

Original article

Emotional and instrumental support influencing male caregivers for people with dementia living at home

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Abstract

Object: To clarify the emotional and instrumental support influencing male caregivers for people with dementia living at home.

Patients/Materials and Methods: The subjects were 298 male caregivers. Nursing care burden was assessed using the Zarit Caregiver Burden Scale. Ability to cope with care problems was assessed using the Nursing Care Problems Coping Scale for Male Caregivers for People with Dementia Living at Home (NCSM). Emotional support was assessed using the Emotional Support Network Scale. Instrumental support was assessed using the question “Do you have someone to help when you have a problem with nursing care?”.

Results: There was a significant correlation ($P < 0.04$) between the point (index) of NCSM and Zarit Caregiver Burden Scale. A positive significant correlation was found in three coping styles. A negative significant correlation was found in one coping style, and no significant correlation in one coping style. The ‘Solve the problem’ coping style was linked to support from both within and beyond the family. Both ‘Emotional avoidance’ and ‘Cognitive transformation’ coping styles were linked to support from within the family, and “Request assistance” style only to external support. There were no correlations between the source of support and the “Careful supervision and waiting” coping style.

Conclusion: Emotional and instrumental support for male caregivers was more than three times more likely to be obtained from within the family than outside it. With families becoming smaller, it is becoming more important for communities and society in general to provide emotional and instrumental support for male caregivers. Male caregivers need support from someone with whom they feel comfortable. It is particularly necessary to consider how to support male caregivers who use the “Emotional avoidance” coping style.

Key words: male caregivers, dementia, coping with care problems, emotional support

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Introduction

In 2012, the number of older adults with dementia requiring nursing care in Japan was 4.72 million. By 2025, this figure is expected to reach more than 7.00 million¹⁾. With a rapidly aging population and greater life expectancy²⁾, it is estimated that by 2025, 25% of the population over the age of 65 years will have dementia³⁾. In 2012, the World Health Organization (WHO) recognized dementia as a Public Health Priority and started to provide information and raise awareness about dementia. It has also tried to strengthen public and private efforts to improve care and support for people with dementia and their caregivers. Dementia is a syndrome in which there is deterioration in memory, thinking, behavior and the ability to perform everyday activities⁴⁾. Extra care is required for people with dementia with behavioral and psychological symptoms, which places a burden on caregivers and may damage their psychological health⁴⁾. In Japan, families with just two generations living together accounted for just 6% of the total number of households in 2012, but this is expected to change because of a change in family structure and an increase in family size^{5, 6)}. 17.0% of the population were unmarried men in their fifties in 2010, but this is expected to increase to 25.2% by 2030. The proportion of unmarried men in their sixties was 9.1% in 2010, but is expected to more than double to 19.8% by 2030. The number of male caregivers of people living at home with dementia has quadrupled from 8.2% in 1981 to 32.2% in 2010, and this group now represents about 30% of total caregivers. Three-quarters of male caregivers of people with dementia are husbands, and 25% are sons^{5, 7)}.

Male caregivers have been reported to have health problems and social issues⁷⁾. They suffer from depression⁸⁾, ten-

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sion⁹), and dissatisfaction¹⁰), and their needs are not represented^{11, 12}). Male caregivers often do not seek counseling or support from friends or other people¹³) and they can easily become isolated from their local community¹⁴). They are often so devoted to the care they provide that they cannot work or pursue personal interests¹⁵). The problems that male caregivers face can affect each other, reducing quality of life and affecting psychological condition¹⁶). Male caregivers often experience problems providing care, and these problems are not effectively managed. It is predicted that male caregivers will be found not to ask friends and family to help solve nursing problems. Male caregivers are also more likely to abuse the person for whom they are providing care¹⁷), so providing suitable support for this group is important.

The purpose of this study was to clarify the emotional and instrumental support influencing male caregivers for people with dementia living at home.

Methods

Study subjects

The subjects were 762 male caregivers recruited from five places: (1) caregivers of outpatients with dementia in Fukuoka University Hospital Department of Psychiatry and Department of Neurology, (2) caregivers of inpatients at the Special Hospital for Dementia, (3) members of the Male Caregivers Association nationwide, (4) members of associations of dementia patients' families nationwide, and (5) members of a cooking school for male caregivers. The subjects completed a self-administered questionnaire. The study was performed from September 2013 and January 2015.

Measurements

We wanted to examine issues of age, household composition, relationship with the caregiver, employment situation and period spent providing nursing care. It was thought that support might vary with employment status, so we also asked about whether the person was employed or unemployed.

