Living with dementia in care homes: the nature, role, and impact of pharmaceutical care provision by community pharmacists

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DECLARATION

I hereby declare that this thesis has not been and will not be, submitted in whole or in part to another University for the award of any other degree

Signature: .....

DEDICATION

To my parents and siblings for whom this PhD answers a prayer, and to my husband and children for their continued support and encouragement

Beryl B Navti: Doctor of Philosophy (PhD) in Pharmacy Practice

Title: Living with dementia in care homes: the nature, role and impact of pharmaceutical care provision by community pharmacists

SUMMARY

Background

Dementia poses a great challenge for health care systems worldwide, with the population of affected people over the age of 60 estimated to reach 152 million by the year 2050.
Dementia is acknowledged as being one of the strongest determinants of entry into residential care in people aged over 65 and it is estimated that nearly 70% of residents have dementia.
Medication remains the most frequently used intervention for dementia patients, and pharmacists are arguably the nation's experts on medication. In Great Britain, they are easily accessible and provide services to care homes as an enhanced service in the pharmacy contract. This research sought to establish the role and impact of community pharmacists on the pharmaceutical care of people living with dementia in care homes.

Methods

The research was conducted in four stages employing qualitative and quantitative methodology. A qualitative study was conducted with community pharmacists who provided services to care homes for residents living with dementia in Essex and in Kent. This was followed by a quantitative survey of a wider population of community pharmacists across England.
Qualitative interviews with care home staff explored their views about pharmacy services provided to residents with dementia. Finally, a dementia intervention tool to support pharmaceutical care through comprehensive medication reviews was developed and tested among a focus group of pharmacists.

Results

My research revealed that pharmacists mainly provided medication supply services to residents with dementia. Barriers to optimal pharmaceutical care included time, knowledge, communication, and access to patient records.
Care staff revealed a desire for timely supply of medication, and help dealing with residents' challenging behavior including refusal to take medications. Better

communication between MDTs and training of care home staff would improve patient care.
The dementia medication review intervention toolkit was deemed useful by the focus group of pharmacists following preliminary testing.

Conclusion

Participating pharmacists considered their service provision as meeting contractual obligations despite structural barriers. A tool to facilitate effective medication review was deemed useful as an aide-memoire. Further feasibility research to support wider adoption is needed.

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LIST OF ABBREVIATIONS

ACB	Anticholinergic Burden Scale
AD	Alzheimer's Disease
BMA	British Medical Association
BNF	British National Formulary
BPSD	Behavioural and Psychological Symptoms of Dementia
CCG	Clinical Commissioning Groups
CPPE	Centre for Postgraduate Pharmacy Education
CQC	Care Quality Commission
DLB	Dementia with Lewy Bodies
DOH	Department of Health
DRP	Drug Related Problem
DSM	Diseases and Statistical Manual
FD	Frontotemporal Dementia
GP	General Practitioner
GPhC	General Pharmaceutical Council
ICD	International Classification of Diseases
MDT	Multidisciplinary Team
MMSE	Mini Mental Scale Examination
MOCH	Medicine Optimisation in Care Homes
NHS	National Health Service
NICE	National Institute of Health and Care Excellence
PCN	Primary Care Networks
PhiF	Pharmacy integration fund
PSNC	Pharmaceutical Services Negotiation Committee
QS	Quality Standards
RPS	Royal Pharmaceutical Society
VaD	Vascular Dementia
WHO	World Health Organisation

CHAPTER 1
BACKGROUND

1.0

1.1 Introduction and chapter overview

Dementia affects about 7.1% of adults over the age of 65 and about 1 in 6 people over 80 years of age (Alzheimer's Society, 2014).

With continuous improvement in healthcare around the world, and consequent rise in life expectancy there is increasing prevalence of chronic diseases such as dementia (Alzheimer's Disease International, 2015). An exponential surge in research within this area over the last few decades has thus ensued. This can be attributed to an increasing awareness of the rising global prevalence of dementia; knowledge of its progressive nature, the current lack of a cure together with progress in the understanding of the genetics and neuro-pathophysiology of dementia, as well as its current and future economic impact.

Dementia may be caused by a range of diseases; these may be neurodegenerative (e.g. Alzheimer's disease, Dementia with Lewy bodies, Frontotemporal dementia) or secondary to another disease condition (e.g. Vascular dementia, Parkinson's disease dementia) (Gelder, Harrison and Cowen, 2006). Knowledge of the underlying cause of dementia (or its subtype) as well as early detection is key in the prognosis and treatment of the condition. This is not always easy because of its insidious and variable onset (Burns and Lliffe, 2009), with people sometimes presenting with symptoms of more than one type of dementia.

While scientists grapple with the challenges of finding a cure for dementia, current strategies for dealing with the illness largely involve the use of medication to delay disease progression and manage symptoms, and at the same time, provide carers

with help in coping with the increased physical dependency of people with dementia as the disease progresses.

Pharmaceutical care encompasses the responsibility to ensure medicines safety, appropriateness and clinical effectiveness of medicines use as well as the provision of advice on medicine administration, a responsibility that often falls to pharmacists amongst other healthcare professionals.

This chapter presents a definition of dementia, a brief history of the disease condition, its prevalence in the UK and worldwide, epidemiology, and an examination of its current impact within the UK society and worldwide.

The concept of pharmaceutical care is defined and its application to care for people living with dementia will be discussed.

The role of pharmacists in the care of people living with dementia and current service provision will also be discussed in this chapter. This will be followed by a presentation of the research question, aims and objectives of my research.

1.2 Definition

Dementia is a broad generic term used to describe a range of progressive, degenerative, terminal organic brain diseases all characterised by continuous deterioration in cognitive function (Burns, 2009).

Neurologists have over the years, tended to define dementia as impairment in higher intellectual function manifesting itself usually as memory loss, difficulty with orientation to time, place, or person, decreased fund for general information, difficulty with performing tasks of abstract reasoning such as calculations,

similarities and differences, as well as lack of judgement (Feigenson, 1978). However, this earlier definition does not fully encompass the spectrum of mental states resulting from the variable causes of dementia.

The Diagnostic and Statistical Manual (DSM-IV) (American Psychiatric Association, 2000) and International Classification of diseases (ICD-10) (World Health Organisation, 1992) both propounded different criteria for dementia, with no common core definition of dementia. Both required impairment in two or more cognitive domains (memory, language, abstract thinking and judgement, praxis, personality and social conduct), representing a decline in previously higher level of functioning that is sufficiently severe to interfere with social or occupational functioning.

However, the DSM-V (American Psychiatric Association, 2013) renamed dementia as a "major cognitive disorder" and modified the criteria such that impairments in learning and memory were no longer necessary for diagnosis, but at the same time recognising less severe forms of cognitive impairment (mild neurocognitive disorder). This reclassification was aimed at reducing stigma associated with dementia and aligning the diagnostic guidelines with current clinical practice (Dementia Australia, 2018) and delineating specific aetiological subtypes.

The drawback with differing sets of criteria defining the same condition is that clinicians selectively use the criteria to meet their own clinical judgement of the concept of dementia (Breitner, 2006). This potentially influences diagnoses and prevalence studies of dementia.

An all-inclusive definition of dementia would differentiate it from delirium (similar to, and sometimes coexistent with dementia, but characterised by alterations in levels of consciousness) and other cognitive syndromes (like in the DSM-V), whilst describing its course and severity (like in ICD-10). The World Health Organisation (WHO 2019) definition of dementia comes close to achieving this:

"Dementia is a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation". (Dementia, WHO 2019)

1.3 History

Solon (ca 630-560BC), considered by some as the father of modern-day thinking, wrote about the impairment of judgement in humans through `physical pain, violence, drugs, old age or the persuasion of a woman'(Freeman 1926). In medieval times, not much was recorded due to attribution of many medical conditions to mysticism, as a result of the proliferation of religions in this time period, but senile dementia became a disease in the 19th century when affected individuals were treated by medical practitioners called 'alienists' (Assal, 2019).

Present day understanding of dementia follows on from early observations of scientists such as Aretaeus of Cappadocia in the second century A.D., Phillipe Pinel (1745-1826), Jean Etienne Esquirol (1772-1840) and much later in 1907, Alois

Alzheimer (Boller, Bick and Duyckaerts, 2007). The word 'dementia' is derived from the Latin root 'demens' (being out of one's mind) and verbal usages of the word can be found before the 18th century (Berrios, 1987).

Although dementia was brought to the world's attention by the German neuropathologist and clinician, Alois Alzheimer, who is generally accepted to have discovered the condition that bears his name (Alzheimer's disease) (Ramirez-Bermudez, 2012); the diseases that can produce dementia existed long before the last century, and probably date as far back as the beginning of mankind itself (Boller and Forbes, 1998). Use of the term "dementia" is traceable back to 1381 in France, but it wasn't until 1797 that Phillippe Pinel (1745-1826) who is credited with the discovery of modern psychiatry, first provided a sound description of dementia (Boller, Bick and Duychaerts, 2007). The six conceptual strands that shape the concept of dementia (a disorder of cognition, any age group affected, results in behavioural incompetence, potential complication of both a functional and psychiatric disorder and the fact that it could be acquired or congenital) were brought together in the 18th century (Berrios, 1987).

As a result of the heterogeneity of the dementia syndrome, the term "dementia" was dropped by DSM V (American Psychiatric Association 2013) in favour of "major cognitive disorders" as earlier discussed.

1.4 Incidence, prevalence and global burden of dementia

Epidemiological studies of dementia can be characterised by immense diversity with high levels of clinical and methodological variations (Kiejna et al. 2011). As the risk of developing dementia is often associated with ageing, lifestyle and

cardiovascular health (Nowrangi, Rao and Lyketsos, 2011), there is a need to design studies that determine country-specific dementia incidence and prevalence taking into consideration population specific lifestyles, diets and genetic dispositions, in a bid to develop preventive strategies and plan for future care.

Determination of the incidence and prevalence of dementia is not an exact science (Kukull and Bowen, 2002), mainly because of difficulties in defining and detecting dementia in varying populations. A case in point is the United Kingdom (UK) where determining the exact number of people living with dementia has remained a challenge (Knapp et al 2014). It has been suggested that difficulties with updating prevalence and incidence data on dementia could be partly due to the considerably high economic costs of door-to-door surveys or questionnaire-based studies (Pojoan et al 2019).

As age is a main known risk factor for the disease, dementia constitutes one of the major causes of disability in later life and according to a World Health Organisation report (Dementia: A public health priority 2012), prevalence doubles for every five-year increment in age after 65. This is a huge concern, considering that the population of people over the age of 60 increased from below 500million in 1950 to over a billion in 2009, and is estimated to be over 2 billion in 2050 (World Population Ageing, 2009). Furthermore, dementia does not affect only older people and an estimated 9% of total dementia cases are attributed to people with young onset dementia (which is defined as dementia where onset of symptoms occur before the age of 65) (Alzheimer's Disease International and WHO, 2017).

By 2010, the number of dementia sufferers worldwide was 35.6million, with projected increases over 20 years to 65.7 million, reaching 115million by 2050

(World Alzheimer's Report 2009). The total number of new cases of dementia is nearly 7.7million each year, worldwide, giving an alarming estimate of one new case every four seconds (WHO, Dementia: a public health priority, 2012). These estimates have changed over the years and the number of people now living with dementia worldwide in 2018 was 50million, set to rise by 204% to 132million by 2050 (WHO Dementia Fact Sheet 2017). More recent figures indicate that number of people living with dementia by 2050 will be an estimated 152 million worldwide (WHO 2019).

A Delphi consensus study commissioned by the World Health Organisation in 2005 (Ferri et al, 2005) to determine prevalence of dementia in 14 of its world regions (based on geography), revealed that China and its developing western-pacific neighbours had the highest number of people living with dementia followed by Western Europe. It projected that Africa and Latin America will experience a 235-393% surge in their numbers by 2040.

However, when Prince et al (2013) conducted a systematic review and meta-analysis of global prevalence in dementia, they concluded that there was little variation in age-specific prevalence of dementia between world regions. Although this study was meticulously designed to include only studies with sufficient sample sizes and robust designs, becoming one of the few available evidence bases for policy formulation with regards to dementia care at the time, it had poor coverage of evidence base from many world regions (particularly Africa) and considered only papers published in PUBMED and MEDLINE databases. This limited the generalisability of their conclusions.

In the UK, dementia was considered the most common psychiatric disorder in the community, affecting: 1 in 1400 of those aged 40-64, 1 in 100 of those aged 65-69, 1 in 25 in those aged 70-79, and 1 in 6 in those aged over 80 years, altogether amounting to over 800,000 dementia sufferers. This was deemed likely to rise to 1.7million by the year 2021 (Alzheimer's Society, 2011). Additionally, it was estimated that dementia accounted for 60,000 deaths in the UK every year, with 1 in 3 people over the age of 65 likely to die from dementia. By 2014, the total number of people living with dementia was an estimated 850,000 predicted to rise to 2million by 2050 (Prince et al 2014). These figures and predictions were maintained by Alzheimer's Research UK in 2018 (Dementia Statistics Hub 2018).

The prevalence of dementia is higher in women; this could be partly due to their greater longevity, but as most epidemiological studies show increasing incidence rate for women, their longer lifespan cannot be the only factor, and other explanations could be related to the confounding effects of education and hormonal influences (NICE-SCIE Dementia guideline, 2007).

Of relevance to management and care strategies, is the prevalence of the range of diseases that cause dementia. Studies indicate that Alzheimer's disease accounts for 50-60% of dementia cases, closely followed by Vascular Dementia (20-25%) and Dementia with Lewy bodies (10-15%), with Frontotemporal dementia underlying around 7% of later life dementia (Gelder, Harrison and Cowen, 2006)

Despite the difficulties in determining incidence and prevalence of dementia, it is clear that dementia causes substantial global burden (Mathers and Leonardi, 2000) and significantly affects those who suffer from it, their family and friends, on personal, financial and emotional levels. It is important that every society

understands the costs of dementia and how these impact upon families, health and social care services (Alzheimer's Disease International 2016).

The total global societal cost of dementia was estimated to be US $818 billion in 2015 corresponding to 1.1% of global gross domestic product, and it was predicted that by 2030, the cost of caring for people with dementia will exceed US $2 trillion, a figure which could potentially undermine global socio-economic development and overwhelm health, social services as well as long term care services (WHO 2015).

In the UK, the annual cost of dementia was an estimated £23 billion per year, set to rise to £50billion by 2038, and the consequent impact on family and friends, in real terms, means that over 25million people will be affected by dementia (Alzheimer's Society, 2012). Additionally, there's an estimated 670,000 carers of people with dementia in the UK with family carers saving the government over £8 billion a year. Nonetheless the cost to the taxpayer is still considerably high since over a third of those suffering from dementia live in care homes (Alzheimer's society, 2012).

There are low levels of understanding about dementia with symptoms being perceived differently in different parts of the world, leading to various misconceptions and resulting in stigma prevalent in most countries at various levels (Batsch et al 2012). The lack of awareness and understanding of dementia that results in stigmatisation has been blamed for the worldwide under-diagnosis of dementia and fragmentation of long-term care pathways for people living with dementia (WHO 2017).

The World Health Organisation in its "Global action plan on the public health response to dementia" (WHO 2017) proposed that when addressing the global challenges posed by dementia, an expansion of health and social care workforce with appropriate skill mixes, availability of necessary interventions and services were all essential for the prevention, timely diagnoses, treatment and care for people living with dementia. To this effect, in February 2015, the UK government published "The Challenge on Dementia 2020" (Powell and Baker 2019), in which the then Prime Minister, David Cameron, set key objectives for dementia care in England: The plan was to achieve the best support in the world for people with dementia, their carers and families and for England to be the best place in the world for them to live in. To achieve this, the challenge set many objectives; including increasing public awareness about dementia risks, enabling equal access to dementia diagnosis as for other conditions, ensuring that every person diagnosed with dementia received meaningful care according to NICE Quality Standards (NICE QS184 2019), and ensuring all hospitals and care homes became dementia friendly health and care settings, amongst other objectives.

Involving pharmacists in all care settings to deliver pharmaceutical care to people with dementia was deemed essential, in order to achieve these goals (NHS Scotland 2014).

1.5 Pharmaceutical care and its application to care of people with dementia

In 1975, pharmaceutical care was considered "*the care that a given patient requires and receives which assures safe and rational drug usage"* (Mikael et al, 1975).

However the concept in its modern sense was defined as the *"determination of the drug needs for a given individual and the provision not only of the drug required but also the necessary services (before, during and after treatment) to assure optimally safe and effective treatment"* (Brodie, Parish and Poston 1980).

In the ensuing decades, other definitions of pharmaceutical care have been advanced, with the most frequently cited being that of Hepler and Strand (1990) as *"the responsible provision of drug therapy for the purpose of achieving definite outcomes that improve a patient's quality of life".* This definition was further expanded to include a "patient-centred approach" in which pharmacists assumed responsibility, and were held responsible for a patient's medication-related needs (Cipolle, Strand and Morley, 1998). Later, the Pharmaceutical Care Network Europe (PCNE 2014) systematically reviewed the various definitions of the concept over the years, and came to a consensus that *"Pharmaceutical Care is the pharmacist's contribution to the care of individuals in order to optimize medicines use and improve health outcomes".*

Ensuring appropriateness and clinical effectiveness of medicines use as well as the provision of advice on medicine administration are all dimensions of pharmaceutical care. But more central to this philosophy, is the social responsibility, patient-centeredness and provision of care through the establishment of therapeutic relations that lead to better clinical outcomes for patients (Awaisu and Mottram 2018).

As a working methodology for health professionals involved in the medication process, pharmaceutical care is essential for improving the safe use of medicines

and contributes to the optimisation of outcomes from medicines while preventing harm and inappropriate use (Cousins et al 2012).

People living with dementia are often prescribed medication to manage the symptoms of the disease, to control the behavioural and psychological symptoms of dementia, or frequently to manage co-morbid conditions such as depression or epilepsy (Jordan et al., 2015). Healthcare professionals including pharmacists have a responsibility to ensure that the extent to which dementia compromises quality of life in sufferers is limited, and that their medication and other co-morbid conditions do not impact negatively on their overall functioning. Approximately a third of patients over the age of 65 in developed countries are prescribed five or more medicines a day (Qato et al 2008) and incidentally, most people living with dementia fall within this age group. The consequences of potentially inappropriate prescribing, especially in the older adult population with co-morbidities such as dementia, include functional and cognitive impairment, which can worsen health outcomes (Hilmer & Gnjidic, 2008).

Medication can be inappropriately used or prescribed when the risks associated with its use surpass the clinical benefit for which they are prescribed (Eshetie et al 2019).

Evidence from an increasing number of research studies have shown that people with dementia are commonly prescribed potentially inappropriate medication (Banerjee 2009, Parsons 2017, Gnjidic et al 2018, Eshetie et al 2019). It is recognised that managing medication for people with dementia is a complex process which can result in medication errors and medication-related hospital admissions (Smith et al 2017). Initiation of acetylcholinesterase inhibitors for

treatment of dementia has also been linked to sequential polypharmacy to treat adverse drug reactions such as diarrhoea, syncope and bradycardia that are related to these drugs (Gill et al 2005, Park-Wyllie et al 2009, Gill et al 2009, Rochon et al 2018). Furthermore, polypharmacy is common in people living in care homes, who are often prescribed five medications or more across Europe (Bronskill et al 2012) and on average eight medications each in the UK (Barber et al 2009). This has been attributed to the care home population (at least 70% of which are living with dementia) being made up predominantly of frail elderly people more prone to multiple long-term conditions (Payne and Duerden 2015).

Pharmaceutical care is invaluable for managing people with long term conditions; in dementia it would entail applying its conceptual principles to assessment of the person with dementia as well as all their drug therapies to optimise their treatment. This would ensure that medication prescribed is appropriate (identification of all co-morbidities and ascertaining that there is a clinical indication for each medication prescribed). The effectiveness of their medication (best drug at sufficient dose), its safety (consideration of adverse drug reactions) and any issues with compliance are also addressed (Cipolle, Strand and Morley 2004), in order to identify drug therapy problems and create an individualised pharmaceutical care plan for each patient.

Pharmaceutical care is thus an exemplar model of patient–centred pharmacy practice that involves the pharmacist taking responsibility for all a patient's medicine-related needs to achieve better outcomes and improve their quality of life.

There is an overwhelming need for a bespoke model of pharmaceutical care for people with dementia that can respond to local opportunities and local patients' needs as well as contribute to the achievement of defined public health goals. A pharmaceutical care service, if expertly provided, may lead to a decrease in drug-related problems and help in lowering care costs by reducing the number of these patients admitted into hospitals from care homes as a result of adverse drug events.

For people with dementia resident in care homes, delivering healthcare interventions, including pharmaceutical care can be challenging, since these environments serve the dual purpose of catering for the needs of people with complex long term needs, as well as being a home for them (Hughes 2019).

While it is recognised that care homes which accommodate a large population of physically and cognitively impaired residents require comprehensive and holistic pharmaceutical care (Lapane et al 2011), the impact of pharmaceutical care interventions, usually medication reviews, on outcomes such as reductions in falls, hospitalisations and mortality have been limited (Alldred et al 2016, Hughes 2019).

1.6 Care homes

Care homes are long –term care facilities offering accommodation and personal care to people who need help and support in their daily lives. The Care Standards Act 2000 (Part 1, Section 3) considers an establishment a care home *if it provides accommodation, together with nursing or personal care, for any of the following persons: persons who are or have been ill, persons who have or have had a mental*

disorder, persons who are disabled or infirm, persons who are or have been dependent on alcohol or drugs (DOH 2003). This does not include hospitals, independent clinics or children's homes.

Facilities providing long term care are referred to using different terms around the world: in the United States, they are known as "long term care facilities", in Australia "aged-care facilities" and in the UK, "care homes" (Alldred et al 2016). However, for clarity in my research, the term "care homes" will be used throughout.

In the UK, care home services are predominantly provided by independently (privately) owned facilities. These establishments all provide accommodation and personal care, but are registered for different purposes: Care homes (offer personal care, help with washing, dressing, taking medication), nursing homes (offer personal care plus care from qualified nurses), care homes with dementia (designed to accommodate people with dementia and make them feel comfortable and safe), and dual-registered care homes that accept individuals that need personal care and or nursing care (Age UK 2019).

The NHS (NHS UK 2019) advises consideration of a care home when an individual is struggling to live alone despite assistance from family, friends, or paid carers, or has a complex medical condition that needs specialist attention.

Residents of care homes differ in terms of their healthcare requirements, but in the UK, the average care home inhabitant is likely to have over six clinical diagnoses, taking more than seven medications and living with physical disabilities, mental infirmity or cognitive impairment (Gladman et al 2015). Over half of the care

home population in the UK is aged 85 and above and suffer from dementia (Gladman et al 2015, Hoffman et al 2014). Medication use amongst this population has been the focus of much research (Hughes 2019) owing to the high prevalence of polypharmacy (Jokanovic et al 2015) and its consequences which include drug-drug interactions and/or drug-disease interactions (van Marum 2017).

Inappropriate prescribing of medication, and polypharmacy are more prevalent amongst people living with dementia in care homes than in their community dwelling counterparts (Shah et al 2011). They also usually have at least four other active medical diagnoses (Patterson et al 2010) indicating that careful monitoring and medicines optimisation is required in these environments.

1.7 Role of pharmacists

Pharmacists began moving away from their traditional roles of compounding and supply of medicines as far back as the 1990s, and are now recognised as professionals with the skills and knowledge to improve the outcomes of drug therapy, focusing not only on the services they provide, but also on the effect of their services on patients' quality of life (Penna 1990, Wiedenmayer et al 2006). Acknowledging that community pharmacies are the most frequently visited healthcare destinations has led policymakers to advocate extension of community pharmacists' roles to accommodate growing public healthcare demands (DOH 2008, Eades et al 2011, NHS England 2013).

This shift in roles is fortuitous for people living with dementia in their own homes or in care homes, as pharmacists can play a significant role in supporting them through various clinically focused roles (Stafford 2015). These include but are not

limited to: help with managing adherence, as people with dementia reportedly do not take their medication as intended (Arlt et al 2008, Luzny, Ivanova and Jurickova 2014), managing symptoms of dementia and optimising drug therapy.

The dementia syndrome is characterised by symptoms of cognitive decline such as loss of memory and orientation, and the development of behavioural and psychological symptoms of dementia (BPSD) such as aggression, agitation, wandering, hallucinations and sexual disinhibition (Cerejeira, Largato and Mukaetova-Ladinska 2012). These can lead to challenging behaviour in patients and elicit prescribing of psychotropic drugs that are deemed harmful to them in the long run (Banerjee 2009, Brechin et al 2013, Brooker et al 2016).

Furthermore, significant differences in the pathology and clinical progression of various dementia sub-types directly impact their pharmacological management, each sub-type having a distinct pathology (Madhusoodanan and Ting 2014.)

Thus, when a pharmacist is dealing with prescriptions for dementia patients, there are many key points to consider:

- the classification of sub-type
- appropriateness of the prescribed medicine
- impact of potential adverse effects of the drugs on the patients' cognition
- medicines optimisation

In the UK, managing medication for people with dementia was emphasised in the National Dementia Strategy issued by the Department of Health in 2009, focusing mainly on appropriateness of antipsychotic medication in this patient group (DOH 2009).

Since the publication of the Banerjee Report (Banerjee 2009) highlighting inappropriate prescribing of antipsychotics to people with dementia and the harm that can be caused by this practice, pharmacists in the UK have been involved in reviewing anti-psychotic prescribing to patients with dementia, including those in care homes (Ballard et al. 2009, Redmond and Cavan, 2011, Child et al. 2012; Gadhia 2014, Maidment et al. 2016). While these interventions have led to a reduction in anti-psychotic prescribing amongst patients with dementia, medication management in general is still recognised as the missing link in dementia interventions and there are concerns that singularly targeting antipsychotics may result in clinicians reverting to prescribing alternatives like benzodiazepines which also have serious side effects (Maidment et al. 2011).

To this effect, pharmacists' involvement in medication management/review for people with dementia has focused more broadly on identifying potentially inappropriate prescribing (Pfister, Jonsson and Gustafsson 2017, Bala et al 2019, Eshetie et al 2019) and patient-centred care for dementia patients has been advocated (Blagburn 2017) especially with regards to managing behavioural and psychological symptoms of dementia.

Person centred care is a term often used in relation to people with dementia which can mean different things to different people or healthcare services. It can be considered as a concept which encompasses four key elements: valuing people with dementia and those who care for them, treating people with dementia as individuals, looking at the world from their point of view, and having a positive social environment in which they can live relatively well (Brooker 2003).

In a patient-centred approach to dementia care, clinical pharmacists can be instrumental in the identification and management of under-treatment, ineffective medication, unsuitable dosage forms/regimens and proposal of non-pharmacological approaches, all of which could lead to reduced healthcare costs and improvement in care quality (Zwietering et al 2018).

Pharmacists can team up with other healthcare professionals to educate staff/carers of people living with dementia about clinical features of different forms of the disease, names of medications prescribed and their benefits/side effects, whilst also helping them look beyond medication by sign-posting where appropriate to other services such as physiotherapists and optometrists (Riachi 2016).

Community pharmacists are amongst the most easily accessible healthcare professionals in primary care. They are highly visible and frequently form long-standing relationships with their patients (Chang et al 2015), so they play an essential role in the overall health and wellbeing of the community in which they practise. People living with dementia both in the community and in care homes can benefit from the expertise of community pharmacists, who are trained to understand how medicines affect cognitive function.

In 2013, the 'dementia friends' initiative was launched to increase awareness of dementia in communities, promote understanding of the disease and the 'small things' that can make a difference to people living with dementia (Dementia Friends 2013). The idea is to train ordinary people to become 'dementia friends' or 'dementia friends champions' within communities. Community pharmacists have been encouraged to become more dementia friendly (Bearman 2013) with the

current community pharmacy contractual framework for 2019/20-2023/24 requiring pharmacies to complete “dementia friendly environments” checklists (DOH 2019).

There has been research leading to proposals about the role community pharmacists can play in managing medication for people living with dementia in the community (Maidment et al 2016). For people with dementia in care homes, clinical pharmacy input has mainly been provided by specialist dementia pharmacists (Maidment et al 2018), care home independent prescribing pharmacists (Inch et al 2019) or medicines optimisation pharmacists in care homes (Andalo 2014, Copeland 2016, NHS England MOCH Programme 2018).

There is a paucity of published academic research concerning community pharmacist-led services targeting people with dementia in care homes in England. The increasing work load of community pharmacists (Gidman 2011), potential lack of adequate knowledge and skills in the field of dementia, lack of access to patient care records and inadequate communication with prescribers have all been suggested as possible reasons why an optimal pharmaceutical care service could not be provided by community pharmacists to people with dementia in general and those in care homes in particular. In fact, some researchers have opined that the ability of community pharmacists to contribute to chronic disease management is limited, and that policy initiatives aimed at developing a clinical role for community pharmacists in dementia care are unlikely to succeed (Maidment et al 2017).

However, in acknowledgement of the uniqueness of the medication-related needs of people living with dementia, NHS Education for Scotland (NES) published a

resource pack entitled 'Pharmaceutical Care of People with Dementia', designed to meet the education and training needs of pharmacists and pharmacy technicians delivering services to people with dementia, their families and carers (NES 2014). The extent to which this resource pack has been used has not been tested.

The Alzheimer's society (2016) asserted that overall care of people living with dementia in care homes was substandard. This view was echoed by Yeo et al (2017) with specific reference to pharmaceutical care, when they used the American Geriatric Society (AGS) Beers criteria (2015) to evaluate the quality of pharmaceutical care of people living with dementia in America. Based on their study which revealed that at least half of a large cohort of elderly dementia patients was receiving at least one potentially inappropriate medication, they concluded that this reflected poor quality pharmaceutical care in a patient population already deemed vulnerable. This reiterated a need for a bespoke pharmaceutical care service to care homes with specific focus on people with dementia.

In October 2016, NHS England (NHS Commissioning Pharmacy Integration Fund, 2016 (PhIF)) confirmed that from April 2017, the PhIF would fund the deployment of pharmacy professionals in care homes, including development of the workforce through educational grants. This has led to the previously mentioned "Medicines Optimisation in Care Homes" (MOCH) programme (2018) that has seen pharmacy teams being funded to work in participating care homes till 2019/2020. This was a welcome development for care home residents, particularly those with chronic, progressive diseases such as dementia.

However, whilst deployment of clinical pharmacists in care homes could greatly improve disease management in residents (Royal Pharmaceutical Society (RPS), 2016), this was a relatively small workforce and the service was not consistently offered in all care homes. In fact, NHS England announced in February 2018 that it would recruit 240 pharmacy professionals (including 180 pharmacists) into care homes by March 2019 but failed to meet this target by the deadline (Pharmaceutical Journal: News in Brief May 2019).

The above implies that not all care homes are benefitting from pharmaceutical care services offered by specialist care home pharmacy teams, making current provision inadequate, particularly for the majority who are living with dementia. There have been suggestions that in addition to providing services through the national contract and locally commissioned services, community pharmacists could have direct contractual agreements with care homes either individually or in clusters (Webber 2015). Improvements of cognitive functioning of people with dementia in care homes, reduction in medication wastage and overall improvements in quality of life are outcomes that can inform the decision to involve community pharmacists more, and research is needed to explore their current capacity to do so.

1.8 Research Rationale

Dementia is a worldwide healthcare priority as determined by the World Health Organisation (2012), and as a result of its cost and burden, many countries have developed a strategy for managing the care of those suffering from it, in addition to supporting research on its prevention and treatment.

Within the last two decades, various schools of thought have explored the role community pharmacists could contribute to dementia care for people living with dementia in the community (Child et al 2012, Rubio-Valera et al 2014, McGrattan et al 2017), with one suggestion being for a wider role conducting medication reviews in patients' homes (Oswald 2017). Other suggested roles include supporting people with dementia and their carers to manage their medication better, and signposting them to other services that will enable them to live well with their condition (Lindauer et al 2017, Maidment et al 2017)

There has been a push by professional bodies and governments to move community pharmacists towards fulfilling more clinical roles.

For people with dementia, this would entail pharmacists being integrated with other healthcare providers to practice pharmaceutical care in its entirety, resulting in identification of drug therapy problems, and creation of care plans tailored to each patient, depending on individual need, ultimately leading to improved, measurable health outcomes.

The British Medical Association (BMA) recognises this and recently pointed out that the direction of travel for community pharmacists is one focused on transitioning them from a business model to one which is more reliant on providing clinical services such as medication use reviews, enabling them to integrate better with the rest of the NHS (BMA and PSNC 2019). Whilst such services would be beneficial to people with dementia in the community, those in care homes where the services of dedicated care home pharmacists are not commissioned could also benefit from having their medication reviewed and drug

therapy problems addressed by local community pharmacists with knowledge of the disease, its features and appropriate management.

The Alzheimer's Society estimated that over 70% of care home residents in the UK are living with dementia; mostly because their disease has progressed to a point where they require more intensive support (Fix Dementia: NHS and Care Homes, Alzheimer's Society 2016a). Often, the decision to be admitted into a care home is difficult for the person with dementia and this decision can be made easier if there is reassurance that once in the homes, residents receive the same or improved access to care services. This not the case; the report mentioned above by the Alzheimers' Society concluded that dementia care in care homes was not sufficiently patient-centred, leading to damage to the health and wellbeing of dementia sufferers. The same report also concluded that the levels of pharmacy services were below the minimum needed, and supported the recommendation that *"pharmacists should lead a programme of regular medicine reviews and staff training, working in an integrated team with other healthcare practitioners ensuring medicines safety"* (The Right Medicine: Improving Care in Care Homes, RPS 2016). Each care home should have a dedicated pharmacist with responsibility for its overall medication management.

In England, NHS England is the national commissioner for the NHS community pharmacy services to care homes. Through their local teams, NHS England commissions pharmacies to provide *"advice and support to the residents and staff within the care home, over and above an essential dispensing service, to ensure proper and effective ordering of drugs and appliances, their clinical and cost effectiveness, storage, supply and administration, and proper record keeping"*

(Pharmaceutical Services Negotiating Committee (PNSC 2005). However, clinical commissioning groups are also free to develop their own local services in response to identified local needs (PSNC 2019). Additionally, NHS England (NHS Commissioning Pharmacy Integration Fund 2016) only funded the deployment of pharmacy professionals in care homes for two years from March 2018, after which primary care networks were expected to continue (Andalo 2019), but how this will be implemented is currently unclear.

What is clear from the above narrative is that some care homes will have more pharmacy input than others, as not all care homes will have a dedicated care home pharmacist, but community pharmacists are accessible to all.

This realisation drove my desire to explore the possibility of community pharmacists expanding their role beyond the provision of essential services to care homes, to include targeted services for people with dementia in residential care.

I thus set out to explore community pharmacists' perspectives about the pharmaceutical care needs of people living with dementia in care homes; to examine their training needs in this domain and identify any barriers to the provision of the aforementioned targeted service. My research also explored the perceptions of care home staff about the medication-related needs of people living with dementia in this sector.

1.9 Research question, aim and objectives

1.9.1 Research question

What is the nature, role and impact of community pharmacists in the pharmaceutical care of people with dementia resident in care homes in England?

1.9.2 Aim

To explore the role of community pharmacists in the pharmaceutical care for people living with dementia in care homes, and to understand the barriers they face in an expanded role targeting this vulnerable patient group.

1.9.3 Objectives

- Review the literature on dementia, its subtypes, diagnosis and treatment and their implications for pharmaceutical care
- Conduct a qualitative study utilising semi-structured interviews to explore the views and perceptions of community pharmacists about the pharmaceutical care needs of people living with dementia in care homes
- Use the results of the qualitative study to develop a questionnaire survey for a wider audience of community pharmacists in England
    - Investigate the medication-related needs of people with dementia from the perspective of care home staff and explore their views about the services they receive from pharmacy.
    - Develop an intervention tool to facilitate pharmaceutical care in dementia.

CHAPTER 2
LITERATURE REVIEW

2.0

2.1 Introduction and chapter overview

There is a plethora of published literature on dementia, its prevalence, and global impact, risk factors for developing it, its diagnosis, pharmacological and non-pharmacological management

Existing literature was reviewed by searching specific healthcare databases: MEDLINE, EMBASE, PychInfo and PubMed.

Relevant publications by the Department of Health (DOH), National Institute for health and Care Excellence (NICE) and Royal Pharmaceutical Society (RPS) were also reviewed for information regarding the role of pharmaceutical care to dementia diagnosis, risk factors, clinical features and sub-types.

Hand searching of publications by experts in the field was also carried out, including publications in specific journals such as the 'British Medical Journal', 'Pharmaceutical Journal' and 'Age and Ageing'.

The following search terms were used, alone or in combination:

- Dementia, dementia care, drug therapy, medical care, pharmaceutical care, clinical pharmacist, community pharmacist, pharmacist attitude, Alzheimer's disease, vascular dementia, frontotemporal dementia, dementia with Lewy bodies, dementia diagnosis, pharmacological, non-pharmacological management.

Abstracts of retrieved articles were assessed for relevance to the study, duplicates were removed, and those not directly relevant to an overview of dementia, its identification, management and role of pharmacists were discarded.

Chapter 2 presents an overview of dementia including its risk factors, clinical features and sub-types. The pathophysiology of each dementia sub-type and its relevance to therapeutic choice for each person with dementia is discussed.

The behavioural and psychological symptoms (BPSD) of dementia and their impact on the therapeutic management of dementia is also addressed.

There is a discussion about dementia diagnosis which includes a review of the assessment and detection of dementia in individuals referred for this purpose or are showing some level of cognitive decline. The potential role for pharmacists in care homes and the community in promoting early diagnosis is also considered.

A critical review of current pharmacological and non-pharmacological interventions available for people with dementia is conducted.

Finally, a summary of the knowledge gaps that set the scene for the rest of my research, a description of my chosen research methodology, followed by an outline of the ensuing chapters is included.

2.2 Dementia Risk Factors and Clinical Features

There are many neurodegenerative disorders that lead to dementia; thus the clinical features and risk factors of dementia may differ depending on the sub-type (cause) of dementia. However, there are some features that apply to most types of

dementia. This section presents some features that are common to most dementias.

2.2.1 Risk Factors

With current projections indicating an escalation in numbers of patients with dementia and an increased cost to the society, there is a need to examine the risk factors for dementia in order to identify ways in which individuals can make efforts towards prevention and mitigating risk. There is no way of definitively preventing dementia, but several key risk factors have been identified such as age, genetics, medical history (especially cardiovascular), lifestyle and environment (Alzheimer Scotland, 2011). While factors like age, genetics and gender, cannot be modified, it is possible to mitigate other risks and at least attempt to delay the onset of dementia. The Lancet Commission (Livingston et al 2017) estimated that an approximate 35% of dementia cases could be attributed to potentially modifiable factors like midlife hypertension, low education attainment, midlife obesity, hearing loss, late-life depression, diabetes, physical inactivity, smoking and social isolation. Risk factors associated with dementia are discussed here, but it must be noted that some risk factors can pre-dispose individuals more to one sub-type of dementia than another; for example, age and genetic factors are most associated with Alzheimer's disease whilst vascular risk factors are linked to both vascular dementia and Alzheimer's disease (Larson 2019).

Age

Age is the biggest risk factor for dementia, and the effect of age ing is a consistent risk factor across various ethnic groups, with the risk of dementia increasing with age (Ferri et al, 2005, Prince et al, 2013). This is particularly true for Alzheimer's

disease whose incidence approximately doubles every 10 years from the age of 60. In total, it is estimated that 85% of dementia cases are in the 75 and above age group (Niu et al 2017).

Genetics

A common genetic polymorphism, apolipoprotein E (ApoE) gene e4 allele greatly increases the risk of dementia but some people who have one or more copies of ApoE4 do not develop dementia, while others develop dementia without the gene at all. Some scientists have thus argued that the presence of the gene does not necessarily determine whether a person gets dementia, but rather when they get it, the presence of the gene being more predictive of late onset dementia (Alzheimer Scotland, 2011).

The largest amount of data available on genetic risk factors is available for Alzheimer's disease as it is the most prevalent subtype (Larson 2019), but a family history of dementia is commonly present in frontotemporal dementia too. It must be noted that the risk estimates taper off the older the parent is at diagnosis, meaning there is no risk to offspring if a parent is diagnosed after 80 (Wolters et al 2017)

Gender

The female sex has been associated with increased risk of developing Alzheimer's disease since the ApoE4 gene appears to have a greater deleterious effect on gross hippocampal pathology and memory in women than in men (Azad et al, 2007). However, the association between gender and dementia risk can be complicated by

lifestyle, ethnicity and other factors which need to be considered when exploring the link between sex and dementia risk (Chen, Lin and Chen 2009).

Vascular risk factors

Vascular risk factors such as hypertension, diabetes, lipid disorders (hypercholesterolaemia) are associated with increased risk of development of Alzheimer's disease and vascular dementia (Sahathevan, Brodtmann and Donnan, 2012). However, there exists a common vascular pathology to most causes of dementia, suggesting that early diagnosis and treatment of vascular disorders could modulate the onset of dementia, but epidemiological studies that group together all forms of dementia can hide individual patterns of risks, clinical manifestations and treatment success (Ritchie and Lovestone, 2002). Associations between vascular risk factors and dementia are best measured in midlife rather than later in life when multiple other factors have to be considered (Larson 2019).

Lifestyle

Smoking, excessive alcohol consumption, inflammation, a lack of physical exercise, lack of education, diet and environmental factors (aluminium, iron, copper, zinc in and obesity) have all been linked to increased risk of dementia (Chen, Lin and Chen, 2009).These environmental factors are thought to combine with genetic predisposing factors to cause cellular changes which result in progressive neuronal degeneration possibly involving mitochondrial dysfunction and failure of protein degradation machinery at the cellular level (Ghandi and Wood, 2005).

With the upsurge in research activity in various aspects of dementia, many investigations are on-going, but so far there is no indication that the environmental

and lifestyle factors linked to dementia are fully understood. However, since prevalence and incidence of Alzheimer's disease seem to be much lower in some developing regions, there may be some indication that some environmental risk factors are much less prevalent in these settings (WHO, 2006).

Risk of dementia has been broadly associated with lifestyle components such as mental, physical and social activity, using various biologically plausible hypotheses including the cognitive reserve, vascular and stress hypotheses (Fratiglioni, Paillard-Borg and Winblad 2004). Of interest, is the theory that higher levels of education, combined with cognitive and social activity builds a cognitive reserve that reduces the impact of neurodegeneration on cognitive function.

Others

There have been links between a wide range of other factors and increased risk of dementia. These include depression chronic disease and medical illnesses, head trauma, depression, hearing loss, obstructive sleep apnoea and exposure to certain toxins (Larson 2019).

A detailed examination of these risk factors is beyond the scope of this chapter. However an understanding of the aetiology and pathophysiology of the subtypes of dementia will help to shed light on how these factors play a role in the development of dementia.

2.2.2 Clinical Features of dementia

Clinical features of dementia may differ depending on the underlying cause and can be subjective depending on the individual's premorbid personality, lifestyle, significant relationships and physical health (WHO 2006).

The presenting complaint is usually of memory loss (usually for more recent than more remote material), with forgetfulness usually being early and prominent, while impaired attention and concentration are common, non-specific features (Gelder, Harrison and Cowen, 2006). In more severe dementia, individuals may forget previously learned material including the names of loved ones, and have difficulty learning new material (Ameen, 2004).

In general, the clinical features of dementia can be grouped into three different categories:

- A first stage of cognitive impairments (including memory impairments, language difficulties), apraxia, aphasia and agnosia.
- A second stage that comprises of neuropsychiatric features such as depression, paranoia, wandering, anxiety, (all known as behavioural and psychological symptoms of dementia or BPSD);
- A third stage comprising deficits in activities of daily living such as self-neglect or diet (Grand, Caspar and Mcdonald, 2011). Disorientation for time, place and person, poor judgement and impoverished thinking can also occur, as well as distress, irritability, aggression, blunted emotional response and other behavioural problems (Gelder, Harrison and Cowen, 2006).

It is worth noting that memory loss is no longer essential for dementia diagnosis as key clinical features can differ depending on the underlying cause of the dementia e.g. early deficits in attention and visio-spatial focus are more relevant in dementia with Lewy bodies, while in frontotemporal dementia, memory loss is absent or occurs later (Kester and Scheltens, 2009).

Behavioural and psychological symptoms of dementia (BPSD), a set of non-cognitive symptoms (agitation, aggression, wandering, and psychosis) occur commonly in Alzheimer's disease, especially in the middle and late stages of the disease (Turner 2014). These will be discussed in more detail later in this chapter as many potentially inappropriate medications are started in people with dementia as a result of BPSD.

There is also recognition of a prodromal or transitional state for dementia called mild cognitive impairment (MCI), which is a phase between healthy ageing and dementia (Busse, Angermeyer and Riedel-Heller, 2006). This is relevant because up to 20% of people with MCI progress to dementia every year.

The above core symptoms and signs can be balanced with additional specific features to form the basis for clinically differentiating between various causes of dementia.

An awareness of the risk factors and clinical features of dementia enables community pharmacists to support community dwelling individuals with dementia and their carers in medication management and signpost them to appropriate services (Criddle 2014).

2.3 Main Causes (sub-types) of Dementia, their pathophysiology, clinical presentations and implications for pharmaceutical care

2.3.1 Introduction

Distinctions have been made in the classification of dementia; these have implications for understanding the pathophysiology of each type of dementia. It is

important to understand the pathophysiology and the clinical presentations of various dementia subtypes in order to differentiate one type from another.

Dementia cannot be assigned a single nosological entity; it can be grouped into different classes on the basis that each dementia type has a different neuropathophysiology. One such distinction is classifying dementia into cortical and subcortical dementias (Gelder, Harrison and Cowen, 2006). The distinction between cortical and subcortical dementia is blurred, but subcortical dementia types (Parkinson's disease dementia, Wilson's disease, HIV associated dementia) are primarily characterised by movement disorders, slowness of thought, while cortical dementias (Alzheimer's disease, Frontotemporal dementia) are characterised by memory impairment (Semple and Smyth, 2008).

Another method of distinction for the dementias is differentiating between primary neurodegenerative dementias such as Alzheimer's disease, dementia with Lewy bodies and frontotemporal dementia, from dementia secondary to another disease process such as HIV associated dementia. However, as complex interactive effects of genetic predisposition, neurochemical changes and disease co-morbidities of dementia become clearer with research, such simplistic distinctions are being revised (Ritchie and Lovestone, 2002). The cortical/subcortical dichotomy for example, has been revisited as subcortical deficits such as seen in Parkinson's disease can also be found in cortical dementias such as Alzheimer's disease and vice versa (Hickey et al, 2008).

Histopathological studies have shown that different forms of dementia can share the same underlying pathologies and that mixed states where people present with the features of more than one type of dementia are more common than pure

dementia syndromes. This implies that grouping together all forms of dementia can mask individual patterns of risk, clinical manifestation, and treatment outcomes.

A molecular based method for distinction emerged from the theory that neurodegenerative dementias involved two forms of abnormal proteins called *synuclein* and *tau*, resulting in classifications of dementia into *synucleiopathies* (Dementia with Lewy bodies, Parkinson Disease) and *taupathies* (Alzheimers disease, Frontotemporal dementia), which scientists found more useful (Hickey et al, 2008). Vascular dementia is a notable exception from this grouping as it is not neurodegenerative. It has also become increasingly clear that most neurodegenerative diseases that lead to dementia are characterised by processes that result in aberrant polymerisation of proteins. A small number of people with these diseases develop dementia as a direct result of the presence of mutations or polymorphisms in genes that influence these processes (Holmes, 2012).

The relevance of understanding how clinical sub types of dementia correspond to underlying pathophysiology is that it becomes easier to assign patients to appropriate therapeutic protocols (Mesulam, 1985).

Other distinctions have been made based on time of onset (early onset, late onset dementia) or severity (mild, moderate, severe), but these tend to apply mainly within each sub-type.

The pathophysiologies of Alzheimer's disease (AD) vascular dementia (VaD), Dementia with Lewy bodies (DLB) and Frontotemporal dementia (FtD) are discussed next.

2.3.2 Alzheimer's disease (AD)

Several diseases cause dementia, but by the far the most common cause is Alzheimer's disease (AD) also called dementia of the Alzheimer type (DAT) (Plum, 1986; Silvestrelli et al, 2006; Moreira et al, 2010). It accounts for almost 50-60% of dementia cases (Gelder, Harrison and Cowen, 2006, Alzheimer's Research UK, 2018).

Over 100 years ago in 1907, Alois Alzheimer reported the case of Auguste D, a 55-year-old woman whose brain exhibited unusual neuro-pathophysiological features. Post-mortem examination showed a brain with an abnormally thin cerebral cortex and microscopic features of senile plaques and neurofibrillary tangles, but it was his colleague, Kraepelin who named the disease (Maurer and Maurer, 2003). In the years since, research has led to a better understanding of AD, but the cause of the disease remains unknown. Many case control studies have linked several risk factors such as age, family history, small head circumference, head injury, apolipoprotein (Apo E4) status, depression, hypertension, diabetes, high cholesterol, atrial fibrillation, presence of cerebral emboli, and low physical and cognitive activity to the disease (Burns and Illiffe, 2009).

Advances in research have led to an understanding and characterisation of the hallmarks of AD earlier observed by Alzheimer (plaques composed of amyloid beta or Aβ, and tangles composed of hyperphosphorylated *tau*), and this knowledge has resulted in an appreciation of the complex nature of AD pathogenesis (Blennow, de Leon and Zetterberg, 2006, Keene, Montine and Kuller, 2019). These hallmarks need to be defined, in order to contextualise the theories that have been put forward by scientists to explain histological changes in AD pathology:

In AD, the brain shrinks, and microscopic examination reveals the cardinal diagnostic features that are neurofibrillary tangles (NFT) and senile (amyloid) plaques in the cerebral cortex and many sub-cortical regions (Gelder, Harrison and Cowen, 2006). Amyloid plaques are deposits of insoluble proteins which occur together with degenerating neurites and glia, in the space between neurons. At the centre of the senile (amyloid) plaques, is a protein called β-amyloid (Aβ) which is a 39-42 amino acid peptide. Production and accumulation of Aβ peptide is central to the pathogenesis of AD (Wood and Cummings, 2004). Isolation of Aβ paved the way for the discovery of the amyloid precursor protein (APP) gene which was cloned in 1984, and led to the connection between Aβ and the protein from which it is derived (DeKosky, 2001). Aβ is a fragment cleaved from the full length of the APP, and Aβ has been found to be neurotoxic *in vitro* leading to cell death and the overexpression of human amyloid precursor protein in transgenic mouse models of Alzheimer's disease, which results in neuritic plaques similar to those seen in humans with Alzheimer's disease (Wood and Cummings, 2004). The other hallmark, NFT, are the remains of defective neurons where the centre of each cell is filled with remains of microtubules wrapped around each other to form highly ordered spirals called paired helical filaments. The filaments are then composed of several proteins including tau and Aβ. The presence of tangles leads to dysfunction and death of the neuron. NFT and amyloid plaques are found in the areas of the brain where neuronal loss is most severe. The density of filaments formed from tau proteins within the neurons in the brain is directly related to the severity of dementia (Silvestrelli et al, 2006). The number of plaques in the cerebral cortex is directly proportional to an individual's intellectual function; so the greater the

incidence of plaque deposition, the more impaired is intellectual function. It is not yet clear whether tangles are linked to plaque formation.

Many pathogenic hypothesis have been postulated based on Aβ, the more prominent being the amyloid cascade hypothesis, the genetic hypothesis and the inflammatory hypothesis.

The *amyloid cascade theory* which resulted from research into APP has become predominant as the molecular model for AD. In this hypothesis, the central pathogenic event is the increased formation and deposition of β-amyloid (Aβ) protein (the main component of neuritic plaques), particularly the 42-amino acid variant, leading to formation of neurofibrillary tangles, cell loss and vascular damage leading to dementia (Hardy and Higgins, 1992). The amyloid precursor protein (APP) can be cleaved by one of three enzymes called secretases: α-secretase, β-secretase, or ϒ-secretase. When α-secretase predominates, there is no formation of Aβ, but in AD, APP is predominantly formed via β-secretase and ϒ-secretase pathways leading to increased β-amyloid formation hence dementia. Additionally, cholesterol metabolism is heavily implicated in liberation of Aβ.

The implication of this for dementia care is that pharmacological treatments can be developed that inhibit β-secretase and ϒ-secretase leading to reduction in production of the toxic Aβ (Wood and Cummings, 2004). This also implies that statins can have a role in preventing AD.

The *genetic hypothesis* of AD is based on research implicating various risk genes that have been isolated (Keene, Montine and Kuller, 2019). One such gene is the human apolipoprotein E (ApoE4), defined as a pleiotropic lipoprotein thought to

be involved in multiple cellular processes such as cholesterol transport, synaptic plasticity and immune regulation to name a few.

The mechanism by which inheritance of ApoE4 increases AD risk is unclear; but a popular theory is that ApoE4 impairs clearance of Aβ from the cerebrum (Castellano et al 2011).

The *inflammatory hypothesis* in relation to AD builds on evidence of the involvement of inflammatory processes in AD pathogenis documented over the years (Zotova et al. 2010). The inflammatory reaction referred to in this hypothesis is considered a downstream effect of accumulated amyloid beta (Aβ) and tau. According to this hypothesis, Aβ found in the CNS (central nervous system) brings about activation of microglia (resident phagocytes of the CNS) which initiates a pro-inflammatory cascade. This causes the release of substances such as cytokines, chemokines, reactive oxygen, nitrogen species and proteolytic enzymes which are potentially neourotoxic, and lead to degenerative changes to the neurons (Zotova et al. 2010, Heneka et al 2018).

Despite evidence that inflammation is involved in AD pathogenis and exacerbates the course of the disease, the inflammatory hypothesis is mostly based on mechanisms observed in animal models, and the type of inflammation is not well defined in the human brain (Zotova et al. 2010). However, from a pharmaceutical perspective, there are implications that drugs with anti-inflammatory properties can be explored for their protective properties against development of AD.

Pharmacotherapy of AD

The *neurotransmitter hypothesis* of AD pathogenesis has great implications for development of therapeutic agents for treatment of the disease. The cholinergic system is critical to normal memory and other cognitive functions and in AD, it has been discovered that there is selective loss of cells that produce acetylcholine (ACh) in the basal forebrain. Research in the field of AD in the 1970s identified the loss of the synthetic enzyme choline acetyltransferase (DeKosky, 2001) and as cholinergic function is required for short-term memory function, it was determined that cholinergic deficit in AD was responsible for much of the short term memory deficit. Loss of choline acetyltransferase (ChAT) is the most consistent finding in post mortem AD, and its deficit corresponds to loss of cognitive function (Keverne and Ray, 2008). The elucidation of this hypothesis led to the development of current symptomatic medications for AD, the acetylcholinesterase inhibitors, which prolong the half –life of ACh at the cholinergic synapse (DeKosky, 2001, Brodaty et al, 2001, Grossberg, 2003). Cholinesterase inhibitors reduce breakdown of ACh and have been found to enhance cognitive performance and improve behavioural symptoms of AD including depression, agitation and apathy.

The neurotransmitter glutamate is also decreased in AD. Glutamate is the main excitatory neurotransmitter in the brain; loss of glutaminergic neurons as well as glutamate activity in AD patients correlates with severity of dementia, with the hypothesis that glutaminergic disruption may be involved in the cognitive symptoms of the disorder (Keverne and Ray, 2008). Overstimulation of NMDA receptors by glutamate is implicated in neurodegenerative disorders such as AD as

overstimulation may result in neuronal damage (Sylvestrelli et al, 2006). Glutamate stimulation of post synaptic receptors including NMDA has been implicated in memory processes, dementia and the pathogenesis of AD (Wood and Cummings, 2004). A therapeutic agent, memantine, a non-competitive NMDA receptor antagonist, reduces glutamate over stimulation and is currently widely used in the treatment of moderate to severe AD.

Several other hypotheses have been advanced for the pathogenesis of AD, including inflammatory mechanism (Imbimbo, Solfrizzi and Panza, 2010), oxidative hypothesis, mitochondrial dysfunction (Moreira et al, 2010) and abnormalities in proteins regulating the cell cycle. However, even though these mechanisms contribute somewhat towards explaining AD pathogenesis, there is no knowledge yet of how they drive the neurodegenerative process (Blennow, de Leon and Zetterberg, 2006). Developing treatment strategies based on these can therefore be challenging.

Even though knowledge and understanding of the pathophysiology of AD has grown in leaps and bounds in the past two decades, a cure for the dreaded disease remains elusive. It is hoped that with the availability of increasingly sophisticated neuro-imaging techniques and advances in molecular biology, enabling a better understanding of the underlying pathobiology of AD, medications can be developed to slow the progression of the disease more effectively, or even prevent its emergence.

2.3.3 Vascular Dementia (VaD)

Vascular dementia is the second most common form of dementia in the elderly after AD (Roman, 2002). The current prevalence of Vascular Dementia ranges from

4.5% to 39% in clinical studies (Jellinger, 2007). It is caused by cerebrovascular disease and was referred to in the past as “atherosclerotic psychosis” (Gelder, Harrison and Cowen, 2006). However, this dementia, which is insidious and slow progressing is not due to atherosclerosis. It was often associated with multiple infarcts, leading Hachinski et al (1974) to suggest the name “multi-infarct dementia”. This term is still sometimes used, but research has shown that patients with “multi-infarct dementia” are a subgroup of a larger group of patients who have dementia caused by vascular disease.

To this effect, Vascular Dementia (VaD) can be classified according to the underlying mechanism into: dementia associated with ischaemic or haemorrhagic lesions, multi-infarct dementia, slowly progressing dementia and dementia with border zone infarction (Takahashi, 2006; Jellinger, 2008). These classifications can however be misleading as they appear to indicate that VaD can result from distinct processes in isolation. In reality, the disease is best understood as a heterogeneous syndrome whose underlying cause is some form of cerebrovascular disease ultimately manifesting as dementia (Smith and Wright 2019).

In VaD, whilst it is accepted that the pathogenic mechanisms of VaD are varied, there is generally a history of transient ischaemic attack (TIA), hypertension or stroke. This explains the current consensus that these pathogenic mechanisms include atherosclerosis and micro (infarcts) in addition to amyloid angiopathy (Wolters and Ikram, 2019). Vascular changes caused by these processes result in cognitive decline in a pattern consistent with models of disturbed cortical and subcortical circuits (Jellinger, 2008).

Despite advances in dementia research, it has been hard to get a widely accepted neuropathological criteria for vascular dementia because it is very difficult to define neuropathological thresholds for considering lesions as being causative of cognitive decline (Grinberg and Heinsen, 2010). Cognitive decline does not depend only on the amount of lesion in the strategic area, but is rather a complex equation involving the amount of tissue loss, location, and brain capacity for compensating the changes. It is therefore not rare to find descriptions of non-demented patients presenting with the same kind and severity of lesions found in demented patients (Grinberg and Heinsen, 2010). Further complications in defining criteria include the fact that AD can also be caused by cerebrovascular disease; Apolipoprotein E, which plays a role in AD, also has a role in the vessel pathology of the ageing brain. There is thus a high prevalence of VaD co-morbid with AD.

Pharmacotherapy of VaD

The therapeutic implication of these theories for VaD pathogenesis is that measures taken to reduce risk of developing cerebrovascular disease such as smoking cessation, control of diabetes, reduction of alcohol consumption and management of blood pressure, can be applied to preventing Vascular dementia.

Another important aspect of VaD pathology is that neurochemical studies have shown abnormalities in key neurotransmitter systems, particularly in the basal forebrain cholinergic system which is related to diffuse white matter lesions. Since cholinergic mechanisms play a role in the regulation of cerebral blood flow, there are implications for VaD pathogenesis (Jellinger, 2008). Studies have also shown significant reductions in cholineacetyl transferase (ChAT) activity in the hippocampus of multi-infarct encephalopathy. The clinical implication of this is

that acetylcholinesterase inhibitors, currently used in AD pharmacotherapy, could play a role in VaD.

Additionally, it is thought that hypertension may be the cause in up to 50% of cases of VaD (NES 2014), indicating that failure to take blood pressure tablets correctly could lead to worsening of dementia symptoms, creating a vicious cycle (Oswald 2017).

2.3.4 Dementia with Lewy Bodies

Dementia with Lewy bodies (DLB) is a common form of dementia in old age which accounts for about 10-15% of cases seen in neuropathological studies (McKeith, 2002), suggesting that it is one of the most frequent causes of dementia.

DLB is characterised by the presence of cytoplasmic inclusions of α-synuclein in the cerebral cortex and nuclei of the brain stem (Rampello et al, 2004). The cardinal neuropathologic feature is the presence of Lewy bodies in the cerebral cortex. The Lewy body (an intracytoplasmic inclusion of a round hyaline mass) was first characterised as the neuropathologic hallmark for Parkinson's disease (PD) in 1912(Ferman, 2000). Frederick Lewy described these bodies in the cerebral cortex and substantia nigra in 1923.

DLB was often overlooked pathologically due to challenges in identifying cortical Lewy Bodies using histochemical stains. However with the advent of immunohistochemical stains, its prevalence is now better characterised, although distinguishing it from other degenerative dementias continues to be challenging (Latimer and Montine 2019) due to increased prevalence of concomitant AD neuropathological changes in DLB (Lemstra et al 2017).

In DLB, as with AD, amyloid plaques can be abundant, but neurofibrillary tangles are absent. Theories for formation of Lewy bodies include the postulation that they may form because α-synuclein becomes insoluble or are more able to aggregate for some reason, or abnormally processed by a dysfunctional proteasome system, producing toxic protofibrils (McKeith et al, 2004).

The presence of Lewy bodies in the autonomic ganglia cause postural hypotension, possibly explaining the frequency of falls in patients with DLB. Their occurrence in the neocortex and limbic cortex produce cognitive failure and psychosis. DLB is also associated with widespread reduction in choline acetyl transferase (ChAT) in the neocortex, and loss of dopaminergic markers in the caudate nucleus. High incidences of psychiatric symptoms in DLB is associated with these neurochemical changes (Gelder, Harrison and Cowen, 2006). Many researchers associate the localisation and density of Lewy bodies with the severity of clinical syndromes. It is assumed that the presence of Lewy bodies in the brain stem is responsible for movement disorders; in the limbic system with psychosis and in the cortex with depression (Rampello et al, 2004).

Pharmacotherapy of DLB

The pathogenesis of DLB has many implications on its pharmacological management and in the pharmaceutical care of people living with it. As there are proven cholinergic deficits in DLB, acetylcholinesterase inhibitors (Galantamine, donepezil and rivastigmine) may be of use in improving cognition and decreasing apathy in some patients with DLB.

Due to dopamine depletion which is characteristic of DLB, patients with this condition are extremely sensitive to even the smallest doses of antipsychotics (Armstrong et al 2016), and the use of antipsychotics in this group of dementia patients can be fatal especially when the potential to cause neuroleptic malignant syndrome is considered. It is therefore very important to diagnose DLB early, as this will minimise the risk of exposing patients to potentially fatal treatments such as antipsychotics.

In a web based survey of 962 caregivers of patients with DLB over a six month period, Galvin et al (2010) found that caregivers were often frustrated with their experiences with physicians who took considerable lengths of time and several visits to diagnose DLB, causing significant delay in initiation of therapy. This study was limited by the fact that the researchers did not make any independent observations of patients' medical notes, the need for education and training of caregivers, and any improvement of time to diagnosis by physicians.

The implication of α-synuclein aggregation in how DLB manifests itself and progresses in human and animal cell models has led to research attempts to develop therapeutic strategies aimed at reducing α-synuclein in the brain, such as immunisation with antibodies which promote its degradation (Zang, Kim and Narayan 2015).

2.3.5 Frontotemporal Dementia (FTD)

Frontotemporal dementia (FTD) is the second most common type of pre-senile dementia and fourth most common type of senile dementia (Sjorgen and Anderson, 2006), underlying about 7% of late life dementias. FTD comprise a broader, more heterogenous range of clinical presentations than common

dementias, and it is the most frequent clinical phenotype under the spectrum of frontotemporal lobar degenerative diseases (FTLD), further categorised by abnormal protein inclusions due to tau and other proteins (Lee 2019).

