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The Current Status of Family Caregiving for Older Adults and Strategies to Help Families through Community Care from Gender Perspective

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Ⅰ. Purpose and Necessity

□ Previous research and policy development work on elderly care has a tendency to divide policy targets separately into care receivers and caregivers (e.g. caregiving workers, family caregivers). There have been many researches on family elderly care focusing on a relationship between a caregiver and a care receiver as well as their life quality and mental health; however, they have a limitation in identifying the dynamic of a complicated caregiving relationship.

□ The purpose of this study is to examine the status of family elderly care from the perspectives of a dynamic (caregiving relationship) between a care receiver and a care giver(s), sharing and assuming

of caregiving responsibilities, and a caregiving environment (caregiving combination). In that sense, elderly care, in this study, is not confined to medical care, but also extends help with daily activities, and a family is assumed to be a unit where elderly care is primarily provided.

□ This study is also intended to make policy suggestions on community elderly care from the gender perspective, as policy discussions on community care and aging in place are robustly underway.

□ In other words, based on the results of analyzing the status of family elderly care, this study seeks for specific ways to support the proper setup of a caregiving relationship and a caregiving combination for sustainable and efficient elderly care in the family and to achieve the continuum of elderly care in the community, from the perspectives of family and gender.

Ⅱ. Contents and Method

1. Contents

□ Analyze relationships in the family involving elderly care based on caregiving right and responsibility

□ Examine the status of caregiving combinations in the family

□ Identify needs of policy-making on community care from the family's perspective

□ Present ways to improve the structure of conflicts involving family elderly care as well as policy suggestions on community elderly care from the gender perspective

2. Methods

□ Literature study: review theoretical discussions and prior researches on the status and gender structure of family elderly care and on family & formal elderly care; overseas policies for support of family caregivers; and data for community care projects.

□ Survey: Target about 620 family members who are ‘primary caregivers’ of aging parents in need of care.

□ Focused group interview (FGI): Target 25 primary caregivers caring for a parent(s) (categorized into five groups of relationship with a care receiver: wives and husbands caring for their spouse, daughters and sons looking after their parent(s), mothers-in-law taking care of a parent(s)-in-law)

□ Expert Advisory Panel: collect inputs from managers for the priority project on community care and experts from academia.

Ⅲ. Results: Focusing on inequality of family elderly care

1. Care continuum and aging in place for the elderly care policy on condition of family care: family care and vertical continuum of care

□ The development direction of the elderly care policy should be redefined such that it reflects families' perspectives comprehensively. From the family's perspective, the continuum of care can be achieved in the following ways: ① identify care needs depending on older persons' condition including health, ② gather information on available formal care services ③ strive to get eligibility to receive formal care services ④ choose a suitable type of formal care service and institution ⑤ get a family member take charge of coordinating and managing the schedule and tasks of caregiving. Such concept can be described as the "vertical continuum of care."

□ In addition, "aging in place" is a hard-to-achieve challenge with no condition that older persons are provided with help and care by their family on a continuous and regular basis, regardless of whether they live together.

2. Care provided based on eligibility criteria for formal services, not on actual needs: formal services and horizontal continuum of care

□ It is revealed by the results of FGI of this study that the level of reliability is low in the rigor and objectivity of the eligibility selection process of long-term care insurance (LTCI). It is also found that family caregivers are very unsatisfied with the current way of allocating care services where no support is provided to non-LTCI recipients in spite of their needs for care. It is highly probable that the horizontal continuum of care has been broken because care services are provided in a segmented way, without being delicately connected to meet the care needs of older persons.

□ In particular, older persons who are not eligible for LTCI, super aged, or in rehabilitation at home have no choice but to rely on family support such as cooking and housework, and are highly likely to have no other channel for social support due to old age and limited mobility. That is to say, the burden of caring for older persons, without eligibility for LTCI, are transfered entirely to their family.

□ It is identified by the FGI of this study that there is a high demand of home-to-hospital-to-home escort and in-home rehabilitation services for older persons who are not eligible for LTCI.

□ That is to say, it can be possible to improve the horizontal continuum of care significantly if a narrow concept of care that non-LTCI recipients can take at home on an as-needed basis is formally provided, rather than a broad concept of care across daily life.

3. Inequality of family care and gender implications

3.1 Results of analysis of survey

〈Table 1〉 Characteristics of respondents – Primary caregivers

(Unit: persons, %)

Caregivers		No. of respondents	%
Total		(612)	100.0
Sex	Male	(358)	58.5
	Female	(254)	41.5
Marital status	With a spouse (incl. common law marriage)	(412)	67.3
	Without a spouse(e.g. unmarried, divorced, bereaved)	(200)	32.7

Caregivers		No. of respondents	%
Health conditions	Very bad	(5)	0.8
	Bad	(68)	11.1
	Fair	(276)	45.1
	Good	(224)	36.6
	Very good	(39)	6.4
Employment status	Employed	(501)	81.9
	Unemployed	(111)	18.1
Weekly caregiving time	Less than 10 hours	(82)	13.4
	10 to 20 hours	(41)	6.7
	20 to 30 hours	(80)	13.1
	30 to 40 hours	(110)	18.0
	More than 40 hours	(299)	48.9
Final academic decree	Middle school or lower	(4)	0.7
	High School	(79)	12.9
	Enrolled in and graduated from college	(67)	10.9
	Enrolled in and graduated from university	(383)	62.6
	Enrolled in and graduated from graduate school	(79)	12.9

〈Table 2〉 Characteristics of the elderly cared for by respondents

(Unit: Persons, %)

The elderly		No. of respondents	%
Total		(612)	100.0
Age	60s	(123)	20.1
	70s	(258)	42.2
	80s	(189)	30.9
	90s or older	(42)	6.9

