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Perception About Family Centred Care Among Caregivers of Children with Cerebral Palsy- An Exploratory Study

Deepalaxmi Paresh Poojari, ShashikiranUmakanth, G. Arun Maiya, Bhamini Krishna Rao Manipal College of Health Professions, Manipal Academy of Higher Education, Karnataka

Introduction/Rationale: Cerebral Palsy (CP) is a disorder of the development of movement and posture attributed to non-progressive disturbances of fetal or infant brain, having a prevalence of 1.5 to 2.5 per 1000 live births. CP is responsible for considerable long term morbidity not only for the children, but also for their caregivers. Existing approaches to rehabilitation is child focused and Institution based. However, considering the limited resources and poor accessibility, implementation of family centred care in the community is indispensable. Therefore, it is important to understand the perception about family centred care among caregivers of children with CP.

Objective: To explore the perception about family-centred care among caregivers of children with CP.

Method: A qualitative study was conducted on caregivers of children with CP living in the coastal region of Karnataka. Face-to-face interview was conducted on 12 caregivers of children with CP aged between 4 to 12 years using a semi structured interview guide developed and validated by 5 experts. The interviews were conducted in local language either at participant's residence or in CP clinic. Interviews were audio-recorded and transcribed for analysis. Content-analysis approach was used to analyse the data.

Results: Themes were generated based on family centred care model. Transcribed data showed the following themes: (I) Enabling and partnership including (Ia) information about the child's condition, (Ib) treatment options for their child, (Ic) discussion and planning of treatment goal and (Id) opportunities for decision making. (II) Providing general information including (IIa) knowledge about the government and NGO. (III) Respectful and supportive care towards the caregiver including (IIIa) supportive groups, (IIIb) behaviour of professionals towards caregiver and (IIIc) confidence about the health care services received for the child. (IV) Providing specific information about the child.

Conclusion: The observed results explored the aspects like need for constant guidance and support, information about the disease condition and prognosis, inter-professional communication and goal setting with mutual accordance in order to improvise the family centred approach. Understanding the aspects derived from these themes will help developing strategies to deal with them. This may enhance the caregivers' capacity and help them deliver better care to their children, thus improving the quality of life and participation of the child in the community.

Keywords: Neuro-developmental delay, <u>Family</u> centred approach, Parents.