

# Comparison of the Information to the Family in the Terminal Situations of Cancer and Dementia in Japan and South Korea

Sung Hee Lee<sup>†</sup>, Taeko Nakashima, Ph.D<sup>††</sup>, Daisuke Watanabe Ph.D<sup>†††</sup>, Shinichi Ogami<sup>††††</sup>, Kanao Tsuji, M.D.<sup>†††††</sup>

<sup>†</sup> Korean Alzheimer's Association <sup>††</sup> Institute for Health Economics and Policy <sup>†††</sup> Seikei University <sup>††††</sup> ILC Japan <sup>†††††</sup> Life Care System.

## Purpose:

Family is very important for person especially in terminal phase. Professionals need to explain his/her family about the situation and some information in detail. Comparing with Japan and South Korea among three professionals, the purpose of this study was to investigate what information is attached importance by professionals.

## Methods:

Data were drawn from a sample of 1311 medical staffs (physicians and nurses), social workers/care managers (SW/CM), and caregivers from Japan and South Korea in October to December 2011. Investigation centered care facilities and clinics which had experienced terminal care service. To clarify the ideal terminal approach and realistic one, the questionnaire included a fictitious case of person with cancer who was given one month to live (Case A) and person with dementia who was diagnosed as pneumonia and was unable to swallow foods (Case B). Differences among professionals about information were analyzed with chi-square tests.

Information contents: 1. Remaining life expectancy; 2. Living will; 3. Alternative therapy; 4. Mrs. A/B's suffering and pain; 5. Available medical/long-term care systems; 6. The moment of death; 7. Future financial costs; 8. Future family care burden; 9. Grief after death.

The study was approved by the Institutional Review Board of the International Longevity Center, Japan.

## Results:

Japanese professionals had higher proportion that they explain all information except for 6 and 9 of Case A and except for 6 of Case B than South Korea. Information 5 had the most difference proportion between countries (Case A: Japan 77.4%, South Korea 37.0%; Case B: Japan 83.0%, South Korea 22.2%).

Among professionals in each country, chi-square tests show some information was significantly associated with professionals. In Japan, social workers/care managers tend to explain more about burden. In South Korea, in general low proportions of caregivers explain about information.

## Conclusion:

These results show the gaps between professionals about what information are explained to family. In terminal situation, professionals require collaboration of people with various occupations. In order to make good collaboration, we try to make consensus about what and which set of information are important to family in each country. And to improve terminal situation, we need to investigate family's needs in next stage.

Table1: overviews of countries of this study

	Japan	South Korea
Ageing rate (65+), 2010	23.1%	11.0%
LE. at birth*, 2009 male / female	M: 79.6 F: 86.4	76.8 83.8
Old age social spending**, 2007	8.8%	1.6%
Length of stay***: 2008/2009	18.5	—
QOD score, 2010	4.7	3.7

\* Life Expectancy at birth,

\*\* Old age social spending: public social expenditure as a percentage of GDP

\*\*\* Average length of stay: acute care, Days

Sources:

Eiu.com, 2010, *The Quality of Death: Ranking end-of-life care across the world.*

IMF, 2011, *World Economic Outlook Database.*

OECD, 2010, *Key Tables from OECD.*

OECD, 2011, *Health Statistics.*

## Fictitious Case of Mrs. A.

Mrs. A (85 yrs. old) is a terminal cancer patient and has 1 month to live. She is currently hospitalized and needs medicine to control pain on a daily basis. She sometimes becomes semi-conscious, but she can communicate verbally and has sufficient memory retention to lead daily life without problems. However, her physical capacity is declining, and she needs assistance in toileting. Her husband has already passed away, and her son and his wife live close by (15 min. drive). Yet, both the son and his wife work outside and do not have much time on weekdays. Mrs. A's primary income is her pension, and it is difficult for her to pay for renovating her house (e.g. bathroom). Mrs. A prefers to spend her final days at home, where she has memories with her husband, but she says "I shouldn't ask for too much."

