#### **UNIVERSITY OF SOUTHAMPTON**

#### **FACULTY OF HEALTH SCIENCES**

Nurse prescribers' exploration of diabetes patients' beliefs about their medicines

by

**Andrew Mark Sibley** 

Thesis submitted for the degree of Doctor of Philosophy

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#### UNIVERSITY OF SOUTHAMPTON

## **ABSTRACT**

#### **FACULTY OF HEALTH SCIENCES**

Thesis for the degree of Doctor of Philosophy

## NURSE PRESCRIBERS' EXPLORATION OF DIABETES PATIENTS' BELIEFS ABOUT THEIR MEDICINES

Andrew Mark Sibley

Evidence suggests that non-adherence to medicines is an ongoing problem for people with diabetes and can adversely affect mortality, morbidity and health outcomes. Recent evidence and national guidance has reported patients' medicine beliefs as an important antecedent of non-adherence, however, a review of the entire medicine beliefs literature has yet to be conducted and no research has explored the experience of nurses and patients involved in an exploration of patients' medicine beliefs in routine practice settings. Conclusions from chapters 2 and 3 indicated nurse prescribers' are not, but should be, exploring patients' medicines beliefs in routine practice to optimise adherence and health outcomes.

A mixed methods concurrent triangulation design was used to (a) quantitatively observe and measure nurse prescribers' exploration in routine consultations, (b) qualitatively investigate the barriers and facilitators to nurse prescribers' exploration, and (c) qualitatively investigate diabetes patients' perceptions of consultation discussion having participated in consultations whereby nurse prescribers' explored diabetes patients' medicine beliefs. Findings were integrated in order to develop additional inferences.

Fourteen nurse prescribers' audio-recorded 154 routine consultations with diabetes patients over several time-points and 620 instances of medicine discussion were observed. Medicine beliefs sub-concepts, concerns and necessity, were conceptually mapped to MEDICODE themes and the analysis indicated nurse prescribers' were moderately exploring patients' medicine beliefs.

A thematic analysis of thirty interviews with nurse prescribers identified a range of nurse, patient, and contextual tensions that influenced nurses' exploration attempts. These included patients' willingness to engage, different exploration approaches by nurses, patient characteristics, and a wide range of contextual problems such as inadequate time, disruptive settings, and competing agendas. Thematic findings from 28 patient interviews also identified a range of perceptions about the experience of having their medicine beliefs explored. Nurse-patient rapport was considered vital for exploration by both nurses and patients.

All three study components were integrated in the discussion and developed into a conceptual model of the perceptions and influences on patients' medicine beliefs exploration by nurse prescribers. This thesis was the first attempt to understand the practical reality of this consultation activity. Exploration of patients' medicine beliefs in routine practice settings was difficult and subject to a number of tensions, facilitators and barriers within the context of diabetes care. Importantly, future research can utilise these findings to develop strategies to support interventions to address medication non-adherence aimed at patients or health care professionals.

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**DECLARATION OF AUTHORSHIP** 

I, Andrew Mark Sibley

declare that the thesis entitled

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and the work presented in the thesis are both my own, and have been generated by me

as the result of my own original research. I confirm that:

this work was done wholly or mainly while in candidature for a research degree at

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where any part of this thesis has previously been submitted for a degree or any

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### 1. Medication non-adherence in diabetes care

#### 1.1 Introduction

The overall aim of the research reported in this thesis was to understand the experience of, and the influential factors upon, the exploration of patients' medication beliefs by nurse prescribers in practice settings. This chapter will explore issues relevant to the thesis aim and discuss the foundation of the research. Important areas of research to examine were the value of the medicine beliefs literature and the position of medicine beliefs exploration as an element of nurse prescribers' work. This chapter will provide the broad rationale for the study and the need for the reviews conducted in Chapters 2 and 3.

The specific aims of this chapter are to (i) present an overview of the problem of non-adherence in the context of diabetes, (ii) present background to the nature of nurses' medication-related activities, (iii) provide detail on the relationship of this thesis to the wider study it was embedded within, and (iv) provide an overview of the content of the thesis.

### 1.2 The increasing burden of diabetes

Currently, there are over 15 million people in England with a long term condition. As frequent users of health services, they account for 55% of GP appointments, 68% of outpatient and A&E attendances and 77% of inpatient bed days (Department of Health 2007a). Diabetes mellitus is one of the most common long-term conditions, affecting approximately 246 million people worldwide (Diabetes UK 2009) and 2 million people in England, with a prevalence rate of 3.7% (Diabetes UK 2008a). Over 130,000 people were diagnosed with diabetes in the UK in the last year and five million people are expected to be living with the condition by 2030 (Diabetes UK 2012a). Moreover, annual spending on diabetes in the UK is expected to increase from £9.8 billion to £16.9 billion over the next 25 years, the latter accounting for 17% of the entire NHS budget (Diabetes UK 2012b).

Currently, more than one in ten (11%) deaths among 20 to 79 year-olds in England can be attributed to diabetes (Yorkshire and Humber Public Health Observatory 2008). According to statistics from recent national reports, diabetes causes more deaths than breast and prostate cancer combined; 80% of people with diabetes will die from cardiovascular complications; diabetes is now the leading cause of end stage renal failure; it is the leading cause of blindness in people of working age

(Diabetes UK 2004); and 100 people a week in England have a limb amputated as a result of diabetes (National Diabetes Support Team 2006).

Diabetes is a condition in which the amount of glucose in the blood is too high because the body cannot use it properly. Glucose comes from the digestion of starchy foods, sugar and other sweet foods, and from the liver. Insulin is a hormone produced by the pancreas, which helps the glucose to enter cells where it is used as fuel by the body (Diabetes UK 2008b). There are two main types of diabetes, Type 1 develops if the body is unable to produce any insulin and Type 2 develops when the body can still make some insulin but not enough, or when the insulin that is produced does not work properly.

The number of patients with diabetes in England according to the diabetes Quality and Outcomes Framework (QOF) register in 2006/2007 was 1,961,976 (prevalence 3.7%) (Department of Health 2007b). Approximately 90% of people with diabetes have Type 2 diabetes, therefore, approximately 1.7 million patients in England were diagnosed with Type 2 diabetes (York Consortium, 2010). Recently, the overall number had dramatically increased to 3.2 million in 2013, but the proportion of Type 1 and 2 diagnoses had remained roughly the same (Quality and Outcomes Framework, 2013).

As medications are the main therapeutic intervention offered by clinicians for diabetes in the NHS, and with the prevalence of diabetes rising, optimising treatment for diabetes is of high importance. Adopting this focus will help to avoid negative outcomes for people with diabetes and reduce the burden on the healthcare system.

## 1.3 The problem of non-adherence to medication

It's widely understood that adherence to medication is a complex problem. It has generated a large amount of research interest and has been considered a seriously overlooked problem for clinicians (Becker, 1985). The issue has been brought to the surface by changes in the health demographics of modern society, particularly the increase in long-term condition diagnoses, people living longer, and the need for effective self-management of life-long conditions. (DiMatteo, 2004).

Non-adherence to medication is a global health problem (World Health Organization 2003) and represents a significant waste of resources to health services and a missed opportunity to effectively manage patient care (DiMatteo 2004). To quantify the level of waste, a review of seven systematic reviews and interviews with 16 health care organizations, insurers, drug makers and

technology companies (NEHI, 2009), conducted in the US, reported waste as a \$290 billion problem. In the UK, estimates have suggested that each year between £100-£800 million worth of dispensed NHS medicines go unused and are ultimately discarded (York Consortium, 2010). However, there are many reasons for wastage, some unrelated to non-adherence or patient behaviour and therefore not relevant to this thesis. Wastage related to patients' recovering before the end of their treatment, therapies being stopped or a failure to dispense cannot be attributed to non-adherence or patients' personal medicine-taking behaviour. Thus, the focus of this thesis on patients' medicine beliefs and their resultant medicine adherence behaviour can only partially address the broad issue of medicine wastage. Estimates of how much the cost of medicine wastage is directly related to non-adherence or patients' behaviour are hard to find, but a recent UK evaluation estimated a 'high proportion' of the preventable NHS medicines waste is due to adherence issues (York Consortium, 2010). The degree to which patients' behaviour determines wastage, as an antecedent of non-adherence, is even harder to quantify but reviews of the literature indicate patients' intentional behaviour to not adhere to their prescribed medication are a 'significant factor' in explanatory and intervention studies of non-adherence (Haynes et al., 2008; Horne et al., 2005; Vermeire et al., 2001).

Importantly, non-adherence to medication is not just an issue of financial wastage. Optimal adherence to medication can half the risk of mortality (Simpson et al. 2006) in cardiovascular and HIV conditions and has been linked to significantly lower risk of mortality for those taking cardio-protective medicines (Ho et al. 2006). Despite the benefit of taking correctly prescribed medications, broad reviews of the area estimate 30-50% of medicines for long-term conditions are not taken as recommended (Myers & Midence 1998; Wertheimer & Santella 2003; World Health Organization 2003).

# 1.4 The problem of non-adherence in the diabetes context

The overall health costs and financial costs of not optimising medication use are important to know, but the impacts of not optimising medication use in the context of diabetes care must be taken into account.

Currently, diabetes is an incurable condition. Maintaining blood glucose levels within safe boundaries is an important goal for people with diabetes to avoid short-term complications, such as hypoglycaemia, and the long-term complications described above (American Diabetes Association 2008). People with Type 1 must

carefully balance food intake, insulin medicine and physical activity. People with Type 2 are often prescribed oral medicines that increase insulin production, decrease insulin resistance, or block carbohydrate absorption and may have to take exogenous insulin to achieve adequate metabolic control. In both types of diabetes, medicines are heavily relied upon to assist in the maintenance of blood glucose levels (Gaster & Hirsch 1998; Zinman 1998).

Many people with diabetes are not taking their medication (Emslie-Smith et al. 2003, Cramer 2004, Peyrot et al. 2005). For example, in a large survey of 2849 people with Type 2 diabetes prescribed medication over a 12 month period, only 31% of those prescribed sulphonylureas as monotherapy took their medication as prescribed. Moreover, only 34% of people prescribed Metformin as monotherapy took their medication as prescribed and only 13% of people on more than one drug were taking their medication as prescribed (Diabetes Audit and Research in Tayside Scotland study; Donnan et al. 2002).

#### 1.4.1 The cost of medication non-adherence in the context of diabetes

In the context of diabetes and this thesis, estimates of the cost of non-adherence come from a combination of US and UK findings. In the US, not taking medications as prescribed costs over \$100 billion a year in excess diabetes-related hospitalisations (Sokol et al., 2005) and diabetes patients with poor medication adherence have a 30% annual risk of hospitalisation compared to a 13% risk for those who adhere (Sokol et al., 2005). Total annual health care spending for a diabetes patient with low medication adherence (\$16,499) is almost twice the amount for a patient with high adherence (\$8,886) (Ho et al., 2006) and nonadherent diabetes patients have significantly higher mortality rates (12.1%) than comparable adherent patients (6.7%) (Ho et al. 2006). In the UK, an economic analysis of Type 2 diabetes patients reported good adherence was linked to a reduction in the expected annual cost per patient of approximately £128 (York Consortium, 2010). This was based on GP and nurse surgery visiting costs, nonelective inpatient costs, and medication costs. The expected annual cost of an adherent patient (>80% adherence) was £950 compared to a partially adherent patient (<80% adherence) at £1078, with the latter patients estimated to cost the NHS over £100 million in avoidable medication costs per annum (York Consortium, 2010).

## 1.4.2 The clinical impact of medication non-adherence in the context of diabetes

The mechanism that optimal adherence supports is, of course, beneficial HbA1c levels in the blood which reduce complications. Studies have reported high medication adherence to be predictive of low (beneficial) HbA1c scores in regression analyses (Balkrishnan et al. 2007; Donnelly et al. 2007; Heisler et al. 2007) and a recent review of diabetes adherence and its association with clinical and economic outcomes has confirmed this finding (Asche et al. 2011). In addition, high levels of medicines adherence can reduce micro-vascular complications (Yu et al. 2010) and decrease the risk of hospitalization (Hong & Kang 2011). Detailed research on the latter in the United States reported good adherence to diabetes medications was associated with 13% lower odds of hospitalization or emergency department visits – saving an estimated \$4.7 billion through 341,000 less hospitalizations and 699,000 less emergency department visits annually (Jha et al. 2012).

Despite these benefits, optimal adherence to medication has been hard to achieve. Studies commonly cite 90% (of medicines taken or collected from pharmacies) as optimal adherence but patient self-reported levels of adherence to oral hypoglycaemic medications have been much lower, ranging between 36-93% (Cramer 2004; Tiv et al. 2012). Studies using self-reported adherence found a third of diabetes patients cease to collect prescriptions within the first 12 months of treatment (Hertz et al. 2005) but a recent study using electronic prescription monitoring found 68.6% of patients collected their diabetes prescriptions (Fischer et al. 2010). Despite a more accurate picture from improvements in adherence measurement, a significant level of non-adherence persists. This is worrying considering the central importance of medicines to assist in the maintenance of blood glucose levels (Gaster & Hirsch 1998; Zinman 1998) for diabetes patients.

In conclusion, these findings highlighted that adherence to prescribed medication is a 'good thing' with positive impacts for the individual and the wider healthcare system. Therefore, it is not surprising that medication non-adherence has become a large and heavily researched area over the last 50 years. As the purpose of the research reported in this thesis was to understand the experience of, and influences upon, nurse prescribers' exploration of medication beliefs, a complete review of all medication non-adherence research was not warranted. For example, investigating issues of how non-adherence is defined, conceptualised, or measured was not considered vital. What was vital, however, was an investigation about how medication beliefs emerged as an important antecedent of non-adherence and how

medication beliefs have been defined by researchers. The former has been discussed in the next section and the latter discussed in chapter 2.

## 1.5 Researching the antecedents of medication nonadherence

Medications are the main therapeutic intervention offered by clinicians in the NHS. Pharmacological usage has increased each year with one billion prescription items issued in NHS England general practice settings in 2011 and approximately 20% NHS England's total budget is spent on medication (Payne et al., 2011). On this basis alone, medicine-taking behaviour and the outcome of not taking medicines as prescribed has remained a major research interest. It has driven researchers to investigate further into the problem, examining a high number of variables to determine antecedents. Discussing the trajectory of research in this field highlights how the work in this thesis arrived at the point of investigating nurse prescribers' action to explore patients' medication beliefs.

Previous research has indicated non-adherence is a significant financial and clinical problem but research to establish the antecedents of non-adherent behaviour has discovered, over several decades, that non-adherence is a complex phenomenon, and over 200 potential factors contributing to non-adherent behaviour have been investigated (Cameron 1996). However, many researchers have found these factors have an inconsistent relationship with non-adherence and explain only a fraction of the variance in adherence behaviour (Lassen 1998; Vermeire et al. 2001; World Health Organization 2003; Horne et al. 2005; Haynes et al. 2008). Weak associations between non-adherence and commonly examined 'fixed sociodemographic factors' (age, sex, ethnicity, income, education) and disease/clinical factors are commonplace (Vermeire et al. 2001) and the idea of labelling patients either 'adherent' or 'non-adherent' has been dismissed as providing limited insight (Britten 2003). The inconsistency of possible antecedents has directed research away from fixed trait characteristics and toward patients' 'modifiable characteristics' such as depression, regimen complexity, cost, health literacy, and patients' health beliefs (Gazmararian et al. 2006; Rieckmann et al. 2006; Mann et al. 2007). These modifiable characteristics have provided more stability to the area and replicable findings linking them to non-adherence.

These modifiable characteristics are often categorised by researchers into two groups, unintentional and intentional reasons for non-adherence (Johnson et al. 1999). Unintentional non-adherence occurs when patients do not recall the instructions for medication use or have difficulty administering the medication

(e.g. bottle opening). Intentional non-adherence is a deliberate act on behalf of the patient and driven by their beliefs about illness or treatment. To date, this typology has largely been used to manage the high number of variables assessed. Only one study has estimated the proportion of unintentional and intentional non-adherence. In a study of common long-term conditions (Barber et al., 2004), including diabetes patients, 55% of non-adherence was attributed to unintentional reasons and 45% to intentional reasons. This proportion remained stable 10 days and one month after the baseline assessment. This finding has served to suggest that intentional reasons for non-adherence are equally important as practical problems with medication administration. Moreover, it has served to highlight patients' negative beliefs and/or misconceptions about their medication as important intentional reasons for non-adherence.

Reviews of medicine adherence highlighted patients' 'health' beliefs are important intentional reasons of non-adherence (Vermeire et al., 2001) but further differentiation of these 'health' beliefs has now been conducted. Specifically, patients' 'illness-specific beliefs' and 'treatment beliefs' have received considerable interest in recent years (McHorney & Gadkari 2010). Interest in patients' medicine beliefs was initiated by key examinations of patients' ideas about medication (Fallsberg 1991; Britten 1994), the former using a phenomenological approach to analyse conceptions of medicines elicited during interviews with 90 Swedish patients diagnosed with a chronic condition. Broad conceptions about medicines in general were reported: medicines were either seen as positive and beneficial, negative and harmful, or recognised the dual nature of medicines being both harmful but necessary. The latter found similar conceptions with a UK study of attitudes to medication in a sample of general practice patients. Much of this work led to the operationalisation of medicine beliefs (Horne 1997) and the definition used for this thesis (see Figure 2.1).

In the years that followed, qualitative research continued and a meta-synthesis of qualitative studies investigating medicine-taking, albeit a much broader concept than medicine beliefs, concluded that people's concerns about medicines were the main reason they did not take them as prescribed and highlighted a general societal resistance toward medication (Pound et al. 2005). The concepts of concern and resistance are both linked to the definition used in this thesis. Importantly, since 1999 and the development of the Beliefs about Medication Questionnaire (BMQ, Horne & Weinman, 1999), a plethora of quantitative research has been conducted. This has been largely guided by the work of the BMQ authors and their necessity-concerns framework (Horne & Weinman, 1999; Clifford et al., 2008). To date, a high number of cross-sectional observation studies have been conducted

across a very broad range of conditions and contexts. Therefore, much of the available evidence to judge the value of medicine beliefs as a variable is reliant on the quantitative literature.

To date, there is a need to review the existing cross-sectional observational quantitative studies focused on medicine beliefs, the continuing qualitative studies and determine if any intervention studies have been conducted. This will provide an evidence base to judge the value and strength of medicine beliefs as an antecedent of non-adherence. An examination of this evidence base was an important step to build a key part of the rationale required to justify a focus on the topic of this thesis. Specifically, to understand the experience of, and the influential factors upon, the exploration of patients' medication beliefs by nurse prescribers in practice settings. To address the overall thesis aim, chapter 2 examined the medicine beliefs literature.

#### 1.6 Nurses' medication-related activities

To address the overall thesis aim, a second literature review was required (presented in chapter 3) to understand if and how medicines beliefs were explored in practice. The review in Chapter 3 maintained its focus on medication non-adherence as the key problem the thesis must address, but extended its focus to nurses' activity when engaged in medicines work. The review of research about nurses' medication activity in Chapter 3 highlighted a number of research intensive areas and a number of shortcomings that supported the rationale for this thesis.

Section 1.6 of this chapter provides background and context on the medication-related activity of nurses and its perceived value by stakeholders.

#### 1.6.1 Nurses' and prescribed medication

Prescribed medicines are the most common form of health intervention (National Prescribing Centre 2008) and in 2010 the National Health Service (NHS) spent over £11 billion per year on prescribed medicines (NHS Prescription Services 2010). Whilst only a fraction of nurses are engaged in the act of prescribing, the broad activity of 'medicine management' is part of most nurses work remit (Murphy 2012). Therefore, activity to address medicines non-adherence is also a large part of nurses' work. It has been estimated that up to 40% of nurses' time in typical hospital settings is linked to medicine-related activity (Audit Commission 2001; Armitage & Knapman 2003) and requires a number of advanced skills. These skills

include pharmacological knowledge about drug reactions and interactions, dose monitoring, knowledge of ethical and legal issues, and communication skills (National Prescribing Centre 2010). The latter skill is of considerable importance as nurses have a central role in the education of patients about their medicines (Manias 2010; Salem & Harvie 2010). Furthermore, medicines management extends beyond the administration of medicines and education of patients to an appreciation of individual patient needs; considering the best fit for them in terms of specific circumstances. By considering patients' needs, preferences, beliefs and experiences, the scope of medication management broadens from a medical view of assistance and compliance and incorporates the many factors that influence a person's ability to take medicines (Shafer 2005).

Nurses represent the largest number of healthcare workers worldwide (Shishani et al. 2012) and their role in medicines activity continues to increase in response to increasing recognition of the value of their involvement. Fortunately, the dynamics of modern nursing have moved on from Stein's (1967) seminal work about doctor and nurse roles, which outlined the influence of nurses in medication decision making:

"The nurse is to be bold...have initiative, and be responsible for making significant recommendations, while at the same time she must appear passive".

Modern developments such as nurse-led clinics/care have changed the perception of nurses' role in medicine-related activity to the point that Schools of Nursing have shown leadership in the area of drug demand reduction (Wright et al. 2005), research has reported nurse administered structured interviews about medication can improve treatment in community settings (Rogers 2003a), and nurses are considered vital to addressing the long-standing issue of patient medication adherence in general (Peters et al. 2001) and in the diabetes context (Lyles & Schillinger 2013).

Despite these benefits, one study identified patients and different types of health professionals have incongruent ideas about who should provide essential medication-related information (Tarn et al. 2009). As these authors point out, differing expectations by stakeholders could lead to overlapping, inefficient efforts that result in communication deficiencies when patients receive a new medication. Nonetheless, it is historically apparent that nurses from a range of backgrounds are heavily involved in medicines activity. This is exemplified by a recent survey of New Zealand senior registered nurses (Jutel & Menkes 2010) that reported only two

of ninety-six nurse respondents indicated they had formal prescribing rights but 40% reported they initiated prescriptions, 18% renewed them, 79% recommended treatments, 47% wrote out prescriptions for the doctor to sign, and 78% provided advice to patients about over-the-counter medicines.

#### 1.6.2 Nurses' medicine-related activities

To understand how medication beliefs exploration fits into the variety of medicinerelated activity, it is important to consider how nurses are involved in medicine management. By investigating this issue, some insight can be drawn about whether medicine beliefs exploration has occurred and thus if effective medicines non-adherence work has occurred.

Few definitions exist to conceptualise nurses' medicine-related activity due to the varied type of nurses and their activities within specific health contexts. However, health professionals would probably agree with the broad outline of generic tasks (Ampt & Westbrook 2007) required of nurses when involved in medicines activity. Regardless of whether a nurse has a prescribing qualification or not, they could be involved in medicines tasks such as: finding the order (looking for medication charts/records with drug order), prepping for drug (activity around drug preparation and clean up), clarifying (confirmation of any part of the drug order with clinicians or other information source), checking drug (checking with and cosigning of another nurse's or doctor's medication, administering (giving medication to a patient), charting (recording drug administration details), ordering (ordering stock or non-stock items for patients), discussing (talking about a drug with another health professional or patient or relative), and reviewing (looking over drug orders as part of planning care). Clearly, this thesis is concerned with the latter two activities and this definition serves to start the discussion to highlight an important point of this thesis. The range of nurses' medication activities is bias toward the administration of medicines. Thus, at this point, it would be reasonable to infer that medicines non-adherence work by nurses does not fully address the problem.

Importantly, the act of prescribing is missing from the broad outline above and is now a daily reality for over 54,000 nurse and midwife prescribers and over 19,000 nurse independent and supplementary prescribers across the UK (Royal College of Nursing 2012). The ability of nurses to prescribe medicines originates from pressure upon the National Health Service (NHS) to increase the speed and availability of medicines to the general public, and better utilize the skills of the workforce (Department of Health 2000a). However, this began many years before

with the Cumberledge report (Department of Health 1986), which placed the prescribing debate into a policy arena and a government assessment of the potential benefits of nurse prescribing was published in the Crown report (Department of Health 1989). Since the mid-nineties, pilot sites provided evidence of the value of nurses' prescribing medicines for patients, culminating in a 'review of the supply and administration of medicines' to the Department of Health (Department of Health 1999). At present, to obtain the prescribing qualification nurses are required to undertake additional training in consultation communication, assessment skills, and pharmacology as part of a university regulated 26-day course. Qualified nurses currently prescribe medicines through two main models of prescribing: Nurse Supplementary Prescribing (NSP) or Nurse Independent Prescribing (NIP).

#### NSP is defined as:

"A voluntary prescribing partnership between an independent prescriber (a doctor or dentist) and a supplementary prescriber (a pharmacist, nurse or midwife) to implement an agreed patient-specific Clinical Management Plan with the patient's agreement" (Department of Health 2005).

#### NIP is defined as:

"Prescribing by a practitioner (e.g. doctor, dentist, nurse, pharmacist) responsible and accountable for the assessment of patients with undiagnosed or diagnosed conditions and for decisions about the clinical management required, including prescribing" (Department of Health 2006).

NIP has become the dominant model of nurse prescribing and appropriately qualified nurses are now able to prescribe any licensed medicine within their competence, including controlled drugs. Currently, 54,000 nurse and midwife prescribers and over 19,000 nurse independent and supplementary prescribers across the UK (Royal College of Nursing 2012) have the ability to prescribe medicines according to their prescribing status. Data from NHS Prescription Services (2010) reported 12.8 million items were prescribed by nurses in a twelve month period, representing a 10% increase on the previous year. Furthermore, estimates from primary research indicate nurse prescribers are issuing a prescription every 2.82 consultations (Latter et al. 2007a) and are highly likely to be engaged in medicines discussion.

This new role for nurses has been evaluated and the benefits reported in several multi-site evaluations in the UK (Latter et al. 2005; Norman et al. 2010; Latter et al. 2011) and a common set of competencies now underpin prescribing regardless of health professional background (National Prescribing Centre 2012). However, these competencies are largely focused on what Bajcar (2006) considers the *act of prescribing* - those being the administration / accurate prescribing work of prescribers. This suggests nurses have yet to engage in detailed discussions about patients' beliefs about their medications, and thus are not engaged in effective medicines non-adherence work. However, some may report that guidance does exist to support nurses in this task.

#### 1.6.3 Guidance for medicine-related communication

Good communication about medicines is promoted in nursing guidance (Nursing and Midwifery Council 2007) but a review of this literature suggested it is currently biased toward a biomedical approach that ignores research from other disciplines (e.g. health psychology) relevant to the broad remit of medicines management. This was apparent in the Standards for Medicines Management (Nursing and Midwifery Council 2007) guidance which outlined twenty-six standards arranged into ten sections. It predominantly focused on administration tasks such as checking, transcribing and dispensing, storage and transport, delegation, disposal, and management of adverse events. This particular guidance failed to account for patients' views and attitudes about their medicines which have increasingly become of equal, if not more, importance as 'administrative medicines discussion'. The nearest this guideline comes to addressing patients' views about their medicines is Standard 9 (Assessment) which stated:

"As a registrant, you are responsible for the initial and continued assessment of patients who are self-administering and have continuing responsibility for recognising and acting upon changes in a patient's condition with regards to safety of the patient and others."

This standard is vague about the specific tasks required of nurses. Moreover, due to the overall biomedical/administrative focus of the guideline, nurses are likely to assume assessment refers to the act of prescribing or administration of medication.

Furthermore, NMC (2007) guidance Standard 16 (Aids to support compliance through reminder charts, large print labels and non-childproof tops) was in conflict with important aspects of recent guidance on medicines adherence. Guidance on medicines adherence (National Institute for Health and Clinical Excellence 2009)

differentiated between 'unintentional reasons for non-adherence' (e.g. inability to open bottles, unavailability of medicines, memory loss) and 'intentional reasons for non-adherence' (e.g. patients' motivations, beliefs, views) (Johnson et al. 1999). Clearly, the compliance aids in the NMC guidance refer to the former even though the latter is increasingly considered more important for optimal medicines adherence in published reviews (Cox et al. 2004; Horne et al. 2005). The focus of nurses' guidance about medicines has overlooked the views of patients, or assumed it will be dealt with automatically, and pre-conditioned nurses to think administratively about what a model of medicine activity by Bajcar (2006) considers 'medicine-taking acts'. In NMC (2007) guidance, little attention was given to what Bajcar (2006) refers to as (a) making sense of medication taking, (b) engaging in mediation-taking self-assessment, and (c) considering the context of medication taking.

Section 1.6 of this chapter has built the argument for the need for a complementary medicines discussion agenda, namely 'affective medicines discussion', in addition to administrative medicines discussion between nurses and patients. It is within this type of medicines discussion that medication beliefs exploration is positioned. Such a distinction is not new in the context of general clinician communication, often termed 'instrumental' and 'affective' discussion (Bensing & Dronkers 1992). The former to address patients' need to know the problem, the facts, and the treatment options, and the latter to address psychosocial needs so patients feel known and understood. However, in the specific context of medicines discussion, it appears formal nursing guidance does not support both.

Fortunately, in recent years, further guidance has been published that supports the need for an affective medicines discussion agenda. Recently published, the National Prescribing Centre's Single Competency Framework for all prescribers (National Prescribing Centre 2012) encourages affective medicines discussion, to effectively address medicines non-adherence, in the context of shared decision making between clinicians and patients. In addition to outlining administrative competencies (e.g. knowledge, medical assessment for medication need, medicine error monitoring) the guidance also focuses on shared decision making (with parents, care-givers or advocates where appropriate) in Competency 3. More specifically it states that prescribers should:

"Identify and respect the patients' values, beliefs and expectations about medicines" and "deal sensitively with patients' emotions and concerns about their medicines."

Similarly, NICE guidance on promoting optimal medicines adherence has stated that health care professionals should:

"Be aware that patients' concerns about medicines, and whether they believe they need them, affect how and whether they take their prescribed medicines." (National Institute for Health and Clinical Excellence 2009)

Nurses' exploration of patients' medicine beliefs can be positioned as a form of affective medicines discussion and recent guidance (National Institute for Health and Clinical Excellence 2009; National Prescribing Centre 2012) supports this activity. However, a critical problem with these guidance documents are they may only be read by nurses with the prescribing qualification. Other nurses may refer to previous NMC (2007) guidance and only pursue an administrative medicines discussion agenda.

#### 1.6.4 Additional influences on nurses' medicines communication

Likely influences on the beneficial development of the National Prescribing Centre's Single Competency Framework for all prescribers (National Prescribing Centre 2012) include literature published in the areas of concordance (RPS, 1997), shared decision-making and patient centeredness. In the UK, shared decision-making (see research by e.g. Balint, 1969; Mead & Bower, 2000; Lewin et al., 2001) is now considered an ethical imperative which should become a norm in the NHS and appropriate for decisions about whether to prescribe or take medication (Coulter & Collins 2011). This approach to patient care can be viewed as a golden thread through many guidance documents about patient care in recent years and nurses are likely to report their awareness of it.

Some comparisons of these concepts have been attempted (e.g. Holmstrome & Roing, 2010; Rohrer et al., 2008), however, debate about the definition of all these concepts has been limited and a rigourous comparison yet to be done. Broadly speaking, they all share similar principles of shared power, therapeutic alliance, and recognition of patients' beliefs (Weiss & Britten 2003; Weiss et al. 2004). For example, a good position on their overlap has been suggested by Cribb (2011). Consistently at the forefront of UK thinking in relation to the concordance agenda (Horne et al, 2005; Cribb and Owens, 2010; Cribb and Entwistle, 2011), Cribb (2011) justifies general patient involvement in care decisions as paying attention to, and taking note of, several patient perspectives. Firstly, patient involvement will respect the autonomy of patients, secondly, will improve decision quality as

patient preferences are vital to determining what counts as the best treatment (including no treatment), and finally, will enhance ongoing effectiveness through 'informed adherence' or 'concordance'. Shared decision-making thus allows clinical expertise and patient values and preferences to be optimally combined (Cribb, 2011: 49).

An examination of this overlapping and complementary body of literature has two valuable points to make for this thesis.

Firstly, on the issue of patients' preferences referred to above, central to this action by health professionals is the need to explore patients' general attitudes and beliefs. The importance of patients' beliefs is recognised as a key element in the most recent operationalised definition of concordance (Snowden & Marland, 2013), alongside knowledge and collaboration elements. In the specific context of medicine-taking, others have suggested patients' beliefs are central to achieving concordance based on the idea that patients and practitioners should work together towards an agreement on treatment choice (Stevenson & Scrambler, 2005). Coupled with the key role of patients' beliefs in patient-centeredness and shared decision-making, the exploration of medication beliefs can be considered a specific form of activity under the auspices and approach of these broader concepts.

With this in mind, the exploration of patients' beliefs about their medication can and should be positioned within the broader remit of patient centeredness, concordance and shared decision-making. However, to what extent medicines beliefs have been formally incorporated and/or operationalised in these broader framework is not yet known. Its lack of formal integration has likely hindered the use of medicine beliefs as a concept of interest for nurses to manage medicines non-adherence.

The second message from the broad, over-overlapping and complementary body of work on patient involvement is related to the impact of health professional and patient consultation communication on adherence behaviour. Research has consistently shown the quality of the consultation discussion between healthcare professionals and patients has an impact on medication adherence. The mechanisms of negative impact on adherence include poor patient satisfaction with prescribed medication (Ley, 1988), the lack of a friendly health professional taking time to engage with patients' issues (Donovan et al., 1992; Cameron, 1996), health professionals using complex language that confuse patients (DiMatteo et al., 1982), and the lack of patient-centred advice (Clifford et al 2006). Importantly, these studies had a range of outcomes of interest and

methodologically focused on qualitative explorations or cross-sectional survey comparisons. A scoping review in 2005 with a broad focus on concordance and adherence, reported few studies had looked directly at the empirical effects of consultation on medicine-taking behaviour and adherence, and the extent to which changes in consultation process and content can affect changes in medicine-taking behaviour (Horne et al. 2005). This was until a key meta-analysis of doctor-patient communication by Zolnierek & DiMatteo (2009). This review included 106 studies and identified good doctor communication was significantly positively correlated with patient adherence. Patients whose doctor communicated poorly had a 19% higher risk of non-adherence compared to patients linked to doctors with better communication skills.

As poor communication will impact on patients' adherence behaviour and good communication must involve an exploration of patients' beliefs, the long-established rationale for patient involvement is also an important rationale for focusing on medicine beliefs exploration in this thesis. Beliefs have been increasingly recognised as an important patient barrier to non-adherence (Brand et al. 2013) and current guidance drawn from the research literature would support this position.

In summary, section 1.6 of this chapter has positioned medication beliefs exploration within the wider context of medicine-related research. It has also highlighted some problems with current nursing guidance on medication activity, namely the predominance of an administrative agenda toward medication communication, which may lead to ineffective medicines non-adherence work. Whilst some problems exist, it has highlighted the tremendous possibilities for nurses to effectively manage medicines non-adherence through effective medicines beliefs exploration. Broad guidance available from the research literature, which included health professionals in general, has highlighted the potential impact of health professionals' communication on patients' adherence behaviour. What was missing from this review of literature about medicines activity was a clear understanding of two issues. Firstly, the value of medicines beliefs as a variable of interest, and secondly, a clear understanding of whether nurses are or are not already engaged in explorations about patients' medicines beliefs. Investigating both these issues had implications for the design and focus of this thesis. The former issue is addressed in chapter 2 and the latter issue addressed in chapter 3.

# 1.7 The relationship between the wider intervention study and this thesis

#### 1.7.1 Introduction

The research described in this thesis was carried out in parallel with an educational intervention study to improve medicine-taking in diabetes care (Latter et al 2010). The aim of section 1.7 is to provide an overview of the intervention study and its similarities and differences with this thesis.

In summary, the work undertaken for this thesis was embedded within the intervention study. Both studies had similar components and used the same participants, but there were differences in the focus and extent of investigation for each study. Importantly, many components considered part of the intervention study were operationalised by the thesis candidate as part of his full-time research assistant role to support the development of the educational intervention.

#### 1.7.2 The educational intervention study

The 'Improving medicine-taking in diabetes care: an evaluation of education for nurse prescribers' study was a 'Phase 1 or modelling study' based on guidelines for developing complex interventions (Medical Research Council 2000). The purpose of the Phase 1 or modelling step was to define and standardise the intervention, and develop an understanding of the intervention and its possible effects. Qualitative and quantitative methods were used to investigate the 'active ingredients' of the intervention and its delivery (Medical Research Council 2000). An application for study approval was submitted on the 7th March 2007 to the NHS Southampton and South West Hampshire Research Ethics Committee. The study received a favourable decision on the 11th May 2007 (project reference number: 07/Q1702/45).

The aim of the intervention study (Latter et al. 2010) was to evaluate the effectiveness of an educational intervention for nurse prescribers designed to improve medicine-taking in people with diabetes. The objectives were to (1) deliver an educational intervention for nurse prescribers to improve their skills in negotiating diabetes patients' beliefs about medicines, (2) empirically examine pre- and post-intervention changes in nurses' skills, and (3) investigate nurse prescribers' views on implementing the intervention in practice.

The wider intervention study used a mixed method design with repeated measures. Educational workshop content was developed to address its first aim. Audio-recordings of pre- and post-intervention nurse prescriber consultations with diabetes patients were conducted to address its second aim. Interviews with the nurse prescribers post-intervention were conducted to address its third aim.

As highlighted by Glasziou et al. (2008), it is important to report the detail of an intervention; not only so researchers can assess the focus and rigour of the intervention but also to potentially improve its uptake in practice by clinicians. The wider study involved a series of four one-day workshops designed to facilitate skills acquisition and behaviour change amongst the nurse prescribers. Designed to support nurse prescribers' exploration of patients' medicine beliefs, the intervention was theoretically informed by concepts predictive of effectiveness in (a) promoting medicine-taking in patients and (b) supporting change in nurses' practice in consultations. The former was addressed using evidence about medicine beliefs and the latter promoted the use of a set of patient-centred communication skills (listening, discovery questioning and confirming) and an empowerment framework for nurses' interactions (Funnell et al. 1991). In addition, specific verbal behavioural techniques based on the four sources of self-efficacy mastery experience, role modelling, verbal persuasion and the regulation of physiological and affective states (Bandura 1997) - were used to guide the development of workshop tasks as part of the intervention. The nurses were guided in reflecting on their practice as a key self-efficacy building technique.

Observations of nurse prescribers' consultations were undertaken to determine a wide range of change in their medicine discussions. In addition, post-intervention interviews with participating nurses examined a range of issues including the feasibility and sustainability of the intervention and the salient ingredients of the intervention.

Nurse prescribers embarked on a series of interactive workshop tasks designed to promote the importance of medicine beliefs in medicine-taking. These were delivered to three staggered training cohorts with approximately six nurse prescribers in each cohort. The small group approach was an important part of the intervention which aimed to provide the capacity for reflection of nurses' current practice and facilitate a meaningful change in their consultation behaviour. The first cohort of 4 one-day workshops took place between October 2007 and January 2008, the second cohort between February 2008 and May 2008, and the third cohort between May 2008 and July 2008. The workshops were one month apart for the first two cohorts. The time between workshops was reduced to two weeks for

the third cohort due to time limitations linked to the six-month follow up period for data collection. The intervention workshops for the first and third cohort took place at the Faculty of Health Sciences, University of Southampton. The intervention workshops for the second cohort took place at the Department of Health Sciences, University of Leicester.

#### 1.7.3 Similarities and differences with this thesis

Several aspects of this thesis relied upon the wider study. Work undertaken for this thesis should be considered embedded within the wider study.

Firstly, nurses and diabetes patients were recruited for both the wider study and this thesis at the same time. These were the same people in both studies. The methods of recruitment and targets for recruitment were the same, despite the subtly different focus of the wider study (intervention active ingredients) and this thesis (specific focus on exploration of medication beliefs).

Secondly, the sampling decisions and data collection methods for this thesis were based on the needs of the wider study. For example, it was important to obtain an appropriately representative sample of nurses to participate in the intervention, namely nurses from primary care and secondary care. Also, due to the need to conduct interviews with nurses for the wider study and this thesis, it was pragmatic to include all the interview topics into a single interview. Similarly, the diabetes patients present in nurses' consultation recordings were ideally placed to report on issues linked to beliefs exploration, therefore different samples of diabetes patients were not sought for this thesis. This thesis benefitted from these robust design decisions in the wider study.

Thirdly, data from the quantitative measurement of nurses' medication discussion topics (second aim of the wider study) using MEDICODE has been used in this thesis to identify the extent and content of nurses medication beliefs exploration. This data has been published (Latter et al. 2010) and the author of this thesis was a co-author on the paper. Permission to use the MEDICODE data was granted by the research team. Importantly, in terms of contribution, the author of this thesis was responsible for the recruitment and administration in obtaining the nurse consultation recordings. The author was also involved in the analysis of the MEDICODE data.

Importantly, several aspects of this thesis differentiate it from the wider study and build towards an original contribution. First and foremost, this thesis has a specific focus on patients' medicine beliefs throughout and has more refined aims to

address this focus. The wider study was primarily concerned with the feasibility and active ingredients of the intervention and the impact of the intervention process. Secondly, chapter 2 of this thesis represents the first substantive review of all available medicine beliefs literature. Its conclusions support the rationale for this thesis but also offer an original contribution to the wider literature. Thirdly, the interview themes were not as fully developed during the analysis of nurse interviews for the wider study. Fourth, this thesis has analysed and reported unpublished findings from patient interviews. These interviews sought to investigate diabetes patients' perceptions of medication consultation discussion with their nurse prescriber. Fifth, unlike the wider study, this thesis fully adopted a mixed method approach and integrated findings from chapters 5, 6 & 7 to develop combined conclusions and implications. Sixth, unlike the wider study, this thesis developed an integrated conceptual model (in chapter 8) of medication beliefs exploration by nurses for examination in future research.

On the issue of contribution and authorship, I was responsible for the data collection and majority of analysis for the quantitative element of the wider intervention study and all the qualitative components. Importantly, whilst I supported the development of some parts of the intervention, I was not involved in the delivery of the intervention. This decision ensured I would be distanced from nurse prescribers during the evaluation phase of the wider study.

In summary, the wider study had a broader focus on the feasibility and measurable effects of the educational intervention developed for nurses. This thesis focused on the experience of, and the influential factors upon, exploring patients' beliefs about their medicines in the complex situation of normal practice.

#### 1.8 Overview of the content of this thesis

This chapter has provided an overview of the problem of non-adherence to medication and the nature of nurses' medicines-related activities. It has also discussed how this thesis was carried out in parallel with a wider study. This section will provide an outline of the content of the thesis.

The overall aim of the research was to understand the experience of, and the influential factors upon, the exploration of patients' medication beliefs by nurse prescribers in practice settings. Chapter 2 examines the value of medicine beliefs as an antecedent of medicines non-adherence. This includes an exploration of the quantitative survey data that sought to determine links with non-adherence and findings from qualitative studies that investigated the value of medicine beliefs

more broadly. As there has not been a complete review of the medicine beliefs literature to date, many findings were apparent but those relevant to this thesis were drawn out and guided the study.

The literature review in Chapter 3 explores several practice-related issues, such as what research has been conducted on nurses' medicines work and do nurses already discuss patients' medicine beliefs. Chapter 3 builds on the conclusions of section 1.6 by presenting a narrative review of available research in order to clarify nurses' activities in relation to prescribed medicines. The literature review indicated nurses' discussion about medicines had an administrative focus, i.e. largely talking about medicine instructions and dosage, at the detriment of affective medicines discussion such as patients' medicines beliefs. It also highlighted medication explorations would constitute a new type of work for nurse prescribers and thus required objective measurement of their activity and an assessment of influencing factors.

Having provided three background chapters discussing the key issues of this thesis, Chapter 4 discusses the methodology used in this thesis and the necessity for a mixed methods approach. The theoretical underpinnings and implications for the conduct of this thesis are described here. A mixed method concurrent triangulation design was used to address three research questions in this thesis.

The overall aim of the research was to understand the experience of, and the influential factors upon, the exploration of patients' medication beliefs by nurse prescribers in practice settings. To address this aim, three perspectives were chosen. Firstly, a quantifiable assessment of nurse prescribers' observed consultation medicine discussion was undertaken. This provided a measure of the extent of nurse prescribers' exploration of patients' medicine beliefs. Secondly, a qualitative investigation of barriers and facilitators to nurse prescribers' exploration of patients' medicine beliefs was conducted. Thirdly, a qualitative investigation of diabetes patients' perceptions of consultation discussion having participated in consultations whereby nurse prescribers' explored diabetes patients' medicine beliefs.

Chapter 5 presents findings from the quantitative consultation analysis, chapter 6 presents thematic findings from the nurse prescriber interviews and highlights a range of tensions are present in medicine beliefs explorations. Chapter 7 presents thematic findings from the patient interviews and chapter 8 discusses the findings of each component and integrates them into existing literature. In addition, findings from different components are integrated to develop further inferences.

The overall conclusions, implications of the study and recommendations for future research are presented at the end of chapter 8.

As a result of the literature reviews, I propose in this thesis that patients' medicine beliefs are an important associate of non-adherence, are currently under-explored by nurses during medication consultations, and lack an investigation into the experience of engaging in such an exploration. Having investigated this role, it was evident this was new and difficult work to engage with in practice settings due to a range of tensions, facilitators, and barriers.

Non-adherence to prescribed medicines continues to be a global health problem leading to poorer patient outcomes and significant waste of health care resources. It would seem that despite research evidence suggesting medicine beliefs are a key antecedent of medicines non-adherence, operationalising an exploration of patients' medicines beliefs has challenges. Uncovering these challenges to optimise medicines non-adherence work by nurses has been the key contribution of this thesis to the wider research community.

# 2. A review of studies about patients' medicines beliefs

### 2.1 Introduction

The previous chapter provided an overview of the problem of non-adherence to medication and the nature of nurses' medicines-related activities. It highlighted the need for a complete review of medicine beliefs literature to assess its value, as this had yet to be done. Understanding the strength of the evidence base was a vital process for this thesis, as it would only be prudent to investigate nurses' medicines beliefs exploration work if the literature deemed it to be beneficial to medicine-taking and health outcomes.

A review was needed of the existing cross-sectional observational quantitative studies focused on medicine beliefs, the continuing qualitative studies and any intervention studies identified. The review provided an evidence base to judge the value and strength of medicine beliefs as an antecedent of non-adherence. An examination of this evidence base was an important step to build a key part of the rationale required to justify and direct the focus of this thesis.

To address the overall thesis aim – to understand the experience of, and the influential factors upon, the exploration of patients' medication beliefs by nurse prescribers – this chapter examined the medicine beliefs literature as a whole from published primary research focused specifically on patients' medicine beliefs. This included an exploration of the quantitative survey data that sought to determine links with non-adherence and findings from qualitative studies that investigated the value of medicine beliefs more broadly. With no complete review of the medicine beliefs literature to date, many findings emerged but those relevant to this thesis were drawn out and guided the study.

Due to a paucity of research in the diabetes-specific context, all research on this topic was included in the review. Three methodologically distinct collections of literature (quantitative, qualitative, and interventions to address medicine beliefs) were examined independently, and their individual and combined conclusions are discussed. Different approaches were required to review the methodologically different studies.

This chapter has highlighted the relationship between medicines non-adherence and the measured variables within an accepted definition of medicine beliefs. It has also demonstrated how medicine beliefs have been conceptualised by qualitative studies and link to medicines non-adherence. This chapter revealed some significant gaps in the literature which provide a clear rationale for this thesis.

### 2.2 Defining medicine beliefs

#### 2.2.1 Defining a belief

Before reviewing the evidence base, it is important to define a 'belief' and a 'medicine belief'. Each of us make daily judgments and decisions upon what we hold to be true, whether this be in a religious, political, social, or health context. Research on beliefs is wide-ranging, exploring its definition, nature, and power across psychological, sociological and philosophical boundaries (Halligan & Aylward, 2006).

The definition of a 'belief' is contested amongst philosophers and can vary depending on epistemological, ontological and cultural standpoints, as well as the context in which the term is applied (Bell et al., 2006). However, a recent definition in the Stanford Encyclopedia of Philosophy describes the essence of a belief as: 'a psychological state in which an individual holds a proposition or premise to be true' (Schwitzgebel, 2006). This definition highlights that the knowledge underpinning a belief is relative to the individual making the proposition. This definition is adequate to work with given the health context of this review; patients with diabetes are required to self-manage their condition and may frequently base their decisions upon what they believe to be true (Funnell et al., 1991).

Within the context of health care research, the concept of beliefs is well established. The International Classification of Functioning (ICF) framework (Wade & Halligan, 2004) highlighted the importance of patients' personal context toward the perception of their illness. Patients' beliefs, i.e. their set of expectations about their illness or treatment, can be considered crucial to their comprehension of what has happened before and during their illness. Psychological research often recognizes a 'belief' as the smallest, most basic mental building block and frequently appears within the psychological literature (Cameron & Leventhal, 2003; Conner & Norman, 2005). As a concept, belief is regarded as a precursor to the larger construct 'attitude' which has been operationalised in the Theory of Planned Behaviour (Ajzen, 1985). Within the context of medicine-taking, medicine beliefs have been investigated as discrete entities and found to be increasingly influential in medication non-adherence (Horne et al., 2005).

#### 2.2.2 Defining a medicine belief

General beliefs about medicine, or prototypical beliefs, have been explored and highlighted as a potential influence on health (Bishop 1991; Fallsberg, 1991). The latter study, as a seminal study in this area, identified three categories of prototypical general beliefs amongst people with long-term conditions: those who believed that medicine worked together with the body to improve health, those who believed that medicine had only negative effects and those who believed they will suffer side-effects despite any beneficial effects of medicine. Lorish et al. (1990) provided more evidence of prototypical beliefs through patients' beliefs that the most effective medicines would often have the most unwanted sideeffects. In the late 1990's, further seminal work by Horne (1997) refined the concept of a medicine belief through a review of research into general negative medicine beliefs about dependence (Conrad, 1985), the long term dangers of continued medicine use (Morgan & Watkin, 1988), the chemical nature of manmade medicine (Gabe & Thorogood, 1986), and medicines as poisonous agents (Fallsberg, 1991). The research described above was qualitative in nature and based on the exploration of the patients' views about medicines. Further developments by Horne et al. involved the development of a quantitative measure of patients' medicine beliefs, the Beliefs about Medicines Questionnaire (BMQ, Horne et al., 1999). This has permitted the investigation of predictive links between non-adherence and clinical outcomes variables. Using the BMQ, general beliefs about medicines are conceptually categorized into general beliefs about the 'overuse' of medicines and general beliefs about the 'harmful or addictive nature' of medicines. This categorisation forms the first section of the outcome measure.

In addition to general medicine beliefs, qualitative studies have shown that patients also hold specific medicine beliefs regarding their current medicine for conditions such as epilepsy (Conrad, 1985) and hypertension (Morgan & Watkins, 1988). Those that used a quantitative approach to assess specific medicine beliefs have used different questionnaires and focused on different conceptual element of medicine beliefs (Echabe et al., 1992; Farmer et al., 2006; Horne et al., 1999; Riekert & Drotar, 2002; Svarstad et al., 1999; Woller et al., 1993) so comparisons or typologies of medicine beliefs have been difficult to establish. However, a well-designed study of 1200 patients with a range of long-term conditions demonstrated that specific medicine beliefs could be grouped into two conceptual categories. These are medicine beliefs about the 'necessity for' and 'concerns about' specific medicines (Horne & Weinman, 1999). These operationalised concepts of medicine beliefs form the second section of the BMQ (Horne et al., 1999). These concepts have often been referred to as the 'Necessity-Concerns

Framework' (Horne et al., 2007) and have been explored with a range of different patient groups (Horne & Weinman, 1999; Horne et al., 2002; Farmer et al., 2006; Horne et al., 2007; Katz & Goldberg, 2007; Clifford et al., 2008; Clatworthy et al., 2009).

The decision to use the Horne et al. definition of medicine beliefs in this study was determined by three clear advantages. Firstly, to date, it is the only comprehensive attempt to define the concept of medicine beliefs. Various investigations by Horne et al. build to provide the most comprehensive development of patients' medicine beliefs as a concept (Horne, 1997; Horne et al., 2007). Horne (1997) brought together different concepts initially investigated separately, such as addiction and concerns, into categories that could be investigated empirically and in conjunction with hypothesised associate variables such as non-adherence. Secondly, other investigations of patients' ideas about their medicines often conceptually stray from the topic of medication itself, for example, into patients' beliefs about their illness (Riekert and Drotar, 2002) or other behaviour such as overall medical knowledge (Barnes et al., 2013), medicine-taking practicalities (Svarstad et al., 1999) or dealing with health care professionals (McDonald-Miszczak et al., 2004). Thirdly, despite the criticism that evidence about patients' medicine beliefs is largely cross-sectional and observational in nature (Horne et al., 2005), findings from the wide range of studies and the medicine beliefs concepts developed by Horne et al. have been adopted into clinical guidance for optimal medicines adherence (National Institute for Health and Clinical Excellence 2009).

The concepts presented in Horne et al.'s definition of patients' medicine beliefs (see Figure 2.1) provided a conceptual anchor for this thesis. Importantly, they are more developed than other attempts to use medicine beliefs in conceptual groups. This conceptual anchor of specific and general beliefs, and at a lower conceptual level on necessity and concerns beliefs, has provided a focus for the examination of patients' medicine beliefs in practice for this thesis. As part of the quantitative element of this thesis (see Chapter 5 for findings), I sought to determine if these conceptual topics were present in medicine discussions between nurse prescribers and diabetes patients.

Figure 2.1 Medicine beliefs concepts from the Beliefs about Medicines Questionnaire (BMQ; Horne et al., 1999)

#### **BMQ-Specific**

Two subscales: Specific-Necessity and Specific-Concerns

-We would like to ask you about your personal views about medicines prescribed for you.

-These are statements other people have made about their medicines.

- -Please indicate the extent to which you agree or disagree with them by ticking the appropriate box.
- -There are no right or wrong answers. We are interested in your personal views.
- -To elicit beliefs about individual components of the treatment regimen the reference statement should refer to the medicine by name e.g. your views about aspirin prescribed for you. Additionally items can refer to a named illness e.g. your views about medicines prescribed for your asthma.

Rated: (1) strongly disagree, disagree, uncertain, agree, strongly agree (5)

- 1. (Sp-N) My health, at present, depends on my medicines
- 2. (Sp-C) Having to take medicines worries me
- 3. (Sp-N) My life would be impossible without my medicines
- 4. (Sp-N) Without my medicines I would be very ill
- 5. (Sp-C) I sometimes worry about long-term effects of my medicines
- 6. (Sp-C) My medicines are a mystery to me
- 7. (Sp-N) My health in the future will depend on my medicines
- 8. (Sp-C) My medicines disrupt my life
- 9. (Sp-C) I sometimes worry about becoming too dependent on my medicines
- 10.(Sp-N) My medicines protect me from becoming worse

#### **BMQ-General**

Two subscales: General-Harm and General-Overuse

- -We would like to ask you about your personal views about medicines in general.
- -These are statements other people have made about medicines in general.
- -Please indicate the extent to which you agree or disagree with them by ticking the appropriate box.
- -There are no right or wrong answers. We are interested in your personal views. Rated: (1) strongly disagree, disagree, uncertain, agree, strongly agree (5)
- 1. (Gen-O) Doctors use too many medicines
- 2. (Gen-O) People who take medicines should stop their treatment for a while every now and again
- 3. (Gen-H) Most medicines are addictive
- 4. (Gen-H) Natural remedies are safer than medicines
- 5. (Gen-H) Medicines do more harm than good
- 6. (Gen-H) All medicines are poisons
- 7. (Gen-O) Doctors place too much trust on medicines
- 8. (Gen-O) If doctors had more time with patients they would prescribe fewer medicines.

#### 2.3 Main aim of the review

To address the overall thesis aim – to understand the experience of, and the influential factors upon, the exploration of patients' medication beliefs by nurse prescribers – it was important to review all the available literature pertaining to patients' medicine beliefs. As mentioned in chapter 1, over 200 variables have been explored to understand antecedents of medicines non-adherence. However a full review of medicines beliefs literature had not been completed. The value of this literature would be largely judged by its links to medicines non-adherence. By

investigating and establishing these links, it would validate medicine beliefs as a discussion topic worth investigating by nurses in practice consultations.

The main aim of the review in this chapter was to critically assess the value of research about patients' medicine beliefs, the conclusions of which were expected to support or refute the need to engage with patients' medicine beliefs in practice settings. Addressing the main aim was done through several sub-aims depending on the methodological position of the studies reviewed.

In relation to the quantitative studies, the bulk of identified studies fell into this category. Several sub-aims were developed to address the nature of these studies. The details of the sub-aims of the quantitative review are outlined in the next section. They are largely concerned with statistical links between the measured concepts of patients' medicine beliefs and adherence to medication.

In relation to the qualitative studies, the aim was to assess available qualitative literature on medication beliefs, based on the definition of medicine beliefs used in this thesis, and its relationship with medication adherence. Similarly, the aim of the short review of identified interventions was to further examine the value of medicine beliefs research and its impact on medicines adherence.

Deliberately broad search terms were used to identify studies with any methodological background. However, slightly different criteria were used to include or exclude studies from each part of the review. The integration of these studies occurred in the final sections of this chapter. The conclusions of each body of work was brought together to address the aim of the review. On the issue of how this review was presented, a structured approach was undertaken similar to reporting a systematic review.

#### 2.3.1 Search terms

Searching for all published research about patients' medicine beliefs is inherently difficult due to the use of commonplace search terms, e.g. 'medicine', which can produce a vast amount of irrelevant literature. Based on this, search terms were developed to provide a focused but reasonably flexible approach. EBSCO databases MEDLINE, PsycINFO, and CINAHL were searched using these terms and truncation: ("medic\* belief\*" OR "belief\* about medic\*" OR "treatment belief\*" OR "belief\* about treatment" AND "patient\*") anywhere in the title or abstract. Limits were used whilst searching and included: published primary research and studies dated between January 1999 and September 2012. This date range was considered appropriate to gather a suitable range of literature whilst keeping it manageable

for a single postgraduate reviewer. Moreover, the starting point of the date range was the year the literature began to consolidate under the definition of medicine beliefs provided earlier in this chapter. Therefore, the work presented in this review does not suffer with problems of differing definitions of the concept and categories of patients' medicine beliefs. The end date of the literature review was shortly before the first submission of this thesis.

These search terms were used to identify all the literature in this review. A total of 1,122 studies were identified from these search terms.

Preliminary reviewing quickly highlighted the methodological diversity of this body of literature. Therefore, studies in this review were processed separately and organised into three distinct areas to reflect the methodological range in this field.

It was evident the quantitative studies represented the bulk of the review so these were reviewed first to examine the value of patients' medicine beliefs through its empirical association with medicines adherence. Qualitative studies were synthesised in a separate section and the limited number of intervention studies that focused on addressing medicine beliefs were reported separately.

Importantly, the order of the three main sections in this chapter does not reflect the order of activity in this area of research. A range of qualitative work preceded the quantitative work; however, in the last 10 years researchers have predominately focused on quantifying medicine beliefs and assessing their links with adherence and a variety of health outcomes. To date, interventions to support medicine beliefs are limited.

It was also evident that limited research existed in the field of diabetes; therefore, a broad review was conducted to draw cross-conditional conclusions about the value of medication beliefs research. Where studies were conducted in the diabetes context, they were given due attention in this review. Implications for diabetes and adherence research are considered.

### 2.4 Review of quantitative studies

#### 2.4.1 Rationale and aims of the review of quantitative studies

In order to investigate the value of patients' medicine beliefs through its association with medicines adherence, a focused review using systematic methods examined studies that empirically measured patients' medicines beliefs and medicines adherence. Studies that did this were extracted from the total number

of studies found (n=1122). Due to the nature of the available data and in order to undertake a manageable review for this thesis, this review focused on the prevalence and ratio of significant and non-significant associations with adherence when patients' medicine beliefs were measured in empirical studies. Significant and non-significant associations between other factors and adherence, reported in the included studies, were summarised and compared against patients' medicine beliefs. Importantly, complex meta-analytic techniques were not undertaken for justifiable reasons.

Despite a fast expanding body of quantitative literature, the area as a whole has yet to be reviewed. Favourable findings about patients medicine beliefs have been reported in several reviews of medicines adherence for individual conditions (Karamanidou et al. 2008a; Jackson et al. 2010; Salt & Frazier 2010; Selinger et al. 2011; van den Bemt et al. 2012) but an overall view of the value of medicine beliefs studies has not been done. Moreover, whilst comparisons with other variables have been made in individual studies, this has yet to be brought together in a review of the area.

Initial searches indicated a limited number of diabetes studies, therefore, all available studies were included in the review to assess the value of this body of research.

In order to assess the value of patients' medicine beliefs and its associations with medicines adherence, a focused review of research that empirically measured patients' medicines beliefs was undertaken. In order to undertake a manageable review for this thesis, a number of decisions were made to reduce the size and complexity of the review. The three main decisions are outlined below and the minor decisions are listed in the inclusion and exclusion criteria.

