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The well-being of carers of older Aboriginal people living in the Kimberley region of remote Western Australia: Empowerment, depression, and carer burden

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The wellbeing of carers of older Aboriginal people living in the Kimberley region of remote Western Australia: Empowerment, depression and carer burden.

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Abstract

Objective: To describe demographic features and wellbeing of carers of Aboriginal Australians aged ≥ 45 years in remote Western Australia.

Methods: Carer burden, empowerment, and depression were assessed in 124 Aboriginal carers in four remote Aboriginal communities.

Results: Carers were aged 38.8 ± 15.0 years, 73.4% were female, and 75.8% were children or grandchildren of the person cared for. The mean Zarit-6 score was 3.7 ± 3.6 . Attending high school (OR=0.3; 95% CI 0.1, 0.7) and feeling empowered (OR=0.2; 95% CI 0.1, 0.8) were inversely associated with carer burden; female carers were less likely to feel empowered (OR=0.4; 95% CI 0.2, 0.9); and empowerment was inversely associated with depression (OR=0.3; 95% CI 0.1, 0.7).

Discussion: Aboriginal carers in remote communities are relatively young and most are children or grandchildren. Carer burden was lower than anticipated. However, existing tools may not adequately measure Aboriginal perspectives. Education and empowerment are key factors which support programs must consider.

Key words: Aboriginal, carers, older people, carer burden, empowerment, Indigenous

Introduction

Aboriginal and Torres Strait Islander peoples are ageing, with the proportion of older people predicted to double by 2025 (ABS, 2013). Aboriginal and Torres Strait Islander peoples experience a burden of disease and injury more than twice that of all Australians, due to high rates of multi-morbidity and chronic illness, and inequitable social and environmental factors based on a long history of traumatic policy decisions and racism (Vos, Barker, Begg, Stanley, & Lopez, 2009). Recent research has highlighted high rates of dementia and frailty occurring at a younger age than expected (Hyde et al., 2016; Lo Giudice et al., 2016). Other conditions such as functional disability and mental illness are disproportionately higher in Aboriginal and Torres Strait Islander communities (Randall, Lujic, Havard, Eades, & Jorm, 2018; Vos et al., 2009). Carers of those with dementia, frailty, mental health disabilities, chronic conditions and those requiring palliative care, often experience high levels of carer burden and depression (Bom, Bakx, Schut, & van Doorslaer, 2018; Brodaty, Woodward, Boundy, Ames, & Balshaw, 2014; Choi & Seo, 2019; Lambert et al., 2017). However, there is limited data for Aboriginal and Torres Strait Islander peoples, particularly those living in remote and regional areas where factors such as overcrowded housing, poor health linkages, financial barriers and poor service access may contribute to carer burden (Broe & Jackson-Pulver, 2007; Carroll et al., 2010).

As we have previously reported, carers of older Aboriginal Australians with dementia living in remote communities report considerable stress (Smith et al., 2011). Carers describe fulfilling multiple roles, including looking after several family members and maintaining cultural responsibilities. Limited services often culminate in a sense of isolation. In order to understand the carer role in Aboriginal and Torres Strait Islander communities, the importance of place and country as a “site of customary and relational belonging” must be considered, as well as traditional and cultural factors and responsibilities (Browne et al., 2014; Dal Bello-Haas, Cammer, Morgan, Stewart, & Kosteniuk, 2014; Jervis, Jackson, & Manson, 2002; Kerse, Lapsley, Moyes, Mules, & Edlin, 2016). Caring for an older family member at home enables that person to continue to fulfil their important cultural role as an Elder¹, benefiting the whole family.

¹ It should be noted that Aboriginal people focus on maturity and life stage rather than chronological age, and that Elders and older people are not always one and the same (Lohoar, Butera, & Kennedy, 2014).

Multiple caring roles, frequent deaths within families, illnesses and accidents may impact on carer morale and wellbeing, with mental health issues such as depression being more clinically significant (Almeida et al., 2014) and less likely to be detected in remote communities (Senate Select Committee on Mental Health, 2006). Further burden stems from desire to support older people to remain in their communities (Ganesharajah, 2009; McGrath, 2006), because for many older people, returning to their country at their end of life has significant spiritual and cultural importance. This may not always be possible due to lack of appropriate services, and can lead to distress for both the person requiring residential care away from community and their carers.

Models which take into account the multiple interactions within the social, economic, psychological and physical aspects of caregiving have been developed (Pearlin, Mullan, Semple, & Skaff, 1990; Ying, Yap, Gandhi, & Liew, 2018). Programs and interventions with the aim of alleviating carer burden and depression and enhancing wellbeing and quality of life, particularly for carers of people with dementia, have been undertaken successfully (Gilhooly et al., 2016). However, relatively little research has been conducted with regard to the needs of Aboriginal and Torres Strait Islander carers living within their communities, and other First Nation peoples internationally (Hokanson, Quinn, Schüz, de Salas, & Scott, 2018). Programs most likely to be successful in these communities are those with a Community Based Participatory Action Research (CBPAR) approach, which take into account culture and tradition and are based on genuine collaboration in design and implementation (Wallerstein & Duran, 2010). Community-based approaches lead to a greater sense of empowerment and wellbeing (Haynes et al., 2019; Laliberte, Haswell, & Tsey, 2012). However, before culturally-responsive programs for carers can be developed and evaluated, the unique needs of this population must be understood.