The elderly		No. of respondents	%
Sex	Male	(242)	39.5
	Female	(370)	60.5
Type of Cohabitation	Live alone	(189)	30.9
	Live with a spouse	(119)	19.4
	Live with a child(ren)	(158)	25.8
	Live with a spouse and a child(dren)	(116)	19.0
	Live with other family member(s) or relative(s) (w/o a spouse or a child(ren))	(19)	3.1
	Others	(11)	1.8
Level of LTCI	Level 1 & 2	(29)	4.7
	Level 3 to 5	(143)	23.4
	Extra Level (A, B, C)	(97)	15.8
	Applied but not qualified for LTCI	(106)	17.3
	Didn't apply for LTCI but need help for daily activities	(237)	38.7
Diagnosis with dementia	Yes	(85)	13.9
	No	(527)	86.1
Living Place	Large city (special & metropolitan cities)	(394)	64.4
	Small & middle city	(157)	25.7
	Town & Township (Eup & Myeon)	(61)	10.0

□ As a result of examining the status of family elderly care, it is found that inequality and asymmetry exist in caregiving multi-dimensionally depending on the gender of a caregiver and a care receiver and their gender combination.

3.1.1. Caregiving inequality experienced by caregivers

□ There exist disparity and inequality among family members' sense of caregiving responsibility, and between the expectation (caregiving right) and the reality of caregiving. Due to disparity among care that caregivers think they have to provide, want to provide, are expected or forced to provide by a older person or other family members and actually provide, family caregivers have experienced negative feeling such as being pressured, overwhelmed, and stressed.

〈Table 3〉 Awareness of family caregiving responsibility
- Percentage of 'strongly agree'

(Unit: %)

Respondents		(1) The primary responsibility of care lies in the family.	(2) Family caregivers should change or give up daily life or work.	(3) Formal care should be provided first and complemented with family care.	(4) It is possible to care for the elderly in the facility without their consent if family care is not available.
Caregiver	Male	33.2	14.8	31.0	28.2
	Female	22.4	16.1	35.0	27.6
The elderly	Male	26.4	19.0	32.6	26.4
	Female	30.3	13.0	32.7	28.9
Level of LTCI	Level 1-5	34.9	16.3	41.9	32.0
	Extra	24.6	13.3	28.6	24.6
	Not Applied	27.8	16.5	29.5	27.8
Total		28.8	15.4	32.7	27.9

〈Table 4〉 Thought on family's right for caregiving – Percentage of respondents who 'strongly agree'

(Unit: %)

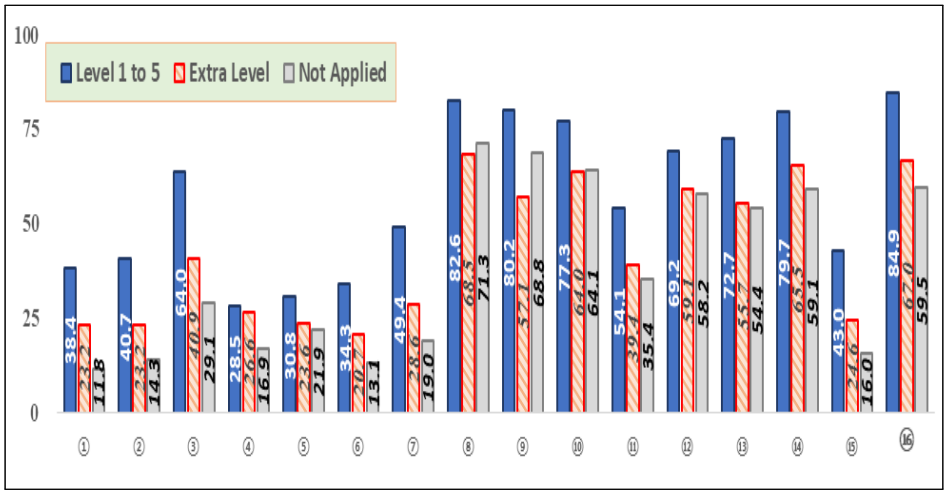
Respondents		(1) An environment should be created where family members care for the elderly at home, if they want.	(2) It should be possible to change work or working hours freely to take care of the elderly.	(3) Formal care should be provided sufficiently to complement family care (e.g. allowing the dual use of home visit care service and daycare center service).	(4) It should be possible to choose the way and form of caregiving fit for the elderly's health condition and ability to perform daily activities, irrespective of family situation.
Caregiver	Male	31.8	36.9	49.2	38.5
	Female	37.8	42.1	58.7	41.3
The elderly	Male	33.9	43.8	51.2	42.1
	Female	34.6	35.9	54.3	38.1
Level of LTCI	Level 1-5	34.9	40.1	58.1	41.9
	Extra level	29.6	35.5	44.8	35.0
	Not applied	38.0	41.4	56.5	42.2
Total		34.3	39.1	53.1	39.7

□ Additionally, caregivers experienced disadvantage at different levels such as loss of employment, income, time and health. The survey results of this study also identified that caregivers experienced diverse difficulties involving caregiving, ambivalent feeling towards a care receiver, conflict with a care receiver and/or a family member(s), emotional labor to embrace the negative feeling of a care receiver, resentment and despair over a family member(s)'s passive attitude and non-involvement in caregiving, being bound to caregiving even during non-caregiving time, and excessive self-centeredness of a care receiver.

3.1.2. Caregiving inequality depending on the gender of a caregiver and a care receiver

□ The inequality of family elderly care takes several forms depending on the gender of a caregiver and a care receiver. There is a tendency that male caregivers have a higher sense of caregiving responsibility than female caregivers do, but provide less care than female caregivers do.