Firstly, studies were required to have measured patients' medicine beliefs. This was a different start point compared to related reviews (Karamanidou et al. 2008a; Jackson et al. 2010; Salt & Frazier 2010; Selinger et al. 2011; van den Bemt et al. 2012) that included all possible determinants of adherence as the start point. The benefit of the approach taken in this chapter was an immediate focus on patients' medicine beliefs and the prevalence of associations with adherence. This does not mean other variables with significant associations were not accounted for in this review; many were reported in the included studies and their prevalence is part of this chapter.

Secondly, studies must have measured patients' medicine beliefs using the widely used Beliefs about Medication Questionnaire (BMQ) (Horne et al. 1999). It is the

predominant measure and most widely used conceptual definition of medicine beliefs. Focusing on this measure provided a degree of homogeneity to the review and this consistency supported the conclusions drawn. Based on the date of the published BMQ, this review was focused on contemporary studies of patients' medicine beliefs and included studies dated from 1999 onwards.

Thirdly, early indications during the review process pointed toward a largely observational, cross-sectional, heterogeneous set of studies with a wide range of contexts, sample sizes, and methods of adherence measurement. This was not unexpected but it has been claimed that detailed meta-analytic procedures produce distorted findings due these reasons (Egger et al. 1998). Due to these reasons and the need for a manageable review, a formal meta-analysis was not conducted. This is not uncommon as related reviews had the same problem and only make comparisons between different variables at the level of narrative description or frequency of occurrence (Karamanidou et al. 2008a; Jackson et al. 2010; Salt & Frazier 2010; Selinger et al. 2011; van den Bemt et al. 2012).

On the spectrum of review types, this review was positioned between a narrative review and meta-analysis. Narrative reviews primarily focus on study conclusions whereas meta-analyses focus on sample sizes, data, and the magnitude of effect sizes. Due to early indications during the review process, the decision to focus on prevalence of significant associations was operationalised by undertaking a form of 'vote counting' review (Bushman 1994). This type of review embraced the standardisation of meta-analysis, focused on the findings as opposed to the conclusions, but did not go as far in its analysis or subsequent claims. This type of review often adds up the number of positive and negative findings and makes limited conclusions on the importance of factors on this basis. Importantly, this method does not provide an estimate of the effect size of factors but does offer the ability to draw together a broad range of literature and guide the field when more sophisticated methods are not possible (Bushman 1994). Moreover, the value of vote counting as a method was strengthened in a review of forty intervention studies with adult cancer patients (Cwikel et al. 2000). This study conducted a meta-analysis and vote counting procedure and reported the review findings were highly correlated.

The reporting of prevalence in this review provided a means to assess the extent of patients' medicines beliefs as a factor repeatedly associated with medicines adherence. In addition, the prevalence of all other significant variables reported in the included studies were tallied and tabulated. Thus, comparisons of prevalence of all significant associations were possible.

The aims of the review of quantitative studies were to:

- (1) Determine the characteristics of all available literature that measured patients' medicine beliefs using the BMQ and medicines adherence.
- (2) Determine the prevalence and ratio to which patients' medicine beliefs concepts were significantly or not significantly associated with medicines adherence.
- (3) Determine the prevalence and ratio of other factors present in the included studies and their significant or non-significant associations with medicines adherence.

#### 2.4.2 Methods

#### 2.4.2.1 Inclusion/exclusion criteria

A number of factors were considered vital to use as inclusion and exclusion criteria. The research area of medicines non-adherence was vast; therefore, criteria were established to keep the review focused on medicines non-adherence, medicines beliefs, people with diabetes, and on medications relevant to diabetes care.

For the review of quantitative literature, studies were included based on the following criteria:

- Involved adult (18 years old and above) patients
- Involved licensed and prescribed medicines
- Involved medication in the form of oral tablets, inhalers or injections
- Studies that investigated patients' beliefs about medicines using the Beliefs about Medication Questionnaire (BMQ; Horne et al., 1999)
- Studies were primary research
- Studies sought to empirically compare medicine beliefs concepts with a measure of adherence. All author-created and/or validated adherence measures were included.
- Studies reached or exceeded the minimum quality cut-off score (Kmet et al. 2004).

The reviewer was aware of a wide range of studies that investigated medicines beliefs but whose aims diverged from the aims of this review and thesis. These studies could be categorised into three areas. Firstly, some studies were descriptive and made no attempt to link them to medicines non-adherence. These studies precluded the possibility of contributing to the evidence base this chapter sought to establish. Secondly, another group of studies focused on other types of people's beliefs about their medicines. This thesis was concerned with the exploration of diabetes patients' beliefs, therefore, health professionals' or carers' ideas about medication were not relevant. Thirdly, a large body of work has focused on patients beliefs at a wider level, such as beliefs about different conditions. As this thesis was focused on medicines communication, this group of studies were not considered relevant. Studies about unregulated medications were excluded as the vast majority of diabetes patients are engaged in the use of a small number of regulated medications for their condition.

Studies were excluded based on the following criteria:

- Qualitative or quantitative studies describing the nature, type, and extent of medicine beliefs.
- Studies that focused on healthcare professionals' beliefs, carers' beliefs, the general public or consumers' beliefs.
- Studies that primarily focused on patients' general health beliefs, illness perceptions, personal models of illness, medicine outcome expectancies and beliefs about the efficacy of medicines.
- Studies about non-prescribed medicines, complementary or cultural medicines.

#### 2.4.2.2 Search results

The number of studies identified across the databases after the removal of duplicates was 1,122. All abstracts were reviewed and 219 quantitative studies were selected for a full paper reading. A total of 59 studies met the inclusion criteria. Three more studies were identified from hand-searching, raising the total number of included studies to 62. Importantly, two studies (Horne & Weinman 1999; Kurlander et al. 2009) involved more than one patient population and comparisons with adherence were made independently with each population which resulted in an increase in 'collections' of condition-specific data (n=64). Therefore, discussion about the studies in this chapter was based on the 64 collections of data available from the 62 included studies unless otherwise stated.

#### 2.4.2.3 Data extraction

Findings from included studies were tabulated to assist critical review (see Appendix Tables 1 to 8 in Appendix 1). Information was extracted about the number of participants, study design and origin, the main statistical analyses, measure(s) of adherence, and variables associated or not associated with adherence/non-adherence as reported in the results sections of the included studies. In terms of determining the main statistical analysis, bivariate correlations were considered inferior to regression analyses or structural equation modelling that appeared in the same study and not extracted in those situations. Where the main statistical tests focused on more than one measure of adherence/non-adherence, the variables included in each individual analysis were extracted. A universal cut-off point of p<0.05 was used to determine whether the variable was listed as 'associated' or 'not associated' with adherence/non-adherence. Direction of findings (e.g. a variable being linked to either adherence or non-adherence) was difficult to determine due inconsistencies with reporting.

#### 2.4.2.4 Quality assessment

Reviews allow clinicians to stay apprised of recommendations for best practice and several consensus statements promote higher quality of reporting, including QUOROM recommendations for reporting meta-analyses (Moher et al. 1999), CONSORT for randomised trials (Moher et al. 2003), and MOOSE for meta-analyses of observational studies (Stroup et al. 2000). However, even within the confines of single designs, such as randomised controlled trials, the reliability, validity, feasibility and utility of different quality assessment tools are variable (Lohr & Carey 1999). Furthermore, quantitative and qualitative reviews are seldom assessed using the same criteria. Both these issues would indicate the use of separate but ultimately incomparable quality assessment tools. This raised the question of the existence of an appraisal tool, for this particular review, to permit comparison of quantitative and qualitative studies.

This question was driven by the certainty of finding a methodologically diverse set of studies investigating patients' medicine beliefs. Previous quality assessment guidelines suggest hierarchical ordering of study designs (Sackett, 2000) should be used to define a minimum quality threshold for study inclusion. However, due to the broad range of quantitative designs and qualitative approaches evident in search findings, this approach would immediately place the qualitative research in a subordinate position. As this thesis took a mixed methods pragmatic approach and considered evidence from quantitative and qualitative studies of equal value, it was not appropriate for this review.

Standardised quality assessment criteria for evaluating primary research papers from a variety of fields has been developed in response to a lack of tools to do so (Kmet et al. 2004). This framework acknowledges the differences in epistemological positions and evaluative criteria between quantitative and qualitative research, and does not seek to provide an all-encompassing measure of study quality. It pragmatically developed two scoring systems, a generic system for appraising quantitative studies and a generic system appraising for qualitative studies. Different questions are asked in each scoring system for the reviewer to consider. Quality is judged in both scoring systems in terms of the internal validity / credibility of the studies and the extent to which the design, conduct and analyses minimized errors and biases.

In terms of the quantitative quality appraisal tool, the Kmet et al. (2004) framework recommends quality-based exclusion if studies score 55% or lower on their 14-item checklist for assessing the quality of diverse quantitative studies. A quality score was calculated for each included study and reported in Appendix Tables 1 to 8 (see Appendix 1). Due to the nature of conducting a review for a doctoral thesis, only one reviewer independently assessed the quality of included studies.

Criticisms of this generic appraisal tool are related to its limited inter-rater reliability testing (Webb & Roe 2007); however, it is not uncommon for appraisal tools to be under-evaluated due to the plethora of tools available and resources required to evaluate them. A previous reliability assessment for this quantitative scoring system reported the question level agreement ranged from 73% to 100% and the kappa for overall score as 0.76 between raters (Kmet et al. 2004). This level of agreement is considered by many as 'substantial' (between 0.61 – 0.80) but not 'highly substantial' agreement (greater than 0.81) (Viera & Garrett, 2005). Whilst it's not the highest form of agreement, it is comparable to many other generic quantitative appraisal tools. For example, Crowe's critical appraisal tool reported inter-rater reliability at 0.74 (kappa) for total score (Crowe and Sheppard, 2011), the 'quality assessment tool' reported inter-rater reliability as 'substantial' to 'very substantial' (kappa ranging from 0.69 to 0.91) for question level agreement (Sirriyeh et al. 2012), and a Canadian appraisal tool by Pace et al. reported inter-rater reliability of their total score at 0.71 (Pace et al, 2012).

Evidence of the similarity was also apparent in the content of these generic quantitative appraisal tools. All had 'yes, no, partial' approaches to scoring, all asked approximately 15 questions, and all asked very similar questions on 11 generic factors relevant to a range of quantitative methods. These included a clear

statement of the aim(s), a clear research question(s), representative sampling, description of the procedure for data collection, method of analysis appropriate to methodology and research question, detailed recruitment data, and discussion of strengths and limitations. If an intervention study was assessed, descriptions of randomisation, allocation concealment, blinding, and drop-out rates were included.

In addition to its similarity with other appraisal tools, an important reason for choosing the Kmet et al. (2004) appraisal tool was the need to appraise a range of methodologically diverse studies, both qualitative and quantitative, and diverse quantitative studies (e.g. observational and longitudinal), in order to draw conclusions about the relative value of methodologically distinct sets of literature on the same topic. To that end, the Kmet et al. tool has been used in many other systematic health reviews (e.g. Lee et al., 2005; Roe et al., 2011; Wassenaar et al., 2014) due to its unique ability to compare quality appraisal scores from quantitative and qualitative studies in the synthesis of a review.

#### 2.4.2.5 Data synthesis

Every variable in the included studies reporting a significant (p<0.05) or non-significant (p>0.05) relationship with adherence/non-adherence in their main statistical analysis was tallied so a measure of prevalence was possible. The ratio of significant/non-significant findings for each variable could then be determined and provided the means to identify consistently significant/non-significant variables. Subsequently, descriptive judgements could be made about the prevalence and ratio of findings against other variables assessed at the same time as patients' medicine beliefs variables.

This review focused largely on findings from the whole body of research. However, discussion of the findings was also conducted at the health condition level. The former sought to provide an overview of the area and assess the contribution of patients' medicines beliefs in comparison to commonly compared variables. The latter sought to clarify the idiosyncrasies, extent and quality of medicine beliefs research within specific contexts. Synthesis of the whole area also included discussion about the relative value of groups of variables, in particular the commonly occurring categories of demographic, clinical, and illness perception variables.

#### 2.4.3 Characteristics of included studies

Studies exploring the relationship between adherence and medicine beliefs were abundant and have been summarised by health condition (see Appendix Tables 1 to 6 in Appendix 1). In addition, a number of included studies were grouped together due to their focus on general patient populations/mixed conditions (see Appendix Table 7 in Appendix 1). Fourteen studies involving a variety of other conditions were grouped into an 'other' category (see Appendix Table 8 in Appendix 1).

Included studies were spread across a wide range of health conditions. Nine studies were conducted in the area of cardiology (Horne & Weinman 1999; Ross et al. 2004; Byrne et al. 2005; Bane et al. 2006; George & Shalansky 2007; Khanderia et al. 2008; Maguire et al. 2008; Allen LaPointe et al. 2011; Bermingham et al. 2011) and another nine involved general patient populations/mixed conditions whose analyses were based on the whole sample in each study (Horne et al. 1999; Phatak & Thomas 2006; Mardby et al. 2007; Clifford et al. 2008; Gatti et al. 2009; Schuz et al. 2011; Unni & Farris 2011; Gadkari & McHorney 2012; Kung et al. 2012). Eight studies were conducted in the field of mental health (Maidment et al. 2002; Aikens et al. 2005; Brown et al. 2005; Patel et al. 2008; Russell & Kazantzis 2008; Clatworthy et al. 2009; Beck et al. 2011; Fawzi et al. 2012) and another eight involved HIV patients (Llewellyn et al. 2003; Horne et al. 2004a; Gauchet et al. 2007; Gonzalez et al. 2007; Horne et al. 2007; Cooper et al. 2011; Johnson et al. 2012; Sumari-de Boer et al. 2012). Six studies were focused on asthma (Horne & Weinman 1999; Byer & Myers 2000; Horne & Weinman 2002; Conn et al. 2005; Conn et al. 2007; Menckeberg et al. 2008), five studies in the area of rheumatoid arthritis (Treharne et al. 2004; Neame & Hammond 2005; Wong & Mulherin 2007; van den Bemt et al. 2009; de Thurah et al. 2010) and another five in diabetes (Barnes et al. 2004; Aikens & Piette 2009; Kurlander et al. 2009; Mann et al. 2009; Schoenthaler et al. 2012). The remaining 14 studies involved a wide range of health conditions and are presented in Appendix Table 8 (see Appendix 1). The wide range conditions investigated was valuable as it offered the opportunity to aggregate the collective findings for a broad sense of value and determine if patients' medicine beliefs were associated with non-adherence regardless of the condition.

The majority of studies originated from the UK (38.7%, n=24) or the United States (27.4%, n=17). Four studies were based in New Zealand, three studies in both Sweden and The Netherlands, two studies in both Canada and the Republic of Ireland, and one study each from Australia, Denmark, Egypt, France, Germany,

Japan, and Switzerland. A total of 40,186 participants were involved in the included studies, having included partitioned findings from two studies (Horne & Weinman 1999; Kurlander et al. 2009). Two studies did not report the age of its participants but the majority of studies involved participants aged between 35-65 years old (71.8%, n=46) and a quarter involved older (65+) participants (25.0%, n=16). The samples in most studies involved either predominantly (greater than 55%) female (43.8%, n=28) or predominately male (32.8%, n=21) participants. Only a few study samples were equal (within 10%) in gender distribution (17.2%, n=11) and four studies did not report the gender of their participants. Almost half of the included studies did not report ethnicity (46.9%, n=30); those that did predominantly involved Caucasian participants (34.4%, n=22) but some studies predominately involved African-American participants (10.9%, n=7). The bias of geographical context was not unexpected as the BMQ, its use in studies an important inclusion criterion, was a measure developed in the UK.

The majority of studies in this review were cross-sectional (89.1%, n=57), including three studies that undertook cross-sectional analyses within wider studies (Conn et al. 2005; Clifford et al. 2008; Cooper et al. 2011). However, seven studies had explored the relationship of patients' medicine beliefs and adherence over time using a variety of research designs (Gonzalez et al. 2007; Horne et al. 2007; de Thurah et al. 2010; Bermingham et al. 2011; O'Carroll et al. 2011; Schuz et al. 2011; Unni & Farris 2011).

Included studies measured some form of adherence/non-adherence on 86 occasions and in 33 different ways (e.g. unintentional non-adherence, intentional non-adherence, using different measures of adherence, or at different time points in longitudinal studies). One study measured adherence six times (Unni & Farris 2011), five studies measured adherence three times (Byer & Myers 2000; Iihara et al. 2008; Allen LaPointe et al. 2011; Daleboudt et al. 2011; Griva et al. 2012), seven studies measured adherence twice (Aikens et al. 2005; Menckeberg et al. 2008; Aikens & Piette 2009; Rees et al. 2010; O'Carroll et al. 2011; Wileman et al. 2011; Johnson et al. 2012) and the remainder (n=51) measured some form of adherence once. The vast majority of studies used patient self-report methods to measure adherence (90.3%, n=56); only six studies attempted to objectively measure adherence (George & Shalansky 2007; Gonzalez et al. 2007; Menckeberg et al. 2008; Wileman et al. 2011; Schoenthaler et al. 2012; Sumari-de Boer et al. 2012).

The most widely used self-reported measure was the five-item Medication Adherence Report Scale (MARS) (Horne & Hankins 2001) (n=18) but despite its wide

use, it has yet to be formally validated in this format. Although, several recent translation and validation studies have been conducted using the MARS in different languages and specific contexts and reported satisfactory psychometric findings (Cohen et al. 2009; Jacobsen et al. 2009; Mahler et al. 2010; Back et al. 2012). Most of the included studies reported the use of the original 5-item scale but one study reported the use of a 9-item version (Horne & Weinman 2002). The MARS was used in a range of international contexts which contrasts with the second most widely used self-reported measure, the Morisky Medication Adherence Scale (MMAS) (Morisky et al. 1986) (n=11) which was primarily used in United States studies except for two UK studies (Ross et al. 2004; Bane et al. 2006) and one study in the Republic of Ireland (Bermingham et al. 2011).

Authors of the included studies varied in their use of the BMQ subscales. Almost half only used the Specific-Concerns and Specific Necessity subscales (46.9%, n=30) but over a third used all four of the BMQ subscales (Specific-Concerns; Specific-Necessity; General-Overuse; General-Harm) (34.4%, n=22). A few authors used different configurations of the subscales, including the limited use of the newly developed General-Benefits and General-Distrust subscales. The latter being a composite score of General-Overuse and General-Harm subscales. Due to the selective use of medicine beliefs concepts, a review of patients' medicines beliefs must occur at the subscale level. This review will analyse the relative contributions of definition-relevant concepts in the next section.

#### 2.4.4 Results

## 2.4.4.1 Significant associations between patients' medicines beliefs and adherence – overview of all studies

Table 2.1 presents the prevalence and ratio of medicine beliefs variables (at the subscale level) and commonly compared variables appearing in the same main analyses of included studies.

Of the different BMQ subscales, the Specific-Necessity and Specific-Concerns concepts were the most common medicine beliefs concepts assessed. Specific-Concerns was the most prevalent (assessments n=70) with 41 significant findings and 29 non-significant findings. Although not quite as prevalent (assessments n=67), Specific-necessity had a better ratio of significant (n=43) and non-significant (n=24) findings and was associated with adherence 64.2% of the time compared to Specific-Concerns 58.6%. The Necessity-Concerns Differential score was not as frequently used but was significantly associated with adherence in 73.3% of cases. The General-Overuse and General-Harm concepts were examined in 25 separate assessments each but 72.0% and 68.0% of the time respectively were not significantly linked to adherence. A number of composite scores were also examined in the included studies, for example, the General-Harm and General-Overuse combined score – which was significantly associated with adherence 85.7% of the time.

Table 2.1 Patients' medicine beliefs concepts and their associations with adherence

	Associated	Not associated	Total	% Associated	% Not associated
Medicine beliefs sub	scales				
BMQ Specific- Concerns	41	29	70	58.6	41.4
BMQ Specific- Necessity	43	24	67	64.2	35.8
BMQ General-Harm	8	17	25	32.0	68.0
BMQ General- Overuse	7	18	25	28.0	72.0
BMQ Necessity- Concerns Differential	11	4	15	73.3	26.7
BMQ GenH & GenO composite score	6	1	7	85.7	14.3
BMQ General-Benefits	1	3	4	25.0	75.0
BMQ General Concerns (HIV only)	2	2	4	50.0	50.0
BMQ General-Distrust (Harm & Overuse)	1	1	2	50.0	50.0
BMQ total score	1	0	1	100.0	0

The most common variables compared to adherence at the same time as medicine beliefs can be categorised as demographic, clinical or related to patients' illness perceptions. The most common demographic (age, gender, education, ethnicity, and income) and clinical (number of prescribed medications, duration of condition, relationship with physician, a diagnosis of depression, condition severity, and number of medication side effects) variables and illness perception concepts are presented in Table 2.2.

Of the commonly compared demographic variables, patients' age and patients' income were significantly associated with adherence 59.3% and 66.7% of the time. Despite commonly occurring in the same analyses as medicine beliefs, patients' gender, level of education, and ethnicity were rarely significantly associated with adherence.

Of the commonly compared clinical variables, the number of prescribed medications, a diagnosis of depression, the duration of the condition, and severity of condition were not significantly associated with adherence in two-thirds of cases. In five assessments of the level of relationship with a physician, when

involved in the same analyses as medicine beliefs, all five were not significantly associated with adherence. The number of side effects was only involved in three assessments that also involved medicines beliefs. Of these, two of the three were significantly associated with adherence.

The third group of commonly assessed variables related to patients' perceptions about their illness. These were measured using one of three related methods: the Illness Perceptions Questionnaire (IPQ) (Weinman et al. 1996), Revised Illness Perceptions Questionnaire (IPQ-R) (Moss-Morris et al. 2002) or the Brief Illness Perceptions Questionnaire (IPQ-B) (Broadbent et al. 2006). In order to present these findings, concepts from the IPQ and IPQ-B were mapped to related concepts on the IPQ-R.

Of the commonly compared illness perception concepts, only the combined Cause concepts were in anyway frequently associated with adherence (57.1% of findings were associated with adherence). Generally, illness perception concepts were not frequently associated with adherence when involved in the same main analyses as medicine beliefs concepts.

Table 2.2 Commonly compared variables and their associations with adherence

Associated	Not	Total	%	% Not
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		associated		Associated	associated
Demographic variables	,				
Age	29	20	49	59.2	40.8
Gender	7	33	40	17.5	82.5
Education	5	18	23	21.7	78.3
Ethnicity	1	11	12	8.3	91.7
Income	4	2	6	66.7	33.3
Clinical variables					
No. of prescribed medications	7	16	23	30.4	69.6
Diagnosed with depression	4	9	13	30.8	69.2
Duration of condition	3	8	11	27.3	72.7
Condition severity	2	5	7	28.6	71.4
Relationship with physician	0	5	5	0	100
No. of side effects	2	1	3	66.7	33.3
Illness perception cond	epts				
Control/Cure *	2	14	16	12.5	87.5
Timeline (acute/chronic)	2	8	10	20.0	80.0
Illness Identity	2	7	9	22.2	77.8
Cause **	4	3	7	57.1	42.9
Consequences	2	5	7	28.6	71.4
Illness coherence	0	5	5	0	100
Emotional response	2	3	5	40.0	60.0

<sup>\*</sup> Study findings about IPQ control/cure, IPQ-B treatment control, IPQ-R personal control, and IPQ-R treatment control were collapsed into one variable.

On the issue of study quality, the majority of included studies scored much higher than the inclusion requirement of 55%. Only nine of the sixty-four collections of included data (individual included studies n=62) scored below 80%. Of the nine,

<sup>\*\*</sup>Study findings about all types of IPQ Cause and IPQ-R Cause were collapsed into one variable.

most had similar problems which affected their quality score. The most common problem was insufficient reporting of study findings; in particular, the reporting of variables that were significantly related to adherence but omission of those that did not (Byer & Myers 2000; Grunfeld et al. 2005; Neame & Hammond 2005; Bane et al. 2006; Conn et al. 2007; Clifford et al. 2008; Russell & Kazantzis 2008). Other common problems were the partial reporting of study design and characteristics of participants (Byer & Myers 2000; Treharne et al. 2004; Grunfeld et al. 2005; Bane et al. 2006; Wong & Mulherin 2007; Russell & Kazantzis 2008) and questionable selection of methods to measure adherence (Byer & Myers 2000; Neame & Hammond 2005; Wong & Mulherin 2007; Clifford et al. 2008). For example, one study reduced its assessment of adherence to an author-determined single-item measure (Neame & Hammond 2005) and another study used author-determined adherent/non-adherent groups (Wong & Mulherin 2007) despite the existence of validated measures. Finally, four studies could be criticised for having a borderline appropriate sample size in relation to the analyses conducted (Byer & Myers 2000; Treharne et al. 2004; Wong & Mulherin 2007; Russell & Kazantzis 2008). The lowest of these was 64 participants (Byer & Myers 2000) and casts some doubt on the power of the multiple regressions performed and conclusions drawn.

# 2.4.4.2 Significant associations between patients' medicines beliefs and adherence – overview by health condition

Importantly, an assessment of included studies must account for potential differences at the health-condition level as the value of medicines beliefs and other commonly compared variables may change depending on the characteristics of a condition and its treatments. Included studies were grouped into six health conditions (see Appendix Tables 1 to 6 in Appendix 1) based on their participants. In addition, a seventh group of included studies was created; these were combined due to their focus on general patient populations/mixed conditions and analyses based on their entire sample (see Appendix Table 7 in Appendix 1).

Table 2.3 presents the frequency of medicine belief and adherence associations by health condition. Included studies in the areas of mental health, cardiology, asthma, general population/mixed condition studies, and diabetes resembled the overall trend toward more significant than non-significant findings for BMQ Specific-Concerns and BMQ Specific-Necessity. However, findings from rheumatoid arthritis studies resembled the overall trend for BMQ Specific-Necessity but not for BMQ Specific-Concerns. Findings from HIV studies did not follow the overall trend;

eight of twelve BMQ Specific-Concerns assessments and seven of thirteen BMQ Specific-Necessity assessments were not significantly related to adherence.

The Necessity-minus-Concerns Differential score is inherently linked to the variables above and likely to mirror their performance. However, the differential score was significantly associated with adherence in all the assessments made across the health condition groups, except diabetes which did not assess this variable, compared to the overall assessment previously discussed.

The overall trend of more non-significant than significant associations between both BMQ General-Harm and BMQ General-Overuse with adherence was seen with included studies in the area of mental health. The remainder of assessments across each condition was small and presented a mixed picture. However, some evidence of more significant findings was found for both these variables in the area of asthma.

Table 2.3 Patients' medicine beliefs concepts and their associations with adherence by health condition

Health		Cardio		Asthma				Rheum Arthritis				General populations	
Sig	NS	Sig	NS	Sig	NS	Sig	NS	Sig	NS	Sig	NS	Sig	NS

Medicine beliefs	Medicine beliefs subscales													
BMQ Specific- Concerns	8	0	5	3	3	0	4	8	2	3	3	2	10	2
BMQ Specific- Necessity	5	2	5	2	5	1	6	7	4	1	3	2	6	0
BMQ General- Harm	0	4	1	1	2	0	1	0	0	2	-	-	1	3
BMQ General- Overuse	1	3	2	1	1	0	0	1	1	1	-	-	2	2
BMQ Necessity- Concerns Differential	2	0	2	0	4	0	1	0	1	0	-	-	1	0
BMQ GenH & GenO composite score	0	2	1	0	-	-	-	-	-	-	1	0	-	-
BMQ General- Benefits	-	-	-	-	-	-	0	1	-	-	-	-	0	1
BMQ General Concerns (HIV only)	-	-	-	-	-	-	2	2	-	-	-	-	-	-
BMQ General- Distrust (Harm & Overuse)	0	1	-	-	-	-	1	0	-	-	•	-	-	-
BMQ total score	-	-	-	-	-	-	-	-	-	-	-	-	1	0

Sig = statistically significant; NS = not statistically significant

Of the commonly assessed demographic variables (see Table 2.4), the trend for age being frequently associated with adherence, as previously seen in the overall summation, was only noticeable in studies in the areas of cardiology, general population/mixed condition, and rheumatoid arthritis. Age was more often unrelated to adherence in mental health, asthma, HIV, and diabetes studies. The overall trend of gender was mirrored in almost all health conditions; the only exception was two out of three assessments in the area of rheumatoid arthritis were significantly linked to adherence. The overall trend of patients' education-level being unrelated to adherence was mirrored in mental health, asthma, and diabetes studies; and particularly so in general population/mixed condition studies. A mixed picture was apparent in cardiology, HIV and rheumatoid arthritis studies but the small number of assessments limits interpretation.

Of the commonly assessed clinical variables (see Table 2.4), the number of prescribed medicines largely resembled the overall trend as it was unrelated to adherence across all conditions except for rheumatoid arthritis and general

population/mixed condition studies. Similarly, the trend toward non-significant findings for the variables: diagnosis of depression, duration of condition, condition severity, and relationship with physician was largely repeated across all conditions. Minor exceptions included two out of three assessments for depression diagnosis were significantly related to adherence in cardiology studies, and duration of condition was found to be significantly linked to adherence in single assessments in the areas of rheumatoid arthritis and diabetes. The assessments of the variable: number of side effects, were limited to the area of mental health and thus replicated the overall findings.

Of the commonly assessed illness perceptions concepts (see Table 2.4), all concepts largely followed the trend of the overall findings in cardiology and HIV studies. More mixed findings were apparent in asthma, diabetes, and general population/mixed condition studies. For example, in diabetes studies, control/cure, timeline (acute/chronic), illness coherence and emotional response concepts followed the overall trend of findings, however, all assessments of the Cause and Consequence concepts were found to be significantly associated with adherence. Illness perception concepts were not present in the analyses of studies about patients with mental health or rheumatoid arthritis diagnoses.

Table 2.4 Commonly compared variables and their associations with adherence by health condition

	Mental Health				Cardio		Asthma				Rheum Arthritis		Diabetes		General populations	
	Sig	NS	Sig	NS	Sig	NS	Sig	NS	Sig	NS	Sig	NS	Sig	NS		
Demographic va																
Age	0	4	8	2	1	2	2	6	2	1	0	1	5	2		

Condon	_	4	,	_	^	_	_	,	_	-	_	٠.	-	
Gender	0	4	1	5	0	2	0	1	2	1	0	1	1	9
Education	0	3	1	1	0	3	1	1	1	1	0	1	2	8
Ethnicity	0	1	-	-	1	0	0	1	-	-	-	-	0	7
Income	-	-	1	0	-	-	0	1	-	_	0	1	2	0
Clinical variables														
No. of prescribed medicines	0	1	2	4	0	2	0	1	1	1	-	-	2	1
Diagnosed with depression	-	-	2	1	-	-	0	3	0	1	1	0	-	-
Duration of condition	-	-	0	1	0	1	0	2	1	0	1	0	-	-
Condition severity	1	2	0	1	0	1	-	-	-	-	-	-	-	-
Relationship with physician	-	-	-	-	0	1	-	-	0	1	1	0	-	-
No. of side effects	2	1	-	-	-	-	-	-	-	-	-	-	-	-
Illness perception	on co	nce	ots											
Control/Cure *	-	-	1	3	0	1	0	2	-	-	0	2	1	0
Timeline (acute/chronic)	-	-	1	0	1	1	0	2	-	-	0	1	-	-
Illness Identity	-	-	0	1	1	1	1	1	-	-	-	-	0	1
Cause **	-	-	0	3	1	0	-	-	-	-	3	0	-	-
Consequences	-	-	0	2	1	0	0	2	-	-	1	0	-	-
Illness coherence	-	-	0	1	-	-	-	-	-	-	0	1	0	1
Emotional response	-	-	1	1	-	-	-	-	-	-	0	1	1	0

Sig = statistically significant; NS = not statistically significant

Note: this data has omitted findings from the 'other' category.

On the issue of study quality by health condition, studies involving mental health patients varied in their overall quality and had consistently low to moderate sample sizes in comparison to cardiology and general population/mixed condition studies. Two cardiology studies (Byrne et al. 2005; Allen LaPointe et al. 2011) and two general population/mixed condition studies (Unni & Farris 2011; Gadkari & McHorney 2012) (cardiology n=1,084 and n=973 respectively; general population/mixed condition n=1,513 and n=24,017 respectively) with large sample

<sup>\*</sup> Study findings about IPQ control/cure, IPQ-B treatment control, IPQ-R personal control, and IPQ-R treatment control were collapsed into one variable.

<sup>\*\*</sup>Study findings about all types of IPQ Cause and IPQ-R Cause were collapsed into one variable.

sizes all found BMQ Specific-Concerns, BMQ Specific-Necessity, and patients' age to be significantly associated with medicines adherence. Coupled with their high quality scores (≥90%), the breadth of these four studies suggests their findings should be considered prominent amongst the included studies.

In contrast to the consistently high level of study quality found in HIV studies, three rheumatoid arthritis studies scored 75% (Treharne et al. 2004; Neame & Hammond 2005; Wong & Mulherin 2007). These reasonably low quality scores, in comparison to other included studies, draws into question their findings about patients' age, patients' level of anxiety, BMQ Specific-Concerns, BMQ Specific-Necessity, BMQ General-Overuse, and the Necessity-Concerns Differential score as significant links to adherence in this context.

Included studies in the area of diabetes were largely consistent in quality but varied in sample size and method of adherence assessment. Despite the small number of studies in this area, BMQ Specific-Concerns, BMQ Specific-Necessity and a number of single assessments of clinical variables were often significantly related to adherence. Conversely, demographic variables were infrequently related to adherence in this context.

#### 2.4.5 Discussion

This review identified a large number of studies assessing patients' medicines beliefs concepts and their associations with adherence across a wide range of health conditions. It established the prevalence and ratio in which medicine beliefs concepts were significantly and non-significantly associated with adherence. In addition, it summarised the prevalence and ratio of commonly assessed variables in the same main analyses as assessments of medicine beliefs concepts. Although not a formal meta-analysis, this review provides an indication of important variables linked to medicines adherence and trends of findings across the whole area and in a range of health conditions.

# 2.4.5.1 Prevalence and ratio of patients' medicine beliefs concepts as a significant associate of medicines adherence

Overall, the most assessed measures of patients' medicine beliefs were the BMQ sub-concepts Specific-Concerns and Specific-Necessity. These concepts were used to assess patients' medicines beliefs more than twice as many times as the BMQ sub-scales General-Harm and General-Overuse. Less frequently assessed were the Necessity-Concerns Differential score, other composite scores and author-adapted subscales (e.g. BMQ General-Benefits subscale). Due to the differences in authors'

use of concepts, any assessment of patients' medicine beliefs must occur at the sub-scale level.

The ratio of significant and non-significant associations with adherence was highest for BMQ Specific-Necessity (64.2% of assessments were significantly related to adherence). BMQ Specific-Concerns had a similar ratio albeit slightly less prominent (58.6% of assessments were significantly related to adherence). These favourable ratios were consolidated by a high percentage of significant findings for the Necessity-Concerns differential score. The ratios above were in stark contrast to limited significant findings for BMQ General-Harm (32.0% of assessments significant) and BMQ General-Overuse (28.0% of assessments significant) and highlight the fundamental difference between patients' specific and general beliefs about their medicines. These findings suggest patients' beliefs about their medicines for specific conditions are more frequently linked to whether or not they take their medication as recommended.

Most demographic, clinical, and illness perception variables assessed alongside medicine beliefs in the main analyses of included studies were not consistently associated with adherence. Only patients' age approached a similar level of consistency as Specific-Concerns and Specific-Necessity across all studies. Other commonly compared factors (gender 17.5% of assessments significant; level of education 21.7% of assessments significant; ethnicity 8.3% of assessments significant) were infrequently associated with adherence. Patients' income was frequently associated with adherence (66.7%); however, the low number of assessments (n=6) within the included studies limits this conclusion. Of the commonly compared clinical variables, only the number of side effects was significantly associated with adherence to a comparable level as BMQ Specific-Concerns and BMQ Specific-Necessity concepts, however, this factor was limited in assessments and to the mental health context. Similarly, illness perception concepts were infrequently associated with adherence when involved in the same main analyses as medicine beliefs concepts. This suggests illness perceptions are not as important as medicine beliefs concepts when considering patients' adherence behaviour.

Alternatively, whilst viewing the findings presented in section 2.4.4 it would be reasonable to conclude a mixed picture exists in relation to the associative links between patients' medicine beliefs and adherence. However, a trend pointing toward the importance of patients' medicine beliefs was apparent as more significant findings were identified than non-significant findings. In addition, BMQ Specific-Concerns and BMQ Specific-Necessity concepts were far more prevalent

and had better ratios compared to demographic and clinical factors involved in the same analyses.

Importantly, the prevalence and ratio of significant findings for both medicine beliefs concepts and commonly compared factors altered depending on patients' health condition. Across all condition groupings, studies involving general populations/mixed conditions were the most congruent with the trends found in the overall summation. Findings from studies of HIV patients appeared to be the most incongruent; having found BMQ Specific-Concerns, BMQ Specific-Necessity, and patients' age more often non-significantly linked to adherence.

#### 2.4.5.2 Implications in the diabetes context

Several findings from the overall analysis have implications for studies about patients' medicine beliefs in the diabetes context. Firstly, the overall trend of findings linked to categories used as part of the definition of medicine beliefs in this thesis (specific-necessity, specific-concerns, general-overuse, general-harm) were present in the five diabetes studies (Barnes et al. 2004; Aikens & Piette 2009; Kurlander et al. 2009; Mann et al. 2009; Schoenthaler et al. 2012). Findings from the diabetes studies resembled the overall trend toward more significant than non-significant findings for BMQ Specific-Concerns and BMQ Specific-Necessity. This suggests the necessity and concerns categories are valuable and valid in the context of diabetes, although the types of the concerns are likely to differ with other conditions.

Secondly, the overall trend of patients' age and education-level being unrelated to adherence was present in diabetes studies. This was an interesting finding as patients' age and education level are frequently assessed as important in reviews of adherence behaviour to diabetes medication (Vermeire et al., 2009; Bailey & Kodack, 2011). However, this review suggests when these variables and patients' medication beliefs are compared in the same analyses, the latter would appear to be more salient to adherence behaviour in the diabetes context.

Thirdly, the overall trend of medicine beliefs being more often associated with adherence compared to illness perceptions was also present in the diabetes studies. This finding was interesting as a good deal of research has focused on diabetes patients perceptions of their condition, often known as their personal model of diabetes, but this review suggests patients' medicine beliefs are more important to consider when clinicians are attempting to facilitate optimal adherence to medication.

In addition, in the five diabetes studies reviewed, there was some uncertainty about the conceptual stability of the definition of medicine beliefs used in this thesis. Whilst the concepts related to patients' specific medications (necessity and concerns) were congruent with the overall trends, the concepts of general-harm and general-overuse were not often measured in the diabetes studies. They were assessed once as a composite score and found to be significantly associated with adherence (Kurlander et al. 2009). However, they were also measured in another study but not entered into the main statistical analyses (Schoenthal et al. 2012). As these concepts were not entered into the multiple linear regression conducted, it must be assumed the variables did not make the cut-off for inclusion in the analyses. The outcome of these issues was uncertainty about the conceptual validity of the general-harm and general-overuse concepts in the diabetes context. Therefore, in this thesis, measuring patients' necessity for and concerns about their specific medication was considered more conceptually reliable and important for clinicians.

Finally, the patient characteristics reported in the diabetes studies present a specific demographic profile. This profile must be considered linked to the combined findings of adherence related variables in the diabetes studies. Collectively, all five diabetes studies were reasonably similar and all focused on Type 2 diabetes patients who had lived with the condition for many years (range 5.3 to 13 years). All focused on oral medication for blood glucose control, on patients with elevated HbA1c levels (range 7.1 to 9), and were conducted in countries where English was their first language. In order to develop continuity with the available literature, this thesis was mindful of this profile during sampling and analyses.

In the context of this thesis, these findings continue to build on the positive value of patients' medicine beliefs, and thus provide an important rationale for understanding more about how they're explored in practice. The first, second and third implications support the value of patients' medicine beliefs and the fourth and fifth implications describe caveats to the evidence available in the diabetes context.

#### 2.4.5.3 Methodological limitations of included studies

A number of methodological limitations of the included studies provide caveats to the findings from the quantitative review of research on patients' medicine beliefs.

Study design grading criteria (Clinical Guidance Outcomes Group, 1996) provide further insight into the quality of evidence produced by this review. Grading levels

include: Grade 1 (Strong evidence) (RCTs or reviews of RCTs); Grade 2 (Fairly strong evidence) (Prospective study with a comparison group (non-randomized controlled trial, good observational study or retrospective study that controls effectively for confounding variables); Grade 3 (Weaker evidence) (Retrospective or observational studies); Grade 4 (Weak evidence) (Cross-sectional studies; Delphi exercise; consensus of experts). A tenth of studies in this review were prospective and provided Grade 2 evidence demonstrating medicine beliefs concepts as common associates of adherence but the majority of evidence across all included studies could be considered Grade 3 and 4. At present, the predominance of crosssectional survey studies precludes a more rigorous assessment of the value of the variables and their relationship with adherence. The development of RCTs and complex cohort studies might potentially bolster the promising trend of findings to date. This in turn would likely encourage researchers to develop more complex studies whereby beliefs are formally compared to other salient medicine-taking variables. This would address unanswered questions about the value of medicine beliefs and potentially clarify further their importance for exploration by clinicians. The development of such studies would permit meta-analyses, move forward the debate about medicine beliefs, and clarify the individual and combined value of variables in the field of medication adherence research.

The findings from this body of research may only be relevant to a specific demographic profile of patients. The vast majority of studies were based in American or European countries and involved populations of predominantly Caucasian ethnicity. A western bias has implications for the concepts that underpin the definition of medicine beliefs used in this thesis and the questions it attempts to answer in the field of medication adherence research. There is a need to examine the appropriateness of these concepts with other ethnic backgrounds as cultural and sub-cultural beliefs about illness and medicines are known to differ (Barnes et al. 2004; Horne et al. 2004b). The need for cultural adaption can be partially inferred from the adaptation of the BMQ reported in an included study from Japan (lihara et al. 2008). In addition, the majority of participants within the included studies were middle-aged females, however, whilst important to highlight this demographic bias, gender was not consistently linked to adherence so may not be relevant in this context. This issue is also relevant for the broader problem of adherence research. Patients' medicine beliefs are notably different than other commonly studied fixed variables such as demographic and clinical factors. Patients' medicine beliefs are potentially changeable and subject to patients' motivation and other behavioural influences. If adherence is predicted by demographic (age, gender, ethnicity) or clinical variables, the influence of culture

is potentially less of an issue. However, if medicine beliefs are culturally based and more predictive of adherence than other factors, it is not unreasonable to hypothesise that adherence behaviour overall is culturally determined. Although these issues are beyond the remit of this thesis, it was considered sensible to consider the review findings in the context of the demographic/culture profile of the patient group chosen for this thesis.

A wide range of measures were used to assess medicines adherence and the majority used patient self-report measures. This is not uncommon in the field of adherence research as this method is an inexpensive alternative to more objective methods such as electronic monitoring (Garber et al. 2004) but well known problems of patient exaggeration of adherence (Haynes et al. 1980) and the wording of the measures (Horne et al. 2005) remain relevant. In addition, one-fifth of authors created their own measure which only compounds the traditional problems of self-reported adherence. The most frequently used self-reported adherence measure was MARS and although some psychometric properties of the MARS have been examined as part of translation studies (Mahler et al. 2010; Back et al. 2012) and provide support for the measure, it has limited psychometric validity with general populations. Importantly, the continuous evolution of this measure and deployment of short and long versions across many studies forces a conservative approach to analysis. In addition, caution whilst interpreting the findings of this review is further justified by recent findings about individuals responding to medicine-belief surveys. A study of survey respondents and nonrespondents found the latter had significantly worse adherence and persistence than the former (Gadkari et al. 2011) which suggests an important group of patients are unlikely to be represented in the included studies.

An important concern that may affect the profile of findings in this review relates to authors' reporting. It was impossible to ascertain if authors included variables into analyses appropriately or reported all relevant findings. Due to the large number of included studies, no attempt to contact individual authors was undertaken. In terms of appropriate analyses, the majority of main analyses were regression-based and some authors stated their method of retaining variables within their analyses, e.g. variables trending to a significant (p<0.10) relationship with adherence were retained (Nakhutina et al. 2011), but others did not report this level of detail.

A number of studies did not report variables that were not associated with adherence (Byer & Myers 2000; Neame & Hammond 2005; Bane et al. 2006; Horne et al. 2007; Clifford et al. 2008; Menckeberg et al. 2008; Russell & Kazantzis 2008;

de Thurah et al. 2010; Griva et al. 2012). Whilst it cannot be assumed there were non-significant findings, the lack of comprehensive reporting potentially inhibits the ability to determine a fair tally of significant and non-significant findings in this review.

As a result of the division of findings by health conditions, some conditions had low numbers of assessments and precluded an in-depth examination, however, highly assessed variables such as BMQ Specific-Concerns and BMQ Specific-Necessity concepts and some demographic variables were comparable across conditions.

These issues combine to indicate the included studies had a range of limitations but this was not unexpected considering the breadth of studies examined. Overall, most studies were well powered and faithful to their chosen methodological approaches. Despite the methodological issues to resolve in this field of research, this body of research represents a large cumulative attempt to measure patients' beliefs using an accepted definition and determine the sub-concepts' association with medication adherence. To that end, it has succeeded at bolstering expectations that exploring patients' medicine beliefs in practice will influence adherence behaviour (Horne et al. 2005; NICE 2009).

#### 2.4.5.4 Limitations of the quantitative review

As previously discussed, the vote counting procedure embraced the standardisation of meta-analysis and focused on findings as opposed to conclusions but did not go as far in its analyses or subsequent claims. Despite this, the prevalence and ratio of medicine beliefs concepts and commonly compared factors was established in this review. The conclusions about the value of individual factors as indicators of patients' adherence behaviour was limited to a 'significant' or 'non-significant' level of inference but the trends uncovered are a step forward toward a better understanding of patient medicine beliefs as an antecedent of medicines adherence.

As this review did not conduct a meta-analysis, two important statistical measures are not reported. Firstly, to summarise the prevalence and ratio of variables associated or not associated with adherence, it was necessary to establish a universal cut-off point for significance (p<0.05). By setting this cut-off point, a measure of the magnitude of findings, i.e. being significant (p<0.05) or very significant (p<0.0001) was not taken into account. In addition, several studies reported the amount of variance in the data explained by the associated

variable(s), however, as this was not universally reported and this review was not a meta-analysis, this approach was not undertaken.

#### 2.4.6 Conclusions from the quantitative review

The aims of the quantitative review were to summarise all available literature that measured patients' medicine beliefs and medication adherence, and examine the prevalence and ratio of the link between medicine beliefs concepts and adherence in comparison to other concepts measured in the same analyses. Findings from this review provide an assessment of the value of this research and an understanding of its limitations.

Six conclusions about the value of patients' medicine beliefs can be drawn from this review. These conclusions indicate patients' medicine beliefs are an important associate of medicines adherence.

Firstly, due to the nature of the investigations undertaken by researchers, the value of patients' medicine beliefs in the quantitative literature must occur at the concept level. Several concepts/categories of patients' beliefs have been defined and measured in the included studies. Of these, patients' concerns about their condition-specific medicines (Specific-Concerns) and necessity for their conditionspecific medicines (Specific-Necessity) reported the best ratio of significant to nonsignificant associations with adherence than any other medicine beliefs concepts. Moreover, most demographic, clinical, and illness perception factors appearing in the same main analyses as medicine beliefs concepts were infrequently associated with adherence. The only factor to match the prevalence and ratio of the Specific-Concerns and Specific-Necessity concepts was patients' age. This factor was involved in most analyses whereby patients' specific concerns about, and necessity for, their medicines were measured and was slightly more associated with adherence than Specific-Concerns but slightly less than Specific-Necessity. Based on accumulated data from 62 studies, the overall trend suggests an emerging importance of patients' medicine beliefs as a prevalent and significant associate of medicines adherence and limits the value of demographic and clinical factors appearing in the same analyses.

Secondly, an assessment of significant associations by health condition produced a range of slightly different results profiles but when analysed by health condition, the findings were generally similar to the overall trends. The only prominent difference involved HIV studies which reported more non-significant than significant links between adherence and Specific-Concerns, Specific-Necessity, and patients' age respectively. Importantly, in the context of this thesis, the

accumulated findings from the five diabetes studies did not differ from the overall trends outlined above.

Thirdly, there are conceptual caveats to the medicine beliefs definition by Horne et al. used in this thesis. Patients' necessity for, and their concerns about, their condition-specific medication were important associates of adherence. However, patients' general concerns about the ability of medicines to harm them (General-Harm) and perceptions of medicines being over-prescribed (General-Overuse) reported more non-significant than significant associations with adherence. This suggested the specific and general concepts are conceptually distinct and should be examined separately. This was compounded by the use of various composite scores. Several differential scores were used by authors but the most commonly used Necessity-Concerns differential score was associated with adherence in almost three-quarters of analyses. However, a composite score using the BMQ General Harm and General-Overuse concepts did also demonstrate a high (85%) number of significant associations with adherence, but when these concepts were measured separately the reverse was true. The implication of this caveat is related to what clinicians may attempt to do during beliefs exploration. This conclusion suggests clinicians should be aware that patients' medicine beliefs about their condition-specific medication can be incongruent with their beliefs about medicines in general.

Fourth, the predominance of cross-sectional survey studies in this area, albeit largely well designed, executed and reported, precludes a more rigourous assessment of these variables and their relationship with adherence when they appear in the same main analyses. To date, the evidence demonstrates strong trends in favour of patients' medicine beliefs as a vital associate of medication adherence, but more could be done. More prospective studies and randomised controlled trials would provide the methodological rigour required to examine beliefs as a variable against other commonly examined antecedents of adherence. With such a development, further examination in systematic reviews could be conducted and finally include medicine beliefs in reviews of medicine-taking and adherence to determine its value more effectively.

Fifth, this review of quantitative studies has demonstrated the considerable value of patients' medicine beliefs as a variable frequently associated with adherence to medication. However, it was apparent this body of research was primarily concerned with measuring patients' medicine beliefs via cross-sectional self-report studies to determine empirical links with adherence and other clinical outcomes. This methodological approach to research has dominated the style of investigation

of the quantitative studies. No studies were found to have investigated or measured medicine beliefs exploration in practice during consultations with clinicians.

Finally, in the context of this thesis, the findings from the five diabetes studies are closely related to the overall trends described previously. However, the patient characteristics reported in the diabetes studies present a specific demographic profile. Collectively, all five diabetes studies were reasonably similar, all studies focused on experienced Type 2 diabetes patients on oral medication for blood glucose control and spoke English as their first language. In order to develop continuity with the available literature, this thesis was mindful of this profile during sampling and analyses.

# 2.5 Review of qualitative studies

#### 2.5.1 Aim of the review of qualitative studies

To address the main aim of this chapter, to determine the value of research focused on medicine beliefs, this review explored the available qualitative literature.

In addition to the inclusion and exclusion criteria presented in section 2.5.2 below, there are important caveats to this review and boundaries were developed to keep the review manageable for a single postgraduate reviewer. Importantly, this is not a review of medicine-taking in general (e.g. Pound et al. 2005) or medication non-adherence (e.g. Horne et al. 2005). Both these areas involve activity and concepts beyond the investigation of patients' ideas about their medication, such as the practical aspects of taking medication or the relationship between medicines and patients' identity. Therefore, this review targeted studies focused on medicines beliefs, as defined in this thesis, in order to appraise the nature of research in this specific area. A study was included if it had a clear focus on, or one of its aims was about, patients' medication beliefs.

Importantly, this did not mean broader reviews were not relevant to the review conducted. On the contrary, they offered an important starting point and framework to discuss the findings. But, it is important to note any discussion about medicine-taking or adherence is inherently broader than a discussion about medicine beliefs.

A comprehensive synthesis of qualitative studies of medicine-taking studies by Pound et al. (2005) demonstrated the breadth of interest in medicine-taking and subsequently provided boundaries for this review. Pound et al. identified three elements to medicine-taking in qualitative studies: (i) the relationship between medicines and identity, (ii) the way patients take their medicines, and (iii) the way patients evaluate their medicines. The review of qualitative studies for this thesis was preoccupied with the latter issue – how people evaluate their medicines. Patients' evaluations of medicines are based on their belief of what has happened or will happen in the future. Therefore, the themes identified in Pound et al. about lay evaluation medicines were important to consider during the review.

Similarly, a review of research about medicine beliefs conducted many years ago (Horne, 1997) identified some qualitative research eliciting patients' perspectives and representations of medication. The themes of which guided the development

of the definition of medication beliefs used in this thesis. The themes included patients' views about the general nature of medicines (healing and harm - the dual nature of medicines), negative views about addiction and dependence, long term dangers, chemical vs natural medications, medicines as poisons, and doctors overuse of medicines.

Both the Pound et al. (2005) and Horne (1997) reviews searched literature up to the year 2000, so it was considered appropriate and manageable for this review to search for literature from that point forward. This review sought to investigate the nature of recent qualitative research on patients' medication beliefs and its relationship with medication adherence, and discuss this within the context of wider reviews. Findings are also discussed in the context of supporting the purpose of this thesis.

On the issue of reporting style, due to the number of studies under review, a structured approach was undertaken similar to reporting a qualitative systematic review.

#### 2.5.2 Methods

## 2.5.2.1 Search methods and inclusion/exclusion criteria

The electronic database search for this part of the review used the same broad search terms and timeframe as described earlier in the chapter. However, inclusion and exclusion criteria for the review of qualitative studies were slightly different to ensure methodologically relevant studies were included.

Studies were included based on the following criteria:

- Had a clear focus on, or one of its aims was about, patients' medication beliefs
- Involved adult (18 years old and above) patients
- Involved licensed and prescribed medicines
- Involved medication in the form of oral tablets or injections
- Studies were primary research using qualitative methods of enquiry and analysis
- Studies reached or exceeded the minimum quality cut-off score (Kmet et al. 2004)

Studies were excluded based on the following criteria:

- Quantitative surveys describing the nature, type, and extent of medicine beliefs
- Studies that focused on healthcare professionals' beliefs, carers' beliefs, the general public or consumers' beliefs
- Studies that primarily focused on patients' general health beliefs, illness perceptions, personal models of illness, medicine outcome expectancies and beliefs about the efficacy of medicines
- Studies about non-prescribed medicines, complementary or cultural medicines

#### 2.5.2.2 Search results

Of the 1,122 studies identified from the broad search terms, the abstracts were read again and 56 studies considered qualitative and about medication were selected for a full reading of the publication. A total of 17 studies met the inclusion criteria.

Many studies were excluded because of their focus on patients' general health beliefs, illness perceptions, and personal models of illness. This review was specifically interested in patients' beliefs about their medication. In addition, some studies were excluded based on a conflict between their methodological labelling of the study and methods used. These studies described themselves as qualitative but used structured survey methods and descriptive statistics. As this review sought detailed insight into the nature of patients' medicine beliefs, studies with a confused methodological approach were excluded. Similarly, studies using interview approaches but quantitative methods of analysis, e.g. content analysis, as seen in Angermeyer et al. (2001), were excluded as they provided very limited information on the nature of findings beyond the reporting of its frequency.

The number of qualitative studies identified was not high but this was not unexpected. Even in broader reviews of medicine-taking, the number of studies was relatively small for the number of years searched. For example, the broad review of medicine-taking by Pound et al. (2005) identified only 37 qualitative studies between 1992 and 2001. Similarly, an update to this review focused on psychotropic medicine-taking (Britten et al. 2010) identified only seven more qualitative articles between 2002 and 2008.

#### 2.5.2.3 Quality assessment and data extraction

A plethora of appraisal tools exist for the critical evaluation of qualitative studies. These have been met with criticism particularly around the use of overly prescriptive checklists (Barbour, 2000). Popular technical fixes such as purposive

sampling, multiple coding, triangulation, and respondent validation are often prescribed to ensure rigour. However, none confer rigour automatically, but can if such action is embedded in a broader understanding of qualitative research design and data analysis. Moreover, overly prescriptive checklists, no matter how extensive, have been criticised as 'the tail wagging the dog' (Barbour, 2000). With this in mind, a broader approach to appraisal was sought rather than a lengthy list of criteria to appraise on.

The reasons for using Kmet et al. (2004) appraisal tool for the review of qualitative studies are threefold. Firstly, the questions posed by the Kmet et al. appraisal tool are broad and use ten 'guiding questions' rather than present/absent questions on very specific issues. The appraisal topics include appraisal of the research question, qualitative design, clear context for the study, connection to wider literature/theoretical framework, appropriate sampling, appropriate data collection and analysis, credibility assessment, appropriate conclusions and the degree of reflexivity. Other frameworks were considered but rejected based on the problem of being too onerous for a single reviewer, unwieldy in practice and often relevant for other types of qualitative research such as evaluation of policy issues. An example which met all these criteria was the Quality Framework produced from a synthesis of 29 appraisal tools by the National Centre for Social Research (2003).

Secondly, the questions posed by the Kmet et al. tool were not dissimilar from many other broader focused tools e.g. CASP - Critical Appraisal Skills Programme checklist (Public Health Resource Unit 1998) and the tool developed by Dixon-Woods et al. (2004). These tools had a similar number of broad questions on nearly identical appraisal topics.

Thirdly, the value of using the same appraisal tool for the quantitative review (albeit different questions were asked in the quantitative and qualitative tools) would be for a degree of comparison between the quantitative and qualitative literature on the same area of research literature. As previously mentioned in section 2.4.2.4, the Kmet et al. tool has been used in many other health reviews (e.g. Lee et al., 2005; Roe et al., 2011; Wassenaar et al., 2014) due to its unique ability to compare quality appraisal scores from quantitative and qualitative studies in the synthesis of a review. Knowing more about the general level of quality of each type of research supported the integrated conclusions of this chapter.

Therefore, in this review, qualitative studies identified as using methods such as focus groups, semi-structured interviews, etc. were quality appraised using the Kmet et al. (2004) scoring system for qualitative studies. The qualitative scoring

system consisted of ten items with scores from 0 to 2, with the maximum total score being 20. A summary score was calculated for each study by summing the total score obtained across the ten items and dividing them by the total possible score of 20. The appraisal tool recommends quality-based exclusion if studies score 55% or lower on their 10-item checklist. A quality score was calculated for each included study and reported in Appendix Table 9 in Appendix 2. Due to the nature of conducting a review for a doctoral thesis, only one reviewer independently assessed the quality of included studies. Overall, the quality of studies was good with a mean quality score of 80.3% across all studies.

Only one study (Fancher et al. 2010) was excluded from the review due to poor quality/levels of reporting and failed to meet the quality cut-off score. This study was initially included as it focused on perspectives of depression medication but only 11 people were interviewed which is contrary to common guidance of recruiting approximately 30 individuals to ensure data saturation is achieved (Adler & Adler 2012). Also, some participants were friends of the interviewer and could have biased the nature of the interview and subsequent analysis. In addition, the grounded theory approach was not sufficiently described, there was no member checking or reflexivity and the publication had limited discussion.

Although only one study was excluded, some studies were deemed less reliable during the synthesis process due to quality issues. They were not excluded due to the acknowledged tension between quality-based exclusion and relevance of studies to the review undertaken (Dixon-Woods et al. 2007). Due to the limited number of studies identified for this review, studies that scored over the cut-off but considered moderate quality (quality score <80%) were included. Those seven studies had the same problems of questionable level of recruitment to ensure data saturation and an absence of reflexivity on the issue of researchers' background during their process of analyses (Arnaert et al. 2006; Dahab et al. 2008; Dolovich et al. 2008; Lawton et al. 2008; Gebremariam et al. 2010; Tordoff et al. 2010; Chambers et al. 2011). For example, in Chambers et al. (2011) the sample size was dictated by the number of people reporting low adherence to their medication and not as a consequence of saturation of themes being reached. It is therefore possible that themes relating to medication adherence were missed. In addition, several suffered with limited description of the analysis and reporting of themes (Arnaert et al. 2006; Dahab et al. 2008; Tordoff et al. 2010).

To address the moderate quality of seven included studies, a sensitivity analysis was conducted by re-analysing the data after removing these studies from the synthesis. The outcome of this process is reported in the findings section.

Included qualitative studies were read and key information extracted and tabulated in Appendix Table 9 in Appendix 2. Information about the authors, date of publication, aims of the study, qualitative method, qualitative method of analysis, medication under investigation, reported themes/sub-themes from qualitative analyses, the country of origin and study quality were included in the summary table. The summary table was the starting point for the synthesis of findings but an iterative approach of revisiting the original publication was undertaken when clarification was required.

#### 2.5.2.4 Data synthesis

Approaches to data synthesis in qualitative reviews are broad and debated (Barnett-Page & Thomas, 2009). A range of different methods for synthesising qualitative research have emerged (Barbour & Barbour, 2003; Dixon-Woods et al. 2005) and many were considered for this review. Due to the constraint of a single postgraduate reviewer, advanced methods such as meta-ethnography and methods linked to philosophical approaches (e.g. grounded theory) were not undertaken in this thesis.

