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Effects of home, outside leisure, social, and peer activity on psychological health among Japanese family caregivers

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Abstract

Objective—Previous research has indicated that informal caregivers' personal activities are disrupted by their caregiving role, leading to psychological stress and lower life satisfaction. However, the extent to which engagement in personal activities affects caregivers' psychological health remains unclear. This study examines the relationship between different types and frequencies of activities and both positive and negative parameters of the psychological health of caregivers.

Methods—A mail survey was conducted with 727 family caregivers of older persons using adult day care services in the Tokyo metropolitan area. Perceived caregiver burden, care satisfaction, life satisfaction, and depression were used as psychological health outcomes. Engagement in home, outside leisure, social, and peer activities, as well as caregiver and care-recipient characteristics and caregiving situations, were assessed using a multivariate regression analysis.

Results—Engagement in home activities was related to lower scores on burden and depression and greater care satisfaction after controlling for care needs and caregiver characteristics, and social and peer activities were associated with greater life satisfaction. More frequent engagement was also associated with better psychological health, but a moderate involvement in home activities was most strongly associated with better care satisfaction. The amount of outside leisure activity was not significantly related with any of the outcomes.

Conclusion—This study shows that activity type and frequency are associated with caregivers' psychological health, extending previous findings and providing practical implications for the support of family caregivers through programs to improve their participation in specific types of activities.

Keywords

informal caregiving; social activity; leisure activity; burden; depression

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Introduction

Although a national long-term care insurance system was implemented in 2000, and long-term care services have been widely used by older people, informal caregivers still play an important role in long-term care. In Japan, 16% of elderly people are certified as needing care or support, and the total number of these individuals reached 4.5 million in 2008 (Cabinet Office Japan, 2011). Approximately 70% of the care recipients depend on family members as their primary caregivers, and more than 60% of the elderly expect family members to support them in later life (Cabinet Office Japan, 2011). However, the sustainability of informal caregiving depends on the psychological health of the caregivers (Lieberman & Kramer, 1991). Alleviating the burden on caregivers and maintaining their psychological health are thus high priorities for Japan's long-term care system.

The caregiving role changes an individual's life (Cantor, 1983). Caregivers reported less social activity and less leisure-time than non-caregivers or than they enjoyed before beginning care (Fredman, Bertrand, Martire, Hochberg, & Harris, 2006; George & Gwyther, 1986; Lopez, Lopez-Arrieta, & Crespo, 2005). In 2007, almost 145,000 Japanese caregivers changed or left their jobs because of caregiving (Cabinet Office Japan, 2011).

Limited engagement in personal activities is an important problem for caregiver's psychological health (Miller & Montgomery, 1990). Reduced leisure activity is related to increased emotional stress and depression and reduced life satisfaction among caregivers (Losada et al., 2010; Mausbach, Patterson, & Grant, 2008; White-Means & Chang, 1994). The benefits of leisure on psychological health may arise from escape from the responsibilities of caregiving, opportunities for supportive companionship, and increased perceptions of freedom, control, and competence (Coleman & Isoahola, 1993; Kelly & Steinkamp, 1986; Losada, et al., 2010). Social activity also is an important means of coping with caregiving stress (Haley, Levine, Brown, & Bartolucci, 1987; Pearlin, Mullan, Semple, & Skaff, 1990; Thompson, Futterman, Gallagher-Thompson, Rose, & Lovett, 1993). It allows caregivers to temporarily escape the responsibilities of caregiving (Barusch, 1988; Bedini & Guinan, 1996) and participate in peer support activities, which provide important opportunities for sharing both stressful and rewarding experiences (Sabir, Pillemer, Suitor, & Patterson, 2003). Social ties and leisure activity appear to mediate the effect of care demands on depression--the effect of caregiving on depression is reduced when activity restriction is taken into account (Cannuscio et al., 2004; Mausbach, Patterson, et al., 2008; Nieboer et al., 1998; Williamson, Shaffer, & Schulz, 1998).

