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Family Caregiving to Patients in a Persistent Vegetative State in India: A Multi Family Member Perspective

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Abstract

This study explores the dynamics of adaptation and resilience among families providing long-term care for patients in persistent vegetative states (PVS) at home in India. In the absence of adequate government support services and formal healthcare infrastructure, it becomes imperative for families to undertake the comprehensive and continuous care of patients in PVS. Utilising qualitative research methods and Multi-Family Member Interview Analysis (MFMIA), narratives from six family caregivers were analysed. The findings revealed five overarching themes: struggles with adversity, family values, belief systems, strengthened family bonds, and perceived social support. Caregivers reported significant burdens, including ambiguous loss, emotional distress, and diminished social status. Despite these challenges, families mobilised internal resources such as shared values, cultural beliefs, and social networks to adapt and build resilience. Notable variations in family functioning and adaptation processes were observed, emphasising the need for tailored, cost-effective home care services. These findings offer important insights that will assist family therapists in navigating the complexities of caregiving dynamics and the processes of family resilience in the context of PVS caregiving.

Keywords: family resilience; adaptation processes; cultural beliefs; caregiving burden; therapeutic support