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## The long-term care needs of main caregivers caring for children with adrenoleukodystrophy

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**A**drenoleukodystrophy (ALD) is a rare recessive hereditary metabolic disease. At the disease onset, the child exhibits gradual deterioration of physical functions. The child ultimately relies on the primary caregiver for long-term home care until death. Purpose is to understand the care needs of the primary caregivers as they care for the ALD children. This qualitative study used semi-structured interview for data collection. There were six primary caregivers of ALD children who participated in this study. The results revealed there were three themes of care needs emerged during the phase of “onset of disease to confirmation of diagnosis”: “facing parental perception of child’s abnormal behaviors”, “needs for collaborative outpatient care”, “prompt confirmation of diagnosis”. During the second phase “deterioration after confirmation of diagnosis”, three themes of care needs were identified: “swift comprehension of the disease information and resources”, “learned accurate knowledge, skills and application of facilitating equipment”, and “received timely assistance”. There were three themes of care needs during the phase of “long-term bedridden to death”: “provision of individualized care during hospitalization”, “provision of long-term homecare service”, and “provision of hospice care at home”. The researcher hopes to provide mental support and palliative accompaniment through the establishment of a collaborative pediatric palliative care team, a care management system for children with rare diseases, and integrated care between discharge preparation and home care. Recommends development of temporary childcare services at nursing home of the university hospital so that the primarily caregivers and the family may rest and improve the quality of home care for the ALD children.

### Biography

Ms. Jui-Chun Feng is a head nurse at pediatric ward at MacKay Memorial hospital in Taiwan.

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