Wellbeing in Long-term Primary Carers: Biopsychosocial Outcomes

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Abstract

Carers are vital to sustaining the independence and optimal functioning of some of the most vulnerable members of the community, yet carers themselves are at risk of poor health and wellbeing outcomes. Indeed, carers often subjugate their own needs in order to fulfill their caring role. This study examined wellbeing outcomes in long-term primary carers. The consequences of providing extended informal care were investigated using a mixed methodology, including questionnaires, saliva sampling and individual interviews. Carers and age and gender matched non-carers were compared across stress, distress, and subjective wellbeing as well as sleep variables and stress hormones. The findings are used to explore the biopsychosocial bases of carer wellbeing. This research has the potential to inform policy on the growing population of Australian carers and to add to the developing wellbeing literature.

Introduction

An informal caregiver, or carer, is someone who "provides care and support for their parent, partner, child or friend who has a disability, is frail aged, or who has a chronic mental or physical illness" (Carers Association South Australia Inc, 1999). This involves the provision of "extraordinary care" that far exceeds what might be provided within an ordinary spousal, parental, or other relationship and which is considered to consume disproportionate time and energy (Schulz & Quittner, 1998, p.107).

In Australia more than 2.6 million people are recognised as carers (Australian Bureau of Statistics, 2003). Around one fifth of these are described as primary carers who provide the bulk of care for a given individual (Australian Bureau of Statistics, 2003). Informal caregiving in Australia is said to be vital and to have an estimated replacement cost of around $31b per annum (Access Economics, 2005), yet the personal cost to carers from providing such unpaid work is largely unrecognised (Noon, 1999). For carers who enable those they care for to sustain independence and achieve optimal functioning (Vitaliano, Scanlan, & Zhang, 2003), it is likely that the cost to their own welfare will be exorbitant.

It is generally acknowledged that caregiving is a severe and persistent stressor (Schulz & Quittner, 1998). Caregiving is seen as a problem of over-demand combined with few available response options (Wheaton, 1997). This is consistent with Lazarus and Folkman's (1984) notion of stress as the result of an appraisal of one's environment as exceeding resources and endangering well-being. According to Lazarus (1999), the main outcomes of successful adaptation to stress are: 1) subjective wellbeing; 2) work and social functioning; and 3) physical health. These domains clearly correspond to an holistic biopsychosocial model of health and wellbeing (Inui, 2003).

For many carers, the difficulty of juggling care work with other roles and their own needs leads to substantial personal distress (Briggs & Fisher, 2000) and carers typically forfeit work, education, leisure and relationship opportunities (Carers Association South Australia Inc, 1999). There is strong evidence that carers commonly experience depression and anxiety (Pakenham, Stebbins, Cannon, & Samios, 2005; Schulz & Quittner, 1998). Thus, while carers commonly report a conviction that care recipients have the right to the best possible quality of life (Vitaliano et al., 2003) recent reports indicate that carers themselves report extremely low levels of subjective wellbeing (Cummins et al., 2007). Subjective wellbeing, SWB, is said to comprise a cognitive component involving the assessment of life satisfaction in addition to an affective component of felt happiness and is an extremely stable trait that is kept in the upper positive range (Cummins, Gullone, & Lau, 2002). It is usually resistant to external circumstances, however low carer SWB levels are thought to reflect a failure of the capacity of internal cognitive mechanisms to maintain life satisfaction in the face of extreme objective life circumstances (Cummins, 2003). Furthermore, once substantial caregiving is required, the disability of the recipient seems to be irrelevant to the effects of the role on subjective wellbeing (Cummins, 2001).

There is also evidence, though less robust, that carers report poor physical health and greater sleep problems and fatigue than non-carers (Briggs & Fisher, 2000; Shewchuk, Richards, & Elliott, 1998; Vitaliano & Young, 2004). Metabolic dysregulation has also been detected amongst caregivers (Vitaliano et al., 2005). In addition, biochemical characteristics that reflect stress, such as morning cortisol levels, have been found to be elevated in dementia carers (de Vugt et al., 2005) even after controlling for depression (Da Rosa Davis & Cowen, 2001). Caregiver distress has also been associated with higher cortisol levels (de Vugt et al., 2005). Nevertheless other studies have found no differences in cortisol levels (Vedhara et al., 1999).

