

笹川記念保健協力財団 研究助成

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公益財団法人 笹川記念保健協力財団

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## 2016年度ホスピス緩和ケアに関する研究助成

### 研 究 報 告 書

標記について、下記の通り研究報告書を添付し提出いたします。

#### 記

研究課題

終末期がん患者の家族介護者に対する自宅療養に向けた支援プログラムの開発

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**【研究の目的】**

がん患者が終末期となり残された時間を自宅で過ごしたいと望んでも、家族介護者の不安などにより早く退院できない場合がある。終末期における自宅療養では家族の介護力などが重要であるが、家族介護者への退院支援が実際にどの程度行われているのかは明らかにされていない。本研究の目的は、緩和ケア病棟看護師が認識している終末期がん患者の家族介護者への退院支援の必要性とその実施が一致しているか否かを明らかにすることである。また、家族介護者への支援内容を整理し、退院支援実施のための尺度を開発して支援プログラムの開発につなげることとする。

**【研究の内容・実施経過】**

この横断研究は、日本ホスピス緩和ケア協会に正会員として登録している全国の緩和ケア病棟の管理者に研究協力を依頼し、承諾が得られた 102 施設に勤務する看護師 1,227 名を対象としている。本研究のデータは、2015 年 10 月から 2016 年 2 月に収集した。退院が困難な状況にある患者家族に対する支援 57 項目それぞれについて、6 段階リッカート尺度による無記名自記式質問紙を作成し使用した。対象者にはそれぞれの退院支援がどの程度必要だと思うかとその支援の実施についてそれぞれ 6 段階で評価することを求めた。そしてそれらのスコアの差について対応のある t 検定を行った。次に、退院支援 57 項目のスコアを因子分析にかけた結果、4 因子に分類された。

**【研究の成果】**

対象者のうち 1,023 名(83.4%)から調査票の返送があった。対象者のほとんどが女性で、看護師経験年数は平均 16.4 (SD 8.3) 年であった。家族介護者への退院支援のすべての項目において、緩和ケア病棟看護師は支援が必要であると認識していたが、それと比較してその実施は有意に低かった( $P < 0.001$ )。また、家族介護者への退院支援は 47 項目 4 因子(家族介護者が自宅での生活をイメージ出来るための支援、病院側と家族介護者との関係構築のための支援、自宅療養の実現性を高める支援、退院後も病院との関わりが継続することを保証する支援)に分類された。

**【今後の課題】**

緩和ケア病棟の看護師は、終末期がん患者の家族介護者に対して退院支援が必要だと認識しているものの十分に退院支援が実施できていないことが明らかになった。緩和ケア病棟の看護師は、終末期がん患者の家族介護者に対して退院支援をより一層実施する必要がある。そのためには退院支援項目を基に支援プログラムを作成し、今後は支援プログラムを使用した介入群と対照群の無作為化比較試験を実施していく予定である。

**【研究の成果等の公表予定】**

BMC Palliative Care に投稿予定

## 【研究の目的】

The aim of this study was to investigate the discrepancies between the supports needed for discharge of terminal cancer patients to their family caregivers and what supports were actually provided by palliative care unit nurses (PCUNs) in Japan. We will also organize the content of support for family caregivers, develop a scale for implementation of hospitalization support, and lead to the development of support programs.

## 【研究の内容・実施経過】

## Questionnaire preparation

In advance of the data collection, we developed questionnaire items designed to assess the supports needed by family caregivers of terminal cancer patients for their discharge based on the literature review, and interview surveys. In addition, their validity was tested using three preliminary studies among 58 PCUNs. Details of these surveys were as follows.

First, we conducted a literature review of previous studies to identify the types of supports for discharge that nurses provided to families by searching the PubMed, CINAHL, and Igaku Chuo Zasshi websites using "terminal-care or end-of-life-care," "family or caregiver," "discharge," and "cancer" as keywords.

