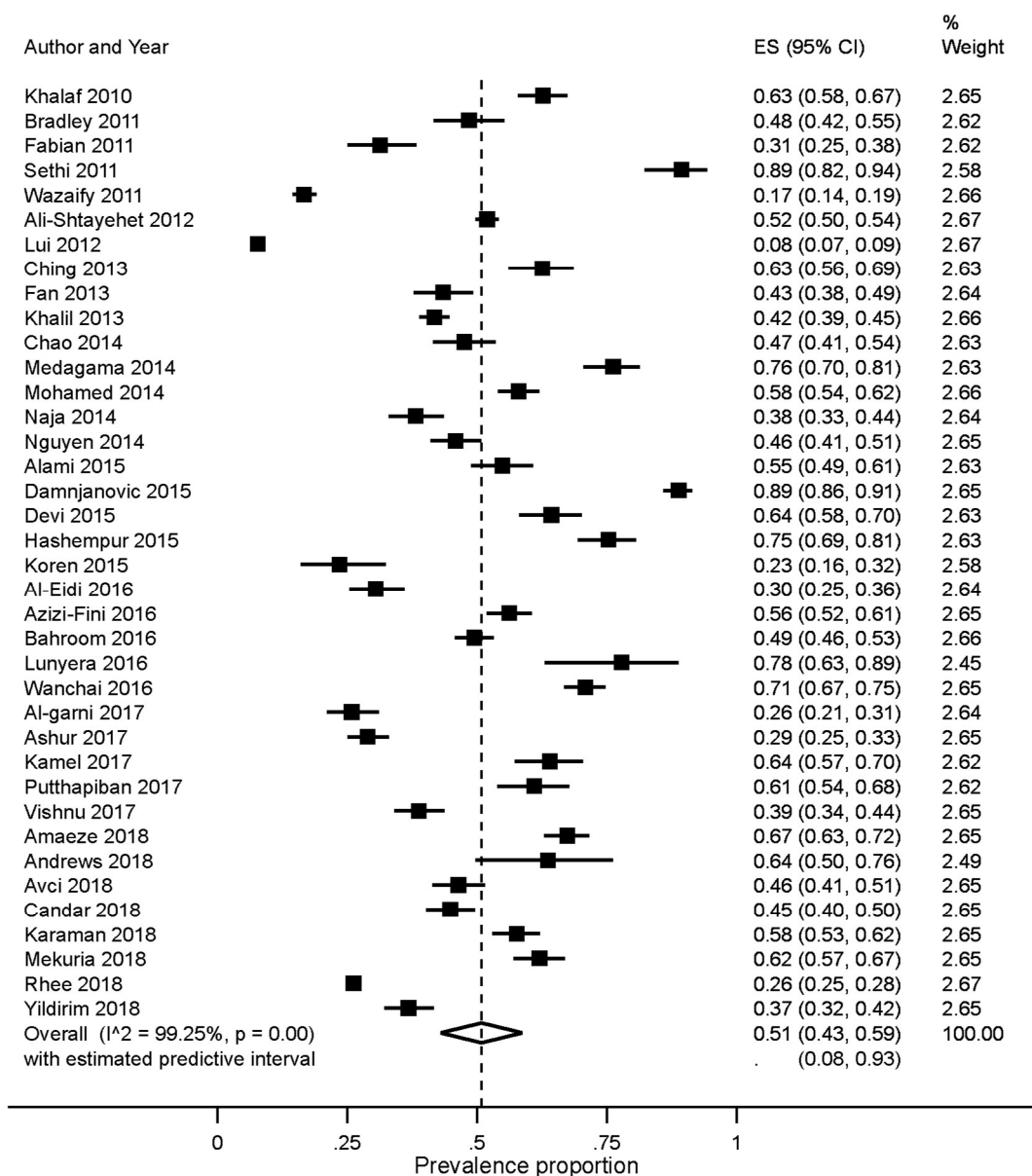
Guatemala	Andrews, Wyne, & Svenson, 2018	55	63.64%	35	20	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
Bahrain	Khalaf & Whitford, 2010	402	62.69%	252	150	149	69	68%	103	81	56%	NR	NR	NR	NR	NR	NR	48	51	48%	204	99	67%
Malaysia	Ching et al., 2013	240	62.50%	150	90	96	49	66%	54	41	57%	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
Ethiopia	Mekuria et al., 2018	387	62.02%	240	147	149	73	67%	91	74	55%	NR	NR	NR	NR	NR	NR	168	60	74%	72	87	45%
Thailand	Putthapiban et al., 2017	200	61.00%	122	78	76	42	64%	46	36	56%	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
Sudan	Mohamed Ali, & Mahfouz, 2014	600	58.00%	348	252	206	167	55%	142	85	63%	NR	NR	NR	NR	NR	NR	67	76	47%	281	176	61%
Turkey	Karaman et al., 2018	455	57.58%	262	193	225	148	60%	37	45	45%	53	49	52%	209	114	65%	51	62	45%	211	131	62%
Iran	Azizi-Fini et al., 2016	500	56.20%	281	219	203	153	57%	78	66	54%	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
Morocco	Alami et al., 2015	279	54.84%	153	126	117	83	59%	36	43	46%	36	43	46%	117	83	59%	NR	NR	NR	NR	NR	NR
Palestine	Ali-Shtayeh et al., 2012	1883	51.89%	977	906	519	470	52%	458	436	51%	114	84	58%	863	822	51%	341	325	51%	636	581	52%
Malaysia	Bahroom, Shamsul & Rotina, 2016	680	49.41%	336	344	224	175	56%	112	169	40%	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
USA	Bradley et al., 2011	219	48.40%	106	113	47	50	48%	59	63	48%	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR

USA	Chao et al., 2014	278	47.48%	132	146	101	38	73%	31	108	22%	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	
Turkey	Avci., 2018	386	46.37%	179	207	95	122	44%	84	85	50%	29	16	64%	150	191	44%	68	107	39%	111	100	53%
USA	Nguyen et al., 2014	410	45.85%	188	222	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	
Turkey	Candar et al., 2018	442	44.80%	198	244	137	134	51%	61	110	36%	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	
Singapore	Fan et al., 2013	304	43.42%	132	172	67	69	49%	65	103	39%	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	
Egypt	Khalil et al., 2013	1100	41.73%	459	641	252	359	41%	207	282	42%	NR	NR	NR	NR	NR	NR	87	202	30%	372	439	46%
India	Vishnu, Mini & Thankappan, 2017	400	38.75%	155	245	73	109	40%	82	136	38%	NR	NR	NR	NR	NR	NR	95	142	40%	60	103	37%
Lebanon	Naja et al., 2014	333	38.14%	127	206	51	98	34%	76	108	41%	NR	NR	NR	NR	NR	NR	34	77	31%	93	129	42%
Turkey	Yildirim & Marakoglu, 2018	400	36.75%	147	253	91	115	44%	56	138	29%	NR	NR	NR	NR	NR	NR	77	149	34%	70	104	40%
Austria	Fabian et al., 2011	198	31.31%	62	136	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
Saudi	Al-Eidi et al., 2016	302	30.46%	92	210	50	121	29%	42	89	32%	NR	NR	NR	NR	NR	NR	24	93	21%	68	117	37%
Libya	Ashur et al., 2017	523	28.87%	151	372	102	206	33%	49	166	23%	NR	NR	NR	NR	NR	NR	86	226	28%	65	146	31%
USA	Rhee, Westberg, & Harris, 2018	3386	26.17%	886	2500	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR

Saudi	Al-garni, Al-Raddadi & Al-Amri, 2017	310	25.81%	80	230	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
Israel	Koren et al., 2015	111	23.42%	26	85	12	37	24%	14	48	23%	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
Jordan	Wazaify et al., 2011	1000	16.60%	166	834	99	432	19%	67	402	14%	8	44	15%	158	790	17%	NR	NR	NR	NR	NR	NR
Australia	Lui et al., 2012	3337	7.73%	258	3079	157	1727	8%	101	1352	7%	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR

CAM: Complementary and Alternative Medicine; NR: Not reported

Figure 4.2 : Forest plot showing pooled prevalence of Complementary and Alternative Medicine in Diabetes.



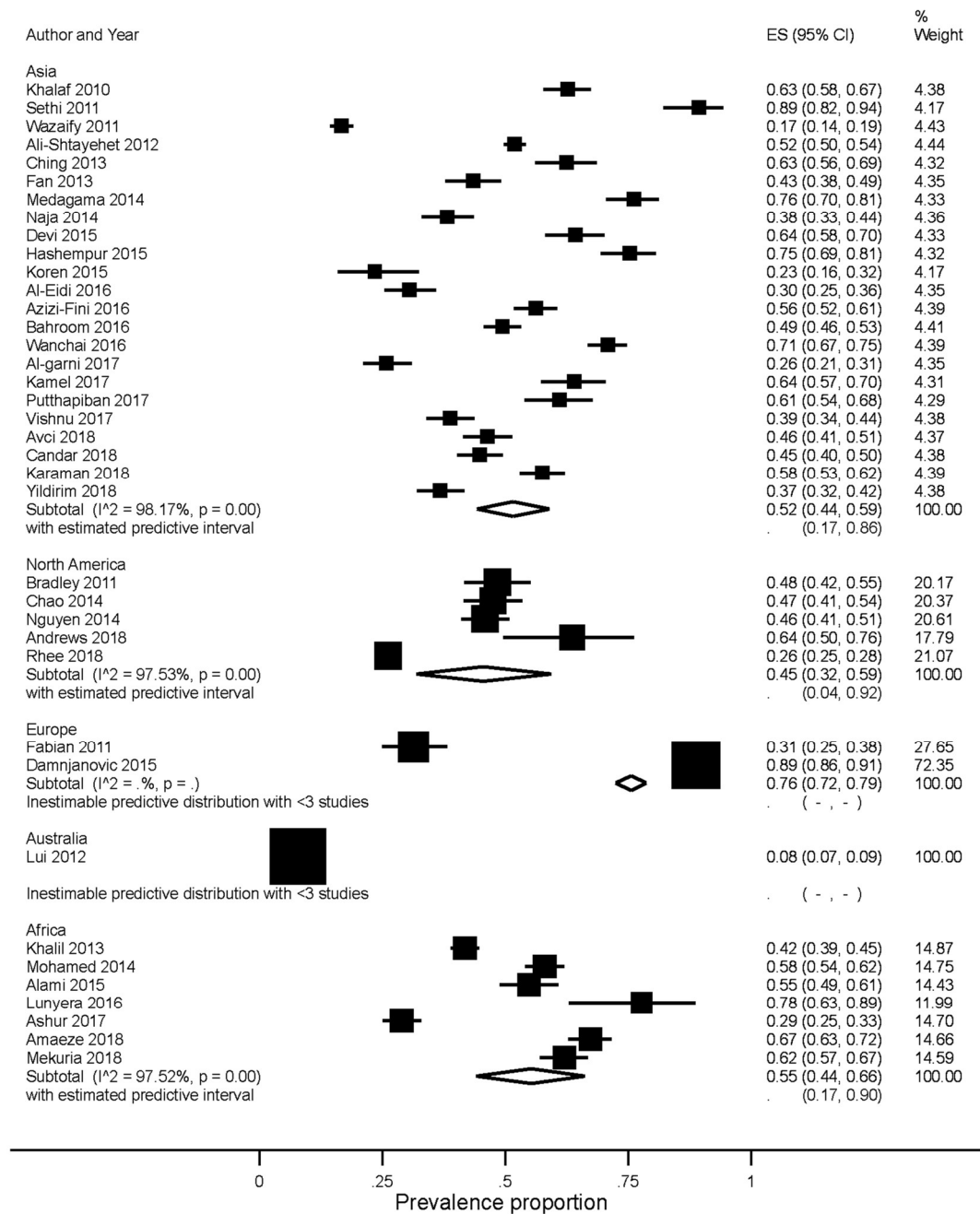
4.4.4 Subgroup analysis

Study level factors

Meta-analysis was conducted for results stratified at study level by continent. I^2 was 97.5% and predictive intervals were found to be wide. The highest prevalence rates of 76% were observed in Europe (PrI inestimable), followed by Africa 55%, (95%PrI 0.17,

0.90) from 7 studies. The lowest prevalence rates were observed in North America 45%, (95%PrI 0.04, 0.92) from 5 studies (Figure 4.3).

Figure 4.3: Meta-analysis of study level factors in relation to CAM use (prevalence proportion by continent)

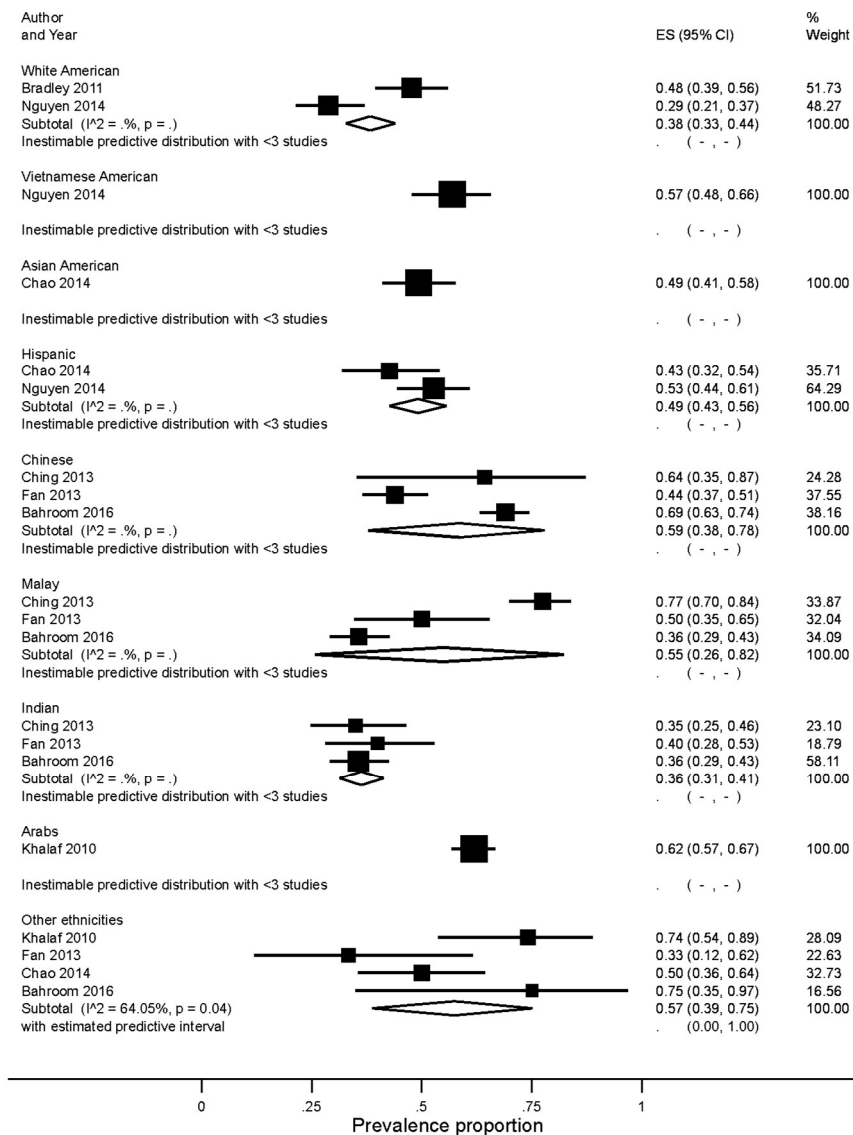


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Patient level factors

Subgroup analyses were conducted across ethnicity (reported in 8 studies), All meta-analyses at subgroup level also showed high levels of heterogeneity. Results were as follows: for the ethnicity subgroup, no predictive interval could be estimated other than PrI for the group of 'other ethnicities' prevalence ratio 0.57 (95%CI 0.39-0.75); the estimated predictive intervals ranged between (0.00-1.00, $I^2= 64.05\%$) (Figure 4.4).

Figure 4.4 : Ethnicity subgroup forest plot showing prevalence of CAM use



For analysis stratified by binary subgroups within-study comparative data were extractable for sex (31 studies), type of diabetes (7 studies), duration of diabetes (15 Studies) and presence or absence of diabetic complications (10 Studies). Within study pooled estimates PRs for patients with no diabetic complications versus patients with diabetic complications gave a prevalence ratio (PR) 0.81 (95%CI 0.66, 0.99), (95%PrI 0.39-1.67) ($I^2=89\%$) (Supplementary Figure S 4.1). For patients who had had diabetes for more than 5 years versus less than 5 years pooled PR was 1.71 (95%CI 1.04, 1.32), (95%PrI 0.73, 1.88) (I^2 of 83%) (Supplementary Figure S 4.2). For male versus female participants pooled PR was 0.86 (95%CI 0.81, 0.91), (95%PrI 0.64, 1.16) (I^2 of 72%) (Supplementary Figure S 4.3). Pooled PR for patients with T2D versus T1D patients was 1.00 (95%CI 0.83, 1.20), 95%(PrI 0.56, 1.77) ($I^2=75\%$) (Supplementary Figure S 4.4).

4.4.5 Additional outcomes

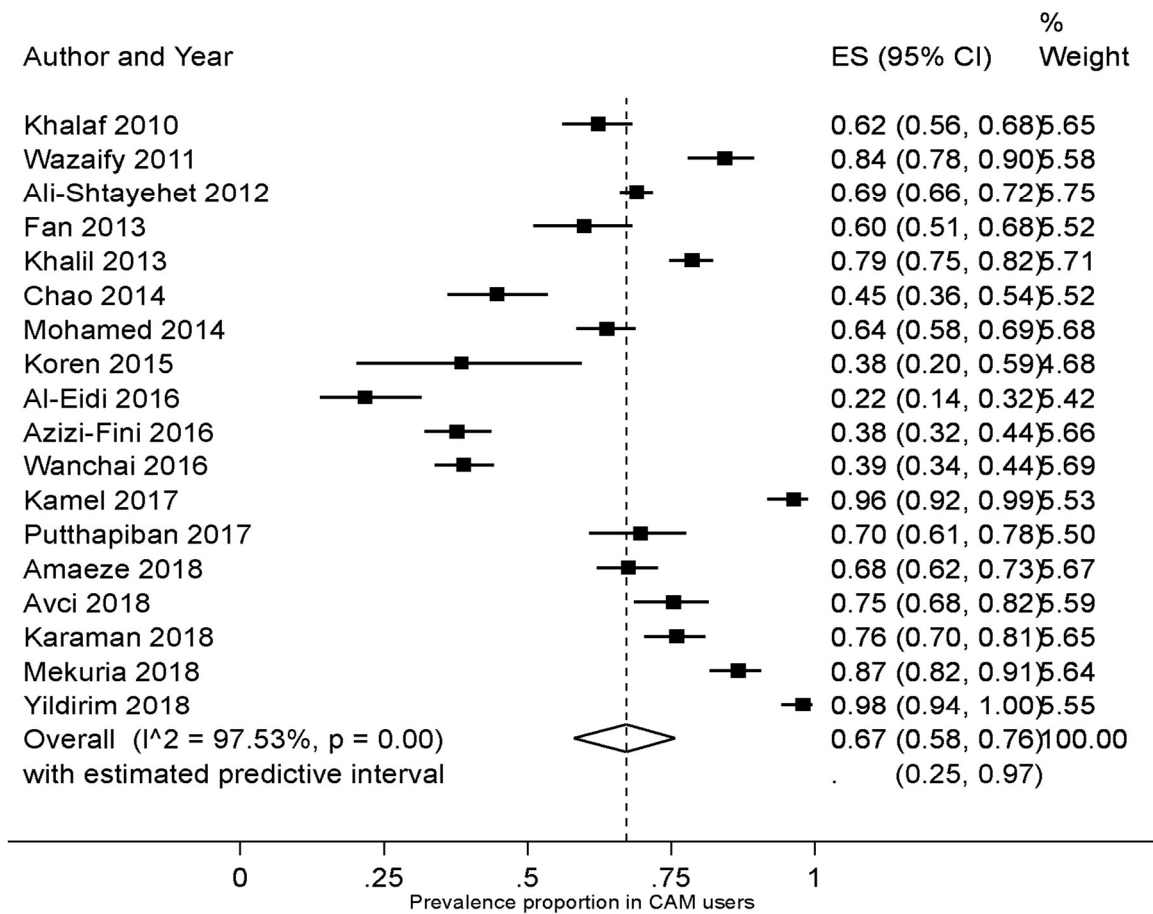
CAM as a complementary or alternative treatment

Eight of the 38 included studies assessed whether CAM was used as an additional treatment or as an alternative treatment to conventional medicines. Prevalence of CAM use as an additional treatment to prescribed medicine was 78% (95%CI 56%, 94%) with 95% PrI (4%, 1.00%) ($I^2=98\%$), and the percentage of patients who used CAM as an alternative to their prescribed medicine was 21% (95%CI 12%, 31%) with 95% PrI (0.%, 63%) ($I^2=89\%$) (Supplementary Figures S 4.5, S 4.6).

Patients' disclosure of CAM use to healthcare professionals:

The percentage of patients who do not disclose their CAM use to healthcare professionals was 67% (95%CI 58%, 76%) with 95% PrI (25%, 97%) ($I^2 = 98%$) (Figure 4.5).

Figure 4.5 : Patients who do not disclose the use of CAM to the healthcare professionals



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4.5 Discussion

This study provides up-to-date data on the global prevalence of CAM use by diabetic patients as reported in the peer reviewed research literature. The last literature review on diabetic patients' CAM use was published in 2007.³¹ which reviewed studies conducted in 9 countries and reported prevalence ranging from 17% to 73%. A similarly wide variation in prevalence rate of 8%-89% was observed in our updated review that included studies from 25 countries.

According to the included studies, CAM use is common among diabetic patients for the purpose of diabetes management. Most of the studies showed that the participants they recruited used CAM as an additional approach to conventional treatment, while in other studies, the reason for CAM use (additional or alternative) was not specified. Only seven studies reported that some diabetic patients used CAM as the sole means of managing their diabetes. Most of the included studies were conducted in healthcare settings. Therefore, patients who do not use conventional treatments for diabetes may not have been included. The prevalence of diabetic patients who use CAM in the general diabetic population is hence likely to be higher than the estimates provided by the included studies.

The meta-analysis of the prevalence data demonstrated extreme variation in prevalence of CAM use among diabetic patients across studies.

Strengths and limitations

This systematic review was a protocol driven review with a pre-specified aim, objectives and methodology. A range of relevant databases were used which covered the prevalence of CAM used by diabetic patients globally. Data collection methods

varied among studies. Some studies used structured questionnaires while other studies used semi-structured questionnaires. In addition there was a wide variation in the nature of the study settings. The content of the questionnaires used to collect the data on prevalence and nature of CAM are likely to influence patient response. Therefore the included studies may have underreported the nature and extent of CAM use by study participants. In addition, our study only included studies published in the English language.

Implications for practice and research

This systematic review shows that CAM use among diabetic patients is prevalent in many populations. This review suggests that healthcare professionals should consider diabetic patients' use of CAM when advising them about using their prescribed treatments and monitor their medication adherence while using any forms of CAM. They should also be aware of patients' use of herbal supplements as some forms of herbal medicine can lead to herb-drug interactions.¹⁴⁸ For example, the most frequently mentioned herbal supplement used by diabetic patient was cinnamon. It is reported that cinnamon has a potentiating effect on diabetic drugs increasing the risk of hypoglycaemia.⁴⁰ For example, cinnamon shows an inhibitory effect on the CYP3A4 enzyme in rabbits which potentiates the effect of pioglitazone if combined with cinnamon, leading to a hypoglycaemic effect.¹⁴⁹ Aloe vera, which was the most frequently reported CAM by the studies included in our review has been linked to potential interaction with 45 different drugs including diabetic drugs such as glimepiride¹⁵⁰ Concomitant use of Aloe vera and glimepiride can produce hypoglycaemic effects as Aloe vera has an inhibiting effect on ATP sensitive potassium channels in pancreatic β cells leading to additional release of insulin.¹⁵¹

Understanding patterns of CAM use and considering any possible interactions between them and other potential medications could help healthcare professionals to appropriately minimise drug related problems, or drug-herb interactions. It could help them to encourage their patient to discuss their CAM use and offer the opportunity to provide better advice for diabetic patients.

The observed prevalence of CAM, and the many varieties of CAM that are used by diabetic patients call for revision of diabetes management guidelines. The National Institute for Health and Care Excellence (NICE) guideline on management of diabetes does not explicitly advise healthcare professionals to discuss patient use of herbal medicines or CAM in their consultation.¹⁰⁸ Guidelines should enable healthcare professionals to counsel diabetic patients, their families, and carers, who should all be educated about the safe use of CAM in conjunction with prescribed medicines.

Due to the variable and often high prevalence of CAM use amongst diabetic patients across the world, research that generates evidence-based information about CAM is needed. This includes effectiveness and safety profiles of commonly used CAM including herbal medicines as identified in this systematic review.

This systematic review has identified that on average up to two third of patients who use CAM do not disclose this to their healthcare professionals. Use of CAM such as herbal medicines could be incorporated as part of comprehensive medication review services offered in community pharmacy and primary care.¹⁵²

Future studies need to consider the perspectives of diabetic patients who do not visit conventional healthcare facilities for the management of diabetes to provide a better

estimate of prevalence rates. In addition, there is a need to gather evidence on the factors that affect diabetic patients' use and non-use of CAM.

4.6 Conclusion

A wide variation in prevalence rate of CAM use in diabetes (8%-89%) was observed and pooled prevalence of CAM use was 51%. Our findings show that CAM use by diabetes patients is common. Healthcare professionals should be aware of their diabetic patients' use of CAM to ensure treatment optimization and medication adherence. Future studies should incorporate patient and healthcare professionals' perspectives of CAM use in diabetes, evaluate patient outcomes through the use of healthcare databases and carefully designed prospective studies; and identify opportunities to promote rational use of CAM through evidence-based guidelines and patient-centred approaches.

Summary of the chapter

This chapter provided an overview of the global prevalence of CAM use by diabetic patients. It also provided a list of CAM types used by diabetic patients. The high prevalence and the large number of CAM types provided an indication of the scope of CAM use amongst diabetic patients. The following chapter will discuss the factors associated with CAM use by diabetic patients.

CHAPTER 5: Factors affecting complementary and alternative medicine (CAM) use by adult diabetic patients: A systematic review using the theoretical domains framework (TDF).

Chapter overview: This chapter uses a systematic review to identify the factors associated with CAM use by diabetic patients. The Theoretical Domains Framework was applied to interpret the findings.

Citation: Alzahrani AS, Greenfield SM, Paudyal V. Factors affecting complementary and alternative medicine (CAM) use by adult diabetic patients: A systematic review using the theoretical domains framework (TDF). *Res Social Adm Pharm.* 2022;S1551-7411(22)00001-8. doi:10.1016/j.sapharm.2022.01.001

Authors' contributions

Abdulaziz Alzahrani designed and conducted all the stages of the study.

Vibhu Paudyal and Sheila Greenfield supervised Abdulaziz Alzahrani's PhD.

Abdulaziz Alzahrani led the drafting of the chapter to which all authors contributed through editing and revision.

All authors had access to the data sets and agreed to the final version of this chapter.

Ethics approval statement

Not applicable

Patient consent statement

Not applicable

5.1 Abstract

Background

It is estimated that approximately 50% of patients with diabetes use some form of complementary and alternative medicine (CAM) to manage their condition.

Objectives

The objective of this study was to undertake a systematic review to explore factors that influence the use of CAM by diabetic patients.

Methods

A systematic review of literature was conducted using Cochrane and PRISMA guidelines. Nine databases including MEDLINE and EMBASE were searched from 2010 to March 2021 using medical subject headings and natural language keywords. Data in relation to factors associated with use of CAM in diabetic patients 18 years of age and older were extracted and further categorised as per the theoretical domains framework (TDF).

Results

Forty-three studies from 28 countries were included. A total of 84 factors were identified. Key factors related to the 'intentions (to treat and relieve symptoms) and goals' domain of the TDF. Accessibility and affordability compared to physician visits and modern medicines (TDF- environmental context and resources), 'Social influences' from family members, friends, religious and spiritual scholars were amongst other factors reported to be important. Users also reported lack of trust in modern medicines and perceived CAM to be safer and free from adverse effects.

Conclusions

Decisions to use CAM in diabetes can be multifactorial. Healthcare professionals' awareness of diabetic patients' CAM use and associated factors can inform effective counselling and communication practices to promote optimisation and adherence to prescribed treatments, and patient safety through avoidance of drug-CAM interactions. Alleviating patients' concerns, fears and reluctance to use prescribed treatments are imperative to achieve therapeutic goals. Improving access and affordability is imperative where high costs of prescribed treatments prevent their use leading patients to resort to CAM as a standalone therapy.

5.2 Background

Current evidence-based recommendations for the management of diabetes include prescribed medicines including oral hypoglycaemic agents such as metformin and pioglitazone as well as insulin therapy. When used in appropriate patients following individual tailored made treatment these medicines are beneficial for controlling blood glucose levels and preventing future complications.¹⁵ In addition to these recommendations, patients often use additional self-care measures which include the use of complementary and alternative medicines (CAM).³¹ The World Health Organization (WHO) defines CAM as a "broad set of health care practices that are not part of that country's own tradition or conventional medicine and are not fully integrated into the dominant health-care system".³⁸ A recent systematic review showed that up to 51% of diabetic patients worldwide use CAM either in conjunction with or as a replacement for orthodox treatments.¹⁵³

The evidence base in relation to the effectiveness of CAM in diabetes is limited. Herbal and Dietary Supplements (HDS) such as fenugreek and ginseng have been identified to decrease carbohydrate absorption and increased insulin secretion and to lower blood glucose levels by acting similarly to insulin or by altering hepatic glucose metabolism respectively.¹⁵⁴ CAM also includes the application of non-HDS products and practices such as Yoga, Homeopathy, Acupuncture and Ayurveda. Yoga has been shown to improve glycaemic control in adults with type 2 diabetes mellitus.¹⁵⁵ However, currently there is a lack of research in relation to effectiveness and safety (particularly in relation to drug-CAM and CAM-disease interactions) of over 35 CAM types reported to be used by diabetic patients.¹⁵³

It is important for healthcare professionals to be familiar with the factors that influence diabetic patients to use CAM in order to understand patient perspectives on its use.