We used several scales, including the Japanese version of the Zarit Caregiver Burden Scale (J-ZBI)¹⁸), The Care Problems Coping Scale, or Nursing Care Problems Coping for Male Caregivers for People with Dementia Living at Home (NCSM)¹⁹⁻²⁴). Emotional Support was assessed using the Emotional Support Network Scale²⁵).

1) J-ZBI: This scale consists of 22 items, and is a care burden scale that was translated into Japanese by Arai *et al.*¹⁸). Its reliability and validity have been verified, and it has been used in many previous studies in Japan. Its main focus is the burdens arising from providing care, having to start

to provide care, and overall. It uses a five-point Likert-type scale with choices ranging from never = 0, through rarely = 1, sometimes = 2, and quite often = 3 to nearly always = 4.

2) NCSM: This scale consists of 15 items and five factors¹⁹⁻²⁵). Its main focus is nursing care problems encountered by men caring for someone with dementia at home. The five factors are divided into 'Solve the problem', 'Emotional avoidance', 'Cognitive transformation', 'Careful supervision and waiting' and 'Assistance request' styles of coping.

3) Munakata's Emotional Support Network Scale: This scale consists of 10 items, and looks at where people obtain emotional support, and particularly whether this is from within the family or outside.

4) Instrumental support question: A single question asking whether you have anyone who can help when you have a nursing care problem. This question was also split into family and non-family support.

We also asked about the care recipient's age, diagnosis of dementia, certification of long-term care need, and degree of autonomy criteria for dementia in older adults²⁶).

Statistical analyses

We performed two main statistical analyses:

1) We looked at the answer distribution compared with the mean and standard deviation.

2) We examined correlations between NCSM scores and the measures adopted as external criteria (Emotional Support Network Scale and Instrumental Support Question).

All statistical analyses were performed using the Japanese version of SPSS22.0 for Windows. The level of statistical significance was set at 0.05 (two-tailed).

Ethical approval

We obtained ethical approval for this study from the ethics committee of Fukuoka University (approval code: 13-7-07). The study conforms to the provisions of the Declaration of Helsinki in 1995 (as revised in Tokyo in 2004). Consent was obtained from hospitals, a care facility, and the Men's Caregiver and Family Association. The purpose of the study was explained orally and in writing to the relevant parties. Subjects were informed that their information and data would be treated confidentially. Subjects gave their consent by returning completed questionnaires.

Results

Demographic data of the subjects

We received valid responses from 298 people, a response rate of 39.1%. The mean subject age was 70.1 (SD 11.2) years. The care recipient was the caregiver's wife in

Table 1 Participants' demographic information

	Variable	Results (%)
Age	Mean age	70.1 (SD = 11.2)
Relationship with the caregiver	Wife	190 (63.8)
	Parent	103 (34.6)
	Another relative	4 (0.2)
Employment status	Employed	99 (29.9)
	Farmer	43 (14.4)
	Company employee	28 (9.4)
	Family-operated business	24 (8.1)
	Unemployed	104 (34.9)
Nursing care hours	The mean time spent providing nursing care	12.0 (SD = 8.6)
J-ZBI*	Mean point score (SD)	2.1 (SD = 1.2)

*Japanese version of the Zarit Caregiver Burden Scale. SD: standard deviation.

Table 2 Overview of people with dementia

	Variable	Results (%)
Age	Mean	78.1 (SD = 9.8)
Dementia diagnosis	Alzheimer's type	179 (54.6)
	Lewy bodies	68 (28.8)
	Frontotemporal lobar degeneration	12 (4.0)
	Cerebrovascular type	9 (2.7)
Level of certification of long-term care need	Care support 1 or 2	20 (6.7)
	Care need 1	65 (21.8)
	Care need 2	47 (15.7)
	Care need 3	41 (13.7)
	Care need 4	41 (13.7)
	Care need 5	53 (17.8)
	Not applicable or unspecified	31 (10.4)

Care support is a less intensive level of support required than care need. The numbers refer to increasing levels of care required. SD: standard deviation.

190 cases (63.8%), the parent of the caregiver in 103 cases (34.6%), and another relative in four cases (0.2%). Of the respondents, 99 (29.9%) were employed, of whom 43 (14.4%) were farmers, 28 (9.4%) were company employees, and 24 (8.1%) worked in a family-operated business. The mean time spent providing nursing care was 12.0 (SD 8.6) hours per day. The J-ZBI of overall care burden mean score was 2.1 (SD 1.2) (Table 1).