Table 2: results of  $\chi^2$  tests (cancer)

Cancer Case (Mr. A)	Japan					South Korea				
	medical staff	SW/CM	caregivers	$\chi^2$	<i>p</i>	medical staff	SW/CM	caregivers	$\chi^2$	<i>p</i>
1. Remaining life expectancy	52.4	40.9	51.9	5.100	0.078 †	13.4	14.1	8.5	4.884	0.087 †
2. Living will	23.1	27.3	23.2	0.918	0.632	9.8	16.3	8.8	4.627	0.014 *
3. Alternative therapy	16.9	15.2	23.2	4.100	0.129	16.6	7.6	10.2	8.601	0.014 *
4. Mrs. A/B's suffering and pain	70.2	59.8	64.3	4.202	0.122	59.6	56.5	55.8	1.038	0.595
5. Available medical/long-term care systems	74.2	79.5	81.6	3.473	0.176	42.7	53.3	28.6	25.686	<0.001 ***
6. The moment of death	36.0	22.9	13.5	27.738	<0.001 ***	30.3	28.3	36.5	4.011	0.135
7. Future financial costs	33.3	62.1	43.2	28.046	<0.001 ***	25.4	22.8	16.5	8.290	0.016 *
8. Future family care burden	52.0	76.5	55.7	22.169	<0.001 ***	38.1	42.4	23.4	22.440	<0.001 ***
9. Grief after death	8.9	8.3	5.9	1.313	0.519	9.8	17.4	4.4	18.478	<0.001 ***

† *p* < .10, \* *p* < .05, \*\* *p* < .01, \*\*\* *p* < .001

Table 3: results of  $\chi^2$  tests (dementia)

Dementia Case (Mrs. B)	Japan					South Korea				
	medical staff	SW/CM	caregivers	$\chi^2$	<i>p</i>	medical staff	SW/CM	caregivers	$\chi^2$	<i>p</i>
1. Remaining life expectancy	34.5	19.7	31.0	8.963	0.011 *	14.4	19.8	10.3	6.535	0.038 *
2. Living will	14.3	18.2	16.3	0.993	0.627	9.2	15.4	7.8	5.014	0.082 †
3. Alternative therapy	16.1	18.2	24.5	4.630	0.099 †	18.3	8.8	11.4	8.848	0.012 *
4. Mrs. A/B's suffering and pain	39.9	39.4	39.1	0.027	0.987	27.5	20.9	25.8	1.580	0.454
5. Available medical/long-term care systems	81.6	90.2	81.5	5.371	0.068 †	31.4	27.5	13.1	33.808	<0.001 ***
6. The moment of death	20.2	17.4	9.2	9.444	0.009 **	46.1	49.5	36.9	7.927	0.019 *
7. Future financial costs	38.1	59.8	38.0	19.220	<0.001 ***	24.2	18.7	11.4	18.918	<0.001 ***
8. Future family care burden	78.5	91.7	79.9	10.864	0.004 **	52.9	48.4	33.3	27.115	<0.001 ***
9. Grief after death	6.7	9.8	8.2	1.112	0.573	6.9	15.4	5.0	12.046	0.002 **

† *p* < .10, \* *p* < .05, \*\* *p* < .01, \*\*\* *p* < .001

# Between Ideal and Realistic Practice of Terminal Situations of Cancer and Dementia in Japan and Korea: Focus on Decision-making leader

**Taeko Nakashima, Ph.D<sup>†</sup>, Daisuke Watanabe Ph.D<sup>††</sup>, Sung Hee Lee<sup>†††</sup>, Shinichi Ogami<sup>††††</sup>, Kanao Tsuji, M.D. <sup>†††††</sup>**

<sup>†</sup> Institute for Health Economics and Policy <sup>††</sup> Seikei University <sup>†††</sup> Korean Alzheimer's Association <sup>††††</sup> ILC Japan <sup>†††††</sup> Life Care System.

## Purpose:

In the terminal situation, it is important that whose opinions are suitable to have priority in a discussion to set a direction of medical treatment and terminal care especially for people with dementia. Comparing between Japan and South Korea among three professionals who deal with terminal phase of cancer and dementia, the purpose of this study is to investigate factors of an ideal and realistic choice about a leader who makes a decision of care policy and to understand gap between two choices in both countries.

## Methods:

Data were drawn from a sample of 1311 medical staffs (physicians and nurses), social workers/care managers (SW/CM), and caregivers from Japan and South Korea in October to December 2011. To clarify the ideal terminal approach and realistic one, the questionnaire included a fictitious case of person with cancer who was given one month to live (CaseA) and person with dementia who was diagnosed as pneumonia and was unable to swallow foods (CaseB).

Multinomial logistic regression was used to determine the ideal and realistic choices of leader (Mrs.A/Mr.B, family, professional) as outcome variables. Explanatory variables are years of home-based long-term care experiences (home care experiences), occupations, and experiences of patient's death at work of CaseA. Analyzed CaseB, we added current workplace as explanatory variable.

