Of Love and Isolation: Narratives of Siblings of Children with Cerebral Palsy in Sri Lanka

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Abstract : Aim: Siblings of children with cerebral palsy are often in the periphery of discussions; their views not always taken into account. The aim of this study was to uncover the narratives of young siblings of children with cerebral palsy in Sri Lanka. Methods: Semi-structured interviews and artwork were gathered from 10 children who have siblings diagnosed with cerebral palsy. The data was analyzed using the key principles of Framework Analysis to determine the key themes within the narratives. Results: The key themes to emerge were complex and nuanced. These included themes of love and feeling of protectiveness; jealousy and uncertainly; guilt and hope. Conclusions: The results highlight the need to take document the views of siblings who are often on the margins of the family and of family decisions and discussions. It also supports the need to offer safe spaces and opportunities for siblings of children with disabilities to express their feelings and to receive support where required.

Keywords: disability, grandmothers, mothers, narratives, women

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