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Caring for those living with dementia

Appreciating perspectives for rural primary care teams

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Caring for those living with dementia: appreciating perspectives for rural primary care teams

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Table of Contents

Acknowledgments.....	iii
List of Figures	ix
Abbreviations.....	x
Abstract.....	1
Background and introduction	1
Methodology.....	2
Results.....	2
Discussion & Conclusions.....	3
Outputs arising from this research	5
Conference presentations.....	5
Chapter 1: Introduction and Background	6
Introduction	6
Background	6
The needs of ageing populations	6
Long Term Conditions	7
Dementia.....	8
Providing care for patients with dementia	10
Population changes in rural settings.....	12
Implications for healthcare delivery in rural settings	12
Health Care Professionals in rural settings	14
Dementia in the rural setting.....	14
Rural carers for patients with dementia	16
Conclusion.....	16
Chapter 2: Review	18
Basis for scoping literature review.....	18
Aim of scoping review.....	18

Scoping review methods.....	18
Review question.....	19
Search process	19
Inclusion criteria.....	20
Exclusion criteria	20
Selection process	20
Data extraction	21
Results of scoping review.....	21
Overview of included articles.....	22
Provision of Services	24
The spatial dimensions of geography	25
Norms of community values	26
Specialist knowledge regarding dementia.....	27
Community support network and services.....	28
Summary and gaps in knowledge	29
Chapter 3: Methodology and Methods	30
Research aim.....	30
Research objectives	30
Methodology.....	31
Choice of method for this study	32
Semi structured interviews	33
Focus groups	33
Methods.....	34
Study design.....	34
Context and setting of study.....	35
Study subjects	35
Study sample.....	35
Inclusion / Exclusion criteria	35

Sample strategy / recruitment.....	35
Data Collection.....	36
Data analysis	38
The rationale behind the choice of template analysis.....	39
Research Governance	40
Data Quality Assurance and Security.....	40
Ethical considerations	41
Chapter 4: Considering Reflexivity.....	42
Chapter 5: Results.....	44
Derivation of the starting coding template	44
Formal and informal care and support services	46
Carers and support services.....	46
Informal caring roles and the dynamics of family.....	48
The journey to diagnosis.....	51
Health care professionals’ perceptions of the diagnostic process	51
Involvement of the entire primary care team in this patient journey.....	55
Aspects of rural living.....	58
Farming and economic implications	58
The challenge of geography.....	60
Potential future innovations	61
Capitalising on rural community assets	61
Further thoughts for improvement	64
Chapter 6: Discussion.....	65
Diagnosis and management of dementia	66
Education	68
Role of non-medical members of the rural primary care team.....	68
Provision of services.....	69
Carers	71

The spatial dimensions of geography	71
Farming	72
Key implications	75
Limitations	74
Chapter 7: Conclusions	77
Chapter 8: Personal Reflections.....	80
References	Error! Bookmark not defined.
Appendix 1- Data capture table of scoping review articles	89
Appendix 2 – Invitation letter	93
Appendix 3 – Consent forms.....	94
Appendix 4 – Focus group schedule	96
Appendix 5 – Starting coding template	98
Appendix 6 – Revised coding template.....	101
Appendix 7 – Focus group 1 transcript	104
Appendix 8 – Focus group 2 transcript	116

List of Figures

Figure 1: A pie chart showing the types and prevalence of dementia in the UK in 2014.....	9
Figure 2: Prisma Diagram of the scoping review literature search.....	22

Abbreviations

AD- Alzheimer's disease

BPS- British Psychological Society

DN- District nurse

GP – General Practitioner

GPCOG- General Practitioner assessment of cognition

LBD- Lewy body dementia

LTC- Long term conditions

PCT- Primary care team

PDD- Parkinson's Disease Dementia

PM- Practice manager

SW- Social worker

WHO- World Health Organisation

Abstract

Background and introduction

Concerns about managing the healthcare needs of an aging population are growing. Significant among these relate to dementia and its impact on the individual, caregivers and healthcare system. It is estimated that 850,000 people are living with dementia in the UK. This figure is expected to grow rapidly by up to 146% by 2050. The consequent health and social care expenditure on services for people with dementia could be expected to double within 20 years. Currently in the UK 61% of people living with dementia do so in the community, with only 39% in care homes, with the primary care team the first point of call for these patients. Currently in Northern Ireland there are 14, 728 people living with a diagnosis of dementia. According to the dementia statistics hub from 2006/07 to 2015/16 the number of people on the dementia register rose from 9,500 to 13,617, an increase of 43%.

Official figures show that the rural population in the UK will increase by 6 per cent over the next decade. Challenges for people in these areas include transport to services eg hospital appointments in urban areas, expense of travel, isolation and loneliness.

The double impact of living with dementia and rural isolation can lead to negative impact on QOL and health. People with dementia often stop doing things they enjoy in the community as their disease progresses, due to lack of understanding, stigma and inaccessible environments and support facilities. This is compounded for people living in a rural community.

A broad literature search was carried out which revealed that some studies have been done to assess the challenges for carers of patients with dementia in rural areas but less information was available looking at challenges for rural primary care teams.

A subsequent scoping literature review was carried out which posed the question; what is known in the literature about challenges for rural primary care teams in providing care for patients with dementia? The main perceived challenges related to geography, lack of both specialist and community resources, the stigma attached to a small rural community and distance to services. The studies in this review were mainly all pertaining to rural physicians i.e. doctors. It appears that there is a paucity of published literature looking at the multidisciplinary primary care team as a whole. In addition to this there were only a

small number of published studies in the UK and Ireland in this area and none were found that specifically addressed challenges for rural primary care teams looking after patients with dementia in Northern Ireland.

Methodology

The overall aim of this study was to identify challenges for the rural primary care teams in Northern Ireland in providing care for patients with dementia and suggest ways in which care might be improved.

A qualitative approach was carried out involving focus groups consisting of members of multidisciplinary primary care teams in Northern Ireland. The data collected was transcribed, coded and analysed using a template analysis method.

Results

Following analysis of the data four main themes emerged. These themes were 1. Sources of formal and informal care and support (which included the input of carers and support services, and the dynamics of family input) 2. The journey to diagnosis (including healthcare professionals' perceptions of the diagnostic process and the involvement in this of the entire primary care team) 3. Aspects of rural living (including the challenges of geography with insight to the complications of living with dementia within farming families) 4. Suggestions for future innovations (included examples of capitalising on assets already existing within the community).

Some findings from the focus groups echoed those found in the literature, for example the challenge of geography and lack of support services in rural areas. The primary care teams in the focus groups found that length of time to diagnosis was a huge challenge facing patients, their families, carers and the entire healthcare team, with GPs suggesting that the ability to formally diagnose dementia and prescribe medications in primary care would be hugely beneficial. Staff also felt that more community-based staff would be beneficial to support patients with dementia and their families.

Discussion & Conclusions

This study suggested the need for further training and education of all members of the rural primary care team, both medical and non-medical, in the area of dementia and its impact on those living with it, as well as their families and carers. It also highlighted the benefits of community input, from statutory and voluntary sectors. It highlighted that rural primary care team members value the input of these organisations and would be keen to improve the interface with them and welcome them as members of the multidisciplinary primary care team. Members of the groups offered innovative suggestions such as the development of existing community assets such as social farms, of which patients and their families may avail. The data from the focus groups identified the unique and valuable contribution of primary care staff such as receptionists who are very aware of their local community and are the first point of contact for patients to health care services. This suggests that it would be worthwhile for their contribution to be recognised and formalised as an essential element to the overall provision of care for the benefit of the patient and their family.

The difficulties around farming and associated financial complexities which were mentioned in this study had not been previously noted in the literature.

Outputs arising from this research

Conference presentations

2020

“Challenges for rural primary care teams in providing care for patients with dementia – scoping review update”

GP ACF conference Bristol Feb 2020 – oral presentation

Abstracts accepted for Alzheimer’s Society Annual Conference – London, May 2020 and

Society for Academic Primary Care Annual Conference – Leeds, July 2020

(both cancelled due to Covid 19 pandemic)

2019

“Challenges for rural primary care teams in providing care for patients with dementia”

GP ACF conference Manchester – poster presentation

2021

“Challenges for rural primary care teams in providing care for patients with dementia”

AUDGPI March 2021- oral presentation

Chapter 1: Introduction and Background

“The baby boomers are getting older, and will stay older for longer. And they will run right into the dementia firing range. How will a society cope? Especially a society that can't so readily rely on those stable family relationships that traditionally provided the backbone of care?”

Sir Terry Pratchett (Author who lived with a diagnosis of Alzheimer's Disease)

Introduction

As a healthcare profession and as a society as a whole, we know that more people than ever are living longer. As people get older their likelihood of developing of a long term condition increases. Dementia is a long term condition which can have a huge impact not only on the person living with the disease, but their families, friends and carers. For those people who live in rural areas this impact can be felt greatly, with the local primary care team often the first point of call for them particularly in times of crisis. This study aims to both explore and appreciate the challenges for rural primary care teams in providing care for patients with dementia.

Background

The needs of ageing populations

Concerns are growing about managing the healthcare needs of an aging population.(1) National population statistics indicate populations in the United Kingdom and Ireland that are increasingly living into older age. Recent figures from the Office of National Statistics 2018 in England suggest that in fifty years' time there are likely to be 8.5million more people aged 65 and over.(2) As a result of the post-'World War II' baby boom, it is predicted that the numbers of adults over eighty-five in the 2030s will rise quickly. (2) Projections estimate that in 2041 the 1960's 'baby boomers' will be in their seventies or eighties. The ONS 2018 report further highlights this increase in people living longer, stating that “in

1997, around one in every six people (15.9%) were aged 65 years and over. This increased to one in every five people (18.2%) in 2017 and is projected to increase further to around one in every four people (24%) by 2037.” Similarly in Ireland the Department of Finance 2018 report that there are currently around 5 persons of working age for each person aged 65 and over, by 2050 the equivalent figure will be around just over 2.(3)

An enlarging older population presents a number of challenges, including the health and social care needs of people as they get older. In addition to living longer, many people are living with long term conditions which require ongoing review and management by primary and secondary care teams, in their local area. In 2017 Jaun and Barron commented that clinicians and the public health community “need to develop a culture of sensitivity to the needs of this aging population and its subgroups.”(4) They added that when caring for older adults as a clinician or as a caregiver, “predicting the future and planning for the most likely aging trajectories are key steps.”

Long Term Conditions

The World Health Organisation (WHO) defines chronic diseases as “having one or more of the following characteristics: they are permanent, leave residual disability, are caused by non-reversible pathological alteration, require special training of the patient for rehabilitation, or may be expected to require a long period of supervision, observation, or care.”(5) Chronic diseases are increasingly referred to as Long Term Conditions (LTCs). People with LTCs (for example COPD, asthma, diabetes and hypertension) are increasingly more likely to be looked after in specialised clinics based in primary care and run by practice nurses, nurse practitioners or pharmacists. LTCs are now considered a ‘norm’ among the elderly of our population, with 65% of those over 65 and 85% of those over 85 years old having two or more LTCs.(5) In the UK it is estimated that at any one time there are more than 17.5 million people living with at least one LTC. Cardiovascular disease, osteoarthritis, osteoporosis and dementia are common LTCs among older people.

Dementia

Significant among LTCs is the growing prevalence of dementia. Dementia is a term used to describe a collection of symptoms including confusion, memory difficulties, mood changes and difficulty with day-to-day tasks such as dressing, shopping and cleaning, and finances. It is a progressive condition, meaning that over time often the symptoms get worse and patients require increasing care from family, friends, carers and healthcare teams. The variation in symptoms is large and each person can be affected in different ways and each experience will be different.(6)

Recent figures from the Dementia Statistics hub estimate that over 525,000 people in the UK have a diagnosis of dementia(6), with figures from the dementia statistics hub stating that there are 14,728 people with a dementia diagnosis living in Northern Ireland.

However, the dementia diagnosis rate in Northern Ireland is estimated to be 73% so the true numbers are likely to be higher.(6) According to the dementia statistics hub from 2006/07 to 2015/16 the number of people on the dementia register in Northern Ireland rose from 9,500 to 13,617, an increase of 43%.

The number of people with dementia in the UK is expected to grow rapidly by up to 146% by 2050.(6) NICE guidelines on dementia published in 2018 reported that in December 2017 there were 450,000 patients reported on GP registers in the UK with a formal diagnosis of dementia, an increase from 290,000 in 2009/2010. Health and social care expenditure on services for people with dementia therefore, could be estimated to double within 20 years.(7) Currently in the UK 61% of people living with dementia do so in the community, with only 39% in care homes,(6) with the primary care team the first point of call for these individuals. Providing adequate and efficient healthcare to these increasing numbers of patients is an important health priority.

It is estimated that there are 55,000 people in Republic of Ireland are living with dementia, half a million of us have had a family member with dementia and each year over 4,000 people are diagnosed with dementia. The number of people with dementia in Ireland is expected to more than double over the next 20 years, from 55,000 today to 113,000 in 2036.(8)

There are four main types of dementia:

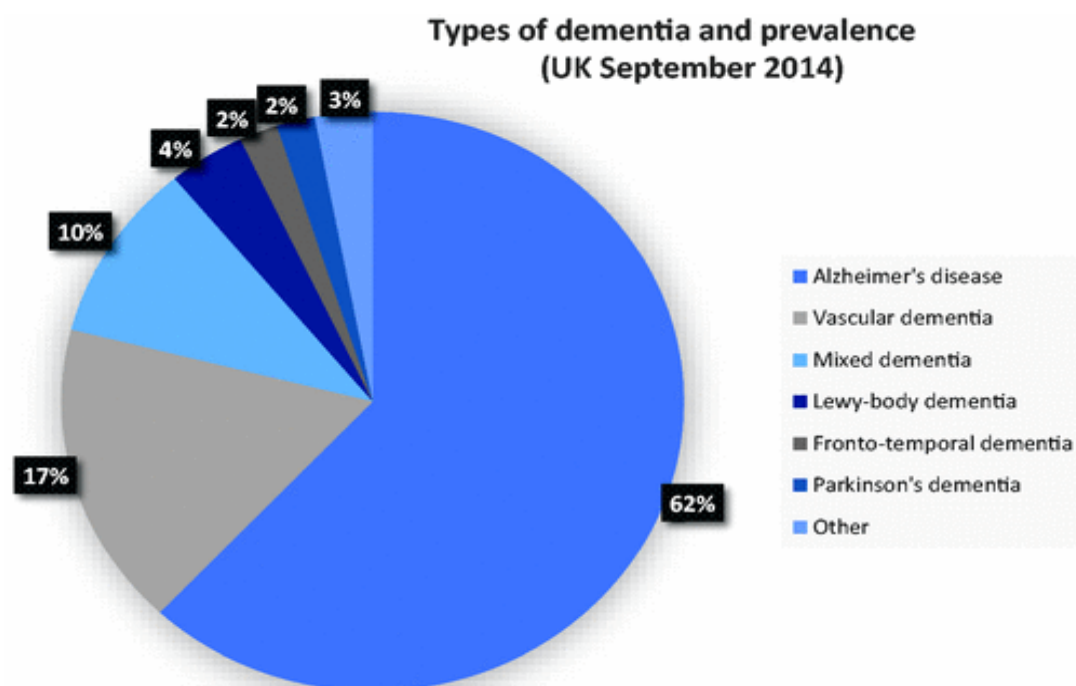
- Alzheimer's disease (AD)
- Vascular

- Lewy Body dementia (LBD)
- Mixed

Less common types include Parkinson's disease dementia (PDD) and fronto-temporal dementia.

Each of these types is a unique entity although symptoms of each may overlap and are not always easy to distinguish from the outset. Although dementia can affect a person at any age it most commonly presents in people aged over 65.(6)

Figure 1 below from the Alzheimer's Association shows the types and prevalence of dementia in the UK in 2014.



Data source: Alzheimer's Association (2016).

Figure 1: A pie chart showing the types and prevalence of dementia in the UK in 2014

The causes of dementia are still not fully understood.(9) In Alzheimer's disease the neuropathological changes are of extracellular amyloid beta plaques, and neurofibrillary tangles comprised of intracellular accumulation of hyper phosphorylated tau protein.(10)

Various risk genes have been implicated in the pathogenesis of AD e.g. apolipoprotein E (APOE). One mechanism by which inheritance of the APOE e4 may increase AD risk is by impairing amyloid beta clearance from the cerebrum.(11)

Vascular dementia is primarily caused by cerebrovascular disease or impaired cerebral blood flow. It is typically recognised in two clinical scenarios i.e. a clinically diagnosed stroke followed by dementia, or where brain imaging identifies vascular brain injury in a patient with dementia. In either case a clinical judgement must be made as to whether the location and severity of the cerebrovascular disease is sufficient to cause dementia.(12) Vascular brain disease is often seen in patients with AD producing a mixed picture of disease.(13)

Lewy Body dementia (LBD) is a clinical syndrome characterised by fluctuating cognitive impairment, hallucinations and Parkinsonism. The pathological hallmarks are the presence of Lewy bodies composed of alpha-synuclein.(14) It is thought that Lewy body pathology is responsible for dementia in most patients with Parkinson's disease rather than the pathological changes found in AD or vascular dementia.(15)

The presentation of the various types of dementia, whilst having many similar characteristics, also differ slightly. In AD the onset is slow and there is progressive memory loss and difficulty making decisions for example difficulties with financial matters. Vascular dementia presents with a more sudden decline in function, can be associated with falls, weakness and sometimes delusions. Fronto-temporal dementia can cause mood and/or personality change whilst Lewy-body dementia can present with visual hallucinations, depression and features of parkinsonism.(16)

In Parkinson's disease dementia (PDD), dementia occurs in the setting of well-established Parkinson's disease, while in LBD, dementia usually occurs before or very soon after the emergence of parkinsonian signs.(17)

Providing care for patients with dementia

When a person demonstrates or shows symptoms such as problems with memory, behaviour change or difficulty with activities of daily living the first point of call by either the patient or a concerned relative is usually their GP or primary care team. NICE recommends a number of steps which can be taken to investigate such patients to include history, both cognitive and psychosocial as well as physical examination, blood tests and approved screening.(7) These include the Memory Impairment Screen, Mini Mental State Examination, General Practitioner assessment of Cognition (GPCOG) and Functional Activities Questionnaire.(18)

After initial tests it is recommended that people with suspected dementia should be referred for specialist investigations and possible initiation of medications in the secondary care setting and diagnosis of a dementia subtype. NICE also recommend that after diagnosis of dementia the patient, their families and carers “must have access to memory clinic services or equivalent hospital or primary care based multidisciplinary dementia service”.(7)

After diagnosis there are a multitude of areas in which patients and their families need supported and guided through. Care coordination and planning, advanced care planning, support for carers, assessing and managing co-morbidities as well as pharmacological treatments are all areas which need explored and addressed.(7) Often these cannot be covered in a secondary care setting and long term care and support from the patient’s own primary care team is of vital importance. Patients and families who have received a diagnosis of dementia have complex support needs, including emotional and psychological as well as social requirements. Many members of the primary care team should be involved in looking after these individuals and their families, from doctors, pharmacists, social workers, occupational therapists to the wider voluntary sector groups in their local area. Co-coordinating this input is a vital role of the patient’s primary care team.

In 2015 the British Psychological Society (BPS) published guidance on dementia and people with intellectual disabilities. They noted that, in keeping with the overall trends of aging, life expectancy for those with Down Syndrome has also increased and the number of older people with the condition is also on the rise.(19) Often it can be more difficult to recognize the symptoms or signs of dementia in a patient with Down’s syndrome. The BPS guidance commented that a key feature in identifying dementia in a person with Down’s syndrome is to note a decline from their functioning baseline. They recommended that with increasing age a baseline assessment should be “carried out at 30 and then again frequently every two years in their forties and annually for those aged fifty and over with Down’s Syndrome.” In addition to this once a diagnosis of dementia has been suspected in these patients a period of regular assessment should be carried out. (19)

Population changes in rural settings

Over the last twenty to thirty years, it has been noted that rural areas have seen greater population increases in average age than urban areas.(20) Predictions suggest that there will be no significant increase in the young population in rural areas which will lead to these areas having more older people than younger residing in them.(1,2)

Defining rurality and exactly how to describe a rural population presents difficulties with no single definition. National Geographic describes rurality as:

“ A rural area is an open swath of land that has few homes or other buildings, and not very many people. A rural area’s population density is very low” (21)

The Government UK website defines rurality through the Rural Urban classification. The Rural Urban Classification is used to distinguish rural and urban areas. The Classification defines areas as rural if they fall outside of settlements with more than 10,000 resident population. (22)

In his article published in Rural and Remote Health about rural healthcare in Malawi, Muula commented that in the past several years, interest has grown in rural health issues and rural medicine. (23) Reported issues of interest include that compared to urban communities, rural communities have limited access to health care, suffer more preventable morbidity and mortality and have lower numbers and diversity in specialty of health professionals per population.

In Northern Ireland itself there is an absence of clarity of distinction between ‘urban’ and ‘rural’.(20) However, official figures suggest that the rural population in the UK will “increase by six percent over the next decade as people choose to leave cities and settle in the countryside.”(2)

Implications for healthcare delivery in rural settings

In the journal, The Nursing Times, Deaville commented that the lack of a measure of rurality has hampered academic research and disadvantaged rural areas. The paper reported that health care delivery problems were common due to difficulty with access for patients to both primary care teams in the local area and to specialist care in urban centres. It also

commented on healthcare staff having larger areas to cover than those in urban areas and spending longer time travelling to see patients.(24)

Contrastingly the health of people in rural areas is on average better than that of urban areas with higher life expectancy and infant mortality and a lower number of potential years of life lost from cancers, coronary artery disease and stroke. However, as the rural population is older, the prevalence of these conditions is higher. (25)

Advantages to rural healthcare mentioned in the literature include close relationships between clinicians, their families and other members of the healthcare service in the area. (26) Health care workers are often extremely familiar with their patients having known the patients and their entire families all their lives, which can confer a huge benefit in terms of patient care.

In relation to dementia, a report by the Alzheimer's Society in 2018 stated that funding for public health services is significantly lower in rural than urban areas and due to the wide geographical area in rural settings many support services are oversubscribed and cost more to run.(27) Social support can be difficult to secure on discharge from hospital for those living in remote areas. This in turn increases the work load and pressure on the local primary care team to provide support as well as medical care to these patients in their area. Deaville reiterated this in her paper, commenting that increased clinical responsibility, due to increased distance from specialist centres, as well as distance and remoteness can lead to a feeling of professional isolation amongst staff working in rural primary care teams.

On the other hand it has been reported that those living in rural areas feel very much part of a community and that the members of the primary care team know the patients and their families extremely well.(27) Patients living with chronic diseases in rural areas may never have been to an urban centre for treatment and are content and well with the treatment they have received in their local area from their own GP and primary healthcare team.