Second, based on the literature review, semi-structured interview surveys were conducted among 16 PCUNs who were involved with at least three family caregivers of terminal cancer patients per year. In these interviews, we investigated the types of supports provided to family caregivers of terminal cancer patients prior to the initiation of home-based care, and the precautions observed in the actually provided supports.

Third, after examining survey items with the collaborating researchers, appropriateness of the items was determined in a preliminary survey conducted on 58 nurses in each palliative care unit at three hospitals in the Tokyo Metropolitan area. No ceiling or floor effects were seen in any of the items. In this survey, 57 items were determined to be appropriate for investigating the supports to family caregivers of terminal cancer patients to help them receive hospice care at home.

Based on the above-mentioned surveys, we prepared an anonymous, self-administered questionnaire. This questionnaire consisted of questions regarding reasons for difficulties in transition to home-based care (for example, the family caregivers have anxiety about home-based care, or there are inter-individual differences in the intentions among the family caregivers), using a 6-point Likert scale on the supports needed for smooth initiation of home-based care and what supports were actually provided. The

following anchors were used as responses: 1 = "strongly disagree that it is necessary," 2 = "disagree that it is necessary," 3 = "somewhat disagree that it is necessary," 4 = "somewhat agree that it is necessary," 5 = "agree that it is necessary," and 6 = "strongly agree that it is necessary." The responses were then scored on a scale ranging from 1-6 points (hereinafter referred to as "perceived importance"). Higher scores of perceived importance indicate that PCUNs thought it more necessary. For the same family caregiver support items, a 6-point Likert scale was used to determine to what extent such forms of supports were actually provided, by using the following anchors for responses: 1 = "never performed," 2 = "rarely performed," 3 = "sometimes performed," 4 = "moderately performed," 5 = "often performed," and 6 = "always performed." These results were also scored (hereinafter referred to as "actual supply"). Higher scores of actual supply indicate that the PCUNs were more likely to have actually carried out family caregiver support.

We confirmed the validity by repeated discussion of the contents of family caregiver support items with family caregiver support specialist nurses, oncology specialist nurses, and medical statistics researchers. In addition, prior to the cross-sectional study among the 1,227 PCUNs, we conducted three preliminary surveys on 58 PCUNs using a draft questionnaire developed together with our collaborating researchers, to recheck the appropriateness of the above items.

#### Statistical analysis

All statistical analyses were performed using the statistical package SAS ver. 9.4 (SAS Institute, Cary, North Carolina, USA). All p-values were two-sided and statistical significance was set at  $p < 0.05$ . Missing values were handled by complete case analysis. In other words, observations with missing values were not used in our analyses.

Paired t-tests were used to test the differences between the scores on perceived importance and the scores on actual supply of the supports to the family caregivers as previously reported.

We explored the underlying structure of the items by exploratory factor analysis. We calculated a response distribution for all 57 items of the supports for discharge to the family caregivers to look for ceiling and floor effects. The supports actually provided were classified by factor analysis with promax rotation repeated measure analysis. The data's suitability for exploratory factor analysis was also assessed using Bartlett's test of sphericity to test the overall significant differences in the correlation matrix, and the Kaiser-Meyer-Olkin test to check that sample adequacy was appropriate. The extraction method was the major factor method and the total explained variance was 55.19% (four factors). Cronbach's  $\alpha$  coefficient, a measure of internal consistency, was calculated for

family caregiver support items for each factor, and 0.8 or higher was set as the indicator judgment criteria. Mean scores on the supports belonging to each category were used as the dependent variables of the following regression analyses.

#### 【研究の成果】

The paired t-tests showed that the scores of the perceived importance of supports to family caregivers [overall mean 5.09 (SD 0.4)] were consistently significantly higher than those of their actual supply [overall mean 4.29 (SD 0.7)] for all 57 items .