FTD is now the preferred umbrella term for three presentations namely: two forms of primary progressive aphasia (PPA), and behavioural variant FTD (bvFTD). A clear distinction between the clinical and neuropathologic terminology is essential. BvFTD is the most common clinical subtype of FTD, its hallmark being a progressive change in behaviour and personality (Johnson et al 2005).

In the majority of FTD cases, which are often sporadic in nature, the pathophysiology is unknown. In hereditary FTD, mutations of different tau proteins are implicated (Sjorgren and Anderson, 2006), where abnormal tau may lead to aggregation of tau or disruption of microtubules thereby severely impinging the intraneuronal transport system. FTD differs from AD and DLB in not showing cholinergic deficits, and dopamine also appears to be unaffected. All forms of FTD show gross atrophy of the temporal and frontal lobes, with neuronal loss, gliosis, spongiform changes in the cortex, and often ballooned cells and neuronal inclusions that stain for ubiquitin, tau and phosphorylated neurofilaments (Gelder, Harrison and Cowen, 2006). Tau protein involvement is central to the pathogenesis of FTD. Other hypotheses that have been proposed for pathogenesis of FTD include involvement of autoimmune mechanisms and involvement of cytoskeleton proteins (Sjorgen and Wallin, 2001).

Due to its heterogeneous nature, FTD is difficult to diagnose despite existence of diagnostic criteria, and there are few investigations to aid diagnosis. It has been reported that FTD is associated with movement disorders and studies have

provided evidence of Parkinsonism signs in familial cases due to mutations in tau proteins (Padovan et al, 2007).

Pharmacotherapy of FTD

The uncertainty about the pathophysiology and aetiology of FTD means no curative agents are available yet. Pharmacotherapy therefore involves symptomatic treatment with antidepressants and neuroleptic agents for control of behavioural symptoms. As a result of a hypothesis formulated by Constantinidis and Tissot (1981) who proposed that excess zinc is accumulated in the brains of patients with FTD, heavy metal chelators have been used to treat FTD resulting in clinical improvements in several frontal functions. Though there is cognitive dysfunction in FTD, it is not mediated via the cholinergic pathway, so theoretically, cholinesterase inhibitors will have little effect.

2.4. Behavioural and psychological symptoms of dementia (BPSD)

As dementia progresses, irrespective of subtype, functional and cognitive impairment worsens and individuals begin to suffer from a range of heterogeneous psychological and psychiatric symptoms often referred to as the behavioural and psychological symptoms of dementia (BPSD). These are also called 'neuropsychiatric disorders' (Ritchie and Lovestone 2002), 'challenging behaviours', 'non-cognitive symptoms', 'behaviour that challenges' or 'responsive behaviours' (Finkel 2000, Dupius, Wiersna and Loiselle 2012). However, as the term BPSD is widely used in the UK, these behaviours will be termed as such in this thesis.

BPSD is defined as "*signs and symptoms of disturbed perception, thought content, mood or behaviour*" (Finkel et al 1997) manifested by people living with dementia. Mood disorder includes anxiety, depression, suicidal behaviour, and apathy and behavioural disorders exhibited often are agitation, disinhibition, perseveration, hypersexuality and eating disorders, whilst psychotic features include hallucinations and delusions (Ritchie and Lovestone 2002).

It is essential to examine BPSD because it is estimated that between 80% (Mathys 2018) and 97% (Steinberg et al 2008) of people with dementia will suffer from these symptoms, with subjective severity, as their disease progresses. BPSD are a source of significant morbidity in dementia patients and stress for their caregivers, leading to poor quality of life in both sets of individuals (Ryu et al 2011), and have an immense negative impact on both the physical and psychological wellbeing of both formal and informal caregivers (Ballad et al 2000).

The causes of BPSD are complex and remain largely unknown, but they are thought to be an ineffective attempt by the person with dementia to cope with environmental or physiological stress factors (Cerejeira et al 2012). Another theory postulated by Kales et al (2015) following a comprehensive literature review, was that neurodegeneration associated with dementia affected the ability of a person with dementia to interact with others and their environment, and the resultant disruption in brain circuits for behaviour and emotion increased risks of developing BPSD. Other theories include changes in personality traits, physical disorders and pain, and stressful life events (Tible et al 2017).

Pharmacotherapy of BPSD

The relevance of understanding BPSD in the context of pharmaceutical care is that aggressiveness and psychotic symptoms in people with dementia have been shown to result in a two-fold increase in their likelihood of being prescribed antipsychotics (Chui et al 2006). Though the effects of antipsychotics on the natural course of BPSD is unclear, their deleterious side effects in older adults are well documented (Maidment et al 2016, 2017) (Hernandez et al 2019). Due to the complex nature of BPSD aetiopathogenesis and multi-morbidity in sufferers, treatment is highly challenging. Emphasis is placed on non-drug measures, following a person-centred, caregiver-focused approach (Tible et al 2017), though the evidence for this is weak. The use of antipsychotics is discouraged due to the increased risk of cerebrovascular events and mortality they pose to dementia patients. Pertinently, a qualitative study evaluating the role of community pharmacists in reviewing use of antipsychotics in BPSD found many barriers (lack of access to patient notes, lack of knowledge of dementia) limiting their ability to contribute to reduction of antipsychotic prescribing in dementia (Maidment et al 2016). However, this study was a small qualitative study with limited generalisability.

An understanding of the underlying causes of BPSD, the role of medication toxicity in precipitating them, as well as non-pharmacological therapies could significantly contribute towards effective management of the condition. Despite the general consensus that non-pharmacological methods are preferable, the concepts of person-centred care, considered the best approach when caring for people with

dementia (NICE NG97 2018), must be employed when considering treatment for BPSD in each person with dementia.

In considering a pharmacological approach as an alternative to non-pharmacological management of BPSD, a weighted analysis of the severity of BPSD against the risks and benefits of a medication based intervention, is required so that an optimal pharmacological regimen can be implemented (Mathys 2018).

2.5 Dementia Diagnosis

2.5.1 Introduction

As the prevalence of dementia increases worldwide, the need to develop effective treatments for the conditions becomes increasingly imperative. Similarly the developments of diagnostic strategies to improve early detection of the disease and define the different forms of dementia both selectively and specifically are also equally important. Significant benefits can be obtained for patients if diagnosis and therapeutics of dementia are combined, but since different syndromes make up the total picture of dementia, ensuring accurate diagnosis is vital.

Whilst it is recognised that improved diagnosis of dementia and better treatment of mild cognitive impairment will help alter the grim picture painted by current predictions of the rising numbers of dementia sufferers, including increasing socio-economic burden, diagnosing dementia is deemed a major challenge for many health care systems (Herloz, Perani and Morris, 2006).

The Alzheimer's Society UK (2014) statistics showed that about 46% of people living with dementia receive a diagnosis during their lifetime. Within these

statistics, the rate of diagnosis varied dramatically from as low as 35% in South West England to as high as 70% in parts of Scotland and Northern Ireland. The UK government pledged in 2013 (DOH 2013) to address the issue of people unknowingly living with dementia and launched a huge campaign to raise awareness of the condition. Diagnoses rates have improved significantly since then, though still widely variable: Wales, 53%; Scotland, 67%; England, 57.8% and Northern Ireland, 73% (Dementia Statistics Hub 2018). Concerns that many community dwelling people with dementia remain undiagnosed still exist (Eichler et al, 2015).

The Alzheimer's society reiterates the importance of a diagnosis, since without one, people with dementia cannot receive the support, information and treatment they need in order to live well with dementia, and services cannot be planned as needed [Alzheimer's Society 2014).

Early detection and diagnosis of dementia depends largely on patients or their carers/relatives recognising symptoms and making initial contact with health care professionals (Chrisp et al, 2012). It is important to understand the journey undertaken by people suspected to have dementia (and their carers) before a diagnosis is reached, as this helps health care professionals to formulate suggestions and strategies for improving the care experience for patients and their families.

As the neuropathology of dementia starts before clinical symptoms manifest, often by several years, early detection and diagnosis form part of the key steps to mitigating the progression and burden of dementia (Henderson 2012).

The National Institute for Health and Care Excellence (NICE, 2018) proposes a pathway for diagnosis and assessment of dementia which involves an initial basic screen on first contact by the general practitioner, during which reversible causes of cognitive decline such as delirium, depression, medication are investigated and ruled out and if dementia is still suspected, it is followed by referral to a specialist. The specialist conducts a comprehensive assessment before making a diagnosis of dementia, followed by tests to determine the dementia sub-type.

2.5.2 Assessment of Dementia

Diagnosis of dementia is based on a patient's history (including the use of information supplied by sources other than the patient), and clinical examination.

At this stage, it is worth pointing out that cognitive decline is manifested in several ways which include memory loss, suspiciousness, inappropriate social behaviour, hoarding and perceptual distortions. Part of the average ageing process includes mild levels of cognitive inefficiency, but more significant impairment in the cognitive spheres of memory, language and judgement are often signs of a dementing disorder (Weiner and Lipton, 2012). As people age, impaired memory becomes more prevalent, so differentiating normal ageing from pathological cognitive decline is a significant part of the early detection of dementia.

In summary, evaluation of cognitive impairment and dementia ideally consists of three stages:

(1)-Recognition of deficits in cognition;

(2)-an initial or basic screen to decide whether dementia is present and

(3)-determination of the cause of impaired cognition, once impairment is confirmed (Herholz, Perani and Morris, 2006).

There are challenges at each stage, but it is necessary for all three to be completed in order to formulate an accurate diagnosis.

The General Practitioner

The first point of contact for a person who suspects they have dementia symptoms is their general practitioner (GP) (Alzheimer's Society 2014).

The GP puts the individual through a basic dementia screen that helps to differentiate true dementia from pseudo-dementia (ailments that mimic dementia such as delirium, depression, anxiety), and will seek to exclude other causes of cognitive decline such as normal age-associated memory changes, drug reactions, vision and hearing problems (de Souza et al. 2009, NICE 2018).

Cognitive assessment is essential in order to make a clinical diagnosis of dementia. Cognitive impairment can be quantified using several standardised screening tools. NICE guidelines for dementia assessment (2018) recommend the use of brief structured cognitive instruments such as the 10-point cognitive screener (10-CS), the 6-item cognitive impairment test (6-IT), memory impairment screen (MIS) or the Mini-Cog.

The most widely used is the Mini Mental State Examination (MMSE) developed by Folstein et al (1975). The MMSE is a 30-item cognitive screening test available in several languages that tests orientation, language, memory, attention, ability to follow commands and praxis. Use of MMSE which is under patent, is not

recommended by NICE (2018) when instruments of similar sensitivity are available for free.

Following initial assessments, a general practitioner may feel the need to make a diagnosis of dementia (Alzheimer's Society 2014) but the knowledge and expertise to determine the cause of dementia or make a sub-type specific diagnosis lies with specialists (NICE 2018). Additionally, diagnostic uncertainty at early stages and feelings of embarrassment about conducting cognitive assessments as well as difficulty in communicating diagnosis pose serious obstacles for GPs (Van Hout et al. 2000). In the United Kingdom, the National Institute of Health and Care Excellence (NICE Pathways, 2013) recommends memory assessment services (memory clinics) as the single point of referral for people with possible dementia.

A Role for Pharmacists

It has been suggested that community pharmacists could administer cognitive tests during medication reviews using simple standardised instruments such as the Mini-Cog or the General Practitioner test of cognition (GPCOG), to assist early detection of dementia in clients they suspect of showing cognitive decline (Elliot 2018), but such a service has not been developed and tested in the UK.

2.5.3 Memory Clinics

Memory clinics, first described in the 1980s, have become accepted worldwide as useful for improving practice in the identification, investigation and treatment of memory disorders including dementia (Jolley, Benbow and Grizzell, 2006). Their aim is to facilitate referral from GPs, other specialists, or self-referral from patients or their families, helping to avoid the stigma associated with psychiatric services.

At the memory clinic, a fuller assessment of the person with suspected dementia is undertaken, including reviewing shared notes from the GP and extensive history taking for reasons described above under initial screening. The multi-disciplinary role of the memory clinic includes being a point of referral, performing specialist assessments and investigations, facilitating early diagnosis, education and counselling of patients and their carers and referral to other appropriate agencies (Passmore and Craig, 2004).

Specialist memory clinics have the benefits of detailed neuropsychological assessments and brain imaging necessary to make a dementia diagnosis and determine the underlying cause, using standardised criteria.

2.5.4 Diagnosing Dementia using standard criteria

Dementia is a clinical diagnosis and various diagnostic strategies have been proposed for identification of individuals with dementia. Clinical assessments, aided by results of neuropsychological tests are the only in-vivo non-invasive screening and diagnostic tool for dementia (Herholz Perani and Morris 2006). In order to effectively treat dementia, an agreement on diagnosis is essential. However, due to the existence of various different classification systems, different diagnostic conclusions can be reached by different clinicians (Erkinjuntti et al. 1997). Currently, criteria from the Diagnostic and Statistical Manual, 5th Edition from the American Psychiatric Association (2013) and the World Health Organisation (WHO) International Classification of Diseases, 10th Edition (ICD-10; World Health Organisation 1992) are used to determine a diagnosis of dementia.

The Diagnostic and Statistical Manual 5th Edition (DSM-V) (APA, 2013) is the widely used diagnostic scheme in Canada and the United States of America, hence commonly seen in many research.

In the DSM-V, dementia is named "major neurocognitive disorder" allowing for recognition of less severe levels of cognitive impairment (mild neurocognitive disorder) so that less disabling syndromes which nonetheless cause concern can be diagnosed and treated. The term neurocognitive disorder (NCD) was introduced in the DSM-V to address limitations of the term dementia, and to tackle the stigma associated with it, whilst at the same time capturing the many different causes and manifestations of significant cognitive impairment that can affect people of all ages (Dementia Australia 2012).

A diagnosis of major NCD (dementia) requires evidence of significant decline in one or more cognitive domains, namely: complex attention, executive function, learning and memory, language, perceptual-motor function and social cognition. This decline must not be attributable to any other mental disorder, and loss of independent function differentiates major from mild NCD.

The DSM-V criteria for dementia diagnosis further renames the main causes (sub-types) of dementia as major or mild neurocognitive disorder due to Alzheimer's disease, major or mild frontotemporal neurocognitive disorder, major or mild neurocognitive disorder with Lewy bodies and major or mild vascular neurocognitive disorder.

ICD-10 diagnostic criteria are used often in the United Kingdom but do not often appear in research literature (Lejbak and Haugrud, 2010).

A diagnosis of dementia using these criteria would require in general: evidence of decline in memory and other cognitive abilities (characterised by deterioration in judgement and thinking), preserved consciousness, decline in emotional control and/or motivation, with symptoms (especially memory decline) lasting a minimum of six months. The diagnosis is further supported by evidence of damage to other higher cortical functions, such as aphasia, agnosia and apraxia. ICD-10 also includes specific criteria for diagnosing dementia sub-type.

Even though there are some similarities between the two diagnostic schemes (DSM-V and ICD-10), using separate criteria to diagnose the same condition could lead to clinicians coming to different diagnostic conclusions depending on which scheme they apply. This was exemplified when Henderson et al (1994) surveyed 1045 persons 70 years old or over and found that 3.2% were given a diagnosis of dementia based on the ICD-10 criteria and 7.3% when the third, revised edition of the DSM (DSM-III-R)(American Psychiatric Association 1987) was used.

Whichever criteria are used, it is essential that each patient's characteristics in relation to age, educational level, culture and language are taken into consideration when conducting assessments for the purposes of diagnosing dementia.

2.5.5 Diagnosis of Sub-types of Dementia

NICE dementia guidelines (2018) recommend that diagnosis of sub-type of dementia be carried out in specialist dementia diagnostic services using international standardised criteria set out as follows:

Type of Dementia	Recommended validated criteria for diagnosing dementia sub-type
Alzheimer's Disease	National Institute on Aging (NIA) and a test of verbal episodic memory.
Vascular Dementia	NINDS-AIREN (National Institute of Neurological Disorders and Stroke and Association Internationale pour la Recherche et l'Enseignement en Neurosciences)
Dementia with Lewy bodies	International Consensus criteria for dementia with Lewy bodies
Frontotemporal dementia	International Frontotemporal Dementia Consortium for behavioural variant frontotemporal dementia

Table 1: Recommended criteria for diagnosing dementia sub-type adapted from NICE clinical guidelines (NG97)

In order to assist diagnosis of particular dementia sub-types and exclude other cerebral pathologies, NICE guidelines also recommend the use of structural imaging such as Magnetic Resonance Imaging (MRI) which is preferred or Computerised Tomography (CT) as an alternative.

The sub-types of dementia in Table 1 above have more over-lapping signs and symptoms than defining ones, further complicating the prospects of successful differential diagnosis, but accurate diagnosis is important as each sub-type has unique prognostic and treatment considerations (Focht 2009).

Further tests recommended in NICE guidelines (2018), where diagnosis is uncertain include:

- Alzheimer's disease: Fluorodeoxyglucose-positron emission tomography-CT (FDG-PET) or single-photon emission CT (SPECT) if FDG-PET is unavailable. An

examination of cerebrospinal fluid for either total tau or amyloid beta proteins is also a recommended alternative

- Dementia with Lewy bodies: assessment of the dopamine transporter in vivo with specific ligands, such as [^{123}I]-2b-carbomethoxy-3b-(4-iodophenyl)-N-(3-fluoropropyl) nortropane (^{123}I-FP-CIT) single-photon emission CT (^{123}I-FP-CIT SPECT)
- Frontotemporal dementia: FDG-PET or perfusion SPECT
- Vascular dementia: MRI or CT if MRI unavailable or contraindicated

None of the dementia sub-types should be ruled out solely based on results of the structural or metabolic imaging tests recommended above.

Pharmaceutical care

From a pharmacy practice point of view, knowing the sub-type of dementia, through a precise diagnostic work-up is essential for accurate management and for prognosis. A case in point is DLB whose features include hallucinations, and misdiagnosis as another sub-type could lead to a prescription of an antipsychotic such as haloperidol, which can expose the sufferer to severe deterioration (McKeith et al 1992).

2.5.6 Diagnosing Dementia in Care Homes

Most people with potential dementia diagnosis live in the community (Ruths, Straand and Nygaard 2003) and are presumed to receive their diagnostic work up in primary care.

Typically, local health authorities plan healthcare needs by assessing people who live in their own homes, so people living in care homes may be neglected (British Geriatric Society 2012, Alzheimer's Society 2016a)

A great number of people receive their dementia diagnosis while in hospital suffering from a physical condition (Alzheimer's society 2014). Within care homes, there is still no clear pathway for assessing potential dementia in residents.

Lithgow, Jackson and Browne (2012) performed cognitive testing of 341 randomly selected nursing home residents in Glasgow, Scotland. They found that even though 58% of the sample already had a dementia diagnosis, 31.8% scored within the range of possible dementia (less than 24/30 in the MMSE) but had no diagnosis of dementia.

Care home residents not yet diagnosed, but suspected of suffering from dementia are at a disadvantage because in most areas of the UK, diagnosis takes place in community locations which can be difficult to get to (Burns, 2014) and their access to GPs is limited or costly (Alzheimer Society 2016a). Ensuring that residents with dementia are diagnosed can improve their care as staff could better plan their care, inappropriate medication stopped and those who could still benefit from cognitive enhancers treated. Visiting GPs and geriatricians can play a leading role in identification and diagnosis of dementia in care home residents, and staff from memory clinics have been encouraged to develop in-reach services with care homes so that people living there can be assessed and diagnosed and have access to treatment (Alzheimer's society, 2014).

There could also be consideration given to linking this to a national enhanced service for dementia (Burns, 2014). As some community pharmacists are already commissioned for the provision of enhanced services to care homes, their role in the domain of identification of residents with cognitive impairment and dementia could be explored.

2.6 Pharmacological management of dementia

Following nearly 36 years of biochemical and clinical/pathological studies, very little has changed in terms of available anti-dementia medication (Mukaetova-Landska, 2018). Two classes of drugs approved for prescribing in the UK, for the purpose of combatting dementia symptoms remain the acetylcholinesterase inhibitors (donepezil, rivastigmine and galantamine) and the N-methyl-D-aspartic acid (NMDA) receptor antagonist (memantine) (Grand, Caspar and Macdonald 2011, O'brien et al 2017, Pink et al 2018).

Acetylcholinesterase inhibitors work by increasing cholinergic transmission and inhibiting the enzyme cholinesterase at the synaptic cleft, which provides some symptomatic relief in some people with dementia, particularly AD where reduced synthesis of acetylcholine causes impaired cortical cholinergic function (Press and Alexander 2019).

Memantine, on the other hand, is thought to be neuroprotective as the NMDA receptor plays a role in memory and learning (Danysz and Parsons 1998). It has been shown to have some benefit in moderate to severe AD, but little or no benefit when used to treat mild AD (McShane et al 2019).

Though there are many agents in on-going trials with putative disease-modifying properties, no new drugs have been licensed for AD or other dementias (O'brien et al 2017).

NICE guidelines (2018) advise that pharmacological treatments are initiated only on advice of clinicians with specialist expertise in the diagnosis and treatment of dementia.

Alzheimer's disease

For Alzheimer's disease (AD), donepezil, rivastigmine and galantamine are recommended for mild to moderate disease, with addition of memantine recommended for moderate to severe AD (NICE NG97 2018, Press and Alexander 2019).

Lewy body dementia

NICE Guidelines (2018) recommend donepezil or rivastigmine for people diagnosed with mild, moderate or severe Lewy body dementia (DLB), and memantine if cholinesterase inhibitors are not tolerated. A combination of cognitive, neuropsychiatric, autonomic and motor features in people with DLB make management extremely challenging for clinicians (O'Brien et al 2017).

Pharmacists with knowledge of the interplay of symptoms, mechanism of action of drugs for DLB and co-morbid medical conditions as well as consequences of prescribing medication that worsen these features are an essential addition to multidisciplinary teams dealing with dementia sufferers.

Not everyone with a dementia diagnosis will benefit from AChEIs but there is research showing that 40-70% of people with dementia treated with these drugs

benefit from them, particularly reducing anxiety levels, and improvements to levels of confidence, memory and thinking observed (Alzheimer's Society 2017).

Vascular dementia

There are currently no pharmacological treatments licenced for treating people suffering from vascular dementia (VaD), but cholinesterase inhibitors or memantine can be considered if it is co-morbid with AD, DLB or Parkinson's disease dementia. Strategies for managing this heterogeneous condition focus largely on controlling cardiovascular and cerebrovascular risk factors.

Frontotemporal dementia

Cholinesterase inhibitors are not recommended for people with frontotemporal dementia (FTD), but there is evidence that serotonin re-uptake inhibitors may be useful in treating behavioural, though not cognitive features (O'Brien et al 2017).

BPSD

Pink et al (2018) in their summary of NICE (2018) dementia guidelines, highlight the recommendations for managing BPSD, emphasising that antipsychotics should only be offered if individuals living with dementia are at risk of harm to themselves and are experiencing agitation, hallucination or delusions which cause them severe distress. These agents are only to be used at the lowest possible dose for the shortest period of time. Antidepressants are not recommended for routine prescribing in those with dementia who have mild to moderate depression.

Stopping cholinesterase inhibitors

A final note about when to stop cholinesterase inhibitors is necessary as there has been conflicting evidence, with some researchers recommending that when dementia is severe, sufferers no longer benefit from these drugs and there is increased risk of adverse outcomes (Gill et al 2009). However, another study (Howard et al 2012) demonstrated continued cognitive benefits from donepezil in people with severe dementia compared to placebo. To this end, NICE guidelines stress that cholinesterase inhibitors must not be stopped simply because of disease severity.

Drugs in development

With regards to drugs in development for dementia, octohydroaminoacridine is a novel cholinesterase inhibitor that showed a dose dependent significant improvement in cognition and behaviour in participants with AD during phase II trials, (Xiao et al 2017). The trial had limitations such as small numbers of participants and short duration (16 weeks).

In a similar vein, two pharmaceutical companies working in collaboration, Biogen and Eisai, developed a monoclonal antibody Aducanumab® which they found dose-dependently reduced amyloid deposition in six cortical regions of the brain, following phase III clinical trials (Alzforum 2019). Due to a prediction that the drug trials would not prove benefit compared to placebo, both companies decided to terminate further work on Aducanumab®. They later announced that a re-analysis had found the drug produced a significant reduction in decline on the primary endpoint at higher doses, so an application was made to the FDA in October 2019

for regulatory approval. It is thought that this move will lead to an opening of the floodgates for Alzheimer's drugs (Selkoe 2019).

Other agents that have been considered include gingko biloba, hormone replacement therapy (HRT), folate, vitamin B12 and therapeutic non-invasive brain stimulation (O'Brien et al 2017). None of these have resulted in any new treatments for dementia.

2.7 Non-Pharmacologic treatment of dementia

There has been much interest (Berg-Weger and Stewart, 2017, de Oliviera et al 2015) in research exploring non-pharmacological interventions for managing dementia, either on their own or in conjunction with drug treatments (Grand, Casper and Macdonald 2011). Whilst the clinical efficacies of these treatments have not been fully evaluated, they are primarily aimed towards improving quality of life for people living with dementia.

Two of the most widely used non-pharmacological approaches are cognitive training and cognitive rehabilitation techniques, usually applied during early stages of dementia and involve training of cognitive domains with emphasis on memory, attention and executive function (cognitive training) or geared towards enhancing functioning in everyday life (cognitive rehabilitation) (Clare et al 2003).

Other non-pharmacological treatments include psychosocial therapies such as reminiscence therapy and validation therapy intended to bring about enhancements of self-esteem and wellbeing. Additionally, formal exercise programs have been suggested as a non-pharmacological approach since they may improve physical functioning, but they do not seem to improve cognitive

functioning in adults with dementia (Forbes et al 2015) so their benefits and those of other non-pharmacological interventions need further investigation.

However, NICE guidelines for assessment and management of dementia (2018) does recommend that a range of activities to promote wellbeing, group cognitive stimulation and reminiscence therapy and cognitive rehabilitation be considered as interventions to promote cognition, independence and wellbeing in people with dementia.

2.8 Prevention of Dementia

Primary prevention of dementia involves adopting a lifestyle that reduces the risks of developing it, such as exemplified in a recent study that showed that a healthy diet (with daily portions of fruit and vegetables) is associated with a significant reduction in risk of dementia from middle age onwards (Lee et al 2017).

Secondary and tertiary prevention techniques are geared towards preventing clinical progression in symptoms of dementia but pharmaceutical interventions being investigated for this purpose have been largely unsuccessful (O'Brien et al 2017, Tipton and Graff-Radford 2018).

There is as yet, no evidence in research that supports any single intervention that can be used to delay or prevent dementia, but there is some that supports the fact that modifying the risks and/or treatment with antihypertensive drugs, particularly in midlife (45-65 years) can potentially delay/prevent the rise of dementia cases worldwide (Gottesman et al 2014, Mogi 2019, Livingston et al 2017). Additionally, when the profound individual and societal costs of dementia are considered, it is a sensible proposition that strategies to prevent or delay its

onset be made a public health priority in countries worldwide (Livingston et al 2017).

Pharmacists, as healthcare professionals at the hearts of communities they operate in, can play a pivotal role in promoting healthy lifestyles such as smoking cessation, exercise and primary prevention strategies, during medication review sessions.

2.9 Summary and gaps in knowledge

In summary deducing from the background and literature review I have expounded so far; dementia is highly prevalent and the trend of growth in numbers of those affected will continue to increase exponentially over the next few decades. As the population of older adults with chronic/long term conditions such as dementia increases, the number of those living in care homes will also snowball.

There is a need to provide high quality healthcare that meets their complex needs and that includes pharmaceutical care. However, research shows that inappropriate prescribing is common in this population (Pfister et al 2017) and pharmaceutical care delivery to those with dementia is poor (Mehta et al 2017).

We know that secondary care specialist pharmacists can deliver interventions to improve quality of prescribing in people with dementia (Dementia Alliance 2008, Maidment et al 2018). We also know that community pharmacists are the most accessible patient facing healthcare professionals who could play a big role in medicines optimisation for people with dementia living in the community (Maidment et al 2017).

There is research exploring the perspectives of family members of people with dementia in care homes (Cronfalk et al 2017), as well as research exploring attitudes of care home staff towards people with dementia (Lee et al 2013). Inappropriate prescribing in people with dementia has also been explored (Holmes et al 2008, Parsons et al 2012). However, despite existing research on the roles of various healthcare professionals in care of people with dementia resident in care homes, few qualitative and quantitative studies have addressed the exact role community pharmacists play in the care of people with dementia living in care homes. To this effect we sought to:

- Explore the nature of services provided by pharmacists to people with dementia in care homes
- Investigate Community Pharmacists' knowledge of dementia and their ability to provide pharmaceutical care services to people with dementia
- Examine any factors influencing pharmaceutical care provision to people with dementia in care homes
- Explore the views of care home staff about the medication-related needs of residents with dementia and determine their views about the services they receive from community pharmacists contracted to deliver pharmaceutical services to their establishments.
- Determine whether a tool designed to aid systematic review of prescriptions for people with dementia will be useful for pharmacists and assist them to improve quality of prescribing in people with dementia.

2.10 Methodological approach

I approached this research with the intention of selecting the most suitable methods to answer the research question posed at the beginning (Sackett and Wennberg 1997). Consequently, I decided to use *pragmatism*, a research philosophy which maintains that the point of research is to provide answers to the research question (Morgan 2014).

Traditional research paradigms include *positivism* and *interpretivism* which are opposing notions: Positivism is associated with singular reality requiring the collection of measurable objective facts and aims to discover laws using quantitative methods (Bowling 2014, Morgan 2014). *Interpretivism* (also known as constructivism) on the other hand, is about studying people in their 'natural' settings and involves finding 'meanings' or constructed knowledge through qualitative research (Winit-Watjana 2016).

Pragmatism provides a middle ground through which multiple philosophies can be used, if needed, to answer the research question, and values both quantitative and qualitative methods as approaches to conducting relevant, high quality research (Creswell and Clark 2017).

This approach appealed to me as a pharmacist because of its focus on practicality, allowing me to select the most appropriate methods for my research, which was mixed methods. Using mixed methods research is a synthesis that can include findings from both qualitative and quantitative research, and this approach is increasingly used in pharmacy practice as it encourages methodological flexibility and encourages multi-disciplinary team working (Babar 2015). Additionally, for my research, combining qualitative and quantitative methods enabled both to be

used complementarily to address different aspects of the research question (O'Cathian et al 2007).

2.10.1 Study design

A sequential mixed methods design which involved collection of data on an iterative basis (data collected in one phase contributes to data collection in another phase) (Driscoll et al 2007) was employed for chapters 3, 4, 5, and 7. The research journey is depicted in Figure 1, and a brief outline of the rest of the thesis is presented.

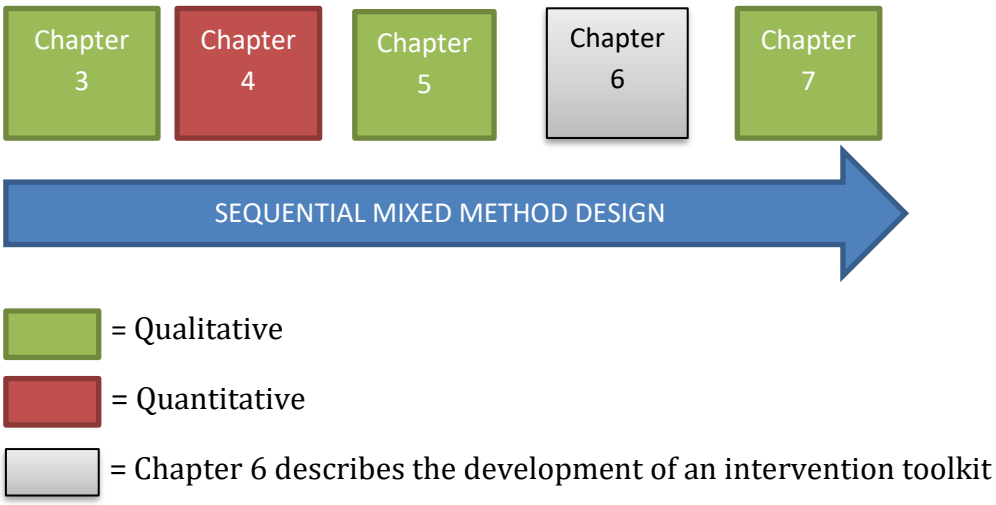

Figure 1: Research outline

2.10.2 Outline of the rest of the thesis

Chapter 3: Describes qualitative, face-to-face, semi-structured interviews exploring the knowledge, views and perceptions of pharmacists who provide services to people living with dementia in care homes

Chapter 4: A quantitative, questionnaire survey of a random sample of pharmacists in England, on the pharmaceutical care needs of people living with dementia and the services they provide to care homes

Chapter 5: Qualitative, face-to-face, semi-structured interviews exploring the views and perceptions of care home staff about the medication-related services provided to people living with dementia in care homes.

Chapter 6: Based on findings from my research and up-to-date published evidence concerning appropriate pharmaceutical care in dementia, a practical, educational tool to be used in the clinical screening and systematic review of prescriptions for people living with dementia will be developed

Chapter 7: Feasibility study of the DEMENTIAS intervention tool among a focus group of pharmacists, conducting a review of prescriptions for patients living with dementia

Chapter 8: General discussion.

CHAPTER 3
LIVING WITH DEMENTIA IN CARE HOMES: A QUALITATIVE EXPLORATION OF COMMUNITY PHARMACISTS VIEWS OF PHARMACEUTICAL CARE PROVISION TO RESIDENTS

3.0

3.1 Introduction and chapter overview

There is a paucity of research exploring the perceptions of community pharmacists about their pharmaceutical care provision to people with dementia living in care homes.

Though the majority of people who have dementia live in their own homes, many have to relocate to long term care facilities such as care homes due to their limited ability to self-care, or to their symptoms worsening to a point where they can no longer be cared for in the community (Corbet et al, 2013).

This chapter encompassed the first stage of my research and involved a qualitative pilot study aimed at generating data to inform the development of a questionnaire for a wider population of pharmacists, that would broadly explore their knowledge and understanding of the pharmaceutical care needs of patients living with dementia in care homes in England. It also supported the identification of factors that may affect service provision.

Additionally, I conceptualised that conducting interviews with a sample of pharmacists who provided services to care homes would yield some information about their awareness of the pharmaceutical care needs of care home residents in general and people with dementia in particular, and would identify training needs for pharmacists in this field of practice.

3.2 Methods

3.2.1 Aims and objectives

3.2.1.1 Aims

- To explore the views of pharmacists about the pharmaceutical care needs of dementia patients living in care homes
- To establish the nature of pharmaceutical services provided to these residents

3.2.1.2 Objectives

- To investigate pharmacists' awareness of the pharmaceutical care needs of dementia patients
- To examine the nature of services provided by pharmacists to dementia patients in care homes
- To seek pharmacists' opinion about their knowledge and ability to provide pharmaceutical services to dementia patients
- To determine the factors that influence the provision of pharmaceutical services to dementia patients
- To use the responses from these pharmacists to inform the development of a survey instrument on pharmaceutical care in dementia.

3.2.2 Study Design

A qualitative study design utilising a face-to-face semi-structured interview format was employed to explore the views and perceptions of pharmacists who provide services to care homes that have people living with dementia. A qualitative

approach following the Consolidated Criteria for Reporting Qualitative studies (COREQ) guidelines (Tong et al 2007), was chosen to support in−depth exploration of issues from the perspective of research participants. Ethical approval was obtained from the Cross-Schools Research Ethics Committee (C-REC) at the University of Sussex (Appendix 3a).

3.2.2.1 Participant recruitment

Community pharmacists were invited to participate in two ways. A purposive sample, based on the selection of individuals with a particular characteristic for a study, is normally used in gaining understanding of complex issues and to generate a hypothesis. First, a purposive sample of all 17 care homes in the Thurrock (Essex) area that have dementia patients or a mixture of dementia and non-dementia patients was identified by searching the website, www.carehome.co.uk (Care Homes Residential Homes UK Guide, 2015). Thurrock (Essex) and Kent areas were chosen for because of close geographical proximity to the researcher.

The researcher contacted the homes identified to ascertain the main provider of their pharmaceutical services. Pharmacists working in pharmacies identified by the care homes were contacted by the researcher and invited to participate in the study. Their contact details were obtained from the NHS Choices website (2014). A written letter of invitation including detailed information about the study was sent to the pharmacists identified (Appendix 3b). This was followed up by a phone call after five working days to ascertain the willingness of the pharmacist to participate. As there were 17 care homes to be contacted, there was a possibility that more than 10 pharmacists would be identified. The plan was that care homes would be ranked in order of the number of dementia beds per care home as

published on the website, carehome.co.uk. Pharmacists delivering care to the 10 care homes with the highest proportion of dementia beds would be initially selected and approached to participate in the pilot study. Where there was a failure to recruit 10 pharmacists providing pharmacy services to these care homes, recruitment would continue from the care homes lower down the list until 10 pharmacists are recruited.

10 pharmacists consented to participate. This was not a statistical sample based on a power calculation as these are thought to be inappropriate for qualitative research (Smith 2005), unlike quantitative studies, where power calculations are employed to determine a statistically appropriate sample size for a study.

In a similar manner, 5 pharmacists were recruited from the Kent area, a different locality, to validate original findings from Thurrock and follow an iterative process. To ensure anonymity, pharmacists interviewed in Thurrock were designated P1 to P10 and those interviewed in Kent were designated K1 to K5.

All pharmacists who agreed to participate were sent a participant information leaflet (PLP) (Appendix 3c). Figure 2 shows a flow chart of the study process.

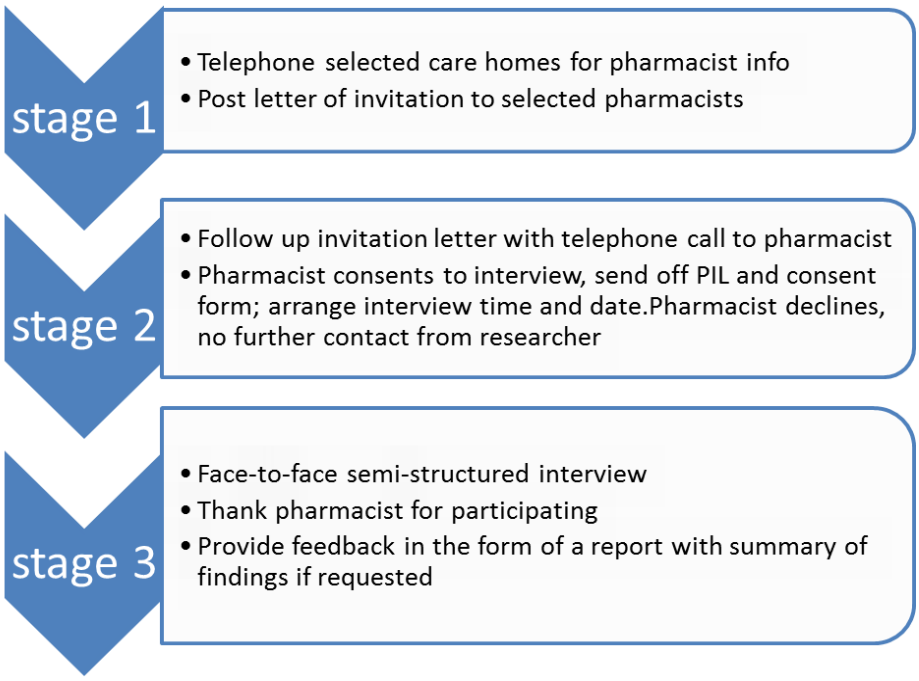

Figure 2: Study Flow Chart

3.2.2.2 Inclusion criteria

Pharmacists providing services to care homes with dementia patients or have a mixed clientele that include patients with dementia

3.2.2.3 Exclusion criteria

Locum or relief pharmacists who do not regularly provide services to care homes that have residents with dementia

3.2.2.4 Informed consent

Informed consent from pharmacist participants was confirmed by the receipt of a completed consent form by the researcher (Appendix 3d)

3.2.2.5 Dissemination strategy

Participants who indicated that they would like to be informed of the results were provided with a summary report of the findings of the study.

3.2.2.6 Timescale

It was anticipated that the pilot study would span a period of 11 weeks (see study timetable in Appendix 3e) but the study took considerably longer due to a variety of unforeseen circumstances. Data was collected between June 2014 and May 2015.

3.2.2.7 Data Collection

Semi-structured face-to-face interviews were carried out with consenting participants employing an interview schedule with fixed questions covering:

- Number of care homes serviced
- Proportion of dementia patients in these homes
- Nature of services provided to them and
- Perceived sufficiency of these services (See Appendix 3f for interview schedule).

Furthermore, respondents were able to raise issues not covered by the interview schedule.

The academic supervisor, a registered pharmacist, verified the schedule. Interviews were carried out and recorded by the researcher at a time of convenience for the participants, at their place of work. As these were face to face, the researcher used the opportunity to clarify any inconsistencies and probe for fuller responses. However, this approach had the disadvantage that it could be expensive and time consuming, and sometimes, interviewer bias could be introduced (Bowling 2009). In this study, the length of each interview varied between 10-30 minutes.

3.2.2.8 Data handling

Interviews were digitally recorded, and the device stored safely in a locked filing cabinet at the research supervisor's office at the University of Sussex. All data was securely erased from the digital device once transcribed. Verbatim transcripts were anonymised.

3.2.2.9 Data analysis

Following each interview, audio- tapes were reviewed for familiarisation with the data obtained. Interview tapes were transcribed verbatim and content analysis carried out using a thematic framework approach for sorting, categorisation and interpretation of recorded interviews (Bowling, 2009).

The thematic framework included:

- Analysis for emerging themes
- Coding of emerging themes
- Rearranging the data according to identified themes
- Mapping and interpretation

Transcripts were independently reviewed by the research supervisor, who met with the researcher for mapping, interpretation and comparison of findings to ensure consistency. Figure 3 shows the data analysis process.

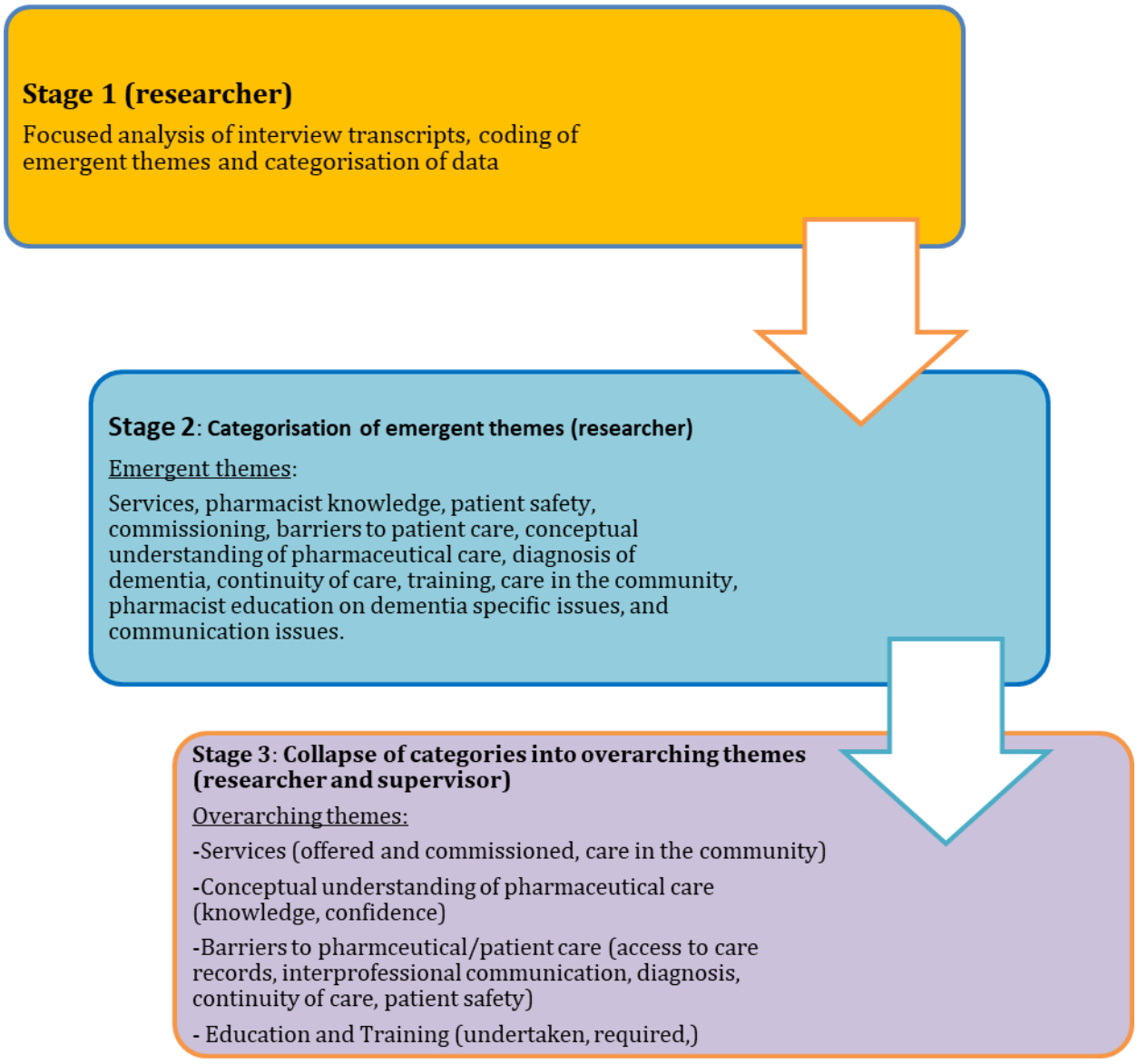

Figure 3: Data analysis process

3.3 Results

In Thurrock, 10 pharmacists participated in the study, six male and four female pharmacists who have been qualified in the UK between 3 years and 40 years. 9 pharmacists supplied services to care homes with dementia patients and the 10th, a practice support pharmacist reviewing medication in care homes (Table 2).

Pharmacist code	Gender	Year of qualification	Nature of Pharmacy	Practice setting
P1	F	2010	High Street	Community
P2	F	1974	Shopping Mall	Community
P3	F	2009	High Street	Community
P4	M	2002	High Street	Community
P5	M	2012	Town Centre	Community
P6	M	2007	High Street	Community
P7	M	2005	High Street	Community
P8	M	2005	High Street	Community
P9	M	2005	Town Centre	Community
P10	F	1981	CCG	Primary Care

Table 2: Demographics of pharmacists interviewed in Thurrock (Essex)

In the Kent arm of the study, six pharmacists initially consented to participate but one subsequently dropped out. One male and four female pharmacists who have been qualified in the UK between 3 years and 20 years participated in the study. All were community pharmacists working in a high street, health centre or shopping mall setting (Table 2).

Pharmacist code	Gender	Year of qualification	Nature of Pharmacy	Practice setting
K1	F	2010	Shopping Mall	Community
K3	M	2001	High Street	Community
K4	F	2012	Health Centre	Community
K5	F	1995	Shopping Mall	Community
K6	F	1996	Shopping Mall	Community

Table 3: Demographics of pharmacists interviewed in Kent

A focused analysis of the interview transcripts was performed by exploring the responses provided with consistencies and variances being highlighted.

Data saturation (no new information forthcoming) was achieved by the 10th interview in Thurrock and the sixth in Kent. This fact was verified by the researcher and confirmed by the research supervisor. *Appendix 3g* shows COREQ guidelines (Tong et al 2007) followed for this study.

The emergent themes were reviewed for patterns and connections within and between the categories, deriving four main overarching themes, which were independently verified by the research supervisor. These were:

- Services.
- Conceptual understanding of pharmaceutical care (knowledge and confidence);
- Barriers to pharmaceutical care provision and
- Pharmacist education and training.

3.3.1 Services

3.3.1.1 Medication supply

The main pharmaceutical service provided by pharmacists in both locations involved the dispensing of medication in monitored dosage systems (dosette boxes) with subsequent delivery to the care home.

"…we only blister their medication, that's the only service that we provide, then once a year, we'll go and do a 'care home visit' (P3).

"…we provide nomads (dosette boxes)…..we prepare the medication and then deliver to them" (K3)

Expanding further on the clinical nature of the supply service provided, other pharmacists stated:

"…we monitor their medication. Where there are changes, we check with the doctors…..we basically deal with their prescriptions, medications and deliveries (P5)

"…checking medication to be delivered monthly, as well as intra-medication they may request between their monthly instalments" (K5)

The consensus amongst participants in Thurrock was that they could do little with care homes beyond supplying their medication and offering medicines-related advice when required to. This was what they were contracted to do and they did not have the funding or resources to offer more.

One pharmacist explained this by stating:

"I think it is quite difficult for the pharmacist to input beyond making sure the medication is in the dosette…..it is quite difficult for the community pharmacist to do anything other than maybe enable the person to have things they can easily open" (P10)

In contrast, pharmacists interviewed in Kent, supplied more than prescription medicines to their care homes under contract. Their service model extended to include minor ailments management and the provision of pharmaceutical advice, which involved reviewing storage and management of medication supplied:

"Apart from the usual repeat dispensing and obviously getting their monthly medications for them, we also offer pharmacist advice visits, where we go there and just look into standards, regulations and standards on how to manage medication in care homes" (K1)

"I go like once a month to ensure that they're taking their medication on time, and then if they have any issues or any problems, then they can discuss with me" (K3)

"*…sometimes when they have minor ailments, we are able to provide them with things like paracetamol and medicines for constipation, just the little things that will take their doctors' time…"* (K4)

This showed recognition of their role as medicines experts, in the provision of medication-related advice as part of an integrated team of healthcare professionals, freeing up GPs to focus on medical issues. Though resources and service specifications may play a role on service delivery, pharmacists' attitudes also matter in determining positive outcomes for pharmaceutical services provided to care homes.

3.3.1.2 Medication reviews

A medication review is defined as a critical examination of a patient's medication with a view to reducing medication-related problems, optimising impact of medicines and reducing waste (Primary Care Pharmacy Association, 2013).

Amongst the Thurrock study participants, only one pharmacist conducted medication reviews in care homes. Other participants did not provide this service because their local clinical commissioning group (CCG) did not commission it.

"We don't get paid for it, so we don't do it" (P2)

P2 however elaborated that in some areas, trained pharmacists are commissioned to visit care homes and review medication, especially antipsychotics prescribed to people living with dementia:

"*They do have a team of people who are employed by the CCG to go out and do a lot of medicines optimisation. So where I could do anti-psychotics audits, they're normally done for me….."* (P2)

The other study participants from Thurrock did not provide medication review or medicines optimisation services to their care homes and did not know whether the homes received these services from specially commissioned pharmacists. They considered it to be the responsibility of the local clinical commissioning group to commission the service.

"We haven't offered any because of the simple reason that I don't think the PCT will allow it" (P7)

Participants in Kent however used the opportunity of supplying medication to care homes, to conduct medicine use reviews, without indicating whether this service was specifically commissioned:

"…I do like, medicine use reviews there, to see whether there are any compliance issues or any problems; then we go from there. It's for the GP then." (K3)

Another community pharmacist participant in this location expanded that he went the extra mile to follow work-based protocols and check residents' medication:

"If they were on antipsychotic medication, there's this separate set of protocols to look through to make sure that it's being used properly. For dementia medication, it would be like any other: checking dose, side effects, history, interactions with what else they are taking, that they're being administered correctly, just as you would in any normal medicine use review" (K5)

This demonstrates that some pharmacists consider medication reviews to be integral to the provision of pharmaceutical care, though community pharmacists are not currently remunerated for this service by clinical commissioning groups (CCGs).

3.3.1.3 Care home Staff Training

One of the intended outcomes of the NHS community pharmacy contractual framework, for pharmacies offering the care home enhanced service, is the provision of training to help improve the skills of care home staff including ordering, storage, administration, disposal and record keeping of medicines (PSNC 2005).

Only half of the participants interviewed in the Thurrock area confirmed fulfilling this part of the contract (P1, P2, P3, P4, and P7)

*"…Basically we train on administrations, importance of MAR sheets, how to read medication labels and what a prescription looks like and what the controlled drug is…"(*P7)

The other participants did not provide any form of training to their care home staff, with one stating that they themselves were not trained to do this:

"We're not trained in that…..we don't do any kind of training with care homes" (P6)

In the Kent study, two pharmacists indicated that this part of the contract was fulfilled; one pharmacist stated that care home staff were trained by a pharmacy technician when a contract to provide services was signed with a care home:

"So anytime we sign up, we draw a contract with the care home and before we start issuing medication to them, she goes there to train all the staff, just for them to understand our policy" (K1)

"There is a lead in the care home unit who, if a request is put in for some training or some advice, they would go and do that, and also there is an internet site for care home staff to access on different aspects of care home procedure and illnesses and I believe dementia is one of them" (K5)

The other pharmacists did not provide training support to care homes for various reasons.

"I can't because I don't have the time" (K3)

Pharmacist K4 didn't have it in her remit, while K6 was not personally involved in training and was unsure of what her establishment offered their care homes in terms of training.

3.3.1.4 Adequacy of services provided to care homes

All participants were asked to comment on whether the pharmaceutical services they provided to care homes were sufficient to meet the needs of the residents.

A majority of the community pharmacists interviewed in Thurrock acknowledged that the services they provided did not fully meet the pharmaceutical care needs of patients in the care homes, including dementia patients; however they were willing to do more, recognising their role in highlighting and resolving drug-therapy problems.

"Personally, I would love to see more involvement of pharmacists in dementia care. That's really the future, I think, just like American pharmacists are doing" (P6).

"I think we can help train up carers to some extent in terms of communication, what medication they need to take. The education aspect can be better" (P9)

It is clear that an extension in the role of the community pharmacist was supported by some participants, despite the constraints of the contractual framework pointed out by P1 above.

In contrast, 3 participants stated that the services they supplied were sufficient and in line with their contractual obligation.

"We are not specifically trained to provide services for dementia patients, but we do provide services within the framework that we have, which is the supply them, and what happens beyond supply is beyond our control" (P1)

"When you're working in the pharmacy, you're working on your own. So it's very hard to leave" (P4)

In Kent, 3 pharmacists expressed the belief that the services they provided were adequate, while two expressed their opinion that the services they provided did not fully meet the pharmaceutical care needs of patients in care homes, including people with dementia.

Interestingly, those who said they were providing an adequate service focused solely on medication supply and responding to medication queries:

"…they are satisfied with the service because we do deliver to them on time….." (K3)

"Yeah, well, we deliver to them when they need it, so, yeah, definitely. It's sufficient for their needs" (K4)

"I think so, yes…..we're also chasing them on medication they haven't ordered, that the homes may have forgotten or have overlooked…" (K6)

However, an extension in the role of the community pharmacist was supported by K1, who expressed a view that more could be done:

"I think there is a lot we can do…..medicine reconciliation and also a lot of audits…..I don't think we are doing enough. More involvement, pharmacists being involved more in their care can really help" (K1)

3.3.2 Conceptual understanding of pharmaceutical care in dementia: Knowledge and confidence

3.3.2.1 Pharmaceutical care

Participants were asked what they believed were the pharmaceutical care needs of people with dementia.

Of the 10 pharmacists interviewed in Thurrock, 9 indicated that the pharmaceutical care needs of dementia patients generally involved ensuring these patients were taking the correct medication in a formulation suitable for their individual needs, and monitoring the patients to ascertain compliance (achieved through reviewing medication administration records (MAR)).

Two were unsure what the pharmaceutical needs of people with dementia were, stating:

"It is difficult for me to know because I don't see them; usually I don't see them so it's difficult for me to really know what their needs are". (P8)

"I don't think we have time for our patients to sit down and talk about their needs" (P3)

Of the 5 pharmacists interviewed in Kent, 2 (K1, K4) indicated that they thought the pharmaceutical care needs of dementia patients generally involved ensuring these patients were taking the correct medication, in a timely manner.

The others expressed concern about the amount of medication being given to people with dementia without rigorous needs assessment (K5, K6) and highlighted the importance of identifying drug therapy problems such as drug interactions and side effects (K1,K3) as well as ensuring symptoms are diagnosed correctly before initiating drug treatment in dementia patients (K5).

"…you ask about any interactions, and like, say, any problems, any side effects…" (K3)

One pharmacist was concerned about the inappropriateness of medication prescribed for dementia patients, stating:

"We give out these medications that the doctor prescribes but it worries you the amount of, you know, certain medications that go out and ones that are there to relax them and make them go off to sleep and you think, actually, is that appropriate?"(K6)

In comparison, participants in the Thurrock arm of the study were more aware of key aspects of pharmaceutical care such as, ensuring that a patient gets the right medication at the right time in a suitable dosage form, and are compliant with it. A fundamental principle of pharmaceutical care, to ensure that the patients' medications are **safe** as well as effective (Hepler and Strand, 1990, Alleman et al 2014) was not mentioned by either group of pharmacists.

The debilitating nature of dementia both in patients within the community and in care homes, usually means care is delivered through an intermediary in the form of a carer (family member, social worker, care home staff). Perhaps these are further confounding factors that community pharmacists have to navigate in order to provide a multi-faceted pharmaceutical care service.

Strand et al (2004), describing pharmaceutical care practice and its positive outcomes over 25 years of practice, provided services only to patients in ambulatory clinics who were considered to be easier to access and to communicate with.

Use of Compliance Aids

The issue of dementia patients forgetting to take their medication and requiring prompts was pointed out by all 10 pharmacists interviewed in the Thurrock arm of the study, as a pharmaceutical care need.

Four pharmacists shared opinions about the type of monitored dosage systems (dosette boxes) patients were supplied with, to remind them to take their medication on time:

Pharmacist P10 insisted that the four-weekly disposable dosette boxes were *"probably the worst innovation of all time"* in reference to community dwelling dementia patients, since there was no way of knowing if the medicines were actually taken or not.

Though this was mentioned in reference to the practice of community pharmacists supplying multiple compartment compliance aids to dementia patients in the community, the view that patient safety may be compromised by the use of these aids is not unique to this participant as poor use of monitored dosage systems was highlighted as one of the causes of medication errors in care homes (Barber et al, 2009).

Two pharmacists elaborated on a system that incorporated an alarm to alert patients/carers of medication times. Another was investing in the Biodose © system, a monitored dosage system that accommodates both liquid and solid dosage forms in a patented unit (Biodose® 2015).

While each monitored dosage system has its advantages and disadvantages, their provision to care homes is a substantial unfunded service provided by community pharmacists to help care homes improve their management of residents' medicines (Barber et al, 2009).

3.3.2.2 Pharmacist knowledge of the pharmaceutical care needs of people with dementia

More specific questions were put to the participants about medicines dispensed specifically for the treatment of dementia. These included probing questions

concerning their knowledge of adverse effects of medicines and their clinically significant interactions, which are key components of pharmaceutical care provision.

While the main adverse effects of dementia medicines were not clearly identified by the pharmacists when asked during the interviews, they were confident of where to find such information. From the pharmacists in Thurrock:

"I always make sure I go through the leaflet" (P3)

"To be honest, I wouldn't know without looking at the BNF" (P5)

Similar responses were obtained from the pharmacists in Kent:

"I always check the BNF and look at other medications" (K5)

"…I always check that in the BNF" (K4)

With regards to knowledge of any clinically significant interactions relating to dementia medicines, none of the Thurrock participants could think of any. Most, like other healthcare professionals, rely on their computer programs to flag up any interactions of concern.

"Looking at Donepezil as a classic example, no major interactions have come to my attention" (P1)

"Only what the machines are able to throw up at us" (P2)

Whilst it is correct that pharmacy computer systems are programmed to flag up clinically significant drug-drug interactions, it is important for pharmacists to note that knowledge of the disease condition and how it affects patients is critical in managing dementia patients.

Antipsychotics, for example, may not be flagged up on dispensing software as interacting with some dementia medication such as rivastigmine, but these drugs have been shown to increase the cholinergic burden in dementia patients, which is

associated with increased mortality in this patient group (Prentice and Wright, 2014).

Kent pharmacists did not display much knowledge on dementia medication-related interactions either:

"I'm not sure, to be honest. That for me, there would be a lack of knowledge" (K6)

"I'm just going blank, I don't know why" (K1)

This is in contrast with some of the participants in the Thurrock arm of the study who indicated that they would rely on computer programmes to flag up clinically significant interactions. It is important to note that an underlying knowledge base of the disease condition and how it affects patients is critical in ensuring appropriate, safe and effective drug therapy in these patients.

Another Kent participant when asked what clinically significant interactions she would consider when dispensing medication for dementia responded:

"Clinically significant interactions, with those ones that are like the anticholinesterase ones, I would say a significant one would be because they can cause dry mouth and things like that, so that's the only one I can think of at the moment" (K4)

This particular pharmacist thus mixed up adverse drug reaction and drug interaction, and confused acetylcholinesterase inhibitors (anti-dementia medication) with anticholinergic drugs. Anticholinergic drugs are drugs from various classes indicated in treatment of many ailments such as depression, allergies, Parkinson's disease and epilepsy, amongst others (Richardson et al 2018).

However, one participant who displaying a deeper perspective, and correctly highlighted the anticholinergic side effects of antihistamines, opined that several dementia patients were burdened with many medications they did not need, or

medication for physical conditions which in turn caused deterioration in their cognitive function:

"*Most people have dry skin and it itches and because of that we give them an antihistamine and it affects their cognition…..and sometimes things like bladder control medicines affect cognition. I look at polypharmacy because a lot of times a person would be on medication which could be of limited value"* (P10)

This could be attributed to the fact that this participant had prior experience of working with primary care trusts to conduct medication reviews in care homes.

Knowledge of the Behavioural and Psychological Symptoms of Dementia

Knowledge of behavioural and psychological symptoms of dementia (BPSD) in dementia is essential to support pharmacists' ability to challenge inappropriate prescribing of antipsychotics to people with dementia.

In the Thurrock arm, a majority of pharmacists understood BPSD, stating some of the symptoms, with agitation being the most mentioned. However, some training needs were evident.

For the Kent arm one participant, demonstrating a clear understanding of BPSD, outlined succinctly, his opinion on how pharmacists could play a role in helping care homes manage patients with BPSD by suggesting that alternatives to medication should be tried:

"….most people, when I speak to them, they say because they've got a very idle lifestyle and they feel really lonely…..that's when the symptoms are more prominent. When they interact….then the symptoms are less"

"….there are quite a few support therapies in dementia and so normally, I advise to try that first"… (K3)

In support of this view, Corbett et al (2014) discourages the routine use of antipsychotics to treat aggression in dementia patients who have BPSD and recommends non-pharmacological strategies as first line treatment.

3.3.3 Barriers to Pharmaceutical Care

Participants estimated that the proportion of dementia patients in their care homes ranged from 10% to 85%. Lack of time, poor inter-professional communication and funding for services were cited by most as clear barriers to pharmaceutical care and patient safety. While all participants had engaged with continued professional development (CPD), the majority had not undertaken any training in the field of dementia in the past one year. Judging from this, it could be deduced that lack of training was another barrier.

3.3.3.1 Time constraints

Participants in Thurrock, Essex shared the opinion that current community pharmacy practice made it difficult to provide optimised care to patients in care homes.

"There is need for a change of working approach. If you are a dispensing machine, you don't have time" (P10)

Like the participants interviewed in Essex, Kent participants shared the opinion that current community pharmacy practice made it difficult to provide better care to patients in care homes.

"I need to go during my lunchtime and then I speak to them so time is very limited because I am the only pharmacist here and I should be here working, I don't get any cover, so it's only during my lunchtime I tend to fit in the visit…" (K3)

"Time. Time, because sometimes they give you time to go there and come back and most of the time I realise that whenever you get there, other activities take away your time and by the time you realise it, it's time for you to get back to the pharmacy so you just do everything very quickly instead of really taking your time….." (K1)

This sentiment was echoed by Barber and Wilson (2013) who recommended a "step shift away from a service regarded as 'dispensing of prescriptions' to one

where its main focus is providing NHS pharmaceutical care and an increased emphasis on providing direct care to patients"

This lack of time to deliver a focused service to people with dementia and other long-term conditions could potentially be linked to the increased workload for community pharmacists that arose as a result of the new pharmacy contractual framework implemented since 2005.