Health Care Professionals in rural settings

In recent years the number of health care professionals in rural and remote settings in the UK have been dropping.(28) For instance In Northern Ireland last year it was reported that following closures of two single-handed practices in rural Fermanagh, Northern Ireland, patients were being taken by minibus to a nearby town fifteen minutes away to be seen by a doctor.(29) This is a problem which is not unique to Northern Ireland with similar shortages reported in other parts of the UK, particularly in Scotland and surrounding small islands. There has been a drop in the number of sole practitioner GPs in England (1,949 in 2004 to 1,266 in 2009) with an increase in larger practices and the introduction of multidisciplinary teams within local practices.(28) This is a situation which is echoed in other parts of the world for example in Australia where remote areas continue to see the lowest number of doctors.(9) This impacts rural communities and increases travel time.(27) Those primary care teams which are functioning are therefore under an immense amount of pressure with patients having difficulty accessing appointments, some waiting up to several weeks for routine appointments. As services are stretched those with chronic diseases including dementia could face long delays in appointments whilst their condition has potential to deteriorate.

Dementia in the rural setting

As the number of elderly patients in rural areas is increasing, significant challenges are placed upon those responsible for looking after these people when they become chronically unwell. Significant amongst these challenges are those related to dementia. Providing support and care for these patients and their families in these communities is particularly difficult and requires complex assessment, attention and planning.

A document published in 2018 by the Alzheimer's Society entitled Dementia Friendly Communities highlighted some of the challenges facing patients and carers of patients with dementia living in rural areas of the United Kingdom.(27) It acknowledged that the double impact of living with a diagnosis of dementia and living in a rural area can have a significant negative impact on quality of life. From the onset of the disease, patients in rural areas may face more challenges than those living in urban areas, such as distance to appointments in secondary care. They may find they have to travel a significant distance to a pharmacy to collect their prescriptions and there may be limited public transport compared with those

living in more built up areas. Third sector volunteer groups may be less common in small villages with smaller populations. As mentioned previously accessing an appointment with their GP may pose a long waiting time, and a lengthy journey to the appointment. Once seen they may be referred to a secondary care centre for specialist input and subsequent review and follow up. This may be some distance away with possible difficulty accessing direct public transport. The report from the Alzheimer's Society also highlighted that support services for patients with dementia in rural areas can be limited. Often there are the same numbers of staff employed for the service as in an urban area, but with a much larger geographical space to cover. This in turn reduces support not only for patients and families but puts pressure on the local primary care teams to provide it. Loneliness was noted as a key problem for those living in rural areas. Some people may rely on a visit from their GP or district nurse for interaction and company. In addition to this Holwerda et al 2012 reported that people who are lonely have "a 64 percent increased risk of developing dementia".(30) Compounded by the possibility of patients with dementia forgetting to charge their mobile phone or computer and possible poor Wi-Fi or broadband in a rural area, isolation is a big challenge.

In 2014 Dal Bello-Haasm et al conducted a review of rural and remote dementia care challenges and needs. In their study they looked at the perspectives of formal caregivers residing in rural Canada.(30) Interestingly 48% of physicians reported that they were satisfied with support services available to people with dementia and their caregivers in their community, although one third did indicate that additional services were required such as support services, occupational therapy and counselling, as well as care of the elderly expertise. They acknowledged the uniqueness of the remote rural setting and highlighted the complexity and challenges of boundaries in providing care. For example, the challenge of health professional/patient relationships in small settings as people are very aware of each other and can be linked through other domains or businesses. In this study they found that only fifty percent of the primary care physician respondents were "fairly comfortable with diagnosis and management of dementia." The study made a small comment that primary care physicians suggested increased levels of training in this area could be useful to improve the situation. Perhaps one of the challenges for the primary care team in caring for patients with dementia will be recognizing their own limitations in doing so and exploring areas where they may be less confident for example in diagnosis or during the follow up period. The study also remarked that other members of the primary care

team reported that they “felt uncomfortable with their ability to recognize the signs and symptoms of dementia.”(31) A large proportion of those who took part suggested that increasing education on dementia such as workshops would be beneficial.

Rural carers for patients with dementia

In the literature, work has been done looking at challenges posed to carers of patients with dementia in the rural setting. Themes identified in a study from the Open Journal of Nursing on ‘what rural dementia caregivers find stressful’ include social isolation and the unremitting burden of providing care when access to respite is limited.(32) Many of the themes identified were not unique to rural settings but highlighted the general stresses for carers looking after patients with dementia. Carers mentioned “feelings of powerlessness” and “inadequacy in their caring role” and impact of the behavioural and psychological symptoms of dementia on them personally.

In 2014 a study carried out in rural Tasmania highlighted the importance of carers in the day to day living of patients with dementia.(33) It highlighted that often the caring role is perceived negatively as a job of unrelenting burden, and that in fact many rural caregivers do not see their role as a negative or deprived one. They did comment that some carers reported dissatisfaction with the lack of respite services available in rural areas and the knowledge of formal service providers such as General Practitioners was perhaps lacking.

The study authors concluded that the caring role is dependent upon many relationships, including that of the carer and the patient with dementia, the carer and the professional care giver or doctor and the relationship between the carer and the patient’s family.

Conclusion

With an increase in people living with dementia in rural areas in the coming years, research into identifying key challenges and barriers in caring for these individuals is essential for the improvement of care delivery. Although there is some difficulty defining rurality it is accepted that rural healthcare has a unique entity on which there has been a defined research focus. Whilst there are notable advantages to rural healthcare there are also significant challenges facing both patients, their families and their healthcare teams.

Furthermore caring for those living with dementia involves a holistic approach, encompassing medical, social, psychological and financial support for those living with dementia and their families. This support is essential right throughout the diagnostic process and thereafter. Given the challenges mentioned such as transport, distance to services and lack of resources, providing this service in a rural environment may be difficult.

Some work has been carried out that assessed the challenges facing carers of patients in the rural setting but little published evidence exists that considers how to address the challenges specifically for the community based health and social care team to care effectively for these individuals.

Through my research I aim to assist health and social care planning for those with dementia over the coming years and aim to answer the following questions:

1. What are the challenges for the delivery of health and social care for those living with dementia by community-based health and social care multidisciplinary teams in rural and remote settings?
2. How can we improve care for patients living with dementia in rural areas and support the primary care team looking after them?

Chapter 2: Review

Basis for scoping literature review

With an aging population the numbers of people with dementia is set to increase over the next several decades. De-urbanisation means that there is a trend of people moving out of urban areas to rural areas as they get older with official figures supporting this. As a result, there will be more people with dementia living in rural areas than ever before, with the first point of call for these people being their local primary care team.

In order to address the question of challenges for these primary care teams in providing care for these patients a scoping review has been conducted. This was conducted in line with the Arksey and O'Malley framework. (34)

Aim of scoping review

The aim of the scoping review was to ascertain from the literature the challenges facing the rural primary care team, to include general practitioners, nurses and other members of the multidisciplinary team, involved in looking after patients with dementia. The scoping review aimed to uncover the main themes of research that has been conducted in this area.

Scoping review methods

The Arksey and O'Malley framework which was produced in 2005 is a widely used guideline to carry out scoping reviews, which broadly search the literature on a particular topic. Although now widely recognised, no absolute definition of a scoping review exists. Scoping reviews differ to systematic reviews in that researchers do not critique the literature, rather they 'map' what has previously been discovered. Arksey and O'Malley developed a six step framework to guide authors in undertaking a scoping review. (34) This was further refined in 2010 by Danielle Lavee and colleagues. The six steps are as follows:

1. Identifying the research question

2. Searching for relevant studies
3. Selecting studies
4. Charting the data
5. Collating, summarizing and reporting results
6. Consulting with stakeholders to inform or validate study findings

This sixth step is optional and has not been carried out in this study.

Review question

The search was guided by the research question:

“What are the challenges for the rural primary care team in providing care for patients with dementia?”

Search process

An initial broad literature search was carried out in autumn 2018. This showed, as discussed previously, that some work has been done which shows the challenges for rural carers of patients with dementia. Findings from this are discussed in the background section of the thesis.

In November 2018 a more detailed formal search was carried out with the aim of finding articles specifically relating to the research question. The expertise of the medical librarian was sought to ensure correct use of search terms and a wide range of databases used.

Four databases were searched in total. PubMed, Embase, Scopus and Web of Science.

The following terms were used when searching the databases with very minor adaptations between databases to account for the slightly different subject headings used:

Allied, health, personnel, community, workers, dementia, district, nurs*, family, nurse, practitioners, practice, general, home, aides, hospitals, rural, specialists, nurses', nurses, nutritionists, occupational, therapists, pharmacists, physical,

therapists, assistants, physicians, primary, care, psychiatric, public, nursing, services, rural*

Inclusion criteria

Articles were included if:

Members of the multidisciplinary primary care team were involved (one or more members)

and

the study was based in rural settings.

All countries were included.

There was no discrimination between what type of research had been used for the article.

Exclusion criteria

Articles were excluded if they were:

- exclusively related to carers,
- not specifically related to rural issues
- related to rural healthcare in general, as opposed to specifically dementia

Selection process

Initial screening process was carried out by the researcher. This included scanning of abstract titles in the first instance and assessing relevance to the research question. A second screening process involved reading of the abstracts of each paper and in some instances a more detailed look at the full article was required. Those which were deemed ineligible by the researcher were screened out. The remaining articles were then coded as potential articles and reviewed by the principal supervisor and a second collaborator with an interest in this area. A consensus was reached after discussion regarding possible differing opinions.

Data extraction

A data extraction sheet was created by the researcher in the form of a table using Microsoft Excel. The table was populated with data extracted for each article. This included the title of the article, authors, country of origin and where the study took place, source or journal the article was taken from, the study design, how the data was captured, main themes of each article and any additional key comments. A summary table of extracted data is shown in Appendix 1.

Results of scoping review

After the screening process above was carried out, references of the selected papers were screened. This search only revealed one further paper which was included. Twelve articles were included in the final review.

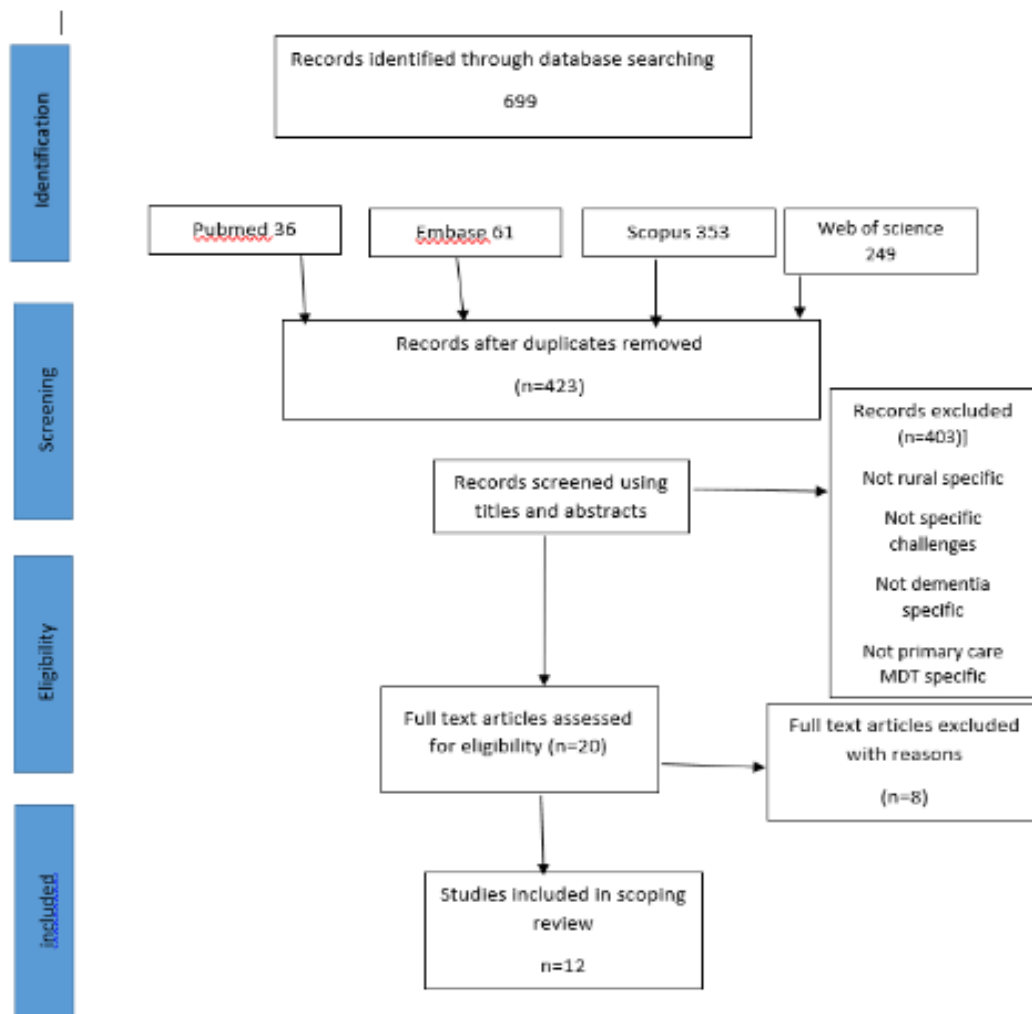


Figure 2: Prisma Diagram of the scoping review literature search

Overview of included articles

Three articles were Canadian studies, from a variety of sources including the Canadian Journal of Aging, Rural and Remote Health and Primary Healthcare Research and Development. Two were from the USA, one from Aging and Health, the other from the American journal of Alzheimer's disease and other dementias. Two articles were from the Australian Journal of Primary Health. Three from the UK were articles from the International Journal of Geriatric psychiatry and Journal of Primary Care and Community Health. A third study, published in Sage journals was carried out in rural Scotland. One Irish

study was published in Maturitas. The final study which was added from a reference search was published in Biomed Central Journal.

The twelve articles included in the study featured a range of study designs. Two of the articles were literature reviews and two were systematic reviews. The others were qualitative studies carried out by either interviews, semi structured, in person, or by telephone, or focus groups, or a combination of these.

Two of the literature review based articles focused on issues surrounding diagnosing dementia in rural areas and the challenges associated with this for rural general practitioners and family physicians, as well as post diagnostic support issues. Another systematic review looked at formal care-givers of persons with dementia and the challenges they face.

Focus groups was a common method of data capture throughout these articles. These differed greatly in size and nature. One study in Australia included a focus group made up of various members of the multidisciplinary care team including General Practitioners, community and hospital nurses, community support workers and family members of patients with dementia. Meanwhile a smaller study in Ireland included only a small number of rural General Practitioners

Several themes were identified from the review of the included papers. These were broadly categorised into

1. Provision of services
2. The Spatial Dimensions of Geography
3. Norms of Community Values
4. Specialist Knowledge Regarding Dementia and
5. Community Support Network and Services.

Each theme has been discussed in turn below. Although predominantly challenges and barriers to care were identified through this review some facilitators and positive aspects of rural living were identified which have been mentioned also.

Provision of Services

Provision of services was commonly cited as a challenge facing rural areas. This was mentioned in almost all studies, in particular lack of access to specialist services, resulting increase in waiting times and more onus on the GP to provide care in the interim. One study cited that a lack of local specialist services caused inequity in patient care between rural and urban areas and “placed a burden on family practitioners to fill in the gaps for their patients.”(35) Cahil et al found that of rural GPs surveyed “fewer than half had immediate access to OAP services and fewer again to General Medical services.”(36) A focus group carried out within that study revealed that rural GPs had difficulty accessing locally based investigations such as CT and MRI scans, a difference that they felt would not happen in an urban area. They found that time delays in diagnosis due to the wait for specialist services also delayed treatment and access to community services going forward.

A study in the US looking at rural practitioner’s experience of dementia diagnosis and treatment found access to consultative resources problematic because of limited availability of visiting consultants and the long distances patients had to travel to specialists in the urban areas.(37) A further study in Illinois reiterated this mentioning that resources such as laboratory facilities and support personnel were either not available or inadequate(26), with a Canadian study citing that over half of their physician respondents indicated that more care facilities would enhance currently available services.(38)

One study commented that the short length of the GP consultation impacted the capacity of rural GPs to make a diagnosis.(39) However, some studies did mention advantages to GPs working on their own in rural areas. For example one study did mention that due to poor access to services, rural GPs were more likely to diagnose dementia themselves, compared with their urban counterparts, citing also that rural GPs tended to take a more autonomous approach in their practice and did not need to rely on referral to specialist to make a diagnosis.(39)

The spatial dimensions of geography

Distance to services was a commonly cited challenge by rural healthcare workers. Distance from specialist services in urban areas, in terms of both from the patient's perspective, including the addition of cost of travel,(39) and from healthcare worker's perspective, particularly rural GPs in distance to domiciliary visits. In a study in Canada one of the physicians commented on the "difference" between rural and urban patients and the difference in diagnosing an elderly patient from a rural area with dementia and an elderly patient from an urban area "It's a tougher diagnosis to give an 85 year old farmer than an 85 year old executive guy... You don't just take the guy away from the farm."(40)

Another smaller study in America looking at physicians experiences in rural Illinois cited that 13 percent of respondents described "the general depressed economic situation of the (rural) area and the people as a disadvantage to diagnosis and treatment."(26)

Hansen et al (2005) highlighted distance and isolation as two coexisting entities, and reported that distance from resources such as expert specialists and 'dementia specific units' were barriers to care.(41) They also reported that distance limited the capacity of carers and family to visit their relatives if they had to travel long distances to a residential home, and this would reduce the likelihood of carers moving their relative with dementia into a residential home and thus increase carer burden. Similarly Constantinescu et al (2018) described geography as a barrier in many cases as people are reluctant to leave their community to pursue further care or respite in an urban area, as well as not wanting to be further away from family.(40) In this paper lack of extra financial compensation for rural physicians to make house calls was also mentioned as a barrier for busy rural physicians caring for patients with dementia.

An American study in Kansas looking at rural practitioner's experiences in diagnosis and treatment of dementia commented that lower population densities and remote locations in rural settings often mean a lack of availability of social and technical support services.(37) It also found that there was often 'extreme' distances for patients to travel to a specialist appointment as well as a considerable delay, resulting in a delay in diagnosis.

Lack of transport, particularly to specialist care, both personal and public was cited as a challenge, and barrier to accessing timely care and thus impeding diagnosis in some cases.(42)

This was echoed in an Australian study in particular in areas of high Aboriginal populations. Travel needs and burdens included patient's having to obtain government authority for healthcare related travel, lack of personal or government funds for travel to specialist appointments in urban areas and being unable to access public transport such as buses on a daily basis due to poor timetabling and running hours.

In general geography was seen as a big challenge to care in rural areas but one study did acknowledge that it can be a facilitator as well as a barrier to good care, with a GP reporting that knowing the patients well can help with diagnosis. "In rural areas we tend to know the people (with dementia) that we need to tap on the shoulder and bring in." (40)

Norms of community values

A general theme that transpired when reviewing the articles was that of the impact, both positive and negative, of the rural community and the values within it. Glasser et al (1993) described how rural physicians confer an advantage, as due to working autonomously they get the opportunity to know patients very well over a long period of time, and as such become "part of their family". "Many of the patients are coming in for years and years – it is easier to see the changes first hand." (26) Constantinescu et al commented that close community relationships were a great help to physicians when caring for patients with dementia, mentioning that in small communities there were often close supportive neighbours to look in on the patients. However, conversely they commented that some physicians felt that different relatives' expectations could complicate and hinder care, especially from family members who do not live nearby. (40) 'Stigma' was cited frequently as a reason to hold back on diagnosing dementia by rural physicians, particularly those practicing on their own, with a general practitioner in a small Irish study commenting "It's ok if they approach you" (43), adding that a diagnosis of dementia was an unwanted label, putting the person immediately into a "high risk" category. (36) This was reiterated by Greenway-Crombie et al who reported that a paper looking into barriers to the management of patients with dementia in primary care in 2010 by Koch T et al, (44) agreed that stigma can be greater in rural areas where "everyone knows everyone", and due to lack of adequate transport and increased distance to services there is an even greater reliance on the ability to drive independently. This can lead to a denial of symptoms due to

fear of negative impact on the person's lifestyle. Syzymczynska et al (2011) commented that due to a perceived lack of privacy rural patients were less likely to use existing services.(42)

Similarly, Dal Bello Haseem presented the idea that the rural setting is complex and unique with challenges of therapeutic boundaries, as many people have intertwining relationships for example the patient may be the doctor's mechanic, postal worker etc. They commented that these familiarities are often unavoidable in the rural context.(38)

From a positive perspective in a Canadian study found that practising in a rural area was considered an advantage in terms of close relationships between physicians, their families and other members of the healthcare service in the area.(35) Similarly Innes et al commented that informal support in rural areas by family members was of a significant value.(45) Kostentiuk et al also found that an advantage to rural practice was a high degree of social proximity between family physicians, patients and their families, and that knowing their patients well helped them to facilitate the placement process more effectively.(35)

A study in rural Tasmania also revealed a close-knit rural community, in which strong informal networks between different healthcare groups had been created which were felt to provide good care for patients with dementia. However, in this same study members of a multidisciplinary care team took part in a focus group to investigate barriers to care.(41) In this focus group community nurses described rural families being uncomfortable about asking for help as it was felt that "families should manage themselves" and that 'stoicism' or perceived stoicism was a barrier to asking for help in rural areas. As well as this, the feeling that the patients know the healthcare professionals added a sense of awkwardness and put people off trying to get respite in case they would know the staff.

Specialist knowledge regarding dementia

Throughout review of the papers it was apparent that some rural physicians felt that lack of specialist knowledge regarding dementia, both diagnosis and management was a challenge in caring for patients. Physicians in a study in Canada cited lack of experience, lack of training and a poor understanding of the process of placement in their area as barriers to care.(40) One commented that they "sometimes delay making the diagnosis as they don't have a clue what to do".

'Knowledge gaps' by the entire rural healthcare team, including carers was mentioned as a significant barrier to care in a Tasmanian study, although no specific explanations as to why in particular were given.(41) They commented that in this study carers felt the community nurses had the best knowledge of services and played a vital role in the care of patients with dementia and their families.

Community support network and services

Community resources were found to be lacking by some of the studies. Constantinescu et al (2018) commented that the physicians in their study felt that there was a lack of multidisciplinary services which would be helpful for patients with dementia available in the rural area such as mental health services, occupational therapy, respite services and home help.(40) They also cited long waiting times for assisted living or long term care in their area as a barrier to care. Glasser et al (1993) echoed this in their study in Illinois, citing that 57 percent of the rural physicians interviewed felt that the rural setting was inadequate with regard to resources and support personnel,(26) whilst Dal Bello-Haas et al (2014) found in their study in Canada that both formal and informal caregivers of patients with dementia identified a need for improved services in rural and remote settings.(38) Cahill et al (2008) found that a lengthy wait for specialist appointments delayed community services input as a diagnosis was required before referral could be made to community agencies.(36) Kosteniuk et al (2011) reported on a Canadian study that concluded that rural physicians were not aware of community resources available to them, and similarly were not aware of community resources for caregivers of patients with dementia.(35) In their review of post diagnostic support for people with dementia in rural areas Symczynska et al (2011) reported that services in rural communities in Scotland, Canada, Tasmania and Australia were significantly limited.(42) In contrast a study in Tasmania found that although there were in general a lack of resources, due to the size of the small rural community, uptake was generally low and for this reason there were often respite places available and spare hospital beds if needed.(41) The same paper however did also comment on barriers associated with lack of community resources, in particular limited options available for local residential care facilities. Interestingly they noted that some care homes were far away from a patient's home and there were no live-in facilities for a patient's partner or spouse to live or even stay with them. Similarly, a rural physician in a Canadian study felt that a

small community meant that the doctors had a closer relationship and good line of communication with the homecare nurses which proved advantageous.(40)

Summary and gaps in knowledge

The scoping review has highlighted that a body of research has already been carried out looking into the challenges for rural primary care teams providing care for patients with dementia. The main perceived challenges as mentioned above relate to geography, lack of both specialist and community resources, the stigma attached to a small rural community and distance to services. However, the studies in this review were mainly all pertaining to rural physicians. It appears that there is a paucity of published literature looking at the multidisciplinary primary care team as a whole. In addition to this there were only a small number of published studies in the UK and Ireland in this area and none were found that specifically addressed challenges for rural primary care teams looking after patients with dementia in Northern Ireland. Whilst there certainly were some positive aspects to rurality and care including help from neighbours and the advantage for rural practitioners in knowing patients and families well, significant challenges have been repeatedly identified. Building on this the scoping review results allow for important questions to be asked and addressed for which there remains a gap in the literature. This gap can be summarised in the question:

What are the challenges specific to rural multidisciplinary care teams caring for patients with dementia and with these in mind what ways could care be better delivered?

