

Association between family satisfaction and caregiver burden in cancer patients receiving outreach palliative care at home

YOKO NAOKI, M.D.,¹ YOSHINOBU MATSUDA, M.D.,² ISSEKI MAEDA, M.D., PH.D.,³
HIDEKA KAMINO, M.D.,⁴ YOKO KOZAKI, M.D.,⁵ AKIHIRO TOKORO, M.D.,²
NORIMASA MAKI, M.D., PH.D.,⁶ AND MINORU TAKADA, M.D., PH.D.⁷

¹Department of Internal Medicine, Tohoku University Graduate School of Medicine, Sendai, Japan

²Department of Psychosomatic Internal Medicine and Supportive and Palliative Care Team, National Hospital Organization Kinki-Chuo Chest Medical Center, Sakai, Osaka, Japan

³Garatia Hospital Hospice, Minoo, Osaka, Japan

⁴Home Care Support Center, Hanwa Daiichi Senboku Hospital, Sakai, Osaka, Japan

⁵Department of Home Healthcare Sales Promotion, Teijin Home Healthcare Limited, Sakai, Osaka, Japan

⁶Maki Clinic, Sakai, Osaka, Japan

⁷Department of Internal Medicine, Hanwa Daini Senboku Hospital, Sakai, Osaka, Japan

(RECEIVED September 9, 2016; ACCEPTED March 9, 2017)

ABSTRACT

Objective: Little is known about the associations between family satisfaction with end-of-life care and caregiver burden. We conducted a researcher-assisted questionnaire survey to clarify the impact of caregiver burden on family satisfaction and to determine the types of burden that decrease family satisfaction.

Method: Bereaved family caregivers of patients with advanced cancer who received our outreach palliative care service were retrospectively identified. Family satisfaction with the end-of-life care provided by the palliative care service and caregiver burden were quantified using the Japanese versions of the FAMCARE Scale and the Zarit Burden Interview (ZBI), respectively.

Results: Our study subjects included 23 family caregivers. The mean scores on the FAMCARE Scale and the ZBI for the total population were 72.8 ± 11.2 and 22.8 ± 17.3 , respectively, indicating moderate-to-high satisfaction and low-to-moderate burden. Caregiver burden had a strong negative correlation to family satisfaction with end-of-life care (Spearman's rho [ρ] = -0.560 , $p = 0.005$), which remained after adjustment for potential confounders (standardized beta [β] = -0.563 , $p = 0.01$). Several burden items—including loss of control, personal time, social engagement with others, feeling angry with the patient, feeling that the patient wants more help than he/she needs, and a wish to leave the care to someone else—were associated with decreased satisfaction. The major cause of dissatisfaction for family members included the information provided regarding prognosis, family conferences with medical professionals, and the method of involvement of family members in care decisions.

Significance of results: Caregiver burden can be a barrier to family satisfaction with end-of-life care at home. A home care model focused on caregiver burden could improve end-of-life experiences for patients and family caregivers.

KEYWORDS: Family satisfaction, Caregiver burden, End-of-life care, Cancer

Address correspondence and reprint requests to: Yoshinobu Matsuda, Department of Psychosomatic Internal Medicine and the Supportive and Palliative Care Team, National Hospital Organization, Kinki-Chuo Chest Medical Center, 1180 Nagasone-cho, Kita-ku, Sakai, Osaka, 591-0021, Japan. E-mail: ymatsuda@kch.hosp.go.jp.

INTRODUCTION

Caring for the patient and family as a unit is a fundamental principle of palliative care. Likewise, improving family members' end-of-life experience and

satisfaction with end-of-life care is a major goal of palliative care (World Health Organization, 2002).

Previous studies have indicated that several factors (including sufficient symptom relief, time spent with the patient, clear goals of care, accessibility and continuity of hospice care, and good communication with hospice staff) are the main determinants of high family satisfaction (Morita et al., 2002; Pottie et al., 2014; Rhodes et al., 2008; Ringdal et al., 2002).

Family members are often involved in end-of-life care as informal caregivers. They may experience caregiver burden, which is defined as the extent to which caregivers feel that their emotional or physical health, social life, and financial status have suffered as a result of providing care for their loved one (Zarit et al., 1980). Feeling burdened may be a strong predictor of anxiety and depression in family caregivers (Park et al., 2013), and it is one of the biggest concerns of advanced cancer patients when choosing to stay at home during the final days of their lives (Yamagishi et al., 2012). In previous studies, routine care increased care burden and decreased family satisfaction (Jansma et al., 2005; Johansson et al., 2007; Northouse et al., 2010). Paying attention to and alleviating caregiver burden are strong requirements for palliative care clinicians. There is a significant association between receiving care/support and family satisfaction (Ozcelik et al., 2015). However, only a few studies have examined the direct association between caregiver burden and family satisfaction with end-of-life care (Chang et al., 2013; Hwang et al., 2003). Caregiving is an interpersonal exchange (Braun et al., 2007), so that caregiver burden connected to such relational factors as feeling angry with the patient or feeling that the patient wants more help than he/she needs may be an important determinant of family satisfaction. Little is known about what kind of caregiver burden reduces family members' satisfaction with care (Schulz, 2013). Addressing the direct impact of caregiver burden on family satisfaction with end-of-life care and specifying the kinds of burdens that decrease family satisfaction are important for the development of a home care model to improve patients' and family members' end-of-life experiences.

