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DEVELOPMENT OF AN INTERVENTION TO IMPROVE THE MANAGEMENT OF BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA IN GENERAL PRACTICE IN IRELAND

Volume 1 of 2

A thesis presented by

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for the degree of

Doctor of Philosophy

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List of Abbreviations

AP	Antipsychotic
APEASE	Affordability, Practicability, Effectiveness, Acceptability, Side effects, Equity
BCT(s)	Behaviour Change Techniques
BCW	Behaviour Change Wheel
BPSD	Behavioural and Psychological Symptoms of Dementia
CERQual	Confidence in the Evidence from Reviews of Qualitative Research
COM-B	Capability Opportunity Motivation and Behaviour
CPD	Continuous Professional Development
ENTREQ	Enhancing transparency in reporting the synthesis of qualitative research
FDA	Food and Drug Administration
FEMPI	Financial Emergency Measures in the Public Interest
GMS	General Medical Scheme
GP	General Practitioner
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
ICGP	Irish College of General Practitioners
IPE	Interprofessional Education
IPCRN	Irish Primary Care Research Network
MRC	Medical Research Council
PCP(s)	Primary Care Physician(s)
PCT(s)	Primary Care Team(s)
PREPARED	Primary care Education, Pathways and Research in Dementia
PRISMA(-P)	Preferred Reporting Items for Systematic review and Meta-Analysis (Protocols)
QOF	Quality and Outcomes Framework
RCT	Randomised Controlled Trial
SSRIs	Selective Serotonin Re-uptake Inhibitors
STOPPFrail	Screening Tool of Older Persons Prescriptions in Frail adults
TIDieR	Template for Intervention Description and Replication
TDF	Theoretical Domains Framework

Declaration

I declare that this thesis has not been submitted for another degree at this or any other university. I declare that this thesis is entirely my own work. The work, upon which this thesis is based, was carried out in collaboration with a team of researchers and supervisors who are duly acknowledged in the text of the thesis. The library may lend or copy this thesis upon request.

_____ _____

Signed Date

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Thesis Abstract

Background

General practitioners (GPs) play a pivotal and increasing role in the care of people with dementia. However, GPs are challenged by the complexities of dementia care. A triangulated educational needs analysis conducted by the PREPARED project identified that GPs find the management of behavioural and psychological symptoms of dementia (BPSD) a particularly challenging aspect of dementia care. BPSD encompasses a wide range of non-cognitive symptoms such as anxiety and hallucinations that affect people with dementia. Although BPSD has been identified as a challenging area for GPs, an area in which they lack confidence, we do not have a good understanding of *why* this is a challenging area for GPs or the root causes of their lack of confidence. Furthermore, evidence suggests that current management of BPSD is sub-optimal. In BPSD non-pharmacological strategies are recommended first-line but uptake of these strategies is low. Despite their adverse effects, potentially harmful pharmacological treatments, such as antipsychotics, are frequently employed. Interventions are needed to improve the management of BPSD. It is apposite that these interventions should target GPs. However, interventions to date to improve the management of BPSD have either not targeted GPs or not effectively involved GPs in intervention development, a notable gap in the literature.

Aim

To enhance our understanding of the management of BPSD in general practice with a view to informing a theoretically-based, behaviour change intervention to improve the management of BPSD.

Methods

This was a mixed methods study underpinned by the UK Medical Research Council (MRC) guidance on the development of complex interventions in health care. Existing evidence on GPs' knowledge of, attitudes towards and experiences with BPSD was systematically reviewed using a mixed methods approach and synthesised using meta-ethnography. Findings of this review were supplemented with new evidence from three studies. A descriptive interpretive qualitative study which explored GPs experiences of managing BPSD. The data collected from 16 semi-structured interviews with a purposively selected sample of GPs were then thematically analysed. The second study was a cross-sectional descriptive study which assessed GPs' knowledge of and attitudes towards pain in dementia, a key trigger for BPSD. In this study, a postal questionnaire was sent to a census sample of all GPs in Cork. The results were statistically analysed to explore associations between demographic data and responses. To further investigate the findings of the qualitative study a descriptive cross-sectional study was conducted that aimed to explore the knowledge and attitudes of GPs to the prescribing of antipsychotics in people with dementia. The study used an anonymous postal questionnaires that was sent to a census sample of all GPs based in Cork and Kerry. To develop the intervention, results from the systematic review, the qualitative and the two cross-sectional studies were integrated, using the behavioural change theoretical approach outlined in the Behaviour Change Wheel (BCW). In addition, a modified eDelphi study was conducted with multidisciplinary experts on antipsychotic prescribing in dementia. The eDelphi study helped to achieve consensus on the clinical components of the intervention.

Findings

The over-arching finding from the systematic review was that a lack of practical, implementable non-pharmacological treatment strategies created a therapeutic void for GPs, which led to over-reliance on family caregivers and on psychotropic medications. In the qualitative study some GPs described the challenges of managing BPSD as insurmountable and many struggled at an ethical level with the decision to prescribe potentially harmful psychotropic medication but felt they had little else to offer. Key challenges identified by GPs were; stretched resources, unrealistic expectations and a lack of implementable clinical guidelines. The cross-sectional descriptive study of GPs' knowledge of and attitudes towards the management of pain identified aspects of GPs' management of pain in dementia that could be improved upon and highlighted the importance of good relationships between GP and nursing home staff when managing dementia. The descriptive cross-sectional study of GPs' attitudes towards antipsychotic prescribing in dementia found that the majority of GPs recommended non-pharmacological strategies first line when managing BPSD. The GPs reported that the main influencers of prescribing antipsychotics in BPSD were nursing staff and family. Of note the majority of respondents did not routinely monitor antipsychotic prescribing in people with dementia

Using the approach outlined in the Behaviour Change Wheel the findings of these four studies were used to select an aspect of GPs' behaviour in the management of BPSD to target with an intervention: *'GPs to systematically monitor their prescribing of antipsychotic medication to people with dementia in nursing home settings'.* To address this behaviour, a three-component intervention was developed, consisting of: an interprofessional educational

session with GPs and nursing home staff; a repeat prescribing monitoring tool and the facilitation of a self-audit.

Conclusion

The research presented in this thesis adds depth to existing literature and advances our knowledge of the management of BPSD in general practice. Prior to this research it was known that GPs found BPSD challenging but the reasons for why GPs found BPSD to be challenging had not been explored. This research offers new insights into GPs' perspectives on the management of BPSD. This new insight helps to explain apparent discrepancies between best practice recommendations in BPSD and real-life clinical practice. This deeper understanding of GPs' management of BPSD informed the development of an intervention to improve an aspect of BPSD management that was identified as being sub-optimal. The intervention developed focuses on GP self-monitoring of their prescribing of antipsychotic medication to people with BPSD in nursing home settings. This intervention has the potential to improve GPs' management of BPSD.

CHAPTER 1: THESIS OVERVIEW

1.1 THESIS AIM AND OBJECTIVES

The aim of this research is to develop an intervention to improve the management of BPSD in Irish general practice. Broadly, this involves gaining insights into GP's current practice in BPSD and integrating these insights with behavioural theory to develop an evidence-based, theoretically-informed, behaviour change intervention to support and improve the management of BPSD in general practice.

To achieve this aim, the objectives of this research were;

(i) To systematically review and synthesise the qualitative and quantitative evidence on GPs' knowledge of, attitudes towards and experiences with the management of BPSD.

(ii) To explore the challenges GPs experience when managing BPSD

(iii) To integrate the evidence gained from objectives (i) and (ii) with behavioural theory in order to inform the development of an intervention targeted at GPs.

1.2 THESIS OUTLINE

This thesis contains 9 chapters.

In *chapter 2,* I will discuss dementia in terms of its prevalence and impact. I will explore the research context of general practice. I will examine how general practice is modelled internationally and then describe the structure of general practice in Ireland. I will outline

how the current model of general practice impacts on dementia care. Finally, I will discuss the wider research project that I have worked on for the past three years the PREPARED – (*Primary Care Education, Pathways and Research of Dementia)* project, how this PhD thesis fits within the context of PREPARED and why the focus of this PhD became the management of BPSD in general practice.

Chapter 3 provides an overview of the literature on BPSD that has informed my work. I will discuss BPSD in terms of its prevalence, impact, evidence base for pharmacological and non-pharmacological treatments. I will review interventions developed to date that have aimed to improve the management of BPSD in the community and in nursing home settings with a particular focus on the role played by GPs in these interventions.

In *chapter 4,* I describe the philosophical approach underpinning this research and the methodological framework employed to address the thesis' objectives.

Chapters 5, 6, 7, 8, 9, 1O represent phases of the intervention design process outlined in the MRC framework. In chapter 5, the existing evidence on GPs' knowledge of, attitudes towards and experiences with the management of BPSD is systematically reviewed and synthesised. This chapter is divided into two parts; part one is the published protocol for this systematic review and part two is the published systematic review. Chapter 6 is a qualitative study that explored the challenges GPs experience when managing BPSD. Chapter 7 describes a cross-sectional study that examined GPs' knowledge of and attitudes towards the management of pain in dementia. Chapter 8 describes a cross-sectional study that assesses GPs' knowledge of and attitudes towards the prescribing of antipsychotic medication in BPSD. Chapter 9 describes an eDelphi consensus process used to decide

aspects of the clinical content of the intervention. In chapter 10, the process of developing a theory-based intervention for GPs managing BPSD is described.

Chapter 11 provides an overall discussion of the research, including the main findings, limitations and implications for policy and practice.

1.3 AUTHOR'S CONTRIBUTION TO INCLUDED STUDIES

I was the lead author of the research studies outlined in Chapters 5 to 10. This involved developing the protocol for each study, literature searching, collecting, managing and analysing the data and drafting each manuscript.

With regards to the specific studies included as part of this thesis (chapters 5 -10). Professor Colin Bradley, Professor Alice Coffey, Professor John Browne and Dr Tony Foley provided advice on the design, conduct and write-up of the systematic review protocol described in part one of Chapter 5. They also participated in the abstract screening, data synthesis and provided editorial feedback for Chapter 5. Professor Colin Bradley, Professor John Browne and Dr Tony Foley provided advice on the design, conduct and write-up of the qualitative study described in chapter 6. Dr Tony Foley also contributed to the data analysis of the qualitative study. Dr Tony Foley and Professor John Browne provided advice on the design, conduct and write-up of the cross-sectional descriptive study described in chapter 7. Dr Tony Foley provided advice on the design, conduct and write up of the cross-sectional descriptive study described in Chapter 8 and the eDelphi study described in Chapter 9. Professor Colin Bradley, Professor John Browne and Dr Tony Foley provided advice on the

design, conduct and write-up of the intervention development study described in chapter 10.

The following people provided additional expertise.

1. Mr Kieran Walsh, PhD Candidate, School of Pharmacy, UCC

   In the systematic review (chapter 5) Kieran provided feedback on the data analysis and synthesis, assisted with the completion of the CERQual assessment and provided editorial comments on the manuscript drafts.

2. Dr Sheena Mc Hugh, Lecturer, School of Public Health, UCC

   In the qualitative study (chapter 6) Sheena provided methodological advice, coded a subset of the interviews and provided editorial comments on the manuscript drafts.

3. Dr Maura Linehan, GP, Kinsale Medical Practice, Cork

   In the cross-sectional descriptive study (chapter 7) Maura contributed to the overall study concept. She assisted with the data collection and provided editorial comments on the manuscript drafts.

4. Dr Jenny Mc Sharry, Lecturer, School of Psychology, NUIG, Galway

   Jenny has a particular expertise in intervention design and, thus, provided methodological advice for chapter 8. She also participated in the expert panel outlined in chapter 8 and provided editorial feedback on the chapter.

5. Dr Naoihse Guerin, Medical Intern, Cork Teaching Hospitals

   Naoihse contributed to the eDelphi consensus study (outlined in Chapter 8). Naoihse assisted in the data collection process by sending out the Delphi rounds to participants and she assisted in collating the results.

1.4 AUTHOR'S PROFESSIONAL ROLE

While conducting this research I also worked clinically as a GP. I worked 1.5 days a week as a GP for the first year of the PhD from November 2015- November 2016. In the second year of my PhD, November 2016 – November 2017 I worked as a GP for 1 day per week. For the first six months of the final year of my PhD I worked 0.5 days per week as a GP. For the final six months of my PhD I temporarily suspended all clinical work to allow for completion of my PhD. During these years I also worked on the wider research project – PREPARED. As part as my role in the PREPARED project I worked on the following projects:

(i) The development of the online dementia resource for healthcare professionals – www.dementiapathways.ie. I was responsible for the design, content, implementation and evaluation of this resource.

(ii) In collaboration with Dr Tony Foley, P.I of the PREPARED project, I developed BPSD and other dementia workshops for GPs that were rolled out nationally through peer-led, practice based educational workshops. Over 700 GPs have participated in these workshops. I delivered some of these workshops and I was also involved in training the GP facilitators who delivered these workshops. Finally, I contributed to the evaluation of these workshops.

(iii) I was responsible for the development, delivery and evaluation of a new 12 week online continuous professional development (CPD) dementia course for GPs.

(iv) I contributed the development of a 10 unit e-learning dementia programme for GPs in conjunction with the Irish College of General Practitioners (ICGP). I led on the development of the content for the unit on BPSD.

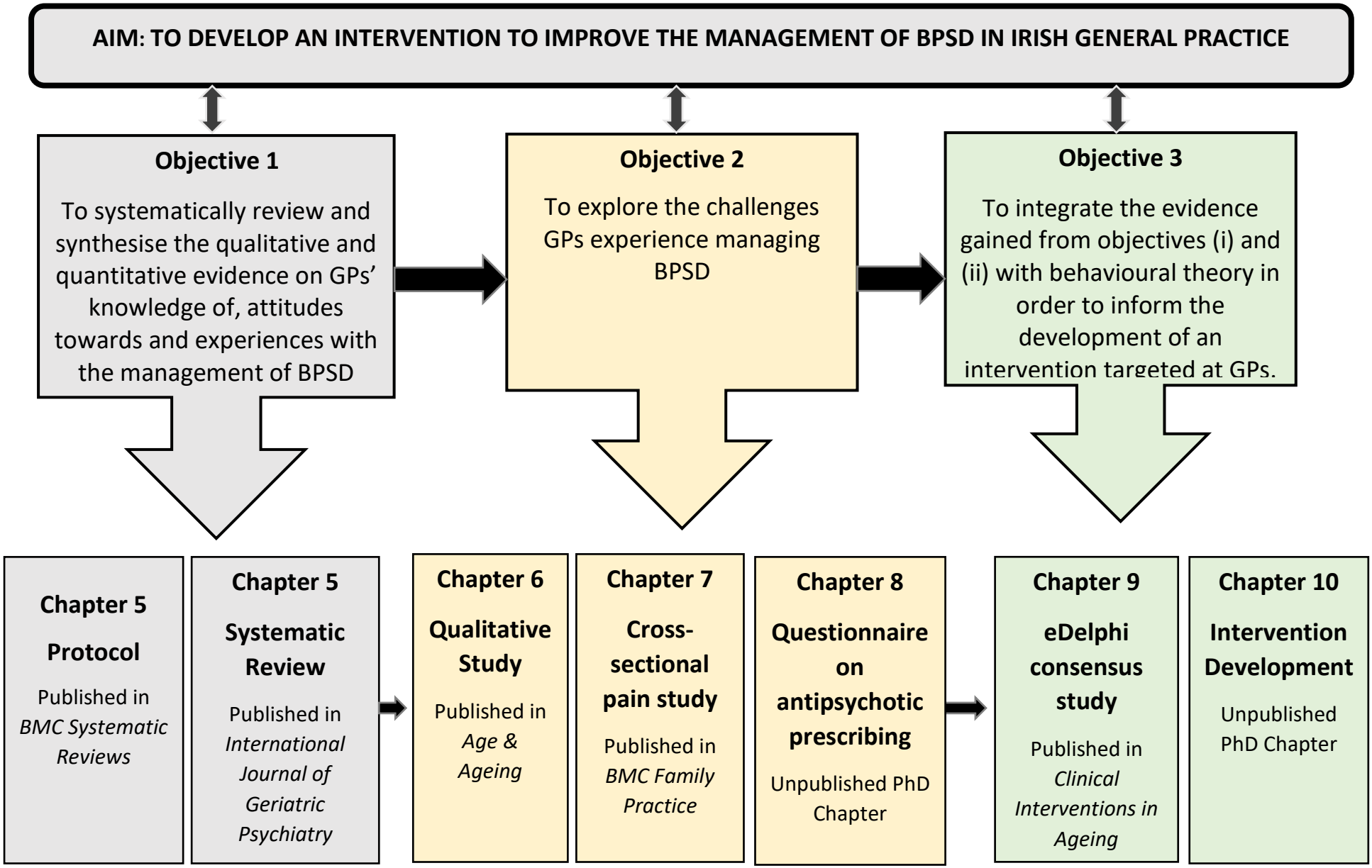
(v) I helped to design an interprofessional dementia workshop for primary care teams and contributed to the evaluation of the pilot phase of these workshops.

(vi) In association with the ICGP and the Irish Primary Care Research Network (iPCRN) I contributed to the development of dementia audit tools for use by GPs.

1.5 AIM AND OBJECTIVES MAPPED TO THESIS CHAPTERS

The following schematic (Figure 1) gives an overview of the thesis aim and objectives and how these objectives are mapped to the relevant chapters.

Figure 1. Thesis aims and objectives mapped to relevant chapters



CHAPTER 2: THE RESEARCH CONTEXT

This research is focused on the management of dementia in primary care with a particular focus on the role of GPs. There are multiple health care professionals involved in the care of a person with dementia. In the community setting public health nurses, occupational therapists, speech and language therapists, physiotherapists and other members of the primary care team have significant roles to play in the care of a person with dementia.[1] In Ireland the availability, and the existence, of these primary care teams can vary significantly from one primary care area to the next. [2] In the nursing home setting, nurses [3] and health care assistants [4] play a central role in the care of people with dementia. While all these healthcare professionals play important roles at different times in the progression of the illness, the GP is the constant health care professional throughout the journey of people with dementia and their families [5-7] In this research I focus on the perspective and the role of the GP in the care of a person with dementia and, in particular, in the management of behavioural and psychological symptoms.

In this chapter I will describe briefly the context for the research that follows. The chapter is divided into five main sections. In the first section, 2.1, I will give an overview of dementia, its prevalence and impact. I will discuss the development of national dementia strategies internationally with a particular focus on the Irish national dementia strategy. In section 2.2 I will describe international models of general practice. In section 2.3 I will focus on the organisational and economic structure of general practice In Ireland. In section 2.4. I will examine the impact of the structure and function of general practice on dementia care. In the final section, 2.5, I will explain the wider research project on which I have worked for the

past three years (the PREPARED - *Primary Care Education, Pathways and Research of Dementia* project) and how this PhD thesis fits within the context of PREPARED.

2.1 DEMENTIA

Dementia is a disorder that is characterised by a decline in cognition involving one or more cognitive domains (learning and memory, language, executive function, complex attention, perceptual-motor, social cognition). The deficits must represent a decline from previous level of function and be severe enough to interfere with daily function and independence. Dementia was renamed 'major neurocognitive disorder' in the new Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), published in 2013. [8] However, the term dementia is still used as an acceptable alternative and will be used throughout this thesis. There are a number of sub-types of dementia; Alzheimer's disease, vascular dementia, mixed dementia types and Lewy body dementia. The listed sub-types account for approximately 90% of all dementias. [9]

2.1.1 Prevalence of dementia

As the world's population ages, the number of people living with dementia grows. [10] It is estimated that there are currently 47 million people living with dementia worldwide and this figure is predicted to triple by 2050. [11] However, age is not the only risk factor for dementia. There are other modifiable risk factors for dementia such as diabetes and hypertension. [12] Estimates suggest that the combinations of these 'modifiable' risk factors means that up to 30% of dementia cases may be 'preventable'. [12] There is recent evidence that the incidence of dementia is falling across successive generations in higher-income countries. [13-15] Therefore, in higher income countries the estimates of future dementia prevalence may not be at the level predicted from previous projections. The Cognitive

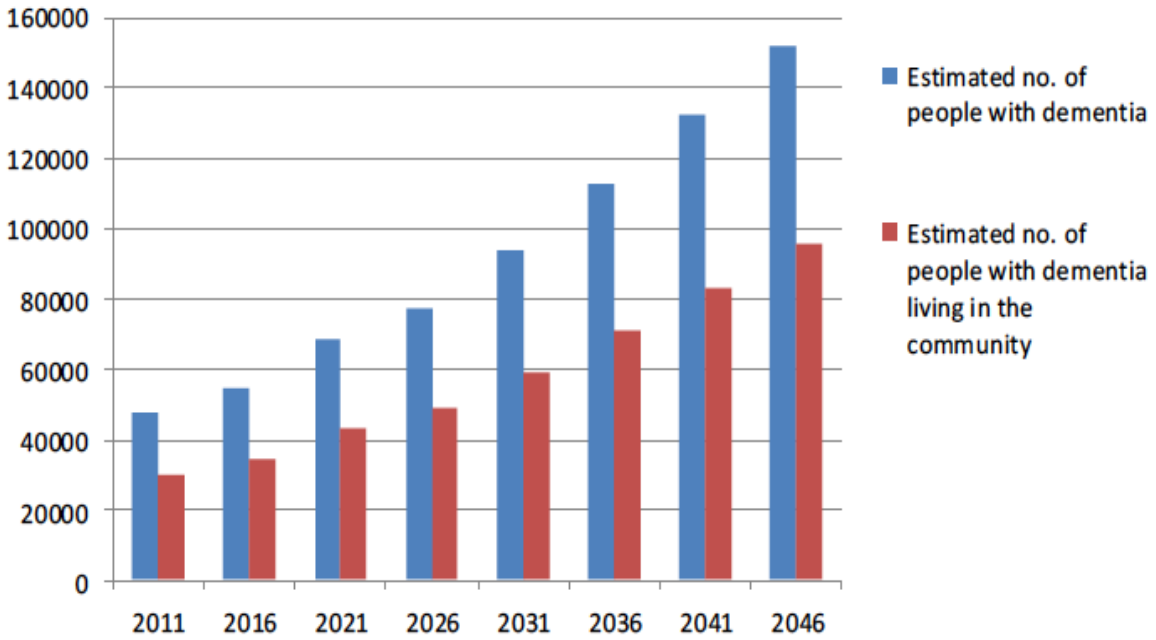
Functional Ageing Study was conducted over an interval of two decades at multiple sites in the UK and reported a 20% drop in dementia incidence. [15] That study found a far smaller increase than would have been expected from extrapolation of earlier estimates of dementia prevalence. The authors concluded that a reduction in age-specific incidence of dementia means that the numbers of people estimated to develop dementia in any one year in the UK has remained relatively stable. [15] Whereas, in lower income countries evidence suggests that previous estimates may have underestimated the burden of dementia. [16]

There are a number of potential explanations for this reduction in age-specific incidence of dementia in higher-income countries including improvements in the management of modifiable risk factors and improvements in "protective" factors such as education. Education has been transformed in higher-income countries over the past number of decades with resulting improvements in cognition.[13] The impact of improvements in vascular risk reduction on the incidence of dementia is complex. The IMPACT-BAM study conducted in the UK identified that, although age-specific dementia is declining in the UK, the actual number of people with dementia in the UK is likely to increase by 57% from 2016 to 2040. [17] The authors concluded that the projected increases in the burden of dementia, despite the significant downward trend in age specific incidence of dementia, is largely a consequence of improvements in life expectancy. So vascular risk reduction is driving down age-specific dementia incidence but is also leading to increased life expectancy which results in larger numbers of people who are susceptible to dementia. Therefore, although the evidence suggests that the incidence of dementia is declining, the magnitude of the decline is less certain. [17]

It is unclear how these different trends will impact on dementia prevalence in Ireland. Ireland is predicted to have the largest growth in the older population of all European countries in the coming decades. [18] The most recent figures available estimate that, in 2016, there were 55,000 people living with dementia in Ireland and this figure was predicted to rise to 147,000 by 2041 [19] (see Figure 2). These estimates were developed by applying dementia prevalence rates to Irish census data. Of the 55,000 people living with dementia in Ireland it is estimated that 63% live at home in the community, 34% live in nursing homes while the remaining 3% of people with dementia reside in the acute hospital or psychiatric setting.[20] The majority of people with dementia live either at home or in a nursing home, therefore, their first point of medical contact is their GP.

Figure 2. Estimates of expected numbers of people with dementia in Ireland 2011 – 2046

[21]



2.1.2 Personal and societal impact of dementia

Dementia is an incurable and largely untreatable disease. [10] However, many of the manifestations of dementia are now known to be manageable and although the underlying illness is not curable, the course of the disease might be modifiable with good dementia care. [10] For many decades dementia has been associated with negative stereotyping and stigma. [22] Public awareness campaigns, such as the *Understand Together* campaign [23] which was recently run in Ireland, improves societal and individual understanding of dementia. [24] This increased public awareness is welcomed but dementia remains a devastating diagnosis for many people. A diagnosis that is filled with uncertainty and isolation.[25] The majority of people with dementia live at home and are cared for by their families. The burden of caring for a person with dementia can be significant for a family. Caring for a person with dementia can impact on a carer's physical and psychological health.[26] Quantifying the personal and societal impact of dementia, or any illness, is challenging. One approach to measuring the personal impact of dementia is to use the Global Burden of Disease (GBD) estimates which expresses the impact of the disease in terms of associated disability and mortality. [5] A key metric used in the GBD estimates is the Disability Adjusted Life Year (DALY). This metric is a composite measure of disease burden calculated as the combined sum of Years Lived with Disability (YLD) and Years of Life Lost (YLL). The World Health Organisation (WHO) engaged in wide international consensus when developing the WHO GBD Report. In this report disability from dementia, as estimated by the DALY metric, was accorded a higher disability weight than that for any other condition, with the exception of severe developmental disorders. [5]

2.1.3 Economic impact of dementia

The annual global cost of dementia is estimated to be US$818 billion. [5] When compared to other illnesses dementia has a relatively high cost burden. A UK study conducted in 2012 found the health and social care services cost burden of dementia (£10.9 billion) to be significantly higher than the cost burden of cancer (£4.5 billion), stroke (£2.7 billion) or heart disease (£2.5 billion).[27] Around 85% of the costs associated with dementia are related to family and social care rather than medical care. [10] In Ireland, in 2010, the total annual cost of dementia was estimated to be €1.69 billion, with 47% attributable to informal care and 43% attributable to residential care. [20]

In summary, dementia is a subject of increasing concern internationally as a result of the increasing prevalence rates and its significant impact on the healthcare system, the people living with dementia and their families.

2.1.4 National Dementia Strategies

In response to the rising prevalence of dementia and its significant societal and economic impact, many countries have developed national dementia strategies. [28-30] These national dementia strategies broadly reflect the recommendations from the Kyoto Declaration which was published in 2004 by members of the Alzheimer's Disease International. [31] The Kyoto Declaration was a consensus document that made 10 key recommendations to combat dementia. The recommendations have a strong focus on the provision of care in the community and highlights the important role of primary care. In 2006 the Paris Declaration was published by members of Alzheimer's Europe. [32] The Paris Declaration built on the Kyoto Declaration and called upon the World Health Organisation and the European Union to recognise dementia as a major public health challenge and to promote the development

and implementation of national programmes to address dementia. Following these declarations national dementia strategies have been developed worldwide.

2.1.4.1 The Irish National Dementia Strategy

Ireland's first National Dementia Strategy was published in December 2014. [29] The Irish National Dementia Strategy identified six key priority areas for dementia care in Ireland:

(i) Better awareness and understanding

(ii) Timely diagnosis and intervention

(iii) Integrated services and supports for people with dementia and their carers

(iv) Training and education

(v) Research and information systems

(vi) Leadership

Like many national dementia strategies, the Irish National Dementia Strategy highlights the central role of GPs in dementia care. The strategy particularly emphasises the central role of the GP in the key priority areas of timely diagnosis and integrated services and supports. Other areas of dementia care where GPs play an important role are also highlighted, namely palliative care and the management of behavioural and psychological symptoms of dementia. The Irish National Dementia Strategy acknowledges the pivotal role GPs play in the implementation of the key elements of the strategy. However, the strategy fails to acknowledge the current resource constraints in Irish general practice and fails to consider how these constraints may restrict a GP's ability to implement the strategy.

2.2 INTERNATIONAL MODELS OF GENERAL PRACTICE

I will now focus on the context of my research area – general practice. I will first discuss the different models of general practice internationally. I will then outline the economic structure and function of general practice in Ireland and how this impacts on the provision of chronic disease management, nursing home care and dementia care.

2.2.1 Healthcare funding and international approaches to allocation of funding to general practice

Internationally healthcare is funded through multiple sources, usually through general tax revenue, statutory health insurance, private health insurance or a combination of these sources. [33] There is considerable variation in the amount of gross domestic product (GDP) that is dedicated to health across different countries. Analysis of the OECD data on health spending from 2016 shows that Ireland spends only 7.8% of its GDP on health, lagging significantly behind countries such as Germany (11.3% of GDP), France (11% of GDP), Canada (10.3% of GDP) and the UK (9.2% of GDP). [33] Within health services the approach to allocating money to general practice varies internationally but typically follows one of the following systems; capitation, payment-for-performance or fees-for-service. Capitation payments are related to the characteristics of the patient population registered in a practice, such as age of the patient, and are not linked to any measure of the quality of care provided. In several countries, including Sweden and New Zealand, the capitation payment system is combined with a 'pay-for-performance' model. [34] This approach attempts to link additional funding to GPs who reach certain targets. For example, in Ireland GPs receive payments for meeting childhood vaccination targets. The third model, the 'fee-for-service' model, is the predominant GP payment system in Australia [34] and the U.S.. This model

allows GPs to be reimbursed for providing a specific service. The capitation system is present to some extent in most countries and is often combined with the fee-for-service model. This combined system is the funding model for general practice in Ireland, Germany and France. The Netherlands recently changed their model of general practice funding to include all three payment models; capitation payments account for ~75% of spending, fees-for-service represent about 15% and additional funding of 10% that is negotiated at individual GP level. [33]

There are pros and cons to each funding model. For example, the capitation model is criticised for its inflexibility and the fact that it does not incentivise GPs to treat time-consuming patients. [35] The 'pay-for performance' model was introduced in England and Northern Ireland through the quality and outcomes framework (QOF). However, the system has been criticised by some as being reductive, acting as a barrier to the provision of patient-focused care. The 'evidence' on which the QOF is based has also been called into question. [36] The pay-for-performance model is highly dependent on the quality indicators that underpin it and generally fails to account for the most significant influence on health outcomes – the social determinants of health. [37] The third model, the fee-for-service model, has also been criticised for being costly, inefficient and for not promoting integrated care. [35] Ultimately, there is no consensus on what approach to funding general practice is best but it is likely to be a combination of several approaches. The funding approach chosen has consequences for the demand for general practice, GPs' workload and the GP's role within the healthcare system.

2.3.2 The role of the GP internationally

The role of the GP varies across countries. In general, GPs are patients' first point of contact in the healthcare system providing 'cradle to the grave' care. In many countries, such as in Ireland, the UK, Australia and Canada, GPs have a gatekeeper role, controlling access to secondary care. [38] In other countries, such as Sweden and Germany, although GPs are often the natural first point of contact within the healthcare system, a GP referral is not required to access secondary care. There are pros and cons to GPs acting as a gatekeeper. [38] The presence of a GP gatekeeper can lead to lower use of health services and can protect against over treatment. However, the gatekeeping role is thought by some to negate the ethos of patient choice and empowerment. [38] It can also increase GPs' workload. In many countries such as Ireland, New Zealand, France and the Netherlands, GPs are self-employed and function much like a small business. [33] However, in other countries, such as Sweden, GPs are salaried government employees. [33] The model of GP care where a GP fulfils these multiple functions of; gatekeeper for the healthcare system, advocate for the patient and owner of a small business, can create tensions for GPs who may struggle to maintain their primary advocacy role for their patient amidst these potentially conflicting roles.

2.3.3 Changes to GP workload

Internationally, the important role of primary care in delivering care to people living in the community with chronic diseases is being increasingly recognised. Modern day general practice in which the GP is a member of a multidisciplinary team and is supported by computerised medical records is aptly placed to deliver chronic disease management. [39] Internationally, there has been a shift away from hospital-led specialist care to community-led generalist care. However, this shift has also created tensions for GPs. Managing chronic

diseases in general practice is complex. [40] It often involves managing people with multiple comorbidities which results in more frequent attendances, [41] longer consultation times and typically requires input from multiple different health care professionals which can create challenges for GPs as the co-ordinators of care.[42] As practice size increases and the number of GPs in full-time practice decreases, GPs can struggle to provide the continuity of care that is the hallmark of general practice and an important component of effective chronic disease management. Furthermore, poor integration of primary and secondary care services can negatively impact on a GP's ability to effectively co-ordinate the care of a person with a chronic disease. Finally, this shift in the care provided in general practice requires a re-direction of resources into primary care if it is to be successful.[39,43]

I will now focus on general practice in Ireland. I will explore the changes that have occurred in general practice in Ireland over the past number of decades and how these changes have impacted upon the function and structure of general practice in Ireland.

2.3 GENERAL PRACTICE IN IRELAND

The changes in general practice workforce and patterns of work that have occurred in Ireland over the past few decades mirror changes that have occurred in general practice internationally. [44] Thirty years ago the typical Irish GP was a single handed practitioner, usually operating from his/her own home and permanently 'on-call'. This traditional model has undergone significant transition over the past 30 years. A study published in 2015 provides a picture of the changing face of general practice in Ireland by comparing data from equivalent national GP surveys conducted at four points in time – 1982, 1992, 2005

and 2015. [45] The 2015 survey found that 97% of GPs in Ireland now work in purpose-built or specially adapted premises. The overwhelming majority (99%) of GPs in Ireland are now part of an out-of-hours co-operative or rota.[45] There has been a substantial decline in the traditional single handed practice (from 63% of GPs working in single handed practices in 1982 to just 18% of GPs in 2015).[45] The vast majority of GP practices (94%) are now computerised. Additionally, the percentage of GPs in full-time practice has fallen – from 97% of GPs in full-time practice in 1992 to 84% in 2015. [45] Despite these changes, satisfaction rates with general practice remain high. [46] However, GPs working in Ireland in 2015 reported higher stress and lower morale than was reported in any previous survey. The proportion of GPs reporting low morale tripled between 2005 and 2015. Similarly, the levels of self-reported stress increased from 12% in 2005 to 58% in 2015. [45] The reasons for the low morale and high stress levels of GPs is multifactorial. The authors of the 2015 survey postulated that it could be a reflection of the low morale of the country over those years due to the economic collapse.[45] However, it is likely that low morale is also related, at least in part, to the organisational and economic structure of general practice in Ireland. General practice in Ireland has transformed over the past thirty years but the economic structure of Irish general practice has not evolved in response to this transformation. I will now outline the economic structure of Irish general practice and the impact of government policies on the organisational structure of general practice.

2.3.1 The economic structure of Irish general practice

Healthcare in Ireland is a mix of private and public provision. The vast majority of GPs in Ireland are self-employed 'independent contractors' of the Irish Health Service Executive (HSE) for those patients eligible for state-funded care through the state-run General Medical

Service (GMS) scheme.[45] In Ireland the main system for allocating money to general practice is predominantly through annual capitation payments. Ireland is unusual internationally in terms of the relatively high proportion of people that pay out-of-pocket charges to attend a GP. [47] These charges are paid in full at the point of contact without any subsidisation, insurance or other rebate. In Ireland 'medical cards', which allow free access to GP care and most medications, are strictly means-tested. [48] If a patient has a medical card then they must register with a specific GP. Only 37% of the Irish population qualify for state-funded GP care in the form of 'medical cards'. Medical cards can also sometimes be granted on medical grounds, such as advancing terminal illness. People who don't qualify for a medical card may qualify for a 'GP visit card' which allows the person to attend their GP without charge but they must pay for all medication costs. In total approximately 43% of the Irish population are covered by either a medical card or a GP visit card.

GPs in Ireland receive a capitation payment for their GMS patients based on the patient's age and gender. [49] For example, for a male GMS patient aged 68 years of age who lives at home in the community, a GP would receive an annual capitation fee of €129.72 per annum regardless of the number of times the patient attended the GP. Whereas, for a male GMS patient aged 70 years of age a GP would receive a substantially higher annual capitation fee of €271.62 per annum. [50] GPs who provide care to nursing home residents under the GMS scheme receive an annual capitation on a scale of €121.29 - €434.15 per patient depending on the age of the patient. [50] Most GPs also provide care for private patients (i.e. the 57% of the population not eligible for state-funded care) on a scale of fees the GPs set themselves. For people that are not eligible for a medical card, the fee for attending a GP in Ireland is typically €50 - €60 per consultation. There is evidence that these costs do deter some people from attending their GP, [51] particularly people in the middle income range. [52] In

contrast to general practice fees, hospital treatment is either highly-subsidised by the government or covered by a patient's private medical insurance, (about 43% of the Irish population has private medical insurance). [48]

2.3.2 The impact of government policy on the organisational structure of general practice in Ireland

Funding of the Irish healthcare system has been historically hospital-centric.[53] Culturally and economically the focus of the health care system has been on the provision of hospital care rather than on the provision of care in the community. While there was a 61% increase in GPs in Ireland between 1982 and 2015 the corresponding increase in public hospital consultants was 153%. [45] The health care focus on hospitals meant that successive governments have not invested in primary care in Ireland to the extent seen in other (similar) countries. In Ireland 4.5% of the overall health budget is expended on general practice, significantly lower than other European countries. [54] I will now outline how government policies have impacted on Irish general practice.

2.3.2.1 The impact of austerity

In response to the economic crisis Ireland faced in 2008 the government introduced a series of austerity measures. One such provision was a piece of legislation called the Financial Emergency Measures in the Public Interest (FEMPI) Act 2009. This FEMPI Act resulted in a series of reductions in the government payments to all public servants including GMS payments to GPs. [55] As a result of the implementation of FEMPI, capitation payments to GPs were reduced by about 30% over a four year period from 2009 to 2013. The economic situation in Ireland has since improved. Cuts to government payments to many public service workers under FEMPI have since been rolled back. However, roll back in cuts to

government payments to GPs has yet to occur. Of note, the capitation fee now paid to GPs attending nursing homes is ~30% less than it would have been before the introduction of FEMPI. Additionally, prior to 2009 all people over the age of 70 were automatically entitled to a medical card. However, in 2009 in a cost saving measure, the government removed this 'automatic' entitlement and since then people over the age of 70 are eligible for a doctor's visit card but they must satisfy a means test to receive a medical card. [56] This measure had a disproportionate effect on nursing home residents.[57] With the loss of this automatic entitlement of patients over 70 years to a medical cards GPs also lost an annual capitation payment of €720 per nursing home resident they attended. As a result of the combined FEMPI cuts and the loss of the 'top-up' capitation payment for providing care to a nursing home resident many GPs report that they can no longer provide care to nursing homes. [58]

2.3.2.2 The GP Contract

A further challenge facing general practice in Ireland is the current GP contract between the HSE and GPs. This contract is now four decades old. In keeping with the type of clinical care delivered by GPs at the time this contract was first developed, the focus of the current contract is on the delivery of acute medical care without any focus on chronic disease management. GPs in Ireland have long advocated for re-negotiation of their contract. In 2015 a new cycle of care was introduced for people with diabetes whereby GPs are now paid a once-off registration fee of €30 per GMS patient with diabetes and enhanced capitation payments of €100 per patient with diabetes for conducting two reviews annually. There has yet to be any evaluation of the impact of the introduction of this 'diabetes cycle of care' on the quality of care provided to people with diabetes. However, recent Irish research that evaluated the primary care led diabetes structured care programme in the Midlands region did show that the programme led to some promising improvements in the

quality of diabetes care provided over time.[59] There are currently no incentivisation schemes for the management of any other chronic disease in adults in Irish general practice but the introduction of the diabetes cycle of care is a promising precedent.

2.3.2.3 Primary Care Teams

In recognition of the need to increase Ireland's healthcare focus on primary care, in 2001 the Department of Health in Ireland launched a report named 'Primary Care - A New Direction'. [60] This report signalled a substantial reform in the approach to health care in Ireland. It acknowledged the central role of primary care in the future development of the Irish health service and proposed an inter-disciplinary team based approach. The members of the team were to include GPs, nurses, physiotherapists, occupational therapists, social workers, home helps and the team would be further supported by a wider network of primary care professionals. However, the implementation of this strategy has been challenging. Ten years after the launch of the governments 'New Direction' plan, a national survey of GPs conducted by the Irish College of General Practitioners (ICGP) found that only 58.4% of responding GPs were part of a Primary Care Team (PCT) and that of these GPs 64.7% felt the PCT was poorly functioning. [2] The 2011 ICGP report identified a number of barriers to GPs engaging in PCT meetings. One such barrier was that GPs may be assigned to several different PCTs, as patients are assigned to teams based on their geographical location rather than on their general practice registration. The report also identified specific sources of frustration for the GP, such as the fact that in most instances residents in private nursing homes are not eligible for PCT care. The ICGP report made a number of recommendations on how GP involvement in PCTs could be improved. One recommendation was that resources be provided to support the implementation of PCTs. Another was that resources needed to move from secondary to primary care in order to

optimise chronic disease management. A subsequent 2016 survey of GPs and primary care professionals identified that adequate resources and GP participation were the most important elements of effective PCTs. [61] The majority of respondents to the 2016 survey reported that little or no progress had been made with the implementation of the 2001 Primary Care Strategy.[61] At the time of writing this thesis no steps have been taken to change the structure of PCTs in Ireland. The limited evidence available suggests that functioning PCTs, that meet regularly to provide an integrated care system, are a rare entity.[62]

2.3.2.4 Sláintecare

The Irish government (at the time of writing, 2018) is committed to rolling out free GP care at the point of contact to the entire population. Sláintecare is the name of the government's plan to provide universal healthcare to all in Ireland.[63] Sláintecare proposes a health reform plan that will be rolled out over the next ten years. The result will be a shift in the emphasis of the Irish health care system out of the hospitals and into the community. Over a five-year period all Irish citizens will be eligible for a Carta Sláinte (health card) that will enable them to access a wide range of health services (including general practice) that will be free at the point of contact. The aim of Sláintecare is to provide *"a universal, single-tier health services where patients are treated on the basis of health need not ability to pay".*[63] The Sláintecare Implementation Strategy was published on the 8th of August 2018 but has been criticised for not providing specific details on how the plan will be implemented and financed. [64]

2.3.2.5 The current manpower crisis in Irish General Practice

Sláintecare represents a new vision for Irish healthcare. However, in order for this vision to become a reality significant investment into general practice is required to increase current capacity. [47] Currently there is an ageing cohort of GPs in Ireland with 14% of practising GPs

now over the age of 65.[45] Over 660 GPs in Ireland (approximately 25% of all GPs in Ireland) are due to retire in next seven years.[65] Rural Irish general practice will be particularly affected. In some rural counties up to 50% of GPs are due to retire in the next seven years.[66] Over 2,500 new GPs are required to meet existing and future demands within the next 7 years. However, Ireland is failing to retain GP graduates, with one in five choosing to immigrate within a year of graduation.[67] In a recent survey of Irish GP graduates conducted over 3 years from 2014 -2017, emigrating GPs reported that the decision to leave Irish general practice was primarily influenced by quality of life and financial considerations.[67] Of the newly qualified GPs who decide to remain in Ireland the majority plan to only work part-time and do not want senior partnership roles. [67] This combination of an ageing cohort of GPs and the high levels of GP graduates emigrating has led to a substantial recruitment crisis in Irish general practice. In 2015 the government introduced 'free' GP care for children under-6 at the point of contact. This led to a 28% increase in GP visits for this patient population.[68] If Sláintecare is implemented, extending free GP visits to the entire Irish population, without the necessary investment in general practice to improve capacity, it is likely that the government's plans for free GP care will result in long waiting times for GP appointments and put further strain on an already over-stretched service.

2.3.2.5 The impact of these policies on dementia care

Between 2015 and 2018 the number of people in Ireland with medical cards fell from 1.75 million to just under 1.6 million but 30% are GP visit cards. [69] The number of people with 'full' medical cards fell from 1.65 million to 1 million over this three year period. The Irish government is increasing the number of GP visit cards, which provide free access to the GP, but significantly reducing the number of 'full' medical cards. It is these "full" medical cards that fund medication costs and provide access to community health services such as public

health nurses and allied health care professionals. The deficits in primary care funding, the GP manpower crisis and the restrictions in access to medical cards impact to varying degrees on the public at large, but for the person with dementia they can have a particularly negative impact. People with dementia and their families need access to multi-disciplinary supports but, as outlined, functioning multi-disciplinary primary care teams are few and far between. Furthermore, even if such a functioning primary care team exists in the area, the person with dementia may not be able to access these supports as they have no automatic entitlement to a medical card. I will now examine in detail the impact of the current model of general practice on dementia care.

2.4 THE IMPACT OF THE CURRENT MODEL OF GENERAL PRACTICE ON DEMENTIA CARE

In dementia care the role of a GP is increasing, partly as a result of the rising prevalence but also as a result of national strategies that aim to move the care of people with dementia out of hospitals and into the community. General practice is the most appropriate place for chronic disease management and dementia is an example of one such chronic disease that is particularly suited to the continuity and holistic care that general practice can offer. However, increasing demand on GP practices in the context of reduced remuneration, limited access to multidisciplinary support and a substantial manpower crisis has meant that many GPs feel they are unable to provide structured chronic disease care, unless adequately resourced to do so. [43] Furthermore, dementia care poses a number of unique challenges for GPs who report finding many aspects of dementia care, such as diagnosis, post-diagnostic

support and the management of behavioural and psychological symptoms of dementia, particularly difficult.

2.4.1 Dementia diagnosis

GPs are, in many ways, uniquely placed to notice some of the early symptoms of dementia such as missed appointments, issues around drug adherence, and changes in personality or mood. Often in general practice it is a family member that presents with concerns rather than the individual with the emerging dementia. However, the variable and insidious onset of dementia can make recognition of the illness problematic in primary care. [70] Furthermore, research has identified a reluctance on the part of GPs to be directly involved in the diagnosis of dementia, with GPs reporting concerns about lack of resources and lack of confidence in making and disclosing a diagnosis of dementia.[71] Other barriers to diagnosing dementia in general practice include lack of support for the patient and caregiver, time constraints, stigma and therapeutic nihilism. [72] However, the complexities of making a timely diagnosis of dementia in general practice need to be understood. The nuanced balancing judgements adopted by GPs when deciding on the timeliness of a dementia diagnosis should not be conflated with a GP's lack of awareness of the importance of making diagnosis. It does not necessarily represent any specific training need, rather it highlights the need for a personalised approach to the diagnosis of dementia. [73]

In Ireland there is no financial incentive for GPs to make a diagnosis of dementia. In England GPs are financially incentivised for making a dementia diagnosis under the QOF programme. The scheme was criticised as being unethical [74] and described as "crossing a line". [75] A recent evaluation of the scheme demonstrated that the incentive scheme appears to have closed the gap between recorded and expected prevalence of dementia in general practice.

[76] The authors concluded that the findings support evidence that financial incentives can motivate improved performance in dementia care in general practice. [76] In line with existing NICE guidance, [77] the Irish national dementia strategy recommends that GPs refer for specialist confirmation of the diagnosis and for subtyping of the dementia. [29] However, GPs in Ireland can experience difficulties accessing secondary care services to investigate or confirm a diagnosis of dementia. Ideally, GPs would be able to refer to a memory clinic for confirmation of the diagnosis and subtyping. However, memory clinics are a variable and inconsistent entity in Ireland. A 2017 review found that there are large areas of the country without any access to a memory clinic. [78] Only two clinics have full access to PET and CSF biomarkers as part of diagnostic work-up.[78] Furthermore, there is variability in terms of the compliment of allied healthcare professionals and services offered in the different memory clinics with no standardised approach. [78,79]

2.4.2 Post diagnostic support

The Irish National Dementia Strategy also highlights the important role GPs play in the provision of post-diagnostic support to people with dementia. However, providing advice on local dementia services and supports is a particularly challenging aspect of dementia care for GPs. [80-83] This can be because of the limited availability of services and supports or because GPs are often unaware of the existences of these services. [72] The GP co-ordinates the care of the person with dementia in the community but can be constrained by the resource limitations of the healthcare system in which they operate. As outlined in section 2.3.2.3 many GPs in Ireland do not function within a primary care team nor do they have access to multidisciplinary support from allied primary healthcare professionals. [2] This can result in difficulties accessing multidisciplinary supports in the community for people with

dementia. Additionally, people with dementia in Ireland are not automatically entitled to a medical card. This can further impede the provision of care as many services, such as access to a Public Health Nurse, are only available to people with medical cards. There can also be significant difficulties accessing community based services such as home help hours. These services are vital as they enable people to live at home for as long as possible, delaying transitions to long term care settings. Recent health planning estimates predict that Ireland's need for home help will continue to increase with an expected increased need from 300,000 home help hours required in 2017 to 2,270,000 in 2022. [84] However, despite the increased need there has not been any substantial investment in home help hours. Indeed many caregivers are finding it increasingly difficult to access any home help. A report from 2016 indicated that fewer funds were being spent on home care than were spent in 2008. [85] With these resource constraints GPs can find providing optimum care to people with dementia and their families to be challenging. Furthermore, it can create a two-tiered system where families that can afford to pay privately for services such as home help receive them but those that cannot afford to pay for them must go without.

2.4.3 BPSD

The management of behavioural and psychological symptoms of dementia (BPSD) is an aspect of dementia care that GPs consistently report they find challenging. [86-90] The assessment and management of behaviours such as aggression, wandering and symptoms such as depression and apathy can be time-intensive and would, ideally, involve support from a multidisciplinary team. The presence of BPSD can be particularly traumatic for families who may then present to their GP in crisis and disarray. [91] The Irish National Dementia Strategy highlighted the importance of appropriate management of BPSD and

emphasised that the current BPSD treatment model that focuses on pharmacological management rather than non-pharmacological management of BPSD needs to be addressed. [29] BPSD can affect a person with dementia at any stage of their illness but is typically associated with moderate to advanced stages of dementia [92] and with residence in a nursing home. [93] I will now examine the role of the GP in nursing home settings in Ireland.

2.4.4 The role of the GP in the provision of nursing home care

In the UK in the 1990's the long-term care of older people moved from hospitals to nursing homes. [94] Consequently, the medical responsibility for these patients moved from hospital specialists to general practitioners. [95] A similar shift occurred in Ireland. One-third of people with dementia in Ireland now live in residential care, [20] which, in Ireland, means residing in a nursing home. In Ireland, nursing home care refers to care homes that provide all the day-to-day care and medical needs of its residents. The nursing homes are staffed by nurses who are on-duty all day and all night. This is really the only kind of care home environment on offer in Ireland. In this thesis, when reference is made to long-term care or nursing homes, this fully-staffed nursing-led nursing home is the model of care being referred to. As is the case in many countries, [95,96] in Ireland GPs can choose to provide care to people residing in long term care settings, in addition to care they provide to their patients in the community. A recent survey of European geriatric medicine societies asked respondents to estimate the proportion of nursing home care delivered by various physician specialities. [97] The study found that in 17 of the 22 countries surveyed, over 70% of the medical care in nursing homes is delivered by GPs. In that study it was estimated that, in Ireland, GPs provide 75% of the medical care to nursing home residents. [97]

In Ireland, nursing homes are comprised of a mixture of state-funded nursing homes and private nursing homes. Based on data obtained from personal correspondence with Nursing Home Ireland, the national representative organisation for the private and voluntary nursing home sector, there are currently 450 nursing homes in Ireland; 130 of these nursing homes are state run and the remaining 320 are private. GPs who attend large, state-run nursing homes may be supported by secondary care colleagues – old age psychiatrists or geriatricians who also provide care to the nursing homes. However, the majority of GPs providing care in nursing homes do not have any formal support from a hospital specialist. The nursing home commitment of a GP in Ireland varies considerably; some GPs have no nursing home commitment, some provide care to just a few nursing home residents and others provide care to large numbers of nursing home residents. There are advantages to a GP caring for a large number of nursing home residents. Research has demonstrated that the likelihood of a GP providing regular, structured visits to a nursing home increases with the number of residents in the care home registered with the GP. [95] However, a potential drawback is the loss of continuity of care when a new resident switches care from their life-long GP to the GP who provides the majority of care in the nursing home. [96] In Ireland the exact proportion of GPs providing care to nursing homes and the extent of their nursing home commitment is unknown.

Nursing homes in Ireland are regulated by HIQA (Health Information and Quality Authority). HIQA was established in 2007 and is responsible for developing standards and guidance, as well as inspecting and reviewing nursing homes. HIQA has improved standards of care being provided to nursing home residents but some would argue it has also placed an enormous administrative burden on nursing homes. [98] Some of this burden has been passed on to GPs. GPs report that minor illnesses that would have previously been managed by the nursing

home staff are now being referred to the GP [58] for fear of breaching a perceived HIQA regulation. [98] Although HIQA regulations do not advise on how these medical issues should be handled, the fear of an adverse report from the regulatory body has changed nursing home policy on the management of minor illness away from the nursing staff and toward the GP. The increased workload of attending nursing homes, in the context of the reduced remuneration to GPs providing this care, has led to a general dissatisfaction of GPs in Ireland providing care to nursing homes,[98] echoing similar dissatisfaction reported by GPs in Australia [99] and the UK [100] and prompting calls by GPs in Ireland that the provision of nursing home care be explicitly dealt with in any new GP contract. [58]

2.5 THE PREPARED PROJECT

The Irish National Dementia Strategy was developed with input from an expert advisory group. One of the key recommendations of the Irish National Dementia Strategy was the importance of training of health care professionals in dementia care. In acknowledgement of the importance of upskilling primary care based health professionals in dementia care, Dr Tony Foley was awarded funding for the PREPARED (PRimary care Education, Pathways And Research in Dementia) project. PREPARED is one of the three implementation work-streams of the National Dementia Strategy. The aim of PREPARED is to develop, deliver and evaluate training and education interventions to GPs and primary care clinicians. PREPARED is a three year project (2015-2018) and is funded by the Health Service Executive and Atlantic Philanthropies.

2.5.1 GPs' educational needs in dementia care

To inform the development of PREPARED's educational interventions it was important that the educational needs of GPs in Ireland were identified. Therefore, a triangulated educational needs analysis was conducted.[87] (Published paper available in appendix 12). Semi-structured interviews were conducted with GPs (n=14), people with dementia (n=5) and family carers (n=12). The aim of these interviews was to get multiple perspectives on what GPs' educational needs were in dementia care. In addition to asking GPs what their needs were, people living with dementia and their family caregivers were also asked about what their experience was with their GP- what they felt their GP did well and what they could have done better. The interviews were thematically analysed. [101] Five main themes on GPs' educational needs in dementia care were developed. These themes were; (i) diagnosis (ii) disclosure (iii) BPSD (iv) signposting services and supports (v) counselling. The management of BPSD was a significant theme, particularly among GPs but also among carers. GPs described prescribing dilemmas in BPSD:

> *'When do you add in psychotropic medication, what type of medication, what dosages, for how long?'* (GP3)

While carers spoke about the lack of guidance their GP was able to provide on the management of BPSD:

> *'…I had to develop a technique to try to snap him out of that, and I used to try reminiscing and that kind of thing and that worked, but I learnt all that myself through the internet, to be quite honest with you'* (FC1)

BPSD emerged as a particularly challenging area for GPs, therefore, this specific topic became the focus of my PhD.

2.4 CONCLUSION

Rising dementia prevalence combined with policy objectives of keeping people with dementia living in the community has resulted in GPs taking on an increasing role in dementia care. The Irish National Dementia Strategy, echoing dementia strategies internationally, advocates for community centred dementia care, yet current Irish healthcare policy does not have a community-centric approach to healthcare delivery. In the context of diminishing resources and economic structures that focus on the provision of acute care, GPs struggle to provide chronic disease management. The challenges of providing chronic disease management in general practice are particularly apparent when it comes to dementia care. Dementia is a complex, evolving illness that needs continuity of care and multidisciplinary input. As identified in the triangulated educational needs analysis conducted by the PREPARED project, GPs are challenged by the specific complexities of dementia care. In particular, they are challenged by the management of BPSD. The Irish National Dementia Strategy calls for integrated, multidisciplinary, community-led care for people with dementia. The strategy advocates for the up-skilling of all clinicians, including GPs who are encouraged in the strategy to take on an increasing amount of dementia care and to improve their current management of BPSD. In order for this recommendation to become a reality we need to understand the evidence for best practice in BPSD. We need to understand how these best practice recommendations compare with the reality of how care is currently provided to people with BPSD in general practice in Ireland.

CHAPTER 3. A REVIEW OF THE BPSD LITERATURE

3.1 INTRODUCTION

This chapter provides an overview of the literature on BPSD that has informed my work. I begin by describing the problem of BPSD; its definition, prevalence and impact on people with dementia, their caregivers and the wider health system. I will then discuss best practice approaches to the assessment of BPSD. I will review the current evidence base for the management of BPSD, both non-pharmacological and pharmacological. Finally, I will review interventions developed to date that have aimed to improve the management of BPSD in primary care, with a particular focus on the role of GPs in these interventions.

3.2 BPSD: WHAT'S IN A NAME?

Cognitive impairment in dementia is often associated with behavioural and psychological symptoms. BPSD is an umbrella term that embraces a heterogeneous group of non-cognitive symptoms and behaviours that occur in people with dementia. [91] Traditionally these symptoms and behaviours were discussed as single entities, such as depression, aggression and wandering. The term BPSD was first coined in 1996 by the International Psychiatric Association (IPA). [102] The term BPSD categorised these symptoms and behaviours into observed behaviours and or elicited psychological symptoms. [102] Observed behaviours are usually identified on the basis of observation of the patient, including physical aggression, screaming, restlessness, agitation, wandering, culturally inappropriate behaviours, sexual disinhibition, hoarding, cursing and shadowing. Psychological symptoms

are mainly assessed on the basis of interviews with patients and relatives; these symptoms include anxiety, depressive mood, hallucinations and delusions. This division has been criticised as being an over-simplification of these behaviours and symptoms that, in real clinical practice, tend to overlap and occur together in clusters rather than as isolated symptoms [91]. Research to date has demonstrated significant association between the following pairs of symptoms and behaviours; anxiety/ depression, psychosis/ apathy, irritability/ persecution, wandering/ sleep problems. [103]

There are other terms used to describe these behaviours and symptoms. The term BPSD is challenged by some as being pejorative. Consequently, people may describe these behaviours and symptoms as 'behaviours that challenge', 'responsive behaviours' or 'non-cognitive symptoms'. For this thesis the term BPSD will be used in preference to these other terms. It was felt that these other terms do not fully encompass all the behaviours and symptoms covered by the term BPSD. Some of the symptoms of BPSD, such as apathy, may not necessarily 'challenge'. Likewise, 'responsive behaviour' may not cover all aspects of BPSD, since not all of the behaviours are necessarily 'in response' to a specific trigger. For example, delusions and hallucinations in a person living with dementia are not typically in response to an external trigger. The term 'non-cognitive symptoms' encompasses all symptoms that affect people living with dementia that are not related to cognition. However, it is a very broad term that could, in theory, include other non-memory dementia symptoms such as apraxia or agnosia. The term 'non-cognitive neuropsychiatric symptoms' is also used in the literature to describe these behaviours and symptoms [104] and is a comprehensive term. However, in view of the extensive use of the term BPSD, both in academic research and in clinical practice, the term BPSD will be used throughout this thesis

to describe the psychological symptoms and behaviours that affect people living with dementia.

3.3 THE PREVALENCE OF BPSD

The majority of people with dementia will experience BPSD at some time during their illness, particularly in the middle and later stages. [103] Estimates of prevalence vary [105,106] and the presence of BPSD can be influenced by several factors including dementia severity. [107] A cross-sectional study conducted in the United States in 2002 estimated the prevalence of BPSD in the population using data from the Cardiovascular Health study and found that 80% (n=233) of people with dementia exhibited at least one symptom of BPSD at some stage in their illness. [106] In 2009, a large population- based cohort study estimated the prevalence of twelve behavioural and psychological symptoms in the population of England and Wales. [103] The prevalence of the symptoms were estimated in participants with dementia (n= 587) and those without dementia (n =2050). This data was supported by interviews (n =1782) with participants and their caregivers. Each symptom, apart from sleeping problems, was more common in the population with dementia. Apathy was the most prevalent symptom in people with dementia. The study concluded that BPSD affects nearly every person with dementia at some stage in the illness.

3.4 THE IMPACT OF BPSD

BPSD is one of the most complex, stressful and costly aspects of dementia care. [108] BPSD is associated with many of the negative outcomes of dementia; nursing home placements, caregiver stress and depression, and decreased quality of life for the person with dementia

and their caregiver.[109] In this section I will outline the impact of BPSD on the person with dementia, their caregiver and the wider healthcare system.

3.4.1 The impact of BPSD on the person living with dementia

BPSD can negatively impact on a person with dementia's quality of life. A longitudinal study conducted in nine nursing homes in the Netherlands used two measurements, the Qualidem questionnaire and the neuropsychiatric inventory, to assess quality of life in 290 people with dementia. [110] The study found that the changes in the neuropsychiatric score consistently and negatively affected quality of life. [110] An earlier U.S. study examined the impact of BPSD in 62 people with Alzheimer's disease and their caregivers. [111] Each person with dementia and their caregiver completed patient quality of life ratings. The study found that the presence of BPSD negatively correlated with the quality of life of a person with dementia. Furthermore, the presence of BPSD is associated with a myriad of negative health outcomes including; increased morbidity and mortality, [112] longer in-patient hospital stays [113] and early placement in a nursing homes. [114]

3.4.2 The impact of BPSD on family caregivers

The negative impact of BPSD on the caregiver is well established. It is acknowledged that dementia care is different from other types of caregiving. Dementia caregivers spend more hours per week providing care than non-dementia caregivers. [115] They also report greater negative impacts in terms of employment complications, mental and physical health problems and family conflict. [115] BPSD is a major contributor to caregiver stress and depression in caregivers. [116] A recent systematic review and meta-analysis investigated the role of the individual symptoms of BPSD in relation to their impact on family care-giver well-being and found that depressive symptoms were the most distressing for care-givers

followed by agitation/aggression and apathy. [117] BPSD is reported to be more stressful for caregivers than the cognitive or functional problems that occur as part of dementia. [118] [119] This may be related to the fact that cognitive symptoms generally tend to follow an expected steady decline, whereas BPSD can ebb and flow in a less predictable way. Additionally, BPSD can affect a person's personality and so may contribute more dramatically to a caregivers' sense of loss than the cognitive symptoms. [116] A recent systematic review and meta-ethnographic synthesis explored the challenges for family carers of managing BPSD. [120] The authors found that the sense that people with dementia "lose their identity" or become "dehumanised" was a key explanatory theme for the challenges of managing BPSD in a family setting. In the meta-ethnographic synthesis BPSD was described as "an invader" which "creeps up on people and steals them from themselves". [120] Furthermore, caregivers generally understand that cognitive symptoms develop as part of dementia. However, they may not be aware that BPSD can also occur as part of the illness. Recent research found that family carers observed significant levels of agitated behaviour when caring for their loved ones with dementia, behaviour that they felt unprepared for as they were unaware that agitation could occur as part of dementia. [121] In this context it is, perhaps, unsurprising that caregivers can have a negative emotional response to BPSD. Research has found that BPSD is associated with more caregiver anger and resentment toward the person with dementia than the aspects of the illness associated with cognitive decline. [118] This can create a vicious cycle where caregiver stress impacts on their ability to effectively communicate with the person with dementia, exacerbating symptoms of BPSD, which in turn further increases caregiver stress. The negative impact of BPSD on a caregiver's physical and mental health can mean that caregivers become "the forgotten patient" in dementia care. [122] Although the presence of BPSD is often a trigger

for nursing home placement, it is important to note that the impact of caring for a person with dementia does not necessarily stop with a nursing home placement. Ongoing, as yet unpublished research, on which I am collaborating on has explored the impact on the family caregiver of an admission of a person with dementia to a nursing home. Qualitative semi-structured interviews were conducted with family caregivers in the period after admission to a nursing home. This research has found that caregivers can have conflicted emotions when a person with dementia is admitted to nursing home care. [123] Family caregivers described feeling guilty about the decision to admit a family member to a nursing home. Caregivers reported feeling like they have failed their loved one. They also described the practical and logistical challenges of visiting the nursing home regularly, as the nursing home can often be located quite a distance from the family home.

3.4.3 The impact of BPSD on formal caregivers

The impact of BPSD on formal carers in a nursing home setting can be substantial. The presence of BPSD was found to be significantly correlated with higher formal caregiver burden in a 2010 study conducted in Japan. [124] The behaviour that was the strongest predictor of formal caregiver burden was aggression. This finding is, perhaps, unsurprising as aggression, especially physical aggression, has the potential to harm not only the formal caregiver but also other residents. A meta-ethnography that explored the experience of hospital staff of caring for people with dementia, identified the challenges of providing optimal care in the context of organisational constraints. [125] It highlighted the benefits of adopting person-centred care approaches and identified the need for training of healthcare professionals. Education, particularly education that improves caregivers' communicative behaviour, can provide formal caregivers with the skills to improve their interaction with

people experiencing BPSD, [126] thus lessening the burden caregivers experience managing BPSD. Therefore, education and training of formal caregivers' needs to be appropriately resourced.

3.4.4 The economic and social costs associated with BPSD

In 2014, Connolly et al. used a cost of illness approach to provide an estimate of the social and economic costs of dementia in Ireland. [127] The total cost of dementia in Ireland was estimated to be €1.69 billion per annum. 48% of these costs were attributed to the opportunity cost of informal care typically provided by family and friends. 43% of the costs were attributable to residential care with only 9% of the total cost attributed to formal health and social care costs. [127] The specific impact of BPSD on the economic and social costs associated with providing dementia care in Ireland has yet to be determined. However, we know that the presence of BPSD results in increased rates of admission to long term care facilities [93] [128] and longer in-patient hospital stays. [113] These are costly pathways of care for the health service.

The costs of managing BPSD in the community are also substantial. The high opportunity costs of informal dementia care in the community are evident in the 2014 Connolly study. [127] These opportunity costs refer to the cost associated with the loss of economic (labour) and leisure time valued by the carer. Studies from other healthcare settings have looked specifically at how the presence of BPSD impacts on the opportunity costs associated with managing BPSD in the community. An Israeli study used interviews with 71 community dwelling people with Alzheimer's disease and their caregivers to explore the costs of BPSD within a prospective study that examined the overall cost of Alzheimer's disease in Israel. [129] The study found that 30% of the total annual cost of Alzheimer's disease is invested in the

direct management of BPSD. Likewise, a U.S. study interviewed caregivers of 128 people with dementia and found that the existence of BPSD significantly increased the direct cost of care. [130]

3.5 CAUSES OF BPSD

BPSD is not a diagnosis in itself but a collection of varied symptoms and behaviours. [91] BPSD is a consequence of the confluence of multiple, but sometimes modifiable, interacting factors internal and external to a person with dementia. BPSD is closely linked to the underlying brain disease causing cognitive symptoms and also results, in part, from a heightened vulnerability to the environment as cognitive ability declines. [104] As a result of the neurodegeneration associated with dementia, a person with dementia has an increased vulnerability to stressors which changes their ability to interact with others and the environment. BPSD can have many potential causes and triggers. The Unmet Needs Model postulates that BPSD results from unmet needs. [131] The model stems from the concept that a person with dementia may be unable to either identify their needs or communicate their needs verbally. As a result, they may react to situations with behaviour that is disturbing to others. Identifying what 'need' they are trying to communicate is the key to assessing and ultimately managing BPSD.