This will enable healthcare professionals to better advise patients, support adherence to their prescribed medicines and identify the risks of interactions and adverse effects with prescribed treatments. Current international guidelines around diabetes management do not explicitly recommend that healthcare professionals should discuss CAM use with patients.^{15, 156} Consideration of wider self-care measures in clinical consultations allows shared decision making, promotes patient involvement as partners in their care and avoids adverse outcomes from the treatments.¹⁵⁶

The Theoretical Domains Framework (TDF) is an integrative framework that was developed for the purpose of implementing new practices that requires changes in the behaviour of the parties involved. Currently, there is a lack of theory based research that aims to identify factors related to CAM use by diabetic patients. Theoretical perspectives are important for identifying determinants of a behaviour and developing effective behaviour change interventions. The TDF has been previously used in systematic reviews to synthesise data from primary research to apply theoretical perspectives into understanding factors associated with a particular behaviour. For example, in a recent systematic review, authors used TDF to understand the constructs that influence referral of people with chronic obstructive pulmonary disease (COPD) to pulmonary rehabilitation.¹⁵⁷ In another recent review, TDF was used to identify the barriers and enablers for a triage, treatment, and transfer of clinical intervention to manage acute stroke patients in the emergency department.¹⁵⁸

A previous systematic review and meta-analysis of CAM use in diabetes suggested that up to 67% of patients do not disclose their CAM use to healthcare professionals.¹⁵³ Healthcare professionals' awareness of diabetic patients' CAM use and associated factors can inform effective counselling and communication practices during clinical consultations. For example, addressing patient fears, concerns about prescribed

treatments can be important factors in regards to patient use of CAM and can enable promotion of treatment optimisation and adherence to prescribed treatments, and patient safety through avoidance of any drug-CAM interactions. The aim of this systematic review was to identify factors reported in the published literature in regards to CAM use by diabetic patients using the TDF.

5.3 Method

This systematic review was informed by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines and checklist.⁵⁸ A protocol was developed as per the PRISMA protocol guideline (protocol ID CRD42019125036).

5.3.1 Data Sources and Searches

Cochrane Library, MEDLINE, Embase, CINAHL, AMED, Web of Science, and Google Scholar databases were searched from the year 2010 to March 2021. Open Grey was searched for grey literature. Search terms are listed in Supplementary Table S 5.1. The review was restricted to studies published in English.

5.3.2 Study Selection

5.3.2.1 Inclusion criteria

- Studies that addressed the factors that influenced diabetic patients to use CAM.
- Studies that recruited patients 18 years or older.
- Studies that were conducted between 2010 to 2021.

5.3.2.2 Exclusion criteria

- Studies discussing the effectiveness of one or more CAM types as an intervention.
- Studies that were conducted before the year 2010.

5.3.2.3 Screening and selection

Screening and selection was performed independently by two review authors (AA, VP) and was carried out in three phases. Titles and abstracts were screened for inclusion of possible relevant studies followed by assessment of full texts for eligibility. Reference lists of included studies were screened. If a title was considered relevant; the study was manually searched and the abstract examined.

Studies which included data on factors that influence CAM usage by adult diabetic patients 18 years of age and older were included. The review included studies that discussed partially or exclusively the factors that influence diabetic patients to use CAM. We included studies conducted with patients as well as healthcare professionals. In the latter case, factors associated with patient use of CAM from healthcare professionals' perspectives were included. All study designs were considered for inclusion.

5.3.3 Data Extraction and Quality Assessment

Data on study characteristics, influencing factors for CAM use as well as types of CAM used by diabetic patients were extracted. Two review authors (AA, VP) independently assessed the quality of included studies using the critical appraisal tool from the Joanna Briggs Institute (JBI) checklist.⁶² The quality assessment for included studies was focused on three fields: clarity of participants' inclusion criteria, study setting and sampling, appropriateness of data collection and analysis methods. Included studies were judged to be of 'high quality' if quality criteria were satisfied by at least 7 items, 'moderate quality' for scores of 3-6 and 'low quality' for scores ≤ 2 .⁶⁵ All studies were included regardless of their quality (Supplementary Table S 5.2).

5.3.4 Data Synthesis and Analysis

The factors deemed to be relevant to participants' use of CAM in diabetes were extracted from the included studies as reported by the study authors and listed. These factors could relate to those that positively or negatively influence a diabetic patients' use of CAM. Each of the extracted factors were then classified according to the Theoretical Domain Framework (TDF) into one of its 14 domains. TDF was developed through a collaboration of behavioural scientists and new health practices implementation researchers identified theories related to behaviours and includes 14 domains related to goals, intentions, social and environmental influences on behaviour.¹⁰¹ The use of the TDF can help to restructure and simplify data concerning a certain behaviour into a set of theoretical domains which would make it more useful for further applications. In order to achieve this, information relating to a specific behavioural determinant is categorised into any relevant domain(s) of TDF. Descriptions of TDF domains are provided in (Supplementary Table S 5.3).

5.4 Results

A total of 3554 unique titles were screened of which 43 articles met the inclusion criteria (figure 5.1).^{50, 110-115, 117, 119, 120, 122, 123, 126-134, 137, 139-147, 159-170} Table 5.1 shows that included studies were conducted between 2010 and March 2021 and originated from 28 different countries. Participants were mostly recruited from healthcare centres. Eighteen of the included studies enrolled participants either with type 1 diabetes (T1D) or type 2 diabetes (T2D) and twenty-four studies included only patients with T2D, one also included traditional healers, and another study also enrolled doctors (Table 5.2).^{120, 161} One of the included studies enrolled only healthcare professionals. Out of the 43 studies included, 40 were cross-sectional surveys (39 on diabetic patients and

1 on healthcare professionals) and two studies were qualitative interviews, one used mixed methods and one analysed data from a cohort study. Studies utilising a survey design mainly aimed to identify the prevalence of use and factors associated with use reported as secondary outcomes. Questionnaire administration methods for cross-sectional studies varied between self-administration, interviewer assisted administration and telephone administration (Table 5.1).

Figure: 5.1: PRISMA flow diagram

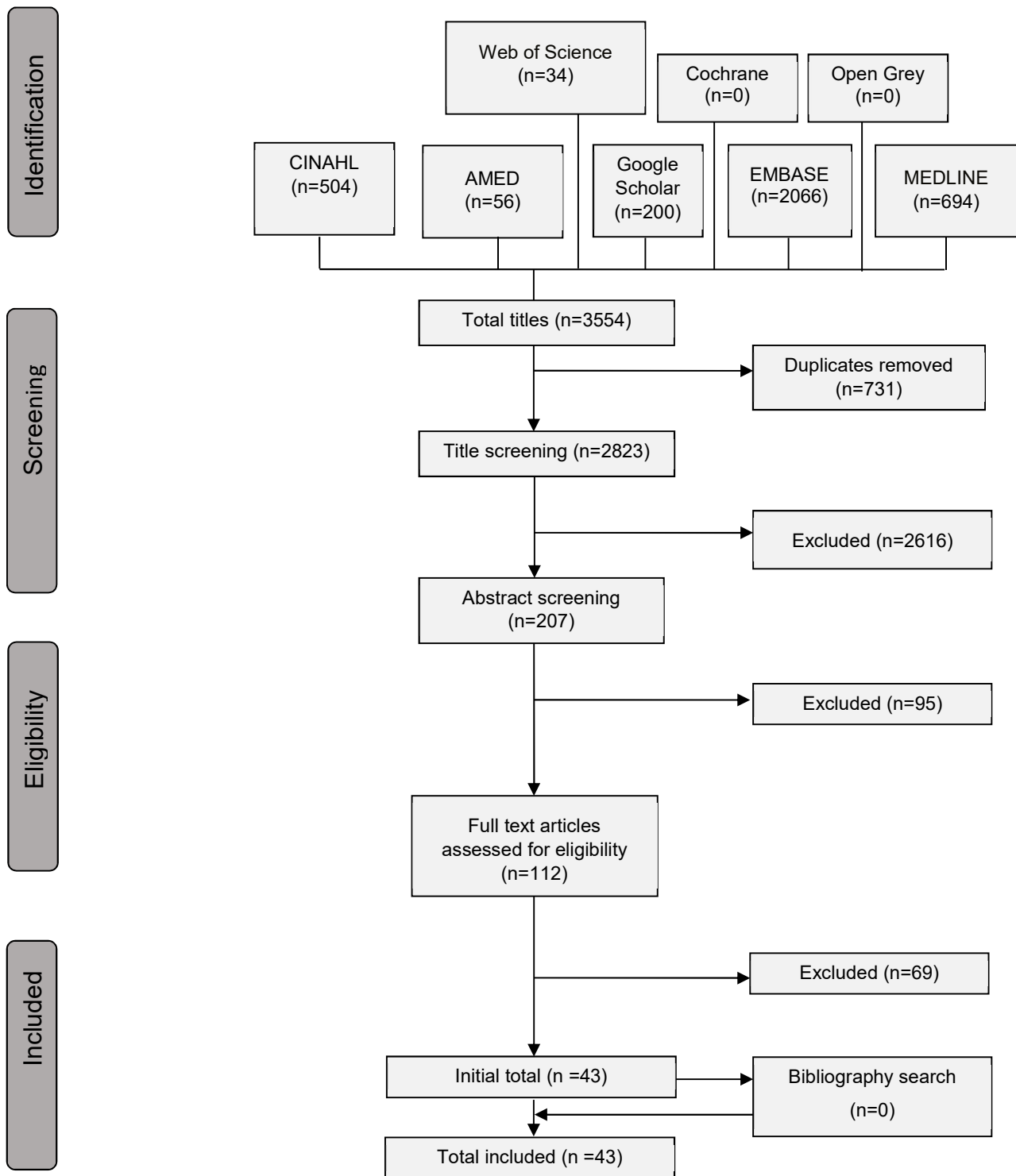


Table 5.2: Study characteristics.

Author and date	Country of study	Aim of the study	Research focus of the study	Study settings and recruitment of participants	Study design	Data collection method	Study participants
Yildirim & Marakoglu, 2018 ¹⁴⁷	Turkey	Prevalence of CAM use	CAM use	Outpatient diabetes education clinic in Turkey	cross-sectional	Face-to-face interview using a structured questionnaire	T2D patients
Rhee, Westberg, & Harris, 2018 ¹⁴⁴	USA	Prevalence of CAM use	CAM use	Data were from the 2012 NHIS, which was administrated by the National Centre for Health Statistics of the Centres for Disease Control and Prevention	cross-sectional	Data were from the 2012 NHIS, which was administrated by the National Centre for Health Statistics of the Centres for Disease Control and Prevention	T1D and T2D patients
Mekuria et al., 2018 ¹³⁹	Ethiopia	Prevalence of Herbal supplements use	Herbal supplements use	Diabetes care clinic Gondar town, north-western Ethiopia	cross-sectional	Interviewer-administered questionnaires	T1D and T2D patients
Karaman et al., 2018 ¹¹⁰	Turkey	Prevalence of Herbal supplements use	Herbal supplements use	Endocrinology clinics of two hospitals in Izmir	cross-sectional	Face-to-face interview using a structured questionnaire	T1D and T2D patients
Bukhsh et al., 2018 ¹⁶³	Pakistan	Patients' perspectives towards CAM	Trends in CAM use	Akhuwat Diabetes Clinic Lahore and Awan Medical Complex Lahore	qualitative	Semi-structured one to one in-depth interviews	T2D patients

Avci., 2018 ¹²²	Turkey	Prevalence of CAM use	CAM use	Van Yuzuncu Yil University, Van	cross-sectional	Semi-structured questionnaires	T1D and T2D patients
Andrews, Wyne, & Svenson, 2018 ¹²⁰	Guatemala	Prevalence of CAM use	CAM use	interview three groups in the San Lucas Tolimán area: people with diabetes, health promoters, and traditional healers/naturalists	cross-sectional	Semi-structured questionnaires	T2D patients Health promoters Traditional healers
Amaeze et al., 2018 ¹¹⁹	Nigeria	Prevalence of Herbal supplements use	Herbal supplements use	5 secondary health care facilities across Lagos State	cross-sectional	Interviewer-administered questionnaires	T2D patients
Mohamed Ali, & Mahfouz, 2014 ¹⁴⁰	Sudan	Prevalence of Herbal supplements use	Herbal supplements use	Primary health care centres in Khartoum. The total number of PHCCs is 125. The number of patients in daily attendance at each of those centres is approximately equal. Most of the patients attended for primary health care on an appointment basis	cross-sectional	Interviewer-administered questionnaires	T2D patients
Vishnu, Mini & Thankappan, 2017 ¹⁴⁵	India	Prevalence of CAM use	CAM use	Rural Kollam district of the Indian state of Kerala (community based)	cross-sectional	Interviewer-administered structured questionnaires	T1D and T2D patients
Putthapiban, Sukhumthammarat & Sriphrapadang, 2017 ¹⁴³	Thailand	Prevalence of Herbal supplements use	Herbal supplements use	At the Endocrine Clinic in Ramathibodi Hospital, Bangkok	cross-sectional	Face-to-face interview using a structured questionnaire	T2D patients

Porqueddu, 2017 ¹⁶⁰	United Kingdom	Use of herbal supplements	Use of herbal supplements for diabetes control	Ethnographic study conducted among Indian and Pakistani migrants living in Edinburgh.	qualitative	Unstructured interviews	T2D patients
Kamel et al., 2017 ¹³²	Saudi	Prevalence of Herbal supplements use	Herbal supplements use	King Abdul-Aziz University and King Fahad General Hospitals in Jeddah	cross-sectional	Interviewer-administered structured questionnaires	T1D and T2D patients
Atwine & Hjelm, 2017 ¹⁶¹	Uganda	Professionals' perspective	Healthcare professionals' knowledge, attitudes and practice the use of CAM among persons with diabetes	Healthcare providers working with management of diabetes in a certain region of south-western Uganda, including rural and urban areas	cross-sectional	Self-administered structured questionnaire	Healthcare professionals
Wanchai & Phrompayak, 2016 ¹⁴⁶	Thailand	Prevalence of CAM use	CAM use	Four primary healthcare units and two secondary hospitals in the north of Thailand	cross-sectional	Semi-structured questionnaire	T2D patients
Lunyera et al., 2016 ¹³⁷	Tanzania	Prevalence of Herbal supplements use	Herbal supplements use	Kilimanjaro Region of Tanzania	cross-sectional	Verbally administered structured questionnaire	T1D and T2D patients
Bahroom, Shamsul & Rotina, 2016 ¹²³	Malaysia	Prevalence of CAM use	CAM use	45 government health clinics across Negeri Sembilan	cross-sectional	Interviewer-administered structured questionnaires	T2D patients
Azizi-Fini, Adib-Hajbaghery & Gharehbohlou, 2016 ¹¹¹	Iran	Prevalence of Herbal supplements use	Herbal supplements use	Golabchi and Naqavi diabetes clinics in the Kashan city	cross-sectional	Interviewer-administered structured questionnaires	T2D patients

Al-Eidi et al., 2016 ⁵⁰	Saudi	Prevalence of CAM use	CAM use	Diabetic Centre of King Salman bin Abdul-Aziz Hospital, in Riyadh city	cross-sectional	Face-to-face interview using a structured questionnaire	T2D patients
Koren et al., 2015 ¹⁶⁸	Israel	Prevalence of Herbal supplements use	Herbal supplements use	Internal medicine department at Assaf Harofeh Medical Centre, Zerifin	cross-sectional	Interviewer-administered structured questionnaires	T2D patients
Hashempur et al., 2015 ¹³¹	Iran	Prevalence of CAM use	CAM use	Two outpatient diabetes clinics affiliated with the Shiraz University of Medical Sciences, Shiraz	cross-sectional	Face-to-face interview using semi-structured questionnaire	T1D and T2D patients
Devi et al., 2015 ¹²⁸	India	Prevalence of CAM use	CAM use	Diabetes Health camp conducted by VS micro lab, Madurai	cross-sectional	Structured questionnaires	T2D patients
Damnjanovic et al., 2015 ¹²⁷	Serbia	Prevalence of Herbal supplements use	Herbal supplements use	6 Remedia Pharmacy Health Facilities in the territory of Nis	cross-sectional	Structured questionnaires	T2D patients
Alami et al., 2015 ¹¹⁷	Morocco	Prevalence of Herbal supplements use	Herbal supplements use	Mohammad VI university hospital ,Oujda	cross-sectional	Face-to-face interview using a Semi-structured questionnaire	T1D and T2D patients
Nguyen et al., 2014 ¹⁴²	USA	Prevalence of CAM use	CAM use	Patients were recruited from seven primary care or endocrinology clinics affiliated with an academic medical centre in Southern California	cross-sectional	Self-administered structured questionnaire	T2D patients
Naja et al., 2014 ¹⁴¹	Lebanon	Prevalence of CAM use	CAM use	Ppatients recruited from two major referral centres in Beirut- a public hospital and a	cross-sectional	Face-to-face interview using a structured questionnaire	T2D patients

				private academic medical centre			
Khalil et al., 2013 ¹³⁴	Egypt	Prevalence of Herbal supplements use	Herbal supplements use	Outpatient clinics of Alexandria University Hospital, from seven health insurance centres, six hospitals, and one private healthcare facility.	cross-sectional	Questionnaires (administration method not reported)	T2D patients
Fan et al., 2013 ¹³⁰	Singapore	Prevalence and Factors for CAM use	CAM use	Single centre study conducted in an outpatient diabetes Centre in Singapore with an average load of 2500 patients a month	cross-sectional	Self-administered questionnaires.	T2D patients
Ching et al., 2013 ¹²⁶	Malaysia	Prevalence of CAM use	CAM use	primary health care clinic at Salak in Sepang	cross-sectional	Face-to-face interview using a structured questionnaire	T2D patients
Lui et al., 2012 ¹⁶⁵	Australia	Prevalence of CAM practitioner use	CAM practitioner use	Data reported here are taken from the Living with Diabetes Study (LWDS), a five-year, prospective cohort study being conducted in the State of Queensland	data from cohort study	Questionnaires	T1D and T2D patients
Ali-Shtayeh et al., 2012 ¹¹⁴	Palestine	Prevalence of CAM use	CAM use	Patients attending outpatient departments at Governmental Hospitals in 7 towns in the Palestinian territories (Jenin, Nablus, Tulkarm, Qalqilia, Tubas, Ramalla, and Hebron)	cross-sectional	Structured questionnaires	T1D and T2D patients

Wazaify et al., 2011 ¹¹⁵	Jordan	Prevalence of Herbal supplements use	Herbal supplements use	Outpatient departments at The National Centre for Diabetes, Endocrine and Genetics a specialized centre in Jordan to which most DM cases are referred.	cross-sectional	Face-to-face interview using a Semi-structured questionnaire	T1D and T2D patients
Sethi, Srivastava & Madhu, 2011 ¹¹²	India	Prevalence of CAM use	CAM use	Tertiary care centre in Delhi	cross-sectional	Face-to-face interview using a Semi-structured questionnaire	T1D and T2D patients
Fabian et al., 2011 ¹²⁹	Austria	Prevalence of Herbal supplements use	Herbal supplements use	Diabetes Centre of the Division of Endocrinology and Metabolism, Department of Internal Medicine, Medical University of Graz	cross-sectional	Face-to-face interview using a structured questionnaire	T1D and T2D patients
Bradley et al., 2011 ¹¹³	USA	Prevalence of CAM use	CAM use	Patients with moderately to poorly controlled type 2 diabetes who receive care from Group Health Cooperative , a large non-profit, integrated health care system in Washington State.	cross-sectional	Telephone-administered questionnaires.	T2D patients
Khalaf & Whitford, 2010 ¹³³	Bahrain	Prevalence of CAM use	CAM use	Patients attending two hospital diabetes clinics	cross-sectional	Questionnaires	T1D and T2D patients

Alqathama et al., 2020 ¹⁶⁶	Saudi	Prevalence of herbal supplements use	knowledge and beliefs about herbal use	13 medical centres in Makkah	cross-sectional	Structured questionnaire	T2D patients and doctors
Cengiz & Budak, 2019 ¹⁶⁷	Turkey	Prevalence of CAM use	CAM use	Patients hospitalized at endocrine clinics in university hospital in eastern region.	cross-sectional	Face-to-face interview using a structured questionnaire	T1D and T2D patients
Kasole & Kimiywe, 2019 ¹⁶⁹	Tanzania	Patients' and herbalists' practices and perspectives	CAM use	Kilimanjaro Christian Medical Centre in Kilimanjaro, and Mount Meru Hospital in Arusha	cross-sectional	Mixed-methods design which included a quantitative and a qualitative component	T1D and T2D patients and local herbalists
Meshesha, Gebretekle, & Fenta, 2020 ¹⁷⁰	Ethiopia	Prevalence of herbal supplements use	Knowledge and beliefs about herbal use	Health facility-based in Addis Ababa	cross-sectional and qualitative	Mixed-methods design which included a quantitative and a qualitative component	T1D and T2D patients
Owusu et al., 2020 ¹⁶⁴	Jamaica	Prevalence of CAM use	CAM use	Seven chronic disease clinics in western region	cross-sectional	Investigator-administered questionnaire	T2D patients
Radwan et al., 2020 ¹⁵⁹	United Arab Emirates	Prevalence of CAM use	CAM use	Outpatient clinics in the two governmental hospitals in Dubai and Sharjah	cross-sectional	Face-to-face interviews	T2D patients

Raja et al., 2019 162	Pakistan	Knowledge and attitude toward CAM	CAM use	Institute of diabetology in a tertiary care hospital	cross-sectional	Face-to-face interviews	T2D patients
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The two qualitative studies included in the review used in-depth interviews with patients.^{160, 163} One study was conducted in Akhuwat Diabetes Clinic Lahore and Awan Medical Complex Lahore Pakistan¹⁶³. The participants were interviewed using semi-structured and open-ended interviews. The study was focused on spiritual practices and homeopathic, herbal and home remedies for diabetes management, side effects and poor control. The second qualitative study was conducted in Edinburgh, United Kingdom.¹⁶⁰ It consisted of an ethnographic study conducted among Indian and Pakistani migrants living in Edinburgh. The study was conducted using unstructured interviews and was focused on the use of CAM for diabetes control.

Only one study investigated the perspectives of healthcare professionals regarding their patients' use of CAM. This study was conducted in Uganda and was qualitative in design, in addition to another study that enrolled both T2D patients and physicians, and this study was cross-sectional in design.^{161, 166} One of the studies that enrolled patients with both T1D and T2D also enrolled local herbalists and another study enrolled health promoters and traditional healers in addition to T2D patients, both were cross-sectional studies.^{120, 169}

5.5 Factors affecting the use of CAM among diabetic patients

A total of 84 factors in relation to patient use of CAM were identified and extracted from the included studies. Domains were arranged in descending order based on the number of studies which reported factors associated with each domain (Table 5.2).

Table 5.3: Factors for using CAM distributed to the TDF domains

TDF domains and descriptions	Factors	Studies citing the domain
1. Knowledge	CAM user’s knowledge about CAM benefits including the effect on blood glucose	147, 159
	Patients’ unfamiliarity with interaction between conventional medicine and herbs	132, 143
	Herbal medicine use is popular because of the existence of various natural flora for which patients are aware of its uses	139
2. Skills	Health promoters learned the most popular plants used from working with people with diabetes	120
3. Social/ Professional Role and Identity	There is a relationship between occupation and CAM use, unemployed and housewives are more likely to use CAM followed by farmers, retired and lastly officers	146
	Patients’ belief that herbal products are natural	160
4. Beliefs about Capabilities	Patients tried several treatments by weighing out effectiveness with side effects, as they belief that they are capable to find the best treatment	160
	Patients thought that they are able to improve the control of blood glucose levels	113
5. Optimism	Patients’ belief in benefits of CAM including that CAM can treat diabetes, help the diabetes control and slow diabetes progression	114, 130, 132, 139, 147, 162
	Patients’ belief CAM can cures all kinds of illnesses including diabetes	112, 115, 119, 141, 161
	Patients’ belief CAM cure the cause of diabetes not like conventional treatments that focused on ‘manifestations and symptoms’	160
	Patients’ belief in God and use prayers for good health	163
	Patients rejected first treatment and used CAM instead	160
6. Beliefs about Consequences	Patient lack of knowledge about long-term consequence of diabetes	120
	Herbal medicines perceived safe because they are natural	119, 164
	Patients’ belief conventional treatment was not effective and are harmful	145
	Patients perceived threat of their illness	50, 128, 161
	Patient’s belief that CAM is more effective than conventional medicines	50, 123, 134, 137, 141, 145,
		164
	Patients’ belief that they have obtained the wanted result from CAM	132, 133, 165, 166
	Patients aware of the importance of self-care	114
High motivation to self-care including CAM use	129	
Patients’ belief that CAM is safer with fewer side effects	137, 142, 143, 162, 166	

	Patients' belief that CAM is free from adverse effects	145
	Influence of religious scholar/spiritual person.	163
	Experience of CAM use considered positive by others	140
	Patients who used CAM recommended CAM for someone with diabetes	129, 132, 145
	Family and friends made patients try CAM.	160, 163, 166
	Healthcare providers stated giving recommendations for using CAM therapies but to a limited extent	161
	Patients knew someone who uses / practice this CAM	123
7. Reinforcement	CAM use was suggested by other CAM users	128
	Having good example from the other user of CAM	130
	CAM recommendations by healthcare professionals	50, 111, 114, 115, 127-129, 132, 145, 162, 166
	Patients received information about CAM from pharmacist	50, 114, 115, 127, 129, 134
	Patients received information about CAM from herbalist	50, 115
	Patients received information about CAM from dietician	50, 129
	Patients received information about CAM from traditional healers	50, 132
	Treating diabetes	50, 110, 114, 115, 119, 123, 130, 133, 134, 137, 139, 143- 145, 160, 165, 167
	Treating other medical problems	111, 119, 123, 130, 137, 139, 143, 144, 165, 168
8. Intentions	Lowering blood glucose level	110-113, 168, 169
	General health and well-being	111, 123, 137, 141, 143
	Treating side effects of prescribed diabetic medications	114, 115, 160, 161
	Patients' use of CAM to control the side effects of non-diabetic medications	160, 161, 170
	Prevent or manage diabetic complications	110, 111, 132, 161
	Increase the drug's effect	132
	Prevent progression of diabetes	114, 115, 141, 159
	Relieving symptoms of diabetes	114, 115, 147, 159, 167
9. Goals	Cure of diabetes	114, 115, 159, 164, 170
	Management of diabetes	50, 110, 111, 113, 119, 123, 132-134, 139, 141, 143-145, 147, 160, 161, 167, 168

10. Memory, Attention and Decision Processes	Patients think that plants that tasted bitter like medications do were effective	120
	Patients experienced discomfort when taking diabetes medications	123, 160
	Patients use home-self-medication or traditional healers before they turn to conventional treatments	161
	Patients know CAM therapist with good reputation	161
	Signs and symptoms attributed to poor glycaemic control that were not controlled by conventional medicine led patients to try CAM.	123, 128, 161, 165
	Patients used CAM to have a break from conventional medicine	161
	Patients' lack of trust on conventional medicine	50, 117, 162
	Trying CAM as an experiment as patients look for other solutions	129, 141, 169
11. Environmental Context and Resources	CAM is more affordable	50, 115, 117, 119, 122, 123, 130, 132, 137, 141, 142, 145, 161, 162, 167, 169, 170
	CAM is easily accessible	50, 115, 119, 123, 130, 137, 140, 141, 145, 161, 162, 169, 170
	Patients living in villages use CAM more often than patients living in cities.	147
	Long waiting time between clinics' appointments	50, 162
	Inefficient communication with doctors.	50
	Limited access to remotely located healthcare services from patients	161
	Lack of qualified and specialized doctors	163
	Convenience of using CAM, as neither a prescription nor a physician visit is required.	140
12. Social influences	Cultural beliefs encourage the use of CAM.	137, 139, 140
	The type of herbal products used is related to cultural beliefs	123, 132, 142
	Recommendations from herbal companies selling medicinal plants in the market	120
	Recommendations from CAM practitioners or herbalists	131, 140, 145
	CAM used for religious reasons	137
	Family members, friends, Internet, TV and/or advertisement	50, 110-112, 114, 115, 117, 119, 120, 122, 126-131, 139-

		141, 143, 145, 147, 159-161, 166, 169
13. Emotion	CAM use made patients feel that they are in control over their health	144
	CAM made patients feel better emotionally	144
	CAM made it easier to cope with the illness	144
	Dissatisfaction with conventional therapy	144, 159
	Satisfaction with the use of CAM	128, 145, 160, 161
	Spiritual Healing	163
	Patients' unwillingness to accept their illness and its treatment	120
	Lost hope with conventional therapy	117, 130, 141, 143, 161
14. Behavioural Regulation	Discontinuation of insulin therapy due to exhaustion	163
	CAM was user friendly	145
	Too frequent daily dosage of diabetic medications	160
	Patients fail to do regular follow-up often resort to (Traditional healers)(Spiritual healers)(Home-self-medication)	161
	Patients who are on external insulin were 2 times less likely to use CAM compared to other diabetic patients.	131
	Patients who performed self-monitoring blood glucose (SMBG) monthly more likely to use CAM compared to patients who do not perform SMBG or do it less often than monthly	126

5.5.1 Intentions

Factors related to intentions either with stability or stages of change in intention fall under this domain.¹⁰¹ Treating diabetes, or other medical problems, lowering blood glucose levels, prevention or management of diabetic complications, relieving symptoms of the diabetes as well as preventing progression of diabetes by using CAM were the intentions described in the included literature.^{50, 110-115, 119, 123, 130, 132-134, 137, 139, 141, 143-145, 147, 159-161, 165, 167-170} Other factors included potentiating the effect of conventional treatments, treating side effects of prescribed diabetic medications and non-diabetic medications, and perceived positive effects on general health and well-being.^{50, 110-115, 119, 123, 130, 132-134, 137, 139, 141, 143-145, 147, 160, 161, 165, 168}

5.5.2 Beliefs about consequences

Beliefs about consequences, outcome expectancies and anticipated regret played an important role in influencing diabetic patients to use CAM as reported in 21 studies.^{50, 114, 117, 119, 120, 123, 128, 129, 131, 133, 134, 137, 141-143, 145, 161, 162, 164-166} Study participants were aware of the consequences of unmanaged diabetes and that awareness was a motivation to use CAM. Study participants in these studies chose CAM because they believed that CAM was more effective and safer than conventional medicines with fewer side effects and was free from adverse effects.