The primary aim of the present study was to examine the impact of caregiver burden on family satisfaction with end-of-life care, the types of burdens that decrease family satisfaction, and family members' dissatisfaction within the home care setting.

METHODS

Settings and Outreach Care Service

The National Hospital Organization (NHO) Kinki-Chuo Chest Medical Center and the Sakai Hospital

Kinki University Faculty of Medicine are acute hospitals located in the city of Sakai in Japan. An outreach palliative care service for patients discharged from the hospitals' respiratory or oncology wards was implemented in 2005. Most home-based care services in Japan are routinely provided by primary care physicians; however, most do not have sufficient oncology and palliative care practice expertise. In the outreach palliative care service, general care (treatments for comorbidities, fluid therapy, nutritional support, and assistance with daily living) was provided by home care physicians and home-visit nurses. Specialized care (advanced symptom management and end-of-life discussions with patient and family) was provided by the outreach care team. This team included two hospital oncologists with expertise in palliative care, two nurses, and a medical social worker supporting the home care physician and home-visit nurses. If a patient required admission to a hospital, the oncologists provided hospitalized care for them. Clinical information was shared between the home care team and outreach palliative care team by telephone conversations and by using patient-held medical records. All costs were covered by national healthcare insurance.

Participants

We retrospectively reviewed 37 patients with far-advanced cancer who were discharged from our institutions and received outreach palliative care between January of 2005 and December of 2010. One principal caregiver for each patient was identified based on information found in the medical records. We could not contact 13 of the bereaved family caregivers because of the death of the family member or the lack of a contact address. Of the remaining 24 bereaved family members, 1 refused to participate in our study. We obtained written consent for study participation from 23 bereaved family caregivers (response rate = 96%).

Procedure

Two trained researchers conducted the researcher-assisted questionnaire at the patient's home between 1 August 2011 and 21 March 2012. These researchers were not medical staff and were not involved in patient care. Nor did they have experience in clinical medicine. They helped participants to complete self-administrated questionnaire depending on their ability to understand the questions. Participants took about 30 minutes to complete the study questionnaire. Our study was approved by the ethics committee of the NHO Kinki-Chuo Chest Medical Center.

Measurements

Patient characteristics, number of outreach visits, and the place and date of death were obtained from the medical records. Patient and family member preferences regarding place of death were evaluated by means of the survey.

Family Satisfaction with Care

Family satisfaction with end-of-life care was quantified using the Japanese version of the FAMCARE Scale (Kristjanson, 1993; Shimozuma et al., 2008). This 20-item instrument (see http://www.npcrc.org/files/news/famcare_scale.pdf) was developed to measure family satisfaction with the care provided for advanced cancer patients, including palliative care patients (Hudson et al., 2010; Teresi et al., 2014; Lo et al., 2009). The FAMCARE Scale was originally developed within a conceptual framework of four dimensions—information giving, availability of care, physical care, and psychosocial care—though a later study revealed the unidimensionality of this instrument (Ringdal et al., 2003). Family caregivers were asked to rate their satisfaction with care on a 5-point Likert-type scale, ranging from “very satisfied” to “very dissatisfied.” The total score ranged from 20 to 100, with a higher score indicating higher satisfaction. This scale had high internal validity and reliability in its original language (Cronbach’s α = 0.93 and test–retest reliability = 0.92, respectively) (Kristjanson, 1993). The validity and reliability of the Japanese version of the FAMCARE has also been tested (research in preparation).

Caregiver Burden

The 22-item Zarit Burden Interview (ZBI) (Zarit et al., 1985) was utilized to measure caregiver burden. This scale was originally developed to evaluate the caregiver burden of patients with dementia, but it has been widely used in various settings, including caregivers of patients with advanced cancer (Garlo et al., 2010; Higginson & Gao, 2008). The ZBI can evaluate broad areas of subjective (distress, worry, guilt) and objective (direct tasks, indirect tasks, dealing with the emotional needs of the patient, effects of caregiving on other aspects of life) caregiver burden as classified previously (Sales, 2003). Each question is scored on a 5-point Likert-type scale ranging from 0 (“never”) to 4 (“nearly always”). The total score ranges from 0 to 88, with a higher score indicating a heavier burden. Sufficient internal consistency and reliability were confirmed (Cronbach’s α = 0.89, test–retest reliability = 0.71) (Zarit et al., 1985). We employed the Japanese version of the ZBI, which also has sufficient reliability and validity (Cronbach’s

α = 0.93, test–retest reliability = 0.76) (Arai et al., 1997).