A narrative synthesis approach (Lucas et al. 2007) was chosen as this process encouraged the findings and context of studies to be organised in detail and would investigate the meaning and content of the included studies. Summaries of the findings of each study were created (see Appendix Table 9 in Appendix 2) to investigate the relationship of findings from medicine beliefs studies with medicines adherence beyond the reporting of main themes (Thomas and Harden, 2008). Importantly, the narrative synthesis approach was considered more likely to make transparent the heterogeneity between studies and make full use of its findings (Lucas et al. 2007).

The synthesis was undertaken in three stages: firstly, studies were inspected for similarities and differences and grouped by key characteristics. These characteristics were (1) the type of medicine beliefs investigated and (2) the described impact of patients' medicines beliefs on medicines adherence. Secondly, study commentaries were produced to note key aspects in relation to their subgroup. Thirdly, a sub-group synthesis was developed and conclusions drawn in relation to each sub-group.

For the synthesis of medicine beliefs types, themes and sub-themes reported in the findings sections of the included studies were extracted. If a theme was reported in more than one paper it was not treated as more important. But a level of validity in the theme can be inferred when this did occur. Therefore, each occurrence of a theme and its origin are presented in Table 2.5. Second order themes were also developed to group the themes/sub-themes reported in the included studies and provide structure and insight for the discussion. For the synthesis of the impacts of medicine beliefs on adherence, themes and sub-themes reported in the findings sections and discussion points arising from the findings were extracted from the included studies.

#### 2.5.3 Characteristics of included studies

Appendix Table 9 in Appendix 2 characterises the included studies and highlights considerable heterogeneity in conditions under investigation. A total of 17 studies met the inclusion criteria from 7 different countries. Seven were conducted in the UK (Carrick et al. 2004; Gordon et al. 2007; Hall et al. 2007; Lawton et al. 2008; Stack et al. 2008; Chambers et al. 2011; Kumar et al. 2011), three in the USA (Woodard et al. 2005; Givens et al. 2006; Choi et al. 2008), three in Canada (Arnaert et al. 2006; Dolovich et al. 2008; Lau et al. 2008), and one each from South Africa (Dahab et al. 2008), Sweden (Attebring et al. 2005), Ethiopia (Gebremariam et al. 2010), and New Zealand (Tordoff et al. 2010). Except for two studies about cardiac conditions (Attebring et al. 2005; Gordon et al. 2007), two about multiple medications (Dolovich et al. 2008; Tordoff et al. 2010), and two about diabetes medication (Lawton et al. 2008; Stack et al. 2008), each study investigated a separate condition.

Slightly more homogeneity was apparent in the use of qualitative methods. Including multiple use of analytical methods within studies, the majority used semi-structured interviews as their only method or in combination with other methods (n=14), others used focus groups (n=5), and one was a case study. Two main analytical approaches were undertaken, thematic analysis (n=13) and grounded theory (n=6). One study used a hermeneutic approach to analysis.

Demographically, participating patients in the included studies were reasonably homogeneous. Although three studies did not report patients' age (Gordon et al. 2007; Dahab et al. 2008; Gebremariam et al. 2010), the age of participants was reasonably similar (range 39-75, mean age 58.9) and indicated all participants were middle to older aged. The majority of studies (n=11) had reasonably equal levels of male and female participants. Many studies did not report ethnicity (n=8) but participants in five of the nine studies that did were predominantly Caucasian.

As with the review of quantitative studies, the aggregated demographic characteristics of the qualitative studies indicated the findings of this review were relevant only to a particular demographic profile of patients. Most studies were

conducted in American or European countries, and patients' were middle to older aged experienced users of health services, ethnically Caucasian, but representative of both genders. This was significant and welcome as the majority of people living with diabetes in the UK fit this demographic profile. This guided the methods section in this thesis to recruit people with this profile and permitted comparability with the findings of this thesis.

Most studies had broad aims of focusing on patients' experiences, ideas, perceptions and expectations of their medications. This implied a focus on medication beliefs and elements of their studies such as the interview topics confirmed this interest. Two studies started with an explicit focus on patients' medication beliefs (Choi et al 2008; Kumar et al. 2011). The former sought to identify patients' beliefs about asthma medications and to assess these beliefs according patient and asthma characteristics, including asthma severity and patient-reported medication adherence. The latter sought to investigate factors that influence beliefs about medicines in patients of South Asian origin with rheumatoid arthritis and systemic lupus erythematosus. This highlighted the predominance of quantitative approaches to the topic of medicine beliefs at this point in time.

#### 2.5.4 Findings

All reported themes in the included studies were extracted. The exploration of the included studies synthesised findings into two themes. Most studies were represented in both themes but some only contributed to the first (Tordoff et al. 2010; Kumar et al. 2011; Dolovich et al. 2008). The themes were (1) type of medication beliefs investigated and (2) described impact of medicine beliefs on medicines adherence research and practice. These themes directly addressed the aim of this review. Themes and sub-themes are presented in Table 2.5.

Other than the two main themes, no other discernible main themes were identified when demographic and clinical factors were considered. These factors did not affect the structure of the thematic analysis. This highlighted two issues, firstly, that patterns of medicine belief types and impacts are comparable across conditions, and secondly, that demographic and clinical factors are unlikely to play the leading role in patients' adherence behaviour.

The sensitivity analysis, to address the moderate quality of seven included studies (Arnaert et al. 2006; Dahab et al. 2008; Dolovich et al. 2008; Lawton et al. 2008; Gebremariam et al. 2010; Tordoff et al. 2010; Chambers et al. 2011), indicated the main findings of the synthesis were robust having excluded these seven studies

and limited the synthesis to the highest quality (quality score >80%) studies. The removal of themes and reported impacts on adherence did not affect the conceptual basis of the main themes identified. In the majority of cases, the removal of findings from the seven studies meant only one less example within a well-evidenced theme/sub-theme.

## 2.5.4.1 Type of medication beliefs investigated

A typology of patients' medicine beliefs was apparent across the included studies. Extracted themes were synthesised into second order themes and presented in Table 2.5. An important narrative to the typology was patients' concerns. All included studies, in one form or another, highlighted the issue of patients' concerns about medication. Another narrative through the collected findings was the issue of temporality. It was apparent from the themes reported in the included studies that patients' beliefs about medication have a temporal element to them, i.e. they may relate to either predictions of future medication use, previous experience, or emanate from a standpoint of being generally concerned about medications. All these issues were discussed within the context of optimal medicines adherence.

#### 2.5.4.1.1 A generally concerned worldview of medication

Three studies reported concerns about medication in general as influential on medicines adherence (Tordoff et al. 2010; Hall et al. 2007; Choi et al. 2008). Single theme examples from other studies (see Table 2.5) included concerns that taking too many medicines is bad, is not natural, is a slippery slope, is a burden, some should be lower status than other medications, and the belief that clinicians overprescribe medication.

#### 2.5.4.1.2 Experientially-based negative beliefs

Many patients held negative beliefs about medications clearly derived from previous experience. Negative experiences of side effects (Gordon et al. 2007; Kumar et al. 2011; Carrick et al. 2004; Choi et al. 2008; Lau et al. 2008; Arnaert et al. 2006; Gebremariam et al. 2010; Stack et al. 2008) and unspecified adverse events (Tordoff et al. 2010; Arnaert et al. 2006; Givens et al. 2006; Lawton et al. 2008) were prevalent across a range of included studies. Moreover, three studies reported patients' previous negative experiences of medication affected their beliefs about their current medication (Givens et al. 2006; Dolovich et al. 2008; Lawton et al. 2008). Two studies based in the US and Canadian health systems

reported patients' negative experience of the high cost of medications negatively affected their outlook on medication (Woodard et al. 2005; Dolovich et al. 2008).

#### 2.5.4.1.3 Experientially-based positive beliefs

Nine studies reported positive beliefs about the need for medication from patients' previous medication use (Tordoff et al. 2010; Gordon et al. 2007; Hall et al. 2007; Dahab et al. 2008; Kumar et al. 2011; Choi et al. 2008; Lau et al. 2008; Arnaert et al. 2006; Dolovich et al. 2008) and a further four (Choi et al. 2008; Carrick et al. 2004; Dolovich et al. 2008; Gebremariam et al. 2010) acknowledged the benefit of their medication to support their well-being. Moreover, one study reported patients' previous experience of medication positively affected beliefs about their current medication (Lawton et al. 2008) and patients in a study of anti-psychotic medication reported positive side-effects, such as vivid dreams and mentally feeling good, encouraged adherence (Carrick et al. 2004).

#### 2.5.4.1.4 Future predictions of medication related problems

In contrast to patients' experiential concerns, patients from twelve of the seventeen included studies also reported future concerns about medications. These included several studies reporting concerns about future dependency (Hall et al. 2007; Carrick et al. 2004; Arnaert et al. 2006; Givens et al. 2006), concerns that following instructions would be difficult (Tordoff et al. 2010; Gordon et al. 2007; Lau et al. 2008), and concerns that the medication will not work (Woodard et al. 2005; Kumar et al. 2011; Arnaert et al. 2006). A range of themes were reported as concerns in six studies as individual examples (see Table 2.5). These included (e.g.) concern that the medication will have a long-term detrimental effect, concern that the medication experience will be negative, concern about the medication intruding into daily life, concern of potential adverse effects of new medication, and concern about over-prescribing.

#### 2.5.4.1.5 Future predictions of medication need

Three included studies reported five types of patients' perceived need for their medication in the future (Choi et al. 2008; Chambers et al. 2011; Attebring et al. 2005). These included beliefs that taking medication will provide symptom control, will reduce fear, will allow the patient to be normal, will make the patient safe from future problems, and that missing medication would have consequences.

Table 2.5 Typology of patients' medication beliefs from the qualitative studies

Grouping	Theme/sub-theme	Country, Author, Year
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theme			
Future predictions of medication related problems	Concerns about dependency on medication	UK (Hall et al. 2007; Carrick et al. 2004); Canada (Arnaert et al. 2006); USA (Givens et al. 2006)	
	Belief that following instructions will be difficult	New Zealand (Tordoff et al. 2010); UK (Gordon et al. 2007); Canada (Lau et al. 2008)	
	Belief that medicine will not work	USA (Woodard et al. 2005); UK (Kumar et al. 2011); Canada (Arnaert et al. 2006)	
	Concern that medication has long-term detrimental effect	UK (Lawton et al. 2008)	
	Concerns about changing medication	UK (Kumar et al. 2011)	
	Concerns about taking multiple medications	UK (Kumar et al. 2011)	
	Concern that negative aspect of medication will be uncovered by research at a later date	Canada (Lau et al. 2008)	
	Concern that medication experience will be entirely negative	UK (Carrick et al. 2004)	
	Fear of new medication because of potential adverse reactions	UK (Carrick et al. 2004)	
	Belief that the medication produces symptoms caused by medication	Sweden (Attebring et al. 2005)	
	Belief that medication intrudes upon their daily life	Sweden (Attebring et al. 2005)	
	Methadone is for junkies	Canada (Arnaert et al. 2006)	
	Methadone is a narcotic and that is a bad thing	Canada (Arnaert et al. 2006)	
	Concerns about over-prescribing	UK (Stack et al. 2008)	
Future predictions of medication need	Taking medication will give me control	USA (Choi et al. 2008)	
	Taking medication will reduce fear	USA (Choi et al. 2008)	
	Taking medication will allow me to be normal	USA (Choi et al. 2008)	
	Belief that missing medication would have consequences	UK (Chambers et al. 2011)	
	Belief that medication makes them safe from future problems	Sweden (Attebring et al. 2005)	
Experientially based negative beliefs	Concerns about side effects	UK (Gordon et al. 2007; Kumar et al. 2011; Carrick et al. 2004); USA (Choi et al. 2008) Canada (Lau et al. 2008; Arnaert et al. 2006); Ethiopia (Gebremariam et al. 2010)	
	Adverse effects of medication (unspecified)	New Zealand (Tordoff et al. 2010); Canada (Arnaert et al.	

		2006); USA (Givens et al. 2006); UK (Lawton et al. 2008)	
	Previous negative experience of medication affect beliefs about current medication	USA (Givens et al. 2006); Canada (Dolovich et al. 2008); UK (Lawton et al. 2008; Stack et al. 2008)	
	Belief that medicines are not affordable	USA (Woodard et al. 2005); Canada (Dolovich et al. 2008)	
Experientially based positive beliefs	Recognised need for medication	New Zealand (Tordoff et al. 2010); UK (Gordon et al. 2007; Hall et al. 2007; Dahab et al. 2008; Stack et al. 2008; Kumar et al. 2011); USA (Choi et al. 2008); Canada (Lau et al. 2008; Arnaert et al. 2006; Dolovich et al. 2008)	
	Acknowledged benefit of medication	USA (Choi et al. 2008); UK (Carrick et al. 2004); Canada (Dolovich et al. 2008); Ethiopia (Gebremariam et al. 2010)	
	Previous positive experience of medication affect beliefs about current medication	UK (Lawton et al. 2008)	
	Has positive side-effects	UK (Carrick et al. 2004)	
A generally concerned worldview of medication	Concerns about medicines (unspecified)	New Zealand (Tordoff et al. 2010); UK (Hall et al. 2007); USA (Choi et al. 2008)	
	Taking too many medicines is bad	Canada (Dolovich et al. 2008)	
	Taking medication is not natural	UK (Lawton et al. 2008)	
	Going onto medication from diet-only treatment is a slippery slope and failure to control diet	UK (Lawton et al. 2008)	
	Practitioners over-prescribe medication	UK (Stack et al. 2008)	
	Some medication are given a lower status then others	UK (Stack et al. 2008)	
	Taking too many medicines is a burden	Ethiopia (Gebremariam et al. 2010)	

# 2.5.4.2 Perceived impact on medicines adherence research and practice

The second main theme of the synthesis was perceptions about the impact of medicine beliefs on medicines adherence. Despite four studies providing limited findings and discussion on impacts (Woodard et al. 2005; Tordoff et al. 2010; Kumar et al. 2011; Dolovich et al. 2008), several themes about adherence impacts are outlined below.

The majority of studies (n=12) explicitly stated via their identified themes that medicine beliefs influenced, often cited in the form of barriers and facilitators, medicines adherence. But some studies were less interested in adherence and focused on the influence of medicine beliefs from a treatment experience (Attebring 2005; Tordoff et al. 2010) or condition-specific outcomes (Woodard et al) standpoint. Moreover, two studies examined the influence of medication beliefs from the view of resistance to medication (Givens et al. 2006) and acceptance of medication (Hall et al. 2007) rather than adherence to medication. These studies were not excluded due to the conceptual similarity between these outcomes. Importantly, the impacts on adherence themes are presented with an acceptance that qualitative links have been made between medicine beliefs and medicines adherence across the included studies.

#### 2.5.4.2.1 Further medicine beliefs research to support medicines adherence

Many studies made broad claims that further medicine beliefs research was required and that it should be part of available support for adherence (Dahab et al. 2008, Lau et al. 2008, Lawton et al. 2008, Stack et al. 2008, Gordon et al. 2007, Hall et al. 2007). Generally, it was noted that although non-adherence is widely documented in the research literature and medicines beliefs research on the increase, both receive minimal attention in clinician consultations (Gordon et al. 2007). Further research is also needed to identify differences in medication beliefs when patient characteristics are variable, e.g. better quality of life, with more recent onset of disease, under different care conditions and with different levels of actual adherence (Hall et al. 2007). Also, several studies reported an important development for improving adherence was the need to develop intervention studies to address patients' medicine beliefs (Stack et al. 2008, Gebremariam et al. 2010, Chambers et al. 2011, Gordon et al. 2007). For example, interventions aimed at eliciting and challenging low adherers' specific concerns regarding the negative consequences versus the benefits of taking their medication might be effective in addressing intentional non-adherence (Chambers et al. 2011). Finally, one study reiterated the value of the quantitative research base on medicine beliefs indicating more studies were needed to know the extent of beliefs held and if they are empirically related to adherence (Stack et al. 2008).

## 2.5.4.2.2 Biased focus on strategies to address non-adherence

Two qualitative studies highlighted most strategies for non-adherence are still focused on unintentional reasons for non-adherence (e.g. reminders, dose diary) (Lau et al. 2008; Lawton et al. 2008). This was not unexpected as most intervention studies to address non-adherence do not engage in complex variables

such as patients' beliefs, as reported in a review of interventions to support medicines adherence (Haynes et al. 2008). However, it does reiterate a paucity of strategies to address patients' beliefs despite their apparent value in the literature. Moreover, if the aim is to develop multifaceted strategies to promote adherence (Horne et al. 2005), research must be conducted to explore how to intervene with patients' medicines beliefs. Lawton et al. (2008) suggested such methods could include education to address misconceptions and structured feedback for patients on the impact of missing doses on glycaemic control.

## 2.5.4.2.3 Requesting clinicians to explore medicine beliefs

Many studies explicitly stated they require clinicians to explore medicine beliefs in practice to aid the problem of non-adherence to medication (Stack et al. 2008, Gebremariam et al. 2010, Chambers et al. 2011, Gordon et al. 2007, Givens et al. 2006, Arnaert et al. 2006). It was considered important that future research should explore how clinicians can address patients' beliefs (Stack et al. 2008) and particularly how nurses, specifically, can address patients' misconceptions (Arnaert et al. 2006, Gebremariam et al. 2010). The majority of studies were vaque about how or when to do this except for four studies. One study highlighted that clinicians should be aware that patients' beliefs about their medicines may be medicine specific and change over time (Gordon et al. 2007). In addition, although the Attebring et al. study was largely focused on treatment experience as a whole, it considered work on exploring beliefs as secondary preventive work and the starting point was dealing with patients' beliefs about treatment provided. Furthermore, one study indicated medication beliefs exploration would fit into the broader framework of patient-centred care to maximise optimal adherence (Givens et al. 2006) and another indicated clinician-patient trust would likely be vital for belief change (Woodard et al. 2005, Arnaert et al. 2006).

#### 2.5.4.2.4 Tailored support

In addition to promoting explorations, several studies claimed that tailoring of adherence support was needed (Lau et al. 2008, Gordon et al. 2007, Gebremariam et al. 2010). An implication for medicines adherence was the need for counselling to address adherence problems (Gebremariam et al. 2010) and because each patient's reasons for non-adherence might be different, depending on individual beliefs, strategies to improve adherence to medications should be individualised accordingly (Lau et al. 2008). Another study made the important point that no assumptions should be made in consultations regarding if, and how, patients use their medicines. Moreover, to promote appropriate medicines adherence, patients'

perspectives, expectations, and concerns need to be incorporated into discussions about their medicines (Gordon et al. 2007).

#### 2.5.4.2.5 Polypharmacy medicine beliefs

Patients' medicine beliefs were reported as having the potential to compound adherence to multiple medications (Hall et al. 2007, Stack et al. 2008, Gebremariam et al. 2010). Some individuals on multiple medications self-regulated their medication, showed reluctance to take drugs, and an inability to be free of them (Hall et al. 2007). Others assigned a lower status to particular medications (Stack et al. 2008). The latter diabetes example involved patients' undervaluing their cardiology and lipid lowering medications compared to their diabetes medication. This finding was also seen in patients' beliefs about tuberculosis and HIV treatment, whereby some discontinued one or both treatments after weighing up benefits and costs of each medication (Gebremariam et al. 2010).

#### 2.5.4.2.6 Characteristics of patients' medicine beliefs activity

The final theme highlights patients' activity when engaging their medicine beliefs systems. Firstly, two studies reported patients' being engaged in a costs and benefits analysis about their medication (Carrick et al. 2004, Arnaert et al. 2006). In the case of patients' taking antipsychotic medication (Carrick et al. 2004) weighing up the costs and benefits of the medication was done not just in terms of symptom reduction but the combined level of distress caused by those symptoms and/or by side effects. In addition, patients' perceptions of methadone medication (Arnaert et al. 2006) promoted adherence when the benefits of having pain control using methadone outweighed the cost of potentially incurring the label of 'junkie' from others and led to acceptance of and adherence with the medication regimen.

Secondly, it was apparent patients' can be cognitively dissonant about their medication. In one study, patients' acknowledged both benefits and drawbacks of asthma medications when adhering and not adhering (Choi et al. 2008). Also, patients are often subject to conflicting advice on medication from different clinicians and not certain what to believe. This was reported as a barrier to medicines adherence (Lau et al. 2008). Further dissonance may occur in asymptomatic conditions such as one included study about osteoporosis medication (Lau et al. 2008). In the absence of symptoms, patients' may not fully develop necessity beliefs for their medication and subsequently not adhere. Also, in one study about oral medication for diabetes, in spite of concerns and adverse side-effects, patients still reported appropriate levels of medication adherence

(Lawton et al. 2008). This motivation seemed to arise from patients observing the medication work.

Thirdly, one study highlighted patients were not necessarily passive in their belief formation or adherence activity (Lawton et al. 2008). Patients were generally committed to finding ways of addressing problems so they could adhere to the prescribed medication. The findings above clearly complicate the relationship between patients' medicine beliefs and medicines adherence. Nonetheless, understanding the profile, combination, and selection of patients' medicine beliefs would appear to be important to further understanding medication adherence.

#### 2.5.5 Discussion

This broad synthesis has shown qualitative studies about patients' medicine beliefs are primarily involved in the investigation of medicine belief types and the resultant impact on medicine outcomes. The latter predominantly concerned with adherence to medication. Studies represented a broad range of long-term conditions but the participants within them had some degree of similarity on age, equal gender distribution, and ethnicity.

The exploration of the included studies was synthesised into two themes, type of medication beliefs investigated and described impact of medicine beliefs on medicines adherence research and practice. This synthesis has gone some way to address the uncertainties of the value of patients' medicines beliefs and their relationship with medicines adherence. It has summarised the position of the research literature and recommended action for clinicians. The first main theme was not as relevant to the work of this thesis, i.e. the typology of medicine beliefs. It was interesting to determine the typology but the second main theme provided more insight into the value of the qualitative evidence available. It helped to address the aim of chapter 2, i.e. to determine if medicine beliefs research had value, and ultimately made a contribution to the rationale for the thesis by justifying an investigation of the challenges of medicine beliefs exploration by nurses.

#### 2.5.5.1 Medicine beliefs typology

The first main theme, the typology of medicine beliefs identified in the included studies, does support the definition of medicine beliefs used in this thesis. It complemented the existing literature and offered a new dimension - the temporality of medicine beliefs.

Patients' concerns about their medication were present in all included studies and commonly discussed in the context of high concerns leading to poor adherence to medication. This broad finding was first identified in early research about patients' ideas about medication which reported patients had many fears and negative images of medication (Echabe et al. 1992; Britten et al. 1994). Moreover, a metareview of qualitative medicine-taking studies considered patients' concerns about their medication a major reason many people are resistant to taking them (Pound et al. 2005). Findings from the present review also indicated patients' concerns could be focused on specific medication and held as part of a general worldview about medication. This distinction has also been established by previous research whereby medicine beliefs have been separately by patients' concerns for their specific medication and patients' concerns in general about harm and overuse (Horne and Weinman, 1999; Horne et al. 2005; Horne et al., 2007).

Furthermore, nine included studies reported positive beliefs about the need for medication emanating from patients previous medication use and one study reported patients previous experience of medication positively affected beliefs about their current medication (Lawton et al. 2008). The former issue of perceived need for medication has been established as an important element of the necessity-concerns framework used widely to establish the empirical relationship between patients' medicine beliefs, medicines adherence and clinical outcomes (Horne et al. 2007; Clifford et al. 2008). The latter issue has been examined less, as has the impact of positive side-effects, which encouraged adherence in one of the included studies (Carrick et al. 2004).

Patients' negative experiences of side effects and adverse effects were prevalent in the included studies and affected patients outlook on medication. The broad issue of adverse events was an important theme in the Pound et al. (2005) metasynthesis which highlighted patients can be right to be cautious about taking medicines due to known adverse reactions (Heath, 2003). Moreover, patients may develop beliefs about adverse effects from these experiences and abstract worries about the future, i.e. through long-term effects and dependence (WHO, 2003).

The definition of medicine beliefs used in this thesis has very similar concepts to those identified in the review. Use of these concepts would serve to provide a stable base for clinicians to start any exploration of patients' medication beliefs. As a development, considering patients present and future concerns would seem to be an important addition to the current definition of medicine beliefs. Differentiating between them would potentially offer more clarity to clinicians when attempting to engage and work with patients' medication beliefs.

## 2.5.5.2 Impacts of medicine beliefs on adherence

The second main theme highlighted numerous impacts of patients' medicine beliefs on adherence which suggest medicine beliefs are worth exploring to optimise medicines adherence. These included the recommendation that clinicians explore medicine beliefs in practice, tailor such explorations, be mindful of multiple medication issues and thus multiple medicine beliefs systems, and be aware that patients often take an active role when managing their long-term condition.

Importantly, the majority of studies explicitly stated via their identified themes that medicine beliefs influenced, often cited in the form of barriers and facilitators, medicines adherence. Moreover, many studies claimed more research on medicine beliefs, such as intervention studies to address beliefs, was required to support adherence work by clinicians. These claims have been made as far back as early research on patients' representations of medication (Fallsberg, 1991; Britten et al. 1994) but little was reported about how to go about this and, as will be seen in later in this chapter, few intervention studies have been developed to date.

Findings about attempts to support adherence are largely focused on unintentional reasons why patients fail to adhere, rather than belief-related intentional reasons. This has been noted in systematic reviews of adherence generally (Vermeire et al. 2001; Haynes et al. 2008) and presents challenges for clinicians when called upon to support adherence. Some may feel unfamiliar with a different approach compared to using arguably easier methods, such as diaries, reminders and practical support with bottle/boxes.

Most studies reported the need for clinicians to engage with patients' medication beliefs, in a tailored manner, in practice to aid the problem of non-adherence to medication. This action has been recommended by several reviews (Horne et al. 2005; Pound et al. 2005; Malpass et al. 2009) and national guidance (NICE, 2009) but no research was identified that investigated the issues and experience of doing so. This would also indicate that engaging with patients' medicine beliefs would likely be new work for clinicians. Some guidance was reported such as treating beliefs exploration as secondary preventive work and the starting point for adherence support was dealing with patients' beliefs (Attebring et al. 2005). Moreover, it was recommended clinicians should not assume medicine beliefs remain unchanged throughout the course of an individual's care (Gordon et al. 2007). Importantly, as found in the Pound et al. (2005) review, for clinicians to explore medicine beliefs they are going to require training to do this effectively

and adopt the known evidence into practice settings. At minimum, an investigation of the factors that influence such activity would appear to be required.

Patients' medicine beliefs were reported as having the potential to compound adherence to multiple medications through the assignment of a lower status to particular medications (Stack et al. 2008). This demonstrated patients can hold different medicine beliefs systems about different medicines. This further complicates traditional polypharmacy issues and requires further research to understand its complexities.

Finally, patients took an active role and used their medicine beliefs to guide their decisions to adhere or not. They were found to engage in costs and benefits analyses about their medication, also reported as weighing and balancing (Pound et al. 2005), often in the form of considering the degree of necessity for, and concerns about, the medicine in question (Horne et al. 2005; Horne et al. 2007). The latter commonly referred to as the necessity-concerns framework Horne et al. 2007; Clifford et al. 2008). Patients in this synthesis could also be cognitively dissonant about their medication which complemented previous research. Clatworthy et al. (2009) identified four attitudinal groups of patients depending on their level of concern and perceived need for their medication. Sceptical patients had high concern but low need; ambivalent patients had high concern and high need, indifferent patients had low concern and low need, and accepting patients had low concern and high need. Moreover, Pound et al. (2005) also identified different types of patient approaches to the broader action of medicine-taking. These included patients being passive or active accepters of medication. Previous research has indicated clinicians may find changeable medicines behaviour bewildering (Blaxter and Britten, 1996) but this can be overcome by understanding patients are generally resistant to medication (Pound et al. 2005) and by using core medicine beliefs concepts and attitudinal groupings as starting points for exploration activities.

#### 2.5.5.3 Issues from the diabetes studies

Due to the heterogeneity of health conditions investigated in the included studies, there was no benefit of grouping studies by condition. However, because of the focus on diabetes for this thesis, it was important to highlight findings pertaining to the diabetes studies included in the qualitative review (Lawton et al. 2008; Stack et al. 2008).

The thematic findings of the two diabetes studies, both UK-based and good quality, were largely congruent with the main findings of the synthesis.

Participants in both studies had future concerns, Lawton et al. (2008) about the long-term effects of diabetic medication and Stack et al. (2008) about overprescribing of cardiovascular medication alongside diabetes medication. They also held negative experiential beliefs about adverse effects of medication (Lawton et al. 2008) and over-prescribing (Stack et al. 2008). Similarly, both held positive experiential beliefs, both highlighted patients' supportive beliefs were optimised from seeing the medication work (Lawton et al. 2008; Stack et al. 2008). Both also held broad worldview concerns about diabetes medication. Participants in Stack et al. (2008) maintained their concerns about over-prescribing of cardiovascular medication and participants in Lawton et al. believed taking medication was not natural and going onto medication from diet-only treatment was a slippery slope and demonstrated failure to control their diet.

The only exception to the congruence with the overall synthesis was neither diabetes studies reported medicine beliefs about future need for medication. This may have been due to the demographic profile of the patients. The mean age of participants was 60 (Lawton et al. 2008) and 65 (Stack et al. 2008) and most had been on medication for over four years. These were reasonably experienced patients and whilst it would be intuitive to assume they had strong necessity beliefs about their medication, having strong concerns at the same time could develop 'ambivalent' beliefs toward their medication (Clatworthy et al. 2009) and negatively affect adherence behaviour.

Stack et al. (2008) was concerned with issues of multiple medicines for diabetes, which is a common situation for patients with Type 2 diabetes. Moreover, the cardiovascular disease medication regime can be complex. Although participants were aware of evidence on the severity of cardiovascular complications in Type 2 diabetes, Stack et al. (2008) reported participants undervalued their cardiovascular medication. This suggests diabetes patients hold/develop separate belief systems for each medication they're prescribed. Understanding patients myriad of concerns and perceived need for all medications prescribed to manage their condition(s) should be important exploratory work for clinicians.

As for perceived impacts on adherence, like most of the included studies, both diabetes studies explicitly stated the themes they identified were influences on medicines adherence. Also, they both reported more research on patients' medicine beliefs was needed to support adherence and called for clinicians to explore medicine beliefs. Like many of the included studies, the diabetes studies did not elaborate on how or when exploration should occur, nor did they investigate the influential factors upon such activity. This was seen as a clear gap

in the literature, broadly and within the diabetes context. Overall, there was limited qualitative research about diabetes patients' medicine beliefs.

#### 2.5.5.4 Limitations of the qualitative review

The systematic selection of studies, audit trail and critical appraisal using a published tool arguably improved the rigour of the synthesis. However, an obvious and important limitation of a single postgraduate reviewer was an absence of coreviewers to verify synthesis interpretations.

The qualitative review sought to establish the nature of the available literature focused on medicine beliefs. It identified medicine beliefs typologies and impacts on adherence, however, this was a targeted review and some themes within the included studies were excluded, e.g. problems with access to the services (Gordon et al. 2007), as these pertained to the wider issue of medicine-taking problems. Potentially, patients' medicine beliefs may influence wider problems, e.g. access to medicines, in unknown ways. To date, studies have largely focused on the relationship between medicine beliefs and medicines adherence and this was the main problem driving this review, but the potential for a wider review including less examined outcomes may provide a richer perspective of the value of patients' medicine beliefs.

Limited research about medicine beliefs has emerged from the qualitative field in the last ten years. Of the available literature, it has largely focused broadly on the topic of medicine-taking. This affected the review as fewer studies than expected were specifically focused on the issue of patients' medicines beliefs. In contrast, studies specifically focused on medicine beliefs were far more prevalent in the quantitative review. Therefore, the qualitative review was slightly less focused than the quantitative review. Its possible qualitative researchers believe this area has been taken on by philosophically different approaches, or are waiting for quantitative research to be developed into interventions whereby they can be evaluated using qualitative approaches. Either way, more research on the nature and exploration of this factor is required.

As with most qualitative reviews, causal relationships between patients' medication beliefs and adherence cannot be confirmed due to the nature of the methodology. Moreover, the stated relationships between these factors were bound to the context of each study. Although the demographic profile (age, gender distribution, ethnicity) of participants in the included studies were similar, a wide range of health conditions and medications were present in the included studies. This was not dissimilar from other qualitative reviews (e.g. Pound et al. 2005) but does raise

the point that findings should be used with caution across different conditions, particularly for conditions not represented in the review.

## 2.5.5.5 Conclusions from the qualitative review

The aim of this part of the review was to explore and assess available qualitative literature focused on medication beliefs. Moreover, this part of the review was done to determine if and what elements demonstrated value to optimising medication adherence. Some of the literature was interesting, i.e. it demonstrated a typology of medicine beliefs, but evidence to demonstrate impact was more apparent in the second main theme identified. It provided more insight into the value of the qualitative evidence to optimise medicines adherence. It helped to address the aim of chapter 2, i.e. to determine if medicine beliefs research had value, and ultimately made a contribution to the rationale for the thesis by justifying an investigation of the challenges of medicine beliefs exploration by nurses.

Three conclusions were drawn from the review of qualitative studies. Firstly, patients' medicine beliefs were frequently reported as influencing factors on medicines adherence. The relationship between these two factors was complex and varied, but largely demonstrated through various belief typologies and perceived impacts on adherence.

Secondly, the identified medicine beliefs typologies supported the definition of medicine beliefs used in this thesis. Patients' concerns about, and perceived need for, their medication were recurrent themes in the synthesis, as was patients' general worldviews about medication.

Thirdly, most included qualitative studies reported the need for clinicians to engage with patients' medicine beliefs but no qualitative research was found that investigated the issues and experience of doing so. Such activity is likely to represent new work for clinicians, i.e. using the medicine beliefs concepts as discussion tools, and an investigation of the factors that influence such activity would appear to be required. This supported the rationale for the thesis.

## 2.6 Review of interventions

The previously stated search terms also identified a small number of intervention studies. The aim of this short review was to further examine the value of medicine beliefs research and its impact on medicines adherence. Studies were included if they developed an intervention which addressed patients' medicine beliefs to some degree.

Four intervention studies were identified from the search results. One was a controlled intervention study (Petrie et al. 2012), one was a pilot controlled intervention study (Karamanidou et al., 2008b), one was a before and after intervention study (Magadza et al., 2009) and the fourth was a randomised controlled trial (Clifford et al., 2006).

All developed broad educational interventions and incorporated information about the value of medicine beliefs as part of their intervention. The broad interventions were aimed at improving understanding of the need for phosphate-binding medication (Karamanidou et al. 2008b), assessing the effects of pharmacists giving advice to meet patients' needs after starting a new medicine for a chronic condition (Clifford et al. 2006), investigating the effect of an educational intervention on selected hypertensive participants' level of knowledge about hypertension, their beliefs about medicines, and adherence to antihypertensive therapy (Magadza et al. 2009), and knowing whether a tailored text message programme targeted at changing patients' illness and medication beliefs would improve adherence in young adult asthma patients (Petrie et al. 2012). None focused on diabetes.

All studies based their educational component about medicine beliefs on concepts known to underpin medicine beliefs (e.g. necessity and concerns) and thus were congruent with the definition of medicine beliefs used in this thesis. Two studies used technology to support their educational intervention (Clifford et al. 2006; Petrie et al. 2012). A British randomised controlled trial (Clifford et al., 2006) evaluated a telephone-intervention provided by a community pharmacist. The intervention group received a telephone call two weeks after the patient was recruited. The nature of the intervention phone call was based on discussion topics linked to concepts in the necessity-concerns framework (Horne & Weinman, 1999; Horne et al., 2007; Clifford et al., 2008; Clatworthy et al., 2009). Intervention group participants in the New Zealand controlled intervention study (Petrie et al. 2012) received tailored text messages for 18 weeks. Prior to the study, a range of concept-informed text messages were generated with approximately 24 texts for

each targeted medicine belief concept (low necessity and high concerns). The two other studies used a combination of information leaflets and face-to-face discussions in their attempts to influence hypertension medication beliefs (Magadza et al. 2009) and improve understanding of the need for phosphate-binding medication (Karamanidou et al. 2008b).

Interestingly, three of the four studies used researchers as the interventionist. Only one study used trained clinicians, community pharmacists (Clifford et al. 2006), to deliver the educational intervention. This has important implications for the value of these interventions as using researchers would clearly not be sustainable in practice. It would appear prudent to train clinicians to explore and manage patients' medicine beliefs effectively in order to fit in with care pathways for each condition.

Before considering the collective findings, it is important to note all had a quality score >75% using the Kmet et al. (2004) quantitative appraisal system. However, the findings from two studies must be considered questionable due to low sample sizes. Magadza et al. (2009) started with a sample of 69 but loss to follow-up reduced that number to 45 and Karamanidou et al.'s (2008b) study had only 19 patients in the intervention and 20 in the control group.

All studies reported positive effects on medicine beliefs and/or medicines adherence. The two well designed and executed studies (Clifford et al. 2006; Petrie et al. 2012) both reported non-adherence was significantly less frequent, and there were significantly fewer problems, in the intervention group compared to the control group at their follow-up points (4 weeks and 18 weeks respectively).

In addition, both studies reported significant positive changes in patients' medicine beliefs. In Clifford et al. (2006) the necessity-concerns differential score (the difference between patients' beliefs about the necessity of their medicine and their concerns about taking it) was significantly higher in the intervention group than the control group. This indicated the intervention group were significantly more likely to have more positive beliefs about their medicines, with a greater tendency to rate their personal need for the new medicine as high, relative to their concerns. This balance of beliefs has been linked to higher rates of medication adherence (Horne et al. 2007; Clatworthy et al. 2009). Also, the intervention group in Petrie et al. (2012) had increased their perceived necessity of asthma preventer medication 18 weeks after the intervention ended.

An addition benefit of the Clifford et al. intervention was an economic analysis (Elliott et al., 2008), based on the data from Clifford et al., to establish the cost-

effectiveness of the education intervention. The mean total patient costs at the two-month follow-up were significantly lower for the intervention group (p<0.0001) (intervention: £187.7; control: £282.8) indicating the intervention was less costly as well as being more effective than usual care.

Fewer positive findings were reported by Karamanidou et al. (2008b) and Magadza et al. (2009). Despite immediate positive post-intervention effects within the intervention group on all variables, including significant improvements in patients' perceptions of medication necessity (z=-2:06; p<0.05), these variables were not significantly different than the control group at 1 and 4 months post-intervention. Moreover, adherence levels did not significantly improve at any time-point or between groups (Karamanidou et al. 2008b). Similarly, the adherence levels of participants in Magadza et al. (2009) did not significantly increase postintervention but scores on relevant medicine beliefs concepts were significantly improved post intervention: BMQ Necessity-Concerns differential (p<0.05), BMQ Specific-Concerns (p<0.05), and BMQ General-Harm (p<0.05). The conflicting findings of the four intervention studies may be due to the under-powered samples in Magadza et al. (2009) and Karamanidou et al. (2008b). Whilst trends toward the importance of addressing patients' medicine beliefs to optimise medicines adherence have been reported, further research with larger samples and high quality randomised trials are required.

Interestingly, none of the interventions investigated or discussed the issues of implementing their intervention. The issue of implementation has become increasingly important in order to ensure evidence, in these cases in the form of education interventions, is transferred into practice effectively (Grimshaw et al. 2001; Boaz et al. 2011). This may have accounted for the mixed findings from the two underpowered studies. The authors of the interventions in this review reported they were all aware of the Haynes et al. (2008) Cochrane review which found most interventions to address non-adherence are complex, difficult to implement in practice and resource intensive. The authors developed reasonably simple education interventions to address, in part, patients' medicine beliefs. However, it's possible the Haynes et al. conclusions also apply to interventions to engage in medicine beliefs exploration and optimisation. In order to facilitate wide spread access to education about medicine beliefs, interventions must be delivered by clinicians during routine consultations and those contexts require investigation to understand the barriers and facilitators that permit beliefs exploration.

In summary, the interventions of the four included studies addressed medicine beliefs in part and within a broader intervention. All studies based their education

about medicine beliefs on the concepts known to underpin medicine beliefs. All but one study used researchers as the interventionists which is unsustainable if the interventions are designed for practice. Two studies intervened by distance using technology and two used face to-face interventions. It was not possible to determine whether the different methods had any effect on the intervention, but it's reasonable to assume technological interventions may suffer from patients' lack of familiarity with the technology and face-to face interventions may be difficult to access in a large scale. All studies provided findings that pointed toward the importance of addressing patients' medicine beliefs to optimise medicines adherence but further research on the effectiveness of these interventions through larger trials, and their implementation into routine practice, is required.

## 2.7 Combined conclusions from all three reviews

Non-adherence to medication persists as a clinical and research problem, is costly in terms of service expenditure, and facilitates poorer patient health outcomes. In recent years, the examination of fixed trait characteristics has shifted toward more modifiable factors and revealed patients' beliefs as an important antecedent of non-adherence. The aim of this review was to assess the value of the broad range of research about patients' medicine beliefs. Six conclusions were drawn from the combination of findings across the three methodologically separate reviews.

Firstly, it was apparent that patients' medicine beliefs had important links with medicines adherence. Irrespective of methodology, all three parts of this review reported patients' medicine beliefs were an influencing factor on medicines adherence. This can be inferred from the accumulated data of 62 studies in the quantitative review that reported the necessity for, and concerns about, concepts had the best ratio of significant to non-significant associations with adherence than any other medicine beliefs concepts. This finding was enhanced by an additional finding that most demographic, clinical, and illness perception factors appearing in the same main analyses as medicine beliefs concepts were infrequently associated with adherence. This finding was also enhanced by qualitative findings that reported a range of medicine belief impacts on adherence in the form of recommendations to improve clinical practice. The few intervention studies identified also support the trend toward the increasingly important value of patients' medicine beliefs, although the findings of the interventions are mixed due to methodological limitations. Overall, the quality of the quantitative and qualitative studies was good and comparable (mean quality score 87% and 80%

respectively) and only one study, from the qualitative review, that met the inclusion criteria was excluded. Therefore, the combined conclusions were bolstered by the quality of the included studies.

Secondly, although the trends for the importance of patients' medicine beliefs are present, there are methodological caveats to the combined findings. The quantitative review indicated a predominance of cross-sectional survey studies in this area. These were largely well designed, executed and reported, but more rigourous assessment of medicine beliefs and its relationship with adherence is required. More prospective studies and randomised controlled trials would provide the methodological rigour required to examine beliefs as a variable against other commonly examined antecedents of adherence. Additionally, as with most qualitative reviews, causal relationships between patients' medication beliefs and adherence could not be established due to the nature of the methodology, but the studies provided much needed depth to the assessment of the relationship. The final caveat was demographic. Although all included studies focused on a wide range of health conditions and medications, participants across all parts of this review were demographically similar on a number of factors. The vast majority of studies were based in American or European countries and involved populations of predominantly Caucasian ethnicity. In addition, participants were largely middle to older aged experienced users of health services. This presented a demographic profile bias, linked to the findings, and must be considered when interpreting the combined findings.

Thirdly, when taking into account the findings from all parts of this review, it was apparent the definition of medicine beliefs used in this thesis was conceptually stable. All intervention studies based their education about medicine beliefs on the concepts provided in the definition used in this thesis. Conceptual caveats were identified in the quantitative review but these were not identified in the qualitative review. In the quantitative review, patients' necessity for, and their concerns about, their condition-specific medication were important associates of adherence. However, patients' general concerns about the ability of medicines to harm them (General-Harm) and perceptions of medicines being over-prescribed (General-Overuse) reported more non-significant than significant associations with adherence. This suggested the specific and general concepts are conceptually distinct and should be treated separately. However, themes identified in the qualitative review contradict this position, as a theme about patients' generally concerned worldview of medication was identified in the qualitative review. The conceptual stability of the definition was further bolstered when the concepts of necessity and concerns about specific medication were identified in a number of

ways in the experiential and future themes in the qualitative review. These qualitative findings did not alter during the sensitivity analysis and support the robustness of this conclusion.

Fourth, it was clear from the findings of the quantitative and qualitative reviews that clinicians should be engaged in medicine beliefs exploration to address the wider problem of medicines non-adherence. This was concluded from the empirical links identified in the quantitative review and as a theme identified in the qualitative review. Only the qualitative review gave some indication of how to go about an exploration, although this was very limited, highlighting medicine beliefs could be the important start point for exploration and unlikely to remain unchanged throughout the course of an individual's care. Importantly, an investigation of the factors that influence such activity would appear to be required.

Fifth, the focus of medicine beliefs research was largely quantitative and investigating variable relationships. The trajectory of medicine beliefs research was apparent from the findings of this review. Chronologically, qualitative research preceded the development of a large body of quantitative research. To date, only a limited number of interventions to address medicine beliefs have been developed. Across all parts of this review, there was a noted absence of research about the exploration of medicine beliefs during consultations with clinicians. Research to understand the operationalization and implementation of explorations had yet to be developed. On the former issue, only four intervention studies were identified and they all incorporated medicine beliefs education as part of wider goals. In addition, only one used clinicians to deliver the intervention. On the latter issue, none of the interventions reported information about how their attempt to work with beliefs in practice was undertaken. Overall, a better appreciation of the use and experience of exploring patients' medicine beliefs was clearly apparent.

Finally, in support of the clinical focus of this study, diabetes studies in both the quantitative and qualitative reviews did not differ in their findings from the overall trends reported in each of those reviews. This indicated the value of patients' medicine beliefs was just as relevant to the diabetes context as to the collective findings. However, when considering only the diabetes studies included in the quantitative and qualitative reviews, all the studies were reasonably similar. All the studies focused on Type 2 diabetes patients on oral medication for blood glucose control, who had lived with the condition for many years, were predominantly ethnically Caucasian, and spoke English as their first language. The only exception to the congruence with the overall findings was in the qualitative synthesis

whereby neither diabetes studies reported medicine beliefs about future need for medication. However, this may have been due to the experienced situation of the participants involved. In order to develop continuity with the available literature, this thesis was mindful of the diabetes demographic profile during sampling and analyses.

# 2.8 Implications of this review

This review is the first to provide a broad appreciation of all research focused patients' medicines beliefs. This review highlights medicine beliefs concepts are frequently and predominantly associated with medicines adherence. This finding supported the rationale for focusing on this topic for a doctoral study.

In addition, the findings of this review confirm and expand on previous recommendations from early findings (Horne & Weinman 1999), condition-specific reviews (Jackson et al. 2010; Selinger et al. 2011; van den Bemt et al. 2012) and a broad scoping review about adherence (Horne et al. 2005), for health care professionals to explore patients' concerns about, and necessity for, their medicines in practice in order to positively affect the non-adherence problem.

Patients' perceptions about their medicines may not readily emerge during medical consultations and therefore may need to be elicited by the clinician (Horne 1999; Dawson et al. 2005; Fahey et al. 2008). This potential work by clinicians should not be considered out of their remit as clinicians have long been encouraged to recognise patients' attitudes toward treatment (Kundhal & Kundhal 2003), however, the emergence of defined concepts and methods of measuring patients' medicine beliefs represents an important development. These innovations provide the opportunity to support health care professionals to effectively focus their efforts during consultation discussion and potentially strengthen accurate beliefs and/or challenge misconceptions (Dawson et al. 2005).

At present, research in this area remains largely focused on establishing causal links between medicine beliefs, adherence, and relevant health outcomes, although interventions to address patients' potential misconceptions are emerging. Despite repeated calls for exploration, no research has focused on practice issues such what an exploration of patients' medicine beliefs might involve, if it would be feasible, what challenges nurse prescribers face, and how patients might feel about it.

Now that a review of the area has been done and patients' medicine beliefs recognised as an important associate of adherence, practice-related questions

such as 'are nurses already exploring patients' medicine beliefs?', 'what is the current practice of nurses when engaged in medicines discussion with patients?', and 'what is the role of patients in discussions about their own medicine beliefs?' are important and relevant. These questions are addressed in the next chapter and further develop the rationale for investigating the experience of nurse prescribers and patients as they engage in medicine belief discussion.

# 3. Nurses' medicines work: a narrative review

# 3.1 Introduction

Building on the key messages from chapter 1, this literature review explored if and how nurses were routinely engaging patients about their medication beliefs. This chapter had two aims. Firstly, to position medication beliefs *exploration* within the wider context of medicine-related research, and secondly, to critically review available research on nurses' medicine-related work to highlight important shortcomings in this research area.

A systematic review of all medicine-related research relevant to nurses was considered beyond the remit of a doctoral thesis. Therefore, when a research area is vast or limited to only a few studies of good methodological quality, narrative reviews represent an appropriate alternative (Green et al. 2006). Moreover, narrative reviews allow analogies to be made with other fields of research and hence integrate evidence from more than one independent field of research (Bollini et al. 2006; Green et al. 2006; van Gestel et al. 2012). The narrative review in this chapter outlined major areas of research and further developed the rationale for, and context of, this thesis. Limited nurse-related medicines research was available in the diabetes context.

The following discussion centred on major areas of research focused on nurses' medicine-related activity. Findings from this review highlighted some important shortcomings of research focused on the specific activity of nurses' medication communication. In conjunction with the findings from chapter 1, the shortcomings in chapter 2 led to the development of the research questions for this thesis.

# 3.2 Research on the role of nurses and their medicines activity

In addition to issues gleaned from general medication research and nursing policy guidance on medicines activity, as outlined in section 1.6, a targeted review was undertaken to search for primary research on nurses' medication activity. The aim of this chapter was to determine the nature of the literature and how its issues inform this thesis. This review of research about nurses' medication activity highlighted a number of research intensive areas. In addition, a number of shortcomings from this review supported the rationale for this thesis.

## 3.2.1 Search strategy

Studies for this narrative review were identified by searching Medline, CINAHL, and PsycINFO using the search terms (AB communic\* OR AB discuss\*) AND (AB medicine\* OR AB medication\* OR AB prescription\* OR AB drug\*) AND TI nurs\*. These terms were chosen to deliver a broad range of medication-related studies but only within the context of nursing care. Studies were sought between January 2000 to December 2012, involving primary research and not limited by methodology. This date range was considered appropriate to gather a suitable range of literature whilst keeping it manageable for a single postgraduate reviewer. Moreover, the starting point of the date range was the year the literature began to consolidate under the definition of medicine beliefs provided earlier in this chapter. The end date of the literature review was shortly before the first submission of this thesis. Initial searches indicated a paucity of studies in the diabetes context, therefore, no search terms were used that would limit the searches to that context. In total, 1032 studies were identified after the removal of duplicates. These studies were read over the course of several months and thematic messages were discernible from the available literature.

#### 3.2.2 Medicine-taking agendas

It was apparent from the identified research literature that most medicine-related research focused on nurses' medication safety, medication administration, or interprofessional communication about medicines. There were noticeably more studies conducted in these areas compared to literature about nurses' medication discussion with patients. In that sense, the latter could be considered an overlooked 'Cinderella agenda'.

My point here is not to argue against the importance of medication safety, as this is clearly needed and much time and energy has been appropriately spent on ensuring medication errors are minimised internationally (Woodward 2011; Kohn et al. 1999) and in the UK (Department of Health 2000b). Nor is it to dismiss the importance of accurate administration of medicines. Many studies have been conducted in this area to improve effective documentation of medicine management (Aitken et al. 2006), improve electronic monitoring systems (Ross 2008; Tschannen et al. 2012), clinical practice algorithms (Bulat et al. 2008), interruption to nurses' activity (Palese et al. 2009; Kosits & Jones 2011; Westbrook et al. 2011), and linking nurses' medicine activity to their general workload (Ampt et al. 2007; Munyisia et al. 2011; Anderson et al. 2012). On the latter activity, observational work reported hospital ward nurses spent 13% of their time dealing with medications but, importantly, these activities were largely requesting, giving, and chasing up medication, and less about discussion medications (Ampt et al. 2007). Similarly, a review of nurses' role in the process of medication management identified training methods for medicines administration as ritualistic and unreflective of the complexity and multi-disciplinary practice of medicines management (Choo et al. 2010). My point here is similar to that made by Bajcar (2006) and the points made earlier about the absence of affective medication discussion - which medicine beliefs exploration can be positioned within.

## 3.2.3 Extent and nature of nurses medication discussion

In section 1.6, it was apparent that limited guidance exists for the specific act of medication discussion. General nursing guidance has a bias approach toward the act of prescribing and the general research guidance on consultation communication, whilst relevant, operates at a broader level than this specific activity. With this in mind, it was not surprising to find limited research on nurses' medication discussion with patients.

Three other issues on the extent and nature of nurses' medication discussion were evident from the identified literature. Firstly, no research was found on the *extent* of nurses' face-to-face medication discussion with patients. By this I mean empirical measurement of discussion topics relevant to medication management. This would appear contrary to the way nurses have long been considered to have great potential to communicate effectively about medicines (World Health Organization 2003) and nurse prescribers are well placed to utilize their additional training in communication, assessment and pharmacology to effectively support medicine-taking. Importantly, not only do nurses require robust pharmacological knowledge but the ability to communicate it (Murphy 2012) as in-depth knowledge

of medicines can influence patients' treatment goals (Tyreman 2010) and enhance or impede the way medicines are managed (Manias 2008).

Secondly, whilst good research has quantified the amount and type of medicines administration undertaken by nurses e.g. (Westbrook et al. 2011), research about the specific *content and nature* of discussion about medicines between nurses and patients has been reported as very limited (Stevenson et al. 2004). This is in stark contrast to research about doctor-patient medicines communication which has mapped common discussion themes and their extent in routine consultations in primary care (Richard & Lussier 2006a; Richard & Lussier 2007). At this point, it is important to review the available research to gauge the type of discussion undertaken by nurses when discussing medicines with patients. This will provide insight as to whether nurses are already exploring patients' medicine beliefs.

A review of literature pertaining to two-way medicines communication between nurses and adult patients identified a number of studies but no specific reviews. However, a systematic review of medicines communication between a range of health care professionals and adult patients did include studies involving nurses. As part of this large, complex and well executed review, Stevenson et al. (2004) summarised the extent of research about nurses' medicines communication with patients from primary research papers published between 1991 and 2000. Of the 116 descriptive studies found, only 4 involved nurses (Lavies et al. 1992; Oates et al. 1994; Altman et al. 2000; Latter et al. 2000) and of the 16 intervention studies found, only 4 involved nurses (Wilder-Smith & Schuler 1992; Hanna 1993; Kelly et al. 1999; Mills et al. 1999). A review of methods used in these studies highlighted that all but two of the descriptive and intervention studies reported by Stevenson et al. (2004) failed to provide a detailed appreciation of the nature of medicine communication in terms of specific topics of discussion and/or the extent of their discussion. The majority of studies were primarily 'outcome focused' and investigated the impact of nurses' communication as a mediator of outcomes relevant to the study topic.

Exceptions to the above were found in the studies by Mills et al. (1999) and Latter et al. (2000), but, the only medicine-related discussion in the former study was about side effects of anti-epileptic drugs and this was simply measured as either present or absent. Latter et al. (2000) reported findings on the nature of medicine discussion from a thematic analysis of observations. This study provides some of the most relevant and in-depth research to support this thesis. Firstly, a literature review identified dimensions, sub-components and constituents of the concept 'medication education' and was followed by a survey of educationalists to

investigate the extent to which patient education skills, pharmacology knowledge and communication skills were components of nurse education curricula (Latter et al. 2001).

These studies confirmed the third issue, that research conducted on the nature of nurses' medication discussion rarely identified affective medication discussion present in consultations, as evidenced by Latter al.'s (2000) case-study phase focused on nurses' contribution to medication education across a range of nursing contexts (including one General Practice-based diabetes clinic). Making comparisons with the key dimensions of medication education identified from the literature review and using a range of methods, including audio-recordings of nurse-patient interactions, this phase revealed nurse-patient medicines discussions were limited to simple information about medicines, e.g. their name, colour, number of, and frequency of administration.

Studies published since the Stevenson et al. (2004) review provided more research on the nature and extent of the medicine discussion with patients. These include two qualitative interview-based studies but they were limited in their detail. Although these reported the content of nurse-patient medicines discussion, they are potentially biased by stakeholders' perceptions about what they thought occurred, but, they do provide a useful comparison for relevant observational studies conducted post-2000. These studies highlighted Australian mental health nurses' perception of always discussing medicine side-effects with patients (Quinn et al. 2012) and Danish multidisciplinary pain centre nurses' perception of always enacting pain control, administration of medication, and problems related to living with chronic pain (Samuelsen & Voigt 2001).

Several studies with an observational component provide yet more assessment of nurses' medicine discussion with patients. Two related studies in the context of nurse telephone support for diabetes medications and glycaemic control identified 'adherence and side-effects' were discussed in 45% of nurse-patient discussions and non-diabetes medications were discussed in 32% of discussions (Piette et al. 2000). Slightly better findings were reported in a repeat study (Piette et al. 2001) in which nurses' discussed adherence and side-effects of hypoglycaemic medications 66% of the time, however, slightly worse findings were found from observations of 85 consultations with 13 diabetes nurses in which only 25% of nurses asked about patient compliance (Abdulhadi et al. 2006). Although this would appear positive, these studies still lacked the detail necessary to unpick the 'adherence and side-effects' discussion beyond the frequency of its occurrence.

Compounding the apparent moderate exploration of adherence issues was the manner in which nurses do so. An observational study of general consultation communication (Labhardt et al. 2009), which included medicines discussion, between nurses and patients used Roter's Interactional Analysis System to analyse consultation observations and reported most of nurses' questions were closed questions (percentage of total utterances: 70.2%). These findings suggest a varied degree of adherence discussion but are inconclusive as to what exactly this discussion specifically involved. In addition, the closed question nature of consultation communication would be unlikely to encourage detailed discussion about patients' attitudes toward their medication.

Fortunately, several studies have provided more detail on the content of nurses' medicine discussion with patients. In hospital settings, findings reported nurses' provided information about the medication in 53% of cases (Duxbury et al. 2010) and at the time of the drug round, the most common observed initial question related to the need for the medication (42.9%) (Schafheutle et al. 2004). However, on very few occasions did nurses enquire if patients were experiencing problems with taking medication (17%) and enquiries regarding the patient's general health (35%) were also low (Duxbury et al. 2010). Similar findings were found by Latter et al. (2005) as the most frequently observed nurse prescribing communication competency was giving patients 'clear instructions on how to take their medicine' (89%) and reported that patients' general beliefs and expectations were only 'listened to and understood' in 64% of consultations. The only contrary finding was reported by Courtenay et al. (2009) which reported consultation assessors agreed that all participating nurses 'listened and understood patient general beliefs and expectations' and 'dealt sensitively with patient emotions and concerns'. Overall, findings from observational studies suggest limited discussion about patients' general beliefs and expectations and thus affective discussion about patients' medicine beliefs was likely to be limited.

## 3.2.4 Engaging in affective discussion

Although few studies identified nurses' engagement in affective *medication* discussion, insights on doing so were gleaned from studies focused on affective discussion on medication work generally. A number of studies identified in this review investigated affective medication discussion in the context of patient involvement discussion. Unfortunately, the story of this body of literature was one of problems and confusion about what exactly professionals were being asked to achieve and relating it to the realities of practice. This is best summarised through the findings of two systematic reviews of health care professionals' perceived

barriers and facilitators whilst implementing shared decision-making (SDM) (Gravel et al., 2006; Legare et al. 2008). These reviews reported several barriers to nurses enacting patient involvement in discussion, including a lack of awareness of the nature of this type of discussion, not agreeing with the necessity of this type of discussion, time pressures and a lack of self-efficacy. Although studies have yet to investigate barriers and facilitators to affective medication discussion, it is likely these issues will be relevant in that specific contact.

The barriers identified above raised a second issue, that being the ability and competency of nurses to engage in affective medication discussion. This was best evidenced in a study by Bolster & Manias (2010) whereby they reported only a third of nurses highlighted the importance of involving patients in medication discussion and decisions. Moreover, most nurses wanted to keep patients informed but this involved administrative issues only and not exploring concerns or attitudes. Most nurses did not explain why a medication was needed, and nurses reported having to 'get to know' their patients as a crucial precursor to discussing patients' needs and preferences.

The plethora of studies to support general patient involvement discussion by professionals suggests this type of work is not only promoted, but fundamentally *new work*. In the case of affective medication discussion, i.e. exploring patients' medication beliefs, this is certainly the case. However, this is not to say nurses cannot effectively engage in affective medication discussion. Nurses are well placed to play an influential role and drive evidence-based clinical practice and medication adherence. Nurses have been referred to as 'natural' or 'primary' advocates in practice-improvement efforts because they are multidisciplinary team members and strategically positioned to observe and elicit critical information from their patients (Moore & Crom, 2006). Although, studies have identified shortcomings in nurses ability to solicit patients' concerns in primary care consultations (Weiss et al. 2013) so uncertainty would appear to exist regarding the ability and willingness of nurses to engage in this type of activity.