5.5.3 Optimism

Optimism was perceived as important in 11 studies.^{112, 115, 119, 130, 132, 139, 141, 160-163} For example, study participants in some of the studies were optimistic that CAM could completely cure diabetes. They were also optimistic that CAM could slow diabetes progression as well as being able to cure the cause of the diabetes. Diabetic patients

perceived conventional treatments as an approach that only focused on treating symptoms and not treating the disease itself. Moreover, patients were optimistic that they would not have to use conventional medicine if they use CAM, therefore patients rejected orthodox treatment and used CAM instead.^{112, 114, 115, 119, 130, 132, 139, 141, 147, 160, 161, 163}

5.5.4 Environmental context and resources

Factors in this domain played an important role in influencing diabetic patients to use CAM. Long waiting times between clinic appointments and lack of access to clinics and ineffective communications with doctors were among the reported factors.^{50, 162, 163} Moreover, studies reported that patients living in villages use CAM more often than patients living in urban areas due to limited access to healthcare services in the former areas.^{140, 147, 161} In general, participants said they used CAM as it is more accessible and affordable.^{50, 115, 117, 119, 122, 123, 130, 132, 137, 140-142, 145, 161, 162, 167, 169, 170}

5.5.5 Memory and decision processes

Memory, attention, decision making, cognitive overload or tiredness contributed to diabetic patients' use of CAM as reported in 12 studies.^{50, 117, 120, 123, 128, 129, 141, 160-162, 165, 169} Many diabetic patients described using CAM due to lack of trust in conventional medicine.^{50, 117} Many study participants deemed that plants that tasted bitter like medications taste were effective.¹²⁰ For some study participants the decision making process leading to CAM use was mostly about experimenting with new approaches for diabetes management or as a break from conventional medicine.^{129, 141, 161} Experience of discomfort or poor glycaemic control when taking diabetes medications also led to some patients actively seeking and using CAM.^{123, 128, 160, 161, 165}

5.5.6 Social influences

Factors under this domain were reported by 29 studies.^{50, 110-112, 114, 115, 117, 119, 120, 122, 123, 126-132, 134, 137, 139-143, 145, 147, 160, 161} These factors could be categorized into four subgroups including a) cultural and religious beliefs, b) healthcare professionals' encouragement including pharmacists, herbalists or dieticians, c) family members, friends and d) media and internet advertisements.

5.5.7 Reinforcement

Patients might use CAM due to a positive influence by religious scholars on their CAM use; healthcare professionals' recommendations and the portrayal of a positive experience of CAM use by other users were reported as factors influencing diabetic patients to use CAM.^{123, 128-130, 132, 140, 145, 160, 161, 163, 166}

5.5.8 Emotion

Emotions such as anxiety, fear, stress, depression, or burn-out have been associated with diabetic patients' CAM use. Factors related to this domain were reported in 12 studies.^{117, 120, 128, 130, 141, 143-145, 159-161, 163} For example, participants in one study reported that CAM use made patients feel more in control over their health and made it easier to cope and made them feel better emotionally.¹⁴⁴ Factors such as dissatisfaction and 'loss of hope' with conventional therapy, satisfaction with the use of CAM, and patients' unwillingness to accept their illness and its treatment were reported.

5.5.9 Goals

The main goals of using CAM by diabetic patients were either to cure diabetes or to manage diabetes.^{50, 110, 111, 113-115, 119, 123, 132-134, 139, 141, 143-145, 147, 160, 161, 167, 168}

5.5.10 Behavioural regulation

Factors in this domain were associated with self-monitoring, breaking habits or action planning.¹⁰¹ These factors were reported in 6 studies.^{126, 131, 145, 160, 161, 163} Diabetic patients turned to using CAM as a result of being exhausted by insulin therapy or due to too frequent daily dosage of diabetic medications because they perceived CAM as 'user friendly'. The included studies also reported that diabetic patients who are unable to keep up with regular follow-up with their healthcare professionals usually resort to traditional healers, spiritual healers and home-self-medication.

5.5.11 Knowledge

One study reported that herbal medicine use was popular because patients were aware of the uses of the existing various natural flora in their local environment.¹³⁹ Level of knowledge about interaction between conventional medicine and CAM was reported as a reason for using or not using CAM by patients with diabetes in two studies.^{132, 143}

5.5.12 Social/professional role and identity

One study reported that there was a relationship between profession and CAM use. Occupation was shown to be an important factor in CAM use. For example, the unemployed and housewives were more likely to use CAM than other occupations, followed by farmers or retired people.¹⁴⁶

5.5.13 Beliefs about capabilities

One study reported that patients perceived themselves to be capable of weighing up effectiveness with side effects in their decision making process around their use of CAM.¹⁶⁰

5.5.14 Skills

Health promoters, individuals who work to treat diabetic patients in rural areas in Guatemala without undertaking any medical education or training, used skills in relation to CAM use for treating their diabetic patients as they learned about the most popular plants used for diabetes from working with people with diabetes.¹²⁰

5.6 Discussion

Factors most commonly reported across the included studies related to the optimism, beliefs about consequences and social influences domains of the TDF. Key factors were related to the domains of TDF intentions and goals which were to treat and relieve symptoms. The environmental context and resources domain was populated by factors related to accessibility and affordability of CAM compared to physician visits and conventional medicines, factors such as influences by family members, friends, religious and spiritual scholars fell under the social influences domain of the TDF.

Behavioural interventions could be a helpful tool for healthcare professionals including pharmacists to help integrate CAM with prescribed medicines to guide patients through their diabetes management routine to ensure treatment optimization and medication adherence. Some of the factors identified in this review such as those related to the behavioural regulations domain including the factor of discontinuation of insulin therapy due to exhaustion or the factor of too frequent daily dosage of diabetic medications.

Exhaustion that diabetic patients experience as a result of these factors could be mitigated by dose simplification.¹⁷¹

Diabetic patients seek information from pharmacists in diverse settings. Recent COVID-19 pandemic has also shown pharmacy staff increasing involvement in CAM related advice and support to patients.¹⁷² Awareness of the factors as reported in this study that influence diabetic patients to use CAM would assist pharmacists to offer evidence based advice around the use of CAM along with prescribed treatments, promote medicines adherence and consider CAM-drug interactions where applicable. For example, patients' emotions such as frustrations or tiredness resulting from lack of treatment optimisation that in turn lead to patients resorting to CAM use instead of prescribed medicines could be addressed as part of medication reviews.

Barriers to accessibility and affordability of modern treatments led many participants in the included studies to resort to CAM. Improving access to diabetes care and treatment could address some of the barriers to access or use of evidenced-based treatment approaches.

Most of the included studies in this review used a surveys as a data collection tool often restricting participants in relation to the range of potential influences they could mention. Moreover, participants' answers to interview questions might be influenced by social desirability bias i.e. when participants answer questions in a way they think acceptable to others.¹⁷³

Implications for practice and research

A previous systematic review has shown that up to 51% of diabetic patients use some forms of CAM for the management of diabetes and approximately 2/3rd of diabetic

patients using CAM do not disclose their use to their healthcare providers.¹⁵³ Therefore, CAM use should be proactively explored as part of diabetes communication and counselling. Healthcare professionals should take into consideration the factors that increase the likelihood of CAM use by diabetic patients. The more of these factors that apply to a patient the more likely that the patient might resort to CAM use. By anticipating diabetic patients might use CAM, healthcare professionals could help to minimise any possible interactions between CAM and other medications. Moreover, it could also help healthcare professionals to address medication adherence by encouraging their patient to discuss their CAM use and offers the opportunity to provide better advice for them. Many CAM products are supplied through pharmacy alongside many over-the-counter products.¹⁷² It is imperative that education of healthcare professionals should include CAM use by patients with long term health conditions.^{174,}

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In light of this, research that provides evidence-based information about CAM is crucial because of the large number of factors that increase the likelihood of CAM use amongst diabetic patients. Safety and efficacy studies as well as studies on herb-drug interactions, the mechanism and impact on patients of commonly used CAM as identified in our previous prevalence systematic review are vital to ensure patients benefit the most from both prescribed drugs and CAM.¹⁵³

Included studies did not distinguish between different types of CAM such as HDS and non-HDS. Further qualitative studies that focused on specific types of CAM would be helpful to examine HDS or non-HDS specific patient perspectives.

Study limitation

This review only included studies which are published in English language. In recent years, the term 'integrative medicine' is being increasingly used to refer to CAM which was not captured in the search strategy used by this systematic review. The term was recommended by a peer reviewer after the review was complete. The PhD researcher considered the terminology based on the scoping search and the research team deemed that missing relevant outputs were unlikely and that the systematic review had most likely identified and included all relevant studies. Views expressed by patients other than in formal research settings such as in patient online forums have not been captured in this study. Such forums can also offer valuable data.

5.7 Conclusion

Decisions to use CAM in diabetes can be multifactorial. Healthcare professionals' awareness of diabetic patients' use of CAM can inform effective advice to promote optimisation of and adherence to prescribed treatments, and promotion of patient safety through avoidance of drug-CAM interactions. Alleviating patients' concerns, and reluctance to use prescribed treatments are imperative to achieve therapeutic goals.

Summary of the chapter

This chapter addressed the factors associated with CAM use by diabetic patients using systematic review. The factors were reported as identified in existing literature. The factors reported by the included studies were based on data collected from participants in formal research settings. For more comprehensive view, the next chapter will analyse data from patient online forums to explore patient perspectives on CAM use in diabetes out of formal research settings.

CHAPTER 6: STUDY OF PATIENT ONLINE FORUMS

Chapter overview

This chapter will explore the views and experiences of diabetic patients about CAM use by utilising conversation in patients' online forums.

Study Title: Complementary and alternative medicines use in self-management of diabetes: A study of patient and user conversations in online forums.

Note for plagiarism check:

This chapter in its entirety is submitted for publication and now is under review in a peer-reviewed journal. It might be published or be available online by the time of the plagiarism check.

Author's contributions

Abdulaziz Alzahrani designed and conducted all the stages of the study.

Vibhu Paudyal and Sheila Greenfield supervised Abdulaziz Alzahrani's PhD.

Abdulaziz Alzahrani led the drafting of the chapter to which all authors contributed through editing and revision.

All authors had access to the data sets and agreed to the final version of this chapter.

Ethics approval statement

Ethical approval for the study was obtained from the University of Birmingham Science, Technology, Engineering and Mathematics Ethical Review Committee. ERN_20-1431

Patient consent statement

Obtaining informed consent from forum users was not required in this study as the information was available in the public domain. Personal details of forum users were kept anonymous to maintain confidentiality.

6.1 Abstract

Background

An important part of diabetes self-management includes discussing and seeking informal advice from others. This study aimed to explore the perspectives of patients in relation to their use of complementary and alternative medicine (CAM) in diabetes through the use of data from online patient forum discussions.

Methods

Google search engine was used to identify relevant web-based online discussion forums focussing on CAM use in diabetes. A qualitative content analysis was adopted for analysis.

Results

Twenty-two online forums containing 77 threads with 1156 posts and replies were identified. Seven major themes with their respective sub-themes emerged from the data analysis. Patients used online forums to seek information about the benefits, side effects and share positive and negative experiences of CAM use. Feeling stressed, frustrated or overwhelmed with the condition and prescribed medications was often linked to their decisions to use CAM. They described that healthcare professionals were often unaware or unable to help in regards to their queries around CAM. They sought and shared literature to support or refute claims around perceived benefits and harms.

Conclusions

This study demonstrates that diabetic patients use online forums to seek and offer advice and share experiences in regards to reasons, perceived effectiveness and harm from CAM use. There is a scope for professional organisations, patient charities and health systems to offer such online platform to patients for discussion which can allow exploration of key concerns and queries and provision of evidence-based information to patients.

6.2 Background

Self-management practices are linked to disease management and clinical outcomes in diabetic patients.¹⁷⁶ Self-management approaches include but are not limited to diet, physical activities and continuous monitoring of blood glucose.¹⁷⁷

In addition to conventional medicines prescribed in healthcare settings, It is estimated that 51% of diabetic patients use CAM as a form of diabetes self-management either as a substitute or add on to their prescribed treatments.¹⁵³ Diabetic patients use a variety of CAM types including Herbal Medicine, Homeopathy, Acupuncture, Ayurveda, Yoga, Massage, Chiropractic and Meditation.¹⁵³

Healthcare professionals provide formal advice about diabetes self-management but patients also seek informal advice and information to help them with the management of diabetes.¹⁷⁸ Patients' health information seeking behaviours have changed during the digital age contributed to by the increased availability of health information online and access to mobile technology. Online health information sources include for example websites, articles and online forums and it has been suggested that health information is one of the most searched topics online.⁸⁶ Accessibility, convenience and speed have been suggested as the main reasons that make online sources more appealing to patients.¹⁷⁹ Patients also exchange health information, share experiences and provide advice to one another through online forums and discussion boards.⁸⁷ Since the COVID-19 pandemic began, information seeking online has been suggested to be on the rise due to lack of face-to-face appointments and people spending more time online during lockdown.¹⁸⁰

Online discussion boards or online forums usually work by allowing forum users to create a post or a blog. The post can be a question, a story, an opinion or any other thought. The posts can be replied to by other forum users. The original post and the

replies form what is called a thread. Some forums require a membership to post or reply to posts, others do not require membership and are available on public domains.

In formal research settings, participants may be more constrained as to what they say due to social desirability bias and therefore might not allow participants to fully and sincerely express their views and opinions.¹⁷³ Online forums hence allow exploration of patient perspectives which may not have been reported in previous studies conducted in a formal research setting. In addition, content validity of research tools is critical to obtaining reliable data in research studies.

Patient online forums and discussion boards are being recognized as an important source of 'natural' data and exploring them for patients' experiences has become a method used in medical research. For example, a previous study that aimed to understand patient perspectives of epilepsy treatment analyzed user posting in three online support groups.⁸⁸ The study concluded that analyzing discussions in online forums can help guide effective provider-patient communication.

Another study aimed to explore patient perspectives on cancer chemotherapy.⁸⁹ A total of 11 related online forums were analyzed which showed that quality of life was impacted by isolation and depression as a result of the side effects that patients were previously not warned about.

A recent systematic review suggested that the internet is the main source of information for diabetic patients.¹⁸¹ Information shared online between forum users is likely to play a role in shaping patients' beliefs regarding using CAM for diabetes management.¹⁵³ However, there is a lack of research that addresses this and therefore, a study design that uses novel and non-traditional information sources

would be valuable to offer patient oriented and evidence based information in regards to CAM use in diabetes.⁸⁷

This study set out to explore the perspectives of patients on their beliefs, experiences and preferences in relation to their use of CAM in diabetes through the use of data from online patient forum discussions. It also aimed to identify factors that attract diabetic patients to use CAM or drive them away from conventional medicine to CAM as well as diabetic patients' positive and negative impressions of CAM use for the management of diabetes.

6.3 Method

The study was conducted in accordance with the British Psychological Society's Ethics guidelines for internet-mediated research and the Association of Internet Researchers' Internet Research: Ethical Guidelines.^{77, 78} Ethics approval for the study was granted by the University of Birmingham Science, Technology, Engineering and Mathematics Ethical Review Committee, ethical approval number ERN_20-1431.

An internet search for related forums and discussion boards was conducted using Google search engine. Google® is known to dominate over 90 % of the search engines market 'for more than 10 years, and therefore it is most likely to yield the most comprehensive results from our searches.¹⁸² Search terms were compiled from the results of a systematic review of global prevalence of CAM use and the most popular CAM types among diabetic patients previously conducted by the authors.¹⁵³ The most commonly cited CAM types used by diabetic patients identified by the systematic review were: (Acupuncture, Homeopathy, Religious and Spiritual healing, Ayurveda, Yoga, Massage, Chiropractic, Meditation and Herbal Medicine) as well as the most commonly used herbs (Aloe vera, Cinnamon, Fenugreek, Black seed and Ginger).¹⁵³ The above terms were combined with the words "diabetes" and "forum". The search

settings were set to rank the results based on relevancy to the search terms rather than the most recent results in order to facilitate the manual search for relevant forums as the search results were arranged by showing the most relevant results first. A forum was deemed relevant if it contained discussion about patients' views and experiences regarding using CAM for diabetes. The Google® search engine was set for the outputs to be displayed as per the relevance. The results were then accessed one by one until all relevant results were accessed. Stopping criteria was set as 10 search results in a row that did not meet the inclusion criteria. This study was restricted to forums that were available in the English language.

A forum was deemed relevant if it had as a focus on CAM use by diabetic patients. Forums were included whether the posts were in diabetes forums or in CAM forums. Posts that appeared by their phrasing to be written by diabetic patients (both type 1 and type 2) or individuals who were directly involved in the care of diabetic patients, e.g. families and carers of diabetic patients, were included. Only posts in forums that did not require membership to access their content were included as these forums are available on public domains where there is likely no perception and/or expectation of privacy by the forum users.

6.4 Data analysis

A qualitative, inductive, content and thematic analysis was adopted for the analysis of the posts to allow the data to determine the emerging themes.⁹³ This is an approach to analysis that is both objective and systematic in term of recognizing specified features in textual and non-quantitative data. It is mostly used to analyze content in the field of communications by sectioning parts of the communications that are relevant to the focus of the study and assigning the codes for the resulting sections in order to identify emerging themes.¹⁸³

All threads that were deemed relevant based on content were extracted from included forums. Relevant posts were defined as those where reasons for using CAM by diabetic patients, experiences of CAM use for diabetes or concerns raised from using CAM for diabetes management were discussed.

Posts that were extracted were coded based on their content. If a single post contained more than one concept, the post was segmented accordingly and each resulting segment was coded independently. Similar segments that were coded with the same code were grouped and brought together. Selection of posts was performed independently, emerging codes discussed and the final coding frame agreed by all three authors (AA, VP and SG).

6.5 Results

6.5.1 Key themes and summary of the findings

The search identified 22 forums containing 77 threads with 1156 posts and replies. Following thematic content analysis on the extracted posts, 359 quotes were identified as relevant to the study objectives (Table 6.1).⁹⁴

Table 6.1: List of Forums with the numbers of extracted posts

	Forum Name	Number of Extracted Posts
	Total	359
1	www.diabetesdaily.com	135
2	forum.tudiabetes.org	71
3	www.diabetes.co.uk	46
4	abchomeopathy.com	13
5	forum.jdrf.org	10
6	www.shareayurveda.com	8
7	www.researchgate.net	7
8	www.diabetesforum.com	6
9	blog.resonanceschoolofhomeopathy.com	6
10	www.quora.com	6
11	www.homesteadingtoday.com	6
12	forum.diabetes.org.uk	5
13	forums.childrenwithdiabetes.com	5
14	www.vipassanaforum.net	5
15	www.internationalskeptics.com	5
16	www.drjoedispenza.net	4
17	healthunlocked.com	4
18	www.r2iclubforums.com	4
19	health.ccm.net	4
20	www.bogleheads.org	3
21	permies.com	3
22	www.city-data.com	3

Seven main themes, each with their respective subthemes, were identified from the extracted data (Table 6.2). The first theme explained the attitudes, feelings and experiences of CAM use by diabetic forum users. The second theme illustrated the information seeking behaviors by forum users about CAM. The next three themes illustrated efficacy, evidence of effectiveness and safety concerns about the use of CAM for diabetes management. The next theme showed patients' views on CAM use as an alternative or additional therapy. The last theme related to cost- related factors influencing users to resort to CAM. The number of quotes that made up each subtheme along with the related CAM type are listed in Table 6.2.

Table 6.2: Frequency of Quotes

Themes	Sub-themes	Frequency of Posts													
		Herbal	Aloe Vera	Cinnamon	Ginger	Fenugreek	Black seed	Homeopath	Acupunctur	Religious	Ayurveda	Yoga	Massage	Chiropractic	Meditation
Attitude and feelings toward CAM use	Forum users express how they feel about their diabetes	2	1	0	1	0	0	1	0	3	0	1	0	1	2
	Decision making process.	3	1	1	0	0	1	1	2	1	1	1	1	2	3
	Forum users' attitude toward the use of CAM for diabetes	32	4	5	0	1	0	7	5	5	14	5	2	6	5
	Experiences associated with conventional medicines as a factor in forum users' perceptions of CAM.	8	0	0	0	0	0	3	0	0	2	0	0	0	0
	Forum users convey their healthcare providers' attitude toward CAM	3	0	1	0	0	0	0	1	0	0	1	0	2	0
Seeking other users' experience with using CAM for treatment of diabetes	Seeking information	9	3	1	2	1	1	3	3	0	1	1	2	0	5
	Seeking or giving instructions about how to 'properly' use CAM	4	0	3	1	1	0	6	1	1	1	0	0	0	3
Did CAM work for my diabetes at all	Experience of CAM use	25	4	10	3	4	2	4	7	0	3	6	2	2	7
	Forum users experience an effect of CAM on diabetes while using CAM for other reasons	0	0	0	0	0	0	0	0	0	0	0	2	1	0
perception about	Forum users views on scientific studies that about the effectiveness of CAM for diabetes.	9	0	0	0	1	0	1	2	0	3	0	0	0	0

evidence base of CAM effectiveness	Forum users giving explanations to CAM effectiveness	2	2	0	0	4	0	4	0	0	1	6	3	0	2
Forum users' perception on CAM safety	Perception on CAM and/or conventional medicine safety	7	0	0	0	0	0	0	1	0	0	0	1	0	0
	Using online forums to discuss CAM side effects versus conventional medicines.	4	3	1	0	0	0	0	1	0	0	0	2	0	0
CAM as an additional or replacement treatment	Forum users' use or views on CAM as a complementary Therapy	4	0	0	0	0	0	1	0	0	0	0	0	0	0
	Forum users' use or views on CAM as an alternative Therapy	5	1	0	0	0	0	1	0	0	0	0	0	0	0
Economic issues around the use of CAM for the management of diabetes	Access and cost related issues from the perspective of forum users	2	0	0	0	0	0	0	0	0	0	0	0	0	1
	Forum users' perspective on the role of corporations on CAM recognition of CAM by medical insurers.	4	0	0	0	0	0	1	0	0	1	1	0	0	0

6.5.1.1 *Is CAM worth a try? Forum users' attitude and feelings toward CAM use.*

6.5.1.1.1 Forum users express how they feel about their diabetes.

Forum users used online forums to convey how they felt about their diabetes and expressed the feelings that they were prepared to take any necessary steps to get rid of their diabetes. Patients were especially frustrated because they felt that every state of mind they are in would affect their blood glucose levels, i.e., being happy or sad.

“Type 1 diabetes is one of the issues I have that I would like get rid of but just now starting to try and figure out a way to go about it. Anything we might be able to help each other or anyone else with would be great.” (A thread about Meditation).

“Basically every system that affects your bg when the weather changes or you are upset or happy... Sadly, weird things affecting our bg is the world we live in” (A thread about Herbal Medicine).

6.5.1.1.2 Decision making process.

Feeling stressed, frustrated or overwhelmed about managing diabetes was linked to forum users' decisions to use CAM. Forum users also wrote about hearing about a CAM type that is beneficial for diabetes and then conducting online searches on it. The information they found online was enough for them to try using CAM for diabetes.

“In general, mindfulness can be a useful tool to help increase our ability to tolerate the stress of managing diabetes and to increase our willingness to engage in the challenges of managing it. Example: if my blood sugar is 217, I could think about how awful that is and beat myself up thinking about how it should be better and ruminate about how I keep screwing up my diabetes control. That's probably just going to get me frustrated, depressed, and on my way to feeling overwhelmed/burned out though, and, ironically, might lead to less willingness to

test next time if I know that if it's a "bad" blood sugar, I'm going to go through all of that. I might end up avoiding testing as a result." (A thread about Meditation).

6.5.1.1.3 Forum users' attitude toward the use of CAM for diabetes

Many forum users expressed positive attitudes toward using CAM for diabetes. This was apparent mostly with Ayurveda followed by Herbal Medicine and Homeopathy (Table 6.2). It was often mentioned in the forums that CAM can cure diabetes in contrast to conventional medicine.

"You said, diabetes once set, can't be reversed. This is NOT the truth- as you see the UK homeopath cured himself, and the Hpathy article talks about 15 % cured cases in the literature. You don't know who could be one of the lucky ones who are cured, and even if not totally cured well worth it to have reduced the need for medicines." (A thread about Homeopathy).

However, posts about negative attitudes toward CAM were more frequent than posts about positive attitudes. Herbal Medicine ranked at the top of the frequency of quotes related to negative perceptions followed by chiropractic (Table 6.2). Forum users were sceptical and dismissive of the portrayed benefits of CAM for diabetes. A patient explained how it is not feasible to replace insulin injections with acupuncture needles. Suspicions about claims that CAM can cure diabetes were also expressed.

"I am pretty confident that nothing a chiropractor can do will cause the pancreas to start working again. I am also doubtful that anything they do can even change bg levels or insulin needs, no matter how "centered" they make your body." (A thread about Chiropractic).

There are posts about having neutral attitudes towards CAM use. Neutral attitudes were most frequent with Herbal Medicine followed by Acupuncture (Table 6.2). Forum users' attitudes were mostly that they are open to trying CAM as they have nothing to lose or trying CAM would not do any harm.

“I think we all know it wouldn't be this easy, no magic bullet, but maybe part of a therapy that would work is all I am suggesting”. (A thread about Yoga).

6.5.1.14 Experiences associated with conventional medicines as a factor in forum users' perceptions of CAM.

Forum users explained that the reason that drove them to use CAM is that using conventional medicine -especially insulin injections- will have a negative impact on their quality of life. Doubts about the benefits of conventional medicine were expressed. Forum users wrote about how conventional medicine does not work for everyone. Disappointment was also expressed that conventional medicine has no cure for diabetes and CAM could offer that cure.

“Diabetes is the silent killer disease. There is no cure from its roots to the allopath science. Many peoples are dies in world by the diabetes and its related ailments. However, Ayurveda and Panchakarma have total cure for these” (A thread about Ayurveda).

6.5.1.1.5 Forum users convey their healthcare providers' attitude toward CAM

Forum users rarely mentioned the views of their healthcare providers about the use of CAM for the management of diabetes when posting on online forums (Table 6.2). It was mentioned a few times that healthcare providers had not heard about the CAM type they were discussing with them regardless of how qualified and experienced their provider is.

“I have been taking berberine for four or five years with good results. During that time, I have filled out "what medicines do you take?" for probably 20 doctors. Only one had ever heard of berberine” (A thread about Herbal Medicine).

6.5.1.2 Seeking other users' experience with using CAM for treatment of diabetes

6.5.1.2.1 Seeking information

Online discussion forums seem to be an important mechanism for the forum users to ask about past experiences with CAM and seek information about the use of CAM for diabetes. Forum users also seem to seek information specific to the benefits of CAM, frequency of use, or how long CAM takes to be effective.

“It had never occurred to that sticking needles in one self could be beneficial for diabetics. LoL. Has anyone tried it? ” (A thread about acupuncture).

Information seeking was most frequently mentioned for Herbal Medicine in the context of other types of CAM as it was noted 9 times (Table 6.2)

6.5.1.2.2 Seeking or giving instructions about how to 'properly' use CAM

Forum users seemed to seek information from previous users on how to use CAM 'properly'. In addition, people who used CAM often volunteered to explain what they think is the proper way to use it. CAM users often replied to the original enquirer who said that they did not get the required result by CAM by attributing that to improper use of CAM and then they tried to explain how to use CAM properly. Some users also advised others of harmful ingredients and safety implications where CAM were not used in moderation. This subtheme was most frequent for Homeopathy, which emerged 6 times (Table 6.2).

“You need to take the right cinnamon. The kind commonly found in grocery stores, Cassia cinnamon, has a higher amount of a toxin called coumarin, which is hard on your liver. When you take amounts that simply season your food, you can metabolize it alright; but when you take therapeutic amounts for blood sugar, you ingest potentially unsafe amounts. Do some searching and make sure you take Ceylon cinnamon. It has barely a trace of coumarin. And yes, it does work to lower blood sugar.” (a thread about cinnamon).

6.5.1.3 Did CAM work for my diabetes at all?

6.5.1.3.1 Experience of CAM use.

Unlike posts about attitudes towards CAM where posts about negative attitudes towards CAM were the most frequent, among other attitudes, posts about experiencing positive results from using CAM were the most frequent, i.e. rather than negative results or no results (Table 6.2). Posts showed associations between using berberine instead of metformin due to metformin side effects. Berberine is a compound that is extracted from the barberry plant.¹⁸⁴ The reported effects of CAM were mostly lowering blood glucose and preventing morning spikes. Additionally, it was reported that patients use CAM to cope with diabetes.

“It helps me to be able to step back, examine my feelings. Meditation helps me to get a better perspective on what is my reality at that time and be able to accept it. For me this reduces the stresses so I can cope with my challenges.” (A thread about Meditation).

The least frequent posts related to CAM results were posts related to experiencing negative results from CAM. Forum users experienced what one described as ‘disastrous’ effects of CAM on their diabetes, others wrote the condition was deteriorating as a result of using CAM. Negative results of using CAM as experienced

by forum users were hypoglycaemia, hyperglycaemia and what one described as a roller-coaster of blood glucose levels. Details about these side effects communications are described below under the forum users' perception of CAM safety theme.

"I test my blood sugar prior to leaving and it's usually around the normal range between 100-130. I do the Yoga, sweat like crazy and come home and test again and my BS has consistently been around 200-260. This seems crazy because whenever I do aerobic exercises, I'm able to drop my BS down to a normal range."

(A thread about Yoga).

Forum users wrote about trying CAM for diabetes and experiencing no effects. The effect of CAM was measured by seeing if there were no effects on their blood levels, or their insulin needs did not change while using CAM. A patient used CAM for the purpose of curing diabetes and judged the effect based on the fact that CAM did not cure their diabetes.

"My mom tried EVERYTHING to "cure" my diabetes when I was younger. I went along with the idea up til I was around 15 to "cure" the diabetes. by that time I found nothing "cured" diabetes." (A thread about Ayurveda).

6.5.1.3.2 Forum users experience an effect of CAM on diabetes while using CAM for other reasons.

A few users mentioned having an unexpected effect on their diabetes while using CAM for other reasons. One forum user used massage for sore muscles and ended up having unexpected hypoglycaemia, and another forum user used chiropractic and noticed a reduction in his insulin needs.

6.5.1.4 What is the Forum users' perception about the evidence base of CAM effectiveness?

6.5.1.4.1 Forum users' views on scientific studies about the effectiveness of CAM for diabetes.

Forum users discussed studies on CAM effectiveness that they came across. They suspected that the results from those studies cannot be replicated and therefore cannot be used as evidence about the effectiveness of CAM on diabetes. Countries were referenced where a specific type of CAM is popular and linked that to the prevalence of diabetes being still high despite the fact that it is used more frequently in that country.

“Chinese Traditional medicine doesn't seem to be helping the type 2 diabetes epidemic in China, they have surpassed the US in % of instances” (A thread about Acupuncture).

Forum users used online discussion forums to share links to studies that substantiate the effectiveness of CAM on diabetes. They also talked about the studies they read or articles they came across that are about the effectiveness of CAM on diabetes. One user wrote about how Harvard Medical School required its medical students to take a semester of homeopathy as a supporting argument that homeopathy is starting to get medically recognized.

“I just recently started taking berberine. I came across an article about a week ago. What have I got to lose?” (A thread about Herbal Medicine).

6.5.1.4.2 Forum users giving explanations about CAM effectiveness.

Forum users used online discussion forums to add their inputs on how CAM works to manage diabetes. These explanations included that CAM corrected the metabolism or CAM contained soluble fibres that have a blood glucose lowering effect by slowing digestion and absorption. Another explanation was that CAM helps with eating less fried and sweet food as well as acting like an antitoxic, which helps to activate the cells therefore allowing insulin to work on cells. Stimulating the pancreas with yoga was

One of the explanations of the effectiveness of CAM posted by a forum user was that CAM helps with relaxing and relieving stress which leads to lowering the stress hormone therefore lowering insulin needs or was simply a placebo effect.