Statistical Analyses

The characteristics of patients and family caregivers were presented as a median (range) or number (n , %), where appropriate. Scatterplots and Spearman’s ρ were employed to illustrate the correlation between family satisfaction and caregiver burden. The association between FAMCARE and ZBI total scores was examined in an exploratory manner using multiple regression models after adjustment for patient age and sex, place of death (home/other), and concordance between the patient’s preferred and actual place of death (yes/no). ZBI items that had a significant negative correlation with the FAMCARE total score were listed to indicate burden items that reduced satisfaction. One-way ANOVA was used to compare FAMCARE total scores according to severity of care burden. Dissatisfaction items were indicated using barplots for each item of the FAMCARE Scale. Dissatisfaction was defined as the sum of “very dissatisfied” and “dissatisfied” responses for each item. To address the small number of patients with missing data on FAMCARE and ZBI items (less than 2%), the missing values were imputed using median scores for each item. A value of $p < 0.05$ was regarded as statistically significant. All analyses were done using SPSS (v. 18.0; SPSS Inc., Chicago, Illinois, USA).

RESULTS

Characteristics of Participants

Most patients had a diagnosis of lung cancer and poor performance status at discharge. The majority of caregivers were spouses of the patients. One or more live-in alternative caregivers were available for six patients (26.1%). A third of the caregivers ($n = 7$) had no support from additional caregivers who lived locally. Median survival after discharge was 52 days (range = 1–175). The median number of outreach visits was 11 (range = 1–33) during this period. The preferred place of death was at home for 17 patients (73.9%), in hospital for 2 patients (8.7%), and other or unknown for 4 patients (17.4%; Table 1). In actuality, 9 patients died at home. The concordance rate between preferred and actual place of death was 43.5% (10 patients overall: 8 at home, 2 in hospital).

Association Between Family Satisfaction and Caregiver Burden

The mean FAMCARE and ZBI scores in the total population were 72.8 ± 11.2 and 22.8 ± 17.3 , respectively,

Table 1. Characteristics of patients and family members

Patients (<i>n</i> = 23)	Values*
Age	70 (51–86)
Male	14 (60.9%)
Primary cancer site	
Lung	18 (78.3%)
Digestive organs	2 (8.7%)
Others	3 (13.0%)
Performance status at discharge	
0–2	1 (4.3%)
3	10 (43.5%)
4	10 (43.5%)
Preferred place of death	
Home	17 (73.9%)
Hospital	2 (8.7%)
Other/unknown	4 (17.4%)
Actual place of death	
Home	9 (39.1%)
Hospital	12 (52.2%)
Others/missing	2 (8.7%)
Duration of home hospice care, days	52 (1–175)
Family caregivers (<i>n</i> = 23)	
Male	6 (26.1%)
Relationship to the patient	
Husband or wife	20 (87.0%)
Child	3 (13.0%)
Time interval between patient death and interview, years	5.5 (1.0–7.0)

* The values indicate median (range) or *n* (%).

indicating moderate-to-high satisfaction and low-to-moderate burden. Caregiver burden had a strong negative correlation with family satisfaction with end-of-life care (Spearman's $\rho = -0.560$, $p = 0.005$; Figure 1A). For the patients who died at home, a stronger correlation was observed than for the total population (Spearman's $\rho = -0.870$, $p = 0.002$; Figure 1B).

In the multiple regression analysis, the negative association between caregiver burden and family satisfaction with end-of-life care remained significant after adjustment for potential confounders (Table 2). The interaction of place of death and concordance between the patient's preferred and actual place of death was not significant. When the time interval between the date of the patient's death and study inclusion was included in the multiply adjusted model, the association between caregiver burden and satisfaction did not change (data not shown).

Caregiver Burden Items that Decreased Family Satisfaction

The following 8 of 22 care burden items were negatively correlated with satisfaction: feeling that they

do not have enough time for themselves (Spearman's $\rho = -0.621$, $p = 0.002$); feeling angry with the patient (-0.576 , 0.004); feeling a loss of control over their own life caused by the patient's illness (-0.516 , 0.012); feeling that the patient negatively affects relationships with other family members or friends (-0.481 , 0.020); feeling that the patient asks for more help than he/she needs (-0.466 , 0.025); feeling that they do not have enough money to take care of the patient (-0.461 , 0.027); wishing to leave the care to someone else (-0.443 , 0.034); and feeling able to give better care (-0.420 , 0.046) (Figure 2). The most prevalent caregiver burdens were the feeling that the patient is dependent on them (57%) and that they are the only people on whom the patient could depend (48%); however, these items did not show significant correlations with overall satisfaction.

Dissatisfaction

As shown in Figure 3, the dissatisfaction rate was highest for the information provided regarding patient prognosis (dissatisfaction rate = 34.8%), for family conferences held to discuss the patient's illness (26.1%), and for the way the family was included in treatment and care decisions (26.1%). In contrast, almost all caregivers were satisfied or very satisfied with the way the tests and treatments were performed, the availability of nurses to the family, the doctor's attention to the patient's suffering, and the speed with which symptoms were treated.

