

Ethnographic Research to Understand the Care Scenes of an ALS Patient

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Key words: Ethnography, ALS, care

ALS (Amyotrophic Lateral Sclerosis) is designated as an intractable neurological disease. This type of disease gradually deprives one of the physical ability to move, and then finally can even cause spontaneous arrest of respiration and a loss of voice communication. This article reports on and analyzes how "care" for this disease operates.

Regarding the consequence of open-cording, nine categories are extracted from 141 pieces of raw data. Then, a conceptual diagram with two axes for coordinates, a mutual decision-unilateral decision, and a scattered route-contracted route are created. As a result, it is clarified that an ALS patient, the care-giver, and a third person (who can provide care better than the care-giver) mutually relate to each other in order to maintain the demand for care inside the range that the care-giver can provide, as well as to extend the range gradually simultaneously. In brief, in this field, the care-giver obtains new abilities that they did not previously have, and the ALS patient demands that the care-giver provide care in the range of their ability.