Chapter 3: Qualitative Study

Methodology and Methods

Research aim

Following on from the scoping literature review, the overall aim of this study was to identify challenges for the rural primary care teams in Northern Ireland in providing care for patients with dementia and suggest ways in which care might be improved.

Research objectives

1. To identify challenges for the rural primary care team in providing care for patients with dementia
2. To establish the degree of concordance, between findings in the literature and the experience of rural primary care teams in Northern Ireland, of the challenges faced in providing care for patients with dementia
3. To identify ways in which the rural primary care team could improve care for patients with dementia

Methodology

Choice of qualitative research for this work has been discussed below.

Qualitative research is defined as:

“an umbrella term covering an array of interpretative techniques which seek to describe, decode, translate and otherwise come to terms with the meaning, not the frequency, of certain more or less naturally occurring phenomena in the social world” (46)

Qualitative research is increasingly used in health care research. Many health services and health policy researchers have used qualitative methods, either alone or in combination with quantitative approaches.(47)

Research methods may be inductive or deductive. Deductive reasoning begins with a hypothesis and examines possibilities to research a specific logical conclusion. (48)

Quantitative research is based on structure, uses experiments and surveys as methods and tends to be deductive in nature, often using statistical sampling methods.

Inductive reasoning, often used in qualitative research adopts the opposite approach in that it makes broad generalisations from specific observations. (48) Qualitative research is described as an action research using observation and interview methods.

Qualitative research methods are valuable for providing rich descriptions of complex phenomena and seek to understand the opinions and views of those involved in the research which is taking place. In her paper in 1999 Sofaer described qualitative research methods as a tool to enhance understanding of the context of events as well as the events themselves. Thus, qualitative research not only serves the desire to describe; it also helps move inquiry toward more meaningful explanations.(47)

Qualitative research allows the researcher to ask open questions and affords the researcher the ability to ask individuals to describe, in their own way, their experiences and responses to a certain issue or problem. Sofaer described questions asked in quantitative research as more closed ended, with a specific response, and with the sequence of questions predetermined rather than left to the discretion of the researcher.

In the field of health services research, qualitative methods have been used to describe many kinds of complex settings and complex interactions for example interactions among patients, families, and clinicians; within, between, and among professional groups and organizations and communities.(47) This was well described by Glasser and Strauss in the 1960's during their discovery of Grounded Theory.(49) During their study they questioned whether a uniquely scientific approach was appropriate in assessing how patients dealt with the knowledge they were dying and the reactions of healthcare staff caring for these patients. Grounded theory provided an outlook that questioned the view of the time that quantitative methodology is the only valid way to determine truths.(49)

In her article Sofaer also noted that qualitative researchers often find that they are giving voice, in particular, to those who are otherwise rarely heard, such as patients or workers far down in the hierarchical chain of command.

In order to explore and understand the challenges facing rural primary care teams providing care for patients with dementia, and as such, answer the research question a qualitative approach was felt to be appropriate.

Choice of method for this study

There are several methods of data collection which were considered. These include questionnaires, semi structured interviews and focus groups.

Questionnaires can be useful to gather information from a large number of people. They require careful design by the researcher to gain the required data for the purposes of the study. This study sought to identify challenges of a rural primary care team as a whole and it was felt and hoped that anecdotal examples may make up a significant component of responses, therefore it was felt that questionnaires would perhaps be a too closed method of data collection.

Semi structured interviews

Semi structured interviews provide a good platform for asking participants open questions. Researchers make use of interviews when they wish to obtain more detailed and thorough information on a topic than might be gleaned from a questionnaire. (50) Similar to a focus group, the researcher often has a broad framework of pre-prepared questions but can be flexible with these should new issues come to light and an iterative approach is often used.

As mentioned above this study focused on the views of a multidisciplinary primary care team, thus requiring the opinions of several people. One of the main reasons of choosing a focus group over individual semi-structured interviews was the logistics and time constraints of setting up interviews with more than ten people. Although the views of any one participant cannot be probed to same degree as in an interview, the discussions that are facilitated within the groups often result in useful data in a shorter space of time than that required by one-to-one interviews. (51) It was also felt that the integration of the group that works together as a whole may provide more rich discussion. The use of focus groups as a research tool is discussed in further detail below.

Focus groups

Focus groups were originally used for market research but are now commonly used for qualitative and healthcare research. There are many definitions of focus group to be found in the literature, for example

“a group of individuals selected and assembled by researchers to discuss and comment on, from personal experience, the topic that is the subject of the research” (52)

Unlike interviews, where there are direct questions to be answered, focus groups rely on interaction within the group about topics supplied by the researcher or facilitator. (52)

Participants are encouraged to talk to one another, share experiences and stories and generate conversation and ideas. The method has been commended as “useful when it comes to investigating not only what participants think, but why they think that way” (53)

Focus groups can be advantageous when interviewing groups, particularly when trying to gather the thoughts of a group of people as a whole, in this case multidisciplinary health

care professionals and practice staff. Kitzinger in her introduction to focus groups in 1995 highlighted this, commenting that they are a popular means for understanding health behaviours and an “effective technique for understanding the attitudes and needs of staff.” (53)

Focus groups can be a comfortable forum for staff for sharing opinions amongst staff who perhaps would feel a degree of anxiety of taking part in a one on one interview. Discussion amongst participants can lead to ideas and topics being discussed which may not have been asked directly by the interviewer. Kitzinger commented that focus groups can be “empowering” for those taking part, and that less inhibited members of the group can encourage shy members to take part.(53) Conversely it should be noted that the opposite may occur, and there may be participants who tend to dominate the discussion, and it is therefore the role of the facilitator to try and encourage participation from all members of the group.

An additional point to consider when conducting a focus group consisting of participants who work together is the removal of confidentiality. This was explicitly pointed out prior to the focus groups taking place and no participants expressed any concerns regarding this in this study.

Given the nature of the topic I decided that compared with other data collections methods, focus groups would provide the richest source of data. I was keen to collect data from multiple members of the team with varying roles and expertise including administrative and non- medical staff. I decided that as primary researcher it was my role to facilitate these groups. I designed the focus group template and ensured it was an iterative process as fully described below.

Methods

Study design

A qualitative study involving focus groups

Context and setting of study

The setting for this study was rural primary care teams in Northern Ireland.

Study subjects

Members of the primary health care multidisciplinary team in Northern Ireland. These included General Practitioners, District and Practice Nurses, Social Workers, Pharmacists, Practice managers and receptionists.

Study sample

A purposive sample of three primary healthcare teams from different rural areas of Northern Ireland were invited to take part in the research. Due to unforeseen limitations of Covid19 the study was limited to two focus groups.

Inclusion / Exclusion criteria

Inclusion: Members of the rural primary care team were considered for the sample including the groups listed above.

Exclusion: Staff members with less than two years' experience in working in a rural primary care team setting.

GP trainees were not be asked to take part.

Sample strategy / recruitment

An invitation letter (see appendix 2) was sent to eligible staff in two rural practices in Northern Ireland. This was done using a convenience strategy. One Practice was the Practice where I was working in a clinical role as a GP registrar. The second Practice was also a rural setting in a different county in Northern Ireland, to provide a diverse perspective. It was intended that the Primary Care team from a third rural Practice would

be included in the study but due to the onset of Covid-19 the recruitment of a further focus group had to be deferred.¹

The two Practices are known to members of the research team. Recruitment was carried out by sending an initial letter to the Practice manager of each Practice inviting them to forward the study invitation letter to all members of staff in the eligible groups.

Staff within teams from eligible groups were recruited in order of positive replies. The aim was to include a range of members of the multidisciplinary primary care team, ideally approximately two members of each of the groups mentioned above. In the event that a large number of members of one staff group replied they were to be chosen in order of reply. The participants were then provided with an information sheet (Appendix 2) and a consent form in advance of taking part in the focus group. Participants were informed that the focus group they were taking part in was going to be made up of members of the multidisciplinary primary care team from which they work and as such it was very likely they would know the other members of the group. If they did not wish to take part for this reason they could choose not to. An assurance was requested from participants that they had no conflict of interest with regard to this study.

Data Collection

Focus groups were conducted with each recruited team to gather data.

Participants who attended the focus group were asked to sign a consent form (Appendix 3). Participants were reminded that, with their consent, their focus group would be digitally recorded and all discussions would remain strictly confidential. Participants were reminded that due to the sensitive nature of the topic being discussed, that content discussed during the focus group should not be discussed outside of the focus group. Each participant was given a unique identifier. The focus groups were facilitated by me, the primary researcher.

¹ Analysis of the collected data from the two focus groups secured before Covid-19 Lockdown suggested that recruitment of a further Practice to run another focus group would be likely to add little extra of note in the analysis; data sufficiency had been reached. It was therefore agreed between researcher and research supervisors that for pragmatic reasons in light of Covid-19 that the research could be completed with the data already acquired.

I introduced everyone in the group and provided name badges. I explained at the start of each group what would happen and the background to the topic. The focus groups were carried out in line with the schedule set out in Appendix 4.

The focus groups took place in Primary Care centres, both in a quiet room, which was not used for other purposes at that time and was not likely to be interrupted. A sign was placed on the door to ensure this. There was one member of the research team present (me) at each focus group.

Results of scoping review were briefly explained and participants were asked to discuss the challenges they perceived for the rural primary care team in providing care for patients with dementia. Based on this they were asked to suggest potential improvements if any which could be made to improve care in this area. An iterative approach was employed, whereby new issues emerging were fed into the subsequent focus group for discussion. Duration of the focus groups was determined by the conversation generated, however neither lasted over 45 minutes.

A debrief session was carried out at the end of the focus group where participants had an opportunity to ask questions and clarify any responses or queries which may have arisen during the discussion.

Published work or disseminated findings did not mention by name either practice, location or individuals. Any quotes with identifiable information regarding these were removed. The anonymization regarding location will ensure that a quote from a participant would not locate them to a specific geographical area.

Discussions from the focus groups were recorded using two digital Dictaphones and transcribed verbatim. Participants' transcriptions were anonymised using a unique identifier, which will correlate with audio recordings. Following transcription, which was carried out by myself, any identifying information in the transcripts was removed.

Each transcript was labelled by focus group number, page and line number. This enabled the codes to be identified by the notation F-P-L. For example F2-3-24 referred to focus group 2, page 2, line 24.

Data analysis

A qualitative approach was implemented to explore the data. Qualitative approaches allow the researcher to find out about the “why” and the “who” and explore the thoughts behind why things happen and why people think as they do. In 2014 Braun and Clarke described qualitative research as a fundamental tool for healthcare saying that

“Qualitative research offers rich and compelling insights into the real worlds, experiences, and perspectives of patients and health care professionals in ways that are completely different to, but also sometimes complimentary to, the knowledge we can obtain through quantitative methods” (54)

Several qualitative methods exist. Initially a thematic analysis approach was considered. Different definitions of thematic analysis can be found in the literature and as a technique it has become now more widely used in healthcare research. Braun and Clarke described it in 2006 as “a way of minimally organising and describing your data set in rich detail”. They describe thematic analysis as an analytic and reporting process where the researcher looks for patterns and interesting points in the data and then reports these by giving meaning and context to the patterns they have found by organising them somewhat into “themes”. (54) They outline a six step description of the process.

1. Familiarising yourself with the data – transcribing, reading and rereading the data
2. Generating initial codes – coding interesting features
3. Searching for themes – gathering codes into potential themes, and collating data into potential themes
4. Reviewing themes -
5. Defining and naming themes – continuous analysis to refine the specifics of each theme and producing clear names for each theme
6. Producing the report – the last opportunity for analysis. Summary and selection of extracts and examples, relating back to the research questions and producing a report.

This was my first experience of conducting qualitative research, and as such, the concept of data analysis in this form was a new one for me. I had read and learned a little about thematic analysis and felt this would be applicable to my data. However, as explained

below, when I read a little more about template analysis, although similar and a form of thematic analysis, I felt it may be more suited to my work.

The rationale behind the choice of template analysis

Brooks et al defined template analysis as “a form of thematic analysis which emphasises the use of hierarchical coding but balances a relatively high degree of structure in the process of analysing textual data with the flexibility to adapt it to the needs of a particular study.”(55) Template analysis is often used for interview scripts and focus groups.

From previous review of the literature and through a closer look through the scoping review I had become familiar with the themes which present themselves in relation to this topic. As alluded to in the scoping review, similar overarching themes became apparent as results to the question being asked. Similarly, during initial review of the data from the focus groups conducted in my study, whilst new data was presented there was definitely a feeling that there was a backbone of common themes emerging. For this reason, following discussion with my primary supervisor we decided that template analysis may be a better fit for data analysis.

As with thematic analysis there is a suggested six step approach, however in template analysis the researcher can be flexible regarding the style and format of the template produced. Although very similar to the process of thematic analysis one of the main differences is that in a Braun and Clark approach the development of themes and a coding structure takes place after review and coding of the entire data set.(55) With template analysis an initial version of the template can be created on the basis of a subset of data, and themes can be produced early and used to guide further coding, whereas with thematic analysis the themes are usually not decided upon until the end of the entire coding process. Additionally thematic analysis does not specify limits to the levels of coding whereas template analysis can use four or more levels of ‘subthemes’ to capture the richest aspects of the data.(55)

The phases of template analysis in turn as described by Symon et al 2012 (56) are:

1. Become familiar with the data to be analysed – the focus groups were printed out as hard copies, with double line spacing and with line numbers. This was to make the text easier to read and absorb. Some time was spent immersing myself in the

data and simply rereading it and familiarising myself with it. Some field notes which were taken during the focus groups were reread and more notes on initial thoughts were made when reading through the data.

2. Carry out preliminary coding of the data – coding is a “process of highlighting anything in the text that might contribute to his/her understanding” (55) in particular information which is relevant to the research question. Codes, when used in qualitative research are defined as “a word or short phrase that symbolically assigns a summative, salient, essence capturing and / or evocative attribute to a portion of language based or visual data”(57)

Unlike in thematic analysis in template analysis one can start with ‘a priori’ themes, identified in advance, which are likely to be relevant to the analysis. (55)

3. Organise the emerging themes into meaningful clusters, and begin to define how they relate to each other within and between these groupings – this may give rise to subthemes, ie including “hierarchical relationships” between codes. (55)
4. Define an initial coding template – this can be done based on initial preliminary data collection and can be added to as the process goes on
5. Apply the initial template to further data and modify as necessary
6. Finalise the template and apply it to the full data set

Research Governance

Data Quality Assurance and Security

The research progress was supervised by Dr Nigel Hart, Senior Lecturer in the Centre for Medical Education, QUB, as co-lead supervisor; and Dr Bernadette McGuinness, Consultant Geriatrician and Senior Lecturer at QUB, as second supervisor. There were regular meetings with supervisors to ensure satisfactory progress. There was also a review annually via the Annual Progress Review with the Postgraduate Research Committee.

The participants’ data was held during the study in accordance with a data plan set out in Appendix 5. The data was analysed confidentially in the Centre for Medical Education at Queen’s University Belfast. All data that was collected was kept strictly confidential. No participants’ names were related to any comments from the focus groups, nor will they appear on any report or publication resulting from the study.

The audio from the focus groups was analysed and transcribed by me. After transcription and completion of the thesis, the audio files were deleted. Consent forms will be stored in the Centre for Medical Education, Queen's University Belfast. When the study has been completed, the forms will be securely stored for five years, and then destroyed.

Ethical considerations

Ethical approval was gained from the Faculty of Medicine, Health and Life Sciences Research Ethics Committee (Faculty REC) in accordance with the Proportionate Review process. (see Appendix 9)

The study was designed to identify challenges and suggest improvements. None of the researchers disclosed conflict of interest in conducting the study.

The researchers believe the risks of this study were negligible. As discussed previously the participants were aware that they would know each other and as such full anonymity between group members could not be guaranteed. This was included in the consent forms.

The participants were required to give written consent for the focus groups, and were free to withdraw from the project at any stage. All data collected was treated securely, anonymously and confidentially as per QUB research practice policies. Safeguards were put in place to protect the confidentiality of all participants.

Published work or disseminated findings did not mention by name either practice, location or individuals. Any quotes with identifiable information regarding these were removed. The anonymization regarding location ensured that a quote from a participant would not locate them to a specific geographical area.

Anonymous data only was collected and held on Queen's University Belfast password protected electronic storage.

Chapter 4: Considering Reflexivity

“Your selection of things is mostly a reflection of your thoughts, inner feelings, and character.”

Ehsan Sehgal (Poet, Author and Journalist)

Reflexivity is an important concept in qualitative research. It is a process whereby the researcher continually reflects upon the work they are doing and comments on how their position may affect any part of the research. It is important to maintain credibility of the research and to try and reduce potential unintentional bias which may come from the researcher due to their own position or values.(58)

Throughout the thesis I have referred to the researcher, “I”, in the first person. This was a decision I deliberately made following personal consideration and also discussion with colleagues regarding the merits of each possibility.

In order to demonstrate positionality, I feel it is important to explain about who ‘I’ am and where I fit in to this research problem.

The research question incorporates three main areas – dementia, primary care and rurality. Taking each of these in turn. Care of the elderly is an area in which I have always been interested. Prior to GP training I did three years of Core Medical Training, affording me the opportunity to work in several ‘Care of the Elderly’ jobs and it was here I developed an interest in the care of older people and in particular, some of the challenging complex conditions which are more prominent in older age. Dementia is one of these conditions. On a more personal level I have an uncle who suffers with severe dementia and also have friends who have parents with this disease and so the ongoing and future care of those with this condition is important to me.

Primary Care is the specialty that I have chosen to train and spend my working life in. This research has been carried out during my final two years of GP training, in the primary care setting. The research is focused in particular at the primary care team, the individuals that make it up, and how they as a team tackle dementia care. I have first-hand experience of being part of a primary care team, and feel to some extent I understand the workings of a well-functioning primary care team. It is important to note my sense that the primary care

team in which I work is a well-functioning team where members value each other and promote team working and a team based approach.

Rurality and the potential challenges of rural living is an area I didn't realise I was interested in until I started this work. When talking about my work with colleagues, it has been said on several occasions "your interest in rurality really comes across" This was really not something which I appreciated I was passionate about. However, throughout my Medical and General Practice training I have worked in rural areas. In my GP attachment in fourth year at medical school I was placed in a practice in Keady, County Armagh. This was my first experience of General Practice and was one that I thoroughly enjoyed. Looking back, I feel rurality had a large part to play in this. The GPs in the practice came from long generations of GPs and my first experience of a home visit was miles from the surgery. I enjoyed the small town community feeling and the fact that the staff in the practice knew their patients so well.

I have spent a lot of time in the West of Northern Ireland throughout my training and my current attachment is a practice in Lisnaskea in rural county Fermanagh. Due to recent closures of practices in the surrounding areas, the Health Centre has a very large catchment area and serves over 14,000 patients. My experience of working there has made me appreciate the challenges of rural living and rural healthcare. Patients travelling fifteen miles to the surgery for an appointment is commonplace. Home visit days can be a round journey of up to ninety miles. In addition to this I was born in and spent 18 years of my life in Omagh, which is a rural town itself.

I feel it is important to acknowledge therefore that I am a young doctor, from a rural area, working in a rural primary care team, with a significant and personal interest in dementia. I have tried throughout my work to acknowledge this and not let it influence my thoughts or participation. I will comment further on how I feel my position impacted on the focus groups in the personal reflections section later in the thesis.

The above gives rise to the reasons why I have chosen to write in the first person. Because 'I' have an interest in this area and am embedded in each aspect of it I feel the work will be best served by writing in this way.

Rigour

Due to the potential for subjectivity that can arise during qualitative research it was important to try and maintain rigour during all aspects of this process. This was achieved by regular meetings with both supervisors throughout the research journey. More specifically during the analysis of data I met with my principal supervisor very frequently, alternate days during the coding process. Initially I coded the data following attending a course in Oxford University in November 2019 called 'Analysing Qualitative Interviews.'

The primary supervisor independently coded the data and a discussion was had to ensure compatibility. Following this discussion of the methodological framework took place, and as discussed in the results chapter the initial coding template was revised.

Whilst it was initially planned that three focus groups would take place due to the unforeseen circumstances of Covid 19 a third group was not carried out. However, upon discussion with the principal supervisor it was felt that a broad range of data had been gained from the two focus groups, in particular the first one which included multiple disciplines making up the primary care team.

Chapter 5: Results

This study sought to assess what rural primary care teams perceive as challenges to caring for patients with dementia.

As discussed in the previous chapter a template analysis approach was adopted for data analysis.

Derivation of the starting coding template

This process began by going through the transcribed focus groups and assigning codes to the data. Coding, as mentioned previously, was described by Braun and Clarke as "generating pithy labels for important features of the data of relevance to the research

questions”. (59) Whilst the majority of the data was coded by a line by line approach, elements that were in no way relevant to the research question were not coded.

Considering what had been established from the scoping review of the literature and a broad preliminary overview of the data collected I was able to construct a starting coding template. Initially I started with eight broad themes. These included carers and support services, the route to diagnosis, the dynamics of family, the positives of rural living, farming and economic implications, the challenge of geography, and then a section of codes which I hadn’t assigned to a theme entitled ‘no theme’. This table can be shown in appendix 5.

Following this I discussed the starting themes with my primary supervisor, as well as the codes that been assigned to ‘no theme’ and the parts of the transcript which had not been coded.

Following discussion and further review of the transcripts we further organised the themes into meaningful clusters together and arranged them into themes and subthemes. We continued to refine this process until we finished with four broad themes with two subthemes within each. These are shown below. (Appendix 6)

1. Formal and informal care and support
 - a. Carers and support services
 - b. The dynamics of family
2. The journey to diagnosis
 - a. Health care professionals’ perceptions of the diagnostic process
 - b. Involvement of the entire primary care team in this patient journey
3. Aspects of rural living
 - a. Farming and economic implications
 - b. The challenge of geography
4. Potential future innovations
 - a. Capitalising on rural community assets
 - b. Further thoughts for improvement

Formal and informal care and support services

Carers and support services

A lack of carers to look after patients with dementia was frequently mentioned throughout both focus groups, and this was an issue that was raised by medical, nursing and social work staff within the primary care team. Whilst perhaps not immediately obvious it was clear from the discussions within the focus groups that this in turn had an impact on the primary care team.

