

# **Abstract of Doctoral Thesis**

Qualitative Study on Welfare Programs and Family Care for People with ALS  
–Focusing on Korea’s Personal Assistance Service System and Long–Term Care  
Insurance –

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The purpose of this study was to explore the reasons for care burden experienced by family member of Korean people with ALS (amyotrophic lateral sclerosis) from the internal problems of the incurable disease support system and care support system (Personal Assistance Service System & Long–Term Care Insurance) and the conflict situation experienced by family cares. In particular, assumptions of many previous studies on family care--The high care burden of the family is simply derived from the physical condition of the people with ALS-- examined the validity attention to recognition by the administrative side who considers families as care resources, issues within the support system, communication of people with ALS, and family caregivers' family position etc. Therefore, this study examines the specific reasons behind the caregiving burden through essays and Internet posts of people with ALS and their families, news articles, information from welfare programs, and interviews. The results show that the caregiving burden did not decrease despite the existence of relevant programs because the requests of people with ALS and their families were not accepted since the Care support system was created based on a research and system design that did not consider such issues.

This study highlights the burden experienced by children who are caregivers. The reason is that when the Care support system does not function appropriately and the family takes on the bulk of care, including significant financial burden, the children of individuals with ALS will have an obligation to support and bear the caregiving burden.

This study is significant in that it presents the family and social issues surrounding family care, rather than the care issues related to functional losses, such as physical, communication, swallowing, and breathing problems of people with ALS, that place a high burden on caregiving families.