An assessment of the relationship between informal caring and quality of life in older community-dwelling adults - more positives than negatives?

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ABSTRACT

The main objective of the study was to apply the recently developed Index of Capability (ICECAP-O) instrument to measure and value the quality of life of a representative sample of the older South Australian population (aged $\geq$ 65 years) according to carer status. A Health Omnibus survey including the ICECAP-O instrument, carer status (informal carer vs non-carer) and several socio-demographic questions was administered in 2009 as a face to face interview to 789 individuals aged 65 year or older in their own homes. A total of 671 individuals (85%) characterised themselves as a non-carer and 115 individuals (15%) characterised themselves as an informal carer.

In general, carers exhibited relatively high quality of life as measured by the ICECAP-O, with carers having comparable mean ICECAP-O scores to non-carers in the general population (carers: mean (sd) 0.848 (0.123), non-carers: mean (sd) 0.838 (0.147)). The results of the multivariate regression model for the total sample indicated statistically significant variations in overall ICECAP-O scores according to age (with younger participants tending to have slightly higher scores on average), country of birth (with those participants who were born in Australia having higher scores on average than those who were born elsewhere) and household income (with participants with higher income levels having higher scores on average). The results of the multivariate regression model differentiated by carer status also indicated some important differences. Specifically, average ICECAP-O scores were noticeably lower for carers who are

separated or divorced and for carers who lived alone and these differences were statistically significant.

The study findings provide support for the existence of process utility in informal care-giving. The provision of informal care may be associated with a positive impact upon quality of life for many care-givers which may mediate the negative aspects arising from the burden associated with informal care giving.

INTRODUCTION

The number of Australians providing informal care to another person due to disability or ageing has risen markedly in recent years from 2.3 million in 1998 to 2.6 million in 2009 (Australian Bureau of Statistics 1999; Australian Bureau of Statistics 2009). In contrast to formal care provision, an informal carer includes any person, such as a family member, friend or neighbour who is giving regular, ongoing assistance to another person *without payment* for the care given (Australian Institute of Health and Welfare 1998, Australian Bureau of Statistics 2009). The future demand for informal care is predicted to increase significantly in Australia and in many other countries during the coming decades due to several factors. These include an ageing population, with a consequent increase in age-related health conditions and disability, and government policy which seeks to promote ageing in place by allowing older people to remain, and be cared for, in their own homes within the community for as long as possible (Commonwealth Department of Health and Ageing 2007).

The provision of informal care enables people experiencing disability, chronic illness or ageing-related health conditions to continue to live in the community, thereby reducing the pressure that would otherwise be placed on health, disability and aged care systems (Productivity Commission, 2008). In 2005 alone informal carers in Australia provided approximately 1.2 billion hours of care assistance. If this informal care were replaced by paid formal care it has been estimated that the societal cost would be around $30.5 billion (Access Economics, 2005). The needs of informal carers have therefore become a key social policy issue in Australia with the Australian government recently announcing the provision of a National Carers Strategy (Commonwealth Government of Australia, 2010). This strategy formally acknowledges the vital

role that carers play in society and will provide a national framework for the development and implementation of policies, programs and services for carers over the next 10 years.

Previous studies have found that the vast majority of informal carers are the spouses of individuals with cognitive and/or physical impairments, typically women aged 65 or older (aged $\geq$ 65 years) (Lee 2001, Lee & Porteous, 2002, Tooth *et al.* 2008). The burden associated with older informal carers in Australia and internationally has been well documented and has been linked to many factors related to both care recipients and carers. A study of the experiences of family care-giving amongst older Australian women utilised both quantitative and qualitative methods to examine the effects of family care-giving upon physical and emotional wellbeing, finances and leisure among a cohort of Australian women aged 70 to 75 years (Lee 2001). A total of 11,939 women from the general population were included of whom 1235 (10%) identified themselves as carers for frail, ill or disabled family members. It was found that carers were significantly more likely to have lower levels of emotional wellbeing and to feel stressed, rushed and pressured. The qualitative analysis also highlighted the concept of the 'ethics of care', whereby older women report feeling obliged to provide family care despite the negative effects on their wellbeing.

A nested cross-sectional study of 276 older women (aged 78-83 years) enrolled in the Australian Longitudinal Study on Women's Health, who indicated they were providing care for someone living with them, found that 60% were looking after people (mainly husbands) with cognitive and physical impairments (Lee & Porteous 2002). Carers of people exhibiting both types of impairments reported higher scores for objective burden (as measured by two validated measures of the burden of caregiving: the Caregiver Strain Index (CSI) and the Caregiver Burden

Inventory (CBI)), relative to those caring for people with either type of impairment alone. In contrast, scores for how caregiving limited their own lives was highest for women caring for people exhibiting cognitive impairments. The authors conclude that the majority of older women caring for someone else were likely to suffer multifaceted burdens of caring and support for older women who are carers needs to be informed by the type of impairment exhibited by the person they are caring for. Whilst instrumental support from social services, e.g. meals on wheels and personal home care, may relieve some of the burden, carers of people with both cognitive and physical impairments are more likely to require more extensive support such as respite carer or easier access to residential care, to relieve the burden of caring.

Some of the most widely applied outcome measures for carers, including the CSI and CBI have been developed to focus exclusively upon the negative aspects of caring, principally the burden or stressors associated with informal care giving. The CSI comprises 13 items referring to the stressors of caring, each completed with a 'yes/no' response, with the 'yes' responses summed to give an overall score of carer strain (Robinson 1983). The CBI is a 24-item multi-dimensional questionnaire measuring caregiver burden with 5 subscales: (a) Time Dependence; (b) Developmental; (c) Behaviour; (d) Physical Burden; (e) Social Burden; (f) Emotional Burden. Scores for each item are evaluated using a 5-point Likert scale ranging from 0 (not at all disruptive) to 4 (very disruptive). The scores on the 24-item scale are summed and a total score greater than 36 indicates a risk of "burning out" whereas scores near or slightly above 24 indicate a need to seek some form of respite care (Novak & Guest 1989).

