



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

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EVIDENCE BRIEF

Why did we start?

Dementia prevalence is expected to rise by 146% by 2050; the demands of providing care will also grow and Primary Care Teams (PCTS) are playing an ever-increasing role. A projected rural population increase of 6% in the next decade, particularly those of retirement age, will compound the demands. We sought to identify the challenges for rural primary care teams in providing care for patients with dementia and their families.

What did we do?

The aims of this study were to identify challenges for 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 taken 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.

What answer did we get?

Four main themes emerged. 1. Sources of formal and informal care and support. 2 The journey to formal diagnosis which included the role of every member of the primary care team 3. Special considerations of rural communities including farming and economic considerations and 4. The unique potential of capitalising on rural community assets.

In addition to identifying challenges this work demonstrated the unique way in which every member of a rural PCT, medical and non-medical, can play a vital role in optimising care for those living with dementia and their families.

What should be done now?

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

Background

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 e.g 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.

Aims and 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 and methods:

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.

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.

Personal and Public involvement

Throughout this research project I was aware of the importance of personal and public involvement. I was fortunate enough to interview a gentleman who had been diagnosed with dementia a few years previously. He lives in a rural area of Fermanagh and I learnt a great deal from his personal experiences of living with dementia and his interactions with the healthcare team. I also spoke with this wife and shared my research plans with both of them. I liaised with members of the Alzheimer's society and Dementia NI. I also attended the Dementia Analytics Research Users group where I was fortunate enough to be able to learn from other researchers / healthcare professionals / funders and patients and share my research with them. I presented the results of my research to one of the practices who had taken part in the focus groups as well as the gentleman whom I had spoken to at the beginning. This was a privilege to be able to do this as I greatly appreciated their generosity in sharing their difficult experiences with me.

Findings

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.

Practice and policy implications / recommendations

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.

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