6.5.1.5 *What is the forum users' perceptions on the safety of CAM or/and conventional medicine*

6.5.1.5.1 Forum users' perceptions on CAM safety.

Many forum users mostly viewed CAM as a safe form of therapy. They described it as harmless and potentially beneficial for treating diabetes. Experiencing no downside related to CAM use was also reported.

“To me it falls into the unlikely to cause any harm category, so it might be worth giving it a try” (A thread about Herbal Medicine).

Forum users expressed that they could not tolerate metformin due to its side effects. They resorted to using CAM for the management of diabetes solely to avoid metformin side effects. In a post those side effects were described as Metformin Moments or "Metformin Zombie". It was described how metformin side effects have a negative impact on patients' quality of life.

“Metformin did not have any effect on her blood glucose. She only got bad side effects. As her husband, I have no printable things to say about Metformin and the doctor's response to what it did to her. Practically a year of her life was wasted to the zombie effect” (A thread about Herbal Medicine).

6.5.1.5.2 Forum users use online forums to discuss CAM side effects versus conventional medicines.

A forum user described how he had stomach issues while using Herbal Medicine and another replied that that CAM type was killing parasites that already existed in his stomach and that is why he had those stomach issues. In discussing another side effect of CAM, a forum user complained about irregular sleep and high fasting glucose numbers while using acupuncture; another user replied that it is not possible to tell if the high fasting glucose numbers are caused by CAM or sleeping issues. Other side effects reported included hypoglycaemia and vomiting.

“My wife is type 2. I got her a massage for Christmas two years ago because she loves them. But we think she ended up with a deep tissue massage which she didn't want. She ended up throwing up before the massage was even half done. They blamed it on her being diabetic.” (A thread about Herbal Medicine).

6.5.1.6 CAM as an additional or replacement treatment for diabetes.

6.5.1.6.1 Forum users' use or views on CAM as a complementary therapy.

Forum users wrote about their experiences with using CAM together with conventional medicine. Their experiences varied between seeing no additional results from adding CAM to their treatment, to experiencing an effect which they measured by alternating skipping one form of treatment at a time and noticing the change in blood glucose

levels. A patient in one post wondered if using CAM along with conventional medicine would have a synergistic effect.

“I don't know if the 2 together give you double the effect?” (A thread about Herbal Medicine).

6.5.1.6.2 Forum users' use or views on CAM as an alternative therapy.

Forum users wrote about their thoughts and experiences about using CAM for the management of diabetes instead of conventional medicine. They either used CAM instead of conventional medicine as they viewed both approaches as being supposed to have the same effect, or were considering stopping conventional medicine to use CAM alone because they were starting to see an effect of CAM. One user wrote about experiencing abdominal side effects when using conventional medicine together with CAM and decided to use CAM alone.

“Obviously no one only you can make the decision about your tablets but I just couldn't stand the pain I was in. and it looks as if you were having the same problems. I also was going to go to A+E but decided on a couple of day's trial without the tablets. Aloe Vera was on one of the other threads but can't remember which one, so I decided to give it a try. I've been off the tablets for about 4 weeks now and feel great. And haven't had a bad reading since, but as I said I did tell the doc I wasn't happy with them, but I didn't say anything about the Aloe I just started taking that myself after reading the good reports.” (A thread about Aloe vera).

6.5.1.7 Economic issues around the use of CAM for the management of diabetes

6.5.1.7.1 Access and cost related issues from the perspective of forum users.

Forum users wrote about wanting to use CAM but the cost of CAM was the reason they did not use it as insurance companies do not cover CAM treatments or conventional medicine is cheaper than CAM.

“When I needed diabetes meds, I considered it, but cost kept me away. My metformin was only \$1.99 for a 3 month supply” (A thread about Herbal Medicine).

6.5.1.7.2 Recognition of CAM by medical insurers.

Forum users wrote about how insurance companies do not want recognition for the effectiveness of CAM as it will drive people away from orthodox treatment. They said that if CAM becomes more popular, insurance companies will no longer exist as the reason for their existence what was described by a forum user as “absurd health care costs”. Forum users also blamed pharmaceutical companies for the limited research and development in the field of CAM as such research would not be likely to generate revenue for the companies. Regarding CAM, forum users also suspected that commercially available CAM products are just made to exploit forum users to make money from them and do not actually work for diabetes.

“I would like to know whether a proper cure for Diabetes Type I and II is going to be reality in coming years. As I can see we have genome sequence, we have identified gene, SNPs in the gene and then proteins which are switched on or off due to this. What else is needed to find a cure? Or is it as they say "There is cure but no one wants to kill the golden goose” (A thread about Ayurveda).

6.5.2 TDF mapping of behaviours

Behaviours that were identified during thematic analysis were extracted and re-arranged according to the TDF domains (Table 6.3) to inform the recommendations and development of future interventions to optimise CAM use in diabetes.

TDF domain	Behaviour	Sub-theme
1. Knowledge	It was mentioned a few times that healthcare providers had not heard about the CAM type they were discussing with them regardless of how qualified and experienced their provider is	6.5.1.1.5
	Some users advised others of harmful ingredients and safety implications of overuse of CAM.	6.5.1.2.2
	Forum users discussed studies on CAM effectiveness that they came across	6.5.1.4.1
	Forum users used online discussion forums to add their inputs on how CAM works to manage diabetes	6.5.1.4.2
2. Skills	CAM users often replied to the original enquirer who said that they did not get the required outcomes from the use of CAM by attributing the same to 'improper' use of CAM and offered advice on how to use CAM 'properly'	6.5.1.2.2
4. Beliefs about Capabilities	Forum users were sceptical and dismissive of the portrayed benefits of CAM for diabetes.	6.5.1.1.3
5. Optimism	Many forum users expressed positive attitudes toward using CAM for diabetes	6.5.1.1.3
	Posts about negative attitudes towards CAM were more frequent than posts about positive attitudes	6.5.1.1.3
6. Beliefs about Consequences	Forum users' attitudes were mostly that they are open to trying CAM as they have nothing to lose or trying CAM would not do any harm.	6.5.1.1.3
	Many forum users mostly viewed CAM as a safe form of therapy. They described it as harmless and potentially beneficial for treating diabetes	6.5.1.5.1
7. Reinforcement	Forum users also sought information specific to the benefits of CAM, frequency of use, or how long CAM takes to be effective.	6.5.1.2.1
	Experiencing an effect by alternating between various CAM types and prescribed treatments and self-monitoring the changes in blood glucose levels.	6.5.1.6.1
8. Intentions	Curing diabetes	6.5.1.1.3
9. Goals	None Applicable	
10. Memory, Attention and Decision Processes	Forum users also wrote about hearing about a CAM type that is beneficial for diabetes and then conducting online searches on it	6.5.1.1.2

	Forum users experienced what one described as 'disastrous' effects of CAM on their diabetes	6.5.1.3.1
	Forum users wrote about trying CAM for diabetes and experiencing no positive or negative effects. The effect of CAM was measured by seeing if there were no effects on their blood levels, or their insulin needs did not change while using CAM	6.5.1.3.1
	A few users mentioned having an unexpected effect on their diabetes while using CAM	6.5.1.3.2
	A patient in one post wondered if using CAM along with conventional medicine would have a synergistic effect	6.5.1.6.1
	Patients either used CAM instead of conventional medicine as they viewed both approaches as being supposed to have the same effect	6.5.1.6.2
11. Environmental Context and Resources	Forum users wrote about wanting to use CAM but the cost of CAM was the reason they did not use it as insurance companies do not cover CAM treatments	6.5.1.7.1
	Forum users also blamed pharmaceutical companies for the limited research and development in the field of CAM as such research would not be likely to generate revenue for the companies	6.5.1.7.1
12. Social influences	Forum users used online discussion forums to share links to studies that substantiate the effectiveness of CAM on diabetes	6.5.1.4.1
	Forum users seemed to seek information from previous users on how to use CAM 'properly'	6.5.1.2.2
13. Emotion	Forum users used online forums to convey how they felt about their diabetes and expressed the feelings that they were prepared to take any necessary steps to get rid of their diabetes.	6.5.1.1.1
	Feeling stressed, frustrated or overwhelmed about managing diabetes was linked to forum users' decisions to use CAM	6.5.1.1.2
	Patients were especially frustrated because they felt that every state of mind they are in would affect their blood glucose levels, i.e., being happy or sad.	6.5.1.1.1
	Disappointment was also expressed that conventional medicine has no cure for diabetes and CAM could offer that cure.	6.5.1.1.4
14. Behavioural Regulation	Forum users explained that the reason that drove them to use CAM is that using conventional medicine -especially insulin injections- will have a negative impact on their quality of life.	6.5.1.1.4
	Many forum users used CAM to cope with diabetes	6.5.1.3.1
	Forum users expressed that they could not tolerate metformin due to its side effects. They resorted to using CAM for the management of diabetes solely to avoid metformin side effects	6.5.1.5.1
	Stopping conventional medicine to use CAM alone because they were starting to see an effect of CAM	6.5.1.6.2

Table 6.3: TDF mapping of behaviours

6.6 Discussion

Summary and discussion of key findings

This study set out to explore the perspectives of patients on their beliefs, experiences and preferences in relation to their use of CAM in diabetes through the use of data from online patient forum discussions. It also aimed to identify factors that attract diabetic patients to use CAM or drive them away from conventional medicine into using CAM as well as diabetic patients' positive and negative impressions of CAM use for the management of diabetes.

Our findings indicated that patients use online forums to seek information from previous users about the benefits of CAM, frequency of use, how long CAM takes to be effective or how to use CAM 'properly'. Forum users talked about the negative impact of their condition or its management routine had on their quality of life, making them feel stressed, frustrated or overwhelmed about managing diabetes was linked to their decisions to use CAM. Forum users used online forums to share links to studies that substantiate the effectiveness of CAM on diabetes or to add their inputs on how CAM works to manage diabetes. Access and cost related issues from the perspective of forum users and recognition of CAM by medical insurers were one of the subjects that were often discussed by forum users. Forum users often pointed to lack of ability of conventional medicines to cure diabetes as the reason to seek alternative management approaches in a hope to find a permanent cure.

As a qualitative study, the phenomenon was of greater focus and interest than counting.¹⁸⁵ Therefore, the frequency posts while reported were not totalled and quantitative analysis was not performed on data as the study did not aim to quantitatively analyse the posts. However, comparative demonstrations were

mentioned where relevant, e.g. “Unlike posts about attitudes towards CAM where posts about negative attitudes towards CAM were the most frequent, among other attitudes”.

Implications for practice

The study has implications for clinical practice in terms of understanding hidden issues related to CAM safety, effectiveness and medication adherence. The findings could be utilized by healthcare providers to better understand those issues and it would help healthcare providers to be more efficiently involved with their patients’ self-care practices and be able to advise about the rational use of CAM if patients are going to use it, on what they should be aware of.

Implications for research

This results of this study have highlighted the importance of engaging with patients and exploring in-depth their use of CAM through further qualitative study and research in natural settings. Healthcare providers’ point of view regarding their patients’ use of CAM are also important to explore in detail in an attempt to bridge the gap between patients and healthcare providers in term of views on using CAM for the management of diabetes in order for healthcare providers to engage more effectively with their patients. Further research on what makes patients resort to online forums to seek advice and share and discuss their condition rather than carrying out those discussions with their healthcare providers are important to promote better understanding of the issue and better patient-provider interactions. Furthermore, as online health information is constantly changing, online forums can further be utilized in research by

regular analysis of their contents in order to gain a continuously updated view and be able to identify all aspects of diabetic patients' management behaviours and concerns.

Strengths and limitations

Limited qualitative studies on diabetic patients' use of CAM had been previously conducted.^{160, 163} One example is a study that was limited to herbal medicine and it only recruited participants from one single community – Indian and Pakistani migrants – and that study was limited to a narrow context which was to find out if migrants still use CAM from their previous communities. Another example is a study that only recruited participants with type 2 diabetes and discussed only limited CAM types. This study adopted an extensive search strategy that used the most popular CAM types among diabetic patients as it was guided by the results of a global systematic review in order for the study scope to be as comprehensive as possible.¹⁵³ Issues like hidden concerns about conventional medicine such as metformin side effects, diabetic patients' explanations of the effectiveness of CAM and issues related to medical insurance etc. were never brought up by any previous studies and have been identified by this study. Moreover, the fact that this study explored data already available online and not collected from patients in formal research settings is more likely to explore what diabetic patients actually think as their opinions and concerns were expressed freely in a non-restrictive manner.¹⁷³

However, the data included in this study is limited to the subjects discussed in the forums. It was not feasible to probe any further on any part of the data to gain a more in-depth view on any given subject. Even though the data were not restricted to any particular group of patients, information about people posting on the forums such as

age, condition status of the patient and duration of the condition are limited. Moreover, forums are often vulnerable to unsolicited and covert advertising campaigns by product manufactures and there is no reliable way to ensure the validity of each individual post. Lastly, the study was limited to English language forums only and did not include forums in other languages.

6.7 Conclusion

Online forums are a valuable e-source of data for finding out about beliefs and experiences on CAM use by diabetic patients as this study demonstrates that diabetic patients use them to seek and offer advice and share experiences about CAM use. Stakeholders including healthcare professionals could utilise the findings of this study to get an idea about patients' beliefs, concerns and experiences to offer more proactive and reality based patient consultations.

Summary of the chapter

This chapter explored the views of diabetic patients about CAM using posts available in patient online forums. For more comprehensive understanding of CAM use by diabetic patients, factors associated with CAM use by diabetic patients and healthcare professionals' perspectives on CAM use will be further investigated in-depth in subsequent chapters.

CHAPTER 7: QUALITATIVE INTERVIEWS WITH PATIENTS

Chapter overview: This chapter will explore in-depth diabetic patients' beliefs, practices, and factors associated with CAM use. It uses qualitative semi-structured interviews to answer the research aim.

Study Title: Patient perspectives on the use of complementary and alternative medicine (CAM) for the management of diabetes in Saudi Arabia: A qualitative study.

Note for plagiarism check:

This chapter in its entirety is being submitted for publication. It might be published and be available online by the time of the plagiarism check.

Authors' contributions

Abdulaziz Alzahrani designed and conducted all the stages of the study.

Vibhu Paudyal and Sheila Greenfield supervised Abdulaziz Alzahrani's PhD.

Abdulaziz Alzahrani led the drafting of the chapter to which all authors contributed through editing and revision. All authors had access to the data sets and agreed to the final version of this chapter.

Ethics approval statement

Ethical approval for the study was obtained from the Saudi Ministry of Health and the University of Birmingham Science, Technology, Engineering and Mathematics Ethical Review Committee. ERN_20-0637

Patient consent statement

Informed consents were obtained from all participants of this study.

7.1 Abstract

Background:

Saudi Arabia has one of the highest diabetes prevalence worldwide. A recent systematic review has shown a high rate of complementary and alternative medicine (CAM) use by patients with diabetes in the country. This study aims to explore Saudi diabetic patients' beliefs, practices, and factors associated with CAM use.

Methods:

Qualitative study using telephone, one-to-one semi-structured interviews with 21 patients diagnosed with type 1 or type 2 diabetes, recruited through general practices and a diabetes centre. Interviews were analysed using thematic analysis.

Results:

Seven key themes emerged from the data. Patients' denial of diabetes diagnoses, perceptions that conventional medicine causes diabetes to become permanent and apprehensions about diabetes complications were reasons that made patients resort to CAM use. Cultural background played an important role in patients' beliefs about CAM, decisions to use CAM and choice of CAM type such as ruqya and cupping. Patient-provider communications lacked discussion about CAM. Such lack of discussions was often contributed to by patients' distrust of providers' knowledge of CAM.

Conclusion:

Hidden concerns about diabetes often lead patients to use CAM. Participants in this study perceived that such concerns, including the role of CAM in diabetes, were not appropriately addressed during clinical visits due to lack of trust in their providers' knowledge about CAM. This limited discussion about CAM might contribute to making diabetic patients' vulnerable to financial exploitation by some CAM providers. Cultural influences played an important role in diabetic patients' decision to use CAM and choice of CAM type. It is important to understand healthcare professionals' perspectives in future studies to inform better counselling and communication practices.

7.2 Background

Diabetes mellitus is one of the biggest challenges facing Saudi Arabia's healthcare sector. In 2018, Saudi Arabia was ranked seventh highest globally for diabetes cases by the World Health Organization (WHO).^{48, 186} In 2017, the prevalence among adults was estimated to be 18.5%, with 3,852,000 diabetes cases out of the 20,770,000 adult population.⁴⁸

For optimal outcomes, diabetes management requires self-care as well as conventional care such as through prescribed medications. Self-care practices in diabetes include following diets, exercising regularly, and self-monitoring blood glucose levels.¹⁸⁷ Self-care practices can play an essential role in slowing disease progression, limiting disease complications and achieving a better outcome from prescribed medicines.¹⁵

A recent systematic review of the global prevalence of CAM use by diabetic patients reported a prevalence range between 25.8%-64% of patients with diabetes using CAM in Saudi Arabia.¹⁵³ A study in 2016 reported that diabetic patients in Saudi Arabia use various CAM types such as herbal and nutritional supplements and wet cupping.⁵⁰ In another study conducted in Saudi Arabia in 2003, 15.6% of diabetic patients who use CAM perceived that CAM was safe and effective.⁴⁹ It was reported that CAM use was higher among Saudi diabetic patients who experienced diabetic complications and longer duration of diabetes.¹⁸⁸

The decision to use of CAM by diabetic patients is influenced by many factors. There is a dearth of literature that has explored in-depth the use of CAM by diabetic patients worldwide and in Saudi Arabia. Few previous qualitative studies about CAM use for diabetes are available. One example of the available literature is a study conducted in

Edinburgh, United Kingdom.¹⁶⁰ The study aim was limited to investigating the use of CAM for the management of diabetes by Indian and Pakistani migrants living in Edinburgh, UK and the importance of native culture on CAM use. Participants were recruited from shops, religious venues, community centres and private homes. The study concluded that the most common type of CAM used was herbal medicine. It also reported some "resistance to western medicine" among participants due to side effects.

In a qualitative study conducted with patients attending a general practice and a specialised diabetic clinic in Pakistan, religious practices, herbal and household remedies were shown to be the most popular CAM types used by diabetic patients. Most patients used CAM for reasons such as seeking a cure for diabetes, religious beliefs, inconvenience associated with conventional management and lack of trust in conventional medicines.¹⁶³ The main reason reported in the study for patients not using CAM was the lack of trust in CAM for diabetes management. This study did not recruit participants under 30 and excluded newly diagnosed participants.

A study conducted in Saudi Arabia using open-ended and closed questions revealed that 73% of patients experienced benefits from CAM and none experienced side effects. The researcher did not interview the patients and there was no direct engagement between the researcher and the participants. The study recommended further exploration of the subject.¹⁸⁹

Saudi Arabia is a majority Muslim country.⁴⁴ Islamic literature has cited several management approaches for diseases in general.¹⁹⁰ Such cultural connections might influence the views of patients about certain CAM types mentioned in Islamic literature.

As diabetes is a condition with a clear conventional treatment plan which needs to be followed to achieve best outcomes it is imperative that the extent and nature of patients' CAM use and factors associated with its use are known to healthcare professionals to enable effective communication practices. The aim of this study was to explore diabetic patients' beliefs, practices, and factors associated with CAM use.

7.3 Method

This qualitative study used one-to-one in-depth semi-structured interviews with diabetic patients in Saudi Arabia.¹⁹¹ A qualitative design was chosen to allow patients to express their views, and this approach gives the researchers the ability to explore these views further.⁸⁰

7.3.1 Study setting

The study was conducted with participants visiting a specialised diabetes centre and 7 general practice clinics in Al-Baha region in Saudi Arabia between January 2021 and June 2021. The clinics were identified using the Saudi Ministry of Health phone directory. Due to the restrictions set in place during the COVID-19 pandemic, interviews with participants were conducted by telephone.¹⁹² The interviews were conducted, recorded and transcribed in Arabic by the researcher. Interview transcripts were translated into English using a UK based professional translation service approved by the University of Birmingham.

7.3.2 Sampling and recruitment

A purposive maximum variation sampling technique was used.⁸² The maximum variation sampling approach was set to include as far as possible patients from different age groups, gender and length of time since diagnosis. These characteristics

are the most common variables between diabetic patients.⁸² Invitation letters which included the researcher's phone number and e-mail address and participant information sheets were distributed to patients through the general practice clinics and specialised diabetes centre. Clinics were phoned by the researcher and invitation letters were distributed to the clinics by e-mail and then given to participants during their clinic visits via clinic administration staff. Participants who were interested in participating in the study were asked to call the researcher's phone number shown on the invitation letter. Participants who called were assessed for eligibility during the call to determine if they met the inclusion criteria, i.e. adults diagnosed with diabetes. Once participant eligibility was confirmed, they were asked to participate and any questions they had about the study were answered. Informed consent was obtained before the interview, and participants were given 14 days from the interview date to withdraw from the study.¹⁹³ Nine participants were initially recruited and this number was increased by 3 participants at a time until data saturation was achieved, i.e. no new themes emerged, at 15 participants.^{193, 194} Six further interviews were carried out to confirm data saturation increasing the total number of participants to 21.

7.2.3 Data collection

Participants chose the day and time of their interview and were advised to identify a suitable and private place in which to receive the telephone call. The researcher conducted the calls in a designated private location to protect participants' privacy. All interviews were carried out by AA, a PhD student in pharmacy at the University of Birmingham, UK and a native to Albaha region in Saudi Arabia. Participants were given a choice for the interview to be carried out in Arabic or English and all participants chose Arabic. Patient demographic information (gender, age, type of diabetes and time

since diagnosis) was collected at the beginning of each interview. The interview duration ranged between 20 minutes and 35 minutes with an average of 30 minutes.

The interview schedule was developed based on previous findings in the literature and the authors' previous work and was informed by the Theoretical Domains Framework (TDF).^{37, 101, 153, 181} The reason for using the TDF to help develop the topic guide is that CAM use by diabetic patients is mostly individual decision by the patients and hoped that the TDF would do help you to identify the important components of patient's beliefs and behaviours related to their CAM use. The TDF is a framework of theories for understanding behaviours that was developed by a panel of psychological theorists, health service researchers, and health psychologists and consists of 14 domains (Supplementary Table 2).¹⁰¹ Prior to the conduct of interviews, the topic guide was examined by colleagues enrolled in PhD research at the University of Birmingham and their comments were utilized to amend the topic guide. The research team discussed interview questions and agreed on the final interview schedule. Interview questions covered types of CAM used, patients' satisfaction with conventional medicines and CAM, reasons for using CAM for diabetes, expectations from CAM use, perceived effectiveness and side effects experienced with CAM use and discussion of their CAM use with their healthcare professionals. The topic guide is available in Supplementary Table 2.

7.3 Data analysis

An inductive method of analysis where analysis was driven by the data and the framework method were used.^{93, 195} This analytical method is applied to produce themes out of raw qualitative data by grouping similar data into a single theme.¹⁹⁵ Interview transcripts were coded by identifying important pieces of text in the

transcripts and labelling those pieces with keywords or "codes". Parts and segments of transcripts were coded with similar codes and were grouped to form categories based on their similarities. Categories were further assembled into themes. The developed themes were then charted in thematic charts by summarising all the resulting themes. The charts were then analysed using thematic analysis.¹⁹⁵ The data analysis and interpretation were performed based on resulting themes during the transcript coding, categorising and charting process.¹⁹⁵ AA, VB and SG independently examined a selection of interview transcripts and agreed on themes.

7.5 Results

7.5.1 Participants' characteristics

The participants who took part included patients with both T1D and T2D. The sample consisted of 9 females with ages ranging from 18-60 and duration of diabetes ranging from 4-27 years and 12 males with age ranging from 18-75 and duration of diabetes between 5-30 years (Table 1).

Table 7.1: Demographic information of participants.

Participant	Sex	Age (years)	Duration since diagnosis (years)	Type of Diabetes
Participant 1	Female	50	10	T2D
Participant 2	Female	18	1	T1D
Participant 3	Female	52	27	T2D
Participant 4	Female	60	5	T2D
Participant 5	Female	54	22	T2D
Participant 6	Female	27	10	T2D
Participant 7	Female	28	6	T2D
Participant 8	Female	18	2	T1D
Participant 9	Female	27	17	T2D
Participant 10	Male	60	10	T2D
Participant 11	Male	25	7	T1D
Participant 12	Male	75	20	T2D
Participant 13	Male	62	15	T2D
Participant 14	Male	44	13	T2D
Participant 15	Male	58	14	T2D
Participant 16	Male	49	30	T2D
Participant 17	Male	18	5	T2D
Participant 18	Male	65	11	T2D
Participant 19	Male	31	12	T1D
Participant 20	Male	31	16	T1D
Participant 21	Male	24	14	T1D

7.5.2 Key themes and summary of the findings

Seven main themes emerged from the interviews, each with their respective subthemes (Table 2).

Table 7.2: Key Themes and Sub-themes

No.	Themes	Subthemes
1	Knowledge about diabetes and CAM	<i>Knowledge about diabetes complications</i> <i>General perceptions about CAM</i>
2	Sources of CAM and CAM information	<i>Sources of information about CAM</i> <i>CAM types used and sources of CAM</i>
3	Cultural context	<i>Honey</i> <i>Cupping</i> <i>Ruqya</i>
4	Expectations about CAM	<i>Patients expectations from using CAM</i> <i>Patients feelings about diabetes that led to using CAM</i> <i>Patients attitudes toward CAM</i>
5	Reasons for resorting to CAM use	<i>Patients do not accept the fact that they have diabetes</i> <i>Discussing the condition with other people</i> <i>Apprehension about diabetes complications</i>
6	Patients' negative concerns about using CAM for diabetes	<i>Reasons for stopping the use of CAM</i> <i>CAM-related adverse events</i>
7	Interactions with healthcare professionals	<i>Discussing CAM use with healthcare professionals</i> <i>Reasons for not discussing the use of CAM with Healthcare professionals</i>

7.5.2.1 Knowledge about diabetes and CAM.

7.5.2.1.1 Knowledge about diabetes complications.

All participants demonstrated knowledge with regards to long term diabetes complications. Most participants mentioned that they were aware that uncontrolled

diabetes could lead to renal failure, neuropathy and blindness. They emphasised the need to keep blood glucose levels under control.

“I know that diabetes affects the retina, limbs, kidneys, and other things. There are many people who have had these complications due to negligence”

[Participant 16, Male, 49 years old, T2D, 30 years since diagnosis]

7.5.2.1.2 General perceptions about CAM.

Some participants believed that they had some knowledge about CAM effectiveness for diabetes based on what they heard from the general public and other diabetic patients. Some participants pointed out that CAM can sometimes be harmful. The majority of the participants often referred to CAM as natural and therefore ‘not harmful’ or if CAM did not cause improvement, it would not cause harm, especially as regards herbal medicine.

“They are things that exist in nature, so they are harmless and beneficial. They are popular among diabetics, and many diabetics use them .they are natural and found in nature and does not contain harmful chemicals” [Participant 6, Female,

27 years old, T2D, 10 years since diagnosis]

7.5.2.2 Sources of CAM and CAM information.

7.5.2.2.1 Sources of information about CAM

Most of the participants mentioned that they got information about CAM from families, friends, and local communities, including information from diabetic or non-diabetic patients. In addition, patients reported that social media platforms were the primary source of information about CAM, especially WhatsApp®. Some participants reported

that they got their information on CAM from videos circulated via WhatsApp®. One participant reported reading about CAM for diabetes in ancient textbooks.

We have a WhatsApp group, and each one of us shares her experience with the group. Each one of us wants to show that she knows about herbs more than the others. [Participant 5, Female, 54 years old, T2D, 22 years since diagnosis]

“I read about it in a book for an Egyptian author called The Green Book. I read old books, not the new ones online. Old books like The Canon of Medicine by Ibn Sina in 4 volumes. I read all of it.” [Participant 18, Male, 65 years old, T2D, 11 years since diagnosis]

7.5.2.2.2 CAM types used and sources of CAM.

Participants described a range of CAM types being used and these could be categorized into herbal and non-herbal CAM types. Most described using herbal medicine for the management of diabetes such as cinnamon and olive leaves. Spice shops were mentioned as the sources of these types of CAM. Others used plants available in the wild such as mugwort and Judean wormwood. They said they picked them themselves from the wild and brought them home. Some patients used a plant called Indian costus, and they bought it from particular vendors. However, they reported that it is often adulterated, i.e. an incorrect and cheaper species of the plant. Participants reported using non-herbal, traditional culturally embedded CAM types such as honey, cupping and ruqya. A separate theme was developed on CAM use influenced by cultural context detailed below.

7.5.2.3 Cultural contexts

Diabetes was not known at the time of the Islamic prophet and there are no specific recommendations for diabetes management in the Islamic literature. However, patients

reported that they interpreted the general recommendations of disease management in Islamic cultures to be applicable to diabetes management. Diabetic patients' decisions to use CAM were influenced by the recommendations found in Islamic literature especially, honey, cupping and ruqya.

7.5.2.3.1 Honey

Honey, which is regarded as a popular treatment approach for all sorts of diseases in Saudi Arabia and the Islamic world was described by three participants for its benefits on diabetes management.¹⁹⁶ They mentioned honey as an alternative management approach for diabetes. They were introduced to honey as a management approach for diabetes either by advice from friends, advertisements on social media or prescribed by CAM practitioners. One participant said that they used honey when they were first diagnosed with diabetes, and they were cured for 10 years before getting diagnosed again with diabetes.

“A colleague of mine kept bees in a good area, and I used their honey with wax for a month. I was completely cured of diabetes for 10 years without medication or diet or anything, and everything was normal.” [Participant 16, Male, 49 years old, T2D, 30 years since diagnosis]

7.5.2.3.2 Cupping

Cupping involves placing devices shaped like cups on a person's skin and creating a vacuum inside the cup, and then tiny incisions are made to drain blood out of the vacuumed areas.¹⁹⁷ The use of cupping for the management of diabetes was mentioned by five participants. Although participants believed cupping is beneficial for diabetes, four of the five participants who talked about it did not use it as they were afraid of such an invasive procedure and worried about the slow wound healing caused

by diabetes. One participant, even though they described using cupping, mentioned that it did not prove to be of any benefit. However, they were still convinced that cupping is beneficial because they believed that the prophet recommended using it.

“There are people who recommend cupping, but because they are harmful to the body, I have not tried them...People do cupping once or twice ... They say that they are good and reduce sugar. I do not like them. They cure it completely, but I am scared of doing them... I am afraid of the way they are done...Maybe I do not know, but I am afraid of them. This is why I have not tried them...Because they are harmful to the body, they burn and hurt the body, especially since I am a diabetic. I do not know whether they will have good or bad consequences.”