These studies suggest that social and leisure activities are important in maintaining caregivers' psychological health; however, current research has not addressed whether specific personal activities may be more meaningful for caregivers than others. Some authors have focused on social activity, which by definition involves social interactions (Cannuscio, et al., 2004; George & Gwyther, 1986; Haley, et al., 1987), while others have focused on leisure activity (Fredman, et al., 2006; Hughes & Keller, 1992; Lopez, et al., 2005; Losada, et al., 2010; Mannell, Salmoni, & Martin, 2002; White-Means & Chang, 1994). Barusch (1988) examined solitary leisure activities that enable caregivers to engage in the activity without the planning or cooperation of others. In studies that have examined different kinds of activities, summation of different kinds of activity participation into homogeneous categories obscured the analysis of which types of activity might have greater impacts (Bookwala & Schulz, 2000; Iwasaki & Mannell, 2000; Mausbach, Coon, Patterson, & Grant, 2008; Mausbach, Patterson, et al., 2008; Nieboer, et al., 1998; Smith, Williamson, Miller, & Schulz, 2011; Williamson, et al., 1998).

Variation in how engagement is measured affects our ability to compare the effects of different activities. Most previous studies used perceived limitations of free time or social and leisure activities to measure participation, which are subject to bias in caregivers' expectations of their own activity levels (Dunn & Strain, 2001; Miller & Montgomery, 1990). George and Gwyther (1986) are an exception—they added a self-reported measure of participation frequency to these subjective measures of limitation. Frequency is a more objectively comparable measure allowing more reliable comparisons across individuals and activities.

The goal of this research was to examine the relationship between activity type and level of engagement and family caregivers' psychological health. Specifically, we examine frequency of participation in 4 different activity categories (home, outside leisure, social, and peer activity) chosen because of the degree of flexibility, social interaction, and peer support provided by the activity. We examined both positive and negative outcomes for both care-specific and general measures of psychological health, including caregiving burden, care satisfaction, life satisfaction, and depression.

Methods

Sampling and procedures

In 2006, we conducted a cross-sectional study of the primary caregivers of community-dwelling elderly individuals who use adult day-care centers. A convenience sampling technique was employed to select 33 adult day care centers from the 2,087 in Tokyo metropolitan area (Ministry of Health Labour and Welfare, 2006), and all 33 centers agreed to participate. A total of 1,973 self-administered questionnaires were distributed by center staff to the family caregivers of all day-care clients, and 857 (43.4%) were returned. Some of the 1,973 questionnaires were distributed to day-care clients who had no family caregivers; therefore, the nominal response rate was underestimated. We excluded invalid responses which were from the elder care-recipients themselves (n=45) or for which did not provide enough information for our analysis (n=32). We analyzed only responses from caregivers were the spouse, child, or daughter in law of a care recipient 65 years of age or older (n=727). This study was approved by the Research Ethics Committee of the Graduate School of Medicine of the University of Tokyo, Japan.

Measurements

Outcomes

Burden: Care-specific emotional burden was measured by a subscale of the Maslach Burn-out Inventory (Maslach & Jackson, 1981). The scale consists of three subscales: emotional exhaustion, personal accomplishment, and depersonalization. Nakatani (1992) adapted the scale for family caregivers in Japan and demonstrated high internal consistency and construct validity only for the subscale of emotional exhaustion, which we used in this study. The scale was modified to a 4 point Likert-type scale for use in the Japanese context, ranging from 1 (strongly disagree) to 4 (strongly agree) (Nakatani, 1992). The sum of the 8 item scores indicated the severity of emotional burden, with a higher score indicating a greater emotional burden. The internal consistency in our sample was high, with a Cronbach's alpha of 0.913.

Care satisfaction: The Care Satisfaction Index was used to measure caregiving satisfaction (Sakurai, 1999). Caregivers were asked to rate this 14-item instrument from 1 (strongly disagree) to 4 (strongly agree). The overall scores ranged from 14 to 56. Higher scores indicate greater satisfaction with caregiving. The internal consistency of our sample was excellent, with a Cronbach's alpha of 0.933.