Important attributes in managing the carer role include resilience and empowerment, and the mastery of skills such as problem solving and adaptation as necessary (Chan, Glass, Chua, Ali, & Lim, 2018; Petriwskyj, Parker, O'Dwyer, Moyle, & Nucifora, 2016; Sakanashi & Fujita, 2017; Teahan et al., 2018). Conversely, depression, anxiety, and perceived burden (Petriwskyj et al., 2016), are frequently measured outcomes in carer research and inversely

related to positive notions of health, resilience and empowerment. For Aboriginal and Torres Strait Islander Australians, the concept of empowerment has been commonly used in health as a strengths-based approach to healing and recovery in the socio-political setting of years of trans-generational trauma, racism, and social disadvantage (Fogarty, Lovell, Langenberg, & Heron, 2018).

This is the first study addressing the wellbeing of a representative group of carers of older Aboriginal people living in remote Western Australia. The data reported in this study are from a cluster randomised controlled trial called “Strong Carers Strong Communities; Keeping Kimberley Spirit Strong” addressing the needs of carers of older Aboriginal people utilising a CBPAR approach. In this paper we describe the demographic features of carers of people aged ≥ 45 years living in remote communities. Additionally, we describe levels of carer burden, depression and sense of empowerment in this group and measure their associations with carer demographics and care recipient functional needs and service usage. Hypothesising that the characteristics of Aboriginal carers would differ from their non-Aboriginal counterparts (owing to lack of appropriate services in remote areas and high disease burden at younger ages which may affect carer availability), we aimed to determine factors which can inform the development of culturally-appropriate services.

Methods

Setting and participants

This study was undertaken in four communities (Ardyaloon, Looma, Warmun, and Wirrimanu) located in the Kimberley region of Western Australia. These communities were involved in a previous cohort study undertaken by the research team, called the Kimberley Healthy Adults Project (KHAP), documenting physical, mental and functional needs of people aged ≥ 45 years (Lo Giudice et al., 2016). The KHAP is a population-based study that utilised a semi-purposeful sampling strategy to ensure representative coverage of the diverse language and cultural groups of the region. In each community, all people aged ≥ 45 years were invited to participate, with a response fraction of 74% achieved. In this study, carers were identified from KHAP participants and from lists provided by community-based aged care programs and local health clinics. In addition, a snowballing process was utilised asking community members “who else looks after this person?” until a representative cohort of carers were identified. These findings represent the baseline characteristics of participants in a cluster randomised trial undertaken to optimise carer wellbeing and empowerment.

Study design

Research assistants (CJ and RM) administered a structured questionnaire to carers. The engagement with communities and individuals was facilitated by research assistant RM who is a Kija Aboriginal woman from the region. The following domains were assessed:

- (i) Demographic details of the carer and care recipient, including the care recipient’s main health problems;
- (ii) Assistance provided by the carer to the care recipient for functional activities;
- (iii) Use of services including the community clinic, community aged care services, mental health services, hospital, carers respite, disability services, drug and alcohol services, family, friends, and traditional healer;
- (iv) Carer burden - a 6-item questionnaire adapted from the Zarit-6 (Bédard et al., 2001; Higginson, Gao, Jackson, Murray, & Harding, 2010) comprising questions with a 5-item Likert response scale (*never, little bit, sometimes, a lot, nearly always*), with a possible total

score of 30. A score ≥ 9 indicates high levels of caregiving-related burden (Yu, Yap, & Liew, 2019). Face validity of the tool was assessed to ensure cultural and linguistic appropriateness;

(v) KICA-Dep (Kimberley Indigenous Depression Scale) - adapted from the Patient Health Questionnaire and previously validated as a screening tool for depression in the region. The tool is an 11-item questionnaire, in which a score ≥ 8 out of a possible total of 33 points indicates caseness (Almeida et al., 2014). Where participants scored as caseness or indicated potential self-harm, research assistants facilitated referral to local mental health services;

(vi) The Growth and Empowerment Measure (GEM), which measures dimensions of empowerment important to Aboriginal and Torres Strait Islander Australians (Haswell et al., 2010). The wording was adapted with an Aboriginal reference group for local Kimberley language and culture. The GEM comprises two sections:

(a) a 14-item Emotional Empowerment Scale (EES-14) that aims to determine “the way you usually feel about yourself most of the time” with a Likert scale from 1 (least positive) to 5 (most positive), and mean total score ranging from 1-5 calculated;

(b) 12 empowerment scenarios (12S) which measures functional aspects of empowerment. A 6-item short form (Core6) of the 12S previously derived from confirmatory factor analysis (Fitzpatrick et al., 2019) with a mean total score ranging from 1-7 was calculated.

Higher GEM scores indicate greater empowerment.

Ethics

Approval to conduct this study was obtained from the communities involved; the Kimberley Aboriginal Medical Services Council; Kimberley Aboriginal Health Planning Forum Research Subcommittee; the Human Research Ethics Committee of the University of Western Australia; and the WA Aboriginal Health Ethics Committee. All participants provided written informed consent.

Statistical analysis

We analysed the data with the Stata statistical package, version 11.2 (StataCorp, College Station, Texas). Data for participants are presented as means and standard deviations for continuous variables, and as proportions for categorical variables. Missing data were not excluded when calculating proportions (i.e., the denominator is the entire sample) to avoid over-estimation. We used Pearson's Chi square test to investigate associations between categorical variables, and the Mann-Whitney U test and Kruskal-Wallis equality-of-populations rank test for continuous variables. We used binary logistic regression analyses to explore factors associated with the outcomes of carer burden, empowerment, and depression. For each outcome, we initially entered all variables which were significant into a multivariable model, and then removed non-significant covariates in a manual, backwards manner. We used Hosmer and Lemeshow's goodness-of-fit test to assess model fit. For all statistical tests, we considered p values <0.05 statistically significant.