Lack of availability in rural areas as well as being able to find carers locally was a challenge cited by several members of staff, as well as the time constraints of allocating carers to a patient once the need is identified. A shortage of carers was also mentioned in relation to lengthy waits for nursing home places, one social worker reported:

“When it comes to further help in the home you’re lacking carers, you’re lacking support and there’s no beds in the nursing home” (F1-4-76)

Lack of support for carers was also mentioned, as well as a general feeling that there is a lack of incentive for new carers to take on the role, and that they could be paid better and have “better terms and conditions” (F1-2-21). Lack of funding for carers was cited as a challenge. There was a feeling that if the carers felt more valued and had some time off the situation could be better.

“If we looked after the carers a wee bit better”... “they need the respite too” (F1-14-333)

“But it’s getting people to do it and the funding” (F1-14-336)

Lack of nursing home places and respite services was cited as a challenge, particular to a rural area.

“Resources is a big issues in a rural community” (F1-13-322)

A district nurse commented that there was a “gap” (F1-4-82) between deterioration in a patient’s condition and placement in a nursing home, with nothing in between, in turn placing increasing demand on her to provide support in the interim.

“there’s no respite, family are very stressed, they can’t cope, there’s just nowhere for them to go” (F1-4-77)

This was reiterated in the second focus group where a GP mentioned the delay in getting patients into a respite service.

“there’s no facility to get them (patients) in somewhere really quickly for respite, and just get the house sorted,..... that all takes far too long” (F2-1-19)

A need for more services such as respite and nursing homes was mentioned frequently throughout the discussions.

Funding difficulties were again mentioned in relation to lack of respite services for patients in very rural areas, with one social worker mentioning a specific example of a border town needing money from the trust in order to sustain its respite care.

“they’re (respite service) looking for more money from the trust and are sort of lagging behind on that, so can’t accept new referrals in R-----” (F1-8-175)

Similar to lack of carers, lack of staff available to work in respite and nursing homes was mentioned amongst participants, with a suggestion that final year school students would be well placed to help out and gain experience in the caring role.

“there are a lot of people out of school at a certain age who want experience” (F1-8-189-190)

Participants agreed that there was a lack of formal social work support in rural areas to aid both medical staff within the primary care team, and families supporting patients with dementia.

“we need more social workers, more support for families, you know..” (F1-8-183)

“yea..just a bit more support” (F1-11-272)

Medical staff amongst participants acknowledged that while some voluntary local services were helpful in supporting patients with dementia, as a primary care team they weren’t always sure how to access them.

“Voluntary agencies even, there are a lot of people out there who would be willing to do it, (caring roles), it’s just getting them....” (F1-11-259)

More funding was felt to be needed for both carers and staff training.

“It’s a chronic disease, and let’s face it, diabetes is the one that gets all the money and dementia is really needing it and training” (F1-11-276)

Informal caring roles and the dynamics of family

There was general consensus from the participants that family play a major part in caring for patients with dementia in rural areas. Issues around family relationships and family members living near and far and the implications of this on the primary care team was explored.

A social worker in one group commented that while family support was good in one town in the area, she felt this was less apparent in a neighbouring area.

“I would find when I moved to R_____ there is more family support, they seem to look after their own, you come back into L_____ and it's more right, we're entitled to this, whereas in R_____ they do look after their own, more so....” (F1-5-97-99)

One GP commented that they had noticed that the setup of families living in the one household had changed since he was a child commenting that

“I think there's been a shift in families, when I was a child you'd have maybe the grandfather or grandmother living in the house” (F1-4-83)

He later commented that he had noticed that whilst working in a mainly Asian community in England he felt family had maybe taken on more of a caring role, commenting that families often lived together and supported one another and he hadn't noticed this so much since moving back to the rural area

“...all three generations would live in the same house and if they did have dementia, you know, the family would take up the role of carers, but I'm not seeing that so much here, has there been a shift do you think?” (F1-4-84-86)

Good family support was also reported in the second focus group, with one GP reporting that good input and support from the patient's family and the team having a good relationship with them can really help and improve patient care.

“it's like a famine or a feast, so either the family dynamic is close and local and can really make your job easier in terms of keeping an eye and monitoring and navigating risk....” (F2-3-54)

Good family relationships and support were also reported in the context of concerned relatives informing the primary care team about a decline in their relatives or a concern regarding a possible diagnosis of dementia.

“it was his sister in law maybe, was it, got in contact with us, saying he was starting to wander at night..” (F2-1-15)

This was also cited however as a sign of family carer burden or stress, and this being evident to the GP as well as concern for the relative with dementia. Family carer stress was reported more than once and was a concern voiced by participants.

“It can be the opposite... where there is carer burden..... and there’s a lot of expressed emotion of their concern and worry to you, as a GP” (F2-3-57/58)

“You’ve families frustrated and trying to deal with people who are up at night” (F1-2-33)

This was also expressed in terms of lack of respite as mentioned previously.

“there’s no respite, family are very stressed, they can’t cope” (F1-4-77)

On the other hand, family living far away from a relative with suspected or diagnosed dementia was also mentioned as an issue. Relatives living in different areas of the country and in different countries were mentioned as potential contributing challenges.

“the husband and wife both have dementia and the daughter and son both live afar and they’ve got their own family and their own work and they’re doing their best, but you know, it’s not good enough I don’t think” (F1-4-88-90)

Again, GP participants mentioned family living far away as a particular additional challenge for the patient, family and for the PCT.

“if you don’t have family that live with him and can watch him 24/7 then, em, you can run out of options pretty quick I think” (F2-2-31)

“We have a lady at the minute and she is the main carer for her husband who is disabled, but she has dementia, and still early stages but family live further away, and you can tell it’s challenging to navigate.....how do we notice when she stops coping, because there’s no-one locally, and the GP can’t keep a constant eye” (F2-3-64-67)

Participants also reported that whilst there may be family living locally they are not always providing a caring role and that a lot of patients who have dementia live alone with no family support, which in turn placed emphasis on the PCT to provide this.

“sometimes there’s a lack of family interest” (F1-14-331)

“His daughter is in Australia, he has a son here but he just doesn’t keep that eye on him..” (F2-10-220)

An additional challenge identified was family looking after parents who both have dementia.

“the husband and wife both have dementia.....hopefully he’s going to respite on Friday...his wife doesn’t know if he’ll stay and the daughter is more concerned about the wife then, and what’s going to happen to her” (F1-4-88-91)

Another example given was the person with dementia being the main carer for a spouse, and the difficulties around this for all involved.

“She is the main carer for her husband who is disabled, but she has dementia, still early states, but...you can tell it’s challenging to navigate” (F2-3-64-65)

The journey to diagnosis

Health care professionals' perceptions of the diagnostic process

One of the major challenges cited by members of the rural primary care team was the lengthy process the diagnosis and management of dementia entails. The length of time to diagnosis was a challenge mentioned by staff.

“the diagnostic process takes a long, long time” (F2-5-103)

This was a recurring issue amongst staff who felt that this had a big impact both on the patients, their families and also on them as a team looking after them. This was echoed amongst all members of staff with a social worker reporting it a very long process, and with the feeling from medical staff that on average it would take up to a year for a person to be started on medication.

“I think from the referral to nurse-led memory clinic is three to six months, then after that the diagnostic assessment with consultant to start medication is another three to six months, so it's about a year on the NHS, from suspicion of diagnosis to treatment” (F1-3-39-41)

“it's that big long process yea from when you suspect it” (F1-2-31)

There was a general feeling of healthcare worker dissatisfaction at this lengthy diagnostic process with one GP stating that things could deteriorate a lot in that time period.

“by the time the diagnosis comes the problem has already established” (F2-8-180)

Poor access to mental health and psychiatry of old age services was cited as a potential cause for this delay by participants in both focus groups, with a social worker particularly mentioning that they are not able to refer directly to these services, and having to have the GP make the referral added to the time delay.

“I suppose I have this dig about the community mental health team, but we can't refer to them obviously, have to go through GPs and then obviously the GP makes the referral back to the community mental health team, so you're sort of losing time.....” (F1-2-13)

There was a general appreciation that mental health services in these rural areas were “under resourced” (F2-5-120) and that specialists are “thin on the ground” (F1-13-316)

One GP felt that community psychiatric nurses, whilst very good at their jobs were under pressure.

“They are firefighting, when there’s a problem.” (F2-10-222)

There was also some dissatisfaction amongst staff that GPs are not permitted to formally diagnose dementia nor to start appropriate medication. This causes challenges for both them and the other members of the team, in managing the patients while awaiting the diagnosis from secondary care.

“You can know, like ninety nine percent sure, this is an abnormal, early onset dementia, but nothing can swing into gear until we get the formal diagnosis” (F2-5-111)

There was a feeling amongst both nursing staff and GPs that GPs could and should be able to make the diagnosis in primary care, with two GPs saying they felt they would be confident in making the diagnosis, and initiating medication.

“as a GP you recognise it, you do the work up, but then you’re sort of, there’s a bit of time you know and red tape getting the actual diagnosis or certainly starting medications. There are people who I would have been very happy to have just started something..” (F1-2-28)

“you know the drugs they (consultants) are going to use, so you know, give us the authority to prescribe them” (F2-9-204)

Participants also felt that whilst waiting for diagnosis that a lot of responsibility fell on them to manage these patients, in often difficult and challenging situations.

“there’s this period of risk management in the meantime....when you’re like trying to juggle” (F2-3-59)

“you can’t constantly risk assess every time you touch base with them, How do we notice when she (patient) stops coping?” (F2-3-67)

They also felt that this delay could cause more patient distress and suffering.

“is the patient subjected to a more protracted period of distressing symptoms because we can’t get to them you know....” (F2-7-163)

As well as healthcare staff stress, burden and worry

“Then it all comes back, I feel on my doorstep” (F1-2-34)

Participants raised concerns that the time period spent waiting for formal diagnosis caused potential problems for them, for example in terms of issues around consent for help and informing family of important issues.

“its getting consent for that you know, if people aren’t formally diagnosed” (F1-6-146)

Participants in both groups mentioned their frustration at patients being discharged from secondary dementia care services if they do not attend the appointment. Participants felt that given the nature of the illness a less strict policy should be adopted, or that some measures should be put in place to try and prevent this from happening.

“and then if they don’t attend two appointments they get discharged!” (F2-4-95)

“you’d think of all the services that they (secondary care services) would be understanding of that (DNA appts)” (F1-3-38)

“..they should have a better system you know..” (F2-7-167)

It was also mentioned that sometimes too many multidisciplinary members can be involved in a person’s care and that this could result in no-one actually taking lead responsibility.

“That’s when it becomes more difficult, or messy. It’s just there’s so many professionals involved,you know its sort like passing the buck maybe” (F1-2-19-20)

However, on a positive note they acknowledged that GPs had good safety netting mechanism and this was beneficial in caring for patients with dementia.

“I think GPs have good safety netting mechanisms, maybe it’s because they have better access to us, so we can catch stuff inadvertently in the notes” (F2-5-98)

Following on from this, medical staff felt that some training on starting dementia medications in primary care would be helpful and all felt they would be open to this.

“I’d like some training” (F1-12-304)

“To be able to diagnose it and to start medication” (F1-13-308)

Although one GP felt that he would be confident in screening for dementia, he agreed that training on medication initiation would be beneficial.

“I think we could have a training programme for that (starting dementia medications) and what they wanted us to watch out for..” (F2-9-200)

There was a discussion in the first focus group between a nurse and one of the GPs who recalled a BMJ article that encouraged GPs to start medications, with one GP saying she would be anxious about starting medications without any training.

“I got a bit anxious because I thought well I’m not trained up to do this, but it said that we were going to prescribe it.....” (F1-13-311)

In terms of the nature of the disease itself, participants acknowledged that there can be barriers to patients coming forward for help and diagnosis.

“There’s also the stigma of dementia, a diagnosis of dementia.....and also for families, there’s a while lot of fear about dementia” (F2-4-83-85)

In addition to this, it was acknowledged that some rural people may not seek out help until things have really deteriorated.

“ I think that’s the thing about rural, particularly single farmers, you often find really dreadful conditions that you don’t realise until it’s too late” (F2-1-17-18)

Involvement of the entire primary care team in this patient journey

There was a general feeling amongst all participants that all primary care team members play an important role in looking after patients with dementia throughout the diagnostic journey and for the long term. The close knit nature of a rural team and community came across in both focus groups, this in turn enriching the care of their patients.

Familiarity between rural practice staff and patients was evident from talking to the participants, and a strong sense of both care and concern from non- medical staff members came through. A practice receptionist noted that the patients knew her and that this familiarity was part of her role.

“I think at reception my duty would be to meet people, I think...familiarity...I mean you know they know you...” (F1-4-67-69)

Another receptionist added to this, acknowledging that she was aware when the patients had dementia

“When you see they’ve got dementia it’s very obvious, you know you can even hear the confusion on the phone, and you come off the phone and you’re like hmmmmmm...”(F1-6-132)

A real sense of fondness was evident, when she later described a situation where she needed to confirm an appointment with the patient, and because she knew her well, was able to phone the patient’s daughter to clarify it. This fondness however raising the ethical dilemma of confidentiality vs pragmatism.

“I’d a wee woman last week, she couldn’t remember how to answer the phone, Thank God she lifted it she said, but then I had to phone the daughter, because I had consent, to say her mum had phoned me, just so that she was aware of it, and that an appointment had been made for this week, just incase, because she hadn’t

written it down, she didn't have a pen, she didn't have paper, so I felt the need to phone the daughter" (F1-6-133-135)

This was reiterated by her receptionist colleague who agreed she would do the same

"I would say to her, do you give me consent to ring somebody or are you ok..... and I would say, when they're on the phone, because there is a vagueness, a well hold on, you just know there's something not....." (F1-7-154-159)

The reception staff also appreciated that their knowledge of the local people and area helped them with their role in caring for patients with dementia.

"We are very familiar with most of our patients, you could nearly, "awk its her its..." and I think we know families here, we've grown up with families and you know the familiarity of people here, and I think you know yourself from a going up here point of view that you know the family well, but you know there's a vagueness in the conversation that there maybe hasn't been before.." (F1-7-161-164)

".....its good to have local knowledge, you know as reception staff" (F1-7-166-167)

This familiarity and concern for patients was also evident from other members of the primary healthcare team. One of the practice nurses commented that she knew when some patients were forgetting to pick up their tablets, giving one example of a gentleman whom she frequently personally keeps an eye on.

"but he forgets to get his tablets and I try my best to keep looking has he ordered these tablets" (F2-9-210)

She continued by fondly explaining how she had encountered him the next day at the pharmacy.

“just last week you know I contacted him again to get these tablets, and em, it was so funny, the next day he was going to get them, and I was in the chemist that day, and somebody dooted the horn and there he was..” (F2-9-212-215)

She noted however the impossibility of personally keeping a check on every patient with dementia.

“But you can’t keep that up, you know, and you can’t do it for everyone” (F2-10-219)

Another practice nurse commented that if she knew a person with dementia was checking in for an appointment she would try and make sure they got help if they needed it within the health centre.

“if there’s somebody you know, who’s checking in, you know you have a look at their notes and you know they have dementia so you make sure that they get help” (F1-10-234)

Staff agreed that they worked well as a multidisciplinary team and that this was a positive thing in caring for their patients. One GP noted;

“I think on a positive note, I think the primary care team itself works quite well, you know, social work, district nurses feeding into our MDT meeting, and you know, good channels to communicate, that is going quite well...” (F1-2-16)

With a district nurse colleague agreeing

“I’ve a good relationship with everybody who comes to them” (F1-4-75)

Aspects of rural living

Farming and economic implications

Whereas some of the points raised in the focus groups were inevitably about the general challenges faced when looking after patients with dementia, some were specifically unique to rural areas. This was evident in this theme in particular. Farming and land ownership were mentioned several times as were the economic implications surrounding a family member with dementia. One district nurse commented that families are not always financially able to support a person living with dementia, especially when the caring role falls on them.

“I think people have low paid jobs and families to look after.....they’ve got their own family and their own work and they’re doing their best but you know, it’s not good enough I don’t think” (F1-4-87, 89)

There was a discussion in one of the focus groups where the economic implications of a person going into a nursing home were highlighted.

“And then there’s financial implications behind that, if they haven’t farms of land signed over or you know,... they try and keep mummy and daddy at home, and them struggling, as you say there’s maybe a whole safeguarding issue behind that. But if there’s financial implications if you’re gonna lose a farm of land worth.....” (F1-14-340-342)

The discussion continued with the similar concern around losing a farm

“That’s a rural thing, yes it is, it’s a good point and its very real, very real, you think no God I can’t leave this there’s a farm of land here” (F1-14-345)

Participants discussed the expense of a nursing home and also the paper work and legal involvement required, especially when funding applications are involved.

“A nursing home bed is almost 700 pounds a week you know” (F1-14-349)

“Apparently all this was signed with the solicitor seven years ago, but when they went to get the papers or whatever, there’s some clause or something, so she went into the home today, but on the basis that they get this sorted” (F1-14-346-348)

Again, there was an overall sense that these issues in add pressure to the rural primary care team, in particular social workers and district nurses, as there are less people in formal nursing home care, thus increasing workload for them in the community.

The uniqueness of farming and life of rural farmers was mentioned in another way during the second focus group. Participants acknowledged that farmers are often independent people who do not seek help from their local primary care team very often and so can be harder to identify.

“I can think of one wee guy in particular, em Mr T in S____, who was a bachelor farmer, and lived in a wee farmhouse and looked after himself all his life...we hadn’t really had much interaction with him in a long time, and we went out to see him and the house was unbelievable, in squalor” (F2-1-13-17)

The GP commented that it was a family member who had got in touch with them to alert them to his “wandering at night” and acknowledged the potential dangerous living conditions that people can find themselves in due to dementia and living alone.

“I think that’s the thing about rural, particularly single farmers, you often find really dreadful conditions that you don’t realise until it’s too late” (F2-1-17-18)

“...he was lighting fires the whole time, it was, the whole house was charred, it was the worst I’ve seen in years and years” (F2-2-46-47)

The practice staff in the second focus group also acknowledged the concern re. loss of financial independence and implications of farming, with one participant telling an anecdotal story of her own experience of dementia within the family

“Even personally my father passed away last year and my eldest brother got the farm, and my youngest brother got the home house, and mum you know, didn’t get anything, and you know, she is in our house still, but just in case she has to go to a nursing home then she won’t have to pay anything so there is that financial element of it” (F2-4-80-83)

The challenge of geography

The physical and spatial dimensions of geography were mentioned as a challenge for the primary healthcare team in looking after patients with dementia. Medical staff mentioned home visits and the time constraints placed on them due to distance of travel from the surgery. One GP commented

“I travelled over ninety miles on visits one day, and that wasn’t even getting to work that’s just visits” (F1-6-127)

With similar issues cited by a social worker

“There’s a huge distance even from here to R____. It’s a good twenty minutes, you know and then you go there you’d nearly need to stay the day to make it worthwhile, you know for driving there.” (F1-5-113)

One of the GPs commented that compared to urban areas she felt staff had less time with their patients due to the challenge of distance

“There is an inequality too there, you have to schedule sixty patients, and they are all over the place, whereas if you were in Belfast you’d have them all nearby, so you have less time with your patients” (F1-6-122-123)

With another GP adding

“It impacts on where you plan your visits, you try and do them in clusters” (F1-6-125)

Transport was mentioned in two capacities, both in terms of transport for patients travelling to appointments and respite etc and also the implications of patients with dementia having to give up driving.

Participants commented on the rural bus service in their area, which was helpful to patients, however not entirely accessible for everyone and staff were unsure exactly of its operational capacity

“The transport service, Fermanagh rural lift is in operation still, I see it sometimes around my area, I don’t know does it reach everywhere, it’s usually a pound they pay....” (F1-8-193-194)

“you need a bus pass and that’s probably how then its reimbursed, you have to have your bus pass before you can use it” (F1-8-195)

Participants acknowledged that driving is an important issue surrounding dementia particularly in rural areas where people may live lengthy distances from towns, services and families. Team members acknowledged that this can be a delicate issue between the doctor and the patient and can be a significant loss of independence for the patient.

“If you live rurally and you’re driving and you’re diagnosed with dementia, that’s a big problem isn’t it. It’s very tricky for GPs to say sorry but I’m not going to sign the form to renew the license” (F1-5-101-102)

This was reiterated in the second focus group

“Driving, people worry about being told they can’t drive...It’s more so important here, than in an urban area as they live miles away” (F2-4-86, 88)

Potential future innovations

Capitalising on rural community assets

As well as identifying challenges participants identified ways in which rural living has its own unique positives. As mentioned in the ‘journey to diagnosis’ section, familiarity of practice staff to patients in a rural area was reported as an asset and aid to care.

Good support from local voluntary sector groups was reported, and participants felt that this was something that was probably more prominent in rural areas.

“And see for rural areas as well, it’s like sort of the local community groups and community supports that are helpful, for example the older people’s group or whatever it is....the Alzheimer’s society, and all the other charitable things, because the formal structure isn’t sometimes there..” (F2-6-125-128)

One participant made the point that the rural community had really pulled together during the Covid 19 pandemic and that all patients, including those with dementia would have benefited from this.

“There have been more rural voluntary groups set up since Covid obviously” (F2-6-142)

“The transport yea, and the general help, you know the different GAA clubs have been doing deliveries of medication to people who are shielding and things like that and you know, the rural dementia patients would come into that, and so they’re probably more accessible now than they ever were before...” (F2-7-146-148)

“and the local pharmacies would be good support” (F2-7-150)

Some participants felt that rural people can be very independent and have a unique stoicism.

“And probably people exist better in rural areas than they do in urban areas, (F2-8-181)....

“I would think they are likely to have more support” (F2-8-182)

“He does have dementia and he lives on his own and all the rest and he looks after himself alright you know..” (F2-9-209)

On the other hand however, it was recognised that this stoicism could stop people with dementia from accepting help, posing a challenge for primary care teams looking after them.

“There was social work interaction with him, and there was a carer, but he said I don’t need it, sure I don’t need it I’m alright, and so you’re up against the wall” (F2-10-225-226)

Furthermore, it was felt that in a rural area the community is more likely to be aware of a person living on their own, in terms of help and support.

“the rural community is more likely to know the older person who is living alone.”
(F2-8-189-190)

“Urban people can keep to themselves and don’t know their neighbours, and they change all the time, there’s new faces so they don’t get to know their neighbours”
(F2-9-194-195)

Following on from this, participants suggested ways in which they could use their rural community to improve care for patients with dementia and help them as a primary care team to do so.

“I strongly believe in using your community assets, you know using your farms for example, you know things that are already in your community that can be used to support people” (F1-11-267-268)

“use your community voluntary sector, they should be supported and should be integrated within a primary care team” (F1-11-269)

Participants also suggested that school children could help in local nursing homes to gain experience.

