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## **Family-Centered Strategies in Caring for a Child with Cerebral Palsy: A Case Study**

*Sneha Hiren Bhalala*

Assistant Professor, SPB Physiotherapy College, Surat

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### **Introduction**

Cerebral palsy (CP) is a complex neurodevelopmental disorder characterized by impaired movement and posture, affecting approximately 2.0 to 3.5 per 1000 live births globally (Rosenbaum et al., 2007). This case study delves into the intricate dynamics of caring for Dhyana, an 8-year-old girl living with CP, within the context of her tight-knit family residing in an urban environment in Surat. Despite the challenges posed by her condition, Dhyana's family has embraced a holistic approach to her care, integrating her into their daily routines and activities.

In recent years, there has been growing recognition of the importance of family-centered care in managing pediatric disabilities such as CP. Family-centered care emphasizes collaboration between healthcare professionals and families, recognizing families as experts on their children's needs and preferences (Committee on Hospital Care and Institute for Patient- and Family-Centered Care, 2012). This approach acknowledges the significant impact of family dynamics, cultural beliefs, and socioeconomic factors on the care and well-being of children with disabilities (Kuo et al., 2012).

In the case of Dhyana, her family's cultural background and close familial bonds play a crucial role in shaping their caregiving practices. Despite limited resources and access to formal therapy services, Dhyana's family has developed innovative strategies to meet her needs within the confines of their home environment. These strategies encompass a wide range of activities, including personal care, educational support, and community engagement, highlighting the family's resourcefulness and resilience in navigating the challenges of caring for a child with CP.

Through a collaborative effort between healthcare professionals and the family, novel interventions were introduced to enhance Dhyana's participation within the family and community settings. By reframing traditional approaches and fostering cultural competence, this case study highlights the importance of tailoring care strategies to align with the unique needs and beliefs of each family, ultimately promoting a more inclusive and effective care environment for children with CP.

In the following sections, we will delve deeper into the specific strategies employed by Dhyana's family, the challenges they faced, and the collaborative interventions implemented to support their caregiving efforts.

Dhyana is an 8-year-old girl with cerebral palsy. She lives with her mother, father, two brothers, one sister, grandmother, aunt, and four cousins in a small home in an urban environment. Dhyana's parents moved to the Surat when they were teenagers. They have learned to speak Gujarati, but it is not their primary language spoken at home. Dhyana is unable to walk and does not attend school. Her family takes care of her every need. She rarely leaves the house except to go to temple, where she is carried and doesn't have many friends her own age. She has a close family and enjoys many visits from friends and neighbors. Her family takes her regularly to the major medical center for all her medical care. The professionals have recommended a special educational setting for Dhyana, where she would receive all her educational needs and therapies. The family has declined such a placement and prefers to home school her. She is not receiving any therapy at this time. Many professionals who have seen Dhyana have tried to get the family to agree to outside help for Dhyana. They have stressed the importance of teaching her how to function independently. The family members insist that she does not need to do anything, because they will take care of her. They do not even want to get any type of special equipment to help them to take care of her. Dhyana has not had any acute medical issues; however, the team feels that Dhyana could do more for herself. After many years of team recommendations not being followed by Dhyana's family, a new physical therapist offered to make a visit to the family's home to assess the situation. When she arrived, she found a very crowded living arrangement within a very small home. As she stayed to "visit," she observed a typical day in the life of Dhyana. She was amazed to see the whole family involved. One family member bathed and dressed her. Another family member fed her along with the rest of the family. When the other children went off to school, Dhyana's mother spent a few hours teaching her math and reading and doing "exercises" to make her strong. After lunch, Dhyana was carried outside and taken for a walk around the neighborhood and accompanied her father to the store for some groceries in a homemade wagon. After the children returned from school, Dhyana sat outside on the porch

and watched the children as they played. They all included her in their games. The physical therapist realized that Dhyana's family and neighbors had embraced her care as a team. They had developed strategies to care for her and included her in the family's activities. When speaking to Dhyana's mother, she sensed an enormous amount of sense of responsibility for Dhyana's disability, even referred to "punishment for sins that had been committed by her parents." It was obvious that Dhyana's family took great pride in her caretaking. When the physical therapist returned from her visit, she shared the information that she received with the team. She took photos and video of the house and the equipment that the family used. All agreed that Dhyana was being cared for, but that perhaps they were going about helping her in the wrong way. They decided to have a social worker, who was of the same ethnic group, to work with the family on changing its understanding of the disability. Instead of focusing on changing what the family was doing, the team worked to support the family members in what they were doing. Very soon, the family accepted some help from the team. The team was able to give the family members suggestions to make it easier for them to care for Dhyana and gave them suggestions for how she could play a more active role in the family and the community. Clinic visits were not frustrating anymore as the team took a new approach to making recommendations to the family.

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