3.3.3.2 Access to care records

None of the Essex participants in the study had access to patient care records in the care homes for which they provided services, though some shared the view that the level of service they currently provided did not require access to patient records.

Of concern was the fact that pharmacists only saw records of the medicines they dispensed regularly to patients. Care homes are not obliged to use their regular pharmacy for new one-off prescriptions for their residents, outside of the monthly repeat dispensing cycle; it is therefore possible that a pharmacist would not have the full picture of what the patients in their care homes are prescribed.

This was described succinctly by a participant in the Thurrock arm of the study:

"I think what it is, is the pharmacy gets allocated a care home or recruit a care home and all you know is their allergies, what their medication is and that's it. But what we find a lot, what was happening in some of our care homes is that we do their regular medication and if they do have an acute prescription, they'll take it somewhere else. The biggest barrier is, we have no access to health records to what they've had in between. It could clinically be a danger as well in terms of, if there's an interaction with their normal medication, the new pharmacy hasn't got a clue what they're on."(P3)

Two pharmacists in the Kent arm of the study indicated they could, on request, access patient care records in the care homes they provided services to; one was unsure and the other two didn't have access. Their views about the disadvantage of

not having access to patient records were expressed as well as the benefit access would afford:

"....it's only with the medication that we dispense in the pharmacy. I can only have those records so I can only go by that.....it is very difficult because they can't always tell what extra medication they're taking and things like that." (K3)

"I think it will really help because then we know all the medications they are on.....but you know, the clinical side of things and if they've had blood tests, and the history of their past medications and everything so that we can see if there will be any interactions or adverse reactions" (K1)

This showed an awareness by some participants, of the need to have a complete picture of a patient's medical conditions as well as their medication history in order to provide comprehensive pharmaceutical care.

3.3.3.3 Absence of a diagnosis

Another point raised during the study was that pharmacists were not privy to the diagnosis of dementia in many of the patients they catered for, and only became aware if the patient had an anti-dementia medicine on their prescription.

This means that for a care home resident diagnosed with dementia, this information is not routinely shared with the pharmacist dispensing their medication. If this patient is not on an anti-dementia medication, which would give a pharmacist an indication of their dementia diagnosis, they could potentially be given medicines that could worsen their cognition, as the pharmacist would have no reason to raise concern. One Essex Pharmacist opined that:

"*It is very very difficult to get doctors to put a diagnosis of dementia on some people"* (P2)

Lack of a diagnosis in care home residents taking anti-dementia medication was not specifically raised as a concern by the Kent pharmacists interviewed, unlike their Essex counterparts.

However, one participant did admit that their service included audits for patients prescribed dementia medication, to ascertain the presence of a diagnosis, but more time would be required to deliver an effective service:

"We do have audits that we are meant to do for the patients that are taking…that are being prescribed medication for dementia. We are trying to improve on that. I mean, have some time to go there, and do those kind of, I mean audits to see if they have been diagnosed" (K1)

The issue here is that a lack of communication concerning the diagnosis of a care home resident with dementia, limits the pharmacist's role in optimising the patient's therapy.

3.3.3.4 Lack of communication with other healthcare professionals

Lack of communication with hospitals and other health care professionals, specifically GPs regarding medication changes and other medicine-related issues for individual patients was considered by most participants in the study, to be a big obstacle for care. This issue was highlighted by participants in both arms of the study.

In Essex:

"*Another thing is the communication even between hospital and community or GP and the community. While you are dealing with a dosette box, patient has gone into hospital and you don't even know about it, the patient comes out and the medication has changed, and then you have to find ways to get to know what has changed. It is a huge problem"* (P8)

"*Looking at it, the barriers basically maybe related to not having a forward and backward kind of interaction with the prescribers"* (P1)

This account was corroborated by the findings of Barber et al (2009) in the 'Care Homes Use of Medicines Study". The study highlighted the need for improved communication between doctors and pharmacists, doctors and care homes, care homes and pharmacists as well as hospitals and community pharmacists.

In Kent: A lack of communication was considered to be an obstacle to care by two participants in the study:

"*If I see duplications on my sheet and second medications that I might think are not really necessary for the patient taking this, and they do tell me that it is a doctor that said to prescribe it, I want to know the reason behind it, so sometimes I do get their care plans and go through the visits the doctor has had with the patient to get further understanding"* (K1)

This is a laborious process for a pharmacist with limited time schedule to visit a care home. In the absence of pharmacists having access to computerised care records of patients, one model to consider would be to have a pharmacist-doctor communication book in the care home, where the doctor annotates any changes they have made on each visit, thus making it easier for a visiting pharmacists to evaluate medication changes.

This, coupled with access to patient records could improve patient care and reduce medication error arising from poor communication within the healthcare system

3.3.4 Education and Training

Participant opinion was sought as to what knowledge and skills would be required for them to provide a comprehensive pharmaceutical care service to people with dementia. Most participants asserted that a dementia specific training course, which would enable them to understand the disease better, would be helpful, in addition to attending talks on dementia.

One of the pharmacists interviewed in Essex bemoaned the absence of a system wide training standard in England:

"There's no sort of national 'you've got to do this, you've got to do that', maybe that needs to be reviewed for the future" (P2)

Kent pharmacists expressed more views on this subject, acknowledging gaps in their knowledge:

"I need more in-depth knowledge….especially with prescription of antipsychotics. I need to have more communication skills or maybe consultation skills" (K1)

"I think we need to know more about the personality of the individual patients as well, so that we can, rather than just managing with medication, getting lots of other support therapies that will do a lot to improve the condition…" (K3)

"You have to have up to date knowledge of the drugs and how they're used, any local protocols of administration and how they should be diagnosed. Being aware of interactions or at least having the facility to check interactions of their medication and give care homes guidance on dementia itself…"(K5)

This showed that participants understood the need for pharmacists to regularly evaluate their learning needs and undertake relevant education and training to be able to deliver consistently high standards of care to patients.

3.4 Discussion

The views and perceptions on various aspects of pharmaceutical care to people with dementia in care homes were captured, particularly with respect to the services they provided, their understanding of pharmaceutical care and what it meant for people with dementia, and aspects of everyday practice they considered as barriers to providing a comprehensive pharmaceutical service to this patient group.

Services

In this study, the community pharmacists interviewed, delivered pharmaceutical services to care homes ranging from 1 care home in the case of one participant, to over 70 care homes in the case of another. Whilst all participants in this study considered supply of medication to be the main service they provided to care homes, a few undertook medication reviews and some trained care home staff as part of their pharmaceutical service. Though all the participants were selected for the study expressly for their involvement in delivering services to care homes that

had people living with dementia, the services provided were for the care home residents in general, none specifically for residents with dementia.

Dispensing (supply) and repeat dispensing of medicines is an essential service offered by all pharmacy contractors in England, Scotland and Wales (PSNC 2014, Community Pharmacy Wales 2014).

This supply role historically established the image of community pharmacy as a profession in which dispensing, and sales of medication dominates (Varnish 1998). This has led to the perception of pharmacists as the least visible healthcare professionals within the primary care network when compared to roles played by doctors, dentists, midwives, optometrists and nurses (Hassel et al 2011). Following a review of research evidence, the same authors, Hassell et al. (2011), concluded that community pharmacists spend most of their time dispensing prescriptions.

Consequently, over the last three decades, steps have been taken by pharmacy professional bodies and the Department of Health in the UK to expand the role played by pharmacists (DOH 2008, RPS Wales 2016, and BMA&PSNC 2019, RPS Scotland 2019). This led to the incorporation of advanced and enhanced services into the community pharmacy contractual framework (PSNC 2014). Pharmacists began to offer services such as smoking cessation, weight management, appliance use reviews, NMS (New Medicine Service) amongst a myriad of other advanced and enhanced services, to patients/service users in the community (Wright 2016).

However, involvement of pharmacists with other pharmacy-based commissioned services requiring their physical presence on their premises limits their capacity to provide more than an enhanced supply role to care homes in general, and

dementia sufferers in particular. This was highlighted by one of the participants in the current study, who pointed that in order to do more with care homes; they would have to squeeze in the time during their lunchtime. Additionally, expanding the role of community pharmacists and range of services offered such as minor ailment schemes has contributed to significantly increased workload and resultant workplace stress (Jacobs, Johnson and Hassell, 2014). This may be one of the factors that contributed to many pharmacists in this study offering a basic level service of dispensing and supply of medicines, and not medication reviews which they pointed out they were not remunerated for.

While the previous service specification for community pharmacy services to care homes does not cover medication reviews, it has been suggested that community pharmacists can 'build a compelling case to improve medicine management' in care homes by doing just that (Barber et al 2009, Lau 2014, Anderson 2016,). Barry et al (2013) asserted that not only are pharmacists amongst the first healthcare professionals that a person with dementia in the community would encounter before seeking out their general practitioner, pharmacists are also expected to provide pharmaceutical services to patients in advanced stages of dementia living in care homes, which would include reviewing medication.

However, in a review of community pharmacy services commissioned by the Kings Fund, Murray (2016) highlighted that existing contractual mechanisms for pharmacy are complex and poorly understood, in addition to poor integration between community pharmacists and GPs that have led to slow progress as well as patchy utilisation of community pharmacists in the development of new clinical

roles or adoption of extended roles in management of long term conditions. This included roles in community as well as in care homes.

In welcoming the announcement of a £42 million-pound Pharmacy Integration Fund (PhIF) by NHS England in October 2016 (NHS England 2016), the Chief Pharmaceutical Officer for England, Dr Keith Ridge, acknowledged that community pharmacy will have to change the way it works. He asserted that there will be a shift from the old-fashioned view of the pharmacist as dispensers, with integration into a greater NHS role in helping patients.

According to proposals in the Community Pharmacy Contractual Framework for 2016-2018 (DOH 2016), the PhIF will support community pharmacy as it develops new clinical pharmacy services. Part of these will be the deployment of pharmacists into care home settings from April 2017. This was in line with recommendations by the Royal Pharmaceutical Society (2014), that pharmacists should be responsible for medicines and their use in care homes, and that every care home should be assigned to a community pharmacist and GP practice to ensure the provision of co-ordinated care to a consistently high standard.

The PhIF also financed a medicines optimisation in care homes programme (NHS England 2018) intended to support the deployment of 240 pharmacy staff into care homes over two years. Local commissioners had to commit to funding half of the costs of pharmacists/pharmacy technicians to work in care homes as well as continuing the pathway after two years. Whilst this programme also funds education and training of specialist pharmacists and technicians to work in reducing waste and medication errors in care homes, there is no clarity about how community pharmacists delivering services to care homes with no dedicated care

home pharmacist could be supported to provide a comprehensive pharmaceutical care service.

In July 2019 a new Community Pharmacists Contractual Framework was agreed (DOH 2019) with a 5-year life span. This new contract further promotes community pharmacy as an integral part of the NHS delivering clinical services, and requires that all premises complete a dementia-friendly environmental checklist, but it no longer specifically mentions care homes. It is not yet certain how the newly created Primary Care Networks (PCNs) will deploy clinical pharmacists previously dedicated to care homes, or how these organisations might integrate community pharmacists into new models of care so that they can provide more extensive pharmaceutical services to care homes (Taachi 2019).

Pharmaceutical care

The philosophy of pharmaceutical care practise requires that pharmacists engaged in the provision of a comprehensive pharmaceutical care service, must ensure the safe and effective use of medicines in all disease conditions, acute or chronic (Strand et al, 2004). This includes, but is not limited to:

- Making ethical decisions on behalf of patients
- Collaborating with patients, their families and with other healthcare professionals
- Contributing to the professional development of their peers
- Acquiring up to date knowledge in pharmacology, pharmacotherapy and pharmaceutical care practice

In a pharmacist's guide to implementing pharmaceutical care, van Mil (2019) summarises that the ultimate goal of pharmaceutical care, which should exist in all practice settings, is optimising medicines use and improving health outcomes. The same guide indicates that this goal is achieved by performing two major functions: identification of potential pharmacotherapy problems (also known as drug related problems or DRPs) and in collaboration with other healthcare professionals resolving these problems for patients in a manner that prevents the potential problems from becoming real for the patient and their therapy outcomes (van Mil 2019).

The role of the pharmacist in medicine optimisation for dementia patients, theoretically, is being able to review treatment regimens and identify improper drug selection, adverse drug reactions and drug interactions. They are also well placed to be involved in multidisciplinary teams, encouraging the correct use of cholinesterase inhibitors (donepezil, galantamine, rivastigmine) in mild to moderate dementia and memantine in severe dementia. They can also support prescribing decisions around treatment of BPSD which can be complex, often involving starting antipsychotics in an already frail population, further exposing them to serious adverse effects (Locca et al 2008, Maidment et al 2016).

There has been a drive to reduce prescribing of antipsychotics in dementia patients, with many initiatives targeting the care home population, a majority of who are estimated to suffer from dementia (Prentice and Wright 2014). Although most of the reviews of antipsychotic prescribing in care homes are currently carried out by pharmacists trained for this purpose, this task can also be carried out by community pharmacists, especially in the context of the expanding roles of

community pharmacists in managing long term conditions (DOH 2008) (DOH 2019).

In the current study, participants correctly highlighted that the pharmaceutical care needs of people with dementia in care homes involved ensuring they had the right medication in the right formulation, whilst some expressed concern about inappropriate prescribing and polypharmacy experienced by this vulnerable group. However, despite this recognition, participants showed limited knowledge about medication used for dementia and raised many issues representing barriers that prevented them from delivering a comprehensive pharmaceutical care service to care homes in general and to people with dementia in particular.

From another angle, a review by Hughes et al (2010) showed that pharmaceutical care provision from community pharmacies across Europe is still limited because pharmacists are not regularly engaging in patient-centred professional activities such as implementation of therapeutic objectives and monitoring treatment plans.

In France, community pharmacists are encouraged to listen, support, orientate and reassure patients with dementia by building confidential relationships with persons needing help (Dreux 2009). However, French pharmacists, as well as other pharmacists across Europe, also need to be motivated to participate in structured continuing training to adequately assist persons suffering from dementia and other neurodegenerative diseases (European Foundation Initiatives on Dementia 2016).

This indicates a need for policy makers to address some of the barriers highlighted by participants in the current study.

Barriers

Despite the aforementioned professional capabilities of community pharmacists to extend their clinical expertise to care homes, thus benefitting people with dementia in these care settings, participants in this study revealed barriers to such provision including remuneration, time pressure, knowledge, access to resident care records, lack of dementia diagnosis and lack of communication with other healthcare professionals involved in the care of residents within individual long term care settings.

Specific knowledge of medication used in dementia, adverse effects and implications were poorly displayed in this study, though two participants did highlight concern about the prescribing culture in care home residents with dementia.

This concern was justified, and pharmacists dispensing medication to people with dementia in care homes should be aware of the effect of factors such as physical health problems (infections, constipation, undetected pain or discomfort) as well as side effects of medication on the wellbeing of people with dementia (NES 2014).

Pharmacists in the current study were not unique in their limited dementia-specific knowledge.

In the USA, Marvanova and Henkel (2017a) surveyed community pharmacists and found that 50% of participants in the specified research location could not mention a single adverse effect of donepezil and inappropriately recommended insomnia aids to a person on rivastigmine. In a second study, the same authors (2017b) found that participating pharmacists had limited knowledge of Alzheimer's disease

and did not consistently access continuing pharmacy education resources related to dementia.

Building up community pharmacists' knowledge and confidence in providing adequate medication related support to dementia patients and their carers within the community as well as in care homes must be a prime objective. This would require a service specification that ensures that pharmacists are trained and empowered to provide a structured and safe pharmaceutical care service to dementia patients, whether living in care homes or in the community.

Other barriers highlighted by study participants were the lack of access to patient records and inadequate communication links with GPs and other healthcare professionals.

In this light, a joint statement by the Royal Pharmaceutical Society and The Royal College of General Practitioners, Scotland (RPS 2011) contained a recommendation for an integrated care record including medicines prescribed by GPs and dispensed by pharmacies to be developed that will help in management of long-term conditions. The Royal Pharmaceutical Society in Scotland in a recent publication calling for pharmacists to lead on provision of pharmaceutical care to care homes, recommended that all pharmacy team members directly involved in residents' care should have full read/write accesses to residents health and care records (RPS Scotland 2019).

This recommendation had been partially realised when community pharmacists were afforded access to summary care records which contain key clinical

information on what medication the patient is taking, and the indication being managed (Health and Social Care information Centre 2015).

RPS Scotland (2019) also recommended that pharmacists involved in providing care to residents in care homes, should be required to develop competences in care of the elderly, dementia and palliative care. These recommendations further included the drive to build sustainability into care home contracts with community pharmacists to enable continuity of care, long term planning and investment into staff education and training.

If these recommendations were to be implemented, it would support the delivery of a pharmaceutical care service to dementia patients in care homes as well as help to improve communication with general practitioners and other prescribers, leading to improved patient care outcomes.

A relevant service level agreement requires that all pharmacists and staff who are engaged in providing services to care homes be fully trained in all aspects of providing such a service. However, there is no national standard for the level of training required for the provision of pharmaceutical care to patients with dementia by community pharmacists. To this effect, RPS Scotland (2019) stated that an enabler to ensuring safe and effective pharmaceutical care to residents of care homes would be for NHS Education Scotland to develop a national education framework which will support approved standardised, competency-based training for all pharmacists and pharmacy technicians delivering pharmaceutical care to people living in care homes. Development and implementation of such standards could be implemented across the four countries of the United Kingdom, which will

go a long way towards eliminating variation in care for care home residents, particularly those with dementia.

Another deterrent to optimal pharmaceutical care highlighted by participants in the current study was the absence of a dementia diagnosis in residents' records.

However, many GPs are still not confident in making dementia diagnoses (Alzheimers Society 2016) and many residents do not have a formal diagnosis of dementia even though they may have clear symptoms (National Collaboration Centre for Mental Health 2018). It would be beneficial for memory clinics to develop out-reach services with care homes so that people living there can be assessed and diagnosed and given access to treatment (Alzheimer's society 2013). Such services, together with an integrated system of sharing patient records between primary and secondary care, would help pharmacists to improve pharmaceutical care services provided to dementia patients in care homes.

A view put forward by the Royal Pharmaceutical Society (Anderson 2016) is that there should be one named community pharmacy and one GP practice aligned to a care home to enable care co-ordination and consistently high standards of care for all residents.

To offer consistently high standards of pharmaceutical care to care homes, and address medication safety, a novel model of care has been suggested for care homes in which every care home has an on-site pharmacist integrating with nursing staff to improve quality of use of medicines (Kosari et al 2018). This model is similar to the Medicines Optimisation in Care Homes project (NHS England

2018) which saw pharmacists assigned to care homes across England, but this is coming to an end.

If community pharmacists are to contribute to supporting safe and efficient management services in care homes, commissioning of their services must be standardised alongside the aforementioned standardised education and training framework. It could be argued that the sub-optimal use of pharmacists caused by complex commissioning of cognitive pharmaceutical services by CCGs (Wright 2016, RPS 2016, Murray 2016), contributes to a potential de-skilling of highly trained healthcare practitioners (Hindi, Jacobs and Schafheutle, 2018) who have a lot to contribute to improved patient outcomes . This de-skilling is underpinned by a contractual framework that is still heavily linked to prescription numbers and scepticism from community pharmacists about getting involved in offering extended services (Hall et al 2018), despite community pharmacy contracts consistently trying to move away from a supply-centric service through linking pharmacy quality schemes to more clinical services from community pharmacies (NHS England Community Pharmacist Contractual Framework 2019).

This study identified the current nature of services provided by community pharmacists to people living with dementia and other morbidities in care homes; it has also identified areas where pharmacists' roles could be expanded for example, in the training of care home staff and in the provision of medication reviews in care homes. It also established that several barriers currently prevent this from happening. Further research is required to establish whether adequate commissioning and remuneration of pharmacists for these enhanced services

would improve their participation and lead to better outcomes for people living with dementia in care homes.

3.5 Study limitations

This was a small qualitative study, and as such, the findings are not generalizable to the wider community.

The interviews were conducted in community pharmacy consultations rooms but there were constant interruptions as participants often had to stop recording to deal with queries and conduct clinical checks of prescriptions within the pharmacy. This could have disrupted their thought processes and contributed to less than comprehensive answers**.** The ideal setting for the interviews would have either been a quiet room booked for the purpose. Alternatively, if the participant preferred to be interviewed in their pharmacy premise, there should ideally have been a second pharmacist to maintain continuity whilst the participant pharmacist was being interviewed.

3.6 Conclusions

Analysis of semi-structured interviews with 10 pharmacists revealed that the pharmaceutical care provision by community pharmacists to dementia patients in care homes was limited to mainly medication supplies, in accordance with the contractual framework agreed between local authorities and the community pharmacy contractors.

However, the precise pharmaceutical care needs of people living with dementia in care homes still need to be clearly defined. This is necessary to support the

development of a comprehensive evidence-based service framework that underpins a cognitive, transformative and well-defined pharmaceutical service, delivered by pharmacists providing pharmaceutical care to these patients.

CHAPTER 4

LIVING WITH DEMENTIA IN CARE HOMES: A QUANTITATIVE EXPLORATION OF COMMUNITY PHARMACISTS' VIEWS OF THE PHARMACEUTICAL CARE SERVICES PROVIDED TO RESIDENTS

4.0

4.1 Introduction and chapter overview

In chapter 1, the background to the research described the concepts of pharmaceutical care and its potential importance to improving outcomes in people living with dementia.

Chapter 2 presented a comprehensive review of dementia, its causes, diagnosis, treatment and the relevance of these to pharmaceutical care of people who suffer from the condition.

However, despite recommendations for pharmacists to become more involved with the pharmaceutical care of people with dementia (DOH 2009, NES 2014) together with evidence that pharmacist-led medication reviews in care homes can improve quality of prescribing, reduce drug costs and reduce drug burden for elderly residents (Brulhart and Wermeille 2011, Burns and Nair 2014, Lee, Mak and Tang 2019), there is a dearth of research on pharmaceutical care delivery by community pharmacists who are contractually responsible for supplying medication and appliances to people living in care homes.

Chapter 3 described a qualitative pilot study with community pharmacists, exploring their views during face to face semi-structured interviews. Themes generated from this study were used to develop a questionnaire survey tool.

The current chapter represents phase 2 of my research and involves a questionnaire survey of a wider population of community pharmacists,

systematically selected across England. It explores the views of a larger group of community pharmacists about the nature of pharmaceutical care services provided to people living with dementia, with emphasis on those residing in care homes, and includes further investigation of barriers to care identified from findings of the qualitative study, and from published research.

Additionally, using the results of the survey, a structural equational modelling technique was applied to evaluate the relationships between knowledge, barriers, understanding and confidence of pharmacists providing services to people living with dementia in care homes.

4.2 Methods

4.2.1Aims and objectives

4.2.1.1 Aims

- To assess the nature and extent of pharmaceutical services provided by community pharmacists to people living with dementia in care homes in England.
- To investigate their confidence and knowledge base in providing pharmaceutical care services to this patient group in and identify any training needs, which can later be used to design an intervention tool

4.2.1.2 Objectives

- To assess the nature and extent of pharmaceutical services provided to care homes

- To explore the knowledge and confidence of pharmacists in relation to dementia medications and ascertain their expertise in identifying and resolving drug therapy problems
- To identify the barriers to provision of effective pharmaceutical care for people living with dementia in care homes
- To determine whether there is a relationship between knowledge, understanding and confidence of pharmacists, using structural equational modelling (path model)

4.2.2 Study Design

A quantitative research design was used for this phase of the research. Quantitative research involves counting "things" such as people, opinions, behaviours and medicines. It is different from qualitative research which involves either observing, interviewing participants or reading what they write with the aim of gaining understanding of their feelings, attitudes or views on specific topics (Babar 2015).

Quantitative research methods complement qualitative research methods in pharmacy practice by providing estimates of frequency, commonness and size (Babar 2015), and use of self-administered questionnaires has several advantages: easier to get information from a larger number of respondents with less pressure to respond immediately, data analysis is more straightforward. Researcher bias can be reduced through ensuring responders are anonymous (Bowling 2005). The disadvantage of this method is that response rate may be low depending on length of the questionnaire, language used and literacy of respondents; use of tick boxes can limit information gathered (Bowling 2014).

Ethical approval was obtained from the Cross-Schools Research Ethics Committee (C-REC) at the University of Sussex in January 2016 (Appendix 4a).

Self-completion postal questionnaires with prepaid envelopes were sent out to participants between January 2016 and April 2016; this was repeated twice between April 2016 and October 2016 following an extension to the study due to a poor response rate.

4.2.2.1 Questionnaire development

The questionnaire comprised of 6 sections. Each section required participants to respond to a specific set of questions (Appendix 4b*).* The questionnaire design process comprised four stages:

- Planning
- Design
- Piloting
- Modifications and printing

Planning

The questionnaire planning stage involved deciding what topics would be included in the questionnaire. The topics of interest were informed by the overall aims and objectives of the research in both the qualitative and quantitative studies of pharmacists as both arms had the aim of establishing the nature of pharmaceutical care services provided by community pharmacists to people with dementia in care homes and objectives relating to investigating pharmacists' awareness of pharmaceutical care needs of people with dementia, their knowledge and confidence in delivering these services, barriers encountered, and education and

training needs. The qualitative study revealed themes (services, knowledge and confidence of pharmacists in pharmaceutical care of people with dementia, and education and training), which guided the choice of topic areas to focus on when planning the questionnaire. Table 4 depicts topics of generated using data from the qualitative study:

A. Characteristics of participant pharmacists (demographics)
B. Pharmaceutical services provided to care homes
C. Pharmacist knowledge: prescriptions for dementia medication
D. Pharmacist understanding and confidence: Pharmaceutical care of people with dementia
E. Barriers to pharmaceutical care provision
F. Education and training undertaken

Table 4: Topics of interest for questionnaire

Design

As part of the design phase, a literature search for a suitable validated questionnaire that covered the topics identified was conducted in healthcare databases (PubMed, MedLine, PsychInfo, EMBASE, CINAHL). It also sought to ascertain whether there was a consensus process for the design of pharmacy practice research questionnaires.

Two studies were identified that had utilized a questionnaire survey tool to study community pharmacist populations about services to care homes or to people with dementia.

- Barry et al (2013) explored community pharmacists' views, knowledge and attitudes to people with dementia, but this study was mainly focused on the

views, experiences and knowledge of community pharmacists about pain management for people with dementia.

- Schweizer and Hughes (2004) developed a questionnaire and surveyed pharmacists in Northern Ireland about the pharmaceutical care services provided to care homes, but they focused purely on contractual services with no focus on dementia.

A decision was therefore made by the researcher to design a questionnaire specifically for this study. Expert academic publications on designing healthcare or pharmacy practice research questionnaires (Bowling 2014, Gillman 2007, Smith 2010) described best practice for questionnaire design but there was no consensus on the design and conduct of questionnaire surveys.

A questionnaire was thus designed specifically for this study, with consideration of factors such as:

- Format
- Number of sections (these matched the selected topics)
- Language (English), phrasing and length of questions
- Scales for responses (Likert scales chosen)
- Number of questions in each section (they varied)
- Illustration
- Free text boxes for participants to add their own comments.

The content of the questionnaire was built from the results of the qualitative study (chapter 3 of this thesis). However, inspiration was sought from NHS Education Scotland (NES, 2014) publication entitled “The Pharmaceutical Care of People with

Dementia", as well as NICE Guidelines for dementia (NICE CG42, 2006) because both publications described knowledge required by pharmacists and other healthcare professionals to deliver comprehensive pharmaceutical care to people with dementia. Most of the questions utilised were closed questions requiring a tick on a Likert scale, since this was a self-administered postal questionnaire; most respondents do not bother to write down replies to open-ended questions. However, there were open-ended questions following the closed questions in sections A, C and F which required free typing to give the respondents the opportunity to include their own comments.

The resulting questionnaire was discussed with and reviewed by the academic supervisor who suggested improvements in structure, punctuation, and sentence construction.

Table 5 depicts the format and contents of the resulting questionnaire and the full questionnaire can be seen in Appendix 4c.

Section	Content	Required response
Part A	Six questions gathering the socio-demographics of respondents and their employing community pharmacies	Tick box, Yes/No and free text
Part B	Four questions about pharmaceutical services provided to care homes	Tick box
Part C	Nine statements about respondents' knowledge of prescriptions for people with dementia	Level of agreement with each statement on a 3-point Likert Scale with 1=Agree 2= not sure 3=disagree
Part D	Seven statements regarding respondents' understanding and confidence in providing a comprehensive pharmaceutical service to people with dementia	Level of agreement with each statement on a 5-point Likert scale 1=Strongly agree, 2=Agree, 3= neither agree nor disagree, 4=disagree, 5= strongly disagree
Part E	Twelve statements about perceived barriers of respondents to pharmaceutical care provision	Level of agreement with each statement on a 5-point Likert scale 1=Strongly agree, 2=Agree, 3= neither agree nor disagree, 4=disagree, 5= strongly disagree
Part F	Three questions about respondents' education and training on the subject of dementia	Tick box, Yes/No and free text.

Table 5: Format and content of pharmacists' questionnaire

Piloting and validation

For validation and to ensure reliability, the questionnaire was pre-piloted with 5 professional colleagues in the department of pharmacy, and 5 community pharmacists purposively sampled in the researcher's geographical area.

Reliability refers to tests carried out on a survey instrument to ensure that scale items measure the same construct and do not change over a period in which it is

not expected to change (Bowling 2014). The questionnaire developed for this study was tested for reliability during pre-piloting with 5 colleagues in the department. The questionnaire was sent to colleagues by email and returned with comments regarding suggested improvements. The process was repeated a week later after the suggested changes were implemented. This process was repeated twice, and consistency in responses noted.

Validity is assigned to a questionnaire after it has been tested satisfactorily in the populations for which it is designed and is defined as the extent to which it really measures the concepts it was designed to measure (Calnan 2007). There are many forms of validity but the relevant ones to this study were face validity, content validity, criterion, internal and external validity. The 5 community pharmacists who piloted the questionnaire were interviewed to ensure the questions in the instrument were clear and understandable, and to evaluate their use of the Likert Scales. Comments on the format, questions and scales were sought. The following aspects of validity were assessed:

Face validity was established by the researcher and research supervisor who checked the general format, presentation and relevance of the questions to the research objectives.

Content validity, which refers to the extent to which the content of the questionnaire appears to examine and include the full scope of the domain intended to measure (Bowling 2009), was assessed by the researcher consulting with the research supervisor and reviewing comments from colleagues who pre-piloted the questionnaire.

Criterion validity refers to the degree of convergence of a proposed instrument with existing, tried and tested indicators of the concept (Calnan 2007). This could not be assessed, as my research questionnaire study did not correlate with any existing tools.

Internal validity was established after satisfactorily pre-piloting and piloting the questionnaire as described above; external validity, which is the degree of generalisability of the findings to a wider population of community pharmacists was assessed at the conclusion of the study.

Modifications and printing

Modifications suggested by the research supervisor were grammatical corrections and sentence structure, as well as wording of the statements in section E of the questionnaire (Barriers to pharmaceutical care). Colleagues and community pharmacists who piloted the questionnaire made suggestions about the format, indicating that it should be on double sided A4 paper to ensure that there were not too many sheets to complete as this could seem daunting to the respondent. Font size was set at between 12-14 to improve readability (from 10-12 in initial questionnaire). Since there were many boxes to tick in sections C, D and E, suggestions were made to include alternate shading so each question would stand out, and respondents would identify items on the scale and match them to the questions more easily.

No changes to the actual content of the questionnaire or the format were made, so these were not modified. However, after receiving responses from the first round of posting the questionnaires, it was noted that Section C had a three point Likert

Scale (agree, not sure, disagree) whilst sections D and E offered a wider, 5-point scale (agree, strongly agree, neither agree nor disagree, disagree, strongly disagree). This could not be changed for the second round of posting and was addressed during data analysis.

4.2.2.2 Setting and participants

The country setting of the study was England, the researcher's practice base. Focusing on one country out of four that make up the United Kingdom ensured that the pharmacists who responded were practising under the same community pharmacy contractual framework.

Contact details of registered pharmacy premises in England were obtained from the General Pharmaceutical Council's website. A postal questionnaire and detailed information about the study were sent to the pharmacies identified by the sampling method described below. This was followed up by a phone call after five working days to ascertain the receipt of the questionnaire and the willingness of the pharmacist in charge to participate. Pharmacists who wished to participate were instructed to respond to the questionnaire and return directly to the researcher in a pre-paid envelope addressed to the Pharmacy Department at the University of Sussex. Participants were reassured in the information form sent out with the questionnaires that they could contact the researcher at any time for further information or clarification of any issues. Participants were informed that they could withdraw from the study at any time by contacting the researcher. They were also assured in writing (as part of the participant information form) that neither they, nor their premises would be identifiable in the study.

4.2.2.3 Sampling strategy

For this arm of the research, involving a survey of a wider sample of community pharmacists, it was deemed necessary to use a probability sampling technique which ensures every pharmacist working in a registered pharmacy premise in England at the time of the study had an equal chance of being selected, in order to make the study more generalisable.

Choice of probability sampling methods as summarised by Showkat and Parveen (2017) included

- Simple random sampling (obtained through activities such as tossing a coin or throwing a dice)
- Systematic random sampling (this requires complete details of the population under study, arranged randomly to ensure the same error rate. Following selection of the first unit, others are drawn at equal intervals until the full list is sampled).
- Stratified sampling (creation of subgroups of the population under study, then randomly selecting from within the groups)
- Cluster sampling (dividing the population into random clusters and randomly selecting from chosen clusters)

For this study, a systematic sampling method was used as it is one of the simplest sampling methods which allows for selection of a representative sample.

The sampling frame was community pharmacists practising in England, identified via the General Pharmaceutical Council list of community pharmacy registered

premises (since it was not possible to get person identifiable details of individual pharmacists).

According to the Health and Social Care information Centre (2014), trading as NHS Digital (from 2017), there were 11,647 registered pharmacies in England on the 31st of March 2014. A sample size calculation based on 5% confidence interval and 95% confidence level, gave a sample size of 372. This calculation was done using a website with embedded sample size calculator. https://surveysystem.com/sscalc.htm (Creative Research Systems, 2012).

Systematic sampling entails selection from every *k*th unit from the complete list of units in the population to produce a random sample where k = quotient or sampling interval.

The sampling interval $(k) = \frac{population}{sample\ size}$ and, for this study, $k = \frac{11647}{372} = 30$

Therefore systematic random selection of the first pharmacy premise in the randomly arranged list of community pharmacy premises in England, then the 30th, and subsequent selection of every 30 pharmacies thereafter (30, 60, 90...) until 372 pharmacies had been selected resulted in systematic sampling of the population (Aparasu 2011).

4.2.2.4 Inclusion criteria

Community pharmacists providing contractual services from registered pharmacy premises in England, who respond to the questionnaire survey

4.2.2.5 Exclusion criteria

Pharmacists working from premises registered solely for the provision of veterinary services

4.2.2.6 Informed consent

A participant information form (Appendix 4b) was sent to every participant along with the questionnaire. Informed consent was assumed when pharmacists returned their completed questionnaires.

4.2.2.7 Timescale

Ethical approval for this study was obtained from the University of Sussex Cross-schools Research Ethics Committee (C-REC) (Appendix 4a) on the 29th of January 2016. Data was collected over several months, with the researcher resending questionnaires twice between April 2016 and October 2016 to improve the response rate. Final questionnaires were received in October 2016.

4.2.2.8 Data Collection

The questionnaire was piloted amongst my peers in the university pharmacy department, corrections made and reviewed by the main research supervisor.

Each questionnaire was given a serial number corresponding to the pharmacy it would be posted to so that responses could be followed up.

After the first mailing of 372 questionnaire packs, only 33 responses were received. These were ticked off the list and reminder calls made. Further copies were sent to pharmacies where the pharmacist in charge had indicated non-receipt of the original questionnaire. Another 60 responses were received after the first reminder and then a further 11 responses after the second reminder. Two questionnaires were excluded because they were returned blank, one with no explanation and the second with a note explaining that the premises had a registered pharmacist but dealt only with veterinary prescriptions.

4.2.2.9 Data handling

Returned questionnaires were collected from the university postage box and stored in a locked filing cabinet at the School. Once data collection ended, responses were coded and entered on to SPSS software package version 24 and the paper copies stored securely.

4.2.3 Data analysis

The questionnaire design contained a mixture of nominal and ordinal data. The Likert scale (Likert 1932) was used as it is a psychometric item-scoring technique popularly used when attempting to measure the attitudes and opinions of individuals on various issues (Bishop and Herron 2015).

Using SPSS Version 24 (IBM Corp 2016), the analysis was initially conducted using Kolmogorov Smirnov test to assess for normality. This is often used to satisfy the assumptions of parametric statistics and gives an indication of whether the data distribution as a whole deviates from comparable normal distribution (Field 2009). If the test is not significant (meaning $p \geq 0.05$), then the sample distribution does not differ significantly from a normal distribution. If $p \leq 0.05$, the sample distribution differs significantly from normal.

This study contained both continuous variables (such as age of participants) and categorical variables (such as gender, pharmacist's role)

Categorical variables were analysed using Pearson Chi Square for goodness of fit when comparing the observed sample distribution with the expected distribution. For example, in this study, where there were 102 respondents who were male or female, the expected distribution would be 51 male pharmacists and 51 females.

The Chi Square test determines how closely the actual distribution of samples in the study mimic this expected distribution.

Data were weighted according to their frequencies and the following tests applied:

- Pearson Chi Square for independence was used for cross tabulation.
- Fishers' Exact test was used when the frequency in each cell was below five and the percentage of answers with value below five was higher than 20%
- Cronbach's alpha (α) was used for assessing the internal reliability (consistency) of the 3-point-Likert scale questions for each domain (knowledge, understanding/confidence, and barriers).

Median and the interquartile range (IQR) were reported for continuous variables which were non-normally distributed. Interquartile range (IQR) estimates where the middle 50% of the data set is and is often used instead of the median when the difference between the smallest data point and largest data point per variable is too wide.

The Likert scale questions were grouped according to their different parts/domains (pharmacists' knowledge, understanding and confidence, barriers to pharmaceutical care) and for uniformity, ease of analysis and reporting, the 5-point Likert scale in questions (Q12) and 13 (Q13) were reduced to a 3-point scale by merging "strongly agree" with "agree" to form "agree" and merging "strongly disagree" with "disagree" to form "disagree". The middle point remained the same, representing "not sure" / "neither agree nor disagree"

New variables were created for each domain called score variables and these score variables were calculated by adding up all the scores of each domain and dividing

this score by the number of items of each domain. The median and IQR was calculated for this variable as well. An optimal scaling method, called correspondence analysis (CA), which is a quantification used to reveal any relationships existing between and within two groups of variables (Hao 2019) was used to treat multivariate (categorical) data. Abdi and Béra (2014) suggested that CA transform data into two sets of variables called factor scores, which are obtained as a linear combination of rows and columns. These factors provide the best representation of the similarity of the structure and are plotted as visual maps that display the information in the original table. Furthermore, Sourial et al (2010) suggested that CA is a useful tool to uncover the relationship among categorical variables. A p-value <0.05 was considered significant for all tests.

To evaluate the three domains of knowledge, understanding/confidence and barriers, it was considered relevant to use another statistical technique called 'structural equation modelling' (SEM). Among the variance-based structural equation models (SEM), partial least square (PLS) path modelling is regarded as one of the more fully developed. PLS is a technique developed by Herman Wold (1975) for use in econometrics and chemometrics but has since spread to other disciplines such as marketing (Albers, 2010) and social science research (Jacobs et al 2011).

Hensler et al (2009) statement that "*PLS path modelling is recommended in an early stage of theoretical development in order to test and validate exploratory models*", is why it was of interest to apply to the current study.

The aim was to design a basic, simple model for the evaluation of path coefficients among the domains (also called variables or latent variables) to identify any significant correlations.

Due to the small sample size and non-parametric data, analysis was conducted using Smart-PLS (v.3.2.7) (Ringle et al 2015) which involves a series of ordinary squares regressions and bootstrapping recommended for assessing the statistical validity ($p<0.05$) of non-normal variables with 500 iterations and $t>1.96$. The variables with loading coefficient <0.5 were eliminated from the model.

4.3 Results

4.3.1 Response rate

Completed questionnaires were received from 102 pharmacists, providing a response rate of 27.4% (102/372).

4.3.2 Socio-demographic details of the participants

56.9% (n=58) were female and 43.1% (n=44) were male. The gender split did not show a statistically significant difference ($p<0.166$). The age groups most represented were the 25-29 (23.5%) and 30-34 (19.6%), while the least represented was the 55-59 (4.9%). A statistically significant difference was found among the age groups (see Table 2) ($p<0.001$). Seventy-six (74.5%) were pharmacy managers, 11 (10.8%) locum; five (4.9%) second pharmacist.

There were 2 superintendent pharmacists in the 25-29, 35-39, 40-44 and 55-59 age ranges. Locum seemed the most popular choice in the 45-49 and 50-54 age ranges (see Table 6). Manager and sole pharmacists appeared to be chosen by the

vast majority of pharmacists between 20-44 years of age (n=63; 61.7%). The number of pharmacists who held a post-graduate qualification were one in the age range 20-24 and 50-54, two in the 55-59, three in the 30-34, four in the 25-29 and 45-59, six in the 40-44 and seven in the 35-39. Seventy-four (72.5%) did not hold a post-graduate qualification ($p<0.001$). The correspondence analysis presented in Figure 4 shows three quadrants, North West, North East and South East where there is a pattern between age range and role, where pharmacists aged between 20-24 years, 25-29 and 30-35 are second pharmacists or pharmacy managers, whilst older pharmacists 45-49, 50-54 and 55-59 are locum pharmacists or superintendent pharmacists. This was further depicted in a bar chart as seen in Figure 5.

Demographic	N	%	p value
Gender			<0.166
Female	58	56.9	
Male	44	43.1	
Age group			<0.003
25-29	24	23.5	
30-34	20	19.6	
35-39	14	13.7	
40-44	11	10.8	
20-24	10	9.8	
45-49	9	8.8	
50-54	9	8.8	
55-59	5	4.9	
Role			<0.001
Manager / Sole Pharmacist	76	74.5	
Locum	11	10.8	
Superintendent	10	9.8	
Second Pharmacist	5	4.9	
Holding a post-graduate qualification			<0.001
No	74	72.5	
Yes	28	27.5	

Table 6: Pharmacist demographic data

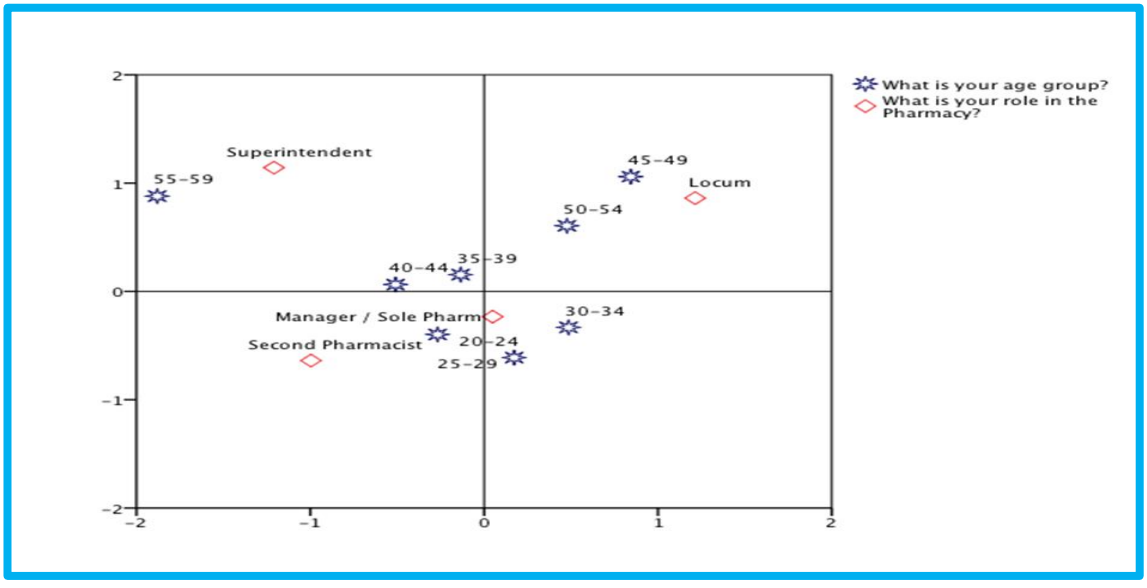

Figure 4: Correspondence analysis between pharmacists' age and role

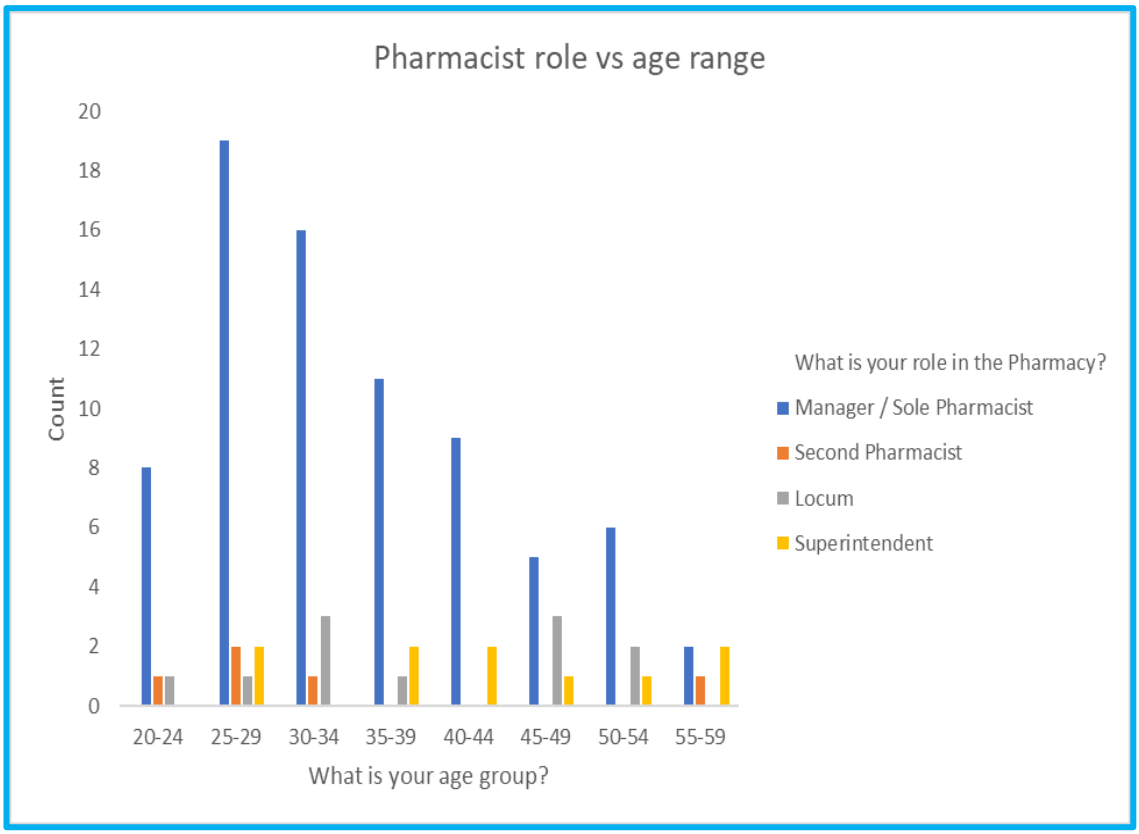

Figure 5: Pharmacist role vs age range

4.3.3 Year of registration

Figure 6 shows a bubble chart indicating the pharmacist's year of registration with the pharmacy regulatory body, compulsory for any pharmacist practising in the UK. The bubble size represents the number of pharmacists who registered in each of the years represented on the chart; therefore, a larger bubble means a higher number while a smaller bubble represents a lower number. Since the bubbles with the larger sizes tended to be concentrated between 2000-2016, it indicated pharmacists who responded mostly registered after the year 2000.

In fact, the year of registration presented a wide range, with some respondents registered in 1980 (n=2) and others 36 years later in 2016 (n=2) so the year-range was 36 (2016-1980), the median year of the registration was 2007 and the

IQR (where 50% of participants were represented) was 1998-2012. The percentage of pharmacists registered between 1980-2000 was 33.3 (n=34), and from 2001-2016 it was 66.7% (n=66)

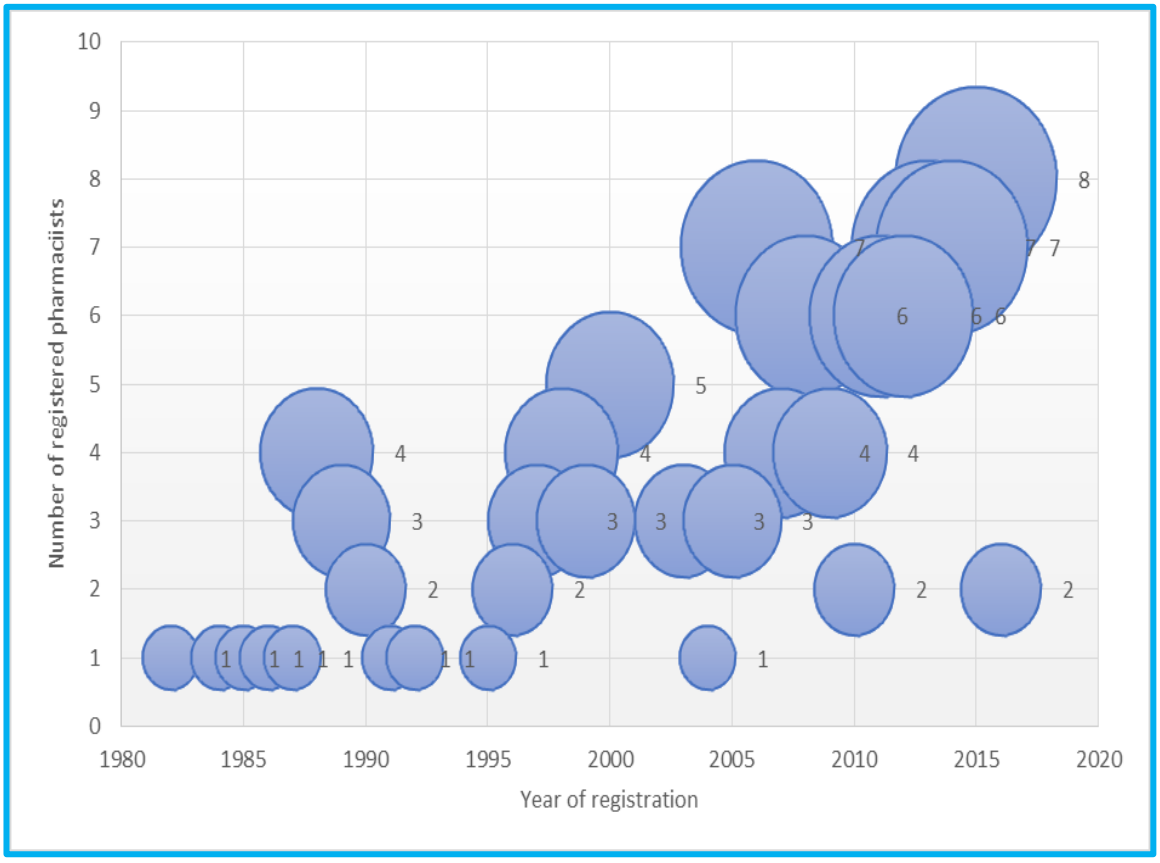

Figure 6: Pharmacists' year of registration

4.3.4 Service provision

Thirty-two (31.4%) pharmacists delivered services to care homes, while 70 (68.6%) did not.

Pharmacists could select more than one option for service provision. The most common services provided were monitored dosage system and medication supply, provided by 25 pharmacists. These were followed by medication delivery service (n=23). Medication reviews and medicines management training were provided by

eight pharmacists (25% of those who worked with care homes). The types of services provided by pharmacists are summarised in Figure 7.

Pharmacists could also indicate by free typing, other services they provided which were not listed in the questionnaire. Though this question required that participants indicate in writing what "other" services they provided, 5 pharmacists ticked the box but did not enter the name of service they provided that was not listed in the survey.

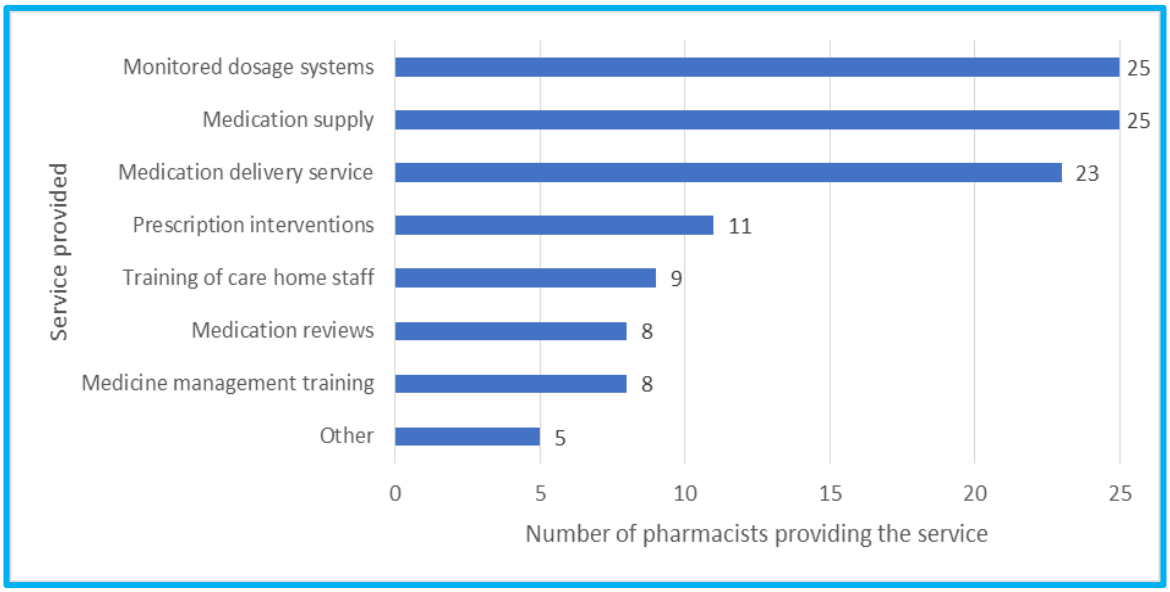

Figure 7: Pharmacists' services to care homes

4.3.4.1 Care home visits

Care home visits were provided by 31% of pharmacists (n=32) participating in this study.

Only 3 of the 32 pharmacists who said they provided services to care homes visited frequently (every three months or less). 8 pharmacists visited the care home every three to six months and 7 pharmacists once a year.

19 pharmacists provided services to residents living with dementia in care homes. All 19 pharmacists indicated that they believed the services they provided were sufficient to meet the pharmaceutical care needs of these residents with dementia.

Table 7 depicts pharmacists' visits and number of Care Homes with residents with dementia.

Care home visits	N	%
How often do you visit the care home		
Never	20	52.63
Every three to six months	8	21.05
Once a year	7	18.42
Every three months or less	3	7.89
Total	38	
(Missing)	(64)	
Does the care home have residents with dementia?		
Yes	19	51.35
I don't know	14	37.84
No	4	10.81
Total	37	
(Missing)	(65)	
Are the services you provide sufficient to cater for their pharmaceutical care needs?		
Yes	19	52.78
Not sure	8	22.22
Partially	6	16.67
Not	3	8.33
Total	36	
(Missing)	(66)	

Table 7: Care Home Visits and number of Care Homes with residents with dementia

4.3.4 Knowledge of pharmacists about prescriptions for people with dementia

Nine statements with a 3-Point-Likert scale were used to assess pharmacists' knowledge of dementia. The internal reliability (Cronbach's alpha) was 0.678. As a rule of thumb, a Cronbach's alpha score of 0.7 and above indicates acceptable consistency and reliability (Gliem and Gliem 2003). This shows that the was

internal reliability in the knowledge domain of the questionnaire since the value of 0.678 can be rounded up to 0.7.

82.4% of pharmacists (n=84) agreed that they needed more training to provide improved pharmaceutical care services to patients living with dementia; while 7.8% were not sure and 9.8% disagreed.

Only 50% of pharmacists (n=51) agreed they could confidently identify drug interactions in prescriptions for people with dementia, however 61.8% confirmed that they had knowledge of the major side effects of drugs used as cognitive enhancers in dementia patients. Pharmacists' responses to these statements are depicted in Figure 8.

Pharmacist knowledge about the behavioural and psychological symptoms of dementia (BPSD) and drugs that cause cognitive impairment appeared strong (86.3% and 68.6% agreed respectively) but only 39.3% agreed they knew what drugs should be avoided in people with dementia and just 32.4% agreed that they could recommend interventions to optimise dementia medicines to GPs. This would explain why 82.4% indicated they required more training to provide better pharmaceutical care to this patient group.

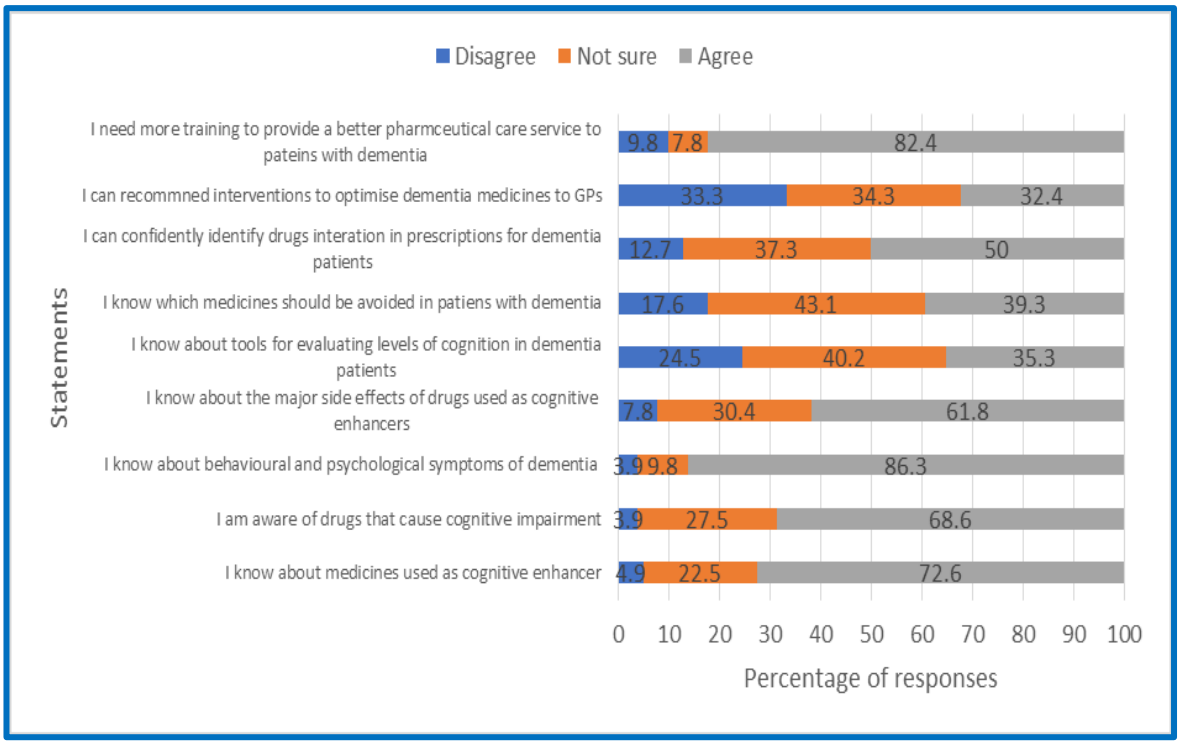

Figure 8: Pharmacists reported Knowledge on Prescriptions for People Living with Dementia

4.3.5 Pharmacists' perceived understanding and confidence in providing Pharmaceutical care for people living with dementia (Q12)

Seven statements with a 3-Point-Likerts scale were used to assess pharmacists' understanding and confidence when providing services for dementia patients. The internal reliability was 0.805 (Cronbach-alpha) which indicates good consistency. The score variable for this domain presented a median value of 2.57 (IQR; 2.85-2.14); 83.2% of the scores were between 3-2 and 16.8% was between 1.86-1.00.

The statements and correspondent response are depicted in Figure 9.

51% of pharmacists asserted that they could use summary care records to improve pharmaceutical care for people with dementia and an equal proportion agreed that they could contribute significantly to multidisciplinary teams providing care, but the rest were unsure or disagreed.

Pharmacists expressed their lowest level of confidence (46%) when asked about their ability to make recommendations for stopping medication that was unnecessary or potentially harmful, but a good number (73.6%) felt they could identify drug interactions. This appears contradictory to the response given in the previous question about knowledge (Q11), where only 50% agreed with the statement "I can confidently identify drug interactions in prescriptions for dementia patients".

74.5% reported feeling confident in signposting people with dementia and/or their carers to relevant services for help and support, and an equally high percentage of pharmacists (71.6%) reported feeling confident in dealing with prescriptions for care homes.

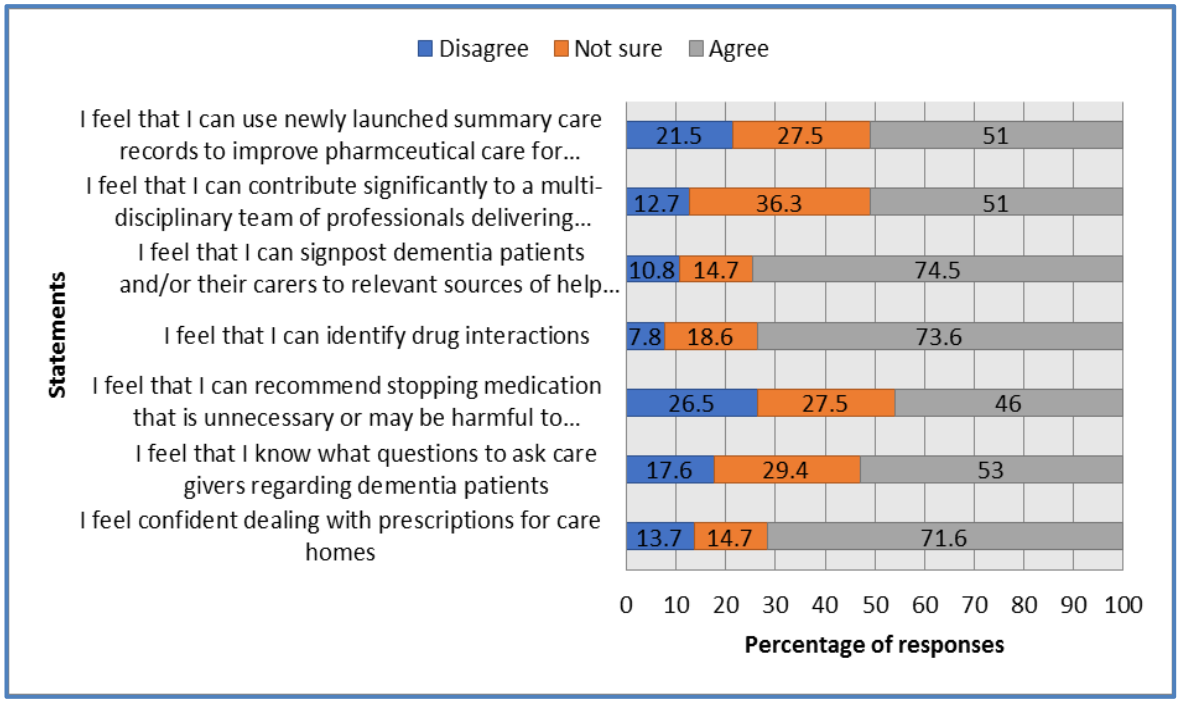

Figure 9: Comprehensive pharmaceutical care including confidence in dealing with prescriptions for people with dementia and pharmaceutical care provision in care homes

4.3.6 Barriers to provision of pharmaceutical care services (Q13)

Building on the results obtained from the qualitative study in Chapter 3 of this thesis, as well as evidence from published research, 12 statements on a 3-Point-Likerts scale were presented to pharmacists to assess the potential barriers to the provision of pharmaceutical care services to people with dementia.