Research accumulated since the development of the CSI and CBI has suggested that positive appraisal and reactions to caring may play an important role in mediating the stress of caring.

Pearlin and colleagues (1990) categorised caregiver stress as a consequence of a process comprising a number of interrelated conditions, including the socioeconomic characteristics and resources of caregivers and the primary and secondary stressors to which they are exposed. Primary stressors include the hardships and problems experienced directly from caregiving. Secondary stressors include the strains experienced in roles and activities outside of caregiving. However, mediating factors including coping and social support can potentially intervene at multiple points along the stress process to alleviate both primary and secondary stressors.

Other studies have noted that care-giving is a complex process and have noted that individuals may perceive caring as rewarding and positive even with a substantial care burden. In a study of informal care in farming families in Northern Ireland, Heenan and colleagues (2005) found that there was resistance to becoming involved with formal social services and individual carers took pride in being able to look after their own family members. The authors challenge the depiction of caring as a one-sided difficult relationship, where the person being cared for is a passive recipient. A Canadian study of informal care-giving in the community noted that whilst the amount of research might suggest most caregivers are at risk of collapse, the reality is that the majority appear to cope reasonably well (Chappell *et al.* 2002). Data were drawn from a representative sample of carers for people living with dementia and non-dementia care receivers in British Columbia, Canada (n=243). Multiple regression techniques were employed to assess the relationships between a series of variables previously identified as central to the caregiving process and their effects on carers' overall well-being. It was found that primary stressors including: the cognitive status of the care recipient, levels of physical functioning and behavioural problems of the care recipient and the number of hours of caregiving during the previous week were negative influencers. Mediating factors, including the perceived level of

social support, frequency of getting a break and hours of formal service use were found to be positive influencers.

Recently Al Janabi and colleagues (2010) have recommended that the mediators of the strain or burden of caring, including the provision of social support and satisfaction from caring, should be more formally included within carer outcome measures. To that end, Al Janabi and colleagues tested the feasibility and validity of the inclusion of five positive aspects of caring into the CSI. It was found that the inclusion of positive aspects of caring (to produce the CSI+) enabled the development of a more rounded measure of strain that was more informative as it facilitated the distinction between carers with negative aspect of care with positive aspects to mediate this, from a carer without such positive aspects. The CSI+ carer outcome measure may therefore be more sensitive in identifying those carers who require more extensive support. The authors conclude that further research is required to further test the CSI+ and to explore alternative ways of incorporating the positive aspects of caring into the carer outcome framework.

Examination of the overall quality of life of caregivers offers a potentially useful way of incorporating the positive aspects of caring alongside the negative aspects within the carer outcome framework (Chappell & Reid, 2002, Brouwer *et al.* 2005). Definitions of quality of life vary widely and at its broadest quality of life may include many life domains including spirituality, health, activity levels, social support, resources, satisfaction with personal accomplishments and life situations (Diener & Suh 1997). In practice, however, many researchers incorporate a somewhat narrower definition of quality of life e.g. health related quality of life. Indeed, several studies have indicated that the burden of caring may lead to reductions in health related quality of life though poorer mental and physical health and

increased morbidity and mortality for individuals identifying themselves as carers relative to non-carers in the general population (Cummins *et al.* 2007, Lee *et al,* 2003, Broe *et al.* 1999). Whilst acting as an informal carer may have a negative impact on health related quality of life due to poorer physical, emotional and/or psychological health, a study by Brouwer and colleagues in the Netherlands indicates that informal carers may derive 'process utility' from the caregiving experience. Process utility is a term originating in the discipline of economics, which describes the positive benefits associated with the process of providing informal care (Brouwer *et al.* 2005). Focusing only upon the negative aspects of informal care may not do justice to the true value of informal care. Process utility may be associated with positive impacts upon quality of life in its broadest sense, where quality of life is assumed to encompass the broad range of factors that are important to people in living their lives rather than a focus upon outcomes e.g. health related quality of life alone.

The Index of Capability (ICECAP-O) is a recently developed instrument for the measurement and valuation of quality of life in its broadest sense in older people aged 65 years plus (Coast *et al*. 2008). The developers of the ICECAP-O aimed to identify the attributes that were most important to older people in determining their overall quality of life through a review of the literature and interviews with older people (Grewal *et al.* 2006). The ICECAP-O has its origins in Sen's capability theory which suggests that quality of life should be measured and valued not according to what individuals actually do (i.e. their functionings) but what they are able to do (i.e. their capabilities). The approach is therefore based on a view of living as a combination of various 'doings and beings', with quality of life to be assessed in terms of the capability to achieve valuable functionings. An example of the distinction between functionings and capabilities is to compare two people who are starving, one due to fasting and one because food

is unavailable. Both individuals have the same level of functioning (they are both starving). However, one person has the capability to obtain food whilst the other does not. Hence, their capabilities are therefore different (Coast *et al*. 2008).

The developers of the ICECAP-O identified a set of functionings that were most important to people; attachment (feelings of love, friendship and companionship), role (having a purpose that is valued), enjoyment (having a sense of pleasure and joy from personal and communal activities), security (feeling safe and secure and not having to worry) and control (being independent and able to make one's own decisions). More importantly, in support of Sen's capability theory, they discovered it was the person's capability to achieve these functioning's (rather than their level of functioning *per se*) that determined their quality of life. Thus, for example, while an individual's state of health impacts on capability it is not the sole determining factor. Other factors including spirituality, health, activity levels, social support, resources, satisfaction with personal accomplishments and life situations may also impact upon capability. The developers of the ICECAP-O have demonstrated the construct validity of the ICECAP-O descriptive system in a population of older people living in the community in the United Kingdom (UK) (Coast *et al.* 2008).

