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# An exploration of the experiences of Australian Grey Nomads travelling with chronic conditions

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# An exploration of the experiences of Australian Grey Nomads travelling with chronic conditions

## **Abstract**

Internationally, the population is ageing and people are living well, longer. In Australia, extended travelling has gained popularity among older Grey Nomads due to time and opportunity post retirement. However, there is limited research available focusing on older Australians' health while travelling. This paper reports the qualitative phase of a larger mixed-method project that explores the experience of Australian Grey Nomads travelling with chronic conditions. Eight Grey Nomads participated in telephone interviews. Data were analysed using inductive thematic analysis. Two themes emerged, namely: continuity of care while travelling and experts on the road. Participants described encountering a fragmented health system, with challenges regarding finding health services; a lack of shared medical records; and difficulties accessing regular medications. Despite these challenges, participants demonstrated health preparedness, an ability to accommodate health on the road, and were all travelling for their health. This study highlights key systems issues that challenge health care while travelling, and identifies opportunities for both usual practices and rural health services to enhance the care provided to this group.

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# **An exploration of the experiences of Australian Grey Nomads travelling with chronic conditions**

Australian Journal of Primary Health Care

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## **Abstract**

Internationally, the population is ageing and people are living well longer. In Australia, extended travelling has gained popularity among older Grey Nomads' due to time and opportunity post retirement. However, there is limited research available focusing on older Australians' health whilst travelling. This paper reports the qualitative phase of a larger mixed method project which explores the experience of Australian Grey Nomads travelling with chronic conditions. Eight Grey Nomads participated in telephone interviews. Data were analysed using inductive thematic analysis. Two themes emerged, namely; Continuity of care whilst travelling and experts on the road. Participants described encountering a fragmented health system, with challenges regarding; finding health services; a lack of shared medical records; and difficulties accessing regular medications. Despite these challenges, participants demonstrated health preparedness, abilities to accommodate health on the road, and were all travelling *for* their health. This study highlights key systems issues that challenge health care whilst travelling and identifies opportunities for both usual practices and rural health services to enhance the care provided to this group.

**Keywords:** chronic disease, electronic medical records, older person, primary care, self management, travel

### **What is known about the topic?**

- Australian Grey Nomads face a number of risks on the road; travelling long distances towards rural and remote areas whilst living with chronic conditions, and have been reported as being insufficiently prepared with their health needs.

### **What does this paper add?**

- Grey Nomads face several barriers to negotiating health services whilst travelling. Many of these are systems related challenges. Participants in this study were largely well equipped with individual strategies to manage their chronic disease. Providing additional support for self-management and addressing the systems issues identified in this paper would likely further enhance health outcomes.

## **Introduction**

Improved survival rates, together with better living conditions and improved health practices have led to increased life expectancy and a growing ageing population (World Health Organisation 2015). With this, the promotion of resources to enable older people to age healthily becomes pertinent (Hommel and Kibele 2016). Healthy ageing does not necessarily mean ageing without illness, but rather involves a “process of developing and maintaining the functional ability that enables wellbeing in older age” (World Health Organisation 2015, p. 28) An ageing population brings a rise in the prevalence of chronic conditions (Marengoni *et al.* 2011). Chronic condition related mortality represents 60% of all deaths worldwide (World Health Organisation 2016). Over 87% of older Australians are living with at least one chronic condition, with 60% having two or more chronic conditions (Australian Institute of Health and Welfare 2016). Those with chronic conditions have to learn to live well with their conditions, maintaining function, reducing exacerbations and slowing symptom progression. To facilitate this it is important that research focuses not only on chronic disease management but also on those who are living well.

Globally, older people are enjoying travelling within their country for extended periods. In America the ‘Snowbirds’ migrate from their homes in winter to visit warmer sunbelt areas (Holloway 2009). In Australia, ‘Grey Nomads’ embark on long-distance journeys for extended periods to explore the vast interior of Australia, visit warmer regions or complete the ‘big lap’ around the country (Raven 2015). Cridland (2008) estimate that Grey Nomads account for some two per cent of the total Australian population. Grey Nomads are reported to take more than 200,000 trips of six or more weeks duration per year (Brayley and Obst 2010) and can travel between 330 and 1000 kilometres each day (Cridland 2008). Like the broader population of older people, Grey Nomads experience a range of chronic health conditions and have a range of lifestyle risk factors that impact on their health and wellbeing (Authors own). Despite this, there has been limited attention paid to the experience of travelling with chronic disease.