[Participant 9, Female, 25 years old, T2D, 17 years since diagnosis]

“I heard that cupping is good for diabetes, but I did not try it. Cupping is good, but you worry about the wound as it might not heal. Then you will have another problem.” [Participant 12, Male, 75 years old, T2D, 20 years since diagnosis]

7.5.2.3.3 *Ruqya*

Ruqya is a practice that is well known in Islamic culture.¹⁹⁸ Ruqya is a form of exorcism usually performed by reciting verses of the Qur'an and prayers for the patient by the person administering the ruqya who is known as Sheikh. Seven participants said that they used ruqya for the management of diabetes. Participants believed that they developed diabetes as a result of the evil eye and deep desire, i.e. when someone wishes to have what someone else has, for example, money or children. They believed that diabetes is not a disease but is merely a symptom of the evil eye and believed that ruqya is the way to cure the evil eye. They believed that once they can be cured of the evil eye, diabetes should disappear. Participants stated many reasons that led them to believe that their diabetes was a result of the evil eye. One participant suggested that

diabetes does not run in the family and is not genetic. The participant stated that their family and friends said that since it is not genetic, the only rational explanation is that diabetes resulted from the evil eye and should be cured using ruqya. Another participant mentioned that they were healthy until they attended a social event, and then they developed diabetes. The participant and their family concluded that the evil eye hit her at that event, and subsequently, they became diabetic. Participants said they had been diagnosed with the evil eye by Sheikhs and were convinced that it hit them.

"The mother was collecting information about different treatments, so I heard about someone who performs ruqya in our tribe. I went to see him, and he said that his daughter had diabetes because of the evil eye. He read Qur'an to me and found signs of the evil eye, but I did not continue with the sessions because the Sheikh moved to another city... The evil eye is true. I am convinced that I was subjected to the evil eye, but I do not know if diabetes will be cured or not."

[Participant 2, Female, 18 years old, T1D, 1 years since diagnosis]

7.5.2.4 Expectations about CAM.

7.5.2.4.1 Patients' expectations from using CAM.

Participants reported many reasons why they resorted to CAM for the management of diabetes. Some described wanting to use CAM in the hope that it might completely cure diabetes as opposed to conventional therapy, which they deemed was merely aimed at controlling blood sugar levels and would not cure diabetes. Participants often said they heard about people who used CAM and were cured of the disease. However, none

of the participants reported that they were permanently cured of diabetes as a result of using CAM.

Patients also expressed feelings of tiredness when using conventional injections or taking pills on a daily basis and wished to use CAM to take a break from the burden of the diabetes dosage regimen.

One participant said that they used olive leaves when the insulin dose they take did not sufficiently lower blood glucose. They also mentioned taking olive leaves infused with water to school instead of insulin as it is easier to take during work hours. The patient also used olive leaves at night instead of insulin as they experienced hypoglycaemia during sleeping if they used insulin before going to bed.

“I do not use olive leaves unless I take my usual dose and the sugar does not drop, then I use olive leaves ... Sometimes, when I go to school, I do not have insulin. I have olive leaves in a water bottle, and when I drink from it, the sugar drops ...When I inject insulin to reduce sugar level slightly, it reduces it significantly, especially when I am sleeping, unlike olive leaves.” [Participant 8, Female, 18 years old, T1D, 2 years since diagnosis]

7.5.2.4.2 Patients' feelings about diabetes that led to using CAM.

Some patients reported that when they were first diagnosed with diabetes, they rejected the diagnosis and resorted to CAM at first in an attempt to reverse the disease from the beginning. They were in a “state of denial” as one participant expressed. Some participants only started using CAM when they had dramatic blood glucose level episodes and had to be hospitalised. In addition to their concerns about the disease

itself, one participant stated that they did not want to be labelled as diabetic, as being diabetic is viewed by society as being abnormal.

“Many people are not convinced that they are diabetics, and they deny that they have diabetes. Like my sister, she never believed that she had diabetes, and now for 4 years, she never took medication and only takes herbs ... patients believe that diabetes is a dangerous thing and abnormal, and they do not want to believe that they have it.” [Participant 1, Female, 50 years old, T2D, 10 years since diagnosis]

7.5.2.4.3 Patients' attitudes towards CAM.

As mentioned previously, many participants demonstrated positive attitudes toward CAM, especially types of CAM with cultural or religious backgrounds, i.e. CAM types which were mentioned in Islamic literature as being therapeutically beneficial were therefore perceived by people as effective for treating diseases such as cupping and ruqya. Many participants also described experiencing positive effects of CAM on diabetes, but they were not sure that the effect was a direct result of using CAM and attributed the results mainly to psychological effects.

One participant said that they believed big pharmaceutical companies will always fight any new potential approach for managing diabetes with CAM as they do not want patients to stop using the medicines they manufacture.

Patients felt that they were subjected to financial exploitation as a result of their condition. One participant said that he felt financially exploited by Sheikhs (people who perform the ruqya) who claimed that they could cure diabetes using ruqya. They diagnosed the condition on the spot as someone affected by the evil eye and charged vast amounts of money. Some participants expressed their frustration at being targeted

by CAM advertisements. One participant said that they were sick and tired of frequently hearing about new CAM types for the management of diabetes. They said that these advertisements target diabetic patients as they make up a significant percentage of the population. Another participant said that owners of farms or herbs market their products to this large segment of society to maximise their profits. These participants expressed that this kind of practice is mentally and physically devastating to patients and added that it is conducted by people who do not even know what diabetes is, let alone have the knowledge about its management.

"Sheikhs charged me huge amounts of money... I decided to stop because I felt it was merely financial exploitation. He recited verses from the Qur'an: the Throne Verse, Al-Fatiha, and the Verses of Refuge... He gave me Zamzam and honey, and when I leave, I pay 1200 to 1300 riyals (£240 - £260) ... I have no problem with the cost, and I can pay for it. I believe in the evil eye, but most Sheikhs exploit you financially. As soon as you see them, they think about money and not your interest. They tell you directly that you suffer from the evil eye, and you must take such and such and such. Most Sheikhs do not ask me any questions to understand my condition. They directly ask what you have? I have diabetes. Then they say it is because of the evil eye. He did not ask any other questions, did not examine my case, and did not delve into the matter, such as when it started, how it started, what was the reason for it, and what is special about me that people will notice." [Participant 21, Male, 24 years old, T1D, 14 years since diagnosis]

7.5.2.5 Reasons for resorting to CAM use.

7.5.2.5.1 Patients do not accept the fact that they have diabetes.

Patients reported that they were not convinced about the diagnosis when they were first diagnosed with diabetes, initially believing that their condition was temporary and

could be cured. However, they believed that if they started using conventional diabetes treatments, diabetes will become permanent. For that reason, patients resorted to using CAM for diabetes in an attempt to reverse the condition.

"At the beginning, I was postponing using the treatment from the hospital because I was told about olive leaves and herbs. I did not want to use diabetes medication because of my mother's advice. She warned me not to take diabetes medications because I will have diabetes for life. The elderly also advised me against it, and I am the type who would listen to such advice." [Participant 5, Female, 54 years old, T2D, 22 years since diagnosis]

7.5.2.5.2 Discussing the condition with other people.

Participants revealed that discussing the condition with people invites all kinds of advice on how to manage their diabetes. The more discussion they had the more they get exposed to a range of different advice from all kinds of people about diabetes management. This exposure to advice could make patients preoccupied with thinking about whether to try the advice and which approach to choose to try to manage their condition, thus increasing the chance of them trying alternative treatments that might or might not be suitable for their condition.

"A person who complains a lot and talks a lot to people about their illness is often more exposed to a large number of advice on treatment methods, receptive to advise and experiences from others without thinking" [Participant 14, Male, 44 years old, T2D, 13 years since diagnosis]

7.5.2.5.3 Apprehension about diabetes complications.

Perceived lack of a patient-centred approach to consultations when visiting doctors was deemed one of the factors that made patients look for alternative management

approaches. Often consultations were deemed to be more ‘instructional’ than ‘collaborative’. Apprehension was raised regarding specific advice, such as overly stressing the importance of diet and warnings about diabetes complications.

“The most important thing is mental health. People with diabetes must be mentally healthy and must accept it. Some doctors frighten you too much. Do not eat this, do not drink that, and do not do this and that etc. It is the reason why patients are desperate and look for alternatives anywhere.” [Participant 11, Male, 25 years old, T1D, 7 years since diagnosis]

7.5.2.6 Patients’ negative concerns about using CAM for diabetes.

7.5.2.6.1 Reasons for stopping the use of CAM.

Some patients who tried CAM had discontinued using it for various reasons. One participant stated that they had to stop using herbal therapy because it was bitter and caused gastrointestinal issues such as stomach pain and too frequent bowel movements, while another participant stated that herbal therapy caused allergies. A participant who said they had good results from using olive leaves for the management of diabetes but had to stop using them because they said they were difficult to obtain, tiring and expensive. They also had to stop using CAM because they had other co-morbidities such as high blood pressure and high cholesterol levels.

Another participant who used raw honey for the management of diabetes stopped using CAM and resorted to conventional therapy because they did not keep bees and could not find the “right type of honey any more”.

One participant stopped using ruqya because the Sheikh administering it had moved to another city, and she could not find a new one. Another participant stated that they

had to discontinue the ruqya sessions because they kept losing consciousness and blood glucose levels dropped significantly during ruqya sessions.

“During the period of my treatment with the Sheikh, I had a severe drop in sugar, to the point that I used to lose consciousness. And since my mother is a teacher, she chose to have sessions during holidays only to be with me. It happens to me after finishing the sessions with the Sheikh and leaving then I lose consciousness. I only wake up by the time I am in the hospital.” [Participant 6, Female, 27 years old, T1D, 17 years since diagnosis]

7.5.2.6.2 CAM-related adverse events.

Besides the participants mentioned above who experienced unconsciousness and severe hypoglycaemia during ruqya sessions, no other participants reported experiencing CAM-related adverse events. However, participants mentioned that they knew others who suffered from severe adverse events. One participant said they knew a woman who used cress seeds, also known as garden cress. They took large quantities of it that accumulated in the intestines and caused a blockage in the intestines. They had to undergo surgery to have the accumulated seed removed. The participant attributed those adverse events to using CAM the wrong way as she said this was supposed to be boiled in water and drunk. She advised that anyone who wants to use CAM should seek advice from people who used it before them for the proper way to use it. Another participant said that herbal therapy had fatal consequences on someone they knew that had used herbs for diabetes that caused his death.

"CAM has serious side effects. I know someone from ... died because of herbs, he had kidney and liver failure from herbs. I don't know what herbs he used, but he

brought them from the UAE. He used them to treat diabetes but instead, they killed him." [Participant 13, Male, 62 years old, T2D, 15 years since diagnosis]

7.5.2.7 Interactions with healthcare professionals.

7.5.2.7.1 Discussing CAM use with healthcare professionals.

Several participants stated that they had attempted to discuss their CAM use with their healthcare professionals. Most patients were not encouraged by their healthcare providers to use CAM to manage diabetes. However, two participants said their healthcare providers did not mind them using CAM as they advised that CAM would not harm them. One participant described that their doctor advised that CAM could be 'effective', but it would not work for everyone. Another participant said that the doctor said that the effect of CAM is primarily psychological. The rest of the participants did not discuss the use of CAM with their healthcare providers. One participant stated that they tried to open up a discussion on the matter with the doctor many times, but the doctor refused to discuss it with her.

"I do not feel that it is opposition as much as it is a refusal to discuss the subject. The doctor might think that it is useful, but they do not have enough knowledge and do not have experience or proof. They refuse to discuss the issue and direct the patient to use standard treatment" [Participant 7, Female, 28 years old, T2D, 6 years since diagnosis]

7.5.2.7.2 Reasons for not discussing the use of CAM with healthcare professionals.

Participants cited many reasons for not discussing their use of CAM with healthcare providers. Many described that the subject was never brought up during clinic visits and the healthcare providers never asked about it. Another reason was that patients were sure that healthcare providers will automatically say 'No to CAM', and therefore

they did not want to discuss it with them. One patient said that they had only a slight effect when using olive leaves compared to insulin. Due to that difference in effectiveness, they did not feel the need to tell the healthcare providers about the type of CAM they used. Some patients did not feel that their providers had enough knowledge to advise them about CAM use. Patients believed that healthcare providers' education and training are limited to the scope of conventional medicine, and they were not specialised in CAM and therefore cannot give advice to patients.

"Doctors only praise the medications they know. Whenever companies produce a new medication, they praise it. They do not know anything about alternative medicine" [Participant 19, Male, 31 years old, T1D, 12 years since diagnosis]

"No, I never discuss it because there are people who are specialised in herbal science, and ordinary doctors do not know enough about it, do not believe in it, and never acknowledge it. There are pharmacologists who are specialised in it and not all doctors. We should only ask a specialist, and not every pharmacist or every doctor knows." [Participant 3, Female, 52 years old, T2D, 27 years since diagnosis]

7.5.3 TDF mapping of behaviours

Behaviours that were identified during thematic analysis were extracted and re-arranged according to the TDF domains (Table 7.3) to inform the recommendations and development of future interventions to optimise CAM use in diabetes.

TDF domain	Behaviour	Sub-theme
1. Knowledge	All participants demonstrated knowledge with regards to long term diabetes complications	7.5.2.1.1
2. Skills	Participants attributed adverse events to using CAM the wrong way	7.5.2.6.2
3. Social/ Professional Role and Identity	Some patients did not feel that their providers had enough knowledge to advise them about CAM use. Patients believed that healthcare providers' education and training are limited to the scope of conventional medicine, and they were not specialised in CAM and therefore could not offer advice to patients	7.5.2.7.2
	Patients were sure that healthcare providers will automatically say 'No to CAM', and therefore they did not want to discuss it with them	7.5.2.7.2
4. Beliefs about Capabilities	The participant stated that their family and friends said that since it is not genetic, the only rational explanation is that diabetes resulted from the evil eye and should be cured using CAM such as ruqya	7.5.2.3.3
5. Optimism	Participants often described that they heard about people who used CAM and were cured of the disease	7.5.2.4.1
6. Beliefs about Consequences	Most participants mentioned that they were aware that uncontrolled diabetes could lead to renal failure, neuropathy and blindness	7.5.2.1.1
	Some participants pointed out that CAM can sometimes be harmful	7.5.2.1.2
	Four of the five participants who talked about cupping did not use it as they were afraid of such an invasive procedure and worried about the slow wound healing caused by diabetes	7.5.2.3.2
	Patients used olive leaves at night instead of insulin as they experienced hypoglycaemia during sleeping if they used insulin before going to bed	7.5.2.4.1

	Patients believed that if they started using conventional diabetes treatments, diabetes will become permanent	7.5.2.5.1
	Apprehension was raised regarding specific advice, such as overly stressing the importance of diet and warnings about diabetes complications	7.5.2.5.3
	One participant said they knew a woman who used cress seeds, also known as garden cress in a large quantity leading to accumulation in the intestines and causing a blockage in the intestines	7.5.2.6.2
	One participant, even though they described using cupping, mentioned that it did not prove to be of any benefit. However, they were still convinced that cupping is beneficial because they believed that the prophet recommended using it.	7.5.2.3.2
	Participants said they had been diagnosed with the evil eye by Sheikhs and were convinced that it hit them.	7.5.2.5.1
7. Reinforcement	Participants revealed that discussing the condition with people invites all kinds of advice on how to manage their diabetes. The more discussion they had the more they get exposed to a range of different advice from all kinds of people about diabetes management.	7.5.2.5.2
	Two participants said their healthcare providers did not mind them using CAM as they advised that CAM would not harm them. One participant described that their doctor advised that CAM could be 'effective', but it would not work for everyone	7.5.2.7.1
	One participant stated that they tried to open up a discussion on the matter with the doctor many times, but the doctor refused to discuss it with her	7.5.2.7.1
8. Intentions	Patients resorted to using CAM for diabetes in an attempt to reverse the condition	7.5.2.5.1
9. Goals	Some described wanting to use CAM in the hope that it might completely cure diabetes as opposed to conventional therapy, which they deemed was merely aimed at controlling blood sugar levels and would not cure diabetes	7.5.2.4.1
	Curing diabetes	7.5.2.4.1

	The majority of the participants often referred to CAM as natural and therefore 'not harmful' or if CAM did not cause improvement, it would not cause harm	7.5.2.1.2
	One participant reported reading about CAM for diabetes in ancient textbooks	7.5.2.2.1
	Participants believed that they developed diabetes as a result of the evil eye and deep desire, i.e. When someone wishes to have what someone else has, for example, money or children	7.5.2.3.3
10. Memory, Attention and Decision Processes	Patients felt that they were subjected to financial exploitation as a result of their condition. One participant said that he felt financially exploited by Sheikhs (people who perform the ruqya) who claimed that they could cure diabetes using ruqya.	7.5.2.4.3
	One participant stated that they had to stop using herbal therapy because it was bitter and caused gastrointestinal issues such as stomach pain and too frequent bowel movements, while another participant stated that herbal therapy caused allergies.	7.5.2.6.1
	One participant stated that they had to discontinue the ruqya sessions because they kept losing consciousness and blood glucose levels dropped significantly during ruqya sessions	7.5.2.6.1
	Patients used plants available in the wild such as mugwort and Judean wormwood.	7.5.2.2.2
11. Environmental Context and Resources	A participant who used raw honey for the management of diabetes stopped using it and resorted to conventional therapy because they did not keep bees and could not find the "right type of honey any more".	7.5.2.4.3
	A participant had to stop using CAM because they said they were difficult to obtain	7.5.2.6.1
	Patients felt that they were subjected to financial exploitation as a result of their condition.	7.5.2.4.3
12. Social influences	Some participants believed that they had some knowledge about CAM effectiveness for diabetes based on what they heard from the general public and other diabetic patients	7.5.2.1.2

	Patients reported that social media platforms were the primary source of information about CAM, especially WhatsApp®	7.5.2.2.1
	Participants reported using non-herbal, traditional culturally embedded CAM types such as honey, cupping and ruqya	7.5.2.2.2
	Honey, which is regarded as a popular treatment approach for all sorts of diseases in Saudi Arabia and the Islamic world was described by three participants for its benefits on diabetes management	7.5.2.3.1
13. Emotion	Some patients reported that when they were first diagnosed with diabetes, they rejected the diagnosis and resorted to CAM at first in an attempt to reverse the disease from the beginning.	7.5.2.4.2
	One participant stated that they did not want to be labelled as diabetic, as being diabetic is viewed by society as being abnormal	7.5.2.4.2
	Many participants also described experiencing positive effects of CAM on diabetes, but they were not sure that the effect was a direct result of using CAM and attributed the results mainly to psychological effects	7.5.2.4.3
	Some participants expressed their frustration at being targeted by CAM advertisements.	7.5.2.4.3
14. Behavioural Regulation	Patients bought CAM from particular vendors. However, they reported that it is often adulterated, i.e. An incorrect and cheaper species of the plant	7.5.2.2.2
	Patients also expressed feelings of tiredness when using conventional injections or taking pills on a daily basis and wished to use CAM to take a break from the burden of the diabetes dosage regimen	7.5.2.4.1

Table 7.3: TDF mapping of behaviours

7.6 Discussion

Saudi Arabia is ranked among the top countries in the world in diabetes prevalence as well as the use of CAM by diabetic patients.^{2, 153} This study provides patient perspectives about their use of CAM for the self-management of diabetes.

A previous study conducted using questionnaires with open-ended questions investigated the use of CAM by diabetic patients in Saudi Arabia.¹⁸⁹ This study however did not use qualitative analysis for the reporting of the findings and was conducted with no direct involvement between the researcher and the participants.

This study was focused and explored in-depth the use of CAM by Saudi diabetic patients and the topic guide was informed by the findings of a systematic review and by the TDF as it addressed behavioural aspects, i.e. patients' choice of using CAM.

7.6.1 Summary and discussion of key findings

A range of perceptions regarding diabetes as a health condition were identified, which affected patients' attitudes and beliefs towards CAM. Patients' denial about having diabetes, especially when they were first diagnosed meant they therefore did not accept diabetes medications and believed that irregular glucose levels they were experiencing was a temporary situation and could be reversed by using CAM. Many other participants believed that the condition was acute and using prescribed medications for it is actually what makes the condition permanent and chronic, and therefore they resorted to CAM use. Such denial has not been reported in previous literature. In addition, many patients described hearing a lot about how horrible diabetes complications could be and they often described experiencing a panic and hence were open to using anything including CAM and this is also has not been reported in previous

literature. As described by participants, clinical consultations and patient education programmes in general about diabetes focus merely on conventional treatments and disease progression and did not include CAM, and this has not been reported in previous literature.

There appears to be a strong cultural influence on participants' beliefs about CAM and practices of CAM use for diabetes. This cultural influence has been previously reported in existing literature and is likely to be different from one country to another based on the specific cultural background.¹⁸¹ Ruqya was also identified to be used by diabetic patients who are not from Saudi Arabia but share an Islamic culture.¹⁵³ Patients interviewed in this study described relying heavily on cultural explanations and embedded practices for their choice of CAM rather than proven effectiveness. Participants in this study were from a majority Muslim country, and they seemed more accepting of any CAM types that are mentioned in Islamic literature to have therapeutic benefits.^{190, 196, 198} The cultural beliefs that patients have extended beyond the benefits of such types of CAM as it also influenced the diagnosis of the disease and patients' perception of diabetes itself, as most participants who used ruqya believed or were convinced by others, i.e. friends or people who administer the ruqya, 'Sheikhs', that they were affected by the evil eye. They believed that diabetes is merely a symptom of the evil eye and not a separate disease on its own, once the evil eye is cured diabetes will disappear. The perception that the evil eye is the cause for diabetes has not been reported in previous literature. This belief was prominent in patients who had difficulties understanding the reasons for their diabetes and tried to associate diabetes causation to something else. Even though patients experienced no benefit from ruqya, they did not dismiss its potential in curing diabetes.

Some participants in this study felt financially exploited as they feel primarily targeted by CAM practitioners and fake advertisements for CAM types because they are vulnerable and desperately looking for relief and this has not been reported in previous literature. These advertisements made patients feel bad about themselves and their condition. Videos circulated via WhatsApp® were one of the main sources of CAM information as described by participants. This calls for more strict regulations on CAM practices and more effective enforcement of direct-to-consumer advertisements on official or social media. As the contents in such videos directly impact diabetic patients' choices of management approach, the contents should be regulated by health authorities. Health authorities should be aware of the content of such videos and should develop educational materials to dispel myths featured in those videos. Saudi Arabia set out regulations for direct-to-consumer herbal supplements as it requires advertisement materials to be licenced by the Saudi FDA.¹⁹⁹ However, there are no regulations in regards to videos circulated through WhatsApp®.

Most participants in this study did not discuss their CAM use with their healthcare provider. It seemed from what participants said as though patients have no trust in their healthcare providers' knowledge in the subject, and they do not trust their provider's ability to counsel them on the subject. As reported by participants, both patients and healthcare providers never bring up the subject. Even though the subject directly impacts diabetes management outcomes and medication adherence, the patients interviewed seemed to view it as something that is out of healthcare providers' scope and not important to be discussed in clinics. Similar reasons for limited discussion about CAM use between patients (not specific to diabetic patients) was reported in a systematic review of 84 studies.²⁰⁰

7.6.2 Implications for practice

The study has highlighted the importance of designing comprehensive diabetes education programmes that consider CAM and offer evidence-based advice as part of diabetes awareness campaigns delivered through health services organisations. The educational programmes should be patient-centred and address patients' fears and concerns rather than merely communicating scientific facts about the disease and its management routine. This study also showed that there was a perception that patient-provider interaction in regards to CAM use was inadequate. These interactions are essential to address all aspects of diabetes management and to acknowledge and integrate patients' choices into clinical consultations to ensure that patients receive all information from a trusted source, i.e. their healthcare providers. Such communications should enhance patients' awareness about CAM and its realistic potential for diabetes management in order to prevent them from being victims or financially exploited and prevent patients from harm. The ability of healthcare providers to discuss in detail all aspects diabetes including CAM use can enable the building of trust between patients and their healthcare providers so that patients would be more willing to discuss their CAM use with their healthcare providers.

Current CAM regulations differ from one country to another. CAM practitioners are not considered medical professionals in many countries.²⁰¹ While CAM practitioners provide patients with choices for management approaches, they should be regulated to some extent as malpractice could pose a risk to patients.

7.6.3 Implications for research

Previous global systematic review revealed that about 2/3rd of diabetic patients who used CAM for diabetes did not disclose their CAM use with healthcare professionals.¹⁵³

The findings of this study provides some reasons for such limited discussions. Participants explained that healthcare professionals did not wish to discuss CAM even if they were asked about it by patients. Therefore, it is essential to understand healthcare providers' views on their patients' use of CAM. Furthermore, the result of this study indicated the importance of cultural context on diabetic patients' CAM use. Further studies should be conducted in different cultural contexts to provide an insight of CAM use by diabetic patients with different cultural background.

Studies on the safety and effectiveness of commonly used CAM types for diabetes would provide evidence-based information that healthcare providers can utilise to assist them to conduct fully informed counselling and consultations with their diabetic patients. This would enable the building of trust between diabetic patients and their healthcare providers and would make clinical consultations more patient centred as it is imperative that patients feel comfortable discussing their own CAM self-management practices and seeking advice about CAM from their healthcare providers.²⁰²

7.5.4 Study strengths and limitations

The sample consisted of close numbers of female and male participants, a wide range of participant ages and duration of diabetes and more T2D patients than T1D patients and thus was able to explore the views of a wide range of diabetic patients. The study also used a topic guide that was developed based on the results of a systematic review and the TDF to maximize the comprehensiveness of produced data.¹⁸¹ Interviews were

carried out by one researcher (AA), a native language speaker, with good knowledge of the cultural context which yielded rich data to the point of data saturation.⁹⁵

The study recruited patients in Saudi who attended clinics for the management of their diabetes. Patients diagnosed with diabetes who do not attend clinics and only use CAM as an alternative management approach are difficult to identify and recruit and might have different opinions than the participants of this study.

7.7 Conclusion

Hidden concerns about diabetes often lead patients to use CAM. Participants in this study perceived that such concerns, including the role of CAM in diabetes, were not appropriately addressed during clinical visits due to lack of trust in their providers' knowledge about CAM. This limited discussion about CAM might have contributed to making diabetic patients' vulnerable to financial exploitation by some CAM providers. Cultural influences played an important role in diabetic patients' decision to use CAM and choice of CAM type. It is important to understand healthcare professional perspectives on CAM use by diabetic patients to inform better counselling and communication practices. It is also important for healthcare professionals to educate patients about diabetes and about CAM, and engage with patients about their CAM use.

Summary of the chapter

This chapter explored diabetic patients' beliefs, practices, and factors associated with CAM use. Some of the findings suggested a lack of communication around CAM use between diabetic patients and their healthcare professionals. For broader view, the next chapter will explore healthcare professionals' perspectives on CAM use by diabetic patients and barriers to effective communications.

CHAPTER 8: QUALITATIVE INTERVIEWS WITH HEALTHCARE PROFESSIONALS

Chapter overview: This chapter will report the views and experiences of healthcare professionals providing care for diabetic patients. The study was conducted using qualitative semi-structured interviews. Recommendations for practice and policy will be made based on the study findings.

Study Title: Healthcare professionals' perspectives on the use of complementary and alternative medicine (CAM) by diabetic patients: A qualitative study.

Note for plagiarism check:

This chapter in its entirety is being submitted for publication. It is likely to be published and be available online by the time of the plagiarism check.

Authors' contributions

Abdulaziz Alzahrani designed and conducted all the stages of the study.

Vibhu Paudyal and Sheila Greenfield supervised Abdulaziz Alzahrani's PhD.

Abdulaziz Alzahrani led the drafting of the chapter to which all authors contributed through editing and revision.

All authors had access to the data sets and agreed to the final version of this chapter.

Ethics approval statement

Ethical approval for the study was obtained from the Saudi Ministry of Health and the University of Birmingham Science, Technology, Engineering and Mathematics Ethical Review Committee. ERN_20-0637

Patient consent statement

Informed consent were obtained from all participants of this study.

8.1 Abstract

Background

Diabetes is highly prevalent worldwide, estimated at 463 million cases in 2019.³ Recent estimates suggest that up to 51% of diabetic patients globally use complementary and alternative medicine (CAM). There is a dearth of literature on healthcare professional perspectives on CAM use by diabetic patients. This study set out to explore healthcare professionals' knowledge, perspective and views on their diabetic patients' use of CAM.

Methods

Qualitative study using one-to-one semi-structured interviews conducted with 22 healthcare professionals involved in the care of diabetic patients (6 endocrinologists, 4 general practitioners, 4 nurses and 8 pharmacists). Participants were recruited through general practices, community pharmacies and a diabetic centre in Saudi Arabia. Data were analysed using thematic analysis.

Results

Five key themes resulted from the analysis. Healthcare professionals generally demonstrated negative perceptions towards CAM, particularly in regards to their evidence-base around effectiveness and safety. They described limited interactions between diabetic patients and providers regarding CAM use due to healthcare professionals' own lack of knowledge about CAM, limited consultation time and strict consultation protocols. They perceived convenience as reason why patients use CAM. They believed that many users lacked patience with prescribed medicines when expecting favourable clinical outcomes and hence resorted to CAM use. Many described feeling less comfortable in offering negative opinions on CAM that had cultural and religious significance from patients' perspectives.

Conclusions

Healthcare professionals described having limited interactions between diabetic patients and healthcare professional regarding CAM. Such limited interactions were attributed to limited knowledge and lack of resources. The gap in communication between diabetic patients and healthcare professionals needs to be improved to optimise treatment outcomes through flexible consultation time, accommodating consultation protocols to allow CAM discussions and through provision of culturally sensitive and evidence-based information provision to both diabetic patients and healthcare professionals.

8.2 Background

The management of diabetes involves the use of conventional medicine and self-care and self-management approaches.¹⁷⁶ The use of CAM for the self-management of diabetes is prevalent globally, estimated at 51%.¹⁵³ The prevalence of CAM use varies between countries, ranging between 8%-89%. The prevalence of diabetic patients' CAM use in Saudi Arabia is one of the highest worldwide ranging between 25.8%-64%.¹⁵³ It is estimated that up to two thirds of diabetic patients who use CAM do not discuss their use of CAM with their healthcare professionals.¹⁵³

Healthcare professionals are expected to support patient self-care and self-management to improve disease outcomes and quality of life.¹⁰⁸ CAM use by diabetic patients that is not taken into account during clinical consultations by qualified healthcare professionals could adversely affect the disease outcomes. For example, patients might completely give up on conventional medicine and use CAM instead as an alternative to their prescribed medicines increasing the risk of developing diabetes related complications.¹¹ Moreover, patients using CAM with their prescribed medicines could encounter CAM-drug interactions, particularly with herbal products, that could interfere with effectiveness of the prescribed medicines as well as lead to harmful outcomes.²⁰³ It is crucial for healthcare professionals who develop and monitor diabetes management plans for their patients to be fully aware of all aspect of their patients' self-management practices including the use of CAM, and benefits and risks associated with CAM use should be discussed openly.