DISCUSSION

Caregiver burden in our study population was negatively correlated with family satisfaction with end-of-life care. Some types of caregiver burden, including the feeling of not having enough private time and feeling angry with the patient, had a significant negative impact on overall satisfaction. Some bereaved family members reported that the information provided regarding the patient's prognosis, having a family conference to discuss the patient's illness, and the method of family involvement in care decisions were major causes of dissatisfaction.

Sufficient symptom relief, information provision concerning the patient's condition and treatment goals, and availability of medical staffs have been reported as key determinants of family satisfaction (Morita et al., 2002; Pottie et al., 2014; Rhodes et al., 2008; Ringdal et al., 2002). However, very little evidence has been gathered regarding the associations between family satisfaction and caregiver burden, and the study results have been inconsistent. Hwang et al. (2003) conducted a survey in 100 cancer

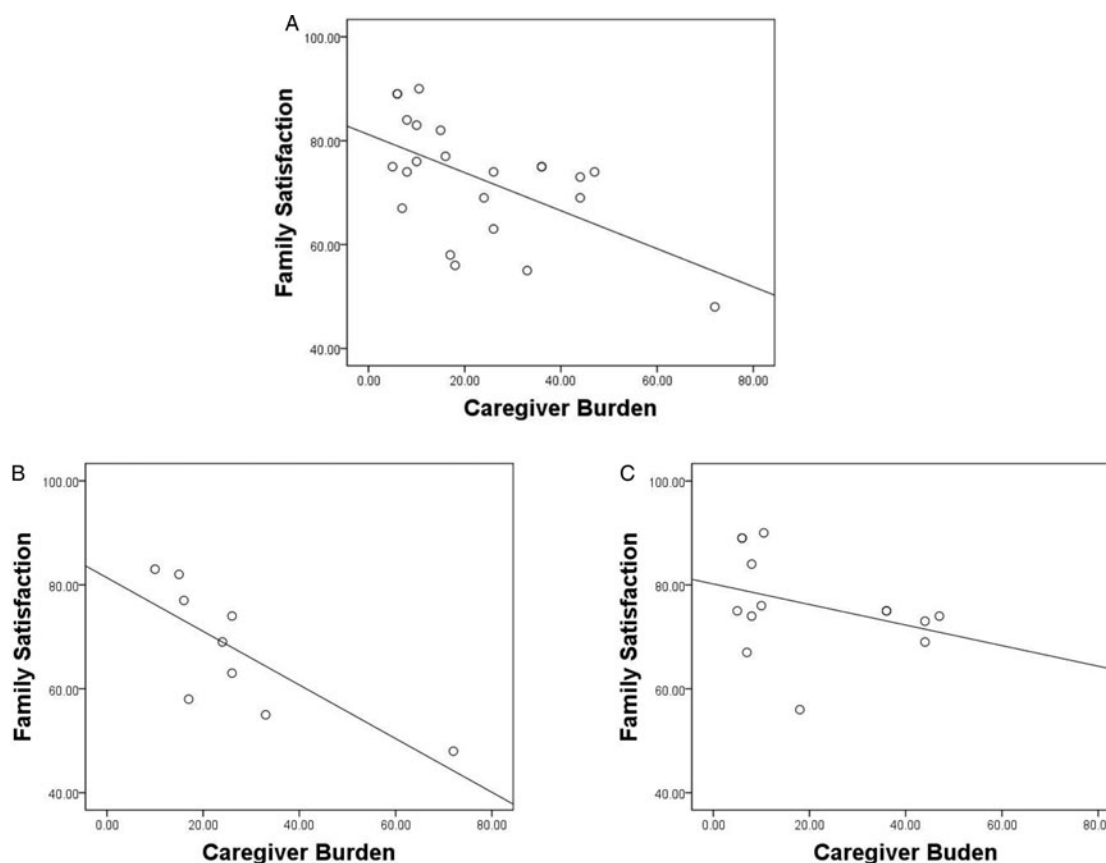


Fig. 1. Association between family satisfaction and caregiver burden. Caregiver burden showed a significant negative correlation with family satisfaction in (A) total population, (B) patients who died at home, and (C) patients who died at other places. Family satisfaction and caregiver burden were measured using FAMCARE total scores and the 22-item Zarit Burden Interview, where higher scores indicate higher satisfaction and perceived heavy burden, respectively.

patient/family caregiver dyads in a Veterans Affairs medical center. Caregiver burden, measured using the Care Strain Index, was not significantly correlated with family satisfaction with care, measured using FAMCARE (Pearson's $r = -0.01$). Chang et al. (2013) explored the factors affecting family satisfaction in terminal cancer patients and their family caregivers in a Korean population and found that

Table 2. Factors associated with family satisfaction (multiple regression model)

	β	Standardized β	p
Caregiver burden ^a	-0.365	-0.563	0.01
Age	0.094	0.081	0.67
Male	-3.603	-0.160	0.43
Home death	-3.899	-0.173	0.43
Concordance ^b	-4.208	-0.190	0.40

Adjusted $R^2 = 0.296$.

^a Measured using the Zarit Burden Interview.