It has been suggested that many carer studies may be confounded by the interactive effects of ageing on health outcomes (Lutgendorf & Costanzo, 2003). Indeed, there has been sparse research investigating biological correlates in younger carers (Kuster & Merkle, 2004). A recent study of non-spousal carers of the elderly found only minor differences between carers and non-carers on psychological and biological measures, including cortisol (Provinciali et al., 2004).

Additionally, few caregiver studies address outcomes on all biopsychosocial dimensions (Smith, Folan, & Haaland, 2002). Yet this is considered to be the most suitable framework for investigating wellbeing under chronic conditions (Fava & Sonino, 2008).

The aim of the current study was to describe wellbeing outcomes in long-term primary carers as one component of a larger study of carer wellbeing. The specific aim was to examine the differences between carer and non-carer outcomes within biological (salivary cortisol levels, sleep measures, and self-reported health), psychological (distress, coping and life satisfaction) and social spheres (social adjustment).

Method

The full study employed a mixed methodology, using morning and evening saliva sampling, self-report questionnaires, a sleep diary and qualitative data derived from personal interviews. Biochemical analyses were still in progress at the time of writing. Further discussion of some findings will be presented in future reports. Thus, a subset of the results and associated methods are reported here.

Participants

Thirty-five primary carers who had been in a caregiving role for a minimum of 12 months were recruited for the study via Carers Queensland support group meetings and regional mailout as well as two articles in local newspapers. Selected carers were parents or spouses, not children, of those requiring care in an attempt to exclude the element of choice of role. Non-carers were individuals without a major caring role and were recruited through the same newspaper articles, as well as flyers and through email mailing lists. They were then placed on a wait list and matched by gender and age to carer participants. If an exact age match was not available the person of nearest age on the wait list was asked to participate.

Four carers were unable to complete the study. The circumstances leading to their withdrawal included: the person being cared for going missing; the carer's own ill health; the injury of another family member (not the person with a disability); and the death of the person being cared for. The final sample consisted of 31 carers (mean of 12.64 years in caring role) and 35 non-carers.

Materials

The psychological measures used in this study were the Perceived Stress Scale, PSS-10 (Cohen, Karmarck, & Mermelstein, 1983); the Depression Anxiety Stress Scale, DASS-21 (Lovibond & Lovibond, 1995); and the Personal Wellbeing Index, PWI (International Wellbeing Group, 2005). These were employed to measure perceived stress; depression, anxiety, and stress symptoms; and subjective wellbeing respectively. An adaptation of the Work and Social Adjustment Scale, WSAS (Mundt, Marks, Shear, & Greist, 2002) was also used to gauge social functioning. The reference to a specific illness in the original scale was replaced, with permission, by "my life circumstances" (Marks, 2007, personal communication).

Procedure

All participants received a participation pack which consisted of a folder containing the scales, demographic questions and a sleep diary. Participants were also asked to list their current medications and to estimate the number of doctors visits they had made in the last year, however no exclusions were made on this basis. The participation pack included saliva sample tubes and instructions for collection of unstimulated saliva. The 7-day sleep diary sought information on sleep patterns, health, and ratings of morning restedness and sleep quality (from very poor to excellent) using a 10cm visual analogue (VAS) scale.

Participants collected all data during one week. They collected approx 4ml saliva on waking and going to bed on two consecutive days. Participants provided bedtime saliva samples at 22:00 hours. Actual collection times differed between participants. However, there was no significant bedtime collection, t(1,33) = 1.305, p =

0.205, difference between the groups. The data for the morning samples were not available at the time of writing. Participants placed saliva samples in their own freezer until collection. Samples were stored below minus 20°C until assaying. All specimens and documents were individually coded to allow data collation. All participants indicated that they had followed the protocol provided. Some participants were unable to provide sufficient bedtime saliva, with subsequent missing cases in the saliva analyses.

The semi-structured interviews were conducted outside the data collection week.

Cortisol Determinations

Coded saliva samples were analysed by an independent biochemist at ARL Pathology, Melbourne Australia. Cortisol levels were determined by competitive electrochemiluminescence immunoassay (ECLIA, Elecsys 2010, Roche Diagnostics) as described elsewhere (Vogeser, Durner, Seliger, & Auernhammer, 2006).