In two rare studies in the diabetes context, Maissi et al. (2011) determined that nurses can be trained to deliver advanced patient discussion techniques such as motivational interviewing and cognitive behavioural therapy. Furthermore, Kettunen et al. (2006) reported nurses could partially engage in complex lifestyle counselling for patients with type 2 diabetes that included 'change talk', however, they also reported nurses required training to identify and encourage patients' change talk and to communicate flexibly according to patients' values. It would appear that affective discussion can be positioned on the professional boundary

between nursing and psychology. This idea is supported by Peters et al. (2011) as they identified significant tensions when nurses attempted to deliver psychological interventions for patients with chronic fatigue syndrome in a primary care trial.

It seems important to recognise affective medication discussion as new work for nurses, as professionals have been observed to avoid or give up the management of non-adherence altogether due to the complexities of the situation (Brand et al. 2013). With this recognition comes a third issue, understanding the challenges of this new work. Cribb (2011) has identified patient involvement in clinical settings is 'hard to do' (Cribb, 2011: 11) and attempts to enact new work, such as concordance or shared decision making, will not succeed unless the practical challenges are explicitly addressed (Cribb, 2011: 5). To address the challenges of the new work of medication beliefs exploration, as a form of affective medication discuss, barriers to this work need to be understood. This was a key rationale for this thesis. Until barriers have been identified, nurses' medication discussion cannot achieve its maximum potential and promote optimal patient adherence behaviour.

## 3.2.5 Patients' perception of face-to-face medication discussion with nurses

Several decades of research has focused on patients' participation in clinical decision making, to include decisions about treatments and how they're used, and recognised the right of patients to be informed about and participate in these decisions (Kassirer 1994; Towle & Godolphin 1999; Stevenson et al. 2000). However, the vast majority of primary research on involving patients, e.g. through interventions to promote shared decision making or concordance, has focused on doctor-patient interactions. This was the first clear message from the studies identified in this part of the review and stood in stark contrast to reports of the potential of nurses to significantly promote patient involvement through e.g. shared decision-making (Gravel et al. 2006; Chewning & Wiederholt 2003). This major gap in the literature may be due to the difficulty of eliciting patient agendas (Carrick et al. 2004) and that failure to do so may have perpetuated patient suboptimal behaviour with their prescribed medication, as seen in Barry et al. (2000) whereby patients frequently altered or abandoned it.

The second clear message was patients do adopt attitudinal positions about their medication. An important review on the broad topic of medicine-taking reported some studies classified their patients as 'rejecters' or 'accepters' of medication advice and treatment (Pound et al. 2005). However, this type of clinician-

determined categorisation does not help an investigation of the content or nature of patients' perceptions about their medication discussion *with nurses*. Such detail has been reported in a review of doctor-patient medication discussion (Cox et al. 2004), in which they report a number of important findings on patients' views, preferences, involvement, and degree of asking questions in relation to medicines discussion. But the attitudinal positions of patients have yet to be explored in the context of nurses' medication discussion.

With the above issues in mind, the large role nurses play in diabetes care, and the expanding number of people with Type 2 diabetes, it is perhaps understandable to find systematic reviewers suggesting the lack of success in adherence research is due to neglect of patients' perspectives (Vermeire 2001). This thesis sought to explore those perspectives as part of a rounded approach to investigating nurses' medication discussion.

## 3.3 Conclusions

This chapter had two aims. Firstly, to position medication beliefs exploration within the wider context of medicine-related research, and secondly, to review available research on nurses' medicine-related work.

The early sections of this chapter positioned medication beliefs exploration within the wider context of medicine-related research and highlighted some problems with current nursing guidance on medication activity, namely the predominance of an administrative agenda toward medication communication. But broad guidance available from the research literature on patient involvement highlighted the potential of health professionals' communication to have a positive impact on patients' adherence behaviour.

The review of nurses' medicine work highlighted important shortcomings in the current literature. Firstly, the majority of nurse-related medication research has focused on safety and administration issues and overlooked medication discussion as a potential source of problems or solutions despite broad initiatives such as shared decision-making and concordance.

Secondly, no research was identified on the quantifiable extent of nurses' face-to-face medication discussion with patients. This may be linked to the apparent lack of guidance for the specific act of medication discussion by nurses but may also be due to the general focus on doctor-patient medication communication. Also, very little research was found on the specific content and nature of discussion about medicines between nurses and patients.

Thirdly, of the few studies that investigated the nature of nurses' medication discussion, the discussion was largely administrative and rarely reported affective medication discussion as present in consultations.

Fourth, affective medication discussion would appear to be new work for nurses and as new work it will have its own set of challenges. Therefore, attempts to enact this new skill are vulnerable to the ongoing and broad problem of moving research evidence into practice. To appropriately address these challenges, research to identify barriers and facilitators to this work are needed.

Fifth, very limited research on patients' perceptions of medication discussion with nurses had been conducted despite the knowledge, as demonstrated in chapter 1, that patients' perceptions about their medications are important to adherence behaviour. There was a clear need for more research about patients' perceptions of their medication discussions with their nurses.

## 3.4 Implications for this thesis

In the context of medicine activity, it is clear that nurses generally have a central and relatively autonomous role and their potential to play a leading role in promoting affective medicines discussion was high. Nurses are well placed to explore psycho-social characteristics of patients' medicines discussion, more specifically patients' medicines beliefs, as avoiding these topics could lead to uncoordinated support, sub-optimal use of medicines, and nurses' perception of confusing behaviour from patients. These reasons support a focus on nurses as agents of exploration in the context of patients' medicines beliefs.

From a nursing perspective, it is important to recognise that discussing, specifically, patients' attitudes and beliefs about medicines is a different form of work than checking, charting or administering medicines, or in the case of nurse prescribers the act of appropriate prescribing. Therefore, objectively measuring if nurses actually engage in this type of activity should be of high importance. In addition, investigating the experience and challenges of nurses' exploration attempts should be conducted with a broad lens in order to capture potential barriers and facilitating factors of this new activity.

From the patients perspective, many wish to have their concerns heard and their perceptions about having their beliefs about medicines explored would provide important insight into how nurses' engage them in this activity. Whilst the experience of medicine beliefs exploration will have different start points and goals for nurses and patients, investigating both their experiences should bring these differences into focus, highlight how both experiences exist together, and offer the opportunity to triangulate findings from several viewpoints.

The conclusions of this review support the rationale for the study and the development of the research questions. Namely, the first, second and third shortcomings led to the first research question 'To what extent do nurse prescribers explore diabetes patients' medicine beliefs in routine practice settings?' The fourth shortcoming led to the second research question 'What are the barriers and facilitators to nurse prescribers' exploration of patients' medicine beliefs?' The fifth shortcoming led to the third research question 'How was consultation discussion perceived by diabetes patients as a result of nurse prescribers' exploration activities?'

The rationale for these research questions was supported by the findings from the literature review in chapter 2. That review concluded medicine beliefs were a significant antecedent of medicines adherence and thus likely to affect diabetes outcomes.

## 4. Methods

## 4.1 Introduction

This chapter provides a discussion and justification of the methodology used for this thesis. A mixed methods concurrent triangulation design was considered the most appropriate design to address the overall aim of this thesis. A discussion about quantitative and qualitative paradigms, issues regarding the use of mixed methods designs, and decisions made for this thesis are presented in this chapter.

Previous chapters have outlined the clinical problem of non-adherence to medication, the importance of patients' medicine beliefs as a statistically significant associate of non-adherence, the shortcomings of nurses' current practice when discussing medication and relevant contextual issues of diabetes care. Chapters 1, 2 and 3 provided important messages and rationale for the study. The research questions in this thesis were developed from those chapters.

The overall aim of the research reported in this thesis was to understand the experience of, and the influential factors upon, the exploration of patients' medication beliefs by nurse prescribers in practice settings.

The research questions for this thesis were:

- 1. To what extent do nurse prescribers explore diabetes patients' medicine beliefs in routine practice settings?
- 2. What are the barriers and facilitators to nurse prescribers' exploration of patients' medicine beliefs?
- 3. How was consultation discussion perceived by diabetes patients as a result of nurse prescribers' exploration activities?

These research questions were translated into objectives (see Figure 4.1):

- 1. To quantitatively observe and measure nurse prescribers' exploration of diabetes patients' medicine beliefs in routine consultations.
- 2. To qualitatively investigate the barriers and facilitators to nurse prescribers' exploration of patients' medicine beliefs.
- 3. To qualitatively investigate diabetes patients' perceptions of consultation discussion having participated in consultations whereby nurse prescribers' explored diabetes patients' medicine beliefs.

A range of methods were required to address these research questions and integrate their findings into a conceptual model of medication beliefs exploration. The need to answer three different types of question, which contributed to answering the overall thesis question, was an important rationale for the use of a mixed-method approach. This chapter presents the methodological outlook of the study, justifies this approach, and outlines the quantitative and qualitative components of the study.

## 4.2 Background

The literature reviews guided the development of the research questions and the discussion in this chapter guided decisions on methodology. To understand the methodological decisions made in this thesis, several issues were reviewed. Firstly, the nature and value of mixed methods research and if it would serve the aim of the thesis. Secondly, as the area of mixed methods has grown in recent years, what form of mixed methods research might this thesis take. Thirdly, how would mixed methods be used in a thesis with these research questions. Fourth, what are the sampling issues for this thesis, and finally, how would each research question be researched through three separate study components.

## 4.2.1 Defining mixed methods research

Before deciding if mixed methods should be adopted for this thesis, it was important to review literature on the definition and position of mixed methods in the wider methodological literature.

The definition of 'mixed methods research' has been an important debate amongst the mixed methods community. To understand the approach taken in this thesis, it was important to determine how mixed methods compare against other research methodologies. An early definition stated a mixed method study as:

"Combining qualitative and quantitative approaches into the research methodology of a single study or multi-phased study" (Tashakkori & Teddlie 1998) (p.17).

Others have pursued tighter definitions, weary of the broad term 'approaches' and specify the need for qualitative and quantitative 'methods' within a single study to justify its mixed status (Greene et al. 1989). Moreover, others have stated a mixed methods study should involve integration of the findings, rather than just collection and separate analysis of the qualitative and quantitative aspects of the study (Creswell et al. 2004). A definition by Tashakkori and Creswell (Tashakkori & Creswell 2007) (p4) has done much to address the ambiguity of previous definitions and defined mixed methods research as:

"Research in which the investigator collects and analyses data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or program of inquiry."

Mixed methods inquiry is not new; the idea of combining qualitative and quantitative methods in one study has been seen in studies from the 1950s onwards (Giddings & Grant 2006). They have been used in evaluation research (Patton 1981) to provide a legitimisation process and to provide enhanced confidence in the conclusions (Denzin 1978). A mixed methods way of thinking is an orientation toward social inquiry that:

"Actively invites us to participate in dialogue about multiple ways of seeing and hearing, multiple ways of making sense of the social world, and multiple standpoints on what is important and to be valued and cherished." (Greene 2008).

In the world of health care, some consider mixed methods research to be the 'foundation for primary care research' (Borkan 2004) (p4) and vital to address the complexities of delivering and evaluating health care services. This was reflected in a recent evaluation of Department of Health commissioned studies (by recognised funding bodies e.g. Service Delivery and Organisation; Health Technology Assessment), between 1994 and 2004, who reported that one-fifth were mixed methods studies (O'Cathain et al. 2007). Of the 75 studies identified by O'Cathain et al., most gave no justification for using mixed methods techniques and where they did it was on pragmatic and not ideological grounds, most had a quantitative priority, and used them for complementary purposes.

Although mixed methods research has been around for a long time, recent developments have focused on much more than merely defining mixed methods research. Questions have been raised about whether mixed methods can include mixing two methods from the same paradigm, e.g. interviews and focus groups (Morse 2003); design typologies and nomenclature (Creswell & Plano Clark 2007); and how to draw inferences and the logistics of teaching and writing about mixed methods (Teddlie & Tashakkori 2009). Numerous books, articles and the emergence of a dedicated peer-review journal are indicators that mixed methods research is an evolving approach and has seen a fast pace of development in the last decade. In a recent editorial, a leading mixed methodologist addressed the question of 'whether mixed methods research was there yet', stating the destination is self-identity, and the community is thriving (Tashakkori 2009).

## 4.2.2 Paradigmatic approaches in mixed methods research

## 4.2.2.1 Approaches to social inquiry

The research question in this thesis required the use of different methods, which would likely draw questions on how to approach the data those methods provided. This section considered the historical positions of quantitative and qualitative research activity. These issues led to the decisions and conclusions made in section 4.3.

Historically, research methodology can be summarised by three distinct movements which have developed their own methods of inquiry, data analysis and nomenclature (Tashakkori & Teddlie 2003). These movements are often described as being divided in their approach, or in their paradigmatic basis, for developing and conducting research. A paradigm has been defined as:

"A worldview or perspective that guides the investigation; not only in the choice of method but in ontologically and epistemologically important ways." (Guba & Lincoln 1994) (p105)

The quantitative movement is largely characterised by the positivist paradigm and value is placed on accurate measurement of research variables and control of confounding factors. The qualitative movement is predominantly guided by social constructionism and characterised by interpretive understanding of social phenomenon. Conflict generated between these movements over many years has led to the culmination of a third recognisable movement: mixed methods research (Gilbert 2006).

The conflict between the first two movements has historically been known as the 'paradigm wars' (Howe 1988). An outcome of this war was the notion of the 'incompatibility thesis' which refers to the perceived inability to successfully integrate techniques from either research movements (Lincoln & Guba 1985). A researcher advocating a mix of techniques could be viewed as unscientific or departing from the principles of one or other paradigms. However, some have seen this conflict as inherently destructive to the advancement of the social and behavioural sciences (Onwuegbuzie & Leech 2005). The polarisation of the quantitative and qualitative movements has led to researchers restricting themselves, or via limitations in the educational provision for methodology, to parsimonious access to the movement contrary to the preference of their research environment. Some researchers recommend that students should be encouraged in both movements to become 'bi-researchers' rather than 'uni-researchers'

(Onwuegbuzie 2000; Onwuegbuzie & Leech 2005). Moreover, they recommend students become 'pragmatist researchers' and encourage institutions to re-design their methodology courses to eliminate the false dichotomy that exists between the two movements (Onwuegbuzie & Teddlie 2003).

Mixed methods research has emerged from the paradigm debate (Gilbert 2006) as the third recognisable movement whereby both numerical and textual data are equally valued and the supposition that they cannot be successfully integrated has been dismissed (Creswell et al. 2004). A critical review (Sale et al. 2002) provides several reasons for the integration of different paradigms and their methods: firstly, paradigms can be combined because they share the goal of understanding the world in which we live (Hasse & Myers 1988), secondly, these paradigms are thought to be compatible because they share the tenets of theory-ladenness of facts, fallibility of knowledge, in determination of theory by fact, and a valueladened inquiry process. They are also united by a common goal of disseminating knowledge for practical use, and a shared commitment for rigour, conscientiousness, and critique in the research process (Reichardt & Rallis 1994). In response to the acceptance of the integration of quantitative and qualitative methods, there has been a development of philosophical positions, such as pragmatism, the complementary strengths thesis and dialectical thesis (Howe 1988). Although the emergence of mixed methods research as an approach with its own principles, research designs, analysis techniques and nomenclature is relatively recent, review papers have demonstrated that many studies over a surprisingly wide timescale had, knowingly or unknowingly, employed mixed methods within their design (Greene et al. 1989; O'Cathain et al. 2007).

## 4.2.2.2 Approaches to mixed methods inquiry

Within the mixed methods community, there were differences in approach to research which required thought to determine how best to operationalise the research questions in this thesis. This review supported the decisions and conclusions made in section 4.3.

Theoretical construct contrast tables are often used to present the different perspectives of paradigmatic stances and assumptions. Lincoln & Guba (1985) compared constructivist and positivist assumptions on five dimensions of contrast: epistemology (assumptions about the value of types of knowledge), ontology (assumptions about the nature of reality), axiology (the role of values in inquiry), the possibility of causal linkages, and the possibility of generalisability. Over the last 20 years, contrast tables have evolved to include four paradigms: positivism; realism; critical theory; and constructivism (Guba & Lincoln 1994), and then five:

'participatory/cooperative' being the additional paradigm (Guba & Lincoln 2005). The result of these contrast tables has been, particularly in the beginning, to dichotomize paradigmatic assumptions, e.g. that reality is multiple, constructed and holistic (constructivism ontology) or reality is single, tangible and fragmentable (positivist ontology). Paradigmatic approaches in mixed methods research reject the either-or choice of subjective or objective inquiry, inductive or deductive logic, are inclusive of the use and integration of confirmatory and exploratory methods, and view paradigmatic dimensions on a single QUAN-MM-QUAL continuum (Teddlie & Tashakkori 2009).

A recent review identified several paradigmatic stances within the community of mixed methods researchers (Greene 2008). As mentioned in the previous section, a purist stance of incompatibility and viewing each paradigm as a coherent and unalterable whole (Lincoln & Guba, 1985) is well known. In the context of mixed methodology, some researchers advocate a complementary strengths stance (Brewer & Hunter 1989; Morse 2003), believing that qualitative and quantitative approaches are not incommensurable but they differ in important ways and should be preserved to maintain methodological integrity. Other researchers promote a dialectic stance (Greene & Caracelli 1997) and engage dialogically with the differences between paradigms to generate new insights for all approaches. Another group of researchers have taken an a-paradigmatic stance (Reichardt & Cook 1979; Patton 2002) indicating that paradigms help to guide thinking, but not the practice of conducting research. Researchers adopting this stance use the context and problem under study as predominate guides to practice. To date, most mixed methods researchers adopt an alternative paradigm stance (Tashakkori & Teddlie 2003; Johnson & Onwuegbuzie 2004). This stance advocates that historical differences among paradigms are reconciled through new and emerging paradigms. So far, three paradigms have been proposed as an appropriate basis for mixed methods research: several variants of realism (Hammersley 1992), the transformative-emancipatory paradigm (Mertens 2003), and pragmatism (Tashakkori & Teddlie 1998). The first two have been discussed but are rarely used in practice (Feilzer 2010) and the latter is most commonly associated with mixed methods research (Tashakkori & Teddlie, 2009). The reasons for this imbalance are currently unknown, but it may be related to the 'problem-focused' approach of health researchers and pragmatism as a paradigm. Pragmatism offers an alternative worldview to positivism and constructivism, and the discussion below helps to inform the theoretical position taken in this thesis.

## 4.2.2.3 Pragmatism

Importantly, it is not my intention to discuss the development of pragmatism as a philosophical position as the history of this movement is vast and been considered 'muddled' (Rorty, 1991). Instead, my aim here is to introduce the area and in the next section discuss how pragmatism, along with mixed methods overall, are relevant to this thesis.

The philosophical position of pragmatism originated in the late 19th century and from the American philosophers: Peirce, James, Dewey, Mead & Bentley (Tashakkori & Teddlie 2003). These philosophers universally agreed that a single scientific method was inadequate to assess the 'real world' and that a multitude of methods would be required to access the 'truth' of a situation or phenomenon (Wolfe 1999). In addition, the context of societal division during late 19th century America helped to define pragmatism further:

"...as a philosophy rooted in common sense and dedicated to the transformation of culture, to the resolution of conflicts that divide us." (Sleeper 1986)

Many philosophies are compared on the levels of ontology, epistemology, axiology, methodology, logic and causality (Tashakkori & Teddlie, 1998). In terms of ontology, pragmatists are accepting of one external reality but recognise that a choice of explanations may exist to produce or explain outcomes. From an epistemological point of view, pragmatists accept that it is possible to have knowledge constructed objectively and subjectively, that the knower and the known are neither exclusively separate (positivist thinking) or inseparable (constructivist thinking). Pragmatists are considered aware of, but not concerned by, the value-ladenness of research inquiry. They are more concerned with the operationalisation of the research in relation to relevant outcomes. In addition, both qualitative and quantitative methods are used, as are inductive and deductive logic to explain, explore or confirm findings. On the issue of causality, pragmatists traditionally recognise the importance of causal relationships but accept that is may never be possible to completely identify the exact causal factors of a situation.

Appealing to a pragmatic philosophical perspective, Onwuegbuzie & Teddlie (Onwuegbuzie & Teddlie 2003) argue that no incompatibility between quantitative and qualitative methods exists at either the level of practice or that of epistemology. Therefore, there are no reasons for researchers to fear forging ahead with 'what works' and taking a needs-based approach to selecting methods

and approaches (Johnson & Onwuegbuzie 2004). This is a refreshing idea for many researchers and this methodological liberalism is a step away from the restrictions of traditional paradigmatic processes. Key tenets of the pragmatic approach are that no single method should restrict the inquiry of social phenomena (Peirce 1966) and that the research question is considered more important than the method used (Tashakkori & Teddlie, 2003).

To date, pragmatism is the philosophical orientation most associated with mixed methods research (Teddlie & Tashakkori, 2009) and has been recently defined as:

"A deconstructive paradigm that debunks concepts such as 'truth' and 'reality' and focuses instead on 'what works' as the truth regarding the research questions under investigation." (Tashakkori & Teddlie, 2003, p713)

Pragmatism rejects the either/or choices associated with the paradigm wars, advocates the use of mixed methods in research, and acknowledges that the values of the researcher play a large role in the interpretation of the results (Tashakkori & Teddlie, 2003). This was vital to incorporate the findings from three different research questions to address the overall thesis question.

## 4.3 The use of mixed methods for this study

This review of mixed methods and the pragmatist approach guided decisions about the use of mixed methods in this thesis. It was apparent it represented a relevant body of literature and would operationalise the thesis aim and research questions developed from the literature reviews. A pragmatic mixed methods approach was chosen for this thesis for three reasons.

Firstly, it was relevant to the context of diabetes care. The reality of diabetes care is complex, involving a range of different health professionals, targets for lifestyle and health outcomes, medication management and significant life-long self-management skills from patients. Attempting to investigate the specific act of medication beliefs exploration by nurses, whilst a number of other care goals are being sought, would not be possible through a singular method approach. To address the overall research aim, it was considered wise to not only objectively measure beliefs exploration but to qualitatively investigate the phenomenon to understand the challenges and experience of this specific activity. Once the extent, challenges and experience were determined, it would be possible to develop a rounded appreciation of the reality of medication beliefs exploration in the diabetes context. Furthermore, pragmatic mixed method researchers develop and

use knowledge constructed objectively and subjectively, and use inductive and deductive logic to explain, explore or confirm findings. Such activity is arguably analogous to the work of diabetes nurses as they collate biometric measures and self-reported information from diabetes patients, further supporting the methodological approach in this thesis.

Secondly, a pragmatic approach welcomed the integration of findings for the development of inferences beyond the component parts of the study. As stated by Saldana (2013, p73), 'sometimes words say it best, sometimes numbers do, and sometimes both can work in concert to compose a richer answer'. A central element of mixed methods research is the process of integrating findings from different methods. This area has been subject to a great deal of discussion (Teddlie & Tashakkori, 2009) but most would agree the ability to develop metainferences from combined findings is a key rationale for using mixed methods. As the research questions required different methods to address a broad aim, it was relevant to develop plans for the integration of findings. Furthermore, such activity has the added benefit of permitting the development of a conceptual model of a phenomenon under study. Developing a model also allows the creation of hypotheses for further study. This is particularly relevant for pragmatists as they are interested in understanding not only the reality of situations, but the 'utility' of the knowledge identified. Knowing what the knowledge can explain and be used for is considered equally important, hence the pragmatic approach in this thesis.

Thirdly, a pragmatic mixed methods approach embraces uncertainty. Although many state mixed methods provide the best opportunity for a rounded appreciation of a phenomenon in comparison to single method studies (Tashakkori & Teddlie 2003; Creswell & Plano Clark 2007; O'Cathain et al. 2007), adopting a pragmatic approach is a commitment to uncertainty and an acknowledgement that any knowledge identified through research is relative and not absolute (Feilzer 2010). As this thesis deals with the complex area of patients' beliefs and patients' interaction with health professionals, being comfortable with uncertainty was relevant and appropriate. Furthermore, the research questions developed were exploratory and it was important to recognise the likelihood that causal relationships would not be established.

To investigate the experience of patients' medicine beliefs exploration, a mixed method pragmatic approach was required. Firstly, it was important to establish an objective measure of medicine beliefs exploration so the extent of nurse prescribers' activity would be known and reliance on self-report could be avoided. This was due to the frequently reported weaknesses of self-reported data (Nisbett

& Ross 1980; Fiske & Taylor 1991) and more specifically research indicating nurses' erroneous estimation of patient-reported adherence (Mason et al. 1995) and their own behaviour during routine consultation activity (Lauder et al. 2008). Secondly, to understand the influential factors acting upon nurse prescribers' attempts to explore patients' medicine beliefs, a qualitative semi-structured interview method was required to gather as rich and diverse range of issues as possible. This method was also undertaken to address the third objective and explore patients' perceptions of consultation discussion having participated in consultations whereby nurse prescribers' attempted to explore their medicine beliefs.

In choosing a mixed methods approach to address these objectives, a review by Greene & Caracelli (1997) provided guidance. They highlighted seven key ways in which the purpose of mixed methods research can be used: for triangulation (to converge findings from different elements), complementarity (one dominant method is supported by another), expansion (different methods are used for different components and discussed side-by-side), iterative (findings generation through a dynamic process with different methods), embedded (one method is located within another), holistic (simultaneous integration of methods throughout the study), and transformative (mixing methods to capture differing value commitments).

Furthermore, broad inquiry designs and strategies for combining qualitative and quantitative methods have been developed by a number of mixed methodologists (Morse 2003; Teddlie & Tashakkori 2006; Creswell & Plano Clark 2007). Two common themes across all design variations include the use of methods either concurrently or sequentially and their relative importance in a proposed study. Methods may be used concurrently in 'parallel mixed designs' (Teddlie & Tashakkori, 2009) whereby the qualitative and quantitative strands occur at the same time. This is in contrast to 'sequential mixed designs' (Teddlie & Tashakkori, 2009) whereby the different strands occur in chronological order.

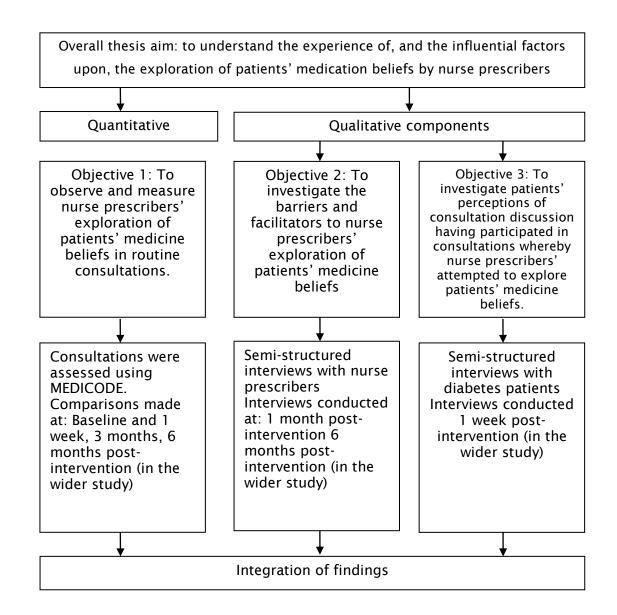
Based on this guidance, Figure 4.1 describes the different components of the study. Collectively, these were used for the purpose of convergence (Greene and Caracelli, 1997). Study components were enacted concurrently and their independent inferences were brought together in the discussion chapter in the form of meta-inferences. Thus, the study adopted a 'concurrent triangulation design' (Tashakkori and Teddlie 2003). Importantly, although the name of this design would imply the well-known method of 'checking' (one method checking

another) through triangulation, the purpose of this design in the context of this thesis was to build up a rounded picture of the activity under study.

## 4.3.1 Criteria for good mixed methods research

As with other paradigms, mixed methods researchers have sought to determine what good mixed methods research would involve. A widely cited checklist of criteria by Cresewell et al. (2004) has been used to guide researchers in their enactment of mixed methods. The five criteria of this checklist include, firstly, the need to provide a thorough rationale clearly identifying and justifying the reasons for employing a mixed methods design. Secondly, to provide a clear explanation and justification of data collection and analytical procedures employed within each approach. Thirdly, to state the priority given to the qualitative and quantitative elements of the study, fourth, to state if sequencing of the element are important in the study. Finally, to make clear the nature and timing at which the research findings are integrated. For this thesis, the first, third, fourth and fifth criteria were addressed in the section above. The second criterion has been address in detail for the quantitative component of the study in section 4.5 and for the qualitative component in section 4.6.

Figure 4.1 Concurrent triangulation design



## 4.4 Sampling strategy

#### 4.4.1 Introduction

Importantly, the mechanisms of participant identification, sampling and recruitment were identical for both the wider study and this thesis. As the wider study was dominant in this relationship and had its own timeframe, many decisions were already made and could not be altered for this thesis.

Based on the traditional categorisation of either probabilistic or purposive sampling methods, the sampling methods were purposive in nature. Purposive sampling techniques are most frequently used in qualitative studies and involve selecting e.g. individuals, groups of individuals, or institutions based on specific purposes associated with answering a research question and/or gathering data that cannot be obtained as well from other options (Maxwell & Loomis 2003). Establishing representativeness is a common goal of purposive sampling (Miles & Huberman 1994) and the primary goal of the sampling method for the wider study and this thesis. A representative range of diabetes care and nursing contexts were sought to include all possible types of medicine discussion.

Importantly, the sampling process needed to strike a balance between the sampling needs of the three study components/objectives. It was important to find the right balance to recruit enough nurses to satisfy the nurse-interview phase (objective 2), obtain a high number of consultation observations for the quantitative analysis of medication communication/medication beliefs (objective 1) and ensure enough diabetes patients could be interviewed to address objective 3. The latter was particularly dependent on the success of gathering consultation recordings as these would be a finite amount. It was only appropriate to interview diabetes patients who had actually discussed their medicine beliefs as part of the purposeful sample of consultation recordings.

## 4.4.2 Scoping exercise

The first stage was to identify a sampling frame to recruit an appropriate cohort of nurse prescribers who saw diabetes patients and through their work allow the three research questions to be addressed. For the wider study and this thesis, a scoping exercise was undertaken. Sampling frames for purposive samples have been defined as 'a resource from which you can select your smaller sample' (Mason 2002). The scoping exercise targeted Strategic Health Authority (SHA) Non-Medical Prescribing Leads (NMPL). These individuals were part of the ten SHAs

across England and have a national view of the non-medical prescribing initiative. They have links to local leads of prescribing services in NHS Trusts and the nurses themselves. The aim was to identify the locations of nurse prescribers who were regularly involved in the care of people with diabetes. Having identified the NMPLs from publically available information on the internet, letters of invitation addressed to nurse prescribers were sent via the NMPLs (see Appendix 3 for ethics committee approved nurse-related recruitment documents). After the researcher (AS) received expressions of interest from individual nurse prescribers, the process of local governance approval was sought. After an expression of interest, a letter of invitation and explanation was also sent to the manager of each nurse prescriber, in the knowledge that every nurse would require permission to attend the intervention workshops.

## 4.4.3 Sample of nurse prescribers

As highlighted in chapter 1, nursing care for diabetes can be delivered by different types of nurses. Therefore, a purposive sample of nurse prescribers who prescribe frequently for people with diabetes were invited to participate. A variety of nurse prescribers were sought to provide a representative range of different diabetes service delivery models. The types of nursing background sought were diabetes nurse specialists, practice nurses and community matrons.

Inclusion criteria for nurse prescribers:

- -A qualified nurse prescriber working within a clinical setting
- -Regularly seeing people with diabetes
- -Regularly engaging people with diabetes in medicine-taking conversation
- -Willing to participate in the wider study intervention and its process of evaluation

All nurse prescribers were aware, prior to the study, that consent to participate in the intervention workshops would also involve participation in its evaluation. Participation involved two interviews each about a broad range of issues and gathering a number of consultation audio-recordings (see Figure 4.2). Importantly, the nurse prescribers participating in the wider intervention were a finite population and recruitment beyond the start of the intervention would not be possible, therefore it was prudent to involve all nurse prescribers in the semi-structured interviews. Nurse prescribers retained the right to withdrawal at any time, from any part of the study and without providing a reason for withdrawal.

Based on the ability to answer the research questions of the wider study and gain a necessary level of data saturation (Pope et al. 2000), the number of nurse prescribers required for the study was estimated at sixteen. It was expected that this number would account for the range of treatment contexts in which people with diabetes are seen and for an adequate range of medicines taken as part of routine diabetes management. Importantly, for logistical reasons of providing three cohorts of small group workshops as part of the wider intervention study, a maximum of twenty nurse prescribers were sought. This was an important restricting factor upon the wider study and this thesis.

The potential number of participating nurse prescribers was likely to be between 16 and 20. Therefore, between 32 and 40 interviews were expected to take place. Deciding how many interviews is enough is a perennial question in qualitative research. Ideally, the goal should be depth and richness of the data obtained (Patton 2002) to achieve data saturation and not numerical superiority (Bryman 2012). Interestingly, however, some authors have recommended numerical sampling levels to graduate students. One author recommended a sample between 12 and 60 participants, with 30 being the mean (Adler & Adler 2012) and another indicated the minimum number of interviews needs to be between twenty and thirty for an interview-based qualitative study to be published (Warren 2002). A study of doctoral thesis abstracts relating to interview-based qualitative studies in Great Britain and Ireland (Mason 2010) found the range was 1 to 95 with the mean 31 and the median 28. Recent thinking has indicated a medium size sample of approximately 30 interviews offers the advantage of penetrating beyond a very small number of people without imposing the hardship of endless data gathering, especially when researchers are faced with time constraints or other pressures upon sampling (Baker & Edwards 2012). In conclusion, the sampling decisions for the wider study and this thesis were considered appropriate for the needs of the research questions.

## 4.4.4 Sample of diabetes patients

The diabetes patients were sampled from the nurses recruited to the study. The aim of understanding diabetes patients' experience of having their medicine beliefs explored was one of the original aspects of this thesis. Importantly, they had to be involved in an audio-recorded consultation with one of the participating nurse prescribers so it could be reasonably certain that medicine beliefs had indeed been explored. The same issues of saturation and quantity outlined above applied for the patient interviews, however, it is important to point out the patient population were a finite population and no ability to recruit beyond the

intervention data collection time-points was possible. This was a natural limitation of the design.

Inclusion criteria for diabetes patients:

- -People with Type 1 and/or Type 2 diabetes aged 18 years old and above.
- An assessment of medicine management was likely to be required, i.e. (a) a new prescription for a diabetes-related medicine or (b) a change to currently prescribed diabetes-related medicines.
- -No existing or pending diagnosis of mental incapacity (e.g. clinical depression) linked to the diabetes patient.
- -English as the first language of the diabetes patient.
- -Was taking part in a post-intervention consultation with a participating nurse prescriber.

Nurse prescribers were provided with patient invitation packs which they posted to patients prior to seeing them at their scheduled appointment (see Appendix 4 for ethics committee approved patient-related recruitment documents). Nurse prescribers were responsible for posting the invitation packs to patients who met the inclusion criteria. On the day of the appointment, the patient chose to have their consultation recorded, and if they did, the patient was given a second opportunity afterwards to withdraw from the study if the discussion within the appointment aroused concerns. Patients who gave consent on the day of their appointment were contacted by the researcher within one week to discuss the study and obtain full consent.

A consecutive sample of diabetic patients (and thus audio-recorded consultation observations), one week after they had consented to take part in a consultation recording with their nurse prescriber, was conducted (see Figure 4.2). Importantly, these were all different patients, individuals were not invited to participate in more than one audio-recording.

From the pool of diabetes patients who had participated in an audio-recording, patients were invited to be interviewed about their experience of medicine beliefs exploration by nurses. To obtain clear perceptions of their audio-recorded consultation, it was important to interview patients as soon as possible after their recorded consultation. Those who were not contactable within one week were excluded. A consecutive sample of diabetes patients invited to be interviewed was

undertaken. More information on data collection and analysis is provided in section 4.7.

## 4.4.5 Sample of consultation observations

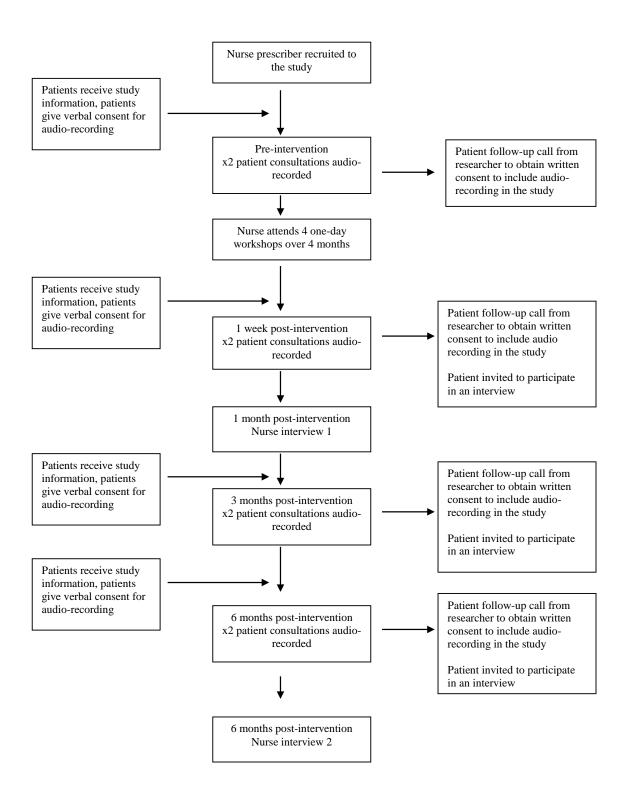
Although the number and type of nurses and patients sampled was purposive, the number of consultation observations each nurse prescriber was required to sample was probabilistic. This was due to decisions about the method of quantitatively measuring the extent of medicine beliefs discussion to address research question 1.

The number of audio-recordings required was determined by a probabilistic method in order to use MEDICODE (Richard & Lussier, 2006a; 2006b). This was determined by a power calculation to ensure the appropriate use of MEDICODE and ability to make distinctions on individual MEDICODE discussion themes over timepoints of the wider study.

The requirements of a sample size are often linked to what would constitute a meaningful change on a primary outcome measure (Streiner & Norman 2008), however, the consultation sample size could not be calculated from the primary outcome measure used in the wider study. Although MEDICODE has been psychometrically validated, its limited use and lack of raw data linked to outcomes precluded the ability to derive a power calculation for sample size estimation. MEDICODE was developed using the basic framework of Roter's Interaction Analysis System Interaction (RIAS) (Roter & Larson 2002) and was used to make psychometric comparisons. Therefore, RIAS was used to derive the size of the sample required to judge statistically significant changes between pre and post intervention MEDICODE findings. The number of consultations required for the study is based on the number of audio-recordings of consultations required to see a significant change in RIAS score. STATA sample size estimation procedures indicate that for a change in mean score for the RIAS socio-emotional variables of 15% (mean 24.0 up to 27.5 and standard deviation 9.0) the proposed number of consultations to be recorded for each time-point (N=32) will give statistical power of the order of 70%. Since the degree of change and the correlation between the different assessments are uncertain, it is not possible to provide a more precise estimate of statistical power. Nevertheless, the indications are that the design is adequately powered. A minimum total of 128 audio-recordings of consultations were sought via the nurse prescribers, with a minimum of 32 recordings per timepoint of the wider study. This was further broken down as a minimum of two consultations per nurse with different people with diabetes prior to the wider

intervention and again at one week, three months and six months after the intervention.

Figure 4.2 Flowchart of participants' pathways through the wider study and data collection time-points



## 4.5 Quantitative component - MEDICODE analysis

#### 4.5.1 Introduction

The quantitative measurement of nurses' medication discussion (in the wider study and to address research question 1) used MEDICODE to identify the extent and content of nurses' medication beliefs exploration. This data has been published (Latter et al. 2010) and the author of this thesis was a co-author on the paper. Permission to use the MEDICODE data was granted by the research team and was used to answer research question 1 of this thesis. Due to the focus of this thesis on medicine beliefs concepts (e.g. concerns about and necessity for), only specific discussion about patients' medicines beliefs was of interest. The extent and changes in this specific activity could be discussed alongside the challenges and experiences uncovered by the qualitative components of this study. To that end, the quantitative component consists of selected findings.

Importantly, in terms of contribution, the author of this thesis was responsible for the recruitment and administration of the nurse consultation recordings. The author was also involved in the data collection and analysis of the MEDICODE data from the wider intervention study.

#### 4.5.2 Consultation observations

Observation is one of the oldest research techniques in the human sciences (Teddlie & Tashakkori, 2009) and involves the systematic and detailed observation of people and events so that behaviour and interactions in natural settings can be understood (Mays & Pope 1995). For the wider study, this author arranged for direct observations between nurse prescribers and diabetes patients to be conducted over several time-points. Direct observation (Drury 1992) is a common method for the observation of health care interactions and is often operationalised with an observer present during the consultation that sits passively and records as accurately as possible what is going on. This method has been used successfully with nurse prescribers before (Latter et al. 2007b). However, in the event that the aim of the observation is to appreciate and reflect upon a complex range of issues during the interaction, it can be particularly useful to make recordings (audio or video) as it can be difficult for an observer to record all events in real time. Both observer consultation notes and audio-recording consultations as methods of direct observation have a high degree of ecological validity, but audio-recording

methods were chosen for this thesis in order to conduct detailed consultation analyses and minimise potential Hawthorne effects (Blum & Naylor 1968).

## 4.5.3 MEDICODE consultation analysis tool

#### 4.5.3.1 Background

Prior to the start of the wider study - and to date - only one objective, empirical and validated measure of medicines discussion exists. For these reasons it was utilised in the wider study and for this thesis.

MEDICODE is designed to analyse medicine discussions during routine consultations and provide a quantifiable assessment of content and participation. A range of discussion themes, generated from preceding qualitative research, provide a standardised method to analyse observations of interactions between health care professionals and patients (Richard & Lussier 2006a; Richard & Lussier 2006b; Richard & Lussier 2007). It was developed to provide a medicines-specific analysis tool based on the RIAS framework (Roter & Larson 2002) but key differences between the two include the medicines-specificity of MEDICODE and the manner of coding. RIAS has a labour-intensive utterance-by-utterance coding system. The MEDICODE coding system simplifies this by coding only the mere mention of a discussion theme. To date, psychometric data on its reliability, face validity and concurrent validity, in comparison with RIAS, have proved its value to study the nature and intensity of discussions about medicines (Richard & Lussier 2006b). The three functions of MEDICODE are outlined in the next sections. The wider study was the first to use MEDICODE to assess nurse-patient medicines discussion.

## 4.5.3.2 MEDICODE functions

MEDICODE has three functions: (1) to determine the 'status' of a medicine being discussed, (2) to determine the type of discussion topics linked to the medicine being discussed, and (3) to determine the level of participation in the discussion about a medicine from each participant.

The status of medicines discussed in consultations is determined by the history of its use and the way it is discussed. The medicine may be used in three ways: it may be 'old' (a drug the patient has previously taken and no longer takes), 'new' (a drug the patient has never taken) or 'active' (a drug the patient is currently taking). These may then be discussed in one of four ways: 'simply discussed', 'prescribed',

'renewed', or 'advised against'. Various combinations of these two factors create the range of medicine statuses as seen in chapter 5.

The MEDICODE manual outlines 40 possible topics/themes of medicine discussion. When a specific medicine is identified in the consultation audio-recording, every discussion theme raised in relation to that medicine is recorded. The presence or mere mention of a theme is sufficient for it to be coded. Importantly and in contrast to the wider study, this thesis is only concerned with MEDICODE discussion themes 'theoretically mapped' to concepts that underpin an accepted definition of patients' medicine beliefs. This is discussed further in the data analysis section (4.5.5) and the conceptually mapped themes are presented in Table 4.1.

Levels of participation in medicine discussion were analysed for the wider study but were not considered pertinent to address the research questions for this thesis. This thesis was primarily concerned with the experience and challenges of nurse prescribers as they enact a new skill and diabetes patients' experiences of having their beliefs explored. Therefore, the main use of MEDICODE in this thesis was to determine the level of medicine beliefs discussion enacted.

### 4.5.3.3 Data coding

The coding of MEDICODE for this thesis was conducted by the author of this thesis, the authors of MEDICODE, and their colleagues at the University of Montreal. The author of this thesis undertook training to analyse the first round of consultation observations obtained for the wider study. The training was provided by the authors of MEDICODE. Due to their experience, expertise, and to develop international links, they were commissioned to conduct the majority of MEDICODE coding of audio-recorded consultations. The large volume of recordings, the timeframe of the wider study, and the need to share activities and responsibilities for later publications also contributed to the decision to use MEDICODE colleagues for the coding process. The Director of Research at the Faculty of Health Sciences approved the use of external colleagues for data coding with respect to the data being used as part of a PhD in July 2008. As this element only formed part of the work undertaken for this thesis, and that the author of this thesis was involved in the coding and MEDICODE analyses, it was considered appropriate to use this data in this thesis.

Regarding the coding process, once an instance of medicine discussion has been identified in a consultation, the coder then recorded a range of information in relation to that medicine. Discussion about the medicine was recorded by noting

the context of the medical problem and discussion themes identified in relation to the medicine were recorded. Often, the name of the medicine was given; however, this did not always occur immediately and sometimes not at all. In the latter case, nurses were asked post-consultation to clarify the name of the medicine under discussion. In the event this was not possible, that instance of medicine discussion and all MEDICODE data linked to it was excluded from the analyses. The definitive status of the medicine was sometimes assigned at the end of the consultation as information about a prescription may not have occurred until then. Information about each medicine was recorded throughout the consultation to capture all possible discussion about the medicine.

### 4.5.4 Data collection

To obtain the sample of consultation observations, nurse prescribers were given a digital audio-recorder each to record their consultations and instructions on how to use the device. Each nurse prescriber was required to purposively sample and audio-record a minimum of two consultations with different people with diabetes at four different time-points:

- -Baseline (prior to the intervention)
- -One week post-intervention
- -Three months post-intervention
- -Six months post-intervention

Updated guidelines on the development of complex interventions (Medical Research Council 2008) recommend that consideration is given to the length of follow-up in order to obtain a clear understanding (or at least clear assumptions) of the pattern of change. For the wider study, a range of follow-up time-points were chosen to capture different stages of change in nurse prescribers' behaviour as they developed and practiced their new skills.

Consultation audio-recordings were returned to the study team for transcription and analysis after each time-point had elapsed. After transcription checks had been completed, the transcriptions were passed onto the authors of MEDICODE and their colleagues at the University of Montreal for coding. Data on the medicine discussion was returned in PASW format (Version 17) for analysis. A flowchart of participants' progress through the study, for both quantitative and qualitative components, is presented in Figure 4.2.

# 4.5.5 Data analysis

The MEDICODE method of analysis focuses on each instance of medicine discussion and not an aggregated assessment of specific medicines or classifications. It was highly likely that several medicines would be repeatedly discussed by the same nurse prescribers in their different consultations; therefore, the instance of medicine discussion was the unit of analysis.

Several MEDICODE discussion themes can be conceptually mapped to an accepted definition of medicine beliefs, as discussed in Chapter 1. The MEDICODE themes presented in Table 4.1 can be conceptually linked to either the 'concerns about medicines' or 'necessity for medicines' constructs of the definition of medicine beliefs developed through the Beliefs about Medication Questionnaire (Horne et al. 1999). This novel approach provided the ability to empirically measure the extent of nurse prescribers' exploration of core concepts of patients' medicine beliefs in routine consultations. In addition to the mapped discussion themes, two more themes were of interest to this thesis. Namely, the themes: 'nurse asks patient opinion about medicine' and 'patient asks question about medicine'. Both these allow a measure of nurses' and patients' explicit attempts to enquire in the context of a medicines discussion.

Characteristics of the medicines discussed and the MEDICODE analysis are reported in Chapter 5. Descriptive statistics were used to report the occurrence of MEDICODE discussion themes at each study time-point. Multiple non-parametric McNemar paired tests were used to reveal significant changes in the frequency of discussion themes. All analyses were conducted with IBM SPSS Data Editor (v.19). The level of significance was p<0.05 for all comparisons.

Demographic details of participating nurses and patients were collected by the nurse prescribers and researcher throughout the study. This information was anonymised and identifiable data was kept confidential and securely stored. Descriptive percentages and reliability statistics were used for the analyses and are discussed in Chapter 5.

# 4.5.6 Rigour of the quantitative component

A number of measures were taken to ensure this component of the study would provide rigorous findings. Firstly, the method of nurse-patient medicine discussion (MEDICODE) was a psychometrically validated tool and had previously been used successfully with general practitioners. Secondly, a power calculation provided an indication of the number of consultations required to discuss enough instances of

medicine discussion in order to detect meaningful change in nurses' consultation behaviour over time. Thirdly, the reliability of the MEDICODE findings was examined by assessments of coding reliability. Inter-coder agreement was based on a sample of 12% of the consultations and test-retest stability was calculated on 18% of data. Finally, the validity of the findings, in terms of generalisability within the diabetes and nurse prescribing contexts, was supported by purposive sampling of different types of nurse prescriber commonly involved in diabetes care: namely diabetes nurse specialists, practice nurses and community matrons. This was done to ensure a representative range of views were obtained from the most relevant sources.

Table 4.1 Key MEDICODE themes and conceptual links

MEDICODE KEY THEMES	MEDICODE DEFINITION	THEORETICALLY MAPPED CONCEPTS
Concerns about medicine	Either nurse prescriber or patient can express their concerns about the nature, strength or expected side effects of the medicine in question.	'Concerns' (from Necessity- Concerns Framework, Horne, 1997; Horne & Weinman, 1999; Horne & Weinman, 2002)
Attitudes toward medicine	Either nurse prescriber or patient can express their opinions, whether favourable, unfavourable or other. Attitudes towards a medicine can vary.	'Concerns' & 'Necessity' (from Necessity-Concerns Framework, Horne, 1997; Horne & Weinman, 1999; Horne & Weinman, 2002)
Reasons for medicine	This refers to the reasons why the medicine is prescribed or recommended for the patient. It may be due to the main effect or another characteristic. What is important here is the explicit causal connection between a characteristic and the prescription or advice. No consideration is given to what is implicit.	'Necessity' (from Necessity- Concerns Framework, Horne, 1997; Horne & Weinman, 1999; Horne & Weinman, 2002)
Action of medicine	This refers to the target and/or dynamics (anatomy, physiology, and metabolism) of the medicine. The medicine's direct chemical action on the mechanisms involved in the health problem. This does not cover effects on symptoms, but rather what the medicine does in the patient's body.	'Necessity' (from Necessity- Concerns Framework, Horne, 1997; Horne & Weinman, 1999; Horne & Weinman, 2002)
Consequences of medicine non-adherence	This refers to possible problems that could be caused by not taking the correct dosage or not following instructions for taking the medicine in question. This deals with the danger of not taking the correct dosage or stopping treatment sooner than planned without consulting the nurse prescriber.	'Necessity' (from Necessity- Concerns Framework, Horne, 1997; Horne & Weinman, 1999; Horne & Weinman, 2002)
Expected effects of medicine	The nurse prescriber or patient talks about the main effect the medicine is expected to have on the patient's physical or psychological symptoms.	'Necessity' (from Necessity- Concerns Framework, Horne, 1997; Horne & Weinman, 1999; Horne & Weinman, 2002)

# 4.6 Qualitative component - Nurse prescriber interviews

### 4.6.1 Introduction

The aims of the wider study and research question 2 for this thesis were addressed at the same time through the same interview stage. Each interview with a participating nurse allowed both studies to pursue their interview discussion topics. The interview approach, process and conduct were the same for both studies, however, the approach to analysis was different for each study. The coding approach and thematic analysis for this thesis was more detailed than the analysis conducted for the wider study. Importantly, the author of this thesis was responsible for all aspects of this interview stage for both studies.

### 4.6.2 Semi-structured interviews with nurse prescribers

To investigate nurse prescribers' challenges when attempting to explore diabetes patients' medication beliefs (research question 2), a qualitative interview technique was required to represent the pragmatic mixed method approach in this thesis. Only a qualitative interview technique would provide the means to answer the research question.

Interviews are a common method for exploring health care issues and are often categorised by a different level of depth to which the interviewer ventures to explore the topic(s) under study. Types of interview include structured, semi-structured or unstructured, which have also been defined as 'standardised openended interview', 'general interview guide approach' and 'informal conversational interview' respectively (Patton 2002).

Structured interviews encourage open responses from participants but the discussion topics are all pre-determined prior to conducting the interview and are often designed for speed and cost-saving research. This would have been inappropriate as the depth to which nurses' challenges were understood would have been restrained, with little room for elaboration by nurses. Similarly, undertaking an unstructured interview approach would potentially have led to unwieldly and unfocused interview data. As the interview stage was designed to service both the wider study and this thesis, a semi-structure approach was considered appropriate to ensure the differing issues under study were captured. The semi-structured or general interview guide approach promoted open-ended responses and allowed room for divergence to expand on topics that were not prejudged to be relevant.

A semi-structured or general interview guide approach was required for this thesis. In using a semi-structured approach, it is beneficial for interviewers to have an interview guide prepared, which is:

"An informal grouping of topics and questions that the interviewer can ask in different ways for different participants." (Lindlof & Taylor 2002)

A topic guide is not normally intended to be followed rigidly (Britten 1995), as allowing a participant to diverge from the pre-determined topics may provide important insight into what the participant truly values (Bryman 2004).

Nurse prescribers' perceptions on a range of issues relevant to the wider intervention and this thesis were obtained via semi-structured interviews with each nurse prescriber at 1-month and 6-months after the intervention. The timing of these interviews was determined by the timetable for the wider study. No adverse effects of this timetabling were perceived. On the contrary, the time gap between each time-point permitted the analyses to encompass nurses' challenges over time. This addressed a common criticism of health beliefs and communication research that it is often only cross-sectional in nature (Horne et al. 2005; Seale et al. 2005).

Questions 1 to 3 and 7 to 9 during the 1-month interview (see Appendix 5) focused on nurse prescribers' perceptions of effective components of the intervention in the wider study. Questions 4-6 were concerned with the early experiences and challenges of enacting an exploration of patients' medicine beliefs for this thesis. In the 6-month interviews (see Appendix 6), questions 4 to 7 were focused on nurse prescribers' use of the general intervention skills over time in the wider study. Questions 1-3 were focused on issues of implementing a medication beliefs exploration, having had time to practice this skill, for this thesis.

Importantly, the wider study had a broader focus and included questions about e.g. diabetes illness representations and developing patient centeredness consultation skills. In order to preserve the distinction between the two studies, interview data linked to nurse prescribers' perceptions and/or exploration of these topics were excluded from the analyses.

### 4.6.3 Data collection and interview conduct

All interviews were conducted face-to-face and took place at nurse prescribers' occupational location. One week prior to the interview, arrangements were made

to book a room to conduct the interview in private and the interview schedule was given to each nurse prescriber. It was deemed appropriate to provide an interview schedule prior to interview as the intervention was an intense experience that involved four one-day workshops and covered a range of professional issues. The interviews asked nurse prescribers to critically reflect on their experiences. Immediately prior to beginning the interview, written consent was sought to digitally audio-record the interviews and assurances about confidentiality and anonymity were provided. The audio-recorded interviews were transcribed verbatim and incorporated into the qualitative data management software NVivo version 8.

# 4.6.4 Data analysis

### 4.6.4.1 Approach to data analysis

Consistent with the pragmatic methodological approach taken in the thesis, the analysis of qualitative data focused on 'what works' by using the 'right tool for the right job' and not necessarily using a prescriptive approach due to predetermined allegiances. Such a pragmatic approach to qualitative inquiry has been encouraged by qualitative researchers (Aronson, 1994; Saldana, 2013).

To determine the approach to qualitative analysis for this thesis I considered the research objective (thesis objective 2) I wished to address, the type of interviews I was planning to conduct, and my own level of qualitative experience. As the objective required an exploratory method I initially considered a range of qualitative analysis techniques. Braun & Clarke (2006) roughly divide these into two categories: those linked to a theoretical or epistemological position such as conversation analysis and interpretative phenomenological analysis, and those unlinked to any theoretical or epistemological position. These authors consider thematic analysis to belong to the latter and its attempts to describe patterns in the data is unbounded by pre-determined positions. An unbounded analytic method suited the pragmatic approach taken in this thesis. This is primarily related to the cross-boundary nature of this thesis and the potential for a number of theoretical positions from the nursing or psychological literature to have funnelled the research toward one or another. Importantly, the problem of adherence and exploration of patients' medication beliefs by nurses can be considered to have a psychological basis but is contextually played-out in the world of nursing/health care. A pre-determined theoretical position may have limited the findings to one or other domain, therefore, thematic analysis appeared appropriate as an analytical approach for this research.

Supporting this decision was the nature of the interviews, i.e. semi-structured. This type of interview can be analysed by most qualitative analytic approaches, however, a few are less appropriate, such as narrative inquiry, which requires less structure to the interview in order to allow the participant to speak at length on any topic they chose to raise. As the nurse interviews in this research also sought to address the aims of the wider study, the interviews consisted of several discussion areas and thus required a degree of structure. The thesis objective and style of interview suggested a broad and flexible approach was required to analyse the nurse interviews. In addition, supporting the choice of thematic analysis was its accessibility for novice qualitative researchers. As one of these, the lack of reliance on a complex theoretical position supported my engagement with the data without additional distraction (Braun & Clarke, 2006).

# 4.6.4.2 Approach to thematic analysis

Thematic analysis, as a broad, flexible and accessible method was chosen for this thesis. However, these characteristics have led to criticism of thematic analysis as having an absence of clear guidelines and an 'anything goes' approach to qualitative research (Antaki et al., 2002). Thus, many researchers in the last decade have focused their efforts on defining the attributes and processes of thematic analysis (Boyatzis 1998; Roulston 2001, Braun & Clarke, 2006).

As recent as 2001, there has been reports of a lack of guidance on how to conduct thematic analysis (Attride-Stirling, 2001). Previous guidance was often accurate in their general approach but desperately lacking in detail, particularly for the novice qualitative researcher. For example, Patton (1987) described three tasks of qualitative data analysis: the data is organised, it is then reduced through summarisation and categorisation, and finally patterns and themes in the data are identified and linked. Whilst this was the broad aim of the nurse interviews, more detail was sought to support the process of the analysis.

Braun & Clarke (2006) provide one of the most relevant and in-depth assessments of the data analytical process for thematic analysis. They recommend a six stage approach to analysis: familiarisation with the data, develop initial codes, organise the data into meaningful themes, review the themes, define and name the themes, and the interpretation and report writing phase. They also recommend researchers consider a number of issues prior to and during the analysis phase. These include inductive or theoretical approaches, developing semantic and/or latent themes, and the recurrent issue of what counts as a code or theme.

As thematic analysis is often used without a theoretical basis and the second objective of the thesis required a flexible and accessible approach, an inductive or 'bottom up' (Frith and Gleeson, 2004) approach was used. This inductive approach ensured themes were closely related to the data. In some ways this resembled techniques used in grounded theory (Glaser, 1992), however, that approach was not considered appropriate as an important feature of grounded theory is the parallel collection and analysis of data; thus data collection would be grounded on previously analysed text (Strauss and Corbin 1998). This approach was unsuitable as the semi-structured interviews from which data was collected for this thesis were logistically linked to the wider study and its aims. For example, it was not possible to change the schedule of interview questions as the evaluation of the workshops, provided by the wider study, required continuity to permit an analysis of change at 1 month and 6 month time-points. Secondly, the method of using selected questions within a broader interview, whilst pragmatically and logistically appropriate for the exploratory element of this thesis, could be challenged as not having enough raw data to generate a formal theory - which is an important goal of grounded theory. However, this does not mean assertions cannot be developed; they were sought and developed as findings from this thesis.

Braun & Clarke (2006) differentiate between semantic (explicit surface meaning) and the latent (underlying ideas, assumptions, and conceptualizations) themes developed from the data. For this thesis, both types of themes were developed where appropriate to reflect the voice of the participants and also the complex value systems which were likely to affect the exploration of patients' medication beliefs.

The method of thematic analysis for the nurse interviews in this thesis was a data-driven inductive approach, open to developing latent and semantic themes, with the goal of assertion development. Whilst this was the primary aim of the analysis, a secondary aim was also pursued. As the nurses were interviewed twice, the opportunity to assess change in their experience of patients' medicine beliefs exploration was possible. The next section elaborates on coding methods to address the thematic analyses of the nurse interview data.

# 4.6.4.3 Approach to coding

In order to address the common 'anything goes' critique of thematic analysis, this section will outline the specific coding methods chosen for this thesis. Importantly, any researcher who wishes to become proficient at doing qualitative analysis must learn to code well and easily, as the excellence of the research rests in large part on the excellence of the coding (Strauss, 1987, p27).

There are decisions to be made when approaching coding as it is an essential ingredient for qualitative inquiry. Relevant to novice researchers is whether to 'lump' or 'split' the data as coding progresses, e.g. code whole sections or line-by-line. For this thesis and its use of specific questions from the interviews, it was considered appropriate to split the data and take a line-by-line approach to identify all possible codes, categories and themes.

