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A study of informal caregivers and the association of caregiving status with health and quality of life

Key Messages

1. This is the first population-based study of informal caregivers in Hong Kong.
2. Informal caregivers provide a substantial proportion of the care for sick and dependent elderly people.
3. Primary caregivers, especially females, have a poor health profile and quality of life.

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Introduction

With the proportion of older people in the population growing rapidly, particularly the 'old-old' aged 85 years and above, the number of people requiring care is expected to increase substantially in the next few decades. Informal caregivers form the backbone of caregiving, especially among those groups unable to afford paid workers. Limited studies have shown that informal caregivers suffer high rates of depression, as well as adverse health and mortality outcomes, probably due to the constant and unrelieved emotional strain that they face.[1] Systematic population-based data on informal caregivers are practically non-existent in Hong Kong. As informal caregivers are vital for the maintenance of elderly patients with dementia or functional limitations in the community, their well-being will have direct implications for health care services.

The objectives of this study were:

- To describe the prevalence of informal caregiving in the Hong Kong population aged 35 years and above.
- To conduct a comparative study on the heath status, and health-related quality of life (QOL) of primary informal caregivers and non-caregivers.
- To investigate the association of the caregiver burden with physical and psychological health and QOL among the primary caregivers.

Methods

This study was conducted from January 2003 to December 2004 and was a cross-sectional study of a random sample of the Hong Kong Chinese adult population aged 35 years or above, recruited by dialling the telephone randomly.

Informal caregivers (CG) were defined as those who provided unpaid assistance with at least one activity of daily living (ADL) or instrumental activity of daily living (IADL) to an elderly care recipient aged 65 years or older; and who spent at least 4 hours per week in caregiving activities. The primary informal caregivers (PCG) were those in the care-recipient's network who were giving the most assistance with ADL or IADL to the recipient. Non-caregivers (NCG) were those who did not, or were not required to, provide support with ADL or IADL to an elderly person or any other type of care recipient.

The association of caregiving status with the outcome variables was estimated using multiple linear and logistic regression models controlling for other lifestyle confounders. Subgroup analyses were carried out to test the secondary hypothesis that some variables (eg perception, social support, resources) will operate as intermediate variables between caregiver status and health outcomes.

Results

Distribution of informal caregivers

Of 5707 phone contacts with eligible target subjects, 3658 interviews were completed, 2637 households with an elderly member (EH) and 1021 households with no elderly members (NEH). The response rate was approximately 64%.

Table 1. Age and sex distribution of primary caregivers (PCG) and non-caregivers (NCG)

Age-group (years)	Male (n=238)		Female (n=507)	
	PCG (n=83)	NCG (n=155)	PCG (n=169)	NCG (n=338)
35-39	10 (12%)	20 (13%)	28 (17%)	56 (17%)
40-44	16 (19%)	32 (21%)	42 (25%)	84 (25%)
45-49	15 (18%)	30 (19%)	22 (13%)	44 (13%)
50-54	16 (19%)	30 (19%)	27 (16%)	54 (16%)
55-59	9 (11%)	9 (6%)	24 (14%)	48 (14%)
60-64	5 (6%)	10 (6%)	10 (6%)	20 (6%)
65-69	2 (2%)	4 (3%)	7 (4%)	14 (4%)
70-74	2 (2%)	4 (3%)	7 (4%)	14 (4%)
75-79	4 (5%)	8 (5%)	1 (1%)	2 (1%)
80-84	4 (5%)	8 (5%)	1 (1%)	2 (1%)

Table 2. Percentage distribution of duration (years) and frequency (hours/week) spent caregiving

Factor	Male (n=83)			Female (n=169)		
	35-49 years (n=41)	50-64 years (n=30)	≥65 years (n=12)	35-49 years (n=92)	50-64 years (n=61)	≥65 years (n=16)
Mean duration* (SD) [years]	7.4 (4.8)	8.7 (7.0)	4.5 (2.9)	6.5 (5.3)	8.0 (7.0)	7.7 (7.4)
Mean frequency* (SD) [hours/week]	16.1 (23.3)	13.3 (11.8)	32.1 (43.9)	27.5 (37.7)	30.4 (41.4)	36.0 (39.9)
Mean burden (SD) [Zarit Score]	23.0†‡ (14.28)	17.0 (10.01)	13.5* (8.33)	23.4 (13.94)	21.9 (10.97)	17.1 (8.87)

* P=0.027

† P<0.05 by multiple range test comparing with the age-group of 50-64 years

‡ P<0.05 by multiple range test comparing with the age-group of ≥65 years

The proportion of households that had a caregiver (aged ≥35 years) was 7% (3% in NEH, 8% in EH). Few (3%) households had more than one CG. In total, 5% of the surveyed population were CG. A total of 252 PCG and 493 NCG were included in this analysis.

