ORIGINAL RESEARCH

# What older people want: evidence from a study of remote Scottish communities

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A B S T R A C T

**Introduction:**  The growing proportions of older people in rural areas have implications for the provision of health and social care services. Older people are more likely to have complex health needs compared with other age groups, requiring a full range of primary, community and acute hospital services. The provision of services to older people in rural areas is challenged by diseconomies of scale, travel costs and difficulties in attracting staff. Policy-makers are requested to include the 'voice' of older people to help provide services that match needs and context. In spite of this, what older people want from health and social care services is a neglected area of investigation. The reported study was conducted in 2005/2006 as part of a European Union Northern Periphery Programme (EU NPP) project called Our Life as Elderly. Its aims were to explore the views of those aged 55 years and over and living in remote communities about current and future health and social care service provision for older people. Evidence was to be collected that could inform policy-makers about changing or improving service delivery. This article summarises emergent themes and considers their implications.

**Methods:**  The study selected two small remote mainland Scottish Highland communities for in-depth case study. Semi-structured interviews (*n* = 23), 10 'informal conversations' and 4 focus groups were held with community members aged 55 years and over, in order to provide different types of qualitative data and 'layers' of data to allow reflection. Data analysis was assisted by computerised data management software and performed using the 'framework analysis' approach.

**Results:** Participants did not consider themselves 'old' and expressed the need for independence in older age to be supported by services. Several aspects of services that were undergoing change or restructuring were identified, including arrangements for home care services, meals provision and technological support. Participants valued elements of the traditional model of care they had been receiving: these were local, personal emphasis and continuity. They were suspicious of new arrangements perceived to emphasise technical efficiency. Health and care services were described as inter-linked with other aspects of rural living, including transport and housing (which might have to be relinquished to pay for care). Proximity to family was desired for social and domestic support only; health and related support should be from generic service providers. Community members were involved in reciprocal help-giving of many types.

**Conclusion:** The findings compare with results of other studies of older rural people internationally, and generic 'principles' of service derived could guide restructuring. There may be systemic challenges to empowering older people's 'voice' in designing sustainable rural services that stem from society's views of older people, attitudes of communities to collective roles and responsibilities, and the fragmented ways that services are sometimes provided.

**Key words:** change, citizen involvement, health policy, older people, rural health care, service restructuring.

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# Introduction

*Economic and social restructuring has altered forever the circumstances and prospects of the majority of people growing old in communities.[1]*

*The localities where older people live are of enormous importance. As they get frailer, their lives are increasingly affected by, and bounded within, their immediate physical and social environments.[2]*

The growing proportions of older people in the population are acknowledged by policy to have implications for providing health and social care services[3]. The challenge is greater for rural areas which have higher percentages of older people compared with urban areas[4], and where the provision of services is more costly[5]. Older people are substantial consumers of health and social care services; in Scotland, the 15% of the population who were aged over 65 years in 2002 consumed 40% of health and social care spending[6]. Leeson has highlighted that, in the UK in comparison with other age groups, spending on older age groups has actually decreased over time as more care moved into the community[7].

As a group, older people have complex health needs, requiring a range of primary, community and acute hospital services[8]. Philip suggests that the greatest challenge facing health and social care systems is to get services right for older people[9]. There have been numerous calls to involve older people in planning their service provision[10], particularly as disparities between what they desire and what service providers think they desire have been noted[11]. However, both asking older people what they want and the study of best practice in involving older people still seem neglected areas of study[12].

In recent years considerable policy[8,13] and growing research attention has turned to older people, in the face of the demographic challenge, but there is still relatively little attention given to the experience of ageing in rural areas. This is surprising given that extant evidence suggests there may be distinct features of rural disadvantage. Isolation may be experienced, particularly by in-migrants who are distanced from families and social networks[4]. Access to public transport is problematic[14], exacerbating difficulties in accessing services that include hospitals, pharmacies and banks[9]. Access to social care is reported as difficult due to few younger people to work or volunteer[15-17]. Conversely,

rural advantages have been found. Support networks, family support and a culture of reciprocity are reported[4,18,19].