Life satisfaction: We used the Japanese version of the Satisfaction with Life Scale (SWLS) as translated and validated by Sumino (1994), which is based on a scale developed by Dinner, Emmons, Larsen, & Griffin (1985). Higher scores indicate greater life satisfaction. The original five-item scale was rated from 1 (strongly disagree) to 7 (strongly agree); however, participants evaluated the 7-point version as too difficult to answer in the Japanese version in pretests of the instrument. Therefore, in order to make it easier for caregivers to answer the questions, we modified the 7-point Likert scale to a 5-point scale as follows, 1 (strongly disagree), 2 (slightly disagree), 3 (neither agree nor disagree), 4 (slightly agree), and 5 (strongly agree). Final scores ranged from 5 to 25. The internal consistency in our sample was good, with a Cronbach's alpha of 0.865.

Depression: We used the Japanese version of the Center for Epidemiologic Studies Depression Scale (CES-D) (Shima, Shikano, Kitamura, & Asai, 1985) to measure symptoms of depression in family caregivers using Radloff's (1977) CES-D scale. Each item is scored 0 (rarely or none of the time) to 3 (most or all of the time) points and the sum of the 20-item scores (range 0–60) indicates the severity of symptoms such that higher scores indicate greater depression. The internal consistency in this sample was good, with a Cronbach's alpha of 0.841.

Home, outside leisure, social, and peer activity—Activities were classified according to differing levels of flexibility, social interaction, and peer support. *Home activity* was defined as a hobby or leisure activity conducted at home, such as reading, listening to music, cooking, drawing, or exercising at home. *Outside leisure activity* was defined as an informal activity conducted outside the home, for example, a hobby, shopping, sports, travel, walking, or going to the theater. *Social activity* was defined as a social or more formal organization, such as community groups, volunteering, or religious activity. *Peer activity* was defined as any function where caregivers could meet and talk to other caregiving peers. For each activity, we categorized subjects into one of 3 groups on the basis of their reported participation as follows: Rarely (a few times a year or less), Monthly (at least once per month), and Weekly (at least once per week). However, because of the small number of caregivers who reported peer activity in our sample, we used only participant (at least once per year) and non-participant (none) categories for this activity.

Caregiver and care-recipient characteristics and caregiving situation— Caregiver's, age, gender, relationship to care recipient, marital status, employment, co-residence with care recipient, and financial situation was determined. In addition, we assessed caregivers' physical health by asking how many days per week their health limited engagement in household, job, or regular activities on a scale of 1 (not at all) to 5 (almost every day), with a higher score indicating greater limitations.

Care recipients' age, gender, limitations in Activities of Daily Living (ADL), and behavior problems due to symptoms of dementia were reported by caregivers. Care recipients were assessed as either dependent (0) or independent (1) in 6 ADL domains: bathing, dressing, toileting, mobility, continence, and feeding. We summed across all activities for a final measure with a range of 0–6. The internal consistency of this measure was good, with a Cronbach's alpha of 0.793. Problematic behavior among care recipients was assessed with the Japanese version of the Troublesome Behavior Scale (Asada et al., 1994). Because of the skewed distribution of responses, we coded this as a dichotomy where "1" indicates any behavioral problems. Caregivers also reported time spent providing care per day, caregiving duration, and whether they had support from family members.

Data analysis

Bivariate analysis was conducted to establish the association between engagement in each activity and psychological health outcomes using analysis of variance (ANOVA) with Bonferroni correction. Missing data affected less that 7% of the sample, so values were imputed using matched mean values. We then conducted a multiple regression analysis to determine which activities were most associated with psychological health outcomes after controlling for caregiver and recipient characteristics and caregiving situations. All activity variables were entered into the models concurrently. We tested for further multi-colinearity among variables with Spearman correlation coefficients, which ranged from 0.000 to 0.364, suggesting that these measures can be considered independent in linear regression analysis. All analyses were conducted using SPSS 17.0 for Windows.

