

Time for a Population Based Approach to Multiple Sclerosis Care

Can. J. Neurol. Sci. 2007; 34: 120

Despite the tremendous advances in understanding and managing multiple sclerosis (MS) in recent years there is much work left to be done. Two papers in this issue of the Canadian Journal of Neurological Sciences^{1,2} document the burden of the disease. While the study by Hopman et al¹ measured outcomes in an MS clinic population, and the study by Pohar et al² analyzed data from the Canadian Community Health Survey, the results paint a remarkably similar and bleak picture.

Pohar et al² show that health related quality of life (HRQL) scores in people with MS are 7.6 times more likely to reflect severe impairment than scores in people without MS and Hopman et al¹ show that all domains of HRQL are impaired. The HRQL scores are not intuitively understood but both papers also highlight several other disease consequences. They show that employment rates in MS populations are lower than 50% despite average disease duration of 15 years. Evidence that an informal caregiver is needed by nearly 50% of people with MS¹ and that over 70% need assistance with one or more tasks² illustrates another consequence of MS. It also hints of the impact that MS can have on family members. It should be noted that these are underestimates of the disease burden because neither study included those most severely affected; people who live in care facilities. Also, while benign MS may be underrepresented in MS clinic samples, the Canadian Community Health Survey would not systematically miss mildly affected individuals. Furthermore, because the average age of MS onset is 30 years most people are affected throughout most of their adult lives.

Given that the prevalence of MS in Canada may be as high as 240 per 100,000³ the societal burden in Canada is also very high. People with MS who live in the community consult a medical doctor nearly twice as frequently as the average community dwelling Canadian, are admitted overnight to a hospital 2.5 times as frequently, and consult a mental health profession 2.6 times as often.² In addition, several symptoms such as pain, depression, and urinary incontinence that significantly reduce HRQL are also identified suggesting that management of these common and treatable MS symptoms could have a major impact on HRQL in MS. These studies therefore imply that improving the health of Canadians with MS could also reduce the societal cost of caring for them.

Finally, these studies provide a baseline estimate of MS disease burden against which we should be able to evaluate the impact of disease modifying therapy on the MS population over the next few decades. Just like the treatment of hypertension has reduced stroke rates, disease modifying therapy for MS should reduce the burden of disease in MS. This outcome however will be dependent on the efficacy of the treatments, the ability of patients to continue therapy over the long term, and the ability of the health care system to get the right treatment to the right people at the right time. Therefore, while the pharmaceutical

industry continues to support research to improve efficacy and tolerance, care providers must recognize that the impact of disease modifying therapy on the MS population will also depend on our ability to optimize use. We have all heard the quote from former US Surgeon General C. Everett Koop that 'drugs don't work if you don't take them' however we must also recognize that the impact of treatment on a population will be reduced if many who should benefit are not even given the opportunity. To ensure that all Canadians who should benefit from MS therapy are given the opportunity we must identify and reduce barriers to the use of evidence based treatment. These barriers include lack of knowledge regarding when treatment is indicated, geographic barriers which limit access to expert neurological opinion, and economic barriers that limit evidence based use of MS disease modifying therapy. This process will require optimizing education about MS and its management, facilitating access to neurologists with expertise in managing MS, and working with provincial governments to make appropriate therapies available to all patients in whom there is appropriate evidence to support therapy. This will also require that neurologists consider the entire MS population, not just people who fall under their care and governments must recognize the importance of this leadership activity. The existence of the Canadian MS Clinics over the past 30 years has been an important step toward population based care but not all Canadians with MS are served by these clinics. Neurologists from the Canadian MS clinics and from the community must continue to participate in the development of better systems of population-based care and must work together to identify and fill gaps in care. Population surveys will continue to be needed to document the overall impact of treatment on people with MS.

Let us be sure we take up these challenges of influencing the health care system and of confirming our successes and ongoing challenges. It will be for the betterment of all people with MS.

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REFERENCES

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