Five years on from the Inquiry: Caring for older Australians, what is the viability of ageing in remote places, in Australia?

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Abstract

The Productivity Commission Inquiry of 2011 outlined a range of community concerns and potentially gave new impetus to the development of policies designed to support ageing-in-place in rural and remote communities. This paper, five years on, compares the recommendations of the Inquiry with the perceptions and experiences of older people living in one remote community in the Northern Territory (NT). Semi-structured interviews and a focus group were conducted with older people living in a small ex-mining town. People ageing in this remote community described not having access to suitable home support and home care services. Ways to support ageing in remote communities can include extending aged care services through current health services, such as primary health networks and remote health clinics. Innovative coordination strategies are needed to forge collaboration between formal service provision and volunteer capacity, which already exists in communities. Aged care is increasingly subject to a marketized economy and this can increase the vulnerability of small ageing communities, unless policy making builds collaboration between current services and local capacity.

Introduction

It is widely acknowledged that people in rural and in particular, remote places, are not well supported with services to age in place[1, 2]. This is an increasing problem judging from trends in population ageing across the north of Australia[3]. Discussion and debate about the state of services to older people in Australia peaked with the 2011 Productivity Commission's Inquiry: *Caring for older Australians* (referred to elsewhere in this report as the *Inquiry*)[4]. Their report made recommendations to support the realization of the Commonwealth Government's aim, to 'ensure that all frail older Australians have timely access to appropriate care and support services as they age'. Our report raises the query: what changes have been effected five years later, for people ageing in the remote northern regions of Australia?

Prior to the 2011 *Inquiry*, a discussion paper released jointly by NRHA and ACSA in 2004, entitled *Older people and aged care in rural, regional and remote Australia*[1], argued that while people preferred to remain and age in their own familiar environment, services to support that happening in the bush were not available. Or, if there were services, standards of care were way below those enjoyed by metropolitan counterparts. Furthermore, while some rural communities theoretically had access to care supports, there were usually long waiting lists as care packages were already allocated[1]. Packaging care, it is argued[5], gives access to people with higher level, complex needs; meanwhile older people miss out, whose needs for support to age in place are less complex but just as critical. The *Inquiry* recommended abandoning care packaging in favour of a flexible range of supports based on entitlements, with direct access to support for low intensity care need.

The *Inquiry* report highlighted the complexity of the aged services system, how difficult it was to navigate, and the limited choice of services within the system. Recommendations from the *Inquiry* were focused towards greater choice of services and ways to access them, as well as preserving older people's independence and maintaining community engagement. To achieve this focus, the *Inquiry* recommended that a simple entry point – a 'gateway' - to the services system be created for older people and their carers when advice is needed or when access to services is required. Furthermore, the gateway agency would be regionalized and could be accessed by local services in regional areas, such as general practitioners (GPs), health clinics and Medicare Locals (now Primary Health Networks: PHN).

The NRHA's (2011) response to the *Inquiry* expressed concern that, despite the setting up of this new agency, older people outside metropolitan areas will continue to 'fall in the cracks' between service sectors, unless there is special focus on how coordination between agencies will be achieved in rural and remote areas[6]. For example, the NRHA[6] emphasized the need for the gateway agency working in conjunction with PHNs, GPs and local aged care service providers, to take responsibility for appropriate transport arrangements for people to attend appointments in the nearest city, or for arranging for visiting medical specialists, allied health and dental workers to run regular local clinics.

Finally, it has been noted in several of these reports that what has been packaged to date as aged care services, is designed and funded on a metropolitan model of aged care; it does not work for small rural and remote places[1, 4].

A recent study into determinants of resilience for people ageing in remote places[7] elicited, as a byproduct, some clear indications of the lived experience of struggle and vulnerability among older people confronting the reality of growing older, in a remote community. These findings are presented below as an entrée into investigating the query reflected in the title of this paper: what has happened five years after the *Inquiry*?

Method

Setting

The study was conducted in a region classified as remote, south west of Darwin. Out of a population of 1,105 residents[8], 220 residents were 60 years or over in 2011. Members of this community were approached through the local sub branch of the Council on the Ageing, Northern Territory (COTA, NT) and invited to participate in the research.

Participants

Fourteen senior members of the community participated voluntarily in an interview of no more than an hour and a half, in length. All participants, except for one 61-year old, were between 65 and 80 years old. This younger participant took part together with her older husband, for whom she acts as a carer. No participant identified as an Indigenous Australian.

Process

A semi structured interview format was used with prompt questions: What is important to you about living here? How important is community to you? What would help you stay on here, in this place, as you grow older?

