

Epidemiology

Influence of family dynamics on burden among family caregivers in aging Japan

Tesshu Kusaba^{a,t}, Kotaro Sato^{a,t}, Shingo Fukuma^{b,c,d,*†}, Yukari Yamada^{b,d}, Yoshinori Matsui^a, Satoshi Matsuda^a, Takashi Ando^a, Ken Sakushima^e and Shunichi Fukuhara^{b,c,d}

^aThe Hokkaido Centre for Family Medicine, Hokkaido, Japan, ^bDepartment of Healthcare Epidemiology, Kyoto University School of Public Health and Graduate School of Medicine, Kyoto, Japan, ^cCenter for Innovative Research for Communities and Clinical Excellence (CIRC2LE), Fukushima Medical University, Fukushima, Japan, ^dInstitute for Health Outcomes and Process Evaluation Research (iHope International), Kyoto, Japan and ^eDepartment of Regulatory Science, Hokkaido University Graduate School of Medicine, Sapporo, Japan.

*Correspondence to Shingo Fukuma, Department of Healthcare Epidemiology, Graduate School of Medicine and Public Health, Kyoto University, Yoshida-Konoe-cho, Sakyo-ku, Kyoto 606-8501, Japan; E-mail: fukuma.shingo.3m@kyoto-u.ac.jp

†The first three authors contributed equally to this study.

Abstract

Background. Long-term care for the elderly is largely shouldered by their family, representing a serious burden in a hyper-aging society. However, although family dynamics are known to play an important role in such care, the influence of caring for the elderly on burden among caregiving family members is poorly understood.

Objective. To examine the influence of family dynamics on burden experienced by family caregivers.

Methods. We conducted a cross-sectional study at six primary care clinics, involving 199 caregivers of adult care receivers who need long-term care. Participants were divided into three groups based on tertile of Index of Family Dynamics for Long-term Care (IF-Long score), where higher scores imply poorer relationships between care receivers and caregiving family: best, <2; intermediate, 2 to <5; worst, ≥5. The mean differences in burden index of caregivers (BIC-11) between the three groups were estimated by linear regression model with adjustment for care receiver's activity of daily living and cognitive function.

Results. Mean age of caregivers was 63.2 years (with 40.7% aged ≥ 65 years). BIC-11 scores were higher in the worst IF-Long group (adjusted mean difference: 4.4, 95% confidence interval: 1.2 to 7.5) than in the best IF-Long group. We also detected a positive trend between IF-Long score and BIC-11 score (*P*-value for trend <0.01).

Conclusion. Our findings indicate that family dynamics strongly influences burden experienced by caregiving family members, regardless of the care receiver's degree of cognitive impairment. These results underscore the importance of evaluating relationships between care receivers and their caregivers when discussing a care regimen for care receivers.

Key words: Aged, caregivers, family, long-term care, primary care physicians, primary health care.

Introduction

Caring for elderly relatives represents a serious issue facing caregiving family members in an aging society. Although caregiving has also a positive aspect for the family members (1,2), the burden of

informal care underscores the need for new methods of enacting sustainable long-term care. Further, in addition to the burden of care experienced by family caregivers due to the care receiver's disease, such as impaired eyesight (3), pressure ulcer (4) and underlying

disease (5), the relationship between care receivers and caregivers has also been shown to play a crucial role in the caregiving process (6–9). Informal care dynamics are complex in the social context of a family (10). Family dynamics, the interactions between family members, and the varied relationships that exist within a family involved in long-term care have been suggested to be influential on the care of frail elderly people; however, these parameters remain difficult to measure (11). Therefore, we previously developed a validated scale (the Index of Family Dynamics for Long-term Care; IF-Long) to describe the relationship between primary caregivers and care receivers before caregiving (12).