Overview of care recipients

The mean age of the care recipients was 78.1 (SD 9.8) years. In total, 179 (54.6%) had Alzheimer's type dementia, 68 (28.8%) had Lewy body type, and eight (2.8%) had frontotemporal lobar degeneration. The biggest group, 65 (21.8%), had a care need rating of 1, 53 (17.8%) had a care need rating of 5, and 47 (15.7%) had a care need rating of 2 (Table 2). Sixty-nine (23.2%) of the patients with dementia were rated

as level IV on the day-to-day functioning and degree of autonomy criteria for older adults with dementia (Table 3), 55 (18.5%) as III, and 50 (16.8%) as I (Table 3).

Significant correlations between the five coping styles of the NCSM and J-ZBI

There was a significant positive correlation between J-ZBI and the 'Solve the problem' coping style for both employed ($r = 0.39$) and unemployed people ($r = 0.22$). A similar correlation was seen for the 'Cognitive transformation' style for both groups (employed people $r = 0.31$ and unemployed people $r = 0.21$). There was a significant negative correlation between 'Emotional avoidance' style and J-ZBI for both groups (employed people $r = -0.46$ and unemployed people $r = -0.23$). There were no significant correlations between 'Careful supervision and waiting' style and J-ZBI. There was a significant correlation between 'Request assistance' style and J-ZBI only for employed people ($r = 0.25$) (Table 4).

Table 3 Day-to-day functioning and degree of autonomy criteria for older adults with dementia

	Variable	Results (%)
I	Have some level of dementia; however, one's home, daily, and social life are almost independent.	50 (16.8)
II	A few difficulties with communication, symptoms, and behaviors that interfere with daily life. Can be self-supporting if someone is there to guide them.	39 (13.1)
II a	Same as II, but applies outside the home.	11 (3.7)
II b	Same as II, but applies inside the home.	29 (9.7)
III	Some difficulties with communication, symptoms, and behaviors that interfere with daily life. Need nursing care.	55 (18.5)
III a	Same as III, but during the day.	19 (6.4)
III b	Same as III, but during the night.	3 (1.0)
IV	Frequent difficulties with communication, and symptoms and behaviors that interfere with daily life. Need continuous nursing care.	69 (23.2)
M	Notable mental health symptoms and problematic action or a serious physical disease. Need specialized medical care.	19 (6.4)

Table 4 Significant correlations between the NCM's five coping styles

	Employed	Unem- ployed
1 Problem solver type I collect information to help with nursing care. I plan for when to do nursing care. When nursing care is not successful, I think about the possible reasons. I think that one can learn from nursing care experiences.	0.39**	0.22**
2 Emotional avoidance type I think that providing nursing care is not my responsibility. I think that providing nursing care is viewed as shameful. I think it is pathetic to provide even this much nursing care. I become emotional or destroy things. I try not to look as I provide nursing care.	-0.46**	-0.23**
3 Cognitive transformation type Having to provide care has been imposed on me. I will try hard to provide nursing care.	0.31**	0.21**
4 Careful supervision and waiting type I will wait until I can provide good nursing care. I am optimistic that I will improve.	n.p	n.p
5 Assistance request type I ask for help from neighbors, family and/or relatives. It is a heavy burden to provide nursing care, so I get support from family members and the people around me.	0.25**	n.p

n.p.: not significant.

Emotional and instrumental supporter

1) Emotional supporter of male caregivers

In total, 144 (48.3%) of respondents stated that they "have someone who calms me down and helps me feel relieved" within the family, and 114 (38.3%) said that they had this outside the family. Large proportions of respondents also had "someone who is always able to guess how I am feeling", 132 (44.3%) within the family, and 101 (33.9%) outside it. Slightly more had "someone who appreciates what I am doing", with 159 (53.4%) within the family, and 128 (43.0%) outside it. The

number claiming to "have someone who I can trust and who will always tell me the truth" was 152 (51.9%) within the family and 82 (27.5%) outside it. There were 114 (38.3%) respondents claiming that they have "someone who is pleased when I develop and grow" within the family and 77 (25.8%) who said they had this outside the family. Respondents also had people with whom they could talk to freely. There were 139 (46.6%) responding that they have "someone to whom I can reveal my personal feelings and secrets" within the family, 108 (36.2%) saying they had this outside the family,

and for “I have someone I can talk to about mutual plans and the future”, the rates were 139 (46.6%) for inside the family, and 91 (30.5%) for outside. There were 87 (29.2%) stating that they “have someone who feels proud of the caregiver” in the family, and 49 (16.4%) who had this outside the family. Large proportions had “someone who agrees with my behavior and ideas”: 156 (52.3%) within and 137 (46.0%) outside the family; likewise, at least half said “I have someone who shares my feelings”, with 148 (50.0%) within and 127 (42.6%) outside the family.