“there’s a lot of people out of school at a certain age who want experience, you know if you got to any of the schools, as well, they had somebody in G or C (nursing homes), they had girls in maybe doing their Alevels.....and that was brilliant they were doing reminiscence therapy, art therapy.....” (F1-8-190-192)

One participant commented that the focus group itself had been helpful in getting people together to come up with ideas.

“it’s good we’re even here talking about it!” (F1-13-328)

Other suggestions included educating the local community about dementia, to increase awareness and the need for help

“An education programme for people on dementia, for the community? The general public, you know?” (F2-10-239)

Further thoughts for improvement

Other more general points suggested for improvement included practical improvements to the health centre building, discussion around which was initiated by the practice manager

“Well I suppose in the likes of those homes they have like signs, certain signs in colour, for the toilet, and you know I suppose putting up certain signs, that’s dementia friendly”(F1-10-228-229)

And practical suggestions for ensuring patients with dementia receiving mail correspondence from the practice, in case they might misplace it or forget to open it.

“a wee post box outside the door, a wee locked box, it was the daughter who opened it and went through the post with the mother, because once it got into the house, it was gone, lost, you know?” (F1-6-143-146)

“Would it be worth getting someone from Dementia UK to come in and have a look and make our building more dementia friendly?” (F1-12-287)

In terms of additional improvements participants felt that more staff based in the community specialising in dementia would be helpful.

“I think it would be just lovely to have someone coming in and checking on people like that, I suppose that would be the dementia nurse” (F2-9-211-212)

“ I think a CPN you know, who would do regular visits, you know, to your rural patients” (F2-7-156)

“if there was some sort of team set up for overall care for their dementia lists, you know who are living in the community” (F2-10-223)

Chapter 6: Discussion

Summary of main findings

This study sought to assess what rural primary care teams perceive as challenges to caring for patients with dementia.

Issues identified by the groups in this study included :

- The diagnosis and management of dementia and the journey to diagnosis
- Uncertainties about roles and responsibilities of primary care doctors in initiating medications relating to dementia
- The need for further education and training not only for medical but also non medical MDT members
- The value of the expertise of non medial team members and the necessity for development of a more holistic care approach and pathway for patients with dementia and their families and carers
- The many challenges in provision of services in a rural area
- Particular geographical considerations including long distances involved in many interactions
- The challenges of driving for patients with dementia and their dementia
- Issues related to farming

The findings in detail with comparison to existing literature

The findings from the focus groups with reference back to reviews of the literature have been considered below.

Diagnosis and management of dementia

One point that really resonated with me and which was raised in both groups was the difficulty in GPs diagnosing dementia and starting dementia medications in primary care. This was felt to have knock on implications for them as a team, as the long time-delay in formal diagnosis caused distress to the patients and also difficulties for them as a team in managing the patient's needs in the interim period. This is of course relevant to all primary care teams, however perhaps more visible to rural teams due to their closer and often more visible role in the community. Often people in a rural community are aware that there is a problem with a relative, friend or neighbour, and wonder why the GP and the primary care team are not acting more quickly and providing a solution to the situation. This in turn could undermine trust in the local team and so timely diagnosis is therefore very important.

At both focus groups there was a feeling that GPs are well placed to diagnose dementia with members from both groups stating that they would be confident in making the diagnosis. This is in marked contrast to a study in Canada where physicians felt lack of training and experience were barriers to care and even caused them to delay diagnosis as they "didn't have a clue what to do".(40)

There were mixed views from the GPs in the focus groups about starting medications however, with all keen to do so, but some admitting they would need training in this area before they would feel comfortable to do so. All agreed they would not start medications in primary care themselves, and identified this as a barrier to care. The NICE guidelines on dementia and the prescribing of dementia medications state that prescribers "should only start treatment on the advice of a clinician who has the necessary knowledge and skills. This could include:

- secondary care medical specialists such as psychiatrists, geriatricians and neurologists
- other healthcare professionals (such as GPs, nurse consultants and advanced nurse practitioners), if they have specialist expertise in diagnosing and treating Alzheimer's disease" (60)

Although these specific guidelines were not discussed within the focus groups, they perhaps provide some explanation as to why GPs do not feel confident in prescribing

dementia medications in primary care. “Specialist expertise” is a term which is open to interpretation and certainly poses the question as to what degree of training would be required to qualify as “specialist expertise.” If there were a change to GPs initiating medications in primary care, this would likely reduce the long wait to see a consultant and perhaps remove some of the extra challenges facing these teams as mentioned previously. This may be an area that would be worth exploring in the future.

There was a discussion in the first focus group between a nurse and one of the GPs who recalled a BMJ article that encouraged GPs to start medications, with one GP saying she would be anxious about starting medications without “any training.”

GP staff felt that training in prescribing medications would be beneficial and something which would be welcomed by them. Where the training would come from and by whom was not considered within the focus groups. Perhaps this is an area which staff have not considered before and therefore they didn’t have immediate suggestions as to how this would be delivered. One possible explanation is that due to being seen as possibly “out of the way” or “out on their own” from main services in a secondary care centre that there is a feeling of lack of training opportunities of GPs and rural teams. Given the new climate which we find ourselves in due to the global pandemic and the increase use of digital technology and video conferencing, perhaps training may be conversely more readily accessible for rural staff.

What impact a change such as this this would have on referral to the memory clinic in secondary care was not discussed, possibly for similar reasons.

This was similar to Hansen et al (2005) where “knowledge gaps” by the entire rural primary care team was mentioned as a barrier to care, although this reference was not specific to medication prescription.(41)

A GP with a specialist interest in dementia was mentioned as a result of this discussion in one focus group. Unfortunately, this was not expanded on further, but was perhaps a good suggestion for improvement in service delivery.

Education

Lack of knowledge about dementia was an area that was mentioned in the focus group as well as in the literature. As well as training on medications all members of the primary care team felt that improved education and awareness of dementia both for themselves and the members of the community could be helpful in improving care for patients. This is similar from findings in the literature, in particular Constantineu et al (2018) in their study in Canada found that rural physicians cited lack of experience, lack of training and a poor understanding of the process of placement in their area as barriers to care.(40)

Interestingly in the focus groups non-medical members of the primary care team introduced the subject of training, with one practice manager suggesting that an education programme about dementia for the community and the general public could be helpful in improving awareness. This came from a feeling that there is generally a lack of knowledge, and a "fear" about dementia in rural areas which also increases barriers to care. Building upon this, perhaps a suggestion going forward would be to think about the implementation of this extra training and what it would look like, both for medical staff and non-medical reception staff who work in the frontline and are often the first interface in looking after patients with dementia. Education for community members in the form of information sessions could be provided by either the local primary care team or the voluntary sector in that area. Given that rural communities appear to be somewhat 'close knit' this may be something which would be welcomed by local members of the community and strengthen relationships between rural communities and their local primary care teams.

Role of non-medical members of the rural primary care team

From both focus groups there was a strong feeling that non-medical members of the rural primary care team played an important role in the care of patients with dementia. This was not very evident from the literature and as such these focus groups provide a unique insight into the workings of the team. Both practice managers' and receptionists' sharing of their experiences of dealing with and communicating with patients with dementia provided information which could be used to further improve care for patients with dementia. Their comments suggest that providing optimum care for patients with any chronic disease, but

in particular dementia, depends upon holistic care from all members of the primary care team and not just medical staff.

Provision of services

The challenge of access to services was a recurring theme throughout the literature, and was mentioned as a challenge in almost all the studies. One study mentioned that GPs felt that a lack of local specialist services caused inequality in patient care between rural and urban areas and “placed a burden on family practitioners to fill in the gaps for their patients”.(24)

Findings from the focus groups carried out show concordance with this, with many examples given by members of the rural primary care team of how poor access limits them in providing optimum care. Interestingly in one study in the literature whilst the short length of GP consultation was noted to impact negatively on the capacity of rural GPs to make a diagnosis of dementia, one study did show that rural GPs may be more likely to diagnose dementia themselves, as compared to urban counterparts. Participants in this study felt that rural GPs tended to take a more autonomous approach in their practice and did not always need to rely on a referral to specialists to make a diagnosis.(29) Similar to this in the focus groups it was apparent that GPs as well as their healthcare colleagues felt that they were in a good position to diagnose dementia themselves in primary care and there was some dissatisfaction that this process was only allowed to take place in secondary care.

Both the literature and the focus groups highlighted the burden that was therefore placed on GPs and the primary care team to care for these patients whilst waiting for a diagnosis. It is worth noting that the papers discussed in the scoping review ranged from twenty years ago to recent times. It is therefore interesting to acknowledge that similar challenges remain at present. It would seem necessary to consider whether diagnosing patients with dementia in primary care should be taking place to improve timely diagnosis and management. Whilst the GPs in the focus groups did feel they should be in a position to do so, there was no formal pathway suggested by them. Again, another factor to consider would be the opinion of secondary care to an idea such as this.

As mentioned previously there was general feeling from the focus group discussions that primary care staff felt that the delay in diagnosis of dementia was a challenge. Reasons for delays in diagnosis included time for an initial appointment with secondary care, delay in correspondence from consultants and delay in initiation of treatment. Although the NICE guidelines do refer to GPs and nurse practitioners being able to commence medications if they have specialist expertise in diagnosing and treating Alzheimer's disease there is a general feeling that this does not take place in practice. Although it is obviously unclear whether this feeling is unique to the two practices studied in the focus groups or the opinion of all primary care practitioners it does lead us to wonder whether this NICE guideline is realistic for primary care teams particularly in rural areas. Lack of access to specialist services was also mentioned in the literature, therefore it would be reasonable to ask whether there is a lack of staff trained to diagnose dementia, and if this is the case how do we take action to improve this and in what form.

There were some suggestions within the focus groups that dedicated community-based staff would be helpful. Staff alluded to a role in which a person would be able to identify patients with dementia in the community before a crisis point is reached and act as a co-ordinator. It was difficult to ascertain exactly what this role might look like whether it be a dedicated dementia specialist nurse from secondary care or someone within the practice. This suggestion from staff members prompts us to consider what kind of roles we need in our primary care teams to improve the current situation.

In 2018 the Department of Health in Northern Ireland announced a new model of care for primary care multidisciplinary teams (MDTs). This involves the expansion of primary care teams with the addition of multidisciplinary staff such as pharmacists, social workers, physiotherapists and specialist nurses. These non-medical staff members are “first contact” staff with patients and offer unique expertise to patients without having to consult with a GP first. One of the main aims of this model was to focus on prevention and early intervention initiatives, “to ensure that patient’s needs are met at the earliest possible opportunity, reducing the need for onward referrals into secondary care services.” (health-

ni.gov.uk) This MDT model might be used within practices to enhance early diagnosis and care for dementia as described in the focus group

Carers

Poor provision of statutory care both at home and in formal care settings i.e. nursing homes was a recurring theme within the focus groups. Participants felt that rurality made the provision of care more problematic due to lack of staff in these areas and potential long travelling distances between patients. The viewpoints of carers were not discussed in the scoping literature review, as many studies had been done already in this area. It is important to note that lack of carers and lack of access to respite services were mentioned repeatedly in both focus groups. Respite care was acknowledged as a necessity in times of crisis and carer exhaustion, and felt to be a vital service, the provision of which was reported to be deficient.

The spatial dimensions of geography

Similar to in the literature, geography was mentioned by focus group participants as a challenge. The difficulty of rural home visits, in particular was highlighted in the literature as well as in the focus groups, with a similar feeling that long distances forced GPs to have time constraints with their patients. Although it is important here to note that this challenge is not particular to dementia, and is more an issue with healthcare in rural areas as a whole, it was none the less a problem which was acknowledged recurrently in both the literature and the focus groups with one GP mentioning that in a day he covered 90 miles on his day as visiting GP.

In the literature distance to care facilities, in particular nursing homes was cited as a particular challenge. Konsteniuk et al reported that distance limited the capacity of carers and family to visit their relatives if they had to travel long distances to a care facility. This tended to reduce the likelihood of carers moving the relative with dementia into a care facility and thus increase carer burden.(31) This was not something that was mentioned in the focus groups, however a lack of nursing home availability was mentioned frequently

and this was acknowledged to place a greater onus on family carers and increase carer burden.

An issue that was not apparent in the scoping literature review was that of driving by patients with dementia. This was in contrast to the prominence it had in both focus groups. It was acknowledged that giving up driving was a significant challenge for those living in rural areas and could potentially cause conflict within the doctor-patient relationship. The focus group contribution that captures this dilemma most succinctly was the person who said, "it is very tricky for GPs to say sorry but I am not going to sign the form to renew the licence".

This is a particularly important issue in rural areas as many people live miles from their local town, support services, and health care services such as pharmacies and health centres. The removal of a driving license can be seen as a great disempowerment of a person, as well as the logistical difficulties it places upon them, their families and their livelihoods. In turn therefore it is more obvious in a rural community if a GP removes the driving license or indeed seems to be hesitating to do so. Again this may undermine trust in the local primary care team or generate a feeling of hostility at removal of something which is seen as such a lifeline to many rural people.

It is important at this point to acknowledge the definition or lack thereof, of rurality. It has been impossible to find a definition of the word rurality, which could relate to every 'rural' setting. Obviously therefore some of the studies in the literature review refer to 'rural' areas in Canada and Australia which are very different to rural areas in Northern Ireland. Therefore, it is impossible to make absolute comparisons between studies which have taken place in these areas. However, despite this it is interesting to note that many of the themes emerging from the literature and the focus groups appear to be similar.

Farming

While issues surrounding farming and people living on farms was mentioned once or twice in the literature, it was a definite theme which emerged from the focus groups. In their Canadian study Constantinescu et al. (2018) did mention the difficulty with diagnosing dementia in farmers and the implications of this.

“It is a tougher diagnosis to give an 85-year-old farmer than an 85-year-old executive guy... You don't just take the guy away from the farm”.

Discussions however in the focus groups were more detailed, with financial issues around actually leaving a farm being highlighted.

It was noted that farmers are often self-reliant people who can be isolated and do not seek help from their local primary care team. They can in turn therefore be more difficult to identify and diagnose with dementia. It was evident that members of the rural primary care teams were aware that rural farmers may be more stoical and independent and therefore this made their job perhaps slightly more difficult.

Unique to this study were suggestions about using local rural community assets to improve care for patients. One of the suggestions was to use local farms as social farms to encourage patients with dementia, and indeed other chronic illnesses to socialise with others and integrate into their community. There is a social farm in rural county Fermanagh like this, where people with many long term conditions such as dementia, mental health problems and other illnesses can partake in farming activities and other tasks in a safe environment as well as meeting others and improving their overall mental health and wellbeing. Another specific example given was encouraging final year school students with an interest in health and social care to volunteer in nursing homes to help out with care of patients, particularly where staffing is a problem.

Taking this a step further, the suggestion was that local community assets be integrated with and supported by primary care teams, so that everyone is aware of resources and support services that are available within the local rural area and can work together to enrich and complement each other.

The focus groups demonstrated that rural primary care teams and communities have good insight into the challenges they face and they have innovative ideas on how they can improve upon these using their own unique assets.

Limitations

In addition to the findings already discussed it is important to reflect on the limitations of the research. There may be others but I provide the following list of limitations to this research.

- We had planned that three focus groups would be undertaken for this study. Unfortunately, as a result of the COVID 19 pandemic practices had to limit face to face meetings and working schedules changed for everyone. Due to the limitations and increased work load of all those working in the healthcare setting including primary care teams, it was not feasible to carry out a third focus group in the time frame allocated for this project.
- Whilst similar themes emerged from both focus groups, perhaps a third focus group in a another different area of Northern Ireland as originally planned, would have enriched the data gathered.
- While the primary care teams who took part in the study are from two different counties, they are from the same overall Trust and going forward it would be both interesting and helpful to explore whether or not similar issues, particularly around delay in diagnosis are similar in other trusts within Northern Ireland.
- The focus groups were made up of members of a primary care team that work together and know each other, therefore complete anonymity could not be ensured. It must be noted therefore that this can be a limitation in terms of this data gathering method but by the nature of the research question this could not be avoided.
- There is an inevitable hierarchy present in a primary care team. This hierarchy includes educational attainment, medical knowledge, experience in healthcare in general, years of service and employee status. Although everyone was encouraged equally to contribute their opinion it is possible that some members may have felt inhibited by their status in the team.
- Both studies were limited to one hour. This was due to the difficulty in organising a time when as many members of the team were available to come together to have the discussion.
- This research was undertaken while I was a GP trainee in one practice whereas the other practice was one in which I had never worked. This may have altered the manner in which the participants responded to me as a researcher.

- Following completion of the study, on reflection it may have been beneficial to include family members and carers within the focus groups to provide further insight.

Key implications and recommendations for policy and practice

Reflecting on the findings of this research I present the following thoughts:

- Delay in diagnosis of dementia is a previously noted and ongoing challenge facing rural primary care teams and patients. This has a knock on detrimental effect on formal and informal carers, families and the entire system.
- How can this be addressed? GPs do feel they are well placed to make a diagnosis of dementia and with some training would be for the most part keen to start medications. Obviously this is only a result of two focus groups and perhaps not representative of all GPs. This concept could be explored further, and if taken forward further work would include developing the training process and establishing who would carry it out.
- These discussions have raised the question of how we can improve or restructure our Primary Care Teams so that there are key staff available in the community to “spot” patients with dementia before they get to a crisis point where emergency respite or psychiatric admission is required. Perhaps we need to identify or define exactly what sort of role this member of staff would have, and would they be employed by primary care teams or by secondary care?
- How can we maximise the involvement of non-medical members of the primary care team in care for patients with dementia? They are already playing a huge role at the frontline and therefore we need to further improve education and understanding of dementia for both them and members of the local rural community to improve patient care and service provision for patients and their families.
- How can we improve the interface between primary care teams, the voluntary sector, such as Alzheimer’s society and Dementia NI, and other community-based services for example social farms, day centres, church groups, so that everyone feels supported and is working together to improve care for patients within their community? This could also alleviate some of the pressure on formal and informal

carers and relieve some carer stress and burden. Ultimately how can we capitalize on the existing supply of rural community assets which have been identified?

What this study adds

This study suggested the need for further training and education of all members of the rural primary care team, both medical and non-medical in the area of dementia and its impact on those living with it, as well as their families and carers.

It also highlighted the benefits of community input, from statutory and voluntary sectors.

It highlighted that rural primary care team members value the input of these organisations and would be keen to improve the interface with them and welcome them as members of the multidisciplinary primary care team. Members of the groups offered innovative suggestions such as the development of existing community assets such as social farms, of which patients and their families may avail.

The data from the focus groups identified the unique and valuable contribution of primary care staff such as receptionists who are very aware of their local community and are the first point of contact for patients to health care services. This suggests that it would be worthwhile for their contribution to be recognised and formalised as an essential element to the overall provision of care for the benefit of the patient and their family.

The difficulties around farming and associated financial complexities which were mentioned in this study had not been previously recognised in the literature.

Chapter 7: Conclusions

The purpose of this work was to ascertain what the challenges are for rural primary care teams in providing care for patients with dementia and their families. We also hoped to explore what ways care could be improved in these areas. Through the literature review and the empirical study, we have been acquainted ourselves with an in-depth understanding of what was already present in the literature about these challenges but also have come to appreciate the unique way rural primary care teams work together to overcome potential difficulties and provide optimum care to patients and their families.

As discussed previously one of the main themes from the focus groups was that the diagnosis and management of dementia may benefit from a change of approach in these rural areas. This was not a comparative study therefore it is not clear whether this the challenge of length of time to diagnosis is a challenge for all primary care teams but it was highlighted in this setting. It is clear that staff feel that a change in the current process would make a big difference to the experience of patients and their families and carers. Medical staff expressed confidence in diagnosis of dementia and willingness to gain further knowledge and expertise in the area of prescribing medications for dementia and this may be an area which could be taken forward in the future. Lack of carers and respite facilities were cited as practical challenges and barriers to care.

On the other hand, this study showed how well a multidisciplinary team can work together. It was heartening to hear the perspectives of non-medical and nursing staff and in particular hear how their fondness and unique knowledge of patients in the practice and in the community, of which they are often a part, optimized and enriched the care of both patients and their families. Non-medical and nursing staff in both focus groups felt they could positively contribute to patient care due to local knowledge. In particular reception staff, who felt themselves to be respected members of the team and were able to recognize patient deterioration and appreciate carer burden. This is an important output from this research and highlights again both the benefit of a cohesive multidisciplinary primary care team as well as the benefits that come from rural people knowing and feeling comfortable with one another and the community. As primary care physicians we should encourage and include our non-medical staff as much as possible as their expertise is often invaluable.

Future research in this area could include exploring methods of education for all team members. The recent switch to online and virtual methods of communication during the Covid 19 pandemic might provide a model for rural teams with better opportunities to engage with education and policy makers and have their voice heard.

It would be interesting to further explore the issues around the diagnosis of dementia in primary care, and development of care pathways with specialist dementia services in secondary care.

This study has identified issues of importance such as driving and the implications around the doctor patient relationship regarding this. An awareness of this will be valuable in planning education in particular developing communication skills in this sensitive area. An awareness of other issues surrounding dementia which have been raised in this study may be useful for primary care team members to acknowledge from the early stages of diagnosis. For examples financial implications of farming and nursing home placements. An awareness of these may prompt earlier involvement of social work teams.

Through this work we have been given a unique insight into how rural primary care teams show initiative and are use the many assets at their disposal. Examples shared in the focus groups included the use of social farms to provide support for both patients with dementia as well as respite for their families is an area where inspiration could be taken for further community initiatives to improve quality of life for patients and reduce carer burden for their carers and families. This work shows that primary care teams in these areas are open to explore these options and a lot can be learnt from their example.

The positive findings set out in the two paragraphs above give insight to how the final title of this thesis was arrived at. When we set out on this research it is true to say, on reflection, that we anticipated that this body of work would primarily (and perhaps exclusively) identify challenges and difficulties. Through this work however we have also found ourselves 'appreciating' (in the sense of 'seeing something that we had not previously recognized or realised'), in addition to, 'appreciating' (in the sense of giving voice to gratitude for something) the unique affordances that primary care teams have to offer in respect of care for those living with dementia.

In addition to this we also chose to use the word 'for' in the title of the thesis – appreciating perspectives for primary care teams. We originally thought we were appreciating

perspectives of primary care teams, and indeed through this work we are, but we also felt we should use this work to inform rural primary care teams as well as reflecting their practice.

It is encouraging and reassuring therefore to be able to highlight things that could (and perhaps should) be addressed but also the many assets that are unique to primary care teams that can be capitalized upon to care for those living with dementia in rural settings.

I plan to disseminate the findings of this study by means of presentations at rural fora in the areas in which the focus groups took place. I am also involved with the Alzheimer's Society in several rural areas through this work and plan to share this work with them. I am keen to promote rural health, perhaps through project ECHO (Extension for Community Healthcare Outcomes) and other digital platforms as mentioned above. I will also continue to attend conferences and present findings of this work through digital, poster or oral presentation format.

Chapter 8: Personal Reflections

This study was my first experience of conducting research and was very much a learning experience for me. Initially I was full of anticipation about whether or not I would be able to plan and carry out this work successfully, given my complete lack of experience. However, I have found this entire process a very rewarding one, one in which I have come to appreciate many things.