A feature of older age is adaptation to changes in health and mobility[2]. Simultaneously expecting older people to adapt to structural change in service provision may be unfair[1]. Milligan notes that neo-liberal social policy has resulted in a push to mixed providers and a focus on care at home and in the community[20]. These changes may be difficult to effect in rural areas due to a lack of private providers and staff generally. Free personal and nursing care (FPNC) is currently available for everyone in Scotland aged 65 years and over, whether at home, in hospital or in a care home. However, this policy is judged to be unsustainable due to the huge financial burden it represents, the gap in funding available to fairly implement the policy and the fact that basic services for older people (eg domestic help and shopping) are being restricted to concentrate on financing FPNC[21].

The present study was conducted as part of a European Union Northern Periphery Programme (EU NPP) project called Our Life as Elderly (OLE). The EU NPP is specifically focused on funding projects that address issues shared by countries in the north of Europe, including harsh climate, sparse population, transport difficulties and uneven demography. The project required partner countries including Sweden, Norway, the Faroe Islands and Finland to find out what older people thought of their health and social care services now, and what they would like to see in the future. The intention was to provide information for policy-makers to help shape future services for older people. Study and commentary on this topic, as with many issues pertaining to the provision of rural health services, converges from geography, rural sociology, health services research and policy. While this article is potentially relevant across these disciplines, the goal is to influence the development of appropriate policy and service provision.

The Scottish aspect of the project involved interviews, 'informal conversations' and focus groups in two remote communities in the Highland region. The study was conducted in 2005/2006 and involved people aged 55 years and over. In this article the findings are presented and their implications for service provision reflected on with the aim of encouraging a 'voice' for older people in local planning.

# Methods

Desiring to be completely open to respondents' views and to understand the world from the subjects' perspective[22], an exploratory design was adopted. Two small remote mainland Scottish Highland communities were selected for in-depth study using three qualitative data collection methods. Ethical committee and NHS R&D approval was gained for the study.

## *Sample and settings*

The study took place in the Scottish Highland region because this area is within the European Union Northern Periphery Programme area. The Highlands covers 39 050 km$^2$ and has a population of 373 000, making the area one of the most sparsely populated within the European Union. Data were collected from two 'very remote' communities (classified as settlements of less than 3000 people and with a drive time of over 60 min to a settlement of 10 000 or more)[23]. Case study site 1 had a population of approximately 400 people and case study site 2 had approximately 900 inhabitants. Both settlements are coastal. The area is characterised by dispersed dwellings and crofting townships. Both study sites have a high proportion of older people. In 2005, 29.9% and 24% of the population were aged over 65 years for sites 1 and 2, respectively, compared with Highland and UK proportions of 16.7% and 16%, respectively. Both are within 70 miles of a rural district general hospital and have day-care facilities and limited respite-care facilities. Both study sites have a general practice/health centre located within the community and GPs who provide out-of-hours cover. Site 2 has nursing home facilities. These communities were purposively chosen to represent 'extreme cases' that it was anticipated would reveal attitudes to service provision and behaviours at the periphery of the mainland. They also had

Highland Community Care Forum (HCCF) workers assigned and these workers recruited study participants.

The HCCF workers recruited participants by approaching people in communities and obtaining initial consent. A sample was requested that included men and women aged 55 years and over; of varied socio-economic background, who had involvement in community activities, and whose lengths of time locally resident ranged from life-long to recent in-migration. For interviews, once initial consent was obtained by the HCCF worker, a researcher contacted the subject, obtained further verbal consent and arranged an interview time. Written, informed consent was obtained prior to interviews. HCCF workers asked a further sample of 10 individuals to be involved in an 'informal conversation'. Researchers specifically asked HCCF workers to try to include people who might normally be 'missed out' or would not put themselves forward to take part in research. This aspect of the study was intended to provide more information on the topics from the perspective of 'one local person to another' and from those who might be reticent about formal interview. Finally, groups of people at each settlement were invited to attend a focus group.

Focus group participants consisted of those who had already participated ($n = 9$) and new participants ($n = 24$; invited through HCCF). The focus groups presented emergent themes from the interviews and informal conversations and asked participants to comment on these. This aspect of the study allowed assessment of whether themes deemed important by the communities had been arrived at, and further discussion of these.

