PMG conference Plenary Session 4 Refection

Parents of adults with multiple sclerosis: what is their role and how does if change over time?

I chose to attend and reflect on this plenary session as someone with relatively little experience in the wheelchair field as a Physiotherapist. I also have a personal and professional interest in the holistic management of MS. This title appealed to me as my father in law has recently been diagnosed with MS. I often consider how my extended family will cope emotionally and practically with his changing condition. As a health professional I naturally had concerns about his mobility and environment as they had chosen to retire to rural Cornwall soon before his diagnosis.

The plenary session provided feedback on a qualitative study looking at the emotional impact that the diagnosis of MS had on parents. It suggested there is limited research looking at the impact of health conditions, such as MS, on family members. As health professionals know, the support network around someone with a progressive neurological condition can be vital.

Grounded theory was used to analyse the interviews carried out with parents of those diagnosed with MS. Themes and ideas were identified, then the data was coded to look for repetition until the data was saturated. The Hospital Anxiety and Depression Scale was the outcome measure chosen. This highlighted that one of the participants may be suffering with depression and five may be suffering with anxiety.

The study revealed trends in the emotions of mothers and fathers who had children with MS. They suggested that parents may feel guilty about being healthy when their child was not. The parents reported missing the relationship they had with the child pre diagnosis. Some felt loss for the retirement that they had planned, and some felt conflict, as they themselves may require care in their older age. They felt they were unable to show emotion in front of their children for fear they would burden their child further. Some parents were working to maintain the child’s independence but found the balance between how much to be involved in their care, difficult to juggle.

This study involved interviewing parents who were keen to tell their stories. The sample size was small at only nine participants and all the participants had been or were still married. All the parents interviewed were British. This makes generalising the results difficult and the sample type may not be reflective of the population.

In summary it suggested that health professionals could spend more time to check in with the care providers to offer mental health support if indicated. I am proud to be able to say that my employer (Guy’s and St Thomas’ Wheelchair Services) offers a counselling service for both wheelchair users and those who support wheelchair them, but I am unsure of how well this is utilised by care givers.

As my father in Law’s condition progresses, I will be happy to offer support as a family member with a professional background. It is however difficult to treat family members and not get emotionally involved. I must juggle my role as an inherently risk adverse Physiotherapist with being a daughter in law to let them enjoy their chosen lifestyle for as long as they can.