To date, work by Saldana (2013) has provided the most in-depth analysis of coding approaches for qualitative inquiry. He has described over 30 different types of coding and made recommendations for their use in certain circumstances. It is from this detailed work that a coding approach was chosen for the needs of this thesis. Importantly, there is always the need to identify a 'good code', i.e. one that captures the qualitative richness of the phenomenon under study (Boyatzis, 1998, p1). In addition, it is important to develop good themes as patterns in the information that at minimum describe and organise the observations and at maximum interpret aspects of the phenomenon (Boyatzis, 1998, p161).

Coding was conducted by hand-coding printed copies of interview transcripts and the use of the qualitative software package Nvivo version 8. This was followed by a clustering of findings into thematic categories as per the Braun & Clarke (2006) process outlined above.

Determining the level of coding has been recognised by Braun and Clarke (2006) as the first of a number of important questions researchers should ask themselves prior to conducting a thematic analysis. Preliminary reading of the interview transcripts led to decisions about which coding methods to primarily focus upon. Whilst there is not space in this thesis to critique each coding type proposed by Saldana (2013), a selection of types are discussed in order to justify those used.

For this thesis, four coding types were chosen for the main thematic analysis: process coding, emotion coding, values coding, and descriptive coding. Reasons for these choices were based on the nature of the nurse-patient consultations discussed during the nurse interviews. During these interviews, nurses' reflections on the process of engaging with patients' medication beliefs were vital to uncover. Furthermore, due to the potential for nurses' to experience hostility by patients as they were challenged about their medication behaviour, coding text about nurses' and patients' emotional state was also important. In addition, nurses and patients were likely to have their own ideas about the importance of medicines beliefs exploration, so coding values was also required. Descriptive coding was conducted as a method of identifying basic contextual aspects of the interview reflections.

Process coding is valuable for most qualitative research and focuses on gerunds ('ing' words) and seeks observable action, e.g. making, playing, drinking, and conceptual action, e.g. struggling, negotiating, adapting. This type of coding is particularly useful for reflections about attempting to achieve a goal and tactics and strategies to achieve it. Emotion coding is valuable for most qualitative research but especially for intra- and inter-personal experience as likely experienced by participating nurse prescribers. In addition, rarely is it possible to separate emotion from action, so coding how nurses and patients felt was important. Values coding is also useful for most qualitative research but especially for intra- and inter-personal experience, and determining worldviews and personal belief systems. Descriptive coding is the basic strategy of most qualitative coders. These codes highlight the topic under discussion, contextual factors and personal/demographic attributes of the situation.

Coding types considered inappropriate for this thesis included holistic coding, i.e. lumping large amounts of text into one code, for reasons explained previously, and coding types commonly linked to grounded theory: focused coding and theoretical coding.

The work of Saldana (2003; 2013) has served to provide a rich description of the work qualitative researchers undertake as they code, hitherto potentially unaware of such activity as the description of the various coding types is new to the field. Saldana's work serves novice qualitative researchers particularly well as it presents a range of techniques, hitherto hidden behind the mist of activities conducted by experienced qualitative researchers. For this thesis, I found this work particularly valuable in guiding my decisions about types of coding to embark upon.

Rigourous qualitative work should provide an audit trail for other researchers to review. For the nurse interviews in this thesis, a relevant element from one coded nurse interview (see Appendix 8) is presented so coding decisions were transparent. Codes-to-category development is demonstrated in Appendix 9.

# 4.7 Qualitative component - Patient interviews

### 4.7.1 Introduction

The aims of the wider study and research question 3 for this thesis were addressed at the same time through the same interview stage. Each interview with a participating diabetes patient allowed both studies to pursue their interview discussion topics. For the wider study, patients' perceptions about their recent consultation with their nurse prescriber in relation to the intervention were of paramount interest. For this thesis, patients' perceptions about their medicine beliefs discussion were of primary interest. The interview approach, process and conduct were the same for both studies, however, the analysis for the wider study was not fully completed and those findings have yet to be published. The analysis completed for this thesis was the only complete thematic analysis conducted on this data. Importantly, the author of this thesis was responsible for all aspects of this interview stage for both studies.

# 4.7.2 Semi-structured telephone interviews with diabetes patients

To qualitatively investigate diabetes patients' perceptions, semi-structured interviews were chosen for the same reasons outlined in section 4.6.2. The only difference was patient interviews were conducted by telephone.

Telephone interviews are a common method in quantitative studies such as surveys but used far less in qualitative research (Sturges and Hanrahan 2004) and considered less desirable than face-to-face interviews. This was recognised in a review of telephone and face-to-face interviewing that identified a bias toward the latter (Novick, 2008). However, this review also identified this bias is not based upon evidence but rather the concerns of researchers. Of the limited research available, it has reported telephone interviews as a versatile method allowing respondents to relax (Carr and Worth 2001) and more likely to freely disclose sensitive information (Hopper 1992). Moreover, it has found no support for the hypothesis that telephone respondents were more likely to satisfice (Jackle et al. 2006) or behave in a dramatically different way (Sturges and Hanrahan 2004).

Although limited evidence exists for the less desirable status of telephone interviews, measures were taken to alleviate commonly cited researcher concerns. Two commonly cited criticisms of telephone interviews include concerns about developing an appropriate level of rapport to elicit information and knowing when to tailor conversation on a sensitive topic, due to the lack of visual cues during the

interview (Rubin & Rubin 1995). To address these issues, even though there was limited research to support these claims, the telephone interview was the second call to each participant. A preliminary telephone conversation was held to go through the consent process and develop a level of rapport prior to the interview itself. The interviewer asked patients about their nurse, home life, and recent experiences so a shared understanding of the patient's context could be developed. Also, the conduct of the interviewer included careful appreciation of when sensitive topics were being discussed. Checking with each participant if it was ok to discuss particular topics was done before and during each interview.

Importantly, there were pragmatic reasons for undertaking telephone interviews with diabetes patients. Firstly, it was important to interview patients as soon as possible after their audio-recorded consultation with their nurse. Attempts to recruit and interview patients were done within one week of their consultation audio-recording. Only these diabetes patients could be recruited as it was vital to interview those who had experienced medication beliefs exploration activities by nurses. This situation has often been described as the need to interview those who have experience related to the phenomenon under research (Patton 2002). Secondly, as a large number of audio-recordings were being collected, it was predicted a large number of patient interviews would be conducted and time to do face-to-face interviews would not be possible. Thirdly, diabetes patients were likely to be spread across a reasonably wide geographical range and funds to cover travel expenses, to either invite them to the University or for a researcher to visit them, was not costed into the grant for the wider study.

# 4.7.3 Data collection and analysis

All interviews were conducted on the telephone and within approximately one week of the patient's participation in an audio-recorded consultation with their nurse prescriber. Informed consent was obtained in writing prior to participation during a preliminary telephone call, and assurances about confidentiality and anonymity were provided. It was estimated that each interview would take approximately 30 minutes in duration. The interview asked patients to reflect on their recent consultation using the questions listed in Appendix 7. All interviews were audio-recorded, transcribed verbatim and managed in the qualitative data management software NVivo version 8. The interviews were analysed using thematic analysis in the same manner outlined in section 4.6.4.

For the patient interviews, the approach to data analysis (see section 4.6.4.1) and thematic analysis (see section 4.6.4.2) was the same as the nurse interviews. As

with the nurse interviews, four coding types were chosen for the thematic analysis: process coding, emotion coding, values coding, and descriptive coding. But as only one round of patient interviews was conducted, no comparison over time was possible. The rationale for choosing the data analysis approach, thematic analysis approach and coding approach was the same as the nurse interviews.

The nurse interview analysis and patient interview analysis were treated separately as they addressed different research questions, question 2 and question 3 respectively. Therefore, no mixing, collating or restructuring of themes was attempted. The only integration of theme findings was done in chapter 8 via the conceptual model developed from the combined findings of the quantitative element and both qualitative elements of this thesis.

Rigourous qualitative work should provide an audit trail for other researchers to review. For the patient interviews conducted in this thesis, a relevant element from one coded patient interview (see Appendix 10) is presented so coding decisions were transparent. Codes-to-category development is demonstrated in Appendix 11.

# 4.8 Rigour of the qualitative components

Trustworthiness is an important concept in qualitative analysis and depends upon a systematic research design, data collection, interpretation, and communication (Mays & Pope, 1995). This broad concept is primarily based on two subordinate concepts of reliability and validity, although, the value of these terms in relation to trustworthiness and qualitative research is debated (Lincoln & Guba, 1985). Four criteria have been popularly used to assess the trustworthiness of qualitative inquiry: credibility, transferability, dependability, and confirmability (Guba 1981).

To address credibility, investigators should attempt to demonstrate that a true picture of the phenomenon under scrutiny is being presented (Shenton 2004). For this study, an appropriate selection of method of investigation, namely interviews, supports this; as does other researchers' perceptions of the research design and data obtained. The former was inherent in the process of obtaining the project grant for the wider study and the latter was addressed by asking one of the project researchers to comment on the findings for peer scrutiny. Therefore, a 10% sample of the nurse and patient transcripts were double coded by a member of the research team in the wider study (SL) and agreement on themes reached through iterative discussion. In addition, for this thesis, four different coding types were chosen for the main thematic analysis (process coding, emotion coding, values

coding, and descriptive coding) as multiple coding methods are recommended to enhance the depth, breadth and credibility of findings (Leech & Onwuegbuzie 2005; Mello 2002).

To support transferability, researchers must provide sufficient detail of the context of the fieldwork for a reader to be able to decide whether the prevailing environment is similar to another situation with which he or she is familiar and whether the findings can justifiably be applied to the other setting (Shenton 2004). This was addressed in each results chapter and in the implications section at the end of the thesis.

Addressing dependability is difficult in qualitative work but researchers should at least strive to enable a future investigator to repeat the study (Shenton 2004). This was addressed through the use of the qualitative analysis program NVivo version 8. This provided an important trail of evidence as thematic categories were developed from the textual data. This was important as research has indicated effective record keeping whilst conducting observations and interviews is conducive to the replication of analyses and conclusions (Ballinger, 2004).

Further examples of an audit trail are provided in the Appendices. For the nurse interviews, a relevant element from one coded nurse interview (see Appendix 8) is presented so coding decisions were transparent. Codes-to-category development is demonstrated in Appendix 9. For the patient interviews, a relevant element of one coded patient interview is presented in Appendix 10 and codes-to-category development is presented in Appendix 11.

To achieve confirmability, researchers must take steps to demonstrate that findings emerge from the data and not their own predispositions (Shenton 2004). This was addressed through the double coding and iterative discussion with team members. It was also addressed through a reflexive exercise to consider the position and values of the author of this thesis. This reflexive exercise is reported in section 6.5 for the nurse interviews and section 7.4 for the patient interviews.

With the broader mixed methods approach in mind and the previous discussion in section 4.3.1, importantly, data quality in mixed methods research is determined by standards of quality in the individual qualitative and quantitative components of a study. Thus if the different components are credible and valid then the mixed method study will also have a high level of rigour (Teddlie and Tashakkori 2009).

# 4.9 Summary of methods chapter

The choice of methods for this thesis was led by the overall thesis research aim and its objectives which had differing methodological requirements. A pragmatic mixed method approach was adopted due to need for multiple methods to address the complex issue of the experience of exploring patients' medication beliefs. A concurrent triangulation design was chosen with one quantitative component and two qualitative components. The quantitative component used a medicationspecific consultation analysis tool to empirically measure the extent of nurse prescribers' exploration of patients' medicine beliefs. The first qualitative component involved interviewing nurse prescribers about their perceptions of influencing factors upon their attempts to explore. The second qualitative component involved interviewing diabetes patients about their perceptions of nurse prescribers' consultations in which their medicine beliefs were explored. Sampling for these differing parts of the thesis required finding a balance to recruit enough nurses who would in turn recruit enough diabetes patients who in turn would take part in audio-recordings of their consultations. Findings from these components are integrated and inferences developed in the discussion chapter.

# 5. Nurse prescribers' exploration of patients' medicine beliefs: an assessment using MEDICODE

# 5.1 Introduction

To address research question 1 of this thesis, this chapter focuses on key MEDICODE themes conceptually mapped to an accepted definition of medicine beliefs presented in section 2.2. The aim of this chapter was to highlight the quantifiable extent of medication beliefs exploration by nurses. Data presented in this chapter has been drawn, with permission, from the wider intervention study. This data has been published (see Latter et al. 2010) and the author of this thesis was a co-author on the paper. Importantly, in terms of contribution, the author of this thesis was responsible for the recruitment and administration to obtain the nurse consultation recordings. The author was also involved in the analysis of the MEDICODE data.

The wider study was designed to assess change in exploration over time, but this was not as important for this thesis as its aims were slightly different. However, in order to address research question 1 for this thesis, it was considered advantageous to utilise the longitudinal data to determine the extent of exploration by nurses. Having assessments at different time points would provide more certainty that exploration was, in fact, occurring and the limitation of a cross-sectional assessment was avoided.

The main message from this chapter was, based on the overall levels of discussion on medicine-related themes in Latter et al. (2010), that a moderate level of medicine beliefs discussion was observed. In conjunction with qualitative findings presented in chapters 6 and 7, the extent of exploration outlined in this chapter support the integrated inferences developed in the discussion chapter.

# 5.2 Descriptive data on study sites, nurse prescribers and consultation audio-recordings

# 5.2.1 Characteristics of study sites

Nurse prescribers who responded to the initial scoping exercise and expressed their consent to participate were further informed about the process of

involvement and asked to obtain permission from their manager to attend the intervention workshops. This scoping exercise, which involved the dissemination of study information through all ten Strategic Health Authority (SHA) non-medical prescribing leads, sought to recruit a representative range of nurse prescribers from different SHAs, NHS organisations, and diabetes service delivery models.

A range of nurse prescribers from ten different Trust sites expressed their interest and availability to participate in the intervention and evaluation. All nurse prescribers required permission to participate from their line manager and the ability to commit to the series of intervention workshops and its evaluation. A maximum of twenty nurse prescribers were recruited across the ten Trust sites.

Table 5.1 indicates that the majority of recruited Trust sites were from South Central SHA (40.0%, n=4), the others were spread across East Midlands SHA (20.0%, n=2), South West SHA (10.0%, n=1), London SHA (10.0%, n=1), West Midlands SHA (10.0%, n=1), and East of England SHA (10.0%, n=1). Most of the ten recruited sites were Primary Care Trusts (60.0%, n=6), others were NHS Trusts (30.0%, n=3) and a Care Trust (10.0%, n=1). However, due to nurse prescriber withdrawals, three sites were closed to recruitment.

Table 5.1 Characteristics of study sites with adjustments for withdrawal

Site	Type of Organization	Strategic Health Authority	Participating nurse prescribers
Α	Primary Care Trust	South Central	8 (reduced to 5)
В	Primary Care Trust	South Central	2
С	NHS Trust	London	2
D	Primary Care Trust	South West	2

E	NHS Trust	East of England	1
F	Care Trust	West Midlands	1
G	NHS Trust	South Central	1
Н	Primary Care Trust	East Midlands	1 (withdrew)
I	Primary Care Trust	South Central	1 (withdrew)
J	Primary Care Trust	East Midlands	1 (withdrew)

# 5.2.2 Characteristics of nurse prescribers

In total, twenty nurses were purposively recruited to the study based on the inclusion criteria. All twenty provided pre-intervention consultation audio-recordings before embarking on the intervention workshops. However, six nurses withdrew after providing pre-intervention audio-recordings, giving a total of fourteen nurses who provided their quota of consultation audio-recordings up to six months post-intervention. Of the six nurses who withdrew, the reasons for withdrawal were a change of job (n=2), an inability to attend the 3rd and 4th workshops (n=1), an inability to identify appropriate diabetes patients to audio record after completing the workshops (n=1), a family bereavement (n=1), and no reason provided (n=1). In terms of the timing of their withdrawal, three nurse prescribers withdrew after completing all the workshops, two after completing workshop 1, and one after completing workshop 1 and 2.

Of the fourteen nurse prescribers who provided their quota of consultation audio-recordings, the majority were employed in South Central SHA (57.2%, n=8), the others were spread across South West SHA (14.3%, n=2), London SHA (14.3, n=2), West Midlands SHA (7.1%, n=1), and East of England SHA (7.1%, n=1). The majority were employed by Primary Care Trusts (64.3%, n=9), others by NHS Trusts (28.5%, n=4) and a Care Trust (7.2%, n=1). The majority of nurses were practice nurses (57.1%, n=8), the others were diabetes specialist nurses (28.6%, n=4) and community matrons (14.3%, n=2). All nurses were Caucasian females and independently prescribing. The mean age was 45.6 (SD 6.75), the mean number of years qualified as a nurse was 14.7 (SD 6.24) and the mean number of months qualified as an independent prescriber was 25.1 (SD 4.18).

# 5.2.3 Characteristics of consultation audio-recordings and diabetes patients

As outlined in section 4.4.5, a minimum consecutive sample of 128 consultation audio-recordings was required with a minimum of 32 recordings at each time-

point. Overall, a total of 170 different consultations, thus different diabetes patients, were recorded. However, some patients were linked to consultations with nurses who withdrew from the study and those consultations were removed from the analyses. After these adjustments, a total of 154 consultations with approximately equal numbers at pre-intervention (n=44), 1 week (n=38), 3 months (n=32) and 6 months (n=40) post-intervention were included in the analyses.

Of the 154 included consultations, demographic data indicated the majority of patients involved in the consultations were diagnosed with Type 2 diabetes (81.8%, n=126) and had been diagnosed for a mean of 10.7 (SD 11.8) years. The majority were Caucasian (89.0%, n=137) with a mean age of 56.6 (SD 14.34) years. Patients were equally distributed by gender, male 51.3% (n=79) and female 48.7% (n=75). Each participating nurse prescriber recorded an average of 11 consultations in total, with an average of 2.75 consultations gathered at each time-point. The unexpected excess of consultation audio-recordings was included in the analyses. This strengthened the statistical findings and subsequent inferences.

# 5.2.4 Summary

Twenty nurse prescribers were initially recruited to participate in the intervention, however, due to withdrawal this number was reduced to fourteen nurse prescribers, who provided consultation recordings at each time-point, for the purposes of the MEDICODE analysis. Section 4.4.3 indicated that an estimated sixteen nurse prescribers were required for data saturation. This number was not achieved for the MEDICODE analyses; however, this was always a possibility from the finite number of nurse prescribers involved in the wider intervention. Importantly, more than the minimum numbers of consultation audio-recordings, overall and at each time-point, were obtained as required by the power calculation and help to offset the slight under-recruitment of nurse prescribers.

# 5.3 Assessment of nurse prescribers' exploration using MEDICODE

MEDICODE (Richard & Lussier 2006a; Richard & Lussier 2006b; Richard & Lussier 2007) is a descriptive consultation analysis tool, designed to analyse medicine discussions during routine consultations and to provide a quantifiable and detailed assessment of discussion content. Firstly, this section will discuss the reliability of the coding, secondly, present an overview of the medicines discussed by pharmacological categorisation and status, and thirdly, report on the conceptually mapped MEDICODE themes.

### 5.3.1 Coding reliability

Three coders received an average 160 hours of training/supervision and carried out the coding of the consultations. Reasons for differences and refinements in coding were discussed between the coders in the event of disagreements. To calculate test-retest stability, they each coded a random sample (18%) of the data twice. To calculate inter-coder agreement, a random sample of 12% of the consultations was used.

The Kappa statistic was chosen due to its previous successful utilisation in other MEDICODE analyses, the familiarity of the method with the research team, and to acknowledge the quantitative approach in this element of the wider study/thesis. Other methods of examining reliability, such as the qualitative technique of having other team members examine the choices of coders (as seen in Roebuck et al. 2001) was not considered appropriate due to its methodological underpinnings and doubt about the added value of this approach.

For test-retest stability, the identification of the medicine under consideration matched in 94.6% of cases and the total number of correctly coded themes was positively correlated (r=0.76). In addition, the stability of the themes discussed in the consultations was generally above an average of 94% agreement and the Kappa statistic calculated for the themes overall was 0.735 (p<0.001).

For inter-coder agreement, the identification of the medicine under consideration matched in 80.6% of cases and the total number of coded themes was positively correlated (r=0.61). In addition, 89.2% of coders agreed on the MEDICODE themes discussed and the Kappa statistic for the themes overall was 0.529 (p<0.001).

Test-retest stability and inter-coder agreement scores for the identification of MEDICODE discussion themes ranged from 'moderate' to 'substantial' agreement (Kappa range: 0.529 to 0.735) based on a known categorisation of agreement (Landis & Koch 1977). Whilst some aspects of coders' agreement could be considered average, this categorisation method has been criticised as unforgiving of measures with a large number of categories, i.e. the multiple MEDICODE themes, which can affect the magnitude of the kappa value (Gwet 2001). Put simply, a recent evaluation of reliability issues indicated the Kappa value will be higher when there are fewer categories of comparison (Sim & Wright 2005). Thus, in evaluating coding agreement with MEDICODE, it is important to recognise this issue and not assume moderate agreement based on debated categorisation methods.

# 5.3.2 Number and type of medicines discussed

Twenty-six medicines were unidentifiable in the audio-recordings and were excluded from the analyses. A total of ninety-nine different medicines were identified and discussed during the 154 audio-recorded consultations. A mean of 4.4 medicines were discussed per consultation. Based on categorisation from the British National Formulary (2007), the majority of medicines were for cardiovascular (32.2%) and endocrine (29.9%) related conditions (see Table 5.2).

Table 5.2 The pharmacological classification of medicines observed based on British National Formulary classifications

British National Formulary categories	Frequency (%)
Cardiovascular	32 (32.2)
Endocrine	29 (29.2)
Infection	9 (9.1)
Central Nervous	7 (7.1)
Other	6 (6.1)
Nutrition	4 (4.1)
Gastro-intestinal	3 (3.05)
Respiratory	3 (3.05)
Musculoskeletal	3 (3.05)
Skin	3 (3.05)
Total	99 (100)

Although a summary of the pharmacological classification highlights the predominance of two main pharmacological categories, the MEDICODE method of analysis focuses on each instance of medicine discussion and not an aggregated assessment of specific medicines or classifications. It was highly likely that several

medicines would be repeatedly discussed by the same nurse prescribers in their different consultations; therefore, the instance of medicine discussion was the unit of analysis.

Overall, there were 620 instances of medicine discussion across the 154 audio-recorded consultations, with roughly equal instances at baseline (pre-intervention time-point) (n=196), 1 week (n=126), 3 months (n=123) and 6 months (n=175) post-intervention.

During the MEDICODE coding process, defining the 'status' of a medicine provides an important element to the profile of medicines under discussion. As previously discussed in the Methods chapter, a medicine can be classified as 'old', 'new' or 'active' (currently taking) and either 'simply discussed', 'prescribed', 'renewed', or 'advised against'. These create a range of categorisations to establish the status of the medicine. The majority of medicines were classified as 'Active & discussed' (72.6%, instances=450) and this distribution was stable across all study time-points (see Table 5.3). The predominance of 'Active & discussed' medicines highlights the stable and ongoing nature of many nurses' role in medicines management with people with diabetes.

Table 5.3 Instances and proportions of medicine discussion by medicine status and time-point

Status of medicine	Instances and proportions of medicine discussion Frequency (%)					
	Total	Baseline	1 week	3 months	6 months	
Active & discussed	450 (72.6)	144 (73.5)	82 (65.1)	102 (82.9)	122 (69.7)	
New & discussed	52 (8.4)	15 (7.7)	15 (11.9)	5 (4.1)	17 (9.7)	
Old & discussed	45 (7.3)	9 (4.6)	11 (8.7)	6 (4.9)	19 (10.9)	
New/Active/Old & excluded	37 (6.0)	15 (7.7)	7 (5.6)	3 (2.4)	12 (6.9)	
New & prescribed	18 (2.9)	5 (2.5)	3 (2.4)	6 (4.9)	4 (2.3)	
Active & renewed	13 (2.1)	7 (3.6)	5 (3.9)	1 (0.8)	-	
Old & prescribed again	5 (0.7)	1 (0.4)	3 (2.4)	-	1 (0.5)	
Totals	620 (100)	196 (100)	126 (100)	123 (100)	175 (100)	

Table 5.4 presents the mean number of discussion themes raised per instance of medicine discussion across different statuses and study time-points. There was

only one instance of discussion about an 'Old & prescribed again' medicine at baseline and this provided an unusually high number of themes. There were less the five instances of medicine discussion within the status at 1 week and 6 months, no instances were recorded at 3 months post-intervention. It is possible that this medicine status is unique in its requirements for extended discussion by nurses but it is not possible to confirm this with so few cases. Due to the singular case and its ability to skew the data to the point of invaliding the use of parametric statistics, this status was removed from the analysis. With this status removed, no significant differences between statuses were found in any comparisons of the mean number of medication discussion themes between time-points.

Post-hoc comparisons of the total mean number of themes for each status between time-points indicated that the total mean for 'Active & discussed' was significantly higher than the total mean for 'New & discussed' (p<0.0001) and significantly lower than total means of 'New & prescribed' (p<0.01). On the whole, nurse prescribers were relatively consistent in the number and proportion of discussion themes raised for each medicine status, overall and at each study time-point.

Table 5.4 Mean number of medicine themes discussed by medicine status and time-point

Status of medicine <sup>a</sup>	Time-point Mean (SD)				
	Total	Baseline	1 week	3 months	6 months
Old & prescribed again	15.8 (8.55)	22.0 †	18.3 †		2.0 †
New & prescribed	9.4 (5.30) *	9.4 (5.94)	7.6 †	9.1 (6.52)	11.2 †
Active & renewed	8.1 (4.68)	8.0 (6.02)	8.8 (3.11)	6.0 †	
New/Active/Old & excluded	6.9 (4.07)	8.8 (4.78)	6.4 (2.22)	7.3 †	4.7 (2.59)
Active & discussed	6.1 (4.03)	6.22 (4.07)	6.5 (3.65)	5.7 (4.15)	6.2 (4.15)
Old & discussed	4.4 (3.57)	7.0 (3.12)	4.0 (3.46)	2.8 (1.83)	4.0 (3.84)
New & discussed	3.2 (2.19) **	3.4 (2.53)	3.4 (2.16)	1.4 (1.14)	3.6 (1.99)
Totals <sup>b</sup>	6.07 (4.22)	6.46 (4.39)	6.31 (4.05)	5.65 (4.30)	5.76 (4.07)

<sup>†</sup> Less than 5 medicines are linked to this status and time-point

# 5.3.3 Nurse prescribers' exploration of MEDICODE themes conceptually linked to patients' medicine beliefs

MEDICODE can code 40 themes of medicine discussion (see Latter et al. 2010 for a full list of themes measured in the wider study), however, this section focuses on eight key themes and presents nurse prescribers' extent of medicine beliefs exploration (see Table 5.5). These key themes have been discussed before as conceptually mapped to concepts of interest (see Table 4.1).

When a specific medicine was identified in the consultation audio-recording (an instance of medicine discussion), every discussion theme raised in relation to that medicine was coded. The presence or mere mention of a theme was sufficient for it to be coded.

As seen in table 5.5, at the pre-intervention time-point, a key theme mapped to medication necessity: 'expected effects of the medicine' was on average discussed 22.4% of the time when a medicine was brought up during consultations. Other key themes mapped to medication necessity had lower and varying levels of

<sup>\*</sup> Total mean for 'Active & discussed' was significantly lower than total means for 'New & prescribed' (p<0.01)

<sup>\*\*</sup> Total mean for Active & Discussed was significantly higher than total mean for 'New & Discussed' (p<0.0001)

a No significant differences in means for individual statuses across time-points b No significant differences in total means for statuses across time-points

occurrence: 'action of medicine' (14.3%), 'reasons for medicine' (8.7%) and 'consequences of medicine non-adherence' (1%).

'Concerns about medicine' rarely appeared in pre-intervention discussions (3.1%), however, the conceptually broader theme of 'attitudes towards medicine' (23%) was raised about a fifth of the time a medicine was brought up during a consultation. Similarly, a fifth of the time nurse prescribers' asked for patients' opinions about their medicine (20.9%) but patients' rarely asked questions about the medicines (5.6%) in pre-intervention consultation observations.

Post-intervention paired McNemar analyses of necessity-related key themes, 'expected effects of medicine', 'action of medicine' and 'reasons for medicine', showed limited and non-significant change in frequency at all time-points. The overall levels of discussion about 'consequences of medicine non-adherence' was infrequent across time-points (less 10%) but there were significant increases in discussion at 1 week post-intervention (p< 0.05) and 6 months post-intervention (p<0.05).

'Concerns about medicine' showed a highly significant rise at 1 week (p<0.001), and a significant increase 6 months (p<0.05) post-intervention. 'Attitudes towards medicine' showed a highly significant rise in frequency at 1 week (p<0.01) but not at any other time-point. The theme 'Nurse prescriber asks patient opinion about medication' had a highly significant increased at 1 week (p<0.01) but at no other time point. Despite this, both this theme and attitudes towards medicine were frequently discussed MEDICODE themes. 'Patients asks about medicine' increased at 1 week and 3 months, albeit non-significantly, before returning to a similar pre-intervention level at 6 months.

Table 5.5 Medicine beliefs discussion by conceptually mapped MEDICODE theme and wider study time-point

MEDICODE	Medicine discussion by time-point and theme					
discussion	Pre-	Pre- 1 week 3 months 6 months				
themes	intervention	intervention Instances= Instances= Instances=				
	Instances=	Instances=   126   123   175				
	196					

	% occurrence	% occurrence	% occurrence	% occurrence
Concerns about	3.1	16.7 (p<0.01)	4.9	9.7 (p<0.05)
Reasons for medicine	8.7	4.0	4.1	6.9
Action of medicine	14.3	11.9	10.6	9.1
Consequences of medicine non-adherence	1.0	7.9 (p<0.05)	3.3	5.7 (p<0.05)
Expected effects of medicine	22.4	23.0	17.1	16.6
Attitudes toward medicine	23.0	38.1 (p<0.01)	30.1	27.4
Nurse prescriber asks patient opinion about medicine	20.9	36.5 (p<0.01)	26.0	21.1
Patient asks about medicine	5.6	7.9	9.8	5.7

Note: McNemar test statistic not reported by IBM SPSS Data Editor (v.19), only the level of significance.

An initial interpretation of the findings indicated limited amount of medicine beliefs discussion with some positive improvements post-intervention. However, the occurrence of other discussion themes must be taken into account to understand the apparently limited level of key themes discussion (see Latter et al., 2010 for a full list of themes).

Overall, thirty-two discussion themes were coded from the 154 audio-recorded consultations. The most frequently discussed themes included 'Medicine named' which was done so for 74.9% to 87.2% of medicines across the time-points. Other frequently raised discussion themes were 'Usage of medicine' (range: 59.5% to 68.4%) and 'Instructions for taking medicine' (range: 42.9% to 51.1%). These three themes remained the most prevalent at all time-points. The extent of discussion between time-points for these three themes was consistent other than 'Medicine named' which significantly decreased at six months post-intervention (p<0.01).

Of the remaining discussion themes, their frequency of occurrence once a medicine was brought up was considerably lower. Moderately raised discussion themes (between 15-40% of the time across time-points) included discussion about 'control of the problem through medicine', 'observed adverse reaction to

medicine', 'class of medicine', and 'possible adverse effects of the medicine'. Many discussion themes were rarely raised (consistently below 5% across time-points), including 'nurse prescriber recommends medicine as needed', 'waiting period for medicine effect', 'substitute medicine suggested', 'duration of treatment', 'contraindications', 'cost of medication', and 'strength of medication'.

Importantly, 43.8% (n=14) of the 32 discussion themes analysed were raised less than 10% of the time (consistently across time-points) when a medicine was brought up in a consultation. Generally, once a medicine was brought up in a consultation, approximately 5 or 6 discussion themes were linked to that medicine of which half were likely to be 'medication named', 'usage of medicine' and/or 'instructions for taking medicine'. With this bias of discussion toward these three themes, the extent of discussion about conceptually mapped themes appears in a better light. In comparison to other themes analysed, a moderate level of medicine beliefs exploration was observed with some positive change over time.

# 5.4 **Summary**

The previous summary in this chapter presented the demographic profile of participating nurse prescribers and diabetes patients engaged in medicine discussion. This summary presents important aspects of the medicine discussion profile of participating nurses and patients.

Fourteen nurse prescribers provided 154 audio-recorded consultations to be analysed using MEDICODE. Measurements of coding reliability were good and 99 different medicines were brought up during the consultations with a mean of 4.4 different medicines discussed in each. The majority of medicines were for cardiovascular and endocrine-related conditions and classified as 'Active & discussed' and this distribution was stable across all study time-points. This suggests that nurses succeeded in obtaining appropriate consultation recordings for the purposes of this study. The finding of most medicines being currently prescribed (active & discussed) was likely due to the demographic profile of diabetes patients (mean age 56.6 years old and mean years diagnosed with diabetes 10.7 years).

The broader analysis in the wider study (see Latter et al. 2010) coded thirty-two different discussion themes of which three, 'medication named', 'usage of medicine' and 'instructions for taking medicine', frequently occurred in consultations averaging 5 to 6 discussion themes per medicine raised. This finding

suggested nurse prescribers' medicine discussion was akin to previous research which highlighted an administrative approach to medicines discussion.

Key themes conceptually mapped to an accepted definition of medicine beliefs were explored by nurse prescribers. Post-intervention increases in the frequency of discussion of several key themes (i.e. concerns about medicine, attitudes toward medicine) were seen initially and to some extent over time. Discussion about patients' concerns was significantly higher at 1 week and 6 months post-intervention. Key themes linked to a patients' perceived need for a medicine (i.e. reasons for medicine) did not change post-intervention. Based on the overall levels of discussion on medicine-related themes (see Latter et al., 2010), a moderate level of medicine beliefs discussion can be inferred.

# 6. Barriers and facilitators of nurse prescribers' exploration of patients' medicine beliefs

# 6.1 Introduction

As previously mentioned in the methods chapter, each nurse prescriber was interviewed one-month and six-months after completing the intervention workshops as part of the wider study. At these time-points, a substantial part of both sets of interviews were focused on the experience and challenge of enacting an exploration of patients' medicine beliefs in order to address research question 2 for this thesis. Research questions for the wider study and this thesis were addressed at the same time through the same interview stage. For this thesis, the first interview (one-month) focused on early experiences of medication beliefs exploration activity and the second (six-month) on nurses' experience having had time to practice this specific skill. The interview approach, process and conduct were the same for the wider study and this thesis, however, the approach to analysis was different for each study. The coding approach and thematic analysis for this thesis was more comprehensive than the analysis conducted for the wider study. Importantly, the author of this thesis was responsible for all aspects of this interview stage for both studies.

This chapter presents findings from two thematic analyses focused on nurses' perceptions specifically related to their attempts to explore patients' medication beliefs. The thematic analyses of the first and second interviews generated broadly similar categories and themes, therefore, an integrated reporting style was used to present the findings.

# 6.2 Characteristics of nurse prescribers

Each interview was audio-recorded, conducted in quiet surroundings and approximately one hour in duration. One-week prior to each interview, informed consent was obtained in writing and a copy of the interview schedule provided to each nurse.

In total, twenty nurses were purposively recruited based on the inclusion criteria; however, three nurses withdrew and did not participate in the first interviews. Two nurse prescribers withdrew after completing the first workshop (wider study

intervention) and one after completing the second workshop. Seventeen nurse prescribers participated in the first round of interviews (see Table 6.1 for their characteristics). At various points after the first interviews, four nurse prescribers were unable to be interviewed a second time (6-months post-intervention for the wider study). Therefore, thirteen nurse prescribers were interviewed a second time. Reasons for nurse prescribers' withdrawal included a change of job (n=2), an inability to attend the 3rd and 4th workshops for the wider study (n=1), an inability to identify appropriate diabetes patients to audio record (n=1), a family bereavement (n=1), time-constraints (n=1), and no reason provided (n=1). It was not considered ethically appropriate to attempt to re-recruit nurses to contribute toward the aims of this thesis. Therefore, sampling for this thesis was always inherently linked to the wider study and subject to pressures upon it.

Of the seventeen nurses who took part in the first interviews, ten were practice-based nurses, four were diabetes specialist nurses and three were community matrons. Compared to nurse prescribers who fully contributed to providing their quota of consultation audio-recordings, two extra practice nurses and one extra community matron participated in the one-month interviews. Of the thirteen nurses who took part in the second interviews, seven were practice-based nurses, four were diabetes specialist nurses and two were community matrons. Compared to nurse prescribers who fully contributed to providing their quota of consultation audio-recordings, the six-month interview stage had one less practice nurse. There were few differences in the profile of nurses who fully contributed to the quantitative component of the study and those who also participated in the interviews. Thus, the profile of participating nurses (largely nurses from primary care, South Central SHA, middle aged, female, qualified as a nurse for a long time, and over one year as an independent prescriber) was consistent between the quantitative element and the first and second round of interviews.

During the interviews, nurses were asked to reflect on their experience of exploring patients' medicine beliefs. These reflections represented a summation of their experience with a range of diabetes patients over several months of exploration activity. Therefore, it was not possible to accurately link issues raised by nurses with specific patient characteristics or situations. However, it was possible to make general assumptions about patient characteristics based on the inclusion criteria for audio-recording consultations in the quantitative element of the study. Nurses were aware their exploration of patients' medicine beliefs was only relevant for this study if they explored them with adult diabetes patients (either Type 1 or 2), not patients with other conditions, and when an assessment of medicine management was likely to be required, i.e. (a) a new prescription for a

diabetes-related medicine or (b) a change to currently prescribed diabetes-related medicines. Therefore, nurses' reflections would be largely related to patients they audio-recorded and within the context of diabetes medication discussions.

Further general assumptions can be drawn from the demographic profile of diabetes patients presented in section 5.2.3. Diabetes patients were predominately diagnosed with Type 2 diabetes (81.8%, n=126) and had been diagnosed for a mean of 10.7 (SD 11.8) years. The majority were Caucasian (89.0%, n=137) with a mean age of 56.6 (SD 14.34) years. Patients were equally distributed by gender, male 51.3% (n=79) and female 48.7% (n=75). These demographic factors indicated nurses were reflecting on their exploration activity with Type 2 diabetes patients who'd lived with their condition for many years and likely to be aware of diabetes treatment, prognosis, and common management strategies. This profile matched the demographic findings from both literature reviews earlier in the thesis, indicating the findings from this thesis were relevant to the wider body of medicine beliefs literature.

Table 6.1 Characteristics of nurse prescribers participating in the first and second interviews

Nurse ID	Age	Nurse type	Years qualified as a nurse	Months qualified as a nurse prescriber	Participated in first interview	Participated in second interview
PN1	50	Practice nurse	13	23	Yes	No
PN2	54		13	33	Yes	No
PN3	46	Practice nurse	13	28		
	ł	Practice nurse			Yes	Yes
PN4	35	Practice nurse	12	10	Yes	Yes
PN5	50	Practice nurse	23	30	Yes	Yes
PN6	45	Practice nurse	12	24	Yes	Yes
PN7	58	Practice nurse	12	34	Yes	Yes
PN8	39	Practice nurse	12	17	Yes	No
PN9	43	Practice nurse	12	23	Yes	Yes
PN10	42	Practice nurse	18	23	Yes	Yes
CM1	45	Community matron	12	24	Yes	Yes
CM2	35	Community matron	18	15	Yes	Yes
CM3	49	Community matron	6	21	Yes	No
DSN1	48	Diabetes Specialist Nurse	15	28	Yes	Yes
DSN2	50	Diabetes Specialist Nurse	23	29	Yes	Yes
DSN3	49	Diabetes Specialist Nurse	13	21	Yes	Yes
DSN4	38	Diabetes Specialist Nurse	18	22	Yes	Yes

# 6.3 Overview of the analysis

The method of thematic analysis for the nurse interviews in this thesis was a data-driven inductive approach, open to developing latent and semantic themes, and the development of assertions. Codes were labelled as descriptive, value-based, process and emotion codes for the benefit of clear coding. However, they were not used as pre-determined categories as it was likely these would encompass a combination of descriptive, process, values and emotional codes.

In the first round of interviews with nurse prescribers, 82 codes, 16 categories and 6 themes were identified from the transcripts. In the second round of interviews, 124 codes, 19 categories and 9 themes were identified from the transcripts. The categories and themes are presented in Table 6.2. An example of interview coding is presented in Appendix 8 and codes-to-category development is presented in Appendix 9. The number of codes generated was deemed appropriate based on expert guidance on judging what was a code (Creswell 2012, Friese 2012, Lichtman 2010). All advocate an appropriately conducted interview study will likely generate between 80-100 codes, organised in 15-20 categories and 5-7 themes. They advocate such output would likely have the right balance between over and under-coding/analysing the text.

The first interviews with nurse prescribers provided a wealth of information about their medicine beliefs exploration activities with diabetes patients. It was evident they all took exploration activity seriously which was testament to their professionalism and experience. Although interviewed only one-month after their educational training as part of the wider study, only a few comments were made that indicated it was 'too soon to tell'. This indicated nurses engaged with this specific activity right from the start, and benefits and issues were noticeable upon returning to their routine consultations.

Findings from the second interviews compared favourably to the first interviews and an integrated reporting of the two analyses seemed appropriate. Three additional themes were generated from the second interview and these are discussed below. In this analysis I attempted to do more than just provide data. Extracts are embedded within an analytical narrative that illustrated the story of this data in relation to research question 2. The narrative I wish to convey is that of 'tensions' surrounding nurses' activities to enact medication beliefs discussion with patients. These were apparent during the first and second round of interviews.

Table 6.2 Integrated categories and themes from all nurse prescriber interviews

Present in first	Categories and themes from interviews with nurse prescribers			
and	Categories Themes			
second	Categories	Themes		
interview				
Both	Disengaged patients (B)	Patients' willingness to engage in		
Both	Engaged patients (F)	explorations about patients' medicine beliefs		
Both	Patient characteristics that enabled exploration (F)	Managing patient characteristics		
Both	Patient characteristics that hindered exploration (B)			
Both	Consultation diplomat	Varying approach to exploration of		
Both	Active listener	medicine beliefs		
Both	Attacking modifier			
Both	Valued the necessity for exploration (F)	Nurse prescribers' willingness to engage in explorations about		
Both	Nurse prescribers concerns (B)	patients' medicine beliefs		
First only	Collegial support (F)	Contextual pressures in practice		
Both	Interruptions (B)	settings		
Both	Wasted consultation time (B)			
Both	Adequate time for exploration (F)			
Both	Inadequate time for exploration (B)			
Both	Medical model agenda (B)	Agendas in the working context		
Both	Patient centred agenda (F)			
Second	Further consultations (F)	Further consultations required for		
only		exploration		
Second	Nurse confidence (F)	Enhanced nurse prescriber		
only		confidence facilitated exploration		
Second	Rapport (F)	Exploration requires good nurse-		
only		patient rapport		

B = Barrier; F = Facilitator

# 6.4 Experiences of exploring patients' medicine beliefs

A thematic analysis of the first interviews identified six themes relating to nurse prescribers' initial experience of engaging patients in medicine beliefs exploration. The six themes were: patients' willingness to engage in medicine beliefs exploration; managing patient characteristics, varying approach to exploration, nurse prescribers' willingness to engage in explorations, contextual pressures in practice settings, and agendas in the working context. The first two themes were patient-related, themes three and four were nurse-related, and themes five and six were context-related. These themes were also present in the analysis of the second round of interviews. The only difference was the addition of one context-related theme, one nurse-related theme, and one linked patient-nurse theme. These were 'further consultations required for exploration', 'enhanced nurse prescriber confidence facilitated exploration' and 'exploration required good nurse-patient rapport' respectively. Due to the similarity of nurse perceptions from the two rounds of interviews, an integrated presentation of the two thematic analyses was conducted.

Six of the nine themes were composed of conflicting categories and these themes represented a 'tension' for nurses to manage within the context of this medication exploration activity (see Table 6.2). The first six themes combined to form a general level of tension across the various factors influencing medication beliefs exploration work by nurses. These six themes served to generate the meta-theme of 'tension' which led the narrative presentation of these analyses. Three other themes were generated from the second round of interviews but did not contribute to the meta-theme of tension due to the singular dimension of those themes.

# 6.4.1 Patients' willingness to engage in medicine beliefs exploration

The majority of nurse prescribers reported patients' willingness to engage in the process of exploring medicine beliefs could be both a facilitating factor and a barrier to exploration. Codes were categorised into 'disengaged patients' and 'engaged patients' and highlighted the difficult task for nurses to determine and navigate patients' reactions being explored. Most nurses' reported that patients' receptivity to discussing their medication beliefs was by no means universal or predictable.

In the first interviews, one practice nurse said: "It very much depends on the patient. Some people will talk to you about their medicines; others it's like pulling teeth." (Practice nurse 7, First interview)

Another practice nurse stated: "It can be really difficult, some patients just don't want to know, they think they are happy where they are at and don't want to talk about it." (Practice nurse 6, First interview).

Although most nurses dichotomised patients into willing and unwilling, some nurses presented a more complex picture and some explanation for the fluctuating receptivity within an individual, as described by this practice nurse:

"...there are moments when you clue into somebody's beliefs, where they are at that moment, and when they're in the mood to discuss. They recognize that you are in the mood to discuss too and you're giving them the time, space and opportunity. There are other times when you can ask them the best questions in the world and they don't want to go there." (Practice nurse 3, First interview)

Other nurse prescribers' expanded described reasons for patients' unwillingness to engage in beliefs discussion. They indicated patients' defensiveness was in response to unexpected questioning of long-term behaviour, as reported by this community matron:

"I think the difficulty has been because I've started to challenge long term behaviours, they're not newly diabetic...that has initially made a couple of them slightly irritated so we've had to work through a bit of conflict and resolve that at the same time as getting to grips with their knowledge base and what they're doing with their diabetes." (Community matron 1, First interview)

In addition, other nurses attributed patients' defensiveness to perceived alterations in the nurse-patient relationship, as stated by this community matron:

"I've seen them [patients] for a little while and the patient-nurse dynamic is fairly set in a sense. I suppose I'm messing that up a bit because I'm approaching them in a slightly different way than I was before. I think some of them are fine but I think some of them find that uncomfortable." (Community matron 1, First interview)

The willingness of patients to engage in an exploration of medication beliefs remained an important theme from the second interviews, and the vast majority of nurse prescribers re-stated their reliance upon it. This nurse described how patients can arrive at the appointment with a clear agenda and affect the ability to explore:

"It's completely variable as to how people are (a) in their character and (b) on that day to ask questions and really think beyond the surface. For example, I had a lady

yesterday who was really not well controlled on her blood results, and I thought 'great one, I'll go right in there', but her agenda was something completely different when she walked through the door and I knew I wasn't really going to get anywhere with her medications and what she was doing. So you have to deal with what people come with". (Practice nurse 3, Second interview)

A key assertion to make is this activity involves more effort that it would appear. It requires careful judgement about patient receptivity, choosing the right moment, and managing defensiveness. Navigating the willingness of patients to engage in beliefs discussion cannot be assumed to be straight forward and could represent a significant stressor for nurses in their consultations.

# 6.4.2 Managing patient characteristics

The second patient-related tension was centred on observable patient characteristics. Nurses' perceived a range of patient characteristics that served as influencing factors. These could either hinder or enable exploration. This was, once again, a significant tension for nurses as they attempted to explore. When asked about factors that hindered exploration, this nurse stated a widely held belief that patients present with different abilities and diabetes health literacy. For example, this nurse said:

"I think it's very much around their intellectual ability and how interested they are in their own health." (Practice nurse 6, First interview)

In addition, this practice nurse also reported on a universal view that exploration with patients can be hindered by limited diabetes medication knowledge:

"[in the context of medication beliefs exploration] I think a lot of the patients recognise that they don't have the knowledge base around their diabetes or the blood pressure medication, or cholesterol lowering etc. so they do rely very heavily on people that they consider to be more knowledgeable." (Practice nurse 6, First interview)

Most nurses also reported that patients had expectations as they entered the consultation. When patients had strongly held preconceived ideas of how the consultation would unfold, these were widely reported as a hindrance to exploration, as reported by this nurse:

"The patients were very confused by the change in approach [beliefs exploration], asking 'what do you mean what do I think? I have come here for you to tell me." (Practice nurse 7, First interview)

Moving away from patients' volitional behaviour to aspects arguably out of their control, a widely reported situation of having to manage patients with learning disabilities and diabetes was reported. In the context of being asked to explore, this nurse stated:

"...we have a population of patients with learning needs...I'm getting a larger number of patients with learning difficulties who have diabetes, so that's challenging." (Practice nurse 6, First interview)

Furthermore, patients diagnosed with depression was widely perceived by nurses as a hindrance to medication beliefs exploration:

"I just wanted to mention depression, obviously it can hinder the success of your consultation. Obviously a lot of patients with chronic illness have depression so, obviously, if they've got this overwhelming them, then it makes it very difficult to try and focus on the business of taking medications appropriately." (Diabetes Specialist Nurse 3, First interview)

The second round of interviews presented similar examples of patient characteristics as influential factors that could hinder or enable exploration. Two notable differences in examples of influential factors were habituation and past experience. This nurse reported on the problem of habituation:

"It is very hard for a lot of people with diabetes to do things differently, even if there is an obvious reason to do it, they still find it hard. Especially people that have been on a particular insulin for a long time, you will talk to them about doing it differently [in the context of medication beliefs exploration]...they will give it a week and go back to what they were doing before...it is just people get comfortable with what they are doing." (Diabetes Specialist Nurse 4, Second interview)

Another nurse stated the problem of previous experience, and how that can influence exploration:

"I am thinking of a lady whose sugars are appalling. She had only recently registered with us and she gave a very bad history of her treatment, e.g. she does not want to see a dietician, because they were all rubbish, nothing works, nobody listens. So that was quite a hindering factor. Past experiences are a definite hindrance, because that is going to take me several visits until she will actually take on board or believe that I have anything to offer...the people who do take it on board, they are more than happy to look at their belief systems to see if there is anything they could change." (Practice nurse 7, Second interview)

A key assertion to make is nurses' face significant hindrances to enact this type of consultation activity based on the characteristics of the patients they care for. Any of the example characteristics, if present or absent, could hinder or enable beliefs exploration. Interestingly, there is potentially the need for nurses to 'profile' patients during/before the consultation so nurses know how best to proceed with those who present with a number of characteristics unconducive to exploration activities. It is possible that some patients with particular profiles cannot or will not engage in medication explorations and there may be nothing nurses can do about it.

# 6.4.3 Varying approach to exploration of medicine beliefs

A nurse-related tension involved nurses' approach to medication beliefs exploration. Typologies of approach were generated from the interpretation of nurses' perceptions, rather than their explicit descriptions. This latent approach was undertaken to deal with the rich information available in the interviews. It appeared nurses, collectively, had three types of approach.

The first inferred approach involved nurses as 'consultation diplomats'. This style was demonstrated by reports of agenda management, advocating for patients, and judgement of patients' capabilities. This was described by this nurse:

"I very much feel that I've got to be their advocate, if you like. So, trying to help them be actively involved in the consultation but knowing their limitations and their mental capacity to actually assimilate information." (Practice nurse 6, First interview)

This style was also inferred from the second round of interviews, as described by this nurse:

"[I've asked] how do they feel about taking tablets...just so that you can get their focus and find out what they want from that consultation, because you have got one idea and they walk in the door and they have got a totally different agenda quite often." (Practice nurse 10, Second interview)

The second inferred approach involved nurses as 'active listeners' during their exploration attempts. This was perceived as vital to get to the truth of patients' beliefs and was demonstrated clearly by this nurse:

"A student came out with me for a day, came and sat in with one of my patients that is a challenging lady. She [the student] said if I hadn't seen what you had done, I would have been in there so many times to fill gaps. I was leaving quite

lengthy gaps to make sure that the patient filled them with information. She did and it was really rich information...it's the power of leaving the gap, if you leave the gap long enough you actually get the true answer." (Community Matron 2, First Interview)

This style was also inferred from the second round of interviews, as described by this nurse:

"I do reflect back to people much more and say 'you mentioned this, what do you mean by that?' I will listen to what they are saying and revisit if they have said something." (Diabetes Specialist Nurse 4, Second interview)

The third inferred approach was 'attacking modifiers'. Statements by nurses explaining their approach were considered pro-active, deliberate and conscious attempts to modify patients' ideas about their medication. For example, this nurse stated:

"I have tried and I've had some success of trying to dig, you know, as to why people are doing what they're doing, and then other times people really don't want to engage." (Practice nurse 3, First interview)

This style was also inferred from the second round of interviews, as described by this nurse:

"...getting them to a place where they can actually think 'Well actually that is what Great Aunt Maud always said' and then you say 'Is Great Aunt Maud all right? She is daft as a box of frogs. So why do you still believe what Great Aunt Maud said?' In some people you can see the light go on. (Practice nurse 7, Second interview)

As a key assertion, nurses' reported the use of different approaches – albeit not always explicitly – to explore medication beliefs, but this was inferred from an amalgamation of interview responses. It wasn't obvious from the transcripts if individual nurses moved between these approaches to suit the situation and patient. Also, no explicit evidence was identified about the order of these approaches.

The tension within this theme of varying approaches was inferred from the findings. Having reported previous tensions of patients' willingness and characteristics, it would seem reasonable that nurses could feel pressured to move between different approaches to suit the situation. The ability to deal with this pressure would be an influential factor, i.e. a barrier if not dealt with and a facilitator if overcome. This may not be a competency issue, as all the nurses in

this study were experienced, but the need to use different approaches under time and contextual pressures could be significant. The latter pressures are reported as themes later in this analysis.

# 6.4.4 Nurse prescribers' willingness to engage in explorations about patients' medicine beliefs

Another nurse-related theme and tension was centred on nurses' own willingness to explore. Nurses reported a range of beliefs about their experience of exploring patients' medication beliefs. All nurses perceived the value of exploration to enhance patient outcomes and their own practice, as described by this nurse:

"It's really, really useful...I think the saddest thing I've heard, was asking a gentleman, 'what are your beliefs? What does it mean to you?' He just turned round and said, I'm going to lose my legs...I'd been seeing for a year up until that point and I kind of thought, how do I not know this about you? '[he said] that's just the way is happens. It doesn't matter what you do, doesn't matter what we talk about, doesn't matter what happens, doesn't matter whether I take my medication or I don't, you lose your legs'." (Community Matron 2, First interview)

This perception was also seen in the second interviews:

"I wish I had done something like this [at the] beginning of my nurse practitioner degree because I think I would have developed those skills a lot sooner and not really at the end of it! I think it would have enhanced a lot of my practice that I did years ago, If I had those skills on board." (Practice Nurse 9, Second interview)

However, a tension was apparent when the majority of nurses also reported two important concerns about exploration activity under their control (i.e. not contextual issues). Firstly, many nurse prescribers voiced the opinion that exploring patients' medicine beliefs was an ongoing learning process and took motivation. All nurses accepted an exploration would be useful but most stated practice was required to learn how to fit this type of activity into their consultations. They reported that focusing on the application of an exploration required a conscious effort, as stated by this diabetes specialist nurse:

"I did a clinic Tuesday afternoon and was really overloaded...it shouldn't take long but you have to be more conscious about it [medicine beliefs exploration]. In these early days, I am hoping more will be assimilated by osmosis so I won't have to think so hard." (Practice nurse 3).

In addition, the second interviews highlighted the need for many nurses to maintain their conscious effort to change, as demonstrated by this nurse:

"I have decided, like with anything else, you need to practice to change the habit, because I have got habits from the last 20 or 30 years and I am consciously trying to use the [exploration] skills so that it becomes unconscious. At the moment I'm having to do it consciously because I'm having to get rid of other habits." (Diabetes Specialist Nurse 2, Second interview)

The second concern reported by nurse prescribers was linked to where medication beliefs exploration might lead them. These concerns were perceived to be a hindering factor as exploring medicine beliefs could potentially be uncomfortable, as stated by this practice nurse:

"There was a point where I was thinking 'oh my god, if I start asking these questions I'm going to open up a can of worms and I'm not going to know where to go with it'...and going out of your, kind of, confidence zone, or where you know that you can help people, is quite uncomfortable." (Practice nurse 10, First interview)

This concern was also expressed by many nurses in the second interviews, for example:

"I've explored and not been unable to offer any sort of help to them...I feel maybe I've opened something, a can of worms and exposed something and I don't feel confident I have made them feel confident going out the door, but maybe the patient has. I don't know." (Practice Nurse 5, Second interview)

Whilst these concerns may inhibit nurse prescribers from their exploration efforts, some nurses did accompany their concerns with the caveat that the means justify the ends. One community matron summarized this point well:

"I've opened a can of worms with some patients, I had been labouring under the misapprehension that they were actually managing quite well, that they understood what they were doing, that they were taking their medications...I'm now, in a sense, creating work for myself because I've found that's not the case. I've had to start working harder with them and getting to grips with what exactly is going on...I'm hoping that in the end, in the long term, it will actually reduce work, I mean its short term misery for long term gain so it's fine." (Community matron 1, First interview)

The conflict between knowing exploration is a good idea but challenging to enact was an important assertion to make. Having learnt about the value of patients' medicine beliefs during the intervention workshops of the wider study, it appears time and energy was required to engage in an exploration of patients' medicine beliefs in practice settings. Nurses' willingness to explore was a facilitator but it co-existed alongside genuine concerns which can be considered barriers. The final quote hinted that nurses could potentially overcome these concerns over the long-term and with more exploration practice. Importantly, it would appear it is not a small matter to explore patients' medication beliefs, it takes energy and focus. Moreover, whilst nurses are attempting to engage with patients' beliefs, they are also engaging with their own.

# 6.4.5 Contextual pressures in practice settings

This theme was generated from a range of contextual pressures reported by nurses. Once again, a tension exists between contextual factors that support and hinder exploration.

Several nurse prescribers described a high level of support from their colleagues in practice settings, however, this was only reported in the first round of interviews. In the context of exploring medicine beliefs, this diabetes specialist nurse stated:

"Colleagues' help and support is also very much valued...I think I've always kind of valued colleagues and you know, bounced ideas, and say, 'Oh can I just discuss this patient', or 'What would you have said?', or 'What would you have done?' But I think having time to reflect and sort of re-evaluate that, that aspect of what we do has been useful." (Diabetes specialist nurse 3, First interview)

Similarly, practice nurses were equally praising of their colleagues, as cited by this practice nurse:

"Everybody is very supportive. They all know what I'm doing and they've all seen copies of it all. When I need extra time, I build it in." (Practice nurse 7, First interview)

Some practice nurses went further and highlighted the nature of involvement with other colleagues:

"I've given a brief summary and overview to the whole clinical team about what I've been doing and talked to them about my explorations...I've had some feedback from the clinical team about some of the different changes in the [patient] notes that I'm making, around beliefs." (Practice nurse 6, First interview)

However, although colleagues supported the activity, exploration attempts could be hindered through the absence of colleagues and having to cover their work, as demonstrated by this practice nurse:

"There have been a lot of changes in the workplace, there's been shortage of staff and people going off sick, so I haven't necessarily had the time I would have like to explore. I think there has certainly been times when it would have been nice to have had more time to explore, experiment with ways of discussing things."

(Practice nurse 4, First interview)

This theme was generated from perceptions of practice nurses and specialist nurses. Interestingly, community matrons did not mention collegial support which may be due to the nature of their work. Despite their placement within community teams and regular contact with other professionals, their day-to-day activity, including consultation scheduling, can be relatively autonomous. But the absence of discussion about collegial issues could also be related to the limited number of community matrons (n=3) present in the interview sample.

A disruptive work setting was a contextually-based barrier reported by many nurse prescribers. Most nurses had to contend with other situations and agendas imposed upon them during their normal working routine. Some nurses were brief to the point of disillusionment in their description, as stated by this hospital-based diabetes specialist nurse:

"Sometimes in a real environment it is quite difficult." (Diabetes specialist nurse 2, First interview)

Some practice-based nurse prescribers working in two physical locations or more highlighted the possibility of different levels of disruption depending on their clinic location, as reported by this nurse:

"Interruptions...here you get interruptions which I discovered. But over the road, you don't tend to get so many...I think again that can definitely affect the train of thought [for medicine beliefs exploration]". (Practice nurse 4, First interview)

Other nurse prescribers elaborated on the nature of these disruptions and what it meant for them and their exploration attempts, as cited by this practice nurse:

"A lot of the equipment is in the room that I work in and you're forever getting taps on the door, 'Can I have this?' So you're just getting into a flow and once or twice I've had to stop and then start." (Practice nurse 10, Second interview)

In addition, nurses in both rounds of interviews highlighted the obvious fact that the absence of patients would hinder exploration and waste consultation time, as reported by this nurse:

"The key problem comes if they don't turn up, then obviously it's a large amount of time that's wasted." (Practice nurse 6, First interview)

The final contextually-based influencing factor was time to explore, i.e. having an adequate or inadequate amount of time to do so. Many nurse prescribers reported time limitations within their work context as a barrier to the exploration of patients' medicine beliefs in practice. This was present in each of the three contexts participating nurses occupied. For example, this practice nurse stated:

"I think you've got to have time [for medicine beliefs exploration] in your consultation. I work to 20 minutes and during that I've got to do eyes, feet, medications, the whole caboose, make sure they've had their retinal screening. So you are kind of tight-ish for time." (Practice nurse 3, First interview)

In addition, this community matron said:

"I think one of the barriers [of medicine beliefs exploration] is time. Knowing that you've got X amount of visits to do in a particular day, and you've got to do them, and to get what you want to get out of a consultation." (Community matron 3, First interview)

Similarly, this diabetes specialist nurses stated:

"I think it has been more difficult at times, because I think to myself I'd like to go further [with medicines beliefs exploration] with this gentleman or lady and I can't because I really have not got the time! So that kind of irritates me a bit, but I think that's just life and just what we do, and the only way I can sort of get round this is to bring them back again." (Diabetes specialist nurse 1, First interview)

Findings from the second interviews indicated time, as an influencing factor, remained relevant. For the majority of nurses, the exploration of patients' medicine beliefs was once again affected by time pressures irrespective of nurses' work context and highlighted the systemic barriers to nurse prescribers' exploration attempts. This diabetes specialist nurse exemplified this belief:

"I suppose the only time when there might be a drop off [in exploration] is when I am really, really busy and just lack of time and having a really busy clinic."

