Korean Women's Development Institute

KWDI ISSUE PAPER

Publisher : Korean Women's Development Institute
Publication Date : May 15, 2021

Research Title Elderly Care in the Family and Support Plan for Integrated Community Care
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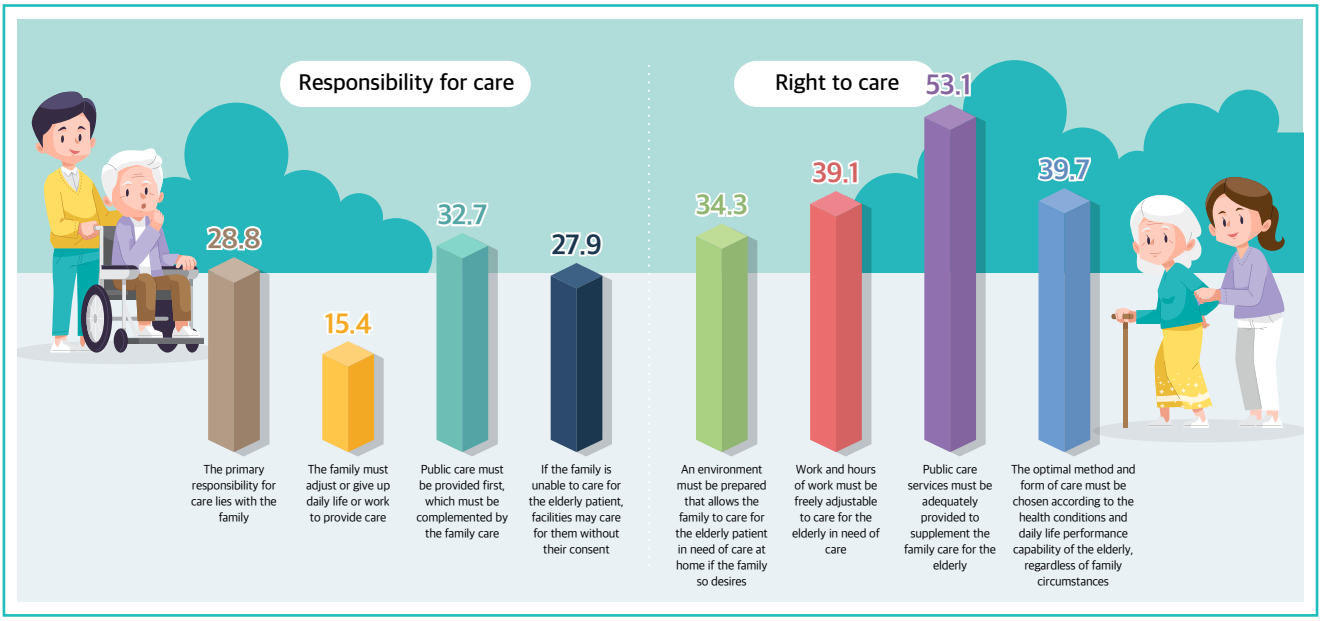
Community Care for the Elderly Reflecting the Perspective of Family Care providers

Abstract

- In this study, specific policy alternatives are proposed from family and gender perspectives which can secure continual care for the elderly within the community while providing support for integrated care(sharing the burden of care, implementation method, and care environment) as well as care relationships (dynamics between the care providers and the elderly they take care of) within sustainable and harmonious families based on the analysis results of the current status of elderly care within families.
- First, care relationships of the elderly within the family were analyzed considering the right to care and the responsibility for care. The care relationship established based on the perception of the right to care and responsibility for care of care providers and the elderly they care elderly they care within the family and the conflict resulting therefrom were examined. Second, the structure of the integrated care according to the care relationship for the elderly within the family was analyzed. The care relationship for the elderly within the family, as well as the manner in which the integrated care is structured in the daily life of the elderly according to the extent of his or her daily life performance capability was examined. Third, the current status of the use of community resources in care for the elderly and related vulnerabilities, as well as the perceptions and needs related to integrated care and "aging in place" were identified and examined. Fourth, implications were derived for policies that could improve the structure of conflict surrounding elderly care within the family and offer practical support for the elderly's aging in the community via integrated care in the community from a gender perspective without aggravating the burden of care for the families.



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Please cite this issue paper as below.