A 2015 study examined unmet needs in 69 nursing home residents living in six nursing homes in the U.S. [131] The study identified, on average, three unmet needs per person. The most prevalent needs identified were boredom/sensory deprivation, loneliness/need for social interaction and need for meaningful activity. [131] However, some behaviours and symptoms of BPSD may not be as a result of an 'unmet need'. For some symptoms, such as psychosis, the disease itself may directly contribute to the development of the symptom by

disrupting brain circuitry involved in behaviour and emotion. [108] However, all attempts need to be made to ensure that a potentially reversible cause of the behaviour is not missed.

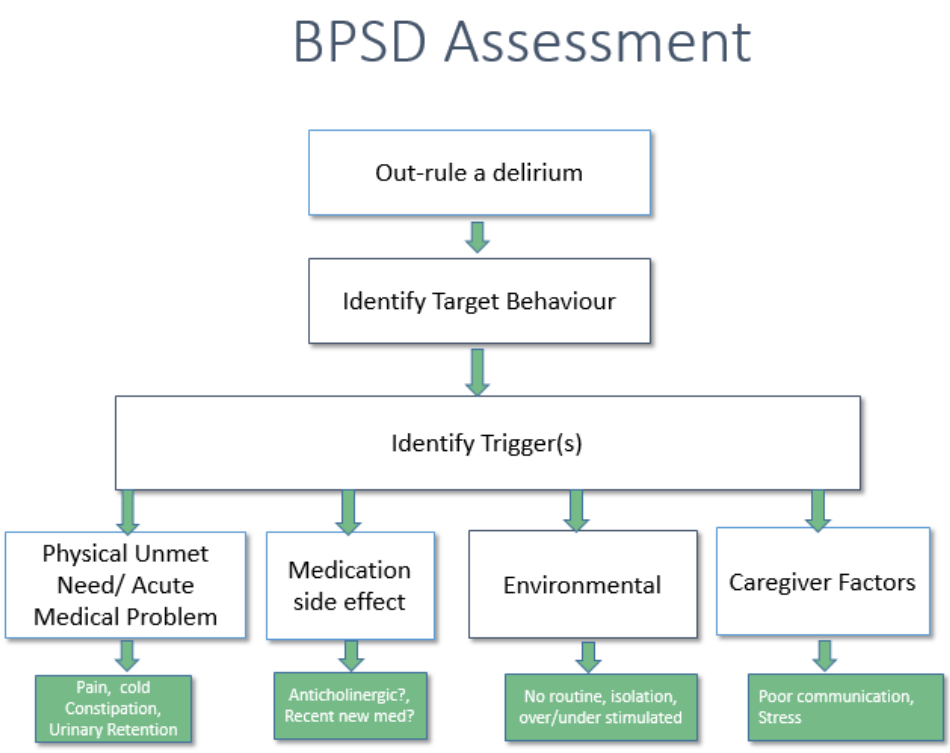
3.6 ASSESSMENT OF BPSD

An approach to assessing BPSD and identifying any underlying triggers is illustrated below (Figure 3). I developed this suggested algorithm following a review of best practice recommendations in the assessment of BPSD. It was developed for use in educational workshops with GPs as part of the wider PREPARED project. [132,133] See appendix 12 for published paper on the development and evaluation of these workshops.

The first step in the proactive management of BPSD is a careful clinical assessment of the patient in order to identify possible underlying reversible causes of the behaviour.[108] BPSD is not a diagnosis in itself, [91] therefore, a thorough assessment is always necessary. As outlined in Figure 3 below there are a number of potential causes of a change in behaviour such as pain, constipation, medication side effects or environmental changes. Assessing for these potential triggers requires at the very least a thorough history of the behaviour, medication review and a physical assessment. Any acute or sub-acute change in behaviour should be considered to be a delirium until proven otherwise. People with dementia are at particularly high risk of developing a delirium [134] and a relatively benign insult, such as a single dose of a sleeping tablet, may be enough to precipitate a delirium. However, identifying delirium in the context of dementia is challenging. [135] This is particularly true of hypoactive delirium, which generally presents with lethargy and sedation and although it is the most common type of delirium it is underdiagnosed. [136] Underlying medical conditions such as an infection can be the cause of the change in behaviour of a person with dementia and need to be considered when assessing any person presenting with BPSD. Pain is a

particularly important trigger to consider as people with dementia have a significantly increased risk of pain, [137] with up to half of people with dementia estimated to be living with chronic pain. [138-140] Non-medical triggers of BPSD that need to be considered include caregiver factors such as how the caregiver interacts and communicates with the person with dementia and environmental factors such as inactivity and a lack of routine. [108] A thorough assessment of the potential triggers of BPSD often negates the need for a treatment plan. If the trigger is identified the management plan is the treatment of the trigger. Assessment is, in itself, the core component of management in BPSD. However, in some cases, despite a thorough assessment, a trigger may not be identified and further management strategies are required.

Figure 3. Suggested approach to BPSD assessment



Source: Jennings A, Foley T, Dementia Care in General Practice: Facilitator's Workshop Guide. Primary Care Education, Pathways and Research of Dementia (PREPARED), University College Cork, 2016

3.7 N0N-PHARMACOLOGICAL MANAGEMENT OF BPSD

Guidelines on the management of BPSD [141,142] recommend that non-pharmacological strategies be used first-line, unless the person with dementia poses a significant risk to themselves or others. The overall aim of non-pharmacological strategies in BPSD should be to provide an intervention that is personalised to the person with BPSD. [143] I will now discuss some of the non-pharmacological strategies that have been shown to be helpful in managing mild to moderate BPSD.

3.7.1 The role of different non-pharmacological strategies in the management of BPSD

Non-pharmacological interventions used in BPSD include the following; reminiscence therapy, [144] personalised music, [145] [146] validation therapy, [147] personalised activities, [144] social interaction, personalised exercise interventions and person-centred care training for care staff.[148] [149] The evidence base for these different non-pharmacological strategies vary with the particular symptom being treated and with the severity of that symptom. The non-pharmacological strategies that have the best evidence base for the management of agitation are personalised activities [144,149] and communication skills training for nursing home staff. [148] [149,150] Music therapy has been shown to have some benefit in the management of agitation and anxiety. [144,148] However, hard evidence alone should perhaps not be the only arbiter of the usefulness of these interventions. Ultimately, these are relatively safe, low-risk, person-centred, respectful approaches that comply with a person's human rights. For example, techniques such as validation therapy have little evidence to support their use. [147,150] However, validation therapy, which is intended to give a person an opportunity to resolve unfinished conflicts by encouraging and validating expression of

feeling, still remains one of the few ways of responding to high expressed emotion in the moment of agitation. The best evidence for the use of non-pharmacological treatments is predominantly for people with mild-to-moderate symptoms of agitation. [149] The use of these strategies may be impractical in people with severe agitation, which carries the greatest distress and risk. Furthermore, implementing many of these non-pharmacological strategies needs time and depends on the presence of a health care professional who is trained to deliver the intervention or to advise a family carer how to implement these interventions. However, both time and relevant expertise in non-pharmacological strategies are often in short supply in a primary care setting.

3.7.2 The uptake of non-pharmacological strategies in primary care settings

Although guidelines are in almost universal agreement that non-pharmacological strategies should be used first line, [141] effective non-pharmacologic strategies for BPSD have not been widely adopted in real-world clinical practice. [151] A 2011 survey by Buhagiar et al [152] looked at the knowledge and attitude of 109 GPs in Ireland towards BPSD. The study did not ascertain whether the GPs had a nursing home commitment in addition to their community practice. 92.5% of the GPs surveyed recognised and highly valued the role of non-pharmacological management in BPSD. Despite this none of GPs surveyed used non-pharmacological management strategies in their daily practice, with all GPs expressing a preference for pharmacological treatments. [152] The study did not explore the reasons for the discrepancy between the GPs' awareness of the importance of non-pharmacological management strategies and their reluctance to recommend these strategies. The study authors postulated that the difficulty a GP may experience accessing advice from specialist services on non-pharmacological strategies could be a contributing factor. They also

suggested that GPs may lack confidence when recommending non-pharmacological strategies. Furthermore, the authors suggested that GPs may come under pressure from caregivers to prescribe medication. Similarly, a survey of GPs in the UK in 2013 examined GPs' perspectives on the challenges of reducing antipsychotics in people with dementia in long term care settings. [153] In this survey GPs reported that they did not find existing guidelines on the management of BPSD clinically useful and that non-pharmacological alternatives to antipsychotics provided in existing guidelines were not implementable given resource constraints. Low staffing levels [154,155] and lack of appropriate resources [155] have also been identified as barriers to GPs recommending non-pharmacological strategies in nursing home settings, thereby resulting in an increased reliance on pharmacological management in BPSD.

3.8 PHARMACOLOGICAL MANAGEMENT OF BPSD

The medications used in the management of BPSD are psychotropic medications. Psychotropic medications include the following classes of drugs; antipsychotics, antidepressants, benzodiazepines, 'Z' drugs (including zopiclone and zolpidem), memantine, acetylcholinesterase inhibitors and anticonvulsants. I will now discuss the role of each of these classes of drugs in the management of BPSD.

3.8.1 The role of antipsychotic medication in BPSD

Antipsychotics are the most commonly prescribed medication in the management of BPSD. [156] [157] However, unless there is a significant risk of harm to either the person with dementia or others, antipsychotic medications are not recommended to treat BPSD. [141] The risks of

antipsychotics to people with dementia has been consistently shown to out-weigh the benefits. [158,159] Antipsychotics are frequently associated with adverse effects, including increased risk of falls and drowsiness, hip fractures, pneumonia, reduced motor function, parkinsonism, akathisia, tardive dyskinesia, social withdrawal, accelerated cognitive decline, QT prolongation and stroke. [160] Studies have shown an association between treatment with antipsychotic drugs and increased morbidity and mortality in people with dementia. [158] [159] In April 2005, a meta-analysis of 17 double blind randomised controlled trials among people with dementia determined a 1.7 time increased risk of all-cause mortality associated with atypical antipsychotic use compared with placebo. [93] This led to the Food and Drug Administration (FDA) in the US giving a "black box warning", the most serious warning the FDA issues, for use of antipsychotic medications in people with dementia. [93]

The definitive CATIE-AD study [160] was a placebo-controlled, double-blind, randomized clinical trial that compared three antipsychotics (quetiapine, risperidone, olanzapine) to each other and to placebo. This study followed 421 out-patients with Alzheimer's disease and psychosis or agitated/ aggressive behaviour over a nine-month period. The study found that there were no significant differences among treatments with regard to the time to the discontinuation of treatment for any reason: olanzapine (median, 8.1 weeks), quetiapine (median, 5.3 weeks), risperidone (median, 7.4 weeks), and placebo (median,8.0 weeks) (P = 0.52). However, those taking any of the three antipsychotic medications were more likely to discontinue use because of intolerable side effects than those taking placebo. The conclusion of the study was that the overall benefit of these medications is offset by intolerability to associated side effects.

Antipsychotics do have a role in certain situations in the management of BPSD. A Cochrane review concluded that certain antipsychotics do have a role when managing aggression or psychosis if the person with dementia is in severe distress or there is substantial risk to the person or others. [161] However, the role of antipsychotics in the management of BPSD is limited by its serious adverse effects and its minimal effectiveness. I will now present the evidence for a number of other psychotropic medications that are most commonly prescribed to people with BPSD namely antidepressants, hypnotics, memantine, cholinesterase inhibitors and anticonvulsants.

3.8.2 The role of antidepressants in BPSD

Studies have examined the role Selective Serotonin Re-uptake Inhibitors (SSRIs) can play in the management of two common aspects of BPSD; agitation and depression.

3.8.2.1 The evidence for antidepressants in the management of agitation in dementia

A Cochrane review in 2011 found some evidence to support the role for antidepressants in the treatment of agitation in dementia but commented on the dearth of studies in this area [162]. Subsequently in 2014 the Cit-AD trial, a large, well-powered 9 week multi-centred placebo-controlled double-blind randomised controlled trial (RCT), looked at the effectiveness of citalopram in managing agitation in people with dementia. [163] Cit-AD found that 40% of patients on citalopram had a moderate or marked improvement from baseline compared to 26% on placebo, a clinically meaningful reduction in agitation comparable to that seen with antipsychotics [163]. However, the citalopram group did see worsening of cognition and QT interval prolongation. The authors of the Cit-AD study concluded that although citalopram does effectively reduce agitation in this patient group, the cognitive and cardiac adverse effects of citalopram may limit its practical application. However, the dose

used in that RCT was 30 mg/day dose and the current prescribing information recommends a maximum daily dose of 20 mg of citalopram for patients over 60 years of age because of substantially higher exposures, decreased clearance, and prolonged cardiac repolarization potential. [164] The RCT did not have enough people in the 20mg group to assess the efficacy of that dose. Overall, it appears that in carefully selected patients there is evidence to support the role of citalopram to treat moderate agitation in dementia. However, prescribers should be aware of a possible risk of worsening of cognition and QT prolongation.

3.8.2.2 The evidence for antidepressants in the management of depression in dementia

A Cochrane review in 2002 looking at the use of antidepressants for the management of depression found that the evidence to support the use of antidepressants was weak, however, this analysis was based on a number of studies of small sample size and the authors commented on the paucity of research in this area [165]. A meta-analysis in 2012 analysed five different studies that examined the effect of SSRIs on depression in people with dementia and found that current evidence does not support the efficacy of SSRI treatment for symptoms of comorbid depression in Alzheimer's Disease. [166] The most recent and definitive trial in this area was the HTA-SADD trial conducted in 2011. This multi-centred, parallel-group, double-blind, placebo-controlled, randomised trial found that when treating depression in people with dementia neither mirtazapine nor sertraline had a benefit over placebo. [167] This was the largest study to date of SSRI treatment for depression in dementia and had 13 and 39 week follow-up. This RCT found that neither sertraline nor mirtazapine reduced severity of clinically significant depression over 39 weeks compared with placebo in people with dementia. In addition, adverse events were more common with antidepressants than with placebo. The HAT-SADD study concluded that it is possible that depression in dementia might be different in terms of neurobiology than depression occurring in those without dementia and that is why

antidepressants are not effective. Based on current evidence antidepressants appear to be ineffective at managing depression in people with dementia, however, it should be noted that the vast majority of these trials focused on sertraline. Despite the lack of evidence for use of antidepressants in dementia with co-morbid depression, in real-world clinical practice, old age psychiatrists, GPs and geriatricians do use antidepressants to treat depression in people with dementia. Furthermore, in clinical practice it can be quite difficult to identify depression in a person with dementia [168] and likewise it can be difficult to assess response to medication.

In summary, the lack of evidence for the use of antidepressants in dementia is disappointing but there are some positive results from studies that SSRIs could have a promising role to play in the management of mild to moderate agitation.

3.8.3 The role of benzodiazepines & Z drugs in the management of BPSD

Benzodiazepines are frequently prescribed to people with BPSD. [169] However, the AGS-Beers criteria includes benzodiazepines in the potentially inappropriate medications class and recommends avoiding their use in older adults, especially for the treatment of insomnia, agitation or delirium. [170] They are also included in the potentially inappropriate medications and classes to avoid in older adults, in particular those with cognitive impairment and dementia as they can worsen cognition.[170] Similarly the STOPP/START tool advises that benzodiazepines should be withdrawn if prescribed long-term (>1 month) or if the person is at risk of falls. [171] A systematic review on the role of benzodiazepine in the management of BPSD found that available data, although limited, does not support the routine use of benzodiazepines for the treatment of BPSD. [172] Likewise, sedative hypnotics are not recommended in older people with insomnia. [173] Overall, due to their significant side effects

including falls, increased confusion, and drowsiness neither benzodiazepines nor hypnotics are recommended for use in patients with dementia. However, benzodiazepines may have a role in certain situations such as in an emergency crisis situation. Expert consensus recommendations has also outlined a potential use for benzodiazepines as short term use in a person with agitation while waiting for a SSRI to take effect. [174]

3.8.4 The role for memantine in the management of BPSD

Previous studies and pooled analysis of studies did indicate that there was significant benefit for memantine versus placebo in treating agitation, delusions and hallucinations in people with dementia [175,176]. However, the problem with these studies is that the trials were initially designed with the purpose of testing cognition so the populations recruited did not necessarily have problematic agitation or high levels of neuropsychiatric symptoms. A more recent trial published in 2012 [177] specifically looked at the efficacy of memantine in treating agitation in people with dementia. This was a well-run randomised double-blind placebo-controlled trial which ran in the UK over a 3 year period with 153 people with dementia. This trial found that memantine is no better than placebo in treating agitation in dementia. Similarly, the 2015 MAIN-AD trial was a randomized double-blind placebo-controlled withdrawal trial comparing memantine with antipsychotics for the treatment of neuropsychiatric symptoms in 199 people with dementia over 24 weeks. The trial found no benefits for memantine in the long-term treatment and prophylaxis of clinically significant neuropsychiatric symptoms. [178] The recent STOPPFrail (Screening Tool of Older Persons Prescriptions in Frail adults with limited life expectancy) consensus validation recommends

discontinuing and monitoring memantine in people with moderate to severe dementia, unless memantine has clearly improved BPSD. [179]

3.8.5 The role of cholinesterase Inhibitors in the management of BPSD

Despite earlier studies that showed cholinesterase inhibitors have a modest benefit in BPSD, [180,181] the definitive study (CALM-AD trial) found that donepezil was no more effective than placebo at managing agitation in people with Alzheimer's disease. [182] In the CALM-AD trial 272 people with Alzheimer's disease who had clinically significant agitation were randomly assigned to receive 10mg of donepezil (n =128) or placebo (n=131) for 12 weeks. The primary outcome measure was a change in the score on the Cohen-Mansfield Agitation Inventory (CMAI). There was no significant difference between the effects of donepezil and those of placebo on the basis of change in the CMAI from baseline to 12 weeks. The study authors concluded that donepezil was no more effective than placebo in the management of agitation in people with Alzheimer's disease. No large randomised controlled trials have been conducted in this area since the CALM-AD trial. Notable side effects of cholinesterase inhibitors include nausea and GI upset both of which could potentially contribute to BPSD.

3.8.6 The role for anticonvulsants in the management of BPSD

There is a paucity of well-conducted studies exploring the efficacy of anticonvulsants such as valproate, carbamazepine and gabapentin in BPSD. A Cochrane review in 2009 on the use of valproate in agitation concluded that valproate preparations are ineffective in treating agitation in people with dementia and noted that valproate therapy is associated with an unacceptable rate of adverse effects.[183] The evidence base for carbamazepine is very small

and there are concerns regarding its tolerability. [184] Side effects of this class of medication include sedation, gait disturbance, hyponatreamia and cognitive impairment. [185] The elderly population, who often are multimorbid with associated polypharmacy, are particularly at risk of pharmacokinetic interactions and side effects from anticonvulsants. The use of anticonvulants in BPSD is limited by both their side effects and the minimal evidence to support their use. [186] At present anticonvulsants are not indicated in the most recently published NICE guideline as a treatment of BPSD. [141]

3.8.7 Summary of the evidence for pharmacological management of BPSD

Antipsychotics are not recommended in the management BPSD unless there is a serious risk of harm to the patient or to others. [187] However, from the evidence outlined above, effective pharmacological alternatives remain scarce. [188] Of the pharmacological agents used to treat BPSD, antipsychotics still have the strongest evidence base, although their benefits are modest at best. [109] Reductions in antipsychotic prescribing could potentially result in a shift to the prescribing of even less efficacious and similarly toxic drugs (such as anticonvulsants and benzodiazepines). [7,104] Apart from the potential role for citalopram in mild-moderate agitation, [163] pharmacological alternatives to antipsychotics appear to have little effect beyond their ability to sedate.

Overall, the lack of evidence for various pharmacological treatments of BPSD, including antipsychotics, is disappointing but perhaps unsurprising. If we accept that a significant proportion of the time there is an unmet physical, environmental, emotional or psychological need that is triggering BPSD then it is unsurprising that medication cannot reverse these needs. While there is a role for medication in managing some of the

symptoms and behaviours associated with BPSD, [189] prescribers need to be aware of the evidence for the pharmacological management options and be aware of the potential adverse effects of treating people with BPSD with these medications. Caution is needed to ensure appropriate prescribing of antipsychotic medications. However, criticising the prescribing of antipsychotics without providing health care professionals with any practical management alternatives is unlikely to improve the care provided to people with dementia. I will now examine the rates of prescribing of these medications to people with dementia in primary care in Ireland.

3.9 CURRENT PRESCRIBING IN BPSD IN IRELAND

There is a paucity of data on the rates of psychotropic prescribing to people with dementia living in the community or in nursing homes in Ireland. Available data is derived from analysis of studies conducted in secondary care**.** Although a systematic review published in 2016 found that Ireland, Austria and Belgium had the highest rates of antipsychotic prescribing in nursing homes in Western Europe [190] this review included just one Irish study that was actually conducted in Northern Ireland and not the Republic of Ireland. [191] To examine this issue of prescribing rates I will first discuss the rates of psychotropic prescribing in dementia in Ireland. Since antipsychotics are the most commonly prescribed psychotropic medication in BPSD, [190] I will then specifically focus on the rates of antipsychotic prescribing in people with dementia in Ireland.

3.9.1 Rates of psychotropic prescribing in people with dementia in primary care in Ireland

A retrospective cross-sectional study explored prescribing patterns in a well-defined cohort of people >70 years who were admitted to any of the six acute hospitals in Cork between 2012 and 2013. [156] The study examined the difference in prescribing patterns between people with and without dementia, in particular the study examined prescribing of psychotropic medications. Of the 598 patients recruited 149 had dementia. Of these 149 patients with dementia, only 53 patients had a known diagnosis of dementia before admission, the remainder were diagnosed after admission. The study found that people with dementia were significantly more likely to be prescribed at least one psychotropic medication and were more than three times more likely to experience psychotropic polypharmacy. Atypical antipsychotics, anti-depressants and anxiolytics were all significantly more likely to be prescribed to people with dementia, even after the authors controlled for age, sex and co-morbidity. [156]

3.9.2 Rates of antipsychotic prescribing in people with dementia in primary care in Ireland

The retrospective cross-sectional study described above [156] also specifically examined the rates of antipsychotic prescribing in the patients admitted. The study found that 28% of people with a known diagnosis of dementia at admission (15/53) were prescribed an antipsychotic medication. People with dementia admitted from a nursing home were almost five times more likely to be prescribed an antipsychotic medication than people with dementia admitted from home. [156] This finding is likely to reflect the fact that nursing home residents are more likely to have more advanced dementia than those residing in the community [192] but is, nonetheless, concerning. Evidence to date has demonstrated that that

people with dementia living in nursing homes are at particularly high risk of inappropriate prescribing. [193]

Gallagher et al conducted an audit of antipsychotic prescribing in people with dementia attending all 35 publically funded hospitals in Ireland in 2013 and found that 29% (190/656) of people with dementia admitted to hospital were prescribed antipsychotic medications *prior* to admission. [194] People with dementia who were admitted from a nursing home were significantly more likely to have an existing prescription for an antipsychotic than those admitted from their own homes. Out of the 243 people with dementia admitted from a nursing home setting, 45% (110/243) had an existing prescription for an antipsychotic. Of the 409 people with dementia admitted from their own homes 19% (78/243) had an existing prescription for an antipsychotic. Using this study to provide data on the rates of prescribing in primary care in Ireland is not without its limitations. To be included in this study the person with dementia had to have been hospitalised for a minimum of five days. We know that, in itself, BPSD can be a cause for admission and can result in prolonged hospital stays.[113] Therefore, this data may not be representative of antipsychotic prescribing in people with dementia and may, in fact, over-estimate the rates of antipsychotic prescribing to people with dementia in Irish primary care. However, when the 2013 Gallagher et al audit is compared with a very similar audit conducted in general hospitals in the UK there is further evidence that the rate of 29% people with dementia in Ireland being prescribed an antipsychotic [194] is high. Comparable findings from the National Dementia Audit in England and Wales found that in 2010 and 2012 respectively, 28.3% and 17.7% of inpatients with dementia were prescribed antipsychotic medication. [195] The dramatic fall in prescribing of antipsychotic medication in the UK between 2010 and 2012 is likely to be as a result of a

number of UK initiatives and calls to action including the 2009 Banerjee Report [196] and the 2009 UK National Dementia Strategy. [28] (The impact of these interventions will be discussed in more detail in section 3.12). The Irish National Dementia strategy was published in 2014 and is still in its implementation stage. Therefore, it is interesting to note that the Irish figure of 29% of people with dementia being prescribed an antipsychotic closely mirrors the UK figures from 2010. The UK reduction indicates that if the problem is addressed with appropriate strategies we could hope for a similar improvement in the prescribing rates in Ireland over the coming years.

3.10 THE ROLE OF THE GP IN THE MANAGEMENT OF BPSD

The GP plays a key role in the assessment and management of BPSD. In the community setting, the GP is the first point of contact for family caregivers. The GP has often known the person with dementia and the wider family for many years. This can be a real advantage when assessing for potential triggers of BPSD. In the nursing home setting a GP may find themselves at a disadvantage if they have not cared for the person prior to admission to the nursing home. In both settings the GP has a role in managing BPSD. In the community setting it generally falls to the GP to recommend non-pharmacological strategies. However, in the triangulated educational needs analysis conducted as part of the wider PREPARED project, carers consistently reported that GPs did not tend to do this well. [87] Furthermore, we know from the Buhagiar et al survey that GPs in Ireland do not feel comfortable advising on non-pharmacological strategies. [152] In a nursing home setting, although GPs do have a role in suggesting and discussing non-pharmacological strategies, the nursing staff are typically responsible for implementing them. GPs have a central role in prescribing

medications for BPSD in both settings. Typically prescribing rates of antipsychotic and other psychotropic medications are higher in nursing home settings than in community settings. [194] A UK study in 2012 [197] looked at the prevalence of anti-psychotic prescribing in dementia in 59 GP practices and found that 15.3% (161/1051) of people on the register were receiving low-dose anti-psychotics. This UK study examined whether the prescription originated in primary or secondary care and found that 43% (70/161) of prescriptions for anti-psychotics were initiated by the GP. Therefore, the majority of prescriptions for antipsychotics in people with dementia in the community originated from secondary care. The origin of prescriptions in nursing home settings is less clear. Given that the GP is often the sole physician providing care to a person with dementia in a nursing home setting it is likely that psychotropic medications used to manage BPSD in nursing home settings are prescribed by, or at least continued by, the GP. Despite their central role in the assessment and management of BPSD, internationally GPs consistently report that BPSD is an area of dementia that they find particularly challenging to manage. [87,88,90,198]

3.11 THE ROLE FOR INTERVENTIONS AIMED AT IMPROVING THE MANAGEMENT OF BPSD IN A PRIMARY CARE SETTING

The high rates of potentially inappropriate prescribing of psychotropic medications in BPSD [156,194] and the low uptake of non-pharmacological strategies [152] indicates a mismatch between best practice recommendations in BPSD [141] and current clinical practice in primary care in Ireland. Interventions are needed to address this discrepancy between recommended and actual care in order to improve the management of BPSD in primary

care. However, in order to develop these interventions we need a better understanding of why this mismatch exists.

I will now describe some of the non-pharmacological interventions that have aimed to improve the management of BPSD in a primary care setting. I will first discuss community based interventions and then discuss interventions conducted in long term care settings. I will specifically focus on interventions that involved GPs.

3.11.1 Community based interventions in BPSD and the role of the GP in the interventions

In 2018 Trivedi et al published a systematic review of the effectiveness of non-pharmacological interventions for BPSD among people with dementia living at home. [199] Studies conducted in long-term care settings were excluded from the review. The review examined evidence from 48 randomised controlled trials and presented the findings in the form of a narrative synthesis. All the interventions targeted people living with dementia and family carers. Although not an exclusion criterion, no intervention included in the systematic review targeted health care professionals. The review found that family carer training and educational programmes for carers can improve outcomes in BPSD. It also established that community based nurses and occupational therapists can play an important role in the delivery of these interventions.

Only one study in the Trivedi et al review involved GPs in the intervention. [200] That study was an RCT conducted in the U.S between 2002 and 2004 evaluating the effectiveness of a collaborative care model to improve the quality of care in people with Alzheimer's disease (n=153) experiencing BPSD. [200] The intervention involved a nurse practitioner meeting the intervention patients and their caregiver regularly over a one year period. If specific BPSD

symptoms were present then an appropriate non-pharmacological approach was recommended. If this approach failed then the person was referred to their GP for consideration of pharmacological treatment. The study found that the intervention resulted in significant improvements in behavioural symptoms and improvements in caregiver distress and depression. There was no significant difference in the use of psychotropic drugs between the intervention and control group, however, this study was conducted before the significant adverse effects of antipsychotics in dementia were known. Although no formal cost-effectiveness was conducted, the cost of the advanced nurse practitioner was estimated to be $1,000 per patient based on a case load of 75 patients per year. In the context of the economic impact of BPSD this cost is not prohibitive.

3.11.2 Nursing home based interventions in BPSD and the role of the GP in the interventions

A well-conducted systematic review published in 2014 by Thompson-Coon et al evaluated the effectiveness of interventions to reduce inappropriate prescribing of antipsychotics to people with dementia living in residential care settings. [201] All 22 intervention studies included in the review targeted health care professionals. The most frequently used intervention component was educational (present in some form in 14 studies). Medication reviews were also used successfully as an intervention to improve antipsychotic prescribing in four studies included in the review. GPs were involved in the interventions as either the primary target [202,203] or one of several healthcare professionals targeted [204] with the intervention. In some studies it was unclear whether the physician targeted with the intervention was a GP or a secondary care doctor. [205-207] Several of the studies that targeted GPs used education in-reach approaches [203,206] which were delivered by up-skilled pharmacists. [203,207] For example, in one study conducted in Northern Ireland in 2010,

specially trained pharmacists visited the nursing home and reviewed the appropriateness of the GP's prescribing of psychotropic medications and then worked with the GPs to improve the prescribing.[203] This led to a significant fall in the proportion of residents taking inappropriate psychotropic medications. [203] Overall, the review found that, where the study design was robust, antipsychotic prescribing fell by between 12% and 20% as a result of the intervention implemented. This fall was regardless of what intervention was implemented - all interventions led to a fall in antipsychotic prescribing. However, the authors commented on the lack of detail provided for many of the interventions, making future replication difficult. Additionally, as a result of the heterogeneity of the included studies and the often poor quality of the included studies or of their reporting, the authors were unable to make any definitive recommendations for practice. Furthermore, the review highlighted the challenges of implementing best practice in appropriate prescribing in the context of time constraints, staffing levels, staff competence with non-pharmacological alternatives and pressure to prescribe. The authors' recommended further qualitative work be conducted in this area.

Since the Thompson-Coon systematic review was published in 2014 there have been additional studies that evaluated interventions for BPSD in long term care settings. In 2018 Birkenhager-Gilesse et al published a systematic review and meta-analysis of the effect of multidisciplinary psychosocial interventions for BPSD on the psychotropic drug prescription rate in nursing homes. [208] The review also included two notable intervention studies involving GPs that were published after 2014. One study was a cluster RCT that involved healthcare professionals (including GPs) participating in five educational sessions where a step-wise approach to the assessment of a person with BPSD was outlined. [209] The intervention resulted in an improvement in BPSD, a significant reduction in antidepressant

use and a non-significant reduction in antipsychotics and sedatives. [209] The second notable intervention that involved GPs was the WHELD study. [210] The WHELD intervention focused on upskilling care home staff and GPs in the principles of person-centred care. [211] In the WHELD study 16 UK nursing homes received a training intervention in person-centred care for 9 months. Intervention care homes were also randomly assigned to antipsychotic review, to a social interaction intervention, and to an exercise intervention for 9 months. The GPs who provided care to nursing homes in the antipsychotic review intervention arm attended interactive educational sessions. [212] Antipsychotic review was found to significantly reduce antipsychotic prescribing. [210] Antipsychotic review combined with the social interaction intervention significantly reduced mortality when compared with the group receiving neither. The WHELD study also examined the impact of the different interventions arms on quality of life.[212] The social interaction intervention resulted in improved health-related quality of life score. The social interaction combined with antipsychotic review intervention showed no deterioration in health-related quality of life. However, the intervention that just introduced an antipsychotic review without any complementary non-pharmacological intervention resulted in significant worsening in two quality of life scores. The study authors' concluded that in the current climate in the UK where there is more judicious prescribing of antipsychotic medication, further reductions in prescribing may not ultimately be beneficial to people with dementia, [210] unless they are provided in conjunction with evidence-based non-pharmacological interventions. [212] 'However, it is important to note that as outlined in section 3.9 the current prescribing rates of antipsychotic medication to people with dementia in Ireland are not as judicious as the UK prescribing rates.

Overall, the Birkenhager-Gilesse et al meta-analysis found that educational interventions that targeted care staff were not more effective than care-as-usual. (Although, the description of what constituted 'care-as-usual' was poorly described in the majority of the studies included in the review.) The review authors argued that education typically only has a temporary impact. To be effective education has to be repeated and imbedded in daily practice. The review found that longer lasting interventions that involved a change of culture or process change were superior to care-as-usual interventions at lowering antipsychotic drug use. [208] The review also found that the involvement of the physician in the intervention was "indispensable for obtaining and maintaining a reduction in the use of antipsychotic drugs". [208]

3.11.3 Summary of interventions in the community and in nursing homes to improve the management of BPSD

Interventions to improve BPSD are poorly described making interpretation of the results and future replication of the studies difficult. [208] [201] Why the particular intervention was chosen and how it was developed is rarely adequately reported. As a result of the limitations in study quality and the poor descriptions of the interventions, the exact components of an intervention that will improve the management of BPSD remains unclear. From the evidence available, there is a potential role for educational interventions in interventions in a nursing home setting. However, in order to be effective in the longer-term these educational interventions need to embedded in daily practice and be part of wider attempt to change the culture of the nursing home. [208] Unsurprisingly, in order to change prescribing behaviour the intervention needs to target the prescribing physician, [208] yet surprisingly GPs involvement in these intervention studies to date has been minimal. Despite the poor understanding of the challenges GPs experience managing BPSD, it

appears that none of the interventions targeting GPs actively sought to understand or address the challenges GPs experience managing BPSD. Furthermore, the studies did not appear to involve GPs in the development of the intervention. Finally, although the vast majority of people with dementia live at home in the community under the care of their GP, interventions involving GPs have focused on the nursing home setting. To my knowledge no study based in the community has targeted GPs and only one community-based study involved GPs in the implementation of the intervention. [200]

3.12 POLICY INTERVENTIONS TO IMPROVE THE APPROPRIATENESS OF PRESCRIBING TO PEOPLE WITH BPSD

Over the past decade, regulatory bodies have issued drug safety warnings on the use of antipsychotics in people with BPSD in Canada,[213] the U.S.[214] and in many European countries.[215-217] However, in Ireland, apart from the aforementioned National Dementia Strategy,[29] there has been little or no national guidance or policy interventions in this area. Nor has any research captured temporal changes to the prescribing of antipsychotics in Ireland. It is important that we explore the impact of policy interventions in the area of prescribing in BPSD in other countries in order to ascertain what lessons can be learned, and potentially applied, to an Irish context. To date, virtually all of the different policy interventions introduced in various countries have focused on the appropriate prescribing of antipsychotics to people with BPSD. I will now summarise some of the policy interventions introduced in the UK and other countries over the past decade. As the UK has a very similar healthcare structure to Ireland I will focus initially on policy interventions introduced in the UK. I will then briefly describe policy intervention introduced in other countries. Finally I will explore the impact of these policy interventions on the rates of prescribing in BPSD.

3.12.1 Policy interventions to reduce inappropriate prescribing of antipsychotics in BPSD

A number of policy interventions have been implemented in the UK since 2004.[218] In 2004 the UK Committee for the Safety of Medicines (CSM) warned all healthcare professionals that neither risperidone nor olanzapine should be used to treat BPSD because of the increased risk of stroke. [219] Data later emerged that demonstrated similar risks for other second-generation antipsychotics and first-generation antipsychotics.[160] In March 2009 the Medicines Healthcare products Regulatory Agency (MHRA) released a drug safety update stating that risperidone was licensed for short term use (<6 weeks) to manage severe aggression in a person with dementia. [220] This was followed by a further warning on the risks of antipsychotics in people with dementia in June 2009.[221] However, this 2009 warning was not disseminated as widely as the original 2004 warning had been. [222] Another important intervention that occurred at this time was the publication of the seminal Banerjee report in October 2009. [196] The report, which was commissioned by the Dept. of Health in the UK, drew some concerning conclusions, such as estimating that up to two-thirds of prescriptions of antipsychotics to people with dementia were unnecessary and potentially harmful. [196] Also in November 2009, in response to the Banerjee report, the UK government pledged to reduce the use of antipsychotics in people with dementia. [223] This pledge was followed by the Prime Minister's challenge in 2012 which was a challenge set by the then Prime Minister to deliver major improvements in dementia care and research by 2015. [224]

Similar warnings and policy recommendations on appropriate prescribing of antipsychotic medication in dementia have been introduced in several other countries including the US

and Canada. In 2005 in the US the FDA issued a black box warning on atypical antipsychotics that stated *"treatment of behavioural disorders in elderly patients with dementia with atypical antipsychotic medications is associated with increased mortality*". [225] This warning was expanded to all antipsychotics in 2008. More recent initiatives include the launch of a national partnership programme to improve the quality of care for nursing home residents with dementia. [226] This programme was launched in 2012 by the Centres for Medicare and Medicaid Services (CMS) and involved public reporting of antipsychotic use, comprehensive training for nursing home staff and a five-star quality rating system for nursing homes. [214]

3.12.2 The impact of policy interventions on prescribing rates

The main measure used to evaluate the outcome of these policy interventions is the percentage of people with dementia, but without primary psychotic disorder, who are prescribed an antipsychotic medication, as this prescription is then presumed to be for BPSD. In the UK two large studies have evaluated the impact of policy efforts to reduce prescribing in BPSD. The first study by Donegan et al published in 2015 was a longitudinal retrospective cohort study which looked at prescribing in dementia in the UK over a 10 year period from 2005-2015. [227] The study found that there was a large reduction in prescriptions for antipsychotic medication in dementia from 22.1% in 2005 to 11.4% in 2015. However, most of this reduction resulted from a decrease in prescribing of first generation antipsychotics (22.1% in 2005 to 11.4% in 2015) with a smaller decrease in second generation (or atypical) antipsychotics (which only reduced from 13.6% in 2005 to 9.7% in 2015). The study also found that prescribing of hypnotics reduced (14.3% in 2005 to 9.5% in 2015) but the prescribing of antidepressants increased (28% in 2005 to 36.6% in 2015). The second study by Stocks et al examined the temporal changes in prescribing of antipsychotics

to people with dementia from 2001 to 2014 but differed slightly in its criteria as it looked only at long-term prescribing of antipsychotic medication (at least two prescriptions in 6 months and 90 days apart) to people with dementia who did not have a diagnosis of psychosis. [218] The Stocks et al study found that although the long-term prescribing of first generation antipsychotics to people with dementia declined substantially between 2001 and 2014 (decrease from 8.9% in 2001 to 1.4% in 2014), the frequency of prescribing of second-generation antipsychotic drugs remained essentially the same in 2014 as 2001 (6.6% in 2001 and 6.9% in 2014). The study noted that since 2013 the decreasing trend in second generation antipsychotic prescribing in people with dementia had plateaued and reported that this plateau had been largely the result of increasing prescribing of risperidone. [218] On a positive note the Stocks et al study did demonstrate the significant and sustained impact of the 2006 NICE guidelines [187] on the rates of antipsychotic prescribing, [218] indicating that the implementation of similar guidance in Ireland may have a similar positive impact on prescribing rates.

Unlike the Donegan et al study, the Stocks et al study did not examine the prescribing of other psychotropic medication to people with dementia during this time. Examining the impact of policy interventions in antipsychotic medications on the prescribing of other psychotropic medications is critical if we are to fully understand the impact on prescribers' behaviours. What does a fall in antipsychotic prescribing truly represent? As Kales & Maust point out in their commentary on the Stocks et al study "*it is critical to understand whether a decline in antipsychotic use represents a true decrease in people with dementia receiving potentially inappropriate psychotropic medication, or whether measuring antipsychotic use has simply led providers to prescribe other medications".* [109] Importantly, the goal should be to reduce inappropriate antipsychotic prescribing while increasing the use of non-

pharmacological strategies but it remains unknown if reductions in antipsychotic prescribing have any such impact on the uptake of non-pharmacological strategies. [109]

Overall, the studies demonstrate that clinicians respond to changes in policy recommendations and to changes in drug safety warnings. [218,227] However, the fact that the prescribing of second generation antipsychotics to people with dementia has remained essentially the same despite various policies and warnings, [218] demonstrates the magnitude of the problem of managing BPSD and the difficulties clinicians experience adhering to safety warnings in this area. Simply communicating to prescribers the dangers these medications pose to people with dementia will not eliminate prescriptions of antipsychotic medications. Increasing awareness of the dangers of antipsychotics without providing healthcare professionals with realistic alternative strategies is unlikely to fully address the problem.

Evaluations of the impact of policy interventions in BPSD in other countries outside of the UK has shown similar trends in prescribing. In the US a time-series analysis estimated the effect of the various warnings on out-patient prescriptions for antipsychotics using national Veterans Affairs data from 1999 to 2007. [228] The study found that the FDA black-box warning was temporally associated with a significant acceleration in the decline in the use of atypical antipsychotics in BPSD. However, importantly the study found that the reductions in antipsychotic use were merely offset by increases in prescriptions of other psychotropic medication to people with dementia - such as a small but significant increase in anticonvulsant prescriptions. [228] There was no overall reduction in psychotropic use, which remained fairly constant throughout the study period at 40%. [228] Similarly, a Canadian study examined the changes over a ten year period (2004-2013) in the dispensing of

antipsychotics and other psychotropic medication among people with dementia living in long-term care facilities. [229] The study found that although prescriptions for atypical antipsychotics decreased over the ten years (decrease of 4%), these reductions were offset by the increases in prescriptions for anticonvulsants and sedating antidepressants.[229] It seems, therefore, that when developing policy to promote the appropriate pharmacological management of BPSD we need to be careful that we do not find ourselves moving from a bad situation to a worse one. We need to be aware that one of the potential consequences of reducing prescriptions for antipsychotic medications is simply moving people from a potential harmful but minimally effective medication to a potentially harmful but ineffective medication.

3.13 SUMMARY AND RESEARCH GAPS

GPs play a central role the management of BPSD. However, BPSD is an aspect of dementia care that GPs find particularly challenging. There is a dearth of research examining GPs experiences of managing BPSD, therefore, the reasons why GPs find BPSD so challenging is unclear. Furthermore, the evidence suggests that current management of BPSD is sup-optimal with high rates of psychotropic prescribing and low uptake of non-pharmacological strategies. There is a discrepancy between best practice recommendations in relation to the management of BPSD and clinical practice. However, the reason for this discrepancy is not clear from the literature. Interventions are required to improve the quality of care provided to people with BPSD in general practice. However, to date, interventions aiming to improve GPs' management of BPSD are limited, particularly in the community setting. Interventions involving GPs in a nursing home setting are often poorly described, so when they are

successful it is not always clear why. There is little evidence that GPs were involved in the intervention development process, nor do the interventions explore GPs experiences of implementing the intervention. In designing the interventions the reasons why GPs find BPSD challenging were not explored. If we do not understand the reasons for the apparent discrepancy between best practice recommendations in BPSD and real-life clinical practice, we cannot design an effective intervention to address the problem. Interventions are required to improve the management of BPSD in general practice and, given the significant role GPs play in the management of BPSD, it is apposite that these interventions focus on GPs. However, to design an effective intervention we need to first have a clear understanding of GPs' knowledge, attitudes and experiences of managing BPSD. We need to understand what GPs' perspectives are on the barriers and enablers to implementing best practice recommendations for BPSD. We need to address this gap in the literature or we run the risk of designing an intervention that is not fit for purpose.

CHAPTER 4: PHILOSOPHICAL AND METHODOLOGICAL APPROACH

This chapter provides a description of the philosophical approach that underpins this research and the methodological framework employed to address the thesis aims and objectives. An overview of the methods used to address each phase of the research is provided here. Each individual chapter provides greater detail on the specific methods employed for each research phase.

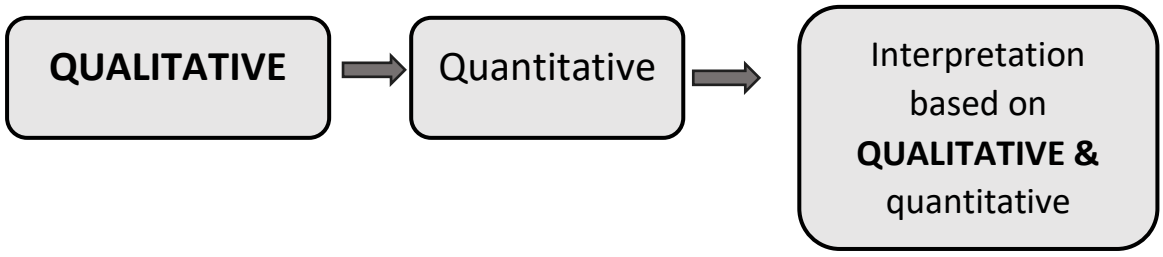
4.1 PHILOSOPHICAL ORIENTATION

A pragmatic paradigm was adopted for this research. The research design and methodology was guided by the aims and objectives of the thesis. Both qualitative and quantitative methods were employed to address the different objectives of the thesis. This decision to include both qualitative and quantitative methods reflects the pragmatic paradigm that underpins this thesis. A major tenet of the concept of pragmatism is that quantitative and qualitative methods are compatible. [230] Pragmatism rejects the forced choice between qualitative and quantitative research methodologies, instead advocating that the choice of method should be informed by the research question. The epistemological differences between qualitative and quantitative approaches are acknowledged. However, these two form of inquiry are not seen as incommensurable. [231] Indeed, it was felt that, given the complexity of the research environment and the complexity of the research question, adopting a mixed methods approach to the thesis was appropriate.

Creswell et al have outlined four designs for mixed methods research; exploratory, explanatory, triangulation and embedded designs. [232] The approach taken to this research was sequential with an exploratory design, in that each step of the research occurred sequentially, informing the next step but with a particular emphasis on the qualitative

component. This approach is graphically outlined in Figure 3. Although mixed methods were used the core component was the qualitative research. The quantitative research functioned as a supplemental component which expanded on the core qualitative data. [233]

Figure 4. Illustration of the sequential exploratory design to mixed methods research as outlined by Creswell et al adapted by Bishop, 2015 [231]*



**Capitals indicate component is typically emphasised or prioritised in the design. Lower case indicates component is used in a supportive capacity.*

To further illustrate this approach I will explain how the different steps in the thesis were timed and the emphasis placed on each. The mixed methods systematic review was conducted first and is reported in Chapter 5. The systematic review findings were analysed and synthesised using a meta-ethnographic approach which is a recognised method of synthesising qualitative data.[234] The next step, described in Chapter 6, was a qualitative study with GPs and explored their experiences of the challenges of managing BPSD. The methodological approach used was descriptive interpretative and the method of analysis was thematic analysis as outlined by Braun and Clarke.[101] In the qualitative study a specific concern was raised by GPs on the challenges of identifying potential causes of BPSD, in

particular pain. This led to the concept for a quantitative descriptive cross-sectional study of GPs' knowledge of and attitudes towards pain management in dementia, which is reported in Chapter 7. A further questionnaire based survey that aimed to assess GPs' attitudes to prescribing antipsychotics in BPSD is reported in Chapter 8. An eDelphi consensus study was employed to achieve consensus on some of the clinical components of the intervention is reported in Chapter 9. The findings from these five studies were then used to inform the development of the intervention in Chapter 8. The intervention development process incorporated behaviour change theory and was facilitated by expert consensus meetings. Finally, the clinical content of the intervention was finalised with qualitative input from stakeholder experts in semi-structured interviews.

Combining these two lines of inquiry (quantitative and qualitative) is not without its challenges. Philosophically, quantitative approaches are traditionally associated with a positivist epistemology while qualitative research approaches are traditionally associated with constructivist or interpretive epistemology. [235] A positivist epistemology assumes there is an absolute knowledge and an objective reality, with the researcher and the researched acting as independent entities. [235] On the other hand, an interpretative epistemology is tied to the ontological position of relativism – the view that reality is subjective and that truth is only knowable through our own conceptual frameworks which, of course, differ from person to person. [231] In this thesis the integrity of each research component was maintained. However, the ontological perspective that underpins the pragmatic approach adopted for this research is one of subtle realism. Subtle realism assumes that we can only know reality from our own perspective of it. The role of the researcher and the influence of the researcher on how the research is interpreted is, therefore, paramount.

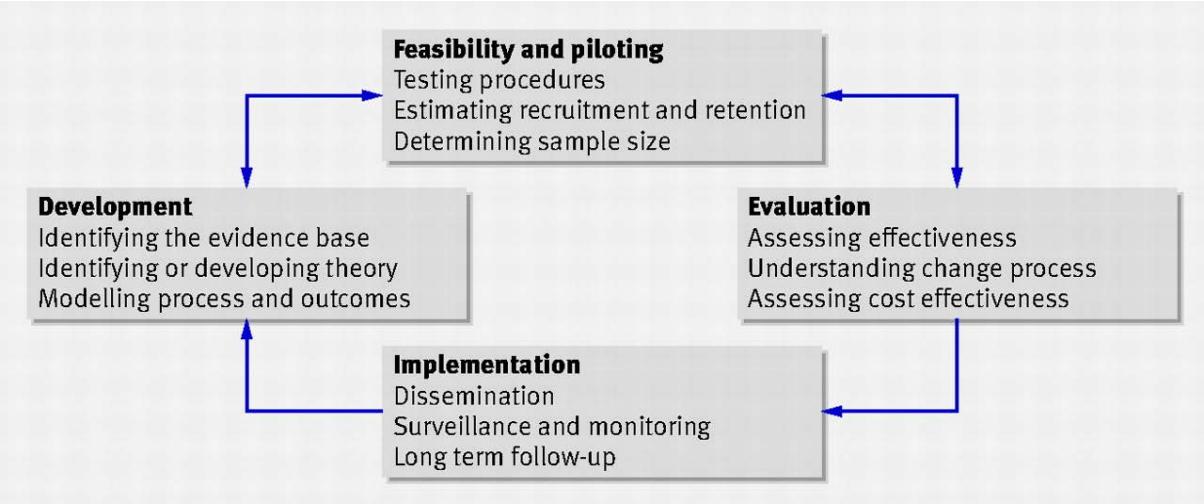
My experience as a GP, who has worked extensively managing BPSD both in the community and in nursing home settings, undoubtedly influenced the topic under scrutiny. My own experiences adjusted the lens with which I conducted and analysed the research. I have worked in a variety of urban and rural general practices. The provision of nursing home care has always been a significant part of my workload as a GP. I have had significant exposure to, and experience with, providing medical care in large and small nursing homes, community hospitals and in residential care settings. I have witnessed the provision of what was, in my opinion, suboptimal care in nursing homes and I have also witnessed the provision of optimal care. In the community setting, I have worked within functioning, proactive primary care teams and I have worked without the support of a primary care team. Furthermore, I qualified as a GP during the economic crash and I have witnessed some of the changes in the funding of general practice that accompanied the economic crash. I have my own personal experiences of how dementia care is provided in nursing homes and in the community. Undoubtedly this has altered my own approach to clinical practice and to how I approached this research. The impact of my own professional experiences and background is acknowledged within the methods sections and occasionally in the limitation sections of the individual chapters that follow.

4.2 METHODOLOGICAL FRAMEWORK

The overall research design is a theory-based, predominantly qualitative, approach to the development of an intervention to improve the management of BPSD in general practice. The methodological approach chosen follows a structured, systematic and transparent approach to the design of an intervention that targets GPs' management of BPSD.

The UK Medical Research Council (MRC) framework for developing complex interventions was the overarching framework for this thesis. (See Figure 4). The MRC framework proposes a phased approach to the development and evaluation of complex interventions.

Figure 5. MRC Framework for the development and evaluation of complex interventions



4.2.1 MRC phase 1: Intervention Development

The first phase of the MRC framework for developing and evaluating a complex intervention focuses on the intervention development. The focus of this thesis is only on this first phase of the MRC framework. This thesis concentrates exclusively on this first part of the MRC framework and explores two of the sub-sections of this phase; identifying the evidence base and identifying or developing theory.

Identifying the evidence base

As outlined in chapter 3 there is a paucity of research on the management of BPSD in general practice. Consequently, it was necessary to conduct research in this area to provide an evidence base that would inform the intervention development process.

Existing evidence

The existing evidence on GPs' knowledge of, attitudes towards and experiences with BPSD was systematically reviewed. To ensure all relevant literature was included, a mixed methods approach was undertaken ensuring all relevant quantitative and qualitative studies were eligible for inclusion in the review. The methodological approach adopted is described in detail in chapter 5.

New evidence

The existing evidence identified from the mixed methods systematic review was supplemented with evidence generated from two new studies:

(i) The first study was a qualitative study with GPs exploring the challenges they experience when managing BPSD and to explore how these challenges influence their management decisions in BPSD. This was a descriptive interpretative study and data analysis followed the principles of thematic analysis as outlined by Braun & Clarke. [101] Further information on the methodological approach employed is outline in chapter 6.

(ii) The second study was a quantitative study that examined GPs' knowledge of and attitudes towards the management of pain in dementia. Assessing and managing pain was identified in the qualitative study as a particularly challenging aspect of managing BPSD. Pain is a common trigger for BPSD, yet pain is underdiagnosed

and undertreated in people with dementia. This study was a cross-sectional descriptive study using questionnaires which were distributed to a representative sample of GPs in Ireland. Statistical analysis was completed using SPSS. A detailed description of the methodology used is available in chapter 7.

(iii) The third study was also a descriptive cross-sectional study which assessed the attitudes of GPs to the prescribing of antipsychotics in BPSD. Statistical analysis was completed using SPSS. This study is reported in detail in chapter 8.

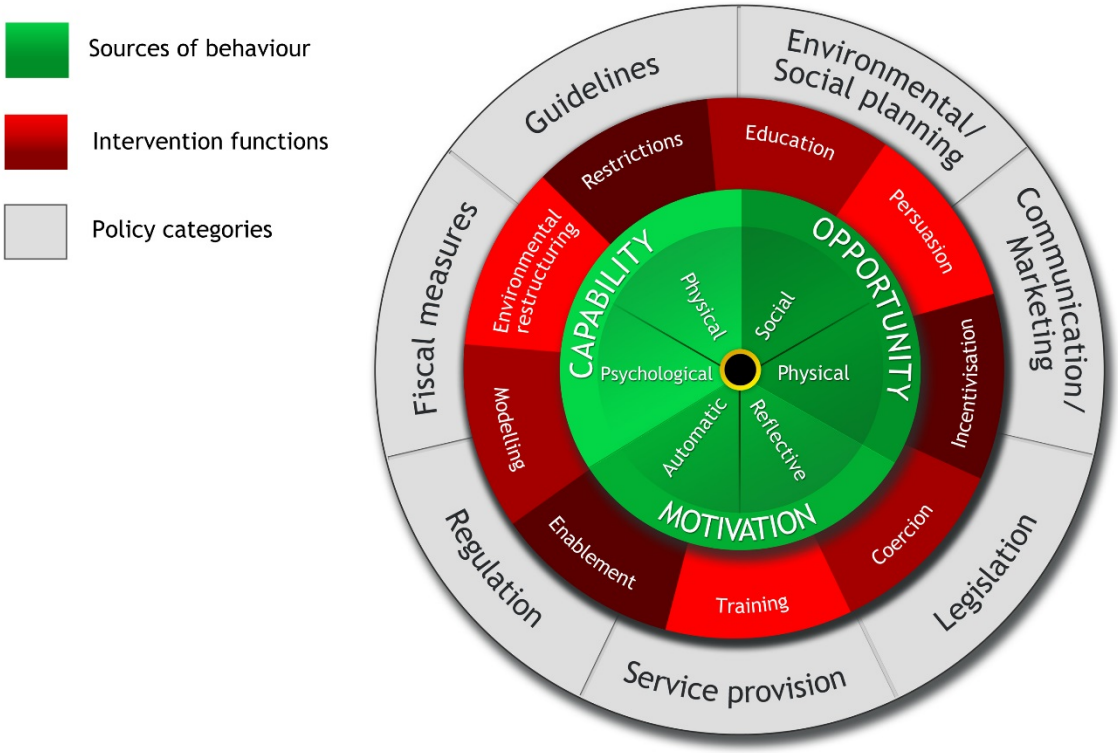
Identifying theory and modelling process and outcomes

The MRC guidance advocates for the use of theory to inform intervention design. The limited success of efforts to implement interventions has previously been attributed to a lack of an explicit rationale for the intervention chosen and the use of inappropriate methods to design interventions. [236] Theory can overcome these issues by providing an explicit statement of the structural and psychological processes that are hypothesised to influence behaviour, thus informing the design of practice change interventions and allowing structured investigation of implementation difficulties. [237] By adopting a theory-based approach to the development of an intervention one targets the causal determinants of behaviour and behaviour change, thus developing a more effective intervention. [238] The Behaviour Change Wheel (BCW) developed by Michie et al describes a structured, reproducible approach to applying behavioural theory to intervention development. [239] (See Figure 6)

In this thesis, the BCW was used to explicitly integrate behaviour theory with the evidence generated in chapters 5, 6, 7 and 8 to develop a complex intervention for BPSD targeted at

GPs. In chapter 10 there is a detailed description of how the BCW was used, within the overarching MRC framework, to design the intervention with input from an expert panel.

Figure 6. The Behavioural Change Wheel [239]



CHAPTER 5: GPs KNOWLEDGE OF, ATTITUDES TOWARDS AND EXPERIENCES WITH THE MANAGEMENT OF BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA: A MIXED METHODS SYSTEMATIC REVIEW AND META-ETHNOGRAPHY

PART ONE: THE PROTOCOL

GPs KNOWLEDGE OF, ATTITUDES TOWARDS AND EXPERIENCES WITH THE MANAGEMENT OF BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA: A PROTOCOL FOR A MIXED METHODS SYSTEMATIC REVIEW AND META-ETHNOGRAPHY

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5.1.1 ABSTRACT

Background

In the context of rising dementia prevalence the workload of General Practitioners (GPs) in dementia care is set to increase. However, there are many aspects of dementia care that GPs find challenging. Behavioural and psychological symptoms of dementia (BPSD) affect the majority of people with dementia and is an aspect of dementia care that GPs find particularly difficult to manage. The aim of this mixed method systematic review is to undertake a synthesis of qualitative and quantitative studies on GP's knowledge, attitudes and experiences of managing BPSD.

Methods

Seven electronic bibliographic databases will be searched from inception to present. All qualitative or quantitative studies that explore the knowledge, attitude or experiences of GPs towards the management of BPSD in community and/or residential settings will be eligible for inclusion. A meta-ethnography will be conducted to synthesise included studies. Primary outcome measures will include GPs' experiences of managing BPSD, GPs' knowledge of BPSD and their attitude to different approaches to the management of BPSD, in particular their attitude to non-pharmacological approaches. All included papers will be independently assessed for methodological validity by two reviewers using the following tools; the Joanna Briggs Institute checklist for qualitative research, the Effective Public Health Practice Project (EPHPP) tool for intervention studies and the National Institute of Health (NIH) quality assessment tool for observational and analytical cross-sectional studies. As there is no agreed quality assessment tool for descriptive cross-sectional studies an original tool will be developed. Two independent reviewers will apply the Confidence in the

Evidence from Reviews of Qualitative Research (CERQual) tool to the review findings. The results will be reported in line with the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) statement.

Discussion

This study will be the first systematic review that synthesises the existing literature of GPs' knowledge, attitudes and experiences of managing BPSD in community and residential care. This review will improve our understanding of GPs' perspectives on the management of BPSD and the results will be used to inform the development of an intervention to improve the management of BPSD in general practice.

Systematic review registration

PROSPERO CRD42017054916

5.1.2 BACKGROUND

General practitioners play a pivotal role in the care of a person with dementia and their families [6]. It is estimated that there are currently 47 million people living with dementia worldwide and this figure is predicted to triple by 2050 [10]. In the context of rising dementia prevalence [11] the dementia workload of general practitioners (GPs) is set to increase further. National dementia strategies have been developed internationally to respond to the challenge posed by increasing dementia prevalence and have emphasized the central role of GPs in successful implementation [28-30]. GPs find many aspects of dementia care, such as diagnosis disclosure and co-ordinating support services, to be challenging [86]. However, the one area that consistently emerges as a particularly challenging aspect of dementia care for GPs internationally is the management of behavioural and psychological symptoms of dementia (BPSD) [86-90].

BPSD encompasses a wide range of symptoms and behaviours that affect people with dementia. BPSD includes behaviours such as aggression, wandering, sexual disinhibition, agitation and symptoms such as anxiety, depression and delusions. These symptoms and behaviours often overlap and occur together rather than occurring as isolated symptoms [91]. The majority of people with dementia will experience BPSD [92]. Estimates of BPSD prevalence vary [105,106] and we know the presence of BPSD can be influenced by several factors including dementia severity [107], however, some studies estimate that up to 80% of people with dementia experience at least one symptom of BPSD at some stage in their illness [106]. The presence of BPSD results in increased rates of admission to long term care facilities [93 128] and longer in-patient hospital stays [113]. The development of BPSD is also associated with a worse prognosis for the patient and a more rapid rate of illness progression [240]. From a carer

perspective, BPSD is a major contributor to stress and depression, even more significant than cognitive decline [116]. For physicians, the assessment of BPSD is complex and effective treatment options are limited [104]. Antipsychotics are associated with serious adverse effects including stroke [158-160] and are not recommended unless there is a serious risk to self or others [187], however, credible pharmacological alternatives remain scarce [188]. There is agreement that in most cases non-pharmacological interventions should be used first line [241], however, effective non-pharmacologic strategies for BPSD have not been translated into real-world clinical practice [151] and are not viewed by many GPs as being credible options [152].

If GPs are to play the pivotal role described in the various national strategies then interventions will be needed to support GPs in their management of BPSD, however, we are unaware of any such interventions. An important first step in intervention design is to establish a thorough understanding of existing behaviour [239,242]. To date no qualitative or quantitative synthesis has been performed on studies which focused on GPs' perspectives on the management of BPSD in community and residential care settings. Primary quantitative studies performed to date, [80,152], have been conducted in different contexts and at different times in the evolution of the management of BPSD. Likewise qualitative studies in this area [153,243], were conducted in different healthcare systems and took different approaches to the evidence. Exploring these contextual differences will improve the depth of our overall understanding of the research question. In order to effectively address our research aim we will include both relevant quantitative and qualitative studies, as a review which "focuses exclusively on one form of evidence presents only half the picture and thus will have limited applicability" [244].

The aim of this mixed methods systematic review is to develop a synthesis of qualitative and quantitative studies on GPs' knowledge, attitudes and experiences of managing BPSD in order to develop a conceptual understanding of the perspective of GPs on the management of BPSD. The results of this systematic review will subsequently inform the development of a future behavioural change intervention.

5.1.3 METHODS

This review protocol was developed using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocol (PRISMA-P) [245] (available in Appendix 1, supplementary material 1). The systematic review was registered with the International Prospective Register of Systematic Reviews (PROSPERO) on the 11th of January 2017 and was last updated on the 25th of July 2017 (registration number 42017054916).

Methodological framework

This mixed methods systematic review will take an integrated approach to synthesis as described by Sandelowski et al. [244,246]. The integrated approach involves assimilating study findings into each other as opposed to the segregated approach, which involves separate qualitative and quantitative syntheses (see Figure 7) [246,247]. The assimilation approach is particularly appropriate when findings are viewed as confirming each other or converging in the same direction [247]. The integrated approach will involve transforming quantitative data, usually obtained from GPs' responses to standardised questionnaires, into qualitative form so that it can be combined with data from qualitative studies and subjected to qualitative analysis. This approach has been used effectively in previous mixed method systematic reviews of similar research questions [120,248]. Once the data is in qualitative form our

approach to qualitative synthesis will follow the seven step model of meta-ethnography as described by Noblit and Hare [234] (see Table 1). Meta-ethnography is explicit when describing the act of 'translation' where terms and concepts which have resonance are enveloped into 'high order constructs' [249] and goes beyond merely describing or summarising the data allowing an original interpretation of the topic under review.

Figure 7. The Integrated Approach to Mixed Method Systematic Review *(adapted from the JBI Reviewers' Manual: Mixed Methods Systematic Reviews)*

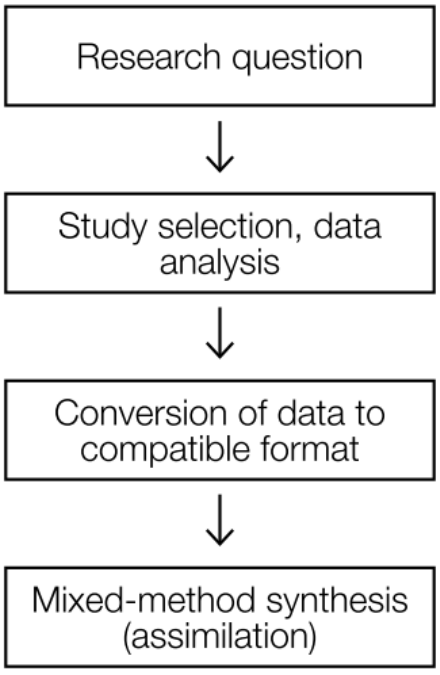


Table 1. Seven steps of Noblit and Hare's meta-ethnography

1. Getting started
2. Deciding what is relevant to the initial interest
3. Reading the studies
4. Determining how the studies are related
5. Translating the studies into one another
6. Synthesising translations
7. Expressing the synthesis

Syntheses of qualitative data have been criticised as being mechanistic. Indeed there is the risk with meta-ethnography that the richness or integrity of the original work will be lost [250], a concern that by overly deconstructing the original qualitative work the researcher attempts to "sum up a poem" [251]. However, when conducted rigorously, a synthesis of qualitative studies leads to a more substantive interpretation of the research phenomenon than is available from a single study [252]. Rather than attempting to totalise concepts, a synthesis of qualitative literature aims to offer fresh new insights into the phenomenon of interest [253]. In order to achieve a deeper understanding of the shared meanings of the area under review, it is essential that rigour is applied to each stage of the review process. In this review all efforts will be made to retain the content and context of the original studies throughout the data extraction and analysis. Each stage of the review process will involve at

least two authors working independently. At every stage a third author, experienced in performing meta-ethnographic synthesis, will be available for consultation.

We will report our results in line with the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) statement [254] and we will express our search strategy results using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram [255].

Eligibility Criteria

Qualitative or quantitative studies that explore the knowledge, attitude or experiences of GPs towards the management of BPSD in nursing homes and/or in the community setting will be eligible for inclusion. All study designs will be included. Qualitative studies that focus more generally on GPs' perspectives on dementia management will be included only if there is a specific reference to BPSD in the results. Quantitative studies that focus on the knowledge and attitude of GPs to other aspects of dementia care will only be included if there is a specific reference to BPSD in the results. Randomised control trials and other intervention studies will be included in the review if they identify the knowledge-base or attitude of GPs towards BPSD during the study. Opinion pieces and non-peer-reviewed articles will be excluded. Studies not written in the English language will be excluded. This is due to resource limitations which prevent employment of formal translation services. However, if eligible non-English language studies are identified, we will attempt to contact the study authors to see if there are any English translations available. A list of possibly relevant titles in other languages will be provided as an appendix. Studies that do not describe in detail the knowledge and attitudes of GPs in relation to BPSD will be excluded. Studies that report on the perspective of non-GP healthcare professionals to BPSD in

addition to GPs will be included so long as the views of GPs are represented or analysed separately. See table 2 for eligibility criteria.