The internal reliability was 0.748 which indicates a reasonable consistency. The score variable for this domain presented a median value of 2.75 (IQR; 2.91-2.58); 97.8% of the scores were between 3.00-2.08 and 0.2% was between 1.75-1.58. Full statements and percentage responses are presented in Table 8 and charted in Figure 10. A large majority of pharmacists surveyed (over 80%) agreed with the first eight statements addressing the:

- need for access to clinical notes,
- improving their knowledge about geriatric medicines,
- making time to visit care homes,
- communicating better with GPs and other healthcare professionals,
- involvement in reducing antipsychotic prescribing to residents with dementia,
- attendance at multidisciplinary team meetings and
- being informed of patient discharge from hospital.

However, 36.3% of the respondent pharmacists were unsure about how the role of the community pharmacy contractual framework at the time of the survey, impacted on the care of people with dementia, though 59.8% agreed that the design of the contractual framework restricted care. They were equally equivocal about the role of clinical commissioning groups (CCGs) (31.4%) though 67.6% agreed that CCGs overseeing commissioning services to care homes led to non-

uniformity of care services. At the time of this study, over half of the participant pharmacists (57.8%) indicated that they had access to summary care records, whilst over a third (35.3%) did not. 60.8% of the respondents thought that it was a good idea for each patient to have a named community pharmacist (like how each patient has a named GP).

	Response (%)			
Statetment	**Disagree**	**Not sure**	**Agree**	**Total**
Limited access to clinical notes hinders the identification of drug therapy problems	6.9	8.1	85	100
Pharmacists' need to improve their knowledge of geriatric medicines	4.4	11.9	83.7	100
Pharmacists should have more time to visit care homes	3.8	13.1	83.1	100
The pharmacist should build better relationships with care home GPs in order to better communicate recommended interventions	3.1	11.9	85	100
Community pharmacists should be notified of patient discharge	4.4	3.1	92.5	100
Pharmacists should attend multi-disciplinary team meetings	0.6	13.8	85.6	100
Pharmacists should be actively involved in helping to reduce the use of anti-psychotics in dementia	2.5	10	87.5	100
Communication with other healthcare professionals would be facilitated by diarised patient medication reviews in care homes	1.3	19.5	79.2	100
The current community pharmacy contractual framework restricts level of care provided to dementia patients	3.8	37.5	58.7	100
Clinical commissioning groups (CCGs) determine what services are provided to dementia patients so care provision in non-uniform across the country	1.3	33.1	65.6	100
Every patient should have a named community pharmacist	17.5	21.3	61.2	100
I have acces to summary care record	35.6	7.5	56.9	100

Table 8: Barriers to providing Pharmaceutical Care to People with Dementia in Care Homes (full statements and % responses)

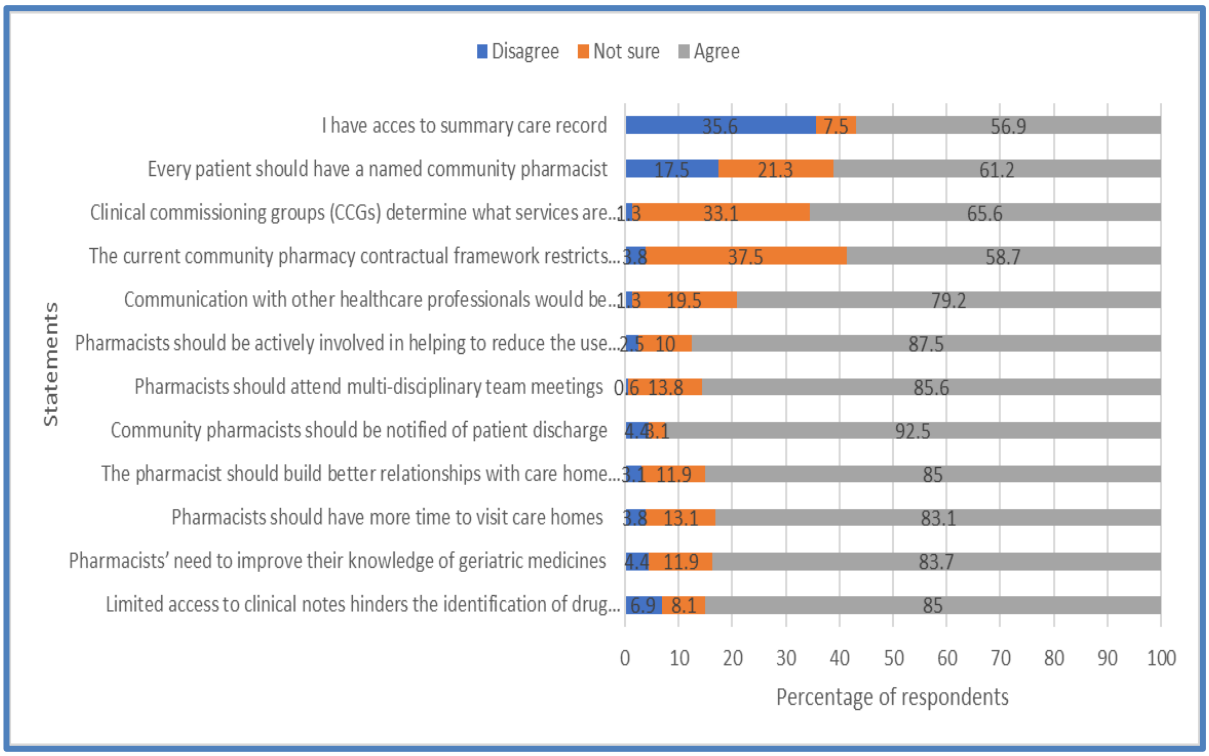

***Figure 10**: Barriers to providing Pharmaceutical Care Services to People with Dementia in Care Homes*

4.3.7 Education and Training

The purpose of this part of the questionnaire was to determine how much dementia-related education and training each respondent had participated in. The percentage of pharmacists who had undertaken any training on prescribing or on medicine optimisation in dementia was 18.6 (n=19), whilst 81.4% (n=83) had not.

The percentage of pharmacists interested in receiving training on dementia was 91.2% (n=93); only 8.8% (n=9) were not interested. A cross tabulation between the two questions was performed but the Fisher's Exact test did not demonstrate statistical significance (p=0.060).

4.3.8 Barriers to undertaking training on dementia

Pharmacists were asked to state the barriers preventing them from pursuing further dementia related training (free text). While most left this section blank, 48

respondents (47%) wrote down a range of barriers, with lack of time being the most frequently cited reason.

These reasons are presented in Figure 11.

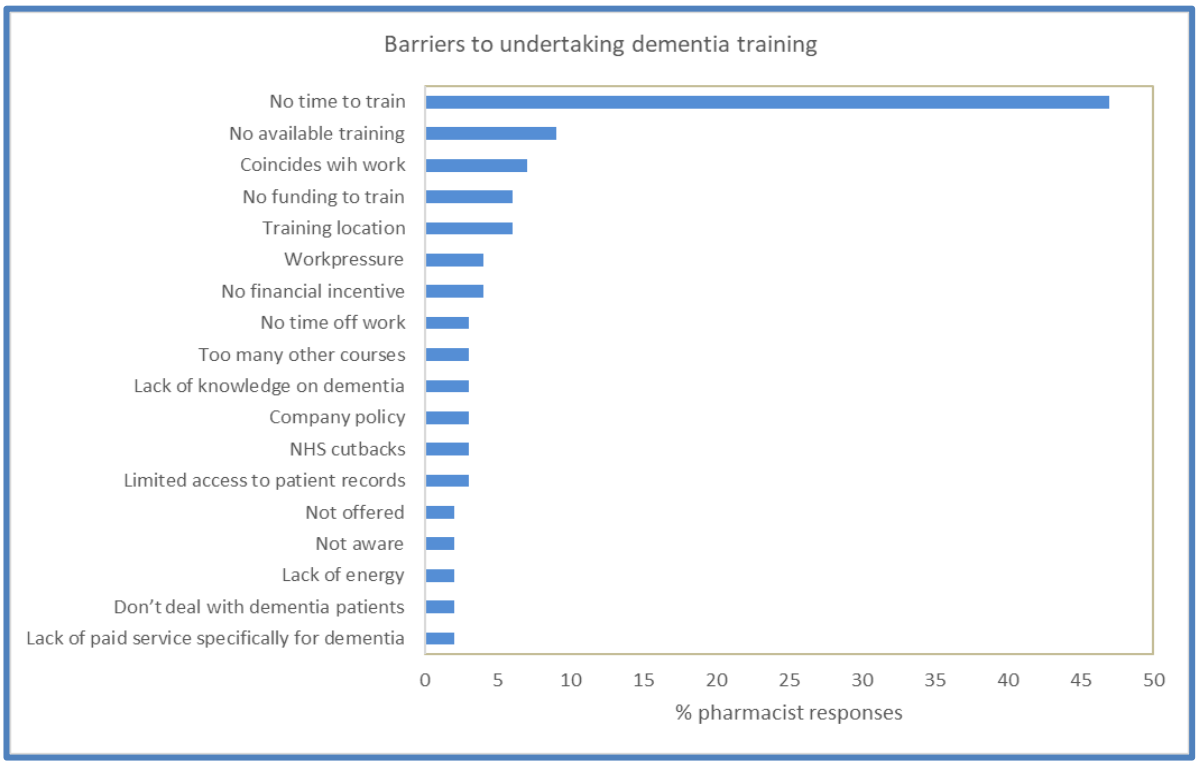

***Figure 11**: Barriers to undertaking dementia training*

4.3.9 Path modelling using PLS (Partial Least Squares)

The answers to the knowledge, understanding/confidence and barriers questions were computed into a structural equational modelling software package (Smart-PLS®) (Ringle et al. 2015). In order to clarify the codes used in the model, and the variables analysed in the model, the questions included in the models and the corresponding percentage affirmative (agreed) responses are first presented in clearly labelled bar charts (Figures 12-14), with the correspondent codes used in the models (Figures 15-16).

The aim of this technique is to determine the relationships between pharmacists' knowledge of dementia, their understanding and confidence, and the perceived barriers to delivering pharmaceutical care to people with dementia in care homes. These relationships can be explored using structural equational modelling, which can be done using different computer software packages. In this study, SmartPLS® was used.

Using the SmartPLS® software to perform structural equation modelling has some advantages (Sander and Lee 2015)

- It offers a path model that describes the relationships between variables, for example, the relationship between pharmacist knowledge and barriers to pharmaceutical care in this study.
- It can handle multiple co-linearity amongst independent variables
- Can be used when the data sample is small, such as that in the current study

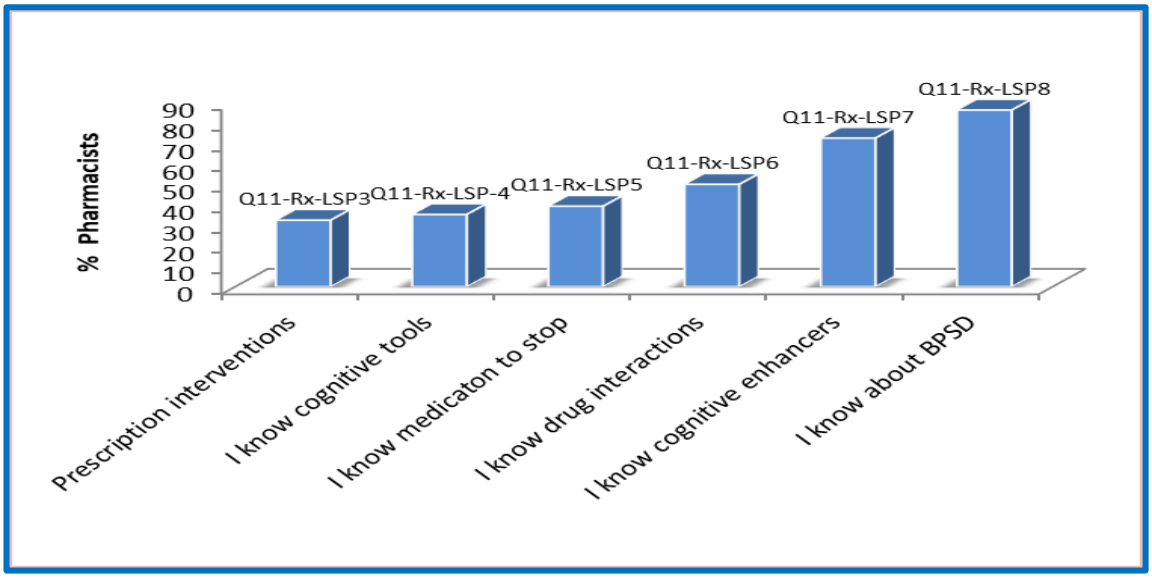

Figure 12: Reported Pharmacist Knowledge (Q11)

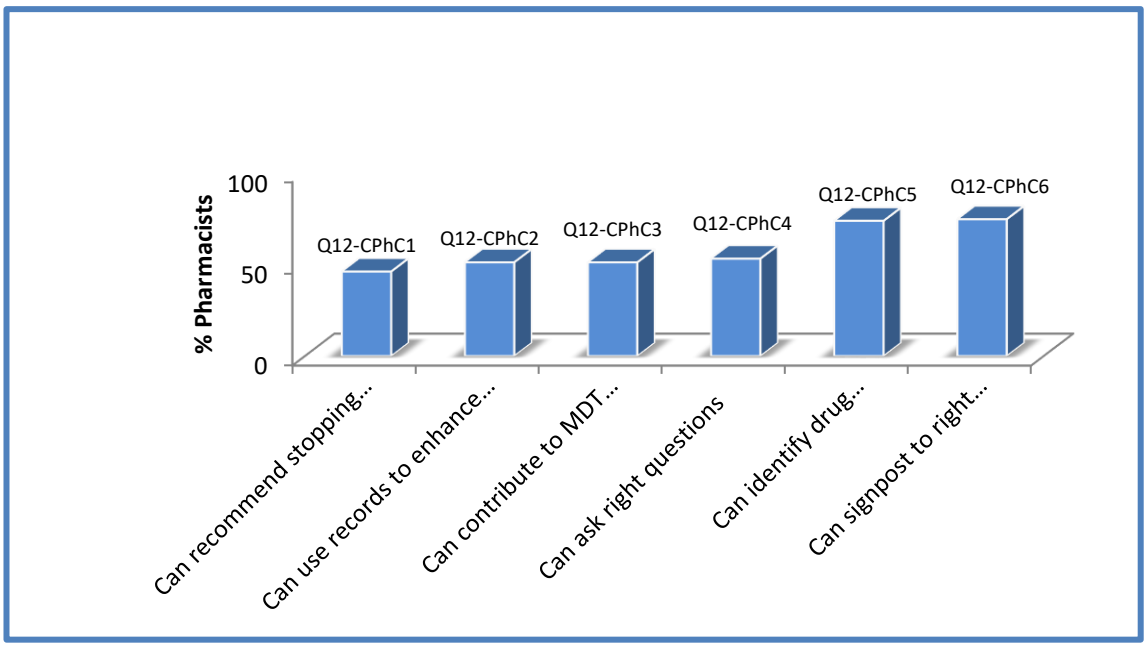

***Figure 13**: Pharmacist Understanding and Confidence (Q12)*

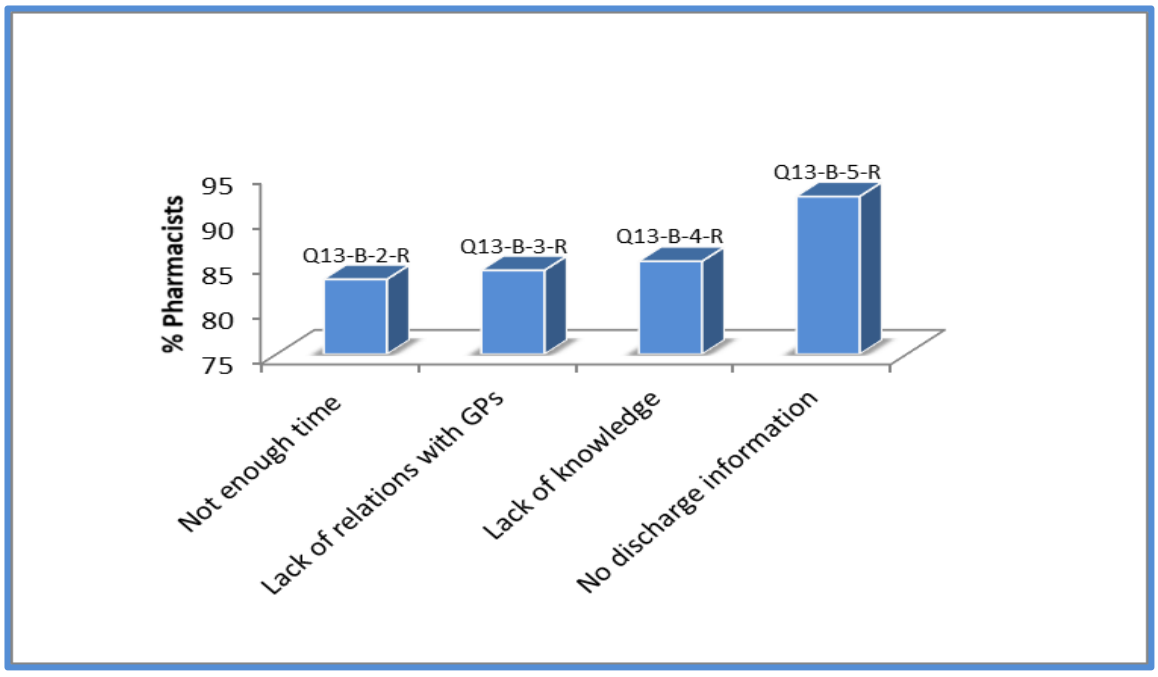

***Figure 14**: Barriers to Pharmaceutical Care (Q13)*

These variables were used in the PLS path model.

Figures 15 and 16 below summarise two types of information: Figure 15 shows the path coefficients, Figure 16 the level of statistical significance. In Figure15 the black bold lines show the most relevant relationships. The loading coefficient with values <0.5 were eliminated from the model as values have to be > 0.5 for good convergent validity.

Results of Path Modelling:

- A *negative* effect of the standardized path coefficient (β= -0.151) was found between knowledge and barriers. This indicates that as knowledge increases, barriers decrease.
- Another *negative* effect of the standardized path coefficient (β= -0.098) was found between barriers and understanding/confidence indicating that when barriers increase, the understanding /confidence decrease.
- A *positive* effect of the standardized path coefficient (β= +0.672) was found between knowledge and understanding-confidence; highlighting that where knowledge increases, understating/confidence increase as well (Figure 15).
- A statistically significant linear relationship was only found between knowledge and understanding and confidence (t=12.70; p<0.001).
- The model explained 48.1% (R2=0.481) of the variance of the understanding/confidence domains (variable).
- The average-variance-extracted (AVE) was >0.451 for knowledge, 0.565 for barriers and 0.544. AVE is a measure used to express how much of the variance of its items are explained by the constructed model. An AVE score of 0.5 or more indicates that the construct explains at least 50% of the variance of its items (Hair et al 2019).

- The composite reliability (CR) was >0.8 for all the three variables, Cronbach alpha >0.77. Rho (R) =0.788 for knowledge, 1.143 for barriers, and 0.863 for understanding / confidence.
- The standardized root mean squared residual (SRMR) was 0.091 meaning an acceptable fit.

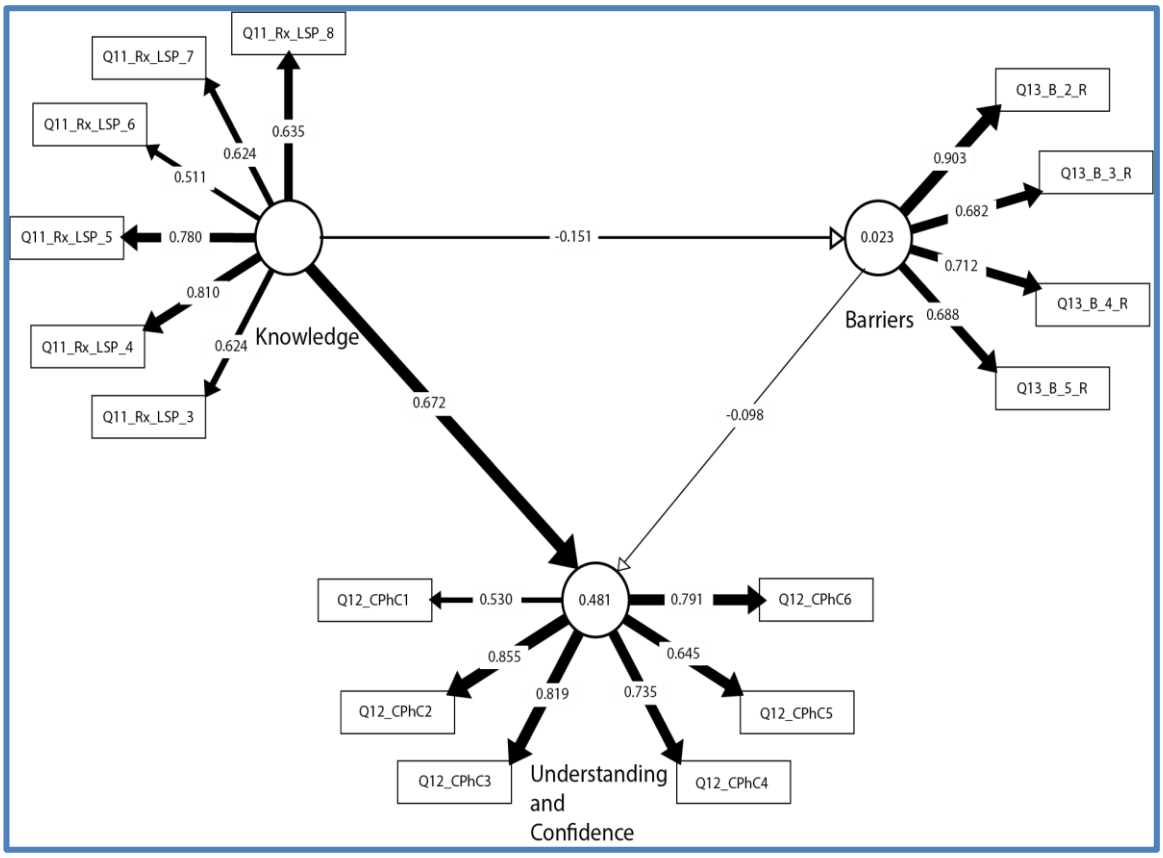

Figure 15: Path coefficients and R values generated using PLS algorithm

Loading coefficients are reported for each variable; path coefficients are overlapping the connecting lines. R2 are reported inside the circle for barriers (R2=0.023) and understanding/confidence (R2= 0.481).

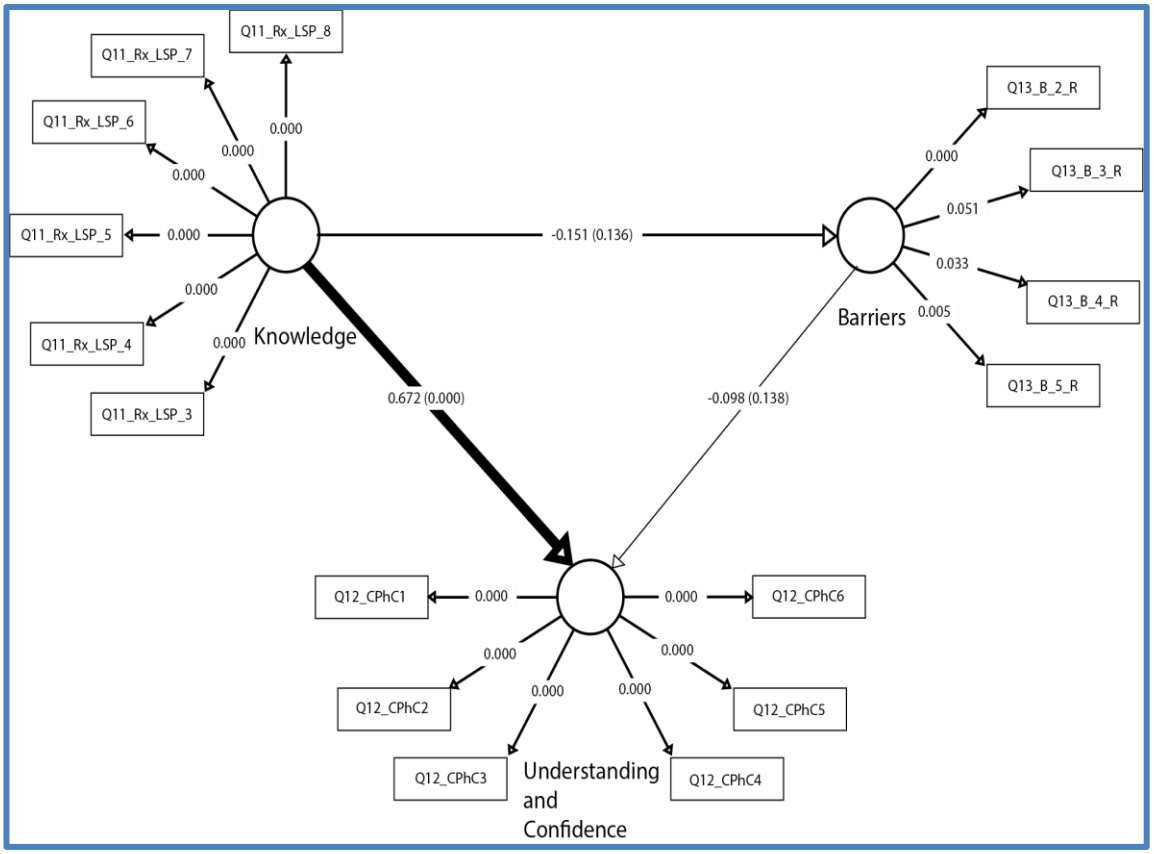

Figure 16: Path model analysis using the complete bootstrapping algorithm with 500 iterations

P values are ported for each loading coefficient; path coefficients are overlapping the connecting lines and their p values are reported in brackets. The only statistically significant path coefficient is represented by 0.672 (p<0.001) which is located between knowledge and understanding/confidence.

In summary, a statistically significant linear relationship was only found between knowledge and understanding/confidence (t=12.70; p<0.001).

The path model provided relevant information regarding the positive and statistically significant relationships between two latent variables: knowledge and understanding/confidence.

4.4 Discussion

Response rate

A questionnaire survey was used for this study as questions can be used to assess the attitudes and beliefs of respondents. It was administered via postage mail as mailed questionnaires provide on average, a better response rate than web administered survey modes (Cho et al 2013).

The response rate of 27.4% was less than that returned by a similar study (Barry et al 2013) which had a response rate of 34% from community pharmacists surveyed, and fell short of the 30%-90% range found by Smith (1997) to be typical of community pharmacists. The response rate might have been improved by offering incentives (Hardigan et al 2016) and/or reducing the length of the 5-page questionnaire but doing this may have compromised the value brought by additional questions included (Sahlqvist et al 2011).

Demographic data

More female pharmacists responded (56.9%) than males (43.1%) but the split was not statistically significant.

Most respondents (66.7%) were registered as pharmacists between 2001 and 2016, with more participation from those who registered around 2010 onwards (figure 2). It is possible that this might be as a result of key publications on dementia during that time period such as, *Dementia UK: The full report* (Alzheimer's Society 2007), *Living well with dementia: A National Dementia Strategy* (DOH 2009), and *the Banerjee Report (Time for Action, an independent review of the use of antipsychotics in elderly people with dementia)* (Banerjee, 2009).

These publications and a series of subsequent ones (such as the Prime Minister's challenge on dementia 2012 and 2015) have kept dementia on the national agenda, raising awareness about the condition, its prevention and living well with dementia, being areas of focus.

The study data also showed that most respondents between the ages of 20-44 (61.7%) were managers/sole pharmacists, whilst older participants were locums or superintendent pharmacists. There are no studies linking choice of employment contract within community pharmacy in the UK to age, but it is possible that younger pharmacists choose managerial roles for job stability and to gain experience.

Service provision

Of 102 pharmacists surveyed, 32 (31.4%) said they provided services to care homes, whilst the others didn't answer yes to providing services to care homes but did supply medication to care homes. The proportion of pharmacists providing services to care homes in this study was lower than that of a study by Barry et al (2013) in Northern Ireland, which had 40% respondent pharmacists delivering services to care home services, but closer to an estimate by the Royal Pharmaceutical Society (RPS 2012) which contended that less than 20% of community pharmacists were involved with care homes. Half of those delivering pharmaceutical services to care homes (59.4%) said their care homes had people living with dementia.

The services presented to participants to choose from were provision of monitored dosage systems, medication supply, delivery of medicines, prescription

interventions, care home staff training, medication reviews, medicine management training. They had the option of stating other services they provided but none did.

These services were based largely on the NHS Community pharmacy contractual framework for enhanced services for care homes (PSNC 2005). This template remains mostly unchanged and is used by various commissioning groups across England for services community pharmacies contracted to deliver pharmaceutical services to care homes are expected to provide.

The service outline (Figure 13) briefly outlines the enhanced services community pharmacies with care home contractual arrangements are expected to deliver, in addition to providing the essential dispensing of medication, and promoting patient safety by a professional focus on ordering, storage, administration and disposal of medicines.

In addition to the services outlined in Figure 13, community pharmacies in England, according to the pharmacy contractual framework, can provide signposting, support for self-care and promotion of healthy lifestyle services to care homes (NHS 2013) but the practicalities of how these are delivered to care homes are unclear.

The survey did not include all the services outlined in the framework (such as audit, advice on medicine policy, and medication waste disposal). This was to curb the length of the questionnaire as lengthy questionnaires can reduce response rate and cause participant attention and motivation to drop towards the latter sections (Lavrakas 2008).

3. Service outline

3.1 The pharmacy will have an agreement with the care home to provide this service.

3.2 The pharmacy contractor has a duty to ensure that pharmacists and staff involved in the provision of the service have relevant knowledge and are appropriately trained in the operation of the service.

3.3 The pharmacy contractor has a duty to ensure that pharmacists and staff involved in the provision of the service are aware of and operate within local protocols.

3.4 The pharmacy should maintain appropriate records to ensure effective ongoing service delivery and audit.

3.5 The initial visit should include provision of advice on safe and effective ordering, storage, clinical and cost effective use, administration and disposal of medicines and appliances and record keeping. Advice will also be provided on the medicines policies and procedures which the care home should have in place.

3.6 Follow up visits will be undertaken to monitor systems at least every six months.

3.7 Pharmacists will ensure that they are aware of any medicines related issues which were raised at the most recent care home inspection organisation visit to the home.

3.8 Records are maintained by the pharmacist of interventions and advice given during visits. Copies of any action plans agreed with the care home should be retained for review at future visits.

3.9 The pharmacist will be responsible for the provision of training for care staff on medicines issues, on an opportunistic basis during regular visits and also at least once a year on a formal basis.

3.10 The pharmacist will advise the care home on the content of their medicines related policy documents, including the administration of medicines for acute conditions, use of 'homely remedies' and procedures when there are alterations to residents medication regimens.

3.11 The PCO will need to provide a framework for the recording of relevant service information for the purposes of audit and the claiming of payment

Figure 17: Section 3 of the NHS community pharmacy contractual framework (enhanced service)-Care homes

Adapted from the NHS Community Pharmacy Contractual Framework Enhanced Service – Care Home (support and advice on storage, supply and administration of drugs and appliances) at https://psnc.org.uk/wpcontent/uploads/2013/07/en5__care_home_support1.pdf

People with dementia are often prescribed complex medication regimes that are difficult to manage, and research has found that they are often prescribed statistically significant higher number of medicines than patients of the same age

without dementia (Clague et al 2017). It stands to reason that they would benefit from cognitive pharmaceutical services such as regular medication reviews.

A cognitive pharmaceutical service is defined as *"any activity in which the pharmacist would use their professional knowledge and abilities to improve pharmacotherapy and disease management by means of interacting with the patient or other healthcare professionals"* (Cipolle, Strand and Morley 2004). Simply put, cognitive pharmaceutical services are "pharmacy services related to the pharmacists' use of specialized knowledge and abilities to help patients achieve effective and safe pharmacotherapy" (Lakic et al 2017)

Benrimoj et al (2010) devised a hierarchical model for classification of cognitive pharmaceutical services based on clinical decision-making, and the degree of shift needed from community pharmacists' traditional roles in order to provide these services (Table 8).

A comparison of the services listed in this model (Table 8) to the service specification for community pharmacists delivering services to care homes (Figure 17) as well as what the community pharmacy contract in England covers, shows only some similarities (medicine information, medication use reviews, medicines reviews).

This study included two services from the hierarchy (prescription intervention and mediation reviews) which would benefit care home residents particularly those with chronic long-term conditions such as dementia.

None, of the survey participants fully complied with the contractual obligations. Of the 32 who indicated that they provided services to care homes, only 25 carried

out medication supply (an essential service), 11 provided prescription interventions (service outline 3.8 in Figure 17), and 9 provided training of care home staff (section 3.9). Medication reviews, which can be carried out by the community pharmacist during routine, contractual visits or by a designated clinical pharmacist, were only carried out by 8 pharmacists in total. Additionally, the requirement to visit care homes a minimum of every six months was met by 11 pharmacists, whilst 7 said they visited once a year. This would indicate a risk to patient safety unless care homes had service provision from specialist pharmacists.

1	Medication information
2	Compliance, adherence and/or concordance
3	Disease screening
4	Disease prevention
5	Clinical intervention or identification and resolving drug related problems
6	Medication use reviews
7	Medication management/medication therapy management a. Home medication reviews b. Residential care home medication reviews c. Medication reviews with continuance follow up
8	Disease state management for chronic conditions
9	Participation in therapeutic decisions with medical practitioners a. In clinical setting b. In the pharmacy
10	Prescribing a. Supplementary b. Dependent

Table 8: Hierarchical model of cognitive pharmaceutical services (Benrimoj et al 2010)

The role of community pharmacists contracted to provide services to care homes in England therefore remains mainly dispensing and supply of medication, and advice on storage and medicine administration. Similarly, Schwiezer and Hughes (2004) reported that community pharmacists delivering services to care homes in

Northern Ireland, were typically involved in medication supply, giving advice on compliance devices, advice on storage and also advice on appropriate dosage forms of medicines such as liquids rather than tablets. They pointed out that these were in line with traditional roles associated with community pharmacists. Earlier in the decade, Furniss et al (2000) had also reported that community pharmacists' involvement with care homes was primarily that of "supply and provision of basic advice about documentation and storage".

The fact that this study has reached the same conclusions shows that not much has changed between community pharmacists and care homes over the last few years despite the much-reported shift in community pharmacists' roles towards more patient –oriented cognitive services.

In the UK, there is a legal requirement for a pharmacist to be present at community pharmacy premises during their opening hours, so it is difficult to see how pharmacists could leave their pharmacies to visit or be more involved with care homes, unless they are assigned a second pharmacist or locum. This is uncommon practice and has cost implications (Schweizer and Hughes 2004).

The RPS (2016) highlighted the need for consistency in medicines optimisation in care homes. This is particularly important for people with dementia who are often subjected to polypharmacy and complex medication regimes (McGrattan et al 2017).

It was noted in the current study that 25 pharmacists (78% of those providing services to care homes) supplied medication in monitored dosage systems (MDS), a practice well established in care homes, advocated because it saves staff time and

standardises processes within the care home, and might improve adherence (Bhattacharya 2005). However, concerns have been raised about this practice as many medicines are not suitable for MDS and there is a high risk of drugs packed together interacting with each other (Webber 2015). This would put patient safety at risk, particularly frail elderly people with long-term conditions such as dementia. Furthermore, pharmacists supplying medication in this manner require robust processes for accuracy checking.

Knowledge of pharmacists about prescriptions for people with dementia

Pharmacists in England providing pharmaceutical services to care homes are required to have the knowledge and confidence the service requires (PSNC 2005) but the exact competencies are not specified. However, the framework for enhanced health in care homes (NHS England 2016) emphasises the importance of conducting medication reviews for people with dementia, focused on reduction in polypharmacy. The framework advocates a multidisciplinary approach to medication reviews, with the incorporation of a pharmacist as part of the team. Research evidence indicates that specialist pharmacist-led interventions can lead to improvement in prescribing in older adults living in the community (O'Riordan et al 2016) and in reduction of items prescribed in care homes (Furniss et al 2000). This may be due to their possession of specialist knowledge to conduct comprehensive drug reviews in this group of patients. Conversely, not many studies have investigated outcomes of medication reviews in care homes conducted by community pharmacists and explored their roles in other sectors such as intermediate care services. Bryant et al. 2009 reported that community pharmacists who had completed some form of postgraduate study or were in the

process of completing one, were significantly more likely than pharmacists who had not, to consider the delivery of clinical services. Increased knowledge is clearly important since pharmacists with postgraduate qualifications said they had the competency required. This is an important finding, as in the current study, 72.5% of respondents had not undertaken any postgraduate study. There is also an implication here for universities offering undergraduate pharmacy courses, as the question of whether pharmacists graduate fully equipped with the knowledge required to deal with contemporary shift in community pharmacist roles must be considered. Another research article succinctly addresses this by stating that contemporary pharmacy practice requires individuals with problem solving skills, who are able to apply both moral and technical authority (Waterfield 2010), confirming the view that pharmacy curricula should engage with more reflective, problem based practice (Droege 2003). Whether this has been addressed in more recent years throughout undergraduate pharmacy training is beyond the scope of my thesis. However my research results show that in terms of cognitive pharmaceutical services being provided to care homes, and to people with dementia, the gaps between theoretical and practical knowledge as well as contractual requirements have not been bridged.

In Wales, an enhanced service model from community pharmacies to care homes exists. It is structured into three tiers which allow community pharmacists to select from a level 1 service involving systematic review of medicines management processes in the care home; level 2 involving pharmaceutical scrutiny of prescribing practices in the care homes; and level three where pharmacists are expected to work with care home GPs to conduct comprehensive medication reviews (NHS Wales 2017). To offer a level 3 service in this model, pharmacists

are required to be competent and knowledgeable in identifying and taking action to minimise harm to residents from side effects, interactions, therapeutic duplication and inappropriate medication doses (NHS Wales 2017).

In the current study, only 50% of pharmacists indicated they were confident that they could identify drug interactions in prescriptions for people with dementia, though a higher percentage (61.8%) said they knew about the major side effects of drugs used as cognitive enhancers.

However, pharmacist knowledge of dementia has been found to be poor by researchers in other parts of the world: Marvano and Henkel (2017) found that half of pharmacists they surveyed in a Chicago (USA) study could not name a single side effect of Donepezil, a drug popularly prescribed to people with mild to moderate dementia, and over a quarter of them readily made inappropriate drug therapy recommendations for a person with Alzheimer's disease taking Rivastigmine (another anti-dementia drug). Similarly, Zerafa and Scerri (2016) investigated the level of knowledge of community pharmacists in Malta, using an Alzheimer 's disease Knowledge Scale and found their knowledge about risk factors, care giving factors and pharmacological management of Alzheimer's disease to be inadequate. Community pharmacist knowledge was also cited as a barrier in a UK based study by Maidment et al (2016) about how they could contribute to management of people with dementia in the community.

The use of technology to support community pharmacist activities has been around for over thirty years (Goundrey-Smith 2018) when it was used primarily to facilitate ordering of drugs from wholesalers. However, advances in technology, particularly with respect to bar code dispensing, means available software can

enable a prescription to be sent electronically to a pharmacy, scanned, checked for side effects and interactions against patient records and dispensed by robot without the input of a pharmacist (Moreton 2017). This is potentially deskilling as it means community pharmacists are not always called on to use their knowledge, and in order to continue to demonstrate specialist knowledge, particularly in areas such as dementia, pharmacists need to engage in reflective practice, using cross referencing, analysis and synthesis of information to contribute to high quality interventions that lead to consistently better outcomes for patients within the healthcare system.

There was disparity between pharmacists' response to their knowledge of drugs that cause cognitive impairment (68.6% agreed they had this knowledge) and the response to knowing which drugs people with dementia needed to avoid (only 39.3% agreed). It would be expected that respondents would know that drugs that worsen cognition should be avoided by people with dementia, as indicated by NICE dementia guidelines (2018) which cautions against use of certain medication, including over the counter medication such as antihistamines, which can worsen cognition in this patient group. However, changes in question wording, even when both pose the same question can result in differences in respondents' responses, and sometimes, the effect of this on results interpretation can be unpredictable (Gendall and Hoek 1990). One possible interpretation of the result obtained is that pharmacists' knowledge of the effect of medication on cognition ranged from poor to moderate.

According to their responses, pharmacists' had good knowledge of BPSD since 86.3% agreed to this, and this can be attributed to the plethora of publications

highlighting the superiority of non-pharmacological approaches to the management of behavioural and psychological symptoms of dementia (BPSD) over prescribing of antipsychotics which pose cardiovascular risks and other physical health risks to people with dementia (Prentice et al 2014, Furniss et al 2000, McGrattan et al 2017, Child et al 2012, Maidment et al 2016, Zerafa and Scerri 2016).

Conversely, only 32.4% of respondents to this questionnaire agreed they could recommend interventions to optimise medication therapy for people with dementia. This corroborates other results within this section of the survey which indicates pharmacists' knowledge of dementia therapy was limited, and confirms conclusions by other researchers that community pharmacists' require more training and support to provide cognitive pharmaceutical services to people with dementia (Barry et al 2013, Maidment et a 2016, McGrattan et al 2017).

Understanding and confidence

Questions in this section were worded differently, asking pharmacists what they "felt".

Confidence has been defined in psychological theory as comprising of four factors: practice experience, personal effort, amount of relevant information available and the act of decision making (Paese and Sniezek 1991).
In this context, the current study showed 51% agreed that they felt confident in their ability to contribute significantly to multidisciplinary (MDT) teams of healthcare professionals providing care to people with dementia. In another study, pharmacists have reported feeling that they lacked confidence in clinical decision

making (Butterworth et al 2017, Frankel and Austin 2013), whilst there has been suggestions that community pharmacists confidence can be improved by making them more accountable for clinical decision making, through taking on prescribing roles, with the right clinical knowledge (Inch et al 2019).

Pharmacists expressed their lowest level of confidence in recommending stopping medication they felt was unnecessary or potentially harmful for people with dementia (46% agreed they could). This was in line with their responses in the previous section of the questionnaire when only 39.3% agreed they knew what drugs should be avoided by people with dementia, and even fewer (32.4%) agreed they could recommend interventions to optimise drug treatment in dementia.

73.5% of respondents agreed they felt confident in identifying drug interactions, which seemed like a contradiction to the previous section where only 50% agreed they could identify drug interaction in prescriptions for people with dementia. This can be explained from the point of view that the statement in the previous section required certainty on the part of the respondent, whilst a similarly worded question in the confidence section only required that they indicate what they "felt" they could do. Additionally, pharmacists can access hard copy or online references for relevant information, which would explain their confidence in the ability to source relevant information when needed.

51% of respondents felt they could use summary care records; a summary care record (SCR) is an electronic record a GP holds which has information on each individual patient's medication, allergies and adverse drug reactions (Greenhalgh et al 2008) for use in unscheduled care or in emergencies. Accessing information on summary care records enables community pharmacists to avoid unnecessarily

referring patients on to other healthcare professionals (The Pharmaceutical Journal, 2015). More than half of the pharmacist respondents responding positively to this statement is understandable considering that summary care record access by community pharmacists was launched in 2015 and a roll out was on going around the time of data collection for this research (The Pharmaceutical Journal 2015).

Community pharmacists have been advocated as key links between people with dementia and the services they require in order to live well with the disease, particularly with respect to up-do-date knowledge of local support services, memory clinics and other services they can signpost people with dementia and their carers to (Brown 2017, Oswald 2017, RPS and CPPE 2017), so it is encouraging that 74.5% of respondents agreed they were able to signpost people to relevant services.

The role of the pharmacist independent prescriber in a care home has been proven to increase pharmacist confidence, and could alleviate pressure on GPs, with appropriately trained pharmacists. However pharmacists still feel that it would be challenging to accommodate this service given their current workloads (Inch et al 2019) and a specific contribution to dementia care through this service still needs to be clearly defined. However, recently, the Pharmacy Defence Association (PDA 2019) advised about the necessity for pharmacists to acquire required knowledge before taking on clinical roles such as prescribing in a chosen field.

Barriers

Barriers encountered by community pharmacists when providing pharmaceutical care to people with dementia in care homes were examined in the qualitative aspect of this research, reported in chapter 3, and were included in the current quantitative study, alongside other barriers identified in literature (Maidment et al 2016, Barry et al 2013). Over 80% of participants agreed with the majority of barriers they were presented with.

The lack of full read/write access to patients' clinical notes for comprehensive medication related services is a well-known barrier for community pharmacists (Barber et al 2009, Murray 2016, Torjesen 2018, and The Pharmaceutical Journal July 2019). Though community pharmacists now have access to summary care records, the information included in these (name, NHS number, drug allergies, medication prescribed) is not considered sufficient to support clinical decision making (Pharmaceutical Journal July 2019).

In the context of care homes, a pharmacist would still be unaware of medication related changes resulting from interventions by multiple healthcare professionals (geriatricians, GPs, community psychiatric nurses, district nurses). In support of this assertion, 86.3% of respondents in this study agreed that their limited access to clinical notes hindered the identification of drug therapy problems.

85.3% of pharmacists agreed they needed to improve their knowledge of geriatric medicine, validating the results of previous sections of the questionnaire survey which showed knowledge deficits for many aspects of pharmaceutical care in dementia.

Other barriers confirmed by over 80% of respondent pharmacists included the need for more pharmacist visits to care homes as well as a recognition that pharmacists needed to build better relationships with care home GPs in order to better communicate recommended interventions. However, pharmacists can sometimes feel inadequate when interacting with general practitioners about clinical issues relating to medication (Bryant et al 2009). One study by Smith et al (2002) found that only 17% of GPs surveyed agreed that community pharmacists should be involved with designing treatment plans, their inadequate clinical knowledge being cited as a barrier (Krska and Veitch 2001).

The use of antipsychotics for people with dementia is associated with many side effects including unwarranted weight gain, extrapyramidal symptoms, stroke and mortality (Gareri et al 2014), even though in some circumstances, antipsychotics may be required (Greenblatt and Greenblatt 2016). Thus it is no surprise that 89.2% of this study's participants agreed that pharmacists should be actively involved in helping to reduce the use of antipsychotics in dementia. However, a study of community pharmacists concerning their potential review of antipsychotic use in people living with dementia in the community (Maidment et al 2016) again revealed knowledge deficits and a lack of access to patient records as barriers for this happening.

In the current study 59.8% of respondent pharmacists agreed that the current pharmacy contractual framework restricts the level of care provided to people with dementia by community pharmacists, a view also expressed in an independent review into community pharmacy services to care homes (Webber 2015). Additionally, 67.6% agreed with the notion that clinical commissioning

groups (CCGs) determine what services are provided to people with dementia in care homes, which leads to non-uniformity of services provided. The RPS report (RPS 2016) also acknowledges that there are many stakeholders in this domain, including CCGs and various NHS organisations, and agrees with the assertion that this leads to non-uniformity of services across England.

Respondents seemed uncertain about every patient having a named community pharmacist, since only 60.8% were in agreement with this notion, but this is to be expected, as even the chief pharmaceutical officer for England, Keith Ridge, expressed his doubts about this concept, declaring that pharmacists should work as part of an integrated care system without bypassing general practitioners (Praities 2018).

Summary care records (SCR) were accessible to 57.8% of respondents in the study, 35.3% had no access, with another 6.9% uncertain whether they had access or not. Conversely, there is recent evidence that shows that despite all community pharmacists being given access to the system in 2015, nearly 85% did not access this in a typical week, and 41% were still likely to ring the GP rather than access the SCR (Wilkinson 2018). Reasons cited for this included lack of time,and fear of the unknown.

Education and training

The final section of the questionnaire which asked participants about dementia - related education and training, had only 18.6% responding that they had accessed some form of relevant training, with the remaining 91.2% agreeing that they required further training in this area of practice. Barriers to pursuing further

training mentioned were lack of time, paucity of local training events, available training coinciding with work hours, amongst others (Figure 7).

There is online distance learning training on the pharmaceutical care of people with dementia, available via the Centre for Postgraduate Pharmacy Education (CPPE). A similarly named package developed by the NHS Education for Scotland (NES 2014) is also available. However, a recent systematic review evaluating targeted training that prepares pharmacists to deliver optimal pharmaceutical care services to care homes, found that there is limited information regarding training and accreditation processes for this service, though pharmacists require expert knowledge for clinical and therapeutic areas such as management of pain, dementia, cardiovascular and antipsychotic prescribing in care homes (Wright et al 2019). These researchers corroborate the findings of the current study which showed that one of the barriers to pharmacists undertaking dementia training was the lack of available training.

Increasing workloads and role overload for community pharmacists have been quoted as resulting in work related stress (Johnson et al 2014) and could impede pursuit of education and training in long-term conditions such as dementia. This can be overcome with the right discussions and the will to do so.

Structural equational modelling using Smart-PLS

Answers to the knowledge, understanding and confidence, and barriers to care, which had good internal validity, were entered into a structural equational model using Smart-PLS® to ascertain any significant correlations. The result was the establishment of a significant correlation between knowledge, understanding and

confidence, in which increase in knowledge showed increases in confidence and understanding. The path model also showed that increase in knowledge led to decrease in barriers.

This is not the first time a structural equational model has been used to evaluate relationships in the field of pharmacy: A partial least squares (PLS) structural equation modelling (SEM) approach was used to establish a bidirectional link between job satisfaction and over-the-counter counselling in community pharmacy (Ubonas and Kubiliene 2016). Similarly, PLS path modelling was used to examine ease of use of electronic prescribing on community pharmacy outcomes (Peikari et al 2014). PLS using SmartPLS highlighted that pharmacists work stress greatly influenced their perception of working environments (Boyle et al 2016).

It is the first time, to the best of the researcher's knowledge that this has been used to link community pharmacists' knowledge of dementia to their understanding and confidence in dealing with people with the disease, as well as establishing a link between knowledge and barriers to care in this subject area.

These correlations, coupled with the responses from pharmacists indicating requirements for more knowledge, education and training in dementia, formed the basis of the development of a bespoke medication review tool for pharmacists later in my research.

4.5 STRENGTHS AND LIMITATIONS

This study is the first to the researchers' knowledge that has undertaken a holistic examination of the nature of services provided by community pharmacists to people with dementia living in care homes and combined their perceptions of their

own clinical knowledge with perceived barriers. It is also the first time an attempt has been made to establish correlations between pharmacist knowledge and barriers to care using structural equational modelling.

An additional limitation of the study was that likely response rate was not factored in when calculating the sample size, and the actual response rate was low, and even though the study findings have been similarly highlighted by other researchers exploring the role of pharmacists in dementia care, the small sample size makes the results less generalizable.

There are standardised questionnaires available in the literature for establishing attitudes to dementia, as well as knowledge of Alzheimer's disease. The use of such validated tools could have made the knowledge and confidence sections of my study more robust.

CONCLUSION

The findings of this study highlight deficits in pharmacists' knowledge of specific aspects of pharmaceutical care in dementia; it also shows that while some community pharmacists contracted to provide services to care homes fulfil their contractual obligations, only a small number of conducted medication reviews or visited the care homes. Both are services that are included in the service specification. More research needs to be undertaken to explore how pharmaceutical services provision from community pharmacies to care homes can be standardised.

Additionally, many barriers exist that prevent more pharmacists from providing comprehensive pharmaceutical care services to care homes, including their role in dementia care for residents not being clearly defined.

Community pharmacists could play a vital role in improving early diagnosis for residents of care homes who show early signs of cognitive impairment, but have not been assessed for a possible dementia diagnosis, and their role in medicines optimisation for people with dementia can be enhanced with more targeted training, funding and resources. This will expand their reach and improve medication related health outcomes for care home residents living with long term conditions, particularly those with dementia.

CHAPTER 5
Living with dementia in care homes: A qualitative exploration of the views of care home staff about medication related needs of residents

5.0

5.1. Introduction and chapter overview

Care homes have, over the years, provided accommodation and personal care (residential homes) plus nursing care (nursing homes) for a growing population of older adults over the age of 65 in the UK. The clientele is usually those who suffer from chronic illness, are disabled or have a mental health disorder that renders them incapable of caring for themselves (Dofournet et al 2019, Verbeek et al 2012).

People living with dementia become increasingly reliant on carers as their disease progresses, due to their complex needs (Poland et al 2014). Dementia has been identified as one of the biggest single health-related determinants of care home admission, with an estimation that 60-70% of care home residents have some form of dementia (Alzheimer's Society 2016b).

In the UK, dementia has overtaken heart disease as the leading cause of death (Office for National Statistics 2012), with the cost of providing care for people living with dementia currently set at approximately £23 billion a year and growing. Community pharmacists are required, as part of service provision to care homes, to ensure appropriateness and clinical effectiveness of medicines use as well as the provision of advice on medicine administration (PSNC 2019) but the exact nature of such services that target chronic illnesses such as dementia are not well defined, and the patterns of medication use in people living with dementia in care homes remain largely uncharacterised (Blass et al 2008).

People living in care homes are at high risk of, and more vulnerable to medication errors than their counterparts living in the community (Saeed and Stretch 2010).

Care home managers are accountable for the day to day running of the homes and, along with care home staff, have a responsibility to provide safe, personalised care for residents.

As part of providing personalised care, care home staff are required to identify and record individual residents' medication related goals, needs and preferences (Sawan et al 2019)

There is a paucity of research investigating the perceptions of care home staff about the medication related needs of people living in care homes with chronic conditions such as dementia, and even less information about their views on the quality of services they receive from pharmacists, or indeed their expectations from pharmacy services.

The impact of specialist clinical pharmacists working in care homes to reduce potentially inappropriate prescribing of medication has been widely researched, but results of specialist cognitive pharmaceutical services geared towards reducing the number of medications prescribed have failed to show clear evidence that such services lead to improvements in adherence or cognitive functioning of residents (Saez-Benito et al 2013).

A clear understanding of the relationships between co-morbidities, medication related needs and overall person-centred care of people with living with dementia in care homes is needed, in order to promote improved health outcomes through pharmacist interventions.

This chapter presents a study that broadly explores the views of care home staff about pharmacy services provision to their care homes. These staff are principally involved in medication administration and management in participants' care homes.

I contend that specifically designated care home staff members are best placed to comment through interviews, about the medication related needs of care home residents. Further exploration could reveal whether care home staff are aware of the specific needs of residents with dementia which can be relayed back to pharmacists looking to deliver enhanced pharmaceutical care services to these establishments.

5.2 Methods

5.2.1 Aims and objectives

Aims

- To explore the views, perceptions and opinions of care home staff about the medication related services provided to care homes that have people living with dementia
- To ascertain the knowledge of care home staff about the medication related needs of residents living with dementia

Objectives

- To investigate the awareness of care home staff about the medication related needs of people living with dementia in their care homes

- To explore the nature of medication-related services provided by community pharmacists and other health care practitioners to people living with dementia in care homes
- To make recommendations for best practice in medication related services for residents living with dementia

5.2.3 Setting

Care homes located in Thurrock Council, Essex, England registered with the Care Quality Commission (CQC), with provision for people with dementia.

5.2.4 Study design

A qualitative approach, involving face to face interviews was utilised to explore the views and perceptions of care home staff caring for people with dementia. A semi-structured interview schedule with fixed questions was used, but respondents were able to raise issues not covered by the schedule (Bowling 2009).

The qualitative study design was chosen because it enabled an in-depth exploration of issues from the perspectives of the research participants.

5.2.4.1 Research Governance and Ethics

Ethics approval was obtained from the University of Sussex Cross-Schools Research Ethics Committee (CREC) before commencement of the study (Appendix 5a)

NHS ethics was not applied for, because when research involves NHS and/or social care staff recruited as research participants because of their profession, it is not required (Health Research Authority 2016).

5.2.4.2 Sampling, participant recruitment and informed consent

A purposive sample of care homes in Thurrock, Essex, that have dementia patients was identified by searching the website https://www.cqc.org.uk/search/site/care%20homes?sort=default&distance=15&mode=html&f%5B0%5D=im_field_popular_services%3A3668 (CQC) (2017). This website has a database of care homes within England and Wales by post code, as well as by the nature of services provided. The Thurrock area was selected for convenience sampling, and the CQC website chosen as opposed to the website used in phase 3 of this research (Chapter 3). This was because in addition to listing care homes in a similar manner, the CQC is the official regulator for health and social care services in the UK, therefore has inspection reports and ratings of each care home listed.

Care home managers of the homes identified were contacted by the researcher and invited to participate in the study or to nominate a care home staff member charged with managing medication in the care home. A purposive non-random sampling approach which is based on selecting individuals with a particular characteristic for a study was used.

There were 17 care homes that were listed as providing care for people with dementia in Thurrock at the time of the study. The researcher aimed to recruit staff from 10 of these. This was not a statistical sample based on a power calculation as this is not required for qualitative research.

The 17 care homes were ranked in order of the number of dementia beds per home as published on CQC website and care home staff of the 10 care homes with the highest number of dementia beds were approached to participate.

A written letter of invitation (Appendix 5b) and participant information (Appendix 5c) about the study were sent to each care home selected. This was followed by a phone call later to ascertain their willingness to participate. Participants were also provided with a consent form (Appendix 5d), and advised that even after agreeing to take part, they could withdraw from the study at any time by contacting the researcher. All information obtained was kept strictly confidential, with intention to remove all person identifiable material from the research report.

5.2.4.3 Inclusion and exclusion criteria

Staff of homes with dementia patients in the study setting were included, whilst those of care homes not registered to provide care for dementia patients were excluded.

5.2.4.4 Research instrument

Semi-structured interviews following a standard format (Appendix 5e) were carried out face to face with consenting care home staff at their place of work. A pilot was not carried out for this study, but the interview schedule was reviewed and approved by the study supervisor.

5.2.4.5 Data handling and analysis

Interviews were conducted in the care home at a time convenient for the participant, recorded digitally and recordings safely stored in a digital safe accessible only by the researcher. Data will be stored for five years following completion of the study to enable verification of findings if required.

The recorded interviews were transcribed verbatim and content analysis carried out using a thematic analytical six step process involving familiarisation with the data, generating initial codes, searching, reviewing and defining themes and finally writing up findings (Braun and Clarke 2006).

The researcher carried out the coding and identification of themes, and the academic supervisor also did the same independently. They then compared notes to identify common trends and define final themes.

During theme development, staff perceptions of the adequacy of pharmacy services and challenges with providing fundamental care for people with dementia seemed like potential themes, but during data analysis, a more flexible approach and wider view of the data was adopted that enabled the realisation of the four main themes prevalent in the results.

Findings were independently verified by the academic supervisor to assure its reliability and confirm data saturation, which was reached by the 10th interview. No person/premise identifiable data was included in the report.

A COREQ (COnsolidated criteria for REporting Qualitative research) checklist was completed and can be found in Appendix 5f.

5.3 Results

11 participants were interviewed for this study as one care home recruited consisted of two wings operating independently of each other, both with varying proportions of people with dementia and varying diagnoses of dementia type (Table 9).

Data were also collected about the qualifications of the care home staff participants and the number of years' experience they had working in this field (Table 10)

The preliminary themes were characterised (Figure 18) and narrowed down to four main themes (Figure 19). These are presented in detail in this section.

