Meeting the needs of people with long-term neurological conditions within rural communities in England

Abstract

Nineteen percent of people in England live in rural areas (LGA and PHE, 2017). Compared to urban populations, the rural population is older, and faces greater difficulties in accessing medical services. At the same time, healthcare teams in rural areas face particular challenges in recruiting and retaining staff, travelling between patients, and keeping specialised knowledge up-to-date. Drawing upon a recent health needs assessment for people living with long-term neurological conditions in a rural English county, and upon a broader review of the literature, this paper considers the challenges of rurality, and discusses potential solutions. Technological and community-based responses have often been suggested as responses to challenges of rurality. However, there is likely to be a need for up-front investment of resources and careful consideration of individual and community needs before these solutions can be applied to rural neurological care.

Keywords: Rural, neurological, community, access to services, professionals, barriers, healthcare

Background

Nineteen percent of the population of England live in rural areas (LGA and PHE, 2017). Compared to urban populations, rural residents are typically older, and have

poorer access to healthcare services (Butow et al., 2012; Brundisini et al., 2013; Todd et al., 2014; LGA and PHE, 2017). At present, however, there is limited research exploring healthcare practitioners' experiences of providing services in rural communities within the UK. Recent National Health Service (NHS) reforms have emphasised the importance of 'place' and localism, but have tended not to directly address the potential challenges of implementing localism within sparsely populated rural areas and areas that are remote from public services. For example, the NHS long-term plan, published in January 2019, encourages a shift away from acute hospitals and towards community care (NHS England, 2019). However, the sole reference to rural healthcare within the plan relates to small acute hospitals, with no discussion of rural challenges within community services.

Rurality can be a challenging concept to define, and definitions vary between countries, even within the UK. In England, a settlement with fewer than 10,000 residents is considered rural, whereas the threshold for Scotland is 3,000 (Office for National Statistics, 2011; Scottish Government, 2012). International studies of rural health often focus upon the needs of indigenous minority populations and upon communities that are significantly more remote than those typically found within the UK. While official definitions of rurality focus upon population density, this hides a significant amount of variation between rural communities. For example, a commuter village in the South-East of England and a former mining village in the North may both be classified as rural based on population density, but that does not necessarily mean they have similar needs, given the different economic and demographic characteristics (Rousseau, 1995).

Population sparsity affects the provision of health services and access to these services. There are debates – but no clear consensus - about the optimum

population to be served by healthcare commissioning bodies, and the trade-offs between factors such as cost-efficiency, expertise, and local responsiveness (Greaves et al., 2012). Ultimately, however, health services, especially those addressing less common health needs or requiring specialised skills or equipment, are likely to have to cover a certain population size to be viable. Health services in sparsely-populated rural areas will therefore usually cover a larger geographic area in order to provide services for the same number of users. As a consequence, people living in rural areas are likely to face increased travel times, with fewer local specialised services (Butow et al., 2012; Brundisini et al., 2013; Ford et al., 2016). Rural residents are also less likely to live within walking distance of community health services such as general practice or community pharmacies (Todd et al., 2014; 2015). The problem of extended travel distances for healthcare may be further exacerbated by low capacity roads, poor public transport and geographic barriers such as rivers and coastline (Jordan et al., 2004). However, Jordan et. al. also report that poor access to services is not solely confined to rural areas: coastal towns may also face long travel distances to secondary health services.

Social and cultural aspects of rural communities may also affect health care utilisation. It has sometimes been suggested that stoicism and strong community ties may mean rural populations are less likely to seek healthcare (Wenger, 2001; Farmer et al., 2006; Butow et al., 2012; Cowling et al., 2013) chosing instead to self-care, or be cared for by family members. However, this could also result in reduced health seeking behaviour where care is really needed. In addition, individual access to community support within a rural area will vary. For example, incomers to a rural community may have weaker community ties and be less prepared to cope with poor

access to health services compared to longer-term residents (Stockdale and MacLeod, 2013).