All interviews were conducted, by choice, in their own or a friend's home. Six participants were interviewed individually while eight volunteered as a couple, and so were interviewed as a couple. Ethics approval to carry out the research was obtained from the Charles Darwin University Human Research Ethics Committee. Interviews were recorded digitally and transcribed verbatim by the lead researcher. Transcripts were then sent back to participants for review. Some participants made significant changes to content, usually eliminating references to the lives of other people.

Data analysis

Once transcripts were reviewed and validated by participants, open coding was carried out using NVivo software for interpretive data analysis.

Interview quotations were organized into a hierarchy of thematic categories giving rise to key thematic areas for further analysis. These are elaborated below.

Wider validation

To validate these findings, a focus group, using these same questions was held with eight seniors in another remote community in the Northern Territory. In a third community a focus group could not be organized due to extreme weather conditions; here a key informant agreed to an informal interview. These discussions yielded similar findings and validated the data we had collected with participants from the first community.

Results

Service deficit

Despite the high level of resilience in this community[7], there was a pervasive sense of helplessness at the inadequacy of support and often hopelessness that they will ultimately, be forced to leave:

> (Person 1) I think that issue of having somewhere to go, that fits with who you think you are, and [the] kind of life you want to have... this is our life and this is what we want to do, but it's quite within the realms of possibility, for health reasons, that we might not be able to continue.

All participants reported that people in these communities have no access to home support such as meals on wheels, personal care or respite care:

(Person 2) And there's another guy here XX, who's another longtime resident, and he is failing; his body is failing [but] his mind is as sharp as a tack...And his wife now, who's still teaching at the school...She's reluctant now to even leave him at the house, but she has her school that she's passionate about and her teaching... They won't have someone there to look after XX unless she gives up her quality of life, I guess, to just step in and just support XX. How do you fix that? I don't know.

The situation is quite desperate for many, prompting some older people to accept help from strangers in exchange for free accommodation in their home:

(Person 3) One of the things I have pushed here, and quite a few people have taken this up. I started getting HelpX here. I used to be a Wooferhost and I changed to HelpX. They are travellers, who in return for accommodation - food and accommodation - will work for four hours a day for you. If people were confident enough, it's a resource you could push.

Lack of public transport to services in the city was cited as the greatest hindrance to ageing in this place. A recent arrangement was cobbled together from older volunteer drivers and the good will of the council, which lent a bus. It was a very indirect journey and ran only once a month. Recently the bus was withdrawn as it was too old. Public transport is a problem that affects not only older people who can no longer drive. In recent years, relocation of public welfare clients (mainly Indigenous) into ex-mining housing and cheap public housing, has meant a high proportion of the population in this town and surrounding areas, are reliant on public transport - which does not exist.

People living in this region described their confusion concerning the availability of any personal care and home support resources. Information about the portal MyAgedCare has not reached these communities; hence they were unsure about their eligibility for any services, or how to go about investigating the matter. The GP who provided services to their community worked out of the remote health centre. This centre provides excellent primary and acute health care, but cannot provide older people with guidance on aged care related matters. Neither can the clinic access aged care services on their behalf.

Services, when offered, are a poor fit to these communities

Stories shared by participants bore testimony to the stoic self-reliance of people generally, who live in remote places:

(Person 4) Well, when you're faced with basically no help from outside organisations, you have to stand on your own two feet and work out ways of doing things. And therefore, you do become independent and resilient. Because you start looking at, how can I do things to help myself before reaching out to the organisations to come and do it for you? As a result, these people become very clear about the best way to go about self care and caring for their loved one.

On occasions, when a person has been discharged from a metropolitan hospital, they have been offered home support and home care services, as part of the rehabilitation plan. The manner of service delivery was very often a poor fit with the recipient's needs and expectations.

> (Person 4) The aged care people did come down and assess the house. But one of the things that we found with them was that they had a set plan, steps 1 to 10. And [they] weren't prepared to deviate: 'you're at this stage and this is what you will have' irrespective of whether what they were offering was safe or adequate or necessary. They were adamant that you would have that. And I think in a lot of cases, people [who] come out to assess patients, should also listen to carers. But the people from the aged care said, 'that's step number eight and that's what you will [have]'. They didn't want to listen and adapt a 1 to 10 step program to an individual.

How services can be brought to remote communities

As well as pointing to the deficit of services, participants were very forthcoming in suggesting ways forward to engage external services and build the capacity of their community to support ageing in place:

> (Person 4) I think what we really need is... they have to come prepared to listen and adapt to how people are living, whether [we] are in a city or a rural area. Adapt to [our] circumstances, not come in with a prescribed 1 to 10 step plan, that has no grey areas or deviation. Not set in concrete.

