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Case management to improve quality of life of older people with early dementia and to reduce caregiver burden

Key Messages

1. Case management was not effective in improving quality of life of mildly demented people or reducing family caregiver burden.
2. Case management reduced depressive symptoms in mildly demented people in the short term.
3. Case management encouraged family caregivers to seek outside help.

Introduction

Psychosocial interventions are important adjuvant therapies that may offer additional benefits for persons with dementia.¹ A combination of cognitive behavioural approach for functional and skill training, coupled with caregiver intervention on problem-solving skills for neuropsychiatric symptoms have shown promise in improving cognitive and behaviour parameters. To optimise potential therapeutic benefits, these interventions should be initiated early.² Nonetheless, intensive therapeutic psychosocial interventions in demented subjects are difficult to sustain, because of limited resource and the underlying disease process. A more feasible approach is case management whereby available resources within both the family and community are used for the benefit of the demented persons and their families. By offering regular contacts and support, the case manager helps the demented persons and their families to adapt to the evolving level of disabilities.

We proposed a case management model for mildly demented persons. In this model, the case manager (occupational therapist) performed functional assessments, advised on coping strategies, skills training and behavioural management, and encouraged the demented persons to be registered with a local social service centre so that the family can tap into the locally available social services. Through regular contacts by telephone or home visits, and a telephone hotline, the progress of the family can be monitored. A randomised controlled trial was performed to evaluate the impact of the programme on the quality of life of the mildly demented older people and on caregiver stress.

Methods

This study was conducted from March 2005 to January 2008. Community-dwelling people aged ≥ 65 years with mild dementia (Chinese Mini-Mental State Examination (MMSE) score of ≥ 15 and a Clinical Dementia Rating of 1) and their family caregivers were recruited from a psychogeriatric outpatient clinic and memory clinics of the Prince of Wales Hospital. After baseline assessment, the subjects were randomly assigned to receive case management (intervention) or usual care (control). The intervention included assessment and continual support by a case manager via home visits and telephone calls, a 3-month home-based cognitive stimulation activities, and a telephone hotline to access the case manager.

All subjects were followed up at months 4 and 12. The primary outcome measures were Personal Wellbeing Index for Intellectual Disability (PWI-ID)³ of the demented elders and the Zarit Burden Interview (ZBI) score of the family caregivers. Secondary outcome measures entailed the Cornell Scale for Depression in Dementia (CSDD),⁴ Neuropsychiatric Inventory (NPI), general health questionnaire (GHQ), and Personal Wellbeing Index for Adult (PWI-A) for family caregivers. Cost analyses of the direct and indirect expenses of the family caregivers and the public health care costs were also performed.

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Results

Of 102 subjects recruited, 59 were randomly assigned to the intervention and 43 to the control groups. At the end of 12 months, 6 and 4 subjects dropped out from the respective groups (Table 1).

At the 4-month follow-up, the CSDD scores decreased significantly for the intervention group ($z = -3.17$, $P = 0.002$, Wilcoxon signed rank test) but not for the control group, whereas the NPI total scores decreased significantly in both groups (Table 2). For the quality-of-life measures, change in PWI-ID was not significant in both groups. For caregiver stress, changes in the PWI-A, ZBI, and GHQ scores were not significant in both groups.

At the 12-month follow-up, the Chinese MMSE scores decreased significantly in both groups ($P < 0.05$, Wilcoxon signed rank test), whereas changes in the CSDD, PWI-ID scores in the demented subjects were not significant in both groups (Table 2). The GHQ scores for caregivers in the intervention group improved significantly ($z = -2.20$, $P = 0.028$, Wilcoxon signed rank test).

At the baseline, the use of paid helpers and day care services was not significantly different in the two groups. At the 4-month and 12-month follow-up, the use of paid helpers and day care services increased significantly in the intervention group ($P < 0.05$, Chi squared test). Home help and respite care were seldom used by either group (Table 3).

Table 1. Demographics of subjects and caregivers at baseline*

Parameter	Intervention (n=59)	Control (n=43)	P value
Subject			
Age (years)	78.6±6.4	78.2±5.5	0.74
Female	35 (59)	24 (56)	0.72
Use of dementia-related drugs	18 (31)	14 (33)	0.83
Use of antipsychotics	9 (15)	3 (7)	0.23
Use of antidepressants	14 (24)	12 (28)	0.65
Mini Mental State Examination score	17.6±5.2	18.0±5.1	0.69
Cornell Scale for Depression in Dementia score	4.8±6.0	4.3±3.8	0.52
Neuropsychiatric Inventory score	18.9±17.2	20.4±17.1	0.63
Personal Wellbeing Index for Intellectually Disabled	69.6±20.0	72.2±18.6	0.53
Caregiver			
Spouse	13 (22)	15 (29)	0.18
Zarit Burden Interview score	33.2±17.8	32.3±15.8	0.81
Personal Wellbeing Index for Adult	63.6±15.1	61.2±18.6	0.46
General Health Questionnaire score	13.1±5.4	14.2±6.6	0.70

* Data are presented as mean±SD or No. (%)

Table 2. Change in demented persons' quality of life and caregiver stress at 4- and 12-month follow-up