Several studies have described reduced stress levels and improved mental health among Grey Nomads (Onyx and Leonard 2007; Cridland 2008; Holloway 2009; Hillman 2013). However, it must also be considered that this group are choosing to travel away from support networks and health providers with whom they have established relationships (Onyx and Leonard 2007). This presents a potential challenge as they “isolate themselves from medical help... when they are likely to be most vulnerable to disease and deterioration” (Onyx and Leonard 2007, p. 385). Many Grey Nomads have pre-existing chronic conditions which impact on their health and wellbeing (Authors own). Additionally, there is physical and mental strain caused by driving long distances and towing large vehicles (Brayley and Obst 2010). The fact that these individuals are travelling long distances across a vast land mass, often in rural and remote areas also creates challenges in accessing health care services. In their study of Grey Nomads, Tate *et al.* (2006) claimed that this group is “poorly prepared with... medication supplies and health summaries” (p. 72) when travelling.

Recent literature demonstrates that few papers focus on the health and health needs of Grey Nomads (Authors own)(Raven 2015). Literature has focused on the economic impacts of Grey Nomad tourism, work undertaken by travellers (Prideaux and McClymont 2006; Mahadevan 2014; Raven 2015) and the travel benefits of long-term travellers (Ferrer *et al.* 2016). Given the high prevalence of chronic disease in the Grey Nomad population (Authors Own), this paper aims to explore the experiences of Grey Nomads travelling with chronic conditions.

## **Method**

### *Study design and participant recruitment*

This paper reports the qualitative descriptive phase of a larger sequential explanatory mixed methods project. The first phase comprised an online survey of individuals recruited from social media sites and caravanning forums who had travelled around Australia for more than 3 months in the last year. Survey data has been reported elsewhere (Authors own).

Survey respondents indicated a willingness to participate in subsequent interviews. Of those who consented for an interview, individuals were purposively selected if they were aged over 60 years and living with at least one chronic condition. Participant recruitment continued by contacting potential participants in a random order until data saturation was achieved, that is, as emergent themes became recurrent and no new patterns were uncovered (Polit and Beck 2017).

### *Data collection*

All interviews were conducted via telephone, due to the geographical dispersion of participants, by one researcher (##) between June – July 2016. A semi-structured interview schedule was developed, using the lens of qualitative descriptive research, following a literature review and consideration of the survey findings. Questions focused on health needs relating to chronic disease, health preparedness and wellbeing whilst travelling. All interviews were audio-recorded and transcribed verbatim by a transcription company.

### *Ethical Considerations*

The Human Research Ethics Committees of the University of ### (Ethics Approval Number: HE15/366) approved the conduct of this study. Written consent was collected prior to each interview. Pseudonyms have been used to preserve confidentiality.

### *Data Analysis*

Inductive thematic analysis, using the Braun and Clarke (2006) framework, was used to analyse the data. This involved the researchers familiarising themselves with the data; generating initial codes; searching for themes; reviewing, naming and defining themes; and producing the report (Braun and Clarke 2006).

## Results

Of the 382 survey respondents, 33 individuals who consented to be contacted were aged over 60 years and living with a chronic condition. Data saturation was achieved after eight interviews and so no further participants were recruited. Interview participants were aged between 62-69 years and most had been travelling for extended periods in regional and rural / remote Australia (Table 1). No participants were travelling together, although many travelled with others. Interviews lasted between 30-88 minutes.

**Table 1.** Participants Demographics

Participant	Age	Gender	Chronic Condition
Alfred	65	Male	Type 2 Diabetes Mellitus, cardiac issues
Bill	62	Male	Type 2 Diabetes Mellitus, hypertension, chronic headaches, arthritis
Ed	65	Male	Hypertension, depression, cardiac issues, arthritis, <i>GORD</i>
Fiona	62	Female	Lupus, osteoarthritis, eye problems from lupus
Gina	62	Female	Osteoarthritis, permanent back and knee injury
Hilda	66	Female	Chronic back injury from work, depression, liver condition, sleep apnoea
Jack	69	Male	Barrett's oesophagus, muscle myopathy, osteoporosis, asthma
Kim	62	Female	Depression, <i>GORD</i> , hypertension, severe back problems, Type 2 Diabetes Mellitus

### *Themes*

Two themes emerged from participant's narratives; Continuity of care whilst travelling and; Experts on the road.

