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Note from the Editors: Instructions for reviewers of study protocols

Since launching in 2011, BMJ Open has published study protocols for planned or ongoing research studies. If data collection is complete, we will not consider the manuscript.

Publishing study protocols enables researchers and funding bodies to stay up to date in their fields by providing exposure to research activity that may not otherwise be widely publicised. This can help prevent unnecessary duplication of work and will hopefully enable collaboration. Publishing protocols in full also makes available more information than is currently required by trial registries and increases transparency, making it easier for others (editors, reviewers and readers) to see and understand any deviations from the protocol that occur during the conduct of the study.

The scientific integrity and the credibility of the study data depend substantially on the study design and methodology, which is why the study protocol requires a thorough peer-review.

BMJ Open will consider for publication protocols for any study design, including observational studies and systematic reviews.

Some things to keep in mind when reviewing the study protocol:

- Protocol papers should report planned or ongoing studies. The dates of the study should be included in the manuscript.
- Unfortunately we are unable to customize the reviewer report form for study protocols. As such, some of the items (i.e., those pertaining to results) on the form should be scored as Not Applicable (N/A).
- While some baseline data can be presented, there should be no results or conclusions present in the study protocol.
- For studies that are ongoing, it is generally the case that very few changes can be made to the methodology. As such, requests for revisions are generally clarifications for the rationale or details relating to the methods. If there is a major flaw in the study that would prevent a sound interpretation of the data, we would expect the study protocol to be rejected.

Scaling the Peaks Research Protocol: understanding the barriers and drivers to providing and using dementia friendly community services in rural areas: a mixed methods study.

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ABSTRACT

Introduction: Scaling the Peaks is a cross-disciplinary research study which draws on medical ethnography, human geography and geo-spatial information science (GIS) to address the issues surrounding the design and delivery of dementia friendly services in rural communities. The research question seeks to understand the barriers and drivers to the development of relevant, robust, reliable and accessible services which make a difference among older rural families affected by dementia.

Methods and analysis:

This mixed methods study recruits families affected by dementia who reside within the Peak District National Park, Derbyshire and also adjacent service providers. The study explores the expectations and experiences of rural dementia by adopting a three part approach: (1) longitudinal ethnographic enquiry with up to 32 families affected by dementia (aged 70 years plus) who identify themselves as rural residents; (2) ethnographic semi-structured interviews and systematic observations of a range of statutory, third sector, private and local community initiative's which seek to support older people living with dementia; (3) geospatial visual mapping of the qualitative and quantitative data. The ethnographic data will be used to explore the ideas of belonging in a community, perceptions of place and identity to determine the factors which influence everyday decisions about living well with dementia and, for the providers, working in a rural community. The geospatial component of the study seeks to incorporate quantitative and qualitative data, such as types and locations of services to produce an interactive visual map for local communities to determine the future design and delivery of services when considering dementia friendly services.

Ethics and dissemination: The study is approved by the Leeds and Humberside Health Research Authority 16/YH/0163. The study is also approved by other participating organisations as required by their own governance procedures. The study includes people with dementia and as such adheres to the ethical considerations when including people with dementia. A publically available interactive visual map of the findings will be produced in relation to current services related to location and, by default, identify gaps in provision. Formal reports and dissemination activities will be undertaken in collaboration with the study advisory group members.

Study Progress

The recruitment began in September 2016. The data analysis commenced June 2017, using 59 provider interviews and 27 family participants. Data collection will be completed June 2018.

Note on Terminology

Please note that the term "families affected by dementia" is the preferred term of usage by the members of the Scaling the Peaks Study Advisory Group.

Keywords: dementia, rural, family caregivers, formal caregivers, social support, health support, health geography, dementia friendly, geo-spatial health, mixed methods research.

Strengths and limitations of this study

- Scaling the Peaks is one of the first and largest rural community specific dementia research study in England
- The study draws on the expertise of local practitioners and organisations beyond health and social care to include agricultural, pastoral, business and charitable in collaboration with clinical and academic expertise from human geographers, dementia specialists, occupational psychologists and organisational theorists
- The study will help to develop further understanding of rural dementia care needs
- A limitation is that this is a mixed-method exploratory design and as such cannot provide a robust measure of effectiveness (such as a full economic costing would) as this was beyond the available remit of the resources

INTRODUCTION

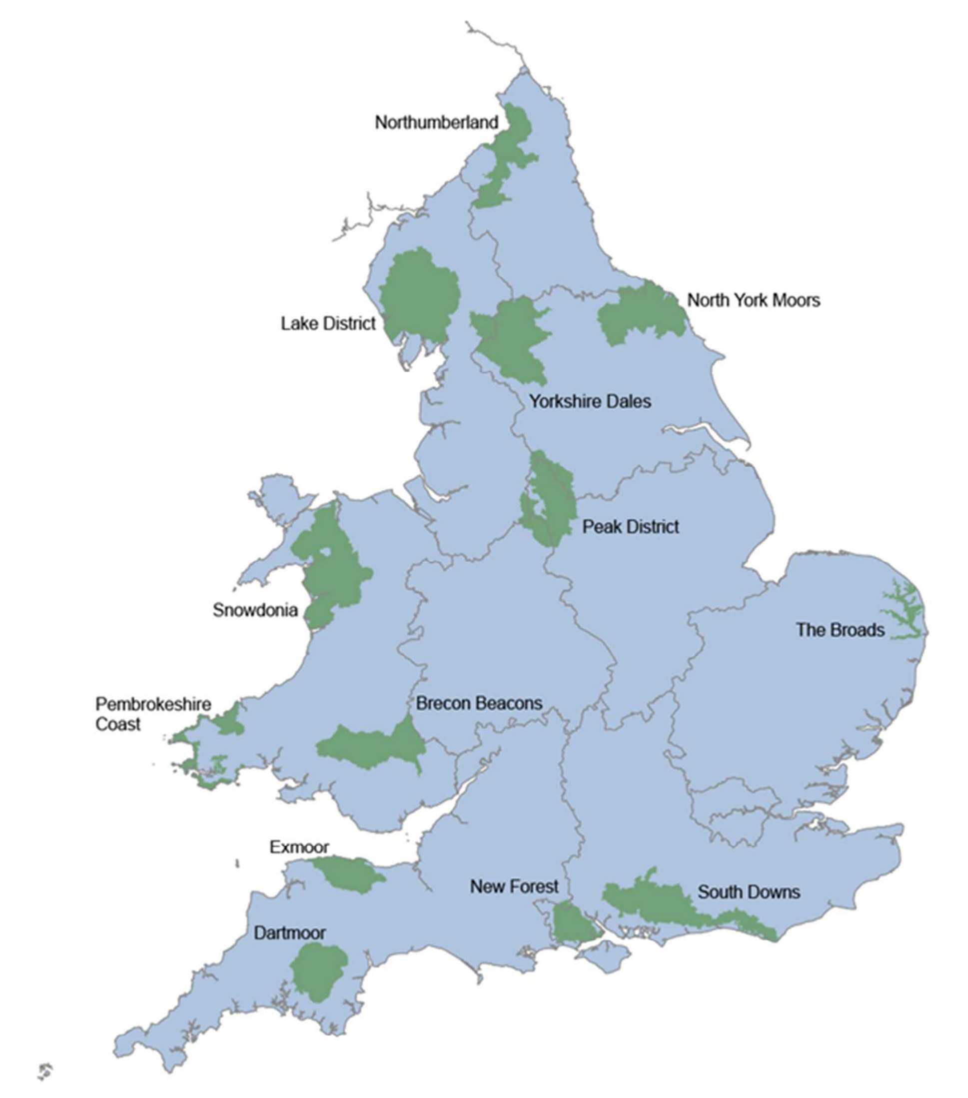
Background

Dementia is a condition which mostly affects older people and it is expected to increase as more people live longer (1). Since there is no cure for dementia, understanding the ways in which well-being can be maintained and enhanced is important for those living with dementia. To date there has been little work which has focused on the ways in which living with dementia in a rural region can be supported in ways specific to rurality, despite the majority of older people living in rural areas worldwide (1). Russ et.al (2) tentatively identified a higher incidence of Alzheimer's Disease among those who are established rural dwellers, which raises questions about not only the epidemiological aspects of dementia in rural areas but also the delivery of appropriate services.