Results

Demographics of carers and care recipients

Table 1 shows the socio-demographic characteristics of the carers. There were 124 carers who participated, aged between 18-88 years, with mean age of 38.8 ± 15.0 years. Three-quarters of carers were female, and almost all (97.6%) identified as Aboriginal (with none identifying as Torres Strait Islander). Eighty-one percent of carers were aged <50 years and only one-fifth completed high school, although the majority (92.7%) completed primary school. Fifty-two (41.9%) carers were children of the care recipient, 42 (33.9%) were grandchildren, and 58.1% of carers lived with the care recipient. Six people had been carers for less than 1 year, while the remainder had been a carer for a mean period of 8.6 ± 8.4 years (range: 1-54 years). Twenty-three people (18.5%) had been carers for more than 10 years, and 32.3% cared for more than one person.

The majority (82.3%) of care recipients were aged ≥ 60 years, and 94 (75.8%) were female. The leading health problems reported were chronic illness (52.4%), dementia/cognitive impairment (36.3%), frailty (33.1%), and physical disability (30.7%). Functional assistance provided by carers is described in Table 1. Carers were assisting with an average of 8.0 ± 1.7 activities of daily living. Services used by the person being cared for are shown in Table 2. An average of 6.6 ± 2.2 services were used. Use of the community clinic, the only medical service within the community, was universal. Similarly, most people had made contact with community aged care services.

Carer burden, depression and sense of empowerment

The mean adapted Zarit-6 score was 3.7 ± 3.6 , with 20.2% of participants not describing any sense of carer burden, and 11.3% scoring ≥ 9 on the scale. Less than 5% answered “a lot” or “nearly always” to the questions comprising the scale, except for the item “You don’t have enough time to do things for yourself”, in which 6.5% responded in the affirmative. The percentage of carers who answered either a “little bit” or “sometimes” are as follows: “Don’t have enough time to do things for yourself” (27%); “It’s too much humbug (too stressful) looking after the person when you have other responsibilities” (16.2%); “Feel upset or bothered when with the person” (22.6%); “The person is affecting your relationship with

partner, family and friends” (7.7%); “Looking after the person has affected your health” (8.9%); and “Looking after the person has taken over your life” (8.5%).

The mean KICA-Dep score was relatively low at 4.5 ± 3.7 . However, 16.9% scored ≥ 8 , indicating clinically relevant depressive symptoms. There were significant differences between the mean scores for carer burden, EES-14, Core6, and KICA-Dep between carers of the four communities, with carers in Wirrimanu expressing greater carer burden, carers in Ardyaloon expressing overall greater sense of empowerment, and those in Looma reporting greater depressive symptoms (Table 3).

Factors associated with carer burden, empowerment and depression

Logistic regression analyses were conducted to determine associations with carer burden, EES-14, and Core6 score in the highest quartile, and KICA-Dep score ≥ 8 . In multivariable models, carers who attended high school (OR=0.3; 95% CI 0.1, 0.7) or reported greater empowerment as measured by Core6 score in the highest quartile (OR=0.2; 95% CI 0.1, 0.8) were less likely to have a high carer burden score. Carers who were female (OR=0.4; 95% CI 0.2, 0.9) or had higher KICA-Dep scores (OR=0.8; 95% CI 0.7, 0.9) were less likely to feel empowered as measured by the EES-14. Those with a lower sense of carer burden (OR=0.8; 95% CI 0.7, 0.9) or higher score on the EES-14 (OR=7.2; 95% CI 2.2, 23.7), were more likely to have a Core6 score in the highest quartile. Finally, those carers reporting a higher sense of empowerment as measured by the EES-14 (OR=0.3; 95% CI 0.1, 0.7) were less likely to score ≥ 8 on the KICA-Dep. There were no associations with carer age, age or sex of care recipient, time caring for the person, functional impairment, or number of services used with any of the outcome measures. Additionally, there were no significant differences in any of the outcome measures in the case of dementia being present in the person cared for (data not shown).

Discussion

Aboriginal carers of older people living in remote communities in Western Australia have a different profile to their non-Aboriginal counterparts, being on average 10-15 years younger, and three-quarters identifying as children or grandchildren of the person cared for (compared with one-quarter in the general population). As in most populations, carers were more commonly female, although the proportion appeared higher: 75% compared to 56% nationally (ABS, 2015). Almost half described undertaking their carer role for over six years and 20% for 10 years or more. On average they provided assistance with eight activities of daily living.

The younger age of Aboriginal carers in remote areas has been previously documented (Hill, Cass, Newton, & Valentine, 2012). This is in keeping with earlier onset of disability and illness (such as dementia and frailty) in care recipients, as well as the overall younger demographic of Aboriginal and Torres Strait Islander peoples (ABS, 2013) compared with the general population. One-third of carers reported that they did not have enough time for themselves, indicating they provided a high level of assistance. In addition, one-third of carers reported caring for others in the community, reflecting the multiple roles that carers play.