#### *1. Continuity of care whilst travelling*

Participants identified several factors which impacted on continuity of care while travelling; accessing health services; lack of shared medical records; and access to regular medications.

##### *a) Accessing health services*

Several participants described difficulties in accessing health services in rural and remote regions.

*A lot of doctors don't take new patients... you might have to wait two... three... four days to get in to see someone because you're not registered for that surgery. [Bill]*

This left some with no alternative but to attend the Emergency Department, which created new challenges:

*I couldn't find a doctor in Esperance that would accept me... so I accessed the hospital ... after a long wait, I got in to see a doctor... he said ... I'd have to go to Perth or Adelaide [approximately 713 km and 2200 km away] to get help and that he never had time to write out scripts for me. [Kim]*

The doctor wrote a prescription for Kim's blood pressure medications, which had ran out, but:

*wouldn't write out any other scripts... he said it's a hospital, it's an emergency ward and we don't have time for that. [Kim]*

Other participants explained that health professionals did not always invest in them as they might with local patients, as they were just passing through. They felt their transient lifestyle influenced the depth of medical assessments, which they had received:

*He wasn't interested...was only going to be there once to get the antibiotics for this infection... you won't be going back so he wasn't too concerned about getting your full history. [Bill]*

#### *b) Shared medical records*

Continuity of care was fractured for many participants due to a lack of a shared medical record between providers at home and those they saw while travelling:

*I thought my doctor that I was going to in Caloundra did have e-Health, but they are only learning about it. [Kim]*

Without access to their medical history and treatment plans, participants described a burden of having to repeatedly tell their story, supply test results and details of ongoing treatment. Even then, tests were repeated when details could not be verified:

*...to try and explain to him my history for that injury was almost impossible. It doesn't seem to link up, the doctors or the medical reports... on the computer of my own doctor, cannot be accessed by any other doctor that I go and see... I actually told the doctor, look I've just undergone a CT scan and they've found out this is what the problem was. But they still made me undergo a CT again. [Alfred]*

This also impacted on participants accessing the results of screening tests. Fiona articulated this clearly:

*I did not have a regular doctor, they wouldn't tell me anything...it's no good saying we'll send them to a doctor in Victoria if I happen to be in WA [Western Australia] at the time.*

The disconnect in care experienced whilst travelling was expressed with frustration by the majority of participants, as it adversely impacted on self-management and access to health services whilst travelling.

### *c) Accessing regular medications*

In addition to the complexity of accessing health services, participants faced challenges in accessing their regular medications. This further aggravated the fragmented care that they received. Pharmacies in some rural and remote areas were reported to have limited or no stock of some medications. Bill described: *"in some of these small towns... they don't carry refrigerated products... I had to go another 120 kilometres to get the Byetta I needed"*. Ed had a similar experience, *"[They] had to order [medications] in so that meant we were stuck there for another three or four days"*.

Additionally, prescriptions written interstate represented a challenge:

*We were in Mitchell in Queensland, and I was on a course of [Clexane] ... and I'd run out. I took it [prescription] to the pharmacy, but they wouldn't fill it because it was... a New South Wales doctor that had done it and so they couldn't verify....* [Ed]

Some participants had developed strategies to manage these challenges. One participant described how “... *I'll go to the chemist [at home] and say we're going to be away... if I'm running out... I just ring them...*” [Ed]. Others left prescriptions with friends or family who will “*get the prescription made up... and sends it to me*” [Gina]. Jack explained how he “*had some [prescriptions] filled in Victoria, others in Queensland...*” to avoid the barriers of acquiring prescription medication. Participants also described how time and experience made them more aware of what they needed to plan for.

## *2. Experts on the road*

Despite the challenges faced around continuity of health care, narratives reflected a range of views and strategies around travel planning. Participants' awareness of their health needs was a prominent subtheme, as well as their self-identified limitations and health management strategies. Lastly, participants described the positive impact of travelling on their health.