Table 2. Eligibility Criteria for studies in the systematic review

Inclusion Criteria	Exclusion Criteria
- Studies that explore the knowledge, attitude or experiences of GPs in the management of BPSD in residential settings and/or in community setting. - Qualitative or quantitative study design - Studies must include GPs	- Studies that do not describe in detail the knowledge and attitudes of General Practitioners in relation to BPSD - Non-English language studies - Studies reporting the perspective of non-GP healthcare professionals where the views of GPs are not represented or analysed separately - Studies reporting on GPs' perspectives on managing another aspect of dementia without any reference to the management of BPSD - Opinion pieces and non-peer reviewed articles

Information Sources & Search Strategy

We will search the following seven electronic bibliographic databases from inception to present with no date limits; MEDLINE (Ovid) 1946- present, EMBASE (Elsevier), CINAHL, PsycINFO, Academic Search Complete, SocIndex, Social Science Full Text. The search

strategy has been developed using database-specific search terms with input from the review team and a health services librarian with expertise in systematic review searching. The MEDLINE search strategy is available in table 3. How these search terms will be combined with Boolean logic are available in Appendix 1, supplementary material 2. Other search methods utilised will include; hand-searching key journals and conference proceedings, forward citation searching of eligible studies and searching reference lists of included studies.

Table 3. The Medline, Ovid search strategy

	Primary Care Physicians	**Dementia**	**BPSD**
MeSH Terms/ Subheadings	Exp Primary Health Care/ Exp General Practice Family Practice/ Exp General Practitioners/ Exp Physicians, Family/ Exp Physicians, Primary Care/	Exp Dementia/ Exp Alzheimer Disease/	Exp Antipsychotic Agents/ Exp Anxiety/ Exp Aggression/ Exp Wandering behavior/ Exp Sleep Disorders/ Exp Apathy/ Exp Irritable Mood/ Exp Psychotic Disorders/ Exp Depression/
Text Words	family medicine.ti,ab	dementia.ti,ab. alzheimer*.ti,ab. (cognitive adj (impairment or decline)).ti,ab	Behavio?ral and psychological symptom*ti,ab BPSD.ti,ab Challenging behavio?r*ti,ab Responsive behavio?r*.ti,ab Neuropsychiatric symptom*.ti,ab Non-cognitive symptom*.ti,ab Noncognitive symptom*.ti,ab Psychological symptom*.ti,ab Psychiatric symptom*.ti,ab Difficult behav*.ti,ab Disruptive behav*.ti,ab Behavio?ral symptom*.ti,ab

			(agitated or agitation).ti,ab (depressed or depression).ti,ab (anxiety or anxious).ti,ab (aggressive* behav*).ti,ab

Data Management

A flow diagram using PRISMA guidelines will be used to report the selection process and all results. The results of our search will be exported to Covidence (www.covidence.org). Duplicates will be identified and removed. Covidence will then be used to manage citations, and perform title and abstract screening.

Study Selection

At the first stage duplicates and clearly irrelevant studies (for example pre-clinical studies) will be removed. In the next stage abstract screening will be conducted. To manage the workload that may result from a large number of citations four reviewers (AJ, TF, AC, CB) will form three paired teams; AJ and TF, AJ and AC, AJ and CB. The search results will be randomly divided into three groups and assigned to a paired team. The two reviewers in each paired team will independently screen each study abstract and assess the study's suitability for inclusion based on pre-determined inclusion and exclusion criteria. Conflicts will be resolved through discussion and where necessary a third reviewer, selected from a different paired team, will act as adjudicator. Subsequently all potentially eligible studies included in full-text screening will be assigned to a paired team for eligibility assessment. Any conflicts regarding the eligibility of a study at full-text screening will be resolved through discussion between the two members of the paired team. Where consensus is not reached through discussion a third reviewer, selected from a different paired team, will

adjudicate and make the final decision regarding inclusion. All studies that are excluded after full-text screening will be displayed, with their reason for exclusion, as an appendix in table form.

Data extraction, analysis and synthesis

We will follow the meta-ethnographic approach as described by Nobilt and Hare when extracting, analysing and synthesising the data. This stage of the review process maps to steps 3- 7 of the meta-ethnographic approach [see Table 1].

Data Extraction

The data extraction and analysis stage will involve four of the reviewers (AJ, TF, KW, CB). All four reviewers will independently read and re-read all the eligible studies in chronological order focusing initially on the content and context (step 3 of meta-ethnography approach). Data concerning participant characteristics, aims, setting and methods will be extracted independently by two reviewers (AJ, TF) and displayed in tabular form. Data extraction will be facilitated by the use of standardised data extraction tables. The data extraction forms will be pilot tested by the reviewers on the first two included studies to ensure consistency and reliability between reviewers. A third reviewer (KW) will oversee the data extraction process and will be available for consultation. If necessary we will contact the study authors to resolve any uncertainties. Table 4 shows data categories that will be extracted from all the included studies.

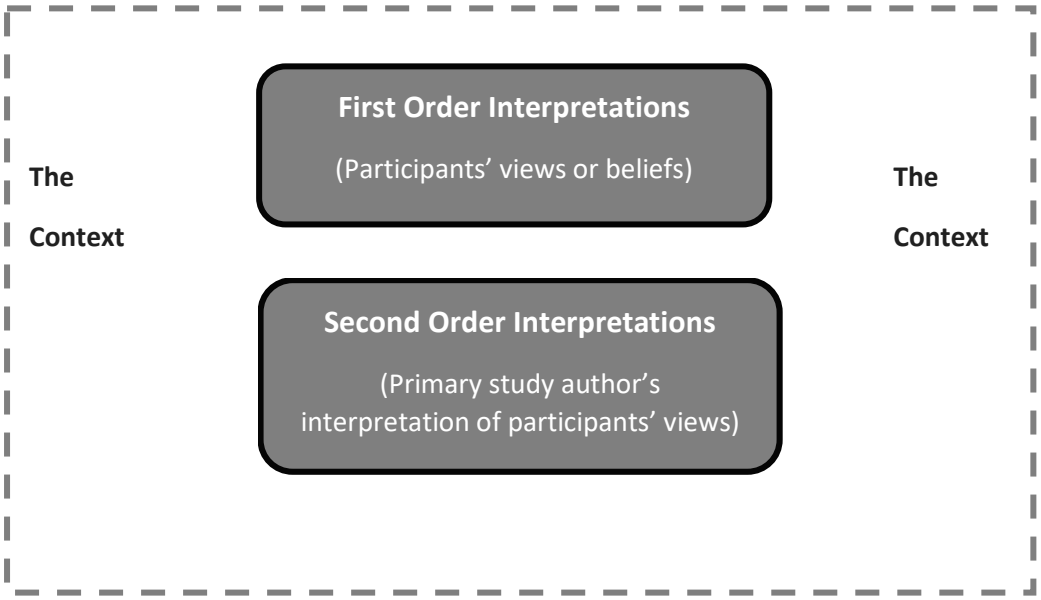
Table 4. Data extraction categories

1. Author
2. Date
3. Country
4. Study Objectives
5. Study Design
6. Analysis
7. Participant Characteristics
8. Setting

Data analysis & synthesis

The lead author (AJ) will open code all the included studies focusing specifically on the first and second order interpretations (Figure 8). First order interpretations refer to the participants' views as they are reported in the results section of the study. In the qualitative studies the first order interpretations will focus on attitudes and experiences of GPs. In the quantitative studies the first order interpretations will involve creating a text file that describes participants' responses to questionnaire items. In the studies that include other healthcare professionals, the study findings, where possible, will be restricted to the views of GPs. Second order interpretations refer to the original study author's interpretation of the participants' views usually found in the discussion section. In the qualitative studies, author-derived themes, conclusions, interpretations, recommendations will form the basis of the second order interpretations. In the quantitative studies the second order interpretations will be derived from the results, recommendations and conclusions. The data will be extracted verbatim for all the included studies to ensure no valuable detail is lost. All efforts will be made to retain the context of the findings from both the qualitative and the quantitative studies during data extraction [256]. At this point the data collected from quantitative and from qualitative studies will be no longer distinguishable in terms of study design, enabling the synthesis of all the data in qualitative form.

Figure 8. First and Second Order Interpretations



We acknowledge that performing the second order interpretations can be challenging as the value of second order constructs lies to an extent in the richness and depth of the analysis performed by the original authors [257]. To ensure credibility and dependability of coding a second reviewer (KW) will code a random selection of studies. Conceptual groupings for each study will be created and illustrated with the development of conceptual mind maps. The two reviewers involved (AJ, KW) will meet regularly to discuss differences in interpretation of the studies. A third reviewer (CB) will oversee the data analysis process and will be available for consultation. Finally all four members of the data extraction and analysis team (AJ, KW, CB, TF) will meet to discuss the key concepts emerging from the analysis of the included studies. The software package NVivo version 11 will be used to facilitate data analysis and synthesis.

Step 4 of the meta-ethnographic approach involves *determining how studies are related* to each other. To facilitate this step a table will be developed to display the identified concepts and themes across all the studies. Relationships between the conceptual groups and themes will be organised and illustrated by the use of conceptual maps. Step 5 of the meta-ethnography involves *translating the studies into one another*. To examine the contribution of each study to a key concept the review team will compare the themes and concepts from study 1 with study 2 and the synthesis of these two studies with study 3 and so on. This process will be conducted in chronological order starting with the earliest study [257]. A chronological approach is appropriate as the included studies are likely to range over multiple decades, during which time significant changes in the management of BPSD occurred. Within the key concepts attention will be paid to deviant cases. Two authors (AJ, KW) will perform reciprocal and refutational analyses to summarise shared themes across the studies. We will attempt at all times to consider the influence of context to the study finding, however, we acknowledge that this may be difficult as previous meta-ethnographies have reported on the challenges of retaining the context of the primary studies when contextual information is often poorly reported [257]. Step 6 will involve *synthesising the translations* in each key concept to iteratively develop third-order interpretations. A synthesis of first and second order interpretations, the third-order interpretations constructs a new model or theory about a problem. The synthesis team (all authors) will link the third-order interpretations into a 'line of argument' which will represent the overarching perspective of GPs towards BPSD. The final step in the meta-ethnography approach involves *expressing the results of the synthesis*. For this step we will use tables, figures and text.

Assessment of confidence in the study findings

Two independent reviewers (AJ, KW) will apply the Confidence in the Evidence from Reviews of Qualitative Research (CERQual) tool to the review findings (i.e. third order interpretations) as conducted in a recent meta-ethnography [3]. The CERQual approach provides a transparent method of assessing the confidence of findings of systematic reviews of qualitative research [258]. There are four key components to the CERQual approach; (i) methodological limitations of the qualitative studies contributing to a review finding, (ii) the relevance to the review question of the studies contributing to a review finding, (iii) the coherence of the review finding, and (iv) the adequacy of data supporting a review finding. Judgements relating to each CERQual component will be summarised in table form. Each review finding will be rated and given an assessment of confidence as high, moderate, low or very low. We will assign high confidence if it is highly likely, moderate confidence if it is likely, low confidence if it is possible and very low confidence if it is unclear if the review finding is a reasonable representation of the phenomenon of interest [258].

Outcomes

Primary outcome measures will include GPs' experiences of managing BPSD, especially their confidence in this field. GPs' knowledge of strategies to manage BPSD and their attitude to different approaches to the management of BPSD, in particular the role of non-pharmacological approaches will also be included. Additionally we will seek to identify data on GPs' needs with respect to skill levels and competencies in this field.

Quality Assessment

All included papers will be independently assessed by two reviewers (AJ, JB) for methodological validity. Agreement on the quality assessment will be measured using Cohen's Kappa and in consideration of previous literature in this area values greater or equal to 0.6 will be considered an acceptable level of agreement [259]. Disagreements will be resolved by discussion between the two reviewers. Given the large number of study designs that will potentially be included in the study a number of quality assessment tools will be required.

The quality assessment tools that will be used to assess the quality of the quantitative studies have been agreed through consultation with the systematic review team. The Effective Public Health Practice Project (EPHPP) tool will be used for intervention studies [260]. The National Institute of Health (NIH) quality assessment tool for observational and analytical cross-sectional studies will be used where appropriate [261]. Since there is no agreed quality assessment tool for assessing the quality of descriptive cross-sectional studies a new original tool will be developed by two of the reviewers (AJ, JB) that will be based on other original tools developed for a similar purpose [248,262]. This new tool will also consider recommendations on how survey questionnaires should be designed [263].

There are a number of quality appraisal tools available for assessing the quality of qualitative studies [264]. However, it is recognised that critical appraisal instruments for qualitative research differ in the criteria they apply to a critical appraisal process [265]. On examining potential quality assessment tools it is clear that many of the existing appraisal instruments for qualitative research use quite broad criteria that often reflects the quality of the *reporting* of the research rather than addressing the core quality issues inherent to

qualitative research; such as issues relating to the credibility, dependability, confirmability and transferability of the research. Qualitative studies may rate as "low quality" when assessed as a result of methodological flaws, a poorly designed quality assessment tool or simply because of lack of reporting; which can often be a consequence of meeting tight word count deadlines for journals. However, these studies may still generate novel concepts and insights [266]. As Dixon-Woods observes some of the most important qualities of qualitative research can be the hardest to measure [267] Appraisal tools, generally, focus on the methodological strength of the paper rather than its conceptual strength [268]. However, a qualitative study that has clearly reported its methods may not generate rich interpretation of the phenomenon of interest. Likewise, a qualitative study that appears to have face validity and offers rich, insightful interpretations might not necessarily do well on quality assessment [257]. This then leads to questions on whether the quality of qualitative can be legitimately judged, or indeed whether it should be judged at all [269].

We have chosen to assess the quality of the qualitative studies. However, quality appraisal will not be used to exclude qualitative or quantitative studies that otherwise meet the inclusion criteria. The CERQual assessment requires an evaluation of the methodological limitations of each of the studies that supports each third order interpretation [258]. Therefore, the quality assessment given to the studies will influence the confidence rating we can give to each review finding. A poor quality assessment will not, on its own, alter the confidence assessment but the results of quality assessment will be considered as part of a wider assessment of the confidence we have in our review findings which will be assessed using the CERQual assessment.

Following a process of consultation and discussion between the members of the review team the Joanna Briggs Institute Critical Appraisal Checklist for Qualitative Research was chosen as the quality assessment tool that will be used to assess the qualitative studies [270]. This particular quality assessment tool was chosen as it was found to focus on the quality of the study design rather than just the reporting rigour. Additionally, this quality assessment tool is specifically designed for use in systematic reviews.

5.1.4 DISCUSSION

This study will be the first systematic review that synthesises the existing literature of GPs' knowledge, attitudes and experiences of managing BPSD in community and residential care. This review will contribute to improved understanding of GPs' perspectives on the management of BPSD. We know that BPSD is a challenging area of dementia care for GPs [86,87], however, this mixed method synthesis of all the available quantitative and qualitative research in this field will offer fresh insights and interpretations into *why* this is a challenging area for GPs. The findings of this review can then be used to inform the development of interventions to improve the management of BPSD in primary care. We believe this review will expose gaps in the literature, gaps that should be the focus of future research. Additionally this review will be valuable to policy makers and health care providers who are attempting to implement national dementia strategies, as many of these strategies depend upon general practitioners taking on an increasing amount of dementia care. In order to effectively implement these strategies the current barriers and facilitators of managing this particularly challenging aspect of dementia in primary care need to be identified and addressed. The use of CERQual will provide policy-makers with a transparent method for assessing the confidence of the review findings.

Strengths and limitations

This systematic review is being conducted as part of a wider national project which is one of the implementation work-streams of the Irish National Dementia Strategy [29]. Due to time constraints associated with the wider project this review will not include a search of the grey literature. However, since our search of the electronic databases will be extensive we feel that the grey literature is unlikely to result in any additional eligible peer-reviewed study.

Existing validated approaches for synthesising quantitative and qualitative data for mixed method systematic reviews will be followed [246,247], however we recognise that the potential heterogeneity of the evidence may make this synthesis challenging. The benefit of using a mixed methods approach here is that it will enable us to integrate the quantitative assessments of GP's knowledge of and attitudes towards BPSD with a more qualitative understanding of GP's experiences of BPSD. Combining these two sources of data into a systematic review will enhance the review's utility and impact. The development of a new original tool to assess the quality of descriptive cross-sectional studies will be a strength of this review. The tool will be useful for researchers undertaking similar mixed methods systematic reviews. Finally, the application of the CERQual tool to our review findings will provide a validated summary of the confidence we have in the study findings.

CHAPTER 5

PART TWO: THE SYSTEMATIC REVIEW

GPs KNOWLEDGE OF, ATTITUDES TOWARDS AND EXPERIENCES WITH THE MANAGEMENT OF BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA: A MIXED METHODS SYSTEMATIC REVIEW

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5.2.1 ABSTRACT

Objectives

To synthesise the existing published literature on GP's knowledge, attitudes and experiences of managing behavioural and psychological symptoms of dementia (BPSD) with a view to informing future interventions.

Methods

We conducted a systematic review and synthesis of quantitative and qualitative studies that explored GPs' experiences of managing BPSD (PROSPERO protocol registration CRD42017054916). 7 electronic databases were searched from inception to October 2017. Each stage of the review process involved at least two authors working independently. The meta-ethnographic approach was employed to synthesise the findings of the included studies while preserving the context of the primary data. The Confidence in the Evidence from Reviews of Qualitative research (CERQual) was used to assess the confidence in our individual review findings.

Results

Of the 1,638 articles identified, 76 full texts were reviewed and 11 were included. Three main concepts specific to GPs' experiences of managing BPSD emerged; unmet primary care resource needs, justification of antipsychotic prescribing and the pivotal role of families. A 'line of argument' was drawn which described how in the context of resource limitations a therapeutic void was created. This resulted in GPs being over reliant on antipsychotics and

family caregivers. These factors appeared to culminate in a reactive response to BPSD whereby behaviours and symptoms could escalate until a crisis point was reached.

Conclusion

This systematic review offers new insights into GPs' perspectives on the management of BPSD and will help to inform the design and development of interventions to support GPs managing BPSD.

5.2.2 INTRODUCTION

General practitioners (GPs) play a pivotal role in the care of people with dementia and their families [5-7]. National strategies developed to address the increased prevalence of dementia [11] have emphasized the role of GPs in successful implementation [28,29,271] but dementia care in the community can be challenging [72,272]. In common with their hospital-based colleagues [273] GPs find the management of the behavioural and psychological symptoms of dementia (BPSD) particularly difficult [87,88,90,198].

BPSD encompasses behaviours such as aggression, wandering, sexual disinhibition, agitation and symptoms such as anxiety, depression and delusions. Most people with dementia will experience BPSD at some time during their illness [103]. BPSD is associated with increased rates of admission to nursing homes [114], longer in-patient hospital stays [113] and is a major contributor to caregiver stress and depression [116]. The assessment of BPSD is complex [108] and effective treatment options are limited. Non-pharmacological interventions are recommended as the first line of treatment in most cases [187]. Personalised non-pharmacological interventions such as personalised music therapy [144,148] and formal caregiver training to enhance communication skills [148] may have a role in the management of BPSD, however, uptake of non-pharmacological strategies is low [151]. Psychotropic medications such as antipsychotics, anxiolytics, hypnotics and antidepressants are frequently used to manage BPSD [156,157]. Antipsychotics are the most commonly prescribed psychotropic in BPSD [157], however, the benefits of antipsychotics in BPSD are modest at best [160]. Furthermore, in BPSD any benefits are usually offset by the significant adverse effects of antipsychotics in dementia, including increased risk of cerebrovascular events and increased mortality [158-160,196]. However, based on current available evidence, pharmacological

alternatives to antipsychotics in BPSD are largely ineffective [177,178,182,274,275]. Although there may be a role for citalopram in managing milder agitation [163], it too can result in significant side-effects including QT prolongation and worsening of cognitive impairment [164].

There is a need for interventions designed to support GPs in their management of BPSD. An important first step in intervention design is to establish a thorough understanding of the existing problem [239,242]. The aim of this systematic review was to gain a deeper understanding of GPs' knowledge, attitudes and experiences of managing BPSD. It will also inform the development of an intervention to assist GPs with the management of BPSD.

5.2.3 METHODS

We performed a systematic review of studies that used qualitative or quantitative methods to explore GPs' experiences of managing BPSD. A mixed methods approach was employed to ensure all relevant literature was included [244]. To synthesise the qualitative and quantitative results an integrated design was adopted [246]. This involved transforming quantitative data obtained from GPs' responses to standardised questionnaires into qualitative form so that it could be combined with data from qualitative studies and subjected to qualitative analysis. Once the data was in qualitative form, the synthesis was guided by the meta-ethnographic approach as described by Noblit and Hare [234]. Meta-ethnography goes beyond merely describing or summarising the literature: the aim is to use the source material to develop original interpretations by accounting for both the context of the research and the reported findings. Further detail on the methodological approach employed is available in the published protocol for this review. [276]

Table 5 outlines the eligibility and exclusion criteria. We included all studies that explored the knowledge, attitude or experiences of GPs in the management of BPSD in the community and in nursing home settings. Studies that did not describe in detail the knowledge and attitudes of practising GPs in relation to BPSD were excluded. Studies that focused on GPs who sub-specialised in elderly care medicine and now work exclusively as specialist elderly care physicians in nursing home settings[277] were excluded from this review. It was considered that, as a result of their specialist training, the knowledge and attitudes of these specialist elderly care physicians towards BPSD would not be representative of GPs generally.

Table 5. Inclusion and Exclusion Criteria

Inclusion Criteria	**Exclusion Criteria**
- Studies that explore the knowledge, attitude or experiences of GPs in the management of BPSD in residential settings and/or in community setting. - Qualitative or quantitative study design - Studies must include GPs	- Studies that do not describe in detail the knowledge and attitudes of General Practitioners in relation to BPSD - Non-English language studies - Studies reporting the perspective of non-GP healthcare professionals where the views of GPs are not represented or analysed separately - Studies reporting on GPs' perspectives on managing another aspect of dementia without any reference to the management of BPSD - Opinion pieces and non-peer reviewed articles

7 electronic bibliographic databases were searched from inception to present; MEDLINE (Ovid), EMBASE (Elsevier), CINAHL, PsychINFO, Academic Search Complete, SocIndex, Social Science Full Text. The initial search was conducted in June 2017 and repeated on 25th of October 2017. The search strategy was developed using database-specific search terms with

input from a health services librarian. The MEDLINE search strategy is available in Appendix 1, supplementary file 2. Other search methods utilised included; hand-searching key journals and conference proceedings, citation searching of highly cited key papers and scanning reference lists of key papers.

For the first stage of abstract screening duplicates and clearly irrelevant studies (for example pre-clinical studies) were removed by one reviewer (AJ). In the next stage two independent reviewers from the screening team (AJ, TF, AC, CB) independently screened each study abstract. All eligible studies were then assessed by two independent reviewers. Any conflicts regarding the eligibility of a study were resolved through discussion between the paired teams. Where necessary, a third reviewer adjudicated and made the final decision regarding inclusion. All studies that were excluded after full-text screening are listed, with their reason for exclusion, in Appendix 1, supplementary material 3.

Data concerning participant characteristics, aims, setting and methods was extracted independently by two reviewers (AJ, TF). Members of the review team independently read and re-read all the eligible studies in chronological order focusing initially on the content and context. The lead author (AJ) open coded all the included studies focusing specifically on the first-order interpretations (views of participants) and second-order interpretations (views of the authors). In the qualitative studies the first order interpretations focused on the attitudes and experiences of GPs as presented in the result sections of the studies. In the quantitative studies the first order interpretations were identified from participants' responses to questionnaire items and a text file was created describing these responses. Second order interpretations were derived from the discussions and conclusions. At this point the data collected from quantitative and qualitative studies were no longer

distinguishable, enabling the synthesis of all the data in qualitative form. The software package NVivo 11 was used to facilitate data analysis and synthesis.

To ensure credibility and dependability of coding a second reviewer (KW) also coded three studies [152,243,278]. Conceptual groupings were created for each study and illustrated with conceptual mind maps. The two reviewers involved (AJ, KW) met regularly to discuss differences in interpretation of the studies. All four members of the analysis team (AJ, KW, CB, TF) met to discuss the key concepts emerging from the analysis of the included studies. To determine how the studies related to each other a table was iteratively developed that displayed the identified concepts and themes across all studies. This table is available in Appendix 1, supplementary material 4. To examine the contribution of each study to a key concept, the review team compared the themes and concepts from each individual study in chronological order. Attention was paid to deviant cases and to the influence of context on the study findings. The third-order interpretations were iteratively developed by the analysis team. Finally, the analysis team collectively linked the third-order interpretations into a 'line of argument' [234] which represents the overarching perspective of GPs towards BPSD.

All included papers were independently assessed by two reviewers (AJ, JB) for methodological validity. AJ was a co-author on one of the included studies [279], therefore, the quality assessment of that study was carried out by CB and JB. The Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Qualitative Research was used to assess the quality of the included qualitative studies [270]. Since there is no agreed quality assessment tool for assessing the quality of descriptive cross-sectional studies a new original tool was developed by two of the reviewers (AJ, JB). This tool was based on other original tools

developed for a similar purpose [248,262] and also considered recommendations on how survey questionnaires should be designed [263]. This tool is available in Appendix 1, supplementary material 5. Judgements on the quality of the study were not used to exclude studies that otherwise meet the inclusion criteria.

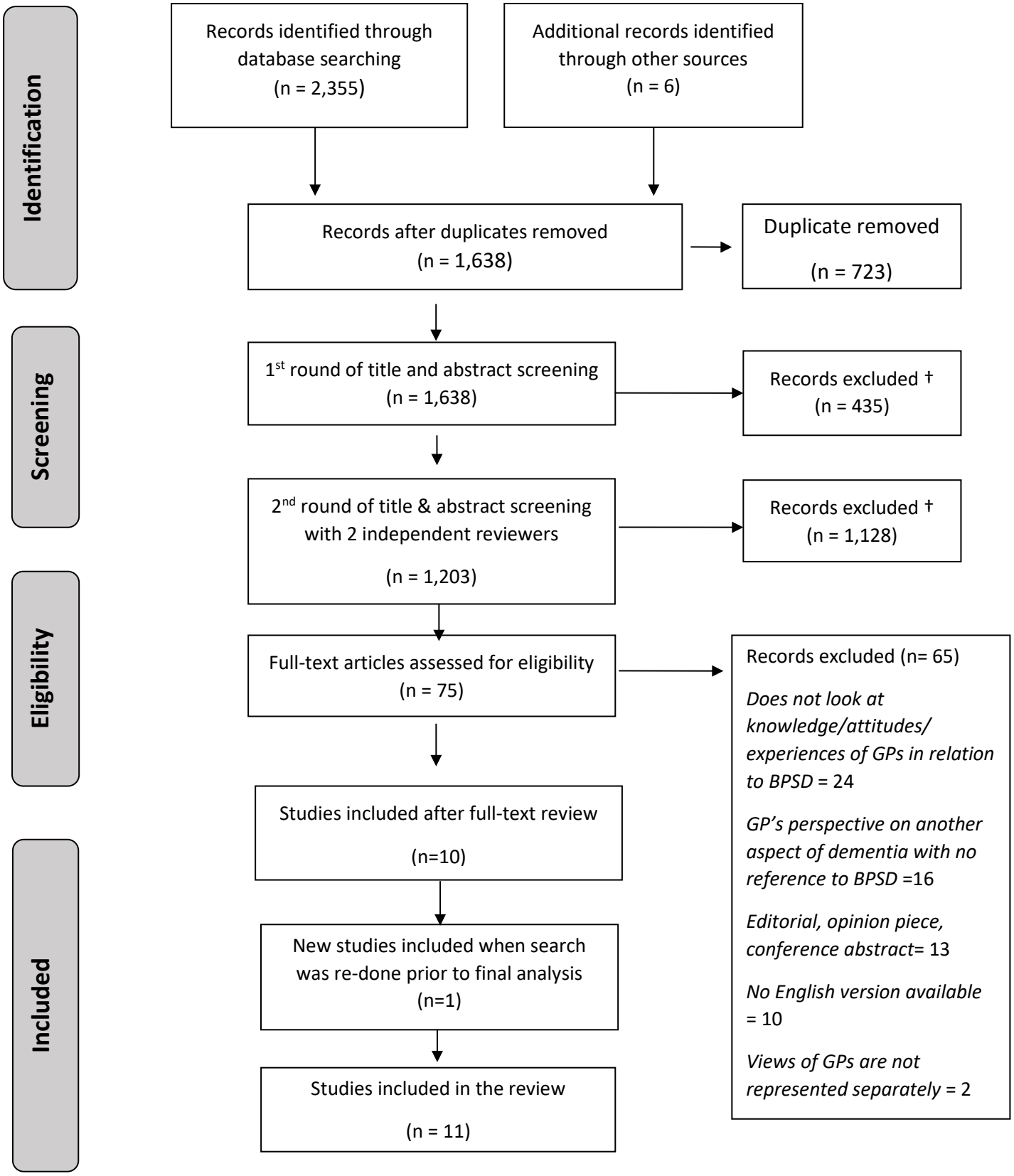
We report our results to conform with the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) statement [254] (Available in Appendix 1, supplementary material 5). We express our search strategy results using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram [255] (Figure 9). Two independent reviewers (AJ, KW) applied the Confidence in the Evidence from Reviews of Qualitative Research (CERQual) tool to the review findings. The CERQual approach provides a transparent method of assessing the confidence of findings of systematic reviews of qualitative research [258].

5.2.4 RESULTS

Search results

The search returned 2,361 citations. 1,638 citations remained to be screened after duplicates were removed. 1,558 citations were removed from abstract screening (Appendix 1, supplementary material 7) leaving 75 full-texts to be assessed for eligibility. Following full-text review 10 eligible studies were included (see figure 9 and appendix 1, supplementary material 3). The final repeat search resulted in the inclusion of 1 additional full-text. Therefore, we included 11 studies which described 9 study cohorts.

Figure 9. PRISMA Flow Diagram



† Reasons for the exclusion of records at the abstract screening stages are available in appendix 1, supplementary material 3

Characteristics of included studies

Of the 11 included studies; 4 were qualitative, 6 were quantitative and 1 was mixed-methods. The characteristics of the included studies are shown in Table 6. In total the views of 526 GPs from five different countries were represented.

Quality Appraisal

We judged the overall quality of the qualitative studies in the review to be high (Appendix 1, supplementary material 8, Table 1). The most common weakness was poor reflexivity: only one study [278] was found to have fully addressed this issue. Three of the descriptive cross-sectional studies were rated as low quality (achieving only 3 out of 7 quality markers). These studies all reported on the same cohort [280-282]. The overall quality of the other 4 descriptive cross-sectional studies ranged from moderate to high (Appendix 1, supplementary material 8, Table 1). Common areas of weakness were, the lack of involvement of the target population in the instrument development [152,280-282] and the lack of clarity on whether the sample used in the study was likely to be representative of the study population [152,280-282]. None of the descriptive cross-sectional studies provided a sample size justification, statistical power description, or variance and effect estimates.

Table 6. Characteristics of studies included in the systematic review

First Author, Year of Publication	Country	Author's Discipline	Study Objectives	Main Findings	Design/ Analysis	GP Participant	Setting
Colenda, 1995	U.S.	Psychiatry of Old Age	To measure the anticipated regret physicians experience when making treatment decisions for patients with dementia who are agitated.	When managing agitation in people with dementia the decision to "act" or intervene generated less anticipated regret than the decision not to "act".	Quantitative. Postal survey. Eight written vignettes describing treatment decisions and outcome for patients with dementia who were agitated. The degree of regret the respondent anticipated they would experience was measured using a 5 point Likert scale.	N = 77	GPs who cared for people with dementia in a community setting
Colenda, 1996	U.S	Psychiatry of Old Age	To understand physician clinical reasoning and clinical practices for community-dwelling patients with dementia who are agitated.	Personal and speciality characteristics influence the types of treatment recommendations made for people with dementia who are agitated.	Quantitative. Postal survey. Used a case vignette to elicit how likely the physician was to carry out one of thirteen different pharmacological and non-pharmacological interventions.	N = 79	GPs who cared for people with dementia in a community setting

First Author, Year of Publication	Country	Author's Discipline	Study Objectives	Main Findings	Design/ Analysis	GP Participant	Setting
Colenda, 1996_1	U.S.	Psychiatry of Old Age	To understand the variables that influence treatment decisions of physicians who treat patients with dementia who are agitated.	Physicians regardless of speciality recommended neuroleptic medication as their primary intervention. PCPs were more likely than other specialities to indicate that the "hassle factor" influenced their decision making.	Quantitative. Postal survey. Respondents were presented with a clinical vignette and then asked to estimate, using a 7-point Likert scale, the extent to which individual patient characteristics, current clinical situation and treatment variables would influence their primary treatment recommendation.	N = 59	GPs who cared for people with dementia in a community setting
Teel, 2004	U.S	Nursing	To describe the experiences of primary care providers in rural settings in diagnosing and treating patients with dementia.	Limited access to consultants, community supports & educational resources impeded the care of people with dementia in rural settings. The influence of family was significant.	Qualitative. Individual semi-structured interviews with GPs Analysis: descriptive	N = 17	Community-based rural family practice

First Author, Year of Publication	Country	Author's Discipline	Study Objectives	Main Findings	Design/ Analysis	GP Participant	Setting
Hinton, 2007	U.S.	Psychiatry of Old Age	To examine how practice constraints contribute to barriers in the care of people with dementia and their families, particularly with respect to behavioural aspects of care.	Insufficient time, difficulty accessing specialists, poor reimbursement and lack of interdisciplinary teams increased reliance on pharmacological management options in BPSD.	Qualitative. Individual semi-structured interviews. Analysis: thematic, used analyst triangulation	N = 40	Community –based urban family practice
Buhagiar, 2011	Ireland	Psychiatry	To assess self-reported confidence and knowledge of general practitioners regarding the identification and management of behavioural and psychological symptoms of dementia.	GPs are knowledgeable on BPSD but are critical of their own skills. GP's confidence in managing BPSD is the issue rather than their knowledge.	Quantitative. Postal survey (2 pg questionnaire)	N = 106	Community-based GPs
Mavrodaris, 2013	UK	Public Health	To investigate antipsychotic prescribing practises and patient review in primary care.	GPs reluctant to discontinue antipsychotics - uncertainty of professional roles & expectation of resistance	Mixed method Survey with open ended questions. Open ended questions thematically analysed.	N =60	Community based GP participants Unclear whether these GPs had a NH commitment or not

First Author, Year of Publication	Country	Author's Discipline	Study Objectives	Main Findings	Design/ Analysis	GP Participant	Setting
Azermai, 2014	Belgium	Pharmacology	To explore the willingness of nurses and general practitioners to discontinue antipsychotics and to identify barriers to antipsychotic discontinuation.	GPs identified a number of barriers to discontinuing antipsychotics; concern that it would negatively impact on the patient's quality of life, concern that it would lead to a re-emergence of BPSD and insufficient non-pharmacological alternatives.	Quantitative 2 multidisciplinary expert meetings using nominal group technique informed the development of a questionnaire. Questionnaires were distributed to GPs and nurses who cared for patients in a nursing home setting. Questionnaires were designed to generate case-specific information. Statistically analysed.	28 GP respondents provided 51 case specific questionnaire responses.	Focus was on GPs with a nursing home commitment. Unclear if also had community commitment. Respondents were GPs who were being prescribed antipsychotics for >1 month in a nursing home. Nursing homes (n =4); 3 private, 1 public
Donyai, 2016	UK	Pharmacy	To explore the use of fallacious arguments in professionals' deliberations about antipsychotic prescribing in dementia in care home settings.	Concept presented by participants was that there was no real alternative to prescribing antipsychotics, therefore, their use was justified in the context of need.	Qualitative Semi-structured face-to-face Interviews with GPs Content analysis	N=5	Participating GPs cared for people with dementia in a nursing home setting.

First Author, Year of Publication	Country	Author's Discipline	Study Objectives	Main Findings	Design/ Analysis	GP Participant	Setting
Foley, 2017	Ireland	General Practice	To explore GPs' dementia care educational needs.	GPs consider BPSD to be a significant educational need in the context of dementia care.	Qualitative Semi-structured face to face interviews with GPs Thematic analysis	N =14	All participating GPs cared for people with dementia in a community setting. Some also cared for people with dementia in a nursing home.
Cousins, 2017	Australia	Pharmacy	To identify factors influencing the prescribing of psychotropic medication by GPs to nursing home residents with dementia.	A lack of nursing staff and resources was cited as the major barrier to GPs recommending non-pharmacological techniques for BPSD.	Quantitative Online and postal survey to GPs 26-questions	N = 177	Community based GPs that provide care to patients with dementia in a nursing home setting.

Translation of included studies

The analysis led to the identification of three key concepts (in bold and numbered below) which encompassed eight sub-themes (in bold below) reflecting GPs' experiences of managing BPSD. Each sub-theme was supported by data from both qualitative and quantitative studies. The findings supporting first-order interpretations are indicated by italicised quotations and those supporting second-order interpretations by non-italicised quotations.

1. **Unmet Primary Care Needs**

GPs' knowledge and self-efficacy

Nearly all the included studies examined issues pertaining to GPs' knowledge and self-efficacy [152,153,155,243,278,279,281,283]. In some studies BPSD was considered by GPs to be "*very difficult to deal with*" [279] and "distressing" [284]. GPs tended to be "critical of their perceived skills in the diagnosis and management of BPSD" [152]. Specifically, in some studies GPs were critical of their knowledge of prescribing psychotropic medications [243,279] : "*When do you add in psychotropic medication, what type of medication, what dosages, for how long?*" [279]. GPs' perceived lack of knowledge impacted upon their confidence prescribing these medications: *"I do rely on psychiatry because I admit that I am not the most knowledgeable person about people with agitation and behavioral problems at home. I get a little nervous about anti-psychotic meds and I tend to send those people to psychiatry"* [243]. GPs also lacked confidence when differentiating BPSD from other potential causes of these behaviours and symptoms [152,243]: "*I want a second opinion too in making sure my diagnosis is correct*" [243]. In addition to GPs' lack of knowledge of and confidence in pharmacological management in BPSD, GPs were also found to lack knowledge on non-pharmacological interventions [278,281]

and, at times, the confidence to recommend them [152] . However, in some of the studies participating GPs demonstrated a good knowledge of both non-pharmacological and pharmacological management options in BPSD [152,153,155]. For example, in one study most GPs reported proactively reducing psychotropic medications and routinely recommending non-pharmacological interventions prior to commencing medications [155], however, these GPs still felt they required "more training" [155] in BPSD.

Lack of defined pathways of care

Several studies identified the need for clearly defined pathways of care that would allow GPs to access advice from relevant experts in the area [152,153,243,279,284]. The difficulty caused by long waiting lists was highlighted [152,243,284] : *"there's a weekly outreach clinic, but it can take several months to get in"* [284]. Additionally, GPs identified difficulty accessing other relevant healthcare professionals: "*dementia care it's a team care, dietician, social work, psychiatry, psychologist, and pharmacist...I feel I don't have this."* [243]. GPs found identifying the relevant members of the primary care team to be a *"struggle"* [279]. In some studies there was "confusion regarding [the GP's] role"[153] in BPSD. In many studies the GP emerged as an isolated figure when managing BPSD [152,153,243,284], expressing "frustration [at] being placed in a situation in which they felt compelled to provide care that they felt was beyond their realm of expertise" [243]. The need for "improved communication and collaboration" [153] between the different healthcare professionals was highlighted to avoid GPs feeling that they are "left to deal with the crisis on their own without back-up" [152].

Time-intensive

The time required to assess and manage BPSD emerged as an issue in several studies [243,280,284]: "*…it's a lot more complicated than the intact 50-year-old hypertensive diabetic" [243].* Addressing the needs of family caregivers also required time [243,280,284]: *"I spend as much time asking how the caregiver's doing as I do the patient"* [284]. GPs sometimes described feeling overwhelmed with the workload that a person with dementia can generate; "*I think we're all drowning … we are all truly trying to keep our heads above water...These people do take a lot of time and energy"* [243]. As a result of the time-intensive nature of managing BPSD and in the context of inadequate *"reimbursement*" [243] some GPs considered managing people with dementia to be burdensome: *"they cause chaos, and so they get referred or something happens*" [243]. The symptoms and behaviours were "neglected" [243] until an "emergency situation" [280] or "time of "crisis" [243].

2. Justification of antipsychotic prescribing

Antipsychotics to facilitate coping

In 4 studies [153,155,278,283] the prescribing of antipsychotics was seen to enable carers, nursing home staff and the person with dementia to cope with BPSD: *"he was weeping for his wife who has been dead for many years … on quetiapine… the uncontrollable weeping had stopped"* [278]. Although in some studies GPs were aware of the risks of antipsychotic prescribing in people with dementia, these risks were seen to relate to longevity of life whereas in BPSD "quality of life issues prevailed"[153]. In several studies GPs' believed antipsychotics positively impacted on the quality of life of people with BPSD [155,278,283]. This

contributed to their reluctance to discontinue antipsychotics [155,278,283]. Additionally, in two studies GPs expressed a concern that discontinuing the antipsychotic would lead to a "return of challenging behaviours" [155,283].

Barriers to implementation of non-pharmacological strategies

Several studies considered the challenges inherent to implementing non-pharmacological strategies in BPSD [152,153,280,283]. A key finding in three of the studies that were conducted in nursing home settings related to the influence of nursing home staff on the implementation of non-pharmacological strategies [153,155,283]. Pressure from staff to prescribe medication [153,155] influenced the GPs' management decisions and acted as a barrier to recommending non-pharmacological strategies: *''often it is pressure from nursing homes … for medication to calm a patient down that is trigger for prescribing" [153]*. One study found that in a nursing home setting "nursing staff have the largest influence on prescribing psychotropic medication" [155]. However, this study also found that experienced GPs (in practice >20 years) were significantly less likely than more recently qualified GPs "to rate pressure to prescribe from aged care facility staff as a barrier" [155] to recommending non-pharmacological strategies.

In a nursing home context, although a GP can recommend non-pharmacological strategies their implementation typically falls to nursing home staff not to the GP. Two of the studies reported that chronic understaffing of nursing homes [155,283] acted as a barrier to the GP recommending non-pharmacological strategy. An additional factor that hindered the implementation of non-pharmacological strategies in nursing home settings was the lack of shared perspectives [153,155,283] between GPs and nursing home staff. For example, one study

identified a “culture of blaming”, reporting that GP felt under pressure from nursing home staff to prescribe, while nursing home staff reported that it was the GPs that insisted on pharmacological treatment [153]. A final barrier to the implementation of non-pharmacological strategies was that, in the context of “healthcare budgets and resource constraints” [153], guidelines on non-pharmacological management strategies were perceived to be impractical [152 153].

Traditional prescribing role

In some studies [152,278,280,281] it was suggested that GPs were more comfortable with their role as prescribers of medications and less comfortable “with the more alien non-pharmacological methods” [152]. In several earlier studies GPs reported a preference for “medication as the primary intervention” [280] and were found to be “ wedded to a traditional medical model of care” [281]. In more recent studies [152,278] the value of non-pharmacological management strategies was increasingly recognised. However, some participating GPs were still reluctant to reduce their prescribing [278]. Although accepting the important role of non-pharmacological management “this belief was not put into clinical practice” [152]. A GP in one study felt that antipsychotics were sometimes the *“easy option, because it’s something as doctors we do, we just prescribe medications”* [278].

3. Pivotal Role of Families

Influence of family

The critical role played by family members in the management of BPSD was highlighted by several studies that explored GPs’ experiences of managing BPSD in the community setting

[243,279,280,284]. GPs' management of the person with BPSD was influenced by the family [152,280,284] who "contributed to making treatment processes either more difficult or more straightforward" [284]. The impact of pressure from families was discussed in 3 studies [152,280,284]. These studies described "repeated phone calls" from family members [280] or a mismatch of expectations of the family and the capabilities of the GP: "*resistant children … who promised they'd never put mom in a nursing home, but they don't want to take her… so we try to hire someone, which is virtually impossible*" [284]. There was some evidence of GPs deflecting responsibility for the management of BPSD back to the family; "*usually, the family deals with it [BPSD]"* [243]. However, the important role a GP plays in supporting carers was emphasised by GPs in several studies [243,279,284]; *"one of the big learnings I've had is … how important carer support is"* [279]. Studies that focused on the management of BPSD in nursing home settings found family members were less influential on prescribing [155].

Community based supports for family caregivers

GPs highlighted the importance of access to community supports for family caregivers [243,279,284]; *"I think you live on this lifeline of getting this respite and that helps you to cope as a carer"* [279]. However, accessing these supports was challenging for GPs. Supports sometimes weren't there; "*we don't have much in the way of support groups ... we are in a no man's land"* [284]; or the GP didn't know how to access the supports; "*I myself wouldn't be able to provide the specifics of it"* [279]; or the GP felt that providing information on these supports was beyond their professional remit and capabilities; *"since I'm not a licensed clinical social worker and I don't know what's available in the community …"* [243].

Impact of context on findings

Some studies focused on a subset of a GP's professional responsibility for people with dementia. Three of the studies focused on GPs who cared for people with dementia in a nursing home setting and excluded those managing dementia in the community [155,278,283]. Four of the studies in the review focused on a singular aspect of the management of BPSD; antipsychotic prescribing [153,155,278,283] and were conducted by pharmacists or pharmacologists [155,278,283]. The authors of the remaining eight studies were from other disciplines including psychiatry, nursing and general practice. They adopted a more holistic approach to discussing the assessment and management of BPSD. Of note, only one study was authored by a GP [279]. Five of the eleven studies included in this review were from the U.S. [243,280-282,284] from which the sub-theme on 'time' emerged. This may be influenced by factors specific to the healthcare system in the U.S.

The studies spanned 22 years (1995 to 2017). Over this time there have been substantial changes to recommendations regarding the management of BPSD. Earlier studies described how antipsychotics "may be the best available option for physicians" [280]. However, as the evidence for the harmful effects of using antipsychotic medications in people with dementia emerged [160,196] there has been a distinct shift. The use of antipsychotics became less acceptable: "antipsychotics should not be prescribed to reduce stress in carers…" [278]. The studies in this review highlight the journey the management of BPSD has travelled over the past two decades - from 'what is the right psychotropic to use?'; to 'should we be using psychotropic medication?'; to 'stop using psychotropic medication'. A parallel journey occurred for non-pharmacological management strategies which received increased emphasis.

Synthesis

Six third –order interpretations were iteratively developed by synthesising the first and second order interpretations. The third order interpretations and their associated CERQual confidence levels are shown in Table 7 and further expanded in appendix 1, supplementary material 9. These third order interpretations were synthesised into a 'line of argument' which is detailed in Table 8 and is represented graphically in Figure 10.

Table 7. Summary of CERQual Assessment

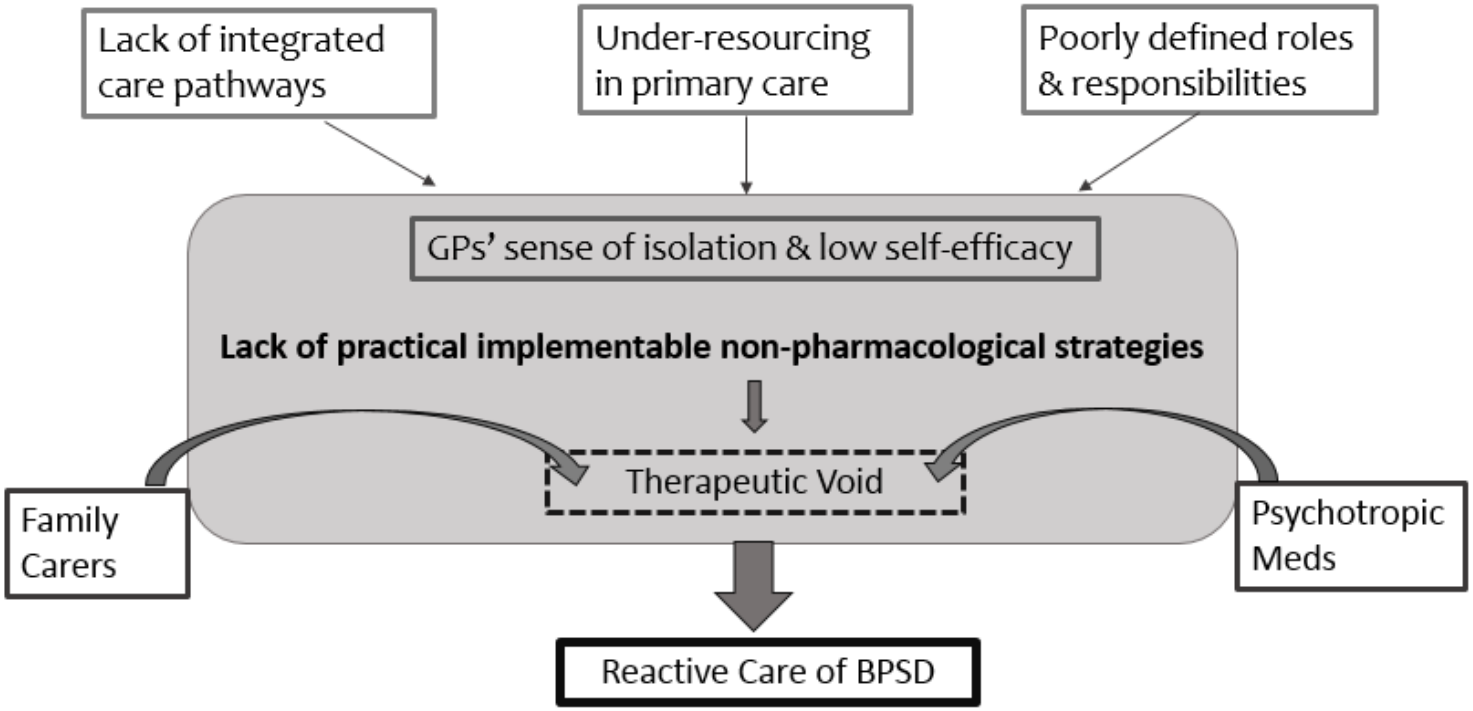
Review findings/ 3rd order interpretation	Relevant papers	CERQual assessment of confidence in the evidence	Explanation of CERQual assessment
Unmet primary care needs			
1. Managing BPSD was complex, resource intensive and sometimes unrewarding for the GP.	243,284	**Low confidence**	Substantial concerns regarding adequacy and minor concerns regarding methodological limitations and relevance.
2. GPs lacked confidence when managing BPSD and wanted input from either secondary care or relevant members of the primary care team. However, the lack of clearly defined care pathways meant that GPs experienced difficulty accessing advice.	152,153,243,279,284	**High confidence**	Minor concerns regarding methodological limitations and adequacy.
Justification of antipsychotic prescribing			
1. GPs were more comfortable prescribing medication than advising on non-pharmacological management strategies.	152,153,278,280,281	**Moderate confidence**	Moderate concerns regarding the adequacy of the data and methodological limitations. Minor concerns about the relevance of the studies.
2. GPs found that antipsychotics enabled the person with dementia, the family caregiver, the nursing home staff and the GPs themselves to cope with BPSD.	153,155,278,283	**High confidence**	Minor concerns regarding methodological limitations, relevance and adequacy.
3. GPs had a tendency to over-estimate the benefits of antipsychotic prescribing. Consequently, in the context of the challenges of implementing non-pharmacological alternatives, the risks associated with antipsychotics were tolerated.	153,155,283	**Low confidence**	Substantial concerns regarding adequacy and minor concerns regarding methodological limitations, relevance and coherence.

Review findings/ 3rd order interpretation	Relevant papers	CERQual assessment of confidence in the evidence	Explanation of CERQual assessment
Pivotal role of family			
1. The family of the person with dementia plays a crucial role in the management of BPSD. However, the needs of the carer could be intensive and challenging for the GP, particularly in the context of limited community supports for family caregivers.	243,279,284	**Moderate confidence**	Minor concerns about methodological limitations, relevance. Moderate concerns regarding data adequacy

Table 8. Line of Argument

Line of argument synthesis:	GPs experience difficulties accessing supports for family caregivers and for themselves when managing BPSD. Under-resourcing, poorly defined roles and a lack of integrated care pathways may contribute to GPs' feelings of isolation and low self-efficacy when managing BPSD. Low self-efficacy is further exacerbated by the lack of practical, implementable non-pharmacological treatment strategies which can lead to an over-reliance on both family care-givers and psychotropic medications to fill the therapeutic void created. It appears that these conditions can culminate in a reactive response to the care of people with BPSD where behaviours and symptoms may escalate until an inevitable crisis point is reached.

Figure 10. Graphical representation of the line of argument synthesis



5.2.5 DISCUSSION

This is first review to systematically review and synthesise the literature on GPs' knowledge, attitudes and experiences of managing BPSD. A wide range of issues were identified including the knowledge and resource needs of GPs, the reliance on antipsychotic medications and the influential role of the family. These are areas that could be targeted to improve the management of this challenging aspect of dementia care.

Comparison with previous research

In this review GPs were found to have a low sense of self-efficacy when managing BPSD. A systematic review on the barriers to diagnosing and managing dementia in general practice identified that GPs' limited knowledge about dementia can act as a barrier to the provision of optimum care to people with dementia [72]. A previous quantitative study of GPs knowledge of and attitude towards dementia found that the vast majority of respondents lacked confidence in the management of BPSD, prompting the authors to recommend that future educational support should focus on BPSD [198]. While educational interventions are a reasonable and important focus [133], it is likely that GPs' low sense of self-efficacy stems from more than a lack of knowledge of BPSD. GPs can find managing dementia stressful [285]. The resource-intensive nature of managing BPSD coupled with the lack of clearly defined pathways of care will impact on a GPs sense of self-efficacy when managing such a complex clinical condition. Previous systematic reviews have identified that to effectively change GPs' behaviour in dementia care education alone is not sufficient; education needs to be combined with service innovation ideally in the form of organisational incentives [286,287]. Although an increase in knowledge would go some way towards improving GPs' self-

efficacy, GPs also need to be supported by clear pathways of care and appropriate resourcing.

Antipsychotics were considered to be justifiable in the context of need. They were perceived to improve the quality of life of people with BPSD and enabled everyone, including the GP, to cope with the constraints imposed by insufficient resources. A recent systematic review examined the influences of decision-making on antipsychotic prescribing in nursing home residents and found that to circumvent the problems of inadequate resourcing antipsychotics were 'employed' as cheap and effective staff members [3]. In this current review the benefits of antipsychotics were often over-estimated and their potential harmful side-effects were sometimes overlooked because these side effects were perceived to relate to longevity of life rather than quality of life. Similarly, the systematic review on prescribing influences in nursing home residents found that inadequate knowledge of the risks and benefits of antipsychotic prescribing in dementia enabled inappropriate prescribing [3]. However, the benefit of antipsychotics in BPSD is minimal [160] and many of the side effects, such as extrapyramidal symptoms and sedation, occur in the short term. GPs' concern that discontinuation of antipsychotics will lead to a re-emergence of BPSD is also challenged by current evidence that suggests, for most people with Alzheimer's type dementia, antipsychotic discontinuation has no detrimental effect on cognition or functional status [288].

The care provided to the person with BPSD in the community hinged on the positive involvement of family care-givers. A recent mixed methods systematic review of the challenges BPSD creates for carers highlighted the importance of acknowledging the unmet psychological needs of carers [120]. The reliance on family caregivers, in the context of inadequate community resources to support them, creates a burden of care that is likely to

further impact on carers' unmet psychological needs. Discussions on non-pharmacological strategies to manage BPSD often focus on a nursing home setting. However, BPSD is not limited to nursing home settings. Recent research has found that family carers observed significant levels of agitated behaviour, behaviour that they felt unprepared for as they were unaware that agitation could occur as part of dementia [121]. Carers value a proactive approach to dementia care from GPs [289]. Therefore, a more proactive initial discussion with family care-givers on BPSD, combined with regular screening questions as part of dementia reviews in general practice, could help to address how unprepared carers feel when faced with managing BPSD at home.

Implications

Our review highlights the complexity of managing BPSD and how, in the face of this complexity, the care provided to people with dementia is often reactive. This raises the question; what does proactive care look like and how can this be delivered by GPs? Particularly in the face of the challenges posed by resource limitations, low self-efficacy and uncertainty regarding roles and responsibilities. We acknowledge that in clinical practice pro-active management of BPSD can be complicated. Firstly, a prerequisite of any open, honest discussion on BPSD is that the person's dementia has been diagnosed and fully disclosed. However, we know that the diagnostic rates of dementia, although improving [227], are low [290]. Furthermore, although the majority of people with dementia wish to know the diagnosis [291] GPs can be reluctant to fully disclose it [87,292,293]. Secondly, GPs may be reluctant to initiate a conversation about BPSD unless they feel comfortable giving practical advice to family caregivers on managing BPSD, something many GPs struggle with [87,294,295]. A final barrier to a successful pro-active conversation on BPSD can be an understandable

unwillingness on the part of family-members, and sometimes the person with dementia, to confront the unpleasant realities of cognitive decline.

This review identifies a number of potential targets for interventions to improve the management of BPSD in general practice. There is a clear need for interventions that address GPs' reliance on psychotropic medications to manage BPSD and GPs' reluctance to discontinue these medications. Other relevant areas to address include the lack of resources in the nursing home setting, the lack of clarity regarding roles and responsibilities of different healthcare professionals and the limited availability of community based supports for family caregivers. The challenge is how to implement effective interventions in the context of resource limitations, pressure to prescribe medications and a lack of clearly defined care pathways that interface appropriately with secondary care and allied health care professionals in the community. Existing interventions aimed at improving the management of dementia care in general practice have focused on educational initiatives [133,286,287,296] . However, we know that educational interventions alone have limited effect when attempting to change GP practice in dementia care [286,287].To improve dementia care educational interventions in general practice should be combined with service innovations such as dementia case managers [287] and supported by resources like decision support software [297] .

From the findings of this review inappropriate antipsychotic prescribing appears to be a relevant and worthwhile behaviour to target. However, in addition to any educational component, an intervention aimed at improving appropriate prescribing of antipsychotics in dementia needs to be supported by practical resources that enable GPs to implement best practice recommendations. A recent randomised controlled trial demonstrated the

potential for biannual, structured, multi-disciplinary medication reviews to improve appropriate prescribing of psychotropic medications in nursing home patients with dementia [298]. Although psychotropic medication reviews may occur in nursing homes, if implemented they are often performed in an ad-hoc manner without adequate resources and usually without multi-disciplinary input.

Medication reviews can reduce inappropriate antipsychotic prescribing in dementia [210]. However, to effectively improve the quality of life of a person with dementia, strategies that aim to reduce antipsychotic prescribing, such as medication reviews, need to be combined with evidence-based non-pharmacological interventions [212]. A systematic review of the effectiveness of interventions to reduce inappropriate prescribing of antipsychotic medications in people with dementia living in residential care settings identified that, for long-term reduction in antipsychotic prescribing, interventions needed to address cultural issues and the poor availability of non-drug alternatives to antipsychotics [201]. It is clear that if an intervention is to achieve a long-term reduction in psychotropic prescribing in dementia it must provide options for practical, implementable, non-resource intensive approaches to non-pharmacological strategies.

Strengths & Limitations

One of the strengths of this review is the rigorous approach employed. Each stage of the review process involved at least two authors working independently. The synthesis of qualitative and quantitative studies has led to a more substantive interpretation of the research phenomenon than is available from a single study. Adding to, rather than totalising, the available literature. Syntheses of qualitative data have been criticised as being

mechanistic. Indeed there is the risk with meta-ethnography that the richness or integrity of the original work will be lost [250], a concern that, by overly deconstructing the original qualitative work, the researcher attempts to "sum up a poem" [251]. Efforts were made to retain the content and context of the original studies throughout the data extraction and analysis. Three members of the review team are practising GPs (AJ, TF, CB), however, the multidisciplinary nature of the review team which included a pharmacist (KW), a public health researcher (JB) and a nurse (AC) helped to reduce the potential for professional biases.

The review did not include a search of the grey literature. Since our search of the electronic databases was extensive we felt that the grey literature was unlikely to result in any additional insights. A number of the studies included in the review focused on a singular aspect of BPSD management; antipsychotic prescribing in a nursing home setting. Hence, issues relating to antipsychotics may be over-represented in this review. Although integrated reviews of qualitative and quantitative research is still a relatively novel approach it has been used effectively in previous mixed method systematic reviews of similar research questions [120,248]. It has enabled the integration of the quantitative assessments of GPs' knowledge of and attitudes towards BPSD with a more qualitative understanding of GPs' experiences of BPSD, enhancing the review's utility and impact.

The focus of this review is on GPs who manage people with dementia living at home and who may also provide care to people with dementia in nursing homes. Other models of care, such as that in The Netherlands where specially trained elderly care physicians provide care to nursing home residents[277], were excluded from this review. However, it was

reassuring to find that many of the findings from studies conducted with physicians working in the Dutch model of nursing home care concurred with our review findings [154,299,300].

To our knowledge this is the first time the CERQual tool has been used to assess the confidence of findings of a mixed methods systematic review of this kind. However, there are limitations to applying the CERQual tool in this instance. In particular, the inherent 'thinness' of the data from the quantitative studies raised concerns when judging the adequacy of the data. Nonetheless, the novel application of the CERQual tool to our review findings does provide a useful indication of the confidence we have in the study findings.

5.2.6 CONCLUSION

This review offers new insights into GPs' perspectives on the management of BPSD and highlights the limited research in this area. Most of the research on dementia care in general practice appears to have focused on diagnosis rather than the long term management of the person with dementia. We need to explore the challenges of managing BPSD in general practice, not at the expense of research on diagnostic challenges, but at least with the same degree of depth. Targeted interventions that are supported by appropriate resourcing could make the provision of high-quality, personalised care to people with BPSD achievable in a primary care setting. This review will help to inform the design and development of interventions to support GPs managing BPSD which should ultimately improve the quality of care delivered to people living with dementia.

CHAPTER 6. "Working away in that Grey Area…" A Qualitative Exploration of the Challenges General Practitioners Experience when Managing Behavioural and Psychological Symptoms of Dementia

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6.1 ABSTRACT

Background: General practitioners (GPs) have identified the management of behavioural and psychological symptoms of dementia (BPSD) as a particularly challenging aspect of dementia care. However, there is a paucity of research on why GPs find BPSD challenging and how this influences the care they offer to their patients with dementia.

Objectives: To establish the challenges GPs experience when managing BPSD; to explore how these challenges influence GPs' management decisions; and to identify strategies for overcoming these challenges.

Design: Qualitative study of GPs' experiences of the challenges of managing BPSD.

Methods: Semi-structured interviews were conducted with 16 GPs in the Republic of Ireland. GPs were purposively recruited to include participants with differing levels of experience caring for people with BPSD in nursing homes and in community settings to provide maximum diversity of views. Interviews were analysed thematically.

Results: Three main challenges of managing BPSD were identified; lack of clinical guidance, stretched resources and difficulties managing expectations. The difficulties of accessing clinical guidance negatively impacted on GPs' confidence when managing BPSD. Additionally, in the absence of appropriate resources GPs felt reliant upon sedative medications. GPs believed their advocacy role was further compromised by the difficulties they experienced managing expectations of family caregivers and nursing home staff.

Conclusions: This study helps to explain the apparent discrepancy between best practice recommendations in BPSD and real-life practice. It will be used to inform the design of an intervention to support the management of BPSD in general practice.

6.2 INTRODUCTION

Behavioural and psychological symptoms of dementia (BPSD) is a term that encompasses a wide range of behaviours and symptoms that affect the majority of people with dementia at some point in their illness [92]. BPSD includes behaviours and symptoms such as agitation, aggression, wandering, depression and sleep disturbance. The presence of BPSD results in an increased risk of admission to long term care facilities [128], longer in-patient hospital stays [113] and is a major contributor to caregiver stress and depression, even more significant than cognitive decline [116].

The management of BPSD is complex as there are many contributing factors including unmet care needs, underlying acute medical conditions and environmental triggers [108]. In addition to the complexities in assessment, effective treatments are limited. Best practice recommendations encourage the use of individualised non-pharmacological management strategies such as music therapy [241], however, these are often difficult to translate into implementable management strategies. Psychotropic medications continue to be used to manage BPSD in both residential and community settings [156,197], despite their well-known risk to people with dementia [159,160] and calls for action to reduce antipsychotic prescribing [196].

General Practitioners (GPs) play a pivotal role in managing BPSD, however, previous quantitative research has found they lack confidence in this area [80,152,301]. In one survey most GPs acknowledged the importance of non-pharmacological approaches to managing BPSD, however, they found non-pharmacological difficult to implement in practice and reported using pharmacological management strategies instead [152]. Furthermore, practice constraints such as insufficient time, poor connections with community services and lack of

interdisciplinary teams can act as barriers to GPs caring for people with BPSD [243]. Interventions are needed to support GPs in their management of BPSD. However, we are unaware of any such interventions. Recent research has identified education in BPSD as a priority for GPs [279] but we do not have a good understanding of how GPs currently manage BPSD and the root causes of their lack of confidence. An important first step in intervention design is to establish a thorough understanding of existing behaviour [239,242]. However, GPs' experiences of managing BPSD have not been previously researched. The aim of this study is to identify the challenges GPs experience when managing people with BPSD and to explore how these challenges influence their management decisions. Potential strategies that GPs use to overcome these challenges will also be identified. The findings of this study will be used to inform the design of an intervention to improve the management of BPSD in general practice.

6.3 METHODS

Semi-structured interviews were conducted with GPs to explore the challenges they experience managing BPSD. Ethical approval was granted by the Social Research Ethics Committee in University College Cork (2016-098).

Sampling and recruitment

Given the high prevalence of BPSD in residential care settings [302] initial sampling focused on GPs with a nursing home commitment. Twenty-three nursing homes in the southern region of the Republic of Ireland were contacted and the GP who attended the nursing home was identified. From this population a sample was purposively selected to include GPs with

differing practice locations (urban/rural), years in practice and dementia workload with the goal of achieving maximum variation. The recruitment process occurred concurrently with, and in response to, the data analysis. During the analysis process it was identified that GPs with no nursing home commitment may have different experiences of managing BPSD, consequently, these GPs were also invited to participate. Using the same criteria as above this sample of GPs was purposively recruited by identifying GPs in a national medical directory.

GPs were contacted by letter and invited to participate. One week later the GPs were contacted by telephone. If they agreed to participate an information sheet was forwarded and an interview was scheduled. Criteria for reporting qualitative research as described in the COREQ guidance were followed [303].

Semi-structured interview process

The interviews were conducted in the GP's surgery or in an office in University College Cork between October 2016 and April 2017. The lead author (AJ), a GP with an interest in dementia, conducted all of the interviews. There was one telephone interview. Written informed consent was obtained prior to each interview. All of the interviews, bar one, were audio-recorded and transcribed verbatim. The one interview that was not recorded, at the request of the participating GP, was typed up from field notes. The lead author (AJ) de-identified the transcripts and assigned the transcripts anonymised codes (e.g. GP01) to protect the identity of the participants. Furthermore, to ensure confidentiality identifiable information was removed from the quotes selected. NVivo 11 software was used to manage the data. The topic guide was informed by a literature review of GPs' knowledge of and attitudes towards BPSD and the professional experiences of three of the authors (AJ, TF, CB)

all of whom are practising GPs. The literature review identified issues such as self-confidence which were used as prompts during the interview. The topic guide was iteratively developed through a process of consensus with the multidisciplinary research team which included expertise in general practice (AJ, TF, CB), dementia in primary care (TF, AJ), public health and health services research (JB, SMcH). The topic guide was then piloted with a convenience sample of two GPs. Minor amendments were made to the script sheet and use of probes as a result of this piloting. (The topic guide is available in appendix 2, supplementary material 10). Throughout the interviews participants were encouraged to discuss their own clinical cases.