The study was approved by the Institutional Review Board of the International Longevity Center, Japan.

## Results:

In Japan and South Korea, all professionals selected *Mrs. A* as ideal decision maker and *Mrs. A's son* as realistic one(CaseA), and selected *Mr. B's wife* as both ideal and realistic ones (CaseB).

As the results of multinomial logistic regression to medical staffs, ideal choice (Japan, both cases) was significant associated with home care experiences (CaseA: OR 1.07, CaseB: OR 1.21).

On the other hand, ideal choice of South Korea (CaseA) was significant associated with professionals (medical staffs: OR 0.45, SW/CM: OR 0.38). And, CaseB was significant associated with experiences of patient's death at work (OR 0.47).

A proportion of gap between ideal and realistic was 29.1% in Japan, was 30.1% in South Korea in CaseA, was 14.8% in Japan, and was 12.8% in South Korea in CaseB. The proportions of gap were not significantly different between Japan and South Korea.

## Conclusion:

The results show that decision-making leaders are different between Japan and South Korea. These are reflected on differences of family bargaining power structure and education for medical and care professionals between the countries.

## Fictitious Case of Mr. B.

*Mr. B Mr. B (80 yrs. old) lives with his wife at home. It has been 10 years since he was diagnosed with dementia (Alzheimer's disease). Although his consciousness is not impaired, he only responds to families and direct care workers with eye movements. In general, it is extremely difficult for him to communicate with others. About a half month ago, he had high fever and cough, so he went to hospital and was diagnosed with pneumonia. Currently, he is unable to swallow foods, and he takes medicine and nutrition through IV (intravenous drip). Because he cannot receive nutrition by mouth, he may need artificial nutrition (e.g. tube feeding) shortly. His wife (80 yrs. old) hopes to have him stay and spend last days at home. She also hopes to spend as long a time with him as possible. Their financial condition is stable because they own a house and receive employee's pension. Yet, her caregiving capacity is low, and there is no relative nearby. Therefore, she is very worried about her additional caregiving burden.*

Table1, 2: ratio of ideal and real decision-making leader

Cancer Case					Dementia Case				
		medical staff	SW / CM	caregivers			medical staff	SW / CM	caregivers
ideal	Japan	64.0%	75.8%	70.8%	ideal	Japan	80.1%	76.2%	71.3%
(Mrs. A)	Koria	66.4%	66.4%	47.9%	(Mr. B's wife)	Koria	54.7%	60.9%	41.9%
realistic	Japan	73.0%	65.9%	76.2%	realistic	Japan	59.7%	66.2%	62.9%
(Mrs. A's son)	Koria	57.2%	58.7%	45.4%	(Mr. B's wife)	Koria	68.7%	76.1%	52.1%

Table3, 4: results of multinomial logistic regression (ref. Mrs.A/Mr.B)

Japan		idela choice (CaseA)		idela choice (CaseB)	
		medical staffs	family	medical staffs	family
variable (reference)	value	OR	OR	OR	OR
home-based long-term care experiences		1.068 *	.993	1.211 **	1.147 *
professionals (caregivers)	medical staffs	1.386	2.037 *	2.040	3.351 *
	SW / CM	.535	.920	.750	1.219
experiences of patient's death at work (no)	yes	.704	.446 **	.439	.656
	not in the last 12 month	.976	.645	.933	.654
current workplace (home care agency)	hospital, clinic			1.135	.837
	long-term care facility			2.592	2.845 *
Model fit					
Negelkerkes's R square		.049		.066	
N		505		470	

Korea		idela choice (CaseA)		idela choice (CaseB)	
		medical staffs	family	medical staffs	family
variable(reference)	value	OR	OR	OR	OR
home-based long-term care experiences		.987	.938 *	.972	.982
professionals (caregivers)	medical staffs	.451 ***	.583 *	1.456	2.800 **
	SW / CM	.379 **	.447 *	.936	2.162 *
experiences of patient's death at work (no)	yes	.699	.885	.467 **	.562 *
	not in the last 12 month	.485	.903	.631	.849
current workplace (home care agency)	hospital, clinic			.922	.432
	long-term care facility			2.776	1.078
Model fit					
Negelkerkes's R square		.063		.079	
N		749		744	

\* p<.05, \*\* p<.01, \*\*\* p<.001