Results

The demographic and biopsychosocial data for the carer and non-carer groups are given in Table 1.

One-way between-groups multivariate analyses of variance were performed to investigate the differences between carers and non-carers on clusters of dependent variables. Preliminary assumption testing was conducted to check for normality, linearity, univariate and multivariate outliers, homogeneity of variance-covariance matrices, and multicollinearity with no serious violations observed. Due to the high correlation between sleep quality and morning restedness, r = .88, N = 66, p<.001, sleep quality was excluded from subsequent multivariate analyses.

There was a statistically significant difference between carers and non-carers on the dependent sleep variable combining sleep time and morning restedness, F (2,63), = p <.001. The partial eta squared value for the overall MANOVA model was .403. However, only morning restedness made a unique statistically significant contribution, F (1,64) = 42.49, p<.001, with carers experiencing lower restedness on awakening.

Cortisol and health-related variables were explored using independent t-tests (with a Bonferroni adjusted alpha level of .02) due to missing data and unequal variance. Bedtime cortisol levels did not differ significantly between the two groups, t(1,47) = 1.22, p = .233. Similarly, doctors visits were not significantly different between carers and non-carers, t(1,61) =1.97, p = .056. However, carers reported significantly lower self-rated health than non-carers, t(1,59) = -3.27, p = .002.

Table 1: Carer and non-carer group comparisons on demographic and biopsychosocial outcomes.

Variable	Carer (n = 31)	Non-carer (n = 35)
Demographics		
Gender, female (%)	87.5	85.7
Age, in years (M±SD)	54.56 ±15.25	55.46 ±14.05
Sleep-related measures		
Sleep, hours/night (M±SD)	6.62±1.05	7.02± .95
Sleep quality (M±SD)	4.08±1.44	6.19±1.52
Morning restedness (M±SD)	3.77±1.61	6.32±1.54
Cortisol levels		
Bedtime Cortisol, nmol/L (M±SD)	6.95±5.69 (N=21)	5.33±2.56 (N=28)
Health-related measures		
Doctors visits, past year (M±SD)	8.75±11.61	4.46±3.75
Self-rated Health (M±SD)	6.08±1. 9	7.46±1.3
Psychological measures		
Perceived Stress Scale, PSS-10 (M±SD)	23.27±5.64	14.83±5.8
DASS-21 Depression (M±SD)	16.4±10.78	6.34±8.47
DASS-21 Anxiety (M±SD)	12.2±9.5	5.05±4.59
DASS-21 Stress (M±SD)	21.16±11.55	10.35±6.56
Personal Wellbeing Index, PWI (M±SD)	51.01±20.25	70.2±12.4
Social measures		
Social Functioning, WSAS (M±SD)	14.84±9.94	29.69±8.98

Table 2: Correlations for PSS and DASS scores.

	Depression	Anxiety	Stress
PSS	.660**	.573**	.681**
Depression		.611**	.674**
Anxiety			.683**

** correlation is significant at the .01 level (2-tailed)

Carers' mean DASS scores for depression, anxiety and stress place them within the moderate range for all three indicators of psychological distress, whereas non-carer means were indicative of non-clinical Australian norms (Lovibond & Lovibond, 1995). Due to strong positive correlation between the DASS subscale scores and the PSS scores (see Table 2), a new variable, distress, was created from the mean of these psychological measures. Distress and SWB were then compared across the groups using MANOVA. There was a significant difference between the two groups on the combined psychological variable, F(2,63) = 16.742, p<.001, with a partial eta squared for the model of .354. Carer distress was significantly higher than that of non-carers F(1,64) = 29.14, p<.001. Carer subjective wellbeing scores were very similar to recent Australian norms (Cummins et al., 2007) and significantly lower than those of the non-carers, F(1,64) = 20.56, p<.001.

Social functioning among carers was also significantly lower, t(1,64) = -6.375, p<.001.

In order to examine the key differences between the groups on biopsychosocial wellbeing a MANOVA was conducted using the key differentiating variables from previous analyses. These were morning restedness, self-rated health, distress, SWB and social functioning. This model contained fewer cases than previous models due to missing health ratings for some participants. Nevertheless, carers and non-carers differed significantly on the combined outcome variable, F(5,50) = 13.003, p<.001, with each of the contributing variables differing significantly between groups. Partial eta squared for the full model was .565.