Characteristics of primary informal caregivers

Most PCG were female and aged below 65 years. Relatively few PCG (15% of males and 10% of females) were aged 65 years or above (Table 1). The majority (78%) of the male PCG aged below 65 years were working, and more than one third of the female PCG were homemakers. The younger, and the male PCG had higher levels of education.

Burden of caregiving

A few of the PCG (12% of males and 9% of females) took care of two or more dependent elderly people. Overall, 37% of the male PCG, compared with 27% of the female PCG did not seek counselling when they developed difficulties with caregiving. A significant proportion (43-71%) of PCG felt that government support was insufficient and this feeling was stronger among the younger PCG. Less than 10% utilised home helpers and the use of other community services was minimal.

A large proportion of PCG (61% of males and 53% of females) assisted with one to three tasks for their elderly care recipients. These included housework, transport to health clinics, and movement. More women were involved in demanding personal care tasks such as bathing, cleaning up after bladder or bowel accidents, etc.

The mean duration of caregiving ranged from 4.5 (standard deviation [SD], 2.9) to 8.7 (SD, 7.0) years. Female PCG spent longer hours of caregiving compared with the male PCG; 13% gave more than 50 hours per week. The older female PCG (≥50 years) had a higher burden score than their male counterparts (Table 2), but the burden score declined with age, particularly among men.

Health aspects comparing primary informal caregivers and non-caregivers

A higher percentage of PCG reported poorer physical and mental health, ranging from an increased number of doctor visits to having depressive symptoms. Male PCG were 2.8-fold more likely to visit doctors than NCG. Compared with NCG, female PCG were more likely to have insomnia, 2.7-fold more likely to have depression (odds ratio [OR]=2.8; 95% confidence interval [CI], 1.7-4.6), and about 1.5-fold more likely to report symptoms (headache, dizziness, heart palpitations, and worsening memory).

Both male and female PCG had about a 2-fold risk of feeling tension when compared with the NCG. More of the female than the male PCG (OR=2.2; 95% CI, 1.2-4.0) had insomnia problems.

Quality of life

Female PCG had significantly lower scores in all QOL domains, as assessed by the Chinese version of Short-Form Health Survey (SF-36), when compared to the NCG. By contrast, the male PCG had significantly lower scores than the NCG only in the domains ‘bodily pain’, ‘general health’, ‘vitality’, and ‘social functioning’. Female PCG

Table 3. Quality of life assessed using Short-Form Health Survey (SF-36) in primary caregivers (PCG) and non-caregivers (NCG), using the *t* test to compare the distributions of mean scores between cases and controls

	Male (n=238)[*]		Female (n=507)[*]	
	NCG (n=155)	PCG (n=83)	NCG (n=338)	PCG (n=169)
Physical functioning	91.10 ± 8.79	92.95 ± 9.31	94.45 ± 9.78	90.41 ± 13.08[ǁ]
Physical role[†]	84.84 ± 2.12	75.90 ± 36.93	84.04 ± 27.40	68.34 ± 36.75[ǁ]
Bodily pain	92.15 ± 16.70	84.87 ± 24.00[‡]	84.57 ± 22.18	73.24 ± 29.03[ǁ]
General health	67.49 ± 19.22	60.64 ± 21.80[‡]	64.74 ± 18.87	59.07 ± 21.49[§]
Vitality	64.52 ± 18.97	56.57 ± 23.81[§]	61.38 ± 19.17	55.74 ± 19.16[§]
Social functioning	94.84 ± 11.38	83.43 ± 23.02[ǁ]	91.57 ± 17.55	79.66 ± 24.35[ǁ]
Emotional role[†]	81.94 ± 29.73	76.31 ± 35.13	83.93 ± 29.52	66.86 ± 39.42[ǁ]
Mental health	76.26 ± 16.10	72.96 ± 20.80	76.65 ± 16.84	72.31 ± 18.30[‡]

[*] Data are shown in mean ± SD
[†] Physical role denotes role limitations due to physical problems, emotional role denotes role limitations due to mental problems
[‡] P<0.05
[§] P<0.01
[ǁ] P<0.001

Table 4. Multiple linear regression factors associated with Zarit Burden Score among the primary caregivers (n=252)

Factor	β	SE	P value	R^2
Sex (women vs men)	2.838	1.687	0.094	0.011
Age	-3.460	1.147 (sex adjusted)	0.003	0.046
Expenses	6.939	2.317	0.003	0.046
Personal care I	4.438	1.637	0.007	0.040
Personal care II	7.334	1.667	<0.001	0.083
Caregiving duration (years)	-0.091	0.113	0.420	0.014
10 hours/week of caregiving	0.907	0.220	<0.001	0.074
No. of tasks given	1.641	0.354	<0.001	0.090
No. of community services	0.793	0.990	0.424	0.014
No. of medical services	2.168	0.683	0.002	0.050