Analysis

Data analysis followed the principles of thematic analysis as outlined by Braun & Clarke [101]. Data analysis was performed concurrently with data collection, allowing emerging themes to be further explored in subsequent interviews. An extensive familiarisation process was conducted by two researchers (AJ, TF) who read and re-read all transcripts. The lead author (AJ) open-coded all the transcripts. The second researcher (TF) independently open coded a subset of the interviews (>50% of the transcripts) that were purposively selected to ensure a wide range of years of experience and dementia workload. Regular meetings were held throughout the interview process to discuss emerging themes and to examine convergence and divergence of the researchers' findings. Any uncertainties were discussed with a third researcher (SMcH) who also independently coded two interviews that were purposively selected to include participants with different dementia workloads.

6.4 RESULTS

Twenty-four GPs were invited to participate in a semi-structured interview, sixteen of whom agreed to participate. The reason for non-participation was documented where possible; the main reason given for non-participation was lack of time. The characteristics of participants are shown in Table 9. Overall, conceptual data saturation was reached after thirteen interviews. After this three more interviews were conducted during which no new data emerged, confirming data saturation [304]. Interviews were, on average, 37 minutes in duration (range 20 to 63 minutes).

Table 9. Characteristics of GPs who participated in the interviews

	Participants, n (%)
Length Qualified	
<10 years	4 (25)
10-19 years	7 (44)
>20 years	5 (31)
Nursing Home Commitment	
Attends Weekly	8 (50)
Attends Monthly	3 (19)
No formal Nursing Home commitment	5 (31)
Practice Location	
Urban	6 (37)
Rural	3 (19)
Mixed	7 (44)
Type of Practice	
Small (1 – 3 GPs)	7 (44)
Large (>3 GPs)	9 (56)
Sex	
Male	8 (50)
Female	8 (50)

GPs' experiences of managing dementia

The complexity of dementia care was highlighted by many of the participants. Overall their attitude to dementia care, and in particular, BPSD, was pessimistic. It was perceived by many to be an 'an unsolvable problem'.

> *"I think, what is the answer to really challenging behaviour associated with dementia in the community? That's not just something that I am missing, it is something that we are all missing in this society"* GP_02

Nearly all the participants struggled at a professional, and sometimes at a personal level, with what they saw as the limited treatment options available. Rather than deciding on the 'best' treatment option, they felt they were merely making a decision on whether or not to sedate.

> *"It is awful to watch somebody who has dementia and it seems to be awful to experience dementia so the temptation is to just sedate people through that process and it is hard to decide. When you step back and think about that it seems awful that you just sedate them through this end part of their lives."* GP_05

In the context of this experience three main challenges of managing BPSD were identified.

1. Lack of clinical guidance
2. Stretched resources
3. Conflicting expectations

The impact of each challenge on the GP's management decision was identified. Factors identified by GPs as helpful in overcoming the challenges of managing BPSD were also established (Table 10).

Table 10. The challenges of BPSD, how they impact on the GP's decision making and what factors help GPs to overcome these challenges

Challenge ⟹	Impact of Challenge on Management of BPSD	Factors that helped overcome this challenge
Lack of Clinical Guidance - Guidelines - Access to expert advice	⟹ Decreased physician confidence	Experience of managing BPSD Ability to utilise personal contact to access experts
Stretched Resources	⟹ Decreased ability to recommend non-pharmacological strategies	Relationships with community based allied health care professionals
Conflicting Expectations - Families - Nursing Staff	⟹ Increased pressure to prescribe	Having family on-board Continuity of care leading to good working relationships

Challenges of managing BPSD

Lack of clinical guidance

Assessment and management of BPSD was seen as a clinically complex area. The lack of clinical guidance, both in terms of GP-specific guidelines and access to clinical advice, was identified as a challenge. Thus, the management of behavioural and psychological symptoms was seen as a 'grey area'.

In the absence of what the GPs considered to be implementable guidelines for the management of BPSD they felt they were often making decisions in a vacuum. While accepting that the evidence for the various pharmacological options was limited, participants wanted clarity on what medications were appropriate or not.

> "*I think there is probably no magic solution to this but I think a clear algorithm of medications that are appropriate [is needed]. I think [it] would be the most practical thing… maybe they do not have a massive amounts of evidence but GPs, they would feel they need something in their armoury. "* GP_05

The lack of available guidelines, in particular pharmacological guidelines, meant that prescribing decisions were primarily informed by the GPs own personal beliefs about the drug. These beliefs were shaped by their previous experience of prescribing the drug. Experience was often viewed as being superior to knowledge acquired through formal learning.

> *"In my experience I have learned on the job, it's not that I do extensive reading, it's not that I go to a lot of meetings… It's very easy for me because it's intuitive – I do it all the time."* GP_04

In addition to professional experience, personal experience of having a family member with dementia was identified by several GPs as being a very valuable source of knowledge.

While many participants found the lack of guidelines challenging, others seemed quite content to base their decisions on their own experience rather than evidence and felt this was an inevitable part of general practice.

> *"A lot of what we do on a day-to-day basis isn't written in any journal, you know, while you try to be evidence based, a lot of it is from experience."* GP_10

Although most participants wanted guidelines in BPSD, some participants argued that having a guideline in this area may not be appropriate. As they saw it, there was no 'one-size fits all' solution to the problem.

> *"I just think that it is such a variable - like hypertension is hypertension and hypertension it isn't really, you know. I think the problem with dementia is that it affects everybody completely differently."* GP_15

As well as prescribing dilemmas participants frequently spoke about the difficulties associated with assessing for potentially reversible causes of BPSD, such as pain. Several participants wanted clinical guidance on how to better assess for alternative causes of these behaviours.

In addition to lack of guidelines many participants also experienced difficulty accessing clinical advice from secondary care. Some participants were uncertain about what service to access. They found the lack of clear referral pathways to secondary care challenging.

> *"[If] you need to talk to someone about a chest pain well you clearly know who to go to whereas it is not as clear here I think."* GP_01

There were some suggestions that the lack of a GP expert in the area of dementia meant that they lacked the support of a colleague with a special interest in the area. As a result, although colleagues were mentioned as important sources of emotional support, other GPs were not usually considered as sources of clinical support.

Some participants described how they relied on personal contacts to access advice and reassurance from secondary care colleagues.

> *"You know, when you just want to ask a simple straight forward question but it isn't easy to access people, you know... I probably call in favours…"* GP_10 [GP with no nursing home commitment]

This view was usually expressed by GPs who had no nursing home commitment. In contrast, where the participating GP had a nursing home commitment there was often an established relationship with either a geriatrician, or old age psychiatrist who attended that nursing home. This relationship gave GPs what they sought most from consultant colleagues- reassurance.

> "*Neither of them mind me calling them directly on their mobiles, they are very very accessible… just the reassurance that you are probably doing things okay, you know."* GP_09 [GP who attends several nursing homes]

The challenge of lack of guidance impacted on their management (Figure 11).

The participants who had significant experience of managing dementia and who were supported by access to consultant advice appeared to have more confidence in managing BPSD. This confidence influenced their management, making them more willing to engage in trial prescribing, more cognisant of avoiding crisis presentations and more aware of their own limits.

> "*What I've learnt, that lingo from the psychogeriatricians, is that you 'give it as a trial' and sometimes it's absolutely bingo and sometimes it bounces off and you move off it pretty quickly and try the next one."* GP_04 [GP with large nursing home commitment]

However, this confidence did not seem to extend to non-pharmacological management strategies. Even the GPs with extensive professional dementia experience often lacked confidence in recommending non-pharmacological strategies to family carers. Some participants either underestimated, or were unaware of, advice that they could provide to families of people living with dementia in the community. Other GPs did not think it was their role to give advice on non-pharmacological strategies. They felt they lacked the time and the skills to do this. However, the majority felt that it was their role to refer a patient to the relevant person who could provide this advice.

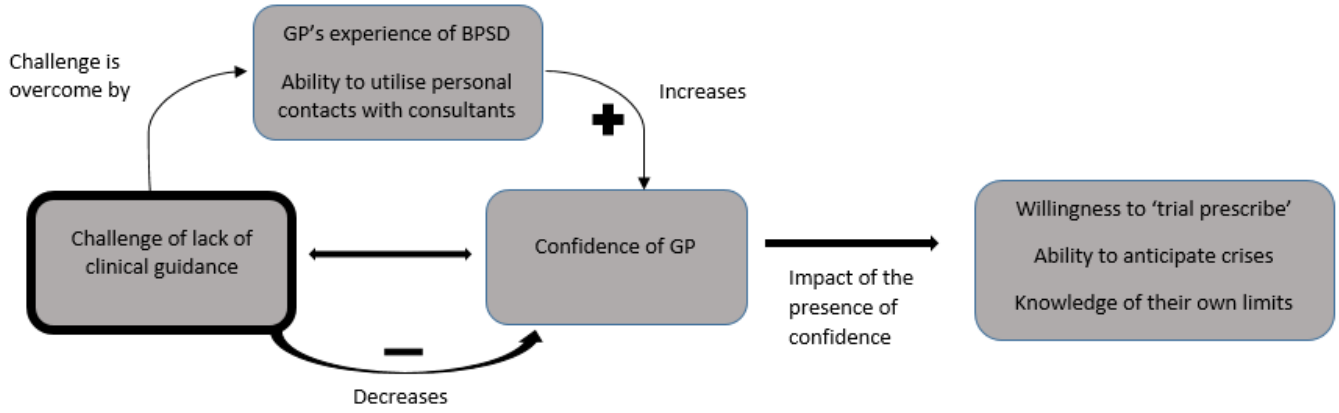
> *"I mightn't have the skills myself but I would be able to refer them to people who would have the skills."* GP_15

In general, GPs who had personal experience of dementia strongly advocated for non-pharmacological strategies and were more confident in giving non-pharmacological advice.

They had little faith in the role of medications for BPSD beyond its role to sedate. They actively sought to identify and manage carer burden.

> *"Putting signs up everywhere and all these small things that actually to people who are living it day to day probably make a big difference…. I don't personally think this is a problem that is going to be solved by medication. This patient has dementia. This is part of the illness. Unless you just sedate them all to the point where they are sitting asleep all day – which with having a Dad with dementia you would sometimes have to wonder would that just be easier." GP_05*

Figure 11. The challenge and impact of the lack of clinical guidance in BPSD



Stretched Resources

Participants found it difficult to recommend non-pharmacological strategies when the appropriate resources were not in place to support these strategies.

> *"You would like to be able to say 'I think this patient will benefit from art or music therapy'. You can suggest those but it might be easier to see those happen if there was a primary care element that was providing them."* GP_05

In particular, the absence of sufficient community-based resources, such as adequate home-help hours, were frequently mentioned as a barrier to providing optimal care in the community.

> "*There isn't enough home help anyway … If he had more support at home he could stay at home and he would love to stay at home but he can't."* GP_14

Resources available depended upon whether the GP was supported by a fully-functioning primary care team and on the extent of voluntary support agencies in the area. Availability of resources was not related to the size or setting of the GP practice. Participants felt the challenge presented by the inadequacy of resources was outside of their control, describing how this challenge stemmed from government policy or from nursing home management decisions. Good working relationships with allied health care professionals helped participants to overcome this challenge. However, several participants reiterated that, although helpful, good relationships alone could not overcome the challenge posed by limited resources.

Resource limitations in nursing homes also impacted on GPs' decision making as it reduced their management choices. For example, several participants reported that low staffing levels acted as a barrier to recommending labour-intensive non-pharmacological strategies.

> "*To be honest it is kind of awkward because I am not going to be the one doing the work and I am asking people who are working very hard and are very stretched."* GP_03

Many participants described being unable to access resource-intensive management strategies, such as one-to-one nursing care, when needed. This, in turn, resulted in increased prescribing of sedative medication.

> *"The only thing that would work is if somebody stayed talking to her continuously. Which wasn't practical so we tried every pharmacological intervention that was possible. Eventually she got the ultimate cure, a PE [pulmonary embolism] which was, unfortunately, I think the only thing that gave her relief."* GP_13

Conflicting expectations

Tension arose when the family had expectations, deemed unreasonable by the GP, of what the GP could do to improve these behaviours.

> *"It's their children that are very difficult, you know, very demanding, expecting us to provide a lot of stuff that we just can't."* GP_14

The expectations of the family at times influenced the GP's decision to prescribe.

> *"I feel you are just prescribing things to keep the family happy because they are at their wits end with it."* GP_06

Having the family 'on-board' with the management plan helped GPs overcome this challenge. While different strategies were employed to engage families, most focused on improving communication with family members.

> *"So I don't interact with them on the phone now anymore. I need to see them in front of me because I need to get a better feel for what they understand that I am trying to do, or not trying to do."* GP_15

Managing the expectations of nursing home staff was also identified by many participants as a challenge. Some participants described how they struggled to maintain their advocacy role for their patients in a nursing home setting.

> *"From a nursing home point of view patients that sleep through the night are the easiest patients to manage… and I think that if patients want to be night owls and stay up late and sleep in that they should be allowed to do that, if that is their own natural way." GP_03*

As a result of these conflicting priorities many GPs described feeling pressurised to prescribe sedative medication. Poor pathways of communication between the general practitioner and the nursing staff further exacerbated the conflict caused by these competing priorities.

> *"… but the Matron is standing over you saying chart it down PRN [as required] and you are saying 'well are they constipated'? 'I don't know, well we have to have to go and ask Mary. Jane will you go and find Mary to ask her.' And then she would say 'oh I wasn't looking after her last night' and twenty minutes later you're like 'oh God okay Seroquel'."* GP_05

In situations where there was a long-standing relationship of trust between the nursing home staff and the GP their priorities were more aligned and there was consequently less pressure. Consistency of care was considered an important factor to building this relationship of trust. Structured visits were seen to facilitate the provision of continuity of care and led to good communication channels between the GP and nurses.

> *"I listen to them because I trust them. I trust the nursing staff."* GP_11

In addition to the expectation of family members and staff in nursing homes, two participants commented on how they felt an expectation from consultant colleagues to follow advice given. They described feeling "compelled" to follow advice even if it conflicted with their own views on what was best for the patient.

> *"If you ask for a review and you are given a review and someone has prescribed something. You feel compelled to go with that then. You know… it is very hard to call them back a second time if you don't take their opinion on the first occasion."* GP_12

However, this view was not held by the majority of participants who felt that consultant colleagues valued their opinion.

6.5 DISCUSSION

The lack of optimism towards the management of BPSD was pervasive. The challenges associated with BPSD were viewed by some participants as insurmountable and outside of the GP's control. Many participating GPs struggled at an ethical level with the decision to prescribe potentially harmful sedative medication but felt they had little else to offer. Overall, GPs felt that when managing people with BPSD their role as an advocate for their

patient was often compromised. What was best for the person with dementia was complicated by competing expectations of family caregivers and the conflicting priorities of nursing home staff. In the absence of appropriate resources for non-pharmacological strategies and in the face of such pressure, GPs felt they had no viable alternatives to sedative medications. In addition to prescribing pressures and resource constraints, GPs were further challenged by the lack of appropriate clinical guidance in the area.

The GP's own experience with a drug emerged as the critical factor that influenced their prescribing decisions. In general practice the practitioner's previous experience with the drug plays an important role in prescribing decisions [305]. It is possible that the lone-working nature of general practice means that GPs are more likely to rely on and trust their own experiences. However, previous qualitative research that explored old age psychiatrists' prescribing decisions in BPSD also found that in most cases choice of medication was based on familiarity and past experience with a drug [273]. This suggests that, in BPSD, the importance of previous experience with a drug when making prescribing decisions might be a reflection of the lack of robust evidence for prescribing in this area rather than particular professional characteristics. In our study GPs' experience of managing BPSD increased their knowledge which subsequently led to greater confidence (see Figure 11). This study builds on existing literature that demonstrated that GPs lack confidence in managing BPSD [80,152,301] and extends our understanding by explaining the factors that affect GPs confidence - namely experience and access to clinical guidance. This study goes further by exploring the impact that this confidence has on their management of BPSD. Confidence allowed GPs to engage in trial prescribing, gave them an awareness of their own limits and enhanced their ability to anticipate potential crises. This finding is supported by existing research suggesting that

confidence in dementia care has the potential to positively influence practitioner behaviour [306].

GPs reported that the paucity of resources made the implementation of non-pharmacological strategies unfeasible and increased the prescribing of sedative medication. This is supported by previous research that has identified the challenge resource constraints creates for GPs managing BPSD [243] and research that has recognised the influence of resource inadequacies on GPs' prescribing of antipsychotics in dementia [153]. Resource constraints clearly act as a barrier to non-pharmacological strategies. However, in our study there was also evidence of a lack of ownership of non-pharmacological strategies by GPs. Whether this role should fall to GPs or is more appropriately led by community based occupational therapists or psychologists who have been trained in this field is debatable, but in the absence of these resources it does inevitably fall to the GP.

Many participants highlighted the important role of the family caregiver and found managing expectations of family, to be very challenging. However, the GPs expectations of family involvement could be, in itself, an unreasonable expectation. In the context of inadequate resources, it is possible that a reasonable request for support from a family member was seen by the resource-poor GP as being an unrealistic expectation. From a nursing home perspective the existence of a good working relationship with nursing home staff helped GPs to manage conflicting priorities. This finding supports research which has shown the importance of good relationships between staff when managing people with dementia in a nursing home [307]. Our study further identified that continuity of care, which was enabled by structured GP visits to the nursing home, facilitated positive working relationships.

The common thread throughout was the challenge posed by insufficient resources. Difficulty accessing advice from secondary care colleagues probably stems from an inadequately resourced service. Inability to meet expectations of family caregivers is influenced by the lack of community based services and supports. The pressure from nursing home staff is related, at least in part, to understaffing and what is often an unsuitable environment.

Strengths and Limitations

The systematic sampling process and the discussion of clinical cases in the interviews, allowed in-depth access to information-rich, real-life cases of BPSD and its management. Concepts emerging in the analysis were brought forward to subsequent interviews and the extent to which emerging themes resonated with the experience of participants was assessed, improving the credibility of the research. The use of analyst triangulation helped to increase the confirmability of the findings. The interviewer was a GP. We believe that having a GP interviewer facilitated recruitment and encouraged GPs to participate in the study. Clinician researchers interviewing other clinicians has the potential to introduce bias as the interviewee might see the clinician researcher as an expert who will judge both their clinical and moral decision making [308]. However, it is also acknowledged that when participants in interviews recognise the researcher as a clinician the interviews tend to provide richer and more personal accounts of attitudes and behaviour in clinical practice [308]. Indeed in this study, having a clinician researcher facilitated the in-depth discussion of clinical cases as part of the interview. We found that having a GP interviewer allowed participating GPs to discuss their experiences in a safe non-judgemental, collegial environment. This facilitated rich descriptions of the clinical challenges they experienced.

Attempts were made to reduce the risk of professional bias by involving a non-clinician in the analysis process.

Implications for research and practice

This study provides a better understanding of GPs' behaviours when managing BPSD which will facilitate the design of a more targeted intervention to support GPs in their delivery of care to these patients [239]. There is a role for educational interventions for GPs in BPSD, in particular interventions that focus on assessment of BPSD and non-pharmacological strategies. However, the complexities of the challenges identified in this study highlight the need for additional interventions to support any educational initiatives. Shared decision making tools may help overcome the challenges presented by managing conflicting expectations from both family care givers and nursing home staff. However, in order for a shared decision making tool to be effective, the GPs need to have the confidence, knowledge and skill to discuss and give advice on the various treatment options [309]. Another challenge in the development of an effective shared prescribing decision tool is the insufficient evidence on the benefits of pharmacological options in BPSD. Furthermore, although there is a need for clinical guidance for GPs in BPSD, formal guidelines may not be appropriate given the heterogeneity of these behaviours and symptoms. However, a flexible management algorithm may be helpful. Clinical pathways or algorithms can help bridge the gap between best practice recommendations and the practical implementation of these recommendations at the coal-face [310], an approach which would be particularly pertinent in BPSD. It is important that future research and practice focuses on appropriate assessment of BPSD in order to identify potentially reversible causes of BPSD rather than choosing between various medications that are largely ineffective and potentially harmful. This

requires a culture shift in how BPSD is managed. Such a culture shift will require appropriate resources, education and clinical guidance.

6.6 CONCLUSION

In the context of rising dementia prevalence the demand for community-based dementia care will increase. This is the first study to investigate the challenges GPs encounter when managing BPSD. This study helps to explain the apparent discrepancy between best practice recommendations in BPSD and real-life practice. The findings will be used to inform the design of an intervention to support the management of BPSD in general practice.

CHAPTER 7. THE KNOWLEDGE AND ATTITUDES OF GENERAL PRACTITIONERS TO THE ASSESSMENT AND MANAGEMENT OF PAIN IN PEOPLE WITH DEMENTIA

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7.1 ABSTRACT

Objectives

Pain in people with dementia is underdiagnosed and undertreated. General practitioners (GPs) play a pivotal role in dementia care but their perspective on pain in people with dementia remains largely under-researched. The aim of this study was to explore GPs' knowledge and attitudes towards pain assessment and management in people with dementia.

Methods

This was a descriptive cross-sectional study. A questionnaire was adapted from a previous study and piloted with GPs. The questionnaire was posted to a census sample of all GPs in Cork city and county in the southern region of Ireland. The questionnaire collected demographic information, responses to a series of Likert statements assessing GPs knowledge and attitudes, and provided an opportunity for the GP to give qualitative feedback on their experiences of managing pain in dementia. SPSS v25 was used for statistical analysis. Qualitative responses were thematically analysed.

Results

Of the 320 questionnaires posted, 157 completed questionnaires were returned (response rate of 49%). The sample was representative of GPs nationally in terms of years in GP practice and practice location. Over two-thirds (108/157) of respondents had a nursing home commitment. Only 10% of respondents (16/157) were aware of any dementia-specific pain assessment tools. The larger the nursing home commitment of the GP the more likely they were to be familiar with these tools ($p = 0.048$). The majority of respondents (113/157)

believed people with dementia could not self-report pain. Respondents were uncertain about the safety of using opioid medications to treat pain in people with dementia with only 51.6% agreeing that they were safe. The qualitative comments highlighted the importance the GPs placed on surrogate reports of pain, GPs' uncertainty regarding the value of formal pain assessment tools and the challenges caused by under-resourcing in general practice.

Conclusion

This study has highlighted aspects of pain assessment and management in dementia that GPs find challenging. Guidance on pain assessment and management in people with dementia do not appear to be translating into clinical practice. The findings will inform educational interventions being developed by our research team as part of the implementation of the Irish national dementia strategy.

7.2 INTRODUCTION

The global prevalence of dementia is increasing. In 2013 it was estimated that 44 million people worldwide were living with dementia and this figure is expected to reach 75 million in 2030 and 135 million by 2050 [311]. Although these estimates may be reduced by improvements in population health, such as reductions in smoking and hypertension, current evidence suggest that only 10% of the expected rise in incidence will be avoided by improvements in these disease control measures [312]. A second major health issue facing the older population is that of chronic pain. The prevalence of pain is strongly correlated with increasing age [313,314]. People with dementia appear to have a significantly increased risk of pain [137], with up to half of people with dementia estimated to be living with chronic pain [138-140]. In one study of nursing home residents the prevalence of chronic pain in residents with dementia was almost double that of residents without dementia [315]. Similarly, in the community setting, pain is more prevalent in people with dementia than in people without dementia [137,139,316]. This increased prevalence is related, at least in part, to the significantly higher burden of co-morbid physical disease in people with dementia [317,318] which contributes to increased musculoskeletal pain [319,320], orofacial pain [321] and neuropathic pain [322]. However, pain in people with dementia is often underdiagnosed, underestimated and undertreated [315,323,324].

The negative impact of undiagnosed, untreated pain in dementia is substantial. In a person with dementia untreated pain can worsen cognitive function, lead to depressive symptoms, reduce quality of life and trigger or exacerbate behavioural and psychological symptoms of dementia (BPSD) [138,315,325,326]. The aetiology of BPSD is often multifactorial [108], however, pain is one of the most important causal factors for BPSD [138]. Indeed interventions targeting pain have been shown to be effective at reducing BPSD [327]. A person with advanced dementia may

not either understand or be able to effectively communicate pain and so pain may be expressed through behaviours such as agitation or aggression [328]. In addition to the distress and discomfort untreated pain can cause, not correctly identifying pain as a trigger for these behaviours can lead to the inappropriate prescribing of potentially harmful psychoactive medications to people with dementia. In one study the presence of pain in nursing home residents was found to be significantly associated with the use of antipsychotic medication [191]. In addition to the harmful side effects of psychotropic medication in people with dementia [159,160] these drugs often have a sedative effect which can mask behaviours that are indicative of pain [329], further contributing to under-diagnosis.

The vast majority of people living with dementia either live at home in the community or in a residential care setting such as a nursing home [21]. The general practitioner (GP) is the key healthcare professional for a person with dementia as they provide care in both the community and in nursing home settings. GPs play a pivotal role in assessing and managing pain in people with dementia, however, they are challenged by many aspects of dementia care including the management of BPSD [87,198,293,330] and providing end of life care [331]. Both the management of BPSD and the provision of end of life care in dementia require GPs to assess for and manage any underlying pain. In a recent qualitative study conducted by the authors, GPs reported difficulty identifying pain as a potential trigger for BPSD [332]. However, to the best of our knowledge no research to date has explored GPs' perspectives on pain management in dementia. The aim of this study was to explore the knowledge and attitudes of Irish general practitioners to the identification and management of pain in people with dementia.

7.3 METHODS

An anonymous postal questionnaire was sent to a census sample of all GPs in Cork city and county in the southern region of Ireland in May 2017. Ethical approval was granted by the Social Research and Ethics Committee in University College Cork (Log2016-050).

Questionnaire

There was no previously validated questionnaire available to address this research question. However, we did identify an appropriate questionnaire that was used in a previous study that explored nurses' knowledge of and attitudes to pain management in dementia [333]. With the original authors' permission we adapted this questionnaire for use with GPs. We (AJ, ML, TF), all practicing GPs with an academic interest in dementia care, reviewed the questionnaire to ensure its appropriateness and relevance to a general practice setting. Furthermore, the questionnaire was piloted with five GPs, all of whom have experience managing people with dementia in community and nursing home settings. Subsequently, minor amendments were made to enhance the clarity of the questionnaire. The final questionnaire developed for use in this study contained three sections. The aim of the first section was to capture demographic information from the GPs. The second section consisted of a series of five-point Likert-type statements exploring GPs' knowledge and attitudes to pain in people with dementia. The final section provided GPs with the opportunity to give free-text responses. (The questionnaire is available in appendix 3, supplementary material 11).

Sample

The questionnaire was posted with an information sheet to all 320 GPs practicing in the Cork region. With a large urban and rural population, a census sample of Cork GPs is largely representative of GPs nationally. The sample size was calculated based on this census population of 320 with desired precision estimates of +/-5% around a prior estimate of 50%. Based on these calculations to adequately power the study the sample size required was 175 respondents. All GPs were identified from the Irish Medical Directory [334]. A stamped addressed envelope was provided to return the questionnaire by post if the GP was willing to participate.

Analysis

The data from the responses were coded and SPSS version 25 was used for statistical analysis. Chi-square tests and Mann-Whitney test were used to explore associations between demographic data and responses, with differences at a level of 95% probability and above regarded as statistically significant. The following demographic associations were explored; years in practice, presence of a nursing home commitment and the extent of the GPs nursing home commitment (as indicated by the number of residents the GP cared for). Free-text responses were entered into MS Word and were thematically analysed [101] by two of the authors (AJ,TF).

7.4 RESULTS

Sample

Of 320 questionnaires sent, a total of 157 completed questionnaires were received, representing a response rate of 49% (157/320). The respondents had a broad mix of practice locations and years of experience. The demographic characteristics of respondents is displayed in Table 11.

Table 11. Demographic characteristics of GP respondents to questionnaire

Participant Demographics	N (%)
Practice Location	
City	45 (28.6)
Town	42 (26.7)
Rural	23 (14.6)
Mixed	47 (29.9)
Years of GP Experience	
0-5 yrs	20 (12.7)
6-15 yrs	48 (30.6)
16-25 yrs	41 (26.1)
>= 26 yrs	48 (30.6)
Nursing Home Commitment	
No commitment	49 (31.2)
Attends 1 nursing home	42 (26.5)
Attends 2 nursing homes	39 (24.8)
Attends 3 or more nursing homes	27 (17.2)

Provision of care

Over two-thirds (108/157) of respondents had a nursing home commitment (mean number of nursing homes +/- SD = 1.35 +/- 1.19; range (0-5)). These GPs provided care to a total of 2,393 people in nursing homes (mean number of patients = 15; range (1-112)). The respondents reported that just over half of these nursing home patients (1,242/2,393) had dementia. Of the GPs who provided care to nursing home residents, the majority (60.2%) did a regular round in the nursing home. Over half of the GPs with a nursing home commitment did 1 or more nursing home round per week (mean number of rounds per week = 1, range (0-5)). Rural GPs were significantly more likely to have a nursing home commitment (*P*–value = 0.042). There was no association found between the numbers of years a GP was in practice and having a nursing home commitment.

Pain assessment in dementia

The overwhelming majority of GPs (98%) agreed that the presence of dementia can make pain difficult to assess (Table 12). A smaller majority of respondents (68.7%) felt that pain was under-recognised in patients with dementia. The majority of GPs surveyed agreed that observing behavioural and physiological indicators of pain and obtaining surrogate reports are important when assessing pain in a person with dementia. However, most GPs were unfamiliar with dementia-specific pain assessment tools with only 10% reporting any knowledge of their existence. The larger the nursing home commitment of the GP, as indicated by the number of nursing home residents they cared for, the more likely they were to be familiar with pain assessment tools for people with dementia (*P*-value = 0.048). However, of the respondents with a nursing home commitment only 14% were aware of

guidelines/policies on pain management in the nursing homes they attended. The numbers of years the GP was in practice was not associated with an increased familiarity with pain assessment tools. Despite the lack of awareness of pain assessment tools, the majority (73.2%) of respondents believed that a pain assessment tool would be useful to increase recognition of pain in patients with dementia in nursing home settings.

Table 12. Responses to Likert statements on assessment of pain in people with dementia

Statement on assessment of pain in people with dementia	Agree * N, (%)	Neither agree nor disagree N, (%)	Disagree* N, (%)
The presence of dementia can make pain assessment difficult.	154 (98.0)	3(1.9)	0
A person with dementia is not able to accurately provide a self-report of their pain.	113 (72.0)	20(14.0)	24 (15.2)
Pain assessment tools used for cognitively intact people are not appropriate for people with dementia.	103 (65.6)	33 (21.0)	21 (13.3)
I am familiar with pain assessment tools specifically available for use with a person with dementia.	16 (10.1)	20 (12.7)	121 (77.0)
When assessing pain in a resident with dementia, it is important to observe behavioural indicators of pain (e.g. facial expressions, body movements, posture).	154 (98.0)	2 (1.2)	1 (0.6)
When assessing pain in a resident with dementia, it is important to consider physiological indicators of pain (e.g. heart rate, blood pressure, temperature).	144 (91.7)	12 (7.6)	1 (0.6)
When assessing pain in a resident with dementia, it is important to consider a family/care givers report	150 (95.5)	7 (5.5)	0

**Note: The original Likert scale options "strongly agree" and "agree" were combined to "agree", whereas the options "strongly disagree" and "disagree" were combined to "disagree".*

Management of pain in dementia

The responding GPs appeared less certain about aspects of the management of pain in dementia (Table 13). The overwhelming majority (95%) agreed that the treatment of pain should follow a step-wise approach. However, 26% either disagreed or neither agreed nor disagreed that optimal treatment of pain is achieved when analgesics are given on a regular basis. The respondents were particularly uncertain about the safety of using opioid medications in people with dementia. Just over half of GPs surveyed (51.6%) agreed with the statement that opioid analgesics are safe to use when treating pain in dementia, while 34.4% neither agreed nor disagreed with the statement and 14% believed opioids were unsafe in this patient group. There was no statistically significant association found between the GP's knowledge of the management of pain in dementia and their number of years in practice or the extent of their nursing home commitment.

Table 13. Responses to Likert-type statements on management of pain in people with dementia

Statement on the management of pain in people with dementia	Agree * N, (%)	Neither agree nor disagree N, (%)	Disagree* N, (%)
Residents with dementia who are experiencing pain should be managed differently to cognitively intact residents.	52 (33.0)	34 (21.6)	71 (45.2)
The drug treatment of pain in a resident with dementia should follow a step-wise approach.	149 (94.9)	5 (3.1)	3 (1.9)
Optimal treatment of pain is achieved when analgesics are given on a regular basis.	116 (73.8)	31 (19.7)	10 (6.3)
Paracetamol is the best analgesic to use for residents with dementia who are experiencing chronic pain.	98 (62.4)	43 (27.3)	16 (10.2)
It is safe to use opioid analgesia to treat pain in residents with dementia.	81 (51.6)	54 (34.4)	22 (14.0)
Residents with dementia are less likely to become addicted to opioid analgesics than cognitively intact patients.	21 (13.3)	65 (41.4)	71 (45.2)
There is a greater risk of side effects from opioid analgesics (e.g. respiratory depression, confusion) when used in residents with dementia.	101 (64.3)	36 (22.9)	20 (12.7)
Non-drug based methods of pain control (e.g. TENs, Heat/Cold, massage, complimentary therapy) are useful in the management of pain in residents with dementia.	129 (82.1)	20 (12.7)	8 (5.09)

*Note: The original Likert scale options “strongly agree” and “agree” were combined to “agree”, whereas the options “strongly disagree” and “disagree” were combined to “disagree”.

Free-text responses

Of the 157 respondents, 49 GPs (31% of respondents) provided additional qualitative feedback in the free text section of the questionnaire. There were a number of themes identified from the free-text responses. The three main themes identified were; (i) the role of pain assessment tools, (ii) the importance of input from carergivers and (iii) challenges of resource limitations. Verbatim quotations are presented here to illustrate the themes. [335] These particular quotations were selected as they were considered to be typical of the responses that underpinned the development of each theme.

Theme 1: Role of pain assessment tools

Several of the responding GPs expressed a desire for guidance in the area of pain assessment and management in dementia:

> "*Would love guidance on pain management in these patients" (Respondent_79, experienced GP, urban practice, no nursing home commitment)*

Some respondents expressed apprehension about introducing pain assessment tools.

> *"I feel a lot of 'tools' can lead to unnecessary work if arbitrarily based on BP readings, heart rates etc e.g. MEWS score in hospital which is why I'd be wary of their use. Would need to be used judiciously"*
>
> *(Respondent_84, recently qualified GP, rural practice, with nursing home commitment)*

Many GPs perceived pain assessment tools as yet another tool that would add to GPs' workload without necessarily improving care.

"A pain assessment tool wouldn't be helpful in nursing homes as it would add more workload to already onerous paperwork"

(Respondent_128, recently qualified GP, urban practice, with nursing home commitment)

Theme 2: The importance of input from caregivers

A second theme identified was the value GPs placed on the input of relevant caregivers, who knew the person with dementia well, when assessing pain:

"Key component to good assessment depends on good collateral history - family/close friends, nursing staff/carers."

(Respondent_46, experienced GP, rural practice, with a nursing home commitment)

In particular many GPs highlighted the important role of nurses in pain assessment:

"Feedback from nurses helps to make appropriate prudent descriptions."

(Respondent_75, experienced GP, mixed practice setting, with a nursing home commitment)

The GPs described how they relied on the nursing staff and trusted their opinion when assessing a person with dementia:

"An experienced nurse is the best person to rely on, they know as do the carers – listen to them and you'll get it right."

(Respondent_140, experienced GP, urban practice, with a nursing home commitment)

Theme 3: The challenges of under-resourcing

A third theme identified was the challenges GPs experienced providing care to people with dementia given the current underfunding of Irish general practice.

> *"Dementia [is] not currently a paid 'chronic disease' in GP, poor remuneration."*
>
> *(Respondent_114, mid-career GP, mixed practice setting, no nursing home commitment)*

The GPs reported extensively about the impact of recent austerity cuts in Ireland which dramatically cut funding to GPs who provide care to nursing home residents:

> *"Usual gripe – fee for attending nursing home residents in now 1/3 of what it was in 2008! Hhhmmmm….."*
>
> *(Respondent_70, mid-career GP, rural practice, with a nursing home commitment)*

Several GPs also stated that they no longer provided care to nursing home patients as a result of these reductions in remunerations:

> *"I have given up nursing home care. Funding poor. Bureaucracy a problem."*
>
> *(Respondent_26, experienced GP, urban practice, no nursing home commitment)*

7.5 DISCUSSION

This is the first study that has explored GPs' assessment and management of pain in people with dementia. Our findings suggest that GPs are confident in many aspects of assessing pain in people with dementia such as the value of observing behavioural and physiological indicators and the importance of surrogate reports but that they are challenged by many

aspects of assessing and managing pain in dementia. The majority of GPs surveyed believed that a person with dementia cannot self-report pain and the vast majority of GPs were unfamiliar with dementia-specific pain assessment tools. In the absence of either a self-report or a standardized observational tool to assess pain, the responding GPs appeared to rely significantly on surrogate reports from family members and nursing home staff when assessing pain in dementia. Although the majority of responding GPs welcomed the idea of guidance in the area of pain assessment and management in dementia, in the free-text comments many questioned the value of a standardized, observational pain tool. Furthermore, when managing pain in people with dementia the GPs were particularly uncertain about the role of opioid medication and the consequences of the use of opioids in people with dementia. While the majority of GPs agreed that in order to achieve optimum pain relief analgesia should be prescribed regularly, over a quarter of GPs surveyed did not agree with this statement. The inference being that these GPs are favouring 'as required' analgesic medication, a sub-optimal method of pain control. Although we did find that GPs with a larger nursing home commitment were more likely to be familiar with dementia-specific pain assessment tools, in general, the experience level of the GP was not associated with increased levels of knowledge or a more positive attitude towards pain assessment and management in dementia.

Comparison with existing literature

Our findings indicate that GPs' value good communication with family members and nursing home staff when managing pain in people with dementia. This finding is similar to previous studies with community pharmacists [316] and nurses [333]. In previous research on GPs'

educational needs in dementia [87] both GPs and family caregivers emphasized the importance of good channels of communication in dementia care. In our study, the GP respondents also emphasized the importance of a report from nursing staff or family carer when assessing pain in the qualitative free-text responses. In our study nursing staff were seen by the GPs to facilitate pain assessment. This is in contrast to findings from a previous study that examined nurses knowledge and attitudes to pain management in dementia where nurses identified a lack of GP support as a barrier to successful pain management [333]. Previous research with GPs found that consistency of care was an important factor in improving relationships between GPs and nursing staff [332]. In that study structured visits by the GP to the nursing home were seen to facilitate the provision of continuity of care and led to good communication channels between the GP and nurses [332]. Effective communication between nursing staff and GPs is an essential component of any optimisation of pain assessment and management in nursing home settings.

The majority of respondents in our study believed that people with dementia could not accurately provide a self-report of pain. However, self-reporting of pain is considered the gold standard method of pain assessment [336] and can be a reliable way of assessing pain in people with dementia [336-338]. Best practice recommendations advise that where possible attempts should always be made to elicit self-reports of pain from the person with dementia [336]. Although in the very advanced stages of dementia many individuals may be unable to self-report pain [320], people with mild-moderate [191,339] and in some cases severe dementia [340] have been found to provide valid self-reports of pain. Our finding echoes previous research with nursing home managers which found that only 8.3% of respondents felt that people with dementia could self-report pain [341]. The large majority of GP respondents agreed with the statement that *'a person with dementia is not able to provide a self-report of pain'.* This

finding could mean that an attempt is not being made to elicit a self-report from a person with dementia. However, this needs to be explored further, ideally with qualitative research, to establish the impact this attitude has on how GPs assess pain in people with dementia.

Nearly all GP respondents agreed that patient observation was a critical part of pain assessment in dementia. Despite this belief the vast majority of respondents were not using any validated, standardised, observational approach. Observational methods are central to clinical assessment, especially when a person lacks the ability to self-report, however, there is a risk of observer bias if there is no standardized approach to the observation [337]. A large array of pain assessment tools exist for use in people with dementia - a recent systematic review of pain assessment tools included twenty-eight such tools [342]. However, the vast majority of GP respondents were unaware of these tools. Similar to previous findings from a study with community pharmacists [316], the more experience the GP had with dementia the more likely he or she was to be aware of these tools. The lack of awareness of dementia-specific pain assessment tools is a particularly noteworthy finding since the majority of respondents thought that having such a pain assessment tool would be helpful. This highlights an incongruity between research in this area and real-life clinical practice. These tools appear to be rarely used in general practice.

The responding GPs lack of familiarity with pain assessment tools may be surprising to researchers in the area but may be unsurprising to front-line GPs. GPs do not readily embrace assessment tools [343,344]. They are inductively trained to rely on their clinical skills. This is in contrast to nursing staff who are specifically trained to use and rely on assessment tools. In the free-text responses some GPs feared the additional workload such tools could bring and questioned what clinical value they would add. Similarly, recent qualitative research exploring

GPs', hospital physicians' and nurses' perspectives on the use of observational pain tools in people with dementia identified a number of barriers to using observational pain tools, one being the perceived lack of value in using them [345]. Furthermore, participants in that qualitative study described using the pain tools to comply with local recommendations but not actually using the results to inform treatment decisions [345]. This echoes some of the concerns raised by participants in our study that a pain tool would become another source of paper-work rather than a tool to aid clinical decision making. GPs are not usually the healthcare professional tasked with completing a pain assessment tool; in a nursing home setting that role would typically fall to the nursing staff. GPs do still need to be aware of these tools in order to interpret the findings and generate appropriate management plans in discussions with nursing staff. However, clinicians and nurses can find the results of pain assessment tools difficult to interpret [346]. Implementing these observational pain assessment tools in isolation, without adequate guidance on how to interpret the results, will not lead to improved treatment of pain [320]. The tools in themselves will not result in improved care unless they are combined with guidance that will help clinicians to translate a pain score into an appropriate treatment plan.

Respondents appeared unsure about the safety of opioid analgesics in people with dementia. This is similar to previous research conducted with nurses [333], nurse managers [341] and community pharmacists [316] all of whom had similar concerns regarding the safety of prescribing opioids to people with dementia. Guidelines on pain management in the older adult do recommend considering opioid analgesics for patients with moderate to severe pain, particularly if the pain is causing functional impairment or reducing quality of life [313]. The uncertainty the GP respondents felt regarding the safety of opioid medication in dementia is perhaps understandable; prescribing opioids to an older adult is not without its complexities.

Age is a significant predictor of opioid related harm [347,348]. Adverse effects of opioids can include respiratory depression, sedation, constipation, nausea and dizziness [349]. Many of these adverse effects increase with age [350] and frailty [348] both of which are associated with dementia. Furthermore, these adverse effects can be particularly problematic to identify in a person with advanced dementia because of their reduced ability to communicate. However, when managing pain in people with dementia the adverse effects of opioids needs to be weighed up against the harmful effects of undertreating pain. Although a narrow majority agreed with the statement that opioids were '*safe in people with dementia'*, a larger majority of respondents agreed with the statement that there is *'a greater risk of side effects from opioid analgesics when used in people with dementia'.* Many respondents appeared to feel that, despite the increased risks, the use of opioids in people with dementia was still "safe". How this belief influences the GP's prescribing is unclear. Previous research suggested that people with dementia may receive less opioids [351]. A qualitative study which examined GPs' perspectives on prescribing opioids for chronic pain found that fear of causing harm was a barrier to prescribing opioids to the older adult [352]. Despite this a recent systematic review identified that, internationally, prescribing of opioids to nursing home residents has increased over time [353]. Similarly, a large Danish study found that buprenorphine and fentanyl patches were more commonly prescribed to people with dementia [354]. It is possible that these opioid patches are perceived as having less side effects than oral opioids or as being more tolerated by people with dementia. However, these transdermal opioid patches typically contain a stronger opioid dose than oral opioids, and since the adverse effects of opioids are dose related these patches are likely to result in more, not less, side effects. Prescribers' perspectives of the role of different opioid medications in the management of pain in dementia is an important area that could be explored in future research.

Although optimal treatment of pain is achieved when analgesics are given on a regular basis [355], over a quarter of respondents in our study did not agree with this statement. A similar finding was reported in previous research with nurses [341] where 20% of respondents either agreed, or neither agreed nor disagreed, with a statement that 'optimal pain treatment of pain relief is achieved when analgesics are given in a PRN (or as required) way'. If the value of regular administration of analgesia is not recognized this could result in the prescribing of analgesics in the less-effective 'as required' way. Research conducted in nursing homes in Northern Ireland in 2015 found that in the majority of residents with dementia, analgesic medication was prescribed 'as required' and not regularly [191]. Likewise, research from the U.S. found that cognitively impaired nursing home residents were less likely than their cognitively intact peers to be prescribed regular, scheduled analgesia and were more likely to be prescribed analgesic medication in an 'as required' way [324]. To receive this 'as required' medication a person would either need to ask the nurse for pain relief or the nurse would need to identify that the person was in pain and give them pain relief [324]. In the case of a person with advanced dementia neither of these situations are very likely to occur. In view of their cognitive and communication difficulties a person with advanced dementia is unlikely to self-request analgesia and we know from existing evidence that there are a number of barriers to nurses identifying and initiating pain relief in a person with dementia [333,341].

Areas for future research & implications for policy & practice

This study highlights several areas of GPs assessment and management of pain in dementia that could be explored with future research. There were some findings that warrant further exploration in future research such as the use of 'as required' medication and the belief that

people with dementia cannot self-report pain. Future qualitative research with GPs in this area would help gain a deeper understanding of the context and nuances that are involved in this complex area. It would be important to ascertain how GPs' knowledge of and attitudes towards pain in people with dementia impacts on their actual prescribing of analgesia to people with dementia. A quantitative study of current prescribing of analgesia to people with dementia both in nursing homes and in the community would be an important complementary study. These studies would lead to a more extensive understanding of the problem and would help to inform the development of effective interventions to improve the management of pain in dementia in primary care settings.

There is a role for educational interventions for GPs that focus on pain assessment and management in dementia. The results of this current study will inform the ongoing, national roll-out of educational interventions for GPs in dementia care that have been developed by our research team [133,356] as part of the implementation of the Irish National Dementia strategy [29]. Previous educational interventions for GPs in the area of pain management in dementia have used teleconferencing technology based on the Project ECHO© model and have been found to improve healthcare professionals' knowledge and self-efficacy of pain assessment and management in advanced dementia [357]. Such educational interventions would be particularly acceptable to general practitioners as they eliminate the need for travel and don't require any prolonged periods away from practice. Another important finding was in relation to educational initiatives was that GPs see nurses as facilitators to optimum pain management, whereas in previous studies [333,341] nurses identified GPs as barriers to optimum pain management. This highlights a communication gap between these two professional groups, both of whom play a pivotal and complementary role in the assessment and management of pain in dementia. This finding underlines the importance of inter-professional

educational initiatives in this area. Palliative care is another professional group that have a significant role to play in the management of pain in dementia, particularly in complex cases, yet we know that many people with dementia are not routinely assessed to determine their palliative care needs [358]. An inter-professional educational approach including all the relevant professional groups could help improve communication and bridge professional divides [359], which would play an important role in improving the care provided to people with dementia who are living with chronic pain.

Although relevant and important, we know that educational interventions alone have limited effect in changing GPs' behaviour in dementia care [286,287]. To effectively improve GPs' performance in dementia care, education needs to be combined with adequate reimbursement and organisational incentives [360]. A previous systematic review highlighted how time constraints and inadequate remuneration act as barriers to optimum diagnosis and management of dementia in primary care [72]. In Ireland general practice receives only 4.5% of the overall health budget, significantly lower than other European countries [54]. Additionally, recent government-led austerity cuts in Ireland have dramatically cut funding to general practice, these cuts have particularly affected general practitioners providing care to nursing home residents. In our study the dissatisfaction of GPs with the current under-resourcing of dementia care was evident in the free-text responses. Many GPs discussed the challenges of providing optimum care to people with dementia in the context of current resource limitations, reporting that they can no longer provide care to nursing home residents. Like many other European countries [361-363], Irish general practice is currently facing a recruitment crisis [67]. This recruitment crisis is particularly affecting rural general practice, therefore, it was notable that rural based GPs were significantly more likely to provide care to nursing home residents than non-rural GPs. In the face of this recruitment crisis and in the context of current

inadequate reimbursement, the future of GP led nursing home care is uncertain. Future policy needs to focus on adequate resourcing of dementia care in both community and nursing home settings.

The study results have several immediate practical implications for GPs caring for people with dementia. The implications for GPs assessing pain in people with dementia include; being more aware of the increased risk of pain in people with dementia, considering pain as a potentially reversible trigger for BPSD, providing people with dementia an opportunity to self-report pain and familiarising themselves with the pain assessment tools that may already be in place in the nursing homes they attend in order to facilitate more effective communication with the nursing home staff. From a pain management perspective one practical implication for GPs is that if pain is identified, or suspected, then it is important that the person's pain is not under-treated. Inappropriate prescribing in people with dementia does not just mean over-prescribing. It also pertains to under-prescribing of appropriate medications that can improve comfort and overall quality of life.

Strengths and Limitations

Although a 49% response rate is modest, it is typical of postal surveys with this professional group [364]. Our response rate is similar to the response rate in a previous national study on GPs attitudes to diagnosis in dementia [301] and significantly higher than a recent online survey of GPs referral patterns in dementia care in Ireland [365]. To adequately power this study a sample size of 175 respondents was required. Therefore, with 157 respondents the study was marginally underpowered. Furthermore, this study was a census study of a specific geographical area in the southern region of the Republic of Ireland. This may affect the

generalisability of the study, however, the respondents' demographic characteristics, in terms of years of experience and practice location, are representative of GPs nationally [45]. A large proportion of respondents had a nursing home commitment. There is currently no Irish data available on the number of GPs who attend nursing homes, therefore, it is difficult to ascertain whether this represents a respondent bias. It is possible that GPs with a nursing home commitment were more likely to respond to the survey as they may have been more interested in the research topic. Finally, this was a cross-sectional survey of self-reported knowledge and there is evidence to suggest that when self-reporting physicians may underestimate their knowledge in an area [366]. The nuances of clinically complex areas such as this are difficulty to fully address with a single study that rely primarily on self-reporting measures. However, since there is very little research exploring GPs experiences of managing pain in people with dementia our chosen methodological approach is a necessary and reasonable place to start.

7.6 CONCLUSIONS

Despite the pivotal role GPs play in dementia care their experience of managing pain in dementia is greatly under-researched. Prior to this study very little was known about GPs' knowledge of and attitudes towards the assessment and management of pain in dementia. This study enriches existing literature in the area of pain management in dementia care and also raises some important issues that should be explored in future research. Pain management in a person with dementia touches on some of the most fundamental aspects of a GP's role as a patient advocate. It is, therefore, challenging to identify aspects of care that could, perhaps, be improved upon. However, without identifying these areas we cannot

design effective interventions to appropriately address them. The results of this study will be used to inform the development of interventions to improve the management of dementia in general practice as part of the wider implementation of the Irish National Dementia Strategy.

CHAPTER 8. GENERAL PRACTITIONERS' KNOWLEDGE OF AND ATTITUDES TOWARDS PRESCRIBING ANTIPSYCHOTICS IN DEMENTIA: A DESCRIPTIVE CROSS-SECTIONAL STUDY

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AN UNPUBLISHED THESIS CHAPTER

8.1 Background

The studies conducted to date in this thesis highlighted the key challenge that antipsychotic prescribing presented to GPs when managing BPSD. One of the main findings from the systematic review, reported in Chapter 5, was that antipsychotics were sometimes used to enable family members and nursing home staff to cope with the behaviours and symptoms. Findings from the qualitative study, reported in Chapter 6, also emphasised the challenges GPs experience when prescribing antipsychotics in BPSD. In the qualitative study some GPs appeared to be unaware of the adverse effects of antipsychotic and over-estimated their benefits in managing BPSD. These studies had established that GPs' prescribing of antipsychotic medication was an aspect of GPs' behaviour when managing BPSD that needed to be explored further. To date no study had explored GPs' prescribing of antipsychotic medications in Ireland. It was not known what psychotropic agents GPs prescribe in BPSD, or in what situations GPs prescribe medications to people with BPSD. It was not known whether GPs monitor their antipsychotic prescribing in BPSD or whether they feel confident to discontinue these medications in BPSD. To further explore the findings of the systematic review and the qualitative study a descriptive cross-sectional study was designed to enhance my understanding of GPs' antipsychotic prescribing in BPSD in Ireland. The aim of this study was to establish GPs' knowledge of and attitudes towards antipsychotic prescribing to inform the development of the intervention.

8.2 Methods

A survey was posted to a census sample of all GPs working in counties Cork and Kerry in the southern region of Ireland. This census sample was identified through the Irish Medical Directory. The sample size was calculated based on this census population of 468 with a margin of error of +/− 5% and a response distribution of 50%. To adequately power the study the sample size required was 212 respondents. All GPs received a leaflet with information about the purpose of the study and a personally addressed letter inviting them to complete and return the questionnaire with the free post envelope provided. Participation was voluntary and consent was assumed through completing the questionnaire. All GPs who returned a completed questionnaire were included in the study.

An anonymous 21-question questionnaire was used to collect data. The questionnaire used was adapted, with permission, from a previous study with Australian GPs. [155] The questionnaire was modified to explore the findings of the systematic review and the qualitative study. The questionnaire was piloted with 3 GPs with an interest in dementia care and refined based on their feedback. The finalised questionnaire had three parts. The first part gathered participant's demographic information. The second part consisted of several five-point Likert-type statements, a series of ranking questions and multiple choice questions that collected information about GPs' prescribing habits. Finally, the last part asked GPs to share any comments they had in the free text area provided. The questionnaire is available in Appendix 4, supplementary material 12.

Ethical approval was received by the Clinical Research Ethics Committee of the Cork teaching hospitals. The questionnaires were printed and posted in April 2018.

Excel and SPSS version 24 were used to conduct the statistical analysis. Chi-square tests and Fisher's tests were used to evaluate associations between demographic variables and GP's responses, with a P-value of <0.05 considered significant. The qualitative comments provided by GPs in the free text responses were entered into Microsoft Word where they were thematically analysed. Responses to Likert-type questions were collapsed into 3 categories as given in Table 15 and Table 16. The original Likert scale options "rarely benefit" and "some patients" were combined to "rarely/some patients", whereas the options "50% of patients" and "most patients" were combined to "more than 50% of patients".

8.3 Results

Of the 468 questionnaires posted, 168 completed questionnaires were returned. 12 uncompleted questionnaires were returned with a note from the GP explaining they had recently retired. Consequently, the corrected sample size of eligible GPs who received the questionnaire was 456, representing a response rate of 36.8%. The sample was representative of GPs nationally in terms of years of practice ($p<0.001$). Participants demographic are displayed in Table 14 below.

Table 14. Demographic characteristics of GP respondents to questionnaire on attitudes to antipsychotic prescribing in BPSD

Participant demographics	Number out of 168 (%)
Gender	
Male	91 (54.2%)
Female	77 (45.8%)
Years of practice as a GP	
1-5 years	3 (1.8%)
6-10 years	11 (6.5%)
11-20 years	46 (27.4%)
21-40 years	85 (50.6%)
40+ years	23(13.7%)
Location of practice	
Rural area	39 (23.2%)
Urban area	53 (31.5%)
Mixed	76 (45.2%)
Practice type	
Single handed practice	40 (23.8%)
Group practice	128 (76.2%)

62.5 % (105/168) of respondents had a nursing home commitment. Of these GPs who had a nursing home commitment, 62.9% (66/105) paid regular visits to the nursing home (at least weekly rounds). The mean number of nursing home attended was 2.05 (SD +/− 1.38; range 1-9). GPs provided care to 2703 nursing home patients in total (mean number of patients in a nursing home = 26; range (1–200)). There was no significant association found between the

years of experience the GP had in primary care and having a nursing home commitment (p=0.24) or between the location of the practice and having a nursing home commitment (p=0.70).

Responses to selected questions regarding prescribing habits are given in Table 15 and Table 16 below. All GPs (100%, 168/168) believed that antipsychotics, benzodiazepines and antidepressants did not benefit all patients with BPSD. A little over half of GPs (56%, 94/168) said they would prescribe an antipsychotic in more than 50% of cases where their patients with dementia were physically aggressive. A small majority (52.4%, 84/168) said they did not have a repeat prescribing policy for patients with dementia on antipsychotics. 70.6% (115/163) of respondents reviewed people with dementia living in the community and on antipsychotics at least three monthly. 79.2% (80/101) of GPs reviewed people with dementia living in a nursing home and on antipsychotics at least three monthly.

Table 15. Responses to question on the benefit of different psychotropic agents in BPSD

	Rarely /benefit some patients	**Benefit more than 50% of patients**	**Benefit all patients**
First generation antipsychotics - such as haloperidol	143/168 (85.1%)	25/168 (14.9%)	0/168 (0%)
Second generation antipsychotics - such as risperidone	107/168 (63.7%)	61/168 (36.3%)	0/168 (0%)
Benzodiazepines	158/168 (94%)	10/168 (6%)	0/168 (0%)
Antidepressants	106/168 (63.1%)	62/168 (36.9%)	0/168 (0%)

Table 16. Responses to question on situations that GPs would prescribe an antipsychotic in BPSD

	Rarely / some patients	More than 50% of patients	All patients
Physical aggression	66/168 (39.2%)	94/168 (56%)	8/168 (4.8%)
Verbal aggression	109/168 (64.9%)	56/168 (33.3%)	3/168 (1.8%)
Wandering	145/168 (86.3%)	21/168 (12.5%)	2/168 (1.2%)
Calling out	146/168 (86.9%)	20/168 (11.9%)	2/168 (1.2%)
Agitation and unsettled	85/168 (50.6%)	77/168 (45.8%)	6/168 (3.6%)

58.4% (98/168) of GPs agreed they found it relatively easy to consult and refer to geriatricians and old age psychiatry if required. There was no significant association found between the practice setting (urban, rural or mixed) and the ease to refer to specialists (p=0.25). 69% (116/168) of respondents agreed that they routinely recommended non-pharmacological interventions for behaviours that are challenging in dementia before considering medication. Nursing staff were ranked as the group of people who most influenced GPs' prescribing of antipsychotics (80%, 133/166).

GPs were asked what they believed to be the barriers to recommending non-pharmacological management strategies for people with BPSD living at home and those living in nursing homes. In the community, the most significant barriers were reported to be: a lack of resources in the primary care team, pressure to prescribe from the relatives and a lack of confidence in advising on non-pharmacological strategies. In the nursing home setting the most significant barriers to recommending non-pharmacological strategies were reported to

be: pressure to prescribe medication from nursing home staff, a lack of nursing home staff and resources and a lack of nursing home staff skills.

63.1% (106/168) of GPs were concerned that withdrawing medication would impact negatively on the quality of life of the resident leading to a return of challenging behaviours or disturbing psychological symptoms. However 54.1% (91/168) of GPs said they felt 'reasonably to totally confident' to reduce or stop psychotropic medication in a stable patient with dementia where the medication was initiated by secondary care or a dementia specialist. No association was found between years of experience as a GP and confidence to withdraw medication (p=0.25). 60.7% (102/168) of GPs said they required more training and experience to improve how they manage BPSD. GPs were asked what would help reduce the usage of psychotropic agents in BPSD. The most influential methods reported were: increasing staff levels at nursing home to implement non-pharmacological strategies, increasing access to geriatricians and old age psychiatrists, and increased funding to GPs for providing elderly care to people with dementia.

35 of the 168 respondents (20.8%) left qualitative comments at the end of the questionnaire. Three major themes emerged from the free-text responses: pressure to prescribe from nursing home staff, inadequate resources and the potential benefit of antipsychotics in some situations. To illustrate the major themes, verbatim quotations considered to be representative of the typical comments that lead to the development of each theme are presented below.

Theme 1: Pressure to prescribe from nursing home staff

GPs reported a high demand for antipsychotics prescription from nursing home staff.

"Have had enormous pressure to 'sedate' patients in nursing homes from nurses." (Respondant_145, experienced GP, mixed practice setting, nursing home commitment)

Some GPs described a lack of understanding from the nursing home staff about the dangers of antipsychotics in dementia.

"*Feel there is a poor understanding of the negative impact of these medications on patients with dementia among relatives and nursing home staff. Often intense pressure to prescribe. Chemical restraints that have taken the place of physical restraints and are no less dangerous.*" (Respondant_8, experienced GP, mixed practice setting, no nursing home commitment)

Some GPs suggested that the demand for antipsychotics from nursing home staff is due to a lack of staff and resources in the nursing home.

"People in nursing homes often have challenging behaviors with dementia. Due to lacked ability to manage in nursing homes, often staff look for something to manage the problem patient. Often due to too many patients per nurse in nursing homes […]" (Respondant_101, mid-career GP, rural practice, nursing home commitment)

Theme 2: Lack of resources

GPs mentioned a lack of resources for non-pharmacological strategies.

"I think better resourcing of day centres for patients with dementia is vital - music, aromatherapy, exercises all vital. Also better division of the above within nursing home setting with more 1 to 1 activities and distraction/entertainment for patients. Better awareness of

pain in dementia." (Respondant_148, recently qualified GP, mixed practice setting, nursing home commitment)

They highlighted a need for increased staffing levels in nursing homes and staff education in the area of BPSD.

"Resources/staffing biggest issues [...] Better staffing/training/education as well as increase community care packages to keep patient comfortable in a familiar environment for as long as possible would be most effective in the long term." (Respondant_6, recently qualified GP, mixed practice setting, nursing home commitment)

Theme 3: Perceived benefit

GPs highlighted that the management of BPSD can be frustrating for clinicians.

"Dementia is very challenging to deal with, needs huge amount of time and the reality is that we just don't have it - patients suffer as a result." (Respondant_84, mid-career GP, mixed practice setting, no nursing home commitment)

GPs reported that in some cases, the use of antipsychotics was found to be beneficial.

" … He was on all appropriate medication but got very agitated in the afternoons. A tiny amount of antipsychotic helped hugely. In a life changing way - he could cope again. I don't know what else we could have done. I cannot stress enough how hard living with dementia is. It is still important to help and I feel antipsychotics still have a small role. " (Respondant_ 51, mid career GP, urban practice, nursing home commitment)

GPs described the complexities of balancing risk to other residents and staff when managing BPSD.

"The dynamic is between managing challenging behaviors especially when staff and other residents are actually being injured and minimizing the use of antipsychotics in the elderly. "

(Respondant_30, experienced GP, rural practice, nursing home commitment)

8.4 Discussion

This study enhances our knowledge on how GPs in Ireland manage the prescribing of antipsychotic medications in BPSD. There were a number of positive findings in this study. The majority of GPs believed most people with BPSD did not benefit from psychotropic medications. The majority of GPs routinely recommended non-pharmacological interventions for behaviours that are challenging in dementia before considering medication. The majority of GPs reviewed people with dementia who were on antipsychotics within the timeframe recommended in guidelines. The majority, albeit a small majority, of GPs reported that they found it relatively easy to access support from secondary care colleagues when managing BPSD. The majority of GPs felt confident to reduce or stop psychotropic medication in a stable patient with dementia even when the medication was initiated by secondary care.

The findings demonstrate that GPs are aware of the limited benefit of psychotropic medications in BPSD, that GPs routinely recommend non-pharmacological strategies first line, that GPs are monitoring their prescribing of antipsychotics and that they seem willing to reduce or stop these medications when a person's symptoms are stable. These are all

encouraging findings. However, there were some conflicting results. Despite the belief that psychotropic medications rarely benefited, or only benefited some people with BPSD, the majority of GPs reported that they would prescribe antipsychotics to most people with dementia who were physically aggressive. Likewise, nearly half of GP respondents reported they would prescribe antipsychotic medication to people with dementia who were agitated or unsettled. There is a discrepancy between the GPs' knowledge on the limited efficacy of antipsychotic medications and their clinical practice. The findings on the barriers to recommending non-pharmacological approaches to BPSD go some way to explaining this discrepancy. Lack of appropriate resources and pressure to prescribe acted as barriers to the GP when attempting to recommend non-pharmacological alternatives. Nursing home staff were identified as the group of people which most influenced GPs' prescribing of antipsychotic medication. Likewise, 'increased staffing levels in nursing homes' was identified as the single change that would most help GPs to reduce the usage of psychotropic medications in BPSD.

Comparison with existing literature

This study highlighted the essential role played by nursing home staff when GPs are making a decision to initiate, reduce or stop an antipsychotics in a person with BPSD. That a nurse would be a key influence on a GPs decision to prescribe an antipsychotic is not, in itself, surprising. In a nursing home setting, the nurse is providing daily one to one care for the person with BPSD. The nurse is, therefore, best placed to report on the person with dementia mood and behaviour. The GP relies on this account from the nurse and it rightly informs the decision making process. However, in this study, in addition to the nurse's

influence, the GPs reported feeling pressurised by nursing home staff to prescribe antipsychotics. Previous studies have identified how pressure from nursing home staff influenced GPs' management decisions in BPSD [153,155,283]. In these studies, nursing staff were often seen as a barrier to a GP recommending non-pharmacological strategies. Similarly, in the qualitative study conducted for this thesis, GPs reported that they found it challenging to manage the expectations of nursing home staff, especially in the context of poor communication pathways between the GP and nursing staff [332].

At what point does the nurse's influence move from an informative aid in a GP's decision making process on whether to prescribe an antipsychotic to a source of pressure? It could depend on GP factors. A previous Australian study found that the more experienced a GP was, in terms of years in practice, the less likely they were to rate 'pressure to prescribe' as a barrier to recommending non-pharmacological treatments in BPSD [155]. In our previous qualitative study we did find that GPs who had experience caring for people with dementia had more confidence in their management of BPSD [332]. However, in this present study neither years in practice nor the extent of the GP's nursing home commitment influenced whether they rated 'pressure to prescribe' as a barrier. The experience of being under pressure to prescribe also could depend on the relationship that exists between the GP and the nursing staff. As identified in the qualitative study reported in Chapter 6, the influence of nursing staff can be helpful and appropriate in the context of a long-standing relationship of trust between the GP and the nurse [332]. A recent systematic review of the qualitative evidence surrounding antipsychotic prescribing in BPSD highlighted the importance of effective communication between healthcare professionals and identified a collaborative approach as the key component of any attempts to reduce inappropriate prescribing of antipsychotic medication. [3] Finally, the experience of being under pressure to prescribe

antipsychotic medication could depend on wider resourcing issues in the nursing home. In this study 'increased staffing levels' was the number one recommendation of participating GPs when asked what would help to reduce the prescribing of psychotropic medications in dementia. Previous studies have identified that chronic understaffing in nursing home can hinder the nursing staff's ability to implement non-pharmacological strategies [367] and, thus, increase pressure on GPs to prescribe sedative psychotropic medications [155,283]. It is likely that the prescribing pressure the GP feels from the nursing staff are a combination of all these factors; the experience level of the GP, the relationship between the nurse and the GP, and the resource constraints of the nursing home. [367]

Strengths and limitations

GPs' demographic characteristics are representative of GPs nationally in terms of years of practice but is not representative in terms of practice location or type. This may, therefore, affect the generalisability of our findings. Due to resource constraints, it was not possible to follow non-responders with reminder letters. A sample size of 212 respondents was required to adequately power this study, which means that with only 168 participants, our study was underpowered. This study is also limited by the circumscribed geographical area of its sample size, which only represents the southern region of the Republic of Ireland. Finally, this study relied on participant recall of what they would do in specific situations. This might have biased responses towards what GPs perceive as best practice but the study does give us an idea of what GPs would ideally do if there were no barriers to this practice.