Rural areas are characterised by low population density compared to land mass, with high levels of agricultural industry. Providing equitable, high quality dementia services to rural areas presents challenges that are complex and often poorly understood (3-5). The stereotype of a rural idyll contrasts with descriptions of isolation such as "beautiful prisons" (6,7). Barriers to the provision and uptake of health and social care services in rural areas include increased costs in time and travel, limited facilities, sparse workforce/service provider, limited choice of provider and lack of sustained support (8). There may also be local issues, e.g. lack of infrastructure to support remote communication, fuel and transport poverty, and lack of privacy in small communities (9). Providers are concerned about the economies of scale, fragile infrastructures and ensuring dementia friendly approaches to service design and delivery (10). As a result, provision may not be well aligned to the nuanced needs of rural communities (6) or the varied lives older people lead, resulting in unmet health and social needs (11). This can lead to cultures, among both families and providers, of implicit low expectation and subsequent demand, thus perpetuating hidden need and a reliance on family carers. There is an urgent need for a better understanding of the relationships between rural place, living with dementia and access to services (12).

Many obstacles may affect access to dementia care in rural communities, such as: cultural values about dementia (ignorance and stigma), working life, and using services (11); concerns about gossip, privacy and interference (13); limited access to GPs who are knowledgeable about dementia (14); limited access to memory assessment services (15); limited access to health and social services due to location, lack of public transport, timing and signposting (4,9). Also, it may be assumed that families will provide more care, or that indeed needs are low because overt demands for support are not being made. Technology that could help may be impracticable because of patchy erratic signal reception and limited broadband connectivity (16, 17). All these obstacles are likely to lead to gaps in understanding the real needs within isolated communities; fragmented and inadequate health and social services; and poor information, support and outcomes for people with dementia and their families (18). A comprehensive study of all these factors is required in many rural areas, of which the Peak District National Park (The Peak) is an exemplar of rural living in England.

For the purpose of the study rurality is defined using the Office for National Statistics (ONS) categorisation of rural and remote (19) with larger townships lying alongside the boundary of the Peak to the North East, East and South of the area. Figure 1 provides a visual map of the location of the national parks in England and Wales, including the Peak District.



Contains Ordnance Survey data © Crown copyright 2016

The Peak

The Peak area (143,646 hectares) of Derbyshire is a typical remote rural area of England. Its population (37,900) has remained fairly stable in numbers but with significant changes in age structure: around 33% of the population aged over 65 and only 21% aged 25-40. By 2028, 49% will be over 65 years with over 85s increasing by 186% (17). These demographics are similar to other UK National Parks and coastal regions where retiree migration is common (19). Numbers of older residents rise because of in-migration of midlife and older retirees while, concurrently, there is net outward youth migration towards urban areas for higher education and employment (20). The ageing population and diminishing workforce have significant implications for meeting older people care policy demands in the UK which predominantly drive for own home care (21).

Because of the age structure of the Peak population, a higher number of people live with dementia than would be expected for the total number of people in the area. Using the NHS England dementia prevalence calculator v3, the prevalence of dementia (of whole adult population) is 1.48% in N Derbyshire, 1.53% in Derbyshire Dales, 1.44% in N Staffordshire and 1.6% in E Cheshire, compared with 1.1% for England as a whole. It is impossible to give a prevalence figure for the over 65s in the Peak because of the organisational boundaries but a conservative estimate suggests around 1300 people aged over 65 currently live with dementia in the Peak area (24). Provision of care for older people and those with dementia is characterised by a low number of care homes, dimishing community hospital beds, a lack of comprehensive home care services and consequential reliance upon family carers, chronic care beds and/or earlier relocation to care home provision outside of locality (24,25).

The cultural and organisational issues involved in ensuring dementia friendly services in rural communities are complex. Many of the rurality issues have already been documented, but less detail is available about the needs of families affected by dementia in terms of social, practical and economic support in remote areas (26). We do know that a significant amount of care is provided by family carers, mostly women, in this rural area, which has implications for working lives and the health of carers (23, 25, 27).

The figures quoted suggest that there may be pockets of unmet need. However, paradoxically, evidence suggests that despite 20% of the older population in the Peak having ill health they are amongst the happiest in England (18), which may reflect current expectations about growing old (7); a possible trade-off between place and low service expectations (28); cultural stoicism (29); and/or resilience in old age (30). This indicates the complex nature of living in a rural area and the impact of expectations and subsequent favoured configurations of living with dementia in a rural area.

Significance of the research

This study will provide an understanding of the current status of dementia care services in the Peak and examine the perceptions of those living with dementia in some of its most rural locations. The study examines what matters most to these residents and the service providers to support dementia friendly communities. Understanding the nuances of managing the challenges associated with growing old with dementia in rural areas can help future decision making by providers to secure the best use of resources which meet the needs of this community.

The study is important because it will:

- contribute towards redefining rural health and social policy for people with dementia by understanding the challenges of identifying and meeting need.
- consider several distinct groups of older people who live in the Peak: established retirees, arrived retirees, carers and those in work who may have differing needs in relation to dementia care.
- provide relevant information for commissioning - most models of commissioning and delivery are based on data from more urban areas; more local innovative responses may be required to address obstacles in local rural and remote communities.
- assess how alternative care models, which support dementia friendly care and accommodate the impact of terrain, climate and remoteness, may be required. This includes surmounting the challenge of providing robust technologies such as internet and mobile phone connections.
- explore the experiences and needs of a range of key service providers including the identification of support and training needs
- identify implications for the estimated 160,000 people living with dementia (using figures from Alzheimer's Society, 2014), carers and service providers in other rural areas of England.
- contribute to the international imperative to meet dementia care needs amongst populations with increasing numbers of older people and a decreasing younger workforce.

This research builds on existing studies with people living with dementia and their family carers in rural areas (29, 30). However, rather than simply obtain more data on inequalities there is a need to understand the complexities of the specific issues about dementia care. The study will concurrently explore the perspectives of all key stakeholders: those living with dementia, family caregivers and service providers. It will also compare the experiences and perceptions of care amongst two significantly different groups: those who are established residents and those who have retired to the area. A study like this has not been conducted before in England and it will make a contribution to the care of people with dementia and family caregivers in England but would also have considerable impact internationally.

Participant Involvement

A core component of this study from inception of the ideas, bid writing to undertaking the work has included a study advisory group who are all rural dwelling family members affected by dementia. This includes individuals who consider themselves to have dementia, those who have cared for a spouse with dementia and those who are continuing to care for a loved one with dementia. These members of the group have changed over time and provide valuable suggestions and critical insights. The group meet on a regular basis for a walk and talk to discuss matters relevant to the study at a location of their choice. This paper has been reviewed by two members prior to submission.

Research design and methods

This study is comprised of two distinct parts: geospatial mapping and qualitative enquiry.