^b Concordance between patient's preferred and actual place of death.

satisfaction with overall care was significantly higher if the patient and family caregiver did not experience much burden (multiply adjusted odds ratio [95% confidence interval] = 2.82 [1.76–4.50] for patients; and 2.94 [1.75–4.93] for caregivers) (Chang et al., 2013). However, satisfaction and caregiver burden were not measured using validated instruments, and no information regarding the type of burden that might negatively impact satisfaction was available. On the other hand, we demonstrated a significant negative correlation between caregiver burden and family satisfaction using well-validated measures. Moreover, we identified the burden items that might decrease family satisfaction, such as changes in lifestyle (loss of control, personal time, and social engagement with others); conflict with the patient (feeling angry with the patient, feeling that the patient wants more help than he/she needs); and a lack of confidence (wishing to leave the care to someone else, feeling capable of giving better care). Feelings of isolation and loneliness and a restricted social network have also been identified as risks for increased caregiver burden (Bishop et al., 2007; Goldstein et al., 2004;

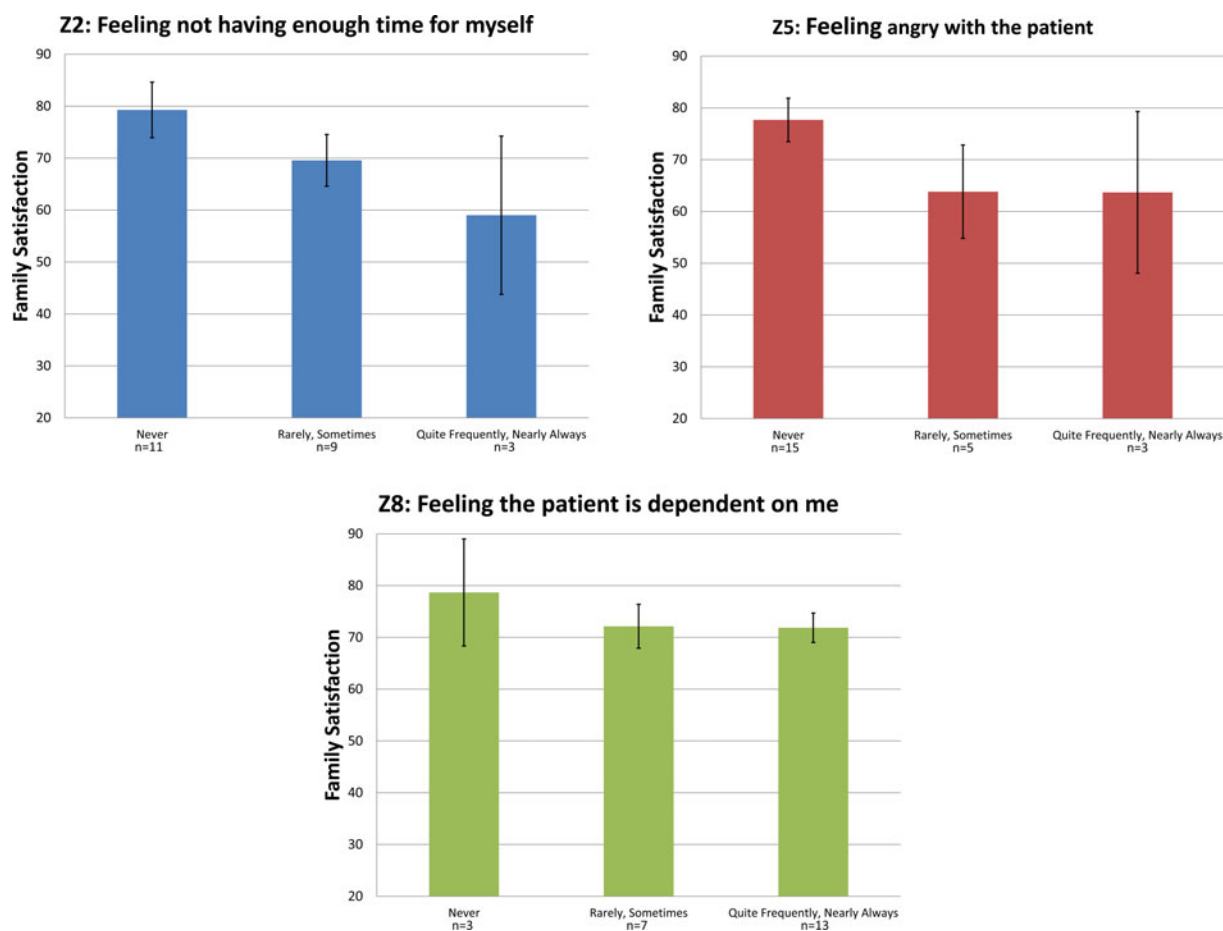


Fig. 2. Association between caregiver burden items and family satisfaction. Overall satisfaction differs significantly according to the severity of “feeling not having enough time for myself” ($p = 0.005$) and “feeling angry with the patient” ($p = 0.011$), but not of “feeling the patient is dependent on me” ($p = 0.647$).