METHODS

This study aimed to utilise the ICECAP-O instrument to assess the quality of life, in its broadest sense, of a representative sample of the older South Australian population (aged $\geq$ 65 years) differentiated according to carer status (carer vs non-carer). Several socio-demographic characteristics were also examined to determine the extent of their influence, if any, on the quality of life of carers and non-carers. The socio-demographic variables included in the study were pre-

selected by an external research organization commissioned by the South Australian Department of Health. However the majority of these were based upon characteristics included in previous studies which have demonstrated an association with quality of life including the age of the carer (previous studies indicating a negative relationship between the age of the carer and quality of life: Robinson, 1983, McCullagh *et al.* 2005) and marital status, education and income levels (previous studies indicating a positive relationship: Robinson 1983, Jones & Peters, 1992, Nijboer *et al.* 1999; McCullagh *et al.* 2005).

The Health Omnibus Survey is an annual face-to-face survey conducted to obtain social statistics for use in the planning, implementation and monitoring of health-related initiatives. Questions are submitted for inclusion in the survey by government and non-government organisations with an interest in the health needs of South Australians. For the 2009 survey, following the granting of ethics approval from the South Australian Health Department a multi-stage, systematic area sample was conducted which resulted in the random selection of 5,200 households. From each of the selected households, one person aged 15 years or older was randomly selected to participate in the South Australian Health Omnibus Survey. The survey was conducted in the participant's own home utilising a face to face interview mode of administration. The ICECAP-O instrument was included in the survey in addition to questions relating to carer status and several socio-demographic variables.

The ICECAP-O was utilised for the *measurement* and *valuation* of the quality of life of the participants. The ICECAP-O incorporates 5 attributes (attachment, security, role, enjoyment and control); each consisting of 4 levels (Figure 1).

Insert Figure 1 about here

For each attribute, participants indicate which level they believe most closely corresponds to their life at present. This is the *measurement* aspect of the instrument. The instrument also includes a preference based scoring algorithm which can be readily applied to obtain a single index value for all possible combinations of individual responses on a scale from 0 to 1, where 0 represents no capability and 1 represents full capability (Table 1). This is the *valuation* aspect of the instrument. Preference based scoring algorithms can be contrasted with simple summative scoring algorithms in that they allow for differential weights to be attached to each attribute (e.g. a one unit improvement in security may be valued much more, or less, highly than a one unit improvement in attachment) as opposed to assuming every attribute within the instrument is of equal importance. The preference based scoring algorithm was developed by applying best-worst scaling discrete choice experiment (DCE) methods to value quality of life states defined by the ICECAP-O with a representative community based sample of older people in the UK (Coast *et al*. 2008).

Insert Table 1 about here

Carer status was defined according to the South Australian Carers Recognition Act 2005. Individuals were identified as a carer if they provided a "yes" response to the following question: *"Do you provide any **unpaid** ongoing care or assistance to a relative, friend or neighbour who is frail, has a disability or a chronic illness, including mental illness?"*
The following explanation was also provided to the participant: *Assistance refers to tasks of everyday life including any activity we perform for another to assist with self-care and/or tasks which enable the individual to live independently in the community*.

The terms 'regular and on-going' were not defined explicitly and were thus open to interpretation by the participants themselves. Data were also collected on several socio-demographic variables including age, gender, country of birth, maritial status, area of residence, household income, level of education and status and field of employment.

The Health Omnibus Survey data were weighted to benchmarks originating from the 2006 Population Census to provide a demographic description of the South Australian population by age and gender. Data relating to younger respondents (aged under 65 years) were excluded from the analysis for this study. The socio-economic status of the study participants was calculated according to the Socio-Economic Indexes for Areas (SEIFA), a series of 4 indexes which rank geographic areas of Australia in regard to their socio-economic characteristics according to details obtained from the Census of Population and Housing (Pink 2006). Each geographic area is assigned a score which indicates how disadvantaged that area is in comparison to other areas within Australia, with lower scores indicating higher levels of disadvantage. Levels of disadvantage and advantage are determined according to income, education, employment, occupation, housing (high mortgage, high or low rent, residing in government housing and overcrowding), internet access, car ownership, disability and single parenthood (Pink 2006A). Initially participants were grouped into quartiles based on the SEIFA Index of Relative Socio-economic Advantage and Disadvantage according to their residential postcode (Australian Bureau of Statistics 2006), but preliminary analysis showed no statistical or practical association with the ICECAP-O (nonetheless in models, adopting a conservative approach, we retain this measure as a dichotomous variable (high vs. low) to minimize small-cell problems in the model for carers).

The relationship between carer and non-carer status was examined in relation to ICECAP-O summary scores, according to key socio-demographic variables and according to the responses of older people to the five individual attributes of the ICECAP-O instrument. The data were analysed using STATA version 12.1. Descriptive summary statistics including means, medians and ranges were estimated. As scores from the ICECAP-O instrument were not normally distributed (assessed with reference to skewness, and joint skewness and kurtosis and the Shapiro-Wilk W test for normal data at the aggregate and sub-sample levels), the difference between groups was assessed by employing non-parametric Kruskal-Wallis one way ANOVA and two group comparison (Mann-Whitney U) test. A series of multivariate ordinary least squares (OLS) linear regression models were also applied to further examine the relationship between ICECAP-O scores and the various socio-demographic variables for the total sample and differentiated according to carer status.