Firstly a geospatial mapping approach will be used to produce an interactive map which amalgamates area specific information such as geography, demographics, population clusters and service locations such as GPs, community hospitals, agency working, support groups and their respective geographical boundaries. This will provide a visual interactive map which can be interrogated by authorised users to model possible future outcomes. Drawing on previous human geography related studies we hypothesise that such representations of data can act as powerful seeds for changing dementia care services in rural areas by;

- geospatial uncertainty modelling; identifying where there are gaps in provision, possibly indicating unmet need (31)
- time-distance-weather- terrain-infrastructure analysis to identify underserved and potentially vulnerable areas, such as those requiring more than a 30 minute drive to GP surgery (32)
- service area analysis to support decisions about resource allocation and placement of clinics, mobile units such as memory clinics (33)
- identify areas of high vulnerability in dementia care where local health and care responses can be targeted (34)
- prompt grassroots action for change and support the case for improved services in local areas such as maintaining reliable bus services to access services (35)
- Provide a baseline to advocate for change and measure future progress (36, 37)
- Promote collaborative working within and between organisations who share decision making in future service design and delivery at local levels (37)

Uniquely this study will also incorporate the more ethnographic data into the GIS mapping to produce a visual representation of the more personal accounts of living in rural and remote communities thus providing a personalised story of living with dementia.

The techniques for undertaking the mapping will be supported by Dr. Ana Basiri within the Geospatial unit at The University of Southampton. Specific health geography expertise will be provided by Dr. Mark Riley, University of Liverpool. Derbyshire County Council and Rural Action Derbyshire, have agreed to host the interactive map and to support the updating of information via their informatics team. It is also anticipated that the map could also be available within the study dedicated website and a link provided on the Alzheimer's Society UK website.

Secondly, the bulk of the study will use qualitative approaches to investigate the expectations and experiences of users *and* providers of services. Interviews will seek to meet the objectives of the study by establishing the connections between users and providers as a qualitative mapping of dementia care. Identification of potential participants will be by prospective sampling, using chain referential sampling (snowballing) (38) which will provide opportunities to identify services and groups which may be unknown to the more formalised providers. This technique will enable access to voluntary groups which are operating in dementia friendly ways but not formally recognised as supporting dementia care or identify themselves as operating as being dementia friendly.

Consent will be sought from all participants in accordance with the Research Ethics Committee guidance and the Good Clinical Practice and any other regulatory requirements that might be introduced during the course of the study. All participants will be provided with written consent. Whilst most participants will have the capacity to consent to take part in the study, some may not due to cognitive impairment such as advanced dementia. For participants who lack capacity, the researcher will approach and inform the identified family caregiver about the study. Carers who indicate that they are willing to act as a potential personal consultee will be given the opportunity to consider signing the declaration to act as a consultee in accordance with the approved procedure.

The user component will actively promote seeking the views of those living with dementia by inclusion in discussions with carers present to support. Specifically, enquiries will be made about the inter-connections between locality, expectations and access to dementia friendly services. Opportunistic conversations will be used with sensitivity to help understand perspectives of everyday life. Observations of everyday and seasonal activities such as walking, attending church, sheep shearing and shopping will be made with the families by the researcher as a naturalistic endeavour to support the participants in sharing their lives with ease, Talking Mats© or similar symbol based language techniques will be used to support communication if required (39).

This will include the use of a newly emergent tracking technique amongst up to 32 families living with dementia or memory difficulties. The participant tracking comprises of up to 4 interviews over 12-18 months to establish the realities of living with dementia in a rural location and the obstacles to access and using local services over time. This technique has been utilised and refined in 3 previous studies (40,41,42) by the applicant and shown to provide a powerful insights about continuing and fluctuating health and care needs amongst older people. The final contact with each family will be concluded by the giving of a thank you card to confirm the ending of the data collection period. Cards can provide tangible aide memoirs for families to discuss their participation in the study.

The provider component of the study will involve inviting key provider representatives to take part in a semi-structured interview, to determine perceptions about working in dementia care and the everyday factors which impact upon delivering high quality relationship-centred care. This will include the examination of individual and organisational aspects of work and the work environment. These will be explored within a model of “healthy work” provided by the British Government Health and Safety Executive (43) and include demands, control and support, relationships, roles and organisational change. In addition dementia and rural specific issues related to working lives will be included in the framework. This will help to inform the future model requirements of the service providers in the context of rural dementia provision.

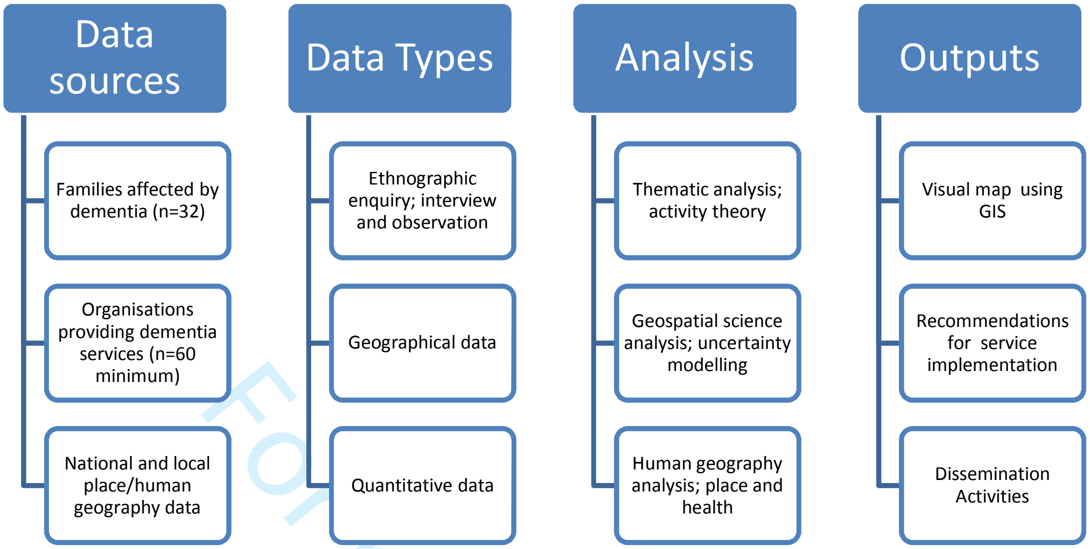


Figure 2 showing the Scaling the Peaks Study design by data sources, data generation, analysis and outputs.

How will the results from this study be used?

1. **Provide** spatial and qualitative evidence to support users and service providers to respond to the local needs of those living with dementia in rural communities. This evidence will be open sourced and kept updated to promote collaboration within communities.

2. **Identify** where there is scope for improvement by contributing towards theoretically sound and evidence based rural care delivery models through working in collaboration with local statutory health, social service, public health, third sector and private sector providers.

3. **Support** the development of a quality outcomes framework which will include the needs of service providers and service users such as meeting training needs, technologies to support remote information systems, dementia friendly provision which is responsive to the needs of users (34,35,36).

This is a mixed methods study located within the rural area of the Peak Park.

The study is comprised of two main components: ethnographic enquiry and geospatial information science (GIS) analysis.

There are five main areas of enquiry:

1. Geospatial analysis of national and local data sets to a) identify and visualise the which impact upon the lives of people living with dementias in the Park such as proximity to carers &services and b) devise a model of interaction to identify the correlations between users and providers.

2. An observational study of the ways in which people living with dementia and their carers manage their everyday lives in terms of navigating services to support their needs

3. An interview study of the ways in which people living with dementia and their carers consider and decide about the ways in which they manage their everyday lives in relation to dementia friendly communities and services

4. An observational study of how service providers manage their resources and meet the needs of those living with dementia who reside in the Park.

5. An interview study of key providers to obtain their perspective of the ways in which they manage to meet the needs of people living with dementia

Sample Size calculation

Whilst this work does not depend upon a stringent sample size the pragmatic approach will be to include at least 32 user dyads and 60 provider interviews until saturation is reached in qualitative analysis themes. These figures take into account drop-out and allow for some flexibility in the final number of participants.

The sample size calculation is not applicable to the more quantitative geospatial mapping techniques, although quantitative techniques will allow for the precision of the findings to be estimated.

If data is sufficient to allow for statistical significance test analysis using simple t and z distribution tests within the quantitative work then this will be undertaken. At this stage it is not clear if the sizes of sample will be large enough.