Table 1 shows the results of the exploratory factor analysis for the actual supply of supports to family caregivers. The supports actually provided were classified into four categories as follows. By referencing eigenvalues and scree plots, a four-factor structure was determined to be the most interpretable. The number of factors was set to four, and then factor analysis by promax rotation repeated measure analysis was performed once again. The use of items with a factor loading of 0.4 or higher resulted in a combination of four factors with 47 items. The factor analysis showed that the actual supply of the hospital's supports to family caregivers had the following four-factor structure: "Supports for visualizing their lives at home after discharge," "Supports for building the relationship between hospital and family caregivers," "Supports to enhance the feasibility of home care," and "Supports for guaranteeing continued support by the hospital to family caregivers." Their Cronbach's  $\alpha$  coefficients were 0.851-0.915 for each factor. As Bartlett's test of sphericity was significant ( $p < 0.001$ ), the data were considered suitable for factor analysis. The Kaiser-Mayer-Olkin value was 0.969, indicating that the sample should produce reliable and distinct factors. Thus, the reliability and validity of factor analysis was guaranteed. The four factors were moderately correlated with each other ( $r = 0.142-0.682$ ).

#### 【今後の課題】

This study investigated the discrepancies between the supports needed for discharge of terminal cancer patients to their family caregivers and what supports were actually provided by the PCUNs in Japan, in addition to their predictors. The primary finding of this study was the significantly higher scores of the supports needed than the scores of the supports actually provided to the family caregivers for all 57 items. These results were just as we expected. They suggest that although the PCUNs recognized that supports for discharge to the family caregivers are necessary, they were not actually fully provided. The present study is the first to clarify the degree to which PCUNs actually

provided supports for discharge of terminal cancer patients to their family caregivers. Previous studies also revealed where terminal cancer patients and their families wanted to spend the rest of the patients' lives and showed the importance of supports for discharge. When family caregivers of patients feel anxiety about home care, frail elderly people including terminal cancer patients may not be able to leave the hospital early. Since the supports for discharge required for family caregivers were not actually provided sufficiently, the PCUNs must provide further support.

In this study, we developed scales to evaluate the levels of actual supply of the supports for hospital discharge of terminal cancer patients to the family caregivers by the PCUNs. The Cronbach's alphas for all the four factors within the four factorial structures were within the acceptable ranges. This suggests that the scales had good content validity, and internal consistency. To our knowledge, this is the first such scale for PCUNs who take care of discharge to family caregivers. These scales also enabled us to explore in detail the predictors of the actual supply of supports to family caregivers. Furthermore, these scales can be used to assess the individual needs of family caregivers and to enable PCUNs to provide such supports as necessary.

The strengths of the present study include the questionnaire design, based on relevant literature reviews, and the consideration of potential confounders in the statistical analyses. Despite these strengths, several limitations should also be acknowledged. First, we cannot exclude the possibility that the results of the study may not be generalizable to other samples of nurses from other departments or countries because the sample selected for this study was limited to PCUNs in Japan. Second, despite the apparent importance of the family caregivers' perspective, we did not investigate this since we thought that asking family caregivers about discharge issues would be a burden to them.

Table 1 Exploratory factor analysis of actual supply of supports for discharge of terminal cancer patients to their family caregivers by palliative care unit nurses (n = 1,011).