RESULTS

A total of 2937 individuals participated in the Health Omnibus Survey from the 5200 household that were randomly selected initially. All individuals aged under 65 years (n=2137) and individuals over 65 years who failed to fully complete the ICECAP-O instrument (n=3) were excluded from the analysis resulting in the full participation of 786 individuals aged 65 years and over. A total of 671 individuals (85%) characterised themselves as a non-carer and 115 individuals (15%) identified themselves as a carer of a relative friend or neighbour. This finding is broadly consistent with the percentages of carers and non-carers in the wider Australian general population recently complied by the Australian Bureau of Statistics, 81% non-carer and 19% carer status (Australian Bureau of Statistics 2009).

Table 2 summarises the mean ICECAP-O scores for the total sample and differentiated according to carer status. As a whole, participants had a relatively high mean ICECAP-O score, indicative of a high level of quality of life. It can also be seen that carers exhibited comparable mean and median ICECAP-O scores to non-carers in the general population and there were no statistically significant differences between the carer and non-carer groups.

Insert Table 2 about here

The mean ICECAP-O tariff scores by categories of key socio-demographic variables differentiated by carer status are presented in Table 3. The socio-demographic characteristics of carers were broadly similar to those of non-carers, although carers were less likely to live alone than non-carers (live alone carers 30% vs non-carers 52%) and were more likely to have income levels greater than $20,000 per annum (carers 59% vs non-carers 37%). Carers who reported themselves as living alone exhibited higher mean ICECAP-O scores on average than non-carers who reported themselves as living alone and this difference was also found to be statistically significant. Specifically for carers the difference was statistically significant at just above the 5% level (test-statistic 1.906, p = 0.057), and for non-carers at the 3% level (test-statistic 2.140, p = 0.032).

Insert Table 3 about here

Table 4 presents the distribution of responses to the ICECAP-O instrument across the levels of attributes differentiated according to carer or non-carer status. The distribution of responses to the attachment and enjoyment attributes was broadly similar across the two groups. A greater proportion of respondents in the non-carer group categorised themselves at the best level for the

security attribute, indicating that they were able to think about the future without any concern (30% of non-carers vs 24% of carers). Carers were more likely than non-carers to categorise themselves at the best level for the role attribute, indicating that they were able to do all the things that make them feel valued (47% of carers versus 37% of non-carers) and were more likely to categorise themselves at the best level for the control attribute, indicating that they were able to be completely independent (56% of carers versus 48% of non-carers). To investigate further the (Cochran-Armitage) chi-square test for a linear trend between row numbers and the fraction of subjects in group was applied for each attribute. There was a statistically significant trend for 'role' of carers vs non-carers (test-statistic 6.47, p-value 0.011), but no other evidence of a linear trend in attributes stratified by carer status.

Insert Table 4 about here

Table 5 presents the tests of association between the individual attributes of the ICECAP-O differentiated according to carer status and living arrangements. The results reinforce the finding of a positive association between the role attribute and carer status. For carers who indicated that they lived alone, positive associations were found between the attachment, role and control attributes of the ICECAP-O, whereas for carers who lived with others a positive association was found for the security attribute, indicating that those carers who lived with others were less likely to be concerned about the future.

Insert Table 5 about here

Table 6 presents the findings of the multivariate regression analyses for the total sample and differentiated by carer status. For each analysis, the ICECAP-O scores (range 0 to 1) were the dependent variable and the key socio-demographic characteristics were independent variables.

For the total sample, the socio-demographic characteristics which were associated with statistically significant variations in overall ICECAP-O scores included age (with younger participants tending to have slightly higher scores on average than older participants), country of birth (with those participants who were born in Australia having higher scores on average than those who indicated that they were born elsewhere) and household income (with those participants with higher income levels having higher scores on average than those with a low income level). The multivariate regression models differentiated by carer status indicated some important differences and confirm our view that the two groups are not homogeneous and models for each group are required to better understand the differentials in the factors influencing the ICECAP-O for carers and non-carers. Specifically, average ICECAP-O scores were noticeably lower for carers who are separated or divorced (and marginally lower for those who are widowed) and these differences were statistically significant. Similarly, carers who lived alone had noticeably lower scores than those carers who lived with others and this difference was highly statistically significant. For non-carers, the results are broadly similar to those of the total pooled sample (principally because the total sample results are driven by non-carers who make up approximately 85% of the sample).

Insert Table 6 about here

To further investigate the strength of the non-significant result for carers vs. non-carers in the model for the total sample models for those living alone and those not living alone were examined. In both models the carer variable was not statistically significant (living alone carer: -0.010, SE 0.033, p-value 0.764; not living alone carer: 0.025, SE 0.016, p-value 0.115) confirming the conclusion reached for the models in Table 6.

DISCUSSION

These findings contribute to the burgeoning literature on the quality of life of informal carers and provide support for the hypothesis that the caring role is often associated with rewarding and positive experiences which contribute positively towards quality of life (Pierce *et al.* 2007, Wong & Ussher, 2009, Bolden & Wicks 2010). The carers in our study exhibited comparable ICECAP-O scores on average to the non- carers. Examination of the distribution of individual responses to the ICECAP-O instrument differentiated according to carer status provides further evidence of the potential existence of process utility with a higher proportion of non-carers categorising themselves at the best level for the role attribute, indicating that they were able to do all the things that make them feel valued (47% of carers versus 37% of non-carers) Carers also reported very similar response patterns to non-carers for the attachment and enjoyment attributes with the majority indicating high levels of love and friendship and enjoyment in their lives. Somewhat surprisingly, a higher proportion of carers than non-carers indicated that they were able to be completely independent which is contrary to what one might expect given the time and work commitments associated with caring. However, it is possible that in responding to this particular question carers may have focused upon the individual they were caring for as their point of reference and therefore contrasting their own ability to be independent with the dependant role of the person they were caring for. It is also possible that carers adapt to their situation over time and have lower aspirations than non-carers which may also contribute to more positive evaluations of quality of life. Further research of a qualitative nature e.g. the application of think aloud techniques whereby participants are prompted and encouraged to speak aloud any words in their mind as they complete the ICECAP-O instrument would be helpful in this regard, in further facilitating and explaining the reasoning behind participant's responses.