Sample

The sample consists of families living with dementia and will include a family caregiver and a person who is considered to have dementia. A formal diagnosis of dementia will not be required in recognition of the decisions many families make not to seek a formal diagnosis. Families will be recruited by study information leaflets displayed in public places such as churches, libraries and cafes. The researcher will also promote the study at local agricultural shows and seasonal events. Word of mouth contacts will be sought via local dementia and older people related groups. No family participants will be recruited by health or social care professionals.

The inclusion criteria for the families are that they consider themselves to be living with dementia, are aged over 70 years, live in the Park and have a regular caregiver (unpaid). The person living with dementia will be able to give consent to take part in the study or have a main caregiver who is willing to provide consultee advice if necessary. We selected 70years as this is the age of eligibility for local older people services in the region.

The inclusion criteria for the family caregivers are that they provide care for at least 4 hours a week with the person with dementia. The definition of care will be self-defined by the caregiver. The caregiver will be aged over 18 years, able to consent and provide assent if required to take part in the study.

The exclusion criteria for families living with dementia will be if both members of the dyad are considered to have dementia and not able to consent for themselves to take part in the study, terminally ill, if they are moving out of area and if they have severe communication difficulties such as severely hard of hearing.

The inclusion criteria for service provider staff, including voluntary organisations will be that they are employed within the statutory sector or provide services on behalf of a charitable/voluntary/private organisation towards older people in the Peak Park.

Methods of data collection

The study consists of three main components. All of these components will be undertaken over a data collection period of 24 months.

Component 1: Observations, semi-structured interviews with key service providers by use of longitudinal approaches over a maximum of 12 months per site.

Component 2: Observations, semi-structured interviews with families by use of longitudinal approaches over a maximum of 18 months per family.

Component 3: Data gathering to combine multiple data sets to construct geo-spatial map of the Peak. This will include data collected from the interviews and observations to determine decision making in relation to time and place such as distance to GP services. Additionally publically available data such as public service locations, public transport routes, climate and topology will be incorporated into the GIS mapping process.

Analysis

Concurrent data analysis during the data collection will take place to enable refinement of the qualitative data collection in particular and enable organisational changes in the local configuration of services to be identified and (re)considered if necessary. The longitudinal design of the study will support the notion that living with dementia and the associated changes of need is a dynamic process which often follows a jagged trajectory.

Qualitative data will be analysed with the support of the Nvivo 9 software to organise and generate general categories, patterns and themes from the textual data, using a broad cultural historical activity theory (CHAT) approach (44). The observational and interview data will be analysed using an activity theory approach which aims to explore the transactive relationships between individual action, material and social environments. Analysis will proceed in parallel with data collection until no new themes are emerging. By associative mapping between the themes, explanations will be developed from the findings enabling theory generation, using an adaptation of the methods proposed by grounded theory (45). This approach supports multi-disciplinary perspectives as it primary considers the ways in which people are shaped and shape the worlds in which they live; in short how they navigate their everyday lives.

Quantitative data will be analysed using a distinctive GIS modelling approach by using combinations of compatible multiple data sets. This will include geographical and infra-structure data from national data sources such as the Ordinance Survey, Google Earth, Office for National Statistics. Specific data related to the places the participating families access will also be considered by the construction of a dedicated database which will maintain the privacy of individual households by use of a radial place measure. Further details of this approach will be detailed during the dissemination phase of the study.

The spatial databases will be used to store and retrieve the data and GIS software and analysis will be customised to devise and model the ways in which participants navigate their social contact. This will be by a standard method utilising the open source QGIS software to construct a visual map of the region and as importantly support the analysis of multiple data sets to determine statistical and spatial relationships between the variables presented by the data (32).

It is also anticipated that by use of emergent spatial data modelling interaction approaches that both the qualitative and quantitative data can be combined to determine relationships with variable by ascribing a value system to each variable (32). This approach can help support the identification of the current ways in which participants and providers prioritise their needs and responses and so help in decision making by providers.

Outcomes

The study will provide understanding of rural communities, dementia friendly communities and living with dementia as a rural dweller. These understandings will also consider the views and practices of a range of providers to determine the services which are generally considered to match the needs of families living with dementia. This information will help to establish current and future provision.

The other part of the study is to provide a visual map derived from the combination of all the data analysis to enable users to:

Find the location and types of current services available to them to help support current and future needs

Support decision makers and campaigners to consider the future design and delivery of services in the rural area of the Park.

It is considered that the use of the map will support users in collaborative decision making based on evidence related to the combination of multiple factors. Previous decision making may have been prone to more urban centric thinking and possibly not reflective of members of the community living in the more remote areas of the Park. As such this method of data presentation may help support the future design and delivery of services based on a more sophisticated understanding of needs and so help to ensure the efficient and equitable distribution of services.

We consider that the use of cross-disciplinary research approaches offers future potential for solving many of the difficulties faced by commissioners and providers face in allocating resources in equitable ways. GIS mapping offers both the assimilation of and visual presentation of data in a highly concise format which can support robust decision making. Use of a visual GIS map, which can be incorporated into any website will support transparency in decision making and also provide a dynamic map which can be updated to reflect the inevitable changes in service configurations.

Discussion

This mixed methods study will provide important information on the everyday lives of families living with dementia who wish to remain in their familiar rural places and spaces. It will further our understanding of what matters most to families living with dementia and help to consider the meanings of dementia friendly communities as dynamic and heterogeneous (47, 48). The study considers the links with time and changes in living with dementia as a reflection of the longitudinal nature of dementia and caregiving.

Previous studies have tended to focus on statutory service provision with little consideration of the plethora of other innovative instances where dementia friendly practices help to support the family to live well with dementia (47, 48). Rural communities can provide enriched understandings of the ways in which everyday lives are lived in prosperous ways which may not require a reliance of more established and traditional ways of dementia care provision. In summary, the study findings will not only provide an important basis for the design and delivery of future services in the Peak at a local level but may act as a template for other rural communities to consider ways of developing and sustaining local dementia friendly communities. In the current challenges facing dementia care evidenced based decisions making is a priority for all providers (49). The study will contribute towards the possible future design of national and international studies in the fields of rural dementia.

Contributors FM is the principle investigator and led the writing of the study protocol and the manuscript. AB wrote the GIS component of the study protocol. AB, MR, AG and SL developed their own work packages. KW,CS,TH, CJ, MR and JD all contributed as members of the Scaling the Peaks Study Advisory Group.

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Competing Interests None declared.

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Scaling the Peaks Research Protocol: understanding the barriers and drivers to providing and using dementia friendly community services in rural areas: a mixed methods study.

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Scaling the Peaks Research Protocol: understanding the barriers and drivers to providing and using dementia friendly community services in rural areas: a mixed methods study.

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ABSTRACT

Introduction: Scaling the Peaks is a cross-disciplinary research study which draws on medical ethnography, human geography and Geospatial Information Science (GIS) to address the issues surrounding the design and delivery of dementia friendly services in rural communities. The research question seeks to understand the barriers and drivers to the development of relevant, robust, reliable and accessible services which make a difference among older rural families affected by dementia.

Methods and analysis:

This mixed methods study recruits both families affected by dementia who reside within the Peak District National Park, Derbyshire, and their service providers. The study explores the expectations and experiences of rural dementia by adopting a three part approach: (1) longitudinal ethnographic enquiry with up to 32 families affected by dementia (aged 70 years plus) who identify themselves as rural residents; (2) ethnographic semi-structured interviews and systematic observations of a range of statutory, third sector, private and local community initiative's which seek to support older people living with dementia; (3) geospatial visual mapping of the qualitative and quantitative data. The ethnographic data will be used to explore the ideas of belonging in a community, perceptions of place and identity to determine the factors which influence everyday decisions about living well with dementia and, for the providers, working in a rural community. The geospatial component of the study seeks to incorporate quantitative and qualitative data, such as types, locations and allocation of services to produce an interactive web-based map for local communities to determine the future design and delivery of services when considering dementia friendly services.