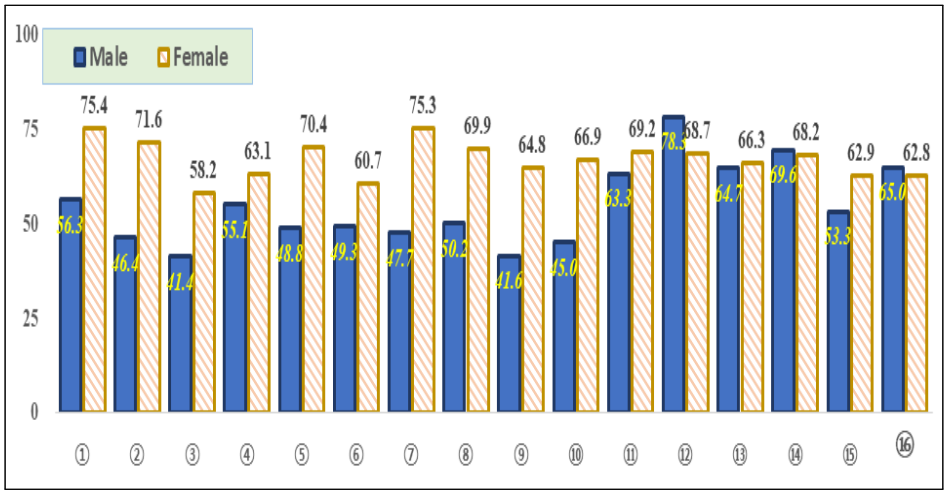
(Unit: %)



Note: ① Dressing ② Washing face, teeth and hair ③ bathing ④ Eating ⑤ Transfering ⑥ Toileting ⑦ Grooming ⑧ Housekeeping ⑨ Preparing meals ⑩ Laundry ⑪ Taking medicine ⑫ Managing finance ⑬ Going out short distance ⑭ Shopping ⑮ Using telephone ⑯ Using transportation

[Figure 1] Daily activities that the elderly need help to perform: by LTCI level

(Unit: %)



Note: ① Dressing ② Washing face, teeth and hair ③ bathing ④ Eating ⑤ Transfering ⑥ Toileting ⑦ Grooming ⑧ Housekeeping ⑨ Preparing meals ⑩ Laundry ⑪ Taking medicine ⑫ Managing finance ⑬ Going out short distance ⑭ Shopping ⑮ Using telephone ⑯ Using transportation

[Figure 2] Percentage of daily activities of the elderly of which primary caregivers take care: by carer's gender

□ Compared to male caregivers, female caregivers take on more caregiving tasks, show a higher level of agreement on caregiving responsibility of the nation, and a higher percentage of becoming a caregiver tacitly. It is also found that female caregivers experience more conflict with a caregiver and other family member(s).

〈Table 5〉 Awareness of national and family care – Percentage of respondents who agree on full + significant responsibility of the nation

(Unit: %)

Respondent		(1) Identify care services.	(2) Link up with care services.	(3) Provide care services directly.	(4) Manage the quality of care services.	(5) Pay the cost of care services.
Caregiver	Male	28.8	37.7	37.2	43.6	36.9
	Female	31.5	39.4	35.0	40.9	35.4
The elderly	Male	31.8	39.3	33.9	38.8	35.1
	Female	28.6	37.8	37.8	44.9	37.0
Level of LTCI	Level 1 – 5	36.6	41.9	43.6	50.6	42.4
	Extra level	26.6	34.5	32.0	38.4	29.6
	Not applied	27.8	39.2	34.6	40.1	37.6
Total		29.9	38.4	36.3	42.5	36.3

〈Table 6〉 How to determine a primary caregiver in the family

(Unit: %)

Respondents		Discussed together including the elderly.	Discussed together excluding the elderly.	I volunteered to become a primary caregiver without discussion.	I tacitly became a primary caregiver without discussion.	Determined by one family member (e.g. oldest son or spouse).	Determined at the request of the elderly.
Caregiver	Male	41.9	16.2	17.3	12.6	10.3	1.7
	Female	39.0	19.3	13.8	19.3	5.5	3.1
The elderly	Male	41.7	22.3	14.9	11.6	7.0	2.5
	Female	40.0	14.3	16.5	17.8	9.2	2.2
Level of LTCI	Level 1–5	41.3	18.0	15.1	15.1	8.1	2.3
	Extra level	39.4	21.7	13.3	11.8	11.8	2.0
	Not applied	41.4	13.5	18.6	18.6	5.5	2.5
Total		40.7	17.5	15.8	15.4	8.3	2.3

〈Table 7〉 Conflict between the elderly and a primary caregiver

(Unit: %)

Respondent		Not at all	Slightly	Moderately	Very	Total
Caregiver	Male	8.1	45.8	42.7	3.4	100.0
	Female	6.3	41.7	44.9	7.1	100.0
The elderly	Male	7.9	38.8	48.3	5.0	100.0
	Female	7.0	47.6	40.5	4.9	100.0
Level of LTCI	Level 1-5	5.2	42.4	47.1	5.2	100.0
	Extra level	4.9	48.3	40.9	5.9	100.0
	Not applied	11.0	41.8	43.5	3.8	100.0
Total		7.4	44.1	43.6	4.9	100.0

〈Table 8〉 Conflict among family members involving elderly care

(Unit: %)

Respondent		Not at all	Slightly	Moderately	Very	Total
Caregiver	Male	12.0	47.8	36.3	3.9	100.0
	Female	11.4	39.0	43.7	5.9	100.0
The elderly	Male	11.6	40.1	43.4	5.0	100.0
	Female	11.9	46.8	36.8	4.6	100.0
Level of LTCI	Level 1-5	11.6	37.2	43.6	7.6	100.0
	Extra level	8.4	48.8	36.5	6.4	100.0
	Not applied	14.8	45.1	38.8	1.3	100.0
Total		11.8	44.1	39.4	4.7	100.0

□ Male caregivers show a higher level of preference for family care than female caregivers do while female caregivers are more concerned about caregiving burden to the family than male caregivers are.