Carer burden was measured by an adapted Zarit-6 scale. The Zarit-6 has been shown to be an effective screen for carer burden, including in the setting of dementia (Bédard et al., 2001). Compared to other populations, carer burden appeared relatively low with an average score of 3.7. One-fifth of carers described no sense of carer burden, and only 11.3% scored ≥ 9 on the scale, which has been identified as the optimal cut-off for high levels of caregiving-related burden (Yu et al., 2019). In contrast, in a review by Higgison (2010), mean Zarit-6 scores were noted as 6.4 for carers of those with cancer, 8.2 for carers of those with dementia and 12.3 for those who cared for people with acquired brain injury. Those interviewed for our study were carers for a heterogeneous group of conditions, including dementia, frailty, chronic illnesses, intellectual disability, and combinations of these, hence numbers in many categories were small. However, overall this population of carers reported less burden than those in other studies which have used the Zarit-6. In particular, the Zarit-6 burden score for

people caring for those with dementia was similar to other carers and substantially lower than reported elsewhere (Higginson et al., 2010).

Several reasons may explain the low scores in our study. Firstly, Aboriginal and Torres Strait Islander peoples may not identify as carers in the same way as other populations, and view the caring role as an integral part of family life (Hill et al., 2012). Secondly, carers may have minimised their reports of burden due to social desirability bias, potentially exacerbated by the face-to-face questionnaire. Additionally, those who felt most burdened by their role may have been reluctant to participate in the study due to their caring responsibilities.

Alternatively, the Western concept of carer burden may not capture the complete picture for Aboriginal carers, where culture, land and place, traditions, community and spirituality are essential contributors to carer general wellbeing (Arkles, Jankelson, Radford, & Jackson Pulver, 2018; Gibson, Crockett, Dudgeon, Bernoth, & Lincoln, 2018). A culturally-responsive tool to assess carer burden which is developed from a community perspective and not simply adapted for language is required.

Our findings showed that carers who attended high school were less likely to score highly on the Zarit-6 scale. The majority of carers in our study completed primary school, but only one-fifth completed high school. A multinational review of burden in carers of those with dementia living in low-middle income countries did not demonstrate an association between carers' level of education and sense of burden as measured by the Zarit Burden Index (Prince et al., 2012). This finding was replicated in a large multi-ethnic study in Singapore addressing carer burden for older people with multiple disabilities (not only dementia), and in which 41% had completed high school (Vaingankar, Chong, Abdin, Picco, Jeyagurunathan et al., 2016). However, a Spanish-based study of carers of people with dementia, found that adult children who were live-in carers were less likely to be married, received a lower level of education, used fewer external resources, and expressed higher sense of burden (Vinas-Diez et al., 2017).

Educational disadvantage is significant in Aboriginal communities, particularly for remote and rural communities, and may be associated with lower health literacy and higher rates of

disability (Edwards, Gray, Baxter, & Hunter, 2009). People with lower education levels are less likely to be employed and therefore more likely to take on the role of carer if others in their family are unavailable. This situation may limit opportunities for further vocational education and training, reinforcing a cycle of disadvantage. It is interesting that carers who reported a stronger sense of empowerment were less likely to score highly on carer burden. This might reflect better coping mechanisms in their role as carers, possibly through pathways associated with health literacy. Further exploration of the association between lower educational attainment and higher carer burden observed in this study is required, and could help identify more effective ways of providing support.

Carers' depression scores were generally low (with a mean score of 4.5 out of a possible 33), suggesting that a high level of depressive symptoms were not experienced by most carers. However, 17% of carers reported scores ≥ 8 , indicating a high prevalence of likely clinical depression. Our previous research in remote Aboriginal communities found a similar prevalence (22% scoring ≥ 8) among both carers and non-carers aged ≥ 45 years (Almeida et al., 2014). Surprisingly, depression scores were not associated with carer demographics, time spent caring, or number of services used. This could suggest that other, more general community factors may have contributed to the high proportion of individuals with depression, such as multiple stressful life events, lack of services, and high rates of poor health in carers themselves.

Observational studies of carers document high rates of psychological co-morbidity. For example, in a multi-ethnic community in Singapore, 8.8% of informal caregivers were identified with non-psychotic psychological symptoms. The factors associated with psychological morbidity in that study included care recipient behavioural and psychological symptoms of dementia, and marital status (Vaingankar, Chong, Abdin, Picco, Shafie et al., 2016). In our study, depressive symptoms were significantly higher in those caring for someone recognised as frail by the carer (mean 5.5 vs 4.0), but not for other conditions, including dementia. Ringer et al. (2016) recently reported that physical frailty is a significant contributor to carer anxiety and depression. However, high quality data on carer burden and frailty is lacking compared with dementia.

We found that depression was associated with lower sense of empowerment. Empowerment and depression are interlinked (Berry, Crowe, Deane, Billingham, & Bhagerutty, 2012; Haswell et al., 2010), and those who feel disempowered are less likely to be able to strategise and cope with the role of carer and vice versa. In our study, females reported a lower sense of empowerment, consistent with the overall carer literature. Women often bear the burden of informal caring, commonly related to traditional and cultural factors and higher levels of socioeconomic disadvantage (Alpass et al., 2013; Bom et al., 2018). Women are often caught in the middle of multiple caring roles, and the support afforded by a parent or grandparent may be unavailable if the latter are themselves disabled or cognitively impaired. The multiple losses experienced by Aboriginal and Torres Strait Islander people is associated with higher levels of stressors and mental health problems, and depression has been found to be more prevalent among Aboriginal women than men in the Kimberley (Almeida et al., 2014). Effective management of depression or carer burden will likely require strategies that incorporate ways to optimise sense of empowerment at both the individual and community level.