(Diabetes specialist nurse 4, Second interview)

Another diabetes specialist nurse elaborated on this point and indicated one of the rare occasions where unexpectedly obtained consultation time can be taken advantage of:

"The problem is, you know, it sounds boring because it is thrashed around so much: 'Sometimes I have got five patients waiting and I really haven't got time to enlarge on this' [to explore medication beliefs]. I mean I have had some occasions where patients have cancelled so I can see another patient for about 45 minutes and achieved quite a lot and then time is a good factor. Maybe I'll think about that and see less patients but more thoroughly and get something more and beneficial from their point of view. So, it is difficult to implement because people just come in with the hordes of referrals but I am going to start seeing less and doing more." (Diabetes specialist nurse 3, Second interview)

Nurses work in dynamic environments with multiple activities ongoing, with a reasonably high chance of interruption, with the problem of missed appointments, and time limitations. When these contextual problems exist, they do not support activity such as the exploration of patients' medicine beliefs. This type of affective consultation discussion requires time, energy and space to enact but this will be difficult to operationalise in disruptive settings or locations that do not acknowledge the importance of this type of activity.

# 6.4.6 Agendas in the working context

An important influencing factor on medication beliefs exploration was agenda in the workplace. Tension existed between tasks to assess and evaluate the biological outcomes of diabetes care and patient-centred activities such as asking questions about diabetes care and medication attitudes.

In both rounds of interviews, some nurses were generally focused on the biological outcomes of diabetes and would appear to prioritise a medical model approach to care. As described by this nurse:

"I get 20 minutes for a diabetes check. Once you start talking to somebody, their medication and other issues, you can just spend that 20 minutes, it just goes and you find you've not done any of the foot checks or other things as well, so it's a case of just weighing up how you are going to spend that time for your consultation." Practice nurse 2, First interview)

Whilst others recognised the need for both agendas:

"It has made me re-evaluate. Instead of just sticking to the template that we have got on our computer screen, it is very focused on getting points on the GPs money." (Practice nurse 10, First interview)

"I am now trying to be much more conscious and focused on the patients' agenda. So allowing patients to kind of have their say more forcefully and perhaps to lead and try and direct the consultation sometimes or more often." (Diabetes Specialist Nurse 3, Second interview)

Furthermore, some nurses recognised that exploring medication beliefs was unlikely to occur using a medical model approach or by focusing solely on biological outcomes in diabetes care, as described by this nurse:

"I think I already had some skills in people listening and open questions, those kind of things. But I was aware that I wasn't necessarily gauging people's beliefs and I had a bit more of a didactic 'you will take your medicine, I know what's best' kind of approach. With tablets it's tended to be just 'do this' so I think I have changed or am changing in the way I look at that." (Practice nurse 3, First interview)

Nurses' reported their experience of medication beliefs exploration in the context of different agenda, namely a medical model agenda and a patient-centred agenda, in diabetes care. Some nurses talked of re-evaluating their approach and avoiding templates for care which highlighted nurses were aware of these two broad agendas and they would appear to be at odds with one another, particularly in the context of having enough consultation time. Nurses acknowledged the benefits of a patient-centred approach but there was a clear tension in task selection and the sense of what could be done in the time available. Furthermore, it would be wise to acknowledge the influence of contextual agendas in the behaviour of nurses; particularly in practice settings whereby templates for care (in the form of the Quality and Outcomes Framework) have their own goals for nurses to focus on. With this in mind, as medication beliefs exploration is arguably new work for nurses, exploration activity is likely to be operationalised in a subordinate position to the medical templates for care currently in use.

# 6.4.7 Further consultations required for exploration

Time limitations were reported in both rounds of interviews, however, in the second interviews the idea of exploration over multiple consultations was a facilitator to exploration. This was only reported in the second interviews. Most nurse prescribers asserted they required time to explore patients' medicine beliefs

and such activity should not be treated as a one-off consultation experience. Furthermore, this perception was present in all three nurse prescriber contexts.

In practice settings, this nurse stated:

"I feel if I'm seeing the patient for the first time and they've got some beliefs that I've discovered, then we have another consultation to have time to explore that." (Practice nurse 5, Second interview)

In addition to highlighting contextual agreement on this issue, this example demonstrated additional consultations could be an answer to disruptive settings:

"I think when you are in a clinic situation you can be pressurized with phones ringing, bleeps going off, and people coming in to ask you to see more patients, and therefore you are constantly interrupted when talking to your patients...on the whole you are better off to bring them back if it's convenient to them." (Diabetes specialist nurse 1, Second interview)

Similarly, community matrons agreed with additional consultations but also suggested there was a natural order in which beliefs exploration would occur in the case of new patients:

"The first couple of meetings are very set orientated tasks to get through the paperwork and then get through the physical assessment. Its only on meeting three of four that you start to bring in questions about exploring their beliefs." (Community matron 2, Second interview)

Nurses recognised the need for space to discuss medication beliefs and adapted. Exploration is complex, new, requiring adaptive action, and would appear to be a lot more work than guidance principles would suggest. 'Exploring beliefs' does not appear to be the kind of task that can be checked off a list when required. Also, it appears it cannot just 'happen' when needed.

# 6.4.8 Enhanced nurse confidence facilitated exploration

At the second interview point and as their exploration experience increased, nurse prescribers' reported an increase in their confidence to explore medication beliefs. This finding was universal across all nurses and this analysis has interpreted this finding as a facilitating factor. All nurse prescribers shared a common view, exemplified by this diabetes specialist nurse:

"I am willing to be a little bit more confrontational or challenging towards the patients and quiz them a bit more about their beliefs. If they say 'well actually I

don't take my Metformin three times a day because actually it gives me diarrhoea...' you now know and it gives you more confidence to probe a bit more to get down to the nitty-gritty. Obviously, when you can do that it is useful because you are finally getting to the bottom of what they feel about medicines and also why their HbA1c is 10%." (Diabetes specialist nurse 3, Second interview)

Nurse prescribers' perceived increase in confidence was a promising sign that they believed in the value of an exploration of patients' medicine beliefs. Subsequently, it is proposed that nurse prescribers' confidence is a facilitating factor as an absence of confidence would likely result in disengagement.

# 6.4.9 Exploration requires good nurse-patient rapport

At the second interview point, many nurse prescribers expressed the opinion that good nurse-patient rapport would facilitate the exploration process.

"I think when you build up a relationship with people over time then they do disclose things to you. They trust that you are not going to put them down or laugh at them and they will then start to tell you other things. I have patients that are saying things to me like 'I will not tell this to anyone else'." (Practice nurse 10, Second interview)

This theme was not surprising as a good relationship was intuitively likely to improve the likelihood of engagement in challenging conversations about patients' beliefs. Having a safe and established rapport would set the scene for discussions that may result in tense moments or attempts to modify/optimise patients' medication behaviour. Importantly, whilst not explicitly stated, this finding could indicate that an absence of rapport could be a significant barrier to beliefs exploration. In situations whereby the nurse knows little about patient characteristics, attitudes, and medication history, it would not be surprising to learn nurses were reluctant to probe into patient ideas about their medication.

# 6.5 Reflexive observations

Consistent with a pragmatic approach, a qualitative method was chosen to operationalise this element of the thesis. Thus, it was considered appropriate to examine my position as a researcher operationalising this study. As previously mentioned in section 4.8, to achieve confirmability researchers must take steps to demonstrate that findings emerge from the data and not their own predispositions (Shenton 2004). A reflexive exercise undertaken during this analysis helped to ensure this.

Throughout the data collection and analytical stages I considered how my actions may influence nurses' activity and responses. This exercise highlighted two ways in which I may have influenced participating nurses. Firstly, as a non-clinical researcher with a psychology background, I have some differences in interests and approach to health care. Also, I do not have diabetes or other long-term condition to provide me with direct experience of diabetes care. All these factors have undoubtedly affected my approach to this research.

Secondly, as a non-clinical researcher, nurses may have responded to me differently than to colleagues with the same background as themselves. Prior to the interviews I took time to familiarise myself with current issues and practice norms. During the interviews I tried to convey a friendly and non-judgemental approach whilst ensuring I was, and appeared to be, informed about their working context. Despite this, some nurses may have tailored their responses to what they perceived as an outsider and held information back. As a male, they may also have responded differently to me given their immediate peer group were likely to be largely composed of female colleagues. Although it was possible the latter two issues affected the interviews, it was not explicitly evident in the interview transcripts or my recollections of the interviews. Therefore, on the whole I concluded the interviews were conducted in the best manner possible and the responses were reflective of nurses' true experience.

# 6.6 Summary

This chapter has presented findings from the two rounds of nurse prescriber interviews. For this thesis, nurse prescribers' initial experience and long-term perceptions of engaging patients' about their medicine beliefs were integrated into one presentation of findings. In the first round of interviews with nurse prescribers, 82 codes, 16 categories and 6 themes were identified from the transcripts. In the second round of interviews, 124 codes, 19 categories and 9 themes were identified from the transcripts.

The first interviews with nurse prescribers provided a wealth of information about their medicine beliefs exploration activities with diabetes patients. Findings from the second interviews compared favourably to the first interviews and an integrated reporting of the two analyses seemed appropriate. Three additional themes were generated from the second round of interviews.

This analysis not only permitted the identification of barriers and facilitating factors, but also generated an analytic narrative that illustrates the story of this

data in relation to research question 2. The narrative present in the data was one of 'tensions' surrounding nurses' activities to enact medication beliefs discussion with patients. These tensions were apparent during the first and second round of interviews. The themes generated, barriers and facilitators were incorporated into the conceptual model developed in chapter 8.

# 7. Diabetes patients' experience of medicine beliefs exploration during routine consultations

# 7.1 Introduction

To evaluate the perceptions of diabetes patients engaged in medicine beliefs exploration with nurse prescribers (objective 3), semi-structured telephone interviews were conducted with a consecutive sample of diabetic patients one week after they had consented to take part in a consultation recording with their nurse prescriber. This chapter presents findings from a thematic analysis of participating diabetes patients.

The method of thematic analysis for the patient interviews was a data-driven inductive approach, open to developing latent and semantic themes, with the goal of assertion development. The nature of data collection, timing and sampling issues has been described in sections 4.4.4 and 4.7. On the issue of authorship, I was responsible for undertaking the interviews and their subsequent analyses.

# 7.2 Characteristics of interviewed diabetes patients

Overall, 154 audio-recorded consultations with diabetes patients were included in the MEDICODE analysis to address objective 1 (see section 5.2.3). It was from this finite number of consultation recordings, in which diabetes patients will have discussed medicine beliefs, that a sample of patients was obtained and interviewed.

Of the 154 audio-recorded consultations, 44 (28.6%) were pre-intervention audio-recordings for the wider study and therefore medication beliefs exploration was unlikely to have occurred. Thus, these diabetes patients were not approached. Of the wider study's post-intervention audio-recordings (n=110), 51 (46.3%) diabetes patients were not contactable within one week of their recorded consultation and therefore excluded, 15 (13.7%) diabetes patients were not contactable at all, 15 (13.7%) diabetes patients declined to participate without giving a reason, and 1 (0.9%) diabetes patient agreed to participate but then withdrew due to ill-health. Twenty-eight diabetes patients (25.4%) were interviewed. As previously mentioned in section 5.4.3, expert discussion has indicated a size sample of approximately 30 interviews offers the advantage of penetrating beyond a very small number of

people without imposing the hardship of endless data gathering, especially when researchers are faced with time constraints or other pressures upon sampling (Baker & Edwards, 2012). As sampling decisions were linked to the wider study, there were constraints on the availability and applicability of diabetes participants. Despite this, an appropriate consecutive sample was obtained. Importantly, no new themes were uncovered in the last three interviews conducted and indicated data saturation had been reached. This provided further assurance of the validity of this sample.

Twenty-eight patients consented to be interviewed about their perceptions of their recent consultation with their nurse prescriber (see Table 7.1). All telephone interviews were 20 to 30 minutes in duration. All participating diabetes patients were Caucasian, most (82.1%) had Type 2 diabetes and the majority were male (60.7%). The mean age was 60.6 (SD 11.8) years and mean duration of diabetes was 13.3 (SD 11.8) years. Most patients were linked to nurses in GP practice settings (71.4%, n=20), with seven linked to diabetes specialist nurses and one to a community matron. This distribution of patients was expected due to the sampling of nurses undertaken. Furthermore, it was representative of the range of nurses involved in diabetes care.

Table 7.1 Characteristics of diabetes patients participating in the interviews

Patient	Age	Gender	Diabetes	Diabetes	Linked to
ID			Туре	duration	nurse
				(years)	
ID01	52	Male	1	45	DSN2
ID02	57	Female	2	4	DSN3
ID03	85	Female	2	7	PN5
ID04	68	Male	2	6	PN3
ID05	62	Male	2	2	PN3
ID06	66	Male	2	9	PN6
ID07	66	Female	2	8	PN6
ID08	64	Male	2	28	PN7
ID09	44	Male	2	8	DSN3
ID10	53	Male	1	26	DSN4
ID11	67	Male	2	3	PN3
ID12	44	Male	1	43	DSN3
ID13	52	Male	1	45	CM1
ID14	73	Male	1	47	PN9
ID15	62	Female	2	4	PN9
ID16	72	Male	2	7	PN9
ID17	65	Female	2	7	PN9
ID18	45	Male	2	3	PN6
ID19	69	Male	2	9	DSN1
ID20	43	Female	2	6	DSN1
ID21	54	Female	2	7	PN7
ID22	56	Female	2	4	PN10
ID23	62	Male	2	3	PN6
ID24	60	Female	2	4	PN6
ID25	60	Female	2	6	PN6
ID26	71	Male	2	9	PN6
ID27	66	Male	2	19	PN9
ID28	26	Female	2	3	PN9

DSN = Diabetes Specialist Nurse; PN = Practice Nurse; CM = Community Matron

# 7.3 Thematic analysis of patient interviews

A thematic analysis of the patient interviews identified 63 codes, 23 categories and 7 themes from the transcripts. An example of interview coding is presented in Appendix 10, code to category development in Appendix 11, and the categories and themes are presented in Table 7.2.

Seven themes accounted for diabetes patients' perceptions of consultation discussion: High satisfaction with nurse prescriber consultation and service; Successful medicine management perceived by patients; Medication beliefs discussed; A sense of rapport facilitated discussion about concerns; Patient-reported concerns about their medication; Patients self-reported approach to exploration discussion; and Patients' perceived nurse approach to exploration.

The first two themes were generated to account for the broad statements about nurse prescribers and their role. Patients were keen to highlight broader issues during the interviews, despite the focus on medication beliefs discussion. With that in mind, I've taken the approach of moving from the broad to the specific in my presentation of this data. In doing so I have acknowledged patients' broader values and kept the discussion of themes focused on addressing the aim of this element of the thesis as much as possible. Issues that affected the depth of data collection are discussed in section 7.5.

### 7.3.1 High satisfaction with nurse prescriber consultations and service

This broad theme encapsulates a range of patients' perceptions regarding a high level of satisfaction with their nurse prescriber consultations. Even though the focus of the interview was largely on medication beliefs exploration, patients were keen to report on their broader experiences. Categories of codes included perceptions of nothing detrimental about their nurse consultation, nothing missing from their nurse consultation, a preference to interact with nurses, reports of good accessibility to their nurse and satisfaction with decisions made by their nurse.

Firstly, patients strongly reported that there was nothing unhelpful or detrimental about the consultations with their nurse prescriber. When invited to discuss negative aspects of their consultations, none were reported and the majority stated a high level of satisfaction with their nurse prescriber. When asked if

anything unhelpful or detrimental occurred during their recent nurse prescriber consultation, this patient responded:

"No I've never really experienced that. If I did I would say at the time, if there was something she said that I didn't like, it would be on the record and I'd tell you." (ID08)

Secondly, many patients reported a high level of satisfaction that there was nothing missing from their nurse prescribers consultations. This patient stated:

"It's always been very complete [the consultation] and I've always gone away happy in the thought that everything has been covered and hopefully everything is under control." (ID11)

Thirdly, many patients reported their satisfaction with the amount of general medication information received within their nurse prescriber consultations. This patient stated:

"I'm told what medication does what, it's all explained thoroughly from start to finish you know, all the tablets, the insulin, yeah she does, she actually starts at the core and works her way up and tells me all which is great." (ID09)

Thirdly, most patients reported good satisfaction with the medication information provided by nurses, as reported by this patient:

"[nurse] wrote everything down for me what I was going to do through the day so it was like, because I am on tablets and the insulin, it was right, you take this one at this time of the day and you take that one at that time of day....[then the nurse said] hang on, I will just write it all down for you and then, you know, we'll go through it again later on, so yes, everything was really made clear." (ID20)

Another form of high satisfaction was evident from the majority of patients' preference to see their nurse for their diabetes care, as reported by this patient:

"I much prefer to see her because she seems to know all about it and everything, I mean I'd much, much rather go to see to her, see her if it's about the diabetes than go and make an appointment with the doctor because I find, I don't know I sort of, you feel that she's so, she knows everything about it and whatever she tells you is the right thing." (ID07)

The majority of patients were also highly satisfied with the accessibility of their nurse, as described by this patient:

"I can pick up the phone to her [nurse] any time when she's on duty in the course of the day if I have any problems, where the doctor is hard to get hold of...you know I get a very good service." (ID09)

It was clear from the various demonstrations of satisfaction that participating patients were content with the services provided by their nurse prescriber. This broad theme perhaps demonstrates the professionalism of participating nurses and their mastery of diabetes support services. Interestingly, it was not possible to disentangle whether the high satisfaction reported was an outcome of the beliefs exploration process in a consultation likely to be highly patient-focused.

Table 7.2 Summary of the thematic analysis of the patient interviews

Categories and themes from the patient interviews

Categories	Themes	
Nothing unhelpful/detrimental about their nurse	High satisfaction with	
consultation	nurse prescriber	
Nothing missing from their nurse consultations	consultation and service	
Satisfaction with general medication information		
received		
Prefers to see a nurse		
Good accessibility to nurse		
Nurse has medication information-providing role	Successful medicine	
Nurse has medication adjustment role	management perceived	
Appropriate medication decisions by nurse	by patients	
Good practicalities / collection of medication		
Medication concerns addressed by nurse	Medication beliefs	
Concerns were not only discussed but acted upon	discussed	
Nurse discuss patients' perceptions of necessity for their		
medicines		
Patients did not perceived a change in consultation		
discussion		
Patients' report the need for rapport	A sense of rapport	
Patients' report link between rapport and discussing	facilitated discussion	
concerns	about concerns	
Generally resistant to medication	Patient-reported	
Side effects concerns	concerns about their medication	
Patients concerned about personal medication	- medicación	
management		
Passive enquirer approach	Patients self-reported	
Self-manager approach	approach to exploration	
	discussion	
Nurse time manager role	Patients' perceived	
Active enquirer role	nurse approach to	
Active listener role	exploration	

# 7.3.2 Successful medicine management perceived by patients

A second broad theme described how most patients perceived medicine management as an important and successful element of nurse prescriber's work in the diabetes context. Categories of codes included perceptions that nurses undertook an information-providing role, a medication adjustment role, undertook appropriate medication decision-making, and appropriate logistical arrangements for medication usage.

Some patients linked their nurse prescriber with a specific informational role relating to the usage of medicines, as demonstrated by this patient:

"She explains to me how I should I take them [medication] before the food, before breakfast or after the food, same for the lunchtime doses and the evening doses." (ID09)

Others reported nurse prescribers' role in proactive adjustment of medication in order to the control the problem, as stated by this patient:

"...she explained to me when she looked at all the results of the different tests on the computer 'oh your sugar level is up 0.2' or 'when it was up 0.2 last time so we are going to put you on another tablet, can you take an extra tablet a day?' and I said 'yes I will take it lunch time'." (ID05)

Also, many patients reported appropriate medication decisions were made by their nurse prescriber, as reported by this patient:

"The decision on what kind of insulin [nurse] put me on now was tremendous...it was delayed because she quite literally wanted to examine all the possibilities as new variations came in and she decided in January of this year...she was right to delay it. She was probably able to come up with a more effective answer by delaying to the end of January." (ID12)

In addition, some patients reported how their nurses organised the collection of medication, for example:

"...she is very good and they have a system whereby they do a printout of all the things I take that I take...if I find that I'm running short of one thing I can put in a prescription and then she will do that immediately and then I get it from the chemist within a couple of days." (ID12).

These examples highlighted patients' perception of nurse prescribers as reliable information providers and managers of diabetes medication. Perceptions on these topics were prevalent and emerged despite specific questioning about medication beliefs exploration. This broad theme builds on the high levels of satisfaction found in the previous theme, and established nurse prescribers are undertaking appropriate medication work and received positively by patients. However, the categories underpinning these first two themes largely relate to administrative medication activities. The next three themes address affective medication communication and activities as perceived by patients.

#### 7.3.3 Medication beliefs were discussed

The third theme brought together a range of codes and categories whereby patients elucidated their experience of having their medication beliefs explored. As previously discussed in chapter 1, medication beliefs can be broadly defined as 'concerns about' and 'necessity for' medication. This theme addressed this broad definition and examples are provided below.

Most patients explicitly reported their medication concerns were addressed by their nurse prescriber, as asserted by this patient:

"I've been taking blood pressure tablets but just recently it was the first time I've sat down with anybody and discussed things [medication concerns]...I said to her [nurse prescriber] that's why all of a sudden I think I got my blood sugars down a bit because it was the first time that anybody had ever sort of really sat down with me, you know, and chatted about things." (ID10)

Another patient highlighted the experience of many that concerns were not only discussed but acted upon, as demonstrated by this patient:

"It was first called Humulin but it turned out I was one of perhaps 5% of people who couldn't have that...I could have pork Act Rapid but unfortunately a message came through from the manufacturer that they were going to stop making it. Anyway, she [nurse prescriber] very kindly found there was another manufacturer also in Denmark." (ID12)

In addition to discussing and acting on patient concerns, patients also described how nurses' engaged in discussion about the need for their medication, as stated by this patient:

"...it was discussed why I was taking it and explained to me if you are overweight the medicine does not work as well because it is covering a bigger area of your body and that sort of thing. It was very informative." (ID05)

This was an important confirmatory theme to support the validity of this thesis. In conjunction with the empirical observations made in the quantitative element of this thesis, there can be no doubt that medication discussion did occur during the consultations.

Although the important elements of medication beliefs appeared to be discussed during consultations, some patients did not perceive a change in consultation discussion. This tension within this theme appeared to have originated from being

asked if the audio-recorded consultation was different in any way. This patient described how some felt:

"No I don't think so, I mean, you build up a relationship with your nurse don't you and over the years I've been going there...I mean we know one another and I think it wasn't any different, I mean if there is any advice I need or I want then I would ask her you know and she would tell me, has helped me. But I don't think it was any different." (ID06)

However, in response to this general question about consultation change, a few patients perceived a noticeable change in consultation discussion. In response to the same question, this patient stated:

"Not really, there just there was one or two things she asked me that I'd never been asked before but I can't remember exactly what they were...that's the only way I can put it." (ID08)

This indicated medication beliefs discussion may be, to some patients, an unrecognisable element of their consultation. It may also indicate that such exploration may be weaved into consultations and overshadowed by familiar routine tasks.

### 7.3.4 A sense of rapport facilitated discussion about concerns

Another theme highlighted patients' perceptions about rapport between nurse and patient in order to discuss medication concerns. The majority of patients perceived a broad sense of rapport with their nurse prescriber as described by this patient:

"I've got a relationship with her and if there is anything, I would just tell her about it and just ask her about it." (ID06)

In addition, many patients linked their sense of rapport to their ability to discuss concerns if they arose:

"I mean our relationship is almost informal which obviously puts me at ease and that's why I've got no problem in bringing up any medicine concerns I have at the consultation because I've got no fear or trepidation within me when I attend."
(ID11)

This theme demonstrated the importance of rapport and trust between patient and nurse. Its presence is highly likely to facilitate beliefs explorations and must be considered when nurses engage in potentially difficult conversations about patients' beliefs.

# 7.3.5 Patient-reported concerns about their medication

This theme drew together several categories on patients' explicitly stated concerns about their medication. Many patients were generally resistant to medication and maintained a strong dislike, as described by this patient:

"I really hate the need to take all these things for your heart, for this, for that." (ID03)

Furthermore, many patients were concerned with the side effects of medication. Many reported bad experiences on medication, as described by this patient:

"I was warned that there might be slight differences in effect...well this turned out to be totally inaccurate, the side effects were not slight, they were major...when it finished I was taken into hospital." (ID12)

Not only were side effects reported, their impact on medication beliefs was also reported, demonstrating a cycle of problems. This patient provided the best description of this issue:

"Any nauseous feelings I was having on this new one that she recommended, I attributed to having too many tablets and that I think was causing another problem." (ID03)

Another category of concern was centred on the management of medication at home. This patient represented most patients given a large amount of control over the administration of their medication in relation to actual or possible side effects:

"I was very concerned about being given management of the medicines...well it's the Metformin again, [nurse] suggesting that I went on slow release Metformin which is not as strong as my Metformin and suggested I take it at night, so the side effects of the diarrhoea didn't mess me up. Because they really did mess me up for a few months actually!" (IDO2)

This theme demonstrated categories of patients' concerns reported in the interviews. Many idiosyncratic concerns were reported and that was expected given the specificity of each patient's situation. In particular, this theme suggested nurses face an important challenge to address actual side effects *and* their impact on medication beliefs of patients. Arguably, addressing only the former could be analogous to fixing the barn door after the horse has left. Damage to necessity beliefs for medications may have been done through the experience of side effects.

### 7.3.6 Patients self-reported approach to exploration discussion

Akin to findings in the nurse interviews, patients also indirectly reported on their own approach during beliefs explorations. Two distinct and opposite approaches were evident. Firstly, patients could take on a 'passive enquirer' role, whereby they wanted information but not wanting to seem too much trouble. This patient demonstrated this approach by many patients:

"I know a little bit about it [medications] but I don't feel I know enough...when I see her again, because I don't like to keep them talking if they are busy and they have got other patients to see, but I would like to know a little bit more." (ID15)

The opposing approach was one of 'self-manager', whereby patients were actively seeking information and managing their situation. Many patients also reported this approach with their nurses when discussing medications, as described by this patient:

"You know the nurse is there and she's got the answers. If there's anything at anytime I'm not sure of, I'll ask because as I say I'm not slow at coming forward in that, it's my health and I've got to look at it in that respect." (ID08)

Two distinct and opposite approaches were evident. However, no evidence was found for patients moving between these approaches or whether they are mutually exclusive. Arguably, these patient approaches will present nurses with a tension during the consultation. Nurses may be required to manage each patient approach differently as well as being aware of their own approach. How these approaches mix and their effects on outcomes would be interesting to determine.

### 7.3.7 Patients' perceived nurse approach to exploration

The final theme was centred on a range of categories describing patients' perceptions of the approach of their nurse to exploration. These were developed indirectly as latent themes as the patients were not specifically asked about exploration approaches. However, it was evident from the transcripts they saw their nurses enact different exploration roles.

Firstly, many patients reported the nurse 'time manager' role. Not in the sense of clock-watching, but whereby nurses sought to organise the consultation or series of consultations to facilitate exploration. Many patients reported nurses found time for this activity, as described by this patient:

"Every so often we have a longer consultation and she goes into everything then, anything I need to ask or question her about I can." (ID07)

Another approach, an 'active enquirer', was demonstrated through the majority of patients reporting their concerns were addressed through pro-active questioning. In the context of medication exploration, this patient stated:

"She is always saying 'well are you concerned about that?' and we have a discussion and then she suggests things and I take on board the suggestions...she addressed my worries in a previous consultation that I was not feeling the hypos when they came, so my body was not warning me which I got a bit scared about, and she addressed keeping my blood sugar levels normal." (ID02)

The third approach identified was nurses as 'active listeners'. This approach was evident from patients' perceptions of nurses taking time to listen as part of the exploration process. This patient described this approach:

"It is the time she spends to listen and discuss...it makes me feel I am not alone in trying to manage my condition...I've not always had that...she is quite focused but she spent the time to get to know me a bit, I really value that." (ID02)

Three different approaches were identified. However, no evidence was found for nurses moving between these approaches or whether they are mutually exclusive. It was apparent nurses engaged in different ways and this may represent a source of tension during the consultation process. This will be particularly problematic if individual nurses are accustomed to or prefer one approach to another. Flexibility to move between approaches may facilitate exploration, whilst inflexibility or inexperience may hinder exploration.

### 7.4 Reflexive observations

Consistent with a pragmatic approach, a qualitative method was chosen to operationalise this element of the thesis. Thus, it was considered appropriate to examine my position as a researcher operationalising this element. As previously mentioned in section 4.8, to achieve confirmability researchers must take steps to demonstrate that findings emerge from the data and not their own predispositions (Shenton 2004). As previous done with the nurse interviews, a reflexive exercise during the patient interview analysis was undertaken.

As a non-clinical researcher with a psychology background who does not have diabetes or long term condition, I took time prior to the telephone interview to build credibility with each patient. This was done during the preliminary phone. As

previously mentioned in section 4.7.2, the telephone interview was the second call to each participant. A preliminary telephone conversation was held to go through the consent process and develop a level of rapport prior to the interview itself. During the preliminary phone call I felt it was vital to build up a level of rapport with each patient. I explained that working on a study involving diabetes patients, immersing myself in the context of diabetes care, and conducting interviews with nurses about diabetes patients gave me valuable insight to discuss patients' experiences and identify with their issues.

Although I strove to identify with diabetes patients, there is an inherent power relationship between researcher and patient. This normally manifests itself through demand characteristics, i.e. patients answering in socially acceptable/predefined way. Prior to the interview I took time to explain the interview was about their experiences, that I would aim to speak very little, and it would be confidential. On the latter issue, I took time to explain there would be no ramifications should they wish to complain or report negative experiences. Importantly, as the majority of the patients had lived with diabetes for many years and knew their nurses well, I took time to explain this was not an exercise in judging if their nurse was simply good or bad at their job. This activity was to potentially offset a deliberately positive spin on nurses' activities by loyal patients.

## 7.5 Problems with the depth of the interview data

The depth of the patient interview data was affected by a number of unforeseen problems. Firstly, contextual pressures of multiple objectives whilst working on the wider study affected the length of time spent on the telephone with diabetes patients. The average length of call was 30-45mins but was always slightly less than the face-to-face nurse interviews. This likely affected the amount of information patients could convey to the researcher. Secondly, despite taking steps to be mindful of developing rapport quickly on the telephone, the anticipated rapport level was not always reached and this may have affected the amount of information provided by the patients. Thirdly, and perhaps most importantly, patients were often distracted away from the interview topics around medicine beliefs discussion. Prior to the interviews, the difficulty and subtlety of interviewing patients about their medicine beliefs was not apparent to me. Patients were more often concerned with the wider picture and wanted to discuss medication usage more so than their attitudes to medicines. This highlighted medicine beliefs are not something commonly thought about by patients - which suggests they are not in the conscious awareness of diabetes patents. This could

be due to medicine beliefs not being commonly discussed or raised by health professionals. This point supports the rationale for the study and need to embed medicine beliefs exploration as a routine part of medicines communication to optimise medicines adherence and improve diabetes outcomes.

The outcome of these issues was the patient interviews were less rich than hoped for. It is important to learn from these experiences and I would do a number of things differently if in a similar situation in the future. I would have piloted the telephone interview approach and a face-to-face interview approach for this cohort of patients. I would also have considered a two-phase interview process to allow the patients to discuss general medication topics first, as they were expecting to discuss those topics, before engaging them on the subtleties of discussing medication beliefs.

Despite the limitations on the depth of this qualitative data, it's important to note the analysis of the patient interviews represents the first attempt to understand patients' perceptions of having their medicine beliefs explored by nurses. It offered early insight into this part of nurse prescriber medication communication in the diabetes context. The themes have been taken to the furthest meaningful depth permitted by the available data.

## 7.6 Summary

This chapter presented a thematic analysis of patients' interviews about their recent consultation in which nurse prescribers discussed medication beliefs. Demographically, participating patients were largely white male experienced patients with Type 2 diabetes. This group was demographically congruent with the larger patient group who took part in audio-recorded consultations. This further supported the demographic profile of diabetes patients in this thesis, as described in section 5.2.3.

This analysis provided a range of findings. Although patients were questioned specifically about their medicines discussion, broad issues of satisfaction with their nurse prescriber and general medicine management issues were present in the interview discussion. When these topics arose, it was evident patients were highly satisfied with the activities of their nurse prescriber and saw medication management as an important role. Interestingly, the fact that a considerable amount of interview time centred on these issues suggests an administrative medication discussion/diabetes care focus in consultations. Patients' recollections may be due to nurses' approach, patients' interests or expectations, or patients

and nurses being unaware of the need to engage in affective medication discussion to get to the heart of some individuals intentional non-adherence.

When patients referred to their discussion about medicines more specifically, it was apparent medication beliefs were discussed, both necessity for and concerns about, which confirmed this activity did take place and its ability to happen during routine consultations.

A key facilitator of medication concerns exploration was patient-nurse rapport. This was widely perceived by patients and its absence could be inferred as a significant barrier to this type of consultation activity.

Although the potential for a myriad of medication concerns was possible, participating patients reported several categories of concerns about their medications. These were general resistance to medication, concerns about side effects, and concerns about personal medication management. This theme suggested nurses face an important challenge to address actual side effects and their impact on medication beliefs of patients at the same time. It appeared side effects and medication beliefs may be related and only addressing for former may not optimise medicine-taking.

The final two themes were generated from patients' perceptions of exploration approach. Firstly, their own approach was evident from the transcripts. Two distinct and opposite approaches were identified, the passive enquirer and the self-manager, and have the potential to increase workload and stress for nurses. Adapting their own approach to harmonise with patients' approach to exploration may be another influential factor, although this can only be considered a hypothesis at this time. Secondly, it was apparent nurses approached beliefs exploration in three different ways, as a time manager, an active enquirer, or in an active listener role. This may represent a source of tension during the consultation process if nurses are accustomed to or prefer one approach to another. Flexibility to move between approaches may facilitate exploration, whilst inflexibility or inexperience may hinder exploration.

### 8. Discussion

In this chapter I have reviewed the main findings from this study in the context of other research and discussed the strengths and limitations of the methods used. In addition, I have discussed the implications of the research and present areas of future research.

## 8.1 Overview of the study aims and methods

In its broadest context, this study was conceived in response to the ongoing and costly problem of ineffective medicines use by patients. More specifically, it was developed to investigate nurse prescribers' and diabetes patients' experience of medicine beliefs exploration in routine settings. A range of literature about the potential value of patients' medicine beliefs as an associate of medicines adherence across many health conditions exists but only a few condition specific reviews have been published (Karamanidou et al. 2008a; Jackson et al. 2010; Salt & Frazier 2010; Selinger et al. 2011; van den Bemt et al. 2012). This evidence was supported by a broad scoping review (Horne et al., 2005) and led to the inclusion of patients' medicine beliefs as part of national guidance (NICE, 2009) to optimise medicines adherence. Despite the existence of reviews and national guidance, the first broad review of studies empirically assessing patients' medicine beliefs was presented in chapter 1 and indicated they are frequently and predominately, in comparison with other variables measured at the same time, associated with medicines adherence.

Having established patients' medicine beliefs as an important associate of medicines adherence in chapter 2, a second review of nurse prescribers' medicine activity was required to explore the nature of this work and if nurses were already exploring medicine beliefs in practice (see Chapter 3). This review reported nurses, and particularly nurse prescribers, have an important role in medicines management in most nursing contexts. Previous national guidance and most research on this aspect of nurses' work focused on medicine safety and interprofessional communication. Considerably less research has focused on medicines communication between nurses and patients. Of the research that has, it reports nurses' approach to medicines discussion as administrative in nature and lacking in psycho-social 'affective' discussion, of which medicine beliefs are an aspect, which is increasingly considered very important to optimise medicine-taking (Cox et al. 2004; Horne et al. 2005; Pound et al. 2005).

Furthermore, chapter 3 highlighted that exploring medication beliefs is new work for nurses and therefore subject to challenges in enacting such activity in practice. With that in mind, it was important to distinguish this work from other types of medicine discussion by objective measurement and investigate the factors influencing nurse prescribers' attempts to explore patients' medicine beliefs in routine settings.

In addition, uncovering patients' perception of beliefs exploration was vital for a rounded understanding of the experience. This was supported by findings from chapter 3. The review reported patients' preferences about their treatment options and views about their medicines are seldom explored for a number of reasons. Whilst it's true that patients may differ in their desire for involvement, many do wish to be involved but frequently report active or accidental resistance by health professionals.

Therefore, the aim of this thesis was to understand the experience of, and the influential factors upon, the exploration of patients' medication beliefs by nurse prescribers in practice settings. The research questions for this thesis were:

- 1. To what extent do nurse prescribers explore diabetes patients' medicine beliefs in routine practice settings?
- 2. What are the barriers and facilitators to nurse prescribers' exploration of patients' medicine beliefs?
- 3. How was consultation discussion perceived by diabetes patients as a result of nurse prescribers' exploration activities?

In order to address these research questions, a mixed methods approach was required and combined quantitative and qualitative methods within a thesis study. To address question 1, this thesis drew on the quantitative output of the wider study and presented selected findings that illuminated the empirical extent and nature of nurse prescribers' exploration of patients' medicines beliefs. This was achieved via a conceptual mapping of selected MEDICODE discussion themes to concepts linked to the definition of medicine beliefs used in this thesis. To address questions 2 and 3, qualitative approaches were chosen to investigate nurse prescribers' experience of exploration work and to investigate patients' experience of having their beliefs explored. Semi-structured interviews and thematic analyses were used to address questions 2 and 3.

# 8.2 The extent of nurse prescribers' exploration of patients' medicine beliefs

Question 1 was successfully addressed using the consultation analysis tool MEDICODE (Richard & Lussier 2006b). It provided the first empirically measured and in-depth assessment of nurse prescribers' and diabetes patients' medicine discussion. Statistical assessments of coders' activity indicated their judgements about the extent of medicine discussion were reliable over time and between different coders.

No differences were found between nurses who withdrew and those who provided all the required consultation recordings which suggest the study findings may apply to them as they have a similar demographic profile. Importantly, for the purposes of generalisability, the demographic profile of the nurses and patients involved in the consultation recordings must be acknowledged. Nurses who participated in this aspect of the study were experienced middle-aged nurses with over 20 years of nursing experience and over 12 months experience as a nurse prescriber. All were Caucasian, the majority based in South Central SHA and just over half were practice nurses. The majority of patients involved in the consultation recordings were diagnosed with Type 2 diabetes, had lived with this condition for over 10 years and were primarily Caucasian. In considering the extent of nurses' beliefs exploration in this thesis, it is important to acknowledge this demographic profile differences in patients' general beliefs about diabetes as an illness (Greenhalgh et al. 1998; Rafique et al. 2006) and patients' views about their diabetes medicines (Moss & McDowell 2005; Pieroni et al. 2007) have been found between ethnic groups. It is possible the characteristics of participating nurses and patients have shaped the extent of beliefs exploration and a different demographic profile of participants would produce different findings.

In addition to the profile of people involved in the recorded consultations, a profile of medicines discussed was also apparent. These were primarily diabetes or cardio-vascular in nature and ones in which patients were currently using (i.e. MEDICODE status: 'Active & Discussed'). Discussion about these types of medicines was expected due to the requirements of diabetes treatment but does firmly focus the interpretation of the findings to this type and status of medicines. It is possible that a different profile of MEDICODE discussion themes would have been coded, including variation in beliefs exploration, if the medicines discussed were primarily a different status (i.e. newly prescribed medicines). This issue was examined in the only study to examine the profile of medicines discussion by

medicine status using MEDICODE (Richard & Lussier 2006b) and reported doctor-patient medication discussions were heterogeneous and vary with the status of the medication and the theme. Interestingly, the mean number of themes raised by nurse prescribers did not significantly differ between medicine statuses which indicated nurses provide equal attention to medicines irrespective of whether the medicine was previously or newly prescribed. This may be reflective of the ongoing nature of nurse prescribers' role in helping patients manage medicines but the absence of significant differences could be related to the low frequency of certain medicine statuses.

Figure 2.1 presented the components of a widely used definition of patients' medicine beliefs and the review in chapter 2 highlighted two constructs as central and reliable associates of medicines adherence: patients' concerns about their condition-specific medicines (Specific-Concerns) and patients' perceptions about the need for their condition-specific medicines (Specific-Necessity). These constructs were conceptually mapped to MEDICODE themes (see Table 4.1) and used to determine the level of medicine beliefs exploration by nurse prescribers.

The extent of nurse prescribers' medicine beliefs exploration was considered *moderate*. This was based on, firstly, the analysis in chapter 5 which reported a limited range of medicines discussion topics overall. Almost half of the possible discussion themes (see Latter et al. 2010 for a full list of discussion themes) were raised less than 10% of time and so interpretation of 'high discussion' was therefore adjusted downward. Of note is the favourable range of nurses' discussion about medicines compared to doctors. In a study using MEDICODE, many more (three-quarters of) MEDICODE discussion themes were raised less than 10% of the time by general practitioners during scheduled follow-up visits and walk-in visits (Richard & Lussier 2006a). Secondly, the analysis in chapter 5 reported the frequency of discussion themes as each medicine was raised across all time-points; this also supported the interpretation of discussion level. Thirdly, descriptive comparisons of MEDICODE-assessed nurse-patient medicine discussion with doctor-patient medicines discussion permitted an additional guide for interpretation.

Patients' concerns about their medicines were infrequently discussed before the intervention (3.1%) (see Table 5.5) but showed significant increases at several post-intervention time-points (between 4.9% and 17.6%). In addition, the conceptually similar theme 'attitudes toward medicine' saw a post-intervention increase and generally was frequently discussed in comparison to other MEDICODE themes – between 23.0% to 38.1% across time-points. These findings compare favourably

with MEDICODE-assessed doctor-patient medicines discussion. Richard & Lussier (2006a) reported doctors' discussion about patients' medicine concerns only occurred 3.6% of the time a medicine was raised. More dramatically, doctors' discussion about patients' broad attitudes toward their medicines occurred much less frequently than nurses, only 6.0% of the time a medicine was raised. The closest nurse-related research on the specific content of medicines discussion reported much higher levels of conceptually similar discussion. Courtenay et al. (2009) reported all non-prescribing nurses 'listened to and understood' patients' *general* beliefs and expectations and Latter et al. (2005) reported nurses did the same in 64% of consultations observations. However, the inclusion of all possible beliefs (i.e. potentially about patients' conditions, their non-prescribed over-the-counter medicines, their treatment options etc) in these studies invites caution in this comparison with the findings for concerns and attitudes about patients' condition-specific medicines in this thesis.

Another positive finding was related to nurses' asking patients' opinions about their medicines (done so for approximately a fifth of medicines across all timepoints) which compared well against doctors low level of enquiry about patients' medicine opinions (only done 1.4% of the time a medicine was raised). In addition, a comparable level of exploration was found in this study, centred largely on nurses in primary care, with a study in hospital settings whereby nurses enquired after patients' medication views in 17% of observations (Duxbury et al. 2010). This suggests that despite the perceived differences in medicine activity across nursing contexts, the extent to which nurses ask patients about their views on medicines appears similar.

Although promising findings were reported for some MEDICODE themes, the combined outlook of the themes conceptually mapped to the Specific-Necessity construct were not as favourable. Of the four mapped themes reported in Table 5.5, only 'consequences of medicine non-adherence' significantly improved post-intervention. Nurses infrequently discussed the reasons the medicine had been prescribed (between 4.0% and 8.7% across time-points) and was less frequent than the 15.4% reported in doctor-patient discussion (Richard & Lussier 2006a). Action of the medicine was discussed slightly more often (between 9.1% and 14.3% across time-points) and more often than doctors (7.4%) (Richard & Lussier 2006a) but nurses' discussion about expected effects of the medicine was on average the most frequently discussed (between 16.6% and 23.0% across time-points). This theme was discussed more often than doctors (14.3%) (Richard & Lussier 2006a) but remained consistent over time. Research in hospital settings reported nurses' discussion about the need for medication was higher (42.9%) (Schafheutle et al.

2009) than reported in this study of nurses largely in primary care. This may be related to the context but may also be related to the longevity of diagnosis of patients involved in consultation observations.

The existence of a MEDICODE-assessed study on doctor-patient medicines discussion (Richard & Lussier 2006a) permitted a detailed comparison of nurse prescribers' performance. Despite the reasonably low levels of discussion on mapped themes, it would appear that nurses' performance against doctors' medicine discussion was congruent with previous research indicating that nurseled consultations were more informative than doctor consultations (Seale et al. 2005).

To support the conclusion that patients' medicine beliefs were only *moderately* explored, it is important to consider the predominant discussion themes reported in the wider study (see Latter et al. 2010). In the wider study, on average, slightly more (5 or 6) discussion themes were brought up per medicine and half of these were likely to be one or more of the three most prevalent themes: medicine named, usage of medicine, or instructions for taking medicine. The predominance of these themes suggested nurses largely talked about 'administrative' issues which was congruent with previous research on nurse-patient medicines communication. It has been reported than nurses' medicine discussion can be limited to the name, colour, number of, and frequency of administration (Latter et al., 2000) and the most frequently observed prescribing communication competency was giving patients 'clear instructions on how to take their medicines' (89.0%) (Latter et al. 2005). This was analogous to Bensing & Dronkers (1992) 'instrumental' discussion and Bajcar's (2006) proposition that nurses focus their medication-related interactions on 'medication-taking acts' rather than discussion focused on making sense of medication taking, engaging in mediation-taking selfassessment, or considering the context of medication taking.

Nurse prescribers' exploration of patients' medicine beliefs appears to have responded reasonably well to a broad intervention to encourage such activity. Whilst discussion about patients' medicine concerns only occurred in a comparatively small number of medicine discussions, the post-intervention increases could be considered to represent a sustained and meaningful shift to a more evidence-based approach to medicine interactions. However, the balance between administrative and affective discussion on the part of nurse prescribers remains heavily biased toward the former. In response to the NICE guideline recommendation that professionals should: 'be aware that patients' concerns about medicines, and whether they believe they need them, affect how and

whether they take their prescribed medicines' (NICE 2009), the extent of the former appeared to be addressed and can be encouraged to be addressed, whilst the extent of the latter appeared to be consistently fixed and less amenable to intervention.

## 8.3 Factors influencing nurse prescribers' exploration of patients' medicine beliefs

Question 2 was addressed using two thematic analyses of nurse prescribers' perceptions of influencing factors upon their exploration attempts. This was the first study to investigate nurse prescribers' perceptions about their attempts to enact the specific skill of exploring patients' medicine beliefs. The fact that this was investigated in routine settings was an important aspect of originality and differentiates itself from existing literature. To date, the vast majority of published research has focused on the empirical measurement of patients' medicine beliefs and their links with relevant medicine-taking outcomes (i.e. non-adherence) and condition-related health outcomes.

In order to understand what an exploration of patients' medicine beliefs involved, it was necessary to investigate nurse prescribers' perceptions of influencing factors. Based on the review findings in chapters 2 and 3, it was apparent that exploring patients' medicine beliefs constituted a theoretically-informed and new activity for nurse prescribers. Furthermore, this new work required an investigation to understand its challenges and this was done via the nurse interviews.

#### 8.3.1 Factors supporting an exploration of patients' medicine beliefs

The nurse-perceived facilitating factors of an exploration of patients' medicine beliefs (see Figure 8.1) were nurse-related, patient-related or contextually-related. This section discusses the potential value of knowing about these perceived facilitators.

Nurse prescribers' willingness to practice their exploration work was a key facilitating factor as nurses clearly had opinions about the necessity and value of exploration. Whilst nurses' negative attitudes toward medications has been found to impede their effective use (Byrne et al., 2005), to this author's knowledge there is no relevant nurse-related communication research within which nurses' beliefs about practice activities can be discussed. However, the willingness to practice explorations in the context of doing *new work* could be considered as adaptation – a type of activity widely considered vital for successful use of new skills (Rogers 2003b; Leeman et al. 2007).

Most nurses reported caveats to their willingness and these are discussed in the next section on barriers. Clearly, if nurses are unwilling to engage with new work, it is unlikely to happen. This has been a common criticism, in the context of all

health professionals, when attempting to change professionals' behaviour (Grimshaw et al. 2001; Boaz et al. 2011), and explains why the majority of research designed to change practice has focused on changing professionals' behaviour.

Another facilitator was nurses' perceived sense of high confidence to enact an exploration in the second interviews. The value of high behaviour/situation specific confidence, i.e. self-efficacy, has long been known to improve the prevalence and quality of specified behaviours (Bandura 1995; 1997). This facilitator was considered vital for successful exploration.

Another nurse-related facilitator was their ability to deal with varying approaches to medication exploration (consultations diplomat, active listener, attacking modifier). This was also conceptually mapped to 'characteristics of individuals'. Whilst it was not possible to clearly demarcate if these were facilitators or barriers, it reasonable to assume that moving between different approaches to suit the patient would be challenging. Furthermore, if individual nurses were not proficient in all approaches or preferred one over another, it's reasonable to predict problems in dealing with patients whose consultation discussion style was incongruent. As far as this author is aware, no literature on nurse and patient consultation style relating to medication discussion exists.

The final nurse-related facilitator was the perception that further consultation assessments were required for exploration. This theme was only present during the second interview. As previously mentioned, contextual adaptation and adjustment is widely considered vital for successful implementation of new skills (Rogers 2003b; Leeman et al. 2007). Therefore, nurses willing to adapt to fit in exploration will be vital for adequate exploration to occur.

Patient related facilitators included nurses' perception of patients' willingness to engage and the presence or absence of rapport between nurse and patient. The majority of nurse prescribers reported patients' willingness to engage could be both a facilitating factor and a barrier to exploration. Most of the examples provided outlined how it could be a hindrance to exploration, therefore this particular theme is addressed in the barriers section. Nonetheless, nurses' opinions were full of caveats that if patients were willing, then exploration was possible.

The facilitating factor of good nurse-patient rapport has clear links to one of the foundations of nursing care: the nurse-patient relationship. A good relationship usually involves one or more of the following: trust, caring, sharing, time, humour,

and role expectations (Paterson and Zderad 1988; Hagerty and Patusky, 2003) with rapport developing from a combination of these factors. This facilitator is consistent with findings that a good relationship is an important aspect of whether patients would discuss their medicine needs or adverse effects with their health professionals (Dolovich et al. 2008). Due to literature acknowledgement that having a strong relationship with the patient is an essential property for moving evidence into practice (Ferlie and Shortell, 2001; Institute of Medicine, 2001), this factor was considered vital for successful medicine beliefs exploration.

Three contextually-related facilitators were identified. Firstly, nurse prescribers' perception of supportive colleagues was found to be a facilitator as it was apparent that a shared receptivity toward the nurses' exploration attempts was present. Moreover, quotes indicated exploration attempts were supported and expected within their organization even though this type of activity was not a group activity. Support from colleagues has been shown to be a significant predictor of health professionals' ability to integrate evidence into practice (Gerrish et al., 2007) and previously been identified as important in the implementation of nurse prescribing more generally (Latter and Courtenay, 2004).

Secondly, having enough time was highlighted as important but most nurse responses focused on a lack of time. Therefore, this issue is discussed in the next section on barriers. Arguably, it is reasonable to suggest that adequate time would facilitate exploration, however, in the reality of practice with various tensions acting on this activity it not surprising nurses had to adapt by e.g. arranging further consultations.

The final contextual facilitator was the degree to which nurses were subject to agendas in their working context. Tension existed between the need to work with biological/structured outcomes determined by their working environment and engaging in less structured open discussion about medication beliefs. The former activity was interpreted as tasks part of a medical model approach and the latter activity as work linked to a patient centred approach. If nurses managed this tension then explorations were possible, however, it was often stated that tasks linked to the former approach often took priority. This is worrying given the equal importance of affective discussion to support adherence, as outlined in chapter 2, and indicated nurses' style of discussion may be driven by deep rooted contextual pressures and not necessarily individual choice.

#### 8.3.2 Barriers to exploring patients' medicine beliefs

Three nurse-related barriers to exploration were identified. Firstly, nurses perceived exploration as an ongoing learning process, and secondly, concerns about where exploration may lead them. These two barriers arguably create tension within the nurse and affect their behaviour, despite reporting the need for exploration to positively affect outcomes (a facilitating factor in the previous section).

The dominant concern was about opening a 'can of worms' having engaged patients about their medicine beliefs. This particular concern has been reported in a qualitative study of 35 practice nurses regarding their communication with patients on issues of sexual health (Gott et al. 2004) and a study of 14 practice nurses regarding their communication about high-risk human papilloma virus and cervical cancer (McSherry et al. 2012). Both studies conceptualise the proverbial can of worms as the concern that information uncovered could take too much time to deal with or be of an unsavoury or troublesome nature. In a similar manner as these cited studies, nurse prescribers in this thesis felt that discussing beliefs about medicines had the potential to create problems because of the sensitivity and complexity of the material under discussion. This may also be compounded by nurses' unwillingness to engage in emotionally demanding communication, as seen in studies on nurses' engagement in patient-centred communication. Two studies in particular reported nurses can sometimes elect to use task-centred communication, as opposed to affective discussion, as a protection mechanism against potential emotional impact of their work (Sines 1995; Kruijver et al. 2001). Gott et al. (2004) also reported nurses felt constrained by a lack of expertise and this may be the case when exploring patients' medicine beliefs. At present, findings would seem to indicate nurse prescribers are wary and perceive a tradeoff between exploring to assist with potential misconceptions about medicines and dealing with a raft of unexpected issues during a routine consultation. This is concerning as skilled and enthusiastic use of new skills are two key features when attempting to engage in new practice work (Klein & Sorra 1996).

The third nurse-related barrier inferred was linked to the varying approaches to exploration theme. Specifically, the inference that if individual nurses were not proficient in all approaches or preferred one over another, it's reasonable to predict problems in dealing with patients whose consultation discussion style was incongruent. No research has examined the stylistic issues of nurse medication communication at this level of detail, however, such work would build upon the

instrumental versus affection discussion typologies already identified (Bensing & Dronkers 1992; Latter et al. 2000; Latter et al. 2005).

The three nurse-related barriers presented a picture that may concern those interested in promoting medication exploration activities. Importantly, any resistance by nurses due to their concerns could be overcome. It would appear there was something more worrying, more challenging, and more fraught with perceived potential problems about beliefs exploration. Nurses appeared to be uncomfortable in challenging some patients' ideas about their medicines and this may be related to how they perceive their role in diabetes care. The issue of whether beliefs exploration is outside the area of competence was not brought up during the interviews but would represent an important unanswered question.

Patient-related barriers were linked to nurses' perception of patients' unwillingness to engage and a range of patent characteristics. On the former issue, this was a surprise considering research findings indicate patients consider talking to health professionals about medicines as very important (Frederikson 1995; Erickson et al. 1998) and report inadequate time to discuss aspects of medicine-taking such as wanting to stop using their medicines or about their concerns (Meystre-Agustoni et al. 2000; Smith et al. 2000). However, contradictory research literature does exist indicating patients are passive and rarely attempt to initiate medicines discussion (Fahy & Smith 1999; Lambert et al. 1999). This was also apparent from the previously discussed findings in chapter 3. Nurses were particularly mindful of the unpredictability of patients' willingness to engage and seemed likely to respect their wishes in most cases. This may result in a difficult dilemma for nurses if they uncover misconceptions about treatment or unfounded concerns that affect adherence levels.

A range of patient characteristics were reported by nurses as direct barriers (low diabetes literacy, expectations of consultation, learning needs, depression, habituation, negative past experience). Whilst each was important, the bigger point to make was the need for idiosyncratic assessment for successful exploration approach. Such activity was not reported by nurses and may represent new work for them, prior to exploration. These idiosyncratic barriers can also be mapped to the 'outer setting' domain, more specifically the extent to which 'patient needs and resources' are accurately known. This is important as many models and theories of moving new evidence into practice acknowledge the importance of working with patient characteristics (Graham & Logan 2004) and profess they must be explored for successful action (Kitson et al. 1998; Rycroft-Malone et al. 2002).

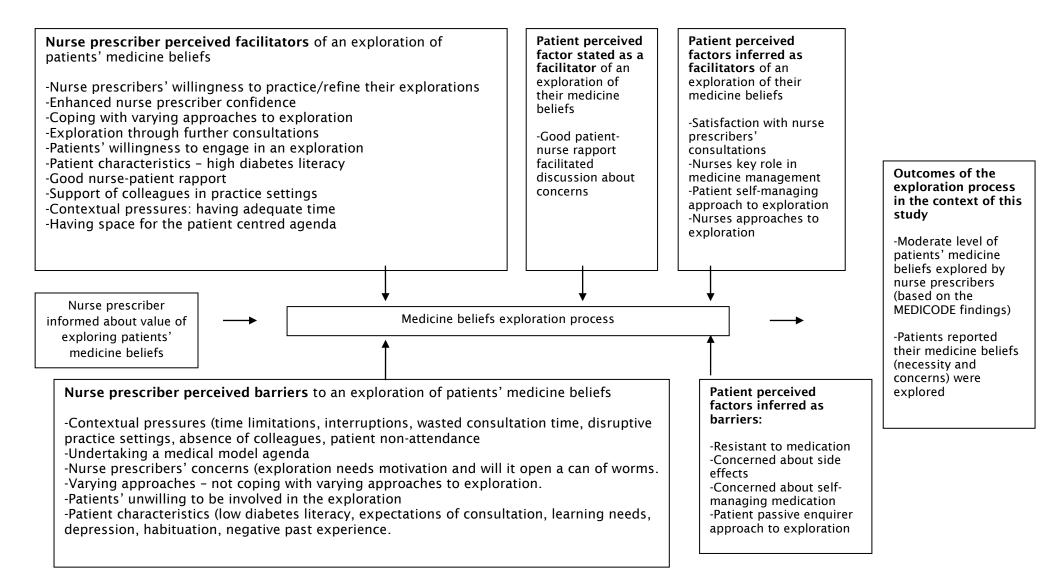
A range of contextually-related barriers were reported by nurses (inadequate time, interruptions, wasted time, disruptive settings, staff absence). These pressures upon the ability to enact an exploration were the most prevalent. Aside from facilitating contextual factors such as collegial support, tension was apparent when nurses considered the realities of practice.

A lack of time has often been lamented by nurses as they attempt to enact new communication skills (Burnard & Morrison 1991; McCabe et al. 2004); as are disruptive settings in the form of interruptions during medicines administration and discussion (Palese et al. 2009; Kosits & Jones 2011; Westbrook et al. 2011). Relevant to both these barriers, was research reporting the need for sufficient time and space to enact a new skill for successful implementation (Nembhard & Edmonson 2006; Klein & Sorra 1996). The absence of colleagues which lead to nurses being forced to cover areas of their work has been previously reported as a problem. Teams with high contextual stability (members are able to be with the team for an adequate period of time and with low turnover) were more likely to successfully enact new skills (Edmondson et al. 2001). Exploring patients' medicine beliefs does not appear to differ in these regards, however, until now this has been largely unknown.

The final contextual barrier was inferred from nurses' discussion on agendas in the work place. As previously mentioned, tension existed between the need to work with biological/structured outcomes determined by their working environment and engaging in less structured open discussion about medication beliefs. The findings indicated nurses were working with two broad approaches. Moving from a medical model approach to a patient centred approach, from dealing with checklist items for the Quality and Outcomes Framework in primary care to potentially opening a can of worms through beliefs discussion, may represent significantly different work. The extent to which this occurred was not apparent but the previously mentioned further consultation facilitator of exploration may have occurred due to this tension. Nurses may not wish to, or struggle with, attempts to achieve two different agendas in one consultation.

