

LIVING ON: AN EXPLORATION OF HEALTHFUL CANCER SURVIVORSHIP AMONG GREY NOMADS IN AUSTRALIA

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WHO ARE GREY NOMADS?

- A retired person who travels independently and for an extended period within their own country, particularly in a caravan or motor home
- Has been reported as a contemporary cultural phenomenon (Onyx 2014)
- May account for 2% of Australian population (Cridland 2008)
- Take 200,000 trips of six weeks or more per year (Braley & Orbst 2010)
- Population among whom improved mental health and well-being has been widely reported (Onyx & Leonard 2007; Cridland 2008; Holloway 2009; Hillman 2013; Halcomb et al 2017; Calma et al 2018)
- Not a homogenous group







Vast land
and
varied climate

<https://www.contentedtraveller.com/far-away-australia-big-country/>



<https://www.lonelyplanet.com/news/2016/07/04/climate-maps-world-weather-australia/>

The study as a whole

Mixed methods study exploring the health and health preparation of long term Australian travelers

- Little literature examining the impact of travelling on the health care systems; on the experience & logistics of health care for the nomad
- Phase 1: Quantitative – survey
- Phase 2: Qualitative: Series of semi-structured in depth interviews
 - i; people who identified as grey nomads and living with chronic conditions
 - ii; people who identified as grey nomads and living with a diagnosis of cancer



THE STUDY AS A WHOLE

- Mixed methods study exploring the health and health preparation of long term Australian travelers
- Approval for the study was gained from the Human Research Ethics Committees of the University of Wollongong (Ethics Approval Number: HE15/366).
- Recruitment through Facebook groups/ Caravan Club Australia and advertisements at Caravan Parks
- Phase one: cross sectional survey
 - 382 respondents travelling for 3 months or more (316 complete data)
- SurveyMonkey
 - Demographics
 - WHO QOL-BREF



The health and health preparation of long-term Australian travellers

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Abstract. A growing number of Australians are travelling domestically for extended periods. This creates challenges in both continuity of health care and burdens on health services. This paper reports a cross-sectional survey aimed to explore the health needs and health planning of long-term travellers. In total, 316 respondents who had travelled for more than 3 months consecutively in the last year participated. Most respondents were retired ($n = 197$; 62.3%); however, ages ranged from 26 to 89 years. Nearly half of the respondents or their travel companion had a long-term illness that affected their daily life ($n = 135$; 42.7%). Nearly half of respondents visited a GP ($n = 133$; 42.1%), nearly one-quarter visited an Emergency Department ($n = 72$; 22.8%) and 19.9% ($n = 63$) visited another health provider while travelling. The level of preparation around health while travelling varied between participants. This study highlights that long-term travellers have significant health needs and are likely to require health services during their extended travel. Additionally, it identifies that currently few strategies are used to plan for health care during travel. This raises issues for rural and remote health services in terms of both capacity and continuity of care.

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Introduction

Australia's varied climate and vast landmass encourages people

and delivering health care. There is significant evidence for interventions to improve lifestyle risk factor profiles :

Table 2. Travel times and travel plans

Travel characteristics	Participants <i>n</i> (%)	Mean
Duration of longest trip in the last 12 months (weeks)		24.6 ± 15.2 weeks
≤15	67 (21.2)	
16–30	133 (42.1)	
31–45	31 (9.8)	
46–61	60 (19.0)	
>62	3 (0.9)	
Missing data	22 (7.0)	
Average time spent travelling each year (months)		
≤1	37 (11.7)	
2–4	91 (28.8)	
5–8	71 (22.5)	
9–12	110 (34.8)	
Missing data	7 (2.2)	
Planned length of current trip (months)		
≤3	17 (11.3)	
4–6	12 (8.0)	
7–9	9 (6.0)	
10–12	38 (25.3)	
≥13	28 (18.7)	
Indefinite travellers	14 (9.3)	
Other – no timeframe; undecided; no plans as yet	7 (4.7)	
Missing data ^A	25 (16.7)	

^AExcluding 166 participants who were not currently travelling.