It is important to note that the data analysis conducted adopts the common practice of assuming a simple random sample and ideally the data should be analyzed using complex survey methods. It would also be beneficial for further research of a quantitative nature to conduct multivariate analyses in larger samples which would allow dis-aggregation of the ICECAP-O to further examine the relationships between responses to the individual dimensions of the ICECAP-O and carer vs non-carer status.

There are a number of limitations to this study which mean that the findings should be necessarily interpreted with caution. The study was nested in a much larger Health Omnibus survey including a range of questions from government and non-government organisations with an interest in the health needs of South Australians. In addition to completion of the ICECAP-O instrument and a series of socio-demographic questions, a question was included in the survey relating to carer status which allowed us to undertake the comparisons reported upon in this paper. Unfortunately it was not possible with this study to further differentiate ICECAP-O scores for carers by identifying the extent of the caring responsibility (e.g. in terms of the number of hours per weeks spent caring or the types of tasks performed by the carer) the exact relationship of the carer to the person who is cared for, the health needs of the person cared for or the general health of the carer. There are also two matters relating to the empirical modelling that may limit the ability to generalise. First, as with all cross-sectional studies, the results show association and at best may be consistent with a theory of causality. Second, the sample size for carers is quite small and the results of this study need to be confirmed with a larger sample. It is also important to note that further research is required to determine what would constitute a minimally important difference between ICECAP-O mean scores of practical importance in this context. The existing ICECAP-O scoring algorithm is based upon the preferences of a United Kingdom

older adult population. However Australian general population specific tariffs for the ICECAP-O are currently being developed by Flynn and colleagues. Once these tariffs become publicly available, they will allow for further valuation of quality of life based upon the preferences for alternative ICECAP-O states generated from a representative sample of the Australian general population (Flynn, 2010).

A previous study by Brouwer and colleagues (2005) indicated that process utility appears to be important in the context of informal care. A large sample of Dutch caregivers were sampled and it was found that a majority of carers would lose a major part of their total happiness if they were forced to give up their care giving role despite the recognition of the burdens imposed upon them. The findings from our study provide further support for this hypothesis. However it is possible that the majority of participants in this study did not perceive themselves to be experiencing a significant care burden. Brouwer and colleagues findings also indicated that for a minority of caregivers who reported that they were substantially burdened, caring was largely viewed as a negative experience and these individuals indicated that they would gain considerably from being relieved from their duties as informal caregivers.

In conclusion, the results from this study indicate that for the majority of older people living in the community in South Australia, a caring role is associated with a relatively high quality of life, that is comparable with the quality of life experienced by older people who categorise themselves in a non-caring role. The study findings also provide further support for the existence of process utility in the context of informal care, highlighting that care-giving is a complex process that may be associated with many positive experiences and a consequent positive impact upon quality of life. Therefore it is possible that many individuals view their

caring role as a rewarding and positive aspect of their lives. However, further research needs to be conducted to improve our current understanding of the quality of life associated with informal caring. Further research will also assist in identifying those informal caregivers in the community who report negative quality of life experiences and/or perceive themselves to be experiencing a significant care burden and who may therefore benefit from additional support.

REFERENCES

Access Economics. (2005) The Economic Value of Informal Care. Report for Carers Australia.

Al Janabi H., Frew E., Brouwer W., Rappange D. & Van Excel J. (2010) The inclusion of positive aspects of caring in the Caregiver Strain Index: tests of feasibility and validity. *I*nternational Journal of Nursing Studies **47**, 984-993.

Australian Bureau of Statistics. (1999) Disability, Ageing and Carers: Summary of Findings. Cat No. 4430. Canberra.

Australian Bureau of Statistics. Socio-Economic Indexes for Areas (SEIFA)-Technical Paper. Cat No. 2039.0.55.001. Canberra: ABS; 2006.

Australian Bureau of Statistics. (2009) Disability, Ageing and Carers: Summary of Findings. Cat No. 4430. Canberra.

Australian Institute of Health and Welfare. (1998) Home and Community Care (HACC) Data Dictionary Version 1.0, Australian Government, Canberra.

Bolden L. & Wicks M. (2010) Predictors of mental health, subjective burden and rewards in family caregivers of patients with chronic liver disease. Archives of Psychiatric Nursing **24**, 89-103.

Broe G., Jorm A., Creasy H. et al. (1999) Carer distress in the general population. results from the Sydney older persons study. Age and Ageing **28**, 307-311.

Brouwer W., van Exel N., van den Berg B., van den Bos G., Koopmanschap M. (2005) Process utility from providing informal care: The benefit of caring. Health Policy **74**, 85-99.

Chappell N. & Reid C. (2002) Burden and well-being among caregivers: examining the distinction. *The Gerentologist* **42**, 772-780.

Coast J., Flynn T., Natarajan L., Sproston K., Lewis J., Louviere J., Peters T. (2008) Valuing the ICECAP capability index for older people. Social Science and Medicine **67**, 874-882.

Coast J., Peters T., Natarajan L., Sproston K., Flynn T. (2008) An assessment of the construct validity of the descriptive system for the ICECAP capability measure for older people. *Quality of Life Research* **17**, 967-976.

Commonwealth Department of Health and Ageing (2007). Aged Care Australia, Canberra.

Commonwealth Government of Australia (2010). Towards a National Carer Strategy, A discussion paper from the Australian Government, Canberra.

Cummins R., Hughes J., Tomyn A., Gibson A., Woerner J., Lai L. (2007) The Wellbeing of Australians – Carer Health and Wellbeing (Special Report). Melbourne: Australian Centre on Quality of Life.