Previous cross-sectional studies have explored healthcare professionals' views on CAM use by patients, however, these are not focused on diabetes.²⁰⁴⁻²⁰⁶ Existing literature exploring healthcare professional perspectives on CAM use by diabetic

patients is limited. One study conducted in Uganda explored the use of CAM by diabetic patients from patient's and healthcare professionals' perspective.¹⁶¹ Another study conducted in Saudi Arabia with T2D patients and physicians only focused on herbal medicines.¹⁶⁶ Both studies were conducted using cross-sectional, closed ended questionnaires. The first study¹⁶¹ reported the healthcare professionals had a relatively positive attitude towards their patients CAM use while the second study¹⁶⁶ described that the majority of participating healthcare professionals had a negative attitude towards their diabetic patients herbal medicine use. There is limited research exploring in-depth, using qualitative design, healthcare professionals' perspectives on their diabetic patients CAM use.

This study aimed to explore the views and experiences of healthcare professionals regarding the use of CAM for diabetes self-management by diabetic patients in Saudi Arabia.

8.3 Method

The study used one-to-one qualitative in-depth semi-structured interviews with healthcare professionals working with diabetic patients in Saudi Arabia.¹⁹¹

8.3.1 Study setting

Due to the restrictions that were set in place during COVID-19 pandemic, interviews with participants were conducted via telephone. The participants selected their interview date and time and were asked to choose an appropriate and private location to receive the interview call to protect participants' privacy and confidentiality. The researcher also made the calls using in a designated private room to protect the privacy of the participants.

8.3.2 Sampling and recruitment

Healthcare professionals directly involved in medical care for diabetic patients were included. Since visiting healthcare facilities was not allowed during COVID-19 lockdown period(s), potential participants were identified through the Saudi Ministry of Health directory, and contacted by phone by calling healthcare facilities in Albaha region, Saudi Arabia. Participants were recruited from hospitals, general practices, community pharmacies and a diabetic centre. Invitation letters were provided to potential participants through clinic's emails. A purposive maximum variation sample was adopted.⁸² The maximum variation sampling approach was set to ensure that the sample was as diverse as possible aiming to include healthcare professionals with different occupational roles in diabetes patient care i.e. pharmacists, general practitioners, nurses and endocrinologists. The sampling strategy was set to recruit participants from all mainstream medical professions that are directly involved in the care of diabetic patients. Participants were asked to confirm their eligibility to participate in the study by confirming that they are directly involved in the care of diabetic patients. A total of 10 participants were initially recruited and this number was increased by 3 participants at a time until data saturation was achieved, i.e. no new themes emerged, at 16 interviews. Six further interviews were carried out to confirm data saturation increasing the total number of participants to 21^{193, 194}

8.4 Data collection

All interviews were carried out by AA, a PhD student in pharmacy at the University of Birmingham, UK and a native to Albaha region in Saudi Arabia. The interviews lasted an average of 45 minutes. The interview schedule (Appendixes) was developed based on previous findings in the literature and the authors' previous work.^{37, 153, 181, 207} Prior

to the conduct of interviews, topic guide was examined by colleagues enrolled in PhD research at the University of Birmingham and their comments were utilized to amend the topic guide. Participants were given a choice for the interview to be carried out in Arabic or English. Based on the participants' preferences, 4 interviews were conducted in English and 18 interviews were conducted in Arabic. Interviews were recorded and transcribed in the original languages of the interview. The interview transcripts of the interviews that were conducted and transcribed in Arabic were translated into English before data analysis using a UK based, University of Birmingham approved, professional translation service. Transcripts sent for translation were assigned different codes than the original transcript codes.

8.5 Data analysis

Data were analysed using thematic analysis.¹⁹⁵ This analytical method is applied in order to produce themes from raw qualitative data by grouping similar data into a single topic.¹⁹⁵ Interview transcripts were coded tagged with keywords or "codes". Parts and segments of transcripts were coded with similar codes and grouped together to form categories based on their similarities. The categories were then grouped into themes. The themes developed were then plotted in thematic illustrations summarizing all the resulting themes. Two of the authors AA and VP independently reviewed interview transcripts and agreed on the themes with further discussion with third author SG where needed.

8.6 Results

8.6.1 Sample characteristics

The 22 healthcare professionals who took part consisted of 8 pharmacists, 6 endocrinologists, 4 general practitioners and 4 nurses. Participants were recruited from

a diabetic centre (9), hospitals (2), general practices (9) and community pharmacies (2). (Table 1). Information about the participants' years of experience and their involvement in the care of diabetic patients were collected at the beginning of each interview.

Table 8.1: Participants information.

Participant	Profession	Years of experience	Place of work
Participant 1	Pharmacist	2	Diabetes Centre
Participant 2	Pharmacist	13	Diabetes Centre
Participant 3	Pharmacist	6	Community Pharmacy
Participant 4	Pharmacist	14	Community Pharmacy
Participant 5	Pharmacist	12	General Practice
Participant 6	Pharmacist	11	General Practice
Participant 7	Pharmacist	7	Hospital Pharmacy
Participant 8	Pharmacist	4	Hospital Pharmacy
Participant 9	Endocrinologist	25	Diabetes Centre
Participant 10	Endocrinologist	15	Diabetes Centre
Participant 11	Endocrinologist	30	Diabetes Centre
Participant 12	Endocrinologist	28	Diabetes Centre
Participant 13	Endocrinologist	9	Diabetes Centre
Participant 14	Endocrinologist	6	Diabetes Centre
Participant 15	General Practitioner	12	General Practice
Participant 16	General Practitioner	10	General Practice
Participant 17	General Practitioner	15	General Practice
Participant 18	General Practitioner	6	General Practice
Participant 19	Nurse	9	Diabetes Centre
Participant 20	Nurse	11	General Practice
Participant 21	Nurse	2	General Practice
Participant 22	Nurse	13	General Practice

8.6.2 Key themes and summary of the findings

From the thematic analysis, five main themes relating to healthcare professionals' attitudes towards CAM, views on their diabetic patients' use of CAM and information about discussing the use of CAM with their diabetic patients emerged from the interviews each with their individual subthemes (Table 2).

Table 8.2: Key themes and subthemes.

No.	Themes	Sub-themes
1	Healthcare professionals' attitude toward their diabetic patients' CAM use	<i>General attitude towards using CAM for the management of diabetes</i> <i>Limited circumstances when healthcare professionals' permit the use of CAM for their patients</i> <i>Circumstances where healthcare professionals advise using CAM to their patients</i>
2	Healthcare professionals' perspectives on the reasons for diabetic patients' use of CAM	<i>Patients' exposure to advice</i> <i>Patients' feelings and expectations</i> <i>Countering side effects of conventional medicines</i> <i>Convenience</i>
3	Healthcare professionals' views on safety and effectiveness of CAM for the management of diabetes	<i>CAM safety and effectiveness</i> <i>Determining CAM effectiveness</i> <i>Reporting CAM related side effects and adverse events</i>
4	Cultural perspectives around certain CAM types	<i>Ruqya</i> <i>Cupping</i> <i>Honey</i> <i>Cauterization</i> <i>Folk healers</i>
5	Discussing CAM use with the diabetic patients	<i>Frequency and nature of discussions</i> <i>Barriers to effective communications around CAM</i>

8.6.2.1 Healthcare professionals' attitudes toward their diabetic patients' CAM use.

8.6.2.1.1 General attitude towards using CAM for the management of diabetes.

Participating healthcare professionals in general had a negative attitude towards their patients using CAM for the management of diabetes. They perceived CAM as ineffective in managing diabetes and possibly harmful. One participant stated that even if a certain type of CAM is promising, CAM lack adequate research and development procedures to establish their effectiveness. Participants also described variations in components of herbal treatments depending on environmental factors and extraction procedures.

“A plant can have the same shape, the same name and belong to the same family. However, it might produce two different components if it was planted in different places. If it were planted in one part of the mountain, it could contain a different component if it was planted in another part of the mountain ... but if we extract the chemical compound from the herb, and it was possible to measure the concentration of the drug and the concentration of the substance, such as digoxin, then it is acceptable because it went through the same stages that chemical drugs go through. However, the way alternative medicine and traditional medicine are currently, I do not agree with them” [Participant 2, Pharmacist, 13 years of experience]

8.6.2.1.2 Limited circumstances when healthcare professionals' permit the use of CAM for their patients.

Some participants were more lenient about the use of CAM for the management of diabetes. They would not mind their patients using some known types of herbs such as cinnamon and fenugreek. They perceived these as well known and harmless. Healthcare professionals also stated that CAM should be taken in small quantities as

using large quantities of CAM or using CAM frequently is unacceptable. Participants mentioned that their patients often brought herbal products with unknown ingredients from countries such as China, India, Indonesia, Egypt and the Ukraine. Healthcare professionals did not often approve of the types of herbs their patients bring from abroad.

“Some patients brought strange herbs from China and India, the ingredients were unknown, and I did not advise them to use them because this could have unknown complications. We advise them to use alternatives from well-known companies whose content is known” [Participant 10, Endocrinologist, 15 years of experience]

8.6.2.1.3 Circumstances where healthcare professionals advise using CAM to their patients.

Most of the participants described never having advised or prescribed CAM to their patients in clinical settings. However, two participants stated that under very limited circumstances such as where patients were feeling ‘hopeless’, they had recommended the use of CAM.

“I use honey on patients. I have honey that I brought from a trusted source. Of course, we are prohibited from using honey in the clinic, but I use it as a desperate measure for hopeless cases” [Participant 20, Nurse, 11 years of experience]

8.6.2.2 Healthcare professionals’ perspectives on the reasons for diabetic patients’ use of CAM

8.6.2.2.1 Patients’ exposure to advice

Participants reported that their diabetic patients often referred to receiving a lot of advice from others, mainly family, friends and other diabetic patients. Healthcare

professionals were aware of CAM related advertisement materials circulated to patients through WhatsApp®. Healthcare professionals believed that these materials had a strong influence on their patients' decisions to try CAM. Participants also reported that direct-to-patient advertisements conducted by dietary supplement sales representatives also influenced diabetic patients' decision to use CAM.

“Some companies' representatives do come here promoting some products to patients claiming they are good for diabetes such as preparations containing vitamins and iron. But to avoid side effect I always tell them not to promote it to any type of patient” [Participant 9, Endocrinologist, 25 years of experience]

8.6.2.2.2 Patients' feelings and expectations.

Patients' feelings of boredom and tiredness from diabetes management routines were deemed by participants to have forced diabetic patients to seek alternative treatments in an attempt to find something that would provide a faster recovery. Moreover, because of the reputation of diabetes having 'horrible' outcomes such as neuropathy and nephropathy patients were often deemed to get desperate and hence were open to try anything. One participant stated that after initial diagnosis, patients usually could not get their blood glucose level under control as the first few weeks were usually for dose adjustment. However, they described that patients often jumped to the conclusion that conventional medicines did not work for them and used CAM as an alternative diabetes management approach. Participants described that patients were aware that conventional medicines do not offer a permanent cure for diabetes and therefore they tried CAM in an attempt to find a cure. Some patients especially ones with uncontrolled diabetes used CAM as they believed it had a synergistic effect that potentiates the effect of conventional medicines, or they use CAM as the last resort after everything

else fails, according to participants. A participating pharmacist said that patients used some plants that had a very strong bitter taste thinking because of their bitterness they could lower blood glucose. Diabetes is translated to 'sugar disease' in Arabic. The name sugar disease has caused a widespread belief that diabetes is caused by sweets, so it is believed that opposite, bitter things, would reverse the disease.

"In some cases, the doctor will prescribe a medication, based on one's condition, and they use it but see no benefit in the first week. They are supposed to follow the treatment given to them by the doctor intensively for the first month to be able to adjust the dose. However, they jump into the conclusion that the doctor could not help them and does not know anything. Then they resort to other solutions"

[Participant 2, Pharmacist, 13 years of experience]

8.6.2.2.3 Countering side effects of conventional medicines

Healthcare professionals described that some patients used CAM to counter the side effects of conventional medicines. Patients had been convinced by folk healers that CAM they provided would not have the side effects that conventional medicines cause. A nurse participant said some patients were convinced prescribed treatments cause sexual health issues and used CAM instead to avoid this, and even though this was a major concern for patients they were reluctant to discuss it,

"Patients use CAM to avoid the effect of diabetes tablets on them sexually, and this is the most important reason...I do not know; I just hear hints from patients. It is impossible for someone to be open about it. But I expect that they read and hear about it, and then they become psychologically affected by it ... They use it as an alternative for treating diabetes because they believe that conventional medications cause erectile dysfunction." [Participant 20, Nurse, 11 years of experience]

8.6.2.2.4 Convenience

Many participants mentioned that diabetic patients resorted to CAM in an attempt to avoid following a strict diet and regular exercise. Some diabetic patients would like to continue their sedentary lifestyle and eat what they want without being worried about the effect on blood glucose levels.

Convenience of location was a perceived factor for using CAM by patients in rural areas as hospitals were far away and appointments were difficult to obtain. Therefore, patients resorted to CAM and to folk healers instead for the management of their diabetes.

“Patients complain that hospitals are overcrowded, appointments are far apart, and it is difficult to communicate with a doctor. They find it easier to go and see someone else, pay them 100 riyals only and end of story...The further the person lives from the city, the more they are inclined to use alternative medicine. It is easier for people living in rural areas to go and see folk healers than to go to the city, which can be 60km away.” [Participant 4, Pharmacist, 14 years of experience]

8.6.2.3 Healthcare professionals' views on safety and effectiveness of CAM for the management of diabetes.

8.6.2.3.1 CAM safety and effectiveness.

Participants' views on the safety of CAM were subjective according to whether the type of CAM used is well known or not. They considered CAM types available in the market such as cinnamon and fenugreek to be safe. Some of the participants perceived them as natural and therefore safe. They were however reluctant to judge the safety of less popular CAM types such as some other herbal medicines, homeopathy or acupuncture.

Participants had a neutral attitude toward the effectiveness of CAM. They did not dismiss the potential of CAM being effective for diabetes but at the same time they did not believe that it is effective as currently there was no evidence of its effectiveness. They reported having no experience of effectiveness of CAM for diabetes except on rare occasions when they observed slight improvements in their patients. One participating pharmacist questioned all indications regarding CAM effectiveness reported by his patients such as noticing lowered blood glucose, and always told their patients that ‘correlation does not imply causation’.

“I believe that they are some kind of medicines like which are completely based extracted from the plant or the natural organic products only they must have some beneficial effects but there are many fake medicines as well so patients should be careful about what they are purchasing and they should know the ingredients from whoever is giving them. I'm telling them again and again to just ask the person whoever is giving and making them the main of the ingredients at least you should know the ingredients because you don't know they just give you and you don't know what you're using.” [Participant 18, General Practitioner, 6 years of experience]

8.6.2.3.2 Determining CAM effectiveness.

Participants stated that there was no feasible and reliable way to measure the effectiveness of CAM. They said the only remotely credible way was to observe improvement reported by patients in their glycaemic control. They described that many other confounding factors such as psychological effects and changes in diet or physical activities could play a role in that improvement.

“I cannot be sure. The improvement may be that she adhered to the treatment better or that the diet was better. If it happened during a period when I changed

her treatment and noticed an improvement, then I can judge that the improvement was caused by the new treatment. For this patient we would have made a dose adjustment for her from the previous time. Therefore, it cannot be judged that the mix was the reason for the improvement.” [Participant 13, Endocrinologist, 9 years of experience]

8.6.2.3.3 Reporting CAM related side effects and adverse events.

None of the participants in this study had ever reported any side effects of CAM to the Saudi National Pharmacovigilance and Drug Safety Centre. One reason according to them was that they have never witnessed side effects or adverse events associated with CAM that were worth reporting. In addition, side effects and adverse events attributed to CAM had never been brought up by patients and therefore professionals would never know if there are any significant side effects or adverse events that should be reported. Moreover, participants did not think that side effects or adverse events that are associated with CAM use for diabetes should be reported as they thought only side effects associated with medicines should.

“If it happens, it is mostly an allergy to the ingredients, but it is rare. For example, you ask a patient about the cause of allergy, and they say that he used such and such. For example, aloe vera, some people are allergic to it ... it is not a well-known product on the market for me to report it. For example, some people are allergic to eggs, it makes no sense that I report that this person is allergic to eggs. Aloe vera is found anywhere, and it is not a medicinal product. If there was a well-known promoted product and I noticed side effects, then I report it.” [Participant 7, Pharmacist, 7 years of experience]

8.6.2.4. Cultural perspectives around certain CAM types.

The majority of Saudi Arabia's population are Muslims.⁴⁴ Several texts in Islamic literature recommend approaches to treating diseases, especially honey, cupping, and ruqya.¹⁹⁰ Participants reported that the recommendations in Islamic literature influenced diabetic patients' choice of CAM use. Diabetic patients also used CAM types that are not recommended in Islamic literature but are popular in local Saudi culture such as cauterization and folk healers. A diagnosis of diabetes was not known to the Islamic prophet, and the Islamic literature does not offer specific advice for treating diabetes. However, participants described that many patients interpret the recommendations found in Islamic literature to be relevant to diabetes management.

8.6.2.4.1 Ruqya.

Ruqya is a practice that is well known in Islamic culture.¹⁹⁸ Ruqya is a form of exorcism usually performed by a person called Sheikh who recite verses of the Qur'an and prayers for the patient. Participants were aware of patients who believed that they were hit by the evil eye and the diabetes they developed was not a disease on its own but rather a symptom of the evil eye, and once the evil eye is cured through ruqya, the diabetes will be cured as well.

Some participants expressed concerns that they knew that Sheikhs often advised patients to stop using diabetes medications and rely on ruqya alone which causes low adherence and results in uncontrolled diabetes. A participating endocrinologist expressed her concerns that if patients started believing that the cause of diabetes is evil eye, they would stop using their prescribed medications as they would naturally believe that conventional medicine would not be effective for the management of their

diabetes; and that would lead to a whole set of issues caused by their uncontrolled diabetes.

Another participating endocrinologist explained that this belief was more prominent among parents with young diabetic children than adult diabetic patients. She explained that the reason for that was when children are first diagnosed with diabetes they start off with the treatment using insulin injections unlike adults who start on oral medications. This was seen by the parents as invasive and they found it difficult to accept or even comprehend the situation. Therefore parents resorted to explaining their children's diagnosis of diabetes to be associated with the evil eye. However, some participants believed that ruqya might be beneficial for other diseases but not diabetes. A participating pharmacist said that if the diabetes is caused by the evil eye, ruqya might slow down diabetes progression and help prevent complications but would never cure it.

“Some Sheikhs convince them that they suffer from evil eye or some type of black magic in the tummy then they stop taking the medication and resort to spiritual treatment and oils etc. Then they believe they are getting better, but it is an illusion, when in fact their condition is getting worse” [Participant 6, Pharmacist, 11 years of experience]

8.6.2.4.2 Cupping.

Cupping involves placing devices shaped like cups on a person's skin and creating a vacuum inside the cup, then small incisions are made to drain blood out of the vacuumed areas.¹⁹⁷ A participating pharmacist doubted that cupping - performed as it is now- would have any impact on diabetes. The participant explained that there were no specialized, fully qualified people that could properly perform cupping. Another

participating pharmacist said that cupping might be beneficial for external illnesses such as headache and muscle aches but would not affect internal diseases such as diabetes. A participating nurse said that cupping had a temporary effect in diabetes, once that initial effect wears off, the condition returned to the way it was, therefore, cupping was not a suitable way to treat diabetes. Participants expressed the difficulties of advising against CAM types that have a religious background.

“Cupping has religious roots. It is difficult to convince patients that cupping has no effect.” [Participant 4, Pharmacist, 14 years of experience]

“I try to respect the socioeconomic and traditional practices of my patients.”
[Participant 9, Endocrinologist, 25 years of experience]

8.6.2.4.3 Honey

Honey is highly regarded in Islamic culture as a treatment for all sort of diseases.¹⁹⁶ Participants described honey as one of the CAM types that is favoured by diabetic patients. Participants also described that they noticed that honey was effective in some cases, especially for diabetic foot. Participants expressed that only pure and natural honey could be beneficial and even allowed honey to be used for patients in clinics.

“I noticed that honey is somewhat more useful than the ointments which are distributed to them from the Centre or hospital in speeding up wound healing if the honey is pure.” [Participant 21, Nurse, 2 years of experience].

“honey is really good it's like kind of expensive I don't know how much they get it for I don't know how much kilo for 300 riyals, something like, but it is very it is very beneficial so if they're bringing the honey with them, we have told the nurses OK fine if they want and if they are satisfied with it OK” [Participant 17, General Practitioner, 15 years of experience].

8.6.2.4.4 Cauterization.

Cauterization or cutaneous cautery refer to the process of using a hot iron rod and applying it to parts of the body causing tissue burns and damages in an attempt to treat diseases.²⁰⁸ Participants said that some patients went to people who perform cauterization in the hope of curing diabetes. The patients got cauterized on their hands, feet, chin, knees and other part of their bodies. One general practitioner said that even though patients did not get any result from it, they seemed satisfied and very happy about being cauterized. A Pharmacist explained that cauterization and acupuncture were similar to a certain extent. Both were assumed to revive the pancreas, but he said that was impossible as the diabetic patient's pancreatic cells are virtually destroyed beyond repair. Participants expressed their concern about the slow healing of wounds in diabetic patients who underwent cauterization and the possibility of getting the cauterization wounds infected.

“Sometimes they use cauterisation on a hand or a leg to treat diabetes, but it causes other problems and end up in an endless maze which they are better off without ... Diabetic patients see people for cauterisation, and then gets into the trouble of cauterising and changing dressings daily while there was no need for the hassle until the cauterisation wound was heals.” [Participant 22, Nurse, 13 years of experience]

8.6.2.4.5 Folk healers.

Participants shared their views and experiences about their diabetic patients visiting folk healers. They expressed their concerns that folk healers were not trained or specialized. They were also concerned that there was no way to be able to tell which folk healers actually knew what they were doing and which were frauds and only

claiming to be able to treat diabetes for financial exploitation. They also explained that folk healers were seen more by patients who lived in rural areas compared to patients who lived in cities. However, patients did travel to other places to see folk healers. Healthcare providers explained that some folk healers claimed they could permanently cure diabetes, while some other folk healers were targeting people with a family history of diabetes that had not been diagnosed with diabetes yet, and claim that they could provide treatments that would prevent its development. Participants expressed their lack of ability to advise patients about what they had been provided with from the folk healers, as the folk healers did not reveal their “secrets of the trade” and patients were provided with remedies with unknown content.

“Folk healers give them mixes which I do not know. They do not give them to the patients to apply them. Instead, the folk healers apply them themselves by giving the patients appointments. I do not know their ingredients. They tell the patients that they cannot give them the herbs to use at home because it is a secret recipe.”
[Participant 20, Nurse, 11 years of experience]

“Diabetes in general has a bad reputation among patients, like it damages kidneys and eyes etc. People in this position are desperate and cling to any hope to recover from it. They look for folk healers and alternative medicine treatments and want to find something to achieve full recovery.” [Participant 5, Pharmacist, 12 years of experience].

“Standard medications are not approved until they are tested by the Food and Drug Authority and checked for impurities. Folk healers must supervised and have whatever they offer to people should be tested.” [Participant 14, Endocrinologist, 6 years of experience].

8.6.2.5 Discussing CAM use with diabetic patients.

8.6.2.5.1 Frequency and nature of discussions.

Healthcare professionals reported that they had never discussed or rarely discussed the use of CAM with their diabetic patients. On the rare occasions that they did, the patients initiated the discussions about their CAM use as it was not part of the regular consultation. On some occasions, patients asked about certain types of CAM for which they read or heard about the benefits for diabetes. Most participants advised patients not to use CAM except on rare occasions when they agreed to their patients using types of CAM that are well-known to be safe. As diabetic patients did not discuss their use of CAM with their professionals, participants acknowledged that limited discussions on CAM use with their diabetic patients would make it difficult to get an accurate evaluation of patients' medication adherence or CAM-drug interactions. A general practitioner participant explained that they do ask the patients in general about anything else they use in an attempt to prevent overdosing, especially in patient with polypharmacy, i.e. patients taking multiple medications at the same time. They described that some patients talk about types of CAM that they use when they asked about that.

“Some patients use medications from outside pharmacy so when they come to us we have to evaluate them. Majority of patients which we see have poly pharmacy we call it that if they use more than five medications at the same time. We ask them are you taking other things from another hospital or some other medications. Some patients replied that they use CAM.” [Participant 16, General Practitioner, 10 years of experience]

8.6.2.5.2 Barriers to effective communications around CAM.

Participants cited many reasons why they did not discuss their diabetic patients' use of CAM during consultations. Short appointments times were cited as a barrier as patients do not have enough time to discuss CAM. Additionally, lack of knowledge was another commonly mentioned barrier. Participants pointed out that CAM was never part of their official medical education or professional training at any stage. On rare occasions that patients did ask for consultations about CAM, healthcare providers said that they did not have any sources or guidelines to use in order to provide professional or reliable advice. Participants explained that even if they hypothetically wanted to discuss the use of CAM with their diabetic patients, they were restricted by the approved protocols that are set in place by the Ministry of Health which do not allow any discussion with the patients outside the scope of conventional management.²⁰⁹ Some described that healthcare professionals would be legally liable if they advise the patients on CAM use for diabetes.

“We do not have in-depth knowledge about them and there are no scientific studies on them. The field is not motivating to conduct studies because they are not recognised anyway. If you look for information related to it, you may face legal consequences if you directed, advised or provided medical advice to a patient on any type of complementary and alternative medicine and they experience complications or risks.” [Participant 3, Pharmacist, 6 years of experience]

“I cannot advice. We do not have the capabilities, resources, laboratories, or sufficient experience and research. Most of the alternative medicine is promoted based on personal experience, regardless of its credibility” [Participant 7, Pharmacist, 7 years of experience]

8.6.3 TDF mapping of behaviours

Behaviours that were identified during thematic analysis were extracted and re-arranged according to the TDF domains (Table 8.3) to inform the recommendations and development of future interventions to optimise CAM use in diabetes.

TDF domain	Behaviour	Sub-theme
1. Knowledge	Participants described variations in components of herbal treatments depending on environmental factors and extraction procedures	8.6.2.1.1
	Participants stated that there was no feasible and reliable way to measure the effectiveness of CAM	8.6.2.3.2
	Participants did not think that side effects or adverse events that are associated with CAM use for diabetes should be reported as they thought only side effects associated with medicines should.	8.6.2.3.3
	A pharmacist explained that cauterization and acupuncture were similar to a certain extent. Both were assumed to revive the pancreas, but he said that was impossible as the diabetic patient's pancreatic cells are virtually destroyed beyond repair	8.6.2.4.4
	Lack of knowledge was a commonly mentioned barrier to communication between patients and healthcare professionals	8.6.2.5.2
2. Skills	Participants shared their views and experiences about their diabetic patients visiting folk healers. They expressed their concerns that folk healers were not trained or specialized.	8.6.2.4.5
	Participants pointed out that CAM was never part of their official medical education or professional training at any stage	8.6.2.5.2
3. Social/ Professional Role and Identity	Participants explained that even if they hypothetically wanted to discuss the use of CAM with their diabetic patients, they were restricted by the approved protocols that are set in place by the Ministry of Health which do not allow any discussion with the patients outside the scope of conventional management	8.6.2.5.2
	Some described that healthcare professionals would be legally liable if they advise the patients on CAM use for diabetes	8.6.2.5.2

	Participants expressed their lack of ability to advise patients about what they had been provided with from the folk healers, as the folk healers did not reveal their “secrets of the trade”	8.6.2.4.5
	One participant stated that even if a certain type of CAM is promising, CAM lack adequate research and development procedures to establish their effectiveness.	8.6.2.1.1
4. Beliefs about Capabilities	Participants were aware of patients who believed that they were hit by the evil eye and the diabetes they developed was not a disease on its own but rather a symptom of the evil eye, and once the evil eye is cured through ruqya, the diabetes will be cured as well.	8.6.2.4.1
	A participating pharmacist doubted that cupping - performed as it is now- would have any impact on diabetes. The participant explained that there were no specialized, fully qualified people that could properly perform cupping	8.6.2.4.2
	Participants had a neutral attitude toward the effectiveness of CAM. They did not dismiss the potential of CAM being effective for diabetes but at the same time they did not believe that it is effective as currently there was no evidence of its effectiveness	8.6.2.3.1
5. Optimism		
	Participants considered CAM types available in the market such as cinnamon and fenugreek to be safe	8.6.2.3.1
	Healthcare professionals did not often approve of the types of herbs their patients bring from abroad	8.6.2.1.2
6. Beliefs about Consequences	Some patients especially ones with uncontrolled diabetes used CAM as they believed it had a synergistic effect that potentiates the effect of conventional medicines	8.6.2.2.2
	Because of the reputation of diabetes having ‘horrible’ outcomes such as neuropathy and nephropathy, patients were often deemed to get desperate and hence were open to try anything	8.6.2.2.2

	Diabetes is translated to 'sugar disease' in Arabic. The name sugar disease has caused a widespread belief that diabetes is caused by sweets, so it is believed that opposite, bitter things, would reverse the disease	8.6.2.2.2
	Side effects and adverse events attributed to CAM had never been brought up by patients and therefore professionals would never know if there are any significant side effects or adverse events that should be reported	8.6.2.3.3
7. Reinforcement	Some participants expressed concerns that they knew that Sheikhs often advised patients to stop using diabetes medications and rely on ruqya alone which causes low adherence and results in uncontrolled diabetes	8.6.2.4.1
	Participants acknowledged that limited discussions on CAM use with their diabetic patients would make it difficult to get an accurate evaluation of patients' medication adherence or CAM-drug interactions	8.6.2.5.1
	Healthcare professionals described that some patients used CAM to counter the side effects of conventional medicines	8.6.2.2.3
8. Intentions	Some other folk healers were targeting people with a family history of diabetes that had not been diagnosed with diabetes yet, and claim that they could provide treatments that would prevent its development	8.6.2.4.5
9. Goals	Participants said that some patients went to people who perform cauterization in the hope of curing diabetes	8.6.2.4.4
	Healthcare professionals said the only remotely credible way was to observe improvement reported by patients in their glycaemic control	8.6.2.3.2
10. Memory, Attention and Decision Processes	Participants expressed that only pure and natural honey could be beneficial and even allowed honey to be used for patients in clinics	8.6.2.4.3
	Patients asked about certain types of CAM for which they read or heard about the benefits for diabetes	8.6.2.5.1
	Convenience of location was a perceived factor for using CAM by patients in rural areas as hospitals were far away and appointments were difficult to obtain	8.6.2.2.4

	Short appointments times were cited as a barrier as patients do not have enough time to discuss CAM	8.6.2.5.2
	Healthcare providers said that they did not have any sources or guidelines to use in order to provide professional or reliable advice	8.6.2.5.2
12. Social influences	Participants reported that their diabetic patients often referred to receiving a lot of advice from others, mainly family, friends and other diabetic patients	8.6.2.2.1
	A nurse participant said some patients were convinced prescribed treatments cause sexual health issues and used CAM instead to avoid this, and even though this was a major concern for patients they were reluctant to discuss it	8.6.2.2.3
13. Emotion	Children start off with the treatment using insulin injections unlike adults who start on oral medications. This was seen by the parents as invasive and they found it difficult to accept or even comprehend the situation. Therefore parents resorted to explaining their children's diagnosis of diabetes to be associated with the evil eye	8.6.2.4.1
	One general practitioner said that even though patients did not get any result from it, they seemed satisfied and very happy about being cauterized	8.6.2.4.4
	Patients' feelings of boredom and tiredness from diabetes management routines were deemed by participants to have forced diabetic patients to seek alternative treatments	8.6.2.2.2
	One participant stated that after initial diagnosis, patients usually could not get their blood glucose level under control as the first few weeks were usually for dose adjustment	8.6.2.2.2
14. Behavioural Regulation	One participant stated that after initial diagnosis, patients usually could not get their blood glucose level under control as the first few weeks were usually for dose adjustment. However, they described that patients often jumped to the conclusion that conventional medicines did not work	8.6.2.2.2
	Many participants mentioned that diabetic patients resorted to CAM in an attempt to avoid following a strict diet and regular exercise	8.6.2.2.4

Table 8.3: TDF mapping of behaviours

8.7 Discussion

8.7.1 Summary and discussion of key findings

The aim of this study was to explore the use of CAM by diabetic patients from the healthcare professionals' perspective. Consistent with existing literature,²⁰⁷ we found that participants in general had a negative attitude towards their patients' use of CAM for the management of diabetes. However, this study highlighted limited circumstances where healthcare professionals would recommend the use of CAM where their safety was perceived to be well known or that they believed would address patient concerns.