## Data collection

Semi-structured face-to-face interviews were held with 11 individuals aged 55–64 years and 12 individuals aged 65 years and over (age range 55–87 years; median age 64 years). Numbers of interviews were approximately evenly split between communities.

A researcher (GK) conducted interviews with individuals that lasted approximately 1 hour, took place in participants' homes and were recorded, with consent. An interview topic guide prompted the interviewer to ask about: experiences of current health and social care services; desired attributes of future services; the role of family and the community in supporting older people; and the role of technology. Additional elements of the topic guide were developed following pilot interviews and four early interviews. These included vignettes to assist with focusing on aspects of service delivery (eg new technology); use of data on morbidity of older people to illustrate that most people would encounter chronic illness in later life; a change from asking 'Do you provide informal help?' to 'What do you do in a normal week?' because participants found it difficult to identify when they were helping others. Demographic data were recorded.

The informal conversations held in each community by the HCCF workers followed guidelines given by researchers and used the same topic guide. Formal written consent was gained. These were not audio-recorded but notes written by HCCF workers following the conversations were given to the researchers.

Two focus groups were held in each community (a total of four; with four, five, six and 18 participants). Author GK and the HCCF workers facilitated the groups. Consent was gained and focus groups recorded.

Using three data collection methods, and at different stages, aided deeper penetration and understanding of the issues as viewed by different participants. Re-visiting the issues in the focus groups allowed reflexivity for researchers and community members. For community members, it was pertinent to discover that both communities raised similar issues.

## Analysis

All data, including recordings and notes, were transcribed verbatim. 'Framework analysis' – a five-stage process,

involving familiarisation with data, development of a coding schedule, data coding, description of main themes, linking themes and developing explanations of their relationships to each other – was employed[24]. Codes were entered into the qualitative data management program NU*DIST QRS International; Melbourne, VIC, Australia). Once codes were applied, data were grouped into categories and thematic analysis was performed, identifying similar and divergent perspectives. Three researchers independently analysed samples of the data to check inter-coder reliability. Data were anonymised to protect participants' identities. In this article provides excerpts from interviews, informal conversations and focus groups to illustrate some of the points.

# Results

## Study participants

The total of 23 participants represented an approximately even mix of men and women. Demographic data were collected at interview and, of the interviewees, nine lived alone and 14 lived with others; 13 had moved into the area in the last 10 years and 10 were long-term locals. Five interviewees were in receipt of 'formal' care, either council provided or purchased privately locally using the 'direct payment' scheme. Several provided informal care for neighbours or relatives.

## (Not) being old

A primary issue for the study was asking people about 'being old'. Some people were concerned that they had been asked to participate in a study about being older. Even the oldest participants did not view themselves as being old:

> I kept thinking about some of the old buddies I know and I thought 'Gosh, if they took ill at night …I don't consider I'm an old buddy living alone. (Female, 82 years, lives alone)

Reluctance to use statutory or voluntary services was a common theme; because participants thought they 'were not old enough', 'don't want charity' or did not want to 'spend time with a lot of old people'.

When asked about needs for care, most participants said it was difficult to imagine 'being old' and needing help to do basic things. Most said they wanted to 'just drop dead!' After several people said this at pilot and initial interviews, data were obtained from the local NHS Board about what happened to people in later life to show that most people required care of varying sorts. While this helped to focus participants on services and care provision, responses to questions tended to draw on their own experiences; for example what had happened when their parents' health declined.

Participants emphasised the importance of maintaining their independence and suggested a key principle for services should be supporting independent living:

> …it might take me half an hour to put the washing in the machine, there's always that, you know, but it's a challenge. I can still do it, I still want to do it. If they [service providers] get someone else to do it, what the hell am I going to do? Sit on my backside watching the news, listening to the radio, reading a book… (Male, 59 years)

There were mixed feelings about what should happen when people could no longer be maintained at home. Some would consider moving into residential care but emphasised it needed to be in the local community or they would lose contact with friends. Others were adamant that they would move only as a last resort. People commented on the facilities that they knew about and did not mention a need to develop new kinds of facilities, such as supported accommodation.