Cognitive impairment including dementia was the second most common health problem identified, affecting over one-third of care recipients. This is noteworthy, because of the unique and often stressful challenges experienced by carers of people with dementia (for example, managing behavioural and psychological symptoms of dementia), and the increased risk of requiring residential care. Dementia is five times more prevalent among Aboriginal Australians compared with their non-Aboriginal counterparts, yet service provision to this population is poor. We have previously documented that carers in remote Aboriginal communities are struggling to cope and have requested better, and culturally safer, community care (Smith et al., 2011). Strategies to improve care have been identified and successfully trialled in a pilot model for disability and aged care in this population (LoGiudice et al., 2012). This model could serve as a template for both policy makers and service providers and help reduce carer burden.

While the community clinic and community aged care services were well-utilised, in practice these services are limited by under-resourcing and, especially for aged care services, long distances from the remote communities served. Other barriers such as lack of education and training, intolerant workforce attitudes, insufficient interpreting services, and a lack of clear clinical pathways and protocols negatively impact service provision (Smith et al., 2011).

Thus, while some services were well-utilised this may reflect lack of choice, and not necessarily satisfaction with service providers. We did not measure satisfaction with services received in this study, but have noted in previous work there is significant scope to improve service delivery in this region (Smith et al., 2011). Still, given ubiquitous use of the community clinic and high prevalence of depression identified, relatively simple interventions such as depression screening could be of benefit. However, this will require appropriate service provision to make a difference. Screening for mental health problems will be of limited benefit unless appropriate services are available. Unfortunately, mental health services were accessed by only 16% of care recipients, despite cognitive impairment and dementia being the second most common health issue identified.

The strength of this study is that it describes a representative group of carers living in remote Aboriginal communities in Western Australia, derived from a previous community-based survey of people aged ≥ 45 years. Additionally, the outcome measures for depression and empowerment were adapted and validated for Aboriginal and/or Torres Strait Islander people. Limitations include the single geographic focus and relatively small sample size. With regard to the latter, this may explain why we did not find statistically significant associations between factors such as time spent in the caring role and carer burden. Larger studies are needed to further explore factors associated with carer wellbeing. Additionally, the Zarit-6 was adapted for language only and may not fully capture the concerns and responsibilities of Aboriginal carers.

Our findings suggest that carer support programs should focus on predominantly younger women caring for their parents or grandparents, and often undertaking multiple caring roles. One such program has already arisen from the high number of referrals of female participants from one remote community to the Kimberley Mental Health and Drug Service. A weekly women's craft group was formed, incorporating a weekly visit by the town-based mental health worker. Support for Aboriginal carers requires an empowering, holistic approach, responsive to traditional ways of seeking help and support, including traditional healers, given that one-third of carers had approached them for support.

In conclusion, this study provides insight for the planning of future support for Aboriginal carers. Depression and empowerment are inversely related; hence education and support to improve confidence in seeking support, feeling strong in self, and feeling supported by the community are key factors policy makers must consider when addressing the needs of carers.

References

- ABS. (2013). Estimates of Aboriginal and Torres Strait Islander Australians, 2011. Canberra: Australian Bureau of Statistics.
- ABS. (2015). Disability, Ageing and Carers, Australia. Canberra: Australian Bureau of Statistics.
- Almeida, O. P., Flicker, L., Fenner, S., Smith, K., Hyde, Z., Atkinson, D., et al. (2014). The Kimberley assessment of depression of older Indigenous Australians: prevalence of depressive disorders, risk factors and validation of the KICA-dep scale. *PLoS One*, 9(4), e94983. doi: 10.1371/journal.pone.0094983
- Alpass, F., Pond, R., Stephens, C., Stevenson, B., Keeling, S., & Towers, A. (2013). The influence of ethnicity and gender on caregiver health in older New Zealanders. *J Gerontol B Psychol Sci Soc Sci*, 68(5), 783-793. doi: 10.1093/geronb/gbt060
- Arkles, R., Jankelson, C., Radford, K., & Jackson Pulver, L. (2018). Family caregiving for older Aboriginal people in urban Australia: Disclosing worlds of meaning in the dementia experience. *Dementia (London)*, Advance online publication. doi: 10.1177/1471301218776761
- Bédard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit Burden Interview. *The Gerontologist*, 41(5), 652-657. doi: 10.1093/geront/41.5.652
- Berry, S. L., Crowe, T. P., Deane, F. P., Billingham, M., & Bhagerutty, Y. (2012). Growth and Empowerment for Indigenous Australians in Substance Abuse treatment. *Int J Ment Health Addiction*, 10, 970-983.
- Bom, J., Bakx, P., Schut, F., & van Doorslaer, E. (2018). The Impact of Informal Caregiving for Older Adults on the Health of Various Types of Caregivers: A Systematic Review. *Gerontologist*, Advance online publication. doi: 10.1093/geront/gny137
- Brodady, H., Woodward, M., Boundy, K., Ames, D., & Balshaw, R. (2014). Prevalence and predictors of burden in caregivers of people with dementia. *Am J Geriatr Psychiatry*, 22(8), 756-765. doi: 10.1016/j.jagp.2013.05.004
- Broe, A., & Jackson-Pulver, L. (2007). Aboriginal ageing: is there such a thing? Sydney: University of NSW.
- Browne, C. V., Mokuau, N., Ka'opua, L. S., Kim, B. J., Higuchi, P., & Braun, K. L. (2014). Listening to the Voices of Native Hawaiian Elders and 'Ohana Caregivers: Discussions on Aging, Health, and Care Preferences. *Journal of Cross Cultural Gerontology*, 29(2), 131-151. doi: 10.1007/s10823-014-9227-8.
- Carroll, E., Smith, K., Flicker, L., LoGiudice, D., Shadforth, G., Ralph, N., et al. (2010). Indigenous services study: Lungurra Ngoora Community Care final report. Perth: Western Australian Centre for Health and Ageing, University of Western Australia.
- Chan, E. Y., Glass, G., Chua, K. C., Ali, N., & Lim, W. S. (2018). Relationship between Mastery and Caregiving Competence in Protecting against Burden, Anxiety and Depression among Caregivers of Frail Older Adults. *The Journal Of Nutrition, Health & Aging*, 22(10), 1238-1245. doi: 10.1007/s12603-018-1098-1
- Choi, S., & Seo, J. (2019). Analysis of caregiver burden in palliative care: An integrated review. *Nurs Forum*, 54(2), 280-290. doi: 10.1111/nuf.12328
- Dal Bello-Haas, V. P., Cammer, A., Morgan, D., Stewart, N., & Kosteniuk, J. (2014). Rural and remote dementia care challenges and needs: perspectives of formal and informal care providers residing in Saskatchewan, Canada. *Rural Remote Health*, 14(3), 2747. doi: 2747 [pii]