Rossi Ferrario et al., 2003; Stenberg et al., 2010). The tiredness of family caregivers is also a common problem in cancer care (Fletcher et al., 2008; Tokoro et al., 2009). Our findings are in line with the results of previous studies.

Caregivers of patients who died under hospice care reported fewer unmet needs when compared with those who died in hospital settings (Dawson, 1991). However, we found some dissatisfaction in bereaved family members mostly concerning information sharing: information provided about the patient’s prognosis, family conferences with the medical professionals, and the way family members were involved in care decisions. In Japan, family conferences between patient and family, hospital physicians and nurses, and home care staffs before discharge have increasingly been held since the national healthcare insurance started financially supporting family conferences in 2006 (~\$100 for a home care physician and \$230 for a hospital). This system facilitates reduction in dissatisfaction with information sharing.

LIMITATIONS OF THE STUDY

Our study has several limitations. First, although we have adjusted for potential confounders, some unmeasured variables (including level of patient function, symptom severity, and financial resources) may have had an influence on our results. These potential confounders should be assessed in future studies. Second, because we asked family caregivers to participate in our survey and recall their satisfaction and burden after a median time interval of 5.5 years from the patient’s death, a recall bias might have also existed. Although our results did not change when we adjusted for the time interval between patient death and time of the survey, we are aware that the long interval might have minimized a caregiver’s recall of the actual physical and emotional burden that they experienced while caring for the patient. In addition, we did not assess the caregiver’s emotional state and stage of grief at the time of the survey. Our results may also be biased by these factors. Prospective studies are required to

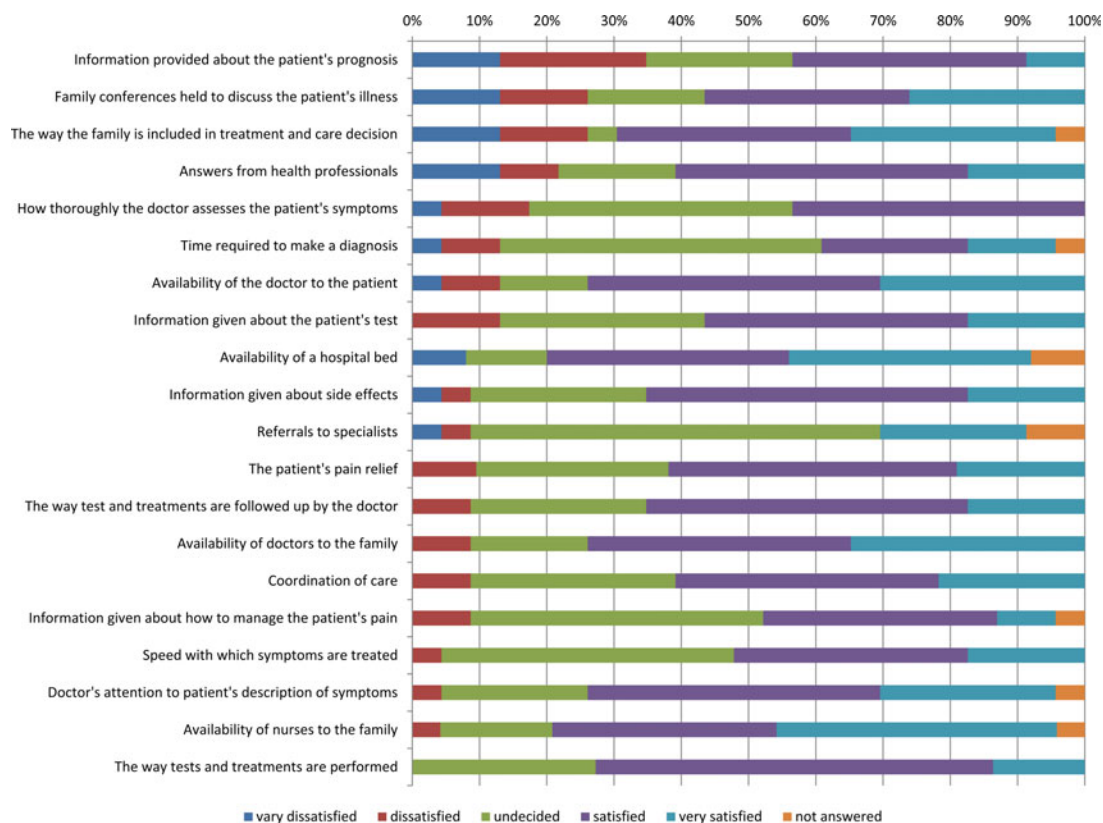


Fig. 3. Dissatisfaction was measured using each item of the FAMCARE Scale. Items are listed according to rate of dissatisfaction, defined as the proportions of very dissatisfied or dissatisfied caregivers. The data utilized were not imputed (raw data).