Staff Code	Care home code	Type of care home	% Residents with Dementia (approx.)	Diagnosed before or after admission to CH?	Type of dementia recorded?
C1	H1	Residential only (P)	97%	Majority before, 2 or 3 after	Some
C2	H2	Residential only (P)	95%	Majority before	Majority AD
C3	H3	With Nursing (P)	99%	All diagnosed before, except 1	83% (VD) remainder unknown
C4	H4	Residential only (P)	75%	Majority before(4 or 5 after)	Yes
C5	H5	With Nursing (P)	80%	All diagnosed before as no admission without diagnosis	Some
C6	H6	Residential (V)	70%	All but one diagnosed before	Majority AD
C7	H7	With Nursing (P)	70%	Majority before	No
C8	H8	Residential only (P)	95%	Majority before	No
C9	H9	Residential only (P)	25%	All before	Yes
C10	H10	Residential (P)	70%	Most before, handful after admission	Some
C11	H11	With Nursing (P)	50%	Half diagnosed before	Yes

Table 9: Type of Care Home and proportion of people with Dementia

AD=Alzheimer's disease, VD=Vascular Dementia DLB=Dementia with Lewy Bodies FD=Frontotemporal Dementia; P=privately owned, V=Voluntary (not for profit)

Care home code	Staff Gender	Qualification	Number of years' experience
C1	Female	RGN, NVQ2, NVQ3	5
C2	Female	Midwife	10
C3	Female	RGN	20
C4	Female	NVQ2 (Health and Social care)	4
C5	Female	RMA+ NVQ3 Assessor	25
C6	Female	NVQ4	23
C7	Female	RGN	7
C8	Female	Teacher, NVQ3 Health & Social care	4.5
C9	Female	NVQ2+NVQ3	8
C10	Female	RGN	14
C11	Female	Not disclosed (Deputy Manager)	13

Table 10: Participant information including qualifications and number of years' experience

NVQ= National Vocational Qualification, RGN = Registered General Nurse

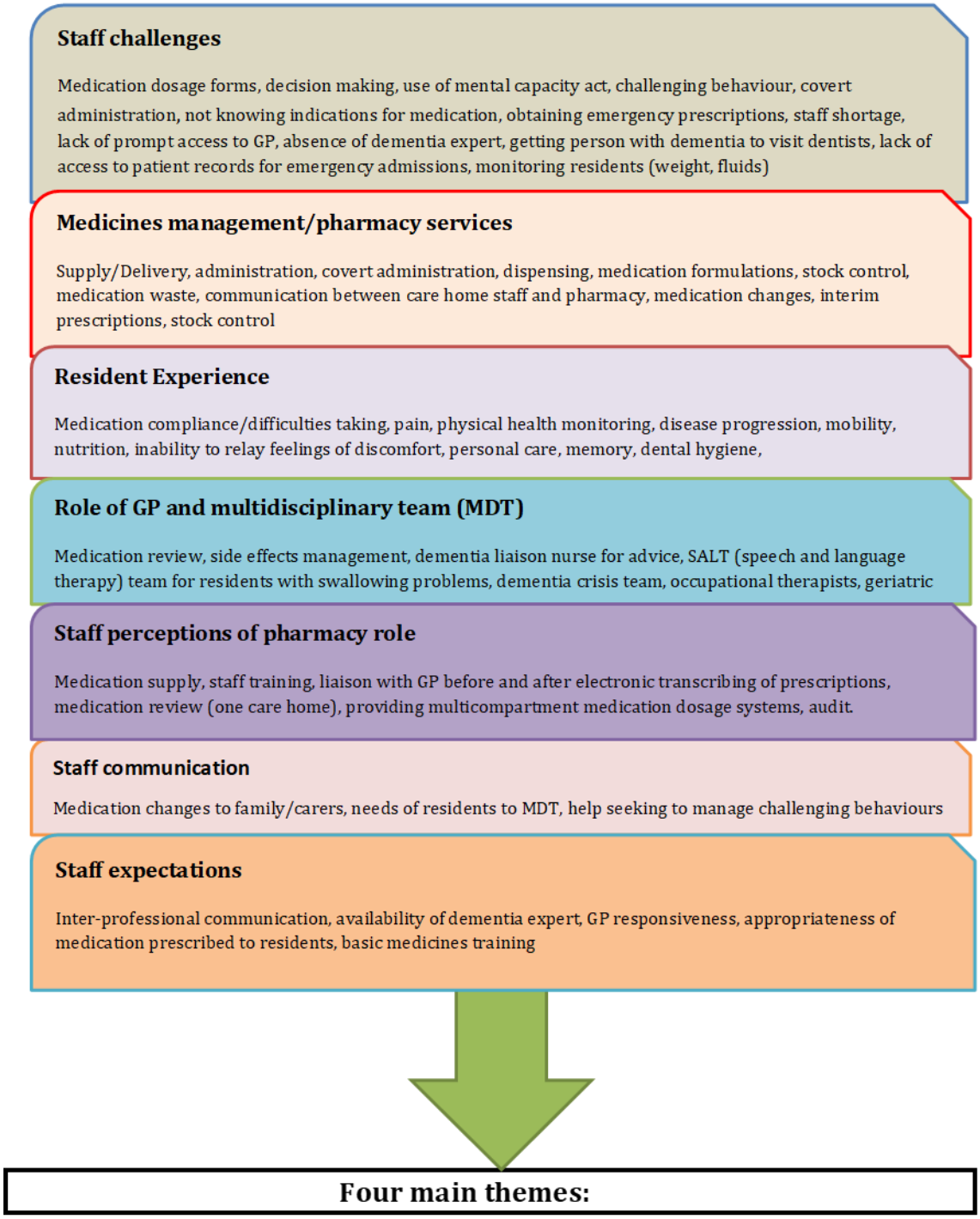

***Figure 18**: Preliminary themes*

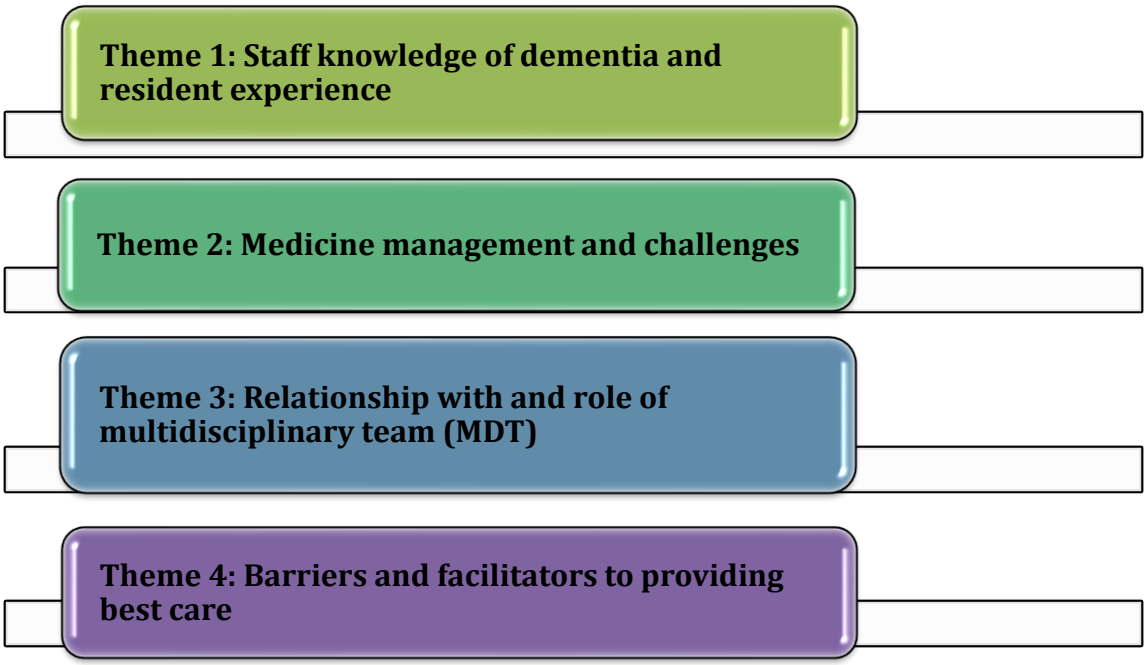

Figure 19: Major themes

5.3.1 Resident and staff information

Seven participating care homes provided residential care only (H1, H2, H4, H6, H8, H9, H10) while the other four (H3, H5, H7, H11) provided residential plus nursing care. The care homes in the study accommodated a varying proportion of residents with dementia from 25% (H9) up to 97% of residents (H1).

The majority of residents with dementia had their diagnosis before admission into the care homes, but fewer were estimated to have the sub-types (causes) of dementia recorded in their notes. Most residents with the causes of dementia recorded had Alzheimer's disease, some had vascular dementia and a few others

had dementia with Lewy bodies. One care home had a resident with frontotemporal dementia, which participating staff called "frontal lobal dementia". Care home staff in the study were all females, and were qualified to various levels (NVQs, registered nurses, a midwife) with their number of years' experience in care homes ranging from at least four years (C4) to 25 years (C5).

5.3.2 Staff knowledge of dementia and residents' experiences of its symptoms

This theme focused on what staff knew about dementia, their subtypes and how residents experienced symptoms.

Participants displayed some knowledge of dementia, the assessment process and dementia subtypes. The general view was that most residents with dementia were diagnosed before admission into care homes and depending on whether they had been seen by the memory clinic, had the sub-type recorded. One care home staff (C1) in response to the question of whether they were informed of the cause of residents' dementia responded:

"Not always-if they have come from the memory service/done scans, yes, if not, records say 'unspecified'" (C1)

Similarly, C9 confirmed that their residents rarely had causes of dementia noted in their records:

"Very rarely, sometimes you'll only get dementia on the assessment form and care staff rely on relatives to tell them what type of dementia the resident has" (C9)

There was also recognition that the sub-type of dementia impacted on the residents' treatment plan:

"We have to know what kind of dementia they've got because we need to know how we're going to treat them. There's Lewy Body and then Vascular dementia. You know their behaviour is different" (C5)

References were made to person-centred care with some care staff expressing the opinion that irrespective of dementia sub-type, each individual resident behaved differently and should be treated as such.

"Everybody's behaviour is going to be different anyway, so regardless of what type they have got, you have to learn their behaviours and what they are like, and what they are going to be behaving like within the care home."(C1)

Additionally, staff demonstrated knowledge of the need to keep a close eye on residents, ensuring that they were eating properly, and generally have their physical health monitored especially if they noticed changes in resident's behaviour:

"We watch their mobility, their eating, obviously especially eating, because of obviously the weight loss….we monitor all…" (C3)

"*We have daily notes that we fill every day, health records and everything, so if we think there's a change in their behaviour or anything the we can monitor that then go through the correct people to let them know-doctors, consultants-to say what we think is happening" "*(C9)

Determining why a resident was resisting personal care, or behaving aggressively was a skill deemed necessary, partly to protect the staff and also to differentiate between behaviour resulting from other physical health conditions or behavioural and psychological symptoms of dementia. Of note, one care home shared her awareness and experience of aggressive behaviour being potentially due to fluctuating sugar levels rather than BPSD:

"…with people's behaviour…if they've got diabetes and they're on insulin and metformin and whatever, you have to look whether this, even though they've got dementia, is it the dementia making them the way they are, or is it because their sugar levels have not been checked? "(C3)

To this effect, care staff interviewed shared the view that it was important to have the mental capacity of residents assessed especially with regards to covert administration of medication.

"If a resident continually refuses, we would usually get an MCA or deprivation to do it covertly" (C8)

With respect to getting an "MCA", the participant (C8) was referring to the care home working within the principles of the Mental Capacity Act (MCA) (2005) which requires that the mental capacity of the resident be assessed and evidence obtained that they lack the capacity to make decisions about their own care, thus allowing the care home to legally make decisions in the residents' best interest. "Deprivation" in this context was in relation to the Deprivation of Liberty Safeguards (DoLS), which the care home applies for, from their local authority which allows them to legally keep a resident in the home without the freedom to leave, because the resident lacks the capacity to consent to arrangements for their own care and treatment (Care Quality Commission 2017). Staff in care homes are required to know about these legislations so that the rights of residents are not violated during attempts to administer care or treatment.

The importance of involving family or carers in decision making in these circumstances was also highlighted.

"If it is early stages of dementia, you can communicate with your resident….but if it is advanced stage and they're refusing medication, you can't communicate with them, you need to communicate with the family" (C7)

Keeping family members of residents informed about medication changes and adverse effects were routine practice in care homes, and it was recognised that good communication links with the family of residents was key.

"We inform the family. The residents are unable to know as they've got dementia. They're unable to retain the information so we ring the family to say that some medication has been started, some medication has been stopped." (C4)

From experience, some staff participants alluded to non-pharmacological care of people with dementia, asserting that to improve quality of life for dementia sufferers in care homes, some level of continued interaction with people outside of care homes would be useful.

"As much as we are trying to take our residents into the garden…..it is not the same as going and being in a group of, a different group of people, other than the same people they see on a day-to-day basis."(C11)

On the whole, staff interviewed displayed good knowledge about the needs of people with dementia especially with regards to developments arising due to disease progression; medication taking; families' wishes, and how to deal with challenging behaviour in a person-centred manner.

Staff views on residents' medication related needs and pharmaceutical care services provided are discussed in-depth in the next section.

5.3.3 Medicine Management and its Challenges

This theme was derived from all the responses related to processes followed by care homes with regards to medication; staff views about medication related needs and challenges associated with caring for residents with dementia as well as staff perceptions about pharmacy service provision.

Staff members interviewed were all involved in one way or another with managing medicines for residents, particularly ordering medication and its administration.

The main perception noted about managing medication is that the process involved:

- receiving medication from pharmacy,
- booking in,
- changing over the trolley for start of new month,
- collecting interim prescriptions required within the month outside of repeat prescription requests and,
- booking these in when delivered.

Medication pre-packed for residents into medicine dosage systems such as dosette boxes or "pods" helped staff manage administration better. Residents missing medication doses was also an issue highlighted:

"..The other thing is the medication administration by staff...I do counts and sometimes, in the odd occasion when somebody signs something and it's not given, we get too many tablets left....there's a signature missing, or there's a signature there and the tablets have not been given. We tried to address that by having 'pods', which is working...instead of people having to select tablets out of each box, all the tablets are put into pods now. So they've got morning and lunch time, a bit like the dosette boxes..." (C6)

Ordering medication and having it dispensed and delivered on time was ranked high when discussing the medication related needs of residents with dementia, particularly those with advanced dementia and receiving end of life care.

When asked to comment on medication related needs of residents with dementia, interviewees highlighted facing challenges with residents who had difficulty with swallowing and therefore needed medication prescribed in formulations easy to swallow such as liquids, dissolvable tablets or patches. For residents with an agreement in place, the ability to conceal medication in food was almost unanimously agreed as a necessity.

"I would say it's mostly around the form of the medication, a form that is easy to swallow. Some of the service users are receiving medication in a covert form, so it is all about prescribing medication that are easy to crush, medication that are easy to dissolve in their mouth, dispersible, oral solutions. I would say it is mostly around the form of medication, with dementia services" (C11)

Staff also faced challenges with residents refusing medication and had clear procedures to manage refusal. This usually involved observation to ascertain the reason for refusal, liaise with GPs to re-evaluate the need for the medication and if swallowing was the problem, involving the SALT team. Care plans were put in place and updated to reflect these.

"Yes, refusal, we get that quite a lot. Obviously when people get quite advance dementia, they tend not to like to take medication, so obviously in their best interest, we know they need to take medication, whether it be for blood pressure, or diabetes, but there is quite a lot of times they will just completely refuse to take it" (C10)

"*If medication refused three times on consecutive days, then we ask the doctor to review the medication and we ask the doctor if it should stop or continue"* (C5)

Cognitive deterioration resulted in some residents needing constant reminders to take their medication as they often forgot, and staff were on hand to offer prompts until taken. Refusal and forgetfulness led to medicine wastage.

Medication related services were outlined as mainly involving prescribing by doctors; and dispensing and supply by community pharmacies.

The main pharmacist involvement, in all but one care home visited was described as supplying medication, liaising with GPs to obtain repeat prescriptions, dispensing and delivery.

"Pharmacy gets the prescriptions, put them into bubble packs and send them" (C9)

Supply of medication from pharmacy was not without challenges, particularly with prescriptions sent over electronically, or when pharmacists went through repeat

prescriptions for a care home and noted medication not prescribed then had to chase doctors.

"They supply all our medication. They will liaise with the GP now. We don't so much get the green prescriptions anymore. We request the prescriptions and they go along electronically to the pharmacy, which can be a little difficult because sometimes we're chasing up medication that we should have, and they're holding it back for the monthly, not aware that sometimes we need it ASAP…."(C2)

However, pharmacists were also involved in auditing in care homes (correct ordering procedures, storage, use of MDS and administration) as well as staff training on using the dosage systems they supplied. These audits were done annually or bi-annually.

Care homes contacted pharmacists for help with verification of adverse effects of medication before going on to GPs for prescription amendments. In addition, pharmacists were quoted as being handy in responding to queries relating to dosage intervals, compatibility of medication with foods/liquids in case covert administration was advised.

…"Pharmacy will advise us, with the doctor, on what medication can be crushed or what can be taken covertly, what can't, and stuff like that…." (C10)

Routine medication reviews were carried out mainly by GPs (intervals ranging from 6-weekly to every six months, or remotely over the phone, in response to phone calls from care homes). The dementia crisis team and dementia liaison nurse were involved in reviewing medication for residents with challenging behaviours.

One care home had a visiting specialist care home pharmacist but this service had only just started so the staff could not comment on the impact of the service, though they did point out that there was lack of communication between the care home pharmacist and the community pharmacist supplying medication.

"…the pharmacist that comes here and the pharmacist that does dispense the medication are two different people. They don't communicate. If they were to communicate a bit more, they might find the system would be a bit better" (C3)

The role of community pharmacy was deemed to be that of supply and delivery and when viewed this way, pharmacy services were considered satisfactory:

"…they deliver the medication on time, especially if we need antibiotics and need that antibiotic today, you call the GP, he will do the prescription, send to pharmacy and they will deliver the same time" (C7)

"They save us time because the previous pharmacy we were with, we had to chase up prescriptions if they weren't printed in time to get medication ready for the next cycle, whereas, they do all that for us now" (C6)

A couple of participants conversely thought that pharmacists could do more, though conceding that pharmacists had time constraints:

"They are well placed because they know the residents. They could do more, I feel, more than they do at the moment to support services, as with dementia, but no, at the moment, there is not much support from the pharmacy team" (C9)

"I think medication need reviewing more often and obviously, I know they are quite busy as well, but maybe pharmacy staff could explain what those medication are, rather than just putting them in a pack and sending because that's what is requested," (C8)

Staff did not think there were any pharmacy services tailored for people with dementia but acknowledged that the dementia liaison nurse and dementia crisis team reviewed medication, particularly in introducing or reducing antipsychotics for those with challenging behaviour.

5.3.4 Relationship with/role of multidisciplinary team (MDT)

This theme was about the contributions of healthcare professionals to care of people with dementia in the care homes visited, and the relationship staff had with members of the multidisciplinary team.

Overall people living with dementia in care homes had input from a plethora of health care professionals, named by care home staff interviewed as:

- Dementia liaison nurse,
- community pharmacists,
- nutritionists,
- dementia crisis team,
- speech and language therapy (SALT) team,
- general practitioner (GP),
- geriatrician,
- district nurses,
- chiropodists,
- occupational therapists,
- falls team,
- physiotherapists,
- Parkinson's nurses and
- podiatric team.

"We have physios, we have Parkinson's nurses, Alzheimer's nurses. There is a geriatrician team that is involved, district nurses, community nurses…..that is part of the team looking after service users with dementia" C11

The greatest input into care homes seemed to come from the dementia liaison nurse, dementia crisis team and GPs. Care homes relied on the dementia nurse and crisis team for advice on managing residents with challenging behaviour.

"We get a doctor, a referral, and then we get this dementia crisis team. If the behaviour is changing, then we need the service of the dementia crisis team to help us out. They have their own doctor, and they can prescribe medication…..it is not our duty to prescribe medication, it is the dementia crisis team….when we get the prescription, it goes to the pharmacy and they're the ones who dispense the medication" (C5)

Not all healthcare professionals were available to all care homes, and one declared that they only had the dementia nurse, crisis team and someone to help the home with general nutrition, but admitted that that they were able to access help when needed:

"If we have any problems, we have got people we can contact….we tend to manage what we can manage in the home. Only when we have got a problem would we call outside services in…..If someone starts becoming really aggressive, so that you can't manage their needs, and it gets to a point where you can't cope anymore, then you would need advice and you would need help from outside" (C1)

Whilst staff knew which member of the MDT to contact with various concerns, it wasn't always the case that they would get a prompt response.

"It is really difficult, though, because we try to refer them as quickly as possible and unfortunately, with the NHS system, they don't always react to it quick enough sometimes and then we have to find another route and that's usually when I bring M in (dementia nurse) especially when it relates to dementia and we troubleshoot it and try and find the best possible route to find the answer to our problem" (C6)

Though healthcare professionals from many disciplines were quoted as available to help care homes, there was no indication during any of the interviews carried out, that these teams collaborated with each other in an integrated manner.

Care homes dealt directly with individual services and updated care plans with the outcomes. This lack of collaboration could result in waste of resources since the same care home would also have a GP, geriatrician, crisis team doctor, and dementia nurse visiting to review medication.

Pharmacists, seen in the traditional role of "suppliers" also needed to provide answers as to whether suspected side effects to medication were attributable to specific medication they had dispensed, and were also consulted to help doctors choose appropriate formulations to suit the needs of residents. However, doctors/GPs/geriatricians/dementia nurses were viewed as the professionals that

could "action" suggested solutions by prescribing alternative medication, stopping medication or giving advice to counter side effects.

The role of pharmacists in the identification of drug therapy problems did not come out in the interviews, as they tended to be seen as adopting a reactive rather than proactive approach. Family or carers of residents were informed of changes to residents' care plans (medication) retrospectively according to staff interviewed.

"First of all, we would update the care plan; there is medication in the care plans, so that's written there. Then in the professional notes, we would write it down, if the service user has capacity, we would discuss it with them. If not, we notify the next of kin to let them know there have been changes to medication." (C11)

In none of the care homes was there mention of families or carers being informed before decisions were made with regards to changes to medication of their loved ones, rather a phone call after the decision had been made to make medication related changes was the usual practice. This appears to reflect another gap with regards to integrated care, as a system where care homes occasionally held multidisciplinary team meetings would accommodate attendance by family members to raise concerns to different healthcare professionals about care of their loved ones.

5.3.5 Barriers and facilitators to care provision

Having talked about challenges faced by staff in relation to medication related needs of residents with dementia, the next theme focused on the barriers they faced to providing care.

Care staff recognised the importance of managing pain in people with dementia, with many interviewees pointing out that affected residents could not communicate their needs effectively.

However, sometimes requests for painkillers from doctors would result in prescriptions being sent directly to the community pharmacy by the GP, and because of a lack of communication between the two regarding the reason for the prescription, the pharmacy would sometimes withhold the prescription till the end of the month for routine delivery. In addition to this, pharmacists often withheld prescriptions with the assumption that care homes were over-ordering, again without communication. Attempts by a particular care home to arrange a three way meeting between their pharmacist, home manager and GP failed.

"…When they get a prescription electronically from the GP, they will keep hold of it. And they will think it is part of the monthly meds, and it's not, we've requested it, we want it now……

"We've tried and tried. We had a meeting with the health centre a couple of months ago and pharmacy was meant to be there, because we had a big issue with who was holding up medication, X Pharmacy did not turn up for the meeting" (C3)

It is noted that care homes are unable to purchase over the counter painkillers for use in residents they know or suspect are in pain, due to company policies that do not allow 'homely remedies'.

"If somebody is in pain, or they've got a bad head, you can watch their body language, you can see. If they are not prescribed PRN (as required) paracetamol, I can't give anything. I've got to let them have a bad head" (C3)

Staff opined that GPs could visit more frequently instead of issuing instructions over the phone or prescriptions electronically, since they sometimes did not know the particular needs of the individual they were prescribing for:

"I think the GPs; they don't always have the needs of the service users in mind when certain medications are prescribed….you can prescribe medication that is easy to swallow. Simple things like that, But I believe they have a big impact on the mental health and wellbeing of service users" (C11)

To facilitate better care for people with dementia to ensure they continue to live well in an environment they are familiar with, one staff interviewed suggested that a consultant dementia specialist could visit the homes to see residents:

"It would be nice to have somebody who specialises in dementia as a consultant, to come in and visit the homes and see the residents and what issues we're having. We deal with as much as we possibly can, but it is a shame when you can deal with it no longer, they get shipped out to another care home, where they just strip them of their medication and start again, whereas they could probably provide the same sort of service here where they're comfortable and where they know the environment" (C6)

A lack of understanding of dementia by emergency care services was also raised as a concern, and participants shared the view that people with dementia should be treated with more dignity:

"It think there needs to be better understanding because especially with hospitals, if unfortunately we have to send someone to A&E,, I think there's very little understanding and I think because they've got dementia and they're old, unless they're loud and causing trouble, they'll force them to wait, and it's almost like that's it, their life is over anyway.."
"I don't think because someone has got dementia and they're in their 80s, you just put a DNR (do not resuscitate) in place and leave it at that, which is what tends to happen" (C8)

"I do understand that from the moment they are diagnosed to the moment they pass away, it might even be up to 15 years, so you want them to have a good quality of life and you want then to be, you know fairly well and medically well."(C11)

Furthermore, when care homes themselves had to accept emergency admissions to care homes, they had no immediate access to patient records to determine what medication to prescribe:

"If we have, let's say emergency admissions of service uses, say there's been an incident at home, and they have to be admitted to us, as an emergency patient, there is very little support. Very often, these service users are not medicated, we don't have access to their

records, we don't know what medication they are on, when they were seen. So there is potentially a lot of work to be done. (C11)

This would indicate a gap for the provision of medicine reconciliation services by pharmacists to care homes. This could be offered remotely if pharmacists were given full access to electronic patient records.

Staff were also of the opinion that there were not enough services to help people with dementia stay active as part of enabling them to live well with their disease. Suggestions included more exercise, more activities and visits to day care centres. The facts that most of these care homes were privately owned coupled with lack of funding from councils were viewed as barriers to providing such services.

"I think, and I mean I know, obviously, finances with councils and things like that are tough as it is for our bosses, they are private owners. I think a lot of people in dementia homes, there should be more facilities to stimulate them…that are tailored for them" (C8)

Providing dental hygiene to people with dementia was mentioned as an area where care could be better.

"I think with teeth, dentist; that would be something that would be beneficial, obviously taking them to the dentist, trying to get them to open their mouth, things like that. Something to be provided as well (because it is hard to actually brush their teeth sometimes), it would be nice if they made some kind of sweet tablet they could take to help clean their teeth" (C8).

This was an example of a lack of standardisation of services provided to every care home since some care homes had visiting dental teams as part of the MDT supporting them.

The streamlining and standardisation of approaches to provide support for people with dementia in care homes to live well is necessary. Every care home should have a list of essential services they have to provide to residents. This would go a long way towards improving the quality of life for this patient group and make care provision easier for staff.

5.4 Discussion

Resident demographics and care home characteristics

This study was carried out in 11 care homes despite the initial intention to select only 10 care homes in the chosen frame. This was because one of the care homes operated as two care homes in one location with one home (named differently) operating as a residential only facility and the other with nursing care.

All care homes selected had people living with dementia in them with proportions ranging from 25% residents with dementia (H9) to 99 %(H3).

Varying proportions of people in care homes are reported to be living with dementia. Two thirds (approx. 66%) was the estimate by the Alzheimer's Society (2007), 69% (Prince et al 2014), 70% (Matthews et al 2013), and more recently, 70% (Alzheimer's Society 2019a). Another report estimated that approximately four in five residents of care homes in the UK had people living with some form of dementia (Alzheimer's society 2013).

The study did not record gender specific data, but on average, it is thought that 53% of male and 71% of female residents of care homes are living with dementia (Prince et al 2014, Ballard et al 2018).

This means that the proportions in some of the homes where staff were interviewed for this study were higher than national average, but this can be attributed to the fact that some care homes were dedicated to catering mainly or exclusively for people with dementia (H1, H3, and H8 in the study).

Most residents with dementia were reportedly diagnosed before admission into the care home, and by implication, this means dementia was the likely reason for the choice to seek residence in a care home.

Research shows that there are many factors that inform an individual's decision to transition into a care home. These can be linked to the Anderson behavioural model (Anderson and Aday 1978) which postulates that utilization of various health care services is sequential and a conditional function of the predisposition of individuals to use a service, their ability to secure the service (economic factor) and the need for the service (health related factors).

People with dementia fall in with the third factor as their disease progresses and their ability to self-care reduces and leads to the need for various care services. To this effect, it can be extrapolated that of the 500,000 people living in over 20,000 care homes in the UK (Cousins et al 2016, Laing 2013), considering upper end of Alzheimer's Society (2013) estimates, up to 400,000 may have some form of dementia, a sobering figure.

Studies examining predictors for admission into care homes have shown that old age, gender (women), cognitive impairment and suffering from some other key chronic medical conditions are the highest risk factors (Sinclair, Stanford and O'Connor, 1988, Kasteridis et al 2016).

Amongst long term conditions, dementia is independently associated with an increased risk of care home placement and though other conditions such as functional dependence and cerebrovascular disease are also associated with placement in care homes, dementia and cognitive impairment are main contributors to institutionalisation in the elderly population (Aguero-Torres et al 2001).

The care homes included in this study were all privately run, supporting the observation that for the last three or four decades, provision of residential accommodation and care has changed steadily from public to almost exclusively private (independent) provision (Lievesley, Crosby and Bowman 2011, Gage et al 2012). Participants in the study were not asked about their opinion of the quality of care their residents received, but homes registered for-profit by small businesses catering for publicly funded residents have been judged to have lower standards than corporate for-profit homes holding specialist registration and charging higher fees (Gage et al 2009).

Staff knowledge of dementia and residents' experience

Care home staff interviewed for this study listed their qualifications and years of experience, with the least number of years' experience being four years, and the minimum disclosed qualification being NVQ level 2. Two care homes employed registered general nurses. The study did not seek to establish whether the number of years' experience declared by care home staff were in the same care home or a variety of others. However, there is a high level of staff turnover in care homes (Royal College of Nursing 2012), even though recent trends show an increasing number of degree level nurses working in care homes which could potentially result in higher quality of care for care home residents (Backhaus et al 2015). Other researchers also found that having a dementia program or dedicated unit were associated with positive commitment towards staying in dementia care (Lee et al 2013).

Additionally, though concerns have previously been raised about the quality of nursing care provided to people living in care homes (CQC 2014), this study did

not seek to establish a link between the level of staff qualification and/or experience to their knowledge of dementia and residents' lived experience. However, considering that numbers of people with dementia living in care homes are continuously on the rise, the importance of health workers in the care home sector having specialist dementia knowledge cannot be over emphasised (Royston et al 2017).

With regards to knowledge about dementia, staff in the current study displayed knowledge of the pathway for assessment and diagnosis of dementia, as well as knowledge of sub-types (causes) of dementia. They stated that most people with dementia in their care homes were already diagnosed before admission, but most didn't have their sub-type recorded unless they came in via the memory clinic.

This is in line with the NICE guidelines (2018) and NICE dementia overview and diagnosis pathway (2019) which have been discussed earlier in this thesis. The importance of determining the dementia sub-type, which affects the management, disease course, outcomes and treatment has also been stressed (Robinson et al 2015. Characterisation of sub-type is also important for care planning purposes (Albretch et al 2019). Staff in the study specifically pointed out that people with vascular dementia behaved differently from those with Lewy Body Dementia, for example.

In the interviews conducted, staff made many references to person-centred care, from pointing out that they needed to learn every individual's behaviours, to expressing views about the need to monitor physical health of residents, and having an understanding of their rights under the mental capacity act for purposes of covert administration of medication, as well as managing challenging behaviour.

This demonstrates a recent focus of dementia care which has directed towards person-centred care since Kitwood (1997), described the necessity of putting the person first before the disease. The person-centred approach acknowledges that the focus of care delivery should be on the individual and their psychological needs, not the disease (Evardsson and Innes 2010).

Though this approach can have a positive impact on staff wellbeing and lead to better job satisfaction, some researchers have shown that residents with dementia often live with many unmet needs (physical, emotional, environmental) which staff, in a bid to see the patient instead of the disease, sometimes struggle to address, sometimes leading to emotional stress for staff (Brownie and Nancarrow 2013, Royston et al 2017). Despite this, staff in the study displayed great insight into factors involved in managing people with dementia, describing the necessity to decipher reasons why residents with dementia would resist personal care or behave aggressively, noting that other physical health conditions such as diabetes may affect sugar levels and cause aggression and agitation.

This corroborates findings by Rapaport et al (2018) where the care home staff interviewed indicated that some of the challenging behaviours exhibited by people with dementia were expressions of unmet emotional, physical or environmental need. However, like highlighted above, this group of staff also struggled emotionally and sometimes felt frightened, powerless, and overwhelmed when attempts to alleviate residents' distress did not work.

From a medication point of view, staff demonstrated knowledge of medication taking needs of residents, stating that as their dementia advanced, people with the disease were increasingly unable to communicate and began to refuse medication,

to the extent that family needed to be involved for decision making about stopping or starting medication.

This finding is similar to findings by Mjorud et al (2017) who interviewed residents in a nursing home and found that they had difficulty communicating their thoughts and feelings, and also described a sense of being lost. The impact of these feelings, along with other symptoms, is that 90% of people suffering with dementia, particularly those with moderate to severe disease suffer from neuropsychiatric symptoms also known as behavioural and psychological symptoms of dementia (BPSD) (Corbett et al 2012). The tendency has been to treat these symptoms with antipsychotics, which are associated with increase cognitive decline for people with dementia, along with increased risk of stroke and death (Banerjee 2009, Schneider, Dagerman and Insel 2005).

Non-pharmacological methods have been advocated as the best approach to treating people with dementia suffering from behavioural and psychological symptoms (Livingston et al 2015). Staff in this study alluded to this, highlighting the fact that continued interaction outside of the care home would benefit residents with dementia and improve their quality of life. It should be noted that with training, and support, care home staff are able to successfully implement psychosocial interventions in care homes (Surr et al 2019).

Medicine management and its challenges

Older adults with dementia often live with frailty, which presents many medication management challenges.

Medication safety in various healthcare facilities is an important issue for policy makers both nationally and internationally, and the medicines management process needs to integrate accurate drug selection, prescribing, ordering, storage,

dispensing, administration and monitoring in order to ensure patient safety (Joos et al 2014).

In the current study, when asked what was involved in managing medication in their care homes, staff interviewed listed a range of activities including receiving, booking in, storage, changing over trolleys for start of new months and administration of medication. This finding is consistent with that of the Care Homes Use of Medicines Survey (Barber et al 2009). They found that care home staff spent 40-50% of their time on medicines related activities, and that there was an error rate of approximately 8.4% during these activities. Another study suggested that these errors could be prevented through frequent intervention by a pharmacist to ensure that medication administration happens at the correct time, and to define clear processes for handling medicines (for example, splitting, crushing, mixing with food) (Silva et al 2015).

Staff highlighted the issue of missed medication doses by residents, medication wastage as well as refusal of medicines by people with dementia, and expressed the opinion that receiving medication from pharmacies already pre-packed in multi-compartment compliance aids, also known as Monitored Dosage Systems (MDS) such as dosette boxes or "pods", made it easier to administer.

MDS are widely used in care homes, and their use remains a contentious issue (Centre for Policy and Ageing, 2011). Some pharmacists opine that MDS facilitates drug administration for care home staff (the staff in this study agreed with this view), whilst others maintain that their use is unsafe due to the inability of staff to identify various tablets in each compartment and the fact that "as required" medication as well as liquid medications have to be excluded from the devices,

whilst many medicines lumped together in them are incompatible with each other (Barber et al 2009, Alldred et al 2011). The Care Quality Commission (CQC 2019a) also discourages the use of these devices, citing a Royal Pharmaceutical Society report (RPS 2016) that concludes that these do not improve outcomes for patients, and advocating alarms, tablet splitters and other methods for facilitating medication administration.

Whatever the views of professional and regulatory bodies, judging from the views of participants in this study, this form of medicines administration remains entrenched in care homes and it is infinitely better to educate staff on best practice than to try and stop it entirely.

Staff in the study considered the dosage form of medication the most important medication related need for people with dementia, citing difficulty swallowing as significant. This is expected, since dysphagia is an important symptom in dementia, is common in older adults, and an estimated 45% of people with dementia are thought to suffer from some form of swallowing difficulty (Horner et al 1994). Swallowing difficulties impact the effectiveness and safety of pharmacotherapy, and dosage adjustments are often required to improve clinical effectiveness, and therefore cognition for people with cognitive impairment and/or dementia (Mastrioanni and Forgerini 2018), since giving a patient the appropriate formulation to suit their needs would lead to improved adherence.

Refusal of medication was also a challenge care home staff indicated they faced often, in this study. Participants interviewed were all aware of processes to follow in this situation, including contacting the prescriber, which is what is advocated by the Alzheimer's Society (2019), who recognised this problem and advises that

alternate dosage forms such as liquids and patches where available be recommended when people with dementia refuse to take their medicines.

However, staff also intimated that cognitive deterioration further complicated the process of medicines administration as individuals with advancing dementia often forgot they had to take medication or that they needed to swallow it. Training of staff to manage these situations is essential.

Care home staff mostly rated the services they received from pharmacy as sufficient, as they quoted medication dispensing, supply, response to queries and advice on storage as the main pharmaceutical services they received. These findings are similar to those of other studies that have investigated pharmaceutical services to care homes (Bolaky et al 2010, Patel and Donyai 2013) who found supply as the main service community pharmacists delivered to care homes.

People with dementia who are often prescribed complex medication regimens would need more pharmacy input, and some participants did express the opinion that pharmacists could do more, echoing Bolaky et al (2010) who highlighted the fact that care home managers would welcome greater pharmacy input especially with training of care home staff. De Witt et al (2013) also advocated an expansion in the role of pharmacists to include regular medication reviews in care homes. Due to the regular occurrence of swallowing problems and medication refusal, crushed medication and liquid formulations are often required, and these are associated with significantly increased odds of medication error (Van den Bemt et al 2009).

Challenges faced by care home staff when administering medication to residents with dementia remain relatively under-researched. Staff in nursing homes struggle with preparation, management and administration of medication to

people living with dementia, with those suffering from moderate to severe forms of the disease presenting even more challenges (De Witt et al 2013). Thus greater input from a pharmacist is clearly an outcome that will improve care for people with dementia in care homes (Lemay et al 2012, Ociaomh et al 2014).

Relationship with/role of Multidisciplinary team (MDT)

Multidisciplinary teams have been shown to improve health outcomes through collaboration between healthcare professionals (Social Care institute for Excellence 2018).

In the context of this study, several healthcare professionals were quoted by participants as having input into the care of people with dementia, and the greatest input came from the dementia liaison nurse, dementia crisis team and GPs.

The dementia liaison nurse role in assisting with management of challenging behaviours, conducting assessments and signposting for medication review demonstrated the importance of this role within a care home MDT, as emphasised by Jenkins et al (2016) who outlined that the specialist dementia nurse as part of MDT, played a central role in referring people with dementia for best care. Their role descriptor included referring staff to pharmacists for medication advice, to occupational therapists for activities and to GPs for assessment and treatment.

Hibberd (2014) also stressed the importance of a specialist dementia nurse and even though she referred mainly to care in the community where the needs of people with dementia were deemed inadequately addressed, their role in

facilitating regular reviews of clinical care was invaluable. The participants in this study rated the services they got from the visiting dementia nurse very highly.

Despite having the potential to obtain services from a diverse team of professionals, staff noted that responses could be tardy, leaving them with the option of having to improvise. This view is echoed by the Alzheimer's Society (2016), whose survey based on 286 care homes with dementia residents, found that they failed to receive timely access to essential services such as podiatry, dentistry and physiotherapy.

Whilst there was evidence of interdisciplinary collaboration within teams (the geriatrician team had their own nurses and other practitioners), the researcher saw no evidence that interdisciplinary collaboration occurred. This could contribute to wastage of resources through fragmentation and/or duplication of services.

An interdisciplinary team approach to medication reviews in care homes including a consultant pharmacist, social service coordinator and psychologist saw a 44.5% drop in psychotropic use (Oakes et al 2010).

Additionally, a pharmacist participating in case conferences alongside doctors and nurses was valued by other members of an MDT in another study (Halvorsen et al 2011) which reported improvement in the quality of prescribing. However, this was offset by the reported inconsistency in pharmacist participation and uncertainty about their continued input into the MDT. In this study, pharmacists delivering pharmaceutical services to the care homes were consulted remotely to respond to medication formulation queries, but were not involved in medication

reviews, which shows that these care homes were not taking full advantage of pharmacists' expertise, since their participation in MDT for medication reviews have been shown to improve patient safety through prevention of medication errors, prescribing advice and recommendations for discontinuing unnecessary treatments (Bondesson et al 2012, Desborough et al 2011, Ballard et al 2002, Chadborn et al 2019).

A positive impact of having a pharmacist in MDTs could also include balancing adherence to treatment guidelines with adverse drug effects, and a pharmacist led medication review in a care home as part of a MDT, could result in improved monitoring of side effects and reduction of drug-drug interactions (Brulhart and Wermeille, 2011). However, some barriers exist to pharmacists performing this role satisfactorily as discussed in the previous chapter of this thesis, not least of which is the low numbers of pharmacists' recommendations actioned by GPs (Maidment et al 2018) and the lack of competencies in therapy areas such as pain and dementia (Wright et al 2019).

Other members of a MDT that would improve outcomes for care home residents are their family members.

However this study showed that though staff communicated decisions to family members of individual residents, they were not seen as part of the MDT.

This indicates that not much has changed in care home settings, as Manthorp (2008) in her evaluation of dementia care quality in care homes showed that family members of patients found themselves excluded from decision making.

Barriers and facilitators to care provision

Staff experienced several barriers to providing optimal care to people with dementia in their care homes, one of the main ones being lack of communication in the three way relationship between care homes and community pharmacies, care homes and GPs, and between GPs and community pharmacies.

This negatively impacted the care of residents particularly those in pain where acute medication could not immediately be made available either due to doctors' not informing pharmacies of its urgency or pharmacies not recognising immediate need.

NICE guidelines (2018) recommend that people living with dementia are regularly assessed for pain using structured observational pain assessment tools, and a step wise protocol which balances pain management with potential adverse effects of drugs used (Pink et al 2018). The needs driven dementia-compromised behaviour theory (Kovach et al 2005, Rapaport et al 2018) purports that people living with dementia would display challenging behaviour, often labelled as disruptive, as a result of unmet need that are related to physical factors (pain thirst, constipation) amongst others.

Additionally, neuropathological changes in the brain affect how people with dementia experience pain and cognitive deficits impair their ability to portray their discomfort (Achterberg et al 2013, van Dalen-Kok et al 2017).

Staff in this study recognised this, which explains their frustration at delays in promptly obtaining medication for residents.

Whilst one of the main benefits of electronic transmission of prescriptions has been touted as improved efficiency in handling prescriptions and in patient safety (Franklin et al 2014, Kauppinen et al 2017), the impact of prescription delays on residents of care homes due to communication breakdown have not been evaluated since electronic transmission of prescriptions was rolled out in the UK.

Even though the need for care home staff to be better trained in assessing and managing pain in people with dementia has been frequently highlighted (Barry et al 2012, Carter 2015, Sawan et al 2019), staff in this study appeared well informed and expressed the desire to see real improvements through multidisciplinary team collaboration. They also lamented bureaucratic barriers that prevented them from keeping "homely remedies" in their care homes that would further empower them to manage residents with dementia better.

Homely remedies are medication that do not require a prescription and can be purchased over the counter for use in managing minor ailments (Care Quality Commission, 2019b). NICE guidelines (SC1) (2014) for managing medication in care homes recognises the need for homely remedies and outlines guidance on their safe storage and administration. The absence of homely remedies in care homes in this study is not reflective of practice in all care homes across England, since some areas do have policies and guidelines to support self-care in residential care facilities as recommended by the Care Quality Commission (2019b).

More frequent visits from GPs and a suggestion that consultant dementia specialists could visit care homes were advocated by participants in the study, as they saw this as a way of preventing residents being unnecessarily transferred as

well as dealing with specific needs of people with dementia such as prescribing appropriate medication formulations.

Poor access to NHS services which results in people with dementia ending up bedbound and sedated has been highlighted by an Alzheimer's Society report calling for parity of esteem for this vulnerable patient population (Alzheimer's Society 2016a). The same report also quoted poor access to GP services leading to people with dementia experiencing unacceptably long waits for treatment and unnecessary hospital admissions.

Access to mental health services by care homes was also advocated, which is a proposal similar to what respondents in this study have suggested.

Staff on their part, could incorporate the recording of medication-related goals of care for each individual with dementia (Sawan et al 2019), to improve goal-direct pharmaceutical care and guide quick decision making when prescribers are required to recommend treatments for various ailments.

Another deterrent to the wellbeing of people with dementia, expressed in the interviews with care home staff was their treatment by hospital staff when they visited hospital emergency rooms. They felt A&E staff had poor understanding of people with dementia, and this view is not unique to participants of this study.

Another study noted impatience of emergency staff at hospitals with people with dementia, and explained this behaviour by citing bureaucratic (Parke and Hunter 2017). According to these researchers, pressure caused by the need to meet targets made dealing with dementia patients challenging as they are unable to communicate their needs in a way that is quick to understand. It was suggested

that emergency services staff be provided with the dementia friends framework as well as training on person-centred care.

It was also highlighted that emergency admissions of people with dementia into care homes lacked sufficient information regarding medication, and care homes did not have access to primary care patient records.

Various methods can be employed to help care homes with medicines reconciliation at the point of admission of a resident. The most obvious is having a dedicated community pharmacist and GP assigned to each care home (RPS 2014). As community pharmacists have access to summary care records, they can provide a basic list of medication the new resident is on.

The Royal Pharmaceutical Society (RPS, 2012) issued guidance in its publication "Keeping patients safe when they transfer between care providers-getting the medicines right" which has been adopted by many hospital and community sites across the UK. A standardisation of practice, where pharmacists designated to care homes take responsibility for medicines reconciliation when new residents are admitted or return to the homes following hospital admission would go a long way towards enhancing patient safety.

Further barriers to care raised by staff in this study were the absence of services to stimulate residents with dementia, and in some care homes, lack of dental services. This indicates that care homes in the study were not fully compliant with NICE guidelines for dementia (2018) which recommend that sufferers be offered interventions to promote cognition, independence and wellbeing, such as cognitive rehabilitation and group reminiscence therapy.

Music therapy has also proven to be a cheap, safe, easy to deliver intervention that can have potential benefits in reducing anxiety, depression and agitated behaviours in elderly people with dementia (Blackburn and Bradshaw 2014).

Poor oral health and hygiene is common in people with dementia (Marchini et al 2019) and is often neglected by care home staff due to prevalence of other demands (Yi Mohammadi et al 2015). Staff in the current study highlighted the challenges they faced getting residents with dementia to open their mouths for oral cleaning and proposed the possible use of an oral cleaning tablet. Such a venture would need the input of a pharmacist to ensure that a tablet used in this manner will have no systemic effects nor interact with any medication a resident is taking.

A holistic multi-disciplinary approach to health and wellbeing of people with dementia living in care homes is essential to achieve better oral health and comfort, and visits by dementia friendly dental hygienists to conduct dental examinations.

Whilst the wellbeing of people with dementia cannot be guaranteed at all times, efforts need to be made by all involved in their care to ensure that they are as comfortable as can be and receive adequate medical and psychological treatments where needed.

5.5 Conclusion

Interviews carried out with care home staff revealed that though they faced several challenges with managing medication for people with dementia, they were satisfied with the dispensing and supply services provided by community

pharmacy, but improvements were needed in obtaining anticipatory medication for residents in end of life care, and gaining information on prescribed medication for emergency admissions.

Improvements were needed for the improved functioning of multidisciplinary teams with better communication and integration between healthcare professionals advocated.

This study preceded policy changes which saw more specialist pharmacists being placed in care homes from 2018, following implementation of the Medicines Optimisation in Care Homes (MOCH) scheme resulting from the establishment of the Pharmacist Integration Fund (PhIF). However, as this scheme only committed to providing funding for 218 pharmacists in care homes, with a stipulation that local commissioners take over after May 2019, it is clear that the role and impact of community pharmacists who remain part of the overall management of people with dementia in care homes through medication supply and medicines information, continue to require further exploration and definition.

Incorporating a medication review tool for use by pharmacists integrated into care home MDTs, to encourage prescribing of required medication or de-prescribing of inappropriate medication could be useful in improving medication use in people living with dementia in long term care facilities.

The next two chapters in this research describes the development and testing of such a tool.

5.6 Study limitations

- This study was a qualitative study based in a small geographical area so the generalisability of the findings are limited
- The interviews were conducted in care homes, where there were interruptions with participants being called out to attend urgent duties within the care home. This could have disrupted their thought processes leading to less comprehensive answers.
- Questions regarding reporting of medication incidents were not asked, and this information would have been useful in evaluation of medication related practices in care homes visited, which would have increased the impact of the research.
- Care home staff may have been reluctant to express opinions that were not complimentary about their care home.
- For a few participants, English was not their first language and though they managed to convey what they wanted to say, eventually, transcripts tended to be much longer and some context may have been lost.
- Though information was gathered about the extent of the experiences of care home staff in terms of the number years spent in the care home sector, this information was not correlated with knowledge in the data analysis.
- Finally, this study was based on face to face interviews which raised the risk of participants giving socially desirable answers.

CHAPTER 6
Living with Dementia in Care Homes: Development of the DEMENTIAS intervention toolkit for systematic review of prescriptions during pharmaceutical care provision

6.0

6.1 Introduction and chapter overview

7 in 10 people living with dementia are also living with other medical conditions and potentially being prescribed multiple drugs (Brown 2017). Healthcare professionals, especially pharmacists, have the responsibility of ensuring that the treatments that follow the dementia diagnosis, are safe, effective, and can be accessed by all who need them (Kennedy and Sud, 2014).

In chapters 3, 4 and 5 of this thesis, the role and impact of pharmacists in managing medication for people with dementia was examined, and a link between their knowledge and barriers to offering an optimal pharmaceutical care service to people with dementia was established. Pharmacists interviewed admitted that they needed to improve their knowledge on dementia, and the majority of those who participated agreed they would be interested in dementia related training.

Pharmacists, given their extensive training on the use of drugs, should be able to ensure that medicines, prescribed to people living with dementia, whether in care homes or in the community, are monitored, reviewed regularly and stopped when they are no longer required.

Prescribing is considered potentially inappropriate when its potential risks outweigh its potential benefits. A systematic review by Morin et al (2015) found that nearly 50% of nursing home residents are exposed to inappropriate medication use during their stay. Community pharmacists who supply medication to care homes have electronic records of residents' medicines in the pharmacy and

are ideally placed to periodically screen for potentially inappropriate prescribing (Tommelein et al 2016).

As discussed in previous chapters of this thesis, people with dementia often also live with other diseases, sometimes up to 4 or 5 other chronic conditions (Guthrie et al 2015), and if each of these conditions are treated according to their individual evidence based guidelines, it is to be expected that this will result in polypharmacy. Polypharmacy is defined as the use of five or more medications daily in one individual (Curtin et al 2019). It is common in older adults, and in many cases, may be clinically appropriate, but as older adults have decreased renal and hepatic function, it is important to identify inappropriate polypharmacy which puts them at increased risk of falls, adverse drug reactions, higher mortality rates, hospital admissions and other poor health outcomes (Masnoon et al 2017). In the Services and Health for Elderly in Long Term Care (SHELTER) project which evaluated prescribing for nursing home residents with advanced cognitive impairment, polypharmacy or excessive polypharmacy was observed in 67.6% of residents (Vetrano et al 2013). For people with dementia, this can be particularly problematic, impaired cognition being a hallmark of dementia, and drugs such as anticholinergics, several psychotropics and drugs for Parkinson's can worsen cognitive decline. Additionally, dementia, a neurodegenerative disease, can lead to impairment of mobility, which could be further worsened by blood pressure lowering drugs e.g. alpha adrenoceptor blocking drugs (van Marum 2017). Other adverse effects of medication that are especially undesirable in people with dementia are myalgia (from drugs such as statins), Parkinsonism (caused by some antipsychotics) and diminished appetite which could lead to malnutrition (van Marum 2017).

Medication reviews and educational interventions can commonly be used to improve prescribing for people with dementia living in care homes (Liu et al 2019). Medication reviews have been found helpful for carers of people with dementia (Maidment et al 2017) and are reported to result in a positive impact on patient health outcomes (Santos Silva et al 2019).

Medication review, an integral component of the provision of pharmaceutical care by pharmacists, facilitates the identification of potentially inappropriate prescribing and highlights drug therapy problems. It is defined as "a structured, critical examination of a patient's medicines with the objective of reaching an agreement with the patient about treatment, optimising the impact of medicines, minimising the number of medicines related problems and reducing waste" (Taskforce on Medicines Partnership and The National Collaborative Medicines Management Service Programme 2002).

The National Prescribing Centre's "A Guide to Medication Review" (National Prescribing Centre 2008) describes three different types of review:

- Type 1: Prescription review- addresses issues relating to the prescription of medicines (patient does not need to be present, nor does it require access to full notes)
- Type 2: Concordance and compliance review – addresses issues relating to the patient's medicine taking behaviour (e.g. medicines use review –MUR- by community pharmacists)

  Type 3: Clinical medication review: requires patient's notes and addresses issues relating to the patient's use of medicines in the context of their clinical condition.

Medication reviews for people with dementia in care homes have to be conducted in a systematic manner, using a structured approach (van Marum 2017).

Crucially, the stage of dementia has to be considered in any medication review process for people with dementia, and Maidment (2013) proposed a model in which cognitive enhancement is optimised in mild dementia, and people with moderate dementia are supported with medication adherence whilst those with moderate to severe dementia have any medication prescribed to manage behavioural symptoms (antipsychotics, hypnotics, anxiolytics) reviewed. In advanced stage dementia, common issues include constipation, continence problems, swallowing problems, infection, pain and breathlessness (NES 2014).

It was envisaged that a simple toolkit purposely designed for use in people with dementia, by pharmacists working in collaboration with GPs and patients/caregivers, would facilitate pharmaceutical care and support a rational approach to prescribing. This toolkit would provide pharmacists with a framework for conducting structured, quality Type 3 medication reviews for people living with dementia. It could also be utilised by community pharmacists conducting a Type 2 review.

6.2 Method/Results

6.2.1 Aim

- To design a dementia intervention toolkit to act as aide-memoire to pharmacists delivering pharmaceutical care to people living with dementia

6.2.2 Objective

- To use guidelines and evidence on medicines optimisation in dementia to develop a tool for conducting systematic medication reviews for people living with the condition.

6.2.3 Process

To develop the toolkit, a literature search was carried out to evaluate existing medication appropriateness tools, publications and guidelines.

Medication appropriateness tools

Though many tools have been developed to classify medication appropriateness in the elderly (Kaufman et al 2014), not many have been used to address potentially inappropriate medication use in people with dementia. Tools used frequently in literature not particularly targeting people with dementia include:

- Beers criteria (American Geriatrics Society Beers Criteria 2019)
- STOPP/START (O'Mahony et al 2015)
- Medication Appropriateness Index (Hanlon et al 1992)
- STRIP (Keijsers et al 2014)
- WHO 6-Step approach to prescribing

Recently developed:

- Ghent Older People's Prescriptions community pharmacy screening (GheOP3S) (Tommelein et al 2016)

For people living with dementia, the consensus criteria developed by Holmes et al (2008) which categorised medication into 'never', 'rarely' 'sometimes' or 'always'

appropriate, remains the most significant development in literature (Parsons 2016). However, this tool was developed for use in people with advanced dementia requiring a palliative approach. More recently, a tool was developed that looked at medication use in people with dementia and other co-morbid health conditions:

- Medication Appropriateness Tool for Comorbid Health Conditions during Dementia (MATCH-D) (Page et al 2016). Though the development of this tool involved the consultation of a large group of experts, it has not yet been fully tested in a clinical setting.

Following the review of available tools, the following were considered for use in the toolkit based on their widespread use in clinical settings and relevance to the current study:

STOPP/START Criteria Version 2

The Screening Tool of Older People's Potentially inappropriate prescriptions (STOPP) and the Screening Tool to Alert doctors to Right Treatment (START) version 2 (O'Mahoney et al 2015) were included as resources in the toolkit for its applicability in reviewing prescriptions for older people with comorbid chronic conditions. The STOPP/START criteria publishers allow reproduction and re-use of the resource for non-commercial purposes as stated in https://doi.org/10.1093/ageing/afx178 as long as the resource is properly referenced. However, permission for its use in this toolkit was sought from the correspondent author (Appendix 6a).

WHO six-step approach and the STRIP tool

The WHO six step approach for rational prescribing (Figure 20) which is a useful, validated tool for teaching and ensuring appropriate prescribing for people in later life (de Vries et al 1994) and the Systematic Tool to Reduce Inappropriate Prescribing (STRIP) (Keijsers et al 2014) were used as guides to ensure that the toolkit incorporated all aspects required for consideration in a holistic approach to medication review and the provision of pharmaceutical care to people with dementia. However, whilst the WHO stepped approach can help doctors prescribe appropriately, it is insufficient on its own for judging the appropriateness of a medication regimen, a process which requires a systematic approach.

The STRIP tool (Keijsers et al 2014) was developed in the Netherlands as a five step process, namely (1) drug history, (2) analysis of drugs, (3) treatment plan, (4) Patient preferences and (5) follow up and monitoring. Though this tool does not specifically target people with dementia, step 2 (analysis of drugs) is meant to prompt considerations about under-treatment, noneffective medication or over-treatment, potential side effects, incorrect doses, contraindications or interactions. Of particular relevance is the pointers to "under-treatment" as people with dementia often suffer from pain (Barry et al 2016) which can go untreated and cause distress.

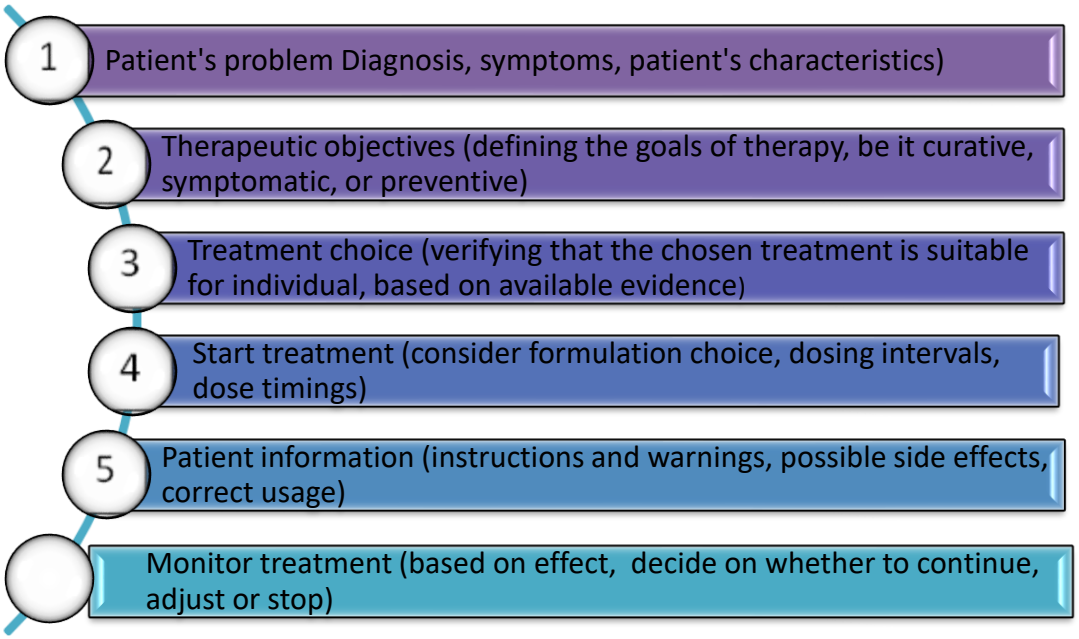

***Figure 20**: adaptation of WHO 6-step approach to rational prescribing*

NICE guidelines (Dementia)

Excerpts from NICE guidelines for dementia (CG42) were used, in part, as a resource. This is permitted by the NICE UK Open Content Licence which allows content to be used freely if the content is used in its original form and referenced. These excerpts were used for the tool in preference to the new updated guidelines (NG97) as they described in more detail, the management of non-cognitive symptoms of dementia, clearly separating pharmacological from non-pharmacological approach, which was judged better by the researcher for use with a focus group of pharmacists

Other considerations

Anticholinergic medication: A medication review tool for a person with dementia requires a prompt to consider the anticholinergic burden of medication prescribed

as people with dementia are particularly sensitive to adverse effects associated with high anticholinergic load (Sura et al 2013).

Psychotropic medication: These include antipsychotics, hypnotics, antidepressants, anticonvulsants, and anxiolytics often prescribed to manage the behavioural and psychological symptoms of dementia (BPSD) also known as neuropsychiatric or non-cognitive symptoms (Thompson Coon et al 2014).

To ensure the above two issues are considered in the systematic medication review pointers to determining the anticholinergic burden (Campbell et al 2010), were added and NICE guidelines CG42 for managing non-cognitive symptoms of dementia were also included as discussed earlier.

A reference to the British National Formulary (Joint Formulary Committee 2019) was added so that drug interactions and side effects of medication prescribed can be considered, in line with advice from the STRIP tool highlighted earlier.

The DEMENTIAS prototype toolkit

A mnemonic was formed using the word “dementias”, since mnemonics can be used to enhance memory and maximise sound decision making (Bruno et al 2012, Sinopoulou et al 2017). Finally, a proforma for recording pharmaceutical care plan was included, styled on one proposed by Cipolle, Strand and Morley (2004). Permission was obtained from McGraw Hill publishers to include this proforma in this thesis (Appendix 6g).

Figure 21 shows the resultant tool:

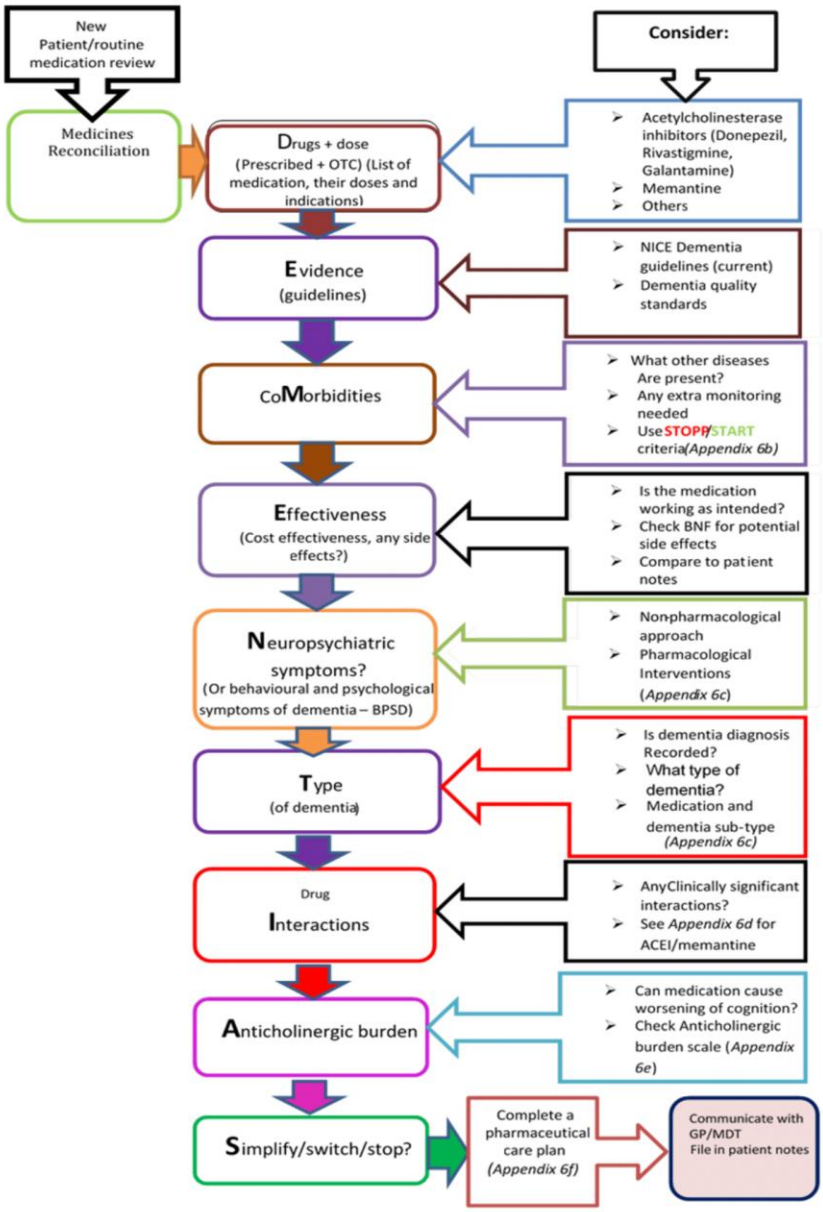

Figure 21: The DEMENTIAS medication review toolkit

6.4 Discussion

The main purpose of pharmaceutical care is to provide and optimise drug therapy in a way that leads to definite outcomes that improve the quality of life of individual patients. This toolkit was developed with a view to incorporating the principles of pharmaceutical care into the process of reviewing medication for people with dementia in manner that facilitates detection of drug therapy problems such as unnecessary drug therapy, need for additional medication, ineffective drugs, dosing issues or adverse drug reactions.

The desire to reduce prescribing of potentially inappropriate medication to older adults, particularly those in care homes who are amongst the frailest patient groups, has led to the design of many medication review tools for this purpose, and their use during medication reviews can help promote rational prescribing.

Appropriateness of medication can be measured by applying validated criteria developed to patients' prescriptions and/or clinical data, and these criteria can be explicit (developed from literature reviews, expert opinion and consensus techniques) which contain drug lists or classes known to cause harm in older people, or implicit criteria (quality indicators of prescribing that can be applied to prescriptions by doctors or pharmacists) (O'Connor et al 2010).

Examples of explicit tools include the Beers Criteria (American Geriatrics Society 2019), the STOPP/START criteria (O'Mahoney et al 2015), and the 'Discontinuing Inappropriate Medication in Nursing Home Residents' (DIM-NHR) (Wouters et al 2014). Other tools to manage medication appropriateness in older adults include the FORTA-USA (Fit fOR The Aged, Pazan et al 2019) which is a classification list

designed to support doctors in the USA with medicines optimisation and for older adults, and the EURO-FORTA (Pazan et al 2018).

Implicit tools in research include the Medication Appropriateness Index (MIA, Hanlon and Schmader 2013) and the Systematic Tool to Reduce Inappropriate Prescribing (STRIP, Keijsers et al 2014). Explicit tools can be applied to prescriptions without need for much clinical judgement, whilst implicit tools require clinical knowledge to administer, but explicit criteria can fail to take into account individual patient preferences, whilst implicit criteria though catering for patient preferences and disease, rely on clinicians' medical knowledge and are time consuming to apply (O'Connor et al 2012)

Though the tools discussed above were developed to address inappropriate prescribing in the older population in general, both the STOPP/START and Beers tools have criteria specifically for people with dementia such as concerning psychotropic and anticholinergic medication. There are few tools specifically designed to detect inappropriate prescribing in people with dementia, and these focus either on prescribing of psychotropic medication, such as the Appropriate Psychotropic drug use in Dementia (APID)(van Der Spek et al 2015) which is an implicit tool, or the Quality use of Medicines in Dementia (QUM-D, Peisah et al 2015), an explicit tool.

The DEMENTIAS toolkit developed in the current study aimed at targeting prescriptions for people with dementia specifically, combining aspects requiring clinical judgement and others needing consultation of appropriate criteria to improve prescribing for this patient group.