〈Table 9〉 The elderly's expectation on care

(Unit: %)

Respondent		Prefer family care rather than formal care.	Prefer family care but feel concerned about becoming a burden.	Reluctant to become a burden, and willing to receive formal care.	Do not expect family care at all.	Total
Caregiver	Male	24.0	59.5	15.4	1.1	100.0
	Female	24.4	62.2	12.6	0.8	100.0
The elderly	Male	28.5	54.1	16.9	0.4	100.0
	Female	21.4	64.9	12.4	1.4	100.0
Level of LTCI	Level 1-5	28.5	52.9	17.4	1.2	100.0
	Extra level	18.7	63.5	16.3	1.5	100.0
	Not applied	25.7	63.7	10.1	0.4	100.0
Total		24.2	60.6	14.2	1.0	100.0

3.1.3. Caregiving inequality depending on four gender combinations of a caregiver and a care receiver

① Combination of a female caregiver and a male care receiver

□ A close look was given to four gender combinations of a caregiver and a care receiver. As a result, it is found that the combination of a female caregiver and a male care receiver experience conflict with each other and other family member(s) more than any other combination. In that gender combination, the percentage of respondents who selected the statement “Expert assistance is needed” to resolve conflict is also higher compared to other gender combinations.

〈Table 10〉 Conflict with the elderly: Percentage of respondents who agree

(Unit: %)

Gender Combination (Giver-Receiver)	Yes	Top 2 types of conflict	Efforts to resolve conflict	
			Together	Follow the request of the elderly
Male-Male	49.3	-Desire for care for a longer time 38.6% -Desire for more various caregiving tasks 22.8%	**55.9**	30.9
Male-Female	**43.8**		57.5	**31.6**
Female-Male	**59.8**	-Desire for care for a longer time 29.4% -Desire for more various caregiving tasks 27.3%	**62.1**	28.7
Female-Female	47.5		61.6	**25.2**
Total	48.5		58.9	29.3

〈Table 11〉 Conflict with other family member(s): Percentage of respondents who agree

(Unit: %)

Gender Combination (Giver-Receiver)	Yes	Top 2 types of conflict	Efforts to resolve conflict	
			Together	Follow the request of other family members
Male-Male	43.2	-Desire for care for a longer time 19.5% -Desire to pay more care cost 19.5%	55.6	**24.8**
Male-Female	**38.1**	-Desire for more various caregiving tasks 20.3% -Difficult to coordinate caregiving time among family members 19.8%	59.3	23.1
Female-Male	**56.4**	-Desire for more various caregiving tasks 17.3% -Difficult to coordinate caregiving time among family members 17.3%	**50.6**	24.7
Female-Female	45.7	-Difficult to coordinate caregiving time among family members 20.1% -Desire to care for a longer time 15.3%	**63.2**	**18.1**
Total	44.1		58.1	22.4

〈Table 12〉 Assistance to resolve conflict: Percentage of respondents who agree

(Unit: %)

Gender Combination (Giver-Receiver)	Caregiving family members need dialogue to resolve conflict	Expert assistance (e.g. consulting, training) is needed to redefine a caregiving relationship	Outside assistance is not needed for family affair	I desire to take consulting or attend a self-help meeting	Total
Male-Male	56.1	22.3	**11.5**	10.1	100.0
Male-Female	**58.1**	**21.4**	9.5	11.0	100.0
Female-Male	**40.4**	**28.7**	**9.1**	**11.7**	100.0
Female-Female	56.9	23.1	11.3	**8.8**	100.0
Total	54.6	23.2	11.9	10.3	100.0

□ It is shown that female caregivers caring for male care receivers experience unnecessary misunderstanding with care receivers, lower priority set on her life and work, social isolation, frustration, and pressure for better caregiving, more than any other gender combination; however, the percentage of respondents who said "Family care is provided as much as possible" is the highest among the four gender combinations.

〈Table 13〉 Difficulties of caregiving: Percentage of respondents who 'strongly agree'

(Unit: %)

Gender Combination (Giver-Receiver)	(1) Misunderstanding with the elderly piles up because communication and mutual understanding are not good.	(2) Priority on myself and my daily life is set lower due to caregiving burden.	(3) I feel burdened to provide better care to the elderly.	(4) I feel guilty of poor caregiving to the elderly.	(5) I feel isolated socially because I am mostly with the elderly.	(6) I feel overwhelmed because caregiving is endless and understood by no one.
Male-Male	13.5	30.4	30.4	22.3	16.2	**18.9**
Male-Female	**11.0**	**20.5**	**28.6**	**24.8**	**9.5**	19.0
Female-Male	**25.5**	**36.2**	**30.9**	20.2	**20.2**	**33.0**

Gender Combination (Giver-Receiver)	(1) Misunderstanding with the elderly piles up because communication and mutual understanding are not good.	(2) Priority on myself and my daily life is set lower due to caregiving burden.	(3) I feel burdened to provide better care to the elderly.	(4) I feel guilty of poor caregiving to the elderly.	(5) I feel isolated socially because I am mostly with the elderly.	(6) I feel overwhelmed because caregiving is endless and understood by no one.
Female-Female	15.6	31.9	28.8	**15.0**	17.5	30.0
Total	15.0	28.3	29.4	20.9	14.9	24.0

〈Table 14〉 Expectation and reality of caregiving: Percentage of respondents who agree

(Unit: %)

Gender Combination (Giver-Receiver)	The elderly' expectation		Reality	
	Prefer family care	Prefer family care but feel concerned about becoming a burden.	Care is provided by family as much as possible.	Family members mainly take care of the elderly and partially use formal care services
Male-Male	**29.7**	**52.0**	50.7	35.8
Male-Female	**20.0**	64.8	51.9	**30.5**
Female-Male	26.6	57.4	**55.3**	31.9
Female-Female	23.1	**65.0**	**50.6**	**38.1**
Total	24.2	60.6	51.8	34.0

② Combination of a male caregiver and a female care receiver

□ It is found that the male caregiver and female care receiver combination shows a tendency to set the lowest priority on care receivers and their care, with the highest percentage of respondents who agreed strongly on the statement “It is possible to care for the elderly in the facility without their consent” and the lowest percentage of respondents who agreed strongly on the statement “It should be possible to adjust work or working hours freely to care for the elderly,” among the four gender combinations.