8.5 Conclusion

This study has provided me with essential data on how GPs approach the initiation, monitoring and reduction of antipsychotic medication in BPSD. This study has added breadth to the depth of information acquired in the qualitative study. The findings of this study will fundamentally inform the intervention development process.

CHAPTER 9. DEVELOPMENT OF A TOOL FOR MONITORING THE PRESCRIBING OF ANTIPSYCHOTIC MEDICATIONS TO PEOPLE WITH DEMENTIA IN GENERAL PRACTICE: A MODIFIED EDELPHI CONSENSUS STUDY

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9.1 Abstract

Background

Despite their adverse effects antipsychotics are frequently used to manage behavioural and psychological symptoms of dementia. Regular monitoring of antipsychotic prescribing has been shown to improve the appropriateness of prescribing. However, there is currently no consensus on what the components of such a monitoring tool would be.

Aim

The aim of this study was to use an expert consensus process to identify the key components of an antipsychotic repeat prescribing tool for use with people with dementia in a general practice setting.

Methods

A modified eDelphi technique was employed. We invited multidisciplinary experts in antipsychotic prescribing to people with dementia to participate. These experts included general practitioners (GPs), geriatricians and old age psychiatrists. The list of statements for round 1 was developed through a review of existing monitoring tools and international best practice guidelines. In the second round of the Delphi any statements which had not reached consensus in the first round were presented for re-rating, with personalised feedback on the group and the individual's response to the specific statement. The final round consisted of a face-to-face expert meeting to resolve any uncertainties from round 2.

Results

A total of 23 items were rated over two eDelphi rounds and one face-to-face consensus meeting to yield a total of 18 endorsed items and 5 rejected items. The endorsed statements informed the development of a structured, repeat prescribing tool for monitoring antipsychotics in people with dementia in primary care.

Conclusions

The repeat prescribing tool developed provides GP with practical advice that is lacking in current guidelines and will help to support GPs by providing a structured format to use when reviewing antipsychotic prescriptions for people with dementia, ultimately improving patient care. The feasibility and acceptability of the tool now needs to be evaluated in clinical practice.

9.2 Introduction

Most people living with dementia will experience behavioural and psychological symptoms of dementia (BPSD) at some stage in the illness [103] with some studies estimating that between 80 to 90% of people with dementia will experience at least one symptom of BPSD. [105] BPSD encompasses a wide range of non-cognitive symptoms that affect people living with dementia and includes behaviours such as agitation or aggression and psychological symptoms such as anxiety or hallucinations. BPSD is associated with increased rates of admission to nursing homes, [114]longer in-patient hospital stays [113] and is a major contributor to caregiver stress and depression. [116] General practitioners (GPs) play a pivotal role in the care of people with dementia, [5,6] providing for the day-to-day medical care of people with dementia living in their own homes and in nursing homes. However, similar to their secondary care colleagues, [273] GPs can find the management of BPSD a particularly challenging aspect of dementia care. [87,332] Non-pharmacological strategies are recommended first line in BPSD. [187] Personalised non-pharmacological interventions such as personalised music therapy [144,148] and formal caregiver training to enhance communication skills [148] may have a role in the management of BPSD, however, uptake of non-pharmacological strategies is low. [151] Psychotropic medication, in particular antipsychotics, are frequently employed to manage BPSD, [151] however, antipsychotics are not recommended unless there is a serious risk of harm to the person with dementia or others. [187] Antipsychotics have particular adverse effects in people with dementia including an increased risk of stroke and increased mortality. [159,160] Furthermore, evidence suggests antipsychotics are, at best, only minimally effective at improving BPSD. [160,368] Despite their adverse effects and minimal effectiveness antipsychotics are still prescribed to people with

dementia experiencing BPSD. [156,157] The rates of antipsychotic prescribing in people with dementia vary from country to country with rates as high as 29% in a 2013 audit conducted in Ireland [194] and lower rates of 17.7% in a comparable 2012 audit in the UK. [195] Nursing home residents, who typically have more advanced dementia, are significantly more likely to be on an antipsychotic medication than people with dementia living in their own homes, [194] up to five times as likely in one study. [156]

The reasons for continued prescribing of these potentially harmful medications is complex. [3] In the context of stretched resources non-pharmacological alternatives to antipsychotic prescribing can be viewed as being impractical and not implementable. [276] The benefit of antipsychotic medication can be over-estimated. [330] Furthermore, both GPs and consultant psychiatrists report that they sometimes feel under pressure from nursing home staff, and occasionally family caregivers, to prescribe medications. [273,332] As a result, antipsychotics are sometimes employed to enable the person with dementia, their caregiver, and the nursing home staff to cope with these behaviours and symptoms. [3]

When prescribed for BPSD, antipsychotics should only be used on a short-term basis and should be reviewed for side-effects and for effectiveness as many of the harmful side-effects of antipsychotics are dose and duration dependent. However, there is evidence that antipsychotics are often inappropriately prescribed to people with dementia for prolonged periods of time, [157] sometimes without a documented indication [369] and with sub-optimal review processes. [370] A systematic review in 2014 examined interventions to reduce inappropriate prescribing of antipsychotic medications in care homes and identified a wide variety of interventions from educational interventions to organisational changes. [201] Medication review was identified as an intervention employed to reduce antipsychotic

prescribing with some promising results. [201] Since that 2014 review other studies have shown that regular monitoring of antipsychotic prescribing can reduce the overall prescribing of antipsychotics in dementia [210] and improve the appropriateness of prescribing. [298] The WHELD study identified the value of antipsychotic review, demonstrating that it can lead to a 50% reduction in antipsychotic use in nursing homes. [210] However, it also highlighted that to positively benefit the person with dementia any intervention to reduce antipsychotic medication needs to be supported by non-pharmacological interventions such as social interaction. [210]

A qualitative study explored the challenges GPs experienced with BPSD. [332] In that study the participating GPs called for GP-specific guidance on the pharmacological management of BPSD. [332] Guidance for GPs in the form of a repeat prescribing tool to monitor the prescribing of antipsychotics in dementia would facilitate the conduct of antipsychotic reviews in general practice. However, there is currently no consensus on what the components of such a tool would be.

The aim of this study was to use an expert consensus process to identify the key components of an antipsychotic repeat prescribing tool for use with people with dementia in a general practice setting.

9.3 Methods

Study design:

A Delphi method was used to establish expert consensus that would inform the development of a repeat prescribing tool for GPs to use when monitoring people with

dementia on antipsychotic medications. The Delphi is a "group facilitation technique that seeks to obtain consensus on the opinions of experts through a series of structured questionnaires" (known as rounds). [371] The key features of the Delphi method include; recruiting relevant experts to the study, compiling a questionnaires with a list of statements that the experts rate for agreement, calculating the results, giving anonymised feedback to participants about how their responses compare to the rest of the group and giving participants the opportunity to revise their responses to the questionnaire in light of this feedback. [372] This iterative process continues over multiple rounds of questionnaires until consensus is reached, with some statistical criterion being used to define consensus. A modified Delphi was employed here, which combines the questionnaire with a physical meeting of experts to discuss the results. [373] This face-to-face meeting is recommended at the end of the last round to exchange views and resolve uncertainties and is, therefore, often considered to function as a final 'round'. [373] We utilised a web-based platform to organise and facilitate communication. This eDelphi approach has practical advantages over the traditional paper-based Delphi model facilitating the participation of experts from different geographical locations and enabling faster response times. [374]

Research steering group:

The research team formed a research steering group. This consisted of the research facilitator (NG) and two general practitioners (TF, AJ) both of whom have clinical and research expertise in the management of BPSD. The function of this working group was to review the literature to inform the development of the first round of the questionnaire and to participate in a final meeting once the eDelphi rounds were completed to discuss any

uncertainties. The members of the research steering group did not complete the eDelphi questionnaires.

Selection and recruitment to the expert panel:

Participants in the Delphi were purposively selected by the research team based on their known expertise in the area. [371] To ensure diversity, a panel of medical experts was recruited from different medical specialities to participate in the Delphi consensus. Medical professionals participating in the eDelphi included GPs, old age psychiatrists and geriatricians.

GPs were eligible to participate if they met the following inclusion criteria; minimum of 10 years as a practicing GP, regularly engaged in the management of patients with BPSD and provide care to people with dementia in a nursing home setting. GPs meeting these inclusion criteria were identified nationally. From this population, a sample of GPs was purposively selected to include GPs of different ages and with different practice locations (rural/ urban) with the goal of achieving maximum variation. Consultant psychiatrists and consultant geriatricians were eligible to participate in the study if they provided care to people with BPSD in a nursing home setting and if they had a research interest in this area with relevant peer-reviewed publications. Once eligible participants were identified they were individually emailed, provided with information on the study and invited to participate in the eDelphi.

Questionnaire development:

The questionnaire was iteratively developed by the research steering group. The content of the questionnaire was informed by a review of existing antipsychotic drug monitoring

templates from the UK and Canada [375-377] and by a review of international guidance documents on antipsychotic prescribing in dementia. [142,378-381]

Analysis of rounds & consensus criteria:

We asked the participants to state the extent to which they agreed with a list of statements using a 5 point Likert scale. The option to provide free-text comments was provided throughout the questionnaire. The level of percentage agreement necessary to reach consensus for this particular study was informed by the literature on consensus criterion in Delphi processes [382] and by Delphi studies exploring similar research areas. [383-385] In cases where a statement received greater than or equal to 80% agreement it was agreed that consensus had been reached. These statements were omitted from further rounds and were automatically included in the monitoring template. Any statement receiving <40% was rejected and, therefore, excluded from the monitoring template. All statements that fell between 40%- 79% agreement were deemed undecided, i.e. had not reached consensus and so these statements were carried forward into the next round to be re-rated.

In the second round of the eDelphi any statements which had not reached consensus in the first round were presented for re-rating using the same 5 point Likert scale. In this round each participant was provided with individualised feedback which included the mean answer of the group response to each statement in round one. Additionally, the participant's own response to the statements in round 1 were provided to illustrate their position in the group. This offered Delphi members an opportunity to revise and refine initial answers based on the group opinion. Free text comments provided by participants in round one were also included as statements in round two if the same suggestion was made by 2 or more participants. For each statement in the second round, it was decided that

>70% agreement was consensus to include the statement and <50% agreement was consensus to exclude the statement.

Study Ethics:

Ethical approval was granted by Clinical Research Ethics Committee of the Cork Teaching Hospitals. Participants were advised in an information sheet and in the initial email they received, that completion of the first round of the eDelphi was considered to be their consent to participate in the study

9.4 Results

Study participation

A total of 17 medical professionals with expertise in dementia care were invited to participate and 14 agreed to participate in the study. This group of 14 experts included; 8 general practitioners, 4 old age psychiatrists and 2 geriatricians (see table 17 for the breakdown of the retention rate for each professional group).

Table 17. eDelphi participants by professional group

	Initially Recruited	Participation in round 1	Participation in round 2
General Practitioners	8	8	7
Psychiatrists	4	4	2
Gerontologists	2	2	2

Items ratings

A total of 23 items were rated over two rounds to yield a total of 18 endorsed items and 5 rejected items. Table 18 details the number of items rated, endorsed and rejected over the two eDelphi rounds.

Table 18. eDelphi statements accepted, rejected and re-rated at each stage

	Number of statements	Statements to be included	Statements excluded	Statements to be re-rated	New statements added
Round 1	21	11	1	9	2
Round 2	11	9	2	2*	0

*2 statements brought to research steering group for discussion were ultimately rejected

Round 1 questionnaire results:

The first-round questionnaire consisted of 21 statements and participants were asked to rate the statements using a 5 point Likert scale (see table 19). Surveys were open for completion for 2 weeks. Nine of the statements reached consensus and were endorsed in round one. These statements were, therefore, included in the monitoring template and were excluded from the second-round survey. One statement received only 28.5% agreement, which was below the cut off of 40%, so this statement was automatically excluded from the monitoring template and from any further rounds of questionnaire. 11 statements did not reach consensus, rating between 40% and 79%, therefore, all these statements were included in round two for re-rating. All statements that were endorsed, rejected or did not reach consensus in round one are presented in table 19.

Table 19. eDelphi round one statements with their associated consensus decisions

Statement	Agreement Rating	Outcome
A repeat prescribing monitoring template for AP use in patients with dementia should include personal details including name, date of birth and patient identification number	92.8%	Endorsed
A repeat prescribing monitoring template for AP use in patients with dementia should include clearly stated medical diagnosis	92.8%	Endorsed
A repeat prescribing monitoring template for AP use in patients with dementia should include the name, dose and duration of AP drug prescribed	92.8%	Endorsed
A repeat prescribing monitoring template for AP use in patients with dementia should include whether or not additional PRN APs were used during period of AP prescription	100%	Endorsed
Medical review prior to initiation of APs for patients with dementia should include documented consent from patient with dementia/patient's next of kin prior to initiation of drug therapy	28.5%	Rejected
Medical review prior to initiation of APs for patients with dementia should include trial of non-pharmacological treatment options prior to initiation of AP drug therapy	92.8%	Endorsed
Prior to initiation of AP drug therpay by GPs, in patients with dementia, the following should be checked and documented		
1. Baseline FBC	78.5%	No consensus
2. Baseline LFTs	64.2%	No consensus
3. Baseline TFTs	78.5%	No consensus
4. Baseline U&Es	78.5%	No consensus
5. Baseline BMI	64.2%	No consensus
6. Baseline ECG	78.5%	No consensus
Adverse drug reactions – GPs should document improvements/disimprovements in BPSD following a period of AP use	100%	Endorsed
The presence/absence of the following medication side effects should be documented prior to repeat prescribing of APs in patients with dementia:		

1. Increase in BMI	71.4%	No consensus
2. Cardiovascular disease/worsening of condition in patients with pre-existing cardiovascular disease	78.5%	No consensus
3. Sedation	100%	Endorsed
4. Extra-pyramidal symptoms/impaired mobility	100%	Endorsed
5. Confusion	92.8%	Endorsed
Regarding review of AP prescription for patients with dementia:		
1. Patients with dementia who are prescribed AP drugs in the community for the first time should have a documented review by their GP at 6 weeks	85.7%	Divided opinion in qualitative feedback
2. Following initial 6 week review patients with dementia on AP therapy should have documented review by their GP at least 3 monthly thereafter	85.7%	Endorsed
3. Medical reasons for continuation/discontinuation of the drug should be documented by the GP at each review	85.7%	Endorsed

Qualitative feedback provided by participants in the free-text comment boxes of round one was thematically analysed. Where a suggestion was made by two or more participants it was included in the questionnaire for round 2. One suggestion made by 2 participants was that urinalysis or mid-stream urine (MSU) should be done as a baseline test prior to initiation of antipsychotic medication.

'…urinalysis should be standard baseline test +/- MSU…' (Old Age Psychiatrist 1)

'I would also do an MSU' (GP 1)

As a result of these comments a statement on performing mid-stream urine analysis was included in the second round questionnaire.

Another item that received several qualitative comments was the statement that recommended medical review should happen six weeks after the antipsychotic medication

was commenced. Three participants suggested that medical review should occur earlier than this:

> *'Earlier initial review may be more appropriate e.g 2 to 4 weeks'* (Old Age Psychiatrist 1)
>
> *'Should be reviewed within a month'* (Geriatrician 2)
>
> *'Review should be earlier than 6 weeks'* (Old Age Psychiatrist 2)

As result of these comments an additional statement was included in the questionnaire for round two stating that review should occur at 4 weeks. Even though the original statement that a review should occur at 6 weeks did achieve consensus in round one, in light of the qualitative feedback, the research steering group decided to include the original statement again in the questionnaire for round 2.

The wording of one of the statements was modified based on the qualitative feedback provided by participants. The modified item related to conducting a body mass index (BMI) measurement. Initially the question was 'The presence/absence of the following medication side-effects should be documented prior to repeat prescribing of antipsychotics in patients with dementia…increase in BMI'. This rating did not reach consensus in round one and concerns were raised about the practicality of measuring the BMI:

> *'BMI risk would not be high up my decision-making process given the typical patient profile…'* (Geriatrician 1)
>
> *'It would not be easy to weigh and measure a patient in a family home setting'* (GP 2)

As a result, this question was modified to include the stem "where feasible" and was included in the second round questionnaire for re-rating.

Finally, concern was raised as to the feasibility of performing an electrocardiograph (ECG) prior to commencing an antipsychotic:

> *'…Re ECG, this is very relevant, but not always possible – again, I don't do this routinely myself. And would you hold down a psychotic patient to do an ECG??'* (Geriatrician 1)

> *'…A baseline ECG could be difficult in a home setting'* (GP 1)

This statement had not achieved consensus in round one (78.5% agreement) so it was included in the second round questionnaire. Additionally, these qualitative comments regarding the feasibility of conducting an ECG were included in the individualised feedback to participants in round two.

Round 2 questionnaire results:

The second-round questionnaire consisted of 13 statements; 11 statements that did not reach consensus in round one and 2 additional statements that were included in response to the qualitative comments provided by participants in round one. Consensus was reached on 12 of the 13 statements in round two. Details on each statement included in round 2 and the consensus outcome are given in table 20. Nine statements achieved ≥70% agreement and these statements were included in the monitoring template. Two statements were rejected as they achieved ≤50% agreement. Two statements did not reach consensus in round 2 but both statements reached a low percentage agreement of 54%. In the context of the low percentage agreement for these two statements and in view of the fact that a third round would include just two statements, these two statements were brought to the Delphi

steering group for discussion. In a modified eDelphi such a face-to-face consensus meeting is often considered to be an additional round. [373]

The first statement discussed by the research steering group was the statement on the documentation of an increase in BMI prior to repeating a prescription for an antipsychotic. After discussion with the steering group this statement was rejected. The decision to exclude the statement was informed by the qualitative feedback in the Delphi rounds, a low percentage agreement of 54% in round two and a 17.4% reduction in percentage agreement from the first round to the second round. The second statement discussed at the meeting was the statement that after initiation of an antipsychotic a patient should have a documented review by their GP within 4 weeks. This statement was added to round 2 after consideration of the qualitative feedback from round one, however, it received only a 54% agreement rating in round 2. The conflicting statement, recommending review at 6 weeks, was endorsed in both round one and round two of the eDelphi. In this context, it was decided to reject this statement that review should occur within 4 weeks in favour of the statement that review should occur at 6 weeks.

The combined consensus from round one and round two resulted in 18 statements that were endorsed by the expert panel. These 18 statements informed the content of an antipsychotic repeat prescribing tool for GPs to use when monitoring people with dementia on antipsychotics. The final tool was developed by the Delphi steering group and is available in supplementary material 13.

Table 20: eDelphi round two statements with their associated consensus decisions

Statement	Agreement Rating	Outcome
Prior to initiation of AP therapy by GPs in patients with dementia, the following should be checked;		
1. FBC	90.9%	Endorsed
2. LFTs	90.9%	Endorsed
3. TFTs	90.9%	Endorsed
4. U&Es	81.8%	Endorsed
5. BMI	50%	Rejected
6. ECG	72.7%	Endorsed
7. Urinalysis	50%	Rejected
Where feasible, the presence/absence of the following medication side effects should be documented prior to repeat prescribing of APs in patients with dementia;		
1. Increase in BMI	54%	Brought for discussion in the research steering group
2. Cardiovascular disease/worsening of condition in patients with pre-existing cardiovascular disease	72.7%	Endorsed
In a monitoring template for repeat prescribing of APs in patients with dementia;		
1. Patients with dementia who are prescribed AP drugs for the first time should have a documented review by their GP within 6 weeks	72.7%	Endorsed
2. Following initial review, patients with dementia on repeat prescribed AP therapy should have documented review by their GP at least 3 monthly thereafter	72.7%	Endorsed
3. Medical reasons for continuation/discontinuation of the drug should be documented by the GP at each review	81.8%	Endorsed
4. Patients with dementia who are prescribed AP drugs for the first time should have a documented review by their GP within 4 weeks	54.5%	Brought for discussion in the research steering group

9.5 Discussion

This study utilised a modified eDelphi expert consensus process to inform the development of an antipsychotic repeat prescribing tool in people with dementia in a general practice setting. This repeat prescribing tool will provide GPs with a practical, relevant and implementable resource that will support them in monitoring their patients with dementia on antipsychotic medications.

A number of key issues regarding the challenges of monitoring antipsychotic prescribing in dementia were identified including use of ECG, measurement of BMI and the scheduled time for review of prescribing. The practical difficulties of obtaining an ECG prior to initiation of antipsychotic medication was highlighted by several participants in the qualitative feedback, however, it did ultimately achieve consensus in round 2 and was, therefore, included in the final tool. International guidelines do not specifically recommend performing an ECG, [142,378,381] however, given the propensity of nearly all antipsychotic medication to cause QT prolongation it is a reasonable consideration, where practical, in advance of initiating these medications. Likewise, although BMI measurement is not recommended in the existing guidelines, [142,378,381] it was included as a statement for review in the eDelphi as antipsychotics are known to result in weight gain. [386] However, the difficulties of measuring BMI prior to initiation of an antipsychotic was highlighted by several participants and this statement was eventually rejected in round 2.

One particularly contentious issue was the recommended time interval after an initial prescription for an antipsychotic during which a GP review of the effect of the medication should be undertaken, with some participants advocating for a review within 4 weeks instead of 6 weeks. However, the statement that a review should occur within 6 weeks was

the statement that was ultimately endorsed. The existing guidelines do vary on this issue of when a review should occur after initiation of an antipsychotic medication in a person with dementia. For instance, the most recent 2018 NICE guidelines on dementia care recommend that initial treatment with an antipsychotic should use the lowest effective dose for the shortest time with a reassessment of the person at least every 6 weeks. [141] This is echoed in the American Psychiatric Association (APA) 2016 guidelines on antipsychotic medications in dementia which recommends a review of symptoms 4-6 weeks after initiation of an antipsychotic. [142] Guidance from Australia recommend that if there is no treatment efficacy within a relatively short timeframe, (e.g. one to two weeks), treatment should be discontinued. [381] Overall, in the different guidance documents the recommended time between medication initiation and GP review of the effect of the medication ranges from 2 to 6 weeks. The different guidance documents do not distinguish between a person with dementia living at home from a person with dementia living in a nursing home setting. However, in a nursing home setting residents are being observed by the nursing home staff, therefore, a GP review at 6 weeks may be acceptable. It is likely, however, that a person with dementia living at home would benefit from an earlier review.

One finding that was overwhelmingly rejected in round one was the statement that 'medical review prior to initiation of antipsychotics for patients with dementia should include documented consent from patient with dementia/patient's next of kin prior to initiation of drug therapy'. This statement was included in the original questionnaire for round one as both the NICE guidance and the APA guidance both recommend discussing the benefits and potential harms with the person and their family member or carer prior to commencing an antipsychotic. The practical challenges of obtaining 'documented consent' may have influenced the rejection of this statement, rather than a reluctance on the part of

participants to discuss the risks and benefits with the person with dementia or their caregiver. Antipsychotics should only be prescribed if the person with dementia is a danger to either themselves or to others. [187] In these situations it may not always be possible to obtain documented consent from either the person with dementia, who may not be able to give informed consent, or their family member, who may not be available.

Comparison with existing literature

The Delphi consensus approach has been used successfully to develop criteria for potentially inappropriate medication in people nearing the end of life. [179] More specifically Delphi studies have been used previously to address the issue of potentially inappropriate prescribing of medication to people with dementia. [387-392] However, we are unaware of any existing literature that used a consensus development method to inform the development of an antipsychotic repeat prescribing tool for use in people with dementia. Previously a modified eDelphi consensus procedure was used to develop practice guidelines on the prescription of antipsychotics to people with dementia living in care homes. [393] The majority of clinicians participating in that expert panel were Old Age Psychiatrists, however, the views of geriatricians and GPs were incorporated. Although the study did not develop a repeat prescribing tool it did address certain issues surrounding antipsychotic initiation and review and the results largely echoed our results, however, there were some notable differences. These differences centred on the consensus reached on the consultation that should take place with family caregivers and on conducting ECGs prior to initiating antipsychotic medication. Firstly, the study recommended that EGG was only necessary in patients with a history of cardiovascular disease or if the patient was on another medication

that can prolong the QT-interval. Secondly, the study affirmed that the patient (if appropriate) and the primary family caregiver should be consulted in the critical phases of treatment, specifying that they should be consulted pre-treatment with an antipsychotic. The study did not discuss what the time interval should be between antipsychotic initiation and review, however, it does state that if there is a lack of improvement, the dose should be increased until side effects appear, and continued for a period of 4 weeks.

Strengths & Limitations

A Delphi method was chosen here as it is particularly appropriate when developing a consensus when existing evidence is insufficient. Other methods of consensus development, such as nominal group technique was not feasible as the experts participating in the consensus development worked in different geographical regions. Another strength of choosing the Delphi technique is that of quasi-anonymity [382] although the participants are known to the researcher, the participants remain anonymous to each other, preserving independent opinion. The multidisciplinary nature of the Delphi participants offered the opportunity to consider the different views of clinicians involved in the care of people with BPSD and enriched the results.

A limitation of this study is the small number of Delphi participants, with only 14 members. However, as little as 10 members have been reported to yield strong evidence in Delphi studies. [394] Another limitation is the relatively high dropout rate of 21.4% after 3 members dropped out of the study in round 2. However, despite this drop out, the response rate remained above 70% for each round, which is the recommended response level in order to yield robust results. [395] We did not, therefore, follow-up with non-responders. The choice of

methodology prevented in-depth discussion amongst the expert participants, however, the ability to provide in-depth qualitative feedback allowed for the sharing of idea. Additionally, the existence of the research steering group facilitated in-depth discussion on selected topics as required. As the content for this eDelphi was quite clinical in nature the decision was made to not include people living with dementia or their caregivers in the initial eDelphi process. However, an important next step would be to get the input of people living with dementia, their caregivers and nursing home staff prior to implementation of the monitoring tool in a clinical setting.

Implications for future research

The existence of a repeat prescribing tool for monitoring antipsychotic prescribing in general practice will not in itself guarantee that monitoring will occur. The feasibility and acceptability of the tool needs to be evaluated in clinical practice. This phase will involve all relevant stakeholders including people with dementia, their caregivers, nursing home staff and community pharmacists.

This tool needs to be evaluated to identify whether implementation of the tool leads to more frequent reviews and more appropriate prescribing and de-prescribing of antipsychotics in people living with dementia. Future research then needs to focus on incorporating this antipsychotic repeat prescribing tool into a wider intervention that addresses all the barriers to conducting antipsychotic reviews in people with dementia in a general practice setting. These challenges can include a lack of knowledge on the part of some GPs of the adverse effects of antipsychotics in dementia and an overestimation of their benefits in BPSD. [155,278] This can lead to a lack of motivation to monitor prescribing on the part of the GP- why monitor if you do not intend to stop the medication? In addition to

highlighting the value of monitoring antipsychotics, GPs need to be further supported by practical advice on how to conduct an antipsychotic review and how to gradually taper antipsychotic medications. This repeat monitoring tool provides general prescribing guidance to GPs monitoring patients with dementia on an antipsychotic. However, patients will need to be assessed and managed at an individual level in accordance with their co-morbidities and risk factors. The tool developed here is intended as an educational device as well as a practical tool. Further GP relevant guidelines on antipsychotic prescribing would support GPs in conducting this task. [332]

9.6 Conclusion

Through an expert consensus process we developed a repeat prescribing tool for use by GPs when initiating and monitoring antipsychotic medications prescribed to people living with dementia in the community or in a nursing home setting. This tool provides GP with practical advice that can be lacking in current guidelines and provides an additional level of detail to GPs to aid clinical decision making. This tool will help to support GPs by providing a structured format to use when reviewing antipsychotic prescriptions in people with dementia, ultimately improving patient care.

CHAPTER 10. DESIGNING AN INTERVENTION TO IMPROVE THE MANAGEMENT OF BEHVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA IN GENERAL PRACTICE USING THE BEHAVIOUR CHANGE WHEEL

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AN UNPUBLISHED THESIS CHAPTER

10.1 INTRODUCTION

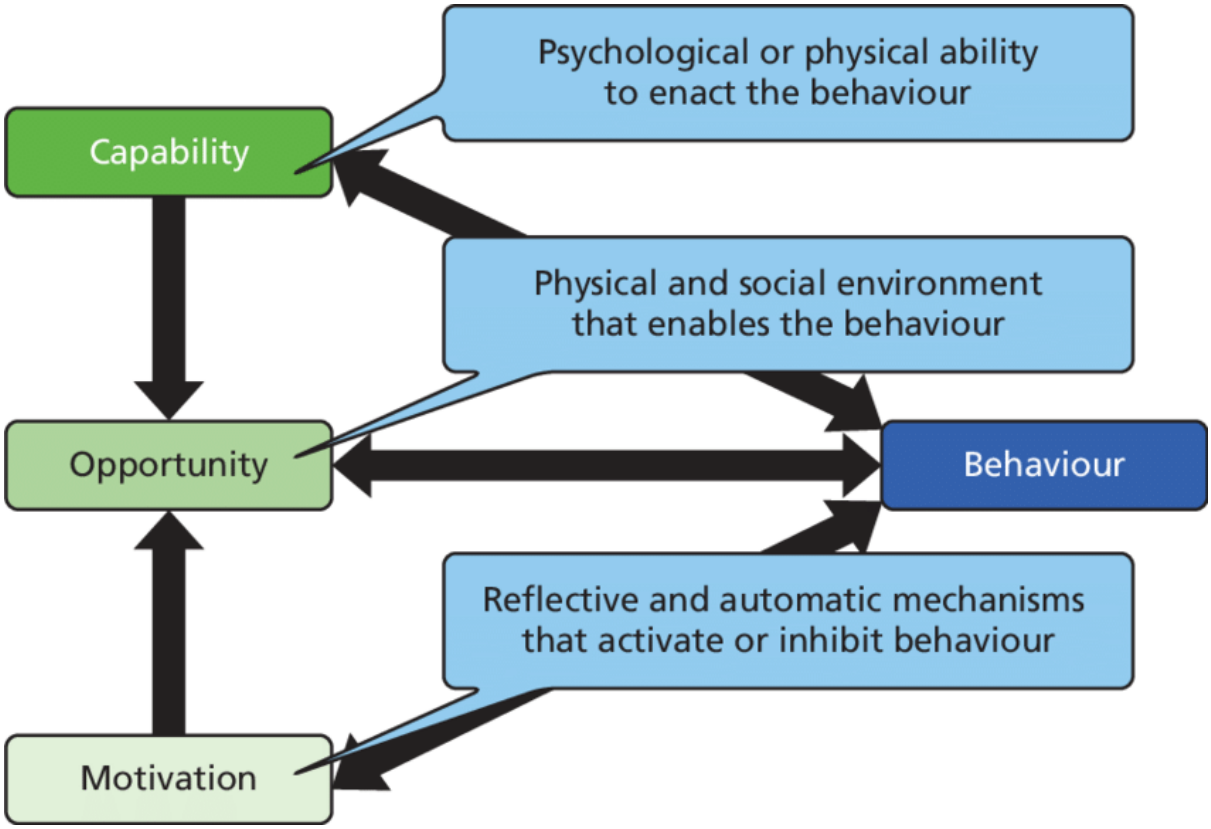
It has been suggested that one of the reasons for the limited success of healthcare behavioural change interventions in the past has been a lack of an explicit rationale for the intervention chosen and the use of inappropriate methods to design interventions. [236] Previously, many interventions have been designed based on researcher intuition or, to use a term coined by Martin Eccles, the principle of 'it seemed like a good idea at the time'. [396] Furthermore, healthcare interventions are notoriously poorly described, [397] making replication arduous or even impossible. [398] In the context of poor intervention design, inadequate intervention description and difficulty replicating healthcare interventions the value of theory based approaches to intervention design is increasingly recognised. The UK Medical Research Council (MRC) guidance on developing complex interventions in healthcare, outlined in Chapter 4 of this thesis, endorses the idea of identifying and developing theory in order to explain the rationale for a complex intervention, identify the changes that are expected from the intervention and to investigate how this change might be achieved. [242] However, the MRC guidance does not advocate for any particular theory and there is a vast array of potential theories to choose from. The Behaviour Change Wheel (BCW) developed by Michie et al offers a potential solution by describing a structured, reproducible approach to applying behavioural theory to intervention development, [239] as previously outlined in Chapter 4 of this thesis. Each step of the structured approach of the BCW can be mapped to the MRC framework for developing complex interventions in healthcare (see Table 21).

Table 21. How the BCW steps map to the three stages of intervention development outlined in the MRC framework (adapted from Sinnott et al) [399]

MRC Development Stage	BCW Stages	BCW Steps
1. Identify the evidence base	1. Understand the behaviour	1. Define the problem in behavioural terms 2. Select the target behaviour 3. Specify the target behaviour
2. Identify/ develop theory	2. Identify intervention options	4. Identify what needs to change 5. Identify appropriate intervention functions 6. Identify policy categories
3. Model process and outcomes	3. Identify content and implementation options	7. Identify behaviour change techniques (BCTs) 8. Determine mode of delivery

At the centre of the BCW is the COM-B model. The COM-B model identifies three core components of behaviour change; *c*apability (the physical or psychological capability to enact the behaviour), *o*pportunity (physical or social environment to enable the behaviour) and *m*otivation (reflective and autonomic mechanisms that activate or inhibit the behaviour (see Figure 12). When considering the reasons why an individual is, or is not, engaging in a behaviour these three core components of behaviour change need to be analysed.

Figure 12. The COM-B model of the BCW (source: Howarth et al, 2017 [400])



The Theoretical Domain Framework (TDF) is an elaboration of the COM-B model. The TDF is a tool for selecting which behavioural change techniques (BCTs) to include in behavioural change interventions. [401] Originally developed to understand health professional behaviour, [402] the TDF has been used primarily in the context of health to understand behaviour at the individual level. [239] Each of the 12 domains of the TDF can be mapped to a COM-B component (see Figure 13). [402] In this chapter we describe how the steps outlined in the BCW approach guided the development of our intervention to improve the management of BPSD in general practice.

Figure 13: The TDF domains and how they map to the COM-B components [402]



Sources of behaviour

TDF Domains

Soc	- Social influences
Env	- Environmental context and resources
Id	- Professional role and identity
Bel Cap	- Beliefs about capabilities
Goals	-Goals, intentions and motivation
Bel Cons	- Beliefs about consequences
Em	- Emotion
Know	- Knowledge
Mem	- Memory, attention and decision process
Beh Reg	- Behavioural regulation
Skills	- Skills

NB. **Nature of behaviours** not considered a source of behaviour (see text for details) and therefore removed from the analysis

10.2 METHODS

The BCW outlines three phases in the intervention design process; understanding the behaviour, identifying possible interventions and identifying content and implementation options.

Phase 1: Understand the behaviour

The BCW begins with a behavioural analysis of the problem. The first step in designing an effective intervention is having a clear understanding of the problem you are attempting to address in behavioural terms. There are four steps outlined in phase 1 of the BCW (as outlined in Table 14).

Step 1: Define the problem in behavioural terms

This step aims to clearly define the problem you are trying to address. We searched for relevant literature in the area of the management of BPSD in general practice. There was no qualitative synthesis or systematic review of the literature conducted to date, therefore, we conducted a mixed methods systematic review and meta-ethnography of GPs' knowledge, attitudes and experiences of managing BPSD [as described in Chapter 5]. [330] The over-arching perspective identified from the meta-ethnography was that in the context of resource limitations a therapeutic void was created in BPSD. This resulted in GPs being over reliant on antipsychotics and family caregivers when managing BPSD. We also conducted a qualitative exploration of GPs' experiences of the challenges of managing BPSD in general practice [as described in Chapter 6]. [332] Many participating GPs struggled at an ethical level with the decision to prescribe potentially harmful sedative medication but felt they had little else to offer. Three main challenges were identified; stretched resources, unrealistic

expectations and the lack of implementable clinical guidelines. In the qualitative study, GPs reported difficulty assessing for potential causes of BPSD, in particular pain. This led to a descriptive cross-sectional study exploring GPs' knowledge and attitudes to the assessment and management of pain in dementia. This study is described in full in Chapter 7. [403] In the study the importance of good communication with family carers and nursing home staff was highlighted, drawing attention to the potential value of an inter-professional approach to educational initiatives in this area. The study also highlighted the challenges of providing optimum care to people with dementia with the current climate of under-resourcing in both nursing home and community settings in Ireland. To further investigate the findings of the qualitative study a descriptive cross-sectional study was conducted that aimed to explore the knowledge and attitudes of GPs to the prescribing of antipsychotics in people with dementia in Ireland. In this study, reported in Chapter 8, the majority of GPs reported recommending non-pharmacological strategies first line when managing BPSD. The GPs reported that the main influencers of prescribing antipsychotics in BPSD were nursing staff and family. Of note the majority of respondents did not routinely monitor antipsychotic prescribing in people with dementia

Step 2: Select the target behaviour

The aggregated data from the meta-ethnography, [330] the interviews with GPs [332] and the quantitative survey of GPs knowledge of and attitudes to the assessment and management of pain in dementia, [403] and the quantitative survey of GPs knowledge of an attitudes towards the prescribing of antipsychotic medications in dementia were thematically analysed. From this analysis a list of potentially modifiable GP behaviours were identified.

We (AJ, TF) then assessed and prioritised the potential behaviours by applying the following criteria outlined by the BCW; [404] the likely impact of changing the behaviour, how easy it is likely to be to change the behaviour, the positive 'spillover effect' that change this behaviour may have on other behaviours, the ease with which one could measure the extent to which the intervention has changed the behaviour. These criteria are outline in Table 22. The list of potential target behaviours were evaluated on these four criteria. For each of the four criteria the potential behaviour was given a score from 'very promising' (score of 3) to 'unpromising' (score of -1), leaving each potential behaviour with a 'total score'. This process led to the identification and prioritisation of the most promising behaviours to target. Through discussions with the wider research team, which included three practising GPs (AJ, TF, CB), a public health researcher (JB) and a health psychologist with expertise in the BCW (JMcS), the target behaviour was selected. The sources of data that informed the decisions made in steps 2-4 are outlined in the schematic below (Figure 13).

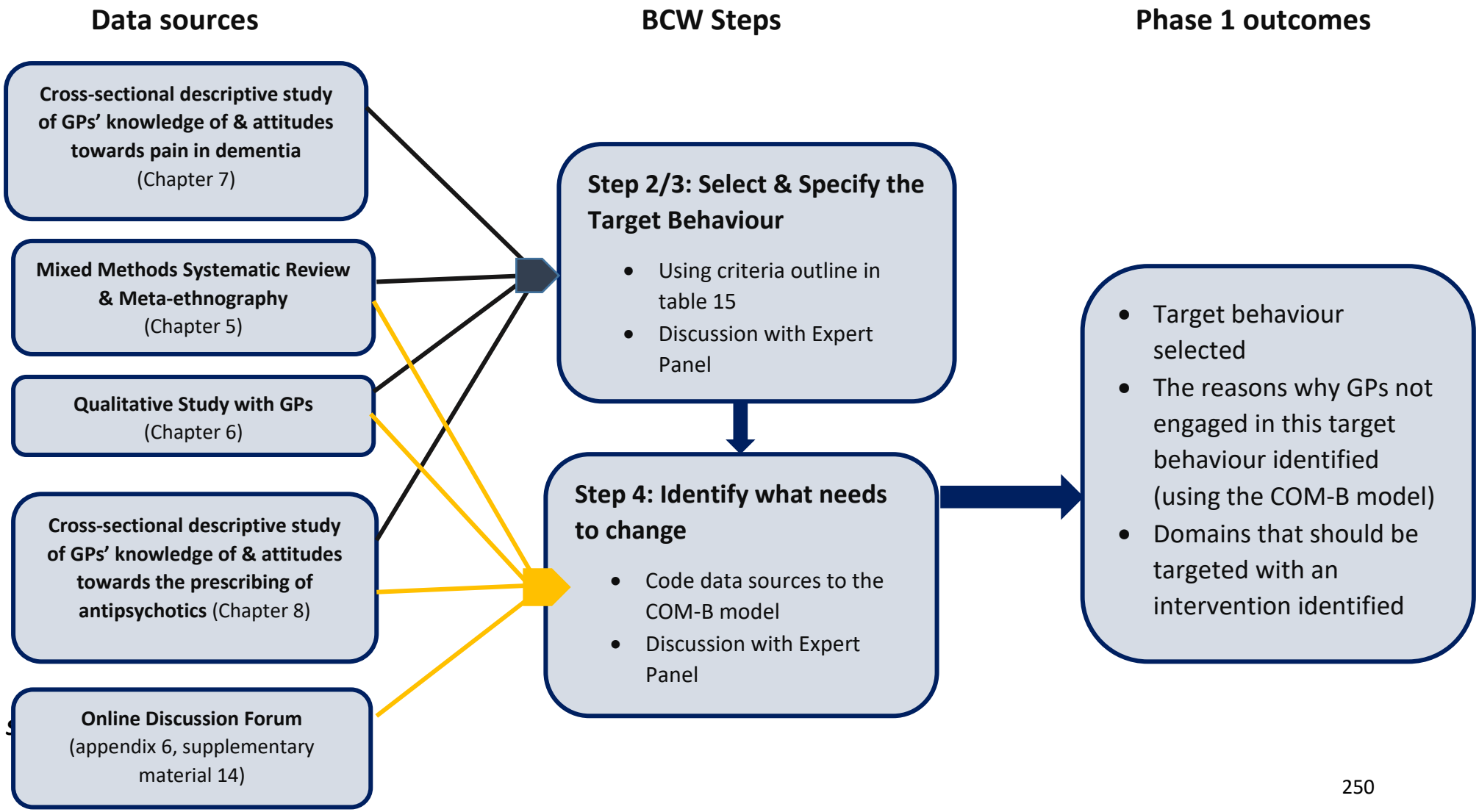
Table 22. The assessment criteria for selecting the target behaviour as outlined in the BCW

Factors to consider when selecting the target behaviour:
• The likely impact of changing the behaviour • How easy it is likely to be to change the behaviour • The positive 'spillover effect' that change this behaviour may have on other behaviours • The ease with which one could measure the extent to which the intervention has changed the behaviour.

Step 3: Specify the target behaviour

The aim of step 3 of the BCW is to specify the behaviour in appropriate detail and in its context. We specified who needed to perform the behaviour, what needed to be done and when, where and how often they need to do it. This step required input from two GPs with a special interest in dementia care (AJ, TF) and a third author (JMcS) who has expertise in intervention design using the BCW. This step also required specific clinical detail to specify the target behaviour. This clinical detail was lacking from existing guidelines. Therefore, the the eDelphi study, reported in Chapter 9, provided consensus on aspects of the clinical content of the intervention and helped informed this step. [405]

Figure 14. BCW Phase 1: Understand the Behaviours



Step 4: Identify what needs to change

The aim of this step is to identify what it will take to bring about the desired behaviour change. This step involves using the COM-B (capability opportunity motivation – behaviour) model to understand the target behaviour in the context in which it occurs. As shown in Figure 14, we used four sources of data to understand why the target behaviour was not being carried out; the primary interview data from the qualitative study,[332] the meta-ethnographic synthesis from the systematic review, [330] the results of the descriptive cross sectional study on the knowledge and attitudes of GPs to the management of BPSD and, finally, data from an online GP dementia module.

The data from the GPs participating in the online dementia module was collected from an online discussion forum for 19 GPs who were engaged in a 12 week blended learning course. Two of the authors (AJ & TF) designed and developed this online module. One unit of the dementia module related to the management of BPSD and ran over two-weeks. Case-based scenarios were used to facilitate an online discussion where GPs shared their knowledge and experiences of managing BPSD. AJ acted as an online tutor for these two weeks. A summary of the methods and results of this analysis of the online discussion forum is available in Appendix 6, supplementary material 14.

We (AJ, TF) coded the original interview data, the original meta-ethnography data, the quantitative results on GPs knowledge and attitudes towards BPSD and the online discussion forum data relevant to the GPs' physical and psychological capabilities, social and physical opportunities and automatic and reflective motivations. The aim of this process was to highlight why GPs were not engaged in the target behaviour and what needed to occur for the target behaviour to be achieved. We further elaborated the COM-B into 14 domains,

using a more detailed tool to understand behaviour, the TDF. The results of this behavioural analysis was then presented to the expert panel for discussion and was refined accordingly.

Phase 2: Identify intervention options

In phase 1 we selected the target behaviour and identified the COM-B components and TDF domains that could be targeted as potential levers of change. The next phase involved considering what types of interventions were likely to bring about this desired behaviour change. This phase consists of two steps.

Step 5: Identify intervention functions

The BCW describes nine intervention functions that were identified following a synthesis of 19 frameworks of behaviour change interventions. [239]The nine intervention functions are; education, incentivisation, environmental restructuring, training, enablement, modelling, persuasion, coercion and restriction. For each of the barriers to achieving the target behaviour (identified in step 4), the intervention function that would best address that barrier was selected from the nine intervention functions. The selection of intervention function was aided by the matrix outlined in the BCW process which links each COM-B component, or TDF domain, with the intervention function which is likely to be effective in bringing about that change. [239] The intervention functions were then graded into first and second line options using the APEASE criteria. The APEASE criteria is an approach outlined in the BCW process. [404] APEASE criteria considers the *a*ffordability, *p*racticability, *e*ffectiveness, *a*cceptability, *s*ide effects and *e*quity of the potential intervention functions.

In addition, previously unreported data from the qualitative interviews with GPs [332] and the meta-ethnography [330] were analysed and the results informed the selection of appropriate intervention functions. During the interviews conducted with GPs, they were asked about strategies they believed would improve the management of BPSD in general practice (see part 3 of the topic guide in appendix 2, supplementary file 10). We (AJ,TF) coded and analysed the data to identify potential intervention features that GPs believed to be important and we identified particular interventions suggested by GPs. Previously unreported data from the studies included in the meta-ethnography were also analysed and coded to identify intervention features suggested by the original authors of the included studies. NVivo 11 was used for data management. We (AJ, TF) used the data from the qualitative interviews, the meta-ethnography and our experience as GPs to rank the intervention functions using the APEASE criteria. A third author with expertise in using the BCW (JMcS) was consulted regularly.

Step 6: Identify policy categories

The BCW suggests which policy categories are likely to be appropriate and effective in supporting each intervention function. For each intervention function identified in step 5 we identified the policy categories that could potentially support the delivery of the intervention functions. We then identified the policy categories that were common across all the identified intervention functions. From this list we selected the most appropriate policy categories for our intervention.

Phase 3: Identify content and implementation options

In the third phase we detailed the content of the intervention and identified the most appropriate method of implementing the intervention.

Step 7: Identify behaviour change techniques

The BCW approach links intervention functions, as identified in step 5, to behavioural change techniques (BCTs). These BCTs are the "active component of an intervention designed to change behaviour". [239] For each intervention function, the BCTs that are outlined in the BCW guidance as being the 'most appropriate' for that function were considered. [239] This resulted in the creation of a 'long list' of potentially relevant BCTs for each intervention function. We (AJ, TF) then narrowed down this list by consulting the BCW book, where there is a table linking intervention functions to the most frequently used BCTs, and by applying the APEASE criteria to the potential BCTs. This resulted in a shortened list of 30 potentially relevant techniques. Each of these BCTs were considered in the context of BPSD management in nursing homes and the most appropriate BCTs were shortlisted by AJ & TF (both of whom have practical experience of providing GP care to nursing homes and, therefore, had a good understanding of the environmental context). The final BCTs to be included in the intervention were agreed through discussion with the wider multidisciplinary research team, which involves expertise in general practice (AJ, TF, CB), dementia in primary care (AJ, TF), prescribing in general practice (CB) and intervention design (JMcS, JB). In a multi-disciplinary research team meeting we collectively assessed the suitability of each of the BCTs. When making a decision to eliminate or retain a BCT the panel was influenced by the findings of the qualitative study,[332] the systematic review,[330] the quantitative results of

GPs' knowledge and attitudes to BPSD management and the findings from the online discussion forum.

Step 8: Identify mode of delivery

To inform the selection of the preferred mode(s) of delivery we sought the input of relevant stakeholders. As noted by Jones et al., when studies are concerned with defining criteria for clinical interventions the most appropriate experts will be clinicians practising in the field; [406] which in this case is GPs. However, the nursing home staff are also a key stakeholder group, as are the community pharmacists attending the nursing home. To identify community pharmacists we contacted two large nursing homes in the Cork area and asked them for the details of the providing pharmacy. We then contacted the pharmacies and asked them to participate in a meeting. Two pharmacists agreed to participate in the meeting where the plans for the intervention were outlined and the pharmacists were asked for their feedback on the intervention. Specifically we enquired about the proposed role of the pharmacist in providing feedback to GPs on their antipsychotic prescribing in a nursing home. Nursing staff that were known to the researchers through their involvement in national guideline development committees were contacted and asked to participate in an interview. Two nurses agreed to review the intervention components and provide feedback in an interview with AJ. To further engage with GPs we discussed the proposed intervention with 16 GPs enrolled in the 2018/9 blended learning dementia module. The intervention was described in a thread of the online discussion forum and participants were invited to give their feedback on the intervention and the supporting material (i.e. the monitoring tool and the audit template). The intervention was also discussed in a face-to-face study day conducted as part of the dementia module. (Further detail available on how

feedback was obtained from these stakeholders is available in Appendix 6, supplementary material 19). In deciding on the most appropriate mode of delivery, in addition to this work with relevant stakeholders, the APEASE criteria and issues related to future evaluation of the intervention were considered by the research team.

In developing the clinical content of the intervention it was noted that there was a lack of consensus on some of the recommendations in existing clinical guidelines on BPSD. To address this lack of consensus a modified eDelphi technique was employed to clarify aspects of the clinical content of the intervention. [405] This eDelphi study is reported in Chapter 9 of this thesis.

We used the TIDieR (Template for Intervention Description and Replication) checklist to describe our final intervention in detail, thus allowing for future replication. [407]

10.3 RESULTS

Phase 1: Understand the behaviour

Step 1: Define the problem in behavioural terms

The healthcare problem was identified as being the mismatch between GPs current approach to the management of BPSD, as identified in the studies conducted as part of the research [330,332,403] and best practice recommendations.

International best practice recommends that non-pharmacological interventions be used first line in BPSD and that pharmacological interventions should only be used where there is a significant risk of harm to either the person with dementia or others. In the qualitative

interviews, the challenges GPs experienced when attempting to implement these best practice recommendations at the coal-face was evident. In the context of resource constraints, a lack of clinical guidelines and prescribing pressures, it was challenging for GPs to *not* prescribe psychotropic medication. The decision to prescribe was often viewed in a finite way with little consideration given to the possibility of stopping or withdrawing the medication in the future. Similarly, in the meta-ethnographic synthesis, a review finding in which we had a high level of confidence was that antipsychotics were used to facilitate coping; their use enabled nursing home staff, family carers, the person with dementia and, at times, the GPs to cope with the behaviours and symptoms.

Step 2: Select the target behaviour

The aggregated synthesis of the four different data sources, [330,332,403] as outlined in Figure 14, enabled the research team to generate a list of potentially modifiable GP behaviours to address the problem (Table 23).

Monitoring of antipsychotic prescribing was considered to have a high likelihood of implementation. Unlike some of the other potential target behaviours monitoring antipsychotic prescribing would not require a significant investment in healthcare funding, although it was recognised that it would require an investment of GPs' time. Addressing the monitoring of antipsychotic prescribing was considered to have very promising effects on 'spill-over behaviours' such as providing an evidence base for prescribing decisions, decreasing reluctance to discontinue or reduce antipsychotics and creating more realistic expectations on the benefits of antipsychotic prescribing. However, it was noted that one potentially negative spill-over effect of monitoring antipsychotic medications in BPSD is that it could result in increased rates of prescribing of other sedative psychotropic medications

such as benzodiazepines and z-drugs. [7,104] These drugs have an inferior evidence base and their sedative effects can result in significant adverse events in this patient population. Although this substitution is more likely to occur if the intervention targeted initiation of antipsychotics rather than monitoring, it is still important that an intervention focusing on the monitoring of antipsychotic medications addresses this potential negative spill-over effect. Finally, it was considered that the extent to which an intervention in this area would change the target behaviour was very measurable.

The other modifiable behaviours were judged to be less promising overall when all the criteria outlined in Table 22 were considered. Some behaviours such as 'maintaining good relationships with primary care team members' were considered to have a low likelihood of implementation given the regional variation of functioning primary care teams. [2] Other behaviours such as 'not relying on family caregivers' were considered to be impractical given that the behaviour was influenced by inadequate community based services and supports. All four data sources highlighted the challenges that GPs face attempting to provide optimum care in a sub-optimum environment with understaffing in nursing homes and inadequate supports in the community. The decision to focus on the monitoring of antipsychotics, rather than the initiation of antipsychotics, was deliberate and was informed by all four data sources. By focusing on the monitoring of antipsychotics we are addressing a specific behaviour where antipsychotics are commenced with no plan for monitoring or discontinuing. Targeting the monitoring of antipsychotics in BPSD was considered to have a high chance of resulting in behaviour change. A review of systematic reviews of effective interventions in primary care found that interventions related to prescribing showed a particularly good effect on quality improvement. [408] Interventions that aim to reduce inappropriate prescribing of psychotropic medications by targeting the monitoring of

prescribing have been shown to be successful. [201,298] In a recent cluster randomised controlled trial conducted in the UK the introduction of antipsychotic reviews was shown to significantly reduce antipsychotic use by up to 50%. [210]

Finally, existing evidence and new evidence conducted for this research suggested that the monitoring of antipsychotic prescribing is currently sub-optimal. In the UK, a national audit of antipsychotic prescribing conducted in 2012 found 1001 (62%) of patients with dementia were prescribed an antipsychotic for more than 6 months and only three-quarters had a documented review of response in the previous 6 months. [370] The national audit identified that medication review of long term prescribing of antipsychotic prescribing as a priority area to improve the care provided to people with BPSD. Findings from our qualitative study, [332] the cross-sectional descriptive study on GPs management of BPSD and the online dementia module all suggested that most GPs in Ireland did not have a formal, systematic, structured approach to monitoring their prescribing of antipsychotic medications to people with BPSD.

Table 23. BCW Step 2/3.

Prioritising modifiable GP behaviours that could improve the management of BPSD in general practice identified from the four data sources

Behaviour	Impact of changing behaviour	Likelihood of Implementation	Spill-over effect on other behaviours	Ease of measurement	Total Score*
Failure to engage in a proactive discussions with family caregivers (SR, QS)	Promising	Promising	Promising *-May improve referrals to support services*	Unpromising but worth considering	7
Focusing on medication management of BPSD rather than assessment (QS) (SR)	Very promising	Promising *-barriers to detailed assessment e.g. time, understaffing*	Very promising *-decrease AP rx*	Promising	10
Not maintaining good relationships with primary care team members (QS)	Promising	Unpromising but worth considering *-PCT often only virtual or not functioning at all*	Promising *-provide support to carers*	Unpromising but worth considering	6
Making decisions on the management of BPSD in a vacuum, without consulting guidelines (QS)	Very promising	Promising *-if guidelines are GP relevant & accessible*	Promising *-decrease AP rx, increase dose reduction & withdrawal of APs, increase non-pharm strategies*	Promising	9
Consulting GP colleagues for emotional support but not clinical support (QS)	Promising	Unpromising but worth considering *-reason for not consulting other GPs is*	Very Promising *-may encourage more proactive care,*	Unpromising but worth considering *-may be difficult to measure the impact*	7

		complex & relates in part to lack GPwSI in dementia so implementation would require development of a group of GPswSI dementia	*encourage use of an evidence-base*		
Relying on pharmacological interventions when managing BPSD instead of non-pharmacological management strategies (SR, QS)	Very promising	Unpromising but worth considering *-heavily resource dependent*	Very promising	Very Promising	10
Using antipsychotics to enable family caregivers and nursing home staff to cope with the behaviours and symptoms (SR, QS)	Promising	Unpromising but worth considering *-resource limitations*	Promising	Promising	7
Basing prescribing decisions on their own personal experience with drug rather than the existing evidence (QS)	Very promising	Unpromising but worth considering *-some GPs prefer to make decisions this way (QS)* *-some of the evidence is limited*	Promising	Promising	8
Incorrectly estimating the risk versus the benefits of medication in BPSD (SR)	Very Promising	Promising *-but if there are no practical alternatives provided given then not v implementable*	Promising	Very promising	10
Failure to discontinue psychotropic medication as concerned this will lead to a re-emergence of symptoms (SR)	Very promising	Promising *-but resourcing may still provide a barrier*	Promising *-could impact on over-estimation of benefits of APs, monitoring of APs*	Very promising	11

Not monitoring the prescribing of antipsychotic medications (SR)	Very Promising	Very promising	Very Promising *-impact on reluctance to d/c, over-estimating benefits, basing prescribing decisions on evidence, not using guidelines, not considering non-pharm strategies. However, over-emphasis on APs could lead to prescribers switching to less effective, sedative medications such as benzodiazepines and Z-drugs.*	Very Promising	12
Not effectively managing expectations of family caregivers (QS) (SR)	Promising	Unpromising but worth considering *-poor diagnostic & disclosure practices impact on this behaviour*	Promising	Unpromising but worth considering	6
Not relying on family caregivers to manage BPSD in the community (QS) (SR)	Unpromising but worth considering	Unpromising but worth considering *-complicated by inadequate community based services & supports*	Promising	Unpromising but worth considering	5

** Sum of individual scores; Very promising = 3, Promising = 2, Unpromising but worth considering = 1, Unacceptable = -1*

Step 3: Specify the target behaviour

The BCW provides guidance on questions that need to be answered in order to specify the target behaviour as precisely as possible. [239]

What is the behaviour that will be targeted for change?

The monitoring of antipsychotic prescribing in people with dementia.

Where is the behaviour performed?

Antipsychotics are prescribed to people with dementia living at home in the community and those living in nursing homes. [194] These two settings, a person living in a nursing home and a person living at home in the community, differ significantly in terms of systems, stakeholders and environmental context. For example, in our systematic review we found that in the community the family plays a pivotal role, however, in the nursing home setting it is the nursing home staff who are the predominant influence on prescribing. [330] Other practical differences exist such as how the medications are prescribed; prescribing in the community setting occurs in a GP practice which, in Ireland, is almost universally computer based; [45] however, prescribing in the nursing home setting is typically paper based. Consequently, it is unlikely that the same intervention could be designed for and effectively implemented in these two diverse settings.

In deciding on which setting to focus on, the research team considered the evidence for the prescribing of antipsychotics in the two settings and consulted with GPs working clinically in both areas. People with dementia living in nursing homes are significantly more likely to be prescribed an antipsychotic than those living in the community. [194] A 2016 Irish study found that 45% (110/243) of people with dementia admitted to hospital from a nursing home had

an existing prescription for an antipsychotic, whereas 19% (78/409) of people with dementia admitted from their own homes had a pre-existing prescription for an antipsychotic. [194] Furthermore, a UK study in 2012 [197] looking at the prevalence of anti-psychotic prescribing in dementia in 59 GP practices found that 15.3% (161/1051) of people on the register were receiving low-dose anti-psychotics. This UK study examined whether the prescription originated in primary or secondary care and found that only 43% (70/161) of these prescriptions for anti-psychotics were initiated by the GP. Therefore, of the 1051 people with dementia living at home who attended these 59 GP practices 70 people (6.6%) were commenced on an antipsychotic by a GP – an average of only 1 person per GP practice. A further issue raised through discussion with our expert panel was that GPs don't tend to monitor their prescribing of any one particular class of drug in the community. Therefore, the acceptability of asking GPs to monitor one specific drug in one specific disease entity was discussed. In contrast, in the nursing home setting, medications are more likely to be monitored and reviewed. In view of the much higher prevalence of antipsychotic prescribing in nursing homes, and considering that medication monitoring is more acceptable in nursing home environment, the research team selected the nursing home setting as the more appropriate setting to target with our intervention.

Who needs to perform the behaviour and with whom do they perform it?

GPs need to monitor their prescribing of antipsychotics to people with dementia. However, they need to be supported by nursing staff. Other relevant stakeholders include; the person with dementia who is prescribed the antipsychotic and their family; the community pharmacist; and, potentially, the visiting old age psychiatrist/ geriatrician.

When is the behaviour performed?

In Ireland the independent nursing home regulator, HIQA, currently requires that nursing homes conduct a general medication review of each resident's medication every three months. There is no specific requirement for reporting on antipsychotic monitoring. However, it was considered that this would be an opportune time to specifically introduce a review of antipsychotic prescribing.

Existing guidelines differ in their recommendations on when reviews of antipsychotic prescribing should occur. For example, the American Psychiatric Association (APA) published practice guidelines on the use of antipsychotics in dementia in 2016. [142] This guideline recommended that if there is no clinically significant response after a 4-week trial of an adequate dose of an antipsychotic drug then the medication should be tapered and withdrawn. However, UK based guidance documents such as the recently updated NICE guidance recommend assessing response at "regular intervals" and reviewing antipsychotic prescribing every 3 months or according to need. [141]

To address some of the inconsistencies in the recommendations around antipsychotic monitoring in people with dementia, the results of the eDelphi consensus on the monitoring of antipsychotic prescribing in dementia were used to inform the specification of the target behaviour. [405] In consideration of the results of the eDelphi study we agreed that the review of antipsychotic prescribing in people with dementia should occur 6 weeks after a new prescription and every 3 months thereafter or more frequently if clinically indicated.

The target behaviour was, therefore, specified *as GPs to systematically monitor their prescribing of antipsychotic medication to people with dementia in nursing home settings after six weeks if a new prescription is initiated and three monthly thereafter.*

Table 24. Specifying the target behaviour

BCW Question	Decision	Reason for decision
What behaviour?	Systematically monitoring the prescribing of antipsychotic medication to people with dementia	Identified as an aspect of BPSD that is sub-optimally management. Considered to have a high likelihood of implementation.
Where is the behaviour performed?	Nursing homes	Antipsychotic prescribing for BPSD is significantly more common in nursing homes than the community. Nursing home regulations mean that monitoring of prescribing is more acceptable.
Who needs to perform the behaviour? And with whom?	GP needs to perform the behaviour, with nursing staff	GPs provide the vast majority of care to nursing home residents and are responsible for prescribing and repeat prescribing.
When and how often?	After 6 weeks if a new prescription is initiated and 3 monthly thereafter (as part of the 3 monthly medication review)	Informed by clinical guidelines and eDelphi consensus study

Step 4: Identify what needs to change

We (AJ, TF) analysed the primary data set from the interview study, the meta-ethnography, the quantitative survey of GPs knowledge and attitudes to the management of BPSD and the online discussion forum from the dementia model using the COM-B model (see Figure 12) to identify GPs' capabilities (C), opportunities (O) and motivations (M) for monitoring, or not monitoring the prescribing of antipsychotic medications in people with dementia. The identified barriers with their associated COM-B components and expanded TDF domains are

available on Table 25. We identified psychological capability, physical opportunity, social opportunity and reflective motivation as potentially important COM-B components to target.

Psychological capability

Some GPs are unaware of the adverse effects of antipsychotics in dementia and over-estimate their benefits in managing BPSD. They, therefore, may not see the benefit of monitoring their prescribing of antipsychotics. Some are also unsure of how to formally monitor their prescribing of antipsychotics.

Physical Opportunity

All data sources confirmed that there is a lack of GP relevant guidelines on antipsychotic prescribing and monitoring in dementia. The four data sources also highlighted that monitoring requires resources. However, nursing home and GP resources are already stretched. A further barrier was the lack of clear pathways of care and difficulties accessing advice from secondary care colleagues regarding antipsychotic prescribing. In the quantitative survey of GPs' knowledge of and attitudes towards BPSD management, increased access to specialist advice was the area ranked second highest that, if improved, would help GPs to reduce their prescribing of psychotropic medications (the first ranked being increased staffing levels in nursing homes). This ability to access advice is particularly salient in the situation where the antipsychotic was originally commenced by secondary care but the patient is no longer under active follow-up with secondary care.

Social Opportunity

Monitoring of antipsychotics in a nursing home setting requires collaboration and a good working relationship with nursing home staff. However, conflicting priorities and poor continuity of care can negatively impact on this collaborative relationship. In this context many GPs, especially less experienced GPs, felt under pressure from nursing home staff to prescribe. This pressure from nursing home staff was evident in all four data sources.

Reflective Motivation

GPs are reluctant to discontinue antipsychotics as antipsychotics fill a therapeutic void. GPs feel they have no implementable alternatives to prescribing antipsychotics. Therefore, the risks associated with antipsychotics are tolerated. A further barrier that impacts on GPs' motivation to monitor prescribing is the concern some GPs have that, if the antipsychotic is removed, the behaviours that triggered the initial prescription may return. This creates a certain amount of clinical inertia when it comes to monitoring antipsychotics. If the antipsychotic improves the behaviour the GP may not intend to discontinue it. If there is no plan to discontinue or reduce the prescription then there is no motivation to monitor prescribing.

Table 25. BCW Step 4: Identify what needs to change

Behavioural Analysis using COM-B & further expanded to TDF: *What are the GP barriers to monitoring their prescribing of antipsychotics in BPSD in a nursing home setting?*			**Intervention Functions** (Step 5)	**Selected behavioural change technique (BCT)** (Step 7)	**Translation of the behaviour change techniques within the intervention**
Barrier with evidence from supporting data	**TDF Domain(s)**	**COM-B**			
Lack of awareness of the adverse effects of antipsychotics and an over-estimation of their benefits in people with dementia <u>Qualitative Study</u> "*I have gone off Olanzapine a bit with the weight gain thing, I think there is a general trend away from Olanzapine because of that. I used to use a bit of Haloperidol I suppose before, again that's kind of gone out of fashion a bit, its Serenace isn't it? Quetiapine not so much, I tend to use that in younger people."* (GP14) I: "*And would you have any reservations about using antipsychotics in people with dementia?"* GP*: "No, I am happy enough. If the situation needs it I would be happy enough*." (GP10) <u>Systematic Review</u> "GPs over- estimated the benefit in symptom relief of second-generation antipsychotics with 63% of GPs expecting benefit in half of all patients." (Cousins et al, **SR**)	Knowledge	Capability - psychological	Education	Information about health consequence (BCT code 5.1)	Provide information on the evidence for the use of antipsychotics in BPSD. Provide information on the adverse effects of antipsychotic medications. Discuss recent best practice national guidelines developed by experts recommending monitoring of antipsychotic prescribing. This information would be best provided in a small group face-to-face setting as proven to suit GPs educational needs in dementia care. [87,133] However, to ensure

"The main barrier GPs identified was that discontinuation would potentially negatively affect the quality of life of the resident,"(Azermai et al, **SR**) <u>Online Module Discussion Forum</u> "*I was surprised by lack of evidence for Seroquel [in the reading material]."* (GP Participant) "*…while I was aware of risks associated with antipsychotics I certainly underestimated the risks and over-estimated the benefits. I don't have a protocol for reviewing/reducing antipsychotics.....YET! I hope I will be making some changes following what I am learning here."* (GP Participant) <u>Quantitative study of GPs' knowledge of & attitudes towards BPSD management</u> Over one-third (36.3%) of respondents felt that the majority of patients with BPSD benefited from second generation antipsychotics					ongoing access to the information it could also be hosted in an online format that would be immediately accessible to GPs on their desktops. [409]
Unclear on how to formally monitor prescribing <u>Qualitative Study</u> *"GP: I wouldn't have much confidence in is how high to go up with Seroquel… do you just keep it on 25mg at night, I wouldn't be 100% confident with that and at what level you would say 'oh god that is way too much'." (*GP6) "*I would think that the challenge for me is spending time and familiarising what the treatment options are, okay, and then having the confidence then to try them and then to write in the chart or make a mental note myself as to how effective or ineffective they were."* (GP7)	Knowledge Skills	Capability - psychological	Education	Prompts/ cues (BCT 7.1)	Provide a prompt (written or IT based) that functions as a checklist of items to consider when conducting a review of an antipsychotic prescription to a person with dementia and would be used at the time of performance of antipsychotic review to guide the GP. Given that the vast majority of nursing homes in Ireland are paper based, a paper

Systematic Review "*As things progress from moderate to more severe, the behavioural management with medication, I think we all just kind of make a stab here and there at what we feel might be appropriate, do you know*?" (Foley et al, **SR**) "Only a third of [nursing] homes report[ed] consistent review of patients initiated on antipsychotics within the six week recommendation." (Mavrodaris et al, **SR**) Online Module *"How do you actually do your repeat prescribing* [of antipsychotics]?" (GP Participant)				Information about others approval (BCT 6.3)	tool would be the most appropriate. Provide educational session from a credible peer where information is provided on best practice guidelines on when and how antipsychotic monitoring in people with dementia should be conducted.
Lack of GP-relevant guidelines Qualitative Study *"Bits and pieces that I would have looked at over the years but again a lot of that would not be appropriate in the community, so not a huge wealth of guidelines there to go with."* (GP3) *"So we are all working, well I am, I am working away in that grey area at the moment."* (GP7) Systematic Review "*When do you add in psychotropic medication, what type of medication, what dosages, for how long? We need guidelines on that"* (Foley et al, **SR)** Online Module Discussion Forum *"In the nursing home… its often the case 'do you remember so and so she reminds me of her that's what worked for her'.....as you can see very scientific!"* (GP Participant)	Environ-mental context and resources	Opportunity-physical	Environmental Restructuring	Adding objects to the environment (BCT 12.5)	Provide guidance on antipsychotic monitoring and initiation to GPs. This could take the form of tool that summarises the main points on best practice in antipsychotic prescribing and facilitates monitoring of antipsychotics.