2) Instrumental supporter of male caregivers:

This question was also divided into within and outside the family, and 178 (59.7%) said they had someone within the family to provide help when they had a problem with nursing care and 130 (43.6%) that they had someone outside the family to do so (Table 5).

Between the five coping styles and emotional and instrumental support.

1) ‘Solve the problem’ style

For employed people, there was a significant positive correlation with “I have someone who agrees with my behavior and ideas” ($r = 0.20$). For unemployed people, there were significant positive correlations with “I have someone who calms me down and helps me feel relieved” ($r = 0.23$), “I have someone who is pleased when I develop and grow” ($r = 0.20$), “I have someone to whom I can reveal personal feelings and secrets” ($r = 0.20$), “I have someone to whom I can talk about mutual plans and the future” ($r = 0.23$), “I have someone who agrees with my behavior and ideas” ($r = 0.25$), and “I have someone who shares my feelings” ($r = 0.21$).

2) Emotional avoidance style

For employed people, there was a significant positive correlation with “I have someone who calms me down and helps me feel relieved” ($r = 0.31$), “I have someone who is always able to guess how I am feeling” ($r = 0.27$), “I have someone who appreciates what I am doing” ($r = 0.31$), “I have someone who is pleased when I develop and grow” ($r = 0.20$), “I have someone to whom I can reveal personal feelings and secrets” ($r = 0.21$), “I have someone who agrees with my behavior and ideas” ($r = 0.29$), “I have someone who shares my feelings” ($r = 0.24$), and “I have someone to help when I have a nursing care problem” ($r = 0.27$). For unemployed people, there were significant positive correlations with “I have someone who appreciates what I am doing” ($r = 0.21$), “I have someone who I can trust and who will always tell me the truth” ($r = 0.25$), “I have someone who agrees with my behavior and ideas” ($r = 0.30$), “I have someone who shares my feelings” ($r = 0.32$), and “I have someone to help when I have a nursing care problem” ($r = 0.21$).

3) Cognitive transformation style

No significant correlations were found for employed

people. For unemployed people, there were significant negative correlations with “I have someone who calms me down and helps me feel relieved” ($r = -0.26$), “I have someone who is always able to guess how I am feeling” ($r = -0.22$), and “I have someone who agrees with my behavior and ideas” ($r = -0.22$).

4) Careful supervision and waiting style

There were no significant correlations between ‘Careful supervision and waiting’ style and emotional and instrumental support among either employed or unemployed people.

5) Request assistance style

For employed people, there were significant positive correlations with “I have someone who is always able to guess how I am feeling” ($r = 0.23$), “I have someone I can trust to tell me the truth” ($r = 0.23$), “I have someone to whom I can reveal personal feelings and secrets” ($r = 0.25$), “I have someone who feels proud of the caregiver” ($r = 0.23$), and “I have someone to help when I have a nursing care problem” ($r = 0.21$). For unemployed people, there were significant positive correlations with “I have someone who calms me down and helps me feel relieved” ($r = 0.21$), and “I have someone who feels proud of the caregiver” ($r = 0.20$) (Table 5).

Discussion

We aimed to clarify the emotional and instrumental support influencing male caregivers for people with dementia living at home. Little has been reported about the problems of male caregivers. The significance of this study is that it focuses only on men, and therefore demonstrates their particular problems providing care. Men may have particular issues in coping with a nursing care problem²⁷. When a male caregiver has trouble with providing nursing care, previous studies have shown that they do not tend to ask for external support²⁸. They have troubled that go to work or remain at home^{18, 29}. We aimed to clarify the association between emotional and instrumental support for male caregivers and their ability to cope with providing care.

Emotional and instrumental supporters

More than 50% of male caregivers in our study did not have any emotional supporter, although over half had an instrumental supporter within the family. This supports earlier studies that it is harder for men to obtain emotional support than women^{30, 32}.