Participants generally had negative views on CAM safety and effectiveness often linked to perceived limited evidence. In addition to expressing lack of evidence from research, in clinical practice, participants also described difficulties determining the effectiveness of any CAM type for the management of diabetes themselves due to confounding factors such as adherence practices and level of physical activities of patients.

A theme was emerged from the interview and was then explored in details. The theme was healthcare professionals' attitude towards CAM types that had religious significance. Participants were reluctant to totally dismiss the effectiveness such CAM types. They believed that these CAM types were effective but CAM practitioners were often not skilled nor qualified. However, they dismissed other types of CAM with a cultural but not religious background such as cauterization and folk healers and deemed cauterization to be harmful, invasive and ineffective and deemed folk healers as 'fraudulent'.

Similar to the findings from previous literature,^{153, 200} this study also shows that discussions around CAM between healthcare professionals and their patients is limited in the context of diabetes. Existing literature (not specific to diabetes) included in a systematic review of 84 studies listed reasons for limited discussion about CAM use between healthcare professionals and patients.¹⁸¹ These included patients' fear of the provider's disapproval and patient perceiving disclosure of CAM use as unimportant.²⁰⁰ This study however provides in-depth reasons around the nature of these limited discussions and the barriers to effective communications. Many participants admitted limited knowledge and limited sources of CAM information were the reasons why they do not discuss CAM with their patients. Others explained that management protocols set by health authorities do not allow such discussions to take place.²⁰⁹ Participants described having limited knowledge about CAM related side effects and none of the participants discussed possible CAM side effects with patients. None of the participants reported any CAM related side effect to the National Pharmacovigilance and Drug Safety Centre, even though the Saudi FDA encourages reporting of herbal products' related side effects.²¹⁰

8.7.2 Implications for practice

This study was conducted in Saudi Arabia but the implications for practice based on the findings could be applicable in Saudi Arabia and other parts of the world, as diabetic patients share similar experiences.^{37, 153, 181} Healthcare professionals should be encouraged to openly discuss CAM with their diabetic patients allowing further opportunity to effectively counsel on medication adherence, detect CAM-drug

interactions or CAM related side effects and adverse events. Participants in this study described that many newly diagnosed patients were known to resort to CAM when they did not feel improvement early when initiating prescribed antidiabetic medicines. Effective communications around medication adherence until and after blood glucose stabilisation are essential. Effective communication with patients is also important to avoid the exploitation of patients and false information reported by both patients and healthcare professionals.

The findings of this study revealed that the healthcare professionals interviewed had limited knowledge on CAM. They stated that there are limited courses on CAM directed at healthcare professionals. Currently, CAM subjects are not widely taught in healthcare education.²¹¹ The available courses were shown to be inconsistent in term of quantity and learning objectives.^{211, 212} Incorporating CAM into healthcare education would allow healthcare professionals to form an informed attitude towards CAM use and thus would be able to better counsel their patients about CAM.²¹³ However, educational materials need to be generalised in healthcare professionals' education and training, and also need to be designed to be inclusive of commonly used CAM types. Resources on CAM use for diabetes should be available to healthcare professionals to use when advising diabetic patients about CAM. Education and training programs should also include culturally sensitive information for healthcare professionals and patients as some CAM types may have religious and cultural significance.²¹⁴

Currently, protocols set by the Ministry of Health in Saudi Arabia do not allow room for discussing CAM use with diabetic patients.²⁰⁹ Health authorities should consider patients' self-management choices and introduce more flexible consultation protocols

to accommodate all aspects of the disease management approaches used by patients including CAM.

8.7.3 Implication for research.

Research to improve counselling and communication practices around self-management practices including the use of CAM are needed. Observational studies with patients and healthcare professionals around communicating practices involving CAM would enable identification of gaps and barriers to effective communications.^{215,}

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As some patients' choice of using CAM for the management of diabetes is influenced by cultural beliefs, studies that aim to develop and evaluate provision of culturally sensitive information around evidence-base on safety and effectiveness of CAM are necessary.

8.7.4 Limitations of this study

Due to restrictions set in place during the COVID-19 pandemic, recruitment and interviews for this study were conducted remotely. Face-to-face recruitment might give a better chance of explaining the subject to the interviewee and developing rapport with the researcher.^{217, 218} Healthcare professionals shared their experiences with diabetic patients visiting their clinics and pharmacies. However, there might be diabetic patients who only use CAM for the management of their diabetes and never visit healthcare clinics or pharmacies. Studies that involve CAM practitioners, folk healers outside clinical settings can enable understanding of their views and experiences about the use of CAM for diabetes as they might have additional inputs to CAM use for diabetes.^{120, 219}

8.8 Conclusion

Healthcare professionals described having limited interactions with diabetic patients regarding CAM. Such limited interactions were attributed to limited healthcare professionals' knowledge and lack of resources. The gap in communication between diabetic patients and healthcare professionals needs to be improved to optimise treatment outcomes through flexible consultation time, accommodating consultation protocols to allow CAM discussions and through provision of culturally sensitive and evidence-based information provision to both diabetic patients and healthcare professionals.

Summary of the chapter

This chapter provided in-depth perspectives of healthcare professionals on diabetic patients' use of CAM. Barriers to effective communications around CAM use in the context of diabetes were identified. The following chapter will discuss and triangulate the findings from all five phases of the PhD and describe clinical and research implications of the study findings.

CHAPTER 9: DISCUSSION

Chapter overview

This chapter aims to provide a summary of the key findings of this PhD study. It will also triangulate the findings from the various phases of the research. The significance of the main findings is discussed. Finally, study strengths and limitations, practice implications and future research areas are discussed followed by conclusions.

9.1 Summary of key findings from the PhD study

9.1.1 Prevalence

This PhD study conducted a global systematic review and meta-analysis to estimate the prevalence of CAM use by diabetic patients.¹⁵³ This systematic review and meta-analysis provided up-to-date data on the global prevalence of CAM use by diabetic patients. It reported a wide variation in the prevalence rate of 8%-89%, as observed in the review that included studies from 25 countries. Based on the meta-analysis of global data, the pooled global prevalence was 51%, demonstrating the extent of CAM use amongst diabetic patients.

9.1.2 Popular CAM types

A total of 35 different CAM types were identified. The most popular were herbal treatments, acupuncture, mind-body therapies, religious and spiritual healing, homeopathy, meditation, massage, Ayurveda, chiropractic massage and yoga. Regarding the use of herbal medicine, a large number of herbs and dietary supplements used by diabetic patients for the management of diabetes as a total of 223 were identified.

9.1.3 Key factors that attract patients to use CAM in diabetes

The systematic review addressing factors associated with diabetic patients CAM use identified a total of 84 factors. Each of the extracted factors were then classified according to the TDF into one of its 14 domains. Key factors associated with the use of CAM related to intentions to treat and relieve symptoms, accessibility and affordability compared to physician visits and modern medicines, social influences by family members, friends. However, most of the included studies used questionnaires for data that only discussed the issue using researchers pre-set questions and responses and did not allow patients to say anything else outside that. However, patient decision making processes were not explored. This PhD study carried out further data collection on CAM use by diabetic patients through online patient forums and semi-structured interviews with diabetic patients and healthcare professionals.

The systematic review of factors associated with CAM use in diabetes, the study of patient online forms and the qualitative interviews with diabetic patients demonstrated that diabetic patients' lack of trust in prescribed medicines often leads to patients using CAM alone for the treatment of diabetes. The distrust was often found to be related to the perception that prescribed medicines do not cure diabetes, and CAM could offer better effectiveness. The study of patient online forums and interviews with patients offered explanations for patients' distrust of prescribed medicine. Many perceived that diabetes is an acute condition and prescribed medicines are often responsible for making diabetes a chronic and permanent condition. Healthcare professionals in the qualitative study explained this distrust to be related to patients' expectations to get results very quickly from orthodox medicine. They suggested that patients often form

early impressions that prescribed medicines do not work when they do not experience results in the rate they expected.

Patient exhaustion from the diabetes management routine was a key factor for patient use of CAM as identified in the systematic review. In the qualitative interview study, patients revealed that they try to cut down dosage frequency by compensating some doses with CAM. Patients either used CAM to have a break from prescribed medicine or used CAM instead of some of the daily dosage. Healthcare professionals in the qualitative study suggested that their patients do in fact consider CAM to be more convenient to use than prescribed medicine. For example, some healthcare professionals described that patients used CAM to avoid adhering to the strict diet and regular exercise associated with conventional management. Healthcare professionals therefore, need to guide and support the self-management of their diabetic patients. Understanding patients' needs and experiences of diabetes and its management routines would allow self-management support for patients to be optimised and would prevent patients resorting to using CAM as a standalone therapy in the management of diabetes.

The systematic review investigating factors influencing diabetic patients to use CAM showed that patients' lack of knowledge about the long-term consequence of diabetes led them to use CAM. This issue however, was not identified in our subsequent qualitative studies. Patients revealed that they understood the possible diabetes complications well but still used CAM. In fact, patients reported that their fear of developing such complications is what led them to try using CAM. Future studies should explore further associations between patient knowledge of diabetes and CAM use and practices.

Healthcare accessibility issues were among the key factors that led diabetic patients to use CAM as identified in the systematic review. Healthcare professionals in the qualitative study also described that easier access to CAM compared to healthcare facilities is one of the factors that attract diabetic patients to use CAM, particularly patients living far away from hospitals and clinics, i.e. in rural areas. However, users of online forums and patients in the qualitative study did not see access to healthcare services as a factor associated with CAM use. Most of the participating patients in the qualitative studies were recruited from clinics and had access to healthcare services and hence this barrier was not stipulated by the study participants.

The systematic review of factors associated with CAM use by diabetic patients identified that patients preferred using CAM as it is more affordable than prescribed medicines. The subsequent qualitative studies were conducted in Saudi Arabia where healthcare services are provided to patients free of charge.⁴⁵ However, healthcare professionals described that the low cost of CAM is still appealing to patients as they are willing to pay these costs to avoid crowded hospitals and wait for appointments. Participating patients mentioned that CAM costs were not a concern as they were willing to pay whatever it costs. However, patients described feeling financially exploited and accused CAM practitioners as well as companies who market CAM products of taking advantage of their vulnerability and desperation and targeting them for financial gain.

9.1.4 Key factors that dissuade patients from using CAM in diabetes

One of the key factors that dissuaded the study patients from using CAM was CAM-related side effects. The systematic review study reported that diabetic patients believed that CAM has fewer side effects compared to conventional or prescribed medications. However, the subsequent qualitative studies revealed that patients did, in fact, experience CAM-related side effects and serious adverse events that made them stop using CAM. Patients on some occasions reported experiencing comas and had to be hospitalised as a result of using CAM instead of prescribed medicine. However, the diabetic patients interviewed mainly attributed those side effects and adverse events to be related to using CAM incorrectly but not to CAM itself.

9.2 Implications for clinical practice

This study has hence generated a comprehensive list of CAM used by diabetic patients and the factors associated with their CAM use, and can be an important source of reference for clinicians, guideline development bodies, pharmacists, health authorities and regulatory agencies.

9.2.1 Adherence to prescribed medicine

Some diabetic patients interviewed in this research were non-adherent to prescribed medicines and used CAM as an alternative management approach instead and some used CAM as an additional or 'complementary' management approach. The qualitative work showed that the diabetic patients who used CAM as an additional management approach used different methods for incorporating CAM into their diabetes management routine. Although some patients reported adhering to their prescribed medicine while using CAM, patients participating in the qualitative study and some

online forum users described lowering the amount of insulin dose that was prescribed to them while using CAM, while others skipped some daily doses in an attempt to compensate for the perceived effect of CAM. Diabetic patients who use CAM as an additional management approach while adjusting their prescribed medicine doses to accommodate CAM are likely to have a risk of having less than optimal medication adherence. Diabetic patients who do not change their prescribed medicine dosage while using CAM could suffer from hypoglycaemia if the CAM type they use affects blood glucose^{40, 151} It is hence imperative to introduce discussion about CAM use in the context of medicines adherence when counselling patients in clinical consultations.

9.2.1.2 Drug-CAM interactions

Cinnamon, for example, was one of the most popular herbs used by diabetic patients for the management of diabetes.¹⁵³ It is reported that cinnamon has a potentiating effect on diabetic drugs, raising the risk of hypoglycaemia.⁴⁰ Cinnamon is known to inhibit the CYP3A4 enzyme in rabbits which potentiates the effect of pioglitazone, leading to hypoglycaemia.¹⁴⁹ Aloe vera, another of the most popular herbs used by diabetic patients to manage diabetes, is reported to have potential interactions with 45 different drugs, including diabetic drugs such as glimepiride.¹⁵⁰ Using Aloe vera alongside glimepiride can also produce hypoglycaemic effects. These herbs are just examples of the interactions between herbal products and diabetes medicine. Some herbs have dual effects, as reported by some of the participants of this study, such as the blood-thinning effect of ginger and turmeric. In addition to the side effects of herbal medicine, participants reported experiencing hypoglycaemia with other types of CAM such as yoga and ruqya. This study shows that healthcare professionals' knowledge about CAM use for diabetes, including drug-CAM interactions is limited. It is important

for healthcare professionals including pharmacists to be aware of such drug interactions and adverse events to offer optimal counselling and advice. Drug-CAM interactions should be listed in national and local prescribing formularies where appropriate.

9.3 Patient education and counselling

The systematic review and meta-analysis chapter identified that out of 51% of diabetic patients who use CAM, around 2/3rd of CAM users do not discuss their use of CAM with their healthcare providers. CAM use among diabetic patients is prevalent to the point that it should be considered by healthcare professionals when counselling patients. Additionally, the variety of CAM types and the variety of herbs used by diabetic patients' calls for closer attention by healthcare professionals by recognising and anticipating their diabetic patients use of these types.

Anticipating and discussing the use of CAM by diabetic patients in clinical settings would help to promote better medication adherence, undertake any dose adjustments, and prevent any unwanted CAM-drug interactions and side effects. Currently, the findings of all studies in this research showed that CAM use by diabetic patients is rarely discussed by healthcare professionals in consultations. This limited discussion could affect diabetes management outcomes, rendering all clinical efforts inadequate. In the research carried out for this study, both diabetic patients and healthcare professionals described reasons for these limited discussions. These reasons mostly revolve around the limited knowledge or perceived limited knowledge that healthcare professionals have about CAM. They either made patients refrain from discussing their CAM use, or healthcare professionals themselves do not feel confident counselling

patients about CAM. Patients do not see the necessity of discussing CAM use as they perceive it as negligible and not as important as discussing conventional management.²⁰⁷ Healthcare professionals who wish to discuss CAM did not have available sources of information to base their consultations on. Moreover, healthcare professionals are confined by the approved management protocols, and could face malpractice and legal consequences if they divert from strictly following these protocols.²⁰⁹

This study shows that interventions to promote diabetes education and knowledge in patients are essential to overall diabetes management outcomes and optimise the use of CAM where patients prefer their use alongside prescribed medications. Patients' knowledge gap about diabetes is associated with increasing the risk of diabetes complications.^{220, 221} Patient education should take into account patient beliefs and practices. It is important that guidelines and healthcare regulations allow for discussion of CAM in clinical settings.

94 Culturally sensitive counselling

Conventional diabetes management approaches are universal and almost identical everywhere in the world regardless of cultural backgrounds or religious beliefs. However, cultural beliefs were identified by the systematic review (chapter 5) as one of the main factors that encouraged diabetic patients to use CAM. Literature included in the systematic review originated from different countries and confirmed the role of culture on CAM use by diabetic patients. Subsequent qualitative interviews confirmed that cultural background played an important role in influencing diabetic patients to use CAM for diabetes. Cultural background influenced CAM use for diabetes, i.e. the

choice of CAM type, the perception around its effectiveness and favouring that specific CAM type over prescribed medicine or even over other CAM types.

In this research, patients and healthcare professionals held CAM types that have cultural backgrounds in high regard. Therefore, if any such CAM type that evidence suggest that it is ineffective or harmful, healthcare professional participants said that it could be challenging to convince patients about it. It was interesting that even when healthcare professionals were aware that CAM types which have cultural influences are ineffective, they were reluctant to dismiss their ineffectiveness.

It is essential for healthcare professionals to offer culturally sensitive counselling and advice.^{214, 222} This recommendation is especially applied to healthcare professionals working or planning to work in a different country or different community than their own. If communications were only based on evidence-based management aspects, issues could arise that would potentially weaken trust between healthcare professionals and their patients. Healthcare professionals need to build a stronger level of trust with their patients in order for their counselling to be taken on board by their patients. Healthcare professionals' involvement in local culture would not only contribute to building a stronger rapport with their patients, but it would also allow healthcare professionals to communicate with their patients using evidence-based counselling while respecting patients' beliefs.

9.5 Impact on pharmacy practice and the possible role of pharmacists

Diabetic patients have relatively easier access to pharmacists compared to other healthcare professionals. Diabetic patients seek information from pharmacists regarding their conventional management and self-care practices, including the use of

CAM. Globally, pharmacy staff noticed an increase in their involvement in advice and support related to CAM use during the recent COVID-19 pandemic.¹⁷² Pharmacists' awareness of the high prevalence of CAM use and, factors associated with it would assist them to be able to anticipate the likelihood of CAM use by their diabetic patients. Pharmacists would be able to initiate conversations and inquire about the possible factors likely to be associated with CAM use. For example, the factor related to diabetic patients' tiredness or frustration due to lack of treatment optimisation or excessive dosage frequency could be addressed as part of medication reviews.

The findings of this study shows that diabetic patients' unfamiliarity with interactions between prescribed medicine and CAM can lead patients attributing adverse events to their prescribed medicine. Therefore, it is important for pharmacists to acquire knowledge about CAM safety including side effects, CAM-drug and CAM-CAM interactions. Conveying evidence based and culturally sensitive information to diabetic patients could improve diabetic patients' trust in pharmacists.

Pharmacists often have the opportunity to counsel diabetic patients during the initial phase of treatment, for example, when patients are newly prescribed an antidiabetic medicine. Findings of the qualitative interviews showed that patients often get frustrated with prescribed medicine as it often takes time to adjust the dose and notice results, and resort to alternative management approaches. As most pharmacies operate on a non-appointment basis throughout the world, pharmacists can be an accessible source of information to alleviate patients' fears, concerns regarding the management of diabetes and could seek information about self-management approaches including CAM. For example, in the UK, the New Medicines Service available in community pharmacies allows patient consultations on new prescribed

medicines especially for chronic diseases, as well as offering consultations on lifestyle changes and self-management approaches.²²³

9.6 Diabetes management protocols and guidelines

The findings of this study highlighted the importance of addressing CAM use by diabetic patients during clinical visits and pharmacy consultations. Current diabetes management protocols, standards of medical care in diabetes and practice guidelines for diabetes management do not incorporate the use of CAM by diabetic patients. This further limits healthcare professionals' ability to discuss CAM use with their diabetic patients. Healthcare professionals who do see the importance of discussing their diabetic patients' use of CAM reported that they were reluctant to do so as they are restricted by abiding and strictly adhering to the approved protocols. Even if healthcare professionals see the necessity to intervene and guide their diabetic patients through their CAM use, they are most likely to face malpractice litigations and legal consequences such as in the context of Saudi Arabia.

Simply recognising the importance of incorporating counselling about CAM use for diabetes by healthcare professionals is not sufficient. Healthcare professionals should be professionally and legally allowed and encouraged to discuss and provide counselling on all aspects of their diabetic patients' management routines, including the use of CAM. Therefore, changes to official diabetes management clinical guidelines and management protocol should be introduced to include counselling on CAM use for diabetes. Stipulation of expectations in clinical guidelines that diabetic patients may be using CAM that deal with CAM use would encourage healthcare

professionals to acquire more evidence based and culturally sensitive information sources.

9.7 Medical education and training

For healthcare professionals to provide practical advice to their diabetic patients, they should have adequate knowledge on CAM used by diabetic patients. If healthcare professionals have limited knowledge on the subject this is likely to dissuade patients from seeking their advice. Therefore, incorporating CAM use for diabetes into medical, nursing and pharmacy education curricula is necessary. CAM use for diabetes should also be introduced to practising healthcare professionals through continuing professional development (CPD). The proposed curricula and training programmes should aim to standardise training and education to improve patients' trust in their healthcare providers and should be designed to include the essential aspects of CAM use for diabetes.

9.8 Regulations

Current CAM regulations differ from one country to another.²²⁴ CAM practitioners are not considered medical professionals in many countries.²²⁵ Therefore, strict medical standards do not apply to their practices. CAM related products such as herbal supplements are not regulated as heavily as prescribed medicines.²²⁴ For example, in the UK and Europe, herbal dietary supplements are regulated and would be granted marketing authorisation based on an assessment of quality and safety but not on clinical effectiveness.²²⁶ In the United States, herbal dietary supplements are regulated as food and not as medical products under Dietary Supplement Health and Education

Act (DSHEA) in 1994.²²⁷ in Saudi Arabia, herbal dietary supplements, while required to be registered before marketing, evidence of clinical effectiveness is not required.²²⁸

Although all of the regulations mentioned above prohibit any medical claims on herbal dietary products, the findings of this study showed that these products are still used by diabetic patients for diabetes management. It is not feasible for new regulations that enforce the assessments of CAM effectiveness as part of marketing authorisation to be introduced. The reason is that research and development are time-consuming and costly, and CAM types are widely available and cannot be patented by companies to ensure covering the costs of research and development. However, the findings of this study could be utilised to identify the most popular CAM types among diabetes patients, and marketing authorisations could be made conditional to introducing warnings on those CAM types that include statements about the limited data on effectiveness for diabetes as well as detailing any confirmed possible diabetes-related side effects and CAM-drug interactions.

9.9 Future research

CAM use by diabetic patients is prevalent, as identified by the study, and the potential for CAM types to have side effects and CAM-drug interactions are probable. Extensive clinical research on CAM safety and effectiveness is the only credible way to further identify side effects and CAM-drug interactions and offer evidence-based advice provision.

The findings of this study showed that cultural beliefs played an important role in diabetic patients' decisions to use CAM and the choice of CAM types. Further qualitative studies need to be conducted in different communities with different cultural

backgrounds to identify how different cultural contexts affect CAM practices. There is a need for the development of better counselling practices about CAM, particularly to offer patient-centred information and advice. The factors that influence diabetic patients to use CAM identified by this study could serve as a basis for future research on education and counselling practices around CAM use.

Some of the research questions grounded in the findings of this PhD study that are worthy of future exploration are:

- What measures should be taken for newly diagnosed diabetic patients to help them accept and cope with diabetes?
- What are the types of educational materials that should be used to enable patient understanding around chronicity of their condition?
- How can healthcare professionals encourage diabetic patients to discuss their CAM use during clinical visits?
- What are the views around CAM use for diabetes from the perspective of patients visiting CAM practitioners?
- How is patient satisfaction with health services linked to the use of CAM?

9.10 Strengths and limitations of this research

Strengths and limitations of individual phases of this research have been already described in the discussion sections of relevant chapters. This research involved a range of studies and methodologies to explore diabetic patients' CAM use i.e. systematic reviews, meta-analysis and qualitative work.

9.10.1 Triangulation

Data collection tools for qualitative studies were based on the results of a systematic review and TDF domains. Triangulation, i.e. the use of various methods or data sources and integrate the findings together to obtain a comprehensive knowledge on the investigated subject, was applied to this research.²²⁹ The conduct of this research allowed the researcher to work with different data collection tools and data analysis approaches as appropriate for each part of this research. It allowed the researcher to reflect on the findings of each phase and draw possible clinical implications and offer learnings for subsequent phases of the research.

The findings from each phase of this PhD study complemented each other to provide a deeper understanding of the subject. The findings sometimes were consistent across all phases and sometimes contradicted each other. For example, searching for cure, lack of trust on prescribed medicine and cultural reasons were described as factors associated with CAM use across all studies. However, limited knowledge about diabetes complications by diabetic patients were listed as a factor for CAM use in the systematic review of literature, however, the qualitative interviews with patients revealed that patient perceive and demonstrated having adequate knowledge on diabetes complications.

9.10.2 Validity

Comprehensive search terms were adopted for the systematic reviews using several relevant databases. The search strategies set out to explore all relevant aspects of the subject, e.g. overall prevalence, different CAM types and factors associated with diabetic patients CAM use.

The study was conducted in Saudi Arabia and identified behaviours around diabetic patients' CAM use in the local cultural context. The specific findings of this research were original to Saudi context. Views of Saudi Arabian participants may differ from those of people from other countries. For example, both patients and healthcare professionals highly regarded CAM types with religious background and healthcare professionals were reluctant to dismiss the presumed benefits of those type for the management of diabetes. Both patients and healthcare professionals believed that Ruqya and cupping are promising types of CAM for diabetes management. Honey which contains sugars and is well known to increase blood glucose level was considered beneficial for diabetes management by many Saudi diabetic participants. Moreover, access to healthcare services was not a factor that is applicable to Saudi diabetic patients as they have access to free healthcare. In fact, patients reported that they were willing to pay excessive amounts of money to use CAM if they believed that it could help with their management of diabetes.

Healthcare professionals in Saudi Arabia reported limited sources for CAM information and restricted consultation protocols limiting their ability to advice patients about CAM. Moreover, healthcare professionals reported that they had never reported any CAM related side effect to the Saudi National Pharmacovigilance and Drug Safety Centre.

The use of theory in research is known to strengthen the robustness and rigour of findings.^{97, 100} In this PhD research, the TDF was adopted for the reporting of the findings of the systematic review of factors influencing diabetic patients CAM use and mapping the behaviours identified in the subsequent qualitative studies. The TDF was also applied when developing the topic guide for the qualitative semi-structured interviews. The TDF being inclusive of behavioural aspects allowed the findings to be

as comprehensive as possible. The use of the TDF will also serve as a base for developing future behavioural intervention studies.

9.10.3 Reviewing

All studies in this PhD were supervised by a supervisory team of 2 members. The supervisory team were multi-disciplinary which provided different perspectives. They supervised all stages of this research. They reviewed transcripts and helped to decide on codes for the qualitative work. Moreover, some studies included within this PhD were published publications to peer-reviewed journals. The published studies went through rigorous peer-review before subsequent publications in high impact factor journals with a wide readerships.

9.10.4 Reliability

The researcher, prior to enrolling in the PhD programme, worked at the Saudi FDA as a member of health products approval committee. During his work, the researcher acquired an extensive knowledge, especially with herbal products. The researcher conducted his studies under the supervision of 2 experts in their fields. VP is senior lecturer in clinical pharmacy and pharmacy practice with expertise in the field pharmacy practice research, and SG is a Professor of Medical Sociology with expertise in the field of CAM research. Advice on statistical analysis was given by an expert in the field, MP, a lecturer in Biostatistics at the University of Birmingham.

All interviews were conducted in Arabic or English, based on participant preference. The researcher's native language is Arabic and also speaks English. Interviews were recorded and carefully transcribed by the researcher in the original interview language. Arabic transcripts were translated into English using UK based professional translation

services. The process of recording, transcribing, and translating allowed all interviews in their entirety to be analysed and allowed access to the data by all research team members.

The researcher was enrolled in various research methodology courses. These included systematic reviews and evidence synthesis module and qualitative research methods module delivered by the Institute of Applied Health Research at the University of Birmingham. The qualitative research methods module addressed the basic principles of qualitative research, its role and purpose, designing qualitative studies, analysing and interpreting qualitative data and critically assess qualitative work. It addressed a variety of qualitative research methods and the analysis process for qualitative data. In addition, the researcher enrolled on a course on analysis of qualitative data organized by the Social Research Association (SRA) offering an overview of the key stages in the analytical process, interpreting qualitative data, understanding the generalisability of qualitative data and evaluating the quality of qualitative analysis. Furthermore, this research included a global systematic review on the prevalence of CAM use among diabetic patients and a systematic review to identify the factors that influenced diabetic patients to use CAM to help the researcher acquire adequate knowledge on the topic area.

9.10.6 Limitations

The systematic reviews phase of the research, even though it explored the issue globally, was limited to studies that were published in English language. Similarly, the study of online forums was limited to posts in English. The researcher had no control over the data of the study of patient online forums, and there are no methods of

validating the data. Moreover, this study was significantly impacted by the COVID-19 pandemic due to limited resources and social restrictions. The major impact of COVID-19 on this research was mostly limited to the research procedure such as recruitment and conduct of the interviews.²³⁰ The recruitment and interviews for the qualitative interviews of this research were conducted via telephone instead to face-to face with implementing additional measures to ensure the privacy and anonymity of participants. The change to telephone interviews was most likely had no significant impact on the nature of data.²¹⁷ This is considered a limitation as face-to face interactions would generate better trust between the researcher and participants. The qualitative phase of the research was limited to some extent to findings that were generated from clinical settings, i.e. with patients visiting clinics and healthcare professionals. Patients who do not visit clinics and CAM practitioners might have different opinions from those recruited in this research.

