

Caregiving burden: congruence of health assessment between caregivers and care receivers

VWQ Lou

Department of Social Work & Social Administration, Sau Po Centre on Ageing, The University of Hong Kong

Correspondence to: Vivian WQ Lou, Department of Social Work & Social Administration, Sau Po Centre on Ageing, The University of Hong Kong, Hong Kong

INTRODUCTION

Family caregivers may enable frail older people to 'age in place'. According to the recently released Thematic Household Survey,¹ about 1 to 3% of older people aged 60 to 74 years need at least one assistant for activities of daily living (ADL); the percentage increases to 9.2% for persons older than 75 years. With regard to instrumental activities of daily living (IADL), the percentages are 6 to 8% for those aged 60 to 69 years, and 13 to 18% for those older than 70 years. 47.6% of elderly persons who need assistance in ADL are supported by informal caregivers, such as a spouse, son or daughter, relative, friend, and/or domestic helper or nurse.¹

Caregiving stress and distress have negative impact on the well-being of both caregivers and care receivers. Burden on caregivers may affect the decision to move the care receivers to residential facilities.² Older Chinese adults are more altruistic towards their children and/or other caregivers, when making decisions about moving to residential facilities despite their wishes to receive care at home.³ The poorer the health of the care receiver, the higher the demand on the caregivers. Caregiving burden is affected by not only the functional ability of the care receivers, but also the caregivers' perceptions towards care receivers' health status. Caregivers with optimistic perceptions towards care receivers' health status are more likely to foster independence and avoid overprotective caregiving behaviour, and are associated with care receivers' higher levels of life satisfaction and self-efficacy.^{4,5} Hence, the congruence between environmental demands and personal perceptions affects the adaptive ageing of care receivers.

This paper examines factors associated with the burden of caring for frail older people, particularly the degree of congruence between older people's and their caregivers' perception of health status of older people.

METHOD

Multi-stage sampling was adopted. Eight out of 18 geographical constituency areas were randomly selected first. From August 2006 to December 2008, all service units providing one of the 4 types of long-term care services (e.g. nursing home, care and attention home, integrated home and community services, and enhanced home and community care services) in the selected eight geographical constituency areas were invited to recruit older people and their primary caregivers to participate. A total of 59 service units participated and recruited 471 dyads of older people and their family caregivers. 435 dyads were successfully interviewed by trained research assistants using a standardised questionnaire. Responses from 159 of the dyads in which care receivers were cognitively intact were included in this analysis. The socio-demographics of the caregivers are shown in **TABLE 1**.

Both caregivers and care receivers were asked to rate the care receivers' health status on a 5-point scale (excellent, good, fair, poor, very poor). Based on the congruence between caregivers and care receivers, 3 groups were set up: (1) caregivers perceived a better health status than that of care receivers (better group or BG), (2) caregivers and care receivers agreed on the health status (agreed group or AG), and (3) caregivers perceived a poorer health status than that of care receivers (poorer group or PG).

TABLE 1
Socio-demographics of the caregivers (n=159)

Socio-demographics	No. (%)
Relationship with the care receiver	
Spouses	45 (28)
Children and in-laws	84 (53)
Other*	30 (19)
Gender	
Male	53 (33)
Female	106 (67)
Age (years)	
≤50	59 (37)
51-60	44 (28)
≥61	56 (35)
Education level	
Primary or below	57 (36)
F1-F7	75 (47)
College or above	27 (17)
Employment	
Full/part time	77 (48)
Retired/homemaker	72 (45)
Other†	10 (6)
Marital status	
Currently not married	36 (23)
Currently married	123 (77)
Mean±SD length of time providing care (years)	5.04±5.68

* Grandchildren, relatives, friends, people from the same hometown, or employees

† Unemployed, students, or resigned from a job to take on the caregiver role

Other measurements analysed were demographic variables, caregiving burden, Barthel ADL and IADL of the older people, and the Short Portable Mental Status Questionnaire (SPMSQ).

RESULTS

21% of the 159 dyads belonged to the BG, 36% to the PG, and 43% to the AG. The PG caregivers were more likely to be spouses of the care receivers, in contrast to BG caregivers (49% vs. 34%, $p < 0.05$). No significant group differences were found regarding caregivers' gender, age, educational attainment, marital status, religious affiliation, or occupational status.

The Barthel ADL score and IADL performance score of the older people did not differ significantly between optimistic and pessimistic groups; older

PG subjects sustained the highest level of ADL and IADL impairment, in contrast to BG subjects. No significant group differences were found in the older people's cognitive score as measured by the SPMSQ (TABLE 2).

The differences between the 3 groups in terms of the caregiving burden related to the emotional burden of the caregivers. PG caregivers reported a significantly higher level of emotional burden as compared to BG caregivers. On the contrary, the BG caregivers reported the lowest level of emotional burden (TABLE 3).