"Elderly Care in the Family and Support Plan for Integrated Community Care" (2020)
by Jung Ga-won, Kim Young-ran, Hong Seung-ah, Bae Ho-joong, Kim Soo-jin, Kim Bo-young. Korea Women's Development Institute (Seoul)

1. Background and Issues

- Previous research and policy development related to care and support for the elderly have tended to target the care service providers in the public sector and family care provider in family with separate policies. In particular, they have a limitation in that they do not fully understand the dynamics of a complex care relationship.
- In this study, care for the elderly has been defined as a concept which encompasses the overall assistance required for the elderly to lead their daily lives beyond nursing care, and the dynamics of the care relationship between the provider(s) of the care and the subject of the care within the family, details of the sharing of the burden of care, the manner of the care's execution, and the status of the care for the elderly within the family from the perspective of the environment of care (integrated care).
- Furthermore, with the recent facilitation of policy discussions of community care (community's integrated care) and aging in place for the elderly, an attempt has been made to propose specific policy alternatives from family and gender perspectives, which may secure continuity of the care for the elderly within the community while providing support for as ustainable and effective family care relationship for the elderly, and the two in combination.

2. Key Research Findings

① Continuity of care for the elderly policies premised on the family's care for the elderly and aging in place in the community : longitudinal continuity of the family care and care

- The future direction of the care for the elderly policy would need to be re-shaped to reflect the perspective of the family more comprehensively. From the family's perspective, continuity of care can only be secured when the family is directly responsible for the process of ① identifying the demand for care according to the status and health of the elderly under care, ② examining the information on the public care services available, ③ making efforts to acquire the qualifications required to benefit from the public care services, ④ selecting the appropriate type and institution of public care services, and ⑤ coordinating and managing the service schedule and details. This may be conceptualized as "longitudinal continuity of care."
- Furthermore, the elderly's aging in place in the community is a difficult task to achieve realistically, regardless of whether the elderly and their families live together, unless it is working from the premise that the family provides assistance and care to the elderly person on a continuing and regular basis.

② Care service provided based on the beneficiary qualification standards for public care for the elderly, not as the actual demand for care of the elderly : horizontal continuity of the public care for the elderly service and care

- According to the findings of the focus group interview conducted in this study, trust in the rigor and objectivity of the process of rating a patient as eligible for long-term care is low, and family care provider were very dissatisfied with the current care service allocation method, under which they could not receive any assistance if they did not receive a rating despite their current need for actual care. It can be said that horizontal continuity of care has been discontinued since various care services are provided segmentally rather than seamlessly to satisfy the care needs of the elderly.
- In particular, for elderly patients who applied for a rating yet did not receive one, extremely old patients, and elderly patients who were discharged from hospital and are undergoing rehabilitation, they have no option but to receive assistance in meal preparations and housework support from their family, and given their age and mobility restrictions it is also highly probable that the only channel of social support would be their family. That is, the entire burden of care is passed on to the family if one has not received a rating for long-term nursing care.
- Through the focus group interview of this study, it was confirmed that there is a very high demand for services such as accompanying the elderly patient to their hospital treatment and taking the elderly patient home thereafter even in the absence of a rating for long-term nursing care, and of providing assistance for the elderly patient in their recovery and rehabilitation following surgery at their home rather than at the nursing care hospital.
- That is, if the elderly patient who has not been granted a rating for long-term nursing care needs focused care rather than a wide scope of care across his or her life while continuing to reside in the community, and if a narrow scope of care that may be used for a short time is provided publicly, it would likely significantly contribute to securing horizontal continuity of care.

③ Imbalance of care within the family and the gender implications

- Through examining the status of care for the elderly within the family in this study, it was found that imbalances in care and asymmetry exist multi-dimensionally according to the gender of the care provider, and the 4 potential gender combinations of the care provider.

A. The imbalance of care experienced by the care provider

- There is a gap and an imbalance between the responsibilities of care provided by the family providing the care, the desire for the care (right to care), and the reality of the actual care provided. Given the imbalance between the care which one thinks he or she must provide, the care which one thinks he or she desires to provide, the care expected and required by the elderly patient and other family members, and the care actually provided, family care provider can experience negative emotions, including a sense of burden, frustration, and stress.

▶ Furthermore, providers of care experience disadvantages across various levels such as loss of employment, income, time, and health due to the care provided. The results of the survey carried out for this study also confirm the various difficulties experienced by the providers of care, the emotions of families towards the elderly they care, conflicts between the elderly they care and family, restrained emotion experienced by the care provider towards negative emotions of the elderly they care, anger and resignation against other family members' passive attitudes or non-intervention for care, inability to be free from care even when the actual care is not provided, and the excessive egocentrism of the elderly they care.

