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## The neonatal nurse role in development and implementation of family centered care

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The concept of family centered care (FCC) is gaining momentum and proved valuable in improving the outcome of patients. FCC has been proved to result in better health outcomes as well as maximum family satisfaction. The modern neonatal intensive care practices in many countries incorporate FCC among its core values. However, there is a gap between policies and implementation which could be remedied by collaboration between various members of the team. Furthermore, wider dissemination of FCC values is required as it is not even recognized or appreciated in many neonatal units especially in the developing countries. The complexity of the milieu of NICU should not be an excuse to limit or abandon FCC. The neonatal nurses hold a pivotal role in empowering families through transparent and unbiased information sharing and consistent involvement, family support and adaptation of FCC to accommodate the cultural, religious and socio-economic diversities. The cornerstone of FCC is the real believe and conviction the family is seen as partners in health care provision and decision. The challenge of implementation and development of FCC requires solid planning as well as measures to monitor application and efficacy. Implementation strategies should be flexible, adaptable and practical. Dynamic provision of family support involves healthy relationship with the family to enable the health care professionals to obtain factual assessment of the family needs, abilities and coping mechanisms. Effective planning should take into consideration the priorities and limitations of each family member and suitable mechanisms put in place to facilitate regular contribution.

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## Between and between: Parents' experiences of living with and caring for children, adolescents and young adults with mucopolysaccharidosis (MPS)

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Mucopolysaccharidosis (MPSs) is one of the many rare inherited metabolic disorders (IMDs) that come under category 3 of life-limiting conditions. The severity of the disease varies according to the specific type, ranging from very mild symptoms to, in most cases, multisystemic, restricted growth or mental and physical disabilities. Recent developments in treatments for some forms of MPS have made dramatic changes in the quality of life for patients. Other forms of treatment are currently under investigation and development. Very little is known about parents' experience of living and caring for these children, adolescents and young adults with MPS. This study aimed to explore and interpret Irish families' experiences of living and caring for children, adolescents and young adults with MPS. A qualitative approach, utilising hermeneutic phenomenology informed by the philosophical constructs of Heidegger (1962), Gadamer (1960/1998) and Van Manen (2007/2014) was undertaken. Van Manen's (2007/2014) phenomenological approach was used as a guide for data collection through serial interviewing and phenomenological data analysis. A purposively selected sample of parents' (N=8) attending the Irish National Centre of Inherited Metabolic Disorders was invited to participate. The data was collected over a 17 month period (August 2013-December 2014). Nine themes and 22 corresponding subthemes were identified during data analysis. In this study, the parents' experience of living with a child with MPS was reflected in a number of ways. The majority of families started their lived experience from the time they received their child's diagnosis and this experience then impacted their life as a whole. They spoke about grief and loss reactions associated with receiving their diagnosis and living day to day with a condition that has no cure. They spoke of their child's quality of life, their healthy children's wellbeing, and for some, the impact on their own physical and psychological wellbeing. They also reflected on issues of stigmatization and isolation in their experience of living with a child with a rare disorder. Parents spoke about their experience of being the parent of a healthy child to being the parent of a child with a life-limiting condition, and they described as living in a state of liminality within this transition. Overall, this study provided a deeper meaning of the lived experience for parents' of children, adolescents and young adults with MPS in the Republic of Ireland through snapshots in time. This study recommends improving current practice and policy implementation to enhance healthcare practitioner's knowledge and understanding. This will, in turn, improve service delivery and partnership care for the children and their families with MPS.

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