## *Services in transition*

Service areas that might be predicted to be problematic for remote areas were reported to be good; including access to ambulance services, support for carers and facilities for residential care. Several services that were in a state of transition or had recently changed were discussed and new arrangements often compared unfavourably with previous arrangements.

Participants were positive about local GPs and nurses who were regarded as 'locals'. As such, they, their practices and their times and places of availability were known. The aspect of being 'local' was emphasised as important as participants believed that knowing individuals, their family and their context contributed to good care. (This also pertained if local people were acting as formal or informal carers). Local GPs were viewed positively because they had opted out of NHS 24 and out-of-hours co-operatives for unscheduled care, choosing instead to be the first line of contact for local people. The NHS 24 Helpline was viewed with suspicion:

> *They* [GPs] *still come out at night, none of this NHS 24 stuff. People here try not to bother the doctor, they only phone if it's urgent. Then they want to speak to someone who knows about them and their medical history.* (Informal conversation, woman, mid-70s).

Arrangements for home-care services had recently changed and there was confusion about who should be providing home care and its costs. Some people had access to 'direct payments' from the local authority. This meant they could purchase care themselves, either from local authority providers or privately. Those purchasing care privately thought this was cheaper, but it could affect local authority provision if several people withdrew because the hours for staff would be few and irregular, making it difficult to recruit staff.

Who should provide care was divided between local authority social services (personal care) and health services (nursing care). Several participants stated that there should be one service provider from a health background to provide all the care that might be needed. Fragmentation of care was a fear, anticipated to cause confusion for the recipient and poorer quality care, due to lack of continuity. Provision of 'intimate' care by local social services carers was considered inappropriate because these people were perceived to lack qualifications and appropriate professional status.

'Meals-on-wheels' (the delivery of meals to people who find it difficult to prepare a meal at home) was another service that had recently changed. This had moved from being a locally cooked and supplied service to one that was outsourced to provide mass-produced frozen, microwaveable meals. Many people thought this epitomised an impersonal approach to service provision and a lack of appreciation that 'meals-on-wheels' was about more than food, as it facilitated social interaction and gave people a sense of community support and belonging.

Technology was perceived to be 'coming' and the researchers wanted to gauge opinions. To do this a vignette was used that discussed home monitoring devices as well as the use of telemedicine at GPs' surgeries. The vignette was used because, in early interviews, participants found it difficult to comment on the abstract idea of technology. Perhaps surprisingly, most participants were supportive of, or accepted the inevitability of, technological support of various types if it would help maintain people at home. Their reservation was that it would remove the personal aspects of care and, as with 'meals on wheels', they emphasised that the social dimension of interaction with health and care professionals was as important as the 'technical' intervention provided.

## *Interconnections*

As with other issues, participants did not strictly focus on health and social care when asked about these services now and in the future. Their discussion quickly moved to issues that they perceived to be intrinsically interconnected. Transport was a key issue. Most thought that living in a

remote area meant accepting an element of personal responsibility in accessing services; for example it was likely to be quicker to drive to hospital rather than calling an ambulance. However for those who could no longer drive, there were mobility problems due to a lack of public transport and implications for community support:

*Contributor 1: It's all very well the government giving out free bus passes, but where are the buses for us to use them on?!" If it weren't for the community spirit in this area a lot of people wouldn't survive.*

*Contributor 2: People look out for one another. You won't be stuck if you need to go somewhere.* (Focus group)

Similarly, consideration of paying for high levels of care and moving from home elicited discussion of housing in remote areas. Several participants were concerned that they would have to sell their houses, but homes in remote Scottish villages are in short supply and they thought it important to keep houses 'in the family'. They did not want their homes sold to incomers for holiday homes. This fear was discussed as a reason for not seeking help from statutory authorities.

### Support networks

Policy seeks 'active ageing'[13] in 'resilient communities'[25]. Simultaneously, remote communities have high proportions of older people and service providers experience difficulties recruiting to care posts. How should older people continue to live in remote communities? To consider this question, we were particularly interested to explore participants' support networks.