B. Imbalance of care according to the gender of the care provider and the elderly they care

▶ The imbalance of the care for an elderly patient within a family was found to vary depending on the gender of the care provider and the elderly they care. Male care provider had a greater sense of responsibility for care than the female care provider, yet tended to engage in the actual care less than the female care provider.

▶ While female care provider provided more care than male care provider, their rate of consent for the state's responsibility for care was found to be higher than that of the male care provider, and the rate of implicitly becoming care provider was found to be higher than that of the male care provider. Conflicts with the elderly patient and other family members surrounding care were also found to be experienced more often by the female care provider.

▶ Meanwhile, for the male elderly they care, the rate of preference for family care was found to be much higher than that of the female elderly they care, while the rate of concern for the family's burden of care was found to be much higher when the elderly they care was female than when the elderly they care was male.

C. Imbalance of care experienced by each of the 4 possible gender combinations of the care provider and the elderly they care

❶ When a female care provider cares for a male elderly they care

▶ By looking at the 4 possible combinations of the care provider's gender and the elderly they care's gender, when a female care provider cares for a male elderly they care, conflicts with the elderly and other family members over care were found to be the highest than with other gender combinations, and the rate of response that expert support is needed for conflict resolution was found to be highest.

▶ When a female care provider cares for a male elderly they care, she was found to experience the most of the following relative to other gender combinations: unnecessary misunderstandings with the elderly patient, having her own life and work lag in terms of priority, social isolation, desolation, and pressure to provide better care. But despite this pressure to provide better care, female care provider caring for a male elderly they care had the highest rate of responses that she was providing the best family care possible among the 4 combinations.

❷ When a male care provider cares for a female elderly they care

- When a male care provider cares for a female elderly they care, the rate of consent to sending the patient to a facility without the elderly patient's consent was found to be very high, and the rate of consent to freely adjusting work to provide care was found to be low, and as such, the tendency of prioritizing the elderly they care and the care itself was found to be the lowest among the 4 combinations.
- Furthermore, the rate of claims of a conflict with the elderly patient or a conflict with family was found to be the lowest among the 4 combinations. Given the fact that the rate of consent to sending the elderly patient to facilities without the elderly's consent was the highest, it may be inferred that the dynamics between the male care provider and the female elderly they care within the family varies from other combinations.

❸ When a female care provider cares for a female elderly they care

- When a female care provider cares for a female elderly they care, the rate of consent to the need to prepare an environment in which one's family can look after the elderly patient in need of care if the family so desires was found to be the highest, as well as the rate of responses claiming that the care provider herself implicitly became the primary care provider.
- Furthermore, the rate of responses that family members other than the elderly gathered and discussed the process of determining the sharing of responsibility for care, and the rate of responses claiming that the responsibility was shared naturally and intelligently without a separate process of discussion was found to be the highest in this gender combination. Based on this, it is evident that in a combination where a female care provider cares for a female elderly they care, discussions related to care are not adequately carried out within the family.

❹ When a male care provider cares for a male elderly they care

- When a male care provider cares for a male elderly they care, the rate of consent to the need for the provision of public care with priority and the family care's role of supplementing such need, and the rate of consent to the need for the adequate provision of public care services to supplement family care was found to be the lowest among the 4 combinations. The rate of perception that the direct provision of care services is "entirely + significantly" the state's responsibility was found to be the lowest as well, demonstrating a relatively high sense of responsibility for the family care.
- The rate of responses claiming that the primary care provider became so autonomously in the process of determining the primary care provider, and the rate of responses that the sharing of responsibility for care is naturally and intelligently carried out without a separate process of discussion were found to be the lowest among all4 combinations. But in connection with care, the rate of responses claiming that the family was working together to resolve conflicts with the elderly was found to be the lowest, and the rate of responses claiming that one person just satisfies the needs of other family members to resolve conflicts was found to be the highest among the 4 combinations.
- Based on this, it is evident that when a male care provider cares for a male elderly they care, while care-related discussions are conducted more frequently than in the other combinations, they are vulnerable in terms of conflict resolution.

