

**COMPARISON OF  
END-OF-LIFE CARE  
EVALUATION  
BETWEEN FAMILY  
CAREGIVERS AND  
NURSES**

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# Background 1:

End-of-life care system is changing in Japan

- Half of the elderly in Japan wish to receive end-of-life care at home.
- If elderly hope to receive end-of-life care in a hospital, they cannot be inpatients for a long term after the cure of acute diseases.
- The reason is
  - The number of elderly is increasing.
  - The number of beds in hospitals is not increasing due to health care policies.

## Background 2:

Evaluating quality of end-of-life care for the elderly is a big issue in Japan.

- All home care providers do not have the ability to provide end-of-life care.
- There is no appropriate measure for evaluation.
- The satisfaction level of family caregivers after end-of-life care is used for evaluation in this research.

# Background 3:

Who evaluates the satisfaction levels of family caregivers?

- It is difficult to ask family caregivers the satisfaction level directly because they are in mourning and because care is concluded.
- Some studies used the satisfaction level by nurses' evaluation. But some studies suggested that there might be difference between the nurses and the family caregivers.

# Objectives

- 1) to examine the congruity between family caregivers' and visiting nurses' evaluation of end-of-life home care,
- 2) to clarify the relationship between provided care and family caregivers' satisfaction level evaluated by family caregivers and by nurses.

# Methods

## The first survey

1,325 Visiting Nurse Stations responded (Of the total all 2,914 Stations in Japan surveyed)

The data from **the visiting nurses, about 1,305 patients** who had used visiting nurse services and died within three months before the survey

## The second survey

428 Visiting Nurse Stations responded (Of the 1,325 stations, the subjects in the first survey)

The data used in this study were from both the 2nd and the 3rd surveys. (229 matched cases)

## The third survey

304 Visiting Nurse Stations responded (Of the 428 stations, the subjects in the second survey)

The data from **the family caregivers of 229 patients** within 1-year after patients' death (Of the 1,305, the data from the second survey)

- Every questionnaire was returned by post.

# Result 1: Characteristics of family caregivers

- Mean age of caregivers was 63.6 years-old (SD=11.2, Range 34-93).
- Of caregivers 83 (36.2%) were spouses, and 71 (31.0%) were daughters in law.
- One hundred and sixty-nine patients (58.5%) died at home.  
–cf. 13.4% of total death in Japan in 2002

## Result 2: (Table 1)

- Of family caregivers, 148 (73.3%) were satisfied with care, and of them, 116 (78.4%) were also evaluated “seem to be satisfied” by nurses.
- Of family caregivers, 35 (17.3%) regretted the process of their care, and of them, 10 (28.6%) were also evaluated “seem to regret” by nurses.
- The  $\kappa$  value was 0.13 (p=0.02).



Table 1. Congruity between family caregivers' and visiting nurses' evaluation of end-of-life home care

<u>Caregivers evaluation</u>	<u>Nurses evaluation</u>			Total
	Regretful	Neither	Satisfactory	
Regretful	10	4	21	35
	28.6	11.4	60.0	100.0
	33.3	18.2	14.0	17.3
Neither	4	2	13	19
	21.1	10.5	68.4	100.0
	13.3	9.1	8.7	9.4
Satisfactory	16	16	116	148
	10.8	10.8	78.4	100.0
	53.3	72.7	77.3	73.3
Total	30	22	150	202
	14.9	10.9	74.3	100.0
	100.0	100.0	100.0	100.0

upper : frequency

middle : percent of nurses evaluation for caregivers evaluation

lower : percent of caregivers evaluation for nurses evaluation

Kappa coefficient = 0.13 (p=0.018)

# Result 3-1: Patients' wish and Caregivers' wish at home

Table 2-1. The relations between satisfaction level and expressed wish to die and to give care at home

		Family caregivers' satisfaction level evaluation (Satisfactory / Unsatisfactory)	
		by themselves	by nurses
<u>Expressed wish to die and to give care at home</u>			
1	Patients' expressed wish to die at home by nurses' assessment	Expressed / Not expressed 0.08	0.08
2	Caregivers' expressed wish to give care at home in end-of-life by nurses' assessment	Expressed / Not expressed 0.16	* 0.16 *
		Phi coefficient	*: p<0.05, **: p<0.01

- Patients' wish **was not related** to the both by themselves and by nurses
- Caregivers' wish **was related** to the both by themselves and by nurses.