Strong emphasis was placed on the need for local coordination of an aged care service, to ensure it was harnessed appropriately to meet care needs in the community. The person in this role would have an understanding of both the point of need and the kinds of resources that could be engaged locally to meet the need - both volunteer and purchased services:

> (Person 5) One of the possibilities is to have maybe attached to the primary health care centre, a community person, a liaison person, who can link people, provide information, coordinate services, what have you.

> (Person 6) ...have trained people there [based at the health clinic], who could go out and do the meals on wheels – arrange for the Tavern to do meals on wheels and go and deliver them, go out and bathe, look after people. And by being at the clinic - not as clinic staff, but as a separate identity that is accessible through the clinic. They would then know what was happening in the community and be able to respond appropriately for the community.

How services need to be delivered

Participants challenged policy makers and service providers to take more responsibility in supporting community capacity, not taking over the community's care of older people:

> *(Person 1) I mean, it's about there's a lot of willing[ness] in a rural community to support one another. And people put energy into that in one way or another. And you don't always know about it if you're not personally involved in it. But if somebody comes along and says, 'well we've got to have all these support services', those support services need to fit with [what's in place], not ride roughshod over it.*

In the experience of those interviewed, services from an external provider usually lack any organic connection with the community's capacity to look after itself. Rather than adding to resources in situ, they often incapacitate this local resource:

> *(Person 1) ...there's limited stuff that we can do, because professional services come in ... quite rightly there's provisions for privacy and so on. But it means, as a community volunteer who might be there helping people, you can't actually talk to a professional about a person, or they can't talk to you about the person. They might listen to what you've got to say without breaching privacy. And so, it actually cuts across and prevents the use of energy, which exists in the town, to support people.*

Remote aged care delivery requires new approaches to establishing collegial respect and mutuality between external professional service providers and volunteers already working in the community.

Policy for planning services to remote communities requires a more innovative way of thinking that doesn't reduce community to its individuals:

> *(Person 8) Services tend to divide communities into individuals. Whereas communities are individuals but Community is more than [just a group of individuals].*

A clear message from participants - services developed for people in urban communities cannot directly translate to this remote area:

> *(Person 1) And you can't just apply an extension to services or infrastructure that's there because it won't work here necessarily;*

> *(Person 8) ...that really comes back to the public sector and the politicians who are influenced much more politically by the urban centres, having a lack of idea[s] about alternatives, other than urbanised alternatives.*

In summary, these people asked for simple support services that integrate local community energy with professional support; these need to be generally inclusive and ensure sustainability:

> (Person 1) It is an important principle about keeping it small and yeah, if you start something don't stop. Don't stop, because everybody's used to people who start things and then stop. [They] buzz off, and they get pissed off with it...what does that mean? It means, if you start this, don't go away.

General discussion

The breaking point for this community is the lack of general support such as transport, personal care assistance and carer respite. The solution, in their view, is simple service access points, which are locally coordinated. The confusion and uncertainty about what is available, compounds the experience shared amongst many; that despite political assurances, when they need a particular kind of support, it is not there.

Despite current circumstances, participants shared the hope that policy makers and provider organizations would gradually understand that remote communities' need engagement and partnership in delivery of services. This points in turn to the building of infrastructure based on local volunteer traditions, with innovative partnering between community, government and provider organizations.

The *Inquiry* indicated support for aged care provision moving to a market based economy, away from the traditional tax-based social welfare system. This system operates on free market forces shaping how services are delivered and reflects a trend throughout the developed world[9, 10]. Here, the emphasis is on people taking more responsibility for their care in the form of user contributions. While the change is framed as increased choice for aged care consumers, several commentators have questioned the extent to which an older person has the freedom to exercise choice between meaningful options[11, 12]. This argument is even more pertinent when basic services are not even available; under marketization of care the introduction of services to small communities is likely to be considered as financially not viable[5].

Conclusion

The increasing ageing of the population in northern Australia will result in increased numbers of small, ageing communities in remote areas. The vulnerability of these communities in a free market system of care delivery will only increase, unless a strategy is developed by the public sector to engage with and support communities to enact local solutions. If not, older people in remote areas will fall further into neglect.

Key points

- The Productivity Commission Inquiry in 2011 drew focus to the shortcomings of policy in providing for the capacity to age-in-place in rural and remote communities.
- Policy discussion focused on better coordination and collaboration between current health agencies, such as primary health networks, general practitioners and aged care providers.
- Recent evidence in this report indicates a lack of appropriate support services for older people living in remote communities, in northern Australia.
- Findings include ideas for new collaborations in developing an ageing support service model that works in remote communities. These include collaborative partnerships harnessing health support agencies, aged care providers and local volunteer 'energies' within the community.

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