The extent of these group differences can perhaps be best illustrated by a few comments from the participants themselves. When asked to describe their life in general the majority of non-carers responded with comments such as “life’s just fine”, “I’m happy” “I’m glad I’m alive” and “I have a good life and I know it”. Carers, on the other hand, tended to respond with “life as I knew it is gone”, “I’m coping, not enjoying”, “it’s hell on earth” and even “at least one day I’ll be dead”.

Discussion

Overall, this study reveals a picture of poor outcomes for long-term primary carers across biological, psychological and social spheres. The current finding that carers had significantly worse outcomes on two indicators of physical wellbeing; restedness after sleep and self-rated health, is in line with previous research (Briggs & Fisher, 2000; Shewchuk et al., 1998; Vitaliano & Young, 2004). Interestingly, differences in sleep quality did not appear to be associated with sleep duration. However, sleep time was well below eight hours in both groups and may rather speak to levels of sleep debt in the general population. Furthermore, cortisol levels, as an objective physiological measure, were not found to be significantly elevated in the carer group in contrast to many previous studies (Da Roza Davis & Cowen, 2001; de Vugt et al., 2005) but in line with Provinciali et al. (2004). Though it may be that the morning cortisol results will show group differences.

The current results provide clear support for previous findings that carers experience reduced psychological health. In addition to evidence of greater levels of depression and anxiety such as found by Schulz and Quittner (1998) and Pakenhan et al. (2005) the current findings provide evidence of more symptoms of stress and greater perceived stress among carers. Taken together these would indicate that carers are struggling to maintain psychological wellbeing. Indeed, distress makes a unique contribution to the final model. In addition, in line with the few studies to date (Cummins, 2001, 2003; Cummins et al., 2007) the results indicate that satisfaction with life provides a unique contribution to the differences between carers and non-carers.

With regard to social functioning, the results clearly point to very different experiences for the two groups. This is an area of carer wellbeing which has had little formal investigation but which appears very sensitive to the caregiving context. Further analysis of the findings on social functioning will be reported elsewhere.

The results of the current study need to be interpreted with caution due to the small sample size and the heterogeneity of the carers involved. It may be that comparisons using larger carer groups with more similar caregiving demands would provide more clearly differentiated effects, particularly on physiological measures such as cortisol levels. Nevertheless, the current findings provide evidence of several sharp differences between carers and non-carers on key variables spanning biopsychosocial spheres. The extent of the impact across life domains points to an urgent need for recognition and support for caregivers.

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References

Access Economics. (2005). *The economic value of informal care*: Carers Australia.

Australian Bureau of Statistics. (2003). *Disability, Ageing and Carers: Summary of Findings*. Canberra: Commonwealth of Australia.

Briggs, H., & Fisher, D. (2000). *Warning: Caring is a Health Hazard.* Canberra: Carers Association of Australia.

Carers Association South Australia Inc. (1999). Statistics. from www.carers-sa.asn.au

Cohen, S., Karmarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior, 24*(4), 385-396.

Cummins, R. A. (2001). The subjective well-being of people caring for a family member with a severe disability at home: a review. *Journal of Intellectual and Developmental Disability, 26*(1), 83-100.

Cummins, R. A. (2003). Normative life satisfaction: Measurement issues and a homeostatic model. *Social Indicators Research, 64*(2), 225-256.

Cummins, R. A., Gullone, E., & Lau, L. D. (2002). A model of subjective well-being homeostasis: the role of personality. In E. Gullone & R. A. Cummins (Eds.), *The Universality of Subjective Wellbeing Indicators: A Multi-Disciplinary and Multi-National Perspective* (Vol. 16). Dordrecht: Kluwer Academic Publishers.

Cummins, R. A., Hughes, J., Tomyn, A., Gibson, A., Woerner, J., & Lai, L. (2007). *Australian Unity Wellbeing Index Special Report: The Wellbeing of Australians - Carer Health and Wellbeing* (No. 17.1). Melbourne: Australian Centre on Quality of Life, Deakin University.

Da Rosa Davis, J. M., & Cowen, P. J. (2001). Biochemical stress of caring. *Psychological Medicine, 31*, 1475-1478.