Ethics and dissemination: The study is approved by the Leeds and Humberside Health Research Authority 16/YH/0163. The study is also approved by other participating organisations as required by their own governance procedures. The study includes people with dementia and as such adheres to the ethical considerations when including people with dementia. A publically available interactive visual map of the findings will be produced in relation to current services related to location and, by default, identify gaps in provision. Formal reports and dissemination activities will be undertaken in collaboration with the study advisory group members.

Study Progress

The recruitment began in September 2016. The data analysis commenced June 2017, using 59 provider interviews and 27 family participants. Data collection will be completed June 2018.

Note on Terminology

Please note that the term "families affected by dementia" is the preferred term of usage by the family members of the Scaling the Peaks Study Advisory Group. The group wish to emphasise that they consider this term to be more representative of their lives than the term living with dementia.

Keywords: dementia, rural, family caregivers, formal caregivers, social support, health support, health geography, dementia friendly, geospatial health, mixed methods research.

Strengths and limitations of this study

- Scaling the Peaks is one of the first and largest rural community specific dementia research study in England
- The study draws on the expertise of local practitioners and organisations beyond health and social care to include agricultural, pastoral, business and Third Sector in collaboration with clinical and academic expertise from human geographers, dementia specialists, occupational psychologists and organisational theorists
- The study will help to develop further understanding of rural dementia care needs, the future design and delivery of services and contribute to the literature
- A limitation is that this is a mixed-method exploratory design and as such cannot provide a robust measure of effectiveness of support (such as a full economic costing would) as this was beyond the available remit of the resources

INTRODUCTION

Background

Dementia is a condition which mostly affects older people and it is expected to increase as more people live longer (1). Since there is no cure for dementia, understanding the ways in which well-being can be maintained and enhanced is important for those living with dementia. To date there has been little work which has focused on the ways in which living with dementia in a rural region can be supported in ways specific to rurality, despite the global rates of rural population ageing exceeding urban and metropolitan populations (2). Older adults are more likely to be living in rural areas worldwide whilst younger people are moving out to the urban areas (2). Russ et.al (3) tentatively identified a higher incidence of Alzheimer's disease among those who are established rural dwellers, which raises questions about not only the epidemiological aspects of dementia in rural areas but also the importance of geographical context especially for families affected by dementia and service providers.

Rural areas are characterised by low population density compared to land mass, with high levels of agricultural industry. Providing equitable, high quality dementia services to rural areas presents challenges that are complex and often poorly understood (3-5). The stereotype of a rural idyll contrasts with descriptions of isolation such as "beautiful prisons" (6, 7). Barriers to the provision and uptake of health and social care services in rural areas include increased costs in time and travel, limited facilities, sparse workforce/service providers, limited choice of providers and lack of sustained support (8). There may also be local issues, e.g. lack of infrastructure to support remote communication, fuel and transport poverty, and lack of privacy in small communities (9). Providers are concerned about the economies of scale, fragile infrastructures and ensuring dementia friendly approaches to service design and delivery (10). As a result, provision may not be well aligned to the nuanced needs of rural communities (6) or the varied lives older people lead, resulting in unmet health and social needs (11). This can lead to cultures, among both families and providers, of implicit low expectation and subsequent demand, thus perpetuating hidden need and a reliance on family carers. There is an urgent need for a better understanding of the relationships between rural place, living with dementia and access to services (12).

Many obstacles may affect access to dementia care in rural communities, such as: cultural values about dementia (ignorance and stigma), working life, and using services (11); concerns about gossip, privacy and interference (13); limited access to General Practitioners' (GPs) who are knowledgeable about dementia (14); limited access to memory assessment services (15); limited access to health and social services due to location, lack of public transport, timing and signposting (4, 9). Also, it may be assumed that families will provide more care, or that indeed needs are low because overt demands for support are not being made. Technology that could help may be impracticable because of patchy erratic signal reception and limited broadband connectivity (16, 17). All these obstacles are likely to lead to gaps in understanding the real needs within isolated communities; fragmented and inadequate health and social services; and poor information, support and outcomes for people with dementia and their families (18). A comprehensive study of all these factors is required in many rural areas, of which The Peak District National Park (The Peak) is an exemplar of rural living in England.

For the purpose of the study rurality is defined using the Office for National Statistics (ONS) categorisation of rural and remote (19) with larger townships lying alongside the boundary of The Peak to the North East, East and South of the area. Figure 1 provides a visual map of the location of the national parks in England and Wales, including The Peak District.

The Peak

The Peak area (143,646 hectares) of Derbyshire is a typical remote rural area of England. Its population (37,900) has remained fairly stable in numbers but with significant changes in age structure: around 33% of the population aged over 65 and only 21% aged 25-40. By 2028, 49% will be over 65 years with over 85s increasing by 186% (17). These demographics are similar to other UK National Parks and coastal regions where retiree migration is common (19). Numbers of older residents rise because of in-migration of midlife and older retirees while, concurrently, there is net outward youth migration towards urban areas for higher education and employment (20). The ageing population and diminishing workforce have significant implications for meeting older people care policy demands in the UK which predominantly promote own home care (21).

Because of the age structure of the Peak population, a higher number of people live with dementia than would be expected for the total number of people in the area. Using the NHS England dementia prevalence calculator v3, the prevalence of dementia (of whole adult population) is 1.48% in N Derbyshire, 1.53% in Derbyshire Dales, 1.44% in N Staffordshire and 1.6% in E Cheshire, compared with 1.1% for England as a whole. It is impossible to give a prevalence figure for the over 65s in the Peak because of the organisational boundaries but a conservative estimate suggests around 1300 people aged over 65 currently live with dementia in The Peak area (22). Provision of care for older people and those with dementia is characterised by a low number of care homes, diminishing community hospital beds, a lack of comprehensive home care services and consequential reliance upon family carers, chronic care beds and/or earlier relocation to care home provision outside of locality (22, 23).

The cultural and organisational issues involved in ensuring dementia friendly services in rural communities are complex. The concepts of a dementia friendly community (and by extension services) are open to differing definitions. In the UK, the term dementia friendly is often associated with physical and social accessibility, political activism and a drive towards attributed status as being “dementia friendly” (24). Emergent literature, from human geographers, explores the more emotional and embodied experience of living with dementia (25). At the outset of the study, the study advisory group decided to dismiss the term dementia friendly in favour of “*familiar places and friendly faces*” to reflect the idea of “*everyday in everyway*” inclusion in a community regardless of dementia (quotes belong to group members). These phrases indicate the need for flexible localised approaches in which a sense of continuity and familiarity persist. We need a better understanding of how families affected by dementia go about their everyday lives and how they manage within their familiar places and spaces. The way forward may be greater use of generic services or everyday environments such as pubs, churches, hairdressers, allotments, supermarkets to provide flexible and effective support to these families.

Working towards dementia friendly rural communities is an important approach which can stimulate novel and localised models of service provision (26). Rather than focus on aged care services in isolation, Menec, advocates that communities as an entire system need to contribute (27). Whilst statutory services tend to be compartmentalised, the potential for consolidated resource sharing at local levels, may help to foster intergenerational social capital and growth in often isolated rural communities.

Significance of the research

This study will provide an understanding of the current status of dementia care services in The Peak and examine the perceptions of those living with dementia in some of its most rural locations. The study examines what matters most to these residents and the service providers to support dementia friendly communities. Understanding the nuances of managing the challenges associated with growing old with dementia in rural areas can help future decision making by providers to secure the best use of resources which meet the needs of this community. It is anticipated that the findings from this study will be transferable to other rural regions of the UK, especially those with similar demographic and geographic profiles.