- Edwards, B., Gray, M., Baxter, J., & Hunter, B. (2009). *The tyranny of distance? Carers in regional and remote areas of Australia*. Deakin: Carers Australia.
- Fitzpatrick, S. A., Haswell, M. R., Williams, M. M., Nathan, S., Meyer, L., Ritchie, J. E., et al. (2019). Learning about Aboriginal health and wellbeing at the postgraduate level: novel application of the Growth and Empowerment Measure. *Rural Remote Health*, 19(2), 4708. doi: 4708 [pii]
10.22605/RRH4708
- Fogarty, W., Lovell, M., Langenberg, J., & Heron, M.-J. (2018). Deficit Discourse and Strengths-based Approaches: Changing the Narrative of Aboriginal and Torres Strait Islander Health and Wellbeing. Carlton South: Lowitja Institute.
- Ganesharajah, C. (2009). *Indigenous Health and Wellbeing: The Importance of Country*. Canberra: Native Title Research Unit, Australian Institute of Aboriginal and Torres Strait Islander Studies.
- Gibson, C., Crockett, J., Dudgeon, P., Bernoth, M., & Lincoln, M. (2018). Sharing and valuing older Aboriginal people's voices about social and emotional wellbeing services: a strength-based approach for service providers. *Aging Ment Health*, Advance online publication. doi: 10.1080/13607863.2018.1544220
- Gilhooly, K. J., Gilhooly, M. L., Sullivan, M. P., McIntyre, A., Wilson, L., Harding, E., et al. (2016). A meta-review of stress, coping and interventions in dementia and dementia caregiving. *BMC Geriatr*, 16, 106. doi: 10.1186/s12877-016-0280-8
- Haswell, M. R., Kavanagh, D., Tsey, K., Reilly, L., Cadet-James, Y., Laliberte, A., et al. (2010). Psychometric validation of the Growth and Empowerment Measure (GEM) applied with Indigenous Australians. *Aust N Z J Psychiatry*, 44(9), 791-799. doi: 10.3109/00048674.2010.482919
- Haynes, E., Marawili, M., Marika, B. M., Mitchell, A. G., Phillips, J., Bessarab, D., et al. (2019). Community-based participatory action research on rheumatic heart disease in an Australian Aboriginal homeland: Evaluation of the 'On track watch' project. *Eval Program Plann*, 74, 38-53. doi: 10.1016/j.evalproplan.2019.02.010
- Higginson, I. J., Gao, W., Jackson, D., Murray, J., & Harding, R. (2010). Short-form Zarit Caregiver Burden Interviews were valid in advanced conditions. *J Clin Epidemiol*, 63(5), 535-542. doi: 10.1016/j.jclinepi.2009.06.014
- Hill, T., Cass, B., Newton, B., & Valentine, K. (2012). *Indigenous Carers*. Canberra: Department Social Services, Commonwealth of Australia.
- Hokanson, L., Quinn, M. G., Schüz, N., de Salas, K., & Scott, J. (2018). A systematic review of Indigenous caregiver functioning and interventions. *Quality Of Life Research: An International Journal Of Quality Of Life Aspects Of Treatment, Care And Rehabilitation*, 27(8), 2007-2017. doi: 10.1007/s11136-018-1836-1
- Hyde, Z., Flicker, L., Smith, K., Atkinson, D., Fenner, S., Skeaf, L., et al. (2016). Prevalence and incidence of frailty in Aboriginal Australians, and associations with mortality and disability. *Maturitas*, 87, 89-94. doi: 10.1016/j.maturitas.2016.02.013
- Jervis, L., Jackson, M., & Manson, S. (2002). Need for, Availability of, and Barriers to the Provision of Long-Term Care Services for Older American Indians. *J Cross Cult Gerontol*, 17(4), 295-311. doi: 10.1023/A:1023027102700
- Kerse, N., Lapsley, H., Moyes, S., Mules, R., & Edlin, R. (2016). *Health, Independence and Caregiving in Advanced Age: Findings from LiLACS NZ*. Auckland: School of Population Health, The University of Auckland.
- Laliberte, A., Haswell, M., & Tsey, K. (2012). Promoting the health of Aboriginal Australians through empowerment: eliciting the components of the family well-being empowerment and leadership programme. *Glob Health Promot*, 19(4), 29-40. doi: 10.1177/1757975912464247