Flynn, T. (2010) Measuring and valuing population quality of life using the ICECAP capability measure for older people. Paper presented to the Paper presented to the Australian Health Economics Society Meeting, Universities of New South Wales and Sydney.

Grewal I., Lewis J., Flynn T., Brown J., Bond J., Coast J. (2006) Developing attributes for a generic quality of life measure for older people: Preferences or capabilities. *Social Science and Medicine* **62**, 1891-1901.

Heenan D. (2005) Informal care in farming families in Northern ireland: some considerations for social work. British Journal of Social Work **30**, 855-866.

Jones D. & Peters T. (2001) Caring for the elderly dependants: effects on the carer's quality of life. *Age and Ageing* **21**, 421-428.

Lee C. & Porteous J. (2002) Experiences of family caregiving among middle-aged Australian Women. Feminism and Psychology **12**, 79-96.

Lee C. (2001) Experiences of family caregiving among older Australian women. Journal of Health Psychology **6**, 393-404.

Lee S., Colditz G., Berkman L., Kawachi I. (2003) Caregiving and risk of coronary heart disease in US women. American Journal of Preventive Medicine **24**, 113-119.

McCullagh E., Brigstocke G., Donaldson N., Kalra L. 2005 Determinants of caregiving burden and quality of life in caregivers of stroke patients. Stroke **36**, 2181-2186.

Nijboer C., Triemstra M., Tempelaar R., Geertrudis A. (1999) Determinants of caregiving experiences and mental helath of partners of cancer patients. *Cancer* **86**, 577-588.

Pierce L., Steiner V., Govoni A., Cervantez-Thompson T., Friedmann ML. (2007) Two sides to the caregiving story Topics in Stroke Rehabilitation **14**, 13-20.

Pink B. (2006) Information Paper: An Introduction to Socio-Economic Indexes for Areas (SEIFA). Cat no. 2039.0. Canberra: Australian Bureau of Statistics.

Pink B. (2006A) Socio-Economic Indexes for Areas (SEIFA) - Technical Paper. Cat no. 2039.0.55.001. Canberra: Australian Bureau of Statistics.

Productivity Commission. (2008) *Trends in Aged Care Services: some implications*. Productivity Commission Research Paper.

Robinson B. (1983)Validation of a Caregiver Strain Index. Journal of Gerontology **38**, 344–348.

Tooth L., Russell A., Lucke J. et al. (2008) Impact of cognitive and physical impairment on carer burden and quality of life. Quality of Life Research **17**, 267-273

Wong W. & Ussher J. (2009) Bereaved informal cancer carers making sense of their palliative care experience at home. *Health and Social Care in the Community* **17**, 274-82.

Figure 1: The ICECAP-O index of capability

ABOUT YOUR QUALITY OF LIFE

By placing a tick (✓) in ONE box in EACH group below, please indicate which statement best describes your quality of life at the moment.

1. Love and Friendship

I can have all of the love and friendship that I want	4
I can have a lot of the love and friendship that I want	3
I can have a little of the love and friendship that I want	2
I cannot have any of the love and friendship that I want	1

2. Thinking about the future

I can think about the future without any concern	4
I can think about the future with only a little concern	3
I can only think about the future with some concern	2
I can only think about the future with a lot of concern	1

3. Doing things that make you feel valued

I am able to do all of the things that make me feel valued	4
I am able to do many of the things that make me feel valued	3
I am able to do a few of the things that make me feel valued	2
I am unable to do any of the things that make me feel valued	1

4. Enjoyment and pleasure

I can have all of the enjoyment and pleasure that I want	4
I can have a lot of the enjoyment and pleasure that I want	3
I can have a little of the enjoyment and pleasure that I want	2
I cannot have any of the enjoyment and pleasure that I want	1

5. Independence

I am able to be completely independent	4
I am able to be independent in many things	3
I am able to be independent in a few things	2
I am unable to be at all independent	1

Tick one box only in each section

Table 1: ICECAP-O scoring weights

Attribute	Value
Attachment	
I can have all of the love and friendship that I want	0.254
I can have a lot of the love and friendship that I want	0.233
I can have a little of the love and friendship that I want	0.134
I cannot have any of the love and friendship that I want	-0.013
Security	
I can think about the future without any concern	0.179
I can think about the future with only a little concern	0.107
I can only think about the future with some concern	0.066
I can only think about the future with a lot of concern	0.032
Role	
I am able to do all of the things that make me feel valued	0.192
I am able to do many of the things that make me feel valued	0.179
I am able to do a few of the things that make me feel valued	0.130
I am unable to do any of the things that make me feel valued	0.015
Enjoyment	
I can have all of the enjoyment and pleasure that I want	0.166
I can have a lot of the enjoyment and pleasure that I want	0.164
I can have a little of the enjoyment and pleasure that I want	0.119
I cannot have any of the enjoyment and pleasure that I want	0.017
Control	
I am able to be completely independent	0.209
I am able to be independent in many things	0.185
I am able to be independent in a few things	0.108
I am unable to be at all independent	-0.051

Reproduced from Coast et al. (2008).