Results

Table 1 describes caregiver and care-recipient characteristics and caregiving situations. The caregivers in our survey ranged from 30 to 93 years old with a mean age of 61 years, and almost 78% were women. Of the caregivers, 29% were spouse and approximately 85% lived with their care recipients. The care recipients' mean age was 83 years, and 67% were female. Although our sampling of caregivers was not random, we compared the characteristics of our sample with national statistics in Japan and found that the distributions are quite similar. An estimated 70% of informal caregivers in Japan are women and 85% of family caregivers lived with their care recipients; 25% of caregivers are spouses, and children and children-in-law make up 18% and 14%, respectively. (Ministry of Health Labour and Welfare, 2007). Approximately 65.9% of care recipients were female, and their age distribution in national data was slightly older than that in our samples. Although there were small differences in the care recipients' age and the distribution of caregiver/care recipient relationships between our sample and the national data, these differences are small enough for us to assume that our sample provides information that is relevant for Japan's population of caregivers. (Table 1)

Table 2 presents the distribution of activity engagement. Caregivers in our sample were more likely to engage in outside leisure activities (72.1%) than home activities (65.8%) or social activities (48.2%). However, caregivers who engage in home activities tend to do so more frequently than they engage in outside leisure. Only about 15 % of caregivers engaged in peer activities.

As shown in Table 3, bivariate analysis indicated that weekly home activity engagement was significantly associated with better psychological health on all indicators. Caregivers who engaged in home activities on a weekly basis showed lower levels of burden and depression and higher levels of life and care satisfaction. Interestingly, monthly home activity showed a greater effect on care satisfaction than more frequent participation. Weekly participation in outside leisure activity was significantly related to lower caregiving burden and greater life satisfaction. Weekly engagement in social activities was positively associated with greater life satisfaction and inversely associated with depression, and even monthly engagement had significant effects on life satisfaction. Finally, engagement in peer activities was significantly associated with life satisfaction.

Table 4 presents the results of our multivariate regression analysis. After controlling for demographic variables and caregiving situation, weekly home activity was related to lower levels of burden, and monthly engagement was related to greater care satisfaction. Home activity was the only activity that related to care-specific outcomes, while social and peer activities were related to general psychological health; the positive relationships between social and peer activities and life satisfaction remained significant. Weekly engagement in home or social activities was significantly related to lower levels of depression. (Table 2, Table 3 and Table 4)

Discussion

This research extends previous work by examining multiple types of activities and their frequency. Our results showed that different types of activities have different impacts on caregivers' psychological health, and that these effects were related to by participation frequency.

Home activity engagement was especially important for care-specific measures, as caregivers who engaged in this activity reported less burden and greater care satisfaction. Outside leisure activity showed a significant relationship with outcomes in bivariate analysis, but this relationship was not significant after controlling for confounding factors. It has been assumed that leisure is important for caregivers because leisure activities provide opportunities for social support (Coleman & Isoahola, 1993; Losada, et al., 2010; White-Means & Chang, 1994). However, in the present study, dividing home and outside leisure activities reveals an interesting distinction: leisure is important, but non-social home activity is more strongly associated with care-specific psychological health. This may reflect the fact that home activity is less social but more flexible. As Barusch (1988) discussed flexible activities are attractive for caregivers because they do not require advance planning, and the flexibility of home activities would presumably create fewer conflicts between caregiving and engaging in activities. Outside leisure activities, which require more planning, could conflict with the irregular demands of caregiving. Additionally, as compared with outside leisure activity, home activity have the advantage that caregivers may be able to engage in some activities while spending time with and being available to their care recipients. As previous research has shown, leisure time is important for caregivers to alleviate their caregiving burden (Coleman & Isoahola, 1993; Losada, et al., 2010; White-Means & Chang, 1994); however, it is often difficult for family caregivers to engage in leisure activities because of time constraints or physical and emotional exhaustion (Dunn & Strain, 2001; Miller & Montgomery, 1990). Care demands, the caregiving situation, and caregiver characteristics all affect activity involvement and the relationships between outside leisure activity and psychological health. Outside leisure might be most beneficial for caregivers who have smaller care demands or conflicts, although further research will be needed to confirm this possibility.