Gaining a clear overview of positive and negative associations between rurality and health is potentially limited by the disparity of definitions, and the interactions between rurality and other factors relevant to health such as socioeconomic status, housing quality and population demographics (DEFRA, n.d.). For example, a reported association between colorectal cancer survivorship and rural residency disappears once socio-economic factors are taken into account (Dejardin et al., 2014). However, financially excluded individuals living in an affluent rural community may face a double disadvantage of social deprivation and poor access to services, masked by the overall affluence of the area (DEFRA, n.d.). Standard measures of local area deprivation may fail to recognise rural deprivation, both because it may occur in very small pockets, and because it may have qualitatively different features to deprivation found in urban areas (Fecht et. al, 2018). Healthcare professionals in rural areas are therefore likely to be working with populations who face reduced access to care, and who may be demographically distinct from urban populations. This may be particularly challenging when working with people living with neurological conditions, who may need ongoing access to specialised advice and support in managing their condition.

Challenges for rural professionals supporting people with neurological conditions – data from a local health needs assessment

To compound the challenges of rural health care access, rural areas also have greater difficulty in attracting and retaining health professionals (Buykx et al., 2010; Kroezen et al., 2015). An older demographic, poor transport links, outward migration

of skilled young adults, and in some cases, reduced attractiveness of rural areas to professionals may all contribute to recruitment difficulties (Green et al., 2018). Interventions have attempted to address a range of issues, including access to childcare and housing, access to mentoring and professional development, adequate remuneration and stress reduction programmes, suggesting these factors are perceived to be areas of dissatisfaction for rural healthcare workers (Buykx et al., 2010; Kroezen et al., 2015; Green et al., 2018). However, the evidence of the effectiveness of such interventions is mixed, suggesting no single factor is decisive.

The authors of this paper conducted a health needs assessment focusing upon people living with neurological conditions in a large rural English county (The full study report is available at: *Reference removed to preserve peer review process*). Neurological conditions include a wide range of health needs involving damage to brain, spinal column or peripheral nerves. It is estimated that between 4 and 8 million people in England are affected by neurological conditions, with the divergent estimates depending on whether dementia, stroke and headaches are included, and they account for a high proportion of GP visits and hospital appointments (Thomas et al., 2010; National Audit Office, 2015).

The needs assessment was commissioned by the local authority. Ethical approval was granted by the University Research Ethics Committee. The project aimed to synthesise evidence upon neurological need and service provision within the county, incorporating a literature review, a review of local health data, and questionnaires. Online and hard-copy questionnaires were distributed via local community and charity networks, receiving responses from 84 respondents: 41 people living with neurological conditions, 19 carers, 11 voluntary sector organisations, and 13 health professionals. These responses were thematically analysed. One section of the

questionnaire asked participants to identify challenges faced by people living with neurological conditions in the county. We found strong levels of agreement between all groups on the responses to this section of the questionnaire, with the two key themes being poor access to specialised services (both in terms of waiting times and travel distances), and lack of knowledge about neurological needs within local health and social care services.

Like patients and carers, health care professionals were frustrated by long waiting lists for services, delays in follow up communication and poor access to specialised advice and support. Specialised services were primarily provided out-of-area, and participants reports that community health services were not always knowledgeable about neurological conditions., As a result, professionals reported instances of patients either not having access to services, or being referred to services that were not appropriate for their needs. For example, both professionals and patients reported referrals to community mental health services sometimes being refused or unsuitable in nature, because services did not always have experience in adapting their provision to meet the needs of people with communication or cognitive difficulties. Community professionals who provided outreach services within people's homes reported long travel distances and difficulty accessing support and training to help them work with patients with complex needs. Similarly, carers reported poor access to support services, and difficulty in accessing healthcare for their relative during a crisis. Voluntary sector services felt that the county had fewer specialised services than other areas of the country. The rurality of the area underpinned many of these problems of poor access to services that met patient needs. The health needs assessment therefore highlighted a need to address specific challenges of rurality in planning and delivering neurological care.

Responses to rurality

Technology has been widely promoted as a solution to some issues of rural and remote care. For example technology has been suggested to have value with regard to remote monitoring of biological data such as blood pressure; providing video appointments for patients; and allowing local primary care providers to access specialised knowledge via teleconferencing (Banbury et al., 2014; Marcin et al., 2015). E-learning could potentially help address the issue of professionals having difficulty accessing training. However, many of the most rural UK communities still lack access to high-speed broadband (Williams et al., 2016), potentially limiting the value of technology as a means of providing rural healthcare. In addition, some services for people with neurological conditions, such as rehabilitation and occupational therapy, may not be suitable for remote provisions. Assistive technologies are not always appropriately tailored for the needs of older service users with disabilities and as a result may not be utilised effectively (Greenhalgh et al., 2015). While technology may help to ameliorate some difficulties of rural health provision, it requires careful tailoring to the needs of the individual.