Table 4. Domain results from the World Health Organization (1998) survey tool to explore demographic, travel issues, health status, risk factors, health planning and quality of life (WHOQOL-BREF)

Domain	≤50 <i>n</i> (%)	51–75 <i>n</i> (%)	≥76–100 <i>n</i> (%)	Mean
Physical health	48 (15.2)	128 (40.5)	140 (44.3)	70.7 ± 19.5 ↑
Psychological	22 (7.0)	147 (46.8)	145 (46.2)	74.9 ± 14.0 ↑
Social relationships	60 (19.0)	151 (47.9)	104 (33.0)	69.6 ± 19.4 ↓
Environment	11 (3.5)	124 (39.2)	181 (57.3)	77.9 ± 13.1 ↑
Total	17 (5.4)	144 (45.6)	146 (46.2)	73.3 ± 13.2

Since publication use of the WHOQOL-Brèf has rapidly risen. However, as yet no population norms have been published as a reference point against which researchers can interpret their findings. This study provides preliminary population norms for this purpose. Randomly sampled community residents from two studies were pooled and used to examine the properties of the WHOQOL-Brèf by age group, gender and health status. The results showed that general norms for the WHOQOL-Brèf domains were 73.5 (SD=18.1) for the Physical health domain, 70.6 (14.0) for Psychological wellbeing, 71.5 (18.2) for Social relationships and 75.1 (13.0) for the Environment domain. In general scores declined slightly by age group. For females scores were stable across the lifespan with an accelerated decline after the age of 60years. Males exhibited a more consistent and even decline across the lifespan. There were significant differences in WHOQOL-Brèf scores when reported by health status, with those in poor health obtaining scores that were up to 50% lower than those in excellent health. Effect sizes between different health status levels are reported. These preliminary norms and effect sizes may be used as reference points for interpreting WHOQOL-Brèf scores. They provide additional information to the numerous national studies already reporting on the validity of the WHOQOL-Brèf.



QUALITATIVE COMPONENTS

- i) Experiences of grey nomads living with chronic conditions;

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Research

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

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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 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.

Additional keywords: chronic disease, electronic medical records, older person, primary care, self-management, travel.

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- ii) Experiences of grey nomads living with a diagnosis of cancer;



EXPERIENCES OF GREY NOMADS LIVING WITH A DIAGNOSIS OF CANCER;

- Participants self nominated via the survey (18 of the 316 who completed the survey)
- Participants were contacted and consent to continue to participate in the study affirmed
- A series of 14 semi-structured, in-depth interviews were conducted over a period of six months with 14 self-identified grey nomads living with a diagnosis of cancer.
- Interviews were undertaken by telephone until data saturation was identified
- Interviews were analysed using inductive thematic analysis.



FINDINGS

- Interviews lasted between 28 and 42 minutes.
- Duration of most recent travel for these participants ranged from four months to 15 years.
- Participants defined travel as being:
 - on the road or living in a caravan/motorhome away from home
- Participants talked about travel and cancer in two key ways:
 - despite of; and
 - because of, their cancer diagnosis.



TRAVELLING DESPITE OF A CANCER DIAGNOSIS

- Expert at planning;
- Planning for ongoing treatment and for follow-up

It's just about planning things and just being aware of whatever ... If you stopped in a town for a little while and you knew you were going to be remote for a while, you just make sure you go to the doctor and get a new script and get a couple of repeats (Eric)

We tried to be back in Brisbane around Christmas every year ... when we were in the area to have any tests done that we needed to have done (Norma)



MANAGING CANCER TREATMENT ON THE ROAD: IT'S NOT A BIG IMPACT

- *.....the ongoing treatment maintains a vigilance and my ongoing medication [oral chemotherapy] keeps me on a level playing field ... I know I need to have the medication and I put in place strategies to deal with that ... (Clara).*
- *Thalidomide, being a controlled drug obviously, you had to organise from the hospital to send that through to you by post (Bettina).*
- *Well, my medication has to be refrigerated, so that had to be taken into consideration — that we had refrigeration or some way of keeping it cool — and those sorts of things. But it was not that big an impact (Andrea).*



CANCER FOLLOW-UP: JUST ANOTHER COMPONENT OF THE TRAVEL PLANS

- *It's not difficult. There's nothing to manage. You've got — as I said, the only thing I've got to worry about is getting the four monthly blood test — so my next blood test's not due for another three months now (Bettina).*
- *We just make appointments over the phone and then when they tell us we've got to be back in the Cairns area, we just make sure we're in a capital city and get a flight up. That's all (Debbie).*
- *I checked with my specialist before I left Adelaide and his comment was, when your mammogram's due, have one wherever you are and if the results are not good, give me a call (Freda).*