〈Table 15〉 Awareness of family's caregiving responsibility and caregiving right
– Percentage of respondents who 'strongly agree'

(Unit: %)

Gender Combination (Giver-Receiver)	Caregiving responsibility				Caregiving right			
	(1) The primary responsibility of care lies in the family.	(2) Family caregivers should change or give up their daily life or work.	(3) Formal care should be provided first and complemented with family care.	(4) It is possible to care for the elderly in the facility without their consent if family care is not available.	(1) An environment should be created where family members care for the elderly at home, if they want.	(2) It should be possible to adjust work or working hours freely to care for the elderly.	(3) Formal care should be sufficiently provided to supplement family care.	(4) The best way/form of care should be selected depending on the health condition and the ability for daily activity of the elderly, regardless of family situation
Male-Male	32.4	18.9	**30.4**	27.0	32.4	39.2	**46.6**	**42.6**
Male-Female	**33.8**	**11.9**	31.4	**29.0**	**31.4**	**35.2**	51.0	**35.7**
Female-male	**17.0**	**19.1**	**36.2**	**25.5**	36.2	**51.1**	58.5	41.5
Female-Female	25.6	14.4	34.4	28.8	**38.8**	36.9	**58.8**	41.3
Total	28.8	15.4	32.7	27.9	34.3	39.1	53.1	39.7

□ In this gender combination, the percentage of respondents who selected the statement "I have conflict with the elderly" and "I have conflict with other family member(s)," is lower compared to the other gender combinations. Considering that this group also has the highest percentage of respondents who agreed strongly on the statement "It is possible to care for the elderly in the facility without their consent," it can be surmised that a dynamic between a male caregiver and a female care receiver in the family is very different compared to the other gender combinations.

③ Combination of a female caregiver and a female care receiver

□ The percentage of respondents who agreed strongly on the statement "An environment should be created where family members care for the elderly at home, if they want" is the highest in the combination of female caregiver and male care receiver and so is the percentage of respondents who selected "I tacitly became a primary caregiver," among the four gender combinations.

〈Table 16〉 Decision-making on caregiving

(Unit: %)

Gender Combination (Giver-Receiver)	Decision on primary caregiver		Decision on sharing of caregiving in the family	
	Decision was made together excluding the elderly.	I tacitly became a primary caregiver.	Decision is made together excluding the elderly.	Decision was made without discussion.
Male-Male	21.6	**10.1**	23.6	**16.9**
Male-Female	**12.4**	14.3	23.8	24.3
Female-Male	**23.4**	13.8	**27.7**	25.5
Female-Female	16.9	**22.5**	**20.6**	**30.6**
Total	17.5	15.4	23.5	24.3

□ In addition, the percentage of respondents who chose the statement "Decision was made together excluding the elderly" and "Decision was made without discussion" in this gender combination are higher than that in the other combinations, which implies a tendency that family discussion on caregiving is not sufficient in this gender combination.

④ Combination of a male caregiver and a male care receiver

□ Among the four gender combinations, the male caregiver and male

care receiver combination shows the lowest percentage of “Strongly Agree” on the statement “Formal care should be provided first and complemented by family care” and “Formal care should be sufficiently provided to complement family care.” The percentage of respondents who believed that the responsibility of elderly care “fully” and “significantly” lies in the nation is lowest in this combination, suggesting a relatively higher level of sense of family caregiving responsibility.

□ The percentage of respondents who indicated “I tacitly became a primary caregiver” and “Decision was made without discussion” is lower compared to the other gender combinations. However, this gender combination has the least number of respondents who chose the statement “Efforts are made together to resolve conflict with the elderly,” but the largest number of respondents who selected the statement “I usually accept the request of other family member(s) to resolve conflict,” among the four gender combinations.

□ Based on that, it is infered that male caregivers who look after male care receivers have more discussion on caregiving than any other gender combination, however they are not good at resolving conflict.

3.1.4. Caregiving inequality between primary and secondary caregivers

□ Last, but not least, it is found that a care receiver depends excessively on a primary family caregiver due to caregiving inequality identified in the FGI.

□ In particular, it is revealed that male care receivers, despite their eligibility, do not use home visit care or daycare center services, but

primarily rely on a family care worker because of their reluctance to be looked after by a third person outside the family.

□ With regard to that, female caregivers expressed difficulty, but accepted the request of male care receivers. It is also exposed that male care receivers do not want anyone other than a primary caregiver to know their condition that they need help and care to perform daily activities.

□ It may be theoretically possible to share caregiving responsibilities in the family; however, it is highly likely that a primary caregiver ends up taking most of the responsibilities despite family agreement on sharing of caregiving responsibilities. Furthermore, the fact that the role of a primary caregiver is assumed mainly by a female in the family has led to gender inequality.

3.2 Results of analysis of FGI

〈Table 17〉 Characteristics of FGI participants

Group	Name	Age	Cohabitation	Level of LTCI	Benefits used	Relation with care receiver
Wife caring for husband	A	75	Yes	3 (Dementia)	Daycare, Family care expense	Husband
	B	70	Yes	1	×	
	C	77	Yes	×	×	
	D	75	Yes	2, Disability Level	Family care expense	
	E	69	Yes	○	×	
Husband caring for wife	F	73	Yes	×	×	Wife
	G	77	Yes	×	×	
	H	73	Yes	×	×	
	I	78	Yes	×	×	
Daughter caring for a parent(s)	J	55	Yes	Prior to eligibility selection	× (Currently in hospitalization)	Mother