### *a) Health preparedness*

Most participants were aware that “*you need to plan ahead*” [Bill] to manage your health whilst travelling. Several participants had health planning schedules prior to travelling:

*I have a diabetes doctor which I see twice a year, ...I've got my podiatrist... my heart specialist... my diabetes specialist... my dentist...my normal doctor wants blood tests two weeks before I go on a long trip... It's a series of events, which takes roughly about six to eight weeks before you go on a long trip.* [Alfred]

Other participants, identified the importance of getting a “*referral, a medical history from your GP*” [Bill]. However, while participants alluded to the GP's role in helping prepare for travel, they highlighted the importance of self-management:

*“I didn’t know much about it [diabetes management], once I studied it, I’d go and ask the doctor about it then... once you brought it up yes they [the doctor] were helpful... it was up to the patient, or up to me to say look, I am going here, here are my concerns”. [Alfred].*

Through their travel experience, participants became better at planning ahead for their health needs. Their preparedness consequently improved their self-awareness of their individual limitations and boundaries.

*b) Accommodating health issues*

Participants faced various health issues whilst travelling with a chronic condition. Alfred acknowledged that *“with diabetes, you’ve got to worry about the temperature control of insulin...”* and because of his other co-morbidities, *“you’ve got to step back a little bit from things you love doing”*. Gina described how she *“can’t get around as much [because] my back aches a bit from being in the bus”*. However, participants were quick to illustrate strategies for accommodating their conditions into their daily activities by allocating rest days to *“try to be adaptable and change things around”* [Hilda].

Living with chronic conditions enabled participants to develop self-management skills and also recognise exacerbations or deteriorations in their health, allowing them to act early on warning signs:

*“I got ill in Western Australia and I knew... I’ve got a mobile phone... and it has got a health app... It takes your blood pressure and oxygen levels and all that.... When my pulse rate was going high – 120 - I knew that because of my heart, I needed to access a doctor, so I rang the ambulance. They came out into where I was camped, and got me and put me in a hospital”. [Kim]*

which positively impacted their health.

While participants’ individual abilities to manage their health were important, many emphasised the key role of their support networks. Ed described how his *“wife plays a big*

*part...we [saw] this psychiatrist but it was only because that she was around that...I was able to hold on... ”. Some participants, however, found that travelling can create a feeling of isolation from traditional social networks, “internet is a major part of my wellbeing” that allowed a participant to “Skype [with] my sister... I’m also in a Facebook girls only camping group...” [Hilda].*

*c) Travel for health*

Participants described different reasons for commencing and keeping travelling. Ed stated that his diagnosis made him “*want to travel more.*” Other participants described a desire to travel before their health deteriorated: “*I think we better get travelling now while I can and do as much as we can before I’m unable to*” [Jack]

Many participants described how “*a lot of stress goes,*” [Alfred] and there is “*a lot less worry and pressure*” [Jack] when travelling. Hilda shared that travelling “*makes [me] happy... being out and seeing the trees and bushes... it’s part of your wellbeing*”. Others found the opportunities for social interaction whilst travelling had a positive impact on their wellbeing as “*you pull up somewhere... immediately swapping stories, names... people have time to interact...*” which they described as “*almost like the best drug in the world*” [Fiona].

Other participants’ described the positive physical benefits of travelling. Alfred “*was a heavy smoker, and that’s stopped... was a heavy drinker and that’s pretty well stopped*”. Other participants expressed being able to “*do more exercise... you’re out doing more physical things... prepare meals properly and eat the right things*” [Bill]

While participants lived with different chronic conditions and faced different health challenges, all shared similar sentiments with regards to how travelling had positively affected their mental health and wellbeing.

## Discussion

In this study, it was evident that Grey Nomads with chronic conditions face several challenges related to continuity of care both at an individual service provider level and at a more broadly based infrastructure level. These challenges represent opportunities for policy change to improve service delivery. One such challenge was the difficulty of either getting medications prescribed or getting the scripts filled at pharmacies. The refusal of ED staff to prescribe regular medications may be seen as a failure to provide a duty of care, however the processes of repeat prescription models have been called into question. GPs in Australia may legally write a prescription without seeing a patient. However, they may only bill Medicare for a face-to-face consultation. Such policy encourages potentially unnecessary consultations for repeat medication prescription. The issues raised in this study highlights the potential for innovations in the process of accessing regular medications to reduce the impact on both consumers and the health system.

The reduced health services in rural and remote areas has been widely reported (Sav *et al.* 2015). With the concentration of health care professionals and services in cities and metropolitan areas (Wilson *et al.* 2009), individuals in rural and remote areas generally have poorer health outcomes than those who reside in cities (Wilson *et al.* 2009). This impacts on the experience of Grey Nomads residing in rural and remote areas for seasonal periods of time as their health needs may place additional strain on an already limited health service. This underscores the importance of planning for health needs whilst travelling as well as disparities in infrastructure, policy and planning with regard to health care service provision for rural and remote communities.

