

Parents' experiences of a Multiple Sclerosis (MS) diagnosis in their young adult sons/daughters: An interpretive phenomenological study

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Multiple Sclerosis is the most common neurological disorder in young people in Ireland, specifically across the ages of 20-40 when initial diagnosis occurs (Rejda, Jackson & Giovannoni, 2010; MS Ireland 2017). Given the complexity of the disease and its impact on an individual's quality of life, research is wide ranging with regards to the needs and experiences of individuals with MS (Irish Health 2013; MS Society UK, 2013). However, when one considers the impact such a disease has on the parents of a young adult, research is significantly underdeveloped in this area in Ireland and worldwide. The aim of this study was to explore parents' lived experiences of their young adult sons' or daughters' MS diagnosis. Themes emerging from the exploration of parents' experiences of an MS diagnosis in their young adult son/daughter were: balance, uncertainty, isolation and support.



Literature to date has failed to explicitly explore parents' experiences of caring for their young adult son/daughter with MS. MS is a chronic illness considered to be a 'family process' in terms of acceptance and impact. This study has focused on this 'family process' in terms of parents' experiences and in identifying the impact the diagnosis has on their lives. Parents struggle with their new undefined role as a parent for a young adult with a chronic illness. They experience a range of emotions and have questions and concerns, yet they have little to no support in answering those questions and in helping them to accept such a life changing diagnosis. By considering the needs of the parents involved and by adopting a truly holistic approach to MS, only then can parents of young adults be informed and supported and equipped with the appropriate resources in which to effectively care within the context of a chronic illness.

All parents identified with elements of each of the four themes. Parents acknowledged a personal struggle with balance. They must now balance their biological need to protect their child with the need to respect their position as a young adult with independent reasoning and decision-making abilities. Uncertainty surrounded all parents' experiences of an MS diagnosis, owing to the instability of the disease itself. Uncertainty manifested in terms of unknown disease progression, silent symptoms and the perceived inability to care effectively. Isolation resulted for a collaboration of other emotions. Fear and guilt experienced by parents often resulted in relationship breakdowns, disruption to family dynamics and contributed to their subsequent inability to ask for help when needed. Experiences of support may have varied among the parents involved but all identified the need for support structures, additional resources and information for those caring for their young adult.

Health care professionals play a vital role in providing support and direction for this particular parent group. This study has identified differences in terms of health care experiences and what the actual support received among parents involved and the impact this subsequently had on the parent. All identified the importance of communication, collaboration and input from health care professionals in providing information and support. Parents look for hope and positivity in dealing with such a diagnosis and health care professionals are in a prime position in which to foster this need.

References:

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