Japan is the world's fastest aging society, with one-quarter of the entire population aged over 65 years in 2013 and a particularly high proportion aged over 75 years (12.3%) (13). Rapid shifts in demographics have created a situation in which many elderly people receive long-term care from family members who themselves are elderly, termed 'elder-to-elder care' (14). The nursing-care insurance system was publicly established in 2000 to support this situation (15). In this scheme, the municipality review board assesses the physical and cognitive function of older people to determine their eligibility and the degree of care required on an individual basis, which by definition defines the extent to which they can avail themselves of formal care services, including but not limited to home support care, personal care, nursing care and respite care (16). Although this system has reduced the burden on family members to some degree (17), informal family caregiving is still expected, partly because the number of formal care services provided by the nursing-care insurance system is not generally sufficient to cover all the care needs of frail elderly people living at home and partly due to the deep-seated desire among many older people to receive care from their family members instead of professionals. This rising demand for long-term care in an aging society and the limitations of resources within the field of long-term care have underscored the global importance of the increased burden on family members in caring for their elderly relatives.

With their holistic perspective on the situation, primary care physicians play an important role in designing sustainable long-term care systems. Given the increasingly important role of family members in caring for elderly relatives in an aging society, future long-term care systems should account for the relationships between family members and their charges. Here, to clarify the influence of family dynamics between primary caregivers and their frail elderly family members on the burden of care experienced by the primary caregiver, we measured these dynamics using our validated scale of IF-Long score (12) and examined its association with burden of care, adjusting for the characteristics of care receivers and caregivers.

Methods

Study design

We conducted a multicenter cross-sectional study at six primary care clinics between July and September 2011. Data used in the study were obtained from multiple sources, as follows: (i) Primary caregivers answered self-administered questionnaires about the nature of caregiving and their burden of care, (ii) The care receiver's primary care physician assessed the family dynamics and the receiver's functional and cognitive status and (iii) The care receiver's care managers provided information on the utilization of formal care services.

Participants and setting

We sequentially selected caregivers who mainly cared for their 'frail elderly' family members receiving outpatient or home treatment due

to chronic disease at any of six primary care clinics. We excluded caregivers who cared for family members being treated as inpatients or living in a nursing home. 'Frail elderly' in this study was defined as either individuals who were approved to be eligible for nursing-care insurance by the municipality review board, or other older people aged ≥ 65 years who either needed some mobility assistance at outpatient clinics or had been diagnosed with cognitive impairment by at least two physicians.

Main exposure: family dynamics

Our main exposure was family dynamics, as measured by IF-Long (12). This scale was initially developed for use by clinicians, generally primary-care physicians, with a long-standing relationship with the care receiver and caregiver, as it assesses problems or undesirable situations that might be alleviated via 'intervention through a family system', such as family consultations or family meetings. The IF-Long comprises four items inquiring about the existence of certain situations between the primary caregivers and care receivers, as follows: 'Disengagement (a situation in which the caregiver feels no sense of fulfilment or accomplishment from caregiving, or feels no joy from the patient's gratitude)', 'Scapegoating (a situation in which the caregiver believes that the family would be happy if only the caregiving were easier)', 'Transfer of problems across generations (a situation in which the care receiver compares the present with his or her past experiences as a caregiver, and, on that basis, is unnecessarily demanding of the caregiver)' and 'Undesirable behaviour patterns (a situation in which the care receiver's daily life has become very dependent on the caregiver and can be sustained only by the caregiver, and in which the caregiver similarly feels dependent or reliant on the care receiver)'. Response options for these four items ranged from 0 (not present) to 3 (definitely present), with IF-Long scores calculated as sums of response values to the four items (possible score range: 0 to 12). Higher IF-Long scores indicated poorer relationships between care receivers and their caregiving relatives. We tested the reliability (0.73) and validity (construct validity and concurrent validity) of the IF-Long scale in a previous study. Care receivers in the present study were divided into three categories based on IF-Long score tertile (best < 2 , intermediate 2 to < 5 , worst ≥ 5).

Main outcome: burden of care for caregivers

Our main outcome was burden of care for caregivers, which was evaluated using the burden index of caregivers (BIC) (18). The BIC comprises 11 items covering five sub-domains (Time-dependent Burden, Emotional Burden, Existential Burden, Physical Burden and Service-related Burden) and one domain of total care burden. BIC scores were calculated as the sum of the response values to the 11 items (possible score range: 0 to 44). The BIC was assessed via a self-administered questionnaire for the caregivers.