Emotional and instrumental support that influences nursing care problems coping style

Most men have very little contact with other people after the loss of a job, therefore difficult to give emotional and

Table 5 Significant correlations between NCM and emotional and instrumental support of male caregivers

	Have a supporter	Problem solver type		Emotional avoidance type		Cognitive transformation type		Careful supervision and waiting type		Request assistance type	
		n	Em- ployed	Unem- ployed	Em- ployed	Unem- ployed	Em- ployed	Unem- ployed	Em- ployed	Unem- ployed	Em- ployed
Emotional support											
I have someone who calms me down and helps me feel relieved.	In the family	144	48.3		0.31**		-0.26**				0.21**
	Outside the family	114	38.3	0.23**							
I have someone who is always able to guess how I am feeling.	In the family	132	44.3		0.27**						0.23**
	Outside the family	101	33.9								
I have someone who appreciates what I am doing.	In the family	159	53.4		0.31**		0.21**				
	Outside the family	128	43								
I have someone whom I can trust to tell me the truth.	In the family	152	51.9				0.25**				0.23**
	Outside the family	82	27.5								
I have someone who is pleased when I develop and grow.	In the family	114	38.3				0.2*				
	Outside the family	77	25.8	0.2**							
I have someone to whom I can reveal personal feelings and secrets.	In the family	139	46.6		0.21**						0.25**
	Outside the family	108	36.2	0.2**							
I have someone I can talk to about mutual plans and the future.	In the family	139	46.6								
	Outside the family	91	30.5	0.23**							
I have someone who feels proud of the caregiver.	In the family	87	29.2								0.23**
	Outside the family	49	16.4								0.2**
I have someone who agrees with my behavior and ideas.	In the family	156	52.3	0.2*	0.29**		0.3**				-0.22**
	Outside the family	137	46	0.25**							
I have someone who shares my feelings.	In the family	148	50		0.24**		0.32**				
	Outside the family	127	42.6	0.21**							
Instrumental support											
I have someone to help when I have a nursing care problem.	In the family	178	59.7		0.27**		0.21**				0.21**
	Outside the family	130	43.6								

The test statistic was Pearson's r correlation coefficient. ** p < 0.01, * p < 0.05.

instrumental support^{25,31}). It is therefore clear that most male caregivers may be quite isolated. For employed caregivers, only the ‘Request assistance’ style is influenced from outside the family, and for unemployed caregivers, the same is seen only for the ‘Solve the problem’ style. The most likely source of influence is another housemate of the caregiver. Male caregivers also tend to be older. It is therefore necessary to ensure that some support is available to help them to continue to provide care. This may require a policy to support caregivers to remain connected with society.

1) Solve the problem style

J-ZBI has a positive correlation with ‘solve the problem’ style in male caregivers, and this style is also connected with emotional support from outside the family. To reduce the care burden of this style of caregiver, it is important to help how caregivers with this style can be helped. After retirement, it is often possible to get better emotional support from outside the family. Solve the problem style is effective coping style^{13, 32}.

2) Emotional avoidance style

This style is negatively correlated with J-ZBI, regardless of employment status, and caregivers using this style tended to have emotional support only from within the family. This may be because caregivers with this coping style do not wish to expose their nursing care problems to anyone outside the family, but this also means that they may not build a network with anyone outside the family. This coping style tend to be a suicide and murder by care providers^{17, 33}. This style may predict problems using and building a network outside the family and there is a case for formal intervention to safeguard the care recipient.

3) Cognitive transformation style

Caregivers with this coping style tend to seek emotional and instrumental support from within the family to address care burdens. The male caregiver role is self-deception¹³, and even those who do not seek support. After retiring or leaving a job, they are less likely to obtain emotional support from outside the family, but instead, they are recognized as a profession nursing care²³. Caregivers can invest all their time and energy in providing care, increasing their social isolation to serious levels³⁴. We have to understand that to provide care is they use how much energy.

4) Careful supervision and waiting style

There were no correlations between this style and J-ZBI, and no influence of emotional support from within or outside the family. A caregiver using this coping strategy is therefore not influenced by problem-solving suggestions, even with a nursing care problem. Whether employed or unemployed, these caregivers do not need support from others, but a sense of fulfilment³³.

5) Assistance request style

This style has both positive and negative correlations with J-ZBI depending on employment status. With or without J-ZBI correlation, family members do not seem to be able to provide sufficient support. These caregivers tend to look outside the family for instrumental support²⁵.

Conclusion

Male caregivers are three times as likely to obtain their emotional and instrumental support from within the family, rather than outside it. Male caregivers tended to be older, and were often living with other people. There are expected to be many smaller family units in the future, which means that communities and society as a whole may need to provide support for male caregivers. It may be particularly important to consider how to provide useful support to men using an ‘Emotional avoidance’ coping style.

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