Group	Name	Age	Cohabitation	Level of LTCI	Benefits used	Relation with care receiver
	K	65	Yes	Level 4	○	Mother
	L	55	No	Disqualified	×	Mother
	M	58	Yes	Level 3	○	Mother
	N	53	No	Level 3	×	Father
	O	41	Yes		×	Father
	P	61	No	Level 3	○	Mother
	Q	63	Yes	Level 3	Family care expense	Mother
Parent caring for a child(ren)	R	45	Yes	Level 4	In-home care service	Father
	S	42	Yes	Level 3	Day/Night Care Center Home visit care	Mother
	T	48	Yes	Level 2	Home visit care	Father
	U	62	No	Never applied	Home visit care	Mother
	V	62	No (Live nearby)	Disqualified	○	Mother
Daughter-in-law caring for a parent(s)-in-law	W	73	Yes	Disqualified	×	Mother-in-law
	X	53	No	×	×	Parents-in-law
	Y	50	No	Dementia	In-home care service	Mother-in-law
	Z	55	No	Never applied	×	Parents-in-law
	AA	49	Live separately (upper and lower floors)	Disqualified	×	Parents-in-law

Gender inequality manifests itself in different forms depending on characteristics of caregivers and combinations of caregivers: inequality of caregiving tasks between husband and wife caregivers, as is the case of an adult son and his wife; inequality of sharing of caregiving responsibility between sibling caregivers, as seen in the case of a daughter caregiver or an unmarried son caregiver; disparity of caregiving tasks and type of caregiving resulting from gender hierarchy in case of spousal caregiving. Such inequality and disparity of caregiving have directly led to insufficient care.

3.2.1. Inequality of caregiving task and time between husband and wife caregivers

Generally, adult sons and their wife who care for a parents(s) assume different caregiving tasks. Adult sons provide mobility support for regular visit to hospital and wives undertake meal preparation, grocery shopping and cleaning. Household chores are daily and essential tasks of family caregiving and take up most of the caregiving time every day. Even if a married son assumes the role of a primary caregiver, the older person is looked after by his/her spouse who lives together or by the son's wife while the son works in the workplace. Even if a married son and his wife can afford time to take care of a parent(s), there is a difference in the type of caregiving tasks that they provide. For example, meals that married sons deliver to his parent(s) are prepared by their wife. As such, daily, essential, and most time-consuming caregiving tasks fall to a female in the family.

A daughter-in-law is an indispensable partner of a married son to assume his caregiving responsibility and a de facto caregiver. In case that the couple live together with an aging parent(s), the daughter-in-law takes the place of her husband who works for a living and becomes a primary caregiver, spending time with a parent(s)-in-law (a daughter-in-law caring for parents-in-law, W). When a care receiver and a caregiver live together, the time and space distance between them gets shorter, which makes it difficult for a caregiver to have enough breaks, often resulting in emotional exhaustion.

3.2.2. Inequality of sharing of caregiving responsibility between siblings depending on their gender

There is still a perception that a primary responsibility of caring for a parent(s) rests on the oldest son's shoulders, even though such perception has gotten weaker. However, if he has a weak sense of such responsibility and is very sensitive to a situation that he faces, the caregiving responsibility frequently falls to a daughter. According to multiple households interviewed, the responsibility of taking care of elderly parents are transfered from a son to a daughter due to situational reasons including conflict with a daughter-in-law. It's because parents, in general, feel more comfortable with a daughter than a son and his wife, as seen in the interview of a spouse caregiver who asked adult children for help (“daughter is easy, but son, especially daughter-in-law is difficult (a husband caring for his wife, F)”). However, daughter caregivers have undergone dramatic changes in their life such as changing a job with more flexible working hours, quitting a job, and living separately from their husband. The fact that daughters take over caregiving responsibility from other siblings despite such distressing changes implies that females are expected or forced to assume a role to resolve a conflict in the family.

> My parents lived together with the youngest brother’s family. Due to COVID-19, they couldn’t go out and my brother’s wife felt stressed and ended up with severe depression. After all, I couldn’t help but come here to live together with parents even though my own family lives in another city. (Daughter caring for parents, M)

> Mom lives together with the youngest brother’s family. My brother decided to do so just because they lived in the same neighborhood. However, he started to grumble “I am not the oldest. Why should I care for Mom?” and hate the

older brother's wife. He is concerned about caregiving burden to his wife. (Daughter caring for a parent, K)

When the caregiving responsibility finally falls to daughters, they have little choice but to fulfill the responsibility because otherwise parents should go to a care facility which should only be considered a last resort. Even though caregiving gets harder over time, however, they cannot rely on other siblings.

3.2.3. Inequality and hierarchy between caregivers and care receivers in the spousal caregiving arrangement

It is found that wives who are primarily cared for by husbands still do housework which take up significant part of caregiving tasks, even though they are care receivers with uncomfortable movement. One husband caregiver interviewed told "I have done cooking, laundry and cleaning (G) since my wife's legs became uncomfortable to move." However, another husband caregiver interviewed believed that he took part in housework by carrying heavy bags of groceries for his wife with uncomfortable movement on her way back home from grocery shopping. It seems that husbands in their seventies or older think that they 'provide care' by gradually undertaking housework after their wife gets too weak to do housework. It implies that the female elderly is likely to remain as a housework provider, not a care receiver in need of proper help.

On the contrary, it is often that husbands who are cared for by their wife receive a higher level of LTCI benefits than those who are cared for by other groups of caregivers, whereas none of them receives in-home care services. Wife caregivers interviewed told that they don't use in-home care services "because their husband doesn't want," and

instead, they take care of their husband by themselves as a family-care worker. It is possible because husbands want to be cared for by family members with no formal care service and are able to make their wife accept their request. Therefore, it is needed to find out how to intervene in which step of sharing caregiving responsibilities to resolve the hierarchy issue which makes it difficult for wives to choose the way of caregiving they want as a care receiver.