Da Roza Davis, J. M., & Cowen, P. J. (2001). Biochemical stress of caring. *Psychological Medicine, 31*, 1475-1478.

de Vugt, M. E., Nicolson, N. A., Aalten, P., Lousberg, R., Jolle, J., & Verhey, F. R. J. (2005). Behavioral problems in dementia patients and salivary cortisol patterns in caregivers. *Journal of Neuropsychiatry and Clinical Neuroscience, 17*(2), 201-206.

Fava, G. A., & Sonino, N. (2008). The biopsychosocial model thirty years later. *Psychotherapy and Psychosomatics, 77*, 1-2.

International Wellbeing Group. (2005). Personal Wellbeing Index. Melbourne: Australian Centre on Quality of Life, Deakin University.

Inui, T. S. (2003). The need for an integrated biopsychosocial approach to research on successful aging. *Annals of Internal Medicine, 139*(5), 391-394.

Kuster, P. A., & Merkle, C. J. (2004). Caregiving stress, immune function, and health: Implications for reseach with parents of medically fragile children. *Issues in Comprehensive Pediatric Nursing, 27*, 257-276.

Lazarus, R. S. (1999). *Stress and Emotion: A New Synthesis*. New York: Springer Publishing Company.

Lazarus, R. S., & Folkman, S. (1984). *Stress, Appraisal and Coping*. New York: Springer Publishing Company.

Lovibond, S. H., & Lovibond, P. F. (1995). Manual for the Depression, Anxiety, Stress Scales. Sydney: Psychology Foundation.

Lutgendorf, S. K., & Costanzo, E. S. (2003). Psychoneuroimmunology and health psychology: An integrative model. *Brain, Behavior, and Immunity, 17*, 225-232.

Mundt, J. C., Marks, I. M., Shear, M. K., & Greist, J. H. (2002). The work and social adjustment scale: a simple measure of impairment in functioning. *British Journal of Psychiatry, 180*, 461-464.

Noon, J. M. (1999). *Counselling and Helping Carers*. Leicester, UK: BPS Books.

Pakenham, K. I., Stebbins, P., Cannon, T., & Samios, C. (2005). *Carers in Contemporary Australia: Relations among Carer Illness/Disability Groups, Biographics, Caring Context, Coping and Distress.* Brisbane: PsyHealth Media.

Provinciali, M., Moresi, R., Muzzioli, M., Tarabelli, D., Sirolla, C., Melchiorre, M. G., et al. (2004). Psychological, neuroendocrine and immune measures in non spousal carers of disabled elderly in Italy. *Neuroendocrinology Letters, 25*(5), 391-396.

Schulz, R., & Quittner, A. L. (1998). Caregiving for children and adults with chronic conditions: Introduction to the special issue. *Health Psychology, 17*(2), 107-111.

Shewchuk, R. M., Richards, J. S., & Elliott, T. R. (1998). Dynamic processes in health outcomes among caregivers of patients with spinal cord injuries. *Health Psychology, 17*(2), 125-129.

Smith, A. L., Folan, T. K., & Haaland, C. D. (2002). Connecting practitioners with the progression of Alzheimer's caregiving. *Journal of Systemic Therapies, 21*(4), 86-100.

Vedhara, K., Cox, N. K. M., Wilcock, G. K., Perks, P., Hunt, M., Anderson, S., et al. (1999). Chronic stress in elderly carers of dementia patients and antibody response to influenza vaccination. *The Lancet, 353*, 627-631.

Vitaliano, P. P., Echeverria, D., Yi, J., Phillips, P. E. M., Young, H., & Siegler, I. C. (2005). Psychophysiological mediators of caregiver stress and differential cognitive decline. *Psychology and Aging, 20*(3), 402-411.

Vitaliano, P. P., Scanlan, J. M., & Zhang, J. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin, 129*(6), 946-972.

Vitaliano, P. P., & Young, H. M. Z., J. (2004). Is caregiving a risk factor for illness? *Current Directions in Psychological Science, 13*(1), 13-16.

Vogeser, M., Durner, J., Seliger, E., & Auernhammer, C. (2006). Measurement of late-night salivary cortisol with an automated immunoassay system. *Clin Chem Lab Med, 44*(12), 1441-1445.

Wheaton, B. (1997). The nature of chronic stress. In B. H. Gottlieb (Ed.), *Coping with Chronic Stress* (pp. 43-73). New York: Plenum Press.