Conclusion

This PhD study allowed the estimation of the global prevalence of CAM use in diabetes. A wide variation in prevalence rate of CAM use in diabetes (8%-89%) was observed and pooled prevalence of CAM use was 51%. Decisions to use CAM in diabetes can be influenced by many personal and socioeconomic factors. Cultural context played an important role in diabetic patients' decision to use CAM and choice of CAM type. Hidden concerns about diabetes often lead patients to use CAM. Patients participating in this research perceived that such concerns, including the role of CAM in diabetes, were not appropriately addressed during clinical visits due to lack of trust in their providers' knowledge about CAM. Many diabetic patients turn to online forums or social

networks to discuss CAM use instead of discussing with healthcare professionals. Diabetic patients use online forums to seek and offer advice and share experiences about CAM use.

Limited interactions between diabetic patients and healthcare professionals regarding CAM exist mainly due to limited knowledge and lack of sources. This limited discussion about CAM made diabetic patients' vulnerable to financial exploitation by some CAM providers. The gap in communication between diabetic patients and healthcare professionals needs to be improved to optimise treatment outcomes through flexible consultation time, accommodating consultation protocols and culturally sensitive and evidence-based information provision to both diabetic patients and healthcare professionals. Healthcare professionals should be aware of their diabetic patients' use of CAM to ensure treatment optimization and medication adherence. Alleviating patients' concerns, and reluctance to use prescribed treatments are imperative to achieve therapeutic goals.

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Supplementary Materials

Table S 4.1: Search terms used for databases searches.

1- Acupressure	22- Traditional Chinese Medicine	35- Among
2- Acupuncture	23- Traditional Medicine	36- Use
3- Alternative	24- Traditional Persian Medicine	37- Prevalence
4- Aromatherapy	25- Yoga	38- Beliefs
5- Ayurveda	26- 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 23 OR 24 OR 25	39- Attitude
6- Balneotherapy	27- Diabetes	40- Knowledge
7- Biofeedback	28- Type 1 diabetes	41- Practice
8- Complementary	29- Type 2 Diabetes	42- Views
9- Cupping	30- Pre-diabetes	43- Behaviour
10- Functional medicine	31- Hyperglycaemia	44- Proportion
11- Herbal	32- Blood glucose	45- Common
12- Homeopathy	33- 27 OR 28 OR 29 OR 30 OR 31 OR 32	46- Survey
13- Hypnotherapy	34- 26 AND 33	47- Interview
14- Leeching		48- Frequent
15- Naturopathy		49- Pattern
16- Oriental		50- Trend
17- Persian		51- 35 OR 36 OR 37 OR 38 OR 39 OR 40 OR 41 OR 42 OR 43 OR 45 OR 46 OR 47 OR 48 OR 49 OR 50
18- Reflexology		52- 26 AND 33 AND 51
19- Reiki		
20- Traditional African Medicine		
21- Traditional Arabic Medicine		

Table S 4.2: Critical Appraisal Summary using Joanna Briggs Institute Critical Appraisal tools (JBI) for quality assessment.

S	Author and date	Country	Study design	Yes	No	Unclear	Not applicable	Overall quality
1	Yildirim & Marakoglu, 2018	Turkey	CS	6	0	2	0	Moderate
2	Rhee, Westberg, & Harris, 2018	USA	CS	7	0	1	0	High
3	Mekuria et al., 2018	Ethiopia	CS	7	1	0	0	High
4	Karaman et al., 2018	Turkey	CS	6	1	0	1	Moderate
5	Candar et al., 2018	Turkey	CS	6	1	1	0	Moderate
6	Avci., 2018	Turkey	CS	6	1	1	0	Moderate
7	Andrews, Wyne, & Svenson, 2018	Guatemala	CS	5	2	1	0	Moderate
8	Amaeze et al., 2018	Nigeria	CS	5	2	1	0	Moderate
9	Mohamed Ali, & Mahfouz, 2014	Sudan	CS	5	2	1	0	Moderate
10	Vishnu, Mini & Thankappan, 2017	India	CS	5	2	1	0	Moderate
11	Putthapiban, et.al., 2017	Thailand	CS	6	1	1	0	Moderate
12	Kamel et al., 2017	Saudi	CS	4	3	1	0	Moderate
13	Ashur et al., 2017	Libya	CS	3	4	1	0	Moderate
14	Al-garni, Al-Raddadi & Al-Amri, 2017	Saudi	CS	5	2	1	0	Moderate
15	Wanchai & Phrompayak, 2016	Thailand	CS	5	2	1	0	Moderate
16	Lunyera et al., 2016	Tanzania	CS	5	2	1	0	Moderate
17	Bahroom, Shamsul & Rotina, 2016	Malaysia	CS	7	1	0	0	High
18	Azizi-Fini, et. al, 2016	Iran	CS	7	1	0	0	High
19	Al-Eidi et al., 2016	Saudi	CS	6	2	0	0	Moderate
20	Koren et al., 2015	Israel	CS	5	2	1	0	Moderate
21	Hashempur et al., 2015	Iran	CS	7	1	0	0	High
22	Devi et al., 2015	India	CS	5	2	1	0	Moderate
23	Damnjanovic et al., 2015	Serbia	CS	5	2	1	0	Moderate
24	Alami et al., 2015	Morocco	CS	6	2	0	0	Moderate
25	Nguyen et al., 2014	USA	CS	6	2	0	0	Moderate
26	Naja et al., 2014	Lebanon	CS	7	1	0	0	High
27	Medagama et al., 2014	Sri Lanka	CS	6	1	1	0	Moderate
28	Chao et al., 2014	USA	CS	4	3	1	0	Moderate
29	Khalil et al., 2013	Egypt	CS	3	2	3	0	Moderate
30	Fan et al., 2013	Singapore	CS	6	0	2	0	Moderate
31	Ching et al., 2013	Malaysia	CS	7	1	0	0	High
32	Lui et al., 2012	Australia	DC	6	0	5	0	Moderate
33	Ali-Shtayehet et al., 2012	Palestine	CS	5	2	1	0	Moderate
34	Wazaify et al., 2011	Jordan	CS	6	2	0	0	Moderate
35	Sethi, Srivastava & Madhu, 2011	India	CS	5	2	1	0	Moderate
36	Fabian et al., 2011	Austria	CS	7	1	0	0	High
37	Bradley et al., 2011	USA	CS	6	1	1	0	Moderate
38	Khalaf & Whitford, 2010	Bahrain	CS	5	1	2	0	Moderate

CS= Cross-Sectional,

DC= data obtained from cohort study.

Table S 4.3: Herbal and dietary supplements cited in included studies and the frequency of citations (each out of 41 studies)

1	Abeere	1	113	Jaadah or Shangoura	1
2	Abyssinian rose	1	114	Jamun	2
3	Agbo iba	1	115	Java tea	2
4	Agbo jedi	1	116	Jiaogulan	1
5	Agunmu	1	117	Johnson grass	1
6	Ajenjo	1	118	Juniper	2
7	Ajuga iva	1	119	Karela	1
8	Almonds	5	120	Khella	1
9	Aloe vera	14	121	Kiwi	1
10	Anise	5	122	Launaea	1
11	Apple	1	123	Lemon	3
12	Argan	1	124	Lemon verbena	1
13	Artichoke	4	125	Lemongrass	1
14	Arugula	1	126	Lentil	1
15	Austrian oak	1	127	Lentisco	1
16	Avocado leaves	2	128	Lettuce	1
17	Barley	2	129	licorice	3
18	Basil leaf	2	130	Lime	4
19	Bay laurel	1	131	Lingzhi mushroom	1
20	Bayleaf	1	132	Loquat leaves	3
21	Bean	1	133	Lupine seeds	5
22	Beet	1	134	Mahaleb cherry	1
23	Bitter aloe	1	135	Malt	1
24	Bitter gourd	3	136	Mango leaves	1
25	Bitter leaf	1	137	Manzana rosa	1
26	Bitter melon	6	138	Marjoram	3
27	Black calla	1	139	Mediterranean wild thyme	1
28	Black mulberry	2	140	Melon	1
29	Black seed	12	141	Milk	1
30	Blackberry	1	142	Milk thistle	1
31	Blueberry	4			

32	Breadnut	1	143	Milkvetch	1
33	Cabbage	2	144	Mint	1
34	Camomile	2	145	Misai Kuching	1
35	Candyleaf	1	146	Mistletoe	1
36	Caraway	1	147	Moringa	5
37	Cardamom	1	148	Mountain banana	1
38	Cardoon	1	149	Musk willow sweat	1
39	Celery	3	150	Muskmelon	1
40	Chamomile	3	151	Mustard seed	1
41	Charlock	1	152	Myrrh	3
42	Cherry stalk	1	153	Myrtle	1
43	Chichipin	1	154	Neem leaves	4
44	Chickpea	3	155	Nerium	1
45	Chicory	1	156	Níspero	1
46	Christ's thorn jujube	1	157	Noni	1
47	Cinnamon	18	158	Oka baba	1
48	Cloves	2	159	Okra seeds and flowers	2
49	Cocoa powder	1	160	Olibanum	1
50	Coconut	2	161	Olive leaf	10
51	Coenzyme Q10	2	162	Omega-3	2
52	Colocynth	2	163	Onion	8
53	Common motherwort	1	164	Orange (peel)	1
54	Common rue	2	165	Oregano (Syrian)	1
55	Coriander	4	166	Oroki	1
56	Costus Indian	1	167	Orris Root	1
57	Crab Apple	1	168	Parsley	2
58	Cranberry	1	169	Passion flower	1
59	Crownvetch	2	170	Pennyroyal	1
60	Cultivated Mushroom	1	171	Pigeon pea	1
61	Cumin	4	172	Pomegranate	6
62	Dandelion	2	173	Prickly pear	2
63	Dates (bitter)	3	174	Prostrate speedwell	1

64	Dill	2	175	Psyllium	1
65	Dong quai	1	176	Psyllium	1
66	Doum	1	177	Purslane	1
67	Dyer's madder	1	178	Quince leaves	2
68	East African rosewood	2	179	Redcurrant	1
69	Ecballium	1	180	Resveratrol	1
70	Echinops	1	181	Rock cherry	1
71	Efinrin	1	182	Roman nettle	1
72	Eggplant	1	183	Rose oil	1
73	Eucalyptus	1	184	Rosehip	1
74	Ewe laali	1	185	Roselle	2
75	Ewe ogbon	1	186	Rosemary	4
76	Felty germander	3	187	Ryeroot	1
77	Fennel	2	188	Sabah snake grass	1
78	Fenugreek	18	189	Sage	8
79	Fig	2	190	Salacia reticulata	1
80	Fish oil	3	191	Sarrasine	1
81	Flaxeed	4	192	Schenkia	1
82	Garden Cress	2	193	Senna	1
83	Garlic	17	194	Sesame	2
84	Gboko cleanser	1	195	Siberian aronia	1
85	Gentian	1	196	Soursop	1
86	Ginger	11	197	Soy	1
87	Gingko	1	198	Spiderwort	1
88	Ginseng	6	199	Spineless yucca	1
89	Globularia	1	200	Splender	1
90	Glucosamine	4	201	St. John's wort	1
91	Goko Cleanser	1	202	Stinging nettle	6
92	Golden Cotula	1	203	Swedish bitter	1
93	Grapefruit	1	204	Tamarisk	1
94	Green chiretta	2	205	Tasmanian blue gum	1
95	Green tea	10	206	Tetraclinis	1

96	Guava leaf	3	207	Thunbergia laurifolia	1
97	Guduchi	1	208	Thyme	7
98	Gum plant	1	209	Thymelaea	1
99	Gurmar	1	210	Timboque	1
100	Gymnena	1	211	Tres puntos	1
101	Harmal	2	212	Turmeric	2
102	Hawthorn	1	213	Verbena	1
103	heart-leaved moonseed	1	214	Verjuice	1
104	Helichrysum	1	215	Vitamins and minerals	8
105	Helteet	1	216	Walnut	4
106	Hibiscus	3	217	Watermelon	1
107	Hierba mora	1	218	Wheat	3
108	Honey	3	219	White horehound	2
109	Horse wood	2	220	Wormwood	5
110	Indian gooseberry	1	221	Yoyo Bitters	1
111	Indian screw tree	1	222	Za'atar	2
112	Ivy gourd	1	223	Ziziphus	4

Table S 5.1: Search terms used for databases searches.

1- Acupressure	22- Traditional Chinese Medicine	35- Among
2- Acupuncture	23- Traditional Medicine	36- Use
3- Alternative	24- Traditional Persian Medicine	37- Prevalence
4- Aromatherapy	25- Yoga	38- Beliefs
5- Ayurveda	26- 1 OR 2 OR 3 OR 4 OR 5	39- Attitude
6- Balneotherapy	OR 6 OR 7 OR 8 OR 9	40- Knowledge
7- Biofeedback	OR 10 OR 11 OR 12 OR	41- Practice
8- Complementary	13 OR 14 OR 15 OR 16	42- Views
9- Cupping	OR 17 OR 18 OR 19 OR	43- Behaviour
10- Functional medicine	20 OR 21 OR 22 OR 23	44- Proportion
11- Herbal	OR 23 OR 24 OR 25	45- Common
12- Homeopathy	27- Diabetes	46- Survey
13- Hypnotherapy	28- Type 1 diabetes	47- Interview
14- Leeching	29- Type 2 Diabetes	48- Frequent
15- Naturopathy	30- Pre-diabetes	49- Pattern
16- Oriental	31- Hyperglycaemia	50- Trend
17- Persian	32- Blood glucose	51- 35 OR 36 OR 37 OR
18- Reflexology	33- 27 OR 28 OR 29 OR 30	38 OR 39 OR 40 OR
19- Reiki	OR 31 OR 32	41 OR 42 OR 43 OR
20- Traditional African Medicine	34- 26 AND 33	45 OR 46 OR 47 OR
21- Traditional Arabic Medicine		48 OR 49 OR 50
		52- 26 AND 33 AND 51

Supplementary Table S 5.2: Critical Appraisal Summary using Joanna Briggs Institute Critical Appraisal tools (JBI) for quality assessment.

No.	Author and date	Study design	Number of critical appraisal tool questions that were answered Yes, No, Unclear, or Not applicable (N/A)			
			Yes	No	Unclear	N/A
1	Yildirim & Marakoglu, 2018	CS	6	0	2	0
2	Rhee, Westberg, & Harris, 2018	CS	7	0	1	0
3	Mekuria et al., 2018	CS	7	1	0	0
4	Karaman et al., 2018	CS	6	1	0	1
5	Bukhsh et al., 2018	Q	8	1	1	0
6	Avci., 2018	CS	6	1	1	0
7	Andrews, Wyne, & Svenson, 2018	CS	5	2	1	0
8	Amaeze et al., 2018	CS	5	2	1	0
9	Mohamed Ali, & Mahfouz, 2014	CS	5	2	1	0
10	Vishnu, Mini & Thankappan, 2017	CS	5	2	1	0
11	Putthapiban, et.al., 2017	CS	6	1	1	0
12	Kamel et al., 2017	CS	4	3	1	0
13	Porqueddu, 2017	Q	8	1	1	0
14	Atwine & Hjelm, 2018	CS	5	1	0	2
15	Wanchai & Phrompayak, 2016	CS	5	2	1	0
16	Lunyera et al., 2016	CS	5	2	1	0
17	Bahroom, Shamsul & Rotina, 2016	CS	7	1	0	0
18	Azizi-Fini, et. al, 2016	CS	7	1	0	0
19	Al-Eidi et al., 2016	CS	6	2	0	0
20	Koren et al., 2015	CS	5	2	1	0
21	Hashempur et al., 2015	CS	7	1	0	0
22	Devi et al., 2015	CS	5	2	1	0
23	Damnjanovic et al., 2015	CS	5	2	1	0
24	Alami et al., 2015	CS	6	2	0	0
25	Nguyen et al., 2014	CS	6	2	0	0
26	Naja et al., 2014	CS	7	1	0	0
27	Khalil et al., 2013	CS	3	2	3	0
28	Fan et al., 2013	CS	6	0	2	0
29	Ching et al., 2013	CS	7	1	0	0
30	Lui et al., 2012	DC	6	0	5	0
31	Ali-Shtayehet et al., 2012	CS	5	2	1	0
32	Wazaify et al., 2011	CS	6	2	0	0
33	Sethi, Srivastava & Madhu, 2011	CS	5	2	1	0
34	Fabian et al., 2011	CS	7	1	0	0
35	Bradley et al., 2011	CS	6	1	1	0
36	Khalaf & Whitford, 2010	CS	5	1	2	0
37	Alqathama et al., 2020	CS	5	1	2	0
38	Cengiz & Budak, 2019	CS	5	0	3	0
39	Kasole & Kimiywe, 2019	CS	5	0	3	0
40	Meshesha, Gebretekle, & Fenta, 2020	CS	4	1	3	0
41	Owusu et al., 2020	CS	6	0	2	0
42	Radwan et al., 2020	CS	5	0	3	0
43	Raja et al., 2019	CS	3	2	3	0

Supplementary Table S 5.3: Critical Appraisal Summary using Joanna Briggs Institute Critical Appraisal tools (JBI) for quality assessment.

TDF domains and descriptions
<p>1. Knowledge Knowledge of condition /scientific rationale, Procedural knowledge, Knowledge of task environment</p>
<p>2. Skills Skills, skill development, Competence, Ability, Interpersonal skills, Practice Skill assessment</p>
<p>3. Social/ Professional Role and Identity Professional identity, Professional role, Social identity, Identity, Professional boundaries, Professional confidence Group identity, Leadership, Organisational commitment</p>
<p>4. Beliefs about Capabilities Self-confidence, Self-confidence Perceived competence Self-efficacy Perceived behavioural control Beliefs Self-esteem Empowerment Professional confidence</p>
<p>5. Optimism Optimism Pessimism Unrealistic optimism, Identity</p>
<p>6. Beliefs about Consequences Outcome expectancies, beliefs, anticipated regret, consequents</p>
<p>7. Reinforcement Incentives, Rewards (proximal/distal, valued/not valued, probable/improbable), Incentives, Punishment, Consequents, Reinforcement, Contingencies, Sanctions</p>
<p>8. Intentions Stability of intentions, Stages of change model, Trans. model/stages of change</p>
<p>9. Goals Goals (distal/proximal), Goal priority, Goal / target setting, Goals (autonomous/controlled), Action planning Implementation intention</p>
<p>10. Memory, Attention and Decision Processes Memory, attention, decision making, cognitive overload, tiredness</p>
<p>11. Environmental Context and Resources Environmental stressors, Resources / material resources, Barriers and facilitators, Organisational culture /climate Person x environment interaction, Salient events / critical incidents</p>
<p>12. Social influences Social pressure, Social norms, Group conformity, Social comparisons, Group norms, Social support, Intergroup, conflict, Power, Group identity, Alienation, Modelling</p>
<p>13. Emotion Anxiety, Fear, Affect, Stress, Depression, Positive / negative affect, Burn-out,</p>
<p>14. Behavioural Regulation Self-monitoring, Breaking habit, Action planning</p>

Adapted from Cane *et al.* 2012, Atkins *et al.* 2017

Figure S 4.1: Prevalence ratio of CAM use between patients with no diabetic complications versus patients with diabetic complications.

Prevalence Ratios by Diabetes complications - Absence/Presence

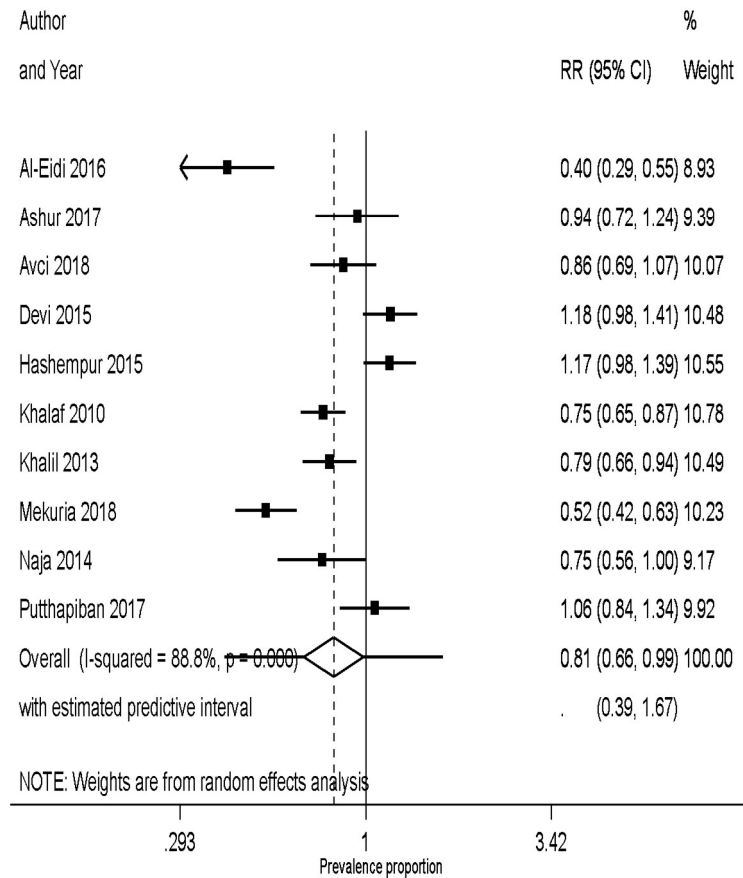


Figure S 4.2: Prevalence ratio of CAM use between patients who have diabetes for more than 5 years versus patients who have diabetes for less than 5 years.

Prevalence Ratios by Diabetes duration - >5y/<5y

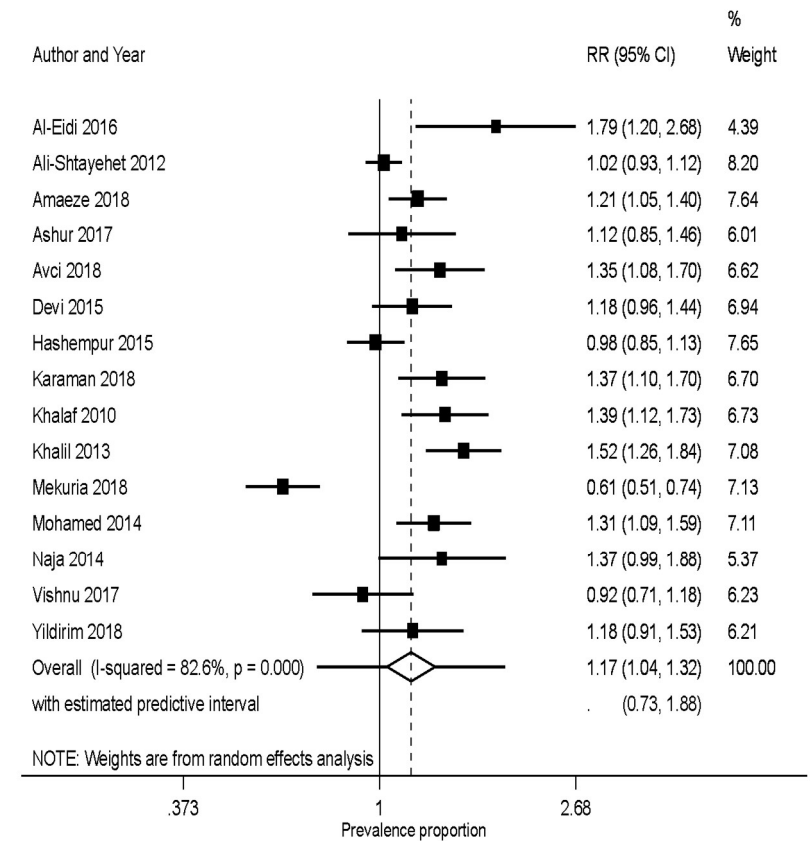


Figure S 4.3 : Prevalence ratio of CAM use between male patients versus female patients.

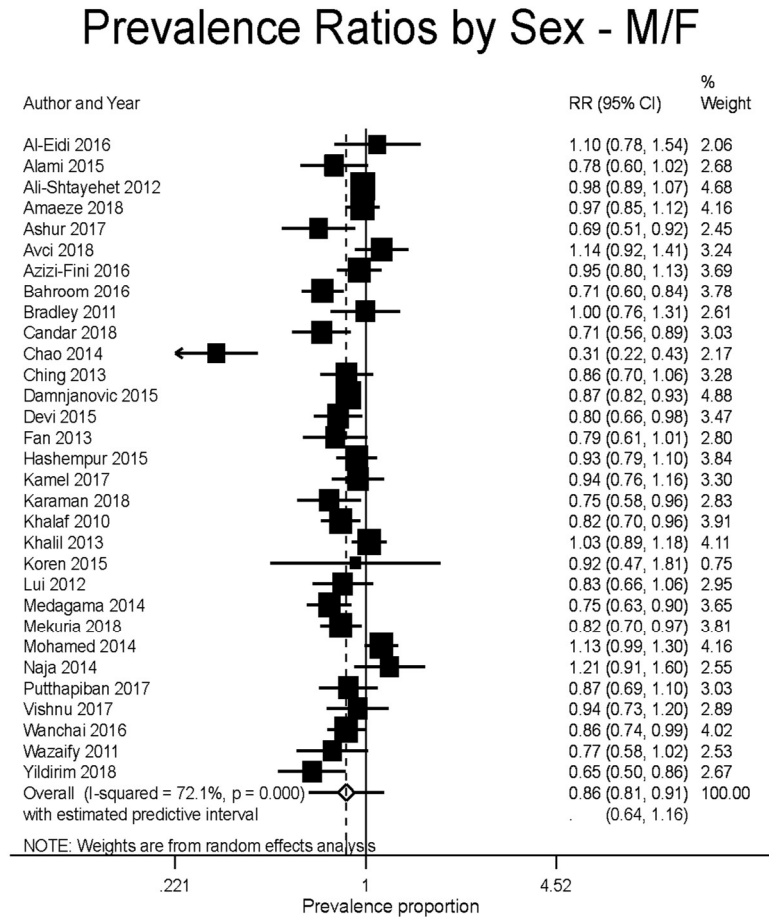


Figure S 4.4: Prevalence of CAM use in T2D patients and T1D patients

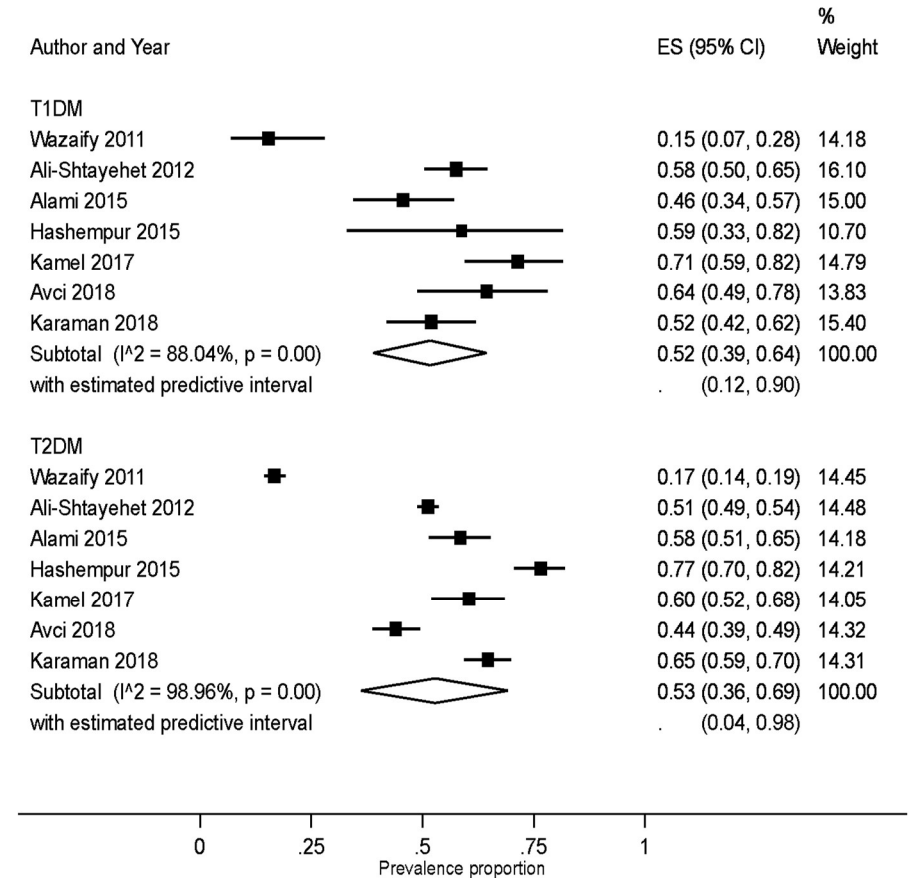


Figure S 4.5: Use of CAM as additional treatment

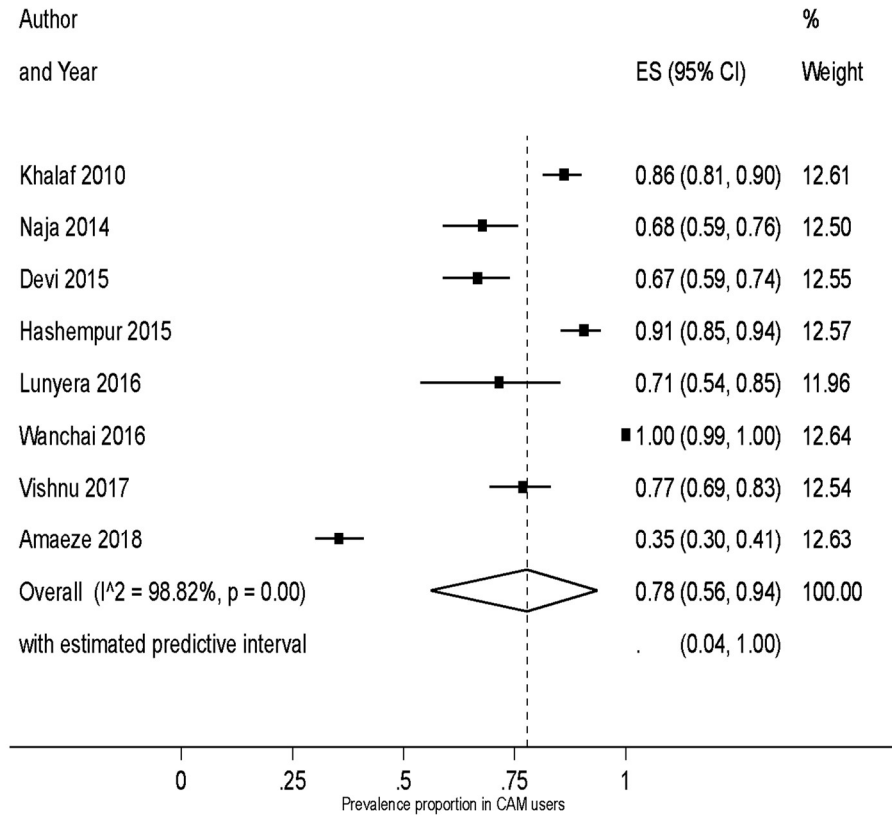


Figure S 4.6 : Use of CAM as alternative treatment