Table 2: Comparison of mean (standard deviation, SD) and median (inter-quartile range, IQR) ICECAP-0 scores for total sample and by carer status

	Mean (SD) [95% CI]	Median (IQR)	N
All participants	0.839 (0.144) [0.829-0.849]	0.868 [0.793-0.928])	786
Carers	0.848 (0.123) [0.825-0.871]	0.868 [0.772-0.927]	115
Non-Carers	0.838 (0.147) [0.827-0.849]	0.868 [0.793-0.928]	671
Mann-Whitney *U* test (p-value) 0.075 (0.940)			

Table 3: Mean ICECAP-O tariff scores by categories of key variables

Socio-Demographic Variable	Carers (n=115)		Non-Carers (n=671)	
	Mean (95% CI)	N (%)	Mean (95% CI)	N (%)
Age				
65-74	0.837 (0.805-0.870)	63 (55)	0.858 (0.845-0.871)	339 (51)
75-84	0.858 (0.821-0.896)	40 (35)	0.822 (0.803-0.841)	267 (40)
85 plus	0.869 (0.799-0.939)	12 (10)	0.797 (0.752-0.842)	65 (10)
Gender				
Male	0.843 (0.798-0.888)	38 (33)	0.837 (0.818-0.856)	260 (39)
Female	0.850 (0.824-0.877)	77 (67)	0.838 (0.824-0.852)	411 (61)
Area of Residence				
Metropolitan	0.853 (0.824-0.881)	83 (72)	0.833 (0.818-0.856)	502 (75)
Rural	0.836 (0.799-0.873)	32 (28)	0.852 (0.835-0.869)	169 (25)
Country of Birth				
Australia	0.845 (0.819-0.872)	79 (69)	0.853 (0.840-0.866)	398 (59)
Other	0.854 (0.808-0.900)	36 (31)	0.815 (0.796-0.834)	273 (41)
Aboriginal or Torres Strait Islander Status				
Aboriginal &/or Torres Strait Islander	-	0 (0)	0.846 (0.726-0.967)	6 (1)
Not Aboriginal &/or Torres Strait Islander	0.848 (0.825-0.871)	115 (100)	0.838 (0.826-0.849)	665 (99)
Marital Status				
Married / De Facto	0.851 (0.826-0.876)	73 (63)	0.868 (0.856-0.880)	318 (47)
Separated / Divorced	0.836 (0.746-0.925)	10 (9)	0.798 (0.758-0.837)	77 (11)
Widowed	0.841 (0.776-0.905)	28 (24)	0.818 (0.797-0.838)	258 (38)
Never Married	0.877 (0.700-1.000)	4 (3)	0.769 (0.671-0.867)	18 (3)
Lives Alone				
Lives alone*	0.868 (0.830-0.905)	35 (30)	0.809 (0.790-0.827)	346 (52)
Lives with others*	0.839 (0.811-0.868)	80 (70)	0.869 (0.857-0.880)	325 (48)
Average Annual Household Income				
≤ $20,000	0.847 (0.801-0.893)	30 (26)	0.817 (0.798-0.836)	280 (42)
$20,001 - $60,000	0.840 (0.805-0.875)	61 (53)	0.859 (0.843-0.875)	197 (29)
$60,001 - $100,000	0.915 (0.861-0.968)	4 (3)	0.893 (0.863-0.923)	31 (5)
≥ $100,001	0.890 (0.583-1.000)	3 (3)	0.918 (0.872-0.965)	23 (3)
Employment Status				
Working full-time or part-time	0.841 (0.748-0.933)	10 (9)	0.886 (0.850-0.922)	42 (6)
Home duties	0.884 (0.830-0.938)	7 (6)	0.837 (0.786-0.889)	26 (4)
Retired	0.846 (0.821-0.871)	96 (83)	0.834 (0.822-0.846)	603 (88)
Highest Educational Qualification				
Currently studying	-	0 (0)	0.820 (0.692-0.948)	10 (1)
Primary or Secondary School	0.856 (0.826-0.885)	62 (54)	0.829 (0.813-0.844)	382 (57)
Tertiary Studies	0.839 (0.802-0.876)	53 (46)	0.851 (0.835-0.866)	279 (42)

Socio-Demographic Variable	Carers (n=115)		Non-Carers (n=671)	
	Mean (95% CI)	N (%)	Mean (95% CI)	N (%)
Socio-Economic Indexes for Areas (SEIFA)				
Quartile 1 (Most disadvantaged)	0.821 (0.771-0.870)	28 (24)	0.840 (0.819-0.862)	172 (26)
Quartile 2	0.837 (0.778-0.895)	32 (28)	0.842 (0.823-0.862)	185 28)
Quartile 3	0.890 (0.863-0.919)	25 (22)	0.838 (0.806-0.857)	162 (24)
Quartile 4 (Least disadvantaged)	0.851 (0.814-0.888)	31 (27)	0.833 (0.812-0.860)	152 (3)
Dichotomous (Bottom 2 quartiles)	0.829 (0.791-0.867)	60 (52)	0.841 (0.827-0.856)	357 (53)
Dichotomous (Top 2 quartiles)	0.868 (0.844-0.893)	55 (48)	0.833 (0.823-0.854)	314 (47)

*Significant at 6% (live alone) and 3% (do not live alone) levels.

Table 4: Distribution of ICECAP-O responses across levels of attributes by carer status

Attribute	Carers (n=115) Frequency (%)	Non-Carers n=671) Frequency (%)
Attachment (Chi-sq (and p-value) for trend)	1.377 (0.241)	
I can have all of the love and friendship that I want	70 (61%)	382 (57%)
I can have a lot of the love and friendship that I want	32 (28%)	184 (27%)
I can have a little of the love and friendship that I want	10 (9%)	85 (13%)
I cannot have any of the love and friendship that I want	2 (2%)	16 (2%)
Security (Chi-sq (and p-value) for trend)	2.077 (0.150)	
I can think about the future without any concern	28 (24%)	204 (30%)
I can think about the future with only a little concern	35 (30%)	212 (32%)
I can only think about the future with some concern	34 (30%)	153 (23%)
I can only think about the future with a lot of concern	18 (16%)	97 (14%)
Role (Chi-sq (and p-value) for trend)	6.477 (0.011)	
I am able to do all of the things that make me feel valued	54 (47%)	245 (37%)
I am able to do many of the things that make me feel valued	44 (38%)	276 (41%)
I am able to do a few of the things that make me feel valued	15 (13%)	124 (18%)
I am unable to do any of the things that make me feel valued	1 (1%)	22 (3%)
Enjoyment (Chi-sq (and p-value) for trend)	0.005 (0.943)	
I can have all of the enjoyment and pleasure that I want	38 (33%)	230 (34%)
I can have a lot of the enjoyment and pleasure that I want	54 (47%)	301 (45%)
I can have a little of the enjoyment and pleasure that I want	21 (18%)	119 (18%)
I cannot have any of the enjoyment and pleasure that I want	2 (2%)	16 (2%)
Control (Chi-sq (and p-value) for trend)	1.444 (0.230)	
I am able to be completely independent	64 (56%)	322 (48%)
I am able to be independent in many things	40 (35%)	266 (40%)
I am able to be independent in a few things	8 (7%)	72 (11%)
I am unable to be at all independent	3 (3%)	9 (1%)