No-one expected their children to look after them in their old age, but they thought having family living close by would help older people to stay at home. The role of family was to help, domestically and socially, but not to provide care for physical or intimate needs:

*I would cramp their style probably. I don't know if they'd want me! My eldest daughter keeps on saying 'I'll have to buy a house, mother, with a granny flat'. I says, 'I don't know who the granny's going to be!'* (Female, 63 years)

If they could not live independently, they would have to live in a residential-care home. Participants wanted to avoid being a 'burden' to their children and reflected on their own experience of caring for their own parents or elderly relatives:

*Having experienced living with my father-in-law…because I really wouldn't want to do that to my children. I don't know what it is, elderly people have become very selfish and self centred and orientated to routine and food and me, me, that's what I felt my father-in-law did and whether that…well, you do see it in older people.* (Female, 64 years)

While feeling they should not be a burden, participants said there was a loss to the social fabric of communities when different generations lived at a distance and that it would be beneficial if families lived more closely together.

Participants were asked about how they helped others in their communities. When asked this question initially, most said they did not provide much help; however, when asked how they 'filled their week', it was found that most contributed to their community, some substantially. For example, one woman provided daily childcare for her neighbour, nursing care to her friend's mother, cooked lunch for an older people's group, spent one day a week helping at a local care home, cooked and baked for activities at the village hall, organised newspaper swaps, conducted fundraising for the community, as well as having a part-time paid job at the general practice. Men spoke about helping each other with crofting tasks like sheep dipping, lambing and peat cutting. These activities were described as 'declining', with fewer villagers crofting and younger men working elsewhere, for example in the offshore oil industry. Some of the men were involved in bowling and sports clubs

and the church. In one community the men cook the annual Christmas dinner for the older people.

Organised voluntary initiatives were thriving, including lunch clubs, a community car scheme, a clothes washing service and social groups for older people. Community members 'kept an eye' on each other. They looked to see if neighbours' house lights went on and off at 'normal' times. Some said house lights were used as communication between houses to signal that things were alright. Participants regarded their help-giving as part of community life. Concern was expressed about whether people would continue to support each other in these ways in the future:

> *Three people do not have family living in* [village] *because when their children grew up, they either went away to university and did not return, or they left the area to find work. This is something that the group are alarmed about. They are concerned about* [village] *becoming an 'ageing population' and they wonder who is going to look after all the 'older people' in the future.* (Focus group)

# Discussion

This study found that older people living in the remote communities rejected the notion of 'being old' and expressed the desire to remain independent. In a situation of service restructuring, they valued local, personal aspects and were suspicious of arrangements they perceived emphasised technical efficiency. Health and care services were described as linked with other aspects of rural living, including transport and housing. Social support networks are key to maintaining older people's quality of life as part of a community. In this study, participants delineated the boundaries of the family support it was fair to expect. They were mostly active in helping others in their community but feared community support networks might be unsustainable.

The study considered only two remote communities, both of which are currently well served by local health professionals and have access to local care facilities. This is not a universal situation in Scotland and the findings are therefore limited because they do not report the thoughts of residents in communities with differing service accessibility. Small numbers of older residents were involved and it is possible that these were more prominent residents, due to our method of sampling using local workers. We did not include older people living in urban settings and therefore cannot comment on contrasts or similarities. Some aspects are likely to be unique, such the fear of losing ancestral cottages in Highland villages sought as holiday destinations. The study's strengths lie in the layers of data collection used. Some participants were involved in two data collection rounds, allowing them time for reflection. Themes were verified at focus groups. While the approach was open (thereby potentially attracting an incoherent range of responses), emergent themes were surprisingly focused, similar in both communities and, importantly, reflected the concerns of older people rather than ideas identified by researchers.

The goal of the study was to collect information about service provision now and in the future, to inform policy-makers and service provision. In many respects, older people in remote Scotland reflect opinions from elsewhere; for example Hinck (USA) noted older people's desire to remain independent at home[26], and the findings agree with Scharf et al's literature review of European studies that rural people use, and contribute to social networks for relationships, help and support[27].