Another possible response to challenges of rurality and remoteness is to develop expertise in local services, reducing the need to travel for care. Recent guidance for commissioners of UK neurological services emphasises building capacity in primary care and developing community resources such as support groups and information resources in order to assist people with managing their condition (Cader et al., 2016). However, within responses to our questionnaires and within the wider literature, informal carers and health professionals already report feeling under significant strain and variable levels of local support and development (Carers UK and Age UK, 2015; Green et al., 2018). In this context, training rural community

practitioners and carers to deliver more specialised care themselves could potentially increase rather than reduce pressure unless accompanied by investment of resources, and clear pathways to escalate in a crisis. Third sector provision may also be less viable in rural areas, where the number of people affected by a health condition may not be large enough to support a voluntary organisation within an accessible travelling distance. Kenny et al. (2015) note that while community participation is often suggested to be a mechanism for improving rural healthcare, the evidence base is limited, and proposals often fail to address a number of practical challenges, including sustainability, governance and ensuring that marginalised populations within rural localities are included and supported. Within the UK, local authorities and Councils for Voluntary Services have historically provided training, advice and support for the voluntary sector, but this support was reduced in many areas due to the financial downturn and the associated reduction in public spending (Bhati and Heywood, 2013). Rural charities, which often cover a smaller population, and face higher transport costs, may be disproportionately affected by reductions in funding and support.

Conclusions

This paper reports upon a Health Needs Assessment including a literature review, data review and surveys of people living with neurological conditions, carers and healthcare practitioners within a rural county. Our findings emphasised rurality as an important component of the challenges in accessing neurological care in the county. Patients, carers, the voluntary sector and professionals all reported that specialised neurological services were often difficult to access, in part due to long travel times, as well as other factors such as long waiting lists. Community and primary care services often lacked understanding of neurological needs. As a result, people living

with neurological conditions and their carers often did not have prompt access to care that met their needs. Health professionals also reported frustrations at the challenges of providing good quality care in rural areas. Given that the challenges of delivering and accessing healthcare in a rural environments were a source of similar frustrations across all groups, this points to the potential for cross-cutting solutions. For example, clear pathways for rural health professionals to develop specialised skills and expertise could both improve staff recruitment and retention and improve patient access to care.

These findings are specific to neurological health needs within one English county, and may not be directly applicable to other areas or needs. Nonetheless, they highlight a potential need for further attention to rural and remote communities within the ongoing context of health and social care improvement and place based commissioning within the NHS. The NHS England (2019) long term plan emphasises the importance of localism in commissioning, but this poses a particular challenge for uncommon and complex health needs in rural areas. Rural service users may be interacting with both specialised and community services, and specialised services are likely to be some distance from their home and potentially outside local health area boundaries. In this context, there is a particular need for liaison between local community services and ‘out-of-area’ services in order to ensure that people living with neurological conditions and their carers experience joined up care pathways and have access to services that meet their needs.

Commonly discussed solutions to issues of rurality, such as technology, use of the voluntary sector and developing skills within generalist provision have potential, but require tailoring to the specific needs of individuals, and to the particular context of local rural communities. These solutions may also face barriers related to rurality,

such as poor online connectivity and difficulties in accessing training and support. As a consequence, there may be a need for investment in rural infrastructure, training and resources before health service reform can take place. Further research into rural and remote health services could beneficially explore the contextual features of rurality and remoteness that may affect health service provision; the implications of rurality for service users with specific needs; and effective mechanisms for developing solutions in conjunction with local communities and healthcare providers.

Key points

Rural communities face particular challenges in accessing good quality health and social care, but these challenges are under-researched, particularly when it comes to specific needs such as patients living with neurological conditions.

Patients, carers and staff report similar problems with the provision of rural neurological services, including long waiting lists, substantial travel times, and lack of appropriate knowledge in community services.

Increasing use of technology, upskilling of the general workforce and smarter use of community and voluntary services are potential responses to challenges of rurality, but require investment and tailoring to individual and community needs.

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