Table 5: Tests of association (P values) between capability attributes as measured by the ICECAP-O and carer and living status using two-sample Wilcoxon rank sum (Mann-Whitney) test (n=786)

Group (N)	Attachment Mean (95% CI)	Security Mean (95% CI)	Role Mean (95% CI)
Carer (115)	1.509 (1.373-1.645)	2.365 (2.177-2.554) ⌐	1.675 (1.539-1.812)
Non-carer (667)	1.603 (1.542-1.663)	2.215 (2.136-2.294) ⌐	1.885 (1.822-1.947)
Live alone (378)	1.810 (1.720-1.900)	2.213 (2.105-2.321)	1.974 (1.885-2.062)
Lives with others (405)	1.381 (1.321-1.440)	2.259 (2.161-2.358)	1.742 (1.670-1.814)
Live alone & carer (35)	1.543 (1.275-1.811)	2.200 (1.869-2.531)	1.629 (1.377-1.880) ⌐
Live alone & not care (341)	1.837 (1.742-1.933)	2.214 (2.100-2.329)	2.010 (1.916-2.102) ⌐
Live with other & carer (80)	1.494 (1.334-1.654)	2.438 (2.206-2.700)	1.696 (1.530-1.862)
Live with other & not carer (325)	1.353 (1.290-1.416)	2.215 (2.107-2.324)	1.753 (1.673-1.833)

	Enjoyment Mean (95% CI)	Control Mean (95% CI)	
Carer	1.887 (1.747-2.027)	1.565 (1.429-1.702)	
Non-carer	1.881 (1.822-1.941)	1.653 (1.598-1.708)	
Live alone	1.968 (1.882-2.055)	1.650 (1.574-1.726)	
Lives with others	1.802 (1.734-1.869)	1.631 (1.562-1.700)	
Live alone & carer	1.743 (1.475-2.011) ⌐	1.371 (1.150-1.593)	
Live alone & not care	1.991 (1.900-2.082) ⌐	1.678 (1.598-1.758)	
Live with other & carer	1.950 (1.784-2.116)	1.650 (1.480-1.820) ⌐	
Live with other & not carer	1.765 (1.692-1.838)	1.627 (1.551-1.702) ⌐	

⌐ Indicates statistically significant difference between 2 rows at 5% significance level.

Table 6: Results of multivariate regression models: relationship been ICECAP-O scores and socio-demographic characteristics

Socio-Demographic Variable	Total Sample Coefficient (SE)		Carers Coefficient (SE)		Non-carers Coefficient (SE)	
Actual Age	-0.002**	(0.001)	0.003	(0.003)	-0.003**	(0.001)
Gender (base male)	0.016	(0.013)	0.016	(0.033)	0.021	(0.014)
Area of Residence (base metropolitan)	0.005	(0.014)	0.022	(0.041)	0.009	(0.015)
Country of Birth (base Australia)	-0.032**	(0.012)	0.032	(0 .036)	-0.038**	(0.013)
Aboriginal or Torres Strait Islander Status	0.018	(0.070)	---	---	0.027	(0.069)
Separated / Divorced	-0.040	(0.035)	-0.178*	(0.083)	0.007	(0.041)
Widowed	-0.024	(0.031)	-0.145**	(0.055)	0.028	(0.037)
Never Married	-0.060	(0.043)	-0.107	(0.089)	-0.025	(0.049)
Lives Alone	-0.001	(0.031)	-0.157**	(0.058)	0.050	(0.037)
Household Income: $20,001 - $60,000	0.021	(0.014)	0.013	(0.031)	0.022	(0.015)
Household Income: $60,001 - $100,000	0.051	(0.028)	0.119	(0.075)	0.042	(0.030)
Household Income: ≥ $100,001	0.081**	(0.031)	0.065	(0.088)	0.081*	(0.033)
Employed: full-time or part-time	-0.009	(0.024)	0.007	(0.055)	-0.007	(0.027)
Home duties	0.052	(0.031)	0.041	(0.062)	0.060	(0.036)
Education: Primary or Secondary School	0.057	(0.049)	0.028	(0.029)	0.049	(0.050)
Education: Tertiary Studies	0.061	(0.050)	---	---	0.061	(0.050)
Socio-Economic Status (base low)	-0.002	(0.012)	0.059	(0.037)	-0.008	(0.013)
Carer	0.011	(0.016)				
Constant	0.923***	(0.000)	0.8011***	(0.000)	0.869***	(0.000)
N	629		98		531	
R-squared	0.083		0.159		0.110	
R-squared Adjusted	0.056		0.050		0.080	
F-statistic (DF)	3.07 (18, 610)		2.23 (15,82)		3.72 (17, 513)	
[p-value]	[0.000]		[0.043]		[0.000]	

* p<0.05, ** p<0.01, *** p<0.001

Note: samples reduced due to missing values