D. Imbalance of care between primary and secondary care provider

- Finally, the imbalance of care verified via the focus group interview allowed for confirmation that the subjects of care had an excessive dependence on a single primary care provider within the family.
- In particular, since male subjects of care are reluctant to receive care from a third party other than their family, they often do not use services even when they are qualified to receive visiting nursing services or day care centers, or it was found that the primary care provider within the family was active as a family care worker.
- Female providers of care demonstrated how they satisfied the demands of the male elderly they care even while complaining about their difficulties, and it also was found that the male subjects of care did not want to disclose to anyone other than their primary care provider that they generally need assistance and care from others in carrying out their daily lives.
- While it may be considered theoretically possible to share the burden of care for the elderly within a family, in practice, even if the family consents to sharing the burden of care, there is a high possibility that the activities of care will be concentrated on a single primary care provider. Furthermore, given that females mainly play the primary care provider role within the family, this is also connected with gender inequality.

<Table 1> Family's perception of the responsibility of care and the right to care : rate of response for "Very strongly agree"

(Unit: %)

Classification	Responsibility for care				Right to care			
	(1) The primary responsibility for care lies with the family.	(2) The family must adjust or give up daily life or work to provide care.	(3) Public care must be provided first, which must be complemented by the family care.	(4) If the family is unable to care for the elderly patient, facilities may care for them without their consent.	(1) An environment must be prepared that allows the family to care for the elderly patient in need of care at home if the family so desires	(2) Work and hours of work must be freely adjustable to care for the elderly in need of care.	(3) Public care services must be adequately provided to supplement the family care for the elderly	(4) The optimal method and form of care must be chosen according to the health conditions and daily life performance capability of the elderly, regardless of family circumstances
Male for male	32.4	18.9	**30.4**	27.0	32.4	39.2	**46.6**	**42.6**
Male for female	**33.8**	**11.9**	31.4	**29.0**	**31.4**	**35.2**	51.0	**35.7**
Female for male	**17.0**	**19.1**	**36.2**	**25.5**	36.2	**51.1**	58.5	41.5
Female for 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

④ Relationship between the state's responsibility and the family's responsibility surrounding the care for the elderly

- In the survey conducted in this study, subjects were asked their thoughts on the state's responsibility and the family's responsibility regarding the following sequence of care for the elderly: ① identifying and understanding the care services needed by the elderly, ② connecting them to the care services they need, ③ directly providing the care services, ④ controlling the quality of care services, and ⑤ paying for the cost of the care services.
- According to the survey, the sequence turned out to be the quality control for care services (68.3%) > connection of care services (67.8%) > direct provision of care services (66.9%) > sharing the burden of the cost of care services (62.9%) > identification of the care services needed (53.6%), and the rate of perception that the state's responsibility is larger relative to the family's responsibility was found to be greater (such that the state is entirely responsible + the state is significantly responsible + the state is much more responsible).
- However, as demonstrated by the results of the focus group interview, the subjects were dissatisfied overall with the Korean government's current efforts to control the quality of the care services for the elderly. In particular, it was noted that the elderly who receive care mainly through nursing facilities perceive entering such facilities as meaning their family was abandoning them, but that they would not think negatively about entering suchfacilities had the facilities been located within the community.
- The rate of connection to the necessary care services also was found to have a high rate of perception that it is the state's responsibility, yet in reality, the family was primarily responsible for seeking information on care services and making choices through the comparison of care services. While the state's direct provision of care services and sharing of the burden of cost are carried out via the long-term nursing care system for the elderly, the quality of the care received by the elderly varies significantly depending on whether the family resources of care are mobilized and on the level of care.
- The family's sense of responsibility for care for the elderly is still very significant, and public care services have been added to share the family's burden of care, but it is evident that the reception of the public care services does not mean the complete replacement of family care.
- However, it is skeptical as to whether such an integrated care will continue to be effective moving forward. The rate of responses claiming that considering the fact that the care provider who is currently faced with the parent's care issue, and the fact that the one in need of care needs to plan and prepare a connection with a care provider in advance, the one in need of care is the most responsible for care, was found to be the highest. While this is interpreted to be a consequence of thinking that the burden of care will mostly be borne by oneself and his or her spouse, and that one's children will not be required to be responsible, the fact that there is a prevailing perception that sons are far more responsible than daughters for the care means that patriarchal values still remain.
- It can be said that, even while the public care for the elderly has expanded as such, various values persist regarding the relative proportion of the state's responsibility and the family's responsibility surrounding

the care for the elderly, and whose responsibility for care is the largest within the family, and they continue to be in conflict. Thus, it is necessary to carry out full-fledged discussions of the care for the elderly across the entire society, and the need to protect the right to care for the family together with the expansion and improvement of public care services ought to be publicized.