We found that frequency of involvement affected the strength of these relationships. Weekly involvement in home activity was more strongly associated with burden and depression while monthly involvement was associated with greater care satisfaction. Caregivers are often hesitant to engage in activities because of care responsibilities (Barusch, 1988; Bedini & Guinan, 1996; Hughes & Keller, 1992). However, monthly home activity involvement appears to be acceptable, leading to care satisfaction without interfering with their responsibilities.

In contrast, social activity engagement was related to general psychological health only. This relationship was also linear, indicating that more involvement in social activity increased caregiver life satisfaction and reduced depression. Although, it is difficult for caregivers to find time to attend activities because of caregiving tasks (Dunn & Strain, 2001), more frequent engagement in social activity would improve their general psychological health.

Finally, peer activity engagement was significantly associated with life satisfaction. As suggested by previous research (Sabir, et al., 2003), we expected engagement in peer activity to affect care-specific outcomes, but no significant effects were seen in our sample. Nevertheless, because caregivers who feel more burdened or depressed might be more likely to seek out formal peer support activities, longitudinal research will be needed to determine whether engagement in peer support is ultimately beneficial for those at risk of psychological distress. In addition, we defined peer activity as any activity in which caregivers can meet and talk to other caregivers; more structured peer activity program might give different results than informal activities. The low reported rates of participation in peer activity may be due to difficulty in finding time because of the time constraints of caregiving or limited available opportunities. Qualitative research will help further our understanding of the benefits of structured peer activity programs for caregivers.

Limitations

This study has some limitations. First, sampling was not random. As discussed above, the characteristics of our sample are similar to those of the national data, and thus relevant for the larger population of caregivers. Second, our findings represent only caregivers whose recipients use adult day-care services. Caregivers who only use home visiting services or who do not use any formal services might engage in activities less frequently because of their limited opportunities to leave their care recipients. In addition, preferences for activity participation might vary across regions, cultures or individual caregivers. Few studies have used activity classifications similar to ours, making it difficult for us to compare our findings with those in other populations; further research in more diverse samples will be required before these results can be generalized. Furthermore, a causal relationship cannot be fully demonstrated because of the cross-sectional research design. Although our results were consistent with previous research on the impact of activities on caregivers’ psychological health, longitudinal studies should be conducted to extend these findings. Finally, we did not investigate the interaction between outcomes and care recipients’ condition, behavior problems, or ADL. Further research will enable us to discern their impact on caregiver activities and psychological health.

Conclusion

Our research suggests that both policymakers and caregivers should be made aware of the important potential benefits of activity engagement for caregiver’s psychological health. It may be possible to promote participation in activities as an effective way to both improve psychological health and facilitate continued caregiving over a longer period of time (i.e., prevent burnout). In particular, the strength of the relationship between home activities and better psychological health on all measures suggests that interventions that may be most beneficial to caregivers with greater caregiving demands and who cannot coordinate outside activities could be as simple and low-cost as promoting home exercise or distributing books and hobby materials.

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Table 1

Table1 Desctiptive Analysis **n=127**

		% M	SD
Caregiver Characteristics			
Age		60.8	±11.6
Gender	Female	77.9	
CG-CR Relationship			
	Wife	22.8	
	Daughter	33.7	
	Daughter in Law	21.3	
	Husband	6.2	
	Son	16.0	
Marital Status			
	Married	75.8	
	Widowed/ Divorced	9.2	
	Single	11.6	
Living	Together	84.6	
Job	Employed	43.6	
Financial Situation			
	Very poor	7.6	
	Somewhat poor	20.1	
	Neither agree nor disagree	37.1	
	Somewhat wealthy	27.4	
	Wealthy	4.7	
Health Difficulty			
	Not at all	64.0	
	1day/w or less	14.7	
	2–3days/w	7.2	
	4–5days/w	1.8	
	Almost Everyday	7.4	
Care Recipient Characteristics			
Age		83.3	± 7.5
Gender Female		67.0	
ADL (0–6)		2.6	± 1.9
Dementia Problematic Behavior		60.7	
Care Situation			
Care Duration			
	Less than 6mon	4.3	
	6mon-less than 1 year	8.7	
	1- less than 3 year	34.9	
	3- less than 5 year	23.8	