All these barriers represent a potential failure of the working context to offer the time and space to support exploration work. This finding was particularly valuable as low levels of available resources to support the movement of evidence into practice has been negatively associated with success (Rabin et al. 2008; Pronovost et al. 2006; Perrin et al. 2006).

Figure 8.1 Conceptual model of the perceptions about, and influences on, diabetes patients' medicine beliefs explorations



## 8.4 Patients' experience of having their medicine beliefs explored

Objective 3 was addressed using a thematic analysis of patients' perceptions of a recent consultation with their nurse prescriber in which their medicine beliefs were discussed. This was the first study to investigate patients' perceptions of having their medicine beliefs explored and supported the preceding thesis elements by presenting the other perspective on this medicine-related consultation activity.

An interpretation of the patients' interviews suggested four types of theme emerged (see Figure 8.1). Firstly, patients' explicit reporting of facilitators of medicine beliefs exploration, secondly, patients' perceptions about their consultation which can be inferred as facilitators and/or thirdly as barriers, and fourth, patients' perceived outcomes of their recent consultation.

Patients clearly specified one facilitator to their discussion about medicine concerns with their nurse prescriber. A good rapport between them and their nurse prescriber was reported as important. This factor was also raised by nurse prescribers as a facilitator and discussed in section 6.4.9. Importantly, it is worth reiterating this finding was consistent with previous research that good relationships have been linked with patients' attitudes toward their medicines (Day et al. 2005) and can influence whether patients discuss their medicine needs with health professionals (Dolovich et al. 2008).

Four themes from the patient interviews were inferred as facilitating factors (see Figure 8.1). Whilst high satisfaction with nurses' consultation activity has been commonly found and in some cases can out-perform other health professionals (Seale et al. 2005), the perceived satisfaction found in this study could be considered a precursor to respect and trust, and eventually support a positive and productive relationship. Furthermore, as aspect of satisfaction perceived by patients was in relation their communication and information needs. The finding of high satisfaction contrasts with previous findings that indicated a lack of communication and patients perceiving nurses as more concerned with completing their tasks than talking to them (McCabe 2004). Interestingly, the notion of nurses' preoccupation with tasks was congruent with the limited level of affective discussion established in chapter 3.

Patients' perceived medicines management was a key role for nurses and contrasts with ambiguity on behalf of health professionals about by whom and how medicines information and support should be delivered (Tarn et al. 2009). It has

already been established that patients consider talking to professionals about medicines to be very important (Frederikson 1995; Erickson et al. 1998) and the examples of satisfaction indicated nurses were giving information, taking an active part, and addressed patients' needs. This level of satisfaction with medication management could be used as a proxy indicator of medicines activities including an exploration of patients' medicine beliefs.

Interestingly, these broad themes highlighted patients' perceptions of nurse prescribers as reliable information providers and managers of medicines. It would appear patients highly valued nurses' attempts to listen and explain in the context of their prescribed medicines and this was consistent with previous findings (Courtenay et al. 2009) and not consistent with findings that practice nurses only engage patients about medicines if they ask (Lip & Beevers 1996; Lip & Beevers 1997).

Two other themes were inferred as facilitators; those focused on patients' perceptions of their own, and their nurse's, approaches to exploration. Some patients were clearly self-managing their situation by asking questions, seeking information and exploring their beliefs. This style of interaction would very likely facilitate nurses' work to explore. Such typologies have been developed before, such as the idea of 'passive accepters', 'active accepters', and 'rejecters' of medication (Pound et al. 2005; Britten et al. 2010). However, these typologies are outcome focused and those developed in this thesis represent new typologies focused on the process of exploration. It could also be inferred from patients' responses that nurses took three different approaches to exploration (time manager, active listener, active enquirer) which were all considered facilitators due to their patient-centred focus. Again, no research has focused on the process of medication beliefs exploration, so the development of these typologies will support further research. An important caveat to this situation was nurse preference or manageability of their approaches. This may represent a source of tension during the consultation process if nurses are accustomed to or prefer one approach to another. Flexibility to move between approaches may facilitate exploration, whilst inflexibility or inexperience may hinder exploration.

In contrast, four patient perceived factors were inferred as barriers. This included three types of patient concerns and an exploration approach style by patients. Patients had concerns about their medication, elucidated as either a general level of resistance, about side effects or about personal medication management. All three have been cited before in a major review of medicine-taking (Pound et al. 2005) but that was in the context of non-adherence to medication. Whilst relevant

to this thesis, these concerns were related to the exploration process which can be seen as a mediator of the outcome non-adherence. Importantly, these findings are novel in that sense.

Interestingly, if these barriers can affect the exploration process *and* non-adherence, then it suggests for nurses these issues are of even more import. As patients medication concerns are 'beliefs', nurses face an important challenge to address observed side effects *and* their impact on medication beliefs on patients at the same time. Some evidence from the interviews indicated side effects and medication beliefs may be related, and only addressing the former may not optimise medicine-taking.

Understandably, patients who approached the exploration process as a 'passive enquirer' were inferred to have been a barrier to exploration. This typology was not as definitive as the 'rejecters' of medication noted in the Pound et al. (2005) review. But this finding must be inferred as a barrier due to the disengaged style of consultation discussion presented by some patients. If and how nurses can engage this type of patient approach was not discernible, however, it's possible an 'active modifier' approach by nurses (as reported in the nurse interviews) would promote exploration.

The final theme from the patient interviews was interpreted as an outcome of the consultation. Patients perceived their medicine concerns were explored by nurse prescribers and this was a qualitative indication of the success of the intervention provided in wider study (Latter et al. 2010). Moreover, it is suggestive of a move toward affective medication discussion, away from instrumental medication discussion (Latter et al. 2000; Latter et al. 2005) and away from the problem of not engaging with patients' preferences (Mulley et al. 2012).

In addition, this finding was contrary to previous findings whereby patients' perceived nurses as too busy to address their concerns about medication (Francke & Theeuwen 1994). In addition, patients' perceptions that medicine concerns discussion took place did not support the idea that patients are uncommunicative about their views about medicines (Lloyd-Williams et al. 2005).

Importantly, patients also perceived the necessity for their medication was discussed. This was considered beneficial even though it was unexpected. Most participating patients were experienced users of diabetes medication and so discussing necessity may not be required as these might normally occur at the newly diagnosed stage. It was considered beneficial knowing that beliefs can be changed by new information, the natural degradation of memory, and habitual

fatigue. Therefore, a regular reminder of the necessity of medication would seem appropriate.

### 8.5 Integrated findings

The aim of this thesis was to observe and explore nurse prescribers' and diabetes patients' experiences whilst involved in the specific act of exploring patients' medicine beliefs in routine practice settings. This aim was addressed using three research questions to investigate different aspects of exploration activity. These were to determine the extent of exploration quantitatively, the influential factors upon this activity, and how patients perceived this activity. A mixed methods concurrent triangulation design was chosen to address these aims but the triangulation used was not as often prescribed, i.e. using one set of data to formally check another. Comparisons made between data sets were done at the discussion level, to enhance the usefulness of the overall findings, and build up a rounded picture. Both these approaches to triangulation are recognised but often lead to confusion about its purpose (Sandelowski 1995).

Findings from each thesis component were brought together in a conceptual model (see Figure 8.1) to support integration discussion. The dynamic model presents the various influences on the exploration process with the empirically observed and qualitatively reported key outcomes. Thus, the model provides a snapshot of exploration work under the specific circumstances of the study.

A range of nurse-perceived factors influenced the exploration process and these were largely interpreted as 'tensions' as most factors could either help or hinder depending on the position of the nurse, patient or context. Findings from the patient interviews also provided a range of barriers and facilitators. Specifying these factors presents the opportunity to develop testable propositions about the exploration of medicine beliefs between nurses and diabetes patients in future research. Corroborating components or discrepancies are presented below.

The first set of integrated findings was related to the *extent of medicine beliefs exploration* by nurse prescribers. The MEDICODE findings presented in chapter 5 indicated that nurses' moderately explored patients' medicine beliefs. However, it can be inferred from the nurse interview data that they were engaged in a much higher level of medicine beliefs exploration having reported increasing confidence, adaption and practiced their exploration skills. Moreover, the patient interviews indicated that nurses explored both necessity for, and concerns about, medicines – the key components of the definition of medicine beliefs used in this thesis.

In light of the MEDICODE findings, nurse prescribers and patients appeared in some respects to have over-reported the extent of their beliefs exploration. This

discrepancy may be explained by the different degrees of precision inherent in qualitative interview data on the one hand and the focused and structured quantitative MEDICODE data on the other. It was also possible there was a social desirability or halo effect in nurse prescribers' reporting about the consultation skills used. A discrepancy between self-reported skills and skills observed in patient empowerment and self-efficacy enhancement models of practice has previously been reported (Koopman Van Den Berg and Van Der Bijl 2001; Anderson and Funnell 2005).

Additionally, nurse prescribers' interviews reported a range of tensions (e.g. patients were receptive/not receptive) which undoubtedly affected the extent of beliefs exploration observed by MEDICODE. As these tensions are dependent on each nurse, each patient, and the context, a universal one-size-fits-all approach to exploration was neither possible nor appropriate, and likely explained the moderate level of discussion.

Although the majority of the barriers were contextual, patients' willingness and nurses' concerns were also important. Arguably, contextual factors could be altered with support. However, with some patients refusing to discuss their ideas about medicines and some nurses concerned about opening a 'can of worms' they cannot control, it was not surprising that exploration levels were observed as moderate – even after participation in an intervention to support this activity.

The second set of integrated findings was related to the *similarity of influential* factors on nurses' exploration work. Two similarities were identified in the profile of influential factors presented in Figure 8.1. Firstly, good nurse-patient rapport was reported as a facilitator of medicine beliefs exploration by both nurses and patients. It would appear this facilitator was vital to ensure any sort of exploration took place. In the context of this study, nurses in the sample were experienced and patients had lived with diabetes for many years. This was likely to have presented nurse-patient dyads with a good level of rapport.

The second similarity was the identification of nurse and patient approaches to exploration. Whilst these approaches were subtly different, acknowledging their existence represented a novel aspect of these findings. Two links can be presented at this point. An 'attacking modifier' approach was seen in the nurse interviews and also inferred from patients' responses about nurses as 'active enquirers'. Similarly, nurses were seen to be 'active listeners' in the both the nurse and patient interviews. However, further research to identify and define these activities is required.

One discrepancy was identified between the type of influencing factors perceived by patients and nurses. Patient perceived facilitators (explicit and inferred) were all nurse-related or medication-related. They did not perceive themselves as an influential factor. This would appear to be in contradiction to nurses' concerns that patient willingness and characteristics could significantly hinder exploration. This may be reflective of patients' narrower view on health care and nurses' broad experience of enacting new skills into practice.

## 8.6 Strengths and limitations of the study

### 8.6.1 Strengths

This was the first study to investigate the reality of exploring patients' medicine beliefs by nurses in routine consultations. Until now, research in the area has largely focused on establishing causal links between medicine beliefs, non-adherence and health outcomes. As an increasingly important associate of non-adherence, an investigation of perceptions about and influences upon medicine beliefs exploration was timely. From this point forward, researchers developing interventions to support health professionals to explore, or interventions to directly influence patients, can refer to a range of findings from this study that may affect their intervention process and evaluation.

Importantly, this thesis has contributed to the evidence base through a multi-angle mixed methods view on the extent of, and influences upon, nurse prescribers' exploration of patients' medicine beliefs. This has provided a rounded appreciation of this consultation activity and developed inferences beyond those developed from each study component. This allowed detailed judgements about the true extent of nurses' exploration, the facilitating factors, and the barriers to exploration as perceived by both nurses and patients. In addition, the development of a conceptual model provided the opportunity to develop a range of testable propositions for further research.

#### 8.6.2 Limitations

The purposive nature of the sampling ensured the profile of settings and participants in this study were limited in its generalisability. However, its intention was to be representative of routine nurse-related diabetes settings. In that task it was reasonably successful and was only affected by the withdrawal of participants as they moved through the stages of the wider study. Unfortunately, the withdrawal of nurses did reduce the number of diabetes nurse specialists and community matrons. Therefore, across all components of this study the predominant type of nurse was practice-based. Thus, the profile of participating nurses has moved away from broad representativeness of nurses working in diabetes care and could now be viewed as largely relevant for practice-based nurses. Other threats to the external validity of the study include additional demographic elements of the participating nurses. Most were experienced and based in South Central SHA Primary Care Trusts. In addition, the predominant type

of diabetes patient was diagnosed with Type 2, approaching retirement age, and had lived with diabetes for many years. Importantly, any attempt to apply the findings from this study to other contexts of diabetes or nursing care should be done carefully.

Nurses' self-selection of audio-recordings may have resulted in atypical consultations; however, it is possible that any bias would have operated across both pre and post intervention time points in the wider study and would therefore be unlikely to have influenced the changes in medicine discussion reported in chapter 5. In the event that nurses did self-select consultations to record so they would appear in a favourable light and demonstrate skills learnt during the intervention, the findings from chapter 5 could potentially be exaggerated. Therefore, the problem of nurses limited affective medicines discussion, including explorations of patients' medicines beliefs, could be far worse than reported.

The length of time nurses spent discussing key themes could have been important. However, MEDICODE can only report the mere mention of a discussion theme and was not designed to measure the salience of issues raised about medicines. In addition, the findings in chapter 5 indicate just as many cardio-vascular medicines were discussed as frontline diabetes medicines. It is possible nurse prescribers focused on diabetes-related medicines in the interviews or engaged in preferential discussion about diabetes medicines.

There were considerable constraints on the availability of diabetes patient participants due to the requirement that they had already been involved in a consultation with a participating nurse prescriber. This forced the decision for a consecutive sampling approach but the method of their selection into the study may have provided a biased sample. However, an important counter to this issue was the finding of no demographic differences between diabetes patients who participated in a consultations recording only, and those who participated in both components of the study.

With hindsight, the patient interview questions were not as successful as hoped, for the purposes of this thesis, and produced a broader array of analytic themes than expected. If repeated, this study element may produce more focused findings, as mentioned previously in section 7.5.

It should be acknowledged that nurse prescribers were never asked to consider issues about moving evidence into practice as part of the wider study. Therefore, they may not have considered how they would explicitly attempt to develop their exploration skills and manage the various facilitating and hindering factors.

However, the nurse interview findings provided an important baseline assessment of nurse prescribers' *normal level* of implementation activity and the readiness of their working contexts when asked to incorporate new ways of working in their routine practice.

#### 8.7 Conclusions

This thesis has contributed to the evidence base through its investigation of a type of nurse-related medicines activity previously unexplored. Moreover, this study has provided a multi-angle view on the extent of, and influences upon, nurse prescribers' exploration of patients' medicine beliefs. This research was timely given the increasing body of research and value placed on this aspect of patients' medicines experience – largely driven by the repeated links between medicine beliefs and non-adherence, and non-adherence and health outcomes.

In the early part of this thesis I established that patients' medicine beliefs are an important associate of non-adherence, are under explored by nurses, and lack an investigation into the experience of engaging in such an exploration. Having investigated the exploration process, it was clear this process was subject to a range of tensions from the nurse point of view and a number of influential factors from the patient point of view.

A range of conclusions were evident from the findings. Firstly, nurse prescribers' extent (research question 1) of exploration was considered moderate despite qualitative findings from nurse and patient interviews professing their exploration, and having attended an intervention as part of the wider study to support this type of activity. Whilst this did represent a move toward more evidence-based medicines discussion and compared favourably with doctors, it also suggested nurses' have yet to fully embrace affective discussion on medicines issues.

Secondly, this study has provided a profile of hitherto unknown factors that influence nurse prescribers' exploration of patients' medicine beliefs (research question 2). Based on the findings from chapters 2 and 3, it was apparent this activity represents a new kind of work and thus subject to the additional pressures of moving evidence into practice. The majority of factors reported by nurses were under tension, existing as facilitators or barriers depending on the nurse, patient of contextual pressure in question. Acknowledgement of these tensions was a novel element of this thesis and addressing them in future work will be vital.

Thirdly, patients had a range of positive views about their nurse prescribers' medicine-related discussion but had much broader views about this type of medicine discussion activity (research question 3). Some of these views were explicit, and others inferred, facilitators of exploration. Both were incorporated into a conceptual model to support understanding of medicine beliefs exploration processes. This model permits hypotheses to be developed and tested in future

research. The main benefits of which would be to further understand the process and determinants of exploration in order to develop interventions to promote effective medicines beliefs exploration.

Fourth, further inferences were developed from the integration of the quantitative and qualitative findings to contribute to the overall aim of understanding the experience of this activity. There appeared to be a disparity between nurses' observed moderate level of exploration and patients' qualitative reporting of this activity. Such interpretation problems are not uncommon and reinforced the rationale for using mixed methods to examine this medication activity. In addition, good nurse-patient rapport was identified as a facilitator of exploration by both nurses and patients, and suggests an important finding from this thesis and focus for future research. Also, the identification of nurse and patient approaches to exploration, whilst subtly different, represents a novel aspect of these findings.

Finally, this thesis revealed the exploration of patients' medicine beliefs in routine consultations was not straight forward and subject to a number of influencing factors. It would seem that exploring beliefs cannot be considered a check-list type of activity. It requires time, energy, and consideration in its approach and must be considered new work, and perhaps beyond the professional comfort zone that diabetes nurses are accustomed.

### 8.8 Implications

An important implication from this study is related to the recommendation from national guidance on medicines adherence, indicating health professionals should:

"Be aware that patients' concerns about medicines, and whether they believe they need them, affect how and whether they take their prescribed medicines." (National Institute for Health and Clinical Excellence 2009)

The findings from this study indicate nurse prescribers' attempts to explore patients' medicine beliefs in diabetes contexts are likely to be difficult and fraught by a range of tensions, facilitators and barriers. Importantly, to simply state the need for this action by no means guarantee it will or can be enacted in practice settings. Therefore, this thesis would recommend nurses' reflect carefully on potential nurse, patient, and contextually-related factors which may impede exploration attempts in their specific context. Moreover, it would recommend to guidance developers to embrace issues of moving evidence into practice and incorporate this into its guidance about medicines use.

A very practical recommendation from this study is to advocate a change in the Nursing and Midwifery Council (2007) medicines management guidance document. The overall biomedical/administrative focus of the guideline is not congruent with findings from the review in chapter 2, nor helpful for enacting an exploration of medicine beliefs as it may have a role in encouraging nurses to play it safe and stick to known ritualistic practices.

Findings from this study indicate nurse prescribers are wary and perceive a tradeoff between exploring to assist with misconceptions about medicines and dealing
with a potential raft of unexpected issues during a routine consultation. This
nurse-related barrier, the concern about opening a can of worms, may potentially
represent the tip of the iceberg for problems linked to affective medication
discussion. As previously discussed, recent research has identified a widespread
and systemic misdiagnosis of patients' preferences by health professionals (Mulley
et al., 2012), and it would appear nurses are not immune from self-protective
consultation behaviour such as using task-centred communication, as opposed to
affective discussion, as a protection mechanism against potential emotional impact
of their work (Sines 1995; Kruijver et al. 2001). The implication of which is a
recommendation for further observational studies to explore what nurses are
actually discussing when engaging patients about their medicines.

Importantly, nurse prescribers may have felt that exploring patients' medicine beliefs was akin to psychological counselling or not part of their standard role. However, there is an increasing body of evidence indicating nurses are well equipped and amenable to delivering interventions based on psychological principles (Maissi et al. 2011; Peters et al. 2011). Moreover, given the numerical superiority of nurses compared to all other health professionals, the potential for rolling out exploration work through nurse-led clinics may have a sizable impact on patients' medication-related outcomes. The implication of dealing with nurse prescribers concerns about opening a can of worms, which may be based on wider concerns of being unqualified, may build increased awareness within the nursing and psychological community of the benefits of developing effective interventions together in partnership.

It is possible the moderate level of medicine beliefs exploration identified in this study may be explained by an emphasis in prescribing training courses on pharmacology and pharmacokinetics, which are novel for nurses, and take precedence over other aspects of the course – including additional communication training. The implication of which would be an increased focus on affective discussion topics, in particular patients' medicine beliefs.

Finally, the findings of this thesis may support further research to optimise medication adherence. As solving the non-adherence problem was the key driving factor for this thesis, adding this investigation to the research literature may increase the exposure of medication beliefs as an influential factor. To date, the majority of medication beliefs work has been qualitative or cross-sectional observational studies. Further work is needed to formally trial interventions involving medication beliefs as active ingredients.

### 8.9 Recommendations for future research

An important recommendation for future research is the replication of the wider study this thesis was embedded within. A larger random sample of nurse prescribers and diabetes patients, with a control group comparison, would increase the validity and generalisability of findings in this thesis. Importantly, the replicated study could develop strategies to support the facilitators and tackle the barriers to nurse prescribers' explorations. This in itself may be part of the larger study and answer questions about the context and dynamics of the exploration 'in the wild'.

An additional curiosity is how nurses from other branches of health care would manage explorations of patients' medicines beliefs. In particular, would there be differences between non-prescribing nurses and those in this study. Several prospective cohort studies using MEDICODE could provide an important baseline of medicine-related discussion for a range of nurses and their working contexts. This would immeasurably move forward this area which up to now has suffered with a general paucity of attention. With increasing numbers of nurses obtaining the prescribing qualification, regular medicine discussion and activity is likely to become the rule rather than the exception – increasing the need for medicines beliefs explorations.

Due to some limitations of MEDICODE, it was not possible to specifically identify types of patients' beliefs when they were coded. Investigating categories of medication concerns and necessity beliefs may further illuminate this consultation activity. Understanding the types of concerns patients elicit about their medicines may support nurse prescribers in their strategies and consultation approaches to deal with patients' misconceptions and disengagement.

The profile of nurse prescribers' work to enact explorations can be considered limited to only a few aspects required for success. Thus, nurses may benefit from increased education about the value and impact of implementation science models and theories. Medication beliefs explorations represents one type of new evidence to be enacted and nurses, as key frontline professionals in diabetes care, are likely to be repeatedly asked to enact new work in the future.

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## Appendix 1

Appendix Tables 1 to 8: Summary tables of included quantitative studies from Chapter 1.

Appendix Table 1: Mental health included studies

Author	N	Study type	BMQ (subscales measured)	Measure(s) of adherence	Main statistical analysis	Factors not associated with medicines adherence/non-adherence in main analysis	Factors associated with medicines adherence/non-adherence in main analysis	Quality score
Maidment et al. 2002 (UK) Uni-polar depression	67	Cross- sectional survey	BMQ (SpN, SpC, GenO, GenH)	GAM	Backwards linear regression	General Health Questionnaire, Geriatric Mental State Schedule Depression Scale, BMQ SpN, BMQ GenO, BMQ GenH.	Questionnaire on Patient Education (adherence increased with more information given); BMQ SpC (adherence decreased with high concerns); Mini- Mental State Examination (adherence increased with higher impairment); Global side effects burden (adherence decreased with severe side effects).	80%
Aikens et al. 2005 (USA) Uni-polar depression	81	Cross- sectional survey	BMQ (SpN, SpC, GenO, GenH)	-Brief Medication Questionnair e (recent adherence) -MMAS (general adherence)	MANOVA	Age, gender, education level, depression severity, duration of depression, social desirability, BMQ GenO and BMQ GenH differential score.	BMQ SpN and BMQ SpC differential score was associated with recent adherence and general adherence.	95%
Brown et al. 2005 (USA) Uni-polar depression	192	Cross- sectional survey	BMQ (SpN, SpC, GenO, GenH)	MMAS	Multiple linear regression	Age, gender, ethnicity, marital status, employment, education, previous mental health visits, BMQ SpN, BMQ GenO, BMQ GenH.	Severity of depressive symptoms; BMQ SpC.	100%
Russell and Kazantzis, 2008 (NZ) Uni-polar depression	85	Cross- sectional survey	BMQ (SpN, SpC)	MARS	Correlations	Not reported	BMQ SpC; Necessity-Concerns differential score; More depressive symptoms (BDI-II).	66.7%
Clatworthy et al. 2009 (UK)	223	Cross- sectional survey	BMQ (SpN, SpC)	MARS	Logistic regression	Age, gender, age of diagnosis, number of drugs prescribed, BDI score, Altman Self-Rating Mania Scale score.	BMQ SpN; BMQ SpC.	95%

Bipolar								
Patel et al. 2008 (UK) Schizophre nia	73	Cross- sectional survey	BMQ (SpN, SpC, GenO, GenH)	ROMI	Multiple linear regression	Patients on oral medication rather than depot medication, Positive and Negative Syndrome Scale total, Global Assessment of Functioning total, Manchester Short Assessment of Quality of Life total, Blood Injection Symptom Scale-fear, Blood Injection Experience Survey total, BMQ GenH.	BMQ SpN; BMQ SpC; BMQ GenO; ESRS total; SAIE total.	95%
Beck et al. 2011 (Switzerlan d) Schizophre nia	150	Cross- sectional survey	BMQ (SpN, SpC, GenD)	(1) Service Engagement Scale (adherence) (2) Brief Adherence Rating Scale (adherence)	Structural equation model	BMQ GenD, Global awareness of Illness.	Variables in model: BMQ SpC, BMQ SpN, BMQ GenD, Global awareness of Illness, Service Engagement Scale (adherence), Brief Adherence Rating Scale (adherence). The CFA fit indices indicate a good fit of the measurement model (x²=43.50, df=34, p=.13, x²/df=1.28, TLI=0.97, CFI=0.98, RMSEA=0.043). Direct predictive variables of adherence: BMQ SpC and BMQ SpN.	95%
Fawzi et al. 2012 (Egypt) Depressive disorder	108	Cross- sectional survey	BMQ (SpN, SpC, GenO, GenH)	MARS	Linear regression	BMQ GenH, BMQ GenO, Udvalg for Kliniske Undersøgelser (UKU) side- effects rating scale (psychiatric subscale)	BMQ Necessity-concerns differential score; Depression level; Patient educational messages given; Udvalg for Kliniske Undersøgelser (UKU) sideeffects rating scale (autonomic subscale).	80%

BMQ = Beliefs about Medication Questionnaire; SpN = Specific-Necessity subscale; SpC = Specific-Concerns subscale; GenO = General-Overuse subscale; GenH = General-Harm subscale; GenD = General-Distrust subscale; MARS = Medication Adherence Report Scale; MMAS = Morisky Medication Adherence Scale; GAM = Global Adherence Measure; ROMI = Rating of Medication Influences; BDI = Becks Depression Inventory; ESRS = Extrapyramidal Symptom Rating Scale; SAIE = Schedule for the Assessment of Insight - Expanded.

Appendix Table 2: Cardiovascular included studies

Author	N	Study type	BMQ (subscales measured)	Measure (s) of adherenc e	Main statistical analysis	Factors not associated with medicines adherence/non-adherence in main analysis	Factors associated with medicines adherence/non-adherence in main analysis	Quali ty score
Horne & Weinman 1999 (UK)	116 *	Cross- sectional survey	BMQ (SpN, SpC)	Author described : a four- item self- report scale	Stepwise multiple linear regression	Gender, educational experience, number of prescribed medicines, dialysis, oncology diagnostic groupings.	Necessity-concerns differential; Illness group: asthma; Age; Illness group: cardiac	95%
Byrne et al., 2005 (Republic of Ireland)	108	Cross- sectional survey	BMQ (SpN, SpC, GenO, GenH)	MARS	Hierarchical multiple regression	Gender, GP consultations in last 6 months, number of months since diagnosis, previous myocardial infarction, IPQ-R Cause-stress, IPQ-R Cause-heredity, IPQ-R Cause-own behaviour, IPQ-R Identity, IPQ-R Consequences, IPQ-R Personal control, IPQ-R Treatment control, IPQ-R Illness coherence, IPQ-R Timeline—cyclical, IPQ-R Emotional representations.	Age; GMS eligibility; IPQ-R Timeline-chronic; BMQ SpN; BMQ SpC; BMQ GenH; BMQ GenO.	90%
Bane et al., 2006 (UK)	122	Cross- sectional survey	BMQ (SpN, SpC)	-MMAS (adapted) **	Correlation s	Not reported	Older patients; Single patients; Patients who lived alone; Patients who spent a higher number of years in education; High scores on the CES-D; High scores on BMQ SpC; High scores on the Necessity-Concerns Differential.	70%
George & Shalansky, 2007 (Canada)	350	Cross- sectional survey	BMQ (SpN, SpC)	Refill adherenc e	Logistic regression	Morisky score >0, Born in North America, Health Belief Model - Perceived benefits score, Use of adherence aids, BMQ SpC, BMQ SpN.	Predictors of refill adherence less than 90% (n=309): Answering positively to the HBM scale item 'Have you changed your daily routine to accommodate your heart failure medication schedule?'; Use of medications; Being a smoker.	85%
Khanderia et al., 2008 (USA)	132	Cross- sectional survey	BMQ (SpN, SpC, GenO, GenH)	MMAS	Backward stepwise logistic regression	Gender	BMQ GenO (high score); Patients are living alone; Annual income (\$50k-\$100k); Younger age.	80%
Ross et al., 2004 (UK) (Hypertensi on)	514	Cross- sectional survey	BMQ (SpN, SpC, GenO, GenH)	MMAS	Multiple logistic regression	Diastolic blood pressure, Gender, BMQ SpC, BMQ GenO, BMQ GenH, IPQ-R consequence perceptions, IPQ-R treatment control beliefs.	Age; BMQ SpN; IPQ-R Emotion; IPQ-R Personal control.	85%
Maguire et al., 2008 (UK) (Hypertensi on)	327	Cross- sectional survey	BMQ (SpN, SpC, GenO, GenH)	RAM	Logistic regression	Gender, Self-efficacy, Social support, Depressive symptoms, BMQ SpC, BMQ SpN.	Age	85%

Allen- LaPointe et al. 2011 (USA)	973	Cross- sectional survey	BMQ (SpN, SpC)	Author created single question on a 4- point scale	Logistic regression	-Adherence to Beta-blockers: In-hospital percutaneous coronary intervention, Number of evidence-based medications, Depression, Angina in past 2 weeks, Participation in diet/exercise program since discharge, Patient strongly agrees or agrees that provider listensAdherence to ACEI/ARB: None reportedAdherence to lipid-lowering therapies: Body Mass Index, Angina in past 2 weeks, Participation in diet/exercise program since discharge, Insurance/program that assists with medication cost, Patient strongly agrees or agrees that provider listens, Appointment with physician since discharge.	(1)Adherence to Beta-blockers: Age; Body Mass Index; BMQ SpC; BMQ SpN; Participation in formal cardiac rehabilitation program since discharge; Insurance/program that assists with medication cost. (2) Adherence to ACEI/ARB: Age; BMQ SpC; BMQ SpN; Inhospital percutaneous coronary intervention; Insurance/program that assists with medication cost; Number of evidence-based medications; ACEI prescribed at discharge; Depression; Angina in past 2 weeks. (3) Adherence to lipid-lowering therapies: Age; BMQ SpC; BMQ SpN; Number of evidence-based medications; Participation in formal cardiac rehabilitation program since discharge; Depression; Re-hospitalization within 3 months; Non-statin prescribed at discharge.	90%
Bermingha m et al. 2011 (Republic of Ireland)	185	Prospecti ve cohort study	BMQ (GenH, GenO)	MMAS	Multiple logistic regression	Age, Body Mass Index, renal function, liver function, high-sensitivity C-reactive protein, number of drugs prescribed, comorbidity index.	BMQ-GenH and GenO combined score; Gender.	90%

<sup>\*</sup>Total sample n=324, Cardiac sample n=116. \*\*MMAS adapted to include a measure of over-adherence. BMQ = Beliefs about Medication Questionnaire; SpN = Specific-Necessity subscale; SpC = Specific-Concerns subscale; GenO = General-Overuse subscale; GenH = General-Harm subscale; IPQ-R = Illness Perception Questionnaire - Revised; MMAS = Morisky Medication Adherence Scale; RAM = Reported Adherence to Medication Scale; MARS = Medication Adherence Report Scale; GMS = General Medical Services; CES-D = Centre for Epidemiological Studies Depression Scale; ACEI = angiotensin-converting enzyme inhibitor; ARB = angiotensin receptor blocker.

Appendix Table 3: Asthma included studies

Author	N	Study type	BMQ (subscales measured)	Measure(s) of adherence	Main statistical analysis	Factors not associated with medicines adherence/non-adherence in main analysis	Factors associated with medicines adherence/non-adherence in main analysis	Qualit y score
Horne and Weinman, 1999 (UK)	78*	Cross- sectional survey	BMQ (SpN, SpC)	Author developed four-item self-report scale	Stepwise multiple linear regression	Gender, education, number of prescribed medicines, dialysis, oncology diagnostic groupings.	Necessity-concerns differential; Age; Illness group: asthma; Illness group: cardiac.	95%
Byer and Myers, 2000 (UK)	64	Cross- sectional survey	BMQ (SpN, SpC)	(1) No. of repeat prescriptions for preventer/reliever inhalers (2) Self- report adherence scale	Stepwise multiple regressions	Not reported	-Number of preventer inhaler prescriptions was predicted by: BMQ SpN; IPQ Cause (external). -Number of reliever inhaler prescriptions was predicted by: IPQ Timeline; Morbidity. -Self-reported adherence was predicted by: BMQ SpN; IPQ Identity.	60%
Horne et al., 2002 (UK)	100	Cross- sectional survey	BMQ (SpN, SpC)	MARS ***	Multiple linear regression	Gender, age, educational status, number of visits to the family doctor, duration of asthma, IPQ identity, IPQ timeline, IPQ control/cure.	Number of asthma-related hospital visits in past year; IPQ consequences; BMQ SpN; BMQ SpC.	90%
Conn et al., 2005 (USA)	67 **	Cross- sectional analysis of data from an RCT	BMQ (SpN, SpC)	MARS	Multivariate linear regression	Parents age, parents education, child's severity, health care professional time with family, BMQ SpN.	BMQ SpC.	85%
Conn et al., 2007 (USA)	622	Cross- sectional survey	BMQ Necessity- Concern Differential categorisatio n	MARS	Multivariate mixed- model linear regression	Parent rating of severity of child's last exacerbation, alternative therapies, number of preventive medications used, trust in doctor's judgment, number of symptoms.	BMQ Necessity-Concern differential score; Ethnic minority.	75%
Menckeberg et al., 2008 (The Netherlands)	233	Cross- sectional survey	BMQ (SpN, SpC, GenO, GenH)	-MARS -Prescription refill	Correlation s	Not reported	Correlations with MARS (n=233): BMQ Necessity- Concerns differential; BMQ SpN; BMQ SpC; BMQ GenH; BMQ GenO. Correlations with prescription refill records (n=222): BMQ Necessity-Concerns differential; BMQ SpN; BMQ GenH.	80%

BMQ = Beliefs about Medication Questionnaire; SpN = Specific-Necessity subscale; SpC = Specific-Concerns subscale; GenO = General-Overuse subscale; GenH = General-Harm subscale; IPQ = Illness Perception Questionnaire; MARS = Medication Adherence Report Scale.

### Appendix Table 4: HIV included studies

Author	N	Study	BMQ	Measure(s)	Main	Factors not associated with medicines	Factors associated with medicines	Quali
		type	(subscales	of	statistical	adherence/non-adherence in main analysis	adherence/non-adherence in main	ty

<sup>\*</sup>Total sample n=324, Asthma sample n=78. \*\*Parents of children with asthma.

<sup>\*\*\*</sup>MARS 9-item scale.

			measured)	adherence	analysis		analysis	score
Llewellyn et al., 2003 (UK)	65 *	Cross- sectional survey	BMQ (SpN, SpC)	Three novel methods of adherence to clotting regimens**	Linear regression	-Factors included in regression for (1) Recommended dose on-demand and (2) Frequency of infusion outcomes: age, HIV status, IPQ identity, IPQ timeline, IPQ consequences, IPQ control, BMQ SpN, BMQ SpCFactors assessed against adherence to recommended dose of clotting factor not explicitly reported.	-Predictors of recommended dose on- demand: Age. -Predictors of frequency of infusion: BMQ SpN and IPQ identity.	85%
Horne et al., 2004a (UK)	109	Cross- sectional survey	BMQ (SpN; SpC; adapted for HAART)	Author created single item relating to HAART medication use	Correlation s	Age, diagnosis (HIV or AIDS), time since diagnosis, viral load, CD4 count, BMQ SpN.	BMQ SpC; BMQ Necessity-concerns differential score.	90%
Gauchet et al., 2007 (France)	127	Cross- sectional survey	BMQ (SpN, SpC, GenO, GenH)	Author created scale ***	Structural equation model	Confidence with therapy, BMQ SpC, BMQ GenO, physician's confidence, values other people, values sexuality, values God and children, values success.	The authors tested whether confidence in physician would relate directly to medication adherence, and would relate indirectly, through patients' beliefs about treatment. The overall model had an adequate fit to the data, X2(120, N=127)=23.16, p=0.001, CFI=0.96, RMSEA=0.05 (95% CI = 0.03-0.06), SRMR=0.07, and all factor loading and specified paths were significant. R2=26.4% of adherenceBMQ SpN R2 = 7.4% of adherence -BMQ GenH R2 = 7.6% of adherence	85%
Gonzalez et al., 2007 (USA)	325	Longitudi nal RCT	BMQ (SpN, SpC, GenB, Gen-D subscale)	-Self report (ACTG) -MEMS cap	Structural equation model	Total reported symptoms, negative mood, viral load, age, time since diagnosis of HIV, education level, income, mean number of HIV doses prescribed in 5 day window, BMQ GenB.	Structural equation modelling conducted (all associations were significant, p<0.05).  Direct links with adherence: BMQ SpC, BMQ SpN, Education, BMQ Gen-D.	82%
Horne et al., 2007 (UK)	117	Prospecti ve follow- up study	BMQ (SpN, SpC adapted for HAART)	VAS	Logistic regression	None reported	Age; Prior ARV (naive vs. experienced); BMQ SpN; BMQ SpC.	90%
Cooper et al. 2011 (UK)	234	RCT (selected findings)	BMQ (SpN; SpC; adapted for HAART)	MASRI	Correlation s	Quality of life (SF12 Health survey-physical component summary)	BMQ SpC; BMQ SpN; Treatment intrusiveness; Quality of life (SF12 Health survey-mental component summary).	93%
Johnson et al.	210	Cross-	BMQ (SpN,	-3 day	Generalised	3-day adherence: Age, length of time on	3-day adherence: Regimen complexity;	90%

2012 (USA)	mal e cou ples	sectional survey	SpC GenConcer ns - adapted for HAART)	adherence (ACTG) -30 day adherence (VAS)	estimating equations	medication, whether the couple was living together, relationship length, couple serostatus, patient depression, patient relationship quality, patient BMQ SpC, patient BMQ SpN, partner depression, partner relationship quality, partner BMQ SpC, partner BMQ GenConcerns.  30-day adherence: Age, regimen complexity, whether the couple was living together, relationship length, couple serostatus, patient depression, patient BMQ SpC, patient BMQ SpN, patient BMQ GenConcerns, partner depression, partner relationship quality, partner BMQ SpC, partner BMQ SpN.	Patient BMQ GenConcerns; Partner BMQ SpN.  30-day adherence: Length of time on medication; Patient relationship quality; Partner BMQ GenConcerns.	0.504
Sumari de-Boer et al. 2012 (The Netherlands)	201	Cross- sectional survey	BMQ (SpN; SpC; adapted for HAART)	Refill adherence (author calculated)	Stepwise multivariat e logistic regression	Immigrant origin, Gender, HIV transmission route, Personalized stigma (HIV stigma scale), BMQ SpN, BMQ SpC.	Disclosure concerns (HIV stigma scale); Prior virological failure.	85%

<sup>\*</sup> The aim of this study was to examine patient's beliefs about their haemophilia; 44% of the responders were HIV positive. \*\*Three novel methods of scoring adherence to clotting factor regimens were developed as there has been no previous attempt to quantify them. Both of the hypotheses were tested using each of the three measures of adherence: (a) Adherence to frequency of prophylactic infusion with clotting factor, (b) Adherence to recommended dose of clotting factor, (c) Adherence to recommended 'on-demand' dose of clotting factor. \*\*\*Author created adherence measure inspired by Tarquinio, Fischer, and Gregoire (2000), 16 statements, and sum of scores can range from 16 to 96 with higher scores indicating greater reported adherence. \*\*\*\*BMQ SpN, SpC, GenO, GenH, GenB subscales but a Confirmatory Factor Analysis of the BMQ was not satisfactory so BMQ GenH & BMQ GenO collapsed into one subscale BMQ 'Distrust'. Some items were removed from BMQ SpN & BMQ SpC subscales. New 14-item BMQ.

BMQ = Beliefs about Medication Questionnaire; SpN = Specific-Necessity subscale; SpC = Specific-Concerns subscale; GenO = General-Overuse subscale; GenH = General-Harm subscale; GenB = General-Benefits subscale; GenD = General Distrust subscale; IPQ = Illness Perceptions Questionnaire; HAART = Highly Active Antiretroviral Therapy; ACTG = Adherence to Combination Therapy Guide; MEMS = Medication Event Monitoring System; MASRI = Medication Adherence Self-Report Inventory; VAS = visual analogue scale.

### Appendix Table 5: Rheumatoid arthritis included studies

Author	N	Study type	BMQ (subscales	Measure(s ) of	Main statistical	Factors not associated with medicines adherence/non-	Factors associated with medicines adherence/non- adherence in main analysis	Quali
		type	measured)	adherence	analysis	adherence in main analysis	danerence in main analysis	score

Treharne et al. 2004 (UK)	85	Cross- sectiona I survey	BMQ (SpN, SpC, GenO, GenH)	CQR	Hierarchical regression analysis	Children at home, Taking steroid medication, MISS affective, MISS cognitive, MISS behavioural, BMQ SpC, BMQ GenH	Total number of medications; BMQ SpN; BMQ GenO.	75%
Neame & Hammon d, 2005 (UK)	344	Cross- sectiona I survey	BMQ (SpN, SpC)	RAI (1 item only)	Correlations	Not reported	Focus slightly different – on factors that correlate with SpN & SpC subscales.  -Necessity-concerns differential was significantly higher for the adherent group than for the non-adherent group (t=2.68; p=0.008).  -Concerns scores of the adherent group were significantly lower than the non-adherent group (t=3.136, p=0.002).	75%
Wong & Mulherin, 2007 (UK)	68	Cross- sectiona I survey	BMQ (SpN, SpC, GenO, GenH)	Two author- determine d groups	Stepwise logistic regression analysis	BMQ SpN, BMQ SpC, BMQ GenO, BMQ GenH, depression, social support, relationship with hospital doctors on early discontinuation of medication.	Age; Anxiety.	75%
Van der Bemt et al. 2009 (The Netherlan ds)	228	Cross- sectiona I survey	BMQ (SpN, SpC)	CQR	Stepwise forward logistic regression	Age, gender, marital status, education level, smoking, number of medicines, Health Assessment Questionnaire, Satisfaction with Information about Medicines Scale, Urecht Coping List, BMQ SpC.	Number of side effects; Disease duration; BMQ SpN.	95%
De Thurah et al. 2010 (Denmark )	126	Prospect ive cohort study	BMQ (SpN, SpC)	CQR	Binomial regression	Not reported	Prevalence of having a CQR score in the bottom quartile (i.e. being non-adherence): was lower for men (seen at baseline and after 9 months); was higher for patients <55 years (seen at baseline only); was higher for patients on a lower dose (seen at baseline only); was lower for patients taking folic acid (seen at baseline and after 9 months); was higher for patients with more than 10 years of education (seen at baseline only); if patients had lower perceptions of medication necessity (seen at baseline and after 9 months); if patients had greater concerns about their medications (seen at 9 months only).	95%

BMQ = Beliefs about Medication Questionnaire; SpN = Specific-Necessity subscale; SpC = Specific-Concerns subscale; GenO = General-Overuse subscale; GenH = General-Harm subscale; CQR = Compliance Questionnaire Rheumatology; RAI = Rheumatology Attitudes Index; MISS = Medical Interview Satisfaction Scale.

Appendix Table 6: Diabetes included studies

Author	N	Study type	BMQ (subscales measured)	Measure(s) of adherence	Main statistical analysis	Factors not associated with medicines adherence/non-adherence in main analysis	Factors associated with medicines adherence/non-adherence in main analysis	Quality score
Barnes	82	Cross-	BMQ (SpN,	MARS	T-tests	IPQ-R Timeline (acute/chronic), IPQ-R	IPQ-R Timeline (cyclical); IPQ-R Consequences;	85%

et al. 2004 (NZ)		section al survey	SpC)			Treatment control, IPQ-R Personal control, IPQ-R Illness coherence, IPQ-R emotional representation, BMQ SpC.	IPQ-R Causes 1 (poor medical care in the past); IPQ-R Causes 2 (environmental pollution; IPQ-R Causes 3 (God's will); BMQ SpN.	
Aikens & Piette, 2009 (USA)	80 6	Cross- section al survey	BMQ (SpN, SpC)	Cost- and non- cost-related medication underuse	Logistic regression	BMQ SpN	Cost-related anti-hyperglycaemic and anti- hypertensive medication underuse: BMQ SpC. Non-cost-related anti-hyperglycaemic and anti- hypertensive underuse: BMQ SpC.	80%
Kurland er et al. 2009 (USA) *	24 5	Cross- section al survey	BMQ composite score of GenO and GenH subscales	Cost-related non-adherence groups (diab, pain, both, none)	Logistic regression	Income, out-of-pocket costs, patient education, satisfaction with medical information.	More depressive symptoms; BMQ composite score.	85%
Mann et al. 2009 (USA)	15 1	Cross- section al survey	BMQ (SpN, SpC) (author adapted)	MMAS	Logistic regression	Disease beliefs: Consequences of diabetes are low, Symptoms of diabetes are minimal, Have low control over diabetes.  Medication beliefs: Worried about addiction to medicines Other beliefs: Significant depressive symptoms, Diabetes significantly interferes with social life	Have diabetes only when sugar is high (disease belief); Don't need diabetes medicines when sugar is normal (SpN medicine belief); Worried about side-effects of medicines (SpC medicine belief); Medicines are hard to take (regime complexity); Little confidence in ability to control diabetes (disease self-efficacy belief).	90%
Schoent haler et al. 2012 (USA)	60 8	Cross- section al survey	BMQ (SpN, SpC, GenO, GenH)	Oral medication possession ratio (MPR)	Multiple linear regression	Age, gender, physician's number of patients, physician's years of service.	Satisfaction with the physician's patient education skills; BMQ SpN; Diabetes-related knowledge; Shorter duration of time with diabetes; Taking only oral hypoglycaemic medications.	90%

\*Kurlander et al. (2009) focused on patients using medications for chronic pain (arthritis, migraines, back pain, or sciatica) and diabetes (oral anti-hyperglycaemia drugs or insulin). Data reported in this table relates to diabetes medications only. BMQ = Beliefs about Medication Questionnaire; SpN = Specific-Necessity subscale; SpC = Specific-Concerns subscale; GenO = General-Overuse subscale; GenH = General-Harm subscale; MARS = Medication Adherence Report Scale; MMAS = Morisky Medication Adherence Scale; IPQ-R = Illness Perceptions Questionnaire - Revised.

# Appendix Table 7: Included studies focusing on general patient populations/mixed conditions with no inter-condition comparisons related to adherence

Author	N	Study	BMQ	Measure(s)	Main statistical	Factors not associated	Factors associated with medicines adherence/non-adherence	Qua
		type	(subscales	of	analysis	with medicines	in main analysis	lity
			measured)	adherence		adherence/non-		scor
						adherence in main		e

						analysis		
Horne et al. 1999 (UK)	524 (1)	Cross- sectional survey	BMQ (SpN, SpC, GenO, GenH)	RAM	Correlations	BMQ GenH	BMQ SpN; BMQ SpC; BMQ GenO.	90%
Phatak & Thoma s, 2006 (USA)	250 (2)	Cross- sectional survey	BMQ (SpN, SpC, GenO, GenH)	MMAS	Ordinary least squares regression	Number of conditions, BMQ GenO, BMQ GenH.	Age; BMQ SpC; BMQ SpN; Number of medications used.	95%
Mardby et al. 2007 (Swede n)	324 (3)	Cross- sectional survey	BMQ (GenO, GenH, GenB)	MARS	Logistic regression	Age, gender, birth country, education, previous medicine use, present medicine use, type of medicines prescribed, BMQ GenO, BMQ GenB.	BMQ Gen-H	95%
Clifford et al. 2008 (UK)	181 (4)	Cross- sectional analysis of data from a longitudi nal study	BMQ (SpN, SpC)	Single item (based on Haynes et al., 2002)	Post-hoc pairwise comparisons using Mann- Whitney U test	Not reported	BMQ SpN; BMQ SpC; BMQ necessity-concerns differential score.	75%
Gatti et al. 2009 (USA)	275 (5)	Cross- sectional survey	BMQ (SpN, SpC, GenO, GenH) total score	MMAS	Logistic regression	Mean number of people in household, number of health conditions.	BMQ total score >47; Age (<65); SEAMS score; Patients who had hyperlipemia.	95%
Schuz et al. 2011 (Germa ny)	309 (6)	Longitudi nal survey	BMQ reduced 9- item version	RAM (2 items only) assessed at time-points 1 and 3.	Hierarchical WLS regression	Age, gender, educational status, number of illnesses, number of medicines, BMQ SpC, BMQ GenH.	Changes in non-adherence were predicted by: BMQ SpN; BMQ GenO.	95%
Unni & Farris, 2011 (USA)	1513 (7)	Longitudi nal survey	BMQ (SpN, SpC)	MMAS scores converted (4 groups: adherent; intentionall y non-adh; unintention ally non-	Logistic regression	Gender, ethnicity, education, insurance status (were not associated in any analyses)	Predictors of non-adherence (combined unintentional and intentional) at baseline: BMQ SpC; Age; Income. Predictors of unintentional non-adherence at baseline: BMQ SpC. Predictors of intentional non-adherence at baseline: BMQ SpN; BMQ SpC. Predictors of non-adherence (combined unintentional and intentional) at follow-up: BMQ SpC. Predictors of unintentional non-adherence at follow-up: BMQ	100

				adh; mixed)			SpC. Predictors of intentional non-adherence at follow-up: BMQ SpN; BMQ SpC; Number of medicines taken regularly.	
Gadkari & McHorn ey, 2012 (USA)	24,017 (8)	Cross- sectional survey	BMQ (SpN, SpC)	Unintention al non- adherence (3 questions)	Multivariate logistic regression	Any unintentional non- adherence: Ethnicity, Disease (Hyperlipidaemia), Disease (Depression).	Any unintentional non-adherence: Age; Gender; Education; Income; Employment status; Self-rated health; Disease (Diabetes); Disease (Osteoporosis); Disease (Asthma); Medication affordability; BMQ SpC; BMQ SpN.	95%
Kung et al. 2012 (New Zealan d)	87 heart, 46 lung, and 193 liver transplan t patients	Cross- sectional survey	BMQ (SpN, SpC, GenO, GenH)	ITAS	Logistic regression	Gender; IPQ-B Identity (medication); IPQ-B Illness coherence; BMQ SpC; Transplant type.	Age; Education; IPQ-B Treatment control; IPQ-B Symptom distress (Emotional response).	95%

BMQ = Beliefs about Medication Questionnaire; SpN = Specific-Necessity subscale; SpC = Specific-Concerns subscale; GenO = General-Overuse subscale; GenH = General-Harm subscale; RAM = Reported Adherence to Medication Scale; MARS = Medication Adherence Report Scale; MMAS = Morisky Medication Adherence Scale; SEAMS = Self-Efficacy for Appropriate Medication Use Scale; ITAS = Immunosuppressant therapy adherence instrument; IPQ-B = Illness Perception Questionnaire - Brief. (1) Patient populations included: asthma, diabetes, psychiatric, renal, cardiac, and general medical; (2) Patients waiting to see a pharmacist at an outpatient pharmacy in a primary care clinic; (3) Patients attending pharmacies; (4) Patient populations included: Stroke, Coronary heart disease, Asthma, Diabetes, Rheumatoid arthritis; (5) Patients attending pharmacies; (6) Patients were older adults (aged 65-85 years old) with at least two health conditions; (7) Patients were aged over 65, English speaking, and enrolled in the Medicare health plan. Baseline survey for regression analyses n=769; follow-up survey (two years) for regression analyses n=744; (8) Patients populations included: asthma, hypertension, diabetes, hyperlipidaemia, osteoporosis, and depression.

### Appendix Table 8: Other included studies

Author	N	Study type	BMQ (subscales measured)	Measure(s) of adherence	Main statistical analysis	Factors not associated with medicines adherence/non-adherence in main analysis	Factors associated with medicines adherence/non-adherence in main analysis	Qualit y score
Grunfeld et al., 2005 (UK) Breast	110	Cross- section al survey	BMQ (SpN, SpC, GenO, GenH)	-Single item question -MARS *	Logistic regressio n	BMQ SpC, BMQ GenH, BMQ GenO.	BMQ SpN.	75%

<sup>\*</sup> Barber N, Parsons J, Clifford S, Darracott R, Horne R. Patients' problems with new medication for chronic conditions. Quality and Safety in Health Care 2004; 13:172-5.

<sup>\*\*</sup> Haynes RB, McDonald HP, Garg AX. Helping patients follow prescribed treatment: clinical applications. JAMA 2002; 288:2880-3.

Ediger et al., 2007 (Canada) IBD	326	Cross- section al survey	BMQ (SpN, SpC, GenO, GenH)	MARS	Logistic regressio n	Demographic/disease factors: disease activity, diagnosis type, marital status, education, disease duration. Psychological factors: BSI, HAQ, BMQ SpN, BMQ SpC, BMQ GenH, BMQ GenO, Mastery, NEO-FFI (openness, conscientiousness, extraversion, neuroticism). Medication factors: number of pill administrations per day, diagnosis type.	Demographic/disease predictors of adherence: Gender; Employed status; Age. Psychological predictors of adherence: Low levels of agreeableness (NEO-FFI). Medication predictors of adherence: Medication prescribed (immunosuppressants); Obstacles to medicine use in men; Obstacles to medicine use in women.	95%
Hedenrud et al., 2008 (Sweden) Migraine	174	Cross- section al survey	BMQ (SpN, SpC, GenO, GenH, GenB)	MARS	Backward stepwise logistic regressio n	BMQ SpC, BMQ GenH, BMQ GenO.	Tricyclic antidepressants use; Beta blocker use.	100%
lihara et al., 2008 (Japan) Liver	151	Cross- section al survey	BMQ (SpN, SpC) translated and adapted	Authors categorised patients **	Correlatio ns	Unintentional non-adherence: BMQ SpC. Intentional non-adherence: BMQ SpN; BMQ SpC; BMQ Necessity-Concerns Differential score. Both types of adherence: BMQ SpN; BMQ SpC; BMQ Necessity-Concerns Differential score.	Unintentional non-adherence: BMQ SpN; BMQ Necessity-Concerns Differential score. Intentional non-adherence: none. Both types of adherence: none.	85%
Moshkovs ka et al., 2009 (UK) Ulcerative colitis	169	Cross- section al survey	BMQ (SpN, SpC)	-Author created self- report questionnair e	Logistic regressio n	Ethnic group, disease duration, BMQ SpC, Satisfaction with Information about Medication Scale, Indices of Multiple Deprivations.	Self-reported non-adherence: Age; BMQ SpN.	90%
Kurlander et al. 2009 (USA) Pain***	245	Cross- section al survey	BMQ composite score of GenO and GenH subscales	Cost-related non- adherence groups (diab, pain, both, none)	Logistic regressio n	Out-of-pocket costs, patient education, depressive symptoms, BMQ composite score.	Income (<\$20,000); Dissatisfaction with medical information.	85%
Nicklas et al. 2010 (UK) Non- malignant chronic pain	217	Cross- section al survey	BMQ (SpN, SpC)	MARS	Structural equation model	Age, gender, educational status, duration of pain, pain rating, number of medicines, IPQ-R (Identity, Timeline (acute/chronic), Time-cycle, Personal control, Treatment control, Consequence, Coherence, and Emotion).	A model including the IPQ-R scales of emotion and consequences and the BMQ scales of necessity and concerns was a good fit for the data (CFI=0.974, RMSEA=0.058, Satorra Bentler Scaled x2=8.15, df=5, p=0.15). To summarise this model, the IPQ-R scales influence adherence indirectly through medication beliefs. Higher IPQ-R consequence scores are correlated with increased IPQ-R emotion, BMQ necessity and BMQ concern scores. Increased IPQ-R emotion is	95%

							associated with increased BMQ concerns scoresBMQ SpN predicted adherence -BMQ SpC predicted non-adherence.	
Rees et al., 2010 (Australia) Glaucoma	131	Cross- section al survey	BMQ (SpN, SpC) adapted	RAM (adapted)	Multiple regressio n	Unintentional non-adherence: BMQ Necessity-Concerns Differential score, BMQ SpN, number of medicines per day, duration of eye drop usage, other health conditions, taking other medications, IPQ-B Consequences. Intentional non-adherence: BMQ Necessity-Concerns Differential score, BMQ SpC, number of reasons against taking eye drops, other health conditions, taking other medications. IPQ-B Illness coherence, IPQ-B Timeline.	Unintentional non-adherence: Age. Intentional non-adherence: Age.	95%
Daleboudt et al. 2011 (New Zealand) Systemic Lupus Erythemat osus	106	Cross- section al survey	BMQ (SpN, SpC, GenO, GenH)	-VAS -MARS	Stepwise linear regressio n and logistic regressio n	VAS level (stepwise linear regression): Cognitive functioning (concentration), BMQ SpC, BMQ GenO. Ethnicity, IPQ-B Emotions. Unintentional non-adherence (MARS) (logistic regression): Cognitive functioning (concentration), BMQ GenO. Intentional non-adherence (MARS) (logistic regression): BMQ GenO, emotional health, religion.	VAS level (stepwise linear regression): Cognitive functioning (Recognition/planning); Age. Unintentional non-adherence (logistic regression): Cognitive functioning (Recognition/planning); Age; BMQ SpC. Intentional non-adherence (logistic regression): BMQ SpC	90%
Nakhutina et al. 2011 (USA) Epilepsy	72	Cross- section al survey	BMQ (SpN, SpC, GenH, GenO, GenB)	MMAS	Correlatio ns	BMQ GenO, BMQ SpN.	BMQ SpC; BMQ GenH; BMQ GenB.	80%
O'Carroll et al. 2011 (UK) Stroke	180	Longitu dinal study	BMQ (SpN, SpC)	MARS (baseline and 6 weeks)	Hierarchi cal multiple regressio n	Baseline: Gender, social deprivation category, stroke severity, perceived risk of further stroke, perception of benefit, desire for medication, IPQ-R chronic timeline, IPQ-R treatment control, HADS emotional distress 6 weeks: Gender, social deprivation category, stroke severity, perceived risk of further stroke, perception of benefit, desire for medication, Cognitive functioning (Mini-Mental State Examination), IPQ-R chronic timeline, IPQ-R treatment control, HADS emotional distress.	Baseline: Age; BMQ SpC; BMQ SpN; Cognitive functioning (Mini-Mental State Examination). 6 weeks:; Age; BMQ SpC; BMQ SpN.	95%
Wileman et al. 2011 (UK) Renal	76	Cross- section al survey	BMQ (SpN, SpC, GenH, GenO)	-MAQ (intentional non- adherence only) -Serum	-Logistic regressio n (MAQ) - Hierarchi cal linear	MAQ intentional non-adherence: GenH, GenO, SpC, Age.  Serum levels: KRU, Kt/V, GenH, GenO, SpC, Gender, MAQ intentional non-adherence.	MAQ intentional non-adherence: BMQ SpN; BMQ Necessity-concerns differential score; Gender. Serum levels: Age; MAQ unintentional non-adherence.	85%

				phosphate levels	regressio n (Serum levels)			
Griva et al. 2012 (UK) Renal	218	Cross- section al survey	BMQ (SpN, SpC)	(1) MARS (Total score) (2) MARS (Intentional) (3) MARS (Unintentional)	Multiple regressio n	Not explicitly reported.	(1) MARS Total: Gender; In a relationship; Dialysis vintage; BMQ SpN; BMQ Necessity-Concerns Differential score; Worry about transplant. (2) MARS Intentional: Dialysis vintage; BMQ SpN; Depression. (3) MARS Unintentional: Age; Dialysis vintage; BMQ SpN; BMQ Necessity-Concerns Differential score; Worry about transplant.	85%
Lennerling & Forsberg, 2012 (Sweden) Renal	250	Cross- section al survey	BMQ (SpN, SpC, GenH, GenO, GenB)	BAASIS	Mann- Whitney	Age, Gender, Number of side effects, BMQ SpN, BMQ SpC, BMQ GenH, BMQ GenO, BMQ GenB.	Extent of support from family and friends.	85%

<sup>\*</sup>The two adherence measures (MARS-5) and single item question were highly correlated (r=0.497, p<0.001) and as such the findings refer to the single item measure only.