Monitoring requires collaboration between nursing home staff and GPs, however, conflicting priorities and lack of continuity can impact on this collaboration. GPs can feel under pressure from nursing home staff to prescribe <u>Qualitative Study</u> *"A lot of the medication can be pushed by the staff in the nursing homes." (*GP9) *"…I can't understand why you are asking me to prescribe an antipsychotic which has got all kinds of potential side effects, you know, because it doesn't suit you that Mrs Murphy is starting to wander a bit, you know."* (GP15) <u>Systematic Review</u> "*Often it is pressure from nursing homes or carers for medication to calm a patient down that is trigger for prescribing. "* (Mavrodaris et al, SR) "Our results suggest that nursing staff have the largest influence on prescribing psychotropic medication in this setting." (Cousins et al, SR) <u>Online Module Discussion Forum</u> *"It can be really difficult not to prescribe something to frustrated, tired carers and nursing staff." (*GP Participant) *"I think the pressure is definitely borne out of initial expectations by carers and nursing home staff that these patients should conform to their idea of appropriate behaviour."* (GP Participant)	Social influences	Opportunity - Social	Enablement Environment -al Restructuring	Social support (practical) (BCT 3.2) Restructuring the physical environment (BCT 12.1)	GPs conducting a review with the input from multidisciplinary colleagues –nursing home staff with input from pharmacy where feasible. Having an interprofessional educational (IPE) session should help align the priorities of the different health care professionals and foster the development of practical social supports[359,410] and engagement with the initiative. Change the physical environment to overcome barriers to collaboration between nursing home staff and GPs. This could involve having the dispensing chart in with the drug kardex so that if a person is on an antipsychotic PRN then the frequency with which this is given is identifiable.

<u>Quantitative study of GPs' knowledge of and attitude to BPSD management</u> When ranking the barriers to recommending non-pharmacological interventions the majority of respondents ranked 'pressure to prescribe medication from nursing home staff/ nurses' as the number 1 barrier. The vast majority (80.1%) of respondents reported that nursing staff were the biggest influence on their prescribing. Free text comments: *"Often intense pressure to prescribe."* (Respondent_8) "*Have had enormous pressure to 'sedate' patients in NH from nurses."* (Respondent_145)					The presence of a repeat prescribing tool could help to keep GPs and nurses 'on the same page' with regards to repeat prescribing.
Concern that discontinuing medications will lead to a re-emergence of symptoms <u>Qualitative Study</u> *"I think everybody would be terrified to stop it in case her behaviours got a bit worse or they would say she slipped more and it was your fault she slipped more. So I think whatever about starting the meds I think it is almost impossible to stop the meds."* (GP15) <u>Systematic Review</u> "Behavioral problems after antipsychotic discontinuation was a major concern, as well as hindrance to others and risk of harm to the resident." (Azermai et al, SR) "Prescribing or maintaining the dose of an already prescribed antipsychotic became the only apparent option." (Donyai, SR)	Beliefs about consequences Goals Optimism	Capability - psychological	Education	Information about health consequence (BCT 5.1) Information of others approval (BCT 6.3) Feedback on outcome of behaviour (BCT 2.7)	In an educational session introduce the evidence that the majority of the time discontinuing APs does not lead to a re-emergence of BPSD. Highlight the recommendations from national guideline on when to attempt withdrawal of APs The qualitative study highlighted the value GPs put on their own experience, even above the evidence. Thus, it would be valuable for the

Online Module Discussion Forum *"Once behaviour has improved all involved are loathe to change any medication for fear of return to troublesome behaviour."* (GP Participant) *"I need to actively consider weaning drugs when things settle gain and withdrawing if possible as I need to consider the longterm risk to the patient. I think I was more inclined to leave well enough alone previously."* (GP Participant) Quantitative study of GPs' knowledge of and attitude to BPSD management When asked to rate their agreement with the following statement *"I am concerned withdrawing medication will impact negatively on the quality of life of the resident leading to a return of challenging behaviours or disturbing psychological symptoms".* The majority of responding GPs agreed with this statement (63%). The rest were either neutral (10.7%) or disagreed (26.2%).			Enablement	Action Planning (BCT 1.4)	GP to be able to monitor the outcome of any reductions/ withdrawal of AP prescribing. GPs could be facilitated in this task if the providing pharmacy could issue a 3 monthly list of residents in the nursing home who are on APs with the AP dose. Explicit detail should be provided in the educational session (and any supporting online material) on how to maximise success when monitoring or withdrawing APs.
Reluctant to discontinue antipsychotics as they fill a therapeutic void. GPs feel they had no alternatives, thus, the adverse effects of antipsychotics are tolerated. Qualitative Study *"There is nothing worse than watching a patient that is agitated. It is terrible. It is torturous. So if there is a possibility I suppose that you will give them something at night and they will get a few hours sleep well then…"* (GP5) *"The only thing that would work is if somebody stayed talking to her continuously. Which wasn't practical and we tried every pharmacological intervention that was possible."* (GP13)	Professional/ social role and identity Beliefs about capabilities Optimism	Capability-psychological	Enablement	Action Planning (BCT 1.4)	It will be necessary to provide some detail to GPs on alternatives to prescribing. Highlighting the importance of a thorough assessment for potential triggers of BPSD e.g. pain. If the monitoring tool also provided a summary of essential components of assessment this could be helpful.

Systematic Review "According to many of the GPs an increased risk of stroke or other cardiovascular outcomes was considered a worthwhile trade-off, if prescription of the antipsychotic would improve the patient's mental wellbeing." (Mavrodaris, SR) "Alternatives are often inaccessible and unaffordable for many people with dementia or care homes." (Azermai, SR) Online Module Discussion Forum *"I have to say I rarely recommend non pharmacological managements … I definitely am not confident recommending [them] and feel ill equipped to recommend"* (GP Participant) Quantitative study of GPs' knowledge of and attitude to BPSD management (Free text comments) *"While I know the adverse effects + risks of AP are true, there are no other options especially in NH setting"* (Respondent_64)	Belief about consequences Intentions Goals			Social support (practical) (BCT 3.2)	GPs will need support from the nursing staff in this regard as alternatives to prescribing rely heavily on input from nursing staff. An IPE session would improve the interprofessional collaboration.
Monitoring is resource-intensive but resources, both GP and nursing home resources, are already stretched Qualitative Study *"[Nursing home rounds can be] very time consuming and it is always stressful, definitely always stressful and the challenges are capacity as well because we [GPs] run a very tight schedule during the day and are kept to a very tight schedule anyway."* (GP3) *"I could see how the nursing care was stretched kind of to the limit" (GP8)*	Environmental resources and context	Opportunity-physical	Environmental Restructuring	Adding objects to the environment (BCT 12.5) Prompts/ cues (BCT 7.1)	Provide resources that would facilitate monitoring of antipsychotics. A tool (IT or paper based) to support GPs conducting antipsychotic reviews. IT tools that identify people with dementia on antipsychotics in a patient database have been developed by the wider research project and

<u>Systematic Review</u> "GPs described inadequate nursing staff levels and resources as the main factors that limit the use of non-pharmacological interventions and their ability to reduce the usage of psychotropic agents in nursing homes." (Cousins et al, SR) "Concern was again expressed regarding resource constraints (Mavrodaris et al, SR) <u>Online Module Discussion Forum</u> "*It all seems to come back to the big word and big deficit-TIME!"* (GP Participant) *"Too few nursing homes have proper dementia units"* (GP Participant) <u>Quantitative study of GPs' knowledge of and attitude to BPSD management</u> When asked what would help them reduce their use of psychotropic agents in BPSD the factor ranked number one most frequently by respondents was 'increased staff levels in nursing homes'. Free text comments *"Resources/staffing biggest issues, low staffing means safety is big issue for patient and staff & at some time safer to medicate a patient with BPSD"* (Respondent_6) *"Dementia is very challenging to deal with, needs huge amount of time + the reality is that we just don't have it - patients suffer as a result."* (Respondent_84)		Motivation-reflective	Incentivisation	Material incentive (BCT 10.1)	could be a valuable part of the intervention. Provide continuous professional development (CPD) points to GPs. 1.Conducting an antipsychotic review would be eligible for internal CPD points. 2. If the GP monitored the outcome of the monitoring process this could form the basis of an audit. An audit is an annual CPD requirement for GPs. If the intervention included an audit template this would further incentivise the GP to conduct the audit and, therefore, engage with the monitoring process. 3. Finally, if there was an education component to the intervention and if we could get that education component accredited for external CPD points then this further incentivise GPs to engage with the intervention.

Phase 2: Identify intervention options

Step 5: Identify intervention functions

We found that all nine intervention functions were potentially relevant. We used the APEASE criteria to determine the most relevant intervention functions in the context of the Irish healthcare system. Our assessment using the APEASE criteria was informed by the authors' clinical experience as practising GPs (AJ, TF, CB) and by previously unreported data from the interview study and meta-ethnography where suggestions for appropriate intervention functions was analysed. This new analysis is presented with relevant supporting quotes in appendix 6, supplementary material 15 and 16. The assessment and grading of each of the nine intervention functions is presented in appendix 6, supplementary material 17 with their relevant categorisation into first line, second line or inappropriate option. The intervention functions judged to be most relevant for our intervention were education, environmental restructuring, incentivisation and enablement. The relationship between the behavioural analysis, as presented in the components of the COM-B analysis and the domains of the TDF, and the different intervention functions considered are shown in Table 25.

Step 6: Identify policy categories

Using the BCW guidance all seven policy categories were identified as potentially appropriate in supporting the four intervention functions identified in step 5. Three policy categories were common across the four selected intervention functions; guidelines, regulations and legislation. Regulation and legislative change was beyond the scope of this project, therefore, we identified guidelines as the most relevant policy category for this intervention. As outlined, the lead author is involved in the development of national

guidelines in the area of prescribing of psychotropic medications to people with BPSD. At the time of writing these guidelines have been approved and prioritised by the National Clinical Excellence Committee (NCEC); the national body who endorse national clinical guidelines in Ireland. Thus, these guidelines will be supported for implementation as a National Clinical Guideline.

Phase 3: Identify content and implementation options

Step 7: Identify behaviour change techniques (BCTs)

Nine BCTs were ultimately selected as being the most relevant ingredients for our intervention.

1) Information about health consequences (BCT code 5.1)
2) Information about others approval (BCT code 6.3)
3) Feedback on outcome of behaviour (BCT code 2.7)
4) Add objects to the environment (BCT code 12.5)
5) Prompts/ cues (BCT code 7.1)
6) Action planning (BCT code 1.4)
7) Restructuring the physical environment (BCT code 12.1)
8) Social support (practical) (BCT code 3.2)
9) Material incentive (BCT code 10.1)

The translation of these BCT components into the final intervention components was an iterative process. AJ & TF met multiple times to discuss how these BCTs could feed into intervention components in a way that was appropriate to the environmental context and

would be considered acceptable to GPs. The BCTs associated with each intervention function and an elaboration of how these BCTs could be used to encourage GPs to monitor their prescribing of antipsychotic medications to people with dementia in nursing homes is outlined in detail in Appendix 4, supplementary file 17. The intervention components were presented to the wider research team in a multidisciplinary research team meeting and agreed upon.

Step 8: Identify mode of delivery

A three-component intervention was developed and is graphically represented in Figure 15. One of the intervention components is a repeat prescribing tool to facilitate the monitoring of antipsychotic medications in BPSD. As there was no consensus in existing guidelines as to what the components of such a monitoring tool would be, the modified eDelphi consensus study reported in Chapter 9 was conducted to identify the key components of an antipsychotic repeat prescribing tool to monitor the prescribing of antipsychotic medications in BPSD in a general practice setting. [405]

To further refine all the components of the intervention, the proposed content and mode of delivery was discussed with the following stakeholders; directors of nursing in nursing homes (n=2), community pharmacists (n=2) and GPs (n=16). AJ conducted individual semi-structured interviews with the directors of nursing and the community pharmacists. Feedback from GPs on the proposed intervention was obtained from discussion of the intervention in an online forum and during a GP dementia study day organised by AJ. Analysis of the feedback from these three stakeholder groups is available in appendix 6, supplementary material 19. Of note, the nurses interviewed anticipated that the main barrier to the successful implementation of the intervention would be lack of engagement

from the GPs. Likewise, the GPs were apprehensive about potential resistance from the nursing staff, particularly if the monitoring of the antipsychotics was to result in plans to reduce or withdraw the antipsychotic medications. In light of the stakeholder feedback, the design and layout of the monitoring tool was further refined. The final monitoring tool is available in appendix 4, supplementary material 19. Once the intervention had been finalised, the TIDieR checklist functioned as a guide and informed the specification of the planned delivery of the intervention content and is available in appendix 4, supplementary material 23.

Description of the Intervention

The final intervention contains three components.

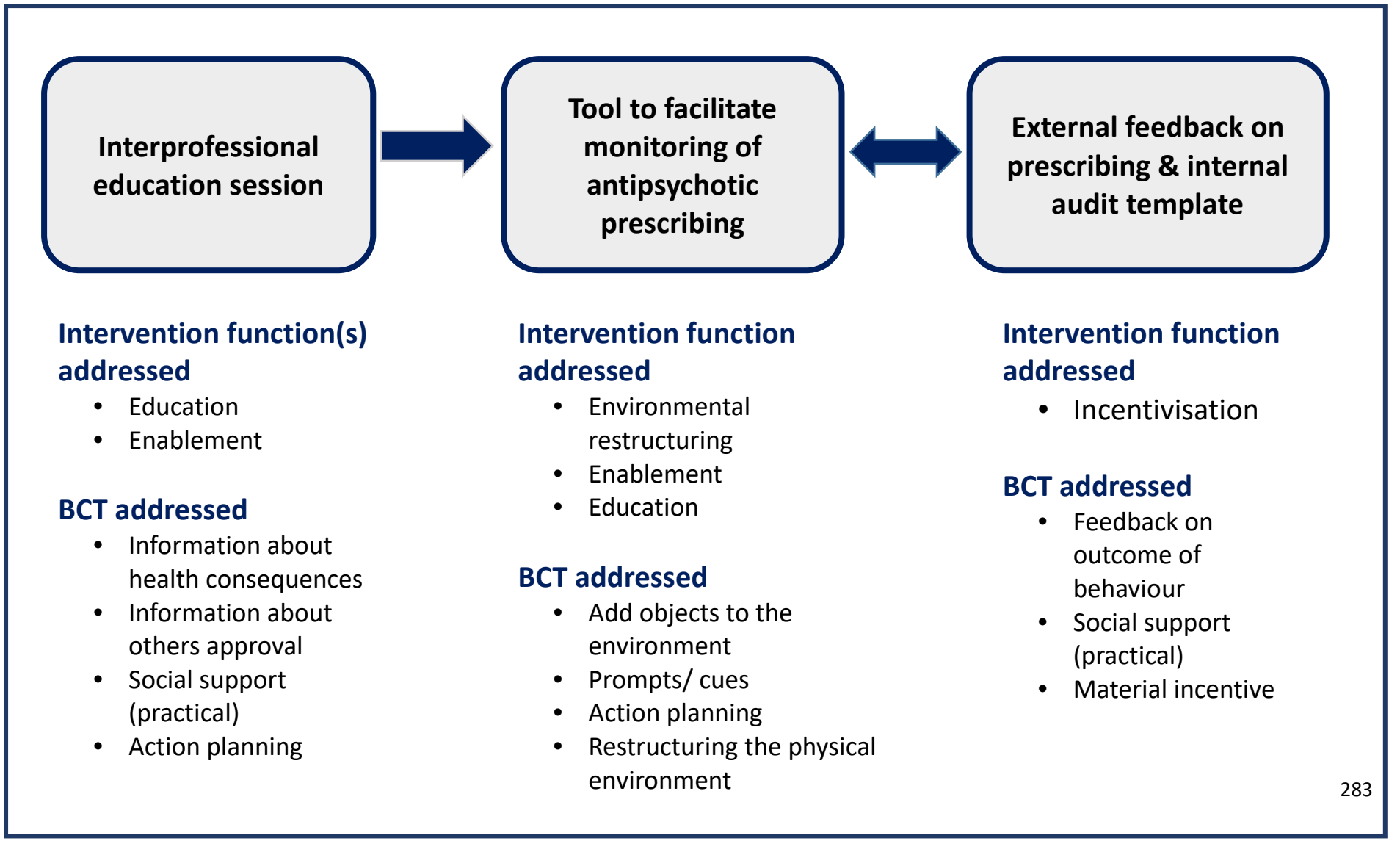
(i) The first component is an **interprofessional educational (IPE) session** on BPSD to be conducted in the nursing home with nursing staff and the visiting GP(s). This IPE session will last approximately one hour and will be co-facilitated by an upskilled GP and a nurse with an interest in dementia care. The content will focus on the learning needs identified in this research; [87,330,332] the assessment of BPSD, the risk/benefits of different psychotropic medications, monitoring and withdrawal of antipsychotic medications. The importance of a structured, systematic approach to antipsychotic monitoring in people with dementia will be highlighted. The educational session will be eligible for GP external continuous professional development (CPD) points. Obtaining CPD points is a professional development requirement for GPs and will, therefore, help to incentivise GPs to attend. (A proposed outline of the IPE session is available in Appendix 4, supplementary material 20).

(ii) The second component of the intervention is a **repeat prescribing tool** to support GPs in the monitoring of their antipsychotic prescribing to people with dementia. The tool will help to facilitate reviews of antipsychotic prescribing to people with dementia as part of the three monthly medication review. This tool will be introduced to the health care professionals in the IPE session outlined above and will also be available for download, with instructions on how to use it, on a website www.dementipathways.ie. This website was developed by the lead author (AJ) as an online clinical dementia resource for GPs and other primary care team members. [409]

(iii) The third component of the intervention provides **feedback to the GP** on their prescribing practices and facilitates the completion of **an internal audit** of their prescribing of antipsychotic medication to people with the dementia. GPs in Ireland must conduct an audit of an aspect of their clinical practice on an annual basis in order to meet professional competency requirements. Three approaches were employed to facilitate the GP in their conduction of an internal audit in this area. Firstly, the pharmacy managing the dispensing for the nursing home will provide feedback on antipsychotic prescribing to the nursing home every three months. Secondly, a paper-based audit tool was developed to provide GPs with a template of how to conduct the audit. (Available in appendix 4, supplementary material 21). Finally, although the majority of nursing homes in Ireland are paper based, in a minority of nursing homes the GP practice software is remotely integrated with the nursing home. This integration allows residents' clinical details and prescriptions to be recorded electronically in the nursing home and allows the GP to access these medical records from the GP practice's electronic medical record system. Where this integrated medical record system is in

place GPs can conduct the audit electronically. To enable these GPs to conduct an electronic audit, a software-finder tool was developed in collaboration with the Irish College of General Practitioners and the Irish Primary Care Research Network (IPCRN).[411] The finder tool creates a list of all patients in the practice that are either coded for dementia or prescribed a dementia specific medication (an acetylcholinesterase inhibitor or memantine). This effectively creates a dementia register for the practice. The finder tool will then search through this dementia register to identify people who are on an antipsychotic medication. It will produce a report for the GP with a list of the people with dementia, what antipsychotic medication they are on and the dose. (Further details on this electronic audit tool is available in Appendix 4, supplementary material 22). It is envisaged that these three elements; feedback from the pharmacy, the audit template and the software finder tool will support and facilitate a GP in conducting the internal audit and, consequently, will enhance GP engagement with this intervention component.

Figure 15. The intervention with the relevant supporting behaviour change techniques and the intervention function that each component of the intervention addresses



10.4 DISCUSSION

This paper describes a systematic, structured approach to the development of an intervention to improve the management of BPSD in general practice. The intervention development process was informed by a mixed methods systematic review,[330] qualitative research with GPs,[332] a quantitative survey of GPs knowledge and attitudes towards pain in dementia, [403] a survey of GPs management of BPSD and analysis of an online GP discussion forum on BPSD. By drawing on the findings of these studies, engagement with an expert panel and theoretical modelling with the BCW, we identified failure to monitor prescribing of antipsychotic medication to people with BPSD living in nursing homes in a systematic and structured way as the key behaviour to target with this intervention. By applying the BCW to our multiple data sources we identified the reasons why GPs were not engaged in this target behaviour and what needed to occur for the target behaviour to be achieved. We identified psychological capability, physical opportunity, social opportunity and reflective motivation as the important COM-B components to target with our intervention. Four intervention functions were identified as being particularly relevant for our intervention with nine associated BCTs. Developing the intervention content involved consultation with an expert panel, engagement with relevant stakeholders and an eDelphi consensus building process. The final intervention involves three key components; an interprofessional education session with GPs and nursing home staff, a tool to facilitate monitoring of antipsychotic prescribing in BPSD and facilitation of a self-audit of GPs' prescribing of antipsychotic medication in BPSD.

We found that the monitoring of antipsychotic medication in BPSD is influenced by many contextual and social factors. The characteristics of the nursing home is an important

contextual factor. The importance of adequate resourcing of nursing homes was emphasised by participating GPs at all stages of this research. [330,332,403] Furthermore, in choosing this particular target behaviour we were aware of the three potential barriers; (i) that a focus on antipsychotic prescribing could increase the prescribing of other less effective sedating psychotropic medications to manage BPSD, (ii) that implementable alternatives to pharmacological approaches would need to be highlighted, (iii) to be effective the intervention would need to involve collaboration between the GPs and the nursing home staff. Through the first component of our intervention, the IPE session, we attempt to address these three potential barriers. The educational session will outline the limited evidence for alternative pharmacological options in BPSD and will also outline an approach to assessment of BPSD. These two features will address the issues of potential substitution of antipsychotics for another less effective psychotropic medication and the need to consider non-pharmacological approaches. In our preliminary work [87,330,332] we also identified a number of specific knowledge deficits such as the overestimation of the benefits of antipsychotic medication in BPSD and an under-estimation of their adverse effects. The educational session will address these identified knowledge gaps. If these knowledge gaps are not addressed then any intervention targeting improving the monitoring of antipsychotic medication in BPSD is likely to be unsuccessful.

We recognise that the passive provision of information does not necessarily translate into improved knowledge. However, research conducted by two of the authors (TF, AJ) supports the value of small-group, peer-led educational sessions in improving dementia knowledge in primary care. [133] Furthermore, by making the education session interprofessional we aim to address the third potential barrier - the need for improved communication and collaboration between nursing home staff and the visiting GP. The feedback on the

intervention provided by GPs and nurses emphasised how each professional group feared resistance from the other and this was seen as the key barrier to successful implementation of the intervention. This finding further highlighting the importance of an interprofessional educational session. A previous systematic review of the effects of IPE has highlighted its role in improving professionals' attitudes to one another and in increasing collaborative knowledge. [359] Specifically in the area of dementia care, IPE has been shown to have the potential to improve collaborative knowledge. [410] Two of the authors (AJ, TF) have previously developed and piloted an interprofessional dementia education workshop for community-based primary care healthcare professionals in Ireland [412] (published paper available in appendix 12). The vast majority of participants in the pilot phase of that interprofessional intervention reported that the workshop positively contributed to enhanced team work and collaboration. Furthermore, that study highlighted the benefits of having two facilitators for an IPE session. Echoing previous research that has found co-facilitation to be an important method of strengthening collaboration and supporting interprofessional facilitators. [413] These findings informed the decision to have two facilitators, from each of the relevant professions (i.e. a GP and nurse), co-facilitate the educational session. We recognise that co-ordinating an IPE session can be logistically difficult, [412] especially since GPs have very limited time available. The impact of time constraints will need to be investigated further in a future feasibility study. However, it is encouraging that the feedback received to date from nursing home staff and GPs on the concept of this IPE session has been positive.

Educational interventions in BPSD have been found to be successful in the past but their beneficial effect has been largely only short-term. [208] The second component of the intervention, the repeat prescribing tool, will have an educational function providing much

needed practical guidance on how to formally monitor antipsychotic prescribing in BPSD. Moreover, by providing the participants in the IPE session with a goal at the end of the session- improve monitoring of antipsychotic medication, and a tool that will facilitate this goal, we hope to achieve more long term change in practice. The tool itself will also be available for download on an existing website that was developed by the lead author (AJ) as an educational resource for primary care team members providing dementia care. [409] This website provides educational material in the area of assessment of BPSD and practical advice on withdrawing antipsychotic medication in people with dementia, further emphasising the learning from the IPE education session. Additionally, the repeat prescribing tool will enable the monitoring process by providing a forum for collaborative, structured review of antipsychotic prescribing. In a recent RCT a multidisciplinary approach to a structured review of antipsychotic prescribing has been shown to significantly improve the appropriateness of antipsychotic prescribing to people with dementia in a nursing home setting. [298] Furthermore, the repeat prescribing tool should facilitate the need for practical social support between the nursing staff and the GP, ensuring that the two professional groups remain 'on the same page' when monitoring antipsychotic medications in BPSD.

The final component of the intervention, the facilitation of an internal audit, will provide GPs and nursing home staff with feedback on the outcome of the monitoring process. Feedback from pharmacies and the audit template will enable GPs to undertake a self-audit. Additionally, if the medical records in the nursing home are integrated electronically with the GPs' practice software, then the IPCRN finder tool will provide further assistance to the GP conducting the audit. Similar IPCRN finder tools have been successfully implemented in Irish GP practices in the areas of mental health [414] antimicrobial prescribing [415] and prescribing in pregnancy. [416] Furthermore, self-audit has been identified as an effective way

of improving the quality of other aspect of dementia care in general practice, such as coding of dementia diagnosis. [417] The audit component of this intervention will also meet the GP's mandatory annual CPD requirement for completion of a self-audit. [418]

Comparison with other work

Two previous systematic reviews have evaluated interventions to improve the management of BPSD in the nursing home setting; one conducted by Thompson-Coon in 2014 [201] and one conducted by Birkenhager-Gilesse in 2018. [208] The Thompson-Coon et al review evaluated the effectiveness of interventions to reduce inappropriate prescribing of antipsychotics to people with dementia living in residential care settings. [201] The Birkenhager-Gilesse et al systematic review was a meta-analysis of the effect of multidisciplinary psychosocial interventions for BPSD on the psychotropic drug prescription rate in nursing homes [208]. Both of these systematic reviews found that interventions designed to improve BPSD are often poorly described making interpretation of the results and future replication of the studies difficult [208] [201]. It appears from these reviews that intervention studies in the area of BPSD often fail to clearly report why the particular intervention was chosen. Furthermore, the intervention development process is often inadequately reported. These reviews identified that in order to change prescribing behaviour the intervention needs to target the prescribing physician, [208] yet surprisingly GPs' involvement in these intervention studies to date has been minimal. Despite the poor understanding of the challenges GPs experience managing BPSD, it appears that none of the interventions targeting GPs actively sought to understand or address this poor understanding. Furthermore, the studies included in these two systematic reviews did not appear to involve GPs in the development of the

intervention. Our study addresses this gap in the literature. By using the BCW approach to our intervention development process we provide a transparent and reproducible guide to the development of an intervention to improve the management of BPSD in general practice. To ensure our intervention was practical and appropriate, GPs were actively involved at all stages of our intervention development process.

Since its introduction in 2011, the BCW has been used as a theoretical model to inform the development of many, complex health-care interventions. These interventions have targeted a diverse range of health issues such as multimorbidity, [399] obesity in pregnancy, [419] diabetes [420] and sexual counselling in cardiac rehabilitation. [421] In some studies the target behaviour was pre-determined based on existing international guidance. [421] In our study, the paucity of existing evidence of current practice in BPSD and the lack of international guidance meant that the target behaviour was not decided in advance. Therefore, similar to other studies which used the BCW to develop complex interventions for general practitioners in the areas of multimorbidity [399] and test ordering, [422] we used the BCW approach to identify what behaviour to target with our intervention. In some instances the BCW has been used to modify existing healthcare interventions. [423] In other studies the intervention content incorporated existing tools. [399] In our study, due to the paucity of interventions in this area that targeted GPs, it was necessary to develop an intervention de novo to address our chosen target behaviour.

Limitations

GPs' behaviour appears to be strongly influenced by their ability to access appropriate supports for the person with dementia both in the community and in nursing homes. However, addressing these resource limitations was beyond the scope of our intervention. Likewise, GPs experienced difficulty accessing clinical support within the healthcare system when managing people with BPSD. One barrier to monitoring the prescribing of antipsychotics in BPSD, which is not addressed with this intervention is the lack of integrated care pathways between secondary care and primary care. The lack of clear pathways makes it difficult for some GPs to access advice and support when monitoring or attempting to withdraw antipsychotic medications in dementia. [332] A particular problem if the GP themselves did not initiate the medication. The impact of these resource and health system limitations will need to be evaluated in future feasibility and pilot phases. The design of the intervention was further restricted by the real world complexities of accessing information on prescribing in Irish general practice. As discussed in Table 7, ideally, in the audit component of our intervention, GPs would receive external feedback that allowed them to benchmark their performance against their peers nationally. A Cochrane review demonstrated that external feedback and audit are effective methods of changing physician practice. [424] Furthermore, external feedback and audit has been demonstrated to be an effective intervention in primary care to reduce potentially inappropriate prescribing in older adults. [425] However, there is no national data set in Ireland that records disease-specific prescribing of antipsychotic medications at general practice level. Therefore, it is not possible to provide GPs with anonymised feedback that would allow them to benchmark their performance with their peers.

The concept of the "treatment culture" of a nursing home has been found to have a significant influence on antipsychotic prescribing in BPSD. [3] One study found that nursing homes with a "resident-focused" culture were associated with lower rates of antipsychotic prescribing. [307] Changing the culture of a nursing home can require a change in organisational structure, resourcing and even architectural structure. Factors such as under-staffing and high staff turnover can lead to organisational instability and a lack of consistent, well-trained nursing staff which negatively impacts on treatment culture. [426] Thus, changing culture was beyond the scope of this intervention. However, a previous stakeholder consensus study identified some of the key characteristics of an "ideal" nursing home in terms of promoting culture change and our intervention does address a number of these key characteristics, namely; improving interprofessional relationships, collaborative decision making and quality improvement processes. [427] Through our IPE session we will attempt *to improve relationships* between GPs and nursing home staff. A recent systematic review on the influences on decision-making regarding antipsychotic prescribing in nursing home residents with dementia identified that nursing home managers can play a significant role in dictating the culture of the nursing home. [3] Therefore, the nurse home managers will be invited to this IPE session. The repeat prescribing tool will involve GPs and nurses in a *collaborative decision making process*. Furthermore, the intervention aims to introduce a *systematic quality improvement* initiative into the nursing home, ultimately improving the care provided to individual residents. Thus, although culture change within the nursing home is beyond the specific remit of the intervention, we hope its various components will collectively have a positive impact on the nursing home culture.

We have drawn on a specific systematic approach to intervention development in this study – the BCW, and made use of the COM-B and TDF to understand our target behaviour.

However, there may be alternative theories that might be applicable to explain GPs' behaviour in the management of BPSD. We believe that the use of a systematic and transparent theoretical approach enabled us to develop an intervention that is evidence-based, reproducible and implementable. That being said, the use of the BCW to guide intervention is not a panacea for all the challenges that accompany an intervention development process. As the authors of the BCW approach themselves attest, the BCW is not a "magic bullet" for intervention design. [404] It provides a guide for the researcher to follow but allows for, and at times demands, the researcher to make a series of subjective decisions. Three of the authors' (AJ, TF, CB) work clinically as GPs. Their clinical experience ultimately influenced some of these subjective decisions. However, the involvement of three practising GPs in this intervention development process; two with academic and clinical interest in dementia (AJ, TF) and one with an academic interest in prescribing (CB) was counter-balanced by the involvement of a BCW expert (JMcS) and an experienced public health researcher (JB). Furthermore, in this instance, we feel that the research teams' knowledge of the clinical context and their professional experience working in nursing home settings was a distinct advantage when making the subjective, pragmatic decisions that the BCW requires. Indeed, we believe that making these decisions without our professional and clinical experience would have been extremely difficult. Additionally, we had a wide range of data sources to inform our decisions ranging from our systematic review, the qualitative study with GPs, two surveys of GPs' knowledge and attitudes to aspects of BPSD management and data from on online GP discussion forum on BPSD. These data sources, combined with the extensive professional experience of the research team, added to the authenticity of the decision making process. Each decision made and the reasons for

choosing, or not choosing, a particular option is documented in the supporting supplementary files, adding to the transparency of our methods.

This study focused on developing an intervention to change the behaviour of one health care professional involved in the management of BPSD- the GP. We could have taken a more complex, multi-faceted approach to our intervention development process that incorporated all the potential relevant stakeholders. However, we wanted to focus on one healthcare professional, whose views on BPSD are often under-represented in the development of interventions that are largely designed to change their practice; the GP. The GP is not the sole health care professional involved in the care of people with dementia. In the nursing home setting the nursing staff play a pivotal role as do the health care assistants and family carers. Allied health care professionals such as occupational therapists and community pharmacists also have a role in the care provided to people experiencing BPSD. However, these stakeholders have different functions and responsibilities in the care of a person with BPSD. Attempting to address the myriad of different behaviours and challenges that face all these different stakeholders when managing BPSD with a single intervention would have led to a very complex and, potentially, unworkable intervention. In our intervention, by focusing on one professional group, we aim to target a specific problem. We strove to reduce the complexity of the intervention whilst addressing the complexities of the behaviours at play. The underlying premise being that a smaller, targeted change is more achievable and more sustainable and is, therefore, more likely to result in significant behavioural change that can be built on in future interventions. [404] Rome wasn't built in a day; but they were laying bricks every hour.

The final intervention targets GPs' behaviour but it also includes two relevant stakeholders; nurses and, more peripherally, community pharmacists. The qualitative study, the systematic review, the two descriptive cross-sectional studies and the analysis of the online discussion forum all highlighted the influence nursing staff have on GPs' management of BPSD in nursing home settings. Additionally, we considered recent research conducted in Ireland with nursing home staff, which explored their perspectives on antipsychotic prescribing in BPSD [367]. That research echoed much of our findings on the barriers to implementing evidence-based prescribing practices for BPSD in nursing home settings and highlighted the importance of the relationship between GP and nursing home staff, [367] giving further support to our chosen intervention. Interventions that aim to make changes to medications do benefit from patient buy-in. [428] In this clinical context achieving patient buy-in is complicated. We are addressing prescribing in a patient cohort who, by the nature of their illness and its probable advanced state (given the presence of significant BPSD and the person's residence in a nursing home), are unlikely to be able to effectively engage in a shared-decision making process. When managing advanced dementia in a nursing home setting that patient buy-in does, in many ways, become nursing buy-in, further emphasising the importance of involving nursing home staff in this intervention. Although the family caregiver typically plays a more significant role in the care of a person with dementia in the community than in the nursing home, it would be import to ascertain the views of family carergivers in any future feasibility study of this intervention.

Community pharmacists were identified as another health care professional that have a role to play in supporting GPs in their monitoring of antipsychotic prescribing in BPSD. A recent RCT conducted in Canada demonstrated that pharmacists can effectively stop the prescribing of inappropriate medications in the elderly. [429] Although pharmacists do not

influence GPs' prescribing in BPSD to the same extent as nurses do, their role in supporting medication reviews in BPSD is acknowledged by GPs. [155] A recent feasibility study conducted in the UK demonstrated the potential impact of pharmacist-led medication reviews in improving the management of BPSD in care homes. [430] However, in an Irish context significant involvement from the providing pharmacist in the review of antipsychotic prescribing is not currently feasible. The pharmacies providing care to Irish nursing homes typically go through a competitive tendering process to win the contract to provide pharmacy services to a nursing home. Consequently, the providing pharmacist can often be located hundreds of miles away, making direct involvement of the providing pharmacy in a medication review logistically challenging. Furthermore, evidence suggests that community pharmacists generally do not feel suitably trained to advise medication changes in the area of BPSD, an area that is viewed by community pharmacists as a 'specialist' area. [431] However, in recognition of the role of pharmacists, we have involved them in the process by requesting they provide feedback on antipsychotic prescribing rates to the nursing homes, thereby facilitating the GPs in conducting a self-audit and enabling GPs to monitor the outcome of their initiative.

Implications for future research

Following the MRC framework recommendations for the development of complex interventions, [242] the next step will involve exploring the feasibility of the intervention. It is important that before any evaluation of effectiveness is undertaken we need to assess if the intervention is feasible, acceptable and leads to behaviour change. To ensure the intervention is implemented as intended, to understand how the intervention produces change and to assess if anything external to the intervention is acting as a barrier to the

implementation of the intervention, an initial process evaluation stage will need to be conducted. [432] Process evaluation has an important role in understanding the feasibility of an intervention and also for optimising its design and implementation. If the intervention is found to be feasible then further research could focus on evaluating its effectiveness in a randomised controlled trial with accompanying economic evaluation. Evidence of effectiveness and economic benefits will help to address the policy categories identified that need to be addressed to support a nationwide implementation of this intervention.

10.5 CONCLUSION

To our knowledge, this is the first intervention to have focused specifically on GPs management of BPSD and has directly involved GPs in the intervention development process. Each decision made has been clearly described and is available for review, either within the text or in the supplementary material provided. Therefore, whether this intervention ultimately proves to be effective or not, we believe this paper is valuable as it provides researchers in intervention development with a worked example of the application of the BCW to this complex clinical problem. Furthermore, this paper provides important information on the clinical context in which these behaviours are performed. In particular, we provide insights into GPs' perspectives on the factors influencing their management of BPSD. Given the limited role GPs have played to date in the development of interventions in BPSD, this paper addresses a specific gap in the research and gives a voice to a pivotal, but under-researched, provider of dementia care.

CHAPTER 11: DISCUSSION

11.1 INTRODUCTION

This chapter will present an overview of the issues raised in this thesis. The main findings of this thesis will be outlined to demonstrate how the different studies included in this thesis converged to address the overall research aim. The strengths and limitations of this thesis will be discussed in detail. Finally, the implications of this thesis in terms of policy, practice and future research will be explored.

11.2 MAIN FINDINGS

This thesis outlines how, in consultation with GPs and in response to the specific challenges GPs encounter when managing BPSD, an intervention was developed to improve the management of BPSD in general practice.

Before we attempt to change healthcare professionals practice, we need to understand what their current practice is and what their perspectives are on the challenges of implementing best practice. In this thesis, the systematic approach adopted for developing the intervention incorporated a number of consecutive phases. These phases aimed to identify current practice in BPSD and the challenges of implementing best practice in general practice. Each phase built upon and informed the next. First, the qualitative and quantitative literature on GPs' knowledge of, attitudes towards and experiences with BPSD was synthesised using a mixed methods integrated approach. By adopting a meta-ethnographic approach to the data analysis and synthesis, a line of argument was

developed. This line of argument described the therapeutic void that GPs face when managing BPSD and identified that to fill this therapeutic void there is an over-reliance on antipsychotic medication and on family carers. The review highlighted the paucity of qualitative literature conducted with GPs that specifically examined GPs' perspectives on the management of BPSD. This gap in the literature was particularly striking when the large number of qualitative studies that have been conducted with GPs in the area of dementia diagnosis are considered. [73,292,433-436] Therefore, to further increase our understanding of the problem, a qualitative study was conducted to explore GPs' experiences of the challenges of managing BPSD. The qualitative study emphasised that BPSD is an area that GPs struggle with professionally and, at times, personally. Participating GPs believed they had no viable alternatives to sedative medications, yet they felt that their decision to prescribe was sometimes in conflict with their primary role as an advocate for their patients. In the qualitative study, the difficulties GPs encountered assessing a person with BPSD for potentially reversible triggers, such as pain, was apparent. This finding was explored further in a descriptive cross-sectional study on GPs' knowledge of and attitudes towards the management of pain in dementia. In addition to identifying aspects of GPs' management of pain in dementia that appear to be sub-optimal, some of the challenges GPs experience providing nursing home care in Ireland were identified. In Chapter 8, these three studies were further integrated with two other data sources; an analysis of an online GP discussion forum on BPSD and a questionnaire based study on GPs' knowledge of and attitudes towards BPSD. The intervention development process was informed by a detailed analysis of these five data sources and, in consultation with an expert panel, followed the systematic approach outlined in the BCW. The final intervention addresses a specific aspect of the management of BPSD- the monitoring of antipsychotic medication. The intervention aims to

promote the targeted and systematic monitoring of antipsychotic medication prescribed to people with BPSD residing in nursing homes. There was a lack of consensus in the literature on some of the clinical aspects of monitoring antipsychotics in BPSD. Therefore, a modified eDelphi consensus process was employed to identify the key components of an antipsychotic monitoring tool. [405]

11.3 STRENGTHS AND LIMITATIONS

This research provides an in-depth analysis of the challenges that GPs encounter when managing BPSD. The research phenomenon was studied in its natural setting and significant consideration was given to the context in which the management of BPSD occurs. This analysis was then used to inform the development of an intervention which aims to improve GPs' behaviour in the management of BPSD using behaviour change theory. I will now explore the strengths and limitations of this research.

A strength of this thesis is that GPs, who are the target population of the intervention, were involved at every stage of the development process. The research question emerged from a learning needs assessment with GPs, people with dementia and family caregivers. [87] The systematic review, qualitative study, cross-sectional study and eDelphi consensus study allowed the selection and tailoring of a contextually appropriate intervention. Subsequent feedback from GPs on the proposed intervention provided further understanding of the cultural and contextual factors at play and enabled refinement of intervention. The high level of engagement with the key stakeholder in the intervention should improve GPs' ownership of the final intervention. Improving ownership of the intervention is considered to be an important component of any successful quality improvement initiative in primary

care. [437] McHugh et al conducted qualitative research with GPs in Ireland in 2010 exploring their attitudes and openness to engaging in quality improvement in general practice. [438] The study identified that GPs' had a sense of inertia towards quality improvements. This inertia stemmed from the competing demands of providing chronic disease management in a health service with inadequate resources. The authors suggested that this inertia could be addressed by involving GPs at an early stage in the intervention development process, an approach adopted in this research. Furthermore, in this thesis the continuous GP involvement ensured the development of a clinically-relevant intervention that attempts to address the real-life complexities of managing BPSD. Using a systematic approach to the intervention development process ensured that this 'real world' intervention was still grounded in evidence. The significant involvement of GPs in the intervention development process also meant that, rather than imposing an intervention on disempowered GPs, the intervention attempts to provide GPs with an opportunity to improve their practice with due consideration of the real-world contextual challenges they face.

A potential limitation is that, despite the exhaustive consultation with and input from GPs, it is possible that this research selectively reached those GPs who were most positive about change and most willing to engage in improvement initiatives. There is a danger, therefore, that the views of the GPs who are most disillusioned with current practices and most resistant to change were not ascertained. Although GP participants in the qualitative study and in the online module may represent a subset of GPs who are more amenable to change and more interested in dementia care than GPs who did not participate in the module, the inclusion of the results of the two cross-sectional descriptive studies in the intervention development process did help to also capture the views of GPs who are potentially less

open to change and less involved with dementia care. For example, in the cross sectional study the dissatisfaction of participating GPs with the current remuneration structure for GPs engaged in dementia care was evident. In the qualitative study, although participating GPs spoke about the challenges of managing BPSD in the context of stretched resources, the resources they sought were primarily improved services and supports, rather than increased remuneration for the GP. It is possible that the GPs who were disillusioned with current provision of dementia care were less likely to engage in the qualitative study. However, this demonstrates the benefit of using multiple sources of data to inform the intervention development process. In this research, the use of a combination of different data sources, from GPs engaged in dementia care at multiple levels, enhanced the authenticity of the overall research findings.

Another potential limitation is that the GPs that participated in the qualitative interviews and the cross-sectional descriptive study were all from one geographical area in the south of Ireland. However, to overcome this limitation participants in the qualitative study were purposively sampled to represent the spectrum of Irish general practice. In the cross-sectional descriptive study the respondents were identified as being representative of GPs nationally. Additionally, the intervention development was informed by GP participants in the dementia module and GPs who participated in the eDelphi consensus study; these GPs were recruited at a national level, thereby improving the transferability of the findings within Ireland. Furthermore, the intervention addresses a number of the challenges identified in the systematic review, which represented the views of GPs internationally, further increasing the likelihood of the intervention's wider applicability.

The under resourcing of community and nursing home services was identified as being a key influence on GP decision-making processes in BPSD.[330,332] However, it was beyond the scope of this thesis to address these wider contextual issues of under-resourcing in primary care in Ireland. It could be suggested, that by introducing this intervention to improve the management of BPSD in general practice, GPs are being asked to change an aspect of their practice without providing them with any increased financial resources to do this. On the other hand, evidence suggests that GPs engage in quality improvement for many reasons including; a desire to improve care, to maintain professional autonomy and for reasons of professional pride. [439] Financial remuneration is just one reason. [439] A 2011 Cochrane review evaluated the impact of financial incentives on healthcare professional behaviour and found that financial incentives may be effective in changing healthcare professional practice. [440] Yet, a recent review of reviews by Chauhan et al evaluated the effectiveness of behaviour change interventions that were specifically directed at primary care health care professionals and found that the use of financial incentives alone did not significantly influence practice in the long term. [441] The review did find that combining financial incentives with educational interventions and audit/feedback can be effective in changing GP's behaviour. [441] This combination of incentivisation and education has been shown to be a promising method of changing GP behaviour in the area of generic prescribing. [442] Similarly, Perry et al in their review of the effects of GP educational interventions in dementia care, highlighted that to effectively change GP practice in dementia care, education needs to be combined with adequate reimbursement and organisational incentives. [360] In the current Irish context of financial austerity and low morale amongst GPs, [45] the success of an intervention, any intervention, which asks GPs to change their practice but does not financially resource them to do this, is potentially contentious.

Engaging health care professionals in change will always be a challenge when the system in which they work is under-resourced. [443] This holds true regardless of the individual merits of the intervention being introduced. The intervention developed here aims to specifically address how care is provided by GPs to people with BPSD in nursing home settings. In this research, the dissatisfaction GPs felt with their roles and responsibilities in the nursing homes they attended was clear. Several GPs in the qualitative study intimated that the only reason they attended nursing homes was out of a sense of civic responsibility. This was particularly true of rural GPs, who were often the only GP in the area. It has been observed that, in healthcare, attempts to change behaviour ultimately depends on human will.[444] In this intervention, significant efforts were made to ensure the GPs would be incentivised to engage with the intervention; through provision of continuous professional development points and by the development of tools to facilitate engagement in the intervention. However, a certain reliance on the GP's goodwill remains. Therefore, it is possible that the GPs who will readily engage with this intervention will be those GPs that, heretofore, are already providing optimal care.

This research targeted the behaviour of GPs. Targeting behaviour is an important component of quality improvement. However, it could be argued that improving the care that healthcare professionals provide requires more than just changing individual behaviour. The systems in which health care professionals work need to change too. The Chronic Care Model provides a framework for the improvement of chronic disease management in primary care. [445] The model outlines the components required for high quality chronic disease management and emphasises that chronic disease management takes place in three overlapping and interdependent spheres; practice, health system and community. The GP's

practice or behaviour, is embedded in a health system, which is embedded within the wider community of policies and resources. Improvements in system-level factors, for example, the provision of community based dementia advisors,[446] have the potential to improve the quality of care a person with BPSD receives. Indeed, there are many factors outside of an individual GP's control that could be targeted to improve the care provided to people with BPSD. However, this intervention aims to specifically target GPs' behaviour and, therefore, focuses on one aspect of GP's management of BPSD that is known to be sub-optimal and is, importantly, within a GP's control.

The systematic approach taken to the intervention development process is a strength of this research. At a high-level, there is some debate on the value of theory in intervention development, [447] with researchers arguing that a better approach may be to use logic and common sense instead of theories. [448] However, proponents of theory-based approaches maintain that theory helps to develop more evidence-based, transparent and ultimately more successful interventions. [236,449,450] Indeed, the poor success of healthcare improvement interventions in the past has been attributed to the failure to adopt a theory-based approach to intervention development.[237] Although, the success of theory based interventions have yet to be directly compared to atheoretical interventions, Davidoff et al argue that theory is always at work in improvement interventions; the issue is not whether researchers use theory but whether they are explicit about the formal or informal theory they are using. [449] Overall, current opinion supports the use of an explicit theory when developing healthcare interventions believing that it produces more sustainable, reproducible interventions and enables researchers to effectively evaluate and learn from the interventions developed.[449] Choosing to adopt a theory based approach in this thesis

did not mean that professional intuition was abandoned or ignored. The use of an explicit theory simply allowed intuition and experience to be incorporated into the design of the intervention in a transparent, systematic way.

The explicit theory that informed this research was the BCW. While advocating for the use of a theory-driven approach to intervention development, some commentators have criticised the BCW. Ogden, one such commentator, contends that the BCW attempts to *"reduce variability"* and *"systematise behaviour"* in way that is both unfeasible and undesirable. [451] Yet, others argue that the advantage of the BCW is that it allows the design of "*real world interventions, especially by those less familiar with the area* [of behaviour change]", [452] a point conceded by Ogden. [453] Personally, as a clinician with no background in health psychology, using the BCW helped to demystify behaviour change theory. The relative accessibility of the BCW, when compared to other potential theories for incorporated behaviour change in intervention development such as Intervention Mapping, [454] increased its appeal and influenced the decision to engage with the BCW approach. However, it is worth considering whether the wide remit and accessibility of the BCW results in a generic 'Theory of Everything' that has the potential to *"create a false sense of security"*, [455] making something appear simple when it is not. [453] A potential limitation of the BCW is that all intervention functions and BCTs are presented as being equally effective in any context. The researcher can choose any BCT as long as it represents that intervention function, without consideration of whether or not that BCT has been shown to be effective. Another limitation is the tendency of the BCW to compartmentalise behaviours, creating an illusion of separateness, when in reality the behaviours are typically inter-connected and inter-dependent. This is, perhaps, a natural consequence of the thorough, systematic

approach it models. In practice, however, it meant that the same behaviour could be coded multiple times under different domains and could be represented in multiple behaviour change techniques. This ensures that the approach taken to the intervention development process is comprehensive and exhaustive. Such a meticulous approach does have consequences. The BCW, although thorough, is not necessarily efficient. That been said, for this thesis, using the BCW provided a language and a framework with which to explicitly and transparently develop the intervention. No theory is perfect but the BCW proved to be a particularly useful approach here.

11.4 IMPLICATIONS FOR POLICY

The publication of the Irish National Dementia Strategy brought a welcome focus to the provision of dementia care in Ireland and recommended a community-led approach to dementia care. Such a community-focus requires a primary care led approach to the management of dementia. This thesis has outlined a number of challenges of providing a primary care approach to the management of BPSD. These challenges need to be addressed at a policy level if the vision of community-led dementia care is to become a reality. I will now outline the policy implications of this research. I will first focus on the community setting, then on the nursing home setting and finally I will consider the need for guideline development.

Supporting people with dementia to live at home for as long as possible is the over-arching aim of nearly all government policies and national dementia strategies internationally.[28-30] There are economic, societal and healthcare benefits associated with supporting people with dementia to continue to live in their own homes. Repeatedly, evidence has shown that

BPSD is a significant trigger for admission to nursing homes. [114] It would seem logical, therefore, that improving how BPSD is managed in the community could effectively postpone a person's admission to a nursing home. This research has identified a number of areas, which if addressed with appropriate policy, would improve the management of BPSD in the community. The systematic review and the qualitative study both highlighted the inadequate resourcing of primary care teams and community supports. This insufficient resourcing of primary care teams was identified as the main barrier to recommending non-pharmacological strategies to manage BPSD in the descriptive cross sectional study of GPs' management of BPSD. GPs need access to community-based multidisciplinary supports to successfully implement non-pharmacological strategies in BPSD. This is not currently the case in Ireland. [2] Several participants highlighted how government led reductions in 'home help' hours can result in an otherwise unnecessary, and significantly more costly, admission to long term care. Furthermore, the lack of effective care pathways between GPs and secondary care colleagues when managing BPSD was apparent in both the systematic review and the qualitative study. Even identifying which specialist to access for advice on the management of BPSD was a challenge for GPs; some felt it was the remit of old age psychiatry, others geriatricians and others still were unsure; relying on 'personal favours' to access advice from secondary care colleagues.[332] Policy that provides for integrated and resourced care pathways would help to facilitate effective communication between primary and secondary care.

This research has also identified a number of policy implications for the management of BPSD in nursing home settings. The lack of nursing home staff and under-resourcing were seen as significant barriers to the provision of optimal care of BPSD in nursing home settings. One of the findings of this thesis was that antipsychotics are employed to enable

nursing home staff to cope with inadequate resourcing. [330,332] If one reflects upon this, it is concerning that both public and privately run organisations are relying on pharmacological prescriptions for residents to enable staff to cope with insufficient resources. The GPs who participated in this research also frequently referred to the pressure from nursing home staff to prescribe psychotropic medications in BPSD.[332] Policy requirements that encourage and support educational training in BPSD assessment and management for nursing home staff could facilitate more consistent engagement with educational initiatives.

Throughout this thesis the need for implementable guidelines was highlighted by GPs. The need for guidelines was also identified and prioritised in the policy category of the BCW intervention development process. As part of the implementation of the Irish National Dementia Strategy a guideline has been developed on the use of psychotropic medications for the management of BPSD. The process of developing this guideline began in October 2017. As a GP, with a clinical and research interest in the area of BPSD, I was invited to be the ICGP representative on this guideline development group. I was also nominated as one of the five individuals to sit on the writing group. In this way I was able to introduce my thesis findings into the guideline development process. This guideline has recently being prioritised by the NCEC (National Clinical Excellence Committee), the national body who endorse clinical guidelines in Ireland. Thus, this guideline will be supported for implementation as a National Clinical Guideline. This means that going forward the prescribing of psychotropic medications to people with dementia will be audited and educational tools and training in the area of BPSD will be implemented. The details of what areas will be targeted for audit have yet to be determined, however, I will be part of the research team tasked with developing an implementation plan for this guideline.

11.5 IMPLICATIONS FOR PRACTICE

This research attempts to close the gap between evidence on best practice approaches to the management of BPSD and the context in which these management decisions are made. Peters et al have highlighted the importance of considering the dynamics of behaviour change when developing an intervention. [456] Specifically, Peters has outlined how the behaviour change methods selected should be carefully matched with the determinants of the behaviour in question; to ensure that the behaviour can, in fact, be changed. [457] GPs participating in the qualitative study considered the challenges associated with managing BPSD to be insurmountable and outside of their control. This intervention demonstrates to GPs that, although they are constrained by the health system in which they work, not all of the challenges associated with managing BPSD are insuperable. Monitoring the prescribing of antipsychotic medication is a manageable task that has the potential to improve the care they provide to people with dementia in nursing homes.

The decision to target the monitoring of antipsychotic medications in BPSD, rather than targeting the initiation of antipsychotic medication in BPSD, reflects an attempt to reconcile the apparent incongruity that exists between best practice recommendations and real-world contextual challenges in BPSD management. In the context of current resource restrictions, the extent to which the initiation of antipsychotic prescribing could truly be changed was questionable. In choosing to target the monitoring of antipsychotic medication, rather than targeting the initiation of these medications, I am not proposing that inappropriate prescribing be tolerated. However, I am accepting that it is not currently possible to completely eliminate the use of antipsychotic medication in BPSD. Nor is it clear that doing so is always advantageous to the person with dementia. [212] There is no “safe”

level of antipsychotic prescribing, nor is there a clear "unsafe" level. However, as the harmful effects of antipsychotics are dose and duration dependent, it is clear that prescribing antipsychotics, without an adequate and effective review process in place, is potentially harmful to the person with BPSD. The intervention addresses a specific area of sub-optimal practice in BPSD – the failure to monitor ongoing prescribing of potentially harmful antipsychotic medication to people with dementia. [370] Effectively addressing the inadequate monitoring of antipsychotics in dementia will improve the management of BPSD by ensuring people with dementia are not inappropriately prescribed antipsychotic medication for prolonged periods of time, without a documented indication and without a scheduled review process in place. Importantly, based on my provisional work, targeting this behaviour appears to be acceptable to GPs, whereas, targeting their clinical decision to initiate antipsychotic medication in the first place is likely to be less acceptable and fraught with contextual limitations. That being said, as outlined in Chapter 8, by selecting monitoring of antipsychotics as the target behaviour for this intervention, a certain 'spill-over' effect on appropriate initiation of antipsychotics is expected.

The intervention developed here is particularly suited to GPs with a large nursing home commitment, where one GP provides regular, structured nursing home care to the majority of the residents. Although this is the model of care provided by many GPs in Ireland, it is not the model for all. But should it be? The descriptive cross-sectional study highlighted that many GPs in Ireland do not provide structured visits to the nursing home they attend. [403] In these instances, nursing home attendance is an 'add-on' to the GP's daily workload, often occurring before the working day begins or during a rushed lunchtime visit. Consequently, the care provided is often reactive, in response to crisis situations or acute problems. Currently GPs could be providing care to just one or two residents in a nursing home. [403]

This nursing home may be a significant distance away from the GP's surgery. For those GPs, structured visits are unfeasible from a resource perspective and it is envisaged that these GPs may be less likely to engage with the proposed intervention. There may be some concerns that having just one GP providing all the medical care in a nursing home could affect patient choice and autonomy. However, the qualitative study conducted as part of this research highlighted many of the benefits of one GP providing all, or the majority of care, in a nursing home. These benefits included increased consistency of care, an upskilled GP and better relationships with nursing home staff. In BPSD management, the importance of good communication pathways between GPs and nursing home staff was emphasised in the systematic review and the qualitative study. [330,332] Additionally, having a large nursing home commitment provides economies of scale for the GP and can enable and encourage a GP to provide more proactive care. [100] Consequently, one consideration for future practice that emerges from this research is whether medical care in nursing homes should be provided by one, upskilled GP. A practice model to consider is the system in place in The Netherlands where a distinct speciality of nursing home medicine exists. [277] A recent systematic review examined how the health outcomes of residents in long term care facilities varied according to which professional group provided the first-line medical care. [458] It found that having a specialist (versus a generalist) doctor providing the first line care was associated with improved prescribing outcomes but the impact on unplanned hospital transfer was less clear and there was no impact on mortality. [458] The findings of this thesis would suggest that where a GP has a large nursing home commitment, they benefit from increased experience of managing BPSD, experience that can improve their confidence and positively impact on the care they provide. [332]

11.6 IMPLICATIONS FOR FUTURE RESEARCH

The next step for this research should be the conduct of a feasibility study. Conducting a feasibility study is important in order to assess the extent to which the limitations identified in section 9.3 impact on the acceptability of the intervention from the perspective of all the relevant stakeholders. The concept for this research emerged from the initial educational needs analysis which was conducted with GPs, people with dementia and their carers. [87] That educational needs analysis was effectively used to inform the development educational material for health care professionals developed as part of the wider PREPARED project. [133,409,412] Carers and people with dementia may also have a role in informing the educational content of the interprofessional education component of this intervention. Furthermore, in order to have outcome measures that are meaningful, it is imperative that the perspectives of people with dementia and their carers are included in any future feasibility study.

There are also more general implications for conducting intervention development research in this area and, in particular, conducting intervention development research with GPs. GPs are frequently the subject of research, particularly healthcare research that focuses on quality improvement initiatives and behaviour change interventions. However, GPs are rarely effective partners in the development of these interventions. Research is often conducted on the decisions GPs make, without an adequate attempt to understand and appreciate the contextual constraints in which they make these decisions. In my own discussions with healthcare researchers they sometimes consider GPs as a 'hard to reach' group who are reluctant to engage with the research process. This can also be seen in the literature. For example, a recent feasibility study that introduced a pharmacist-led medication review to improve the management of BPSD in nursing homes in the UK found it

difficult to engage with GPs, experienced high GP drop-out rates and found that GPs who did participate were very slow to implement the medication changes suggested. [430] The authors postulated the reasons for this lack of GP engagement; considering things like the time required for the GP to engage in the intervention and the GPs relationship with the care home and with the pharmacist. The authors suggested that improved engagement with GPs at the beginning of the intervention with the option of continuous professional development points for the GP might improve future roll-outs. [430] Consequently, the question arises; are GPs truly hard to reach or are attempts made by researchers to include GPs in the research process inadequate, or more importantly, inappropriate? If the aim is to change behaviour then it is critical that we first understand the behaviour and the context in which the behaviour occurs. If the barriers to GPs performing a behaviour are not identified then it is unlikely the intervention developed will effectively target GPs' behaviour. Therefore, research that aims to change GPs behaviour needs to first understand what their current practice is and what their perspectives are on the challenges of implementing best practice. Future research about GPs needs to more proactively and effectively engage with GPs. Involving GPs as equal partners in the research process will also improve their ultimate ownership of the behaviour change intervention. Attempting to change the behaviour of any health care professional group, without attempting to get their 'buy in' may be an exercise in futility. [437]

The attention given to research in the area of BPSD in the past is not reflective of the significant impact BPSD has on healthcare professionals, people with dementia and their caregivers. The management of BPSD in general practice has not received the same level of research focus as other aspects of dementia care. One could postulate that the reason for this lack of attention may be that BPSD is a heterogeneous clinical entity with a limited, and

sometimes, conflicting evidence base. Thus, it does not lend itself to easily measurable outcomes. Research in the area of BPSD may be seen as less quantifiable and inherently more complex. The intervention developed in this thesis focused on one specific, target behaviour. However, this research has systematically identified a number of other behaviours in BPSD that contribute to the sup-optimal management of BPSD in general practice. These behaviours and some potential interventions that could address them have been transparently detailed in this thesis. Thus, this information could provide a starting point for other researchers interested in developing interventions for GPs managing BPSD.

11.7 CONCLUSION

This thesis presents a series of research that advances our knowledge of GPs' perspectives on the management of BPSD. Prior to conducting this research it was known that BPSD was a challenging area for GPs. This research provides a new depth of understanding as to *why* this is a challenging area for GPs. By using this new understanding to inform the development of an intervention to improve the management of BPSD in general practice, this thesis has addressed a specific gap in the literature. A systematically developed and clinically implementable intervention has been developed to address a sub-optimal aspect of BPSD management in general practice. The novel intervention was developed through detailed application of existing and new evidence to models of behaviour change. Thus, this research has made a meaningful contribution to the body of knowledge on BPSD management in general practice and also to the literature on the development of interventions for GPs in areas of clinical complexity. It is anticipated that the outputs of this thesis will contribute to the ultimate goal of improving the quality of care delivered to people living with BPSD.

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DEVELOPMENT OF AN INTERVENTION TO IMPROVE THE MANAGEMENT OF BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA IN GENERAL PRACTICE IN IRELAND

Volume 2 of 2

A thesis presented by

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Appendix 1. Supplementary Material for Chapter 5 - Systematic Review

Supplementary Material 1. PRISMA-P Checklist.