> People told me to use a care helper; however I am still able to do it and my husband feels uncomfortable being cared for by others (Wife caring for her husband, D)

> My husband is hot-tempered and feels so annoyed when he goes to a daycare center. I do look after him because I am still able to do it. (Wife caring for her husband, B)

3.2.4. Inequality of sharing of caregiving resulting from marital status

It is often that a single adult child who lives together with a parent(s) jumps into caring for a parent(s) due deteriorating health of a parent(s). Even though they have other siblings, it is difficult to expect help from siblings probably because they are married or have to work. According to interviewees, it seems to be taken by married siblings for granted that single siblings should take full care of a parent(s) only because married siblings are also responsible for caring for a parent(s)-in-law. Generally, a single adult child who lives together with a parent(s) tends to be the first option to become a caregiver.

> I have a sister, married and living away from us. It is difficult to ask her to look after parents because she is married and not free to visit us frequently except for long national holidays (Son caring for parents, S)

> I have an older sister and an older brother. Both of them are married and live far away and I am single. If I were married, we would discuss together how to take care of our parents because all of us would have parents-in-law. However, they took me for granted only because I am single. I didn't know that I had to care for my parents for that long period of time. There was an atmosphere that every one didn't have to take pains. All of us would be affected especially in the workplace: we could be suddenly called into work and end up being under pressure to quit a job. For those reasons, it was me who was tacitly forced to sacrifice for others. But it's got worse and longer (Daughter caring for parents, O)

Single child caregivers also have to work for living because they don't have a bread winning spouse. Even if they quit a job in order to provide care, they rarely receive financial support from other siblings. As such, marital status has led to economic inequality.

> For the past three years, I struggled to make ends meet. However, no one brought up the issue and attempted to make up for lost income. I didn't request them to do so. They gave some allowance to parents, but paid no regard to me. I thought they would consider my situation to some extent. However, they didn't care about me. (Daughter caring for parents, O)

There exists gender disparity in the status of economic activity of unmarried adult child caregivers: in general, females quit a job whereas males keep working, relying on in-home care services despite parent(s)'s objection. The disparity is also linked to a perception that caregiving is considered a female's primary obligation and based on which, females are forced to quit a job and take caregiving responsibility, when caregiving needs arise. It is likely that such perception creates a social structure that males cannot help but to keep working for a living, no matter how hard it is to take care of parents. Probably, females can

choose to quit a job due to a low level of wage and/or a low chance of promotion. It implies a need to extend the scope of discussion on care policies to include gender disparity in wage and job.

4. Relations between social responsibility and familial responsibility of elderly care

□ In the survey conducted for this study, questions are asked about the responsibility of the nation and the family regarding roles involving elderly care as follows: ① Identify care services needed for the elderly, ② Link up with care services needed, ③ Provide care services directly, ④ Manage the quality of care services, ⑤ pay the expense of care services.

□ According to the results of analyzing the survey, respondents are aware that the nation should take caregiving responsibility fully, significantly and more than the family in the following order: Manage the quality of care services (68.3%)>Link up with care services (67.8%)>Provide care services directly (66.9%)>Pay the expense of care services (62.9%)>Identify care services needed (53.6%).

□ However, as seen in the results of analyzing FGI, current efforts made by the government to manage the quality of elderly care services are found to be generally unsatisfactory. Especially, older persons using institutional care perceive themselves as being abandoned. It is pointed out that such negative perception will fade away and disappear, if the quality of services provided by elderly care facilities is improved and the facilities are located in the community.

□ It is also shown that the percentage of respondents who believe that the nation should take responsibility of linking up with care services is high. However, in reality, it is family members who search for information on care services, and compare and choose the most suitable one. Although the nation provides directly and pays the expense of care services through long term care insurance, the quality of care provided to the elderly varies remarkably depending on the use of family care resources and the level of their use.

□ It is understood that the family still has a strong sense of responsibility of caring for aging parents and use formal care services to ease the burden of care to family caregivers, not to replace family care completely.

□ It is, however, skeptical that such combination of care services will continue to work. A high percentage of caregiver respondents agreed on the statement “the elderly, by themselves, should make planning and preparation for future care needs, thus, the elderly should be most responsible for care for themselves.” This view seems to result from a concern that the elderly will not become a burden to a child(ren), and they or their spouse will take most of caregiving responsibilities. However, the percentage of respondents who believed that a daughter should take more caregiving responsibilities than a son is also high, which suggests that a patriarchal value lingers on.

□ As formal care services expand for the elderly, there seems to exist different and conflicting value perspectives in the amount of caregiving responsibilities resting on the nation and the family, and who should take the largest responsibility of caregiving within the

family. Therefore, it is needed to discuss elderly care in earnest across the society. It is also necessary to create a consensus on a family's right for caregiving and to improve the quantity and quality of formal care services.

5. Relational autonomy in the family care for the elderly

□ According to the results of the survey and FGI conducted for this study, primary caregivers had no idea what they would get into when they chose to take a primary caregiver role. They dived into the caregiving responsibility due to a sudden loss of a care receiver's health condition or a gradual loss of a care receiver's ability to perform daily activities. They thought that it was not a big deal in the beginning, but in most cases, it got worse in terms of caregiving task and time, over time.

□ In particular, a high percentage of females became a caregiver with no prior discussion on caregiving.

□ In order to ensure relational autonomy in the family elderly care, it is required that a caregiver and a care receiver coordinate and adjust the scope of decision on their choices and actions in the caregiving process. The relational autonomy is not a fixed entity, but an issue of degree, and manifest itself in the caregiving process as shared decision-making related to caregiving.

□ It is, however, found that, from the aspect of relational autonomy, decision-making on caregiving or end of life are one-sided, not based on equal and democratic sharing of opinions.

□ Insufficient policy or program to support the caregiving right of a family who is responsible and willing to care for the elderly works as an additional factor that causes family caregivers to get exhausted, thereby undermining the relational autonomy in the family elderly care.