McCann (Ireland) noted a sense of stigma in applying to statutory services for support[15]. In this study, lack of demand for services appeared to be more linked to not wanting to identify oneself as vulnerable, fear of losing independence and perceived threats to continued ownership of property. Further, use of services could be linked to the apparent complexity surrounding their provision. Fragmented experiences of service providers and the different options available (for example direct payments versus council provision and different packages of care) meant confusion. It is important for service providers to be alert to how

community members have to simultaneously cope with ageing, service restructuring, lack of access to information sources and possible limited access to sources of personal support[1]. Participants sought straightforward, trusted, known conduits into 'the system' and saw those with medical and health professional qualifications as credible to fill this role. McCann also noted this desire for personal connection with service providers in an Irish study[15]. Thus, community members were adherent to traditional, local models of provision and suspicious of new ways of service provision. Walsh and O'Shea note the difficulty of achieving 'transcendence' (that is, getting communities to broaden their horizon) beyond the 'what has always happened here'[16].

While participants portrayed their relationships with local health professionals and supportive communities as positive, the objective observer might see a paternalistic context that hinders individual and group responsibility and voice. In addition, these apparently supportive Highland communities can belie complex, enmeshed, limiting relationships[28]. The dilemma of participants with regard to the dark and light sides of 'social support' is perhaps highlighted in their contested perspective on community support for older people. They, personally, should not be a burden to their families or might regard it limiting to be viewed as a 'granny', but families, in the abstract, and communities *should* look after their members.

The study sought to bring the 'voice' of older rural community members to policy-makers. Gaining the input of older people to policy and service design continues to be noted as both important and problematical. Here, it was seen that people did not want to identify with being old or want to try to envisage their needs as an older person because this was complex and depressing. While participants tended not to focus on how particular services, as envisaged by their providers (such as social care), could be specifically improved, their discussions did raise overall 'principles' considered significant in service provision; chiefly, continuity rather than fragmentation, and personal and social emphasis rather than technical efficiency. Participants

viewed services as interconnected, for example connecting rural transport with accessing services was raised. Linking transport with accessibility has been a theme internationally in studies of older rural residents[14,17,29]. Interconnections highlight the need for good 'territorial' community planning processes that treat services together and not in silos[30]. Older people in rural communities are concerned about the future and, in respect of their support from other community members and services, tend to have an ominous view. This is perhaps fertile ground for initiatives that generate solutions and initiatives from older people themselves.

## Conclusion

This paper opened with two quotes: one suggesting how changes to rural society, including service restructuring, have dramatically and irrevocably altered the lives of older people; the other suggesting the fundamental role of place as we age. In common with international work cited, this study highlighted rural community members wrestling with a changing structural environment while they and their communities age. Policy suggests innovative solutions are required from competent communities' to support older rural people to live out their lives in the communities that are, or that they have made, their homes. While the communities in this study appear informally supportive, more formal community structures may be required in the future. If residents want continuing and personal care within a retracting welfare state, they may have to assume responsibilities for community governance and enterprise.

Originally, the study findings provide in-depth and substantiated (through layers of data collection) insights in relation to a group ageing, in a particular context, at a perhaps particularly complex snapshot in time. It has been repeatedly suggested that older people should be more participative in informing their service design, both at a policy and local governance level. This study revealed complex barriers to older people influencing service provision, either through uptake of services and benefits or by using collective 'voice'. There is reluctance even to be

identified as 'older' and therefore to harness the potential of forming a group 'voice'. Older people and their local service providers co-construct a paternalistic context where service providers are regarded as the experts in decision-making. Service providers' emphasis on efficiency is perceived to erode the personal contact associated with valuing older people; therefore, confidence as an older person may be eroded. If vulnerability is admitted, accessing the range of services and benefits is complex, with different types linked to silo-ed service provision. This could hinder service uptake and feedback. Finally, confusion over the conditions under which services are provided may prevent older people coming forward (for example, receiving some care packages is thought to threaten home ownership).

Looking to a vision of the future for older people in rural communities, society perhaps needs to achieve simultaneous 'tipping points'. One, may occur where communities take more formal responsibility for supporting their older members; a second where being older loses stigma; a third where services work interconnectedly in ways that make sense to consumers, rather than providers.

## Acknowledgement

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