Other factors

Information on the characteristics of the caregivers and caregiving (age, gender, employment status, frequency of hospital visits by the caregiver, time required for care and duration of care) was obtained from the caregivers via questionnaire. Care receivers' degree of cognitive impairment was evaluated using Functional Assessment Staging (FAST) (19), and activity of daily living was assessed via mini Functional Independent Measure (mini-FIM) (20) by the primary care physicians. Care managers, who create the care plan for care receivers and their family, provided further information about usage of formal care services.

Data management and ethical issues

We obtained written informed consent from the care receivers and their family members. Because we used an anonymous questionnaire, we printed unique identification numbers on the questionnaire paper and then used the number to link data obtained separately from caregivers, primary care physicians and care managers. Researchers in charge of statistical analysis were blinded to care receivers' clinical data. This study was approved by the institutional review board of Kyoto University.

Statistical analysis

We described caregiver's characteristics and care receivers' mini-FIM and FAST scores based on the three IF-Long score categories. We then calculated the mean BIC score for each IF-Long score category, and trend tests were performed to examine the dose-dependent association between IF-Long score and BIC score. We constructed a linear regression model to estimate adjusted mean difference of BIC

score between categories of IF-Long score. The reference category of IF-Long score was the best IF-Long group (score <2). We included caregiver age and gender, duration of care, time required for care and care receiver's mini-FIM score and FAST score in the model to examine the association between categories of IF-Long score and BIC score after adjusting for potential confounders.

In our initial sensitivity analysis, we defined two categories of IF-Long score (Good <5, Bad ≥5) and estimated probability (propensity score) of being in the bad IF-Long group. We then used the inverse probability of treatment weighting method (IPTW) (21) to adjust for potential confounders. In a subsequent sensitivity analysis, we used the multiple imputation method using chained equations (22) to impute missing values of 'duration of care' ($n = 5$) and 'time required for care' ($n = 13$). All analyses were performed using STATA software (version 14.0; STATA, College Station, TX), with two-sided significance set at 0.05.

Table 1. Characteristics of caregivers ($n = 199$) and care receivers ($n = 199$)

Characteristics	
Caregivers	
Age in years, mean (SD)	63.2 (11.9)
Female, %	79
Relationship, %	
Spouse	27
Children	39
Others	35
Employed, %	34
Regularly visit the hospital, %	64
Time required for care in hours/week, mean (SD)	32.3 (39.1)
Duration of care in years, mean (SD)	5.2 (4.7)
Care receivers	
Mini-FIM, mean (SD)	33.9 (12.5)
FAST categories, %	
1	34.7
2–5 (mild to moderate)	45.2
6–7 (moderately severe to severe)	20.1

Results

Characteristics of caregivers and care receivers

We asked 249 caregivers to answer the questionnaire and received 199 answers (collection rate, 80%). Tables 1 and 2 show characteristics of caregivers and care receivers overall and by categories of IF-Long score, respectively. Among all caregivers, mean age was 63.2 years, with 40% of caregivers aged over 65 years and 19% of caregivers aged over 75 years. A total of 79% of caregivers were female, and 64% required regular visits to the hospital themselves. Mean duration of caring for a family member was 5.2 years, and mean time required for care was 32.3 hours per week. A total of 43% of caregivers cared for their family for more than 3 hours a day. Time required for care was greater in the worst IF-Long group than in the best IF-Long group. In terms of care receivers' characteristics, mean mini-FIM score was 33.9, and 20.1% of care receivers had severe cognitive impairment (FIM score ≥6). IF-Long score varied between 0 and 10 points, with a mean of 2.4 (SD, 2.1). The mean scores of the four items of the IF-Long showed that the worst/best IF-Long group indicated the worst/best in all of the items.