Ⅳ. Policy Suggestions

1. Improve the vertical continuum of elderly care to ease family care burden

1.1. Create an one-stop window to assess the elderly's care needs and to form a caregiving combination

□ The vertical continuum of care for the elderly with a family caregiver is almost impossible to be achieved without family's involvement, under the current policy for elderly care in Korea.

□ Currently, an application process and eligibility selection criteria are defined separately for formal care services and it is required that either the elderly or his/her family member make an application to get care services. Resultantly, older persons with similar care needs can receive different care services depending on family caregivers' decision on elderly care services.

□ Therefore, it is important to prevent the elderly's excessive dependence on their family and to ensure that the elderly receive all necessary services suitable to them. To that end, it is required to create an one-stop window to provide information on elderly care services and resources, assess the elderly's care needs, explain about various care

services, and provide coordination and consulting service so that the elderly is able to choose and use services most suitable to them and their family.

□ The ‘Local Care Information Window’ of the Ministry of Health and Welfare’s priority project on community care currently provides information on care services, receives an application and applies for services on the elderly’s behalf. In addition to them, the one-stop window should function to provide specialized assessment and linkage of care services across the areas of public health and social welfare.

1.2. Enhance the function of lower level local governments to identify and respond to the elderly’s care needs

□ If the community care project expands nationwide, lower level local governments should be granted autonomy and authority to decide the way to operate and the contents of the project at a local level.

□ It is imperative that lower level local governments conduct an integrated analysis of provision of elderly care focusing on the availability of community infrastructure, services and human resources in the areas of public health, social welfare and long-term care as well as identify the characteristics of needs for care required by the elderly in the community. When it takes place, it will be possible to develop an elderly care system based on a community and new elderly care services.

2. Improve the horizontal continuum of elderly care to reduce family care burden

2.1. Expand reliable elderly care facilities in the community

□ In order to ensure that the elderly continues to live in their community, it is essential to help the elderly receive needed care services in their home. It will be possible to protect the caregiving right of a family and extend the horizontal continuum of elderly care at the same time if the quality of services provided by elderly care facilities is improved to the level acceptable by the elderly and their family.

□ It is time for the government to provide financial support actively to respond to high demand for good quality elderly care facilities in the community.

2.2. Operate and expand the community care project with consideration of perspectives of family caregivers

□ The central government has put in place a phased plan: conduct a priority project on community care to expand essential infrastructure from 2018 to 2022; establish a foundation to provide community care from 2023 and 2025; and make community care easily accessible from 2026.

□ In that process, it is imperative to include in the community care project services for the elderly who are not subject to formal care services and resultantly, dependent on family members excessively such as older persons disqualified for long-term care insurance, in extra level, in restoration and rehabilitation after surgery, and super aged.

□ In particular, it is judged that the community care project can provide the elderly and their family members who are expected to have full-scale care needs with the following services: renovation of the house where the elderly lives, escort between home to hospital and home, and specialized consulting to plan and prepare elderly care.

□ It should be in mind that it is possible to identify specific services to reduce caregiving burden to the family who cares for old persons in the community by integrating perspectives of families into the community care project.

3. Support for job, life and caregiving of family caregivers

□ It will be possible to improve the quality of family care and the family's right for caregiving when a policy is implemented to create a condition where exhausted and overwhelmed family caregivers can take respite.

3.1. Expand short-term care service for the elderly

□ It is necessary to establish or designate a respite care facility which provides short-term care options to be freely used when an urgent emergency occurs or a family caregiver needs short-term relief. It can be also possible to develop a new service to send a short-term care helper to the place where the elderly lives.

□ It is also required to find out ways to include in the community care project a short-term care service for the elderly who are not eligible for long-term care insurance but needs care, for example by changing criteria for a short-term care service from "the elderly in LTCI Level 1 to 5" to "the elderly using in-home care services."

3.2. Extend the scope of family care vacation

□ Currently, it is allowed to extend family care vacation from 10 to 20 days for “child care” reason when the issuance of disaster-related crisis alert is raised to the serious level due to spread of infectious disease or when an equivalent disaster occurs. However, elderly care is not included in the scope of this extension.

□ The interruption of formal care services (e.g. shutdown of day and night care centers) is not considered a reason for the extension of family care vacation.

□ In addition, it is revealed by the FGI of this study that there exists a high demand of working caregivers for a hospital escort service. If a care receiver needs to visit a hospital regularly due to a complex chronic disease, currently, it is very difficult to meet the need with 10-days of family care vacation. Therefore, it is necessary to create a specific provision to extend the period of family care vacation for elderly care.

3.3. Extend the period of family care leave

□ It is virtually impossible to restore the condition of older persons in need to the state which no longer needs care, and inevitable to deal with their increasing care needs over time. Therefore, the current family care leave program which allows employees to take up to 90 day off work a year is very rigid and not fit for the characteristics of elderly care.

□ Caregiving while working is not an issue confined to parents with a young child(ren). It is worth considering the inclusion of adult

children who should work while caring for parents into a policy target.

4. Use a community family center to support the family's right for caregiving and the relational autonomy of care

4.1. Role of a community family center for caregivers

□ Dependency and autonomy take turns manifesting themselves in the care relationship, which may result in psychological and emotional difficulties and conflicts. Therefore, it is required that specialized consulting, education & training, caregivers' self-help group be operated systematically by a family center in the community.

□ It is essential to provide expert advice and consulting on planning and preparation related to care such that many decisions which include opinion confrontation, conflict, compromise, acceptance, embracement and giving up between a caregiver and a care receiver are ultimately made towards relational autonomy.

4.2. Specialized consulting and education by a family center for caregivers: "death & dying" and "loss and grief"

□ There are two topics related to family care which require specialized consulting: one is "death & dying" and the other is "loss and grief." If such consulting is provided by a community family center to a caregiver and a care receiver alike, it will hep make better communication on a sensitive topic between parties involving elderly care.

□ It is important to proactively provide caregivers who are difficult to get out of home with in-home consulting and education services on “death and dying” and “loss and grief.”

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