I have learnt that so called 'imposter syndrome' is common when embarking on academic work for the first time, and this shouldn't be something which holds you back! Rather I have used this to ask for lots of help and to make connections and relationships with many people within the Department of General Practice and the wider network of academia and research. Through going to conferences and sharing aspects of this work, and hearing about other research that is being carried out in both Ireland and the UK, I have been gained a much broader knowledge and appreciation of the importance of primary care research.

I have learnt many new things and am grateful to my supervisors, colleagues and peers in my research group who have become good friends to me, both in the 'critical' and true sense.

I am grateful that through this work I have gained the skills necessary to organise a qualitative research study, in particular organising focus groups and coming to appreciate the process of thematic analysis.

I have also been privileged to be given a unique insight into the workings of rural primary care teams and it has been humbling and enriching to have these teams share their personal challenges as well as unique assets with me. I am now acutely aware of the difficulty and lengthy process of diagnosing dementia and the implications this has on those living with dementia, their families and indeed on the primary care team and in particular General Practitioners such as myself. I have become more familiar with the NICE guidance on diagnosing dementia and the possible pharmacological treatments of it. I have come to appreciate that interpretation of national guidance can hugely impact on the way healthcare is delivered. I am more aware than ever of the challenges for those living with dementia and their families and those who care for them. I feel this work will inspire me to

strive to be the best General Practitioner I can be and to always appreciate and learn from the invaluable team of colleagues working around me.

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Appendix 1- Data capture table of scoping review articles

Author	Year	Title	Origin	Source	Study Design	Data Capture	Participants	Themes	Other comments
Constantinescu, A; Li, Hui; Yu, Jennifer; Hoggard, Cassandra; Holroyd-Leduc, Jayna.	2018	Exploring Rural Family Physicians' Challenges in Providing Dementia Care: A Qualitative Study.	Canada	Canadian Journal of aging	Qualitative Research	Semi structured focus groups - TDF used for analysis and COM-B	General practitioners	Negative: Lack of specialist services. Physicians had limited experience with dementia diagnosis and management, as see less dementia patients than in urban areas. Geography both a barrier and a facilitator - closer relationships in rural areas. Home visits more difficult Prolonged waiting times for specialists. Limited resources while being cared for locally Family and caregiver stress and expectation Lack of faith in current dementia medications POSITIVE: physicians value community supports	
Cahill, S; Clark, M; O'Connell, H; Lawlor, B; Coen, R F; Walsh, C	2008	The attitudes and practices of general practitioners regarding dementia diagnosis in Ireland	UK	International Journal of Geriatric Psychiatry	qualitative research	focus group and survey	General practitioners	Negative: lack of access to investigations locally eg CT/MRI. Long term relationship with patient "know them too well to ask". Lack of education at under/post graduate level. Stigma of broaching a sensitive subject Positive: Rural doctors more actively involved in diagnosis than urban	Small focus group - and almost 20 years ago- diagnosis different now
Kosteniuk, Julie; Morgan, Debra; Innes, Anthea; Keady, John; Stewart, Norma; D'Arcy, Carl; Kirk, Andrew	2014	Who steers the ship? Rural family physicians' views on collaborative care models for patients with dementia.	Canada	Primary Health Care Research & Development	qualitative research	telephone interviews	Family practitioners (who had referred at least one patient to the rural and remote memory	Negative: Accessing urban based health care and shortage of local health care resources eg poor staffing leading to lack of respite. Long wait times Burden on rural family practitioners to fill gaps for patients due to a lack of physically proximate services. Inequity in care between urban and rural- although only speculation Positive: high degree of social proximity between FPs,	Also discussed preferred collaborative models - not completely relevant to scoping question here "There is a significant opportunity to improve service delivery and care for rural

Greenway-Crombie, Angela; Snow, Pamela; Disler, Peter; Davis, Sam; Pond, Dimity	2012	<i>Influence of rurality on diagnosing dementia in Australian general practice.</i>	Australia	Australian Journal of Primary Health	qualitative research	Literature review	GPs, physicians, primary care providers	Lack of ununiversally agreed definition of rural can be problematic. Workload of rural GPs barrier to education and training. Limited access to community services and resources for people with dementia and their carers lack of dementia specific training in rural practices limited specialist services Rural GPs more likely to diagnose themselves and more likely not to refer to specialist services due to more autonomous approach to their practice Appt time constraints impacted by overall shortage of rural GPs- no time to use recognised tools for diagnosis	check refs- Cahill et al, Koller et al 2010, Morgan et al 2011, Koch and Ilife 2010, Smith et L
Hansen E., Robinson A., Mudge P., Crack G.	2005	<i>Barriers to the provision of care for people with dementia and their carers in a rural community.</i>	Australia	Australian Journal of Primary Health	Qualitative Research	Focus group and semi structured interviews	GPs, hospital nursing staff, community nurses, dementia support worker and family members of PWD	Distance from services - lack of knowledge of which available Isolation Travel distance long - difficult for elderly Stigma - worry carer would be someone who knew them Professional boundaries- ACAT team seen as "outsiders" - Knowledge gaps	Local hospital often had enough beds due to small community unlike urban counterparts- "respite bed" Distance to nursing homes meant people less likely to send relatives there as wouldn't get to see them Community feeling that families should manage themselves at home Poor communication between members of the MDT - hierarchy between medical and
Morgan D., Innes A., Kosteniuk J.	2011	Dementia care in rural and remote settings: A systematic review of formal or paid	Ireland	Maturitas.	Qualitative Research	Systematic review	Formal and paid carers	Diagnostic processes Service provision Service models and programs Staff education Use of technology and long term care	Research based on small sample sizes No definition of rural or remote was provided in 22 of the 46 articles - difficult to
Teel, CS	2004	Rural practitioners' experiences in dementia diagnosis and treatment	USA	Aging and mental health	Qualitative Research	Semi structured interviews	Primary care providers , GPs	Access to facilities Distance to specialist appts Delays in getting appts Limited local supportive care resources eg dementia outreach services Lack of community support services eg respite Limited availability of community based education	rural physicians less likely to mention lack of time as an impediment

Szymczyńska P, Innes A, Mason A	2011	A Review of Diagnostic Process and Postdiagnostic Support for People With Dementia in Rural Area	UK	Journal of primary care and community health	Qualitative Research	Literature review - thematic analysis		Limited training on supporting PWD Transport difficulties Distance from specialist services Access to diagnostic and postdiagnostic dementia services limited in rural areas Access to carers groups Professional isolation	Most important interventions for PWD in rural communities is consultative support and community based education Highlighted good practices adopted by rural GPs- confidence in diagnosis, display active involvement in dementia screening Hansen et al- GPs less likely to consult with a specialist, due to lack of availability Rural GPs more likely to work autonomously stigma- but more patients and carers as opposed to doctors- but can be difficult to approach by rural doctors as they know their patients well check innes et al Suggestion - rural memory clinic
Glasser M	1993	<i>Alzheimer's disease and dementing disorders: Practices and experiences of rural physicians</i>	USA	American journal of alzheimer's disease and other dementias	Qualitative Research Interviews	Semi structured interviews	Primary care physicians	Unavailability of resources eg laboratory or support No specialist in the area for consultation/referral Long travel time for consultation Advs-	also mentioned depressed economic situation was disadvantage to diagnosis or treatment

Dal Bello Hassam V, Camer A, Morgan D, Stewart N	2014	Rural and remote dementia care challenges and needs: perspectives of formal and informal care providers residing in Saskatchewan, Canada	Canada	Rural and remote health	qualitative research interviews and other methods	Multi-pronged approach TA of consultation meeting with rural health care providers Telephone and mail questionnaires to health care providers TA of referral letters to memory clinic		Need for increased access to physicians specialists, long term care and respite facilities and day programmes Lack of government or personal funds for travel to healthcare facilities Lack of frequent public transport Lack of agreement between rural health care professionals re dealing with problems that arise "Intertwined health professional/patient relationships" in rural settings - unavoidable in rural context	Lack of interpreting services and culturally appropriate assessment tools Physicians generally felt services were adequate whilst other HCPs did not
Innes A, Cox S, Smith A, Mason A	2006	Service provision for people with dementia in rural Scotland: difficulties and innovations	UK	Sage journals	qualitative research	survey and qualitative telephone interviews	explores the views of Scottish service providers drawn from the voluntary, statutory and private sector		
Koch T, Iliffe S	2010	Rapid appraisal of barriers to the diagnosis and management of patients with dementia in primary care: a systematic review	UK	BMC Family Practice	Qualitative research	Systematic review	not exclusively rural, some points applicable only	found during reference search of another paper	

Appendix 2 – Invitation letter



Dear Colleague,

We are writing to invite you to participate in a research study looking at challenges for the rural primary care team in providing care for patients with dementia.

The study is being conducted by the Centre for Medical Education in Queen's University Belfast. A more detailed explanation is provided in the attached information sheet.

Members of the multidisciplinary primary care team in rural areas of Northern Ireland are being asked to participate. The study aims to identify challenges in provision of care to patients with dementia in rural areas, in particular challenges perceived by healthcare professionals who are looking after these patients. We hope to use this information to improve care and service provision for rural patients with dementia and their healthcare providers.

You will be asked to participate in a focus group conducted with one researcher. Further information is provided in the information sheet.

You are invited to reply to a member of our research team by email if you are interested in taking part in this research.

Thank you for considering this.

Yours sincerely

Dr Lucy Hodkinson
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07821 445809

Appendix 3 – Consent forms



**QUEEN'S
UNIVERSITY
BELFAST**

Consent Form for Interview (Participant

Copy)

Challenges for the Rural Primary Care Team in providing care for patients with Dementia

I have read the Information Sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage. I know that:

Please initial box

1. I confirm that I have been given and have read and understand the information leaflet for the above study. I have had the opportunity to ask and receive answers to any questions I may have had. []
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. []
3. I agree to take part in the above study, inclusive of the procedures mentioned in the Information Sheet. []
4. I understand that my participation or non-participation will not affect my career progression or my legal rights being affected in any way. []
5. I agree to the focus groups being recorded. []
6. I understand all data will be treated securely as described by QUB Data Protection and stored appropriately as required by the University. []
7. I understand that I will not be identifiable in any data published in relation to this project. []
8. The results of the project may be published and used for educational purposes but my anonymity will be preserved. []
9. I am aware that due to the sensitive nature of the topic being discussed I will not discuss anything said in the focus group outside of the focus group []
10. I agree to take part in this study. []
11. I would be happy to be contacted in the future about participating in research that relates to rural dementia care. []

Name of Participant

Date

Signature

WITNESS:

Name of Person taking consent
(if different from Researcher)

Date

Signature

Name of Researcher

Date

Signature



Consent Form for Interview (Researcher Copy)

Challenges for the Rural Primary Care Team in providing care for patients with Dementia

I have read the Information Sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage. I know that:

Please initial box

1. I confirm that I have been given and have read and understand the information leaflet for the above study. I have had the opportunity to ask and receive answers to any questions I may have had. []
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. []
3. I agree to take part in the above study, inclusive of the procedures mentioned in the Information Sheet. []
4. I understand that my participation or non-participation will not affect my career progression or my legal rights being affected in any way. []
5. I agree to the focus groups being recorded. []
6. I understand all data will be treated securely as described by QUB Data Protection and stored appropriately as required by the University. []
7. I understand that I will not be identifiable in any data published in relation to this project. []
8. The results of the project may be published and used for educational purposes but my anonymity will be preserved. []
9. I agree to take part in this study. []
10. I am aware that due to the sensitive nature of the topic being discussed I will not discuss anything said in the focus group outside of the focus group []
11. I would be happy to be contacted in the future about participating in research that relates to rural dementia care. []

Name of Participant

Date

Signature

WITNESS:

Name of Person taking consent
(if different from Researcher)

Date

Signature

Name of Researcher

Date

Signature

Appendix 4 – Focus group schedule



Challenges for the rural Primary Care Team in providing care for patients with Dementia

Focus Group Schedule for Rural Primary Care Teams

Initially allow time for participants to arrive, and provide tea / coffee/ food on arrival. Whilst doing this, ensure that all have participant information sheets and get consent forms signed. Also time to answer any questions that participants might have and provide an opportunity to remind everyone that comments will be anonymized and data held securely. I will explain that due to the sensitive nature of the topic being discussed I will give each person a unique identifier. I will remind participants that the content of the focus group should not be discussed outside of the focus group. I will give a brief summary of findings of my scoping review, as this will be applicable to question 2.

Gather everyone around a table, and make sure both Dictaphones are ready to record. Introduce myself, thank everyone for attending and agreeing to participate and then explain how the session will work.

“I’m going to start the recording now – please try to ignore it! As I’ve explained, this focus group is very helpful for my research project. Please remember that anything that is said is confidential, and no comments will be attributed to any specific individual in the analysis or write up. If any issues or concerns arise during the session, please speak to me at the end. I hope not to keep you here for too long – and aim to be finished within one hour at most. I may make some notes during the session – these notes are for my own benefit and are merely prompts / thoughts that arise. If we could start by going around the table and introducing yourself and stating what your role is, just to ensure everyone knows each other. Thank you.”

Proposed topics for interviews:

- 1. Can you talk me through your experience of caring for patients with dementia in the rural area?**
 - a. What worked well for you?
 - b. What didn’t work so well?
 - c. Were there any particular problems or difficulties?
- 2. How do you think your experiences compare with those that have been identified in other areas?**

- a. **What challenges and demands are similar to those in other areas**
 - b. **In what ways do you think your experiences differ to those in other areas?**

- 3. Looking forward is there anything you would change that would improve the care for these patients and their families?**
 - a. **In what ways can the local primary care team improve care for patients**
 - b. **Are there any services which might be helpful**
 - c. **Are there any other ways in which care can be improved**

Appendix 5 – Starting coding template

Template Themes	Codename	Code description	P-L	P-L	P-L	P-L	P-L	P-L	P-L	P-L	P-L
A - Carers and support services	A1	Lack of carers	F1-1-10	F1-2-12	F1-2-21	F1-3-44	F1-3-45	F1-4-76	F1-11-258		P-L
	A2	poor access to mental health services	F1-1-9	F1-2-13							
	A3	No incentive for new carers	F1-2-21								
	A4	Large numbers of patients with dementia	F1-2-24								
	A5	Lack of follow up support from secondary care	F1-3-43	F2-5-119							
	A6	Lack of nursing home / respite	F1-4-76	F1-4-77	F1-4-82	F1-4-90	F1-5-95	F1-8-174	F1-7-178	F1-13-322	F2-1-19
	A7	Access to daycare	F1-7-169/170								
	A8	Lack of social support	F1-8-179	F1-8-183	F1-9-200	F1-11-258	F1-11-272	F1-13-322	F2-1-19		
	A9	Problems with getting staff for nursing homes/	F1-8-190								
	A10	Voluntary sector support	F1-11-259	F1-12-279							
	A11	The need for a dementia team	F1-11-263								
	A12	Support for carers	F1-11-273	F1-14-333	F1-14-335						
	B7	Inequality compared to urban area	F1-12-284								
B - The route to diagnosis	A13	Lack of funding	F1-14-336								
	A14	Good dementia navigator	F2-6-131								
	A1	poor access to mental health services	F1-1-13	F1-13-316	F2-2-91						
	B1	Difficulty diagnosing in primary care	F1-2-28	F1-6-146	F1-7-150	F1-13-320	F2-5-101				
	B2	Delay in starting medication	F1-2-29	F1-13-317	F2-3-59						
	B3	Healthcare worker dissatisfaction at diagnostic	F1-2-31	F1-3-42	F1-3-51	F1-3-55	F2-5-111				
	B4	Lengthy diagnostic process	F1-2-31	F1-2-35	F1-3-40	F1-3-51	F1-5-99	F2-5-103	F2-5-108	F2-6-123	F2-8-180
	B5	Diagnostic uncertainty at presentation	F1-3-52								
	B6	Forgetting medication	F1-10-248	F2-3-63	F2-9-210						
	B7	Inequality compared to urban area	F1-12-283	F2-7-161							
	B8	Staff training	F1-12-304	F1-12-311	F2-9-201	F2-9-205					
	B9	Medical staff desire to initiate medication	F1-13-308	F2-9-204							
	B10	Delay in patient's seeking help	F2-1-18	F2-2-25							
	B11	Accumulation of problems built up over time	F2-2-25								
	B12	Physical decline in patients	F2-3-51	F2-10-241							
	B13	GP role in risk management whilst waiting for d	F2-3-59	F2-3-65	F2-3-66	F2-5-107	F2-2-163				
	B14	Stigma of diagnosis	F2-4-84								
	B15	Lack of knowledge and patient/family fear of d	F2-4-85								
	B16	Under-resourced psychiatry of old age team	F2-5-120	F2-10-222							
	B17	Patient suffering distressing symptoms due to d	F2-7-162								
	B18	Linking in with other medical teams early	F2-8-178								
	B19	Hospital admissions	F2-10-230								

C The dynamics of family	C1	Family carer stress	F1-2-33	F1-4-77	F2-3-57						
	C2	Shift in family setup	F1-4-83								
	C3	Family taking on caring role	F1-4-85	F1-5-97	F1-5-99						
	C4	Challenge of both parents having dementia	F1-4-88	F1-4-91							
	C5	Children/family living far away	F1-4-89	F2-3-57	F2-3-62	F2-3-65	F2-3-67	F2-10-220			
	C6	Lack of family interest	F1-14-331	F2-10-220							
	C7	Family report concerns	F2-1-15	F2-3-58							
	C8	Good family support	F2-2-24	F2-3-55							
	C9	Person living alone, no family support	F2-2-29	F2-3-63	F2-9-209						
	C10	Family living close by	F2-3-54								
	C11	Person with dementia is a carer for a spouse	F2-3-65								
D The positives of rural living	D1	Efficient primary care MDT	F1-2-16	F1-4-75							
	D2	Familiarity of practice staff to patients	F1-4-67	F1-6-132	F1-6-134	F1-7-154	F1-7-155	F1-7-159	F1-7-162/1	F1-7-167	F1-11-262
	D3	Supportive neighbours/friends	F1-4-93	F1-14-332	F2-3-51	F2-8-182	F2-8-192				
	D4	Practice staff concern for patients	F1-4-132	F1-7-155	F1-6-156	F1-10-234	F2-9-210				
	D5	Staff perception of dementia	F1-7-158/5	F1-7-164							
	D6	Good safety netting by GPs	F2-2-98								
	D7	Good support from voluntary sector	F2-6-127	F2-6-142							
	A14	Good dementia navigator	F2-6-131								
	D8	Deliveries of medication by local GAA clubs during	F2-7-147								
	D9	Local pharmacies good support to patients	F2-7-150								
	D10	Rural people cope well on their own	F2-8-181	F2-8-185	F2-9-209						
	D11	Community awareness of a person living alone	F2-8-190								
	D12	Constantly changing community in urban area	F2-9-194								
E Farming and economic implications	E1	Family with low income unable to support sick	F1-4-87								
	E2	Potential loss of a farm	F1-14-340	F1-14-345							
	E3	Land not signed over	F1-14-340								
	E4	Legal documents/requirements/assets	F1-14-347	F1-14-350							
	E5	Cost of nursing home	F1-14-349								
	E6	Independent farmers living alone	F2-1-14								
	E7	Poor/dangerous living conditions as result of de	F2-1-18	F2-2-47							
	E8	Financial consideration of giving up a home/far	F2-4-83								
	E9	Loss of financial independence	F2-4-87								
F- The challenge of geography	F1	Implications of driving	F1-5-101	F2-4-86	F2-4-88						
	F2	Distance to home visits	F1-5-113	F1-6-127							
	F3	Lack of time with patients due to distance to tr	F1-6-122								
	F4	Clustering home visits	F1-6-125								
	F5	Difficulty with transport	F1-8-187	F1-8-195							
	F6	Rural transport/bus	F1-8-193	F1-9-209	F2-6-142						

Z - No Theme	Z1	Too many professionals involved	F1-2-19									
	Z2	Lack of health professional responsibility/ownership	F1-2-20									
	Z3	Healthcare professional stress/burden	F1-2-34									
	Z4	Missed appointments (staff frustration re)	F1-2-36	F1-3-38	F1-6-137	F2-4-95	F2-7-167					
	Z5	Familiarity with the GP causing problem with doctor	F1-5-102	F1-5-101	F1-10-241							
	Z7	Issues with consent	F1-6-138	F1-6-146	F1-7-149	F1-7-157						
	Z8	Practicalities of correspondence	F1-6-141	F1-6-147								
	Z9	Suggestions for improvement	F1-6-143	F1-10-228	F1-11-256	F1-11-262						
	Z10	Non rural specific issues										
	Z11	Focus on medical issues surrounding dementia	F1-8-179									
	Z12	Dementia bus initiative	F1-9-209									
	Z13	Lack of general awareness of dementia	F1-9-224									
	Z14	Issues with living at the border	F1-10-244									
	Z15	Deprivation of liberty assessment	F1-11-264									
	Z15	Use of farms	F1-11-267									
	Z16	Inclusion of community A level students to voluntary work	F1-11-269									
	Z17	Safeguarding of vulnerable adults	F1-11-274	F1-14-341								
	Z18	Increased voluntary services during Covid 19	F2-6-143									
	Z19	Patient's declining support/rural stoicism	F2-10-226									
? thoughts for improvement	G1	Funding for research and training	F1-11-276	F1-14-336								
	G2	Dementia friendly practice	F1-12-287									
	G3	Dementia friendly community	F1-12-292/293									
	G4	Positive focus group discussion	F1-13-328									
	G5	Community dementia team	F2-2-43									
	G6	Diagnosis prior to crisis	F2-2-45									
	G7	Dedicated CPN	F2-7-156	F2-9-212								
	G8	Dedicated community dementia team	F2-10-223									
	G9	Community education programme	F2-10-239									

Appendix 6 – Revised coding template

Themes	Subtheme	Codename	Code description	G-P-L	G-P-L	G-P-L	G-P-L	G-P-L	G-P-L	G-P-L	G-P-L	G-P-L			
Formal and informal care and support	Carers and support services	A1	Lack of carers	F1-1-10	F1-4-76	F1-2-21	F1-2-12	F1-3-44	F1-3-45	F1-11-258					
		A2	Lack of funding for carers	F1-14-336	F1-11-276										
		A3	Lack of nursing home/respice	F2-2-28	F1-4-82	F1-4-77	F2-1-19	F1-8-175	F1-4-76	F1-4-82	F1-4-90	F1-5-95			
		A4	Lack of social support	F2-1-19	F1-8-183	F1-11-272	F1-8-179	F1-11-258							
		A5	Lack of staff for nursing homes	F1-8-189/190											
		A6	Voluntary sector support	F1-11-259	F1-12-279										
		A7	Lack of funding for training	F1-11-276											
		A8	Support for carers	F1-14-333	F1-11-273	F1-14-335									
		A9	No incentive for new carers	F1-2-21											
		A10	Large numbers of patients with dementia	F1-2-24											
		A11	Lack of follow up support from secondary care	F1-3-43	F2-5-119										
		A12	Lack of resources	F1-13-322											
		A13	Inequality in time to diagnosis compared to urban	F1-12-286											
		A14	Supportive neighbours/friends	F1-4-93	F1-14-332	F2-3-51	F2-8-182	F2-8-192							
	The dynamics of family	B1	Family taking on caring role	F1-5-97-98	F1-5-99										
		B2	Shift in family set up	F1-4-83	F1-4-84-86										
		B3	Family living close by	F1-3-54											
		B4	Family report concerns	F2-1-15	F2-3-58	F1-10-246-247									
		B5	Family carer stress/burden	F2-3-57/58	F1-2-33	F1-4-77									
		B6	Children/family living far away	F1-4-89	F2-3-65	F2-3-57	F2-3-62	F2-10-220							
		B7	Challenge of both parents having dementia	F1-4-88	F1-4-88	F1-4-91									
		B8	Lack of family interest	F1-14-331	F2-10-220										
		B9	Person with dementia is carer for a spouse	F2-3-64											
		B10	Good family support	F2-2-24	F2-3-55										
		B11	Person living alone, no family support	F2-2-29	F2-3-63	F2-9-209	F2-2-31								