## Result 3-2: Patients' wish and Caregivers' wish at home (Table 2-1)

- Japanese elderly do not customarily express their own wish to others. Caregivers' wish might have been made based on sympathy with patients.
- There are significant moderate phi coefficient (0.32) between (1) "Patients' expressed wish to die" and (2) "Caregivers' expressed wish to give care".

# Result 4-1: Explanation to caregivers

Table 2-2. The relations between satisfaction level and explanation to family caregivers, one or more times in care process

		Family caregivers' satisfaction level evaluation (Satisfactory / Unsatisfactory)			
		by themselves	by nurses		
<u>Explanation to family caregivers, one or more times in care process</u>					
3	Explanation of end-of-life care goals	Explained / Not explained	0.05	0.19	**
4	Explanation of situations changing suddenly	Explained / Not explained	0.09	0.26	**
		Phi coefficient	*: p<0.05, **: p<0.01		

- Explanation in care process were related to the family caregivers' satisfaction levels **just by nurses.**

# Result 4-2:

## Explanation to caregivers

Table 2-3. The relations between satisfaction level and explanation to family caregivers, within 1-week before patients' death

		Family caregivers' satisfaction level evaluation (Satisfactory / Unsatisfactory)		
		by themselves	by nurses	
<u>Explanation to family caregivers, within 1-week before patients' death</u>				
5	Explanation how to give physical care	Explained / Not explained	-0.01	0.02
6	Explanation of the present and predicted condition of a patient	Explained / Not explained	0.14	0.10
7	Explanation of the signs of dying and emergency treatment	Explained / Not explained	0.23	0.28
8	Reconfirmation of care goals	Reconfirmed / Not reconfirmed	0.21	0.27
9	Explanation of predicted death time	Explained / Not explained	0.15	0.23
10	Explanation how to prepare for after death treatment	Explained / Not explained	0.13	0.33
		Phi coefficient	*: p<0.05, **: p<0.01	

- Explanation of **signs of dying, care goals, predicted death time** just before patients' death were related to caregivers' satisfaction level **both** by themselves and by nurses.

# Result 5:

## Care networks with medical resources and location of death

Table 2-4. The relations between satisfaction level and care networks with medical resources and location of death

		Family caregivers' satisfaction level evaluation (Satisfactory / Unsatisfactory)	
		by themselves	by nurses
<u>Care networks with medical resources</u>			
11	Doctors' attitude to home care	0.16 *	0.26 **
12	Availability of hospital beds if necessary	0.17 *	-0.03
<u>Location of death</u>			
		0.14 *	0.27 **
		Phi coefficient      *: p<0.05, **: p<0.01	

- Doctors' care was related to family caregivers' satisfaction level **both by themselves and by nurses.**
- Availability of hospital beds was related to that just **by themselves.**

# Suggestions 1:

What are important factors for the quality of end-of-life care?

- **The nurses evaluated** the family caregivers' satisfaction level from **the whole of the care process** whereas **the family caregivers** especially evaluated from the receiving of **care just before patients' death**.
  - It is important to **explain about care at the appropriate time**.  
Explanation of treatments and conditions just before patients' death is especially important for family caregivers' satisfaction level.



# Suggestions 2:

- **The cooperation with doctors and hospitals** is important for caregivers receiving end-of-life home care.
  - It is important for nurses to provide options to enter hospitals if necessary.
- **The family caregivers' attitude toward giving care at home** was related to their satisfaction level.
  - The family caregivers' attitude toward care is not stable. It is important to assess it and to provide care for their relief whenever necessary.