\*\*Patients were categorised into three groups: intentional adjustments alone; unintentional forgetfulness alone, and a group with both.

BMQ = Beliefs about Medication Questionnaire; SpN = Specific-Necessity subscale; SpC = Specific-Concerns subscale; GenO = General-Overuse subscale; GenH = General-Harm subscale; GenB = General-Benefits subscale; IPQ-B = Illness Perception Questionnaire - Brief; IPQ-R = Illness Perceptions Questionnaire - Revised; MARS = Medication Adherence Report Scale; RAM = Reported Adherence to Medication Scale; MMAS = Morisky Medication Adherence Scale; VAS = visual analogue scale; BAASIS = Basel Assessment of Adherence with Immunosuppressive medication Scale; MAQ = Medication Adherence Questionnaire; BSI = Brief Symptom Inventory; HAQ = Health Anxiety Questionnaire; NEO-FFI = Neuroticism Extraversion Openness-Five Factor Inventory; HADS Hospital Anxiety and Depression Scale.

<sup>\*\*\*</sup>Kurlander et al. (2009) focused on patients using medications for both chronic pain (arthritis, migraines, back pain, or sciatica) and diabetes (oral anti-hyperglycaemia drugs or insulin). Data reported in this table relates to pain medications only.

# Appendix 2

Appendix Table 9: Summary table of included qualitative studies in Chapter 1.

Author/ Date	Method/ Analysis	Participants	Medication	Aim(s) / Key findings / Themes	Location	Quality score
Carrick et al. 2004	Grounded theory approach, using interviews and a focus group.	Phase 1: 9 patients diagnosed with schizophrenia taking anti- psychotic medication were interviewed. Phase 2: 16 patients taking anti-psychotics for any reason took part in a focus group.	Anti-psychotic medications	This study investigates the subjective experience of side effects of antipsychotic medication to gain a greater understanding of service users' experiences and to gain insights into adherence issues. Core theme: maximizing wellbeing.  Theme: managing treatment -nature of doctor-patient relationship -own coping Theme: understanding of the situation -beliefs about illness -beliefs about side effects -beliefs about medical establishment Theme: evaluating treatment -positive beliefs about treatment: helpful medicine, good side effects, counselling as effective treatmentnegative beliefs about treatment: distressing treatment, distressing side effects, dependence on medication, fear of new medication because of adverse reactions, individual side effects.	UK	80%
Attebring et al. 2005	Narrative interviews with hermeneutic analysis approach.	20 patients (median age 61.5) who had undergone a first time myocardial infarction.	Cardio- protective medications	The purpose of this study was to explore patients' experiences after a first time myocardial infarction in relation to secondary prevention medication.  The analysis resulted in the description of two main themes: the impact of medication and the impact of health care professionals.  Theme: The impact of medication. Sub-themes: -Dealing with symptoms related to the medicationFeeling intruded uponFeeling safe. Theme: The impact of health care professionals. Sub-themes: -Receiving conflicting informationWanting reassurance from the physicianExperiencing the period after discharge as uncertain and precarious.	Sweden	85%
Woodard et al. 2005	Focus groups and thematic analysis	24 with CHD (14 White & 10 African- American)	CHD medications	Main aim: to explore coronary heart disease (CHD) health care experiences and beliefs of African-American and white patients to elicit potential causes of racial disparities in CHD outcomes.  Four themes:	USA	80%

				(1)risk factor knowledge (2)physician-patient relationship (3)medical system access (4)treatment beliefs about efficacy and cost		
Arnaert et al. 2006	Case study design using semi-structured interview and some grounded theory approaches for analysis.	11 patients with chronic nonmalignant pain	Oral methadone therapy	Aim: to explore the beliefs of patients with chronic pain and the challenges they faced coming to terms with and integrating methadone treatment into their lives. A two-phase process of acceptance and integration of methadone treatment was reported.  Acceptance influenced by: -beliefs: methadone is for junkies, methadone is just another narcotic, and methadone will not relieve my paintrust in pain specialistknowledge about methadonefamily supportinadequate pain controlintolerable side effectsfinancial reasons. Integration influenced by: -beliefs: I know why I'm on methadone, others think I'm an addict, methadone can cause harmnegative encounterspast addict experiencessafety issuesbarriers to the health care system.	Canada	75%
Givens et al. 2006	Semi- structured interviews and thematic analysis	42 primary care patients aged 60+. The majority had major depression.	Anti- depressant medication	Aim: To explore attitudes toward antidepressants in a sample of depressed, community-dwelling elders who were offered treatment.  Four themes emerged from an examination of responses expressing reluctance or refusal to use antidepressants: fear of addiction resistance to viewing depression as a medical illness concern that antidepressants will prevent feelings of natural sadness prior negative experiences with medications for depression are an obstacle to treatment.	USA	90%
Gordon et al. 2007	Semi- structured interviews and inductive thematic analysis	98 adult patients prescribed medicines for a cardiovascular condition	Cardiovascular medications	Main aim: to investigate the perspectives of people with cardiovascular disease regarding medication-related problems.  Five broad categories of medication-related problem emerged which were examined in the context of patients' perspectives on, and experiences of, the use of medicines and health services. These were: (1)concerns about and management of side effects (2)differing views regarding the use of medicines (3)cognitive, practical and sensory problems (4)lack of information or understanding (5)problems with access to, and organisation of, services Conclusion: All categories of problem had potential implications for the success of	UK	90%

				therapy in that they created barriers to adherence, access to medication or informed decision-making. The study demonstrated how patients actively engage in decision-making about their medicines in the home, if not in the consultation. Practice implications: The five categories of problem provide a focus for interventions by health professionals to support patients in achieving optimal theory outcomes. They demonstrate the need for a comprehensive approach, spanning patient education to the systems of delivery of care. Within the NHS in Britain, policy and practice initiatives are being designed to achieve this end. Further research should focus on the evaluation of professional practices and service developments in supporting patients in the self-management of their medicines.		
Hall et al. 2007	Semi- structured interviews, focus groups and grounded theory methods of analysis	31 individuals participated (19 female and 12 male). 17 had a diagnosis of ulcerative colitis and 14 crohn's disease	Predominantly steroids	The aim of the study was to assess patients' perspectives and beliefs about their medication and to determine how this relates to medicine taking and other related health behaviour as part of a larger qualitative study on health care related behaviour in patients with IBD.  Themes were: (1) perceived need for medication (2) medication fears and concerns (3) perceived impact of symptoms (4) willingness to self-manage medication There was a clear distinction made between steroids and other preparations. Concerns included the fear of both short and long-term side-effects (mainly steroids), uncertainties about drug interactions and development of long-term immunity. Adapting to and accepting medication use was linked to acceptance of IBD.	UK	90%
Choi et al. 2008	Semi- structured interviews and thematic analysis	52 patients, mean age 43, 87% female	71% taking maintenance medications for asthma	Aim: to identify patients' beliefs about asthma medications and to assess these beliefs according patient and asthma characteristics, including asthma severity and patient-reported medication adherence.  17 categories of beliefs about medications were discerned which were grouped into: (1) perceived benefits (e.g., permit activities, thwart symptoms) (2) perceived drawbacks (e.g., establish a medication routine, ensure supply) Benefits of asthma medications in general -Permit activities -Sense of control -Lessen fear -Improvements in medications -Allow a normal life Drawbacks of asthma medications in general -Need to establish routine -Dislike medications -Side effects -Need to ensure adequate supply -Medications not effective	USA	80%

				-Unsure of what to do with medications Benefits of rescue medications -Thwart symptoms -Relieve symptoms -Give confidence Drawbacks of rescue medications -Need to always have on hand -Afraid if not on hand -Overuse/abuse undesirable Beliefs were not mutually exclusive, with 56% of patients citing both benefits and drawbacks.		
Dahab et al. 2008	Semi- structured interviews and thematic analysis	12 participants: 6 ART patients, 5 health professional and 1 manager	Antiretroviral therapy (ART)	Aim: examines potential barriers to, and facilitators of, adherence to ART. Key barriers to adherence: (1) Individual factors (2) Disease and treatment (3) Patient/health care provider relationship (4) Health system Key facilitators to adherence: (1) Disclosure (2) Having social support (3) A strong belief in the value of treatment	South Africa	65%
Dolovich et al. 2008	Semi- structured interviews and grounded theory approach to analysis	18 community dwelling patients	A range of medications for long-term conditions (mostly cardiac, psychiatric, or pain medication)	To investigate whether patients' expectations influence how they take their medications by looking at the expectations patients have of their medications and the factors that affect these expectations.  Central theme: patients' expectations of their medications were generally more realistic than idealistic. This outlook was informed by other themes: -patients beliefs (about need for, their efficacy, and not taking too many)previous experience of medication -Other peoples' beliefs -Health professional and patient relationship -Cost of medication	Canada	75%
Lau et al. 2008	7 focus groups	37 postmenopaus al women	Currently taking at least 1 prescription for osteoporosis	Aim: to explore the experiences and perceptions of postmenopausal women regarding strategies to improve adherence to osteoporosis therapy. 6 main factors that influenced adherence to medications: (1) belief in the importance of taking medications for osteoporosis (2) medication-specific factors (3) beliefs regarding medications and health (4) relationships with health care providers (5) information exchange (6) strategies to improve adherence Quote from beliefs regarding medications and health theme: "I would like to come off it and wouldn't like to be on it for a lifetime because even though they start off with glowing recommendations, they often decide later, oh that drug has serious side effects and you shouldn't be on it."	Canada	90%

				Results of this study provide a better understanding of how patients' perceptions and experiences affect their adherence to osteoporosis medications. Because each patient's reasons for non-adherence might be different, depending on individual beliefs or circumstances, strategies to improve adherence to medications should be individualized accordingly.		
Lawton et al. 2008	Longitudinal interview design with thematic analysis	20 patients with Type 2 diabetes interviewed 4 times each over 4 years	Oral glucose- lowering medication	The aim of this study was to examine Type 2 diabetic patients' expectations, perceptions and experiences of oral glucose-lowering agents.  Themes:  -concern about harm from medication -concern that medication is not natural -concern that medication has long-term detrimental effect -going onto medication from diet-only treatment was a slippery slope -concern that going onto medication meant they'd failed to control their diet -negative experiences of taking medication (side effects) -positive experience of taking medication (it working) -commitment to taking medication -evidence of medication medication -evidence of medication taking into normal routine -patients took passive role in decision-making about medication -patients wanted more education	UK	70%
Stack et al. 2008	Semi- structured interviews and modified grounded theory analysis	19 patients (mean age 65.3) managing multiple medications (mean 4.8) for Type 2 diabetes and cardiovascular disease	Medications for Type 2 diabetes and cardiovascular disease	Aim: explored perceptions towards multiple medicines expressed by people managing co-morbid Type 2 diabetes and cardiovascular disease. Themes: -Beliefs about over-prescribing and resistance to additional medicines -The importance of medicines: T2D vs. CVD -Low status given to CVD medications -Low status given to lipid-lowering medicines -perceived susceptibility to CVD heightened necessity beliefs for medication.	UK	85%
Gebremaria m et al. 2010	Semi- structured interviews and focus groups, and thematic analysis	15 patients participated in the interviews	TB and HIV medications	The aim was to explore patients' and health care professionals' views about barriers and facilitators to tuberculosis (TB) treatment adherence in TB/HIV coinfected patients on concomitant treatment for TB and HIV. Factors that positively influenced adherence to TB treatment: -beliefs in the curability of TB -in the severity of TB -in the presence of HIV infection -support from families and health professionals Barriers to treatment adherence: -experiencing side effects -pill burden -economic constraints	Ethiopia	75%

				-stigma with lack of disclosure -lack of adequate communication with health professionals		
Tordoff et al. 2010	Structured interviews	20 older patients with a range of conditions. 10 female (mean age 77) and 10 male (mean age 71).	A wide range of 13 different prescription groups. Taken together, two-thirds of prescriptions were for the nervous system (28%), for the cardiovascular system (21%), and for the alimentary tract and metabolism (17%).	Aim: to explore how New Zealanders aged 65 years and older manage their medicines in their own homes, and determine the problems and concerns they might have with taking them.  Themes were explored under the topics: -accessing medicines -remembering to take medicines -following instructions -practical problems -adverse effects -concerns about medicines -beliefs about medicines Although many participants had experienced adverse effects, their beliefs about medicines were mainly positive. Practical problems and concerns should be routinely enquired about and addressed, and prescribing and monitoring optimised to minimize adverse effects, in order to assist older people take their medicines.	New Zealand	75%
Chambers et al. 2011	Semi- structured interviews	13 stroke survivors with self-reported low adherence and 13 with high adherence. Low adherers mean age 64 years and high adherers mean age 61 years.	Multiple medications for stroke management (average participant taking 5/6 per day)	Aim: to qualitatively investigate factors that may explain variance in adherence to medication in stroke patients.  Thematic analysis revealed that those with poor adherence to medication reported both intentional and non-intentional non-adherence.  Two main themes emerged: -the importance of stability of a medication routine -the importance of beliefs about medication and treatment (three sub-themes: consequences of missing medication, dislike of medication, patients' knowledge). High adherers reported remembering to take their medication and seeking support from both family and health professionals. They also had a realistic understanding of the consequences of non-adherence, and believed their medicine did them more good than harm.  Low adherers reported forgetting their medication, sometimes intentionally not taking their medication and receiving poor support from medical staff. They disliked taking their medication, had limited knowledge about the medication rationale or intentions, and often disputed its benefits.	UK	75%
Kumar et al. 2011	Focus groups	32 patients with rheumatoid arthritis and systemic lupus erythematosus	Disease modifying anti- rheumatic drugs (DMARD)	Aim: to investigate factors that influence beliefs about medicines in patients of South Asian origin with rheumatoid arthritis and systemic lupus erythematosus. Three main themes emerged to explain patients beliefs about medicines: (1) Beliefs about the necessity of DMARDs; (2) Concerns about DMARDs and other prescribed medicines including: (a) long-term side-effects; (b) the apparent lack of efficacy of some therapies; (c) concerns about changing from one drug to another and the large numbers of different medicines being taken.	UK	85%

	(3) Contextual factors which informed the patient's view on the necessity for particular medicines and concerns about them including: (a) Beliefs about the causes of disease and the influence of religious beliefs on this; (b) Barriers to communication with health care professionals about the	
	medications being prescribed in clinic.	

### Appendix 3

Ethics committee approved nurse-related recruitment documents



VERSION 2: [27/04/2007]

#### INFORMATION LETTER FOR NURSE MANAGER / NON-MEDICAL PRESCRIBING LEAD

Date:

Dear [nurse manager],

Research study: Improving medicine-taking in diabetes care: an evaluation of education for nurse prescribers.

I'm writing to you about the possibility of recruiting nurse prescribers from your nursing service to become involved in an evaluation of a new professional development initiative to improve medicines management in people with diabetes. The initiative is targeted at helping nurse prescribers improve the effectiveness of their consultations with people with diabetes. This study has been funded by Diabetes UK, in response to the significance of medicine taking in ensuring good clinical outcomes in diabetes care, and the growing role of nurses in prescribing medicines for people with diabetes as part of their role in long term conditions management.

The study has been reviewed by Southampton and South West Hampshire Research Ethics Committee (Ref: 07/Q1702/45) and approval to proceed with the study has been given. Our initial scoping exercise has revealed that several nurse prescribers within your service would be eligible to take part. Our inclusion criteria: the nurses must have a prescribing qualification, have been prescribing for more than 6 months [at the start of the workshops], and regularly see diabetes patients.

Our study objectives are:

- To develop and deliver a professional development initiative focused on work-based training for nurse prescribers. The training is designed to help nurses influence diabetes patients' beliefs about medicines in order to improve the effectiveness of their medicinetaking.
- To evaluate any changes in the nurse prescribers' consultations after they have completed the training.
- To investigate nurse prescribers' views on implementing the training in practice, including identification of the successful components, and the contextual factors that influence the training in practice.
- To investigate patients' views of the value, impact and effectiveness of nurses' prescribing consultations.

Within each Trust site, we would like to conduct the following:

- 1. To invite appropriate nurse prescribers to join a group of nurse prescribers at 4 one-day workshops at the School of Nursing & Midwifery, University of Southampton, to be provided at monthly intervals (exact dates will be on the nurse information letter). The workshops will be provided free of charge and will be facilitated by an experienced Nurse Consultant in Diabetes and a Health Psychologist. The workshops will be a Continuing Professional Development opportunity for nurse prescribers.
- 2. If recruited, each nurse will be asked to audio-record a total of 8 naturally-occurring consultations with different diabetes patients on their caseloads before and after the workshops. Recording devices will be provided.
- 3. The project researcher will interview each participating nurse twice (at 1 month and 6 months after the training) to elicit their opinions of taking part in this professional development initiative.
- 4. The project researcher will interview a random sample of 3 patients from each nurse, 1 week after being involved in the audio-recorded consultation, to assess their opinions of the nurses' approach to medicines management during their audio-recorded consultation.

All interviews will be conducted by a researcher from the University of Southampton. The researcher will liaise with the nurse prescribers about the timing of consultation recordings and schedule interviews at the convenience of the nurse prescribers and patients, either by visiting site premises or by telephone if preferred. The interviews with staff will be brief and are not likely to last more than 30 minutes. Interviews with patients will take around 30 minutes.

The researchers will ensure that every member of staff approached is provided with information on the study and that they understand the nature of their involvement before they decide whether to consent to participate. Similarly, interviews with patients will only be conducted after they have been approached by the nurse responsible for their care and after appropriate consent has been obtained from the patient.

If you are interested in your Trust being involved in this education initiative and its evaluation, we will of course comply with the Research Governance requirements of your Trust, and will initiate an application following your approval to proceed.

We would like to mention that the number of places available for the series of workshops is strictly limited and we are expecting to receive a wide range of interest across several Strategic Health Authorities. If you are interested in allowing your nurses to participate, please let us know as soon as possible.

I will take the liberty of ringing you in 1 week to follow up this letter, answer any queries you or your colleagues might have and ascertain if you are interested in participating. A member of the project team will be glad to call/visit you to discuss further the practicalities of participation. In the meantime do contact me if you have queries or require any further information.

You are welcome to circulate this information to colleagues who might become involved with the project.

the project.			

We look forward to hearing from you.

With good wishes,

Yours sincerely,

Dr Susan Latter Reader School of Nursing & Midwifery University of Southampton Highfield Campus 023 8059 7959 sml@soton.ac.uk

Mr Andrew Sibley Senior Research Associate School of Nursing & Midwifery University of Southampton Highfield Campus 023 8059 7998 ams4@soton.ac.uk



VERSION 2: [27/04/2007]

#### RECRUITMENT LETTER FOR NURSE PRESCRIBER

Date:

Dear [nurse prescriber]

Research study: Improving medicine-taking in diabetes care: an evaluation of education for nurse prescribers.

I'm writing to invite you to be involved in an evaluation of a new professional development initiative to improve medicines management in people with diabetes.

This study has been funded by Diabetes UK, in response to the significance of medicine taking in ensuring good clinical outcomes in diabetes care, and the growing role of nurses in prescribing medicines for people with diabetes as part of their role in long term conditions management.

Our research team is aiming to recruit nurses and patients in a number of Trust locations across the UK. Data will be collected on the impact and value of our new professional development initiative for nurse prescribers.

The study has been approved by the Southampton and South West Hampshire Research Ethics Committee (Ref: 07/Q1702/45).

Our study objectives are:

- To develop and deliver a professional development initiative focused on work-based training for nurse prescribers. The evidence-based training is designed to help nurses improve diabetes patients' medicine-taking.
- To evaluate any changes in nurse prescribers' consultations after they have completed the training.
- To investigate nurse prescribers' views on implementing the training in practice, including identification of the successful components, and the contextual factors that influence the training in practice.
- To investigate patients' views of the value, impact and effectiveness of nurses' prescribing consultations.

We would like to invite you to take part in the study by joining a group of nurse prescribers at 4 one-day training workshops, and to be involved in the evaluation through you audio-recording some of your consultations and taking part in two short interviews with the researcher.

Further details of the project and what your participation would involve are enclosed with this letter.

We would like to mention that the number of places available for the series of workshops is strictly limited and we are expecting to receive a wide range of interest across several Strategic Health Authorities. If you are interested in participating, please discuss this with your manager and let us know as soon as possible.

A member of the project team will be glad to call/visit you to discuss the practicalities of participation further. I will take the liberty of ringing you in 1 week to follow up this letter, answer any queries you or your colleagues might have and to ascertain if you are interested in participating.

With good wishes,

Yours sincerely,

Dr Susan Latter Reader School of Nursing & Midwifery University of Southampton Highfield Campus 023 8059 7959 sml@soton.ac.uk

Mr Andrew Sibley Senior Research Associate School of Nursing & Midwifery University of Southampton Highfield Campus 023 8059 7998 ams4@soton.ac.uk



VERSION 2: [27/04/2007]

#### **INFORMATION SHEET FOR NURSES**

Research study: Improving medicine-taking in diabetes care: an evaluation of education for nurse prescribers.

You are invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

#### What is the purpose of the study?

The problem of ineffective medicine-taking in diabetes and in long term conditions more generally remains a significant one: it is estimated that 50% of people with long-term conditions do not take their medicines as prescribed (Department of Health 2000). Nurses with a prescribing role are well placed to tackle this issue. Through working in partnership with patients, they can address patients' knowledge and beliefs about medicines, both of which have been linked to better medicine-taking. However, nurses often feel frustrated that they are not able to successfully influence patients' medicine-taking, and our previous research shows that there is potential to provide better, evidence-based training for nurse prescribers to enable them to advance their practice further.

This evaluation has been funded by Diabetes UK to assess the impact and value of a new professional development initiative aimed at helping nurse prescribers advance their practice and improve medicine-taking in people with diabetes.

#### Who is conducting the research?

A team of researchers and clinical staff led by the School of Nursing & Midwifery, University of Southampton is conducting the project. The project is led by Dr Susan Latter and the researcher conducting data collection is Mr. Andrew Sibley. Both are based at the School of Nursing & Midwifery, University of Southampton. The project is funded by Diabetes UK.

#### Why are you telling me about the project?

Your Trust was selected as one of the sites in which we would like to provide the new professional development workshops. At each site, we are interested in involving nurse prescribers in the workshops and their subsequent evaluation. As a nurse who often prescribes medicines for people with diabetes, and who has 6 months or more prescribing experience [at the start of the workshops], you have been selected to take part in the study. Your views and experiences of this new initiative would be very valuable. We would therefore like to invite you to take part in the study.

#### Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You will always reserve the right to withdraw at any time and without giving a reason.

#### What will happen to me if I take part?

#### a) Professional development workshops

You are being invited to take part in a series of workshops for nurse prescribers designed to help you influence and improve medicines management for people with diabetes. Four local one-day workshops will be provided free of charge one month apart – dates are on the covering letter. The workshops will be facilitated by an experienced nurse consultant in diabetes care and a health psychologist who are part of our research team. The training will use current research evidence to underpin advanced practice.

#### b) Audio-recording of diabetes patient consultations

As part of the evaluation of the impact and value of the workshops, we would like you to audio-record a total of 8 consultations with people with diabetes on your caseload over several months. We would like you to audio-record 2 patients before taking part in the workshops, 2 at one week, 2 at three months and 2 at six months after taking part in the workshops. The aim of this is to see whether the workshops influence prescribing consultations over time. We expect that additional audio-recordings of consultations will also be used during the training workshops as examples. We will provide you with your own audio-recorder and give you instructions so that you can record the consultations yourself.

#### c) Interviews with nurse prescribers

A researcher would interview you twice (at 1 month & 6 months after the workshops) about your experiences of being involved with the workshops. We estimate that each interview should take about 30 minutes of your time. With your permission, the interview will be audiotaped and will take place at a time and place that is convenient to you. All the information that you give to the researcher will be treated in the strictest confidence and all data will be anonymised to protect your identity.

#### d) Interviews with your patients

Your routine consultations with the patients you select to include in the study will take place in the normal way. The only difference is that we would like you to audio-record the consultation. We are planning to interview a random sample of half of the patients involved in the audio-recordings that take place after the workshops. It is estimated that each patient interview would take approximately 30 minutes. Patients will be given the opportunity to take part in these interviews either by telephone or face to face in a location of their choice. The interviewer will be a researcher who is experienced at conducting interviews with patients. Everything that they tell us will be held in the strictest confidence and we will therefore not be able to provide you or any other member of staff with information on their responses.

#### What are the possible benefits of taking part?

You will receive free training from a team of experts that we hope will have a beneficial effect on your practice. You will also have an opportunity to share views and experiences of advanced practice in nurse prescribing with a group of other nurse prescribers in your area. You will have an opportunity to feed back to the research team on the effectiveness of the training, and we will use your views to influence the future shape of the training that may be used on a wider scale for nurse prescribers in the future. We also hope that people with diabetes will benefit from the study as we hope it will help us understand patients' views and also how best to provide training to improve practice.

#### Will my taking part in the study be kept confidential?

Yes. All the information about your participation in this study will be kept confidential. Data will be stored in a locked filing space and / or password protected computer file in a protected access part of the research team's premises. Data will be stored in accordance with the Data

Protection Act (1998). Your identity will be anonymised in data storage and you will not be referred to by name in any reporting of the results of the study.

However, in the event of any member of the research team witnessing unsafe or unprofessional practice, the Chief Investigator of the project will be obligated to report this to the relevant manager responsible.

#### What if there is a problem?

If you have any concerns about this study or the way it has been carried out, you should contact Dr Susan Latter, RN, PhD, Chief Investigator, in the first instance: Tel: 023 8059 7959. Email: sml@soton.ac.uk

### What will happen to the results of the research study?

The information that we receive from you will be analysed by the research team at the University of Southampton. We will provide a report of the project to Diabetes UK, the charity funding the study. We also plan to publish the results of the study in health care journals to inform other health care professionals and researchers of our findings. Please be assured that no participants will be identified by name in any reports or publications. A summary report of the findings from the study will be available for all participants at the end of the study. Please let Andrew Sibley know if you would like to be sent a copy. Once we have completed the project, the contact details of all our participants, tape recordings of their consultations and interview transcripts will be stored for 15 years in accordance with University of Southampton regulations, and then destroyed.

#### Who has reviewed the study?

Southampton and South West Hampshire Research Ethics Committee (Ref: 07/Q1702/45) has reviewed and approved the study.

THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION.

If you have any queries, or for further information about the project, please contact:

Andrew Sibley
Senior Research Associate
University of Southampton
School of Nursing and Midwifery
Building 67
Highfield Campus
Southampton
SO17 1BJ

Telephone: 023 8059 7998 Email: ams4@soton.ac.uk



Version 1: [01/03/2007]

## **CONSENT FORM: NURSE PRESCRIBER**

Research study: Improving medicine-taking in diabetes care: an evaluation of education for nurse prescribers.
STUDY SITE
PARTICIPANT NAME
Please initial the boxes.
1. $\Box$ I confirm that I have read and understand the information sheet for the above study and have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. $\Box$ I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.
3. □ I agree to take part in the above study.
4. $\Box$ I give consent for the researchers to the use anonymised quotes from my consultations and interviews in reports or publications.
5. $\Box$ I give the researchers permission to store my contact details and consultation and interview transcripts/recordings for the duration of the project.
6. $\Box$ I would like a summary sheet about this study once it has been completed.
Name of Nurse Date Signature
Researcher
Date Signature

Ethics committee approved patient-related recruitment documents

#### PATIENT LETTER FROM TRUST SITE / GP PRACTICE

(Post-intervention: patient audio-recording and interview)

VERSION 1: [01/03/2007]

Date:

Dear [Patient]

Research study: Improving medicine-taking in diabetes care: an evaluation of education for nurse prescribers.

[service/surgery] is writing to inform you about a research project that is being carried out by the University of Southampton. As you may know, some specially qualified nurses are now allowed to prescribe medication to diabetes patients. This study is about evaluating some extra training for nurses to enhance their consultation skills. They would like to involve patients in that evaluation by allowing us to audio-record one of your consultations with your nurse and then possibly interview you, at a later date, about your experiences of being prescribed medicines by a nurse. [service/surgery] and your nurse have decided to take part in this study.

The researchers on the project have asked me to send you some information on the study. In this envelope, you should find a letter from them telling you about the study and an information sheet. Please read the information sheet first before deciding whether to take part.

We have agreed to pass this information on to you. However, we would like to make it clear that you do not have to agree to take part and that your participation in this project is entirely voluntary. Your decision on whether or not to take part in the research will not affect the care that you receive in any way.

The research team would appreciate it if you could indicate your interest in taking part to your nurse at your next consultation. If you have any questions about the study or would like any further information, please contact Mr Andrew Sibley, Research Associate (details enclosed).

Thank you,

Yours faithfully,

Nurse
[service/surgery]



#### PATIENT LETTER FROM RESEARCH TEAM

(Post-intervention: patient audio-recording and interview)

VERSION 1: [01/03/2007]

Date: Dear

Research study: Improving medicine-taking in diabetes care: an evaluation of education for nurse prescribers.

We are writing to invite you to be part of a research study funded by Diabetes UK to evaluate some extra training for nurses to enhance their consultation skills. The staff at [service/surgery] have agreed to take part in our research project. You have been selected by the nurse at the [service surgery] as a possible participant in the study as you are a person who is due to see the nurse soon about their diabetes.

For this reason, I am writing to ask whether you would be willing to allow the nurse to audiorecord your next scheduled consultation with him/her and possibly take part in one short interview with our researcher at a later date.

I enclose an information sheet about the study. Please read through all this information carefully before deciding whether to participate.

If you would like further information before deciding, please contact Andrew Sibley, Research Associate, on [phone number].

Thank you, Yours faithfully,

Dr Susan Latter Chief Investigator Reader School of Nursing & Midwifery University of Southampton Highfield Campus 023 8059 7959 sml@soton.ac.uk

Andrew Sibley
Research Associate
University of Southampton
School of Nursing and Midwifery
Highfield Campus
Southampton
SO17 1BJ

Telephone: 023 8059 7998 Email: ams4@soton.ac.uk



#### **PATIENT INFORMATION SHEET**

(Post-intervention: patient audio-recording and interview)

VERSION 1: [01/03/2007]

Research study: Improving medicine-taking in diabetes care: an evaluation of education for nurse prescribers.

You are invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

#### What is the purpose of the study?

This study has been funded by Diabetes UK to evaluate some extra training for nurses who prescribe medicines for people with diabetes. We want to study if there are any changes in nurses' consultations with patients before and after the training. We are also interested in nurses' views of the training and patients' views about nurses' consultations when they prescribe medicines to help people manage diabetes.

#### Who is conducting the research?

A team of lecturers and clinical staff from the University of Southampton are conducting the project. The project is led by Dr Susan Latter, and the researcher conducting the interviews is Andrew Sibley. Both are based at the School of Nursing & Midwifery, University of Southampton.

#### Why are you talking to me about the study?

You have been contacted because your medication is currently managed by a nurse prescriber who has already agreed to take part in our study. We would therefore like the nurse to audio-record your consultation with her/him and possibly interview you, at a later date, about your views on the nurse prescribing consultation. With your permission, your GP will be notified of your participation in this study.

#### Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do wish to take part, you may keep this information sheet and will be asked to sign a consent form after the audio-recorded consultation. You are free to withdraw from the study at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the treatment and care you receive in any way.

## What will happen to me if I take part?

Firstly, we would like you to indicate to your nurse, at your next consultation, that you are happy for him/her to audio-record the consultation between yourself and your nurse. S/he is already aware of the study and has agreed to take part. S/he will then audio-record the consultation. Other than this, the care and treatment you receive from the nurse will proceed in the usual way. Next, you will have the opportunity to reflect on the content of the

consultation and decide whether you would like it to be included the study. With your permission, the researcher will send you a form to ask for your written consent to a) use the audio-recording in the study and b) participate in an interview with the researcher. You will be asked to return this to the researcher; the researcher may contact you if we do not hear from you within two weeks of sending this form to you.

We will randomly select half of the patients involved in the study to take part in an interview. This may or may not include you. If you are randomly selected, the interview would take place within approximately one week after the audio-recorded consultation and we would like to ask you your views about the consultation. We estimate that this interview would take about 30 minutes of your time. You can either choose to complete the interview over the phone or in person at a time and place of your choice. We will telephone you so that you do not incur any costs. We will ask you to indicate on the consent form after the consultation whether you would like to take part in an interview.

If you are not randomly selected to take part in an interview, we will inform you of this in writing within two weeks after your consultation with the nurse.

### What are the possible benefits of taking part?

You will be contributing to a greater understanding of how we can best train nurses to improve their consultations with diabetes patients about medicines. Diabetes patients may benefit from improvements in the consultation skills of the nurses in the study e.g. through better information about medicines provided by the nurses and through nurses taking time to understand patients' views about medicines. Diabetes patients may also benefit from the opportunity to express their views about nurses' consultation skills and their impact on medicine-taking. These benefits may derive from the value of having their voice heard, and the knowledge that this may influence future education and training for nurse prescribers.

#### Will my taking part in the study be kept confidential?

Yes. All the information about your participation in this study will be kept anonymous and confidential. Any views or information you give to the researcher will not be passed on to any members of staff who are looking after your treatment or care. All data from the study will be kept securely locked in a filing cabinet and / or password protected computer file in a restricted access part of the research team's premises. Data will also be stored in accordance with the Data Protection Act (1998). The information you give will also be anonymised to protect your identity, and so that you will not be recognisable in any reports arising form the project.

#### What if there is a problem?

If you have any concerns about this study or the way it has been carried out, you should contact: Dr Susan Latter, Chief Investigator, in the first instance: Tel: 023 8059 7959. Email: sml@soton.ac.uk

#### What will happen to the results of the research study?

The information from the study will be analysed by the research team at the University of Southampton. Your experiences and satisfaction with your treatment will be compared with that of other people with diabetes who are under the care of other nurse prescribers. We will provide a report of the project to Diabetes UK, the charity funding the study. We also plan to publish the results of the study in health care journals to inform other health care professionals, researchers and people with diabetes. In these reports, we may want to quote some of the things that you have said to us during your interview. If you agree to this, please be assured that you would not be identified by name in any publications. A summary sheet of

the findings will be available for all participants at the end of the study. Please let the researcher, Andrew Sibley, know if you would like to be sent a copy. Once we have completed the project, the contact details of all our participants, tape recordings of their consultations, interviews and interview transcripts will be kept for 15 years in accordance with the University of Southampton regulations, and then disposed of.

#### What do I do now?

It is likely that you will receive this letter within a few days of your scheduled appointment with your nurse.

If you have any questions or would like further information about the study, the researcher, Andrew Sibley, will be available on the telephone number below to answer any questions you may have.

If you are happy to take part in the study, we would like you to tell your nurse, at your appointment, that the consultation can be audio-recorded. After your consultation the researcher will send you a form to ask if you are happy for the recording to be included in the study and to ask you whether you would be willing to take part in an interview with the researcher. If you are still willing to participate, we would like you to send the signed consent form to us. If you do not wish your audio-recorded consultation to be included in the study and / or be considered for an interview, we would like you to return the reply slip we will send you.

#### Who has reviewed the study?

This study has been reviewed and approved by Southampton and South West Hampshire Research Ethics Committee (Ref: 07/Q1702/45)

THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION.

For general information, please contact:

Andrew Sibley, School of Nursing & Midwifery, Building 67, Highfield Campus, University of Southampton, SO17 1BJ. Telephone: 023 8059 7998. Email: ams4@soton.ac.uk

For complaints about the study, please contact:

Dr Susan Latter, Chief Investigator, Reader, School of Nursing & Midwifery, Highfield Campus University of Southampton, SO17 1 BJ. Telephone: 023 8059 7959 E mail: sml@soton.ac.uk



## PATIENT REPLY SLIP FOR NON-PARTICIPATION

Research study: Improving medicine-taking in diabetes care: an evaluation of education for	or
nurse prescribers.	

nurse prescribers.	
(Patient audio-recording and interview)	
VERSION 1: [01/03/2007]	
ONCE COMPLETED PLEASE RETURN IN THE ENVELOPE PROVIDED.	
WE WOULD BE GRATEFUL IF YOU COULD RETURN THIS SLIP IF YO PART IN THE STUDY.	U <u>DO NOT</u> WISH TO TAKE
I do not wish my audio-recorded consultation to be include	ed in the above study.
I do not wish to be interviewed as part of the study.	
YOUR SURNAME	-
YOUR FIRST NAME	



## **CONSENT FORM – PATIENT**

(Patient audio-recording and interview)

VERSION 1: [01/03/2007]	
Research study: Improving medicine-taking in diabetes care: an evaluation of education for nurse prescribers.	
Please tick boxes:	
1. $\qed$ I confirm that I have read and understand the information sheet for the above studhave had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	l .yk
2. $\qed$ I understand that my participation is voluntary and that I am free to withdraw at a time, without giving any reason, and without my medical care or legal rights being affected	
$\Box$ I agree to have my audio-recorded consultation included in the study.	
4. $\qed$ I give consent for the researchers to use anonymised quotes from my consultation interview in reports or publications.	and
5.   ☐I consent to the research team safely storing tapes of my consultation and interview	N.
6.   □ I agree to my GP/consultant being informed of my participation in the study.	
7. □ I agree to be interviewed	
My contact details and any preferred time of contact are as follows:	
8.   ☐ I would like a summary sheet about this study once it has been completed.	
Please sign here	
Name of Patient	
Date	
Signature	
Researcher	
Date	
Signature	

One-month post-intervention interview guide for nurse prescriber interviews from the wider study (Latter et al., 2010) with thesis relevant questions highlighted.

#### Questions:

- 1. What was effective about the learning and teaching in the workshops, and what could have been done differently?
- 2. What was the impact of the intervention on nurses' perceived confidence to engage in exploring patients' beliefs about medicines?
- 3. Was anything effective at increasing nurses' confidence in this area?
- 4. What was the experience of attempting to implement an exploration in practice?
- 5. How easy or difficult is it to explore patients' beliefs about medicines?
- 6. What are the factors that influence your ability to do this in practice?
- 7. Does the ease or difficulty of doing this change over time?
- 8. What was the perceived impact of health beliefs exploration on patient outcomes?
- 9. What is the perceived overall effectiveness of the educational intervention?

Six-month post-intervention interview guide for nurse prescriber interviews from the wider study (Latter et al., 2010) with thesis relevant questions highlighted.

#### Questions:

- 1. What was the experience of attempting to implement an exploration in practice?
- Have there been any changes in your own practice?
- 3. How easy or difficult is it to explore patients' beliefs about medicine over time?
- 4. What was your perceived impact of illness representations/medication beliefs exploration on patient outcomes?
- 5. How has the intervention impacted upon your perceived confidence to engage in exploring patients' beliefs about medicines and illness representations about diabetes?
- 6. If it affected confidence, what specifically was effective at increasing or decreasing nurses' confidence?
- 7. How do you perceive the overall effectiveness of the educational intervention?

Interview guide for patients

#### Questions:

- 1. What did you find useful about your recently audio-recorded consultation? In relation to:
- (a) Your beliefs/attitudes about your medicines?
- (b) Your knowledge about your medicines?
- (c) The management of your medicines?
- 2. Were there any particular examples of questions, discussion topics or skills used by the nurse that you felt were particularly effective at helping you to understand or manage your medicines?
- 3. Was this recently recorded consultation any different from other consultations with your nurse? If yes, what differences did you notice in relation to the management of your medicines?
- 4. What were the valuable parts of the consultation with the nurse?
- 5. What other factors, if any, could be used within nurses' prescribing consultations to help you successfully manage your medicines?
- 6. Were there any aspects of the consultation that you would not wish to experience again? Was there anything unhelpful?
- 7. In general, how helpful is the nurse in helping you manage your medicines?

First interview transcript (Nurse): An extract of interview coding.

Interview transcript ID: (PN6-C3-1M)	Coding
Key: D= Descriptive code, P = Process code, E = Emotion code, V = Value code	
AS: Thank you. It might be too early to say, and it's fine to say that. But, what so far have been your experiences of attempting to implement an exploration in practice?  NURSE: I've enjoyed it. If I'm allowed to say that. I've enjoyed that, because it's a challenge, and that's very important to me, you know, to be effective in the role. So that's been very good. Probably the key thing for me is that the patients have noticed, and you know, that they've said, 'Oh, you've got a slightly different approach today Sister!'  AS: Have they really?  NURSE: Yes. And our new Registrar, who sat with me	E: Enjoyed exploration E: Challenging V: Important to be effective in practice D: Patients have noticed exploration approach D: Colleagues have noticed exploration approach
this morning to listen to some of the diabetes consultations, actually witnessed a patient saying that to me.	
AS: Right.	
NURSE: He said, Gosh Sister, this is a different tack today. So that was around COPD as well as diabetes and smoking sensation etc. So, it is interesting that the patients, the patient this morning, for example, said, 'You're not telling me what to do and I appreciate, you know, as you usually don't tell me what to do, and it's for me to find a way of sorting this out'. So I get that as quite a positive feedback. I think, I must be doing something right, and trying to actually, there's a skill around knowing what questions to ask, when, and if I'm short for time, then I just have to extrapolate a few key points, you know. 'What's your priority today', and that's the constraints that we all work in. I'm a realist in that regard. I can't do everything that I'd like to do on every consultation, it's just not going to happen.	V: Patient acknowledging some responsibility for their care P: Selecting questions to ask P: Time management V: Realist approach to consultation content
AS: Yeah.	
NURSE: But it's just trying to get the key elements.  AS: Of the?	P: Selecting key questions to ask
NURSE: Of the discovery questions particularly	
AS: Right. Yeah.	
NURSE: where we're at. And, it is amazing to hear what patient's beliefs are about medication. Things that I've never known before.	D: Patients medication beliefs E: Amazement at
AS: Really. Any?	diversity of patients medication beliefs
NURSE: Some deep seated, deep seated things around. You know, experiences of childhood for example. So I had a	D: Deeply held

patient who has had very poor concordance with medication, all her adult life. And that was the fact she'd overdosed on her mother's medication when she was six, and nearly died. And she'd only just shared that with me at the age of 40. So that's why she found it difficult to take her pills. She was worried her children were going to take her tablets, and the

AS: Right.

NURSE: ... health beliefs from neighbours, friends, you know. What their mother told them, and, just a variety of different things. So it is important that we understand that

AS: Yes, it's a very interesting point.

NURSE: It's very interesting. That's right. And the fact that patients feel very much that they have to do what the doctor has told them to do. So that's been another key thing. So I just say it's not about what the doctor's telling you to do, you know, what would you like to do? So I'm feeling more able to actually ask those questions. For example, I've helped patients now much more readily, you know, to change from a TDS regime down to a BD regime for their medication, to help improve concordance.

AS: Just for the record, TDS?

NURSE: Oh sorry, three times a day, or twice a day.

AS: Right. OK. Thank you. OK. We'll go onto the next question, how easy, or how difficult, is it to engage people specifically in this exploration of their beliefs? I mean, what helps, and what hinders?

NURSE: Can be really difficult. Some patients just don't want to know. They think that they're happy where they're at, and they don't want to talk about it, you know. Previous bad experience for example. It can be quite challenging, and you know, I certainly don't want to come across as being pushy or aggressive, so there's a very fine line between being caring and assertive. So I think it can be quite useful, knowing the patients, long standing, but sometimes that can be a hindrance as well really.

AS: Yeah. Yeah. I completely understand the patients' level of engagement as a helping or hindering factor. I was wondering also the context you're in here, and your working environment. Is that in any way helpful or a hindrance?

NURSE: Sorry, can you ... I don't quite understand the question.

AS: To explore the patient beliefs and to get involved in that sort of thing, does the context you work in help or hinder in any way?

NURSE: I think the patients certainly, a lot of the patients recognise that they don't have the knowledge base around their Diabetes or the blood pressure medication, or cholesterol lowering etc. so they do rely very heavily on people that they consider to be more knowledgeable. I'm sure you will have picked that up on some of the tapes, as I have. So, they do

beliefs
D: Patient childhood
experiences
D: Non-adherent
patient
D: Reason for nonadherence
E: Patient worried

about medication

D: Influence of other people
V: Values
exploration of patients' medication beliefs
V: Patient beliefs about health professionals

P: Nurse encourages patient reflection D: Confident to ask questions P: Changed dosage

D: Patient
willingness to
engage
V: Patient unwilling
to trust change will
improve situation
E: Nurse doesn't
want to appear
pushy
V: Tension between
challenging beliefs
and caring
D: Knowing patients
can help and hinder

D: Diabetes knowledge

want information. So contrary to some of the information we were given at the workshop about patients don't want information, that was certainly one of the things that came across. They do want information, but they will ask you in a timely manner as to what they want. And, so, I think the context, yes they expect me to be able to give information, so if they ask for information I'll say, you know, 'do you understand that?' And so if they ask for more information, you know, that's what they need in order to make an informed choice, and they can't make an informed choice if they haven't got the information at the time, so maybe, it is difficult, because they still, patients do want us to fix their problem, but you know, that is the reality. And they acknowledge the fact that, you know, we're professional and we do know, so I can give them some guidance, but we're not going to make the decision for them, no. And so I think, you know, we're talking about a long period of change really, to change people's expectations about what their clinical team will be able to give to them. So, I think in some ways that can be a help, but it can also be quite a hindrance I think.

AS: Right.

NURSE: So they look upon me as being, you know, knowledgeable around diabetes, and they will say, 'but the doctor always ask you what to do for diabetes, so, you know, you must know something'.

AS: Yeah.

NURSE: So, um .... Yeah.

AS: OK. Any other factors that help or hinder the effort to talk about these things?

NURSE: Obviously it's around, you know, the individual person I think, really, very much around their intellectual ability, how interested they are in their own health, and their motivation. And it's not appropriate, we do have, historically here we have a population of patients with learning needs because of the mental institutions across here

AS: Oh really

NURSE: as it goes

AS: OK.

NURSE: So, in the locality we do have, so again I'm getting a larger number of patients with learning difficulties, who have diabetes, so that's challenging.

AS: Yeah.

NURSE: So, you have to compromise around goal setting etc. because they're not always actively involved in that, so they've got their carers and we try to help them along the way. So, I very much feel then that I've got to be their sort of advocate, if you like. So, trying to help them be actively involved in the consultation, but knowing their limitations and their mental capacity to actually assimilate that information.

V: Diabetes patients do not have the knowledge base V: Patients want information E: Workshop information tension P: Patients ask in their own time P: Checks understanding V: Patients want to be fixed P: Guiding patients V: Not making decisions for patients V: Change over a long period of time D: Clinical team V: Patients expectations can hinder exploration

V: Patient view nurses as knowledgeable and possessing answers

V: Patient
willingness to
engage
V: Patient
intelligence
V: Patient
motivation about
their health
D: Learning
difficulties

D: Learning difficulties

P: Goal setting

V: Learning difficulties limits

AS: OK.

NURSE: and time, obviously, I suppose everybody says about time constraints. Sometimes you want to engage a patient but, you know, you're just aware that you've got three patients out in the waiting room, waiting.

A.C. D: 1.

AS: Right. What's your consultation time at the

moment?

NURSE: I can have what I want.

AS: Really

NURSE: Yeah.

AS: OK.

NURSE: Yeah. So if it's for diabetes, generally, you have 30

minutes

AS: OK.

NURSE: So I manage long term conditions here. It's one of my key roles. So I have long term conditions. So, for example, I've got a patient whose got diabetes, heart disease and chronic obstructive pulmonary disease, I could actually have an hour long appointment to look at them as a whole person, review their medication and look at each aspect of their, the patients really like that.

AS: Yeah.

NURSE: To be looked at as a whole person. So I'm very fortunate in that regard.

AS: Yes. I agree.

NURSE: The key problem comes if they don't turn up, then obviously it's a large amount of time that's wasted. So we do try to do that, and we've built on that over the last three or four years and patients feed back to us that they very much like that.

goal setting

D: Time limitations on exploration

D: Flexibility with time management

D: Approximate consultation duration time

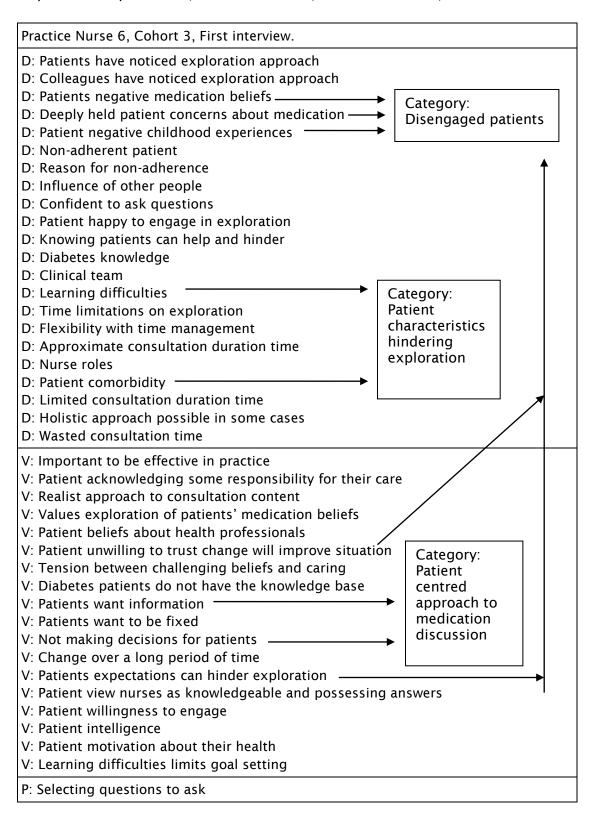
D: Nurse roles
D: Patient
comorbidity
D: Occasional
consultation
duration time
E: Patient enjoy long
consultation

D: Holistic approach possible in some cases

D: Wasted consultation time

An example of an interview coding sheet (Nurse). Total number of codes n=56. Codes and examples of how they linked to categories developed.

Key: D= Descriptive code, P = Process code, E = Emotion code, V = Value code



- P: Time management
- P: Selecting key questions to ask
- P: Nurse encourages patient reflection
- P: Changed dosage
- P: Goal setting
- P: Patients ask in their own time
- P: Checks understanding
- P: Guiding patients
- E: Enjoyed exploration
- E: Challenging
- E: Amazement at diversity of patients medication beliefs
- E: Patient worried about medication
- E: Nurse doesn't want to appear pushy
- E: Patient enjoy long consultation
- E: Workshop information tension

Patient interview transcript: an example of coding.

	Interview transcript Patient ID03		
	D= Descriptive code, P = Process code, E = Emotion code, V = e code		
	Let's start really with the first question. When you were taking in that audio recording consultation do you remember [nurse's e] discussing your attitudes or your beliefs about your medications?		
DP	DP Yes she did. She did yes.		
AS	She did. Do you remember exactly what she mentioned or –	beliefs explored	
woul	DP Well about the things that I feel about it. I suppose I have in mind because when my doctor because of the sugar left and he said that I would have to be on insulin, but of course we had the tablets and I really have got a big thing about tablets.		
AS	Really?	tablets	
DP havii	Yes. Well I mean at my age I am on quite a few tablets and ng to add any more is a bit of a big thing with me.	D: age and medication burden	
AS	Do you mean that is a concern? You do not like them or -?	V: resistant to multiple	
DP	No	medications	
AS	Ok		
	DP Because I think you have to have this tablet for that thing – anyway for me that is. But the tablets that she recommended they have been helping Well they are keeping the sugar levels down –		
AS	Ok		
DP gone is ab	V: resistant to multiple medications		
AS med	Right. Ok, so did she discuss your concerns about whether your icines might harm you in any way?	P: nurse	
day	DP We did discuss but it is mostly [name] I am telling you about, not about anybody else. After you have got more than one or two tablets a day well I mean I did say yes, I did not like having it and that sort of thing, you know. Mmm.		
	AS Ok. And when she was talking about your specific medications, did she discuss the need for them – the necessity for them?		
DP som	P: Necessity for medications discussed		

insulin and she said sometimes if you do not have it right, you have got a chance of going into hypo and all that sort of thing. And I do know for sure she was right about that.	P: Nurse highlighted consequences V: trust in
AS Is there anything else? You said you do not like taking too many medications.	nurse's opinion V: resistant to
DP You have something for your heart, and I think for me they get mixed up inside and I am not looking in my insides for them to go to the right place!	multiple medications
AS Ok, yes.	
DP I mean any nauseous feelings I was having on this new one that she recommended, I attributed to having too many tablets and that I think was causing another problem.	D: Side effects prompted medication belief change
AS Right.	E. E. aliana /
DP As I said it is me. I will not quote that for anybody else, it is just all these feelings.	E: Feelings / worries driving behaviour
AS Ok. We will move on to Question 1 b), in the recent recording that you had with [nurse's name] did she give you enough information about your medicines?	D: Adequate
DP Yes of course she told me that. That is why I am taking them and as I said the sugar level is not as bad as it was. The reason I am taking them diligently is because yes, she did decide because of having this it would be better, and to be fair yes, then the diabetes is a lot better I think.	information provided by nurse D: Outcomes better through adherence
AS Ok. So you feel that you know enough about your medications to deal with them?	
DP Well for what I am having I am going to see somebody on the 24 <sup>th</sup> and I will see whether he has got anything different to suggest. But for the moment, yes I am pressing on with what I have.	P: Medication review with another professional
AS Ok. The last part of Question One, the management of your medicines, does she provide you with enough information to deal with them on a day to day basis?	
DP I think so. I mean I know what I have to take. We are talking specifically about the diabetic medicine?	D: Adequate information provided by nurse
AS Yes.	D: Medication
DP Well I know that I have this with food and make quite sure, or after meals, that sort of thing. And yes, I think she has, yes.	usage knowledge adequate
AS Ok great. On to question two then. We would just like to ask you, during that audio recorded consultation were there any examples of questions or discussion topics, or skills that [nurse's name] used that you thought were really helpful for you to understand and manage your medications?	D: States poor
DP Yes, she must have done that, because as I said I am not good at	adherence D: Successful

taking medicines, but since she has been and spoken to me, I haven't missed out or anything like that because I think that (mind you I could have been scared about what had happened) but I think that she is very, very good and I think (myself) I must say that even after she had gone my daughter said she is very good. And I promise you I am not going to say what she definitely, definitely medical background and she said "I think she's very good, she knows her stuff".

intervention by nurse V: Patient has trust in nurse's judgement

AS Ok, thank you. We will go on to question three then. As part of the recently recorded consultation, was it in any way different from the other consultations that you have had in the past?

P: Nurse actively exploring beliefs

- DP Well I think within myself, as I said, she was more, I do not think that I have had that input with anyone else than I had with her.
- AS Ok. Does she bring up any different topics or did it feel different in any way from any other consultations you have had with [nurse's name]?
- DP Oh you mean just when I was doing the recording?

AS Yes.

DP Well I don't think so. I think she was – well from the time she came she was obviously good as I said. When I am having any new thing or new person my daughter tries to be here because as I said her background is definitely medical. She doesn't say anything but she just lends an ear and she says "Oh yes" you know.

D: Not a huge change in consultation style
D: Family member has medical background

AS Yes.

DP "That is very good". So yes, I think she was very good all through and I was very happy to have her.

P: Patient relies on family member feedback

AS Ok.

E: Fearful of diabetes complications

DP Especially the time I was feeling a bit scared because they were talking about the kidneys and all that sort of thing. So yes I was happy to have her.

- AS Ok, thank you. On to question four, what sort of things do you value about your consultation with your nurse?
- DP Well to be fair I have been rather lucky with doctors and nurses and so she definitely, definitely was helpful to me and knows her stuff. But at the same time in this case she was specific with the diabetes and so in that way I would say she was good and special. But I have not had any bad vibes with nurses and doctors apart from having some fights in the hospital! I think I have been rather, rather lucky with doctors and nurses.
- V: Values health professionals V: Patient has trust in nurse's judgement D: Previous unspecified conflict.
- AS Good I am glad to hear that! Just as another little part of that question really, thinking about [nurse's name] is there anything that is different about her?

E: Fearful of diabetes complications

DP Well as I said, she was at a time when I was really, really scared and frightened, so to put it in that context, well yes I would say that I

gained a lot from her. But I mean how am I to say that if I had another person as good I would not have felt the same way? She came at the time when I am thinking 'oh lord what the devil is going to happen here because why is the sugar so-so' and that is why I am on tablets still now because I am not enamoured with insulin, as I put it, putting holes in myself and I was not even testing the sugar because I thought if I did not test it that is why it was that high I would not know how it was.	V: Does not like medication	
AS Yes		
DP And that is why my Doctor was mad with me. But as I said I have not missed out on anything there because she is that sort of person that gets me	P: Patient sent from doctor to nurse for care V: Rapport	
AS Right. Ok.	present	
DP So I think for me I think she was the right person at the right time.	V: Valued nurse	
AS Ok, thank you. On to question five, were there any other things ongoing in your nurse prescriber consultation to help you successfully manage your medicines?	intervention	
DP I cannot say that, I really and truly cannot think about anything off hand, no.	D: No changes recalled	
AS Ok.		
DP I really cannot at the moment.		
AS Ok. There is nothing additional you would like from your consultations with [nurse's name]?		
DP Well I cannot say that I do at this moment in time. I mean I think it went the way I expected it to go at the time, until I get to see the Specialist which I hope to see on the 24 <sup>th</sup> I think it is.	V: Patients expectations of consultation	
AS Ok. We will move on to question six, were there any aspects of that audio recorded consultation that you would not wish to happen again? Was there anything unhelpful during that consultation?	W. D	
DP I cannot think there was really. I cannot say that I did. No, unless I missed it at a distancebecause as I said she knows about things and her comment was "I think she is good".	V: Patient has trust in nurse's judgement P: Patient	
AS Ok.	relies on family member	
DP I cannot think if there is anything that I missed. But no I have not had anything that I wished could have been different.	feedback V: Content with consultation	
AS Ok. Were there any discussion topics that she brought up? I		
mean talking about your medication use, were you ok with that or did you find that uncomfortable to talk about?		
mean talking about your medication use, were you ok with that or did	V: resistant to multiple medications	

E: Hates Yes. I just absolutely hate it and I suppose when I was in hospital Metformin and took the medicine the nurse said "Oh, ah", it was Metformin with medication something else; Metformin and a very large tablet, and I did not like it D: Large tablet and the nurse said "I can't stand this, I don't know why they keep giving issues people this" and that did not make me happy. V: Nurse belief about AS Oh right! medication DP Yes, and I think that is it. I used to miss out on that and I think V: Intentional that is why I got into trouble. Now what the devil was the name of the non-adherence darn tablet? But I had Metformin and something else. Ok. We will go on to the last question. So in general, how helpful is your Nurse in helping you to manage your medications? V: Nurse really Well I would think she was helpful and she had to have been helpful helpful because if you know me, and as I said I have not missed out on D: Successful any of the tablets since she has been here. As a matter of fact she had intervention by nurse to raise one of them, like a double dose, because I needed a higher P:Dose dose. increase AS Yes. DP So that is something, if you know me, that is something really good that I have not missed out now. AS That is very good, I am glad to hear that. DP No, I really hate the need to take all these things for your heart, E: Hates for this, for that. medication AS Ok. Thank you. Are there any other comments you would like to make? No I really enjoyed having her. I don't enjoy nurses and what have V: Initially resistant to you! It was all right, she was somebody that it was all right to be nursing care around. Yes, well as I said, in general to this date, I have not been too bad with nurses and doctors and I have been over here 58 years; I think I am rather lucky.

AS

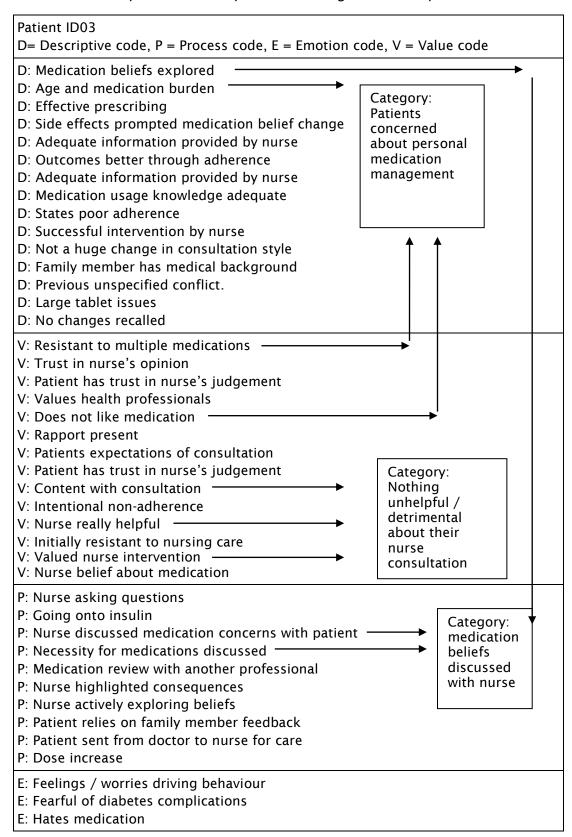
DP

I really appreciate your help today.

Yes, you are welcome.

## **Appendix 11**

An example of an interview coding sheet (Patient). Total number of codes n=42. Codes and examples of how they linked to categories developed.



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