Section and topic	Item Number	Checklist item	Page number(s)
ADMINISTRATIVE INFORMATION			
Title:			
Identification	1a	Identify the report as a protocol of a systematic review	101
Update	1b	If the protocol is for an update of a previous systematic review, identify as such	Not an update
Registration	2	If registered, provide the name of the register (such as PROSPERO) and registration number	102
Authors:			
Contact	3a	Provide name, institutional affiliation, email address of all protocol authors; provide physical mailing address of corresponding author	Title Page of published paper (available in Appendix 12)
Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review	Final page of published paper (available in Appendix 12)
Amendments	4	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes	Not an amendment
Support:			
Sources	5a	Indicate sources of financial or other support for the review	Final page of published paper (available in Appendix 12)
Sponsor	5b	Provide name for the review funder and/or sponsor	Final page of published

			paper (available in Appendix 12)
Role of sponsor or funder	5c	Describe role of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol	Final page of published paper (available in Appendix 12)
INTRODUCTION			
Rationale	6	Describe the rationale for the review in the context of what is already known	103-104
Objectives	7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)	105
METHODS			
Eligibility criteria	8	Specify the study characteristics (such as PICO, study design, setting, time frame) and report characteristics (such as years considered, language, publication status) to be used as criteria for eligibility for the review	109 (Table 2)
Information sources	9	Describe all intended information sources (such as electronic databases, contact with study authors, trials registers or other grey literature sources) with planned dates of coverage	110
Search strategy	10	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated.	116 (Table 3) and Appendix 1, supplementary material 2
Study records:			
Data management	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review	111
Selection process	11b	State the process that will be used for selecting studies (such as two independent reviewers) through each phase of the review (that is, screening, eligibility and inclusion in meta-analysis	111

Data collection process	11c	Describe planned method of extracting data from reports (such as piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators	112
Data items	12	List and define all variables for which data will be sought (such as PICO items, funding source), any pre-planned data assumptions and simplifications	113 (Table 4)
Outcomes and prioritization	13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale	116
Risk of bias in individual studies	14	Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level., or both; state how this information will be used in data synthesis	117-118
Data synthesis	15a	Describe criteria under which study data will be quantitatively synthesised	N/A
	15b	If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data and methods of combining data from studies, including any planned exploration of consistency (such as I2, Kendall's)	N/A
	15c	Describe any proposed additional analyses (such as sensitivity or subgroup analyses, meta-regression)	N/A
	15d	If quantitative synthesis is not appropriate, describe the type of summary planned	113-115
Met-bias(es)	16	Specify any planned assessment of meta-bias(es) (such as publication bias across studies, selective reporting within studies)	N/A

Confidence in cumulative evidence	17	Describe how the strength of the body of evidence will be assesses (such as GRADE)	116

Supplementary Material 2. Search terms for the systematic review

How the search terms were combined with Boolean logic for the Medline, Ovid search

1. Exp Primary Health Care/
2. Exp General Practice
3. Family Practice/
4. Exp General Practitioners/
5. Exp Physicians, Family/
6. Exp Physicians, Primary Care/
7. family medicine.ti,ab
8. 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7
9. Exp Dementia/
10. Exp Alzheimer Disease/
11. dementia.ti,ab. alzheimer*.ti,ab.
12. (cognitive adj (impairment or decline)).ti,ab
13. 9 OR 10 OR 11 OR 12
14. Exp Antipsychotic Agents/
15. Exp Anxiety/
16. Exp Aggression/
17. Exp Wandering behavior/
18. Exp Sleep Disorders/
19. Exp Apathy/
20. Exp Irritable Mood/
21. Exp Psychotic Disorders/
22. Exp Depression/
23. Behavio?ral and psychological symptom*ti,ab
24. BPSD.ti,ab
25. Challenging behavio?r*ti,ab
26. Responsive behavio?r*.ti,ab
27. Neuropsychiatric symptom*.ti,ab
28. Non-cognitive symptom*.ti,ab
29. Noncognitive symptom*.ti,ab
30. Psychological symptom*.ti,ab
31. Psychiatric symptom*.ti,ab
32. Difficult behav*.ti,ab
33. Disruptive behav*.ti,ab
34. Behavio?ral symptom*.ti,ab
35. (agitated or agitation).ti,ab
36. (depressed or depression).ti,ab

37. (anxiety or anxious).ti,ab (aggressive* behav*).ti,ab
38. 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37
39. 8 AND 13 AND 38

Supplementary Material 3. Excluded Studies

Reasons for excluding studies after full text review

#	Authors, Study	Reason for excluding
1	Bowers J, Jorm AF, Henderson S, Harris P. General practitioners' reported knowledge about depression and dementia in elderly patients. Australian and New Zealand Journal of Psychiatry. 1992;26(2):168-74.	Does not describe the knowledge, attitudes or experiences of GPs in relation to BPSD. Focus was on GPs knowledge in relation to dementia diagnosis.
2.	McIntosh IB, Swanson V, Power KG, Rae CAL. General practitioners' and nurses' perceived roles, attitudes and stressors in the management of people with dementia. Health Bulletin. 1999;57(1):35-40.	Focus is on GP & nurse stress in managing dementia. Mentions BPSD only as a source of stress but does not investigate GPs knowledge, attitude or experiences of managing BPSD.
3.	O'Connor DW, Pollitt PA, Hyde JB, Brook CPB, Reiss BB, Roth M. Do general practitioners miss dementia in elderly patients? British Medical Journal. 1988;297(6656):1107-10.	Focus on GP's ability to detect dementia with no reference to BPSD.
4.	Parmar J, Dobbs B, McKay R, Kirwan C, Cooper T, Marin A. Diagnosis and management of dementia in primary care: exploratory study. Canadian family physician Medecin de famille canadien. 2014;60.	Does not describe the knowledge, attitudes or experiences of GPs in relation to BPSD. Did find that BPSD was under-documented in the notes but did not explore GPs knowledge, attitudes or experiences of BPSD.
5.	Parsons C, McCorry N, Murphy K, Byrne S, O'Sullivan D, O'Mahony D, et al. Assessment of factors that influence physician decision making regarding medication use in patients with dementia at the end of life.	Focus on discontinuation of medications in end of life advanced dementia. Does mention discontinuation of antipsychotics but doesn't

	International journal of geriatric psychiatry. 2014;29(3):281-90.	explore this in the context of BPSD.
6.	Patterson SM, Hughes CM, Lapane KL. Assessment of a United States pharmaceutical care model for nursing homes in the United Kingdom. Pharmacy world & science : PWS. 2007;29(5):517-25.	Not specific to dementia or BPSD but focus on prescribing and medication use in NHs. [Conflicting votes, agreed by arbitration that should be excluded on the grounds that it is not dementia or BPSD specific.
7.	Payne M, Gething M, Moore AA, Reid MC. Primary care providers' perspectives on psychoactive medication disorders in older adults. American Journal Geriatric Pharmacotherapy. 2011;9(3):164-72.	Explores PCPs experiences of psychoactive medication misuse in older adults but does not specifically look at dementia or BPSD
8.	Pentzek M, Wollny A, Wiese B, Jessen F, Haller F, Maier W, et al. Apart from nihilism and stigma: what influences general practitioners' accuracy in identifying incident dementia? American Journal of Geriatric Psychiatry.17(11):965-75.	Knowledge and attitude survey of GPs re dementia but does not explore BPSD
9.	Petrazzuoli F, Vinker S, Koskela TH, Frese T, Buono N, Soler JK, et al. Exploring dementia management attitudes in primary care: a key informant survey to primary care physicians in 25 European countries. International Psychogeriatrics. 2017:1-11.	Focus is on dementia diagnosis and initial treatment, not BPSD.
10.	Pond CD, Brodaty H, Stocks NP, Gunn J, Marley J, Disler P, et al. Ageing in general practice (AGP) trial: a cluster randomised trial to examine the effectiveness of peer education on GP diagnostic assessment and management of dementia. BMC family practice. 2012;13:12.	Protocol of a study that focuses on evaluating impact of GP educational intervention on dementia diagnosis. Does not describe the knowledge, attitudes or experiences of GPs in relation to BPSD.
11.	Qazi A, Spector A, Orrell M. User, carer and staff perspectives on anxiety in dementia: a qualitative study. Journal of Affective Disorders.125(1-3):295-300.	No general practitioners included in the focus groups for the study.
12.	Rockwood K, Black SE, Robillard A, Lussier I. Potential treatment effects of donepezil not detected in Alzheimer's disease clinical	Focus is on GPs experiences of the potential treatment effects of Donepezil. The study does not

	trials: a physician survey. International journal of geriatric psychiatry.19(10):954-60.	explore the GPs knowledge & attitudes or experiences of BPSD.
13.	Sawan MJ, Jeon YH, Fois RJ, Chen TF. A qualitative study exploring visible components of organizational culture: what influences the use of psychotropic medicines in nursing homes? International psychogeriatrics / IPA. 2016:1-11.	Semi-structured interviews with health care professionals (including 8 GPs) on what influences the use of antipsychotic prescribing in nursing homes. Minimal identifiable data on GPs. There is no explicit reference to dementia or BPSD. Went to 3rd reviewer for consensus as conflicting votes. Excluded on the basis that study results cannot be presumed to be reflective of GPs experiences to BPSD as not the only reason a nursing home resident could be on an antipsychotic.
14.	Stewart TV, Loskutova N, Galliher JM, Warshaw GA, Coombs LJ, Staton EW, et al. Practice patterns, beliefs, and perceived barriers to care regarding dementia: A report from the American Academy of Family Physicians (AAFP) National Research Network. Journal of the American Board of Family Medicine. 2014;27(2):275-83.	BPSD mentioned as being the most challenging aspect of dementia care but no reflection on GPs knowledge of, attitude towards or experiences of BPSD.
15.	Shaw C, McCormack B, Hughes CM. Prescribing of Psychoactive Drugs for Older People in Nursing Homes: An Analysis of Treatment Culture. Drugs - real world outcomes. 2016;3:121-30.	Not dementia specific, focus is on prescribing of psychoactive drugs which does not necessarily equate to BPSD. Only 1 quote from GP in the paper. Went to third reviewer for arbitration. Decision to exclude on basis that does not explicitly related to BPSD.
16.	Tang EYH, Birdi R, Robinson L. Attitudes to diagnosis and management in dementia care: Views of future general practitioners. International Psychogeriatrics. 2016.	BPSD mentioned as being one of the most challenging aspect of dementia care but no exploration of GP registrars' knowledge of and attitudes towards BPSD.

17.	Tinsley JA, Shadid GE, Li H, Offord KP, Agerter DC. A survey of family physicians and psychiatrists. Psychotropic prescribing practices and educational needs. General Hospital Psychiatry.20(6):360-7.	Does not describe the knowledge, attitudes or experiences of GPs in relation to BPSD
18.	Turner S, Iliffe S, Downs M, Wilcock J, Bryans M, Levin E. General practitioners' knowledge, confidence and attitudes in the diagnosis and management of dementia. Age and ageing. 2004;33.	Examines some of the barriers to good practice. Ranks BPSD as the most difficult aspect of dementia care. However, no specific attitudinal question related to BPSD. Only 1 knowledge question related to depression. Initial conflict between reviewers but through discussion agreed to exclude on the basis that no significant data related to knowledge and attitude towards BPSD.
19.	van Hout HP, Vernooij-Dassen MJ, Stalman WA. Diagnosing dementia with confidence by GPs. Fam Pract. 2007;24(6):616-21.	Focus on diagnosis of dementia not BPSD.
20.	Veneziani F, Panza F, Solfrizzi V, Capozzo R, Barulli MR, Leo A, et al. Examination of level of knowledge in Italian general practitioners attending an education session on diagnosis and management of the early stage of Alzheimer's disease: Pass or fail? International Psychogeriatrics. 2016;28(7):1111-24.	Focus on impact of an educational intervention on knowledge and attitudes to dementia but limited primarily to issues around diagnosis, no exploration of knowledge or attitudes towards BPSD
21.	Werner P, Gafni A, Kitai E. Examining physician-patient-caregiver encounters: the case of Alzheimer's disease patients and family physicians in Israel. Aging & mental health.8(6):498-504.	Looks at how the presence of agitation affected how the GP communicated the diagnosis of dementia and other dementia related information. Went to third reviewer for arbitration decision to exclude on the basis that it does not describe the knowledge, attitudes or experiences of GPs in relation to BPSD.

22.	Wijeratne C, Harris P. Late life depression and dementia: A mental health literacy survey of Australian general practitioners. International Psychogeriatrics. 2009;21(2):330-7.	Focus of survey was on diagnosis not BPSD.
23.	Alexander C, Fraser J. General practitioners' management of patients with mental health conditions: The views of general practitioners working in rural north-western New South Wales. Australian Journal of Rural Health. 2008;16(6):363-9.	Small survey of ~38 GPs looking at their attitudes and confidence to mental health conditions in general but does not specifically explore their attitudes or confidences with BPSD.
24.	Azermai M, Kane J, Liperoti R, Tsolaki M, Landi F, Passmore AP, et al. Management of behavioural and psychological symptoms of dementia: Belgium, Greece, Italy, United Kingdom. European Geriatric Medicine. 2013;4(1):50-8.	Not an original research study. Examines how the same patient with dementia would be managed in different European countries.
25.	Boustani M, Sachs G, Callahan CM. Can primary care meet the biopsychosocial needs of older adults with dementia? Journal of general internal medicine. 2007;22(11):1625-7.	A review article.
26.	Bridges-Webb C, Giles B, Speechly C, Zurynski Y, Hiramanek N. Patients with dementia and their carers in general practice. Australian family physician. 2006;35(11):923-4.	Does not describe the knowledge, attitudes or experiences of GPs in relation to BPSD
27.	Cantegreil-Kallen I, Turbelin C, Olaya E, Blanchon T, Moulin F, Rigaud AS, et al. Disclosure of diagnosis of Alzheimer's disease in French general practice. American journal of Alzheimer's disease and other dementias. 2005;20(4):228-32.	Focus on diagnosis disclosure not on BPSD.
28.	Chang E, Daly J, Johnson A, Harrison K, Easterbrook S, Bidewell J, et al. Challenges for professional care of advanced dementia.	Views of GPs are not represented separately

	International journal of nursing practice. 2009;15(1):41-7.	
29.	Davies N, Mathew R, Wilcock J, Manthorpe J, Sampson EL, Lamahewa K, et al. A co-design process developing heuristics for practitioners providing end of life care for people with dementia. BMC palliative care. 2016;15(1):68.	Describes a co-design process of designing an intervention for end of life care in dementia but does not explore GP's perspective on BPSD.
30.	Donyai P, Ibrahim K, Almutairi S. Stopping medication and decision-making biases. Pharmacoepidemiology and drug safety. 2013;22(6):673-4.	Conference abstract.
31.	Gonzalez-Moneo MJ, Simó M, Pie M, Rivero D. Preferences of general practitioners and carers of Alzheimer patients regarding the use of neuroleptics for behavioural disorders in Alzheimer's disease. International journal of geriatric psychiatry. 2008;23(10):1095-7.	Does not describe the knowledge, attitudes or experiences of GPs in relation to BPSD. Unclear if GPs were even involved. "Physicians" interviewed but no breakdown of background of these physicians.
32.	Gove D, Downs M, Vernooij-Dassen M, Small N. Stigma and GPs' perceptions of dementia. Aging & mental health. 2016;20(4):391-400.	Focus on stigma and factors that influence diagnosis, not BPSD.
33.	Harris DP, Chodosh J, Vassar SD, Vickrey BG, Shapiro MF. Primary care providers' views of challenges and rewards of dementia care relative to other conditions. Journal of the American Geriatrics Society. 2009;57(12):2209-16.	Reports the GP's perspective on another aspect of dementia with no reference to BPSD
34.	Iliffe S, Wilcock J, Haworth D. Obstacles to shared care for patients with dementia: a qualitative study. Fam Pract. 2006;23(3):353-62.	Focus on shared care and issues around diagnosis not BPSD
35.	Kor Pui-Kin P, Lai Kam-Yuk C, Liu Yat-Wa J, Dai Lok-Kwan D, Ting Shuk-Man S, Choi K. A	Does not describe the knowledge, attitudes or

	survey of physician practices in managing people with dementia in Hong Kong. European Journal of Psychiatry. 2015;29(3):183-98.	experiences of GPs in relation to BPSD only discussed in relation to being a reason for referral.
36.	Krolak-Salmon P, Roubaud C, Finne-Soveri H, Riolacci-Dhoyen N, Richard G, Rouch I, et al. Evaluation of a mobile team dedicated to behavioural disorders as recommended by the Alzheimer Cooperative Valuation in Europe joint action: Observational cohort study. European Journal of Neurology. 2016;23(5):979-88.	Does not describe the knowledge, attitudes or experiences of GPs in relation to BPSD.
37.	Manu E, Marks A, Berkman CS, Mullan P, Montagnini M, Vitale CA. Self-perceived competence among medical residents in skills needed to care for patients with advanced dementia versus metastatic cancer. Journal of Cancer Education. 2012;27(3):515-20.	Survey of medical residents, a small number of whom were family medicine residents. However, the number of family medicine residents surveyed was not clear and the views of family medicine residents was not analysed separately.
38.	Midlov P, Bondesson A, Eriksson T, Nerbrand C, Hoglund P. Effects of educational outreach visits on prescribing of benzodiazepines and antipsychotic drugs to elderly patients in primary health care in southern Sweden. Fam Pract. 2006;23(1):60-4.	Does not describe the knowledge, attitudes or experiences of GPs in relation to BPSD
39.	Murphy K, O'Connor DA, Browning CJ, French SD, Michie S, Francis JJ, et al. Understanding diagnosis and management of dementia and guideline implementation in general practice: a qualitative study using the theoretical domains framework. Implement Sci. 2014;9:31.	Focus on dementia diagnosis and identification of co-morbid depression. Note did identify study from references (Teele_2004)
40.	Ólafsdóttir M, Foldevi M, Marcusson J. Dementia in primary care: Why the low	Focus on diagnosis not BPSD.

	detection rate? Scandinavian journal of primary health care. 2001;19(3):194-8	
41.	Downs M, Cook A, Rae C, Collins KE. Caring for patients with dementia: The GP perspective. Aging & mental health. 2000;4(4):301-4.	Does not describe the knowledge, attitudes or experiences of GPs in relation to BPSD.
42.	Gurka P, Bacher R, Kemmler G, Hinterhuber H, Lingg A, Marksteiner J. Pharmacological treatment strategies of residential primary care providers in dementia diseases--results of a representative survey in western Austria. Pharmacopsychiatry.35(4):144-9.	Does not describe the knowledge, attitudes or experiences of GPs in relation to BPSD
43.	Shah S, Harris M. A survey of general practitioner's confidence in their management of elderly patients. Australian family physician.26 Suppl 1:S12-7.	This survey does not focus specifically on dementia or BPSD but looks more generally at GPs confidence in managing an older adult.
44.	Stoppe G, Sandholzer H, Staedt J, Winter S. Sleep disturbances in the demented elderly: Treatment in ambulatory care. Sleep: Journal of Sleep Research & Sleep Medicine. 1995;18(10):844-8.	This survey is quite old. It looks at GPs responses to a vignette of a patient with dementia who has sleep disturbance. The focus of the survey is on the medication chosen to treat the sleep disturbance. The decision made to exclude as it is specifically focused only on sleep disturbance.
45.	Stoppe G, Sandholzer H, Winter S, Kiefer J, Staedt J. Treatment of the memory-disturbed elderly in primary care. Primary Care Psychiatry. 1998;4(4):205-9.	Focus is not on BPSD.
46.	Wilcock J, Iliffe S, Turner S, Bryans M, O'Carroll R, Keady J, et al. Concordance with clinical practice guidelines for dementia in general practice. Aging & mental health.13(2):155-61.	Focus is on GP's adherence to guidelines regarding diagnosis. BPSD mentioned but only whether symptoms enquired about. Does not explore GPs knowledge, attitudes or experiences re BPSD.
47.	Wilcock J, Jain P, Griffin M, Thuné-Boyle I, Lefford F, Rapp D, et al. Diagnosis and management of dementia in family	Only assesses if BPSD was recorded/ asked about/ documented in charts. Does not

	practice. Aging & mental health. 2016;20(4):362-9.	assess K&A or experiences of GPs managing BPSD.
48.	Zwijsen SA, Gerritsen DL, Eefsting JA, Smalbrugge M, Hertogh CMPM, Pot AM. Coming to grips with challenging behaviour: A cluster randomised controlled trial on the effects of a new care programme for challenging behaviour on burnout, job satisfaction and job demands of care staff on dementia special care units. International journal of nursing studies. 2015;52(1):68-74.	No GPs involved- questionnaire to care staff.
49.	Peri K, Kerse N, Moyes S, Scahill S, Chen C, Hong JB, et al. Is psychotropic medication use related to organisational and treatment culture in residential care. Journal of Health Organization & Management. 2015;29(7):1065-79.	Survey questionnaire. Focus is on antipsychotic prescribing and NH treatment culture not on GPs knowledge, attitudes or experiences with BPSD.
50.	Martin RM, Rink E, Wilkinson DG, Mann RD. Did knowledge, opinions, background, and health authority advice influence early prescribing of the novel Alzheimer's disease drug donepezil in general practice? - National postal survey. Pharmacoepidemiology and drug safety. 1999;8(6):413-22.	Reports the GP's perspective on prescribing of Donepezil with no reference to BPSD.
51.	Riancho J, Jiménez-López Y, Sánchez- de la Torre JR, Pardina-Vilella L, Sánchez-Juan P. How much do Spanish clinicians know about dementia? Journal of the Neurological Sciences. 2017;372:468-70	Letter to the Editor. Quant survey. Not focused on BPSD

A further 14 records were excluded from the Full-Text screen without being read in full for the following reasons:

1. Records where no English version was available were excluded from FT reading (n=10).
2. Where only a conference abstract was available the original authors were contacted where possible to see if a full-text version was available. Where no full text was available these records were excluded from FT reading (n=4)

Supplementary Material 4. Development of 3rd order interpretations and line of argument synthesis

Acronyms; PCPs = primary care physicians

Author (year)	**Unmet Primary Care Needs**			**Justification of antipsychotics**				**Pivotal Role of Family**
Sub-themes	Time-intensive	Knowledge & self-efficacy	Care Pathways	To facilitate coping (in PwD, their carers & in NHs)	Barriers to implementation of non-pharm strategies	Traditional prescribing "comfort zone"	Influence of family	Community based supports for the family
Colenda (1995)						The decision to "act" generated less anticipated regret than the decision not to "act" (pg74)		
Colenda (1996 – International Journal of Geriatric Psychiatry)l		PCPs did not endorse referring the patient to an expert in behavioural management. This finding may be				Physician respondents tend to be wedded to a traditional medical model of care when managing		PCPs surveyed had a low likelihood of referring the spouse of the person with dementia to a dementia

		secondary to the fact that they do not know much about the success of behavioural management techniques for these patients. (pg642)				these patients (pg. 641)		support group. (pg. 638)
Colenda (1996- Journal of the American Geriatrics Society)	PCPs also stated that both the time contacted and repeated calls received from caregivers influenced their decision-making when treating agitated patients; these two components were given the title “hassle factor”. (pg1377)				It is easy to understand how this factor could compel physicians to overuse medications for these patients, especially for urgent phone calls that occur in the middle of the night, when agitation offer occurs. (pg1378)	Majority of PCPs chose medication as the primary intervention, only a minority considered psycho-social /behavioural interventions. (pg 1377) An underlying treatment heuristic exists for these patients; if they are agitated give medications. (pg1378)	…repeated calls received from caregivers influenced their [GPs] decision-making … (pg1377)	

Author (year)	Unmet Primary Care Needs			Justification of antipsychotics				Pivotal Role of Family
Sub-themes	Time-intensive	Knowledge & self-efficacy	Care Pathways	To facilitate coping (in PwD, their carers & in NHs)	Barriers to implementation of non-pharm strategies	Traditional prescribing "comfort zone"	Influence of family	Community based supports for the family
Teel (2004)	*"I'm certified in geriatrics, but I don't have time to concentrate on particular things"* (pg427) *'I spend as much time asking how the caregiver's doing as I do the patient'.* (pg426)	Patient aggression, anger and violence were cited as distressing and often difficult to manage. (pg426)	Several PCPs pointed out the difficulties encountered in trying to access or coordinate consultation, either because of the infrequent visits by consultants to the PCP's rural area, the extreme distances patients had to travel to the specialist's office, or the considerable delays in getting appointments				*'some people whose spouses take care of them may be at home for 10 years before they finally become such a problem—or the caregiver's health declines—that they need the nursing home'*. Families contributed to making treatment processes either more difficult or more straightforward (pg425)	*'we don't have much in the way of support groups ... we are in a no man's land'.* *'it's on-the-job training'* (when discussing how families learned about caregiving.) *'number one is family education ... try to teach them what this is, how things are going to change'* (pg426)

			"We don't have anyone here that we can consult with...there's a weekly outreach clinic, but it can take several months to get in to see them." (Pg 424) Participants were frustrated by the limited access to consultative support in their rural communities. (pg428)				"*resistant children who live elsewhere and who promised they'd never put mom in a nursing home, but they don't want to take her …* (pg426) … wants the PCP to 'fix' everything right away, yet is unable to provide any assistance in the process. (pg426) "*they want him bright during the day and telling old stories, and not hurting anyone."* (pg426)	Most PCPs in the current study also identified the need to provide education and support to family caregivers, and all expressed frustration with the limited supportive resources available (pg428) The limited availability of community resources… contributed to difficulties in caring for patients with dementia and their families. (pg428)

Author (year)	Unmet Primary Care Needs			Justification of antipsychotics				Pivotal Role of Family
Sub-themes	Time-intensive	Knowledge & self-efficacy	Care Pathways	To facilitate coping (in PwD, their carers & in NHs)	Barriers to implementation of non-pharm strategies	Traditional prescribing "comfort zone"	Influence of family	Community based supports for the family
Hinton (2007)	*"it's a lot more complicated than the intact 50-year-old hypertensive diabetic but the reimbursement is the same.* (pg1489) Clinicians are pressured to practice in a "time-efficient" fashion ... Dementia created heavier paperwork demands (pg1489) *"we often don't talk*	*"I do rely on psychiatry because I admit that I am not the most knowledgeable person about people with agitation and behavioral problems at home. I'm good at prescribing a little Risperdal but I get a little nervous about anti-psychotic meds and I tend to send those people to psychiatry"* (pg. 1490)	*We have good neurologists, but they are generally scheduled far in advance so it takes a least a month, two months to get an appointment unless the patient's hospitalized. Psychiatrists are more of a problem. There aren't enough of them.* (pg. 1490) *"It's hard, bottom line is it's hard. The feedback is*			Clinicians may rely more on medications if they are less familiar with psychosocial approaches or perceive these as potentially more time consuming. This has important public health implications because recent data question the efficacy and safety of psychotropic medications for older adults with	*It [behavioral problem] isn't something that I have to deal with clinically. Usually, the family deals with it [behavioral problems].* (pg1489) Family members were perceived as having very real and sometimes intense "social and psychological" needs *Most of the time when they come in to see me there may*	*Since I'm not a licensed clinical social worker and I don't know what's available in the community, and I don't know how to, nor do I have time to call up and make arrangements for meals on wheels, or call up and find out what they need for a choreworker, or call up and find out how to access daycare. All I can do is say,*

	adequately with the family in the 15 minutes." As a result of having insufficient time to discuss psychosocial issues and behavioral disturbances, these problems may be neglected until they become severe, leading to what 1 physician characterized as "reactive care." (pg1489) *I think we're all drowning, I do. It's, you know, we are all truly trying to keep our heads above*	*Usually I rely on the psychiatrist because you just get to the point there where, I don't know how to deal with all the hallucinations, the screaming and those kinds of problems. I want a second opinion too in making sure my diagnosis is correct.* (pg. 1490)	*slow [from specialists]...So you don't get anything and then the patient comes back and they are usually, they don't have any idea, and then they're kind of frustrated too.* (pg. 1490) *I just feel, I don't have the network we need, so, because for the dementia care it's a team care, dietician, social work, psychiatry, psychologist, and pharmacist...I feel I don't have this. I don't think anybody has this luxury, but*			dementia, making non-pharmacological approaches more attractive from a risk/benefit perspective. (pg 1491)	*be some specific concerns like, you know, they're [patient] wetting the bed all the time, or they're [patient] wandering, or you know, whatever* (pg1489) Particularly when there were multiple caregivers with competing agendas, conflicts (pg1489)	*you know, these things exist and here's some ways to contact them, there's a green booklet that the County put out a couple of years ago.* (pg. 1490) *I mean, there are books that tell you who, but there's so many listings in those books it's hard to work your way through those to figure out, okay, for this person in this circumstance who are the two or three people that I need to get involved, and it's confusing about who to*

	water...These people [persons with dementia] do take a lot of time and energy and when you're doing all the other stuff that we're doing with all the other patients that, to be honest, sometimes it's like, you know, you just don't want these people in your practice cause a 15-minute visit turns into much more than that. (pg1489) Lack of time and failure to systematically assess behavioral problems may		*the gist of care should be that.* (pg. 1490) *One needs access to a social worker, the nurses who are properly trained in geriatric issues.* (pg. 1490) As a consequence of the problematic access to specialists, physicians often felt they had little choice but to try and manage care as best they could despite a perceived lack of time and training. Some physicians expressed					*see when, and who does what when.* (pg. 1490)

	delay their detection and management until a time of "crisis." (Pg. 1491) *Those people get pushed out of those practices because they cause chaos, and so they get referred or something happens*. (Pg. 1491) *the majority of the visit is hand-holding and listening, that sort of thing. It takes a long time.* (pg1489)		frustration and even some degree of demoralization about being placed in a situation in which they felt compelled to provide care that they felt was beyond their realm of expertise. ((pg. 1490)					

Author (year)	Unmet Primary Care Needs			Justification of antipsychotics				Pivotal Role of Family
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Buhagiar (2011)		Respondents appeared equally self-critical of both their diagnostic and management skills with respect to BPSD. Many of them expressed reservations in their skills to differentiate BPSD from non-dementia behavioural changes. (pg 231) Rather than lack of knowledge, it is the GPs'	The majority of GPs found consulting with specialist services to be difficult. (pg 230) A substantial number of GPs appear to encounter major difficulty in accessing secondary care services whenever they need support with the management of BPSD. (pg 231) GPs may feel they are left to deal		No GP reported finding the implementation of non-pharmacological strategies to be easy. (pg. 230) They may be forced to resort to medications given their better likelihood of immediate gratification compared with a non-pharmacological approach. (pg. 232)	Although nearly all GPs felt that non-pharmacological interventions are important and that non-pharmacological interventions should start before medications no GP reported a preference for non-pharmacological interventions over medicatons (pg. 230)	Pressure from caregivers may force GPs to reluctantly prescribe medications in order to alleviate tensions. (pg 232)	

		level of confidence that needs to be bolstered. (pg231) nearly all GPs reported that they were inclined to institute time-limited prescriptions. (pg. 232) yet they have a very high level of potential, as evidenced by their knowledge base. (pg. 232)	with the crisis on their own without the back-up they would require from specialist services. (pg 232)			all of our respondents reported a preference for the use of pharmacological interventions. (pg. 231) GPs may also have a preference to use medications – tools they are highly more familiar with, compared with the more alien non-pharmacological methods. (pg. 231)		
Azermai (2013)		The message that antipsychotics should and can be discontinued without detrimental behavioral		GPs consider antipsychotic discontinuation to induce more suffering for the nursing home resident and adversely affect the	Shared willingness [to discontinue antipsychotics] was even lower, only 4.2%. The percentages of overlap			

		effects has not yet reached the floor. (pg. 352)		resident's quality of life…important to focus on quality rather than on quantity of life. (pg. 351) Recurrence of behavioral problems after antipsychotic discontinuation was a major concern, as well as hindrance to others and risk of harm to the resident. (pg. 349)	between nurses and GPs were generally low, indicating that nurses and GPs evaluate the same resident differently. (pg. 349)			
Mavrodaris (2013)		*''We have found that after admission when other problems have been resolved, e.g. nutritional,*	GPs alluded to uncertainty of roles and the expectation that primary responsibility should be maintained by	An increased risk of cardiovascular disease was not considered a strong stimulus to discontinue	*''Often it is pressure from nursing homes or carers for medication to calm a patient down that is trigger for*			

		medical that antipsychotic prescriptions can be reviewed and changes made.'' (pg. 36)	secondary care. *''Hopefully elderly mental health is as they are initiating".* (pg 36) . Improved communication and collaboration between psychiatrists, GPs and care home staff at each level of care is fundamental (pg. 37) GPs expressed concern at stopping drugs on their own with the expectation of either guidance or regulation of medication from	antipsychotics as quality of life issues prevailed in addition to, and again, dependence on specialist advice. (pg. 35)	*prescribing"* (pg36) A culture of blaming was expressed in this study. GP's reported pressure from care home staff to maintain a patient on antipsychotics, whereas care home staff reported GP's insisting on maintaining use of antipsychotic therapy. (pg. 37) Many GP participants also expressed concern at the lack of practical non-pharmacological options and indicated that			

			secondary care (consultant psychiatrists or geriatric psychiatrists). (pg. 35) Both GPs and care home participants expressed confusion regarding their roles in the management of patients with BPSD. (pg 38)		current guidelines were not clear or clinically useful. (pg 35) A lack of clarity regarding available and suitable pharmacological and non-pharmacological management options. (pg. 37)			
Donyai (2016)		The interviewees neglected to present other options in their argument, such as a trial reduction of the dose of an antipsychotic, or nonpharmacological		*They* [PwD on AP] are *quieter, more subdued, less distressed. The man that I saw last week … he was weeping for his wife who has been dead for many years, and they put him on quetiapine.*		"*I'm not very familiar with the guidelines. I think, but what I know of them, I think we have to be careful not to go to the other extreme where we just say we're not*		

		approaches for addressing symptoms. (pg 4) *" I think doctors are less afraid of using antipsychotics which wasn't the case before so I would do a prescription for risperidone if I get told, right, increase the dose or can we titrate the dose? Right, fine. I'll call the patient in every month, gradually increase the dose without worrying."* (pg. 4)		*And I mean he gets tearful if you talk about his wife now, but the uncontrollable weeping had stopped.* (pg. 5) The arguments were formulated to illustrate the negative consequences of alternative choices (e.g. reducing the dose or not prescribing) on carers and patients, for example in terms of coping and stress (pg. 5)		*prescribing them."* (pg. 4) *They* [antipsychotics] *should always be justified but I think it's still used as the easy option. Because it's something as doctors, we do, we just prescribe a medicine.* (pg 4)		

Author (year)	Unmet Primary Care Needs			Justification of antipsychotics			Pivotal Role of Family	
Sub-themes	Time-intensive	Knowledge & self-efficacy	Care Pathways	To facilitate coping (in PwD, their carers & in NHs)	Barriers to implementation of non-pharm strategies	Traditional prescribing "comfort zone"	Influence of family	Community based supports for the family
Foley (2017)		*'Some of the behavioural symptoms can be very difficult to deal with…* (pg. 7) GPs expressed a need for education around the prescribing of psychotropics. *'When do you add in psychotropic medication, what type, what dosages, for how long? We need guidelines on that'* (Pg. 7)	Despite recognizing the importance of a multidisciplinary approach, many GPs were unsure of where these services were or of how to access services. *I would probably struggle a bit in identifying the wider team'* (pg. 5)				*'One of the big learnings I've had is the carer support and how important carer support is in the management of the patient'* (pg. 6)	GPs emphasized the need for respite & home-help *'I think you live on this lifeline of getting this respite and that helps you to cope as a carer'* (pg. 5) *'I know that there is some support available … we have a very vague idea of that … but I myself wouldn't be able to provide specifics of it'* (pg. 6)

Cousins (2017)		The vast majority expressed a desire to reduce psychotropic medication in completely settled or stabilized patients. When asked if they routinely recommend non-pharmacological interventions before considering medication, the majority agreed or strongly agreed. (pg1576) Many respondents agreed that they require more training		Many GPs were concerned that withdrawing medication would impact negatively on the quality of life, leading to a return of challenging behaviors and disturbing psychological symptoms. However, around the same number of GPs were not concerned about this (pg4) … over-estimated the benefit in symptom relief of second-generation antipsychotics …with the	Experienced GPs were significantly less likely to rate pressure to prescribe from staff as a barrier to non-pharmacological techniques, than GP practising <5 years. Staffing and resources was highlighted as the number 1 barrier to non-pharmacological methods being utilized in BPSD. (pg4) Additional barriers identified to recommending non-pharm strategies were lack of nursing home staff skill, pressure to		Pressure to prescribe from relatives was not considered as significant a barrier. (Fig 1 pg.1575).	

		to improve how they manage BPSD, however, some disagreed. (pg1576		majority of GPs expecting benefit in half of all patients. (pg. 1577)	prescribe, lack of efficacy of non-pharm techniques. (Fig 1 pg.1575).			
3rd Order Interpretations	• Managing BPSD was complex, resource intensive and sometimes unrewarding for the GP. • GPs lacked confidence when managing BPSD and wanted input from either secondary care or relevant members of the primary care team. However, the lack of clearly defined care pathways meant that GPs experienced difficulty accessing advice.			• GPs were more comfortable prescribing medication than advising on non-pharmacological management strategies. • GPs found that antipsychotics enabled the patient with dementia, the family caregiver, the nursing home staff and the GPs themselves to cope with BPSD. • GPs had a tendency to over-estimate the benefits of antipsychotic prescribing. Consequently, in the context of the challenges of implementing non-pharmacological alternatives, the risks associated with antipsychotics were tolerated.		• The family of the person with dementia plays a crucial role in the management of BPSD. However, the needs of the carer could be intensive and challenging for the GP, particularly in the context of limited community supports for family caregivers.		

Line of argument synthesis:	**GPs experience difficulties accessing supports for family caregivers and for themselves when managing BPSD. Under-resourcing, poorly defined roles and a lack of integrated care pathways may contribute to GPs' feelings of isolation and low self-efficacy when managing BPSD. Low self-efficacy is further exacerbated by the lack of practical, implementable treatment strategies which can lead to an over-reliance on both family care-givers and psychotropic medications to fill the therapeutic void created. It appears that these conditions can culminate in a reactive response to the care of people with BPSD where behaviours and symptoms escalate until an inevitable crisis point is reached.**

Supplementary Material 5. Quality assessment tool for descriptive cross-sectional studies

Reviewer Initials _____

Study Name _____

Author _____

Year _____

		Yes	No	Unclear	Not applicable
1.	Was the research question or objective in this paper clearly stated?	☐	☐	☐	☐
2.	Was the study population clearly specified and defined?	☐	☐	☐	☐
3.	Was the sample likely to be representative of the study population?	☐	☐	☐	☐
4.	Was the target population involved in the instrument development?	☐	☐	☐	☐
5.	Was the questionnaire piloted?	☐	☐	☐	☐
6.	Was a response rate mentioned within the study?	☐	☐	☐	☐
7.	Was a sample size justification, power description, or variance and effect estimates provided?	☐	☐	☐	☐

Any other comments: _____

Supplementary Material 6. ENTREQ Statement

Item	Guide and Description
1.Aim	To develop a synthesis of qualitative and quantitative studies on GPs' knowledge, attitudes and experiences of managing BPSD in order to develop a conceptual understanding of the perspective of GPs on the management of BPSD. The results will be used to inform the development of a behavioural change intervention.
2. Synthesis methodology	Meta-ethnography as described by Noblit & Hare will be used to synthesis the results of this mixed method review
3. Approach to searching	Pre-planned comprehensive search to seek all available studies
4. Inclusion criteria	Phenomenon of interest: The knowledge, attitude or experiences of GPs towards the management of BPSD in community and/or nursing home setting. Population: General Practitioners Language: English language only Year Limits: None Types of studies: Primary studies using qualitative or quantitative research methods Article must be published in full in a peer-reviewed journal
5. Data sources	Electronic databases searched: MEDLINE (Ovid), EMBASE (Elsevier), CINAHL, PsychINFO, Academic Search Complete, SocIndex, Social Science Full Text Initial search was in June 2017 Search was last updated on 25th of October 2017
6. Electronic search strategy	Literature search terms are described in Appendix 1 Supplementary Material 2
7. Study screening methods	At the first stage of study screening duplicates and clearly irrelevant studies (for example pre-clinical studies) were removed by AJ. Abstracts were then screened by teams of two independent reviewers - AJ with either TF, AC or CB. All eligible studies included in full-text screening were also screened by AJ and a second independent reviewer (TF/AC/CB). Any conflicts regarding the eligibility of a study were resolved through discussion between the paired teams. Where consensus was not reached through discussion a third reviewer adjudicated.

8. Study characteristics	Details of the study characteristics are provided in Table 6
9. Study selection results	Figure 9 outlines the study selection process in a PRISMA flow diagram. Supplementary Material 3 and 7 provides details on the excluded studies and the reasons for exclusion.
10. Rational for appraisal	The rational for quality appraisal was to assess the quality of study conduct.
11. Appraisal items	Joanna Briggs Institute Critical Appraisal Checklist for Qualitative Research was used to assess the qualitative studies Since there is no agreed quality assessment tool for assessing the quality of descriptive cross-sectional studies a new original tool was developed by two of the reviewers (AJ, JB) that was based on other original tools developed for a similar purpose. Available in supplementary file 3.
12. Appraisal process	All included papers were independently assessed by two reviewers. AJ & JB independently assessed 10 out of the 11 included studies. As AJ was a co-author on one of the included studies CB & JB independently assessed the quality of that study.
13. Appraisal results	Study quality assessments are available in the supplementary file 6. Studies were not excluded on the basis of quality as we believe that all studies may contribute to some valuable insights to our research question. Additionally, two independent reviewers (AJ, KW) applied the CERQual tool to the review findings. This tool helped to identify potential weaknesses in the included study and was used to evaluate our confidence in our review findings.
14. Data Extraction	All text from the result, discussion and conclusion sections of the included studies were extracted verbatim and imported into a software package for analysis. The following study characteristics were extracted; author, year of publication, country of conduct, study objectives main findings, study design & methods of analysis, participants and setting. These characteristics are displayed in Table 6.
15. Software	NVivo 11
16. Number of reviewers	Four reviewers (AJ, KW, CB, TF) were involved in reading all included studies in detail and constructing the initial key concepts. All six reviewers were involved in the translation and synthesis steps.
17. Coding	Comprehensive, line-by-line, open-coding to search for concepts
18. Study Comparison	To examine the contribution of each study to a key concept the review team compared the themes and concepts from paper 1 with paper 2 and

	the synthesis of these two papers with paper 3 and so on. This process was conducted in chronological order starting with the earliest study. Within the key concepts attention was paid to deviant cases. Two authors (AJ, KW) performed reciprocal and refutational analyses to summarise shared themes across the studies. To facilitate this step a table was developed to display the identified concepts and themes across all the studies (available in supplementary material 4). Relationships between the conceptual groups and themes were organised and illustrated by the use of conceptual maps which were shared with the wider review team.
19. Derivation of themes	The approach taken to developing the key concepts, themes and sub-themes was inductive and iterative.
20. Quotations	Direct quotes from the primary studies are presented in italics and indented in the results section of this manuscript. The interpretations of the authors of these primary studies are also presented in the result section of this manuscript indented but not in italics. These quotes are also presented in more detail in supplementary material 4.
21. Synthesis output	The synthesis team (all authors) linked the third-order interpretations into a 'line of argument' which represents the overarching perspective of GPs towards BPSD.

Supplementary Material 7. Reasons for the exclusion of records at the abstract screening stages

AJ conducted a preliminary screen of titles and abstracts to exclude any studies that were clearly irrelevant. 435 studies were excluded at this point. Reasons for exclusion are listed below.

Reasons for exclusion from stage 1 title and abstract screening (n= 435)

- Study is a book review, book chapter, thesis or dissertation, editorial / opinion piece or conference abstract (n= 75)
- Not on dementia (n= 261)
    - The studies that were excluded were on heart failure, COPD, epilepsy, childhood behavioural disorders. Where there was any potential link to dementia, however tenuous, the study was included.
- Focus was exclusively on cognitive screening tools (n=32)
- Not in primary care setting/ does not involve general practitioners (n= 67)
    - These studies were also not relevant to BPSD. Any studies that were potential relevant to the management of BPSD were included at this initial screen, even if they didn't involve GPs.

1,203 studies were included the second stage of the title and abstract screening. At these stage all titles and abstracts were independently screened against inclusion criteria by at least two reviewers (AJ, AC, TF, CB). 1,123 studies were excluded in this title and abstract stage.

Reasons for exclusion from stage 2 title and abstract screening (n = 1,123)

- Not on dementia (n = 313)
- Study is a case study, book review, book chapter, thesis, editorial, opinion piece, conference abstract, letter or protocol with no data (n=294)
- Does not include GPs (n = 263)
- On dementia prevention/screening/ diagnosis not management (n = 105)
- Not a primary care setting (n = 75)
- Not knowledge or attitude based (n = 48)
- Duplicate (n = 25)

Supplementary Material 8. Quality Appraisal of all Included Studies

Table 1 Quality Appraisal of Included Qualitative Studies

Author (year)	Clear methodological approach (q1)	Qualitative appropriate (q2)	Data collection method (q3)	Result interpretation (q4)	Data analysis (q5)	Clarification of the researcher's stance (q6)	Reflexivity (q7)	Participants represented (q8)	Ethics (q9)	Discussion (q10)	Overall
Teel (2004)	✓	✓	✓	✓	✓	×	×	✓	✓	✓	High
Hinton (2007)	✓	✓	✓	✓	✓	×	×	✓	×	✓	Moderate - High
Donyai (2016)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	High
Foley (2017)	✓	✓	✓	✓	✓	×	✓	✓	✓	✓	High

Table 2 Quality Appraisal of Descriptive Cross-Sectional Studies

Author (year)	Clear aim	Defined study population	Representative sample	Target population involved in instrument development	Piloted	Response rate recorded	Sample size calculations	Overall
Colenda (1995)	✓	✓	×	×	×	✓	×	Low
Colenda (1996, Journal of American Geriatrics Society)	✓	✓	×	×	×	✓	×	Low
Colenda (1996)	✓	✓	×	×	×	✓	×	Low
Buhagiar (2011)	✓	✓	?	×	✓	✓	×	Moderate
Azermai (2014)	✓	✓	?	✓	?	✓	×	Moderate
Mavrodaris (2013)	✓	✓	✓	✓	✓	✓	×	High
Cousins (2017)	✓	✓	✓	?	✓	✓	×	Moderate - high

Supplementary Material 9.
CERQual Assessment of Confidence in Review Findings

Review findings/ 3rd order interpretation	Relevant papers	Methodological Limitations	Relevance	Coherence	Adequacy	Overall CERQual assessment	Explanation of CERQual assessment
Unmet Primary Care Needs							
1. Managing BPSD was complex, resource intensive and sometimes unrewarding for the GP.	243,284	**Minor concerns** One of the studies was judged to be of high quality. The other was of moderate quality, mainly due to concerns regarding reflexivity.	**Minor concerns** Studies were highly applicable to the context specified in our review question. Although focus on community based care highly relevant, here was minor concern regarding the relevance of the setting as both studies were conducted in the US.	**No concerns** Studies were considered to be highly coherent. This finding was well grounded in the data from the primary studies both contextually and conceptually.	**Substantial concerns** Although the data collected to support this review finding was rich in detail there was significant concern about data adequacy. (only two studies)	**Low Confidence**	Substantial concerns regarding adequacy and minor concerns regarding methodological limitations and relevance.

2. GPs lacked confidence when managing BPSD and wanted input from either secondary care or relevant members of the primary care team. However, the lack of clearly defined care pathways meant that GPs experienced difficulty accessing advice.	152,153,243,279,284	**Minor concerns** Three of the studies were judged to be of high quality while the other two studies were of moderate quality. Weakness were mainly poor evidence of reflexivity in the three qualitative studies and sampling concerns in the two quantitative studies.	**No, or very minor concerns** Four of the studies were considered highly relevant. One of the studies was assessed to be moderately relevant due to minor concerns with regards to the population & phenomenon of interest.	**No, or very minor concerns** Data regarding difficulty accessing advice was consistent within and across the studies.	**Minor concerns** Two of the studies offered highly rich data to support this finding. Two of the studies offered moderately rich data. The data in the other study was considered thin.	**High Confidence**	Minor concerns regarding methodological limitations and adequacy.
Justification of Antipsychotics							
1. GPs were more comfortable prescribing medication than advising on non-pharmacological management strategies.	152,153,278,280,281	**Moderate Concerns** Two of the studies here were judged to be of high quality. One study was judged to be of moderate quality. Two of the	**Minor concerns.** Two of the studies were considered to be highly relevant. Two of the studies were conducted >20 yrs ago and	**No, or very minor concerns.** Data were reasonably consistent within and across the five studies that supported this finding.	**Moderate Concerns** This finding was supported by five of the included studies. However, the data generated	**Moderate Confidence**	Moderate concerns regarding the adequacy of the data and methodological limitations. Minor concerns about the relevance of the studies.

		quantitative studies were judged to be of moderate to low quality due to concerns regarding the representativeness of the sample and lack of piloting.	discussed modalities of treatment that are now out-dated, however, this still provided interesting context for the review question. There was minor concerns re the relevance of one of the studies as it included only GPs with a nursing home commitment.		from two of the quantitative studies was considered very thin.		
2. GPs found that antipsychotics enabled the patient with dementia, their carer, the nursing home staff and the GPs themselves to cope with BPSD.	[153,155,278,283]	**Minor concerns** Two of the studies were considered to be of high quality. Two of the studies were considered to be of moderate to high quality.	**Minor concerns** Supporting studies focused explicitly on antipsychotic prescribing in nursing homes. Although this is relevant to our research question there are minor concerns that this may have over-	**No, or very minor concerns** Data regarding the use of antipsychotics to cope with BPSD was reasonably consistent within and across the studies.	**Minor concerns** Two of the studies offered rich data to support this finding. Two of the studies (both quantitative) did not offer the same level of rich data.	**High Confidence**	Minor concerns regarding methodological limitations, relevance and adequacy.

			estimated the relevance of this finding to our overall review question which focuses on both community and nursing home care.				
3. GPs had a tendency to over-estimate the benefits of antipsychotic prescribing. Consequently, in the context of the challenges of implementing non-pharmacological alternatives, the risks associated with antipsychotics were tolerated.	153,155,283	**Minor concerns** The studies ranged from moderate to high quality. Concerns centred on issues related to sampling.	**Minor concerns** Supporting studies focused explicitly on antipsychotic prescribing in nursing homes. Although this is relevant to our research question there are minor concerns that this may have over-estimated the relevance of this finding.	**Minor concerns** Two of the studies were considered to be highly coherent. One of the studies was assessed as being moderately coherent due to some minor contradictory data.	**Substantial concerns** Only three studies support this finding and these studies presented thin data only.	**Low Confidence**	Substantial concerns regarding adequacy and minor concerns regarding methodological limitations, relevance and coherence.

Pivotal role of family							
1. The family of the person with dementia play a crucial role in the management of BPSD. However, the needs of the carer could be intensive and challenging for the GP, particularly in the context of limited community supports for family caregivers.	243,279,284	**Minor concerns** Two of the studies were of high quality and the other study was of moderate-high quality. Methodological concerns were primarily related to reflexivity.	**Minor concerns** One of the studies was considered to be highly relevant to the research question. Two of the studies did not have BPSD as their primary focus; one of these studies was still deemed to be highly relevant, whereas, the other study which focused on GPs educational needs in dementia was considered to be moderately relevant.	**No, or very minor concerns** The studies were considered to be highly coherent. This finding was well grounded in the data of the primary studies both contextually and conceptually.	**Moderate concerns** This finding was supported by rich data in the studies. However, as this finding was represented in only three studies there was moderate concerns regarding the adequacy of the data presented.	**Moderate Confidence**	Minor concerns about methodological limitations, relevance. Moderate concerns regarding data adequacy

APPENDIX 2. Supplementary data for Chapter 6. Qualitative Study

Supplementary Material 10. The topic guide

Script Sheet

1) Introduction

   Firstly I wanted to say thank you for taking the time to meet with me, it is much appreciated.

2) Background Information

   Perhaps it would be helpful for me to give you an overview of the research that will be informed by today's interview and also an overview of the interview itself before we start.

   As part of the wider dementia project we have identified some areas of dementia care that GPs tend to find particularly challenging. The management of behavioural and psychological symptoms of dementia has emerged as a particularly difficult area for GPs (these refer to symptoms such as agitation, anxiety, aggression).

3) Expectations/ Interview Format
   These can often be incredibly challenging clinical situations to manage, either in Primary Care or in Secondary Care. There's no right or wrong answers to these questions. All I want to hear is your own perspective and your own experiences. The results of these interviews will be used to inform the design of an intervention to support GPs managing these patients in Primary Care.

   So with regards to the interview today we will start by discussing how often you encounter dementia in practice. We will chat a little about your experience managing patients with dementia who have challenging behaviours. Hopefully then, we will talk about potential strategies that you feel would better support you managing people with BPSD.

4) Interview ground rules

Topic Guide

Part 1: Introduce the topic of BPSD

Aim: Establish GP's experience of managing BPSD

- Can I ask how long you are in GP Practice?

"There are many ways to describe these behaviours and symptoms that people with dementia experience. Sometimes the acronym BPSD is used to refer to behavioural and psychological symptoms of dementia. Examples of typical behaviours and symptoms that this term covers would include agitation, aggression, wandering, anxiety etc"

- Do you encounter these symptoms much in practice?
    - Have you much experience looking after patients in a nursing home setting?
        - Do you have a regular time allocated to visiting the nursing home or do you attend sporadically as needed? *[introduced in response to the data analysis]*
    - Do you have a community hospital commitment?
    - Do you have many patients with BPSD living at home in the community with family carers?

Part 2: General Challenges and Facilitators of Managing BPSD in the community

Aim: *To explore the possible challenges & facilitators of managing BPSD*

Challenges

- Some GPs find BPSD to be a challenging area to manage. Would this be your experience of BPSD?

  if the GP does not elaborate on the specific challenges of managing BPSD probe further.

    - What aspect(s) of managing BPSD do you find particularly challenging?

If answer doesn't address the following points or if the following points then specifically probe for their attitude towards:

1. <u>Assessing a patient with BPSD</u>

"These patients can be difficult to assess …. "

If not elaborated on probe for how the GP rules out medical, psychological and environmental causes.

- What are the potential causes that you would consider first and how do you go about out-ruling them?
- "These patients can be difficult to assess" Do you feel confident that you can generally out-rule a medical, environmental or psychological cause?
- What would help you with the assessment of these patients?

2. <u>The use of medications in BPSD</u>.

"Some GPs have discussed the difficulty they experience prescribing medications in this patient group."

- How do you feel about prescribing medications in BPSD?

  If not mentioned probe specifically for knowledge of and attitude towards prescribing antipsychotics in BPSD.

  - What are your thoughts on using antipsychotics such as risperidone or quetiapine with these patients?

- What reservations (if any) do you have about prescribing to these patients?

  If not mentioned probe for…

  - Some GPs have mentioned their concern about the sedative nature of a lot of these drugs do you have any thoughts on that? *[introduced in response to the data analysis]*

- How do you decide on which medication to use?
  - Would you feel confident in your choices?
- Do you ever feel under pressure to prescribe?
  - If yes; how do you feel about that?

3. Their attitude towards <u>non-pharmacological management strategies.</u>
   - Do you feel confident advising carers on non-pharmacological management strategies for these behaviours at home?
     - If no… Would you be interesting in training on this?

- Do you see giving this type of advice as part of your role as a GP? *[introduced in response to the data analysis]*

4. Resourcing issues

   - Any aspect of managing BPSD in a community setting that are challenging?
     - Potential Probes
       - How has your experience of managing the carer been?
       - Sometimes in the community setting a certain amount of risk may need to be tolerated in order to ensure patient autonomy- would this be your experience?
       - Are there any resources or multidisciplinary supports in the community that you can avail of for these patients?

Facilitators

"These are clearly complex cases to manage. Are there any resources or supports you might access to help you make management decisions in BPSD?"

If not mentioned probe re the following resources.

Clinical Supports

1. GP Colleagues
   - Would you engage in discussions with colleagues?

2. OAP/ Geriatricians
   - Do you find Geriatricians or OAPs to be helpful resources?
     - Would you ever phone a consultant about cases of BPSD?
     - When would you refer to a consultant?
     - Do you utilise personal relationships to access supports and advice? *[introduced in response to the data analysis]*
   - Are there any barriers to referring to consultants?
     - Are they accessible?
   - Do you find referring these patients beneficial?
     - Under what circumstance is it beneficial or not?
     - What do they typically recommend that you might not have done yourself?
3. Guidelines/ Online Resources
   - Are there any guidelines/ resources you consult when dealing with BPSD?

Doctor Factors

At a personal level what do you feel facilitates you managing these patients?

Prompts;

- Confidence in managing these patients?
- Role of experience?
- Knowledge level?
- Job Satisfaction?
- Knowing your own limits?
- Avoiding crisis presentations where possible? *[introduced in response to the data analysis]*
- Personal experience with dementia? *[introduced in response to the data analysis]*

Part 3: GPs opinion of potential strategies to improve the management of BPSD in Primary Care

Aim:
Probe for potential strategies that may support effective approaches to managing BPSD

- How could you as a GP be better supported in the area of managing people with BPSD?
  - What resources would be helpful? At a nursing home and at a community level?
- Would you be keen to participate in further education?
  - If yes, what form would you like that education to take?
  - What specific aspect would you like education on?
- Have you any suggestions on what might be practically helpful to you when you are deciding on an appropriate management plan for a patient with BPSD?
  - If not mentioned probe for the following strategies:
    - Are there any guidelines you follow currently?
      - If appropriate probe for GPs opinion on relevance of a management algorithm even though evidence supporting the data presented may be low. *[introduced in response to the data analysis]*
- If GP suggests strategies/strategy for behavior change probe for the perceived feasibility of the strategies/ strategy.
- If appropriate, probe for the sustainability of strategies proposed by the GP.

Final Question: Is there anything other aspect of managing patients with BPSD that you would like to highlight as an important issue?

Finishing the Interview

Many thanks for your time today. It is very important that we understand the personal accounts of GPs. This will ensure that the project is informed by the day-to-day experiences of professionals working in General Practice.

APPENDIX 3. Supplementary data for Chapter 7. Cross-sectional study on pain management in dementia

Supplementary material 11. The Questionnaire

Section A: General Information

This section is concerned with gathering information about you and where you work.

1. Where is your practice based? City ☐ Town ☐ Rural ☐ Mixed ☐
2. How many years are you practicing as a GP?

   0-5 ☐ 6-15☐ 16 -25☐ 26+ ☐

3. Do you provide regular care to residents of nursing homes? Yes ☐ No☐

   (if answer to Q3 is "no" then please skip to Q8)

   4. How many nursing homes do you regularly attend? _____

   5. How many nursing home residents do you look after? _____

      a. Approx. how many of these residents suffer from dementia? _____

   6. Do you do regular visits (e.g. weekly round) to nursing homes?

      Yes☐ No☐

      6.1 How many rounds do you do per week? _____

   7. Are there guidelines/policies on pain management in the nursing home?

      Yes ☐ No☐ Don't know☐

8. Do you think that pain is under-recognised in patients with dementia?

   Yes☐ No☐ Don't know☐

9. Do you think that a pain assessment tool, for the recognition of pain in patients with dementia, would be helpful in Nursing Homes?

   Yes☐ No☐ Don't know☐

Section B: Assessment and Management of Pain in Dementia

This section of the questionnaire is divided in to two parts, each of which is concerned with a different aspect of pain in residents with dementia. For each statement please indicate with a tick how strongly you agree or disagree using the scale provided.

ASSESSMENT OF PAIN IN RESIDENTS WITH DEMENTIA					
Statement	***Strongly Agree***	***Agree***	***Neither Agree nor Disagree***	***Disagree***	***Strongly Disagree***
10. The presence of dementia in a person can make pain assessment difficult.					
11. A person with dementia is not able to accurately provide a self-report of their pain.					
12. Pain assessment tools used for cognitively intact residents are not appropriate for people with dementia.					
13. I am familiar with pain assessment tools specifically available for use with a person with dementia.					
14. When assessing pain in a resident with dementia, it is important to observe behavioural indicators of pain (e.g. facial expressions, body movements, posture).					

Statement	*Strongly Agree*	*Agree*	*Neither Agree nor Disagree*	*Disagree*	*Strongly Disagree*
15. When assessing pain in a resident with dementia, it is important to consider physiological indicators of pain (e.g. heart rate, blood pressure, temperature).					
16. When assessing pain in a resident with dementia, it is important to consider a family/care givers report.					
MANAGEMENT AND TREATMENT OF PAIN IN RESIDENTS WITH DEMENTIA					
17. People with dementia who are experiencing pain should be managed differently to people who are cognitively intact.					
18. The drug treatment of pain in a person with dementia should follow a step-wise approach.					
19. Optimal treatment of pain is achieved when analgesics are given on a regular basis.					
20. Paracetamol is the best analgesic to use for people with dementia who are experiencing chronic pain.					
21. It is safe to use opioid analgesia to treat pain in people with dementia.					
22. People with dementia are less likely to become addicted to opioid analgesics than cognitively intact patients.					

Statement	***Strongly Agree***	***Agree***	***Neither Agree nor Disagree***	***Disagree***	***Strongly Disagree***
23. There is a greater risk of side effects from opioid analgesics (e.g. respiratory depression, confusion) when used in people with dementia.					
24. Non-drug based methods of pain control (e.g. TENs, Heat/Cold, massage, complimentary therapy) are useful in the management of pain in people with dementia.					

Have you any further comments or remarks to make in relation to this questionnaire or the subject of pain in patients with dementia?

APPENDIX 4. Supplementary data for Chapter 8. Cross-sectional study on antipsychotic prescribing

Supplementary Material 12. The Questionnaire

APPENDIX 5. Supplementary data for Chapter 9. eDelphi Study

Supplementary Material 13. Monitoring Tool for Antipsychotic Drugs in BPSD

Resident's Name:	Date of Birth:

Initiation of Antipsychotic

Drug Name: _____ Dose: _____ Frequency: _____

Date of initial prescription: _____ prescribed by: GP☐ OAP☐ Geriatrician ☐ Unknown☐

What is/was the reason for initial prescription (specify behaviour/ symptom you are attempting to treat):

PRN antipsychotic medication also prescribed: YES ☐ NO ☐

If yes, specify: medication _____ dose _____ frequency _____

Trial of non-pharmacological treatment options prior to initiation of antipsychotic: YES ☐ NO ☐

Details of non-pharm strategies:

The following were checked and documented (tick where appropriate)

FBC ☐ LFT ☐ TFT ☐ U&E ☐ ECG ☐

Initial medical review at 6 weeks (i.e. 6 weeks after initiation)

Resident's behaviour/symptom has; improved ☐ worsened ☐ stayed the same☐

Details_____

Have any of the following been experienced by the resident since initiation of antipsychotic drug:

1. Sedation ☐ 2. Extra-pyramidal symptoms ☐ 3. Increased confusion ☐ 4. Increased falls ☐

Outcome of initial review (6 weeks after initiation)

Antipsychotic drug treatment will be: continued ☐ discontinued ☐ altered ☐ (specify) _____

Reasons for continuation of antipsychotic drug (where applicable):

This resident will be reviewed at 3 monthly (see overleaf) ☐

Signature: _____ Date: _____

Ongoing monitoring of antipsychotics for resident (available on the back of the initial prescribing & review tool)

Name	AP prescribd	Behaviour/ symptom being treated	Initial dose	Date of review	S.E's	Any changes made? Specify change in dose/freq	If no withdrawal or dose reduction. Give reason why.	Date for next review
B.H	Risperidone	unknown	1mg OD	26/11/17		No change – to stay on 1mg OD	Decision made to initially try to reduce quetiaptine	
	Quetiapine	Physical aggression	25mg BD	26/11/17	Can be sedated/sleepy in morning	Yes – reduced to 25mg nocte		6 weeks' time – 7/01/19

APPENDIX 6. Supplementary data for Chapter 8. Intervention Development

Supplementary Material 14. Analysis of online GP discussion forum on the management of BPSD

Candidate's role in this study: The candidate (AJ) came up with the concept for this study, applied for ethical approval, collected the data and led the data analysis. Dr Tony Foley assisted with the data analysis.

Background

GPs who were participating in an online dementia module were presented with two mock clinical cases in the area of BPSD and were asked to outline how they would approach the case in clinical practice. They discussed their approaches in an online discussion forum. Their responses were then be analysed and common themes were identified with the aim of identifying factors that influence decision making processes.

This study was solely designed to inform this PhD research and will not be published as a separate study. Ethical Approval granted by SREC (Social Research Ethics Committee) in UCC in September 2017; Log number 2017-106.

The aim of the study was to inform the design of an intervention to support the management of BPSD in general practice by specifically looking at what factors that GPs consider when managing BPSD and how these factors influence GPs decisions.

Methods

The participating GPs were all students on a 12 week online postgraduate dementia module that was developed by the PhD candidate and Tony Foley. The PhD candidate is the module co-ordinator. The online module runs annually from September to December. Two weeks of the online module were devoted to the management of BPSD (first two weeks in November). A clinical case related to the topic was posted to the online discussion forum at the beginning of each week and the participating students then contribute to the discussion board with their thoughts on how they would approach the clinical case. The PhD candidate was also the tutor for the two weeks in question.

In the module that ran in 2017 19 of the 20 participating GPs consented to being part of this research study. AJ extracted the qualitative data from the discussion forum, anonymised the data and put it in a text file. The files were then uploaded to NVivo and thematically analysed by AJ. A second researcher (TF) also thematically analysed the anonymised data.

Results

A number of themes emerged namely; feeling resource poor, not having the confidence or knowledge to recommend non-pharmacological treatments and the important role of the GP in the community. I will outline examples of some verbatim quotes that support these themes.

I) Feeling resource poor

The participating GPs felt frustrated by the time-constraints that inadequate resourcing put them under, many spoke in particular about time-constraints;

"At times like that I wish that we were not so time poor."

"I do feel that as GPs our time with patients is so short that it can be very hard to go into too much detail with non pharmacological suggestions apart from encouraging them to seek out day centres which are generally wonderful"

Others felt though, although they were resource poor having upskilled in the assessment of BPSD over the first week of the unit they felt *"empowered to look for other causes for the patients symptoms and not take the easy route and prescribe"*

2) Lacking confidence to recommend non-pharmacological strategies

Some GPs reported lacking the confidence to recommend non-pharmacological strategies.

"I have to say I rarely recommend non pharmacological managements to patients and I will need to change my practice from this module. For some reason I find that I do mention it in a nursing home setting but have not broached it with carers in the same capacity. I definitely am not confident recommending these strategies and feel ill equipped to recommend."

"Now that I am confronted not sure how much I pass on to patients at the surgery as all the non- pharmacological methods are initiated by staff at the nursing home."

However, others were more comfortable recommending these strategies;

"I have found most NH/Community Hospitals and family very receptive to music therapy, especially now when you can easily download older tracks from the Internet, but most nurses and carers are so busy in these places that it's hard."

Others, spoke about how a 'risk-averse' mentality can frequently act as barriers to the implementation of non-pharmacological strategies;

"We have had a baking session "cancelled" by environmental health on the grounds of hygiene concerns. We did it anyway and all survived, enjoying food they helped to prepare."

3) The important role of the GP in the community setting

"I think we have an important role here to support and give information to families."