Table1 Desctiptive Analysis **n=127**

	% **M**	**SD**
5- less than 10 year	14.4	
More than 10 years	7.8	
Giving Care Time/Day		
Less than 4 hours/d	51.9	
4–8hours/d	16.5	
8–16hours/d	15.3	
More than 16hours/d	12.1	
No Support from other family member	28.7	
Outcome		
Burden (8–32)	20.0	± 5.6
Care Satisfaction (14–56)	36.0	± 9.2
Life Satisfaction (5–25)	12.8	± 4.2
Depression (0–60)	16.1	± 8.1

[*] Percentages may not add up to 100% due to rounding and/or missing information.

Table 2

Table2 Activity engagement (%) **n=727**

	Rarely	**Monthly**	**Weekly**
	(Non-participant)	**(Participant)**	
Home activity	34.3	16.1	49.7
Outside leisure activity	27.9	31.8	40.3
Social activity	51.7	23.9	24.3
Peer activity	85.3	14.7	

Percentage may not add up to 100% due to rounding and/or missing information

Table 3

Table3 Mean Scores of outcomes by participation frequency

Frequency of Activities		Mean Scores of outcomes							
		Burden		Care Satisfaction		Life Satisfaction		Depression	
Home	Rarely	21.1		34.5		11.9		17.6	
	Monthly	20.4		37.4	*	12.8		16.6	
	Weekly	19.1	***	36.6	*	13.4	***	14.9	***
Outside	Rarely	20.8		35.0		12.0		16.5	
	Monthly	20.0		35.8		12.8		16.0	
	Weekly	19.4	*	36.8		13.4	**	15.9	
Social	Rarely	20.4		35.4		12.1		17.0	
	Monthly	19.4		37.2		13.4	**	15.2	
	Weekly	19.8		36.1		13.8	***	15.1	*
Peer	Non-participant	20.1		35.8		12.6		16.2	
	Participant	19.6		37.3		14.3	***	15.5	

Bonferoni and t-test were used to examine activity engagement differences compared to Rarely/Non-participant.

***<.00,

**<.01,

*<.05

Burden and Depression: higher scores indicate more burdened and depressed.

Care Satisfaction and Life Satisfaction: higher scores indicate greater satisfaction.

Table 4

Table4 Regression analysis for Psychological Health on Activity participation

		Burden		Care Satisfaction		Life Satisfaction		Depression	
		β		β		β		β	
Activity Engagement									
Home Activity	(Monthly)	−.015		.094	*	−.004		.049	
	(Weekly)	−.121	**	.011		.078		−.139	*
Outside Activity	(Monthly)	.009		.026		−.021		.013	
	(Weekly)	−.014		.030		.021		.050	
Social Activity	(Monthly)	−.074		.063		.086	*	−.043	
	(Weekly)	−.046		.028		.107	*	−.104	*
Peer Activity	Participant	−.036		.048		.121	**	.005	
Intercept		19.291	***	40.555	***	8.237	***	16.594	***
Adjusted R2		0.204		0.067		0.165		0.143	
F		9.157		3.279		7.311		6.315	

*** <.00,

** <.01,

* <.05,

Reference: Home Activity(Rarely), Outside leisure Activity(Rarely), Social Activity(Rarely), Peer Activity(Nonparticipant)

Controlling: CG characteristics(Marital status, relationship, Employment(employed=1), Financial situation, Health difficulty),