This research builds on existing studies with people living with dementia and their family carers in rural areas (28-32). However, rather than simply obtain more data on inequalities there is a need to understand the complexities of the specific issues about dementia care. The study will concurrently explore the perspectives of all key stakeholders: those living with dementia, family caregivers and service providers. It will also compare the experiences and perceptions of care amongst two significantly different groups: those who are established residents and those who have retired to the area. A study like this has not been conducted before in England and it will make a contribution to the care of people with dementia and family caregivers in England but would also have considerable impact internationally.

Public Participant Involvement (PPI)

A core component of this study from inception of the ideas, bid writing to undertaking the work has included a study advisory group who are all rural dwelling family members affected by dementia. This includes individuals who consider themselves to have dementia, those who have cared for a spouse with dementia and those who are continuing to care for a loved one with dementia. None of the members had been involved in research before, in part because of their geographical location. These members of the group have changed over time and provide valuable suggestions and critical insights. The group meet on a regular basis for a walk and talk to discuss matters relevant to the study at a location of their choice. This paper has been reviewed by two members prior to submission.

Study Design

This is a mixed methods study located within the rural area of The Peak.

The study is comprised of two main components: ethnographic enquiry and Geospatial Information Science (GIS) analysis.

There are five main areas of enquiry:

1. Geospatial analysis of national and local data sets to a) identify and visualise the which impact upon the lives of people living with dementias in the Park such as proximity to resources, carers and services and b) devise a model of interaction to identify the correlations between users and providers.

2. An observational study of the ways in which people living with dementia and their carers manage their everyday lives in terms of navigating services to support their needs.

3. An interview study of the ways in which people living with dementia and their carers consider and decide about the ways in which they manage their everyday lives in relation to dementia friendly communities and services

4. An observational study of how service providers manage their resources and meet the needs of those living with dementia who reside in the Park.

5. An interview study of key providers to obtain their perspective of the ways in which they manage to meet the needs of people living with dementia

Philosophical Approach

This study adopts a social constructivist approach which draws on the work of Cultural historical Activity Theory (CHAT) as derived from the cultural-historical school of Russian psychology (33) This approach considers that the worlds in which we live are dynamically constructed by our histories, present and futures within environments by interactions with and between, via the use of artefacts, tools and people (34)). Activity systems applications have extended this approach further to consider the multifaceted nature of the complexity of being in a particular context and how these are attributed by individuals, groups and societies which all influence the ways in which decisions and actions are determined. These transactional, multiple level and highly contextualised interactions can be considered highly relevant in seeking to understand the complexities of rural communities and growing old in place. The inclusion of the historical importance attached to the context seems to lend itself to the particular life course of growing old in place, especially for those families affected by dementia, because of the importance attached to memories and emotions. This approach supports multi-disciplinary perspectives as it primary considers the ways in which people are shaped and shape the worlds in which they live; in short how they navigate their everyday lives.

Research design and methods

This study is comprised of two distinct parts: geospatial mapping and qualitative enquiry.

Firstly a geospatial mapping approach will be used to produce an interactive map which amalgamates area specific information such as geography, demographics, population clusters, accessible networks, facilities and service locations such as GPs, community hospitals, agency working, support groups and their respective geographical boundaries. This will provide a visual interactive map which can be interrogated by authorised users to model possible future outcomes. Drawing on previous human geography related studies we hypothesise that such representations of data can act as powerful seeds for changing dementia care services in rural areas by;

- geospatial uncertainty modelling; identifying where there are gaps in provision, possibly indicating unmet need (35)
- time-distance-weather- terrain-infrastructure analysis to identify underserved and potentially vulnerable areas, such as those requiring more than a 30 minute drive to GP surgery (36)
- service area analysis to support decisions about resource allocation and placement of clinics, mobile units such as memory clinics (37)
- identify areas of high vulnerability in dementia care where local health and care responses can be targeted (38)
- prompt grassroots action for change and support the case for improved services in local areas such as maintaining reliable bus services to access services (39)
- provide a baseline to advocate for change and measure future progress (40,41)
- promote collaborative working within and between organisations who share decision making in future service design and delivery at local levels (41)

Uniquely this study will also incorporate the more ethnographic data into the GIS mapping to produce a visual representation of the more personal accounts of living in rural and remote communities thus providing a personalised story of living with dementia.

The techniques for undertaking the geospatial uncertainty modelling, and development and deployment of an interactive web map application (as a spatial decision support system) for identification and plan for a dementia-friendlier areas will be supported by Dr Anahid Basiri within the Centre for Advanced Spatial Analysis, at University College London. Specific health geography expertise will be provided by Dr Mark Riley, University of Liverpool. Derbyshire County Council and Rural Action Derbyshire have agreed to host the interactive map and to support the updating of information via their informatics team. It is also anticipated that the map could also be available within the study dedicated website and a link provided on the Alzheimer's Society UK website. The depth of the publically available information will be anonymised with the intention that users can explore not only the findings but also obtain contemporaneous information about local resources which include accessibility information such as "real journey" times based on actual routes taken and the weather.

Secondly, the bulk of the study will use qualitative approaches to investigate the expectations and experiences of users *and* providers of services. Interviews will seek to meet the objectives of the study by establishing the connections between users and providers as a qualitative mapping of dementia care. Identification of potential provider participants will be by prospective sampling, using chain referential sampling (snowballing) (42) which will provide opportunities to identify services and groups which may be unknown to the more formalised providers. This technique will enable access to voluntary groups which are operating in dementia friendly ways but not formally recognised as supporting dementia care or identify themselves as operating as being dementia friendly.

Consent will be sought from all participants in accordance with the statutory UK National Health Research Ethics Committee guidance and the Good Clinical Practice and any other regulatory requirements that might be introduced during the course of the study. All participants will be provided with written consent. Whilst most participants will have the capacity to consent to take part in the study, some may not due to cognitive impairment such as advanced dementia. For participants who lack capacity, the researcher will approach and inform the identified family caregiver about the study. Carers who indicate that they are willing to act as a potential personal consultee will be given the opportunity to consider signing the declaration to act as a consultee in accordance with the approved procedure.

The user component will actively promote seeking the views of those living with dementia by inclusion in discussions with carers present to support. Specifically, enquiries will be made about the inter-connections between locality, expectations and access to dementia friendly services. Opportunistic conversations will be used with sensitivity to help understand perspectives of everyday life. Observations of everyday and seasonal activities such as walking, attending church, sheep shearing and shopping will be made with the families by the researcher as a naturalistic endeavour to support the participants in sharing their lives with ease, Talking Mats© or similar symbol based language techniques will be used to support communication if required (43).

This will include the use of a newly emergent tracking technique amongst up to 32 families living with dementia or memory difficulties. The participant tracking comprises of up to 4 interviews over 12-18 months to establish the realities of living with dementia in a rural location and the obstacles to access and using local services over time. This technique has been utilised and refined in 3 previous studies (44-46) by the applicant and shown to provide a powerful insights about continuing and fluctuating health and care needs amongst older people. The final contact with each family will be concluded by the giving of a thank you card to confirm the ending of the data collection period. Cards can provide tangible aide memoirs for families to discuss their participation in the study.

The provider component of the study will involve inviting key provider representatives to take part in a semi-structured interview, to explore perceptions about working in dementia care and the everyday factors which impact upon delivering high quality, relationship-centred care. This will include the examination of individual and organisational aspects of work and the work environment. These will be explored within a model of “healthy work” provided by the British Government Health and Safety Executive (47) and include participant reports of work demands, control and support, relationships, roles and organisational change. In addition dementia and rural specific issues related to working lives will be included in the framework. This will help to inform the future model requirements of the service providers in the context of rural dementia provision.

Figure 2 showing the Scaling the Peaks Study design by data sources, data generation, analysis and outputs.