DISCUSSION

No significant group differences were found in the care receivers' functional dependence as assessed by Barthel ADL, IADL, and cognitive ability as

TABLE 2
Differences between the groups with respect to activities of daily living (ADL), instrumental ADL (IADL), and Short Portable Mental Status Questionnaire (SPMSQ)

Group*	Mean	SD	F-value
ADL			
BG	77.3	14.5	2.80 (p=0.06) BG<PG
AG	82.2	16.0	
PG	85.0	13.8	
IADL			
BG	2.27	1.70	2.65 (p=0.07) BG<PG
AG	3.07	2.23	
PG	3.35	2.31	
SPMSQ			
BG	3.21	2.38	1.11 (p=0.33)
AG	2.52	2.12	
PG	2.72	2.12	

* BG denotes caregivers perceived a better health status than that of care receivers, AG denotes caregivers and care receivers agreed on the health status, and PG denotes caregivers perceived a poorer health status than that of care receivers

TABLE 3
Differences between the groups in terms of caregiving burden

Groups*	Mean	SD	F-value
Overall burden			
BG	59.36	18.22	1.33 (p=0.27)
AG	64.35	17.28	
PG	66.49	16.26	
Physical burden			
BG	12.94	6.40	0.57 (p=0.56)
AG	14.08	6.08	
PG	14.21	4.89	
Time-dependent burden			
BG	15.42	4.31	0.06 (p=0.94)
AG	15.68	3.78	
PG	15.70	3.53	
Emotional burden			
BG	10.70	4.19	2.98 (p=0.05) BG<PG
AG	11.97	4.33	
PG	13.16	5.26	
Developmental burden			
BG	5.68	0.99	0.14 (p=0.87)
AG	5.28	0.65	
PG	4.88	0.65	
Social burden			
BG	8.36	3.87	0.39 (p=0.68)
AG	9.15	3.57	
PG	9.14	3.94	

* BG denotes caregivers perceived a better health status than that of care receivers, AG denotes caregivers and care receivers agreed on the health status, and PG denotes caregivers perceived a poorer health status than that of care receivers

measured by the SPMSQ. However, caregivers vary in perception of care receivers' health status. 43% of the caregivers agreed with the care receivers on their health status, whereas 21% and 36% of caregivers were optimistic and pessimistic, respectively. This supports the notion that the person and the environment function independently, when interacting with each other. Both giving and receiving care involve higher-order systems that might be affected by personal, interpersonal, and environmental factors. Spouse caregivers were more likely to assess care receivers' health as poorer, compared to son/daughter caregivers (73% vs. 43%, $p < 0.01$).

Optimistic caregivers were associated with less caregiving burden than pessimistic caregivers. This indicates that personal-environmental interactions affect caregivers' adaption, as indicated by the caregiving burden. Caregivers need to adapt to both environmental and internal demands. Being optimistic can serve multiple functions that encourage positive psychological adjustment of the caregiver. Optimism is an indicator of positive mental health in caregivers, and help people cope with life's difficulties, given that the future is often uncertain.

There are at least 3 implications for future research and interventions based on the present study. First, policies and interventions for caregivers need to target specific populations; spouse caregivers deserve prioritised support considering their health status and emotional burden. Second, optimism coping can be used to enhance caregivers' expectations for positive outcomes. Third, future research on caregiving should pay attention to the possible incongruence between caregivers' and care receivers'

views by incorporating new methods of assessment. Such methods could go beyond self-reporting, so as to include cognitively-impaired older people.

This study has limitations. First, the sample was selected in multiple stages and the success rate at the first stage was about 56%. Thus, generalisation of its findings should be undertaken with caution. Second, the parameter used as an indicator of congruence/incongruence was based only on one set of measures (i.e. self-rated health of the older person and the caregiver's assessment). Third, the findings were based on the assessment of cognitively sound older persons, and may not apply to those who are cognitively impaired.

ACKNOWLEDGEMENT

This project is supported by Studies in Health Services, Health, Welfare and Food Bureau, Ref. SHS-E-04.

REFERENCES

1. Census and Statistics Department. *Socio-demographic profile, health status and self-care capability of older persons, Thematic Household Survey Report No. 40*. Hong Kong: Hong Kong Government; 2009.
2. Okamoto K, Hasebe Y, Harasawa Y. Caregiver psychological characteristics predict discontinuation of care for disabled elderly at home. *Int J Geriatr Psychiatry* 2007;22:1110-4.
3. Lee JJ, Lo SC. *Research on residential care service needs of the elders*. Hong Kong: Social Welfare Practice and Research Centre, Department of Social Work, The Chinese University of Hong Kong; 2005.
4. Izal M, Montorio I, Marquez M, Losada A. Caregivers' expectations and care receivers' competence: Lawton's ecological model of adaptation and aging revisited. *Arch Gerontol Geriatr* 2005;41:129-40.
5. Connidis I. *Family ties and aging*. 2nd ed. Thousand oaks, CA: Sage Publications; 2009.