The journey to diagnosis	Healthcare professionals perceptions of the diagnostic process	C1	Lengthy diagnostic process	F2-5-103	F1-3-39-41	F1-2-31	F2-8-180	F1-7-150	F1-13-337	F1-2-35	F1-5-99	F2-6-123	F2-8-180
		C2	Poor access to mental health services	F1-2-13	F1-13-316	F1-1-8	F2-2-90-92	F2-5-108					
		C3	Under resourced mental health team	F2-5-120	F2-10-222								
		C4	Healthcare worker dissatisfaction at diagnostic process	F1-2-31	F2-5-111	F1-3-42	F1-3-51	F1-3-55					
		C5	Difficulty diagnosing in primary care	F1-2-28-29	F1-6-146	F1-13-320	F2-5-101						
		C6	Medical staff desire to initiate medication	F2-9-204	F1-13-308	F1-3-55							
		C7	Too many professionals involved in pt's care	F1-2-19-20									
		C8	Good safety netting by GPs	F2-5-98									
		C9	Staff training	F1-12-304	F2-9-201	F1-13-311	F2-9-205	F1-9-211	F1-9-218				
		C10	Stigma of diagnosis	F2-4-83									
		C11	Delay in rural patients seeking help	F2-1-17-18	F2-10-225	F2-2-25							
		C12	Issues with consent	F1-6-146	F1-6-138	F1-6-145	F1-7-157	F1-6-146					
		C13	GP role while waiting for diagnosis	F2-3-59	F2-3-65-67	F2-5-107	F2-7-163						
		C14	Patient suffering due to delay in diagnosis	F2-7-162									
		C15	Healthcare professional stress/burden	F1-2-34									
		C16	Staff frustration re missed appointments	F2-4-95	F1-3-38	F2-7-169	F1-2-36	F1-6-137	F2-7-167				
		C17	Delay in starting medication	F1-2-29									
		C18	Diagnostic uncertainty at presentation	F1-3-52									
		C19	Patients forgetting medication	F1-10-247	F2-3-62	F2-9-210							
		C20	Inequality compared to urban area	F1-12-281-283	F2-7-161								
		C21	Accumulation of problems built up over time	F2-2-25									
		C22	Physical decline in patients	F2-3-51	F2-10-241								
		C23	Lack of knowledge/fear about dementia	F2-4-85									
		C24	Need to liaise in with other medical teams early	F2-8-178									
		C25	Hospital admissions	F2-10-230									
		C26	Dedicated community dementia team	F2-2-44	F2-7-156	F2-10-223	F2-9-212						
		C27	Avoid acute crisis admission	F2-2-26	F2-2-45								
		C28	GP with a specialist interest	F1-11-13									
	Involvement of entire PCT in this patient journey	D1	Familiarity of practice staff to patients	F1-4-67	F1-6-132	F1-6-133-1	F1-7-154-1	F1-7-166-1	F1-7-159	F1-7-162-1	F1-11-262	F2-8-176	F2-9-212/215
		D2	Practice staff concern for patients	F2-9-210	F2-10-234	F1-6-132	F1-7-155-1	F2-2-213-215					
		D3	Efficient primary care MDT	F1-2-16	F1-4-75								
			Staff perception of dementia	F1-7-158/159	F1-7-164								

Aspects of rural living	Farming and economic implications	E1	Family with low income jobs unable to support sick	F1-4-87	F1-4-89												
		E2	Potential loss of a farm	F1-14-340-342	F1-14-345												
		E3	Expense of nursing home	F2-14-349													
		E4	Legal requirements/assets	F1-14-346-348													
		E5	Independent farmers living alone	F2-1-13-17													
		E6	Poor/dangerous living conditions as a result of de	F2-1-18	F2-2-46-47												
		E7	Financial consideration of giving up a home / farm	F2-4-80-83													
	The challenge of geography	F1	Distance to home visits	F1-6-127	F1-5-113												
		F2	Limited time with patients due to travel distance	F1-6-122-123													
		F3	Clustering home visits	F1-6-125													
		F4	Difficulty with transport	F1-8-195	F1-8-187												
		F5	Rural transport/bus service	F1-8-193-194	F1-8-195	F2-6-142											
		F6	Implications of driving	F1-5-101-102	F2-4-86-88												
Potential future innovations	Capatalizing on rural community assets	G1	Good support from voluntary sector	F2-6-125-128	F2-6-142												
		G2	Deliveries of medication by local GAA clubs during	F2-7-146-148													
		G3	Local pharmacies good support to patients	F2-7-150													
		G4	Rural stoicism	F2-8-181	F2-8-185	F2-9-209	F2-10-226										
		G5	Rural people support eachother	F2-8-182													
		G6	Community awareness of a person living alone	F2-8-189-190													
		G7	Constantly changing community in urban area	F2-9-194-195													
		G8	Use of farms	F1-11-267-268													
		G9	Incresed voluntary services during Covid 19	F2-6-143													
		G10	Integrate voluntary sector with PHCT	F1-11-269													
		G11	Inclusion of school students to volunteer in nursir	F1-8-190-191													
		G12	Positive focus group discussion	F1-13-328													
		G13	Community education programme	F2-10-239													
		G14	Dementia friendly practice	F1-10-228-229	F1-12-287												
	Further thoughts for improvement	H1	Invite voluntary groups to practice	F1-12-287													
		H2	GP with specialist interest in dementia	F1-13-317													
		H3	Dementia friendly community	F1-12-291-293	F1-13-353												
		H4	Practicalities of correspondance	F1-6-143-145													

Appendix 7 – Focus group 1 transcript

Unique Identifier	Initials	Role
1	AB	Social worker
2	EH	Senior practice nurse
3	NF	Practice nurse
4	AC	Treatment room nurse
5	SD	District nurse
6	AM	Receptionist
7	MNM	Practice Manager
8	RS	Receptionist
9	HMV	Practice Manager
10	AMC	GP
11	PMC	GP
12	RC	Pharmacist
13	MD	GP

F: First of all thank you all for coming as I've said before. The aim of this meeting is to talk about primary care teams looking after patients with dementia care in rural areas. Can we start by talking about people's experience of caring for patients with dementia in rural areas- what things do you think work well, and what not so well. Would anyone like to start with experience they have had in this area –

1: Well my, my experience I've a client at the minute in Rosslea in Carncourt, suppose it's the support from the community mental health team, its just that lack of recognition that this person has difficulty with dementia and getting their support to take it on board, and be more proactive in their caring role and obviously the lack of carers is an issue that we have in Rosslea

F: Do you find this a lot that carers is an issue?

13: A huge issue yea, huge issue, suppose its so rural, suppose finding the carers is the problem, suppose that's just my experience. But going back to that I suppose I have this dig about the community mental health team but we can't refer to them we obviously have to go through GPs and then obviously the GP makes the referral back to the community mental health team so you're sort of losing time, that's just my..

F: Anyone else?

13: I think on the positive note I think the primary care team itself works quite well, you know social work, district nurses feeding into our MDT meeting and there are, you know, good open channels to communicate, that is going quite well, but then when there are third parties coming in then it becomes difficult

1: That's when it becomes more difficult yea or messy. Its just theres so many professionals involved and its like who takes responsibility for it, you when you say "oh she's not my client, shes yours" you know and its sort of like passing the buck maybe. But I suppose you know as in rural problems its carers that's the problem we have, finding carers, and I suppose

maybe if they were paid better and they had better terms and conditions there may be more incentive for maybe young mothers to go out and do maybe part time work but its just the difficulty around that

F: Do you have a lot of patients under your care with dementia?

1: Em yes, there would be a lot of them with dementia, like I have a caseload of maybe sixty now, you know between Lisnaskea and Rosslea and you could say maybe forty percent of them have dementia

10: Is this with diagnosed dementia?

1: I'd say diagnosed yea or with cognitive impairment yea

10: yea, as a GP you recognize it, you do the work up, but then you're sort of, theres a bit of a time you know and red tape getting the actual diagnosis or certainly starting medication. There are people who I would have been very happy to have just started something, its that red tape of..

1: Its that big long process yea from when you suspect it

10: mmm hmmm [agreeing]

1: But getting it officially diagnosed, and getting the help, you know, and then you've families frustrated and trying to deal with people that are up at night and then it all comes back, I feel, on my doorstep, and you say right, you know obviously go to the GP, and then they go to the GP and then they refer to the psychiatry team and you know its just a whole you know...

10: There's frustration that they don't turn up because they've forgotten the appointment and that's kind of like they've been discharged you know because they didn't turn up...

[general murmurs of agreement amongst GPs] and you'd think of all the services that they [psychiatry clinic] would be understanding of that

11: I think the average is, just to put us in the picture, I think from the referral to the nurse led memory clinic assessment in three to six months then after that the diagnostic assessment with consultant to start medication is another three to six months, so its about a year on the NHS before, from suspicion of diagnosis to treatment

1: yea and then you've us in the middle

13: then after that its only the tablet after that, theres no support

1: and looking for carers, you've to go to a panel, and it doesn't sit until Monday, and then you're waiting and then it goes to Brokebridge in Derry, they look for the carers, you know.. and we don't have the carers anyway it doesn't matter, that process can take its time

F: Talking about diagnosis, some of the work that ive done already has shown that the GPs found difficulty around diagnosis as, as you said, it isn't technically a diagnosis that should be made in primary care and then there is such a long wait especially in rural and remote areas, and they found difficulty wondering what to do with them in the meantime, and they found that that care falls on the primary care team which can be challenging- is that something you've found?

13: yea

2: I was reading something recently that said its depression, delirium or dementia, you know the three things that are very confusing when people come to a certain age because they may present to a&e or tot heir GP with an acute infection, they go into hospital and people aren't sure whats going on because maybe they are delirious because of their infection but again its all really down it a fairly rapid diagnosis, and I think I had read somewhere that they are encouraging GPs now because GPs

are well placed to make the diagnosis and start treatment, em I don't know if in your research that was something that came out....

It did, in some of the papers in particular an Irish study, showed rurality as a positive and a negative, some General Practitioners working on their own cited that increased work load meant they couldn't see all the patients because they were working on their own, whereas on the other side they felt because they were working themselves they had a unique relationship with the patient and were confident in diagnosing them because they knew them very well and had known them all their life and knew their families.

They also said this could be a good thing and a bad thing because they knew their patients too well and didn't want to broach the subject of dementia because they didn't want to offend them and often there can be a stigma associated with dementia in small rural communities.

F: Also found that some rural doctors didn't feel confident in diagnosing it because they didn't have as much access to as much training as people in cities

What about practice staff, any experiences, good or bad that you've had?

8: I think at reception my duty would be to meet people at the front desk, I think familiarity, you know they know you and I think it is very important to have our name on our badges, I know it can drop down but I think even if the badge is on your lapel because they recognize you but they can't recognize you and I think it's important when you're on the phone, I mean you know they know you, but to say, you know you're on the phone to Rosemary, how can I help you, or when you're at the front desk if they see your name tag I think it alleviates that awkwardness for them because they know they are constantly here but they just can't remember your name.

F: What about in the community? A lot of papers have mentioned a lack of services in terms of respite or as you already mentioned, carers, day centres, things like that, what's the general feeling around that?

5: Well definitely the primary care team works well with multidisciplinary meetings and I mean I've a good relationship with everybody who comes to them, but when it comes to further help in the home you're lacking carers, you're lacking support, there's no beds in Gortacharn, there's no respite, family are very stressed, they can't cope, there's just nowhere for them to go. Then if you don't keep these people in familiar surroundings with people that they know well then obviously it enhances their condition as well

F: And any good things about rural areas?

5: Well I do think it's good, but it's just getting that maybe move from, if they need to go out of their home, or they need to get extra care, there's definitely a gap there, there's nowhere for them to go and they have to wait..

10: I think there's been a shift with families, when I was a child you'd have maybe the grandfather or grandmother living in the house [general murmur of agreement] certainly in England in Bradford where I was there was a very heavy Asian community and all three generations would live in the same house and if they did have dementia, you know, the family would take up the role of carers, but I'm not seeing that so much here, has there been a shift do you think?

5: I think people have low paid jobs and families to look after, I mean there's a man on the books at the minute who lives up by the chapel and he's looking to go into respite on Friday, I mean with his daughters we've talked about... the husband and wife both have dementia and the daughter and the son both live afar and they've got their own family and their own work and they're doing their best but you know it's not good enough I don't think, hopefully he's going to go in on Friday but he

doesn't even know if he's going in yet, his wife doesn't know if he'll stay, the daughters more concerned about the wife then, what's going to happen to her.

13: The good thing, I think, I don't know what you think in the community is when I go on a visit and of course its often a crisis is there are always neighbours, friends, and you think well, that's a positive thing about rurality

[general yes in agreement]

There is definitely that going on but then for longer term care I'm not so sure, as that's just what we see when we go on a home visit, you think well..

1: I would find now, from when I moved to Rosslea there is more family support, they seem to look after their own, you come back into Lisnaskea its right, you know, we're entitled to this, whereas in Rosslea they do look after their own, more so.

11: There might be a delay in diagnosis so there might be a lot of undiagnosed dementia patients who have been supported by family and it's disguised the issues, the cognitive issues, because there's someone else to do it. That's another suppose positive and a negative isn't it

2: And if you live rurally and you're driving and you're diagnosed with dementia that's a big problem isn't it. It's very tricky for GPs to say sorry but im not going to sign the form to renew the licence

10: Its tricky isn't it.

11: Yea

2: That can break the relationship, you know, between the doctor and the patient it's a difficult one, I know personally speaking that happened to my dad and that was his lifeline

F: And this is maybe very significant in rural areas because people do drive places, and if its taken away it's a big thing for them

The other sorts of things that were mentioned that were primary care teams in particular GPs in rural areas had felt that the distance they have to travel for example to do home visits, or staff going out to see patients can be much longer and obviously that's a challenge in itself, and also for patients getting to whatever services that are available. Are these things which you have seen here?

10: Yea definitely

1: Theres a huge distance even from here to Rosslea. It's a good twenty minutes, you know and then you go there and you'd nearly need to stay the day to make it worthwhile, you know for driving there

5: That's right

2: Rural lift (Not heard as people talking together at same time)

How do you manage that then?

1: Every day is different, you just do. There's no two days the same in this job.

13: There is an inequality too there, you have to schedule sixty patients and they are all over the place, whereas if you were in Belfast you'd have them all nearby, so you have less time with your patients

1: That's right

10: It impacts on where you plan your visits, you try and do them in clusters

5: That's right yea

10: I travelled over ninety miles on visits one day, that wasn't even getting to work that's just visits, could be in Rosslea, Brookborough and anywhere in between.

Any other issues from anyone else?

1: Just picking up on what RS says. The patient phones to get an appointment to see a doctor. When you see they've got dementia its very obvious, you know you can even hear the confusion on the phone, and you come off the phone and you're like mmmm, like id a wee woman last week she couldn't remember how to answer the phone, thank god she lifted it she said, but then I had to phone the daughter because I had consent, to say her mum had phoned me, just so she was aware of it and that an appointment had been made for this week, just incase, because she hadn't written it down, she didn't have a pen she didn't have paper, so I felt the need to phone the daughter and thank god she had the consent on the record, but its just those wee things, you know theyre DNA'ing because theyre getting a letter and theyre putting it in the bin, or they forget where theyre going and then they're DNA'ing that appointment. Whereas if it was a child it would be care of or parent or guardian of, you know something about that aspect of it, you know, the consentee or something, of this patient

[general yea, mm yes and agreement]

7: I remember back a number of years ago a patient's daughter was wanting us to send two letters for things, so say they were invited to the diabetes clinic, they wanted two letters sent. From a practical point that was going to be very difficult to implement, so my suggestion is, and we used to do this with my mother, was that there was a wee postbox outside the door, where the postman put everything into this box, a wee locked box, and that the daughter had the key of it, so the mother didn't open it, it was the daughter who opened it and went through the post with the mother, [general agreement, yes yes] because once it got into the house it was gone, lost, you know.

1: But its getting the consent for that you know, if people aren't formally diagnosed..

7: ah but that wouldn't be us getting the consent, this would be the daughter having to arrange that, do you know what I mean, it was a suggestion we made to her..

1: But could the GP, whenever its being diagnosed, or whenever the letter comes through, can that not be arranged then, you know, do we have to wait for the formal diagnosis then...

General murmur of consideration

13: Not really.. no, no

10: I think there is a group of suspected patients isn't there, suspected dementia patients, just like there is patients with suspected asthma

8: I agree with you AM, usually you would know the feeling on the phone, sometimes you would say to them, are you ok with this message..

6: I'd say to them do you want me to ring your daughter

8: I'd say do you want me to ring your daughter or do you want me to ring somebody to let them know about this appointment, on the phone I would say to her, or do you give me consent to ring somebody or are you ok, because there might be a name but you it may not be formally, I'll give permission for, you know, my daughter or son to ring. And I would say when they're on the phone cause there is a vagueness, a well hold on, you just know there's something not...

6: She wanted to phone the daughter so she asked me to do it for her

8: And there may not be a diagnosis there may not be, but you just know by the sound, and we are very familiar with most of our patients, you could nearly, "awk its her its..." and I think we know families here, we've grown up with families and you know the familiarity of people here and I think sometimes you know yourself from a growing up here point of view that you know the family well, but you know there's a vagueness in this conversation that there maybe hasn't been before. [general agreement]

And you can ask them on the phone there and then, do you want me to give your daughter or son a ring, or name the daughter or son if you know them, to say do you want me to ring Robert and let him know that you wanted to be seen by the doctor and I think that's where its good to have local knowledge, you know as reception staff

6: Or even that wee knock to say you know, just for appointments..

2: What about the daycare? We don't really know about how many people with dementia attend, or are they maybe who don't have dementia who are attending and is there an inequality there..

1: Well daycare, over here in Drumhew they have sort of a mixture of everything normally, there's one or 2 days in the week mainly for dementia,

2: Ok yes I see yes

1: But the likes of in Rosslea, they can't accept any new referrals because Inspire housing that run day care are in financial difficulties and they're looking for more money from the trust and the trust are sort of lagging behind on that so, at the minute they can't accept new referrals, in Rosslea, and they're like a respite for people really, for families

5: and the people who work in them are obviously very good as well, and the patients feel familiar with them and feel comfortable

1: We need more facilities like that

13: I agree. I think, sometimes theres a focus more on the medical side of things, and I think it's a social issue

10: You're right

1: I think that's true

13: they end up going into hospital and you know they actually need more carers, social workers

1: we need more social workers, more support for families, you know

13: If we could keep them at home it would be more practical

F: What about transport?

5: There is a problem getting people in and out. I mean people in Rosslea will go to Rosslea day centre, but is it on every day

1: Its only Wednesday and Friday, so its only two days a week

5 There are facilities there, there is transport there but its getting more staff in, and then theres a lot of people out of school at a certain age who want experience, you know if you go to any of the schools, as well, they had somebody down was it Gortacharn, or Colorado, they had girls in, maybe doing their Alevels and they wanted experience, and that was brilliant they were doing reminiscance therapy, art therapy, you'd get so much of that if you had a building

2:The transport service, fermanagh rural lift is in operation still, I see it sometimes around my area, I don't know does it reach everywhere, its usually a pound they pay, to get from one particular area into town, it used to be anyway, a pound return..

1; You need your bus pass don't you though, you need a bus pass and that probably how then its reimbursed, you have to have your bus pass before you can use it

2: Ah ok, so that's for age 65 up

1: 65 is it? I'm not sure what age it is

10: Yea

13: The problem with those kinds of services is that they're often charity based and we as a team, as a primary care team are not totally sure is it there, is it still there,

2: Its only that I see it around that I know

7: The fermanagh rural transport asked to meet with me and we organized a meeting for him to come and a date and all and he never turned up! But he wanted to come out and meet and tell us what the services are

10: I saw a charity there advertised there on tv last night about live in carers and I don't know if that is something, ive never heard of that before,

13: Its in England

10: Oh is it

1 The oak healthy living, they have a dementia bus coming now..

F: To pick them up and bring them places?

1: No no an actual bus, a reality bus, that you can get on and actually experience the feelings..

ALL: Oh right, really

1:Yea, its coming here to lisnaskea

13: That would be a good thing to do actually

1:It is a good thing to do, yea

7: Yea

1:Its coming now soon, check it out with Oak healthy living, its coming now sometime in February I think, for the likes of me and you, people who don't have dementia to put you in the shoes

5: I think in the fold they were doing a fire test there yesterday morning, down at the fold, so I don't know why this lady went out but she went out with her carer anyway and the fire alarm was on and they were all told that there was going to be a routine fire test, but this lady had dementia and when she came back in she was frightened, she thought she was going to burn, she thought her life was over, it was really bad what she was put through, just for the fire alarm test

13: there needs to be an awareness doesn't there,

5: Just goes to show something we might see as so simple

7: What about our own building here, for coming in for patients, you know, are we dementia friendly, or are we not, do you know what could we do to improve?

1: Well I suppose in the likes of those homes, they have like signs, certain signs in colour, for the toilet, and you know I suppose putting up certain signs that's dementia friendly

10: I think its bad enough for patients who don't have dementia to know which waiting area to go to, never mind those that do

[general chat about this, agreeing]

7: We need to simplify it

2: If theres somebody you know, who's checking in, you know you have a look at their notes and you know they have dementia so you make sure that they get help

7: See they don't come to the desk for checking in now, they go straight to the machine

2: But they wouldn't really be able to use the machine if they had dementia, so theyd have to come to the desk....

7: Hmmm well I don't know, it depends I suppose

1: It depends on the person's dementia and if there is someone with them, and you know it depends on the level of dementia, [agreement]

1: Do you know theres so many different forms, and stages, yea

10: Even in the screening part, in England, its normal standard practice to test for syphilis, but you know having that conversation, because it's not standard here, is it?