know the actual caregiver burden at the time of patient care. Third, because the patient preference for place of death and satisfaction with care were measured by proxy rating, these measurements might not be completely identical to those of the actual patients. Fourth, patient satisfaction with care was not measured directly. However, we believe that this issue does not undermine our findings because family satisfaction with end-of-life care was the main focus of our study. Fifth, our findings were based on the perspectives of the family caregivers of patients who were discharged and had taken part in our outreach palliative care service, and the sample size was relatively small. Hence, we could not generalize our findings to the experience of all family caregivers whose loved ones could not be discharged due to severe symptom intensity or rapid deterioration of their general condition. Moreover, 57% of the patients needed at least one readmission after discharge from our hospitals; contamination due to hospital readmission might have also affected our findings. Sixth, the interrater reliability of the FAMCARE Scale and the ZBI was not tested in our study. Although the two interviewers were instructed to perform similar tasks by using the same question-

naire, some bias may have been introduced through this issue. Seventh, the question items in the FAMCARE Scale and ZBI are phrased in the present tense. We employed these tools, and there was no validated measurement with which to ask caregivers about satisfaction with care and burden in the past tense. Finally, because this study was conducted in an urban setting with a relatively high availability of home-visiting services and emergency departments, our results cannot be applied to other regions.

CONCLUSIONS

Caregiver burden could be a potential barrier to family satisfaction with the care provided to patients and family members receiving palliative care at home. More attention should be paid to caregiver burden with regard to changes in lifestyle, conflicts with the patient, and lack of confidence. Seeking methods to share information concerning the patient's prognosis with the family and involving family members in the decision-making process are crucial. A home hospice care model focused on these issues could improve the end-of-life experience of patients and family members.

DISCLOSURES AND ACKNOWLEDGMENTS

Yoko Kozaki is an employee of Teijin Home Healthcare Co. Ltd. She contributed to this study as an interviewer of the family caregivers. Teijin Home Healthcare was not involved with the planning, funding, data analysis, or writing of the manuscript. All of the remaining authors hereby declare that they have no conflicts of interest to disclose. Our study was funded by the Osaka Medical Research Foundation for Intractable Diseases (grant no. 14-2-39). We are grateful for the assistance given by Ms. Mori.

REFERENCES

- Arai, Y., Kudo, K., Hosokawa, T., et al. (1997). Reliability and validity of the Japanese version of the Zarit Caregiver Burden Interview. *Psychiatry and Clinical Neurosciences*, 51(5), 281–287. Available from <http://onlinelibrary.wiley.com/doi/10.1111/j.1440-1819.1997.tb03199.x/pdf>.
- Bishop, M.M., Beaumont, J.L., Hahn, E.A., et al. (2007). Late effects of cancer and hematopoietic stem-cell transplantation on spouses or partners compared with survivors and survivor-matched controls. *Journal of Clinical Oncology*, 25(11), 1403–1411. Available from <http://ascopubs.org/doi/10.1200/JCO.2006.07.5705>.
- Braun, M., Mikulincer, M., Rydall, A., et al. (2007). Hidden morbidity in cancer: Spouse caregivers. *Journal of Clinical Oncology*; 25(30), 4829–4834. Available from 17947732.
- Chang, Y.J., Kwon, Y.C., Lee, W.J., et al. (2013). Burdens, needs and satisfaction of terminal cancer patients and their caregivers. *Asian Pacific Journal of Cancer Prevention* 14(1), 209–216. Available from http://journal.waocp.org/article_27306_1336e0535272ff4f4f6c27930088e9dd.pdf.
- Dawson, N.J. (1991). Need satisfaction in terminal care settings. *Social Science & Medicine*, 32(1), 83–87.
- Fletcher, B.S., Paul, S.M., Dodd, M.J., et al. (2008). Prevalence, severity, and impact of symptoms on female family caregivers of patients at the initiation of radiation therapy for prostate cancer. *Journal of Clinical Oncology*, 26(4), 599–605.
- Garlo, K., O'Leary, J.R., Van Ness, P.H., et al. (2010). Burden in caregivers of older adults with advanced illness. *Journal of the American Geriatrics Society*, 58(12), 2315–2322. Epub ahead of print Nov 18. Available from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3058825/>.
- Goldstein, N.E., Concato, J., Fried, T.R., et al. (2004). Factors associated with caregiver burden among caregivers of terminally ill patients with cancer. *Journal of Palliative Care*, 20(1), 38–43.
- Higginson, I.J. & Gao, W. (2008). Caregiver assessment of patients with advanced cancer: Concordance with patients, effect of burden and positivity. *Health and Quality of Life Outcomes*, 6, 42. Available from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2435233/>.
- Hudson, P.L., Trauer, T., Graham, S., et al. (2010). A systematic review of instruments related to family caregivers of palliative care patients. *Palliative Medicine*, 24(7), 656–668. Epub ahead of print Jul 6.
- Hwang, S.S., Chang, V.T., Alejandro, Y., et al. (2003). Caregiver unmet needs, burden, and satisfaction in symptomatic advanced cancer patients at a Veterans Affairs (VA) medical center. *Palliative & Supportive Care*, 1(4), 319–329.
- Jansma, F.F., Schure, L.M. & de Jong, B.M. (2005). Support requirements for caregivers of patients with palliative cancer. *Patient Education and Counseling*, 58(2), 182–186.
- Johansson, M.C., Axelsson, B. & Danielson, E. (2007). Caregivers' perceptions about terminally ill family members' quality of life. *European Journal of Cancer Care*, 16(4), 338–345.
- Kristjanson, L.J. (1993). Validity and reliability testing of the FAMCARE Scale: Measuring family satisfaction with advanced cancer care. *Social Science & Medicine*, 36(5), 693–701.
- Lo, C., Burman, D., Hales, S., et al. (2009). The FAMCARE–Patient scale: Measuring satisfaction with care of outpatients with advanced cancer. *European Journal of Cancer*, 45(18), 3182–3188. Epub ahead of print Sep 26.
- Morita, T., Chihara, S. & Kashiwagi, T. (2002). A scale to measure satisfaction of bereaved family receiving inpatient palliative care. *Palliative Medicine*, 16(2), 141–150.
- Northouse, L.L., Katapodi, M.C., Song, L., et al. (2010). Interventions with family caregivers of cancer patients: Meta-analysis of randomized trials. *CA: A Cancer Journal for Clinicians*, 60(5), 317–339. Epub ahead of print Aug 13. Available from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2946584/>.
- Ozcelik, H., Cakmak, D.E., Fadiloglu, C., et al. (2015). Determining the satisfaction levels of the family members of patients with advanced-stage cancer. *Palliative & Supportive Care*, 13(3), 741–747. Epub ahead of print Jun 3, 2014.
- Park, B., Kim, S.Y., Shin, J.Y., et al. (2013). Prevalence and predictors of anxiety and depression among family caregivers of cancer patients: A nationwide survey of patient–family caregiver dyads in Korea. *Supportive Care in Cancer*, 21(10), 2799–2807. Epub ahead of print Jun 1.
- Pottie, C.G., Burch, K.A., Thomas, L.P., et al. (2014). Informal caregiving of hospice patients. *Journal of Palliative Medicine*, 17(7), 845–856.
- Rhodes, R.L., Mitchell, S.L., Miller, S.C., et al. (2008). Bereaved family members' evaluation of hospice care: What factors influence overall satisfaction with services? *Journal of Pain and Symptom Management*, 35(4), 365–371.
- Ringdal, G.I., Jordhoy, M.S. & Kaasa, S. (2002). Family satisfaction with end-of-life care for cancer patients in a cluster randomized trial. *Journal of Pain and Symptom Management*, 24(1), 53–63.
- Ringdal, G.I., Jordhoy, M.S. & Kaasa, S. (2003). Measuring quality of palliative care: Psychometric properties of the FAMCARE Scale. *Quality of Life Research*, 12(2), 167–176.
- Rossi Ferrario, S., Zotti, A.M., Massara, G., et al. (2003). A comparative assessment of psychological and psychosocial characteristics of cancer patients and their caregivers. *Psycho-Oncology*, 12(1), 1–7.
- Sales, E. (2003). Family burden and quality of life. *Quality of Life Research*, 12(Suppl. 1), 33–41.

