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Title: The lived experience of parents caring for children affected by Mucopolysaccharidosis (MPS): A phenomenological study

ABSTRACT

Mucopolysaccharidosis (MPS) is a rare disease with late onset of symptoms after a brief normal period since birth. Previous studies have identified impacts of physical impairments on the quality of life of the affected child and the care burdens on the families. Few studies investigated the caring experience of parents. The local study is even scarce. This study sought to explore the parents' lived experiences in Hong Kong. In-depth interviews using phenomenological approach were adopted to uncover the lifeworld of nine parents. The Moustakas's eight-step analytic framework was used to identify the essence of experiences. The findings reflected that the parents has experienced an unexpected arrival of child's abnormalities, a delayed diagnosis, and a frustrating path attempting to reverse child's deterioration. Despite hardships, the parents valued every present moment with child and want to share their experience with other families in need. Nevertheless, they expressed a concern for future. The findings not only help health care professionals understand the parent's experiences but also assist policymakers to devise policy to support the families timely.