Table 5. Logistic regression analysis of factors associated with health outcomes among primary caregivers (sex adjusted)

Factor	Odds ratio (95% confidence interval)			
	No. of doctor visits (≥1 vs 0)	Trouble sleeping (yes vs no)	Depression (yes vs no)	Felt tension (yes vs no)
Age (years)				
35-49	1.0	1.0	1.0	1.0
50-64	2.45 (1.33-4.51)	0.62 (0.34-1.13)	0.50 (0.25-0.97)	0.87 (0.50-1.48)
≥65	1.99 (0.80-4.94)	1.53 (0.66-3.58)	0.69 (0.26-1.85)	0.26 (0.09-0.72)
Hours/week (per 10 hours increase)	1.02 (0.94-1.10)	1.07 (1.00-1.16)	1.12 (1.04-1.21)	1.02 (0.95-1.10)
Burden score	1.005 (0.98-1.03)	1.03 (1.004-1.05)	1.06 (1.04-1.09)	1.05 (1.03-1.07)
General burden				
0	1.0	1.0	1.0	1.0
1	1.18 (0.48-2.91)	0.91 (0.41-2.00)	1.25 (0.47-3.29)	1.60 (0.73-3.54)
2	2.77 (1.19-6.43)	1.06 (0.49-2.32)	2.16 (0.86-5.41)	3.02 (1.39-6.58)
≥3	2.70 (1.10-6.63)	2.42 (1.08-5.40)	4.21 (1.66-10.72)	8.23 (3.47-19.53)
Medical services				
0	1.0	1.0	1.0	1.0
1	2.30 (0.72-7.37)	1.16 (0.44-3.01)	4.24 (0.92-19.48)	1.07 (0.44-2.62)
2	2.07 (0.64-6.67)	1.03 (0.40-2.69)	4.77 (1.04-21.78)	1.34 (0.55-3.27)
≥3	2.83 (0.86-9.33)	1.74 (0.65-4.63)	4.30 (0.91-20.32)	1.89 (0.75-4.79)

had generally lower scores than men in all domains, in particular in ‘bodily pain’, ‘physical role’ and ‘emotional role’ (Table 3).

Factors associated with informal caregiver burden and health outcomes among the primary caregivers

Factors statistically significantly associated with the CG burden included expenses associated with caregiving, personal care provided, hours spent caregiving, and the number of tasks given. Also, increasing numbers of medical services needed by the care recipient were related to the CG burden. Nevertheless, the CG burden score seemed to decrease in the older age-groups (Table 4). After adjustment for sex, a more severe CG burden was associated with more visits to the doctor, sleep problems, depression, and tension (Table 5). The CG burden was also negatively associated with all of the SF-36 QOL domains.

Discussion

Our study revealed that 8.4% of EH and 3% of NEH had CG. About 3.9% of the male and 5.2% of the female population aged ≥35 years were CG. Among the PCG identified, over two thirds were women. Female PCG reported a significantly higher risk of suffering from symptoms, tension, and depression when compared with NCG, and had lower scores in all domains of SF-36 QOL measurements. Our data have consolidated information on the extent of the CG burden, identified gender differences in caregiving, adverse effects of caregiving, and age differences in the CG burden.[2,3]

As most older CG have retired from paid work, they may have fewer role conflicts than younger CG. On the other hand, the older CG are often themselves vulnerable, and thus adequate counselling and support for the elderly CG may be necessary.

The key areas of strain identified by this study included financial strain, physical deterioration, negative psychological responses, and reduction of QOL. In time, as reported in other studies, caregivers may experience 'burn-out' and may also become recipients of care in the health care system.[4] Thus, support provided for both the care recipients and CG is important for retention of the role of the informal CG.[5]

Our data also revealed that CG use of community services' support was minimal and that it did not effectively reduce the CG burden. It is worth noting that only a very small proportion (<10%) received community nursing or outreach services, and most were receiving acute medical care rather than supportive services. Over half of the CG in this study felt government support was insufficient and half of the CG had received no counselling.

Implications

This territory-wide, population-based, CG study has revealed a number of factors related to the CG burden, which, in turn, are associated with adverse health outcomes. The cross-sectional study design has limitations when it comes to clearly delineating the temporal relationship between the role of CG and health changes, however. As such, longitudinal studies on the changes in CG needs, their perceived burden, health status, and QOL from the time of becoming PCG to later years will be required. We have found very clear gender differences in the caregiving effect and further studies to identify the reasons for such differences would be useful.

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