- Lambert, S. D., Bowe, S. J., Livingston, P. M., Heckel, L., Cook, S., Kowal, P., et al. (2017). Impact of informal caregiving on older adults' physical and mental health in low-income and middle-income countries: a cross-sectional, secondary analysis based on the WHO's Study on global AGEing and adult health (SAGE). *BMJ Open*, 7(11), e017236. doi: 10.1136/bmjopen-2017-017236
- Lo Giudice, D., Smith, K., Fenner, S., Hyde, Z., Atkinson, D., Skeaf, L., et al. (2016). Incidence and predictors of cognitive impairment and dementia in Aboriginal Australians: A follow-up study of 5 years. *Alzheimers Dement*, 12(3), 252-261. doi: 10.1016/j.jalz.2015.01.009
- LoGiudice, D. C., Smith, K., Shadforth, G., Lindeman, M., Carroll, E., Atkinson, D., et al. (2012). Lungurra Ngoora - a pilot model of care for aged and disabled in a remote Aboriginal community - can it work? *Rural Remote Health*, 12, 2078. doi: 2078 [pii]
- Lohoar, S., Butera, N., & Kennedy, E. (2014). *Strengths of Australian Aboriginal cultural practices in family life and child rearing*. Melbourne: Australian Institute of Family Studies.
- McGrath, P. (2006). Exploring Aboriginal people's experience of relocation for treatment during end-of-life care. *Int J Palliat Nurs*, 12(3), 102-108.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist*, 30(5), 583-594.
- Petriwskyj, A., Parker, D., O'Dwyer, S., Moyle, W., & Nucifora, N. (2016). Interventions to build resilience in family caregivers of people living with dementia: a comprehensive systematic review. *JBI Database System Rev Implement Rep*, 14(6), 238-273. doi: 10.11124/jbisrir-2016-002555
- Prince, M., Brodaty, H., Uwakwe, R., Acosta, D., Ferri, C. P., Guerra, M., et al. (2012). Strain and its correlates among carers of people with dementia in low-income and middle-income countries. A 10/66 Dementia Research Group population-based survey. *Int J Geriatr Psychiatry*, 27(7), 670-682. doi: 10.1002/gps.2727
- Randall, D. A., Lujic, S., Havard, A., Eades, S. J., & Jorm, L. (2018). Multimorbidity among Aboriginal people in New South Wales contributes significantly to their higher mortality. *Med J Aust*, 209(1), 19-23.
- Ringer, T., Hazzan, A. A., Kennedy, C., Karampatos, S., Patterson, C., Marr, S., et al. (2016). Care recipients' physical frailty is independently associated with subjective burden in informal caregivers in the community setting: a cross-sectional study. *BMC Geriatr*, 16. doi: 10.1186/s12877-016-0355-6
- Sakanashi, S., & Fujita, K. (2017). Empowerment of family caregivers of adults and elderly persons: A concept analysis. *Int J Nurs Pract*, 23(5). doi: 10.1111/ijn.12573
- Senate Select Committee on Mental Health. (2006). Chapter 16 - Services for rural, remote and indigenous Australians *A national approach to mental health - from crisis to community. First Report*. Canberra: Commonwealth of Australia.
- Smith, K., Flicker, L., Shadforth, G., Carroll, E., Ralph, N., Atkinson, D., et al. (2011). 'Gotta be sit down and worked out together': views of Aboriginal caregivers and service providers on ways to improve dementia care for Aboriginal Australians. *Rural Remote Health*, 11(2), 1650. doi: 1650 [pii]
- Teahan, A., Lafferty, A., McAuliffe, E., Phelan, A., O'Sullivan, L., O'Shea, D., et al. (2018). Resilience in family caregiving for people with dementia: A systematic review. *International Journal Of Geriatric Psychiatry*, 33(12), 1582-1595. doi: 10.1002/gps.4972
- Vaingankar, J. A., Chong, S. A., Abidin, E., Picco, L., Jeyagurunathan, A., Zhang, Y., et al. (2016). Care participation and burden among informal caregivers of older adults with

- care needs and associations with dementia. *Int Psychogeriatr*, 28(2), 221-231. doi: 10.1017/s104161021500160x
- Vaingankar, J. A., Chong, S. A., Abdin, E., Picco, L., Shafie, S., Seow, E., et al. (2016). Psychiatric morbidity and its correlates among informal caregivers of older adults. *Compr Psychiatry*, 68, 178-185. doi: 10.1016/j.comppsy.2016.04.017
- Vinas-Diez, V., Turro-Garriga, O., Portellano-Ortiz, C., Gascon-Bayarri, J., Rene-Ramirez, R., Garre-Olmo, J., et al. (2017). Kinship and cohabitation in relation to caregiver burden in the context of Alzheimer's disease: a 24-month longitudinal study. *Int J Geriatr Psychiatry*, 32(12), e72-e82. doi: 10.1002/gps.4656
- Vos, T., Barker, B., Begg, S., Stanley, L., & Lopez, A. D. (2009). Burden of disease and injury in Aboriginal and Torres Strait Islander Peoples: the Indigenous health gap. *International Journal of Epidemiology*, 38(2), 470-477. doi: 10.1093/ije/dyn240
- Wallerstein, N., & Duran, B. (2010). Community-based participatory research contributions to intervention research: the intersection of science and practice to improve health equity. *American Journal Public Health*, 100(Suppl 1), S40-46.
- Ying, J., Yap, P., Gandhi, M., & Liew, T. M. (2018). Iterating a framework for the prevention of caregiver depression in dementia: a multi-method approach. *Int Psychogeriatr*, 30(8), 1119-1130. doi: 10.1017/s1041610217002629
- Yu, J., Yap, P., & Liew, T. M. (2019). The optimal short version of the Zarit Burden Interview for dementia caregivers: diagnostic utility and externally validated cutoffs. *Aging Ment Health*, 23(6), 706-710. doi: 10.1080/13607863.2018.1450841