⑤ Relational autonomy of care for the elderly within the family

- According to the results of the survey of this study and the focus group interview, rather than accepting their role as the care provider with the specific expectation that they will experience difficulties and disadvantages related to care before becoming the care provider, most primary care provider became providers of care following the sudden aggravation of the health conditions of their subjects of care, or the subjects of care's incremental loss of ability to carry out their daily lives, thereby compelling their days to become more arduous by the provision of care, which they considered insignificant initially.
- In particular, among female providers of care, the rate of care being provided without any discussion at all regarding care was found to be relatively high.
- As for the care for the elderly within the family, relational autonomy can only be secured if and when the care provider and the elderly they care coordinate and adjust the scope of decision-making authorities for their own choices and actions surrounding the care through the care provision process. Furthermore, such relational autonomy may be considered as a matter of degree rather than a fixed entity, and in the actual care provision process, relational autonomy was found to be a shared decision-making related to care.
- But according to the survey results, it is evident that, from the perspective of relational autonomy, when decisions are made in connection with care or the end of life, they are made with an inclination towards one side rather than through mutually sharing opinions in an equitable and democratic manner.
- The inadequacy of policies or projects which provide support for the right to care of a family who desires to care for their elderly family member as well as having a sense of responsibility to care for the elderly results in the exhaustion of the care provider within the family, which has become an additional factor further undermining relational autonomy in terms of the care for the elderly.

<Table 2> Decision-making related to care: rate of "Yes" response (Unit: %)

Classification	Determination of primary care provider		Determination of the sharing of burden of care within family	
	Family gathers, except the elderly	I became it implicitly	Family gathers, except the elderly	Naturally and intelligently on one's own without separate process of discussion
Male for male	21.6	**10.1**	23.6	**16.9**
Male for female	**12.4**	14.3	23.8	24.3
Female for male	**23.4**	13.8	**27.7**	25.5
Female for female	16.9	**22.5**	**20.6**	**30.6**
Total	17.5	15.4	23.5	24.3

3. Policy Recommendations

① Relaxation of the burden of care for the family through the improvement of longitudinal continuity of care for the elderly

A. Preparation of a unified window equipped with the function of assessing the elderly's need for care and structuring an integrated care

- As such, a unified window equipped with the functions of providing the information related to the public care for the elderly service and the care resources for the elderly needs to be provided to ensure that the elderly are provided with the most appropriate services for themselves and to prevent excessive dependence on their family in their care, assessing the situation for the need for care of the elderly, explaining various services, and providing advice and coordination to ensure that the family and the elderly may select and use the most appropriate services.
- This means that the “Eup, Myeon, and Dong Care Information Window” of the community integrated care leading projects of the Ministry of Health and Welfare ought to go beyond its current role of providing service information, application filing and reception, and agency, and take on the functions of providing specialized assessment and service linkage across health care and social welfare.

B. Strengthening of the ability to identify and respond to the need for care of the elderly inbasic communityunits of local government and eup, myeon, and dong

- If and where the community integrated care projects are expanded across the nation moving forward, recognize the autonomy and unique authorities of the basic units of local government in deciding how to operate the relevant projects and their details.
- Together with an integrated analysis of the supply of care for the elderly such as the infrastructure, services, and the manpower within the community where the basic units of local government may mobilize in the areas of health care, social welfare, and long-term nursing care related to the care for the elderly, identify the characteristics of the need for care for the community’s elderly, and based on this, develop a care system for the elderly focused on the community and a new care service for the elderly.

② Relaxation of the family’s burden of care via the improvement of horizontal continuity of care for the elderly

A. Expansion of nursing care facilities for the elderly within the community which may be trusted and used

- Improve the service quality for the nursing care facilities at a level which may be accepted by the elderly and families, thereby protecting the family's right to care and expanding the horizontal continuity of care for the elderly.
- The government must respond by providing even more active financial support for the large demand for the nursing care facilities for the elderly which provide good services within the community.