Table 2. Characteristics of caregivers and care receivers patients stratified by categories of family dynamics

Characteristics	IF-Long score (family dynamics)		
	Best ($n = 81$)	Intermediate ($n = 92$)	Worst ($n = 26$)
Caregivers			
Age in years, mean (SD)	63.1 (12.1)	62.6 (11.5)	65.6 (12.7)
Female, %	74	85	73
Employed, %	39	29	31
Regularly visit the hospital, %	60	62	81
Time required for care in hours/week, mean (SD)	27.8 (35.2)	32.1 (38.7)	46.3 (48.9)
Duration of care in years, mean (SD)	5.0 (4.8)	5.3 (4.6)	5.2 (5.3)
Care receivers			
Mini-FIM, mean (SD)	35.8 (11.8)	32.7 (13.3)	32.2 (11.6)
FAST categories, %			
1	37.0	34.8	26.9
2–5 (mild to moderate)	49.4	42.4	42.3
6–7 (moderately severe to severe)	13.6	22.8	30.8
Family dynamics between caregivers and care receivers			
Disengagement, mean (SD)	0.1 (0.3)	1.0 (0.5)	1.8 (0.9)
Scapegoating, mean (SD)	0.1 (0.1)	0.9 (0.5)	1.6 (0.6)
Transfer of problems across generations, mean (SD)	0.1 (0.2)	0.5 (0.5)	1.2 (0.8)
Undesirable behaviour patterns, mean (SD)	0.1 (0.3)	0.8 (0.7)	1.6 (0.9)

Burden of care by categories of family dynamics

Table 3 shows BIC score ranked by IF-Long score. Mean BIC scores were 13.9, 15.9 and 19.3 in the best, intermediate and worst IF-Long groups, respectively. The *P*-value for trend was <0.01.

Association between family dynamics and burden of care

Figure 1 shows adjusted mean difference in BIC score among categories of IF-Long score. Compared with the reference category (best IF-Long group), the mean difference of BIC-11 was 2.06 [95% confidence interval (CI), -0.09 to 4.22] and 4.36 (95% CI, 1.22–7.50) in the intermediate and worst IF-Long groups, respectively. To demonstrate the influence of IF-Long score on BIC score, we also described the mean difference of BIC score based on categories of cognitive impairment score (FAST): severe cognitive impairment (FAST score ≥6) was associated with a 4.13-point (95% CI, 0.83–7.42) increase in BIC score compared with the normal cognitive function group (FAST score ≤2).

Sensitivity analyses

We re-defined two categories of IF-Long score (good and bad group) and examined the association between group assignment and BIC score using IPTW to adjust for potential confounders more appropriately. Associations between IF-Long score and BIC score in this instance were found to be similar to original results, and the mean difference between the two groups was 2.70 (95% CI, 0.12–5.29).

In our second sensitivity analysis using the multiple imputation method, associations between IF-Long score and BIC score remained similar to original results after imputing missing data. Mean differences were 1.52 (95% CI, -0.62 to 3.66) and 4.36 (95% CI, 1.19–7.53) in the intermediate and worst IF-Long groups compared to the best IF-Long group, respectively.

Table 3. Burden of care stratified by family dynamics

	Total	IF-Long score (family dynamics)			<i>P</i> -value*
		Best	Intermediate	Worst	
BIC, mean (SD)	15.5 (7.4)	13.9 (6.9)	15.9 (7.6)	19.3 (6.3)	<0.01

**P* value for trend.

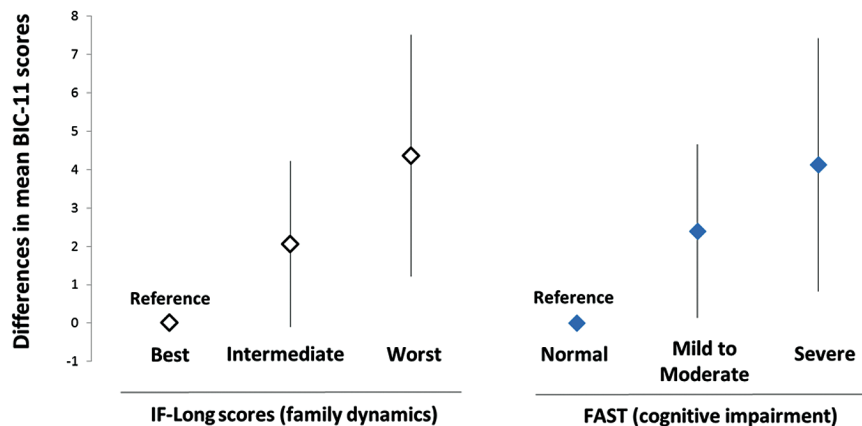


Figure 1. Influence of family dynamics on care burden. We adjusted for caregiver age and gender, duration of care, time required for care, and patient mini-FIM score and FAST score to examine the association between categories of IF-Long score and BIC score.