Tables

Table 1 Characteristics of the carers, (n=124)

Characteristic	n (%) or mean±SD
Age (years)	
18-29	37 (29.8)
30-39	33 (26.6)
40-49	31 (25.0)
50-59	10 (8.1)
60-69	6 (4.8)
70-79	4 (3.2)
≥80	3 (2.4)
Sex	
Male	33 (26.6)
Female	91 (73.4)
Preferred language	
English	92 (74.2)
Other	32 (25.8)
Interpreter present⁹	10 (8.1)

Completed primary school 108 (93.9)

Years of high school

0 22 (17.7)

1-2 20 (16.1)

3-4 56 (45.2)

5 26 (21.0)

Further study 60 (48.4)

TAFE 53 (42.7)

Apprenticeship 1 (0.8)

University 6 (4.8)

Years as a carer

<1 6 (4.8)

1-5 60 (48.4)

6-10 35 (28.2)

>10 23 (18.5)

Look after another person 40 (32.3)

Provide help

Cooking 116 (93.6)

Cleaning 112 (90.3)

Showering and dressing	11 (8.9)
Shopping	110 (88.7)
Providing food	119 (96.0)
Keeping them company	121 (97.6)
Activities they enjoy	90 (72.6)
Transport	88 (71.0)
When they are sick	115 (92.7)
Taking medicine	69 (55.7)
Looking after money	37 (29.8)
Number of ADLs helping with	8.0±1.7

Note: Percentages calculated without excluding missing data (i.e., denominator is entire sample). Numerals in superscript denote number of people with missing data for that variable. ADLs = activities of daily living; SD = standard deviation; TAFE = Technical and Further Education (vocational education and training).

Table 2 Characteristics of the person cared for, (n=124)

Characteristic	n (%) or mean±SD
Carer's relationship to person	
Daughter/son	52 (41.9)
Husband/wife	10 (8.1)
Brother/sister	4 (3.2)
Grandchild	42 (33.9)
Niece/nephew	5 (4.0)
Friend	0 (0.0)
Other	11 (8.9)
Age (years)³	
45-59	19 (15.3)
60-74	59 (47.6)
≥75	43 (34.7)
Sex	
Male	30 (24.2)
Female	94 (75.8)
Aboriginal person	124 (100.0)

Live with carer¹ 72 (58.1)

Main health problem(s)

Physical disability 38 (30.7)

Frailty 41 (33.1)

Dementia/cognitive impairment 45 (36.3)

Mental illness 3 (2.4)

Intellectual disability 2 (1.6)

Head injury 6 (4.8)

Chronic illness 65 (52.4)

Other 26 (21.0)

Don't know 13 (10.5)

Services used

Community aged care services 103 (83.1)

Aboriginal medical service 57 (46.0)

Community clinic 123 (99.2)

Hospital 107 (86.3)

Mental health 20 (16.1)

Disability services 52 (41.9)

Carers respite 67 (54.0)

Drug and alcohol	15 (12.1)
Community office	78 (62.9)
Traditional healer	43 (34.7)
Other service/person	42 (33.9)
Number of services used	6.6[±]2.2

Note: Percentages calculated without excluding missing data (i.e., denominator is entire sample). Numerals in superscript denote number of people with missing data for that variable. Categories for health problems are not mutually exclusive. SD = standard deviation.

Table 3 Carer burden, empowerment (GEM), and depression (KICA-Dep) measures stratified by community, (n=124)

Scale	Overall	By community				<i>p</i> value
		Looma (n=38; 30.7%)	Ardyaloon (n=19; 15.3%)	Wirrimanu (n=28; 22.6%)	Warmun (n=39; 31.5%)	
	Mean±SD	Mean±SD	Mean±SD	Mean±SD	Mean±SD	
Carer burden	3.7±3.6	3.7±2.8	2.3±2.7	5.6±3.8	3.0±4.1	0.001
EES-14¹	4.3±0.5	4.2±0.5	4.5±0.4	4.4±0.6	4.2±0.5	0.011
Core6²	5.0±1.2	5.0±1.3	5.6±1.2	4.6±1.1	5.1±1.2	0.012
KICA-Dep⁵	4.5±3.7	5.8±3.9	3.8±3.4	3.7±2.7	4.2±4.0	0.042

Note: Higher carer burden scores and higher KICA-Dep scores indicate greater carer burden and greater depressive symptoms, respectively.

Higher GEM scores indicate greater empowerment. Numerals in superscript denote number of people with missing data for that variable. Core6

= Core6 Scenario Subset; EES = Emotional Empowerment Scale; GEM = Growth and Empowerment Measure; KICA-Dep = Kimberley

Indigenous Cognitive Assessment Depression scale; SD = standard deviation.