- Schulz, R. (2013). Research priorities in geriatric palliative care: Informal caregiving. *Journal of Palliative Medicine*, 16(9), 1008–1012. Epub ahead of print Jul 24. Available from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3776612/>.
- Shimozuma, K., Yamaguchi, M., Saito, S., et al. (2008). *Translation of the FAMCARE Scale into Japanese*. Report of Item History. Unpublished paper.
- Stenberg, U., Ruland, C.M. & Miaskowski, C. (2010). Review of the literature on the effects of caring for a patient with cancer. *Psycho-Oncology*, 19(10), 1013–1025.
- Teresi, J.A., Ornstein, K., Ocepek-Welikson, K., et al. (2014). Performance of the Family Satisfaction with the End-of-Life Care (FAMCARE) measure in an ethnically diverse cohort: Psychometric analyses using item response theory. *Supportive Care in Cancer*, 22(2), 399–408. Epub ahead of print Oct 5, 2013. Available from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4151612/>.
- Tokoro, A., Ikeyama, H., Matsuda, Y., et al. (2009). The usefulness and limitations of outreach home hospice care provided by cancer specialists in cooperation with home-care physicians [in Japanese]. *Kanwairyogaku*, 11, 214–221.
- World Health Organization (2002). *National Cancer Control Programmes : Policies and Managerial Guidelines*, 2nd ed. Geneva: World Health Organization; 2002. Available from <http://www.who.int/cancer/media/en/408.pdf>.
- Yamagishi, A., Morita, T., Miyashita, M., et al. (2012). Preferred place of care and place of death of the general public and cancer patients in Japan. *Supportive Care in Cancer*, 20(10), 2575–2582. Epub ahead of print Jan 24.
- Zarit, S.H., Reever, K.E. & Bach-Peterson, J. (1980), Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist*, 20(6), 649–655.
- Zarit, S.H., Orr, N.K., Zarit, J.M. (1985). *The Hidden Victims of Alzheimer's Disease: Families under Stress*. New York: New York University Press.