Sample

The family dyad sample will include a family caregiver and a person who is considered to have dementia (n=32 dyads). A formal diagnosis of dementia will not be required in recognition of the decisions many families make not to seek a formal diagnosis. Families will be recruited by study information leaflets displayed in public places such as churches, libraries and cafes. The researcher will also promote the study at local agricultural shows and seasonal events. Word of mouth contacts will be sought via local dementia and older people related groups. No family participants will be recruited by health or social care professionals.

The inclusion criteria for the families are that they consider themselves to be living with dementia, are aged over 70 years, live in The Peak and have a regular caregiver (unpaid). The person living with dementia will be able to give consent to take part in the study or have a main caregiver who is willing to provide consultee advice if necessary. It is assumed that the majority of people will be cognitively capable to consent to take part in the study on an individual basis and sign their own consent form. Over time, it is possible that this cognitive ability to consent to take part in the study may change and so the researcher will ensure at all times with each participant that they understand the role of the researcher and that they are a study participant. The researcher is competent in ensuring that any signs of distress or withdrawal, such as body language, are responded to and that the wellbeing of every participant is attended to regardless of their individual capacity to consent. We selected 70 years as this is the age of eligibility for local older people services in the region. The consent process is outlined in the figure 3 provided below:

Family caregivers are eligible to participate if they provide care for at least 4 hours per week for the person with dementia. The definition of care will be self-defined by the caregiver. The caregiver will be aged over 18 years, able to consent and provide assent if required to take part in the study.

The exclusion criteria for families living with dementia will be if both members of the dyad are considered to have dementia and not able to consent for themselves to take part in the study, terminally ill, if they are moving out of area and/or they have severe communication difficulties such as severely hard of hearing.

The Provider sample will be recruited according to the requirements of their organisation; statutory providers require formal approvals and local site access permissions before any professionals can be recruited. Other providers, such as Third Sector, adhere to their own protocols for research studies, which are variable. Private organisations tend to allow local level decision making. Use of chain referential sampling will be used to enable “hidden” providers, especially those who do not regard themselves as dementia specific to be approached; examples would be cafes, mobile hairdressers and food producers. All providers will be given key written information about the study and the opportunity to consider and discuss prior to giving any consent.

The inclusion criteria for service provider staff, including voluntary organisations will be that they are employed within the statutory sector or provide services on behalf of a charitable/voluntary/private organisation towards older people in the Peak.

Methods of data collection

The study consists of three main components. All of these components will be undertaken over a data collection period of 24 months.

Component 1: Observations, semi-structured interviews with families by use of longitudinal approaches over a maximum of 18 months per family dyad.

Component 2: Observations, semi-structured interviews with key service providers by use of longitudinal approaches over a maximum of 12 months per site.

Component 3: Data gathering to combine multiple data sets to construct geospatial map of The Peak. This will include data collected from the interviews and observations to determine decision making in relation to time and place such as distance to GP services. Additionally publically available data such as public service locations, public transport networks, real-time climate data and topology will be incorporated into the GIS mapping process.

All interviews will follow the interview guide approved by the ethics committee, and piloted prior to data collection. The guides include general themed questions regarding the things that matter most to the participants. The COREQ supplementary form outlines the design of the interview components.

Analysis

Concurrent data analysis during the data collection will take place to enable refinement of the qualitative data collection in particular and enable organisational changes in the local configuration of services to be identified and (re)considered if necessary. The longitudinal design of the study will support the notion that living with dementia and the associated changes of need is a dynamic process which often follows a jagged trajectory.

Qualitative data will be analysed with the support of the Nvivo 11 software to organise and generate general categories, patterns and themes from the textual data, using a broad cultural historical activity theory (CHAT) approach (48). The observational and interview data will be analysed using an activity theory approach which aims to explore the transactive relationships between individual actions, material and social environments. CHAT has been used extensively in organisational studies and is closely aligned to actor-network theory. CHAT provides the framework for rich data, such as ethnographic data, to be analysed at various levels from miso to macro. This is achieved by use of three planes of sociocultural analysis; personal, interpersonal and community planes and the division of activities within these planes as bounded activities to support analysis. Analysis will proceed in parallel with data collection until no new themes are emerging. By associative mapping between the themes, explanations will be developed from the findings enabling theory generation, using an adaptation of the methods proposed by grounded theory (49). Within the qualitative software, NVivo 11, these bounded activities can be organised to support analysis which can explore the relationships within and between the three planes of analysis and the levels of activities. The use of these bounded activities which can then be utilised for use in visual mapping techniques such as GIS to enable the co-development of cross disciplinary research.

Quantitative data will be analysed using a distinctive GIS modelling approach by using combinations of compatible multiple data sets. This will include geographical data from national data sources such as the Ordnance Survey Mater maps, Google Earth, Office for National Statistics, National Travel Survey, and OpenStreetMap (OSM). Specific data related to the places the participating families access will also be considered by the construction of a dedicated database which will maintain the privacy of individual households by use of a radial place measure. Further details of this approach will be detailed during the dissemination phase of the study.

The spatial databases will be used to store and retrieve the data and GIS software and analysis will be customised to devise and model the ways in which participants navigate their social contact. This will be by a standard method utilising the open source ArcGIS software to construct a visual map of the region and as importantly support the analysis of multiple data sets to determine geo-statistical relationships, including associations, between the variables presented by the data (36).

It is expected that using emergent spatial data modelling that both qualitative and quantitative data can be combined to determine relationships with variables by ascribing a value system to each variable (36). This approach can help support the identification of the current ways in which participants and providers prioritise their needs and responses and so help in decision making by providers.

Outcomes

The study will provide understanding of rural communities, dementia friendly communities and living with dementia as a rural dweller. These understandings will also consider the views and practices of a range of providers to determine the services which are generally considered to match the needs of families living with dementia. This information will help to establish current and future provision.

Specifically the results from this study will be used to:

1. **Provide** spatial and qualitative evidence to support users and service providers to respond to the local needs of those living with dementia in rural communities. This evidence will be open sourced and kept updated to promote collaboration within communities.

2. **Identify** where there is scope for improvement by contributing towards theoretically sound and evidence based rural care delivery models through working in collaboration with local statutory health, social service, public health, third sector and private sector providers.

3. **Support** the development of a quality outcomes framework which will include the needs of service providers and service users such as meeting training needs, technologies to support remote information systems, dementia friendly provision which is responsive to the needs of users (38, 39, 40).

It is considered that the use of the map will support users in collaborative decision making based on evidence related to the combination of multiple factors. Previous decision making may have been prone to more urban centric thinking and possibly not reflective of members of the community living in remote areas of the Park. As such this method of data presentation may help support the future design and delivery of services based on a more sophisticated understanding of needs and so help to ensure the efficient and equitable distribution of services.

We consider that the use of cross-disciplinary research approaches offers future potential for solving many of the difficulties faced by commissioners and providers face in allocating resources in equitable ways. GIS mapping offers both the assimilation of and visual presentation of data in a highly concise format which can support robust decision making. Use of an interactive web map, which can be incorporated into any website will support transparency in decision making and also provide a dynamic map which can be updated to reflect the inevitable changes in service configurations.

Discussion

This mixed methods study will provide important information on the everyday lives of families living with dementia who wish to remain in their familiar rural places and spaces. It will further our understanding of what matters most to families living with dementia and help to consider the meanings of dementia friendly communities as dynamic and heterogeneous (50, 51). The study considers the links with time and changes in living with dementia as a reflection of the longitudinal nature of dementia and caregiving.

Previous studies have tended to focus on statutory service provision with little consideration of the plethora of other innovative instances where dementia friendly practices help to support the family to live well with dementia (50, 51). Rural communities can provide enriched understandings of the ways in which everyday lives are lived in prosperous ways which may not require a reliance of more established and traditional ways of dementia care provision. In summary, the study findings will not only provide an important basis for the design and delivery of future services in the Peak at a local level but may act as a template for other rural communities to consider ways of developing and sustaining local dementia friendly communities. In the current challenges facing dementia care evidenced based decisions making is a priority for all providers (52). The study will contribute towards the possible future design of national and international studies in the fields of rural dementia.