Item	Factor loadings
<b>Support for visualizing their lives at home after discharge (<math>\alpha = 0.919</math> <sup>a</sup>)</b>	
Introduce family caregivers to people in similar situations through patient groups and family groups, etc.	0.76
Provide examples of similar illnesses or situations and talk about successful cases of transfer to home care	0.73
Do a home visit before hospital discharge, as well as help family members discuss post-discharge issues	0.72
Explain the costs incurred in home care	0.71
In order to help family caregivers understand that nursing will continue even after being discharged from the hospital, request that the outpatient nurse attend the pre-discharge conference	0.71
Have family members discuss whether the family caregivers should continue working after beginning home care	0.68
Attend family discussions and encourage dialogue so that everyone's intentions can be understood	0.66
Explain the specific care elements such that other family members can support the main family caregivers	0.66
Provide a place where the family members can talk among themselves	0.65
Get family caregivers to meet in-home service providers such as visiting doctors and visiting nurses prior to the pre-discharge conference	0.65
Check the status of the care insurance application and encourage a meeting with the care manager before the pre-discharge conference	0.57
Encourage family caregivers to attend care conferences relating to medical treatment methods and care methods	0.56
Explain the estimated reduction in day-to-day activities in the future by relevant medical personnel (e.g., principal doctor, nurse, physiotherapists, etc.)	0.51
Explain specific decision standards clearly such as at what temperature fever family caregivers should phone in	0.48
Introduce useful care products	0.43
Explain end-of-life care using leaflets or other relevant materials	0.42
Introduce to the family caregivers food products processed so that they are easy for patients to eat or show them meal content and format suited to the state of the patients	0.41

**Support for building the relationship between hospital and family caregivers ( $\alpha = 0.945^a$ )**

Tell family caregivers repeatedly that there is always someone who is ready to respond if they need to talk	0.89
Appreciate the hard work that has already taken place when battling illness and providing care	0.88
Talk proactively with family caregivers and create an atmosphere conducive to talking	0.83
Answer questions from family caregivers honestly	0.79
Verify family caregivers' awareness regarding how much time is thought to be left and provide explanations if this differs from the view of the doctor in charge	0.73
Ask about the role of each family member at home	0.71
Ask whether there is a relative or acquaintance that family caregivers can talk to while providing home care	0.69
Speak to family caregivers when they come for visits and let them know how the patient's hospital stay is going	0.66
Check that family caregivers are not under the impression that patients cannot return home once in the terminal phase, and explain that patients can spend the time at home	0.64
Ask about the change in family caregivers' roles due to this hospitalization	0.64
Inquire about family caregivers' thoughts on the state of the patient at which they would want them home	0.61
Let family caregivers know that even after transferring to home care, they can have their own free time	0.59
Take time to discuss the specifics of what may be worrying the family caregivers	0.59
Ask the family caregivers about their hobbies and what they're passionate about	0.58
Give advice about health issues of the family caregivers themselves	0.54
In considering home remedies, explain that patients do not have a lot of time left	0.54

**Support to enhance the feasibility of home care ( $\alpha = 0.926^a$ )**

Provide instruction and education in care methods appropriate for the	0.98
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situation of the family members				
Provide instruction and education in medical procedures appropriate for the situation of the family members				0.93
Instruct and educate so that the internal medicine such as painkillers can be managed				0.93
Explain how family caregivers can obtain and use medical supplies, as well as medication and nutritional supplements required during home care				0.69
Check which social resource services were being used before hospitalization and if needed, help family members brainstorm which new services should be accessed				0.68
When further explanation beyond the doctor's discussion is deemed necessary, explain, and help the family caregivers understand the information				0.65
Check what the doctor has explained to the family caregivers and verify that the they have understood the information				0.65
Explain the method of transport for the return home				0.49
Explain that aspiration or gastrostoma, etc., can be done by the in-home services				0.44
Suggest trips and overnight stays to make family caregivers believe that living at home can be a reality				0.42
Confirm that there are no financial problems and connect family caregivers to a social worker if needed				0.41
<b>Guaranteeing continued support by hospital even after discharge</b>				
<b>(<math>\alpha = 0.817</math> <sup>a</sup>)</b>				
Explanation from the nurse that patients can come back to the hospital if health deteriorates				0.54
Explain that if family caregivers get tired of caring for the patients, respite hospitalization is available				0.46
Explanation from the doctor that patients can come back to the hospital if health deteriorates				0.45
Number of items	17	16	11	3
Eigenvalue	22.76	4.29	2.73	1.69
Explained variance	39.92	7.52	4.79	2.98

<sup>a</sup> Cronbach's  $\alpha$ .