The toolkit starts with a pointer to consider drugs prescribed and their doses following medicines reconciliation to obtain drug history, as required by NICE guidelines for managing medication in care homes (NICE 2014). This is a similar step to the pharmacotherapy review advocated in the Systematic Tool to Reduce Inappropriate Prescribing (STRIP) (Drenth-Van Maanen et al 2017).

Other steps in the toolkit include ensuring prescribing is evidence based, as well as consideration of co-morbidities for which other medication could be prescribed, with a reference to the STOPP/START (O'Mahony et al 2015) for lists of medication to avoid or commence in such circumstances. The STOPP/START criteria was chosen for comorbid health conditions, in preference to the Beers Criteria which is similar, because the latter focuses on USA prescribers and 50% of medicines included in it are unavailable in Europe, whilst the former has been used to optimise medication for people with dementia (Aziz et al 2018) and has been widely used in Europe (Snyder et al 2014, Nicieza-Garcia et al 2016, Oliviera et al 2015).

This tool also incorporates steps to review effectiveness, cost-effectiveness and side effects of prescribed medication, all of which are integral aspects of medicines optimisation (NHS Brent CCG 2014)). These are particularly important considerations for people with dementia when the impact of side effects such as increased risk of falls and reduced cognition from anticholinergic side effects are factored in (NICE NG97 2018). Furthermore, evidence that long term effectiveness of acetylcholinesterase inhibitors (anti-dementia medication) is not established, requires case by case evaluation of risk versus benefits of discontinuing treatment (Renn et al 2018). Cost effectiveness of prescribed medication for people with

dementia is also an important issue that needs to be addressed as part of medicines optimisation in dementia (Apampa and Navti 2014), and also highlighted by the House of Commons All Party Parliamentary Group on Dementia (2011) who quoted how much was spent prescribing food supplements for people with dementia because they were losing weight, when training staff to communicate better with dementia sufferers could yield better results. Additionally, with reference to anti-dementia medication, combinations of acetylcholinesterase inhibitors are increasingly being prescribed when the economic case for their benefit hasn't been made (Knapp et al 2017).

A separate step requiring assessing presence of and prescribing for neuropsychiatric symptoms (behavioural and psychological symptoms of dementia) was added to the tool, since the majority of people with dementia suffer from these at some point during disease progression (Mar et al 2019). The adverse effects of prescribing pychotropic medication to this patient group are well established (Coon et al 2014, Stocks et al 2017).

The type of dementia suffered by an individual whose medication is being reviewed is important because symptoms across the dementia subtypes are heterogeneous and influence the individual's capability to live well with the condition (Barret and Burns 2014). A step was added to the toolkit to account for this.

People with dementia can be more susceptible to drug-drug interactions especially when they are prescribed medication such as antidepressants, psychotropic medication or gastrointestinal drugs such as omeprazole (Bogetti-Salazar et al

2016). Thus the identification of potential interactions, as well as determination of their clinical significance is useful when reviewing their medication.

In an extension to the step considering medication side effects, a separate step emphasising review of anticholinergic burden of prescribed medication was added to the tool. It is well established that medication with cumulative high anticholinergic burden have many adverse outcomes in elderly people in general and those with dementia in particular (Fox et al 2011). These drugs also antagonise the effects of acetylcholinesterase inhibitors prescribed to slow down progression of dementia (EFjestad et al 2013).

The final step of the tool was a decision-making one requiring the pharmacist to suggest simplifying, switching, or stopping reviewed medication as part of a pharmaceutical care plan which would be communicated to the patient's GP and shared with the relevant multidisciplinary group, with an emphasis on involving the patient/family or carer in the decisions regarding any proposed changes to medication.

6.5 Conclusion

A toolkit was developed to provide pharmacists with a systematic approach to conducting medication reviews for people with dementia, as part of pharmaceutical care delivery to this patient group.

This approach relies predominantly on the reviewer having the relevant clinical knowledge, but provides references to resources that can be used, for those less familiar with the subject area. Unlike most medication appropriateness tools available in research which state their purpose in their mnemonic e.g

STOPP/START (O'Mahoney et al 2015), this toolkit provides at a glance both the purpose, and the process that needs to be followed when addressing inappropriate prescribing in people living with dementia. This would work as a great reminder to any pharmacist taking up this important task.

6.6 Limitations

Though this toolkit has been developed using evidence from national guidelines, validated medication review processes and other implicit and explicit tools, it has not gone through a process of validation via consensus from experts in the field, nor has the process recommended by the Medical Research Council framework for developing complex interventions been applied to the process.

Future research requires that this is done for it to be adopted widely.

Chapter 7
Living with Dementia in Care Homes: Preliminary feasibility study of the DEMENTIAS medication review toolkit among a focus group of pharmacists, conducting a review of prescriptions for patients living with dementia

7.0

7.1 Introduction and chapter overview

As the prevalence of dementia has increased steadily over the past few years, and proportion of people with confirmed diagnosis of dementia has also gone up, the consequence has been that the number of people prescribed anti-dementia medication either on their own or in addition to other medication has also been on the rise. For people living with dementia, this represents an increase in the number of medicines prescribed, also known as polypharmacy (Maher et al. 2014).

This highlights the need for pharmacists who routinely deal with prescriptions for people living with dementia to equip themselves with knowledge and skills to assist sufferers and/or their carers with managing their medication, and on the whole, become part of an integral system striving towards improving quality of care for people living with dementia.

However, evidence from research carried out and reported in chapters 3, 4 and 5 of this study shows that the main pharmaceutical care services delivered by community pharmacists in England to care homes (known to have high proportions of people with dementia), are the supply of medication, training of staff on medication administration and storage, and audit. One of the main barriers to community pharmacists providing optimal pharmaceutical care to people with dementia was insufficient knowledge of dementia and medicines optimisation in dementia, as less than half of the pharmacists interviewed agreed they could recommend interventions to optimise medicines use for people with dementia. The researcher theorized that pharmacists needed to engage in reflective practice, cross referencing and using analytical information to contribute to high quality

interventions for people with dementia. This led to the development of an intervention toolkit described in Chapter 6 to help pharmacists with this process of identifying inappropriate prescribing and optimising medication for people living with dementia.

Though an association between polypharmacy and potentially inappropriate prescribing has been established across Europe and America (Blanco-Reina et al. 2014, Tommelein et al. 2015), and a number of consensus criteria developed to address this amongst the elderly population, most of the tools developed do not focus on people living with dementia (Parsons, 2017).

Chapter 6 described the development of a DEMENTIAS toolkit targeting pharmacists wishing to review or screen prescriptions for people with dementia and on the whole, improve pharmaceutical care delivery to this patient population as well as facilitate identification and reporting of drug therapy problems. The toolkit outlined a step by step approach, each step highlighting key issues for consideration by pharmacists when processing prescriptions for people with dementia.

This chapter reports a feasibility study of the prototype toolkit developed in chapter 6 with the aim of testing its usability, acceptability, and applicability.

Focus group methodology was selected for this arm of the study because this would enable participants to provide insights and comments in the course of discussions (Barbour, 2007), whilst interacting with each other and defending their views, and providing greater insight into their opinions (Oates, 2000) without use of a rigid framework. The expectation of the researcher was that the process

would lead to suggestions that would improve the toolkit. In future, the prototype can be piloted and tested amongst a larger cohort of health care practitioners that deliver care to people with dementia in care homes, such as geriatricians, crisis team, pharmacists and dementia liaison nurses.

This study forms the concluding part of the living with dementia in care homes pharmaceutical care in dementia research, following qualitative face to face interviews with pharmacists, a quantitative questionnaire survey of pharmacists and face to face interviews with care staff working with people living with dementia.

7.2 Method

A qualitative research design involving a focus group of selected pharmacists was used.

7.2.1 Aim

- The aim of this study was to explore the views and opinions of pharmacists about the usability and applicability of the toolkit developed by the researcher, for improving pharmaceutical care for people living with dementia

7.2.2 Objectives

- To determine the feasibility of using the medication review toolkit for reviewing prescribing of medication for people living with dementia
- To test the format of the prototype toolkit and determine whether it is comprehensible and appropriate for use by pharmacists
- To determine whether the toolkit can be used to identify potential drug therapy problems in prescriptions for dementia patients

- To make amendments and revisions to the toolkit based on feedback from the focus group.

7.2.3 Setting

A conference room at a hotel within easy reach for participants, located in Thurrock, Essex was booked for the purpose of this study which took place in July 2019.

7.2.4 Study design

A focus group qualitative research methodology was used.

As a measure of content validity, the toolkit (described in chapter 6) was sent to the research supervisors and comments sought with regards to the structure, clarity of wording and to ensure that no essential areas had been missed out. Minor corrections were made to the toolkit by the researcher, in readiness for piloting with the focus group.

The development of the toolkit used for this part of the study is described fully in chapter 6 of this thesis.

7.2.4.1 Sampling, participant recruitment and informed consent

Pharmacists working in the community pharmacy, care home or mental health sector were identified via NHS England Pharmacy Integration Programme, through The NHS Future Collaboration Platform (https://future.nhs.uk/connect.ti/system/login?nextURL=%2Fconnect%2Eti%2FPharmacyIntegration%2Fgrouphome), where the researcher is a member. This forum was chosen because it was created purposefully to bring together healthcare professionals. There are pharmacists from various practice settings on

this forum and they are empowered to collaborate on projects aimed at delivering high quality health care services.

A purposive non-random sampling approach was initially used. A purposive sample is that which is based on the selection of individuals with a particular characteristic for a study (Bowling, 2014). No assumptions were made that the participants were representative of the wider population of pharmacists.

A call for participants was placed in the Future NHS Collaboration Integrated Pharmacists group. The purpose of the study was described. Pharmacists who expressed an interest were contacted via email and their job role and level of involvement with people suffering from dementia established.

A target sample of 10 pharmacists were to be invited with a view to recruit 6 for the study. This number was chosen based on research that shows that the ideal sample size for a non-commercial focus group is 5 to 9 participants (Krueger and Casey, 2014). Where all 10 pharmacists invited agreed to participate, the 6 with the greatest number of years' experience who fit the inclusion criteria would be selected to take part.

Only two pharmacists were recruited in this manner, well short of the targeted number, so the rest of the participants were identified via snowball sampling.

Snowball sampling is a convenience sampling technique where an initial set of suitable participants are called upon to refer relevant others who may be interested in the topic to be explored (Hutson and Hobson, 2008).

Ethical approval for the study was obtained from the University of Sussex Cross Schools Research and Ethics Committee (Appendix 7a).

Six pharmacists who agreed to participate in the study, were sent an information pack that consisted of participant information about the study (Appendix 7b), consent form (Appendix 7c) and the researcher contact details at the University of Sussex.

The recruited pharmacists were asked to return the signed consent form directly to the researcher in a pre-paid envelope addressed to the University of Sussex. They were advised that they could contact the researcher at any time for further information or clarification of any issues and that they could withdraw from the study at any time by contacting the researcher. Written assurance of the confidentiality of any information obtained during the study was included in the participant information letter.

One of the 6 participants indicated a few days before the day booked for the study that they were unable to attend but recommended another pharmacist who met the criteria for selection and agreed to participate. However, on the day of the study, the pharmacist who had pulled out came along, so the final number of participants in this study was 7. The 7th participant received all relevant information as detailed above on the day of the study.

Participants were given copies of the toolkit and asked to initially discuss its structure and write down comments about the tool length on an evaluation form provided. They were then asked to review prescriptions for two fictitious case studies prepared for the study by the researcher, as they would in routine practice, using the toolkit. The patient and medication details included in the case studies

were derived from the researcher's detailed knowledge of previous patient cases obtained during her role as a mental health pharmacist.

No person identifiable material was used in the case studies presented to the focus group.

Discussions were audio recorded and recordings were sent for transcribing by a professional company that specialises in transcribing data from interviews and focus groups.

7.2.4.2 Inclusion and exclusion criteria

Inclusion criteria

Pharmacists working in the community retail, care home or mental health sector as identified above in the sampling process described in the previous section. This was to ensure a diverse group with relevant experience that could be drawn on during evaluation of the toolkit.

Exclusion criteria

Pharmacists working in administrative, non-patient facing roles.

7.2.4.3 Research instrument

The 'DEMENTIAS' toolkit developed in Chapter 6 (Figure 20), along with the relevant appendices (Appendices 6b to Appendix 6f) were printed and distributed to all participants, along with two case studies (Appendix 7e) for testing the toolkit.

7.2.4.4 Data Handling and Analysis

Focus group discussions were digitally audio recorded following verbal and written consent by participants, and recordings safely stored in a digital safe

accessible only to the researcher. Data will be stored for five years following completion of the study to enable verification of findings if required.

The recorded discussions were transcribed verbatim.

In a similar manner to the approach reported in Chapter 5, content analysis was carried out using a thematic analytical six step process involving familiarisation with the data, generating initial codes, searching, reviewing and defining themes and finally writing up findings (Braun and Clarke, 2006), which enabled data to be described in detail. Codes and themes identified by the researcher were verified by the main research supervisor as described previously with the care home study reported in Chapter 5.

Findings were independently verified by the academic supervisor to assure its reliability and confirm data saturation, which was clear when the participants had nothing more to add during their evaluation. No person/premise identifiable data was included in the report.

7.2.5 Research Governance and Ethics.

Ethics approval was obtained from the University of Sussex Research and Ethics Committee, the Cross-Schools Research Ethics Committee (CREC) before commencement of the study (Appendix 7a)

NHS ethics was not required because the research involved NHS and/or social care staff recruited as research participants by virtue of their profession (Health Research Authority, 2016). Consolidated criteria for reporting qualitative research (COREQ) were completed for this focus group study as with previous qualitative research undertaken in chapters 3 and 5 of this thesis.

7.3 RESULTS

There were 7 participants in total who took part in the focus group study. Their details are presented in Table 11.

There was diversity in area of pharmacy practice of the participants, with most participants practising in more than one sector. One participant (AA) practised in an elderly ward within a community hospital, as well as in other areas of community health services. The other participants were care home pharmacists or mental health pharmacists/community pharmacists.

During the discussion, participants commented on the ease of use of the toolkit, length, its applicability and suggested changes. The results of the study are presented here in sections comprising

- demographic details
- results of discussions about the toolkit
- results from piloting the tool by using it on a couple of case studies
- presentation of the written evaluations of the tool from the participants, and
- final modifications to the toolkit based on focus group recommendations

7.3.1 Pharmacist demographics

Participants in the study were made up of 5 female and 2 male pharmacists with number of years of experience as pharmacists ranging from 5 years to 19 years post registration (Table 11).

Pharmacist initial	Gender	Sector	Years of experience
AA	Female	Community Health Services/Hospital	11
BB	Female	Care Homes	10
BA	Male	Hospital/Mental Health	5.5
BT	Female	Community/Mental Health	16
IM	Male	Care Homes	8
IN	Female	Mental Health/Community	19
OA	Female	Care Homes	5

Table 11: Demographic details of participants and number of years' experience as pharmacists

7.3.2 Results of discussions about the toolkit

The researcher started the discussion by ensuring all consent forms had been completed and making sure the participants knew the objectives of the focus group study. Discussions on the toolkit began after participants had had a chance to review the toolkit. They started by expressing their general views about the instrument and progressed to talking about some of the appendices added to it. The main points discussed, following data review and thematic analysis, with the resulting main points and themes are presented in Table 12.

The themes and main areas covered during the focus group discussion of the 'DEMENTIAS' toolkit have been grouped under three overarching themes, namely:

- Prescribing for people with dementia
- Participants' views about the toolkit
- Recommended improvements to the toolkit

Themes	Main points considered	Main themes
Evidence from guidelines	-NICE guidelines on dementia -guidelines based on disease severity -local guidelines -formulary guidelines -guidelines on continued use of acetylcholinesterase inhibitors	Prescribing for people with dementia
Current prescribing practice	-adherence to guidelines -shared care practice -responsibility for prescribing -changing role of pharmacists -antipsychotic prescribing -role of specialist clinics -diverging practices	
Toolkit Structure	-simplicity -extent of areas covered -use as a checklist	Participants' views about the toolkit
Toolkit usability	-cost considerations -frequency of use -selective use of some aspects of tool -barriers to use (time, communication, access to patient records)	
Toolkit versatility	-relevance to pharmacists -relevance to other healthcare professionals -decision making from recommendations following use of toolkit	
Participants' suggestions for improvements	-updates to appendices -NICE guidelines -ACB scale -Diagnosis and treatment of dementia -addition of other specialist clinics to recommendations	Improvements to the toolkit

Table 12: Main points and themes from 'DEMENTIAS' toolkit focus group discussion

7.3.2.1 Prescribing for people with dementia

Participants in the study discussed at length about the NICE guidelines on dementia (NICE CG42, 2006), particularly the recommendations for pharmacological management of the behavioural and psychological symptoms of dementia.

Whilst most agreed that prescribers generally adhere to national guidelines and recommendations when prescribing antipsychotics to people with dementia, it was acknowledged that prescribing practice differed depending on the clinicians' assessment of the individual with dementia, their disease severity and quality of life:

"For example, care home residents: they might have challenging behaviour. They've factored in the risk, but they also look at quality of life of the resident. So they say 6 weeks, but it goes on for a long period of time….because you're trying to improve their quality of life…..My population, after about 16 months, we know that they're going to pass away, average. So you're trying to make the best life possible for that person. They could be on it for a long time…." BB (care home pharmacist)

There was uncertainty about what the guidelines said with regards to continuing anti-dementia therapy (acetylcholinesterase inhibitors) in people with severe dementia, when they are no longer considered to be of any benefit to the sufferer. The evidence base for the prescribing of anti-dementia medication was queried, but participants concluded that these medications could prevent further deterioration of the individual with dementia.

Some participants pointed out that prescribing practice could vary depending on local guidelines or local prescribing formularies, and shared experiences of consultant psychiatrists diverging from prescribing guideline recommendations,

especially with respect to prescribing antipsychotics to elderly people with dementia:

"The BNF says 'short-term treatment up to six weeks. Well, sometimes, in ward rounds, the consultant would say they're not using it for aggressive behaviour of the patients. They feel the patient is psychotic. Because you can't go above, I think, two milligrams, they go under the cover of…..the reason why they want to increase is because they actually feel the patient is psychotic….and not for the aggression" BT (Community/Mental health pharmacist)

Responsibility for prescribing was also discussed, with some participants explaining that when certain medication for people with dementia was started in secondary care, some GPs did not feel obliged to continue these once patients were discharged back into their care. The practice of shared care protocols for such medication was highlighted, as well as the role of GP practice pharmacists in scrutinizing such prescriptions.

"Certain medications…..it might be a dementia medication that they prescribed and a GP doesn't prescribe that, or isn't familiar with that. Or a GP would not want to continue because of cost, for instance. So, they might request a shared care guideline for the GP to say 'yes, I'll follow on with treatment for the patient'" AA (Community health service pharmacist)

*"Another thing, from working in the community, I notice that with the GPs…..because there are a lot of GPs now with a pharmacist working at the GP practice; if the consultant is trying to change medication and they (the patient) are not stable, they (practice pharmacists) tend to push it back….. "*BT (community/mental health pharmacist)

Aside from GPs and consultant psychiatrists, a view was put forward that there were instances where responsibility for prescribing and medication review was with the memory clinic:

*"The thing is, if someone is on medication for dementia, sometimes they might be under the memory clinic, who then do review that medication every six months, do a pulse rate and Mini Mental State" …*IM (care home pharmacist)

Involving family/carers in decision making about prescribing of antipsychotics to people with dementia was highlighted as a positive by one of the care home pharmacists, who went on to express concern about the lack of physical health monitoring offered to these patients following such prescribing:

"…they will have to do that with the family; letting them know all the risks that are involved. I don't know if it happens across all areas. But we'll have to let the family know because there are risks of stroke, prolonged QT, sudden death and all that stuff…..and then it is prescribed. So, it will be like a best interest type of discussion…." BB (care home pharmacist)

From the above discussions amongst participants in this study, it can be deduced that though only one set of NICE guidelines and NICE quality standards are available for all prescribers to refer to for guidance on prescribing for people with dementia, there is some level of divergence depending on local guidelines, which clinician initiates prescribing for an individual with dementia, and whether the person with dementia is under a memory clinic or remains with their GP practice.

All these issues are relevant for a pharmacist wishing to undertake systematic medication reviews or prescription screening for someone with dementia as any drug related problems will need to be reported to the right clinician.

Discussions within the focus group around varying prescribing practices were interspersed with participants sharing their views about the prototype toolkit.

7.3.2.2 Participants' views about the toolkit

Participants were complimentary about the structure of the toolkit and the level of detail covered:

"I feel it is quite extensive. For someone who has very little mental health background, I feel like it covers a lot of stuff that, in physical health, we look at, which maybe could be something you need to look at for a dementia patient....." AA (Community health service/hospital pharmacist)

"I think it is well structured. It's quite simplistic. It follows step by step. It has sections which are particular to dementia review….IM (Care home pharmacist)

"I think it helps to cover everything because there's a structure. There is a checklist to make sure 'have I done this', 'have I thought about this, and done all that?' That way, you won't miss anything in the medication review" BT (Community/Mental health pharmacist)

Participants also opined about the ease of use and relevance of the toolkit to their practice:

"…I think it's a full holistic review….for example, if I'm in a care home and I'm doing general reviews, I can utilise this, especially when there is a patient with dementia, and there is high population of that in that setting…." IM (care home pharmacist)

"…It's very comprehensive. I feel like I wouldn't miss anything out with this tool" BB (Care home pharmacist)

Two participants shared a view that the toolkit could be useful to other healthcare professionals such as mental health nurses and geriatricians, indicating that it was versatile.

…"If there is an area whereby they don't have the resources, such as a pharmacist or as in my area they have a mental health nurse that goes to the care homes…if they don't have that then this would be a good tool for the GP to use…." BB (Care home pharmacist)

…"Can I just say I second what BB just said, because in respect to the ward I cover….it is very highly medical. Now, if a consultant had this, he would be happy to use it…because once a week we get a mental health doctor to come and review all patients who have dementia…. But me as a pharmacist, it's also quite good for me because we're all about optimising medicines…" AA (Community health service [CHS]/hospital pharmacist)

Due to the existence of local prescribing guidelines and formularies that already advocate cost effective prescribing, one participant did not think the toolkit would add much value as a means of reducing medication costs:

…"When you consider the local guidelines, they would usually cover it already with regards to the cost of this [sic] particular medicine…" OA (care home pharmacist)

A few drawbacks to using the toolkit in practice were mentioned, with all the participants agreeing that it would be time consuming to go through the steps.

*"…I have to fit it in….you want to do it, but how do you fit it in?"…*AA (CHS/hospital pharmacist)

…"Yeah, I was going to say…it would be hard to…with this tool, you're going to be referencing quite a bit. You wouldn't need everything" BB (care home pharmacist)

A few dwelled on the lack of communication between healthcare professionals especially when patients transfer settings, but the fact that many pharmacists were becoming independent prescribers was thought to be a positive, as it would mean they could make some of the warranted changes themselves, following discussions with the responsible clinicians.

"…Between primary and secondary care…even within the same primary care unit…communication is a challenge because we don't let the GP know what you have done. They are not magicians…they won't know what has happened to the patient and by the time the information gets there, something has happened. Especially when you also go between secondary care to intermediate care before you go back to the GP……anything can happen….communication is key" BT (community/mental health pharmacist)

One participant highlighted the importance of communicating not just with the GP but also with the patient themselves depending on their capacity, or with their family. According to this participant, becoming a pharmacist prescriber has helped with decision making regarding making recommendations following the final step of the toolkit.

"…Maybe this is exclusive to where I am…you've spoken to the doctor in one area, then you've spoken to the nurse in one area, then you've got the information together, and you, in your

capacity can prescribe. The last piece of the puzzle, maybe, is to speak to resident or their family to see whether they are okay…" BB (care home pharmacist)

Participants also completed a written evaluation of the toolkit in which they rated its layout/format, appendices included and length, and made comments, some about how to improve the toolkit. These are presented in Table 13.

7.3.2.3 Improvements to the toolkit

The participants made a few suggestions both during the focus group discussion and in their evaluation forms.

One of the first issues of note was the inclusion of an excerpt from NICE guidelines (CGG42, 2006) as an appendix in the tool. This was included to aid decision making about the pharmacological and non-pharmacological management of non-cognitive symptoms of dementia. The guidelines seemed to contradict themselves according to one participant:

…"There is a line here that says 'Alzheimer's disease, vascular dementia, mixed dementias'….people with those should not be prescribed anti-psychotic drugs because of the possibility of increased risk obviously of vascular events….then two bits after that, it says they should not, but then there's a line that says they can…" BA (Hospital/Mental health pharmacist)

A discussion ensued about this leading to another participant suggesting that in terms of evidence, NICE dementia quality standards and local guidelines should be added to the tool. It should be noted that current NICE guidelines for dementia (NG97, 2018) does not have this ambiguity and the recommendations for pharmacological/non-pharmacological management of dementia have been simplified and placed in one section, so one amendment to the tool would be to include these instead of the previous version.

In light of the contribution from another participant that some people with dementia were reviewed by memory clinics, another suggestion was to include memory clinics amongst the list of healthcare professionals to share interventions with, at the end of the medication review process, using the toolkit. However, the final agreement, after consideration that there may be other specialist services linked to the person with dementia, it was agreed that "specialist clinic" be added to this information sharing list, instead of "memory clinic".

One participant had some suggestions relating to the flow of the steps within the toolkit, opining that the "E" for evidence came before "sub-Types", indicating that time would have been wasted going through the steps of the toolkit before finding out what type of dementia they had or whether they even had a diagnosis of dementia:

> *"… sorry, just taking it back to what might be the issue with this: as opposed to being a flow chart, as it is….because in my head, you're looking at the evidence before you actually determine what kind of dementia they have…*
>
> *…rather, you establish what kind of dementia it is or if they have a diagnosis before you start to look at evidence"…*OA (care home pharmacist)

A second participant was concerned about ruining the flow of the toolkit by moving steps around as suggested above:

…"Another way you could do it…that "D"…like she said…so you don't mess up….you can remove the 'drugs' then put diagnosis, then under 'T', 'therapy'/'treatment'" IN (community/mental health pharmacist)

After further debate with the researcher, it was agreed that a "D" for diagnosis should be added at the beginning of the toolkit, and an arrow drawn linking this to the sub-type.

Other suggestions for improving the toolkit were made when the participants completed their evaluation forms as seen in Table 13.

The written evaluations were like those shared during the discussion session, with all participants rating the toolkit's format, length, and its appendices between 'good' and excellent. Overall, the participants wrote that it was useful, well-structured, comprehensive and useful. There were suggestions for improvements to the toolkit but most of those had already been discussed earlier, such as addition of a "D" for diagnosis at the beginning of the toolkit, addition of 'specialist clinic' and 'patient/carer' to the list of individuals/services to communicate medication review results to and removal of NICE guidelines (dementia) excerpts, and replacing with a link, plus explicit guidance on managing behavioural and psychological symptoms of dementia (BPSD).

Another suggestion was to potentially change the order of the toolkit, following discussions about the evaluating evidence before becoming aware of diagnosis or subtype, but it had been previously agreed that a connecting arrow would suffice.

Participant initial	Toolkit evaluation (poor, average, good, very good, excellent)			Comments
	Layout/format	appendices	length	
AA	Very Good	Very	Very good	-very extensive and quite comprehensive -found it useful -could be very handy in my practice
BA	Excellent	Very good	Good	-Well-structured and user friendly -Considered removal of appendices but presence makes them easier to refer to e.g. STOPP/START tool -To add explicit recommendations for antipsychotic therapy for BPSD, or at least the relevant NICE guidelines -NICE guideline excerpts can be removed, and links provided instead
BB	Excellent	Excellent	Excellent	-Comprehensive and useful for that are already prescribed antipsychotics -Great tool which incorporates 'holistic approach' and person-centred approach -Potentially could change order of acronym -communication section to refer to carer or patient
BT	Very good	Excellent	Excellent	-Very useful -add diagnosis at the top and connect to type of dementia -communication: add 'specialist clinic'
IM	Excellent	Very good	Very good	-Well-structured -very useful, in-depth -to add: whether patient is under specialist clinic and last review
IN	Excellent	Excellent	Excellent	-Very useful as it has compressed a wealth of information ensuring every aspect is covered -can be tailored exactly to patients' needs -to add: local guidelines
OA	Very good	Very good	Excellent	-useful for people with dementia -very detailed tool and very relevant -to add: signposting to relevant updated information for ACB score -Consider rearranging/re-wording flow chart

Table 13: Results from written evaluation of 'DEMENTIAS' toolkit

7.3.3 Result of toolkit pilot using two case studies

The participants were split into two groups with Group 1 discussing case study 1 and Group 2 discussing case study 2.

Case studies and the possible drug therapy problems that could have been identified using the toolkit, by both groups can be seen in Appendix 7e.

Group 1, case study 1

The case study discussed by Group 1 had seven potential drug therapy problems to be identified using the toolkit, and they were expected to use the following aspects of the toolkit:

- Drugs prescribed (D).
- Evidence for prescribing them (E).
- Comorbidities (M).
- Side Effects of medication prescribed (E)
- Neuropsychiatric symptoms (N)
- Dementia sub-type (T)
- Interactions (I).
- Anticholinergic burden of medication prescribed (A).
- Opportunities to suggest stopping or switching therapy in their pharmaceutical care plan (S).

The group lead (BA) admitted that they had first read over the case and discussed it amongst themselves before consulting the toolkit.

They consulted NICE Guidelines for dementia, though they used their own judgement for considerations regarding the comorbidities of the person with dementia in the case study, instead of the STOPP/START toolkit attached to the toolkit.

With regards to the drug therapy problems identified by this group, despite not using all expected aspects of the toolkit (see Appendix 1), they used a combination of their own clinical judgement and aspects of the tool to identify 4 out of the 7 possible drug therapy problems.

*"We did check the tool. Atenolol/beta-blockers doesn't give you any cognitive side effects. Salbutamol for asthma is fine as well, so we'll leave that, although SIGN (*Scottish Intercollegiate Guidelines Network) do recommend a corticosteroid as well as a Beta-2….but NICE still says if a patient has not used a PRN inhaler, you can keep them on just that…."* (BA)

The four potential drug therapy problems the group used the toolkit to identify were *drug interactions, initiate an acetylcholinesterase inhibitor, recommend stopping a drug with a high anticholinergic burden, and recommend alternative hypnotic for the patient's sleep problem.* They also considered the cost effectiveness of switching an acetylcholinesterase inhibitor for another based on identified interactions. They missed the fact that the patient's asthma would need monitoring since the proposed addition of a cholinesterase inhibitor could cause worsening control of asthma symptoms (British National Formulary 2019).

*"The toolkit also showed us interactions as well…so I would say it's definitely good, whether you use it at the start or you could use it at the end to check everything…" (*BA*)*

However, the group suggested melatonin as an alternative hypnotic to consider for the case in review, though current NICE guidelines for dementia (NG97, 2018) do not recommend this.

Additionally, they used the toolkit and found an interaction between the acetylcholinesterase inhibitor they recommended (donepezil), and fluoxetine

(antidepressant) the patient was already on and decided to switch the antidepressant instead of choosing a non-interacting cholinesterase inhibitor like rivastigmine. Their rationale was cost considerations. More detail needed here about cost comparison.

The group also did not mention that they considered any physical health monitoring which is referenced in the tool, and would have been a significant drug therapy problem to note since prescribing of a beta-blocker (atenolol) and a cholinesterase inhibitor (donepezil) can exacerbate bradycardia. This is despite one of the participants in this group expressing worry about lack of physical health monitoring in the elderly population during discussions in part 1 of the study:

*"..Like, I'm worried. Because if you're on a mental health ward, if they're, let's say, 65…before you start an anti-psychotic you have to think about ECG, thinking about physical health if you can. But for the elderly population, none of that is factored in…" (*BB*)*

However, they did point out the absence of physical parameters in the case vignette, such as blood pressure and pulse rate, and the absence of a drug history, which indicates that they would have considered these in practice.

When the researcher asked the group about completing the therapeutic care plan included with the toolkit, they indicated they felt they did not have enough information to complete one but would do so in practice. They felt they needed more details such as past medical history and physical health monitoring results (like blood pressure and weight)

Overall, the consensus in this group was that the toolkit was useful and applicable.

Group 2, case study 2

Group 2 discussed a much more straight forward case (case study 2, see Appendix 7e), that required them to go through all the steps of DEMENTIAS toolkit, considering the following:

- Drugs prescribed as well as over the counter medication,
- Evidence for prescribing antipsychotics,
- Any possible co-morbidities (using STOPP/START),
- Effectiveness of prescribed medication,
- The patient's neuropsychiatric symptoms,
- Query type of dementia (even though they were not given this information),
- Anticholinergic burden of over the counter medication and
- Stopping the antipsychotic prescribed based on the all the above considerations.

The group did recognise that based on the case vignette, the patient with dementia had challenging behaviour. Considering NICE guidelines for non-cognitive symptoms as recommended on the toolkit, a non-pharmacological approach was deemed more appropriate than prescribing an antipsychotic (olanzapine in this case).

They also used the toolkit to consider comorbidities, and possibility of side effects as well as switching a codeine-containing painkiller with paracetamol only, but admitted that the toolkit was more useful for more complex cases.

"*I think it was applicable in the sense that you almost… because from the beginning, you kind of gathered that it was a non-pharmacological intervention. However, if we were going to prescribe olanzapine, would it be appropriate, if that makes sense? So, because we didn't have all the information, we were like, "Oh, actually, will it be appropriate?" So, then we had to look at the evidence. But also, NICE guideline says that you can use it but we figured it was non-pharmacological. And we just went down to the neuropsychiatric symptoms and then we did find that we'll definitely go and look at the non-pharmacological interventions. But we didn't use it as extensively, definitely not, as the first (*BB)

"*We looked at the comorbidities and we kind of like just thought maybe having a total review. She's not on a lot of medication as per what we got presented with but things like initiating the STOPP/START, we looked at the pain relief, if she's still in pain. Can she just go on paracetamol? Having the codeine….Codeine we know is a drug that metabolises into morphine, that kind of causes constipation. Again, is her behaviour due to the fact that she might have constipation going on, giving her all that aggression because she's not able to verbalise her feelings per se? So, with regards to comorbidities, it was also quite effective" (*AA)

Despite not using the toolkit systematically, this group indicated that they still found the toolkit useful as a reminder of what to consider:

"I guess, the other thing to think about is the fact that although we didn't use the full tool, having that there was able to prompt us to look at certain things, like neuropsychiatric symptoms. It is part of the tool. So we're not using the full tool, we're using little bits of it" (OA)

They needed prompting to consider the fact that the patient in the case study may have a co-morbid mood disorder.

With regards to further corrections of the tool, the first group did not suggest any further changes following their case study, but one Group 2 participant made a suggestion that the anticholinergic burden scale (ACB) included with the toolkit should have a prompt to inform a potential user that these were not gold standard, since different places assigned different anticholinergic scores to the same medication.

"*You know, say for antidepressants, one of the things that they use quite a lot in my patch is mirtazapine and it has a burden of one. But that isn't on there.*

…" So, probably just ensuring that it is prompted that this is subject to change in different places…" (OA)

The researcher asked the whole group at this point if there was anything else they would like to add regarding the whole study, but no one had any.

Part 1 of the study (discussions on the toolkit) took about 40 minutes and part 2 less than 20 minutes, but this was because recording was only done for actual discussions, not whilst participants were familiarising themselves with the toolkit or deliberating on the case studies.

7.3.3.4 Changes to toolkit from a consideration of all participant comments

Changes suggested by the focus group were discussed with the research supervisor and the following were made:

- Addition of diagnosis to the first box in the flow diagram and connection between this and type of dementia
- Addition of patients/carers and specialist clinic to list of individuals/teams to receive information from completed medication review
- Removal of NICE guideline CG42 excerpts and replacement with relevant excerpts from NG97 (2018) (Appendix 7f)
- Shortening of the pharmaceutical care plan template to reduce time spent completing it, by removing some of the non-essential demographic data required in initial toolkit (Appendix 7g)

- Addition of a link for pharmacists to obtain up to date anticholinergic burdens of drugs from http://www.acbcalc.com/ with permission from the lead author (King, R 2019) (Appendix 7h)
- Removal of drug interactions of acetylcholinesterase inhibitors and memantine, as up to date information on these are best taken from latest BNF

Figure 22 shows the results of the amendments and final toolkit developed following the focus group study.

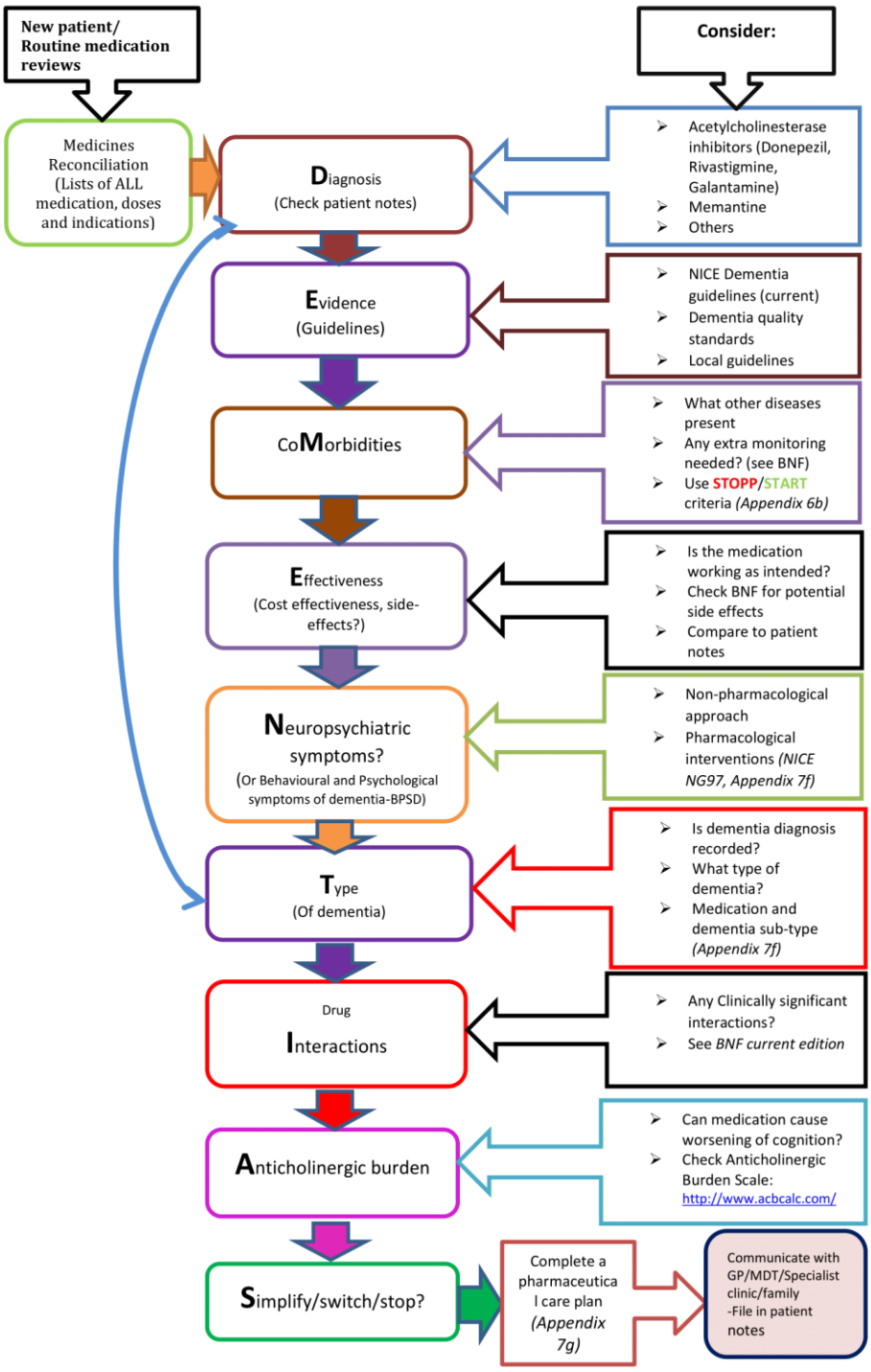

Figure 22: Amended Dementias Toolkit

7.4 DISCUSSION

This study convened a focus group of pharmacists to discuss and review an intervention toolkit developed to aid pharmacists in delivering pharmaceutical care to people living with dementia.

The goal of pharmaceutical care is for pharmacists to work with patients and other healthcare professionals responsible for their care, to promote health, prevent disease, assess, monitor, initiate and modify prescribed medication to ensure that they are safe and effective, through patient-centred care (American Pharmacists Association 1995). When patients are prescribed medication, the principles of pharmaceutical care require that they are appropriate, safe, effective, and that the patient is compliant with the medication regimen (Cipolle, Strand and Morley 2004). Failure to meet these principles results in drug therapy problems (DTP), and pharmacists, alongside other healthcare professionals, have a duty to prevent and/or resolve drug therapy problems (Cipolle, Strand and Morley 2004).

Prescribing appropriately for elderly people is a complex issue which cannot be managed simply by following clinical guidelines (Molist Brunet et al 2016) and for those living with dementia, this is further complicated because the condition is commonly associated with other long term conditions such as diabetes, chronic cardiac failure, chronic obstructive pulmonary disease amongst others (Schubert et al 2006, Delgado et al 2020).

Whilst polypharmacy in itself is not always equivalent to inappropriate prescribing, the added challenge of managing possible adverse side effects and potential drug interactions puts those prescribed multiple medications at higher risk of potentially inappropriate prescribing (Delgado et al 2020, Barry et al 2016)

with those living with dementia particularly affected (Parsons 2017). Despite this, people with dementia are more susceptible to polypharmacy and inappropriate prescribing than those without dementia (Kirstensen et al 2018). Inappropriate medication use is even more prevalent amongst people with dementia living in care homes, so it is essential to have a structured approach to managing medication for people with dementia resident in care homes, including conducting periodic medication reviews in a systematic manner with the purpose of evaluating appropriateness of all medication prescribed (van Marum 2017).

Several tools have been developed over the years to help identity potentially inappropriate prescribing, mostly developed for the general older adult population (Delagado et al 2020, Luccetti and Lucchetti 2017) though Holmes et al (2008) did develop an integrated approach specifically targeting medication appropriateness in people living with advanced dementia.

In this study, a focus group of pharmacists from various sectors of practice evaluated and tested a prototype toolkit developed to serve as a guide to a structured approach to conducting systematic, comprehensive medication reviews for people living with dementia, without specificity on the severity of the disease, though the expectation is that pharmacists should know that medication therapy for people with dementia progresses from preventive measures to symptom delay in mild to moderate disease, to palliative in advanced dementia.

Focus group methodology is often employed in pharmacy practice research as it has the advantage that it provides a safe environment for participants to express their views, perceptions and opinions as well as support each other, compare views and revise opinions based on discussions with others (Minard et al 2016).

In the current study, the participants spent some time initially discussing prescribing practice for people with dementia, before discussing the toolkit specifically. The areas of convergence (use of national guidelines) and divergence (individual prescribers' approach to prescribing psychotropic medication to people with dementia) were discussed.

Prescribers were thought to make prescribing judgements based on a desire to maintain good quality of life in advanced dementia, with an assertion that most people with dementia died within 16 months of admission into care homes, which made the consultant reluctant to discontinue antipsychotics in this group of patients. The view that most residents of care homes with dementia die within 16 months is backed by a systematic review exploring the clinical course of advanced dementia (Mitchell et al 2009); the study found that over half of care home residents with dementia died within 18 months of admission as a result of various co-morbid physical health disorders and frailty.

Though there is a paucity of practical guidelines for prescribing in advanced dementia (Fox et al 2017), in part due to difficulties in conducting research in this population (Murphy et al 2016), palliative care guidelines for people with advanced dementia (NHS North West Coast Strategic Clinical Network Palliative Care Guidelines in Dementia 2018) cautions continued prescribing of medication such as antipsychotics. However, as with the views of participants in this research, many physicians are reluctant to discontinue antipsychotics in people with dementia (Parsons et al 2014).

Pharmacists in this focus group study also cited uncertainty about what guidelines recommended with regards to continued prescribing of acetylcholinesterase

inhibitors in people with dementia as the disease advances, and were not sure if these drugs afforded any benefits to people with severe dementia. Their doubts are in line with research which shows that prescribers have little guidance on when to discontinue therapy with acetylcholinesterase inhibitors (Hermann and Gauthier 2008, Renn et al 2018) even though adverse effects have been associated with discontinuation (Okazaki et al 2006, Shega et al 2009). Furthermore NICE guidelines caution against discontinuation simply based on level of cognitive decline (NICE NG97).

Another issue of interest discussed in this focus group study, which informed their suggestion for the toolkit improvement, was the variation of prescribing as a result of local guidelines or formularies, as well as prescribers diverging from national guidelines with regards to prescribing antipsychotics to people with dementia. Whilst it is true that local prescribing guidelines can lead to variation in prescribing practice (Duerden et al 2011), recent research has also shown that ethnicity and social status of the person with dementia affects physicians' prescribing decisions (Fortinsky et al 2010, Jones et al 2020, Szchepura et al 2016). People from deprived areas or from black or Asian backgrounds were more likely to receive less symptomatic dementia medication treatment and more likely to be prescribed antipsychotics for longer. For example, studies in Norway and Denmark found that people from minority ethnic backgrounds were not being prescribed anti-dementia drugs on an equal basis as those from majority ethnic groups (Alzheimer Europe 2018). Similarly, inequalities were found in a UK study which found that people with dementia from black and ethnic minority backgrounds were more likely to be prescribed antipsychotics for longer than white people (Jones et al 2020).

Considerations about where the responsibility for prescribing lies were discussed. This is salient as it explains some of the inappropriate prescribing in people with dementia since responsibility for monitoring and medication review is sometimes disputable, with GPs firmly believing that this should lie with the specialist clinics/prescribers (Illife et al 2006, Russ et al 2013).

Involving family and carers in decision making was also deemed important in this study; this is also in line with recommendations for managing medication for people with advanced dementia (NHS North West Coast Strategic Clinical Network 2018, Parsons 2017), showing that some of the participants in the focus group were knowledgeable about the subject.

Participants' evaluation of the toolkit during the focus group study were overall very positive, with most pointing out that it will be useful as a reminder to them and other healthcare professionals involved with care of people with dementia, particularly those who live in care homes, of important person centred issues to consider when reviewing prescriptions for people with dementia. They did comment on how time consuming completing the tool would be and wanted to know how often this process would need to be done for each person with dementia. With respect to useability of the toolkit and its versatility, similar tools have been judged useful by pharmacists for identifying inappropriate prescribing in people with dementia (Tommelien et al 2016, Hanlon et al 2013) even though the impact of these on health related quality of life of people with dementia is difficult to quantify (O'connor 2017, Alldred et al 2016, Al Aqqad et al 2014).

The point made that the toolkit was time consuming to follow in practice is a view shared by other researchers that have developed medication processes (De Bock et

al 2018). In answer to participants' queries about how often a process such as that advocated by this toolkit could be carried out, NICE Quality Standard (QS85 2015) for medicines management in care homes recommends a multidisciplinary medication review for each resident, and the frequency guided by the residents' needs. NICE quality standard (QS85 2015) also recommends that the maximum interval between medication reviews should be one year.

Additionally, it has been suggested that a full review starting with medication reconciliation is invaluable in transitions of care such as hospital discharge (De Bock et al 2018).

The frustration expressed by participants in this study over communication challenges between healthcare practitioners in primary and secondary care in the UK is reflected in other research, linked to poor patient outcomes (Forondo et al 2016) and also demonstrated in the earlier part of this research, as expressed by staff of care homes with people living with dementia in Chapter 5. The care home study showed that many providers and healthcare professionals were involved in care of people with dementia in care homes, and research has shown that when many providers are involved in the medication process, there is need for regular communication of information between healthcare professionals to enable periodic review and adjustments of medication (Mahlknecht et al 2019), but, like found in both the care home study (chapter 5) and current study, this communication doesn't happen regularly, thus the increased risk of potentially inappropriate prescribing (Spinewine et al 2007). There have been calls for better inter-professional communication (Olsson et al 2010).

Participants seemed to believe that expansion of pharmacists roles into independent prescribing would help in this domain as they would be able to action some of their own recommendations following medication review in care home environments. This is echoed by Hughes and Lapane (2011) who proposed the implementation of interventions by prescribing pharmacists. Indeed, it has been suggested that the assumption of full responsibility for overall management of care home residents' medicines and monitoring, as well as authorisation of repeat prescriptions based on individualised pharmaceutical care plans by pharmacist independent prescribers, could lead to improved patient outcomes, as well as improved communication of resident specific prescribing decisions to staff, residents and GPs (Inch et al 2019).

The comments made by participants during discussions and written evaluation suggested similar improvements to the toolkit some of which have been actioned (Figure 22). Of note was the suggestion to add family/carer to the list of people to communicate a pharmaceutical care plan to, in addition to the suggestion to add specialist clinics. This was a useful suggestion as family/carers often need to be involved in decision making about the care of their relatives with dementia since they often cannot participate in decision making once dementia is advanced (Parsons and Gamble 2019). The suggestion to add diagnosis at the top of the toolkit process was also considered useful as research has found that a dementia diagnosis increases the likelihood of potentially inappropriate medication prescribing, which is of clinical importance as it may help determine whether interventions to improve prescribing should be implemented following establishment of a dementia diagnosis (Gnjidic et al 2018).

The feasibility study of the toolkit using two case vignettes revealed that even though the toolkit could be used to identify drug related problems when conducting medication reviews for people with dementia, participants did not use all aspects of the toolkit, nor identify all possible drug related problems written into the vignettes.

For the first case study, participants identified most of the drug related problems, but failed to note the need for physical health monitoring. The neglect of physical health monitoring for people living with dementia has been noted in research, with Cooper et al (2017) reporting that this group of people receive fewer physical health checks. This is despite one of the participants in this group expressing concern in earlier discussions in the focus study about precisely this, and in spite of national dementia strategies pushing for prioritisation of healthcare access for people with dementia, particularly those in care homes (Alzheimer's Society 2016a, Cooper et al 2017).

The second case study which was more straight-forward still saw group 2 participants demonstrate uncertainty about tackling low mood in the person with dementia. This could have been solved by consulting the START tool attached as an appendix to the toolkit under study (O'Mahonney et al 2015) as many people with dementia experience depression and social withdrawal during the course of the disease (Sury et al 2013).

Pharmaceutical care plans embedded in the toolkit were not completed by either groups of participants since they considered that they weren't furnished with full information to do so. Inability to access patient's clinical information has been quoted as a barrier to using screening tools to structure medication use reviews in

another study (Cardwell et al 2018), and in addition, when full medication or diagnostic information is unavailable it is difficult to apply every section of a medication appropriateness tool, as pointed out by Hukins et al (2019) in their systematic review of tools for identifying potentially inappropriate prescribing in older people living with dementia.

Overall, participants in this study did not use every aspect of the toolkit to identify drug therapy problems, and expressed the view that the toolkit was more useful for ensuring they remembered important aspects of person centred dementia care to consider, as well as for more complex cases. Researchers who developed the Discontinuing Inappropriate Medication in Nursing Home Residents (DIM-NHR) (Wouters et al 2017) to examine successful discontinuation of inappropriate medication and improve medication prescribing in nursing homes, found that whilst the tool proved useful for this purpose, they were in agreement with Craig et al (2008) that medication reviews conducted in multiple steps should be considered complex healthcare interventions. The toolkit under review in the current focus group study could therefore fall in the category of complex healthcare intervention. Consideration of the toolkit in this study as a healthcare intervention would require that a robust systematic approach to its development is adopted following the UK Medical Research Council complex intervention framework, in order for it to be valid for use in improving clinical practice (Craig et al 2008). The useability of the toolkit would also need to be tested using a valid scale such as the System Usability Scale (Bangor et al 2009).

7.5 CONCLUSION

A group of pharmacists from diverse sectors of practice participated in a focus group study to evaluate the prototype DEMENTIAS resource toolkit developed by the researcher and reported that they found it useful for practice as a checklist to prompt correct identification of issues to address during medication review, as well as a good tool for reviewing medication for complex patients. They made several suggestions for improvement of the tool, and in a feasibility study designed to apply the toolkit to case studies involving prescribing for people living with dementia, found the toolkit partially useful for this purpose.

Further robust experimental design will need to be carried out using a valid framework for testing complex interventions, in order to confirm its useability and applicability in wider practice, especially amongst community pharmacists delivering pharmaceutical services to care homes for people living with dementia, as the toolkit was designed mainly to target this group of pharmacists.

7.6 STUDY STRENGTHS AND LIMITATIONS

Whilst this study describes one of the few intervention toolkits designed specifically for reviewing medication for people with dementia, and had the advantage of being evaluated by pharmacists with knowledge of the subject, there are some limitations, mainly based on the study design:

- Majority of pharmacists who participated had working experience with people who had dementia either through working in care homes or in hospital environments. This counted as a strength in that they were able to critically evaluate the tool effectively, but the disadvantage of this is that they could use

their own judgement to review case studies presented in the feasibility study, making the toolkit which was the focus of the study less relevant

- As this was a focus group, those with more confidence in the subject under discussion tended to contribute more to discussions, meaning the views of the less confident were not well represented
- The testing of the toolkit did not use validated scales testing feasibility or usability and relied on views and judgement of the participants, which could have been biased.
- It is a very small study so the views of the participants are not generalizable. A larger study with more participants, testing the tool with a large sample of people with dementia prescribed medication and following a standardised framework for testing interventions is needed in order to test whether the toolkit can be utilised in practice
- It is assumed that by following the processes described in the toolkit, practitioners will apply the correct principles of care to people with dementia based on their disease severity, however, its usability based on various stages of the disease was not defined.

CHAPTER 8
DISCUSSION AND CONCLUSION

8.0

8.1 Introduction

This final chapter addresses the overall aims and objectives of the body of research undertaken on pharmaceutical care in Dementia by summarising and discussing its findings.

Dementia, a worldwide health care priority as determined by the World Health Organisation (WHO) is a major cause of disability and dependency in the world's older adult population (WHO 2019).

Medicines play a key role primarily in managing the symptoms of dementia (Donegan et al 2017) and are often used in combination with medication prescribed for other comorbid health conditions. Thus, medication management can be very complex for people living with dementia and their carers (Smith et al 2017). Medication is the most common intervention received by care home residents (Hughes et al 2013), and consequently multiple morbidity is associated with polypharmacy, which is particularly problematic for people with dementia, as many drugs worsen cognition, impair mobility or diminish appetite leading to malnutrition (van Marum 2017). The quality of prescribing to the vulnerable care home population is recognised as being poor (Hughes and Goldie 2009).

Community pharmacists are trusted healthcare professionals whose accessibility means they are often the first to be encountered by people with dementia in the community, and thus they have many opportunities to provide pharmaceutical care to these people (Barry et al 2013). They play a vital role through offering a broad spectrum of services (medication advice, drug therapy management and

monitoring) to patients and their caregivers (Duong et al 2017). However, the role of community pharmacists in the pharmaceutical care of people with dementia living in care homes has not been widely explored in research and community pharmacists have, in the past been reported to be only minimally involved with people with dementia with regards to their medicines (Taylor 2009).

Following a quality review in 2014, the Care Quality Commission produced a report on the care of people living with dementia in the UK (Cracks in the Pathway CQC 2014). 90% of care homes inspected were found to provide poor care to residents with dementia, particularly in areas such as:

- Assessing their care needs
- monitoring care quality
- collaboration between care providers
- Involving residents and their families in decision making
- Planning and
- Delivery of care.

This report did not mention the role community pharmacists or pharmacies could play in the dementia care pathway, but Webber (2015) in a review specially commissioned by the General Pharmaceutical Council, recommended that the level of need for pharmacist involvement be considered when developing and defining the pharmacy professional's role in supporting people with dementia living in care homes. People living with dementia are frequently prescribed potentially inappropriate medicines. This has been adduced as being reflective of potentially poor quality of pharmaceutical care provision to this patient group (Mehta et al 2017).

The overall aim of this research was to conduct an in-depth exploration of the role community pharmacists play in the pharmaceutical care of people living with dementia in care homes, establish any impact, and to foster an understanding of any barriers they face in the fulfilment of this role.

In order to achieve this aim, objectives related to: a qualitative and quantitative exploration of community pharmacist views and perceptions of the pharmaceutical care needs of people with dementia in care homes, a qualitative exploration of the medication-related needs of residents with dementia from the perspectives of care home staff.

8.2 RESEARCH FINDINGS

8.2.1 The pharmacists' study

Methodology

This two phase study involved semi-structured interviews with a purposive sample of 15 community pharmacists in the first instance, to explore their awareness of the pharmaceutical care needs of people with dementia and seek their opinion about their knowledge and ability to provide services that meet these needs. The views expressed in this phase were used in a second phase to design a questionnaire survey that was administered to a random selection of community pharmacists across England. The central focus of both was establishing community pharmacists' awareness of the pharmaceutical care needs of people living with dementia, the services provided to those in care homes, pharmacist knowledge and confidence in delivering these services and understanding the barriers they face.

A similar study had been previously carried out in Northern Ireland (Barry et al 2013) in which a quantitative questionnaire survey was used to evaluate the views of community pharmacists about their knowledge of pain management in people living with dementia. The survey tools used in that study could have been adapted for use in the current study since it had similar objectives and the questionnaire had been developed through comprehensive literature searches and the use of validated tools such as the Approaches to Dementia Questionnaire (Lintern et al 2000). Alternatively, Mat Nuri et al (2017) used validated items from the Alzheimer's disease Knowledge Scale (Carpenter et al 2009) to evaluate knowledge of clinical pharmacists in Malaysia on Alzheimer's disease, which could also have been a useful tool to adapt to the current study.

However, though existing questionnaire instruments have track record of reliability and validity, modifying or adapting them to a different study can lead to weakening of that validity (Nichter et al 2002). A formative approach whereby qualitative research is used to inform survey development, similar to that used by Nichter et al 2002 was therefore applied, which helped to inform the researcher about the perspectives of a selected group of community pharmacists of the pharmaceutical care needs of people living with dementia in care homes. The results obtained and issues identified from evidence-based research on dementia care, informed the development of the questionnaire which was distributed to a random sample of community pharmacists across England.

The drawback to this approach was that whilst the qualitative study of pharmacists involved purposive sampling of pharmacists who delivered services to care homes, the quantitative survey utilised a convenience sample. Community

pharmacists (n=372) were contacted via the register of pharmacy premises on the General Pharmaceutical Society website without assumption of service provision to care homes.

This resulted in just over 31% of 102 respondents (n=32) affirming that they delivered services to care homes, a very small sample making generalisations difficult. There is no data on the percentage of community pharmacies that are involved in delivering pharmaceutical services to care homes in England (Webber 2015). However, the Royal Pharmaceutical Society Scotland (RPS Scotland 2012) reported that less than 20% of community pharmacies in Scotland were involved in delivering services to care homes, a figure lower than the 31% of respondents to the questionnaire survey in this research. Whilst the figure for Scotland cannot be extrapolated to determine an estimate for England, it is reasonable to expect that the percentage of community pharmacies delivering services to care homes in England would be higher than in Scotland since the percentage of pharmacists working in a community setting are higher in England (62%) than in Scotland (55%) (General Pharmaceutical Council 2019).

Pharmaceutical Care Services Provision

The results obtained from the qualitative arm of my research study were like those from the questionnaire survey of community pharmacists in terms of pharmaceutical care services provided the following services in varying degrees:

- Medication supplies to care homes
- Delivery services

- Compliance aid service (monitored dosage systems) and to a lesser, variable extent,
- Care home staff training
- Audits
- Medication reviews and
- Prescription interventions.

Pharmaceutical Care Needs

When questioned about the pharmaceutical care needs of people with dementia in care homes during face to face interviews, pharmacists stated that these involved checking prescriptions for drug interactions and ensuring medication was taken correctly and in a timely manner, whilst others expressed concerns about polypharmacy and inappropriate prescribing in this patient group, without specifying what they would do about it.

These views are partially in line with documented pharmaceutical care needs of patients in general (Hepler 2010, Hudgens and Chirico 2010) which are reportedly:

- Timely, accurate responses to signs and symptoms
- Access to safe and cost-effective medication
- Planned professional follow-up, and the
- Design of safe medication use processes.

Knowledge

A review of the appropriateness of drug therapy through medication review and the detection of drug therapy problems are considered integral aspects of the pharmaceutical care process. This requires adequate and up-to-date clinical knowledge by the healthcare professional undertaking the process.

Pharmaceutical care issues relevant to people living with dementia include minimising cognitive side effects from prescribed medication, appropriate prescribing of memory enhancing drugs, and management of behavioural and psychological symptoms of dementia (Paton 2009). This would entail integration of services, in which a pharmacist has the responsibility for the whole system of medicines supply and their use within a care home, alongside a GP (RPS 2016), the promotion of rational prescribing of antipsychotics to people with dementia and playing an enhanced role in pain management for people with advanced dementia, as well as those at the end of life (Thrave 2016).

However, in the current study, when it came to the specific knowledge about medication used to treat dementia, their adverse effects or related side effects, pharmacists interviewed appeared to display a preference for checking reference books or relying on computer software to ascertain the appropriateness of their answers. This finding was consistent with that of the questionnaire survey where respondents displayed similar immediate knowledge deficits about drug interactions and interventions to optimise medication use in people with dementia. However pharmacists in all phases of my research were knowledgeable about behavioural and psychological symptoms of dementia and the detrimental effects of prescribing antipsychotics for people with dementia in care homes.

The issue of professional knowledge cannot be overstated, considering that the Patients Association (2019) recently launched a care home charter which states that any professional working in a care home must have the requisite knowledge and skills to assess, monitor, and review medication to ensure that residents receive medication safely and appropriately via the right route (British Geriatrics Society 2019). Though the existence of computerised clinical decisions support systems go a long way towards assisting pharmacists in identifying drug therapy problems and highlighting requirements for patient counselling, some systems are poorly designed and generate inappropriate medication alerts or fail to work completely (Sutton et al 2020). Pharmacists considering extending their roles to offering targeted pharmaceutical care to people with dementia would need to embark on appropriate continued professional development (CPD) to complement their knowledge in this field.

Education and Training

Education and training were also an area of consensus for both arms of the study as in both cases, only a small fraction of respondents had pursued any dementia training, with most participants agreeing that they would welcome more. It has been suggested that to meet the challenge of making a difference to medicines management in care homes, pharmacists require extra training in topics such as dementia, palliative care and end-of-life care (Oxtoby 2014).

Remuneration for Extended Roles

Remuneration is an aspect of service provision that needs to be tackled through commissioning bodies, who in turn need to ascertain that any proposed enhanced service/role demonstrates value for money. While community pharmacists are

being encouraged to take on more clinical roles in managing long term conditions (Hall et al 2018), variations in commissioning has seen people with dementia in some parts of the country benefit from their input, whilst others have not (Maidment et al 2017).

Some participants in the qualitative study of pharmacists admitted that lack of remuneration hindered their willingness to deliver a pharmaceutical service beyond supply to care homes.

However, the fact that other participants within the same study did go the extra mile demonstrates the point that there are variations in how residents in care homes benefit from pharmacist input across England, and a more standardised commissioning pathway could help in ensuring every care home resident gets the pharmaceutical care they need.

8.2.2 The care home staff study

This phase involved an exploration of the views of care home staff about the medication related needs of people with dementia in residential and nursing care home settings, as well as their opinions of the pharmaceutical services they received.

Pharmacists' Impact on Dementia Care

The care home staff study gave an indication of the impact of community pharmacists on care of people with dementia in the care home setting, stating that they mainly supplied their medication, and in some cases conducted audits, liaised with GPs about supply issues, and gave advice regarding side effects of medication

or the right medicine formulations for residents with swallowing difficulties or those refusing medication.

Multidisciplinary team working

Helmsley (2018) described care homes as a 'healthcare blackhole' owing to the fact that they can be seen as low priority even amongst GPs, a view shared by the Alzheimer's Society (2016) in their 'Fix Dementia Care: NHS and Care Homes' report.

