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The lived experiences of main caregivers caring for children with adrenoleukodystrophy

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Adrenoleukodystrophy (ALD) incurable once diagnosis is confirmed, and the child ultimately relies on the primary caregiver for long-term home care until death. Purpose is to understand the primary caregiver's lived experience. This study used qualitative study. There were six primary caregivers of ALD children who participated in this study. The results revealed with regard to the perceptions of the primary caregivers, five themes and fourteen sub-themes were identified. There are four sub-themes under the theme of "chaos/helplessness while seeking medical attention and forced acceptance": "seeking medical attention for an unknown disease", "panic about inability to determine the current status of the illness", "shock and frustration upon confirmation of the diagnosis", and "objection to the recommendation of palliative care". There were three sub-themes under the theme of "maternal self-blame, worry and guilt": "distressed and felt own it to the child", "frustrated by inability to care for other siblings", and "worried about other siblings may have the disease". There were three sub-themes under the theme of "inspired maternal resilience": "ongoing search for possible treatment options", "commitment to care for the ill child", and "manifestation of maternal resilience". There were two sub-themes under the theme of "gradual family adaptation to the new norm": "making best effort to accompany the child for resolution of self-guilt", and "re-organization of family and social life". There were two sub-themes under the theme of "palliative accompaniment until death": "anticipates the child to receive the best care during bedridden", and "gradual acceptance of palliative care". The researcher hopes to provide mental support and palliative accompaniment through the establishment of a collaborative pediatric palliative care team and a care management system for children with rare diseases.

Biography

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

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