[General no no]

1: Its like that client I have in Rosslea, her son lives across the border, in Monaghan and he said in the south, im not sure if this is true, when youre diagnosed with dementia you're automatically put on antidepressant tablets/medication? I'm not sure if that's right

12: Just when you're talking about medication I'm just thinking from the pharmacy side of things often a patient's relative will ring you and tell you this patient has forgotten to take their medication, and that's often a trigger for us to think right, well why are they actually forgetting, this is like increasingly forgetting it, and that would often trigger from our end, there may be memory impairment, whatever whatever, and that's when the pill box and all the consequential things come into play, just thinking from the pharmacy side of things you know

10: And antimuscarinics/anticholinergics sorry, don't know how that's going to play out in future

F: So to summarize and tie it all together as a primary care team working together what things do we think we could do which could improve care for patients with dementia, locally, ie what would be the top thing that comes into your head if you had to think of what could improve care for patients and their families in these areas, we have mentioned transport, carers..

[general murmur]

5: even the building, some of the doors and toilets

F:Anything specific to rurality?

1: Well just, my issue is the carers, lack of support for families

5: Carers. Voluntary agencies even, there are a lot of people out there who I think would be willing to do it, its just getting them

7: And using that local knowledge that RS was talking about, obviously you know, we'd need consent but if you have that local knowledge, like we away back in the past have some stories to tell, trying to find patients or contact patients, somebody knew somebody who lived next door to somebody, (laughs) but that was that was just local knowledge at reception

10: I think maybe we need something like a dementia team you know you've got other teams, but somebody who can look at the legalities of it, the DOLs assessment is hot topic at the moment, deprivation of liberty (said together with F and AB) and you know about getting stuff for forward planning, because often dementia isn't a sudden thing, there's warning signs like we've discussed and maybe having something that's more proactive that can recognize potential difficulties, that might be something

13: I also strongly believe in using your community assets, you know, using your farms for examples, you know things that you already have in your community that can be used to support people, you know you are talking about children who are doing their alevels who maybe want to, so use your community voluntary sector, they should be supported and they should be integrated within a primary care team, we should all be more aware of what they can do because it is also trying to relieve, you know its not always the right to get care its sometimes just abit more support

1: Yea just abit more support

13: and actually to support the carers too

10: It helps with the safeguarding as well the adult safeguarding and recognizing, just like the child safeguarding its about having key points of access and pattern recognition. [all in agreement] These are vulnerable people.

2: It's a chronic disease, and lets face it, diabetes is the one that gets all the money and dementia is really needing it and training

7 And I suppose it's the sort of thing that progresses over time so people can live probably quite normally, do you know what I mean for a period of time, we can just bang them with a diagnosis and think now they can do nothing for themselves, you know. So its about encouragement. Do you remember the wee thing we ran MD in the Killyhevlan with the IT were talking about the dementia thing, yes yes Soo, F: yes soo, MD: she was talking about technology and using technology and working with mPower. This is only a tiny bit of it isn't it

2: I bet if there was comparison between here and in an urban area there is huge deficits and inequalities [general agreement]

F: What do you think would be the main things?

2:The main things? I think the main things would be basically the diagnosis I think would be quicker, but I think you know with regards to facilities to support families, training for people who work and I suppose we all think that at some age we'll all start dotting ans forgetting things but it is a chronic disease and I mean theres implications for people who are living longer and so we are not really supporting them for a good healthy life with dementia, because I mean it is progressive, but I'd say that's probably where there are imbalances between rural and urban areas

10: Would it be worth getting someone from the dementia UK to come in and have a look and make our building more dementia friendly [general agreement] ive seen it done in practices, they do it for parkinsons, parkinsons uk come in and they look at the risk assessment for the practice, it might be worth asking them.. [yea yes definitely]

1: and to make our local, you know youth clubs, our cafes, our local businesses, try to encourage them all to do what we're doing here, make it dementia friendly

12: I know I----- have actually done a project like that, and they've put name badges on all their staff in cafes

7: Yes a dementia friendly community

2: There is a lady here who is looking after her son who has learning disabilities and she has dementia for a number of years but she loves to go into the town for coffee every day, I mean that's her thing, you know, and so she's always worried about getting back in time, for her son getting off the bus, from his daycare..

1: Aw do you know now she's actually in Meadowview

2: Is she? Is she not at home anymore?

1: No

2: Awh.. do you know her?

F: No

2: So she's not looking after him anymore,

1: no, he now has care morning and night for himself, she is in the nursing home with dementia

10: I'd like training.

12: Yes, for increased awareness

10C: I haven't really had much since medical school, and em

F: In which area?

12: To be able to diagnose it and to start medication

10: Yea

2: There was a BMJ article MD, remember, I showed you that and it said GPs...(trails off, thinking)

13: Yea, should start prescribing yea..i got abit anxious because I thought well I'm not trained up to do this, but it said that we were going to prescribe it and

2:It was a flowchart, on the BMJ last year, and it was encouraging GPs really to take it on, and specialist nurses

13: yea exactly

10: like a portfolio GP? Like a GP with a specialist interest?

2: This was an article on diagnosing dementia and it was focused towards primary care, because I suppose the specialists are thin on the ground and they're saying by the time they get there....

10: I mean if you look at the Addenbrook's test compared to the 6 CIT test, and how heavy it is, but very informative, but sure in a 10 minute consultation...

13: you can't get it done, no. It comes back to resources again doesn't it, The resources need to come from secondary care, primary care and to social care.

1: Resources is the big issue in a rural community

2: And we're all touched by it in some way

That's great thanks does anyone have anything that they haven't mentioned or anything they want to say or any questions or anything they wanted to add?

13: Anything more positive?

10: its good even that we're here talking about it

[General mumbling and laughing]

10: it's a multifactorial issue

7: and a growing issue, sometimes there's a lack of family interest

13: It is amazing though I do think neighbours do do a lot, that's what I always think, oh they're not too bad, they call round for an hour and things. [a lot of talking at the same time] If we looked after the carers a wee bit better too

1: Oh if we looked after the carers and make them feel worthwhile and supported and make them feel like they can go out for a whole day

13: They need the respite too, a wee day away

1: If you give somebody you know, 7 or 8 hours of a day of a break theyd think more of that, but its getting people to do it and the funding

13: Its very chartiy based and then its that cycle of funding

1: And then if we can't provide the care theres no choice but to put them into a nursing home or residential

2: Its terrible when it comes to that

1: And then theres financial implications behind that, if they haven't farms of land signed over or you know, theres another problem, they try and keep mummy and daddy at home and them struggling as you say theres a whole maybe safeguarding issue behind that. But if theres financial implications if youre gonna lose a farm of land worth...

2: And that's a rural thing

[agreement]

1: That's a rural thing, yes it is, it's a good point and its very real, very real , you think no god I can't leave this theres a farm of land here

5: One of your patients moved into the nursing home today, apparently all this was signed with the solicitor seven years ago, but they went to get the papers or whatever and theres some clause or something, so shes went into the home today, but on the basis that they get this sorted out, they don't have the funders, because apparently they'll all sort it out.

1: A nursing home bed is almost 700 pounds a week, you know

2: In the republic of Ireland they have, its like theres this scheme that the government organized and its basically fairer deal so they take 20% for the first three years of the persons assets and then its free after that, maybe the first three or four years..

13: Yea yea- Sometimes when you think about nursing homes, even when I think about myself I think I don't want to end up in a nursing home, like in Holland they have really nice places, villages where you can just walk around

1: Have you put that in writing? [laughs] What about those dementia villages, where is it they have those, Denmark?

13: No, Holland! Where I was brought up

1: Where they can just go into the shop and they can think they're buying something

13: That's what it'd like

[general laughter and chat]

Well thank you all so much that's been brilliant and so helpful for me. I will give you feedback on things going forward. I plan to do another 1 or 2 focus groups in other areas and will let you know how this goes. Thanks again.

Appendix 8 – Focus group 2 transcript

Unique Identifier	Initials	Role
1	ED	GP
2	PH	Practice Nurse
3	GG	Practice Manager
4	RH	GP

F: welcome and thank you everyone for doing this for me. Can everyone introduce themselves, just tell me your name and your role, so that I will recognise your name for the tape.

(All introduce themselves)

F: Great thank you. The first question that I had was general- Can you talk me through your experience of caring for patients with dementia in rural areas- anything in particular you think works well, from a rural perspective or anything you think doesn't work so well and has there been any particular examples of difficulties or problems

4: I can think of one wee guy in particular, em, Mr T in S----- who was a bachelor farmer and em, lived in a wee farmhouse and looked after himself all his life, but then, as he was getting older his niece, or maybe his sister in law maybe, was it, got in contact with us and was saying he was starting to wander at night, we hadn't really had much interaction with him in a long time, and em we went out to see him and the house was unbelievable, in squalor. I think that's the thing about rural, particular single farmers, you often find really dreadful conditions that you don't realise until it's too late. There's no facility to just get them in somewhere really quickly for respite and just get the house sorted, you know, that all takes far too long, and getting the house sorted etc etc. In the end you know he got more confused over a period of a few weeks and he had to be admitted to Ash ward then,

F: That's the psych of old age ward isn't it?

4: The psych of old age ward yea because it just wasn't safe for it at home because he had been confused and wandering, so often times like that in a rural area even though he had good family support, em it just you, just knew that there was so many problems that had built up over the years that you weren't going to be able to fix it, and they have to go into like an acute crisis service really,

F: Is there any type of respite care available?

4: Em, yea, there would be, but I think it always takes too long to organise, when you are at that really, when someone is not safe at home and they don't have somebody living with them the whole time. Em so its alright he had a carer that was coming maybe once or twice a day but if you don't have you know family that live with him that can watch him 24/7 then em you can run out of options pretty quick I think

F: Yea, yea, and you said there were carers in that situation?

4: There was a carer yea every morning who maybe helped him with his medication and helped him with a bit of, well, there wasn't much cleaning...

3: They're not allowed to clean, the carers,

4: Oh right! Well, aye fair enough, well he, he probably didn't let them do too much

F Yes, yes.. and he eventually..

4: He went to the Ash ward and was there for a wee while and now he's in Meadowbank, which is like a residential unit for patients with dementia

F: What sort of things do you think if they'd been available would have been helpful?

4: I suppose if there was like a, you know, some sort of community dementia team, that could look at the overall social supports for somebody, and emm, you know somebody that could identify months or years before you get to crisis point, because you know if somebody needed you know, the house adapted or the house made safer etc, like he was lighting fires the whole time, it was, the whole house was charred, it was the worst I've seen in years and years.

1: Was he healthy otherwise?

4: Aye he wasn't too bad he had diabetes, he had pneumonia, he was admitted a couple of times with pneumonia and UTI and then you know his baseline went down from that physically, and then he wasn't physically able to look after himself and then he was found wandering a couple of times by neighbours.

1: Sometimes in rural areas as well, in terms of like family support, or input, sometimes it's like a famine or a feast, so either the family dynamic is close and local and can really make your job easier in terms of keeping an eye and monitoring and helping navigate risk,

F: yea..

1: Or it can be the opposite, where there is carer burden, and there's family in England or in Belfast and there's a lot of maybe expressed emotion of their concern and worry to you, as a GP, there's the isolated elderly relative you're waiting to get them sorted and there's this period of risk management in the meantime like RH says when you're like trying to juggle

2: We have a wee man like that I think he has relatives in Australia and he always forgets to collect his medicines, (General murmur of agreement). There's one (relative) here but he doesn't have that much input

1: And we have a lady at the minute and she is the main carer for her husband who is disabled, but she has dementia, and still early stages but family live further away and you can tell it's challenging to navigate, and you can't constantly risk assess everytime you touch base with them, shes still coping, but how do we notice when she stops coping because theres no-one there locally and the GP can't get a constant eye

F: So that's both points of view, how families can be helpful but sometimes too far away and checking in isn't enough

To summarise literature that I've read ill just tell you the points that came up, you can maybe tell me if this is your experience or not- distance to the likes of services/appointments, lack of transport, maybe that wouldn't apply so much here, but people living far out in country might have difficulty accessing their appointments, and then lack of training for nurses/doctors in their rural area around dementia. Then in the previous focus group the team mentioned particularly lack of carers- the social worker in that group told me that was a big problem, not enough carers to go in and out to patients and no access to respite at all – the other thing that was mentioned was financial, and issues around farming and giving up of a farm and all that goes with that. That didn't come up in the papers I read....

(general agreement)

3: Even personally my father passed away last year and my eldest brother got the farm, and my youngest brother got the home house, and mum you know didn't get anything, and you know she is in our house still, but just incase she has to go to a nursing home then she won't have to pay anything so there is that financial element of it. There's also the stigma of dementia, of diagnosis of dementia which is a real big one for people who have got a wee bit of insight, and also for families, I don't think that that's while well...theres a lot of education out there needed, a while lot of fear about dementia..

4: Driving, people worry about being told they can't drive

3: And losing their financial independence

4: It's more so important here, than in an urban area as they live miles away

F: Their lifeline is their car, so yes that is a big one..

4: The thing about the distance to memory clinic is not so much an issue here, but obviously the length of time obviously to get an assessment is the, or even to, once your seen its really good but it takes ages to be seen, and it can take months and months and months for them to write the letter and send you back what they've done and

1: And then if they don't attend 2 appointments they get discharged!

4: Yes! From a dementia service

: When a patient doesn't have the executive functioning to engage with the 'this is something that I need to attend to, so I think it's the safety netting mechanism, because I think GPs have good safety netting mechanisms, maybe its because they have better access to us, so we can catch stuff inadvertently in notes, and say oh gosh that never happened, whereas it's kind of a bit of a shut up shop, you didn't attend

2: They need the bloods done for diagnosis for us, and sometimes the bloods aren't done in a timely fashion...

4: The diagnosis process takes a long long time and even last year we had a very young man develop a fronto-temporal dementia, at 51, and it was a really horrible, it was a terrible presentation, it was really obvious from the start that there was something seriously wrong and it just got worse and worse over a period of months. The police were involved because he was acting strangely in the town and we had an awful struggle all of us to get him seen, and eventually we did, but it took four or five months, I don't know If that's specifically rural, but I just know that the dementia service in our area, which is rural, is very hard to access, even for that sort of acute, emergency case of abnormal young presentation

F: And you can't really diagnose it in primary care without the goahead of the dementia service....

4: You can know, like 99% sure, this is a an abnormal early onset dementia, but nothing can swing into gear until we get the formal diagnosis

F: And you were saying about a dementia team, is there any sort of team or dementia specific nurses in the area?

4: Theres the CPN, the psych of old age team, and they're very good, they're helpful, you know and you talk to them and they go out and visit the patient, em but it seems like they, they feedback to the team, and they put the patient back onto the list to be seen by the consultant, at some specified time down the line, so yea there's limited support, theres only one doctor, I don't think they have a junior doctors working for them and so its very under resourced team

Is that in Omagh?

3/4: Yes, here in Omagh. Just the one consultant. And he's very good when you get him, but his waiting list is like 9 months or something like that.

3: And see for rural areas as well , it's like sort of the local community groups and community supports that are helpful in links, so say for example the older people's group or whatever it is, em, that will support them, and then the Alzheimer's society, and all the other charitable things, because the formal structure isn't sometimes there..

F: And are those services readily available/accessible?

1: The dementia navigator G, locally is very good....

F: Is she a nurse, or a social worker...?

1: I think she must be an AHP that knows what's in the toolbox locally and picks, because, sometimes I would deflect back to her,

F: And you can refer to her?

1: Well at time of diagnosis they have a review appointment with her, and they kinda touch base just with that transition to acceptance phase at the start,

F: And you (all) said you were aware of all the services available locally...

3: Awk you'd have an idea yes in your local area, here in O-----, that's not necessarily that rural, , but you're talking about smaller areas, d-----, b-----, s----- which they would feed...

4: The rural link transport and community voluntary groups are there, there have been more rural voluntary groups set up since covid obviously, which is probably more accessible now than it ever was

F: Do you mean transport or in general?

4: The transport yea, and the general help, you the different GAA clubs have been doing deliveries of medication to people who are shielding and things like that and you know, the rural dementia patients would come into that, and so they're probably more accessible now than they ever were before

3: And the local pharmacies would be good support, you know, with the....(pauses to think) weekly meds.. could you diagnose me?! (laughs)

F: The last sort of point, was there anything that you feel that local primary care teams in rural areas could do to improve care for patients with dementia, and if so, what help would be useful...you know what sort of things could be done a bit better if services were available..

4: I think a dedicated CPN you know, who would do regular visits, you know, to your rural patients, because they just seem to be very stretched, you know, someone who would do a check up on your dementia patients who would spot problems, social type problems, like that they're deteriorating slowly and you know could get services in place and help in place before things would deteriorate to crisis point.

1: I just wonder if they looked at that period, in deterioration in state, or cognitive decline in rural patients compared to more urban areas where there is greater support, are they caught later, you know and is the patient subjected to a more protracted period of distressing symptoms because we can't get to them you know, its probably just that increased, the more people you have on the ground the more people you can pick up..

F: From a nursing point of view is there anything you have noticed...

2: I suppose the DNA thing, you know we have diabetics and asthmatics and patients with COPD and you know if we struck them off after 2 DNA's, you know, we would have nobody. They shouldn't be able to do that, they should have a better system, you know..

F: That came up in the other group that I did as well. Also, in that group I had a couple of receptionists (who took part) and they knew the people in the town well, and one of the girls was able to say that she knew herself when the patients were maybe going downhill because she knew them, and then she knew once he had diagnosed that she knew when she answered the phone to him that she had to speak more slowly to him on the phone and she knew that she had to check with family etc. a nice point that came up, in a way that shows that rurality can be helpful..

4: Yea, yea and probably for a lot of our patients somebody in reception would know them or know the family as well, for a good number of them anyway

3: It might be following up with the likes of the continence service and things like that there as well because most of them have problems, nad its maybe tying that kind of support in early, or everyone kind of linking in, just to spot the people, because sometimes by the time the diagnosis comes the problem's already established

And probably people exist better in rural areas than they do in urban areas..

4: I would think they're more likely to have support

3: Like that wee man lasted longer in his own house than he would have if he was in a wee fold here...

F: You mean before he was diagnosed?

3: Yea, because he was active, and he was out doing bits and pieces you know, and he was in his routine

F: That's one of the things that I picked up from the other group, there are a lot of positives of rural living,

4: I actually think they are more likely to become isolated and get into problems when they are urban, you know if they're living alone, then they're more likely to have problems in urban areas, because the rural community is more likely to know the older person who is living alone

2: That's right..

4: And even non family, and even neighbours and stuff are more likely to check on somebody than they would be in the middle of the town

P2 Urban people can keep to themselves sometimes and don't know their neighbours, and they change all the time there's new faces so they don't get to know their neighbours..

F: Well that's great that's basically all, I just want to make sure I've told you everything I needed to tell you, and just the last point, do you feel it would help you to be trained more in dementia?

4: I don't think so really, no I think im happy enough to screen for dementia and you know emm to identify them.. I suppose if they were going to say to us you can start dementia medications, I think we could have a specific training programme for that and what they wanted us to watch out for.. that would be one thing.. while they are a consultant only prescription I don't see the benefit in more training for us...

F: It's a good point though, because there is such a delay with the diagnosis...

4: You know what drugs they are going to use so you know, give us the authority to prescribe them and give us a training day for that, that would be useful

F: That's all and that's great thank you does anyone else have anything they want to say before we finish?

2: I suppose im thinking of my wee man, you know who I'm talking about he's a lovely wee man, he does have dementia and he lives on his own and all the rest and he looks after himself alright you know but he forgets to get his tablets and I try my best to keep looking has he ordered these tablets but he just doesn't come, and he gets his wee trays weekly. And I think it would be just lovely to have someone coming in and checking on people like that, I suppose that would be the dementia nurse.. because that is a big problem for him and you know and just last week you know I contacted him again to get these tablets, and em it was so funny, the next day he was going to get them, and I was in the chemist that day, and somebody dooted the horn and here he was,

(general laughing)

2: It was so funny, but you know, but then he could just forget about that

F: But that's nice because you're checking on him

2: But you can't keep that up, you know, and you can't do it for everyone. And he is somebody, you know, his daughter is in Australia, he has a son here but he just doesn't keep that eye on him, there's that break you know, so he could do with someone like that... (dementia nurse)

4: I suppose, the CPN's that we have, they are more reactive, they are firefighting, when there's a problem. If there was some sort of team set up for overall care for their dementia lists, you know who are living in the community

2: You see there was, social interaction with him, from the social worker, and there was a carer, but he said I don't need it, sure I don't need it I'm alright, and so you're up against that as well

4: It's difficult when the person declines that

3: That's right..

3: Hospital admissions too when people go into hospital too, especially when they're older, they can be picked up in hospital, and sometimes they're not necessarily picked up in the hospital, because nobody spends any time with them only the cleaner, to be honest, you're given your medication and away you go, the doctor might come and see you but overall em, they're shipped in and out pretty fast, and the more hospital admissions they have as they get older the more likely they are, as you said your man had pneumonia..

4: They don't get back to their baseline after admission,

3: And then there's nobody watching out for them and by the time they get to the CPN team there's no proactive approach. But how do you spot that...

4: yea yea..

3: An education programme for people on dementia, for the community? The general public you know?

(general agreement)

4: The hospitals are so busy that they only deal with the physical problems and they are assuming there is help in the community

F: You mean more like picking it up there and then, yes.

Thank you so much for taking part.

Appendix 9: Ethics Approval



Date: 19 November 2019

To: Dr Nigel Hart / Lucy Hodkinson

Faculty REC Reference Number: MHLS 19_11

Full Title: Challenges for the rural primary care team in providing care for patients with dementia

Decision: **APPROVED**

Thank you for your application which was reviewed by the Faculty of Medicine, Health and Life Sciences Research Ethics Committee (Faculty REC) in accordance with the Proportionate Review process.

Your application was considered and some clarification and revisions were requested on 07 November 2019. You submitted the requested information on 14 November 2019.

The clarification and revisions have been reviewed and deemed satisfactory. The application has been **approved**.

Conditions of the Approval

The Faculty REC approval is subject to the following conditions:

- (i) The study must be conducted in accordance with all relevant legislation. All relevant management approvals from organisations involved in the research must be obtained.
- (ii) When the research involves human volunteers the study must be entered on the University's Insurance Database.
- (iii) Monitoring and auditing process must be complied with including submission of annual progress reports to the Faculty REC.

It is the Chief Investigator's responsibility to ensure the study is conducted in accordance with the conditions stipulated.

Any future changes to any part of the submitted application, protocol or supporting documentation must be notified to the Committee prior to these changes taking place.

Approved Documents


The documents approved by the Faculty REC are listed in the table below.

Documentation Received	Version	Date
Application Form (Revised)		Received 14 November 2019
Covering Letter addressing comments		Received 14 November 2019
Research Protocol	2	14 November 2019
Participant Information Sheet (Appendix 2)	2	14 November 2019
Consent Form Focus Group (Appendix 3)	2	14 November 2019
Letter of Invitation (Appendix 1)	2	14 November 2019
Focus Group Interview Schedule (Appendix 4)	2	14 November 2019
Data Management Plan (Appendix 5)	2	14 November 2019

Peer Review (GK)	1	15 October 2019
Peer Review (HR)	1	15 October 2019

If you would like to discuss this further please contact the Research Ethics Officer, Mr Stefan Curran, at facultyrecmhs@gub.ac.uk or by telephone on 028 90972529.

Yours sincerely



pp Professor Michelle McKinley
Chair, MHLS Faculty REC