Curiously, this arm of the study showed that medication reviews were being conducted solely by GPs, geriatricians and nurses, as opposed to pharmacists; at the time of the research, these care homes did not have access to clinical pharmacists who provide specialist services to care homes.

Pharmacy-led medicines optimisation services which can lead to reductions in emergency hospital admissions from care homes and savings on drug costs continue to be advocated (Helmsley 2018). However, this will require pharmacists working as an integral part of multidisciplinary teams (Miller et al 2015), an occurrence found to be lacking in the current study. This clearly indicates a gap that can be filled by community pharmacists trained to fulfil the role, considering the British Medical Association called for GPs not to overstretch themselves when working with care homes (Chaplin 2016, Helmsley 2018). Furthermore, care home staff interviewed stated that they would welcome more input from pharmacists and advocated better communication between pharmacists and GPs.

It is estimated that the care home population will grow by 15% by 2020/2021 (Crawford, Read and Sim 2016) and in a report highlighting the need for

pharmacists to step up from performing a predominantly supply role in care homes, Chaplin (2016) describes expanding role of pharmacists in this sector, whilst pointing out that such a role will require pharmacists to be trained to deliver services essential for the wellbeing of care home residents, a majority of whom will suffer from dementia.

In a cautionary note that acknowledges the suboptimal nature of medicines management in care homes in the UK, Wright (2016) asserted that an effective model proven to improve pharmaceutical care in care homes has not been identified; while the cost effectiveness of community pharmacist involvement remained unknown, the author conceded that they could improve the quality of prescribing and reduce future utilisation of NHS resources. The same report advocated that interventions with different elements be tested robustly for feasibility, to avoid implementation of services based on non-generalisable evidence. The utilisation of community pharmacists in an expanded role delivering comprehensive pharmaceutical care to people with dementia in care homes will therefore be a service that needs robust testing across the UK.

Development of a pharmaceutical care prototype toolkit

Given the partial knowledge and confidence of community pharmacists in regard to dementia care discovered in the pharmacist arms of this research, and their restricted level of involvement in care home medication reviews (care home staff study), a dementia intervention toolkit that would assist pharmacists who wish to conduct systematic, structured medication reviews for people living with dementia was considered useful. A prototype toolkit was therefore developed. It aimed to provide pharmacists with a systematic, stepped care approach to conducting

medication reviews, as part of pharmaceutical care provision for people with dementia. Though this was subsequently tested in a focus group of clinical pharmacists who mostly worked in care homes exclusively or worked in both community and secondary care sectors, the toolkit provides references directing a user less familiar with the subject area to useful resources to aid the process.

8.2.3 DEMENTIAS Intervention Toolkit

Several studies investigating inappropriate medication use in people with dementia, across disease severity, various settings and around the world have demonstrated high prevalence of polypharmacy and potentially inappropriate prescribing. These include: Colloca et al (2012) across Europe, Holmes et al (2008) in the USA, Parsons et al (2012) in the UK, Cross et al (2016) in Australia and Truter (2013) in South Africa.

Parsons et al (2012) noted that inappropriate medication use was more prevalent in people with dementia living in care homes, and in a recent, comprehensive review of the topic (Parsons 2017) highlighted the necessity for the design of the development, testing and validation of tools to assess medication appropriateness specifically for people with dementia.

Tommelien et al (2016) also highlighted the unique opportunities for community pharmacists, whilst dispensing and supplying prescriptions, to conduct periodic screening for potentially inappropriate prescribing of prescription only or over the counter (OTC) medication, and argued that such a process required an evidence based tool.

Future models of care will include the necessity for pharmacists to carry out structured medication reviews in various settings of practice (Primary Care

Pharmacy Association 2019, NHS England GP Contract 2019,) with the likelihood of community pharmacists being drafted to into primary care networks to work alongside other healthcare professionals, following appropriate training.

It is anticipated that the toolkit developed in the concluding part of this research study will be a useful inclusion to any training package for pharmacists delivering cross sector pharmaceutical care; providing appropriate pharmaceutical services to people living with dementia will be inevitable given its growing prevalence.

8.3 Strengths and limitations of my research

Strengths

1. Pharmaceutical Care Needs

a. To the best of the researcher's knowledge, this is the first study in the UK that has explored the views of community pharmacists and established their awareness about the pharmaceutical care needs of people living with dementia in care homes in England.
b. It has sought to understand and highlight the intersectionality of views of pharmacists and those of care home staff working in these establishments and make recommendations to optimise the current provision.
c. The qualitative studies of community pharmacists and care home staff highlighted the challenges each group of healthcare professionals faced when contributing to care of people with dementia in care homes.
d. A toolkit to support pharmacists wishing to conduct medication reviews to people with dementia was developed and piloted.

e. The study also triangulated data through the perspectives of two sets of healthcare professionals involved in the care of people living with dementia in care homes (community pharmacists and care home staff) based in different locations, achieving data saturation in both studies.

2. Structural equation modelling

a. Additionally, the use of structural equation modelling using PLS to find correlations between knowledge, confidence and barriers to care delivery amongst community pharmacists could be replicated in other areas of pharmaceutical care practice.
b. This could inform development of content for continuing education and training of pharmacists.

Limitations

There were several limitations to this study:

a. ***Generalisability:*** The findings of the study have limited generalisability to the wider population of community pharmacists or care home staff because all arms of the study involved small numbers of participants and the sample frame was England only.
b. ***Patient/Carer's Voice:*** The views of people living with dementia in care homes or their family representative were not explored in this study. Thus their pharmaceutical care needs from their own/family's perspectives were not investigated, which could have triangulated the findings. However, people with dementia in care homes are often suffering from more advanced forms of the

disease, with levels of cognitive decline that would have made carrying out this sort of investigation difficult and potentially unethical.

c. ***DEMENTIAS Toolkit:*** The development and testing of the toolkit involved clinical pharmacists with experience of working in secondary care or care homes. Its applicability from the perspective of community pharmacists involved in supplying medication to care homes was not tested and is therefore not known.

d. ***MRC Framework:*** The development and testing of the toolkit did not follow the MRC framework for developing complex interventions (Craig et al 2008). This was beyond the scope of my research. It is suggested that a future feasibility study would employ a collaborative approach between suitably trained teams of community pharmacists, care home GPs and care home staff/managers. It could also involve people with dementia in care homes still able to participate fully in decision making about their medication needs or their family member(s).

8.4 Implications for Pharmacy Practice

The Framework for Enhanced Health for Care Homes (2016) suggests the involvement of pharmacists in medication reviews in care homes, with specific reference to people living with dementia in these establishments. It also recommends collaboration between clinical commissioning groups, local authorities and care homes for the development of care home service specifications and outcomes.

Many studies have explored the role of community pharmacists in medication management for older people (Holland et al 2007, Tommelein et al 2015, Chau et al 2016). Additionally, there is a vast amount of research exploring roles of specialist clinical pharmacists in carrying out clinical interventions to optimise prescribing for older people in care homes (Alldred et al 2016, Wouters et al 2017). There is limited research on roles of community pharmacists in medication management for people living with dementia in the community (Maidment et al 2016, Maidment et al 2017, McGrattan et al 2017). However, there is very little published research in the roles community pharmacists play in delivering pharmaceutical care to people with dementia in care homes, which is something my research sought to address.

The changing landscape of policies in this field is exemplified by the community pharmacy contractual framework (NHS England 2019) which requires all community pharmacy patient-facing staff to become dementia friends, but the medicines optimisation in care homes scheme (NHS England 2018) which placed specialist clinical pharmacists in care homes, is ending. This is due to the re-engineering of care home pharmacists roles under the newly created primary care networks, and plans for dedicated enhanced services such as structured medication reviews which are still to unfold (Farmer 2019).

There remains a paucity of research exploring the roles of community pharmacists delivering care to people living with dementia in care homes. This research is timely in that it highlights the barriers that need to be overcome if community pharmacists are to be utilised in extended roles in care homes that have residents living with dementia.

My research successfully defines barriers (inadequate remuneration, limited clinical knowledge, time constraints, lack of access to patient care records) and facilitators (payment for medication review services, education and training)experienced by community pharmacists delivering pharmaceutical care services to people living with dementia in care homes.

Finally, it is the researcher's belief that given the barriers to undertaking further dementia related education and training which were highlighted by pharmacists participating in this study, considerations should be given to inclusion of undergraduate pharmacy students in projects to enhance healthcare education in dementia such as the "Time for Dementia" programme (Banerjee et al 2016, Alzheimer's Society 2019b), which is designed to create healthcare professionals who have a raised awareness and understanding of dementia.

Dissemination of my research through publications and conference abstracts in presented in Appendix 1 and 2 of this thesis.

8.5 Recommendations for future research

Whilst the capability of community pharmacists to deliver clinical services has been widely recognised by professional bodies, and supported by UK government policy changes, more research needs to be done to establish the cost benefit of an extension of their clinical roles to people with dementia in care homes.

Further research on how community pharmacists could deliver patient-centred care to people with dementia through a comprehensive pharmaceutical care service delivered to care homes (particularly those without specialist pharmacists

in dedicated roles) still needs to be carried out. Positive outcomes anticipated would include:

- Reduction in polypharmacy
- Improved prescribing practice and
- Reduction in use of potentially inappropriate medication

Building in cost effectiveness and quality of health outcome measures into this research would ensure that the impact of such services could be easily evaluated. It should prove useful to policy makers and commissioners of community pharmacy services so that remuneration models can be appropriately evidence-based incentivising pharmacists to update their clinical knowledge on dementia and expand their roles into becoming named pharmacists in care homes as proposed by the RPS (2016).

The DEMENTIAS intervention tool developed and preliminarily tested amongst specialist pharmacists in the focus group arm of my research will need to be reviewed and further optimised in the context of the MRC framework for complex interventions.

8.6 Conclusions

Pharmacists interviewed and surveyed in my research acknowledged that the pharmaceutical care services to people with dementia in care homes provided by community pharmacists could be improved and shared their perceived barriers to improvement. The results were similar between the qualitative and quantitative arms. More research is required to identify the exact role fit for community

pharmacists within multidisciplinary teams in care homes alongside continued professional development.

Care home staff showed good knowledge of the needs of people with dementia living in care homes. Whilst they expressed satisfaction with medication supply and medicines information services offered by community pharmacists, they revealed that overcoming challenges such as obtaining medicines out of hours and medicines reconciliation on admission to care homes would facilitate dementia care. They welcomed more involvement from pharmacists and better communication between pharmacists and GP practices working in care homes.

While the medication review prototype toolkit was found useful by the focus group of pharmacists who completed reviews with the toolkit, it was reported as being time consuming to use; however a shortened version would be a great 'aide-memoire' for both community pharmacists, care home pharmacists and other healthcare professionals wishing to review prescribing and promote rational use of medicines in people living with dementia.

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APPENDICES

Appendix 1: Theses related publications

1. Apampa B, Navti B. Medicines optimization in the dementias. Nurse Prescribing. 2014; 12(11): 567- 60. https://doi.org/10.12968/npre.2014.12.11.557

2. Navti, B., & Apampa, B. (2019). Pharmaceutical care services to people living with dementia in care homes: A qualitative study of community pharmacists' perceptions. *Dementia*, *18*(6), 2282–2302. https://doi.org/10.1177/1471301217743305 (first published December 2017)

Appendix 2: Conference Abstracts (College of Mental Health Pharmacists Annual Conference October 2018, Loughborough United Kingdom)

A. Pharmaceutical care services to people living with dementia in care homes: A quantitative study of community pharmacy services

Bongkwati Navti B[1], Manfrin A[2], Apampa B[2]

[1] North East London NHS Foundation Trust (NELFT) and Sussex Pharmacy, School of Life Sciences, University of Sussex (UK)
[2] Sussex Pharmacy, School of Life Sciences, University of Sussex (UK)

Background/Introduction

Dementia poses a great challenge for health care systems worldwide, with the population of affected people over the age of 60 estimated to reach 2 billion by the year 2050[1]. Dementia is acknowledged as being one of the strongest determinants of entry into residential care in people aged over 65 and up to 69% of care home residents are living with dementia.

While the care home service from community pharmacies is currently provided as an enhanced service in the community pharmacy contractual framework, a Pharmacy Integration Fund (PhIF) [2] launched in 2015 is included in the new funding arrangements for community pharmacy in England.

A key priority for the PhIF is to deploy pharmacists and pharmacy services to primary care settings including GP practices and care homes. This is a welcome development for care home residents, particularly those with chronic, progressive diseases such as dementia.

It is therefore important to establish the nature and extent of the current pharmaceutical services provided to care homes including those that have residents living with dementia.

Aim

To identify the nature and assess the extent of pharmaceutical services provided to people living with dementia in care homes in England.

Objectives:

- To identify the nature of pharmaceutical services provided to care homes
- To assess the extent of pharmacy services provided to care homes

Methods/Design

A questionnaire (survey) was distributed to a random sample of community pharmacists across England. Data were analysed using SPSS version 24. Categorical variables were analysed using Pearson chi square for goodness of fit.

Ethical approval was obtained from the University of Sussex cross-schools research ethics committee (C-REC).

Results

102 pharmacists participated in this study. 57% were female ($p<0.166$). A statistical significant difference was found within the age groups ($p=0.003$), the most represented being 25-29 years (24%), the least 55-59 years (5%) ($p=0.003$). Seventy-five percent were managers or independent pharmacists, 11% locums; and 5% second pharmacists ($p<0.001$). The majority of pharmacists (68%) entered the pharmacy register after 2000.
31% of pharmacists provided services to care homes ($p<0.001$). Nineteen of the care homes had residents with dementia.

Discussion and Conclusion

The main pharmaceutical service provided by pharmacists was the dispensing of medicines in monitored dosage systems and delivery to the home. While the deployment of clinical pharmacists to care homes can greatly improve disease management in residents (Royal Pharmaceutical Society 2016)[3], only one third of the pharmacists surveyed in our study provided cognitive services to care homes. There is thus an overwhelming need for a bespoke model of community pharmaceutical services for dementia patients that is responsive to patients' needs. However, the precise pharmaceutical care needs of people living with dementia in care homes still need to be clearly defined. Additionally, most of the pharmacists acknowledged the need for more dementia training.

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1. Alzheimer's Disease International. (2016). World Alzheimer Report. Improving healthcare for people living with dementia: Coverage, quality and costs now and in the future. London. Available at: https://www.alz.co.uk/research/WorldAlzheimerReport2016.pdf [accessed 30 Oct. 2016]
2. NHS Commissioning Pharmacy Integration Fund. (2016). England.nhs.uk. Available at: https://www.england.nhs.uk/commissioning/primary-care-comm/pharmacy/integration-fund/ Google Scholar [accessed 1 Nov. 2016]
3. RPS. (2016). *Care home round table report: The right medicine*. London: Royal Pharmaceutical Society. Available at: https://www.rpharms.com/Portals/0/RPS%20document%20library/Open%20access/Publications/Care%20Homes%20Round%20Table%20Report.pdfGoogle Scholar [accessed 30 Oct. 2016]

B. Pharmaceutical care in dementia: a quantitative analysis utilising path modelling for evaluating the relationships between knowledge, barriers to care, understanding and confidence of pharmacists providing pharmaceutical services (*shortlisted for an award in the category of 'original research')*

Background/Introduction

All healthcare professionals can play a role in dementia care; pharmacists have a critical role in optimising drug therapy in dementia.

Pharmacists should be responsible for medicines use in care homes[1], however such services will require explicit knowledge and a reduction of barriers to care[2]. The Pharmacy Integration Fund aims to support community pharmacy as it develops new clinical pharmacy services including services to care homes.

Aim

To evaluate the relationship between knowledge, barriers, understanding and confidence of pharmacists providing services to dementia patients in care homes

Objectives:

- To identify the path coefficients between knowledge, barriers, understanding and confidence of pharmacists using a path model
- To assess the statistical significance of the path coefficients and evaluate the variances observed

Methods/Design

A postal questionnaire (survey) was distributed to a random sample of community pharmacists across England**.** Due to the small sample size and non-parametric nature of the data, analysis was conducted with SmartPLS (Ver. 3.2.7), using partial least squares (PLS) path modelling. The analysis involved a series of ordinary squares regressions and bootstrapping recommended for assessing statistical validity ($p<0.05$) of non-normal variables with 500 iterations and $t>1.96$. Ethical approval was obtained from the University of Sussex cross-schools research ethics committee (C-REC).

Results

102 pharmacists completed the survey. Negative effects of the standardized path coefficients were found between knowledge and barriers to care ($\beta= -0.151$), and between barriers to care and understanding/confidence ($\beta= -0.098$). Positive

effect of the standardized path coefficient was found between knowledge and understanding-confidence (β= +0.672). A statistically significant linear relationship was only found between knowledge and understanding-confidence (t=12.70; p<0.001). The model explained 48.1% (R^2=0.481) of the variance of understanding/confidence. Notably 91% of pharmacists surveyed were interested in receiving training on dementia.

Discussion and Conclusion

The path model demonstrates that knowledge and confidence decrease when barriers to care increase. Similar findings were identified in another study[3]. The results suggest a training need for pharmacists in dementia.

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2. Ibrahim K. Rayes, A. (2018). Perception of community pharmacists towards the barriers to enhanced pharmacy services in the healthcare system of Dubai: a quantitative approach. [online] PubMed Central (PMC). Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4482839/ [Accessed 29 Jun. 2018].

3. Maidment, I., Aston, L., Hilton, A., Iqbal, N., Child, A., Shaw, R. (2016). Role of community pharmacists in the use of antipsychotics for behavioural and psychological symptoms of dementia (BPSD): A qualitative study. BMJ Open, 6, e010278. DOI: 10.1136/bmjopen-2015-010278.

Appendix 3a: University of Sussex Certificate of Approval- ER/BN67/1

University of Sussex

Certificate of Approval	
Reference Number:	ER/BN67/1
Title Of Project:	Pharmaceutical Care in Dementia: Exploring the views of pharmacists about the pharmaceutical care needs of dementia patients living in care homes
Principal Investigator (PI):	Beryl Bongkwati Navti
Student:	Beryl Bongkwati Navti
Collaborators:	Prof Bugewa Apampa
Duration Of Approval:	2 months
Expected Start Date:	20-Feb-2014
Date Of Approval:	27-Mar-2014
Approval Expiry Date:	31-May-2014
Approved By:	Richard de Visser
Name of Authorised Signatory:	Richard de Visser
Date:	03-Apr-2014

*NB. If the actual project start date is delayed beyond 12 months of the expected start date, this Certificate of Approval will lapse and the project will need to be reviewed again to take account of changed circumstances such as legislation, sponsor requirements and University procedures.

Please note and follow the requirements for approved submissions:

Amendments to protocol

* Any changes or amendments to approved protocols must be submitted to the C-REC for authorisation prior to implementation.

Feedback regarding the status and conduct of approved projects

* Any incidents with ethical implications that occur during the implementation of the project must be reported immediately to the Chair of the C-REC.

Feedback regarding any adverse and unexpected events

* Any adverse (undesirable and unintended) and unexpected events that occur during the implementation of the project must be reported to the Chair of the Social Sciences C-REC. In the event of a serious adverse event, research must be stopped immediately and the Chair alerted within 24 hours of the occurrence.

For Life Sciences and Psychology projects

* The principal investigator is required to provide a brief annual written statement to the committee, indicating the status and conduct of the approved project. These reports will be reviewed at the annual meeting of the committee. A statement by the PI to the C-REC indicating the status and conduct of the approved project will be required on the Approval Expiration Date as stated above.

Appendix 3b: Letter of invitation to participate in the study

Dear Pharmacist, Date

Pharmaceutical Care in Dementia: Exploring the views of pharmacists about the pharmaceutical care needs of dementia patients living in care homes

I am carrying out a pilot study to explore the pharmaceutical care needs of patients with dementia living in care homes in England, from the perspectives of selected community pharmacists. A care home has identified you as a possible participant for this study.

The study will involve a short face-to-face interview (30 minutes) that will explore your views about the medicines-related needs of these patients. I will also seek your opinion regarding the training needs of pharmacists who provide pharmacy services to these patients.

Information obtained will be digitally recorded, transcribed verbatim and anonymised. Themes emerging will inform the development of a questionnaire to be used in the wider survey of community pharmacists involved in dementia care in England. I would like to assure you that any information obtained will be kept strictly confidential and stored securely at the School.

You are formally invited to participate in this study. I will contact you by telephone within five working days to ascertain whether you are interested in taking part and to answer any questions that you may have.

If you decide to participate, I will arrange a time that is convenient for you for the interview, and you will be sent an information pack in the post, together with a consent form. Please return the signed consent form in the pre-paid envelope that is provided.

Before the commencement of the interview, you will be given an opportunity to ask any questions about the study. Please note that you may withdraw from the study at any time if you wish to.

If you have any further questions, please contact me on 07811264808

Thanks in anticipation.

Yours sincerely

Beryl B Navti
Student

Appendix 3c: Participant Information Sheet

STUDY TITLE

Pharmaceutical Care in Dementia: Exploring the views of pharmacists about the pharmaceutical care needs of dementia patients living in care homes

Name of Researcher: Beryl B Navti

You are being invited to take part in a study. Before you decide if you want to take part, you must understand why the study is being done and what it involves. Please take time to read the following information and to decide if you want to take part or not.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to explore community pharmacists' views of community pharmacy services to patients with dementia in care homes in your locality. The World Health Organisation regards a close working relationship between primary care practitioners (e.g. GPs, nurses, pharmacists) as essential for appropriate care of patients. This study aims to find out to what extent pharmacists are contributing to the care being provided and how they can better meet the needs of these patients.

WHY HAVE I BEEN INVITED TO PARTICIPATE?

The study is being carried out with selected community pharmacists in your locality who provide services to care homes with dementia patients.. These pharmacists were identified by enlisting the help of care homes in the area that are registered as having dementia patients on the website www.carehome.co.uk

DO I HAVE TO TAKE PART?

No. It is up to you to decide whether or not to take part. Even if you agree to take part, you can change your mind at any time without giving any reason. If you decide not to take part in the study, your rights will not be affected in any way. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form.

WHAT WILL HAPPEN TO ME IF I TAKE PART?

The study will involve a short face to face interview with the researcher. You will be asked questions about the services you provide. The interview will take place at your pharmacy if this is convenient, will follow an interview schedule and should take no longer than 30 minutes. The interview session will be recorded with your permission. Any information obtained will be kept strictly confidential. Quotes maybe used from interviews but these will be anonymised and all tapes will be deleted at the end of the study. If you agree to take part, you will be asked to sign a consent form.

WHAT ARE THE POSSIBLE DISADVANTAGES AND RISKS OF TAKING PART? (WHERE APPROPRIATE)

The only risk anticipated would be that the questions will require you to set aside a small portion of your time, which could be an inconvenience. However, every effort will be made to interview you at a time that is most convenient for you.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?
Answering the questions may help identify any learning needs you may have with regards to the pharmaceutical care of patients with dementia living in the care homes you provide services to. You will be provided with a summary of the results obtained from the study if you indicate a wish to receive this information.

WILL MY INFORMATION IN THIS STUDY BE KEPT CONFIDENTIAL?
We will not tell anyone that you have taken part in the study. Once the data from the interview is transcribed and analysed, the results will be used to inform the development of a survey instrument for a larger sample of community pharmacists. Any personal data collected during the course of the pilot study will only be used for academic and research purposes. All anonymised transcripts will be stored for 5 years after completion of the study and then shredded.

WHAT SHOULD I DO IF I WANT TO TAKE PART?
If you would like to take part in this study, please sign the consent form attached and return in the pre-paid envelope.

WHAT WILL HAPPEN TO THE RESULTS OF THE RESEARCH STUDY?
Information obtained will be digitally recorded and transcribed verbatim. Themes emerging will inform the development of a questionnaire to be used in the wider survey of community pharmacists involved in dementia care in England

WHO IS ORGANISING THE RESEARCH?
This study is being undertaken by the researcher who is a pharmacy student at the University of Sussex

WHO HAS APPROVED THIS STUDY?
This study has been approved by the Science and Technology Cross-Schools Research Ethics Committee (C-REC) ethical review process at the University of Sussex.
Email: crecscitec@sussex.ac.uk

CONTACT FOR FURTHER INFORMATION
You may contact the academic supervisor at the address below.
Dr Bugewa Apampa, Director of Pharmacy Development, School of Life Sciences University of Sussex, Falmer Brighton
Tel: 01273 873756|Email: b.apampa@sussex.ac.uk

THANK YOU
Thank you for taking the time to read this participant information leaflet**)**

Appendix 3d: Participant consent form

Participant CONSENT FORM for INTERVIEW

Title of Project:

Pharmaceutical Care in Dementia: Exploring the views of pharmacists about the pharmaceutical care needs of dementia patients living in care homes

Name of Researcher: Beryl B Navti

I have read and understand the information provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily	Initial Here
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and that this will not affect my legal rights	Initial Here
I understand that any personal information collected during the study will be anonymised and remain confidential	Initial Here
I understand that the interview will be digitally audio recorded and that this recording will be transcribed verbatim	Initial Here
I understand that verbatim quotes taken from the recording of our conversation may be used in publications and reports, but that these will be anonymised and not traceable to me	Initial Here
I agree to take part in the interview	Initial Here

Name of Participant (Print) _____

Signature _____ Date _____

Name of Researcher (Print) _____

Signature _____ Date _____

Appendix 3e: Study Gantt chart

TIMETABLE	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6	Week 7	Week 8	Week 9	Week 10	Week 11
Protocol development											
Research ethics application											
Contact Care homes (telephone)											
Pharmacist recruitment: Send out letter of invitations, participant information sheet and consent forms to pharmacists											
Follow up telephone call, organise interviews											
Conduct face-to-face interviews											
Data Analysis											
Dissemination											

Appendix 3f: The Interview schedule

Pharmaceutical Care in Dementia: Exploring the views of pharmacists about the pharmaceutical care needs of dementia patients living in care homes

Interview Schedule

I would like to thank you for consenting to participate in this study. Have you got any questions you would like to ask me about the study before we start the interview?

Services

1. How many care homes do you provide services to?
2. What are the main services that you provide?
3. What proportion of residents in the care homes suffer from dementia?
4. What are the pharmaceutical care needs of people with dementia?
5. Are the services you provide sufficient to cater for their needs, if so how?

Medicines Optimisation

6. What dementia medicines do you supply to these patients?
7. What issues do you consider when dispensing prescriptions for dementia patients?
8. What are the main adverse effects of these medicines?
9. What clinically significant interactions would you consider during screening of prescriptions for dementia patients?
10. Do you offer a medication review service to the care homes, if so, what are the components?

Access to records

11. Describe any barriers to pharmaceutical care provision that you may face
12. Are you able to access patient care records in care homes? If so, how?

Training

13. Briefly explain the behavioural and psychological symptoms of dementia?
14. Describe the knowledge and skills that you consider essential for a comprehensive pharmaceutical care service to dementia patients?
15. What dementia- related training have you undertaken in the past year?
16. Are you involved in training care home staff? If so what training do you provide?

Pharmacist demographics

17. Year of registration as pharmacist in the UK……...
18. Post graduate qualifications……...
19. Gender……
20. Practice type and location……..
21. Position held in pharmacy……..
22. Participation in CPD……

Appendix 3g: Consolidated criteria for reporting qualitative research (COREQ Guidelines)

Domain 1: Research team and reflexivity

1. Who conducted the interviews or the focus group?
The interviews were conducted by the researcher (BN)
2. What were the researcher's credentials?
The researcher (BN) is a qualified pharmacist with many years' experience in the community pharmacy sector.
BN has experience working with people living with dementia in care homes and BA (research supervisor) is an experienced pharmacy practice researcher.
3. What was their occupation at the time of the study?
BN is an advanced mental health pharmacist and part time PhD researcher and BA was a professor of pharmacy education and director of pharmacy at the University of Sussex.
4. Was the researcher male or female?
Female
5. What experience or training did the researcher have?
BN is an advanced mental health pharmacist experienced in dementia care and completed a module at the Brighton and Sussex Medical School on research methods. BA (research supervisor) has conducted numerous qualitative research projects in her capacity as pharmacy educator and academic supervisor.
6. Was a relationship established prior to study commencement?
BN was personally acquainted with one of the study participants in the Thurrock arm of the study but did not know any of the Kent participants prior to the commencement of the study. Full informed consent was obtained. BN conducted the interviews and formally introduced herself and the topic before the interview this included explaining her current role in the project.
7. What did the participants know about the researcher?
The participants knew that BN was a pharmacist, and a postgraduate student at the University of Sussex, and that BA was her academic supervisor.
8. What characteristics were reported about the interviewer/facilitator?
BN reported that she was working as a pharmacist and a postgraduate student at the University of Sussex. BA was reported as the academic supervisor who could be contacted for further information on the study. This information was included in the participant information sheet provided to participants prior to them consenting to take part in the study.

Domain 2: Study design

9. What methodological orientation was stated to underpin the study?
An exploratory, qualitative study was conducted face-to-face semi-structured interviews.
Data were analysed using a thematic framework approach for sorting, categorisation and interpretation of recorded interviews.
10. How were participants selected?
Pharmacists were eligible if they worked in pharmacies that provide services to care homes catering for people with dementia or have a mixed clientele which include patients with dementia. The pharmacies were eligible if they were in the geographical area chosen for the study.
11. How were participants approached?
Care homes in the Thurrock and Kent areas that have people living with dementia, or a mixture of dementia and non-dementia patients were identified by searching the website, http://www.carehome.co.uk/ (2014). This lists a database of care homes within England and Wales by post code, as well as by the nature of services provided. The dementia care homes in the selected areas were identified via this website. The Thurrock and Kent areas were selected for this study for convenience purposes.
BN contacted the identified care homes by telephone to ascertain the pharmacy responsible for their pharmaceutical services. The contact details of the pharmacies were then confirmed through the NHS Choices website (2014) and pharmacists working in the registered pharmacies identified by the care homes were contacted by BN and invited to participate in the study.
Participants were informed that they were selected because they delivered pharmaceutical services to care home(s) that had residents living with dementia. They could contact either BN or BA at any point for further information about the research, and could withdraw from the study at any time.

12. How many participants were in the study?
There were 16 pharmacists (15 community pharmacists and one primary care pharmacist).
13. How many people refused to participate or dropped out?
One participant dropped out after obtaining more detail about the study.
14. Where was the data collected?
Each participant was contacted to arrange a face-to-face interview to be held in the pharmacy premise's consulting room, at a time of their convenience.
15. Was anyone else present besides the participants and researchers?
No-one else was present, but there were constant interruptions as participants often had to stop recording to deal with queries and conduct clinical checks of prescriptions within the pharmacy.
16. What are the important characteristics of the sample?
Pharmacists selected to participate worked in pharmacies that provided pharmaceutical services to care homes that had residents living with dementia, within the localities chosen for the study.
17. Were questions, prompts, guides provided by the authors? Was it pilot tested?
The interview schedule consisted of a combination of open ended and closed questions. The open ended questions enabled participants to express themselves without being led by the researcher. The questions were not piloted.
18. Were repeat interviews carried out?
No interviews were repeated.
19. Did the research use audio or visual recording to collect the data?
An audio recorder was used to record the interviews. Data were transcribed verbatim.
20. Were field notes made during and/or after the interview?
When participants raised issues not covered by the interview schedule, notes were made during the interviews.
21. What was the duration of the interviews?
There was no formal restriction on the duration of the interviews, but BN and BA agreed that interviews would last on average 20–30 minutes. During the study, the shortest interview last 10 minutes and the longest 34 minutes.
22. Was data saturation discussed?
Data saturation was reached in both localities of the study and discussed and agreed between the researcher and research supervisor.
23. Were transcripts returned to participants for comment and/or correction?
Transcripts were not returned to participants but emerging themes were discussed between the researcher and research supervisor
A note was taken of all participants who wanted to be sent the report once the study was completed.

Domain 3: Analysis and findings

24. How many data coders coded the data?
BA independently reviewed the transcripts then met with BN for comparison of findings. Disagreements on the interpretation and analysis of the data were then discussed between BN and BA until consensus was achieved. BN rearranged data according to identified themes and discussed with BA before mapping and interpretation.
25. Did authors provide a description of the coding tree? No.
26. Were themes identified in advance or derived from the data?
Themes were derived from the data. Four main themes emerged from the data.
27. What software, if applicable, was used to manage the data?
No software was used.
28. Did participants provide feedback on the findings?
Participants who requested feedback on the data were given a copy of the final report but none provided feedback.
29. Were participant quotations presented to illustrate the themes/findings? Was each quotation identified?
Extracts from the transcripts were quoted in the results section verbatim from the recordings during the interviews.
30.Was there consistency between the data presented and the findings?
Yes there was consistency between the data presented and the findings.
31. Were major themes clearly presented in the findings?

Four major themes were elicited from the data and presented in the results of the study in named sub-sections.

32. Is there a description of diverse cases or discussion of minor themes?

Yes, diverse cases have been discussed and differences between levels of practice between participants within the same locality and between the two localities studied have been discussed in the findings.

Appendix 4a Certificate of Approval ER/BN67/8

University of Sussex

Certificate of Approval	
Reference Number	ER/BN67/8
Title Of Project	Ammendment and extension of ER/BN67/2: Pharmaceutical care in dementia-exploring the views of community pharmacists about the pharmaceutical care needs of people living with dementia
Principal Investigator (PI):	Bugewa Apampa
Student	Beryl Bongkwati Navti
Collaborators	
Duration Of Approval	3 months
Expected Start Date	27-Jan-2016
Date Of Approval	29-Jan-2016
Approval Expiry Date	30-Apr-2016
Approved By	David Reby
Name of Authorised Signatory	
Date	29-Jan-2016

*NB. If the actual project start date is delayed beyond 12 months of the expected start date, this Certificate of Approval will lapse and the project will need to be reviewed again to take account of changed circumstances such as legislation, sponsor requirements and University procedures.

Please note and follow the requirements for approved submissions:

Amendments to protocol

* Any changes or amendments to approved protocols must be submitted to the C-REC for authorisation prior to implementation.

Feedback regarding the status and conduct of approved projects

* Any incidents with ethical implications that occur during the implementation of the project must be reported immediately to the Chair of the C-REC.

Feedback regarding any adverse and unexpected events

* Any adverse (undesirable and unintended) and unexpected events that occur during the implementation of the project must be reported to the Chair of the Social Sciences C-REC. In the event of a serious adverse event, research must be stopped immediately and the Chair alerted within 24 hours of the occurrence.

For Life Sciences and Psychology projects

* The principal investigator is required to provide a brief annual written statement to the committee, indicating the status and conduct of the approved project. These reports will be reviewed at the annual meeting of the committee. A statement by the PI to the C-REC indicating the status and conduct of the approved project will be required on the Approval Expiration Date as stated above.

Appendix 4b: Participants information sheet-questionnaire survey

PARTICIPANT INFORMATION SHEET

STUDY TITLE: PHARMACEUTICAL CARE IN DEMENTIA: EXPLORING THE VIEWS OF PHARMACISTS ABOUT THE PHARMACEUTICAL CARE NEEDS OF PEOPLE LIVING WITH DEMENTIA

Name of Researcher: Beryl B Navti

You are being invited to take part in a study. Before you decide if you want to take part, you must understand why the study is being done and what it involves. Please take time to read the following information. Ask if anything is not clear or if you would like more information. Please take time to read the following information carefully'.

WHAT IS THE PURPOSE OF THE STUDY?
The purpose of this study is to explore community pharmacists' views of community pharmacy services to patients with dementia in care homes in your locality. The World Health Organisation regards a close working relationship between primary care practitioners (e.g. GPs, nurses, pharmacists) as essential for appropriate care of patients. This study aims to find out to what extent pharmacists are contributing to the care being provided and how they can better meet the needs of these patients

WHY HAVE I BEEN INVITED TO PARTICIPATE?
You have been invited because you are a community pharmacist registered to practice in England.

DO I HAVE TO TAKE PART?
'It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep. If you decide to take part you are still free to withdraw at any time and without giving a reason'. Answering the questionnaire will indicate you have consented to take part in the survey.

WHAT WILL HAPPEN TO ME IF I TAKE PART?
The study will involve a postal questionnaire with randomly selected community pharmacists registered with the General Pharmaceutical Council who provide services in England. You will be asked questions about the services you provide. All questionnaires will be anonymised and you will not be identified in any way.

WHAT ARE THE POSSIBLE DISADVANTAGES AND RISKS OF TAKING PART? (WHERE APPROPRIATE)
The only risk anticipated would be that the questions will require you to set aside a small portion of your time, which could be an inconvenience

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?
Answering the questions may help identify any learning needs you may have with regards to the pharmaceutical care of patients with dementia

WILL MY INFORMATION IN THIS STUDY BE KEPT CONFIDENTIAL?
We will not collect any person identifiable information, nor inform anyone you have taken part in the study. All anonymised questionnaires will be kept for 5 years and then shredded.

WHAT SHOULD I DO IF I WANT TO TAKE PART?
If you decide to take part in this study, please respond to the questionnaire and return it in the prepaid envelope provided

WHAT WILL HAPPEN TO THE RESULTS OF THE RESEARCH STUDY?
Responses to the questionnaire will be analysed and the resulting data reported as part of a thesis on the pharmaceutical care of people with dementia

WHO IS ORGANISING AND FUNDING THE RESEARCH?
This study is being funded by the University of Sussex

WHO HAS APPROVED THIS STUDY?

This project has been looked at and approved by the University of Sussex Research Ethics Committee , the Cross-Schools Research Ethics Committee (C-REC).

CONTACT FOR FURTHER INFORMATION
You may contact the academic supervisor at the address below.
Dr Buge Apampa, Director of Pharmacy Development, School of Life Sciences University of Sussex, Falmer Brighton. Tel: 01273 873756. Email: b.apampa@sussex.ac.uk
THANK YOU
DATE
22/01/2016

Appendix 4c: Pharmacists' questionnaire

PART B: SERVICES

7. Do you provide any services to care homes?
   - ☐ Yes
   - ☐ NO

If you do (Please tick the box which most closely represents your pharmacy)

- ☐ Repeat prescription collection
- ☐ Medicine management training
- ☐ Medication supply
- ☐ Medication reviews
- ☐ Medication delivery service
- ☐ Prescription interventions
- ☐ Training of care home staff
- ☐ Monitored dosage systems (e.g. dosette boxes)
- ☐ Other *(Please specify below)*

8. How often do you visit the care home?
   - ☐ Every three months or less
   - ☐ Every three to six months
   - ☐ Once a year
   - ☐ Never

9. Does the care home have residents with dementia?
   - ☐ Yes
   - ☐ No
   - ☐ I don't know

10. Are the services you provide sufficient to cater for their pharmaceutical care needs?
   - ☐ Yes
   - ☐ No
   - ☐ Partially
   - ☐ Not sure

PART C
Knowledge

11. **Prescriptions for dementia patients**

	Agree	Not sure	Disagree
I know about medicines used as cognitive enhancers	☐	☐	☐
I am aware of drugs that cause cognitive impairment	☐	☐	☐
I know about behavioural and psychological symptoms of dementia	☐	☐	☐
I know about the major side effects of drugs used as cognitive enhancers	☐	☐	☐
I know about tools for evaluating levels of cognition	☐	☐	☐

in dementia patients			
I know which medicines should be avoided in patients with dementia	☐	☐	☐
I can confidently identify drug interactions in prescriptions for dementia patients	☐	☐	☐
I recommend interventions to optimise dementia medicines to GPs	☐	☐	☐
I need more training to provide a better pharmaceutical care service to patients with dementia	☐	☐	☐

Other comments:

PART D: UNDERSTANDING AND CONFIDENCE IN DEALING WITH DEMENTIA PATIENTS

12. Comprehensive Pharmaceutical Care Service

I feel confident...	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
... dealing with prescriptions for care homes	☐	☐	☐	☐	☐
... that I know what questions to ask care givers regarding dementia patients	☐	☐	☐	☐	☐
... that I can recommend stopping medication that is unnecessary or may be harmful to dementia patients	☐	☐	☐	☐	☐
... that I can identify drug interactions	☐	☐	☐	☐	☐
...that I can signpost dementia patients and/or their carers to relevant sources of help and information	☐	☐	☐	☐	☐
....that I can contribute significantly to a multi-disciplinary team of professionals delivering care for people living with dementia	☐	☐	☐	☐	☐
....that I can use newly launched summary care records to improve Pharmaceutical care for people with Dementia	☐	☐	☐	☐	

PART E: BARRIERS TO PROVISION OF PHARMACEUTICAL CARE SERVICES

13. Barriers to providing pharmaceutical care

Barriers	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Limited access to clinical notes hinders the identification of drug therapy problems	☐	☐	☐	☐	☐
Pharmacists' need to improve their knowledge of geriatric medicines	☐	☐	☐	☐	☐
Pharmacists should have more time to visit care homes	☐	☐	☐	☐	☐
The pharmacist should build better relationships with care home GPs in order to better communicate recommended interventions	☐	☐	☐	☐	☐
Community pharmacists should be notified of patient discharge	☐	☐	☐	☐	☐
Pharmacists should attend multi-disciplinary team meetings	☐	☐	☐	☐	☐
Pharmacists should be actively involved in helping to reduce the use of anti-psychotics in dementia	☐	☐	☐	☐	☐
Communication with other healthcare professionals would be facilitated by diarised patient medication reviews in care homes	☐	☐	☐	☐	☐
The current community pharmacy contractual framework restricts level of care provided to dementia patients	☐	☐	☐	☐	☐
Clinical commissioning groups (CCGs) determine what services are provided to dementia patients so care provision in non-uniform across the country	☐	☐	☐	☐	☐
Every patient should have a named community pharmacist	☐	☐	☐	☐	☐
I have access to summary care records	☐	☐	☐	☐	☐

Part F: EDUCATION TRAINING

14. Have you ever attended any training on prescribing or medicine optimisation in dementia? ☐ Yes ☐ No

If yes, please describe:

15. Please list below any barriers to pursuing further training in management and care of dementia patients

☐
☐
☐
☐
☐

16. Would you be interested in receiving training on dementia? ☐ Yes ☐ No

Thank you very much for taking the time to complete this survey.

Your ideas and opinions will be very important in helping to improve the quality of pharmaceutical care provision to dementia patients

Please return the survey in the prepaid envelope provided.

Questionnaire Number | | | | |

Appendix 5a: University of Sussex certificate of approval ER/BN67/9

University of Sussex

Certificate of Approval	
Reference Number	ER/BN67/9
Title Of Project	Ammendment and extension of ER/BN67/2: Pharmaceutical Care in Dementia: exploring the views of care home staff about medication related services provided to care homes
Principal Investigator	Beryl Bongkwati Navti
Student	Beryl Bongkwati Navti
Collaborators	Amendment and extension approved by Chair's action
Duration Of Approval	3 months and 1 week
Expected Start Date	19-Jan-2017
Date Of Approval	16-Feb-2017
Approval Expiry Date	21-May-2017
Approved By	David Reby
Name of Authorised Signatory	
Date	16-Feb-2017

*NB. If the actual project start date is delayed beyond 12 months of the expected start date, this Certificate of Approval will lapse and the project will need to be reviewed again to take account of changed circumstances such as legislation, sponsor requirements and University procedures.

Please note and follow the requirements for approved submissions:

Amendments to protocol

* Any changes or amendments to approved protocols must be submitted to the C-REC for authorisation prior to implementation.

Feedback regarding the status and conduct of approved projects

* Any incidents with ethical implications that occur during the implementation of the project must be reported immediately to the Chair of the C-REC.

Feedback regarding any adverse and unexpected events

* Any adverse (undesirable and unintended) and unexpected events that occur during the implementation of the project must be reported to the Chair of the Social Sciences C-REC. In the event of a serious adverse event, research must be stopped immediately and the Chair alerted within 24 hours of the occurrence.

For Life Sciences and Psychology projects

* The principal investigator is required to provide a brief annual written statement to the committee, indicating the status and conduct of the approved project. These reports will be reviewed at the annual meeting of the committee. A statement by the PI to the C-REC indicating the status and conduct of the approved project will be required on the Approval Expiration Date as stated above.

Appendix 5b: Letter of Invitation to care home staff

University of Sussex
Life Sciences

INVITATION TO PARTICIPATE IN A STUDY

Dear Sir/Madam, Date:

TITLE: Pharmaceutical care in dementia: exploring the views of care home staff about medication related services provided to care homes

I am a student at the University of Sussex, carrying a study to explore the views, perceptions and opinions of care home staff about the medication related services provided to care homes that have people living with dementia in your locality.

Your care home has been identified through the Care Quality Commission website http://www.cqc.org.uk/content/care-homes as one of those providing care for people with dementia.
The study will involve a short face-to-face interview with the care home manager or designated member of staff to explore their views about the medicines-related needs of these residents.

In order to carry out this study, you will be contacted to provide the name of a staff member or care home representative nominated to participate, and the best time for the interview to take place.
I would like to assure you that the care home **will not be named and no person identifiable material** will be used in this study.
I will contact you by telephone in five working days to ascertain whether you are interested in taking part and to answer any questions that you may have.

If you have any questions with regards to this request, please contact the researcher at bn67@sussex.ac.uk .

You can also obtain further information regarding this study from the academic supervisor Professor Buge Apampa, Director of Pharmacy, School of Life Sciences University of Sussex, Falmer Brighton. Tel: 01273 873756.
Email: b.apampa@sussex.ac.uk

Thanks in anticipation.

Yours sincerely

Beryl B Navti

Appendix 5c: Participant information – care home staff

University of Sussex

Participant Information

Title of Project:

Pharmaceutical care in dementia: exploring the views of care home staff about medication related services provided to care homes

Name of Researcher: Beryl B Navti

You are being invited to take part in a study. Before you decide if you want to take part, you must understand why the study is being done and what it involves. Please take time to read the following information and to decide if you want to take part or not.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to explore the views, perceptions and opinions of care home staff about the medication related services provided to care homes that have people living with dementia in your locality. Care home managers or specifically designated staff are best placed to comment through interviews, on the medication related needs of care residents. This study aims to ascertain the awareness of care home staff about the medication related needs of people living with dementia in their care homes, and the nature of services provided by other health care practitioners to residents with dementia.

WHY HAVE I BEEN INVITED TO PARTICIPATE?

The study is being carried out with selected care homes in your locality who have residents with dementia. You have been invited because your care home was identified through the Care Quality Commission website http://www.cqc.org.uk/content/care-homes as a care home that has residents with dementia

DO I HAVE TO TAKE PART?

No. It is up to you to decide whether or not to take part. Even if you agree to take part, you can change your mind at any time without giving any reason. If you decide not to take part in the study, your rights will not be affected in any way. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form.

WHAT WILL HAPPEN TO ME IF I TAKE PART?

The study will involve a short face to face interview with the researcher. You will be asked questions about the services you provide. The interview will take place at your care home if this is convenient, and follow an interview schedule and should take no longer than 30 minutes. The interview session will be recorded with your permission. Any information obtained will be kept strictly confidential. Quotes maybe used from interviews but these will be anonymised and all tapes will be deleted at the end of the study. If you agree to take part, you will be asked to sign a consent form.

University of Sussex

WHAT ARE THE POSSIBLE DISADVANTAGES AND RISKS OF TAKING PART? (WHERE APPROPRIATE)

The only risk anticipated would be that the questions will require you to set aside a small portion of your time, which could be an inconvenience. However, every effort will be made to interview you at a time that is most convenient for you.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

Answering the questions may help identify any learning needs you may have with regards to the medication related needs of residents in your care home living with dementia. You will be provided with a summary of the results obtained from the study if you indicate a wish to receive this information.

WILL MY INFORMATION IN THIS STUDY BE KEPT CONFIDENTIAL?

We will not tell anyone that you have taken part in the study. Any personal data collected during the course of the study will only be used for academic and research purposes. All anonymised transcripts will be stored for 5 years after completion of the study and then shredded.

WHAT WILL HAPPEN TO THE RESULTS OF THE RESEARCH STUDY?

Information obtained will be digitally recorded and transcribed verbatim. Themes emerging will inform the researcher about medication related services provided to people living with dementia in care homes, and enable recommendations for best practice to be made.

WHO IS ORGANISING THE RESEARCH?

This study is being undertaken by the researcher who is a postgraduate pharmacy student at the university of Sussex

WHO HAS APPROVED THIS STUDY?

This study has been approved by the Science and Technology Cross-Schools Research Ethics Committee (C-REC) ethical review process at the University of Sussex. Email: crecscitec@sussex.ac.uk

CONTACT FOR FURTHER INFORMATION

You may contact the academic supervisor at the address below:
Professor Bugewa Apampa, Director of Pharmacy, School of Life Sciences University of Sussex, Falmer, Brighton.
Tel: 01273 873756 Email: b.apampa@sussex.ac.uk

THANK YOU

Thank you for taking the time to read this participant information leaflet

Date: 04/01/2017

Appendix 5d: Participant consent form – care home study

University of Sussex

Participant Consent

Title of Project:

Pharmaceutical care in dementia: exploring the views of care home staff about medication related services provided to care homes

Name of Researcher: Beryl B Navti

I have read and understood the information provided for the above study. I understand that I can contact the project supervisor for any clarifications I require	Initial Here
I understand that my participation is voluntary and I can withdraw from the study at any time by contacting the researcher.	Initial Here
I understand that any personal information collected during the study will be anonymized and remain confidential	Initial Here
I understand that the results from the questionnaire may be used in publications and reports, but that these will be anonymized and not traceable to me	Initial Here

Name of Participant (Print) _____

Signature _____ Date _____

Name of Researcher (Print) _____

Signature _____ Date _____

Appendix 5e: Interview Schedule-care home staff

University of Sussex
Life Sciences

INTERVIEW SCHEDULE

Residents' Information

1. What proportion of your care home residents are diagnosed with dementia?
2. Did they come in with dementia or were diagnosed whilst already resident?
3. Do resident records show what type of dementia they have?

Resident's Medication Needs

4. What are the medication- related needs of residents living with dementia?
5. What medication-related services are provided to your residents?
6. Who provides these services?
7. Which of these services are provided by pharmacy staff?
8. Do the services provided by pharmacy staff meet the resident's needs?
9. Do you have any medication- related services specific targeting residents living with dementia? If so, what are they?

Training Needs

10. What is involved in managing medication for dementia patients?
11. Have you encountered any problems with managing medication for dementia patients?
12. How do staff report/manage suspected side effects to prescribed medication?
13. How do staff report/manage problems relating to administration of medication to residents?
14. How are medication related changes communicated to residents and/or their family/carers?

The Multidisciplinary Team

12. What other professionals are involved in providing care for people living with dementia in your care home?
13. How can overall care for people living with dementia be improved?
14. Are there other services that you consider should be provided?

Care home staff demographics

15. Gender.....
16: Qualifications.....
17: Number of years' experience.....

Appendix 5f: COnsolidated criteria for REporting Qualitative research check list COREQ-care home staff study

Domain 1: Research team and reflexivity

1. Who conducted the interviews or the focus group?

The interviews were conducted by the researcher (BN)

2. What were the researcher's credentials?

The researcher (BN) is a qualified pharmacist with many years' experience in the community pharmacy sector.

BN has experience working with people living with dementia in care homes and BA (research supervisor) is an experienced pharmacy practice researcher.

3. What was their occupation at the time of the study?

BN is an advanced mental health pharmacist and part time PhD researcher and BA was a professor of pharmacy education and director of pharmacy at the University of Sussex.

4. Was the researcher male or female?

Female

5. What experience or training did the researcher have?

BN is an advanced mental health pharmacist experienced in dementia care and completed a module at the Brighton and Sussex Medical School on research methods. BA (research supervisor) has conducted numerous qualitative research projects in her capacity as pharmacy educator and academic supervisor.

6. Was a relationship established prior to study commencement?

BN was not acquainted with any of the study participants. Full informed consent was obtained. BN conducted the interviews and formally introduced herself and the topic before the interview this included explaining her current role in the project.

7. What did the participants know about the researcher?

The participants knew that BN was a pharmacist, and a postgraduate student at the University of Sussex, and that BA was her academic supervisor.

8. What characteristics were reported about the interviewer/facilitator?

BN reported that she was working as a pharmacist and a postgraduate student at the University of

Sussex. BA was reported as the academic supervisor who could be contacted for further information on the study. This information was included in the participant information sheet provided to participants prior to them consenting to take part in the study.

Domain 2: Study design

9. What methodological was stated to underpin the study?

An exploratory, qualitative study was conducted face-to-face semi-structured interviews.

Data were analysed using a thematic analysis approach for sorting, categorisation and interpretation of recorded interviews.

10. How were participants selected?

Care home staff were eligible to participate if they worked in care homes located in Thurrock, Essex, which catered for people with dementia.

11. How were participants approached?

A purposive sample of care homes in Thurrock, Essex, that have dementia patients was identified by searching the website https://www.cqc.org.uk/search/site/care%20homes?sort=default&distance=15&mode=html&f%5B0%5D=im_field_popular_services%3A3668 (CQC) (2017). BN contacted the identified care homes by telephone to ascertain the pharmacy responsible for their pharmaceutical services. The contact details of the pharmacies were then confirmed through the NHS Choices website (2014) and pharmacists working in the registered pharmacies identified by the care homes were contacted by BN and invited to participate in the study.

Participants were informed that they were selected because they worked in care homes that had residents with dementia

12. How many participants were in the study?

There were 11 care home staff

13. How many people refused to participate or dropped out?

None

14. Where was the data collected?

Each participant was interviewed at the care home they worked in, in a quiet room.

15. Was anyone else present besides the participants and researchers?

No-one else was present, but there were occasional interruptions as participants often had to stop recording to deal with queries or care home residents needing assistance

16. What are the important characteristics of the sample?

Care home staff selected to participate worked in care homes that provided residential care or nursing to people living with dementia, within the localities chosen for the study.

17. Were questions, prompts, guides provided by the authors? Was it pilot tested?

The interview schedule consisted of a combination of open ended and closed questions. The open-ended questions enabled participants to express themselves without being led by the researcher. The questions were not piloted, thought the schedule was reviewed and approved by the academic supervisor

18. Were repeat interviews carried out?

No interviews were repeated.

19. Did the research use audio or visual recording to collect the data?

An audio recorder was used to record the interviews. Data were transcribed verbatim by a third party translation service

20. Were field notes made during and/or after the interview?

When participants raised issues not covered by the interview schedule, notes were made during the interviews.

21. What was the duration of the interviews?

There was no formal restriction on the duration of the interviews but the researcher aimed for a 20-30 minute interview

22. Was data saturation discussed?

Data saturation was reached in the study and discussed and agreed between the researcher and research supervisor.

23. Were transcripts returned to participants for comment and/or correction?

Transcripts were not returned to participants, but emerging themes were discussed between the researcher and research supervisor

A note was taken of all participants who wanted to be sent the report once the study was completed.

<u>Domain 3: Analysis and findings</u>

24. How many data coders coded the data?

Two: The academic supervisor independently reviewed and coded the scripts and the researcher (BN) also did, then both met for comparison of findings.

Disagreements on the interpretation and analysis of the data were then discussed between BN and BA until consensus was achieved. BN rearranged data according to identified themes and discussed with BA before mapping and interpretation.

25. Did authors provide a description of the coding tree? *No*.

26. Were themes identified in advance or derived from the data?

Themes were derived from the data. Four main themes emerged from the data.

27. What software, if applicable, was used to manage the data?

No software was used.

28. Did participants provide feedback on the findings?

Participants who requested feedback on the data were given a copy of the final report, but none provided feedback.

29. Were participant quotations presented to illustrate the themes/findings? Was each quotation identified?

Extracts from the transcripts were quoted in the results section verbatim from the recordings during the interviews.

30.Was there consistency between the data presented and the findings?

Yes there was consistency between the data presented and the findings.

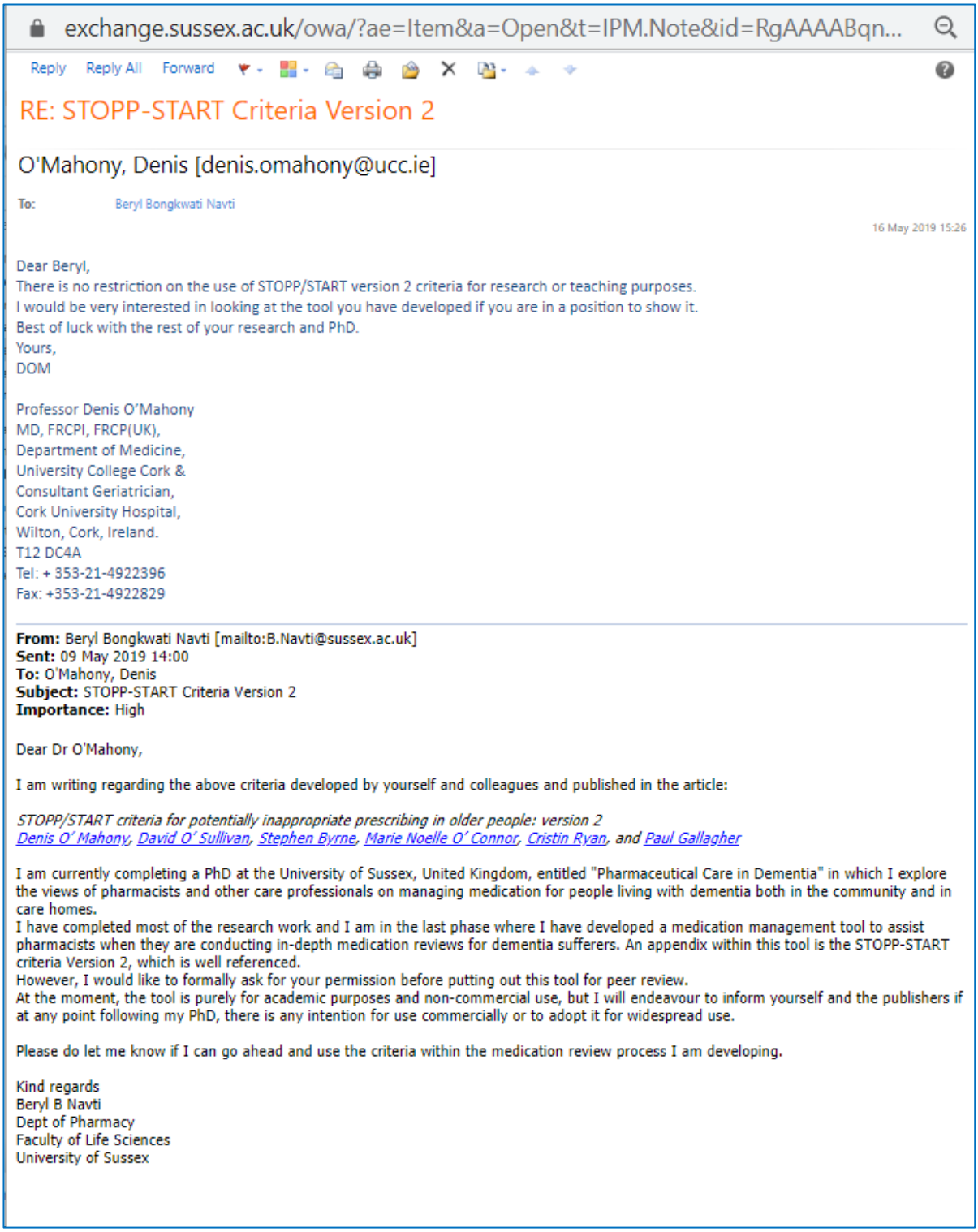
31. Were major themes clearly presented in the findings?

Four major themes were elicited from the data and presented in the results of the study in named sub-sections.

32. Is there a description of diverse cases or discussion of minor themes?

Yes, diverse cases have been discussed and differences between levels of practice between participants within the same locality and between the two localities studied have been discussed in the findings.

Appendix 6a: Permission to use the STOPP/START Version 2 Tool



exchange.sussex.ac.uk/owa/?ae=Item&a=Open&t=IPM.Note&id=RgAAAABqn...

Reply Reply All Forward

RE: STOPP-START Criteria Version 2

O'Mahony, Denis [denis.omahony@ucc.ie]

To: Beryl Bongkwati Navti

16 May 2019 15:26

Dear Beryl,
There is no restriction on the use of STOPP/START version 2 criteria for research or teaching purposes.
I would be very interested in looking at the tool you have developed if you are in a position to show it.
Best of luck with the rest of your research and PhD.
Yours,
DOM

Professor Denis O'Mahony
MD, FRCPI, FRCP(UK),
Department of Medicine,
University College Cork &
Consultant Geriatrician,
Cork University Hospital,
Wilton, Cork, Ireland.
T12 DC4A
Tel: + 353-21-4922396
Fax: +353-21-4922829

From: Beryl Bongkwati Navti [mailto:B.Navti@sussex.ac.uk]
Sent: 09 May 2019 14:00
To: O'Mahony, Denis
Subject: STOPP-START Criteria Version 2
Importance: High

Dear Dr O'Mahony,

I am writing regarding the above criteria developed by yourself and colleagues and published in the article:

STOPP/START criteria for potentially inappropriate prescribing in older people: version 2
Denis O' Mahony, David O' Sullivan, Stephen Byrne, Marie Noelle O' Connor, Cristin Ryan, and Paul Gallagher

I am currently completing a PhD at the University of Sussex, United Kingdom, entitled "Pharmaceutical Care in Dementia" in which I explore the views of pharmacists and other care professionals on managing medication for people living with dementia both in the community and in care homes.
I have completed most of the research work and I am in the last phase where I have developed a medication management tool to assist pharmacists when they are conducting in-depth medication reviews for dementia sufferers. An appendix within this tool is the STOPP-START criteria Version 2, which is well referenced.
However, I would like to formally ask for your permission before putting out this tool for peer review.
At the moment, the tool is purely for academic purposes and non-commercial use, but I will endeavour to inform yourself and the publishers if at any point following my PhD, there is any intention for use commercially or to adopt it for widespread use.

Please do let me know if I can go ahead and use the criteria within the medication review process I am developing.

Kind regards
Beryl B Navti
Dept of Pharmacy
Faculty of Life Sciences
University of Sussex

Appendix 6b: STOPP/ START Criteria Version 2

(Denis O'Mahony, David O'Sullivan, Stephen Byrne, Marie Noelle O'Connor, Cristin Ryan, Paul Gallagher, 2015)

STOPP: Screening Tool of Older People's Potentially Inappropriate Prescriptions

The following drug prescriptions are potentially inappropriate in persons aged 65 years of age and older:

Section A: Indication of medication

1. Any drug prescribed without an evidence-based clinical indication.
2. Any drug prescribed beyond the recommended duration, where treatment duration is well defined.
3. Any duplicate drug class prescription e.g. two concurrent NSAIDs, SSRIs, loop diuretics, ACE inhibitors, anticoagulants (optimisation of monotherapy within a single drug class should be observed prior to considering a new agent).

Section B: Cardiovascular System

1. Digoxin for heart failure with normal systolic ventricular function (no clear evidence of benefit).
2. Verapamil or diltiazem with NYHA Class III or IV heart failure (may worsen heart failure).
3. Beta-blocker in combination with verapamil or diltiazem (risk of heart block).
4. Beta blocker with bradycardia (<50/min), type II heart block or complete heart block (risk of complete heart block, asystole).
5. Amiodarone as first-line antiarrhythmic therapy in supraventricular tachyarrhythmias (higher risk of side-effects than beta-blockers, digoxin, verapamil or diltiazem).
6. Loop diuretic as first-line treatment for hypertension (safer, more effective alternatives available).
7. Loop diuretic for dependent ankle oedema without clinical, biochemical evidence or radiological evidence of heart failure, liver failure, nephrotic syndrome or renal failure (leg elevation and /or compression hosiery usually more appropriate).
8. Thiazide diuretic with current significant hypokalaemia (i.e. serum K+ < 3.0 mmol/l), hyponatraemia (i.e. serum Na+ < 130 mmol/l) hypercalcaemia (i.e. corrected serum calcium > 2.65 mmol/l) or with a history of gout (hypokalaemia, hyponatraemia, hypercalcaemia and gout can be precipitated by thiazide diuretic).
9. Loop diuretic for treatment of hypertension with concurrent urinary incontinence (may exacerbate incontinence).
10. Centrally-acting antihypertensives (e.g. methyldopa, clonidine, moxonidine, rilmenidine, guanfacine), unless clear intolerance of, or lack of efficacy with, other classes of antihypertensives (centrally-active antihypertensives are generally less well tolerated by older people than younger people).
11. ACE inhibitors or Angiotensin Receptor Blockers in patients with hyperkalaemia.
12. Aldosterone antagonists (e.g. spironolactone, eplerenone) with concurrent potassium- conserving drugs (e.g. ACEI's, ARB's, amiloride, triamterene) without monitoring of serum potassium (risk of dangerous hyperkalaemia i.e. > 6.0 mmol/l – serum K should be monitored regularly, i.e. at least every 6 months).
13. Phosphodiesterase type-5 inhibitors (e.g. sildenafil, tadalafil, vardenafil) in severe heart failure characterised by hypotension i.e. systolic BP < 90 mmHg, or concurrent nitrate therapy for angina (risk of cardiovascular collapse).