TRAVELLING BECAUSE OF A CANCER DIAGNOSIS

- The diagnosis of cancer - the catalyst for travel.
- *My diagnosis was — in a way it was a blessing that it happened because it was a wake-up call — made me change a lot of aspects of my life and made me realise that life is precious and that we should seize every opportunity to do the things that we want (Norma).*
- *.....suppose in some ways it made me think I don't have long to live, so therefore let's live life (Andrea).*



HEALTHFUL SURVIVORSHIP

We actually felt that our health all improved while we were travelling. ... I mean we were probably similarly active, but we felt that our health significantly improved while we were travelling — both physically and emotionally (Martha)

Going out and living life to the fullest, is going to make you a happier person, which is going to make your immune system stronger, which is going to make you more able to fight any further cancers (Norma).



DISCUSSION

- Participants engaged with a nomadic lifestyle as part of a healthful response to living on from and with cancer diagnosis
- Findings challenge those of Raven ⁽²⁰¹⁶⁾ and of Tate et al. ⁽²⁰⁰⁶⁾ reporting inadequate preparation for travelling, including lack of health summaries, inadequate medication supplies and unplanned hospital admissions.
- The way that grey nomads normalise life and live on after a cancer diagnosis and can successfully navigate their survivorship provides a new contribution to the literature.
- Participants demonstrated expertise in their planning and organisation. They integrated the work of cancer survivorship ^(Stephens et al 2014) with their everyday work of travel.



THE CONCEPT OF 'LIVING ON'

- The way that participants talked about the ordinariness of living with cancer and managing both cancer treatment and follow-up suggested that they have normalised their cancer survivorship as a component of their nomadic lifestyle.
- The concept of *living on* (Stephens 2012) sought to capture the 'going-on-ness' of participants' lives and the way in which they accommodate the disruptions and chaos created by the changes inherent in being a person diagnosed with a life-threatening or chronic condition.
- Participants chose a healthful lifestyle (Seedhouse 2009) in that they sought autonomy and chose to immerse themselves in the world.



REFERENCES

- Brayley N, Obst PL (2010) The Australian Grey Nomads – are they who we think they are? Enhancing formative research through the quantitative assessment of psychological constructs. *Health Promotion Journal of Australia* 21, 138–142. doi:10.1071/HE10138
- Calma, K, Halcomb, E & Stephens, M (2018) An exploration of the experiences of grey nomads travelling with chronic conditions. *Australian Journal of Primary Health* 24, 183–188
- Cridland S (2008) An analysis of the winter movement of grey nomads to northern Australia: planning for increase senior visitation. PhD thesis, James Cook University, Townsville, Qld, Australia.
- Halcomb E, Stephens M, Smyth E, Meedy S & Tillot S. (2017) The health and health preparation of long-term Australian travellers. *Australian Journal of Primary Health* 23(4), 386–390.
- Hillman W (2013) Grey Nomads travelling in Queensland, Australia: social and health needs. *Ageing and Society* 33, 579–597. doi:10.1017/S0144686X12000116 Holloway DJ (2009) Grey nomads: retirement, leisure and travel in the Australian context. PhD thesis, Edith Cowan University, Perth, WA, Australia.
- Onyx J & Leonard R. (2007) The grey nomad phenomenon: changing the script of aging. *International Journal of Aging & Human Development*; 64(4):381–98 18p.
- Raven M. (2016) Health of grey nomads: On the move and under the health sector radar. *Australian Journal of Rural Health*; 24(3):182–7.
- Seedhouse D. (2009) *Ethics: The Heart of Health Care*. 3rd ed. Sons Wa, editor Wiley and Sons, Chichester, West Sussex,
- Stephens M. (2012) *Living on: A Qualitative Study of the Experience of Living with Multiple Myeloma*. University of Sydney, Sydney, Australia,
- Stephens M, McKenzie H & Jordens CFC (2014) .The work of living with a rare cancer: multiple myeloma. *Journal of Advanced Nursing*; 70(12):2800–9.Halcomb
- Tate J, Mein J, Freeman H & Maguire G. (2006) Grey nomads — health and health preparation of older travellers in remote Australia. *Australian Family Physician*; 35(1–2):70–2.