Participants spoke of challenges due to the lack of electronic medical records and the absence of systems to share medical information between providers. This finding has been previously reported, with rural and remote Australia found to have the poorest capacity in implementing and utilising electronic medical records successfully (Rao 2009; Banbury *et al.*

2014). In Australia the implementation of the national electronic medical records 'My Health Record' (Australian Government - Australian Digital Health Agency 2017) has the potential to positively impact the care delivered to Grey Nomads. However, given the poor uptake by both consumers and providers, a gap remains around suitable mechanisms to communicate medical histories and information. Further work on developing platforms on which to share medical records has the potential to improve communication between providers and enhance the quality of care.

Most participants in this study described some preparation for their health needs during their travels. This finding is consistent with Onyx and Leonard (2007) and Hillman (2013), who reported that Grey Nomads sought approval to travel from their doctors (Onyx and Leonard 2007; Hillman 2013). However, it is in contrast to the work of Tate *et al.* (2006) who found that Grey Nomads were poorly prepared with health summaries. Interestingly, our study found that participants felt that they had a responsibility to develop self-management capacity and seek support from health professionals prior to travelling. This discrepancy demonstrates that support strategies to assist Grey Nomads to prepare for their health needs whilst travelling may improve outcomes. This highlights an important practice implication, in that general practices could take a more active role in supporting their patients and opening or actively engaging in discussions around health care needs whilst travelling. Supporting patients to develop clear, evidence-based plans to manage their health needs whilst travelling can both improve health outcomes and reduce the impact on local health services.

Participants in this study demonstrated expertise in managing themselves as they recognised and responded to their limitations and boundaries. Participants were already experts in the sense of their lived experience (Kennedy 2003) and took this expertise into the travelling environment. This is consistent with the literature, which indicates that consumers who are isolated from services become creative in self-management (Sav *et al.* 2015). As chronic illness is a major burden on health services, promoting and supporting self-management through health

education and strategic planning is an effective strategy in mitigating the reduced health services in rural and remote areas (Newman *et al.* 2009).

The health advantages of travelling seen in this study support the existing literature (Onyx and Leonard 2007; Hillman 2013). Most participants attributed this to the availability of time and freedom to do things out of their previous routine, allowing them to enjoy life and do more physical activities. de Souto Barreto (2014) describe how greater levels of physical activity have been found to induce greater levels of happiness and reduce depression.

Participants valued the diversity of people they encounter on the road, and considered social activities and meeting new people as a huge advantage of travelling. This finding is consistent with previous literature that demonstrates the optimistic side of ageing healthily in living the Grey Nomad lifestyle (Onyx and Leonard 2007; Davies 2011; Hillman 2013). This also corresponds with the recommendations of Hommel and Kibele (2016), encouraging the empowerment of older people to stay involved in social and physical interactions, and in activities wherein a demand of their cognitive skills would be needed in order to promote healthy biological ageing.

### **Study Limitations**

As the first study to explore the experience of Grey Nomads travelling with chronic conditions this provides a unique insight into their life on the road. However, this study has a number of limitations. As survey participants were recruited via social media and caravanning forums and groups, potential participants without Internet access could not participate in the survey and consequently, the interview. Additionally, due to the time between survey completion and interview conduct, some individuals who consented to be contacted could not be reached.

### **Conclusion**

With the increase in Grey Nomads touring Australia and the rise in chronic disease, understanding the experience of living with chronic disease on the road is critical to ensure that

health services meet the needs of this group and that health outcomes are optimised. The fragmentation and lack of continuity of care experienced by participants highlight systems issues that provide opportunities to improve the health care of Grey Nomads. Whilst Grey nomads usual general practices could more proactively assist their patients in planning for their health needs during extended travel, rural and remote health services could provide guidance to travellers about service access and availability within their region to facilitate this planning. The desire expressed by participants to assume responsibility and enhance self-management of their conditions demonstrates an opportunity to enhance healthful ageing through support services and healthcare planning provision by health care clinicians working in partnership with Grey Nomads.

### **Conflict of Interest**

No conflict of interest has been found nor declared by the investigators/authors of this research.

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