Section C: Antiplatelet/Anticoagulant Drugs

1. Long-term aspirin at doses greater than 160mg per day (increased risk of bleeding, no evidence for increased efficacy).
2. Aspirin with a past history of peptic ulcer disease without concomitant PPI (risk of recurrent peptic ulcer).
3. Aspirin, clopidogrel, dipyridamole, vitamin K antagonists, direct thrombin inhibitors or factor Xa inhibitors with concurrent significant bleeding risk, i.e. uncontrolled severe hypertension, bleeding diathesis, recent non-trivial spontaneous bleeding) (high risk of bleeding).
4. Aspirin plus clopidogrel as secondary stroke prevention, unless the patient has a coronary stent(s)

inserted in the previous 12 months or concurrent acute coronary syndrome or has a high grade symptomatic carotid arterial stenosis (no evidence of added benefit over clopidogrel monotherapy).

5. Aspirin in combination with vitamin K antagonist, direct thrombin inhibitor or factor Xa inhibitors in patients with chronic atrial fibrillation (no added benefit from aspirin)
6. Antiplatelet agents with vitamin K antagonist, direct thrombin inhibitor or factor Xa inhibitors in patients with stable coronary, cerebrovascular or peripheral arterial disease (No added benefit from dual therapy).
7. Ticlopidine in any circumstances (clopidogrel and prasugrel have similar efficacy, stronger evidence and fewerside-effects).
8. Vitamin K antagonist, direct thrombin inhibitor or factor Xa inhibitors for first deep venous thrombosis withoutcontinuingprovokingriskfactors(e.g.thrombophilia)for>6months, (no proven addedbenefit).
9. Vitamin K antagonist, direct thrombin inhibitor or factor Xa inhibitors for first pulmonary embolus without continuing provoking risk factors (e.g. thrombophilia) for > 12 months (no proven added benefit).
10. NSAID and vitamin K antagonist, direct thrombin inhibitor or factor Xa inhibitors in combination (risk of major gastrointestinal bleeding).
11. NSAID with concurrent antiplatelet agent(s) without PPI prophylaxis (increased risk of peptic ulcer disease).

Section D: Central Nervous System and Psychotropic Drugs

1. TriCyclic Antidepressants (TCAs) with dementia, narrow angle glaucoma, cardiac conduction abnormalities, prostatism, or prior history of urinary retention (risk of worsening these conditions).
2. Initiation of TriCyclic Antidepressants (TCAs) as first-line antidepressant treatment (higher risk of adverse drug reactions with TCAs than with SSRIs or SNRIs).
3. Neuroleptics with moderate-marked antimuscarinic/anticholinergic effects (chlorpromazine, clozapine, flupenthixol, fluphenzine, pipothiazine, promazine, zuclopenthixol) with a history of prostatism or previous urinary retention (high risk of urinary retention).
4. Selective serotonin re-uptake inhibitors (SSRI's) with current or recent significant hyponatraemia i.e. serum Na+ < 130 mmol/l (risk of exacerbating or precipitating hyponatraemia).
5. Benzodiazepines for ≥ 4 weeks (no indication for longer treatment; risk of prolonged sedation, confusion, impaired balance, falls, road traffic accidents; all benzodiazepines should be withdrawn gradually if taken for more than 4 weeks as there is a risk of causing a benzodiazepine withdrawal syndrome if stopped abruptly).
6. Antipsychotics (i.e. other than quetiapine or clozapine) in those with parkinsonism or Lewy Body Disease (risk of severe extra-pyramidal symptoms).
7. Anticholinergics/antimuscarinics to treat extra-pyramidal side-effects of neuroleptic medications (risk of anticholinergic toxicity),
8. Anticholinergics/antimuscarinics in patients with delirium or dementia (risk of exacerbation of cognitive impairment).
9. Neuroleptic antipsychotic in patients with behavioural and psychological symptoms of dementia (BPSD) unless symptoms are severe and other non-pharmacological treatments have failed (increased risk of stroke).
10. Neuroleptics as hypnotics, unless sleep disorder is due to psychosis or dementia (risk of confusion, hypotension, extra-pyramidal side effects, falls).
11. Acetylcholinesterase inhibitors with a known history of persistent bradycardia (< 60 beats/min.), heart block or recurrent unexplained syncope or concurrent treatment with drugs that reduce heart rate such as beta-blockers, digoxin, diltiazem, verapamil (risk of cardiac conduction failure, syncope and injury).
12. Phenothiazines as first-line treatment, since safer and more efficacious alternatives exist (phenothiazines are sedative, have significant anti-muscarinic toxicity in older people, with the exception of prochlorperazine for nausea/vomiting/vertigo, chlorpromazine for relief of persistent hiccoughs and levomepromazine as an anti-emetic in palliative care).
13. Levodopa or dopamine agonists for benign essential tremor (no evidence of efficacy)
14. First-generation antihistamines (safer, less toxic antihistamines now widely available).

Section E: Renal System

The following drugs are potentially inappropriate in older people with acute or chronic kidney disease with renal function below particular levels of eGFR (refer to summary of product characteristics datasheets and local formulary guidelines)

1. Digoxin at a long-term dose greater than 125µg/day if eGFR < 30 ml/min/1.73m2 (risk of digoxin toxicity if plasma levels not measured).
2. Direct thrombin inhibitors (e.g. dabigatran) if eGFR < 30 ml/min/1.73m2 (risk of bleeding).
3. Factor Xa inhibitors (e.g. rivaroxaban, apixaban) if eGFR < 15 ml/min/1.73m2 (risk of bleeding).
4. NSAID's if eGFR < 50 ml/min/1.73m2 (risk of deterioration in renal function).
5. Colchicine if eGFR < 10 ml/min/1.73m2 (risk of colchicine toxicity).
6. Metformin if eGFR < 30 ml/min/1.73m2 (risk of lactic acidosis).

Section F: Gastrointestinal System

Prochlorperazine or metoclopramide with Parkinsonism (risk of exacerbating Parkinsonian symptoms).

1. PPI for uncomplicated peptic ulcer disease or erosive peptic oesophagitis at full therapeutic dosage for > 8 weeks (dose reduction or earlier discontinuation indicated).
2. Drugs likely to cause constipation (e.g. antimuscarinic/anticholinergic drugs, oral iron, opioids, verapamil, aluminium antacids) in patients with chronic constipation where non- constipating alternatives are available (risk of exacerbation of constipation).
3. Oral elemental iron doses greater than 200 mg daily (e.g. ferrous fumarate > 600 mg/day, ferrous sulphate > 600 mg/day, ferrous gluconate > 1800 mg/day; no evidence of enhanced iron absorption above these doses).

Section G: Respiratory System

1. Theophylline as monotherapy for COPD (safer, more effective alternative; risk of adverse effects due to narrow therapeutic index).
2. Systemic corticosteroids instead of inhaled corticosteroids for maintenance therapy in moderate-severe COPD (unnecessary exposure to long-term side-effects of systemic corticosteroids and effective inhaled therapies are available).
3. Anti-muscarinic bronchodilators (e.g. ipratropium, tiotropium) with a history of narrow angle glaucoma (may exacerbate glaucoma) or bladder outflow obstruction (may cause urinary retention).
4. Benzodiazepines with acute or chronic respiratory failure i.e. pO2 < 8.0 kPa ± pCO2 > 6.5 kPa (risk of exacerbation of respiratory failure).

Section H: Musculoskeletal System

1. Non-steroidal anti-inflammatory drug (NSAID) other than COX-2 selective agents with history of peptic ulcer disease or gastrointestinal bleeding, unless with concurrent PPI or H2 antagonist (risk of peptic ulcer relapse).
2. NSAID with severe hypertension (risk of exacerbation of hypertension) or severe heart failure (risk of exacerbation of heart failure).
3. Long-term use of NSAID (>3 months) for symptom relief of osteoarthritis pain where paracetamol has not been tried (simple analgesics preferable and usually as effective for pain relief).
4. Long-term corticosteroids (>3 months) as monotherapy for rheumatoid arthrtitis (risk of systemic corticosteroid side-effects).
5. Corticosteroids (other than periodic intra-articular injections for mono-articular pain) for osteoarthritis (risk of systemic corticosteroid side-effects).
6. Long-term NSAID or colchicine (>3 months) for chronic treatment of gout where there is no contraindication to a xanthine-oxidase inhibitor (e.g. allopurinol, febuxostat) (xanthine- oxidase inhibitors are first choice prophylactic drugs in gout).
7. COX-2 selective NSAIDs with concurrent cardiovascular disease (increased risk of myocardial infarction and stroke).
8. NSAID with concurrent corticosteroids without PPI prophylaxis (increased risk of peptic ulcer disease).
9. Oral bisphosphonates in patients with a current or recent history of upper gastrointestinal disease i.e.

dysphagia, oesophagitis, gastritis, duodenitis, or peptic ulcer disease, or upper gastrointestinal bleeding (risk of relapse/exacerbation of oesophagitis, oesophageal ulcer, oesophageal stricture).

Section I: Urogenital System

1. Antimuscarinic drugs with dementia, or chronic cognitive impairment (risk of increased confusion, agitation) or narrow-angle glaucoma (risk of acute exacerbation of glaucoma), or chronic prostatism (risk of urinary retention).
2. Selective alpha-1 selective alpha blockers in those with symptomatic orthostatic hypotension or micturition syncope (risk of precipitating recurrent syncope).

Section J. Endocrine System

1. Sulphonylureas with a long duration of action (e.g. glibenclamide, chlorpropamide, glimepiride) with type 2 diabetes mellitus (risk of prolonged hypoglycaemia).
2. Thiazolidenediones (e.g. rosiglitazone, pioglitazone) in patients with heart failure (risk of exacerbation of heartfailure).
3. Beta-blockers in diabetes mellitus with frequent hypoglycaemic episodes (risk of suppressing hypoglycaemic symptoms).
4. Oestrogens with a history of breast cancer or venous thromboembolism (increased risk of recurrence).
5. Oral oestrogens without progestogen in patients with intact uterus (risk of endometrial cancer).
6. Androgens (male sex hormones) in the absence of primary or secondary hypogonadism (risk of androgen toxicity; no proven benefit outside of the hypogonadism indication).

Section K: Drugs that predictably increase the risk of falls in older people

1. Benzodiazepines (sedative, may cause reduced sensorium, impair balance).
2. Neuroleptic drugs (may cause gait dyspraxia, Parkinsonism).
3. Vasodilator drugs (e.g. alpha-1 receptor blockers, calcium channel blockers, long-acting nitrates, ACE inhibitors, angiotensin I receptor blockers,) with persistent postural hypotension i.e. recurrent drop in systolic blood pressure ≥ 20mmHg (risk of syncope, falls).
4. Hypnotic Z-drugs e.g. zopiclone, zolpidem, zaleplon (may cause protracted daytime sedation, ataxia).

Section L: Analgesic Drugs

1. Use of oral or transdermal strong opioids (morphine, oxycodone, fentanyl, buprenorphine, diamorphine, methadone, tramadol, pethidine, pentazocine) as first line therapy for mild pain (WHO analgesic ladder not observed).
2. Use of regular (as distinct from PRN) opioids without concomitant laxative (risk of severe constipation).
3. Long-acting opioids without short-acting opioids for break-through pain (risk of persistence of severe pain).

Section N: Antimuscarinic/Anticholinergic Drug Burden

1. Concomitant use of two or more drugs with antimuscarinic/anticholinergic properties (e.g. bladder antispasmodics, intestinal antispasmodics, tricyclic antidepressants first generation antihistamines) (risk of increased antimuscarinic/anticholinergic toxicity).

START: Screening Tool to Alert to Right Treatment (START), version 2.

Unless an elderly patient's clinical status is end-of-life and therefore requiring a more palliative focus of pharmacotherapy, the following drug therapies should be considered where omitted for no valid clinical reason(s). It is assumed that the prescriber observes all the specific contraindications to these drug therapies prior to recommending them to older patients.

Section A: Cardiovascular System

1. Vitamin K antagonists or direct thrombin inhibitors or factor Xa inhibitors in the presence of chronic atrial fibrillation.
2. Aspirin (75 mg – 160 mg once daily) in the presence of chronic atrial fibrillation, where Vitamin K antagonists or direct thrombin inhibitors or factor Xa inhibitors are contraindicated.
3. Antiplatelet therapy (aspirin or clopidogrel or prasugrel or ticagrelor) with a documented history of coronary, cerebral or peripheral vascular disease.
4. Antihypertensive therapy where systolic blood pressure consistently > 160 mmHg and/or diastolic blood pressure consistently >90 mmHg; if systolic blood pressure > 140 mmHg and /or diastolic blood pressure > 90 mmHg, if diabetic.
5. Statin therapy with a documented history of coronary, cerebral or peripheral vascular disease, unless the patient's status is end-of-life or age is > 85 years.
6. Angiotensin Converting Enzyme (ACE) inhibitor with systolic heart failure and/or documented coronary artery disease.
7. Beta-blocker with ischaemic heart disease.
8. Appropriate beta-blocker (bisoprolol, nebivolol, metoprolol or carvedilol) with stable systolic heart failure.

Section B: Respiratory System

1. Regular inhaled β2 agonist or antimuscarinic bronchodilator (e.g. ipratropium, tiotropium) for mild to moderate asthma or COPD.
2. Regular inhaled corticosteroid for moderate-severe asthma or COPD, where FEV1 <50% of predicted value and repeated exacerbations requiring treatment with oral corticosteroids.
3. Home continuous oxygen with documented chronic hypoxaemia (i.e. pO2 < 8.0 kPa or 60 mmHg or SaO2 < 89%).

Section C: Central Nervous System& Eyes

1. L-DOPA or a dopamine agonist in idiopathic Parkinson's disease with functional impairment and resultant disability.
2. Non-TCA antidepressant drug in the presence of persistent major depressive symptoms.
3. Acetylcholinesterase inhibitor (e.g. donepezil, rivastigmine, galantamine) for mild- moderate Alzheimer's dementia or Lewy Body dementia (rivastigmine).
4. Topical prostaglandin, prostamide or beta-blocker for primary open-angle glaucoma.
5. Selective serotonin reuptake inhibitor (or SNRI or pregabalin if SSRI contraindicated) for persistent severe anxiety that interferes with independent functioning.
6. Dopamine agonist (ropinirole or pramipexole or rotigotine) for Restless Legs Syndrome, once iron deficiency and severe renal failure have been excluded

Section D: Gastrointestinal System

1. Proton Pump Inhibitor with severe gastro-oesophageal reflux disease or peptic stricture requiring dilatation.
2. Fibre supplements (e.g. bran, ispaghula, methylcellulose, sterculia) for diverticulosis with a history of constipation.

Section E: Musculoskeletal System

1. Disease-modifying anti-rheumatic drug (DMARD) with active, disabling rheumatoid disease.
2. Bisphosphonates and vitamin D and calcium in patients taking long-term systemic corticosteroid therapy.

3. Vitamin D and calcium supplement in patients with known osteoporosis and/or previous fragility fracture(s) and/or (Bone Mineral Density T-scores more than -2.5 in multiple sites).
4. Bone anti-resorptive or anabolic therapy (e.g. bisphosphonate, strontium ranelate, teriparatide, denosumab) in patients with documented osteoporosis, where no pharmacological or clinical status contraindication exists (Bone Mineral Density T-scores ->2.5 in multiple sites) and/or previous history of fragility fracture(s).
5. Vitamin D supplement in older people who are housebound or experiencing falls or with osteopenia (Bone Mineral Density T-score is > -1.0 but < -2.5 in multiple sites).
6. Xanthine-oxidase inhibitors (e.g. allopurinol, febuxostat) with a history of recurrent episodes of gout.
7. Folic acid supplement in patients taking methotexate.

Section F: Endocrine System

1. ACE inhibitor or Angiotensin Receptor Blocker (if intolerant of ACE inhibitor) in diabetes with evidence of renal disease i.e. dipstick proteinuria or microalbuminuria (>30mg/24 hours) with or without serum biochemical renal impairment.

Section G: Urogenital System

1. Alpha-1 receptor blocker with symptomatic prostatism, where prostatectomy is not considered necessary.
2. 5-alpha reductase inhibitor with symptomatic prostatism, where prostatectomy is not considered necessary.
3. Topical vaginal oestrogen or vaginal oestrogen pessary for symptomatic atrophic vaginitis.

Section H: Analgesics

1. High-potency opioids in moderate-severe pain, where paracetamol, NSAIDs or low-potency opioids are not appropriate to the pain severity or have been ineffective.
2. Laxatives in patients receiving opioids regularly.

Section I: Vaccines

1. Seasonal trivalent influenza vaccine annually
2. Pneumococcal vaccine at least once after age 65 according to national guidelines

Appendix 6c: NICE guidelines dementia (CG42): excerpt from section 1.7

Dementia: supporting people with dementia and their carers in health and social care (NICE guidelines CG42)
(https://www.nice.org.uk/guidance/cg42)

Non-cognitive symptoms include hallucinations, delusions, anxiety, marked agitation and associated aggressive behaviour. 'Behaviour that challenges' encompasses a wide range of difficulties that are often experienced by people with dementia and that may have an effect on those who provide care. It may include aggression, agitation, wandering, hoarding, sexual disinhibition, apathy and disruptive vocal activity such as shouting.

1.7.1: Non-pharmacological interventions for non-cognitive symptoms and behaviour that challenges
1.7.1.1 People with dementia who develop non-cognitive symptoms that cause them significant distress or who develop behaviour that challenges should be offered an assessment at an early opportunity to establish likely factors that may generate, aggravate or improve such behaviour. The assessment should be comprehensive and include: • the person's physical health • depression • possible undetected pain or discomfort • side effects of medication • individual biography, including religious beliefs and spiritual and cultural identity • psychosocial factors • physical environmental factors • behavioural and functional analysis conducted by professionals with specific skills, in conjunction with carers and care workers. Individually tailored care plans that help carers and staff address the behaviour that challenges should be developed, recorded in the notes and reviewed regularly. The frequency of the review should be agreed by the carers and staff involved and written in the notes.
1.7.1.2 For people with all types and severities of dementia who have comorbid agitation, consideration should be given to providing access to interventions tailored to the person's preferences, skills and abilities. Because people may respond better to one treatment than another, the response to each modality should be monitored and the care plan adapted accordingly. Approaches that may be considered, depending on availability, include: • aromatherapy • multisensory stimulation • therapeutic use of music and/or dancing • animal-assisted therapy • massage. These interventions may be delivered by a range of health and social care staff and volunteers, with appropriate training and supervision. The voluntary sector has a particular role to play in delivering these approaches. Health and social care staff in the NHS and social care, including care homes, should work together to ensure that some of these options are available, because there is some evidence of their clinical effectiveness. More research is needed into their cost effectiveness.

1.7.2 Pharmacological interventions for non-cognitive symptoms andbehaviour that challenges
1.7.2.1 People with dementia who develop non-cognitive symptoms or behaviour that challenges should be offered a pharmacological intervention in the first instance only if they are severely distressed or there is an immediate risk of harm to the person or others. The assessment and care-planning approach, which includes behavioural management, should be followed as soon as possible (see recommendation 1.7.1.1). If distress and/or agitation are less severe, the interventions described in recommendations 1.7.1.2, 1.8.1.2 and 1.8.1.3 should be followed before a pharmacological intervention is considered.
1.7.2.2 People with **Alzheimer's disease, vascular dementia or mixed dementias with mild-to-moderate non- cognitive symptoms should not be prescribed antipsychotic drugs** because of the possible increased risk of cerebrovascular adverse events and death.[18]
1.7.2.3 People with **dementia with Lewy bodies (DLB) with mild-to-moderate non-cognitive symptoms, should not be prescribed antipsychotic drugs**, because those with DLB are at particular risk of severe adverse reactions.
1.7.2.4 People with Alzheimer's disease, vascular dementia, mixed dementias or DLB with severe non-cognitive symptoms (psychosis and/or agitated behaviour causing significant distress) may be offered treatment with an antipsychotic drug after the following conditions have been met. • There should be a full discussion with the person with dementia and/or carers about the possible benefits and risks of treatment. In particular, cerebrovascular risk factors should be assessed and the possible increased risk of stroke/transient ischaemic attack and possible adverse effects on cognition discussed. • Changes in cognition should be assessed and recorded at regular intervals. Alternative medication should be considered if necessary. • Target symptoms should be identified, quantified and documented. • Changes in target symptoms should be assessed and recorded at regular intervals. • The effect of comorbid conditions, such as depression, should be considered. • The choice of antipsychotic should be made after an individual risk–benefit analysis. • The dose should be low initially and then titrated upwards. • Treatment should be time limited and regularly reviewed (every 3 months or according to clinical need). For people with DLB, healthcare professionals should monitor carefully for the emergence of severe untoward reactions, particularly neuroleptic sensitivity reactions (which manifest as the development or worsening of severe extrapyramidal features after treatment in the accepted dose range or acute and severe physical deterioration following prescription of antipsychotic drugs for which there is no other apparent cause).
1.7.2.5 People with mild to moderate Alzheimer's disease who have non-cognitive symptoms and/or behaviour that challenges, causing significant distress or potential harm to the individual, may be offered an acetylcholinesterase inhibitor under all of the conditions specified in 1.6.2.3 and 1.6.2.4, provided: a non-pharmacological approach is inappropriate or has been ineffective, and antipsychotic drugs are inappropriate or have been ineffective.
1.7.2.6 People with moderate Alzheimer's disease who have non-cognitive symptoms and/or behaviour that challenges (as in 1.7.2.5 above) and are intolerant of or have a contraindication to acetylcholinesterase inhibitors, as well as people with severe Alzheimer's disease, may be offered memantine under the conditions specified in 1.6.2.3, provided: a non-pharmacological approach is inappropriate or has been ineffective, and antipsychotic drugs are inappropriate or have been ineffective.
1.7.2.7 People with DLB who have non-cognitive symptoms causing significant distress to the individual, or leading to behaviour that challenges, should be offered an acetylcholinesterase inhibitor.
1.7.2.8 People with vascular dementia who develop non-cognitive symptoms or behaviour that challenges should not be prescribed acetylcholinesterase inhibitors, except as part of properly constructed clinical studies.

Appendix 6d: Drug Interactions

A. Drug interactions between Acetylcholinesterase Inhibitors and other medications (*see current BNF and Stockley's Drug Interactions for up to date list of interactions*)

	Anticholinesterase		
Interacting drug	Donepezil	Galantamine	Rivastigmine
Centrally acting beta-blockers e.g (atenolol, bisoprolol, carvedilol)	Increase level of donepezil and may increase risk of bradycardia ■/●	Concurrent use with galantamine may increase risk of bradycardia	Interaction unlikely
Erythromycin/ Clarithromycin	Increases level of donepezil ■/●	Increases level of galantamine ■	Interaction unlikely
Ketoconazole	Increases level of donepezil by 25% ■	Increases level of galantamine ■	Interaction unlikely
Itraconazole	Increases level of donepezil ■		Interaction unlikely
Fluoxetine	Increases level of donepezil ■	Increases levels of galantamine ■	Interaction unlikely
Paroxetine	Increases level of donepezil ■	Increases levels of galantamine by 40% ●	Interaction unlikely
Quinidine	Increases levels of donepezil ■	Increases levels of galantamine ■	Interaction unlikely
Fluvoxamine	x	Increases levels of galantamine ■	Interaction unlikely
Amitriptyline (and other tricyclic antidepressants)	Might oppose effects of donepezil♦	Might oppose levels of galantamine opposite effect has been reported ●	Might oppose levels of rivastigmine ●
Antiretroviral drugs (Ritonavir, amprenavir etc)	x	Increases levels of galantamine ■/●	Interaction unlikely
Enzyme inducers suchas:Rifampicin, Phenytoin, Carbamazepine, Alcohol, Phenobarbital, Dexamethasone	Decreases level of donepezil ❖	x	x

- ■ Probably clinically insignificant; no dose adjustment of anticholinesterase needed unless adverse side effects (e.g nausea and vomiting) are experienced.
- ❖ Probably clinically insignificant; no dose increase of anticholinesterase needed but use with care
- ● Probably clinically significant increase; a lower anticholinesterase maintenance dose might be appropriate.
- ♦ Monitor concurrent use if adverse effects occur or if there is treatment failure
- X No interaction

B. Drug interactions between Memantine and other medications

(*refer to most recent BNF for up to date list of drug interactions*)

Interacting drug	Effect	Comments
General anaesthetics: KETAMINE	Increased risk of adverse CNS reactions (e.g psychosis) when memantine given with ketamine. **X**	Avoid concurrent use
Analgesics: DEXTROMETHORPHAN	Increased risk of CNS toxicity when memantine given with dextromethorphan because they have similar modes of action **X**	Avoid concurrent use
Dopaminergics: AMANTADINE	Increased risk of CNS toxicity when memantine given with amantadine because they are chemically related **X**	Avoid concurrent use
Anticoagulants: WARFARIN	Memantine may enhance anticoagulant effect of warfarin (cases of raised INR reported when patients on warfarin given memantine) ■	Increase frequency of INR monitoring if memantine started or stopped
Antiepileptics: PRIMIDONE Barbiturates	Memantine may reduce effect of primidone and barbiturates■	Monitor for seizures
Anticholinergics (Antimuscarinics)	Memantine may enhance effect of anticholinergic drugs ■	Monitor for worsening confusion and anticholinergic effects, and adjust treatment accordingly
Antipsychotics	Memantine may reduce effect of antipsychotic drugs ■	Monitor that concurrent use to ensure antipsychotic effect adequate, adjust doses if necessary
Dopamine agonists: LEVODOPA and SELEGILINE etc.	Memantine possibly enhances effects of dopaminergics and selegiline■	Dopaminergic side effects may increase, Monitor and adjust doses if necessary
Muscle relaxants: BACLOFEN and DANTROLENE	Memantine possibly modifies effects of baclofen and dantrolene ■	Monitor for adverse effects, adjust doses if necessary
Cimetidine, Ranitidine, Procainamide, Quinidine, Quinine, Nicotine	These share a renal pathway of elimination and may reduce rate of clearance of memantine potentially leading to higher plasma levels of memantine ■	Monitor for any increased adverse effects of memantine

■: Clinically possibly significant. Monitor for adverse effects.

X: Severe and clinically significant. Avoid combination

Appendix 6e: Anticholinergic Cognitive Burden Scale (ACB) (adapted)

Anticholinergic drugs can oppose the action of acetylcholine and lead to increased confusion, making the addition of acetylcholinesterase drugs (aimed at increasing acetylcholine and improving cognition) ineffective. Each definite anticholinergic medication could increase risk of cognitive impairment by 46% over 6 years (Campbell et al 2010). Cumulative ACB score>3 is considered clinically relevant

Drug class with anticholinergic effects	Examples of drug and level of anticholinergic effect on Anticholinergic Cognitive Burden Scale (1=possible, 2,3=definite)		
	High (3)	Medium (2)	Low (1)
1st Generation Antihistamines	Chlorpheniramine Clemastine Diphenhydramine Promethazine Hydroxyzine	Cyproheptadine	Alimemazine Cetirizine Desloratadine Loratadine Levocetirizine
Antidepressants	Amitriptyline Clomipramine Desipramine Imipramine Nortriptyline Paroxetine Trimipramine		Bupropion Trazodone
Antipsychotics	Clozapine Olanzapine Perphenazine Quetiapine Trifluoperazine	Levomepromazine Pimozide	Aripiprazole Asenapine Risperidone Paliperidone Haloperidol
Anxiolytics			Alprazolam Diazepam
Analgesia		Pethidine	Codeine Fentanyl Morphine
Antiemetics	Hydroxyzine Promethazine Hyoscine hydrobromide		Ondansetron Metoclopamide
Antiepileptics		Carbamazepine Oxcarbazepine	
Antiplatelet			Dipyridamole
Arrhythmia	Disopyramide		
Bladder antispasmodics	Darifenacin Flavoxate Oxybutynin Propantheline Solifenacin Tolterodine		
Cardiovascular			Atenolol Captopril Chlortalidone Digoxin Isosorbide drugs Metoprolol Nifedipine Triamterene
Central Anticholinergics	Orphenadrine Procyclidine Trihexyphenidyl	Amantadine	
GI Antispasmodics	Atropine Dicycloverine Propantheline Propiverine Ranitidine		Loperamide Cimetidine
Gout			Colchicine
Respiratory			Theophylline
Skeletal muscle relaxants	Methocarbamol		

Appendix 6f: Pharmaceutical care plans

Pharmacist's record of medication review and drug therapy problems

Care Home Information			
	Name of Care Home:		Care Home Code (For research purposes):
	Address:		
	Telephone:	Manager:	Manager's email:
	Type of Care Home (Circle appropriate category): a) Residential b) Nursing		
	No. of residents:	No. of dementia patients (diagnosed)	No. of dementia patients (staff report, no official diagnosis):

Patient Basic Details				
	Age:	Date of Birth:	Gender: M / F	Code:
	Weight:	Height:	BMI:	Ethnicity:
	Date of Admission into Home:	Religion:	GP:	GP Address:
	Dementia Suptype:			
	Mobility:			
	History of Falls:	a) In the past twelve months: Y / N	b) If yes, how many?	

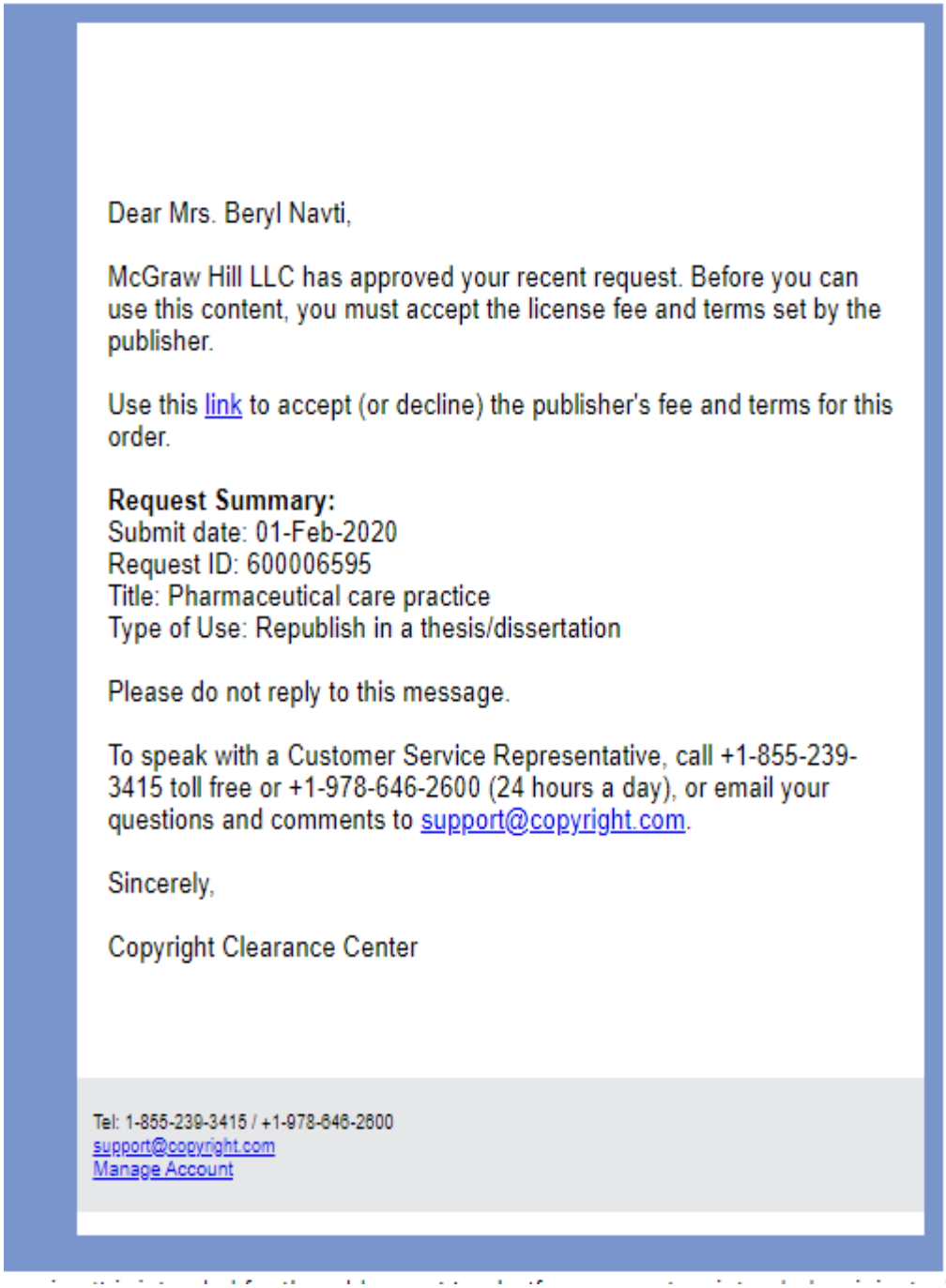
Evidence of pre-admission assessments		
	List cognitive tests coducted:	
	Risk Assessments:	
	Physical health checks:	
	Allergies:	Medication:
		Adverse reactions to drugs in the past:
		Other alerts/Health aids/special needs (sight, hearing, literacy, spiritual):

Current medication (include non-prescription, herbal medicines and vitamins)	Drug name	Date Started	Indication	Dose regimen (dose, frequency, route, duration)	Last taken	Outcome (effectiveness, response)

Record of other conditions or co-morbidities			
	Nutrition/fluid/electrolytes (Food intake, fluid intake, Sodium, Potassium)	Yes	No
	Neuropsychiatric symptoms (apathy, depression, anxiety)		
	Evidence of Behavourial and Psychological symptoms of Dementia (BPSD)		
	General observations (weight changes, appetite, pain, drowsiness?)		
	Cardiovascular conditions (hypertension, hyperlipidaemia, orthostatic hypotension)		
	Gastrointestinal (Dyspepsia, nausea, vomiting, diarrhoea or constipation)		
	Endocrine (diabetes, hypothyrodism, hyperthyrodism, other)		
	Pulmonary (Asthma, COPD, Shortness of breath)		
	Musculoskeletal (arthritis - osteoarthritis or rheumatism, back pain)		
	Infectious diseases:		
	Kidney/Urinary (Kidney function tests, Urinary tract infections)		
	Skin related (eczema/psoriasis, pruritus, rash)		
	Ear, Eye, Nose and Throat (vision, hearing, hay fever, nose bleeds)		

Drug Therapy problems *[Source: Cipolle, R J., Strand, L M., Morley, P C., (2004) Pharmaceutical Care Practice* A Clinicians Guide, 2nd Edition. McGraw-Hill. Page: 168][8]		
	Medical Condition and drug therapy involved	Indication
		Unnecessary drug therapy: - No medical indication - Duplicate therapy - Treating avoidable ADR **Needs additional drup therapy** - untreated condition - preventive/prophylactic - Synergistic/potentiating
	Medical Condition and drug therapy involved	Effectiveness
		Needs more effective drug - More effective drug available - Condition not responding to drug - Dosage form inappropriate - Not effective for condition **Dose too low:** - Wrong dose - Inappropriate frequency - Drug interaction - Duration inappropriate
	Medical Condition and drug therapy involved	Safety
		Adverse drug reaction: - Undesirable effect - Unsafe drug for patient - Dose titration too rapid - Allergic reaction - Contraindications present **Dose too high:** - Wrong dose - Inappropriate frequency - Inappropriate duration - Drug interaction - Incorrect mode of administration
	Medical Condition and drug therapy involved	Compliance
		Non-compliance - Patient cannot swallow - Patient refuses to take medication - Missed doses not fault of patient (staff)

Appendix 6g: Permission from McGraw Hill Education



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Appendix 7a: Ethical Approval ER/BN67/10-Focus group study

UNIVERSITY OF SUSSEX

Sciences & Technology C-REC
crecscitec@admin.susx.ac.uk

Certificate of Approval	
Reference Number	ER/BN67/10
Title Of Project	Pharmaceutical Care in Dementia: Toolkit for supporting pharmacists who conduct patient-centred medication reviews for people living with dementia
Principal Investigator (PI):	Bugewa Apampa
Student	Beryl Bongkwati Navti
Collaborators	
Duration Of Approval	2 months
Expected Start Date	04-Jul-2019
Date Of Approval	04-Jul-2019
Approval Expiry Date	04-Sep-2019
Approved By	Karen Long
Name of Authorised Signatory	
Date	04-Jul-2019

*NB. If the actual project start date is delayed beyond 12 months of the expected start date, this Certificate of Approval will lapse and the project will need to be reviewed again to take account of changed circumstances such as legislation, sponsor requirements and University procedures.

Please note and follow the requirements for approved submissions:

Amendments to protocol

* Any changes or amendments to approved protocols must be submitted to the C-REC for authorisation prior to implementation.

Feedback regarding the status and conduct of approved projects

* Any incidents with ethical implications that occur during the implementation of the project must be reported immediately to the Chair of the C-REC.

Feedback regarding any adverse(1) and unexpected events(2)

* Any adverse (undesirable and unintended) and unexpected events that occur during the implementation of the project must be reported to the Chair of the Science and Technology C-REC. In the event of a serious adverse event, research must be stopped immediately and the Chair alerted within 24 hours of the occurrence.

Monitoring of Approved studies

The University may undertake periodic monitoring of approved studies. Researchers will be requested to report on the outcomes of research activity in relation to approvals that were granted (full applications and amendments).

Research Standards

Failure to conduct University research in alignment with the Code of Practice for Research may be investigated under the Procedure for the Investigation of Allegations of Misconduct in Research or other appropriate internal mechanisms (3). Any queries can be addressed to the Research Governance Office: rgoffice@sussex.ac.uk

(1) An "adverse event" is one that occurs during the course of a research protocol that either causes physical or psychological harm, or increases the risk of physical or psychological harm, or results in a loss of privacy and/or confidentiality to research participant or others.

(2) An "unexpected event" is an occurrence or situation during the course of a research project that was a) harmful to a participant taking part in the research, or b) increased the probability of harm to participants taking part in the research.

(3) http://www.sussex.ac.uk/staff/research/rqi/policy/research-policy

Appendix 7b: Participant information -Focus group study

University of Sussex

Participant Information

Title of Project:

Pharmaceutical care in dementia: Toolkit for supporting pharmacists who conduct patient-centred medication reviews for people living with dementia

Name of Researcher: Beryl B Navti

You are being invited to take part in a focus group study. Before you decide if you want to take part, you must understand why the study is being done and what it involves. Please take time to read the following information and to decide if you want to take part or not.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to explore the views, perceptions and opinions of a select group of pharmacists about the applicability of a medication review toolkit developed by the researcher, to medicines optimisation and in-depth patient-centred review of prescriptions for people living with dementia.

WHY HAVE I BEEN INVITED TO PARTICIPATE?

The study is being carried out with purposively selected diverse group of pharmacists who, by virtue of their job role, routinely manage and optimise medication prescribed to people living with dementia either in the community or in care homes.

DO I HAVE TO TAKE PART?

No. It is up to you to decide whether or not to take part. Even if you agree to take part, you can change your mind at any time without giving any reason. If you decide not to take part in the study, your rights will not be affected in any way. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form.

WHAT WILL HAPPEN TO ME IF I TAKE PART?

The study will involve a short presentation about the toolkit by the researcher. You will be given the opportunity to ask questions and then provided with some prescriptions for people with dementia. You will then be required to use the toolkit to conduct a review of the medication prescribed. Next, there will be a group discussion about the applicability of the tool, ease of use and any proposed amendments. Discussions will be audio recorded for transcription. Quotes maybe used from discussions but these will be anonymised and all tapes will be deleted at the end of the study. It is anticipated that the focus group session will last no more than 2 hours. If you agree to take part, you will be asked to sign a consent form.

WHAT ARE THE POSSIBLE DISADVANTAGES AND RISKS OF TAKING PART? (WHERE APPROPRIATE)

The only risk anticipated would be that the questions will require you to set aside a small portion of your time, which could be an inconvenience. However, every effort will be made to select a date and time that is most convenient for you.

University of Sussex

WHAT ARE THE POSSIBLE DISADVANTAGES AND RISKS OF TAKING PART? (WHERE APPROPRIATE)

The only risk anticipated would be that the questions will require you to set aside a small portion of your time, which could be an inconvenience. However, every effort will be made to select a date and time that is most convenient for you.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

Your participation will help amend and adapt a dementia medication review toolkit that will make it easier to review medication for people living with dementia, and assist pharmacists in making useful drug interventions that may improve quality of prescribing for people with dementia. You will be provided with a summary of the results obtained from the study if you indicate a wish to receive this information.

WILL MY INFORMATION IN THIS STUDY BE KEPT CONFIDENTIAL?

We will not tell anyone that you have taken part in the study. Any personal data collected during the course of the study will only be used for academic and research purposes. All anonymised transcripts will be stored for 5 years after completion of the study and then shredded.

WHAT WILL HAPPEN TO THE RESULTS OF THE RESEARCH STUDY?

Information obtained will be digitally recorded and transcribed verbatim. Themes emerging will enable the researcher to amend the toolkit based on peer review and professional feedback.

WHO IS ORGANISING THE RESEARCH?

This study is being undertaken by the researcher who is a pharmacy student at the University of Sussex

WHO HAS APPROVED THIS STUDY?

This study has been approved by the Science and Technology Cross-Schools Research Ethics Committee (C-REC) ethical review process at the University of Sussex. Email: crecscitec@sussex.ac.uk

CONTACT FOR FURTHER INFORMATION

You may contact the academic supervisor at the address below:
Professor Bugewa Apampa, Director of Pharmacy Development, School of Life Sciences
University of Sussex, Falmer, Brighton.
Tel: 01273 873756 Email: b.apampa@sussex.ac.uk

THANK YOU

Thank you for taking the time to read this participant information leaflet

Date: 17/06/2019

Appendix 7c: Participant Consent-Focus group study

UNIVERSITY OF SUSSEX

CONSENT FORM FOR PROJECT PARTICIPANTS

Title of Project: Toolkit for supporting pharmacists who conduct patient centred medication reviews for people living with dementia: A focus group exercise

Name of Researcher and School: Beryl B Navti, School of Life Sciences
C-REC Ref no: ER/BN67/10

	Please tick box YES	NO
• I agree to participate in the above focus group	☐	☐
• I agree to focus group discussions/consultations being audio-recorded	☐	☐
• I understand that I will be given a transcript of data concerning me for my approval before being included in the write up of the research	☐	☐
• I understand that confidentiality cannot be guaranteed for information which I might disclose in the focus group/s	☐	☐
• I understand that any information I provide is confidential, and that no information that I disclose will lead to the identification of any individual in the reports on the project, either by the researcher or by any other party	☐	☐
• I have read the information sheet, had the opportunity to ask questions and I understand the principles, procedures and possible risks involved.	☐	☐
• I consent to the processing of my personal information and data for the purposes of this research study. I understand that such information will be treated as strictly confidential and handled in accordance with the General Data Protection Regulation (GDPR) 2016.	☐	☐
• I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalised or disadvantaged in any way.	☐	☐
• I understand that I can withdraw permission to use data from my participation within two weeks after the study, in which case the material will be deleted	☐	☐
• I understand that verbatim quotes taken from the recording of our conversation may be used in publications and reports, but that these will be anonymised and not traceable to me	☐	☐
• I agree to take part in the above University of Sussex research project	☐	☐

Name:

Signature

Date:

Template approved by URGC May 2018
Pharmaceutical care in dementia, ER/BN67/10: consent form V4

Appendix 7d: DEMENTIAS Toolkit-Participant evaluation form

UNIVERSITY OF SUSSEX

Evaluation form for medication review toolkit

Date:

Name:

Number of years qualified:

Pharmacist Sector:

	Please tick a box					
Topic	Excellent	Very good	Good	Average	Poor	**Comments**
Layout/ format of tool						
Appendices included						
Length of tool						

1. Do you find the medication review tool for people living with dementia useful?

2. Please state if there is anything that should be added to the tool

3. Please state whether there are any aspects of the tool that should be left out

4. Please add any other comments

Many thanks for reviewing this tool. Your comments are much appreciated.

Appendix 7e: Case studies for testing usability of DEMENTIAS toolkit

Case Study 1

Peter is 75 and has been diagnosed with Alzheimer's disease and has a MMSE 22. He lives in a care home because he is no longer able to look after himself at home.

Current medication:

Atenolol for hypertension

Salbutamol for asthma PRN

Fluoxetine for depression

Amitriptyline for back pain and to help him sleep

His other diseases are:

Hypertension
Asthma
Depression
He doesn't take any other medication bought over the counter.

Please use the Dementias Toolkit to review Peter's medication and to make recommendations for changes that can be considered by the GP for medication review and to determine whether an anticholinesterase inhibitor (donepezil, galantamine or rivastigmine) can be safely prescribed and formulate a pharmaceutical care pla

Case Study 2:

Mrs Carter is an 81 year old woman with severe AD dementia.

He has been living alone for the 6 years since his wife died and has now been admitted in a nursing home.

She has a male keyworker/main carer who attends to her welfare and she is completely dependent on carers for her personal care and every day needs.

She is generally amiable with her main carer but has been known to throw her food at him on occasions out of the blue.

Recently her carer started taking one day off a week, replaced by a young female staff member and on this one day of the week, Mrs Carter becomes verbally abusive, aggressive and resistant to personal care. GP has prescribed Olanzapine 2.5mg daily to deal with this behaviour.

Mrs Carter is also taking Memantine 10mg daily for her dementia and has been prescribed co-codamol 30/500 for pain following a recent assessment by the geriatrician.

She has no other co-morbidities, having been quite healthy before being diagnosed with dementia, however, the care staff has observed that for the past three months, Mrs Carter's mood has dipped significantly, she has lost her appetite, no longer wants to socialise with other residents and become very anxious.

Please evaluate the usefulness of the toolkit for reviewing Mrs Carter's medication.

ANSWERS:

Case study 1- Guide to identification of drug therapy problems

Aspects of DEMENTIAS toolkit

Pharmaceutical care issue identified using toolkit	Description
D (Drugs prescribed) Patient prescribed Amitriptyline	Amitriptyline, Atenolol, Fluoxetine, Salbutamol inhaler
Evidence	NICE guidelines for: Dementia, hypertension, depression in adults
Co-Morbidity	Patient suffers from insomnia, asthma, high blood pressure, pain, lack of sleep
Side Effects	Amitriptyline has anti-cholinergic side effects
Neuropsychiatric symptoms	Depression
Type of dementia	Alzheimer's disease (MMSE = 22)
Interactions	Drug-drug interaction between fluoxetine and donepezil
Anticholinergic burden	Check anticholinergic burden scale
Simplify/stop/switch?	Query Amitriptyline

- Amitriptyline has a high anticholinergic burden (see ACB scale) and would impair the useful effects of an anticholinesterase drug, so should be stopped.
- As amitriptyline was helping him sleep, Peter is observed for insomnia, and if necessary, another hypnotic can be prescribed.
- An anticholinesterase inhibitor can be added as per NICE dementia guidelines, but this may cause bradycardia as with his atenolol (see STOPP/START tool), though the two can be used safely. If an anticholinesterase drug is to be started, his cardiac function should be monitored, and the dose of atenolol reduced if necessary.
- Adding an anticholinesterase drug may cause his asthma control to worsen (see interactions), so his respiratory function should be monitored, and appropriate action taken if necessary, either by increasing the asthma treatment or reducing/ stopping the anticholinesterase drug safely.
- An anticholinesterase drug is worthwhile, feasible, and safe with the monitoring put in place so it can be added if all other person-centred considerations have been made
- Drug-drug interaction between donepezil and fluoxetine, increasing their levels.
- Rivastigmine doesn't interact, so potential anticholinesterase inhibitor of choice.

Case study 2- considerations from toolkit for inclusion in pharmaceutical care plan

Pharmaceutical care issue from toolkit	Description
D (Drugs prescribed)	Memantine, Olanzapine, Co-codamol
Evidence	NICE guidelines for: Dementia
Co-Morbidity	Query low mood
Side Effects	Co-codamol can cause constipation
Neuropsychiatric symptoms	Aggression (see NICE guideline, Dementia). Is olanzapine evidence based?
Type of dementia	Alzheimer's disease
Interactions	Drug-drug interaction between memantine and olanzapine, check if clinically significant
Anticholinergic burden	Check anticholinergic burden scale, co-codamol has codeine, check ACB score
Simplify/stop/switch?	Consider switching co-codamol

- Only Risperidone is licensed for treating aggression in person with dementia
- Co-codamol has codeine which can cause constipation, particularly problematic for people with dementia and can lead to agitation and aggression
- Depression common in people with dementia, this patient's low mood should be investigated.
- Potential drug-drug interaction between olanzapine and memantine
- Consider switching co-codamol to paracetamol and stopping olanzapine.

Appendix 7f: NICE guidelines NG97 excerpt (replaces Appendix 6c in toolkit)

NICE Guidelines NG97: Dementia: assessment, management and support for people living with dementia and their carers

1.7 Managing non-cognitive symptoms

https://www.nice.org.uk/guidance/ng97/chapter/Recommendations#managing-non-cognitive-symptoms

Agitation, aggression, distress and psychosis

1.7.1 Before starting non-pharmacological or pharmacological treatment for distress in people living with dementia, conduct a structured assessment to:
•explore possible reasons for their distress and
•check for and address clinical or environmental causes (for example pain, delirium or inappropriate care).
1.7.2 As initial and ongoing management offer psychosocial and environmental interventions to reduce distress in people living with dementia.
1.7.3 Only offer antipsychotics or people living with dementia who are either:
•at risk of harming themselves or others or
• experiencing agitation, hallucinations or delusions that are causing them severe distress.
1.7.4 Be aware that for people with dementia with Lewy bodies or Parkinson's disease dementia, antipsychotics can worsen the motor features of the condition, and in some cases cause severe antipsychotic sensitivity reactions. For more guidance, see the advice on managing delusions and hallucinations in the NICE guideline on Parkinson's disease. Be aware that interventions may need to be modified for people living with dementia.
1.7.5 Before starting antipsychotics, discuss the benefits and harms with the person and their family members or carers (as appropriate). Consider using a decision aid to support this discussion. NICE has produced a patient decision aid on antipsychotic medicines for treating agitation, aggression and distress in people living with dementia.
1.7.6 When using antipsychotics:
• use the lowest effective dose and use them for the shortest possible time
• reassess the person at least every 6 weeks, to check whether they still need medication.
1.7.7 Stop treatment with antipsychotics:
• if the person is not getting a clear ongoing benefit from taking them and
• after discussion with the person taking them and their family members or carers (as appropriate).
1.7.8 Ensure that people living with dementia can continue to access psychosocial and environmental interventions for distress while they are taking antipsychotics and after they have stopped taking them.
1.7.9 For people living with dementia who experience agitation or aggression, offer personalised activities to promote engagement, pleasure and interest.
1.7.10 Do not offer valproate to manage agitation or aggression in people living with dementia, unless it is indicated for another condition.

Depression and anxiety

1.7.11 For people living with mild to moderate dementia who have mild to moderate depression and/or anxiety, consider psychological treatments.
1.7.12 Do not routinely offer antidepressants to manage mild to moderate depression in people living with mild to moderate dementia, unless they are indicated for a pre-existing severe mental health problem.

Sleep problems

1.7.13 Do not offer melatonin to manage insomnia in people living with Alzheimer's disease.
1.7.14 For people living with dementia who have sleep problems, consider a personalised multicomponent sleep management approach that includes sleep hygiene education, exposure to daylight, exercise and personalised activities.

Appendix 7g: New pharmaceutical care plan (replaces Appendix 6f)

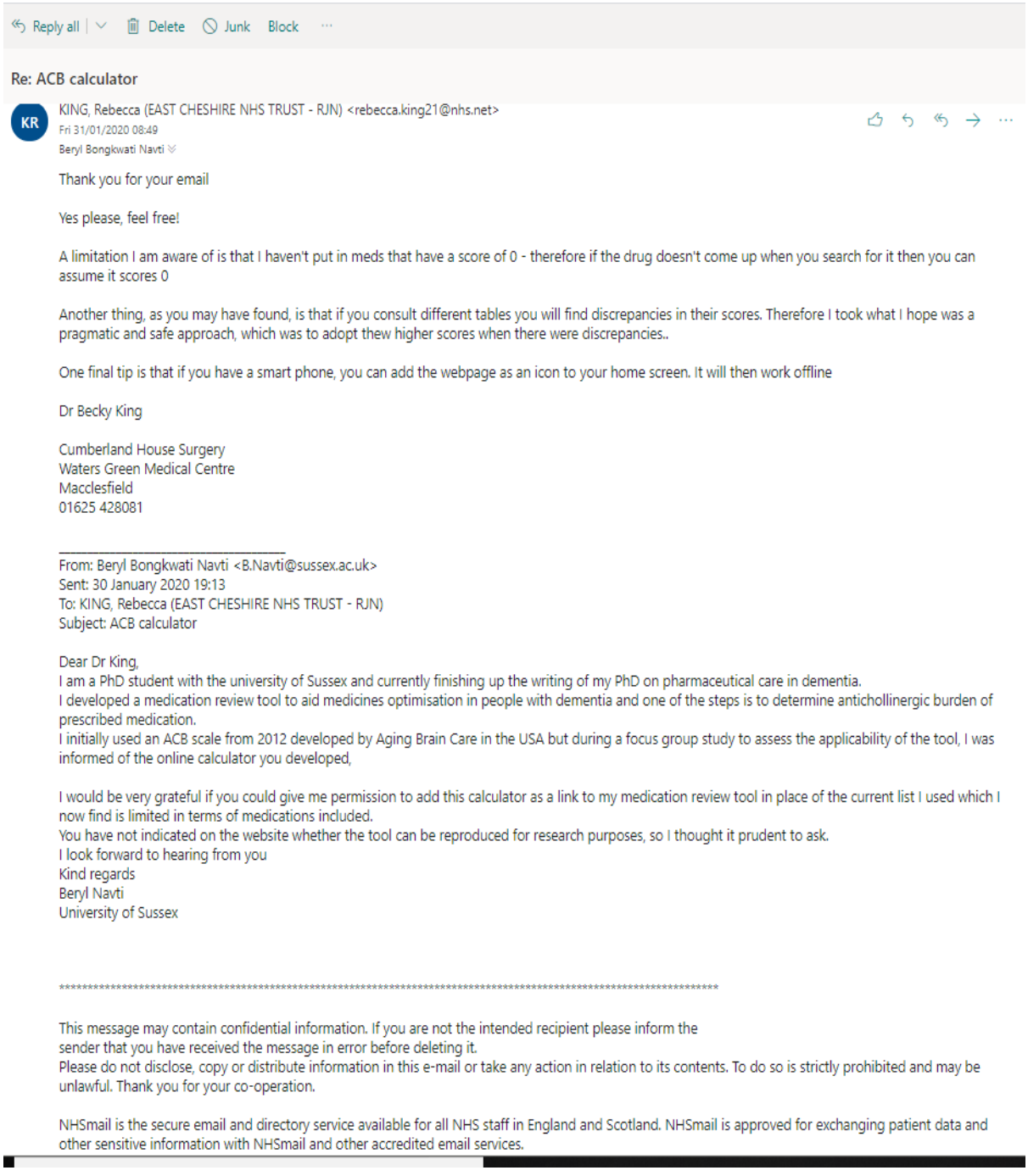
Care Home Information	Name of Care Home:		Care Home Code (For research purposes):
	Address:		
	Telephone:	Manager:	Manager's email:
	Type of Care Home (Circle appropriate category): (a) Residential b) Nursing		
	No. of residents:	No. of dementia patients (diagnosed):	No. of dementia patients (staff report, no official diagnosis):

Patient Basic Details	Age:	Date of Birth:	Gender: M/F	Code:
	Weight:	Height:	BMI:	Ethnicity:
	Date of admission into home:	Religion	GP:	GP address:
	Dementia subtype:			
	Mobility:			
	Please state any other diseases patient has:			
	History of Falls	(a) In the past twelve months: Y/N	(b) If Yes, how many?	

Evidence of pre-admission assessments	List cognitive tests conducted:	
	Risk assessments:	
	Physical health checks:	
	Allergies	Medication:
		Adverse reactions to drugs in the past:
		Other alerts/Health aids/special needs (sight, hearing, literacy, spiritual)

Current medication (include non-prescription, herbal medicines and vitamins)	Drug name	Date started	Indication	Dose regimen (dose, frequency, route, duration)	Last taken	Outcome (effectiveness, response)
Pharmacist pharmaceutical care plan and recommendations						

Appendix 7h: Permission to add online Anticholinergic Burden Scale link to revised DEMENTIAs toolkit



Reply all | Delete | Junk | Block | ...

Re: ACB calculator

KR

KING, Rebecca (EAST CHESHIRE NHS TRUST - RJN) <rebecca.king21@nhs.net>
Fri 31/01/2020 08:49
Beryl Bongkwati Navti

Thank you for your email

Yes please, feel free!

A limitation I am aware of is that I haven't put in meds that have a score of 0 - therefore if the drug doesn't come up when you search for it then you can assume it scores 0

Another thing, as you may have found, is that if you consult different tables you will find discrepancies in their scores. Therefore I took what I hope was a pragmatic and safe approach, which was to adopt thew higher scores when there were discrepancies..

One final tip is that if you have a smart phone, you can add the webpage as an icon to your home screen. It will then work offline

Dr Becky King

Cumberland House Surgery
Waters Green Medical Centre
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01625 428081

_____
From: Beryl Bongkwati Navti <B.Navti@sussex.ac.uk>
Sent: 30 January 2020 19:13
To: KING, Rebecca (EAST CHESHIRE NHS TRUST - RJN)
Subject: ACB calculator

Dear Dr King,
I am a PhD student with the university of Sussex and currently finishing up the writing of my PhD on pharmaceutical care in dementia.
I developed a medication review tool to aid medicines optimisation in people with dementia and one of the steps is to determine anticholinergic burden of prescribed medication.
I initially used an ACB scale from 2012 developed by Aging Brain Care in the USA but during a focus group study to assess the applicability of the tool, I was informed of the online calculator you developed,

I would be very grateful if you could give me permission to add this calculator as a link to my medication review tool in place of the current list I used which I now find is limited in terms of medications included.
You have not indicated on the website whether the tool can be reproduced for research purposes, so I thought it prudent to ask.
I look forward to hearing from you
Kind regards
Beryl Navti
University of Sussex

****

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sender that you have received the message in error before deleting it.
Please do not disclose, copy or distribute information in this e-mail or take any action in relation to its contents. To do so is strictly prohibited and may be unlawful. Thank you for your co-operation.

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Appendix 7i: COnsolidated criteria for REporting Qualitative research check list COREQ-pharmacists' focus group study

Domain 1: Research team and reflexivity

1. Who conducted the interviews or the focus group?

The focus group was moderated by the researcher (BN)

2. What were the researcher's credentials?

The researcher (BN) is a qualified pharmacist with many years' experience in the community pharmacy sector.

BN has experience working with people living with dementia in care homes

3. What was their occupation at the time of the study?

BN is an advanced mental health pharmacist and part time PhD researcher and BA was a professor of pharmacy education and director of pharmacy at the University of Sussex.

4. Was the researcher male or female?

Female

5. What experience or training did the researcher have?

BN is an advanced mental health pharmacist experienced in dementia care and completed a module at the Brighton and Sussex Medical School on research methods. BA (research supervisor) has conducted numerous qualitative research projects in her capacity as pharmacy educator and academic supervisor.

6. Was a relationship established prior to study commencement?

BN belonged in a pharmacist collaboration forum with two participants. Full informed consent was obtained. BN moderated the focus group discussions and formally introduced herself and the topic before the discussions started explaining her and the aim of the focus group.

7. What did the participants know about the researcher?

The participants knew that BN was a specialist pharmacist, and a postgraduate student at the University of Sussex, and that BA was her academic supervisor.

8. What characteristics were reported about the interviewer/facilitator?

BN reported that she was working as a pharmacist and a postgraduate student at the University of Sussex. The group was informed that the study was supervised by BA the academic supervisor who could be contacted for further information on the study. This information was included in the participant information sheet provided to participants prior to them consenting to take part in the study.

Domain 2: Study design

9. What methodological was stated to underpin the study?

A focus group qualitative approach was used

Data were analysed using a thematic analysis approach for sorting, categorisation and interpretation of recorded interviews.

10. How were participants selected?

Pharmacists working in the community pharmacy, care home or mental health sector were selected

11. How were participants approached?

Participants were invited from NHS England Pharmacy Integration Programme, through the "Future NHS Collaboration Platform" (https://future.nhs.uk/connect.ti/system/login?nextURL=%2Fconnect%2Eti%2FPharmacyIntegration%2Fgrouphome), where the researcher is a member

12. How many participants were in the study?

There were 7

13. How many people refused to participate or dropped out?

None

14. Where was the data collected?

A conference room was booked in a hotel within easy reach of all participants

15. Was anyone else present besides the participants and researchers? *No*

16. What are the important characteristics of the sample?

Participants worked in care home environments or hospital settings where they regularly delivered or witnessed care to people living with dementia

17. Were questions, prompts, guides provided by the authors? Was it pilot tested?

The focus group discussion was directed by questions and prompts from the researcher, guided by the views of the participants on the toolkit being reviewed. Toolkit was not piloted but it was reviewed by the academic supervisor

18. Were repeat interviews carried out? *No*

19. Did the research use audio or visual recording to collect the data?

An audio recorder was used to record the interviews. Data were transcribed verbatim by a third-party translation service

20. Were field notes made during and/or after the interview?

Notes were made about amendments participants wanted to see on the toolkit being reviewed

21. What was the duration of the interviews?

The focus group study took approximately one hour to complete

22. Was data saturation discussed?

Data saturation was reached in the study when participants had reviewed the toolkit and had no more comments to make about it.

23. Were transcripts returned to participants for comment and/or correction?

Transcripts were not returned to participants, but themes were discussed between the researcher and research supervisor

A note was taken of all participants who wanted to be sent the report once the study was completed.

Domain 3: Analysis and findings

24. How many data coders coded the data?

Two: The academic supervisor independently reviewed and coded the scripts and the researcher (BN) also did, then both met for comparison of findings.

Disagreements on the interpretation and analysis of the data were then discussed between BN and BA until consensus was achieved. BN rearranged data according to identified themes and discussed with BA before mapping and interpretation.

25. Did authors provide a description of the coding tree? *No*.

26. Were themes identified in advance or derived from the data?

Themes were derived from the data.

27. What software, if applicable, was used to manage the data? *No*

28. Did participants provide feedback on the findings? *No*

29. Were participant quotations presented to illustrate the themes/findings? Was each quotation identified?

Extracts from the transcripts were quoted in the results section verbatim from the recordings obtained during the focus group discussions

30.Was there consistency between the data presented and the findings?

Yes, there was consistency between the data presented and the findings.

31. Were major themes clearly presented in the findings?

Three major themes were elicited from the data and presented in the results of the study in named sub-sections.

32. Is there a description of diverse cases or discussion of minor themes?

Yes, diverse cases have been discussed and differences between levels of practice between participants within the same locality and between the two localities studied have been discussed in the findings.