Discussion

In summary, we found that family dynamics strongly influence burden experienced by primary caregivers, regardless of the care-receiver’s degree of cognitive impairment. Severe issues straining the family dynamics (Worst IF-Long score) were found to exacerbate the burden of care (high BIC score). We also detected a dose-dependent association between IF-Long score and BIC. Taken together, these findings suggest that the relationship between care receivers and their primary caregivers in place before caregiving should be carefully considered when deciding on a care plan for care receivers.

In the present study, we found that caregiving family members tended to be elderly themselves, with 40% of caregivers aged over 65 years. Notably, the mean age of caregivers was similar to national figures for Japan (23), indicating that our findings were not unique to our study or contaminated by outliers. In addition, approximately two-thirds of caregivers themselves visited the hospital regularly to receive treatment for chronic diseases. Given this situation in which elderly individuals care for other elderly individuals, the burden of care is clearly a key factor for consideration when developing a sustainable care system in an aging society.

Implications for practice and education

Measuring family dynamics using the IF-Long score may help primary care physicians identify issues involving these dynamics when developing long-term care plans, thereby allowing physicians to support family members through education and family conferences involving all immediate family, relevant extended family, significant friends and members of the patient’s support network. Developing sustainable long-term care in an aging society will require greater emphasis on ‘family-oriented care’, in which physicians describe the framework of the family and analyse what is happening to the family with respect to their roles in caring for other family members/themselves. Physicians should also evaluate the relationship between family members with respect to the family life cycle and identify potential relationship problems among members. Through such family-oriented care, physicians can determine family dynamics and design specific interventions including target family members and specialized approaches to communication (11).

Of note, the adjusted mean difference of BIC between the worst IF-Long group and best IF-Long group was similar to that between the normal cognitive group and severe cognitive impairment group as defined by FAST score. Previous studies have shown the impact

of FAST on care receivers' adverse events of mortality (24) and unplanned hospitalization (25). These results may therefore suggest that family dynamics are as influential as severity of care receiver's cognitive impairment on family members' burden with long-term care.

Strengths and limitations

Our study had several major strengths. First, we used our validated IF-Long score to quantitatively evaluate family dynamics, an important but difficult-to-measure concept in 'family-oriented care'. Second, we conducted this study at primary care clinics in Japan—a rapidly aging society. This setting ensures that our results can be easily extrapolated to other developed countries with similar aging societies. Third, we obtained consistent results even after using IPTW to adjust for confounding.

However, several limitations to the present study also warrant mention. First, given the cross-sectional nature of our study, we can't eliminate the possibility of reverse causality. Specifically, a poor family relationship may not be the cause of heavy burden of care, but instead the result. Indeed, we observed that the time required for care was longer for caregivers in the worst IF-Long group than among those in the best group. However, the IF-Long questionnaire asks physicians, who can determine a familial relationship based on information obtained from the care receiver and their caregiving family during outpatient care, to describe the relationship before caregiving. Second, we lacked precise data on what kind of care was given to care receivers. Although we adjusted for the measured covariate of 'time required for care', marked differences in the contents of care between the worst and best IF-Long group may confound the association between IF-Long score and BIC. However, we believe that adjusting for care receiver's characteristics (ADL and cognitive impairment) may reduce the effect of residual confounding. In addition, results remained consistent even after adjusting for those confounding factors using IPTW. Given the above limitations, interpretation and generalizing our results should be done with care.

Conclusion

We found that family dynamics strongly influences the burden experienced by caregiving family members, regardless of the care-receiver's degree of cognitive impairment. These results may underscore the importance of evaluating family dynamics between care receivers and their family when discussing burden of care.

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Declaration

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Ethical approval: This study was approved by the institutional review board of Kyoto University (E1165).

Conflict of interest: none.

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