B. Operation and expansion of the integrated care projects of the community that reflect the perspective of the family care provider

- The government has devised a phased plan under which from 2018 to 2022, it will carry out community

integrated care leading projects and expand key infrastructures; from 2023 until 2025, will build a foundation for the provision of the community integrated care; and from 2026, will universalize the community integrated care.

- Without exception, include services for the elderly patients who can be characterized as being forced to have excessive dependence on their family care since they were subject to public care services, including the elderly patients who applied for a rating for the long-term nursing care yet did not receive one, the elderly patients who were not rated, the elderly patients who need recovery and rehabilitation following surgery, and the oldest patients, among the community integrated care projects.
- Moving forward in the area of community integrated care services, the services of safely renovating the homes in which the elderly live, accompanying the elderly to the hospital and taking them home thereafter, and professional counseling services for planning and preparing care for the elderly are services which may be provided for elderly and their families who are expected to have a demand for care on a full-fledged basis.
- It is necessary to identify the specific services which may relax the burden of care for families caring for elderly patients who continue to reside within the community by reflecting the perspectives of such families in the community integrated care projects.

③ Concurrent provision of support for the work, life, and care of the family care provider

A. Expansion of the short-term protection services for the elderly

- It is necessary to install or designate a short-term protection provider institution which the family care provider may use freely in the event of an emergency or when the family care provider needs to take a short break. Develop a service of directly dispatching short-term protection related personnel to the place where the elderly live.
- Review the measure of providing ashort-term protection service for the elderly in need of care and without a rating for the long-term nursing care by expanding the standards for the use of the short-term protection service.

B. Expansion of family care leave for workers caring for the elderly

- In the area of family care leave, there are currently no separate provisions made for the provision of the “care for the elderly” if and when a severe disaster warning is issued or a large scale disaster equivalent thereto has occurred due to the spread of an infectious disease, among others. Despite the fact that the discontinuation of public care services equivalent to the temporary closures of school, kindergartens, and daycare centers, such as the closures of day and night protection centers, has taken place, it has not been reflected as a reason or a cause for the extension of family care leave.
- If a elderly they care requires regular hospital visits due to complex chronic diseases, it may be very difficult to satisfy this need with the current 10-day family care leave. Thus, it is necessary to expand the family care leave by preparing separate regulations for the workers for the elderly.

C. Expansion of the family care leave for the workers caring for the elderly

- The current family care leave, which provides for 90 days per year to be used, is very rigid and does not

reflect the features of care for the elderly since the demand for care will only continue to rise as time passes, and the conditions of the elderly in need of care will never be reversed to the condition where no care will be needed.

- Concurrently carrying out work and care is not an issue limited to parents raising young children, and adult children who are required to concurrently care for the elderly within their family while working must also be considered among the targets of the relevant policy.

④ Provision of support for relational autonomy for the family care provider's right to care and care via the family centers within the community

A. Role of the family centers within the community for the care provider

- Systemically operate specialized counseling, education, and self-assistance groups for family care provider at family centers within the community to address the psychological and emotional difficulties and conflicts arising out of the care relationship.
- Provide professional consulting to ensure that the decision-making process including conflicts of opinion, struggles, compromises, acceptances, inclusions, and abandonments arising out of the care relationship between the care provider and the elderly they care will ultimately be mutually converged in a direction towards the relational autonomy.

B. Professional counseling and education of the family centers for the care provider

- There are 2 topics which require professional counseling surrounding the care relationship within the family. The first of these is "death and dying," and the second is "loss and grief." Provide support for the amicable and efficient communication of sensitive topics between the parties who form the care relationship via professional counseling for the elderly they care as well as for the care provider at family centers within the community.
- Proactively approach the subjects of care if they have difficulty leaving their home, by providing home counseling and educational services, so that they, too, may take advantage of counseling and education related to "death and dying" or "loss and grief."

⑤ Implementation of survey on the status of care

- Produce the basic data needed for the overall care policy by planning and implementing a "status survey of care" to analyze the relationship, perception, and integrated care (service, cost, time, and care provider) between the care provider and the elderly they care moving forward.
- Conduct large scale surveys related to quality of care in Korea as they are conducted by and at the Generation and Gender Program (GGP) of the United Nations Economic Commission for Europe, and reflect their empirical findings in the policy-making process.

Responsible Organizations:	Family Policy Department of the Ministry of Gender Equality and Family; Community Care Promotion Unit of the Ministry of Health and Welfare
Relevant Organizations:	Local self-governing bodies promoting integrated care project for community (for the elderly)