Supplementary Material 15. Additional analysis of the GP interviews

1. Data from the qualitative study on potentially relevant intervention features

The important features of an intervention in the area of BPSD as identified by GPs participating in the qualitative study. The GPs highlighted the need for the intervention to come from a credible source, to be GP relevant, succinct and accessible. The importance of involving relevant stakeholders such as nursing home staff in the intervention was also highlighted. (Table 1)

Intervention Feature	Supporting quote from qualitative study
Clarity around prescribing, solution-orientated	" *[the intervention] would have to provide information that would be useful for GP's and would give them something new, do you know, like I think something that talks maybe about dementia and prescribing in dementia without coming up with some clear solutions and guidance wouldn't be that useful, you know"* (GP1)
Led by a GP expert/ credible peer	*"I mean in an ideal world I suppose you would have a colleague who had a special interest in dementia"* (GP5) *".. from someone that I would trust*" (GP7)
Involve nurses and the nursing home sector	*"We need nursing homes to buy in to that too, the staff in nursing homes, people that run them need to say actually we have a responsibility here making sure that the tablets that ye use are checked to be safe on a regular basis, how can we help you kind of thing. So in terms of nursing home care maybe it could be something that could be put to the nursing home sector as well as the doctors and the nurses as well."* (GP7)
Informed by general practice	"*The idea would be if they could say that most of this information is derived from primary healthcare that would be great. I think that would carry more cogency than something hospital based … that the context is realistic*" (GP7)
Needs to be succinct and accessible	"*something simple with a few points that you could quickly reference" (GP1)* *"It is always just nice to have you know very clear succinct information just to give you answers to questions very quickly.*

	That very digestible information that you feel is very credible and that you can definitely justify and it gives you your options very clearly." (GP2)
Accessible/ Online	*"The days of paper are gone. I can't tell you where anything that I have taken from any meeting in paper form is now because no one want a messy consultation room, everything is much easier to access on your hard drive or on the Internet." (GP1)* *… something that you could draw on when somebody is sitting in front of you that would be significant.*" (GP1)
Format of ongoing, peer-to-peer discussion	*"Talking to colleagues, you know and comparing notes and you know compare specifics even antidotes, you learn. I find I learn a lot from those situations… You do need a forum where you can talk about these things, you know, on a regular basis."* (GP8)

When GPs were asked to suggest an intervention that would support them in caring for people experiencing BPSD interventions that centred around guidance on prescribing were the overwhelming the most common interventions suggested. These format of these prescribing guidance varied from prescribing aids, prescribing guidelines, management algorithms to online educational prescribing resources. Other interventions suggested included; guidance on non-pharmacological supports, increased access to community supports for carers, online modules and community based dementia nurse. (Table 2)

2. Specific interventions suggested by GPs that would support them in their management of BPSD

Intervention Suggested	Supporting quote from qualitative study
Prescribing protocol/ aid/ guideline / algorithm	"*What would be very useful I think like from my perspective would be clarity on you know, I suppose the best of what's there, you know, no medication is ideal but what are the really red flag side effects that you need to think about with a particular class of medication. And what's your most appropriate first line medication. I think there is probably no magic solution to this but I think a clear algorithm of medications that are appropriate. I think would be the most practical thing."* (GP1) *"I think a clear prescribing guideline would be helpful but there are a lot of challenges coming up with that too, a lot of*

	challenges and a lot of the evidence from the big studies is different from anecdotal evidence which can be difficult … it could exist but not be used, whereas you need something that will be used." (GP3) *"I think you need to make sure that you have the appropriate list of possible medications and try such and such, and if such and such doesn't work try something else. Algorithms are always handy I suppose for GP's where you are not trying to flick through a BNF and see what you are supposed to be doing, so maybe those are things that could be up in a Nursing Home you know that you don't necessarily have them with you and it would be part of the nursing home. Maybe do not have a massive amounts of evidence because I think if you were to go round and speak to GP's they would feel they need something in their armoury when they are faced with family members or nursing staff"* (GP5) *"If you had a protocol that would go through things in a step wise fashion okay… then this is what you would recommend … if there is behavioural issues to think down this pathway this and this might be of benefit."* (GP10) *"If there was a straight forward protocol. BPSD it's definitely a bit hap hazard like, yeah the treatment of it. If there was some kind of a semi protocol as to look this is step one, step two, step three, this is what we say we shouldn't use. And this is what we say we would advise. No one is saying that it should be like the guidelines for diabetes or GOLD guidelines or something like - it is not going to be as straight forward as that but maybe they would be such an idea as well we avoid this and here is a group of three that we would prefer to use and these one the less preferable ones. Something along those lines."* (GP12) *"I think clear guidelines would be useful."* (GP13) *"… even guidelines, you know, I don't know whether there are guidelines. Simple guidelines maybe non pharmalogical and then pharmacological then but I certainly haven't seen anything like that anyway."* (GP14)
Key worker/ Dementia nurse	*"A public health nurse that is Dementia specific, because I can imagine that public health nurses have a lot on their plate and there should be something like that, and that they liaise specifically with GPs"* (GP3) *"I think in an ideal world it would be individual care packages with a couple of people who deliver them day to day, a set of*

	carers who look after each patient totally tailored to their needs." (GP5)
Guidance on non-pharmacological strategies	*"I think it would be useful to have a list of ideas for non-pharmacological interventions."* (GP13) *"Simple guidelines maybe non pharmalogical and then pharmacological."* (GP14)
Assessment checklist	*"You know and make sure the bowels are okay and you know they are hydrated and you know it all seems obvious but when you are faced with a demented or a delirious patient it kind of goes out the window a bit. If there was a check list, you know even, I know now we are always get check lists and things but that would be helpful. A kind of a delirium check list you know."* (GP14)
Online Module	*"I think a certain amount of educational support would be good there, maybe through online modules."* (GP7)
Community based services and supports	*"I still think it is going to be more community resources, I still think that's the way to go."* (GP15) "*would probably benefit from saying look this is a clear description of what local services are available, they are limited but this is what you have, you know"* (GP1)

Supplementary Material 16. Additional analysis of the studies included in the Systematic Review

Interventions suggested by authors of the studies included in the systematic review that would improve the management of BPSD in General Practice

Intervention Suggested	Supporting study

Guidelines that are practical, GP relevant and appropriately disseminated	"Evidence-based clinical practice guidelines targeted specifically at the management of BPSD in primary care could, therefore, be beneficial." (Buhagiar) "Practical guidance on pharmacological and nonpharmacological alternatives." (Azermai) "Understandable guidelines for all healthcare workers." (Mavrodaris) "Better dissemination of practice guidelines cautioning about the limited benefit of antipsychotic medication in BPSD may prompt practitioners to more rationally prescribe these medications." (Cousins)
Pathways of care to increase collaboration with specialist services	"Priority needs to be given to developing clear local pathways of dementia care in the community, readily accessible by GPs." (Foley) "The development of structured shared-care frameworks between primary care and specialist services….. Collaboration with specialist services may also facilitate GPs to translate their wealth of clinical knowledge into clinical practice." (Buhagiar)
Education for GPs – with a particular focus on discontinuation of antipsychotics and available non-pharmacological strategies	"GPs need to be supported by educational programmes that bolster their confidence in the care of people with dementia at large. In turn, this can provide them with further confidence in the management of the more specific and challenging aspects of the illness, like BPSD." (Buhagiar) "Physicians learn by experience; therefore, one way to broaden their exposure to nonpharmacological interventions is to include curricula on multidisciplinary dementia care programming into continuing medical education programs." (Colenda, 1996) "Quality of care might be improved by physician education around management of behavioral problems." (Hinton)
Involve nurses	"Antipsychotic discontinuation is only likely to succeed with involvement and cooperation of nurses." (Azermai) "The importance of integrated approaches involving regular prescription review, targeted joint educational programs (for care home staff, pharmacists and physicians) and relationship building strategies." (Mavrodaris)

Provide reimbursements to GPs for care provide	"Reimbursement for treating patients with substantial behavioral complexity and developing incentives for health care organizations to deliver more comprehensive (and costly) care upfront to postpone as long as possible more costly "downstream" outcomes, such as institutionalization." (Hinton)

Supplementary Material 17. BCW Step 5: Identify intervention functions using APEASE criteria

We used the APEASE criteria to judge the merit of each intervention function individually. The acronym stands for affordability, practicability, effectiveness and cost effectiveness, acceptability, side effects/ safety and equity. Using this process we categorised the intervention functions into first line and second line or inappropriate.

AP(s) = antipsychotic(s) PLWD= People living with dementia

BCW Intervention Functions	Affordability	Practicability	Effectiveness & cost effectiveness	Acceptability	Side effects/ unwanted consequences	Equity	Comments	Decision: First line / Second Line / Not appropriate
Education	✓	✓	✓	✓	×	✓	The need to increase knowledge on aspects of AP prescribing and monitoring emerged as a significant area that needs to be addressed in step 4. Educational interventions should aim to increase GPs' awareness of the limited benefits and significant adverse effects of APs in PLWD. To date, a number of educational interventions have been developed and implemented as part of the wider research project. Two of the authors (AJ, TF) have developed and implemented a peer-led, 1 hour workshop on BPSD assessment and management [133]. More than 80 workshops have been run nationwide and these workshops have been attended by over 500 GPs. However, this workshop was not designed to specifically address our target behaviour of improving the monitoring of antipsychotics.	First Line

							Small group workshops that are practice-based are resource intensive. Several GPs interviewed in the qualitative study advocated for educational interventions to be online (See BCW Step 5 outlined in supplementary material 17). Online educational interventions can be provided with less costs, are more practical, equitable and acceptable to GPs. As part of the wider PREPARED project we have developed a dementia elearning module with the ICGP (Irish College of General Practitioners). The lead author (AJ) developed the content for a one hour BPSD elearning unit as part of a suite of dementia elearning modules. It is important that any educational interventions on AP monitoring provides practical information on non-pharmacological alternatives. The target behaviour is the monitoring of AP prescribing not the reduction of AP prescribing, however, a potential unintended consequence of an over-emphasis on the dangers of AP prescribing could be an increase in prescribing of other psychotropic medications such a benzodiazepines that are equally undesirable medications for the management of BPSD. However, we know that educational interventions alone have limited effect when attempting to change GP practice in dementia care [286,287]. Therefore an educational intervention needs to be supported by service innovation service innovations [287] and appropriate resources [297] .	
Incentivisation	✗	✗	✓	✓	✗	✓	In the context of stretched resources and the limited time available to GPs it is essential that they are incentivised to perform antipsychotic prescribing reviews/ monitoring of antipsychotic prescribing. GPs in Ireland providing care to the nursing home residents are not adequately reimbursed and many GPs currently provide care out of a sense of duty and goodwill. Asking GPs to take on an additional task (i.e. monitoring prescribing of APs) may be met with resistance unless they are appropriately incentivised to do so. Incentives have been	First Line

							shown to effectively improve GP rates of dementia diagnosis in the UK. [76] The incentive chosen needs to be affordable and equitable (available to all). It is important that the incentive is linked to monitoring of prescribing rather than reductions in prescribing in order to avoid unwanted consequences such as a reduction of AP prescribing but an increase in other psychotropic medications that are equally harmful. Certain types of financial incentivisation may not be practical or affordable given the current climate of under-resourcing of Irish primary care. An incentive in the form of provision of continuous professional development points might be a poor feasible incentivisation structure. GPs in Ireland need to submit CPD annual. The required CPD points are; 20 external points, 20 internal points (for practice improvement initiatives) and 1 annual audit. This intervention could address all components of the GP's CPD requirements; an educational session could be approved for external CPD points, conducting an antipsychotic review would be eligible for internal CPD points and conducting an audit of the outcome of the review process would provide a GP with their annual audit requirement.	
Environmental restructuring	✓	✓	✓	✓	✗	✓	Changing the current physical and social context is essential in order to successfully change GPs' behaviour regarding the monitoring of APs in PLWD. Any change must be accessible to all (equitable). Interventions such as the improved integration of care pathways between primary & secondary care could improve the monitoring of APs in PLWD. Similarly, the resourcing of designated time to conduct a multi-disciplinary AP review in a nursing home would be effective [298]. However, although these interventions would be effective, they are not all practical. They rely on external resourcing and co-ordination at a	First Line

							government level. Likewise, they may not be equitable, as the ability of nursing homes to resource multi-disciplinary AP reviews may vary. The provision of continuity of care by a single GP might not be realistic or acceptable by GPs, many of whom work part-time or having competing clinical duties. There is also the argument that forcing a one GP per nursing home policy goes against the fundamental right of a patient to choose their care provider. [100] However, other examples of environmental restructuring such as the implementation of a GP relevant AP prescribing guideline would be acceptable by many GPs as was evident in our qualitative study and in the systematic review (see supplementary material 15 and 16) and would also be affordable.	
Training	×	×	✓	×	×	×/-	In addition to education GPs may require training in monitoring antipsychotic medications. If a monitoring tool or guideline is introduced GPs would require training in the use of that tool or guideline. Training in the tool/guideline is likely to increase the effectiveness and the acceptability of the tool/guideline. However, face-to-face training of GPs may not be affordable and, given the busy work day of a GP, it may also not be practical. Consequently it may not be considered acceptable by GPs. Face-to-face training may also not be equitable if the training is not available in all regions. However, if the training in how to use the monitoring tool was introduced as part of the proposed IPE educational session in the nursing home this may be feasible and acceptable. Additionally, although the target behaviour is on monitoring APs rather than using non-pharmacological strategies evidence shows that any attempt to monitor AP prescribing should be supported by access to non-pharmacological strategies [212]. Therefore, training to GPs on how to advise on non-pharmacological strategies may be beneficial. However, training on non-pharmacological strategies may not be	Second Line

							acceptable to GPs who may not consider advising on non-pharmacological strategies within their professional remit, this was evident in data in both the online dementia module and the qualitative study.	
Enablement	✓	✓	✓	✓	×	✓	This intervention function refers to reducing barriers to increase capability (beyond education and training) or opportunity (beyond environmental restructuring). When considering our target behaviour this could refer to providing GPs with support from pharmacy colleagues or access to advice from secondary care colleagues. It could also refer to better communication between nursing staff and GPs enabling a more collaborative shared ownership of antipsychotic monitoring. This intervention function is considered affordable, effective, equitable and should have limited unwanted consequences. Practically speaking an IPE session with nursing colleagues may increase this interprofessional support.	First Line
Modelling	✓	×	?	×	×	×	Modelling involves providing an example, in this case an example of successful implementation of an antipsychotic monitoring process, for people to aspire to. This could be effective as it would address the lack of optimism GPs showed towards the management of BPSD, which was particularly apparent in the qualitative interviews. It would be affordable and should not have any unwanted side-effects. However, it may not be equitable. Different nursing homes have different resources available in terms of staffing ratios and access to specialist advice. In Ireland the majority of nursing homes are private as opposed to state funded. Presenting a model that does not match the GPs own current experience may not be acceptable to GPs and could limit the effectiveness.	Second Line

BCW Intervention Functions	Affordability	Practicability	Effectiveness & cost effectiveness	Acceptability	Side effects/ unwanted consequences	Equity	Comments	Decision: First line Second Line Not appropriate
Persuasion	✓	✓	×	×	×	✓	GPs are made aware of the adverse effects and limited benefits of antipsychotics in the management of BPSD and are supported through environmental restructuring and supports then further persuasion to complete monitoring is unlikely to be effect change. Using persuasion may also be unacceptable to GPs.	Second Line
Coercion	×	×	×	×	✓	×	Creating an expectation of punishment or cost for not monitor. Punishment in the absence of reward/incentivisation for monitoring of antipsychotic prescribing would be particularly unacceptable to GPs. It would also be practically difficult to enforce. Additionally, forcing monitoring upon GPs in such a manner may result in unintended consequences such as monitoring occurring in name only as a 'tick the box' exercise, something that would also affect the effectiveness of the intervention. It may also be inequitable as it fails to recognise the different resources available to GPs in different regions and in different nursing home settings.	Not appropriate
Restriction	×	×	×	×	✓	×	Restriction in this instance would mean using rules to increase the target behaviour (monitoring of antipsychotic prescribing) by reducing the opportunity to engage in competing behaviours. This is impractical as there is no direct competing behaviour here.	Not appropriate

Supplementary Material 18. BCW Step 7 Identification of behaviour change techniques (BCTs)

Intervention functions chosen as useful for our intervention	Potential behavioural change techniques associated with the intervention function	Elaboration on how the behavioural change technique could be used to encourage GPs to monitor their prescribing of antipsychotic medication to people with dementia in nursing homes, based on the definition of that behavioural change technique[404].
Education	Information about health consequences	Provide information to GPs about the consequences of performing the behaviour. In the systematic review it was found that GPs tended to over-estimate the benefits of antipsychotic medications. The risks of antipsychotics to people with dementia was seen to relate to longevity of life rather than quality of life. GPs also felt that if they reduced antipsychotic medications this could lead to a return of the BPSD. These beliefs contributed to GPs reluctance to de-prescribe antipsychotic medications, which in turn contributes to not monitoring antipsychotics. If information provided specifically addressed these concerns this could improve the likelihood of GPs engaging with the target behaviour.
	Information about other's approval	Provide information about what other people think of monitoring antipsychotic medications. In this instance it might be useful to provide information on best practice guidance exists in this area and what these guidance documents recommend when monitoring antipsychotics in dementia. Many GPs in the qualitative study reported the lack of available clinical guidance to be a challenge when managing BPSD. The lead author of the study is part of a multi-disciplinary team developing national guidelines on the use of antipsychotics in dementia care. Sharing the results of the guideline with GPs which will recommend monitoring of antipsychotic medications would help address the challenge posed by the lack of national guidelines in this area. This could be delivered as part of the educational component of the education.
	Feedback on behaviour	Monitor and provide information or evaluative feedback to GPs on performance of the behaviour. In this instance this would involve providing feedback to the GP on their engagement with the monitoring of antipsychotic medications in PLWD (what form it takes, frequency, intensity). This could be a valuable ingredient in the behaviour change strategy as providing

		feedback to GPs on their behaviour has been shown to be an effective method of changing GPs' prescribing behaviour in other areas of clinical care. [459]However, the more relevant measure for GPs might instead be receiving feedback on the outcome of the behaviour.
	Feedback on outcome(s) of the behaviour	Monitor and provide feedback to the GP on the outcome of performance of the behaviour. The outcome here could be the number of antipsychotic reviews conducted or the % of people with dementia in the nursing homes on an antipsychotic medication. However, the % of people with dementia in the nursing homes on an antipsychotic medication is dependent on a number of other factors such as the staffing levels of the nursing home and the physical environment of the nursing home. It would be difficult to provide this feedback at a national level as there is no central database that records the prescribing. In Ireland the PCRS (Primary Care Reimbursement Service) process the payments to GPs and pharmacists. Therefore, it would be possible to identify the number of people with medical cards who were prescribed an antipsychotic. However, there are two limitations. Firstly, this only provides data on patients who have medical cards and excluded private patients. Secondly, there is no way of identifying the reason for the prescription or, indeed, the medical conditions of the patient – so there is no way of knowing if the prescription was for managing BPSD. However, external feedback could be presented to the GP at a nursing home level. Each nursing home has a pharmacy that manages all the prescriptions for the nursing home. That providing pharmacy could provide a list of the nursing home residents who are on an antipsychotic and their associated dosages. This could be provided on a three-monthly basis to facilitate the review process. However, the nursing home would have to identify from this list the residents who had dementia. Still this method of providing external feedback on the outcome of the monitoring process would be feasible and acceptable.
	Self- monitoring of behaviour	Establish a method for GPs to monitor and record their own behaviour as part of the behaviour change strategy. This may be viewed by GPs as an additional task to do. The limited time available to GPs when caring for people with dementia was highlighted in both the interview study and the systematic review. If we give this additional task of self-monitoring to GPs rather

		than facilitating engagement with the target behaviour it may act as a barrier. However, if the self-monitoring was linked to an incentivisation for the GP, for example CPD points or to facilitate an audit, then it may have a role.
Environmental re-structuring	Adding objects to the environment	Add objects to the nursing home environment in order to facilitate monitoring of antipsychotic medications, involving more than verbal, visual, or written information. Where there is an IT software system in place this may involve decision support software as this has been shown to be an effective intervention in dementia management in primary care.[296] Additionally if there are patient software systems in place in the nursing homes then online audit tools could be used to monitor prescribing. The wider project has developed audit tools that will interact with the main patient software systems in Ireland and will identify people with dementia on antipsychotic medication. Audit tools and decision support tools have a particularly useful role in the community setting as the majority of GPs have patient software tools. However, the majority of nursing homes records are still paper based. The addition of a tool that would guide GPs on how to conduct an antipsychotic review would be helpful. In the qualitative study GPs identified that the management of BPSD was often seen as a 'grey area' by GPs who called for support in the form of GP relevant guidance documents. A tool to aid GPs in conducting antipsychotic reviews would positively impact of GPs' confidence in monitoring antipsychotic prescribing in dementia.
	Prompts/cue	Introduce or define environmental or social stimulus with the purpose of prompting the desired behaviour. This could be a prompt to highlight the need for a review of antipsychotic prescribing in a person with dementia. *[also Action Planning]*. This prompt (written or IT based) could take the form of a checklist of items to consider when conducting a review of an antipsychotic prescription to a person with dementia and would be used at the time of performance of antipsychotic review,
	Restructuring the physical environment	Change, or advise to change, the physical environment in order to facilitate the GP to monitor their antipsychotic prescribing in people with dementia. This could involve having the dispensing chart in with the drug kardex so if a person is on an antipsychotic PRN then the frequency with which this is given is identifiable. (In the qualitative study the fact that these two important sources of information are not available together was identified as an issue). Having a patient software system in place that allows the GP to search for people on antipsychotic medications

		would be beneficial but perhaps cost-prohibitive to many. Creation of a designated time and place to conduct the review would help aid the process of antipsychotic review but again needs to be resourced.
	Restructuring the social environment	A change in the social environment in the nursing home that would either facilitate antipsychotic reviews or create barriers to not conducting antipsychotic reviews. The influence of the relationship between the nursing home staff and the GP was highlighted in both the qualitative study and in the systematic review. Poor pathways of communication between the GP and the nursing home staff exacerbated the competing priorities that existed between GPs and nursing home staff. The creation of a relationship of collegiality and trust is an important aspect of successful behaviour change here. However, this may be more easily addressed where the nursing home has one main GP that provides the majority of the care. If there are multiple GPs attending the nursing home with only a few residents under the care of each it may be difficult to restructure the social environment. If the education provided was interprofessional and involved both GPs and nursing home staff this may help to improve the relationship between the two professional groups and help to get both groups 'on the same page'.
Enablement	Social support (practical)	Advise or provide social support that provide practical help for GP in the performance of antipsychotic monitoring. In both the qualitative study and in the systematic review the difficulty accessing practical advice from secondary care colleagues was highlighted. GPs were looking for reassurance from secondary care but found it difficult to access secondary care. If the GP was part of a multidisciplinary team who was collectively conducting this review (including CNM, pharmacist +/- old a psychiatrist or geriatrician) this might further improve the social support that would enable GPs to conduct antipsychotic monitoring. The support of the nursing home staff is key to the practical implementation of this behaviour change strategy. Having an interprofessional forum where the concept of the monitoring of antipsychotics is introduced may help to improve relations and ensure buy in from all professional groups.
	Social support (emotional)	In our qualitative study many GPs described GP colleagues as being important social supports, although they often did not consider them experts in dementia care. However, this emotional support from colleagues could be an important element to consider.

	Goal setting: behaviour	Set or agree on a goal for conducting of antipsychotic monitoring/ reviews. If a GP does not intend to monitor their antipsychotic prescribing in people with dementia it is more likely to be related to a lack of knowledge rather than a lack of intent. For the majority the intent is already there but the practical application is difficult due to the competing demands on their time. The challenge of the intervention will be how to make the target behaviour easier to conduct, rather than simply increasing GPs resolve to do it.
	Goal setting: outcome	Set or agree on a goal defined in terms of a positive outcome of the conduct of antipsychotic monitoring review. The obvious goal here would be reduced antipsychotic prescriptions, however, this outcome in many ways addresses a different target behaviour – that of reducing antipsychotic prescribing. In the current environment of understaffing in nursing homes, insufficient resourcing for key workers such as dementia advisors and activities co-ordinators in nursing homes and in the context of environmental and structural inadequacies that make nursing homes often completely unsuitable for people with dementia an outcome of reduced antipsychotic prescriptions may be very difficult to achieve. In this context, if the outcome of reduced antipsychotic prescribing is not achieved then this could be de-motivating for GPs. The outcome should be the conducting of antipsychotic monitoring, not reducing antipsychotic prescribing. Although it is very likely that reduction in antipsychotic prescribing would be a 'spill-over' impact of the antipsychotic monitoring, it is not the primary outcome.
	Action planning	Detailed planning of how GPs are expected to perform the behaviour. The details of how the monitoring of antipsychotics will occur needs to be explicit. This should include how frequently these medications should be reviewed. In the qualitative study and in the systematic review there was evidence that GPs were uncertain about how to formally conduct an antipsychotic review or monitor antipsychotics so in this context this is considered to be an important element of any behavioural change strategy.
	Review behavioural goals	Review behaviour goal jointly with the GP and consider modifying behaviour change strategy in light of the strategy. This may not be practical to implement as jointly reviewing behaviour goals with the GP would be resource intensive.

	Review outcome goals	Review outcome goals jointly with the GP and consider modifying goals in light of the achievement. Here this could relate to examining how many patients with dementia on antipsychotics are being monitored. Not feasible that the GPs goals could be jointly reviewed as it likely be too resource intensive.
	Reduce negative emotions	Advise GPs on ways of reducing negative emotions to facilitate performance of the behaviour. In the qualitative study the lack of optimism GPs felt when managing people with dementia was apparent. Identifying and addressing these negative emotions may facilitate behaviour change. However, the negative emotions felt by GPs was a consequence of the lack of resources available and their feelings of frustration and, at times, their inability to act as advocates for their patients. The focus of the behaviour change strategy should be around practically facilitating the GPs to engage with the process of antipsychotic monitoring rather than addressing their justifiable emotions that stem from resource inadequacies.
	Conserve mental resources	In order to minimise demands on GPs mental resources they could be encouraged to consult guidelines on antipsychotic monitoring and alternatives to antipsychotic prescribing. In the qualitative study many GPs highlighted what they saw as the lack of GP-relevant, implementable guidelines so such guidelines would have to be developed in order to support GPs and conserve mental resources.
	Discrepancy between current behaviour and goal	Draw attention to discrepancies between a GP's current behaviour (in terms of the form, frequency, and duration of antipsychotic monitoring) and the GP's previously set outcome goals or action plans. If this provided feedback to the GPs and allowed them to improve their behaviour based on this feedback this would function in a similar way to an audit. *(Feedback on behaviour)* Audit has been identified as an effective way of improving coding of dementia diagnosis in primary care. [417]
	Pros and cons	The GP is advised to identify and compare the reasons for wanting (pros) and not wanting (cons) to change their behaviour regarding monitoring of antipsychotic medications. This would be resource intensive for the GP and is more likely to frustrate the GP than enable them.
	Focus on past success	Advise GPs to think about or list previous successes in monitoring antipsychotic prescribing. The cases where antipsychotic monitoring had been successful conducted may have had specific

		features that are not necessarily replicable. The monitoring may have also occurred in an unplanned manner. Therefore, if we highlight these success it may actually detract from the need for the behavioural change strategy we're trying to implement.
	Anticipated regret	Induce or raise awareness of expectations of a GP's future regret about not monitoring prescribing of antipsychotics. This could be achieved by asking the GP to assess the degree of regret they will feel if they do not monitor their prescribing and the person with dementia has an adverse effect as a consequence of the antipsychotic prescribed. This may be perceived as being manipulative or emotionally coersive by GPs. The focus of the behaviour change should be on building on GPs good intentions in this area and facilitating the behaviour change rather than using any kind of coercion.
Incentivisation	Feedback on behaviour	*Discussed under 'Education'*
	Feedback on outcome of behaviour	*Discussed under 'Education'*
	Monitoring of behaviour by others without evidence of feedback	This is unlikely to be acceptable to GPs. To monitor the GPs behaviour without feedback would be seen as a negative threat rather than a positive incentive.
	Monitoring outcome of behaviour by others with evidence of feedback	Feedback to GPs on their benzodiazepine prescribing is an established and accepted method of monitoring GP's prescribing of benzodiazepine prescribing. Therefore, introducing a similar method of monitoring antipsychotic prescribing may be successful. However, we are specifically looking at antipsychotic prescribing in a cohort of patients with dementia. There are many psychiatric conditions that would merit a prescription for an antipsychotic. Implementing an external monitoring system with feedback on antipsychotic prescribing in dementia specifically would be difficult to operationalise as data on the prescribing of antipsychotics could not be linked to a specific clinical condition. This is discussed in more depth under *'Feedback on outcome(s) of the behaviour'*.
	Self-monitoring of behaviour	Establish a method for the GP to monitor and record their own prescribing of antipsychotics. GPs do not tend to self- monitor their prescribing of any one particular drug class. Given existing resource constraints it is unrealistic and unviable to expect GPs to monitor their own prescribing of antipsychotic prescribing unless this was to be performed as part of another feedback.

		However, if the self-monitoring was further incentivised by a “reward” of continuous professional development (CPD) points then this may be successful.
	Material incentive	Inform GPs that money will be delivered if, and only if, there has been effort and/or progress in performing the behaviour. For example, inform GPs that a financial payment will be made every three months if evidence provided that an antipsychotic review has taken place. This is very likely to be successful. Evidence from the UK has shown the impact of the financial incentive on rates of dementia diagnoses. [76] Payment for performance of quality indicators of care are very likely to work as an incentive for GPs to engage with the target behaviour. However, providing such a financial incentive is beyond the scope of this study. Another type of material incentive for GPs may be the accruement of continuous professional development (CPD) points. In Ireland, as in many countries, GPs have to submit evidence of completion of annual CPD in the form of external education, internal practice quality improvements and an audit. Conducting an antipsychotic review would be eligible for internal CPD points. If the GP monitored the outcome of the review process with could take the form of an audit. Finally, if there was an education component to the intervention and if we could get that education component accredited by the Irish College of General Practitioners for external CPD points then this further incentivise GPs to engage with the intervention.

Supplementary Material 19. Stakeholder feedback on intervention concept

Ethical approval was granted by the Social Research Ethics Committee of University College Cork, Log 2017-031 for obtaining input from the pharmacists and nurses. Ethical approval for feedback from GPs via the online dementia module was also granted by Social Research Ethics Committee of University College Cork in a separate application; Log number 2017-106.

1. Feedback from community pharmacists

Aim

To discuss the acceptability of the intervention from pharmacists' perspective and to use these perspectives to refine the intervention developed.

Methods

Identified 2 community-based pharmacists who provide care to two large nursing homes in county Cork. Met with the two pharmacists on 10/10/18. Described the proposed intervention and asked for their feedback on the acceptability of the pharmacists' role in providing feedback to GPs on their prescribing of antipsychotics.

Results

The participating pharmacists reported that it was possible to provide data on the nursing home residents who were on antipsychotic medication. However, it is a resource intensive exercise as it involves the pharmacist going through each residents drug chart manually and identifying a list of residents on an antipsychotic. The software packages used by pharmacies in Ireland would not be able to easily identify this list of patients. It would involve running a search for each individual antipsychotic drug. The search results would list all customers who receive an antipsychotic medication – so would include individuals living in the community and residents of other nursing homes. There is no way to filter the list based on residence. Therefore, this would have to be done manually by the pharmacists. However, once this list was created it could then be used as a template that the pharmacist could edit every 3 months to ensure it was up to date.

Ideally, the pharmacist would be able to provide detail on the current dose and any changes to the dose of the antipsychotic medication. The pharmacists reported that this would be very difficult for them to do as it would involve keeping a weekly record of any changes made to each individual's antipsychotic prescription. The pharmacists felt that the best they could do was to give a snap-shot of the current prescribing dose.

When asked what the incentive was for the pharmacists to do this they replied that there was none. However, they reported that when they take on a contract to be the provider for

the nursing home the contract stipulates that they will help with audits. Therefore, they do see facilitating audits as part of their nursing home workload. However, they highlighted that they already do a significant amount of audits in other areas of prescribing. They showed me two 'audits' that they are currently facilitating for two different nursing homes; one was a summary of all antibiotic prescriptions in a nursing home and the other was a list of all residents on blood pressure medication for another nursing home. It was highlighted that there was a limit to what resources could be allocated to facilitating these time-intensive audits.

Overall, the pharmacists felt that they could provide a list of residents in a nursing home on an antipsychotic medication. However, including recent variations in doses would be quite resource intensive. They felt it was possible to provide this list on a three monthly basis but acknowledge it would be resource intensive for the pharmacy in the context of other requests for prescribing data. Overall, the intervention was acceptable to the pharmacists. One of the pharmacists agreed to collect this data for one of the nursing homes to ascertain the workload and time that it would involve. Given that the pharmacy was not located close to the nursing homes they provided care to the concept of the pharmacist attending the multidisciplinary review meeting to discuss the prescribing was not considered acceptable.

2. Feedback from GPs

Aim

To discuss the acceptability of the intervention from a GP perspective and to use these insights to refine the intervention developed.

Methods

As outlined, the candidate runs a 12 week blended learning dementia course for GPs annually. A previous cohort of GPs who completed this course in 2017-2018 influenced the intervention development process as outlined in Appendix 2. With the concept of the intervention finalised the 2018-2019 cohort of GPs enrolled in the online dementia course were asked to provide feedback on the intervention. The candidate is module co-ordinator for this course and also tutors the weeks of the online discussion forum that is devoted to the management of BPSD. To obtain the GPs' insight into the chosen intervention a thread was opened on the online discussion forum. In this thread the candidate described the proposed intervention and asked for feedback from the GPs on what they saw as the barriers to the intervention. The participants were asked if they would engage with the intervention and the reasons why they would, or would not. The repeat prescribing tool was uploaded to the discussion forum. Participants were encouraged to download the tool and give their feedback on its usability/ practicality. The intervention was also discussed during the face-to-face study day.

Results

Twelve GPs actively engaged in an online discussion on the intervention concept over a five day period.

The GPs were positive about the intervention. Although all the twelve GPs had a nursing home commitment and a commitment to providing quality care, as evidenced by their participation in the dementia course, only one of the twelve GPs had a formal repeat prescribing process in place to monitor the prescribing of antipsychotics in BPSD in the nursing home. They appeared to feel empowered to tackle this aspect of the care they provided.

> *"I don't have a policy for repeat prescribing of antipsychotics or for monitoring them, however, it is something I will try. The tool is very useful*. "(GP_Participant 1)
>
> *"I don't have a formal prescribing or review policy in place but it's something I do informally when doing general chart reviews in the nursing homes or doing repeat prescriptions. I'm currently actively trying to reduce the use of antipsychotics in the nursing homes [I attend] and will give the template a whirl and let you know how I get on."* (GP_Participant2)
>
> *"I think this prescribing tool is a good start Aisling and I intend to discuss its use with the director of nursing at our local community hospital. I like the educational aspect to the tool in that reference is made to non-medication treatment as the first line of management of BPSD and also that the adverse drug reactions are included which helps to focus the minds of staff -that these medications have potentially serious consequences."* (GP_Participant3)

The particular aspect of the intervention that they felt most positive about or felt had the most promise with the repeat prescribing tool.

> *"I have printed off the repeat prescribing template for anti -psychotic drugs -- I do intend to use."* (GP_Participant7)

They felt that having this tool would provide them with a starting point for a conversation with the nursing staff and that it would help everyone be *"on the same page"* (GP_Participant2). The monitoring tool was seen to functions beyond simply monitoring of antipsychotics it was viewed as having potential as an educational tool that might unite GPs and nursing staff so that they would share the same goals.

> *"The template is very helpful and the checklist is a useful aid for remembering what needs to be monitored. I have found that most nursing home patients are often new to us and have been long established on anti-psychotic medication and so deciphering adverse effects can sometimes be difficult, as is the process of introducing a weaning regime. However, I think that having a written guideline can often help to instate change, perhaps due to the official or concrete nature of it*." (GP_Participant4)

> *"Re the Anti-psychotic prescribing tool, or what I might start calling it, the "Pre-Prescribing" tool, I think it's a great idea as it might change the "culture and expectation" of BPSD … it will question the appropriateness of medical intervention with drugs. Because it forces the team requesting this intervention to actually define the target behaviour; the emphasis on non-pharmacological management is clear, and defining what's been tried already here; the date of the initiation of the drug is clear; drug risks cardiovascularly and sedation-wise are highlighted for comment; and the drug review date is clear. The whole team's responsibility is shared - carers (lay or professional) and medical. I really like the review date being clarified so that the risk of long-term indefinite prescribing is controlled for, and de-prescribing can commence from then. Thus the expectation of the drug prescription being intended indefinitely without justification is challenged from the start. So big "likes" from me for this tool!* (GP_Participant8)

The focus on the non-pharmacological management first line was welcomed.

> *"The antipsychotic monitoring tool looks excellent. I like the way that non-pharmacological management strategies tried is up at the top, as first line management, as per current expert guidelines. It should focus the minds of nursing staff too on this point… I think I will be using this tool from now on, and the nursing homes we look after I think would be positive about it too. Like others, I have been overestimating the benefits of antipsychotic meds for BPSD. Thank you for this tool.* (GP_Participant6)

The participants did highlight some potential challenges of implementing a formal repeat prescribing policy for monitoring antipsychotic prescribing in BPSD. These challenges pertained largely to difficulties managing the expectations of the nursing staff.

> *"I insist on having a copy of the kardex beside me, so I can keep the computer prescribing data accurate. I am not good at deprescribing and I find the nurses very resistant to lowering doses. But I will try harder."* (GP_Participant9)

> *"It's easier to deprescribe if the nursing home encourages it."* (GP_Participant10)

> *"I think re lowering does, a lot depends on the nurse you're dealing with. In both NHs we deal with I find the Matrons very amenable to reducing doses, and quite often if nurses on the wards have asked to increase doses the matron will say lets hold tough for a while and see if things will settle. Makes a big difference when you're both on the same page!"* (GP_Participant2)

This challenge was exacerbated when there was frequent turnover of staff.

> *"… [speaking about the director of nursing] her replacement just started -- she is very helpful -- but dealing with a different person who is not that familiar with the patients is not ideal"* (GP_Participant11)

Not knowing the residents prior to their entry into the nursing home was also flagged as a challenge when attempting to deprescribe or reduce antipsychotic medications.

> *"I find it extremely difficult when a new patient arrives and despite extensive notes it is very difficult to become familiar with all the issues -- medically, socially and psychologically."*

Another challenge identified was that some nursing homes did not have the appropriate environment or infrastructure to manage BPSD.

> *Unfortunately, our very expensive newly revamped community hospital is not dementia friendly and they actively discourage patients with BPSD. There is a long way to go before the HSE puts its house in order by providing leadership to ensure that care for our dementia patients is patient and family-centered and safe.* (GP_Participant3)

The audit tool was positively also positively received.

> *"I had decided to do the audit on the use of anti-psychotics. This will be most useful.*" (GP_Participant5)

However, there was less comments on the audit tool when compared to the repeat prescribing tool. Therefore, during a face-to-face study run as part of the dementia module I outlined the audit tool in more detail with the module participants (n=16). Overall, the participating GPs were unsure whether pharmacists would provide the necessary information. They were also unsure whether nurses would be resistant to potential withdrawal of antipsychotic medications that could result from the monitoring process.

3. Feedback from Nursing Staff

Aim

To discuss the acceptability of the intervention from the perspective of the director of nursing in a nursing home and to use these insights to refine the intervention developed.

Methods

I approached two directors of nursing that I identified as being part of a national guideline development group for prescribing in dementia. They both agreed to review the intervention developed and provide feedback on their perspectives on the intervention.

One interview was conducted in a face to face meeting. The other interview was a telephone interview. Both interviews were approximately 30 minutes in duration.

Results

The main barrier the nurses saw to the successful implementation of the intervention was lack of engagement from the GP.

"If I went to [the visiting GP] with that form, I think he would throw his toys out of the pram."

The nurses themselves felt there wouldn't be any significant barriers from the perspective of the nursing home, once the GPs were on board. In order to maximise the likelihood that the GPs would engage with the intervention both nurses felt that the majority of the paperwork should be completed by the nursing staff:

"*You know, if we've the work done for them and it's in an accessible format… if it's complicated and they've to do the work then it won't happen. I think from a nursing perspective if we can educate the nurses and we can have it [the data for the monitoring] ready for the GPs then there won't be a problem."*

A number of suggestions were made on how the repeat prescribing tool could be improved upon and the following refinements were made to the repeat prescribing tool based on suggestions from the nurses.

- A space was added to document who initially prescribed the medication (if known) i.e. GP or old age psychiatrist or geriatrician
- An option was included in the initial review to indicate if the antipsychotic medication was altered (not just continued or discontinued).

A significant refinement that was made as a result of the interviews with the two nurses was that an additional table was added to the back of the monitoring tool. This table included information that the GP would need to conduct the audit. Another benefit of this table was that it effectively dealt with the situation where a resident was on multiple antipsychotics. The nurse who made this suggestion highlighted the benefit in terms of *"reducing paperwork"* and "*keeping all the information on the one sheet",* in order to decrease any negative reaction from the GP.

Apart from a certain level of apprehensiveness that the GP would not engage with the intervention the nurses were positive about it. Specifically, they felt that the regulatory body HIQA "*would be delighted".*

Supplementary Material 20. Outline of Interprofessional Education Session

Proposed duration: 50 minutes

Location: Nursing home where intervention being delivered

Attendees: Visiting GP(s), Nursing home staff (all staff should be encouraged to attend, in particular director of nursing, nurses, care assistants)

Facilitated by: GP and nurse that have attended relevant 'train the trainer' session

Supporting documents: A full facilitator's guide will be provided to facilitators with supporting PowerPoint slides.

Brief outline of Interprofessional Education Session*

*Allow for discussion and encourage group interaction throughout.

1. A typical case of a nursing home resident with dementia presenting with symptoms of dementia will be presented. *(5 mins)*

2. Explain concept of BPSD as means of communicating an 'unmet need'. Provide an approach to assessing this man for potential triggers / unmet needs. This will be detailed in the facilitators guide but example of approach to assessment provided here. *(10 mins)*

P	Physical problems e.g. infection, pain
A	Activity-related e.g. dressing, washing
I	Iatrogenic e.g. side effects of drugs
N	Noise & other environmental factors e.g. lighting

3. Outline some potential non-pharmacological strategies that could be employed in the case presented *(5 mins)*

4. Discuss risk/ benefit of psychotropic medications *(5 mins)*

5. Role for monitoring and attempting withdrawal of antipsychotics *(20 mins)*

- introduce monitoring tool, demonstrate use & distribute amongst participants

-introduce audit tool, demonstrate use & distribute amongst participants

- allow for questions/ discussion

6. Provide links to online resources on www.dementiapathways.ie *(5 mins)*

Supplementary Material 21. Audit Template

Audit Standard

Antipsychotic medication in people with dementia should be regularly reviewed, and the outcome of the review should be documented in the clinical records. The review should take account of a) therapeutic response and b) possible adverse effects. *(NICE Guideline on supporting people with dementia and their carers in health and social care)*

Specifically this audit aims to introduce structured monitoring for nursing home residents on antipsychotic medication for the management of behavioural and psychological symptoms of dementia (BPSD). The audit aims to ensure that these residents have a review of the effectiveness and continued need of the medication prescribed:

- 6 weeks after initial prescription
- 3 monthly thereafter

Audit Cycle 1 (initial data to be collected)

Step 1. Ask providing pharmacist to provide a list of all residents in the nursing home on an antipsychotic medication, including the antipsychotic name, dose and duration.

Step 2. From this list identify residents who have been prescribed an antipsychotic for the management of behavioural and psychological symptoms of dementia (BPSD)

- Exclude residents who have been prescribed an antipsychotic medication for a pre-morbid mental health illness

Step 3*. From this list of residents with BPSD who are on an antipsychotic identify from the notes whether the antipsychotic was reviewed with the outcome of the review documented.

(i) 6 weeks after initial prescription (if prescription was initiated in the nursing home)

(ii) Every 3 months thereafter

*Table 1 in this document provides example of how this data can be recorded. This table, once completed would provide the results for cycle 1 of the audit.

Description of change to be implemented

Introduce the repeat prescribing monitoring tool.

- For each resident identified in Step 2 ask the nursing staff to add the repeat prescribing tool to their medical notes.

- Introduce a schedule for how each of these residents will have their monitoring tool completed over the next few months; e.g. agree that at the end of each structured visit to the nursing home the nurse in charge and the doctor will collaboratively review the antipsychotic prescribing to 3 residents, using the monitoring tool as a guide and for documentation purposes.
- Once all residents on the list have had their antipsychotic medication reviewed by this process, schedule an ongoing 3 monthly review date with the nurse in charge for all the residents with dementia on antipsychotic medication.
    - In advance of this scheduled 3 monthly review the nursing staff will send the providing pharmacy the current list of residents with dementia on an antipsychotic and the pharmacy will update this list as necessary.
    - If a decision is made to reduce or withdraw the antipsychotic medication advice on doing this is available in the BPSD section of the clinical resource menu on this website: www.dementiapathways.ie

Audit Cycle 2 (results of data collection post change)

For audit cycle 2**

Repeat steps 1 – 3 as outlined in audit cycle 1

Step 4. Add an additional columns to your data collection table (as shown in table 2 of this document) indicating whether or not the residents antipsychotic medication is now being reviewed within the recommended time frames, whether the residents remains on the antipsychotic and at what dose

**Ideally there would be a significant time interval from conducting audit cycle 1 to conducting audit cycle 2 to allow for the intervention to be implemented and any potential impact assessed. We would recommend a 6 month interval if possible.

Step 5. Draw conclusions as to what the impact of the change implemented has been.

Table 1. Example of table for data collection for audit cycle 1

Resident's name	Name of antipsychotic prescribed	Date commenced	Current dose	Documented evidence of monitoring of effectiveness	Review of effectiveness documented within 6 weeks of initial prescription	Documented evidence of monitoring every 3 months
B.H	Risperidone	Unknown – prior to NH admission	1mg OD	No	N/A	No
T.O.R	Quetiapine	21st Oct 2017	50mg	Yes – mentioned in notes	No	No

Table 2. Example of table for additional data collected for audit cycle 2

Resident's name	Name of antipsychotic prescribed	Date commenced	Current dose	Documented evidence of monitoring of effectiveness	Review of effectiveness documented within 6 weeks of initial prescription	Evidence of monitoring every 3 months	Is there a documented plan for the monitoring of this resident's AP?	Is the monitoring occurring within the recommend-ed timeframe?	Has there been any changes made to the AP dose?
B.H	Risperidone	Unknown – prior to admission to NH	1mg OD	No	N/A	No	Yes – the monitoring tool completed	Yes – 3 monthly	No – remains on 1mg OD
T.O.R	Quetiapine	21st Oct 2017	50mg	Yes – mentioned in notes	No	No	Yes - the monitoring tool is completed	No but timeframe of cycle 2 did not allow for same. Plan in place	Yes – successfully reduced to 25mg

Supplementary Material 22. IPCRN Software Finder Tool

If the nursing home's medical records are integrated with the electronic monitoring record system of the providing GP then the GP can avail of the following software finder tool to facilitate the conduction of the audit. The GP must be using one of the following GP practice systems to avail of this software finder tool; Socrates, Helix Practice Manager or HealthOne. These account for 3 of the 4 approved accredited software systems and cover the majority of Irish GP practices. >90% of Irish GP practices are computerised and approx. 95% of computerised practices use of the 4 accredited software packages. [45]

1. If not already signed up to IPCRN the providing GP needs to sign up to the IPCRN (Irish Primary Care Research Network) via their website www.ipcrn.ie

2. Once signed up the GP can go to the iPCRN tab on their practice software.

3. They will be asked if they wish to create a list of all the patients in the practice with dementia. The software finder tool built will then search through all patients who are either

    (i) Coded with dementia (either coded with ICPC code or with any of the possible ICD10 codes*)

    OR

    (ii)Any patient on any of the three cholinesterase inhibitors (donepezil, galantamine, rivastigmine) or on mematine. (Since these medications are only indicated in dementia).

    This will generate a list of patients in the practice with a diagnosis of dementia, however, it is possible that some patients who have not had their diagnosis coded or that are not on a cholinesterase inhibitor/ memantine may be missed.

4. Once this list has been created the GP will be able to generate an internal report that lists all these patients and any antipsychotic medication they are currently prescribed and the dose. **

5. They will then be asked if they wish to upload anonymised data to the IPCRN server. This is an optional step. No patient identifying data is included in this upload. This upload will enable the IPCRN to generate a report which will be emailed back to the practice in the form of an EXCEL spreadsheet.

*The list of potential ICPC or ICD10 codes searched for

ICPC (international classification of primary care): only one possible code for dementia in ICPC - P70 Dementia

ICD10 (international classification of diseases – version 2010): multiple potential codes for dementia - F00, F05.1**,** F00.0**,** F05.9**,** F00.1**,** F06.0**,** F00.2**,** F06.7, F00.9**,** F10.7, F01**,** G30**,** G30.8**,** G30.9**,** F01.1, G30.0, F01.2, G30.1, F01.3**,** G31.0**,** F01.8, G31.1**,** F01.9**,** G31.8**,** F02**,** F020, F02.1**,** F02.2 **,** F02.3, F02.4, F02.8**,** F03

** The list of antipsychotic medication that is searched for

ATC	**Generic name**
N05AH04	Quetiapine
N05AD01	Haloperidol
N05AB06	Trifluoperazine
N05AX08	Risperidone
N05AH03	Olanzapine
N05AB02	Fluphenazine
N05AH02	Clozapine
N05AA01	Chlorpromazine
N05ALO5	Amisulpride
N05AX12	Aripiprazole
N05ALO1	Sulpiride
N05AF05	Zuclopenthixol
N05AD07	Benperidol
N05AF01	Flupentixol

Supplementary Material 23. The TIDieR Checklist

Information to include when describing an intervention and the location of the information

Item number	Item	
	BRIEF NAME	
1.	Provide the name or a phrase that describes the intervention.	Intervention to improve the monitoring of antipsychotic medication in people with dementi
	WHY	
2.	Describe any rationale, theory, or goal of the elements essential to the intervention.	This intervention was developed using the Behaviour Change Wheel (BCW) and aims to improve general practitioners (GPs) management of behavioural and psychological symptoms of dementia (BPSD) by improving the monitoring of antipsychotic medication prescribed for BPSD in nursing homes.
	WHAT	
3.	Materials: Describe any physical or informational materials used in the intervention, including those provided to participants or used in intervention delivery or in training of intervention providers. Provide information on where the materials can be accessed (e.g. online appendix, URL).	The intervention includes: (1) An interprofessional educational session with GPs and nursing home staff. (2) A repeat prescribing tool to monitor the prescribing of antipsychotic medication in general practice. (3) A audit template to enable GPs to conduct an audit of their antipsychotic prescribing (4) If medical records in the nursing home are electronic and remotely integrated with the GP's practice software a software finder tool can be used to create a list of people with

		dementia and to identify if they are on an antipsychotic and the dose prescribed, further facilitating completion of an audit. The above materials are available to view as appendices to this PhD chapter and the final published paper. They will also be made available on the following website; www.dementiapathways.ie
4.	Procedures: Describe each of the procedures, activities, and/or processes used in the intervention, including any enabling or support activities.	The interprofessional educational session will be provided by two upskilled facilitators; a GP and a nurse. The GP and nurse will have previously participated in a 'train the trainer' session prior to delivering the interprofessional educational session. The education session will cover key aspects of BPSD management that were identified as being barriers to monitoring antipsychotic prescribing in BPSD; the assessment of BPSD, the risk/benefits of psychotropic medications, monitoring and withdrawal of antipsychotic medications. The GPs will be incentivised to attend the meeting by receiving external CPD points. The repeat prescribing tool and the audit template will be introduced in the educational session allowing a format to answer any questions on how to use them. Each resident with dementia currently on an antipsychotic medication or initiated on an antipsychotic medication in the future will have a copy of the repeat prescribing tool in their chart. In the three monthly medication review this chart will be consulted and updated jointly by the prescribing physician and the nurse.

		The providing pharmacist will provide feedback on the antipsychotic medication in the nursing home every three months. This feedback will support GPs in conducting an annual audit of their antipsychotic. GPs will be further supported in this task by the audit template which will function as a 'how to guide'. The GPs will be incentivised in this task as the audit will meet the GPs annual continuous professional development (CPD) requirement that they must conduct an annual audit.
	WHO PROVIDED	
5.	For each category of intervention provider (e.g. psychologist, nursing assistant), describe their expertise, background and any specific training given.	Criteria for the GP and nurse facilitating the IPE session 1. Have experience of managing BPSD in a nursing home setting. 2. Be available to attend the 'train the trainer' sessions 3. Be available to provide feedback to the research team on acceptability or feasibility issues with the intervention The facilitators will be trained by the research team in a 'train the trainer' session. They will provided with a facilitator guide and with slides for presentation to staff.
	HOW	
6.	Describe the modes of delivery (e.g. face-to-face or by some other mechanism, such as internet or telephone) of the intervention and whether it was provided individually or in a group.	All nursing staff, care assistants and GPs in the nursing home will be invited to attend the face-to-face interprofessional education session. The facilitators will work from a pre-developed facilitators guide. In that session the other two components of the intervention – the repeat prescribing tool and the audit template will be introduced by the facilitators.

	WHERE	
7.	Describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features.	The intervention will take place in nursing homes.
	WHEN and HOW MUCH	
8.	Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose.	The educational interprofessional session will be delivered once and last approx. one hour. The antipsychotic monitoring tool will be introduced for each patient with dementia who is on an antipsychotic and will reviewed every 3 months as part of the resident's medication review. The audit will be conducted on an annual basis.
	TAILORING	N/A (intervention not yet delivered).
9.	If the intervention was planned to be personalised, titrated or adapted, then describe what, why, when, and how.	
	MODIFICATIONS	N/A (intervention not yet delivered).
10.‡	If the intervention was modified during the course of the study, describe the changes (what, why, when, and how).	
	HOW WELL	N/A (intervention not yet delivered).
11.	Planned: If intervention adherence or fidelity was assessed, describe how and by whom, and	

	if any strategies were used to maintain or improve fidelity, describe them.	
12.‡	Actual: If intervention adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned.	

Appendix 7. Research training

February 2016	PG 6008 Qualitative data analysis, UCC
April 2016	PG7016 Systematic Reviews for the Health Sciences (5 Credits), UCC
March 2017	PG6024 Qualitative Research Inquiry (5 Credits), UCC
October 2017	Designing Effective Interventions for Behaviour Change I, School of Psychology, National University of Ireland Galway (NUIG)
February 2018	Designing Effective Interventions for Behaviour Change II, School of Psychology, NUIG
May 2018	Certificate in Teaching & Learning (30 Credits), UCC
April -July 2018	Introduction to Statistics for Health Care Research, Oxford University
July 2018	PG7048, Transferable Skills Portfolio (5 Credits), UCC

Appendix 8. Prizes and awards relating to doctoral research

Awarded the Irish College of General Practitioners Career Research Award - €45,000 over 3 years. This was a peer-reviewed, competitive grant awarded in September 2017. I was the sole recipient of this grant.

James McCormick Prize for Best Research Project at Association of University Departments of General Practice (AUDGPI) and Irish College of General Practitioners (ICGP) Joint Scientific Meeting, March 2018 for research on "General practitioners knowledge of, attitudes towards and experiences with behavioural and psychological symptoms of dementia: a mixed methods systematic review"

AUDGPI Bursary for Best Presentation at AUDGPI & ICGP Joint Scientific Meeting March 2018 for presentation on "General practitioners knowledge of, attitudes towards and experiences with behavioural and psychological symptoms of dementia: a mixed methods systematic review"

Awarded ICGP research paper of the year at the 2018 ICGP AGM, Dublin for the paper "Working away in that grey area…" A qualitative exploration of the challenges general practitioners experience when managing behavioural and psychological symptoms of dementia. Published in Age & Ageing.

Awarded Junior Researcher prize at Society for Academic Primary Care ASM in London in 2018 receiving a bursary to attend North American Primary Care Research Group (NAPCRG) conference. Prize was awarded for my presentation on "General practitioners knowledge of and attitudes towards pain management in dementia"

Appendix 9. Dissemination of doctoral research

Peer-reviewed publications

Jennings AA, Foley T, Walsh KA, Coffey A, Browne JP, Bradley CP. General practitioners' knowledge, attitudes and experiences of managing behavioural and psychological symptoms of dementia: protocol of a mixed methods systematic review and meta-ethnography. *Systematic Reviews.* 2018;7:62.

Jennings AA, Foley T, Walsh KA, Coffey A, Browne JP, Bradley CP. General practitioners' knowledge, attitudes, and experiences of managing behavioural and psychological symptoms of dementia: A mixed-methods systematic review. *Int J Geriatr Psychiatry.* 2018;33(9):1163-1176.

Jennings AA, Foley T, McHugh S, Browne JP, Bradley CP. 'Working away in that Grey Area...' A qualitative exploration of the challenges general practitioners experience when managing behavioural and psychological symptoms of dementia. *Age Ageing.* 2018;47(2).

Jennings AA, Linehan M, Foley T. The knowledge and attitudes of general practitioners to the assessment and management of pain in people with dementia. *BMC Fam Pract.* 2018;19(1):166.

Jennings AA, Guerin N, Foley T. Development of a tool for monitoring the prescribing of antipsychotic medications to people with dementia in general practice: a modified eDelphi consensus study. *Clinical Interventions In Aging.* 2018;13:2107-2117.

Other publications

Aisling A. Jennings. What are GPs' views on BPSD management? *Faculty of Old Age Psychiatry – Royal College of Psychiatrists Newsletter.* January 2018

Aisling A. Jennings. What are GPs' views on BPSD management? British Gerontology Society Newsletter. January 2018

Peer-reviewed abstract publications

Aisling A Jennings, Maura Linehan, Tony Foley. General Practitioners' Knowledge of and Attitude Towards the Assessment and Management of Pain in People with Dementia, *Age and Ageing*, Volume 47, Issue suppl_5, 1 September 2018, Pages v1–v12

Aisling A. Jennings, Tony Foley, Colin P. Bradley. General Practitioners' Perspectives on the Management of Behavioural and Psychological Symptoms of Dementia. *Alzheimer's & Dementia.* July 2017 Volume 13, Issue 7, Supplement, Page P829

Conference proceedings: oral presentations

May 2017 9th International Dementia Conference, Dublin. *The management of BPSD in general practice.*

July 2017 Society of Academic Primary Care, Annual Conference, Warwick University, UK *GPs' perspectives on the management of BPSD.*

Oct 2017 European General Practice Research Network (EGPRN) conference, Dublin, Ireland. *"Working away in that grey Area…" A qualitative exploration of GPs' experiences of managing BPSD.*

March 2018 Association of University Departments of General Practice (AUDGPI) and Irish College of General Practitioners (ICGP) Joint Scientific Meeting, NUIG, Galway, Ireland. *GPs' knowledge of, attitudes towards and experiences with managing BPSD: a mixed methods systematic review and meta-ethnography.*

May 2018 EGPRN (European General Practice Research Network), Lille, France. *GPs' knowledge of, attitudes towards and experiences with managing BPSD: a mixed methods systematic review and meta-ethnography.*

July 2018 Society for Academic Primary Care ASM, London. *GPs knowledge of and attitudes towards pain management in dementia: a descriptive cross-sectional study.*

Society for Academic Primary Care ASM, London. *GPs' knowledge of, attitudes towards and experiences with managing BPSD: a mixed methods systematic review and meta-ethnography.*

Sept 2018 Irish Gerontology Society ASM, Cavan, Ireland. *GPs knowledge of and attitudes towards pain management in dementia: a descriptive cross-sectional study*

Conference proceedings: poster presentation

March 2017 14th Annual Psychology, Health and Medicine Conference, RCSI, Dublin, Ireland. GPs' perspectives on the management of behavioural and psychological symptoms of dementia.

July 2017 Alzheimer Association International Conference (AAIC), London. General Practitioners Perspectives on the Management of Behavioural and Psychological Symptoms of Dementia.

Sept 2018 Irish Gerontology Society ASM, Cavan, Ireland. Development of a tool for monitoring the prescribing of antipsychotic medications to people with dementia in general practice: a modified eDelphi consensus study.

Oct 2018 Alzheimer's Europe annual conference, Barcelona, Spain. Development of a tool for monitoring the prescribing of antipsychotic medications to people with dementia in general practice: a modified eDelphi consensus study.

Oct 2018 Alzheimer's Europe annual conference, Barcelona, Spain. *GPs' knowledge of, attitudes towards and experiences with managing BPSD: a mixed methods systematic review and meta-ethnography.*

Invited presentations

May 2018 Irish College of General Practitioners (ICGP) AGM & Summer School, Dublin

Managing Agitation in Dementia: The Evidence and The Reality; is there a middle ground?

Oct 2018 Association of University Departments of General Practice in Ireland (AUDGPI) Early Career Research Day, University of Limerick

The 'nearly there' PhD: surviving a higher degree

Appendix 10. Additional academic activity conducted during this research

Peer-reviewed publications

Jennings AA, McLoughlin K, Boyle S, Thackeray K, Quinn A, O'Sullivan T, Foley T. Development and evaluation of a primary care interprofessional education intervention to support people with dementia. *Journal of Interprofessional Care. [In press]*

Jennings AA, Boyle S, Foley T. The development and evaluation of an online dementia resource for primary care based health professionals. *Internet Interventions.* 2018;11:47-52.

Foley T, **Jennings A,** Boyle S, Smithson WH. The development and evaluation of peer-facilitated dementia workshops in general practice. *Education for Primary Care.* 2018;29(1):27-34.

Foley T, Boyle S., **Jennings A.,** Smithson W. H. "We're certainly not in our comfort zone": a qualitative study of GPs' dementia-care educational needs. *BMC Fam Pract.* 2017;18(1):66.

McLoughlin K, Pope L, Walsh E, **Jennings A**, Foley T. The MRCGP Clinical Skills Assessment: an integrative review of evidence. *Education for Primary Care.* 2018:1-7.

Foley T, McLoughlin K, Walsh EK, **Jennings AA**. The candidate perspective of the clinical competency test (CCT) of the MICGP examination: a mixed-methods study. *BJGP Open.* 2018.

Other publications

Jennings A. Online Educational Initiative on Dementia. *Forum Journal.* 2017;34(2):18.

Peer-reviewed abstract publications

Aisling A. Jennings, Siobhán Boyle, Tony Foley. The development and evaluation of an online dementia supports directory for primary care. *International Journal for Integrated Care.* 2017; 17(5), A201, pp1-8

Siobhan Boyle, Anne Quinn, Katherine Thackeray, Kathleen McLoughlin, **Aisling Jennings**, Tony Foley. Development and Evaluation of a Dementia Education Workshop for Primary Care Teams in Ireland, *Age and Ageing*, 2017; Volume 46, Issue Suppl_3, Pages iii13–iii59,

Tony Foley, Cormac Sheehan, Trish O' Sullivan, **Aisling A. Jennings** What do Physiotherapists Need to Know about Dementia Care? A Focus Group Study. *Age and Ageing*. 2018; 47 (suppl_5)

Ruby Chang, **Aisling A. Jennings,** Tony Foley. Developing Curricular Priorities for a Dementia Module for General Practitioners Using an eDelphi Consensus. *Age and Ageing*. 2018; 47(suppl_5)

Reports

McLoughlin, K., Thackeray, K., **Jennings, A.,** Boyle, S. and Foley, T. (2017). A guide to clinical audit of dementia care in General Practice: A Guide Developed for the ICGP. https://www.icgp.ie/go/pcs/scheme_framework/clinical_audit

Tony Foley, **Aisling Jennings,** W Henry Smithson, Kathleen Mc Loughlin. Educational interventions to improve the diagnosis and management of dementia in general practice: a protocol for a systematic review of empirical literature. PROSPERO 2017:CRD42017073142

Foley T, **Jennings A.** Dementia Care in General Practice: Facilitator's Guide for GP workshop. Primary Care Education, Pathways and Research of Dementia (PREPARED). 2016 http://dementiapathways.ie/_filecache/d43/336/634-gp-facilitator-workshop-guide.pdf

Foley T, **Jennings A.** Dementia Care in Primary Care - an Interprofessional Approach: Facilitator's Workshop Guide. Primary Care Education, Pathways and Research of Dementia

(PREPARED). 2017 http://dementiapathways.ie/_filecache/d74/b0c/627-pct-guide-for-workshop-faciliatators.pdf

Conference proceedings: oral presentations

May 2017 — 9th International Dementia Conference, Dublin. The development and evaluation of www.dementiapathways.ie an online dementia resource for primary care based health professionals.

Feb 2017 — INMED (Irish Network of Medical Educators) Annual conference, UCC, Cork. Development and Evaluation of an Interprofessional Dementia Education Workshop for Primary Care Teams

Conference proceedings: poster presentations

May 2017 — International Conference on Integrated Care (17th IFIC), Dublin, Ireland. The development and evaluation of an online dementia supports directory for primary care.

Sept 2018 — Irish Gerontology Society ASM, Wexford, Ireland. Development and Evaluation of a Dementia Education Workshop for Primary Care Teams in Ireland

Sept 2018 — Irish Gerontology Society ASM, Cavan, Ireland. What do Physiotherapists Need to Know about Dementia Care? A Focus Group Study.

Sept 2018 — Irish Gerontology Society ASM, Cavan, Ireland. Developing Curricular Priorities for a Dementia Module for General Practitioners Using an eDelphi Consensus.

Oct 2018 — Alzheimer's Europe annual conference, Barcelona, Spain. Development and Evaluation of a Dementia Education Workshop for Primary Care Teams in Ireland

Invited presentations

May 2018 Irish Gerontology Society - Interdisciplinary Education Symposium, Dublin

Enhancing interdisciplinary dementia care by learning and working together - our experience in PREPARED.

Research funding awards

Oct 2018 Co-applicant on grant awarded by the Alzheimer's Society of Ireland for a policy paper on dementia and loneliness

Appendix 11. Other professional activities

During the three years of my PhD, in addition to working GP work and my work on the PREPARED project, which is outlined in Chapter 1, I was also was involved in a number of other professional activities. Here is a brief outline of some of the additional professional activities in which I was engaged over the past three years.

1. The Irish College of General Practitioners (ICGP), Quality in Practice (QIP) Dementia Guide.

I contributed to the update and revision of the ICGP QIP Dementia Guide. This document has been approved by the QIP committee of the ICGP and will shortly be available to all GPs via the ICGP website.

2. The ICGP Nursing Home Group

I was involved in the establishment of a nursing home group within the ICGP. It is a national network of GPs who are involved in the provision of nursing home care. The group meets twice yearly for educational sessions and has an active online discussion forum. I am on the education sub-committee of this group.

3. Cork GPs with a Special Interest in Dementia Care

I was a founding member of this group of Cork GPs who have an interest in dementia care. I am currently the elected secretary for this group. The group, which is still establishing, meets every three months and discusses cases and reviews latest evidence in dementia care. The group is currently planning a collaborative audit of their dementia care.

4. Organised GP Dementia Study Days in UCC 2017 & 2018

As part of my role as module co-ordinator of an online blended learning GP dementia module I have arranged four successful dementia study days for GPs in UCC in 2017/18.

5. Member of the website reference group for the HSE Understand Together website

Invited to be the GP representative on the website reference group for the HSE public awareness campaign entitled Understand Together. http://www.understandtogether.ie/

6. National Dementia Office guideline development group – the development of evidence based guidelines on the appropriate prescribing of psychotropic medications in BPSD

As outlined in the thesis, I was invited to be the GP representative on this guideline development group. I was also one of five people on the writing group of this guideline.

7. ICGP Research Committee

Member of the ICGP research committee from March 2018 to present. This committee meets every three months and its aim is to develop and support research in general practice in Ireland.

8. Undergraduate & postgraduate teaching, University College Cork

I lectured on the following undergraduate modules; HC1002, HC2002, CP3105, GP4000 and on the postgraduate Masters in Dementia care. I also supervised the research projects of three undergraduate final year medical students.

9. Peer-reviewing

I regularly peer-review for the following journals; BMJ Open, BMC Family Practice, International Journal of Geriatric Psychiatry and The Irish Medical Journal.

Appendix 12 Relevant peer-reviewed publications

This appendix provides the full text of the following papers that were components of this thesis:

1. **Jennings AA**, Foley T, Walsh KA, Coffey A, Browne JP, Bradley CP. General practitioners' knowledge, attitudes and experiences of managing behavioural and psychological symptoms of dementia: protocol of a mixed methods systematic review and meta-ethnography. *Systematic Reviews.* 2018;7:62.

2. **Jennings AA**, Foley T, Walsh KA, Coffey A, Browne JP, Bradley CP. General practitioners' knowledge, attitudes, and experiences of managing behavioural and psychological symptoms of dementia: A mixed-methods systematic review. *International Journal of Geriatric Psychiatry.* 2018;33(9):1163-1176.

3. **Jennings AA**, Foley T, McHugh S, Browne JP, Bradley CP. 'Working away in that Grey Area...' A qualitative exploration of the challenges general practitioners experience when managing behavioural and psychological symptoms of dementia. *Age & Ageing.* 2018;47(2).

4. **Jennings AA**, Linehan M, Foley T. The knowledge and attitudes of general practitioners to the assessment and management of pain in people with dementia. *BMC Family Practice.* 2018;19(1):166.

5. **Jennings AA**, Guerin N, Foley T. Development of a tool for monitoring the prescribing of antipsychotic medications to people with dementia in general practice: a modified eDelphi consensus study. *Clinical Interventions In Aging.* 2018;13:2107-2117.

The following papers, which were published during the conduct of my PhD, are also included in this appendix. Although these papers did not directly contribute to my PhD, they do provide relevant supporting data and are discussed in my thesis.

6. Foley T, Boyle S., **Jennings A.,** Smithson W. H. "We're certainly not in our comfort zone": a qualitative study of GPs' dementia-care educational needs. *BMC Family Practice.* 2017;18(1):66.

7. Foley T, **Jennings A**, Boyle S, Smithson WH. The development and evaluation of peer-facilitated dementia workshops in general practice. *Education Primary Care.* 2018;29(1):27-34.

8. **Jennings AA**, Boyle S, Foley T. The development and evaluation of an online dementia resource for primary care based health professionals. *Internet Interventions.* 2018;11:47-52.

9. **Jennings A,** McLoughlin K, Boyle S, et al. Development and evaluation of a primary care interprofessional education intervention to support people with dementia. *Journal of Interprofessional Care.* 2018:1-4.