

Supporting Family and Caregivers in MS- Encouraging Life Enjoyment

Often MS clinics are faced with little time and many patients to see currently exacerbated by new medications with increased risk and complex monitoring programs. However, providing quality and timely supportive care for patients with MS and their family and caregivers is a primary goal of MS nursing care. Often there are many issues at home to consider, some more important to the health care provider and less important to the patient and/or family and caregivers and others vice versa. This poster considers common issues involved in caring for patients with MS and looks to provide a checklist to be used in nursing consultations so that the needs of the patient and family/caregivers are given priority and life enjoyment can possibly be improved.

The Ms Clinic at Westmead Hospital, Australia was established in 2007. At that time it had a small patient load and was easily managed without formal processes. The MS clinic has expanded significantly in the last couple of years to over five hundred patients and it has become apparent that more structured patient care procedures were required. In particular, the redefinition of the evolving MS nurses role was imperative. Previously, referrals were made by the neurologist directly to the MS nurse. While this was satisfactory at the time, there were incidences where the nurse did not receive a referral for a patient despite the patient's significant unmet psychosocial needs. MS nurses are well recognised for the provision of psychosocial support (Burke et.al 2011) and as such are well suited to this important assessment and intervention.

Patients attending the MS Clinic at Westmead Hospital generally reside locally in the western suburbs of Sydney, a region known for areas of socioeconomic disadvantage. This places the MS patient at particular vulnerability due to increased risk of unemployment, poverty, carer strain and social isolation (Mackereth et.al 2008). These patients require extra time, understanding and intervention from health care professionals to ameliorate this disadvantage. In addition, MS patients often require other nursing involvement to manage issues such as fatigue, continence and medications. The MS nurse is ideally suited to addressing these issues which greatly affect quality of life and life enjoyment significantly. It is important that patients are able to address psychosocial issues in the MS clinic and feel that the health care providers view these issues with the same level of concern.

As such, it was decided that the MS Clinic would be restructured so that all patients see an MS nurse. In addition, a tool was needed to ensure that documentation of this assessment was streamlined (see Fig 1). The tool needed to incorporate previous assessments so that the patient's history was available at a glance, especially if a new MS nurse or other health care professional was consulting the patient.

Staff at the MS Clinic will survey patients a year after the introduction of the tool to ensure that our focus remains on the issues that are important to MS patients and their families. We will also conduct interviews with individual patients in a qualitative manner to further guarantee that the clinic addresses patients' quality of life and life enjoyment.

Conclusion: Sometimes the aims of the patient, family and caregiver are not met when there is much to cover in an MS nursing consultation. This checklist has proven to be a valuable resource for the MS nurse and also the patient, caregivers and family as it captures as much information as possible and enables the provision of guidance and resources to improve quality of life and life enjoyment.

References

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- Mackereth, C. & Appleton, J. (2008). Social networks and health inequalities: evidence for working with disadvantaged groups, *Community Practitioner*, 81(8): 23-6.