Contributors FM is the principle investigator and led the writing of the study protocol and the manuscript. AB wrote the GIS component of the study protocol. TD and JG contributed to the original study design and protocol. AB, MR, AG and SL developed their own work packages. Members of the Scaling the Peaks Study Advisory Group supported the development of the protocol and the ongoing study.

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Competing Interests None declared.

Data Sharing: No unpublished data available from the protocol.

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Legend

Figure 1 provides a visual map of the location of the national parks in England and Wales, including The Peak District.

Figure 2 showing the Scaling the Peaks Study design by data sources, data generation, analysis and outputs.

Figure 3 Flow diagram to show the consent process with the person with dementia and their carers to participate in the study

The COREQ supplementary form outlines the design of the interview components.

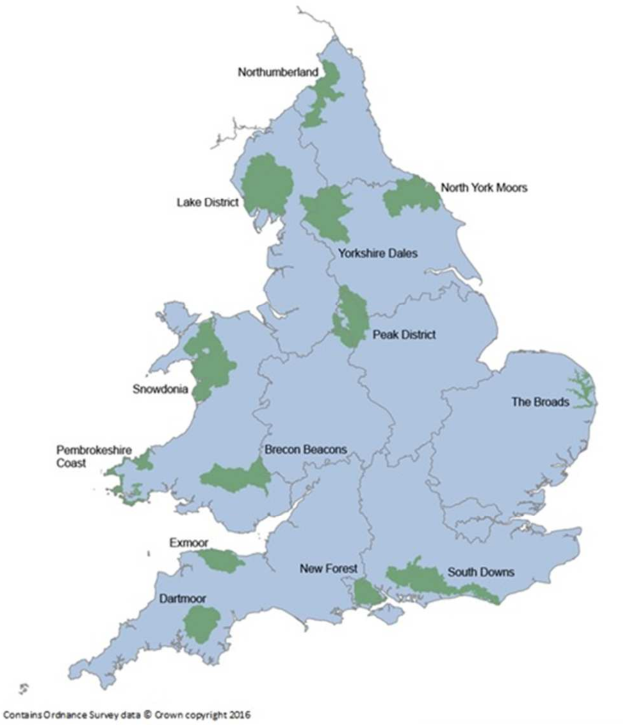


Figure 1

69x51mm (300 x 300 DPI)

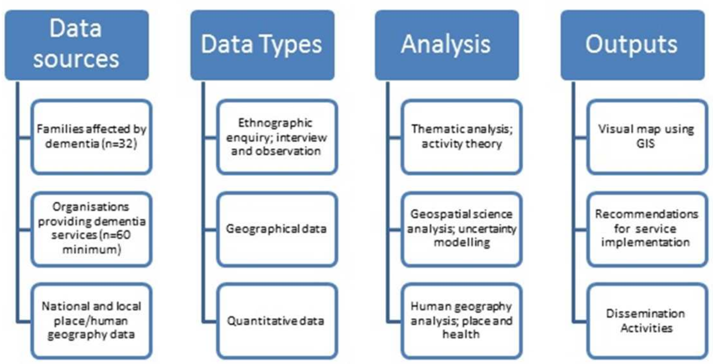
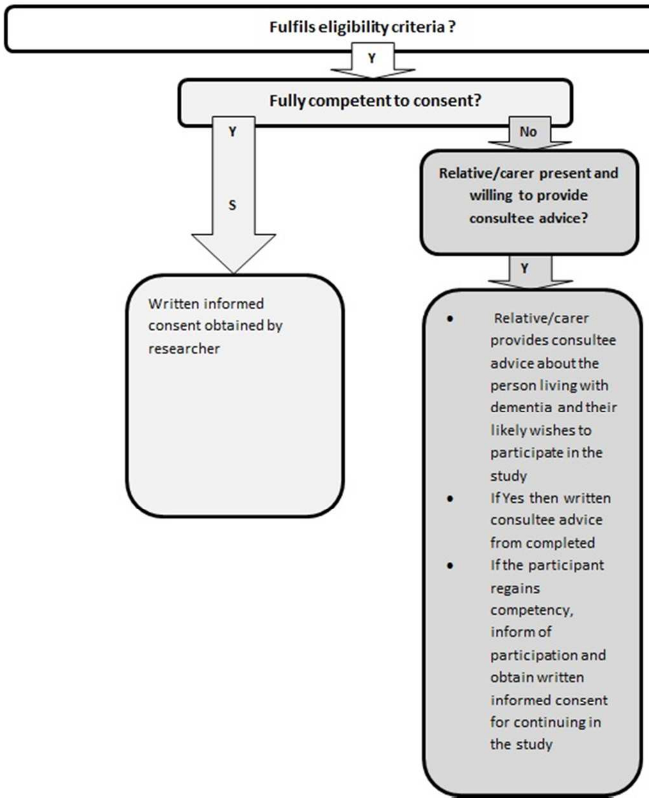

Data sources
Families affected by dementia (n=32)
Organisations providing dementia services (n=60 minimum)
National and local place/human geography data
Data Types
Ethnographic enquiry; interview and observation
Geographical data
Quantitative data
Analysis
Thematic analysis; activity theory
Geospatial science analysis; uncertainty modelling
Human geography analysis; place and health
Outputs
Visual map using GIS
Recommendations for service implementation
Dissemination Activities

Figure 2



Flow diagram to show the consent process with person with dementia and their carers to participate in the study.

Figure 3

69x60mm (300 x 300 DPI)

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:
Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

YOU MUST PROVIDE A RESPONSE FOR ALL ITEMS. ENTER N/A IF NOT APPLICABLE

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	Which author/s conducted the inter view or focus group?	FM
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	PhD
3. Occupation	What was their occupation at the time of the study?	FM; Senior Research Fellow
4. Gender	Was the researcher male or female?	Female
5. Experience and training	What experience or training did the researcher have?	Ethnographer, trained dementia research, 9 years' experience
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	No
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Personal goal, local rural resident, passionate about dementia care
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Personal interest in dementia care, improving care, sharing best practice
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Social constructivism Ethnography, Cultural activity theory (CHAT)

		visual mapping techniques
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	purposive, snowball
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Media, information leaflets and reply slips, publicity
12. Sample size	How many participants were in the study?	At least 32 family dyads and 60 providers
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Not available at present
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Family dyads; home, leisure Professional Providers; workplace
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	No
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Rural dwellers, dementia, caregivers, providers of care
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Family dyad questions co constructed with advisory group members. Pilot tested twice. Professional Provider; Semi-Structured interview schedule Pilot tested twice.
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	Family dyad; up to 3 times
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Audio recorded
20. Field notes	Were field notes made during and/or after the inter view or focus group?	Yes if necessary when not possible to audio record.
21. Duration	What was the duration of the inter views or focus group?	45mins
22. Data saturation	Was data saturation discussed?	N/A
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No but content could be

		discussed for clarification
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	Family dyad coding by FM Professionals coding by FM and AG
25. Description of the coding tree	Did authors provide a description of the coding tree?	N/A
26. Derivation of themes	Were themes identified in advance or derived from the data?	Themes to be derived from data
27. Software	What software, if applicable, was used to manage the data?	NVivo 11
28. Participant checking	Did participants provide feedback on the findings?	N/A at this stage.
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	N/A at this stage.
30. Data and findings consistent	Was there consistency between the data presented and the findings?	N/A at this stage.
31. Clarity of major themes	Were major themes clearly presented in the findings?	N/A at this stage.
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	N/A at this stage.

Once you have completed this checklist, please save a copy and upload it as part of your submission. When requested to do so as part of the upload process, please select the file type: *Checklist*. You will NOT be able to proceed with submission unless the checklist has been uploaded. Please DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.