Parameter	Mean±SD change from baseline to month 4		Mean (95% CI) group difference	Mean±SD change from baseline to month 12		Mean (95% CI) group difference
	Intervention (n=57)	Control (n=42)		Intervention (n=53)	Control (n=39)	
Subject						
Mini Mental State Examination score	-0.46±3.42	0.39±2.95	0.57 (-1.47, 2.60)	1.45±4.17	1.76±3.44	0.23 (-2.24, 2.71)
Cornell Scale for Depression in Dementia score	2.45±5.00†	1.03±3.40	-0.85 (-2.15, 0.45)	0.94±6.47	1.08±3.57	0.65 (-1.11, 2.42)
Neuropsychiatric Inventory score	8.75±14.23†	9.25±14.15†	-1.23 (-7.65, 5.18)	4.62±17.23	10.15±15.43†	3.47 (-3.10, 10.03)
Personal Wellbeing Index for Intellectually Disabled	-3.39±22.89	0.35±20.92	-0.28 (-8.71, 8.16)	-5.48±24.83	-2.49±18.93	-0.67 (-9.68, 8.34)
Caregiver						
Zarit Burden Interview score	-1.12±13.03	-1.95±14.38	0.46 (-6.44, 7.36)	-2.68±15.22	-1.05±14.34	3.06 (-4.34, 10.46)
Personal Wellbeing Index for Adult	-1.80±11.46	1.18±11.78	5.19 (-1.33, 11.71)	1.91±16.42	0.15±11.58	2.46 (-5.03, 9.94)
General Health Questionnaire score	-0.81±4.98	0.25±5.56	0.09 (-1.98, 2.17)	-1.87±6.29*	0.03±4.54	1.22 (-1.09, 3.53)

* $P < 0.05$, Wilcoxon signed rank test

† $P < 0.005$, Wilcoxon signed rank test

Table 3. Use of additional support for dementia care

Support	No. (%) of demented persons					
	Baseline		Month 4		Month 12	
	Intervention	Control	Intervention	Control	Intervention	Control
Paid helpers	19 (32.2)	7 (16.3)	27 (47.4)*	6 (14.6)	21 (39.6)*	7 (17.9)
Day care	28 (47.5)	18 (39.1)	44 (77.2)*	18 (43.9)	37 (69.8)*	14 (35.9)
Home help	5 (8.5)	5 (11.6)	4 (7.0)	3 (7.3)	3 (5.7)	3 (7.7)
Respite care	0 (0)	1 (2.3)	1 (1.8)	0 (0.0)	3 (5.7)	0 (0.0)

* $P < 0.05$, Pearson Chi squared test

The median public health care cost was significantly greater in the intervention than control group (HK\$8526 vs HK\$5993, $P=0.023$, Mann-Whitney U test), primarily because of the cost of case management. From the family caregivers' perspective, the median incremental direct costs per month were significantly greater in the intervention than control group (HK\$170 vs HK\$50 at month 4; HK\$240 vs HK\$7 at month 12; $P<0.05$ for both). The median incremental indirect costs per month increased in the intervention group at month 4 (HK\$0 [interquartile range, HK\$0-3750] vs HK\$0 [interquartile range, HK\$0-950] but not at month 12.

Discussion

Dementia is a common disease of old age. The global deterioration in cognition and independent functioning leads to increased caregiver stress and institutionalisation. The usual care for the demented elders is not suited to community-dwelling persons with mild dementia. The medical service is not geared to early detection of dementia, and treatment is limited by drug budgetary constraints. Psychosocial interventions are not normally available except in the few specialised memory clinics where multidisciplinary therapeutic interventions are provided for a limited number of patients for a limited period of time. We proposed an interdisciplinary approach, based on a community case manager supported by a medically oriented psychiatric or memory clinic. The case manager offered professional advice from cognitive stimulation, behavioural management, carer support to liaise with different welfare agencies.

For mood symptoms, the intervention group showed a positive effect at the 4-month follow-up, but the effect was not sustained at 12 months. There was no significant improvement in quality of life and caregiver burden in the case management approach, despite some therapeutic effects. This may be important for the management of motivational mood symptoms in persons with mild and moderate dementia. The case manager advised on coping strategies, skill training, and behavioural management in the initial few months. Subsequent interventions were less intensive. This may explain the lack of sustainability in mood improvement. Therefore, continual community support for families with demented subjects, especially those with co-existing depression is important.

The use of supportive care could be an indicator for the impact of case management. The intervention group became more well informed and active in seeking support. The reported rate of using a paid helper at home and community day care services increased significantly at both 4- and 12-month follow-up. Although costs of care increased in case management, early use of community care services may help to delay institutionalisation.³

The compliance of the home-based programme on cognitive stimulation was limited by the accessibility and communication skills of family caregivers, and the cooperation of the demented persons. This might have

contributed to the psychological stress and burden by the caregivers. It may be more effective if cognitive training was to be administered by trained staff in day care centres.

The perceived burden and personal wellbeing of family caregivers did not improve with case management. There was some deterioration in psychological health as indicated by a significant increase in the GHQ score. This was not surprising as the cognitive function of the demented person deteriorated, costs of care would increase.

A high proportion of intervention group subjects had already received some day care services. The amount and quality of day care was likely to have a direct impact on the psychological stress experienced by family caregivers. During the study period, most of the day care services for the demented were not funded by subvention. Therefore, there was a problem in accessibility and affordability. With further development in dementia day care, this case management model may have a bigger impact. Ideally, the day care centres should take over case management when demented clients start attending on a regular basis.

The small sample size of this study limited its statistical power and precluded the use of hierarchical linear models. Further studies are needed.

Conclusions

Case management was not effective in improving quality of life of early dementia patients or reducing caregiver burden, but did encourage family caregivers to seek help (paid helpers and day care services). Case management and home visits appeared to reduce depressive symptoms of demented subjects, but the effect was not sustained.

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