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Observational study

Chronic pain in multiple sclerosis: A 10-year longitudinal study

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HIGHLIGHTS

- Over 10 years chronic pain in MS becomes more generalized and greater pain severity.
- There is deterioration in quality of life, chronic pain grade.
- There is impact on living arrangements and increased healthcare utilization.
- Barriers to medications include fear of taking medications and side effects.

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ABSTRACT

Background and purpose: Pain is a common symptom associated with multiple sclerosis (MS), and has lasting effects on an individual's functional capacity and quality of life. A wide range of prevalence rates of pain (between 23% and 90%)have been reported in MS and this is mainly due to the methodological differences amongst the studies such as variability in patient sources, method of sampling and the definition of pain used. Chronic pain in MS, defined as pain lasting for greater than 3–6 months, can have a significant impact on their biopsychosocial health, including negative impact on activities of daily living, relationships and social participation. The long-term course of MS-related pain and its impact in an Australian cohort over a 7-year period has been investigated earlier. The aim of this longitudinal study was to describe the impact of chronic pain, pain-related disability and carer burden in persons with MS over a 10-year period. The aim of this longitudinal study was to describe the impact of chronic pain, pain-related disability and carer burden in persons with MS over a 10-year period.

Methods: This was a prospective longitudinal study conducted at the Rehabilitation Department of Royal Melbourne Hospital (RMH), a tertiary referral hospital in Victoria and Australia. The source of participants was from the RMH MS database and contains detailed MS patient information including demographic data, diagnosis details (using McDonald's criteria), pain characteristics. Structured face-face interviews and validated measures were used, which include the visual analogue scale (VAS); chronic pain grade (CPG); the assessment of quality of life (AQoL) and the carer strain index (CSI). The mean age of the participants ($n = 70$) was 55.3 years and majority (70%) were female.

Results: The mean age of the participants ($n = 70$) was 55.3 years and majority (70%) were female. The findings show that over time (10 years), participants report having greater bilateral bodily pain and greater description of pain as 'worse as it could be'. Pain types were similar to 7-years follow-up but remained higher than baseline. There was a significant deterioration in quality of life in those with more severe CPG over time. Almost half of the participants 31 (44%) required care either from a private carer, institution or from a family member. Although fear of taking medications and side effects were common barriers to treatment for pain, there was an increase in the use of pharmacological treatment over time and an increase in the use of healthcare services, mainly neurologists and general practitioners.

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Conclusions: The pain measures reported by the participants were similar to those at the 7-year follow-up except there was a greater representation of bilateral pain locations (limb, trunk and facial pain) compared to baseline and 7-year follow-up. At 10-year follow-up, more participants used medications compared to 7-year follow-up and there was an increase in the use of health professionals at the 10-year follow-up. At the 10-year follow up QoL of the participants deteriorated significantly and more participants had progressed to higher CPG III and CPG IV. This study demonstrates that chronic pain is a significant issue over time in MS, with clinical and health implications, impact on quality of life, disability and healthcare utilization.

Implications: Greater awareness of chronic pain in pwMS, cognitive classifications and an interdisciplinary approach is required to improve long-term patient outcomes and well-being.

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1. Introduction

Pain is a common symptom associated with multiple sclerosis (MS), and has lasting effects on an individual's functional capacity and quality of life [1–3]. A wide range of prevalence rates of pain (between 23% and 90%) [4,5] have been reported in MS and this is mainly due to the methodological differences amongst the studies such as variability in patient sources, method of sampling and the definition of pain used [3,6,7]. Chronic pain in MS, defined as pain lasting for greater than 3–6 months [8], can have a significant impact on their biopsychosocial health, including negative impact on activities of daily living, relationships and social participation [2,9].

The long-term course of MS-related pain and its impact in an Australian cohort over a 7-year period has been investigated earlier. This longitudinal 7-year follow-up study conducted in a community cohort, showed that though average pain intensity rating did not change over time (at 7 years from baseline), more participants reported higher rates of pain and greater disability limiting their daily activities [3]. Further, there was deterioration in quality of life (QoL) and increased dependency due to pain-related disability. The authors also found that participants were using less pharmacological medication and using other non-conventional therapies, which is mainly due to barriers to access to healthcare services, lack of finances and fear of side effects [3]. A study by Ehde et al. reported high prevalence of chronic pain and increased pain-related disability (44%) in a community cohort of MS [4]. Stenager E et al. in another 5-year longitudinal study, found significant increase in the number of chronic and acute pain syndromes since diagnosis overtime with deterioration in disability [10].

There is a high prevalence of chronic pain in MS which tends to increase over time. To date there is a lack of longitudinal data on chronic pain in MS past 7 years [3,11] and more research is needed to inform clinical practice in regards to MS-related pain and its long-term impact on disability, functional activity, carer stress and environmental factors (such as living arrangements) [3,6,12]. The objective of this study was to examine longer term effects of chronic pain over 10 years in MS in the community and assess the pain-related disability, carer burden, healthcare utilization and management strategies.

2. Methods

2.1. Setting

This was a prospective longitudinal study conducted at the Rehabilitation Department of Royal Melbourne Hospital (RMH), a tertiary referral hospital in Victoria and Australia. The source of participants was from the RMH MS database and contains detailed MS patient information including demographic data, diagnosis details (using McDonald's criteria [13]), pain characteristics, pain severity and management. This study was approved by the Melbourne Health Human Research and Ethics Committee (HREC 2016.021). The profile of patients captured by the RMH MS database is described elsewhere [3,11]. A pilot evaluation of pain outcomes of persons with MS at the RMH was published in 2005 ($n = 101$) and further 7-year follow up study of this cohort ($n = 74$) for long-term outcomes was published in 2013 [3].

2.2. Participants

The participants for the present study were recruited from an initial cohort of MS participants from the RMH MS Database in 2005 ($n = 101$) [11]. The inclusion criteria for the study were: >18 years of age, fulfilled McDonald's diagnostic criteria [13,14] and had chronic pain defined as (constant or intermittent) pain experienced every day for greater than or equal to 3 months in the 6 months before the interview [10].

The exclusion criteria included: participants with significant co-morbidities (medical instability due to brittle diabetes or angina) or unstable psychiatric disorders, patients with acute pain and/or who did not fulfil the criterion of chronic pain.

Caregiver for this study was defined as 'a person who lives with the participant with MS and provides them with the most care and assistance' [15–17].

2.3. Procedure

All eligible patients in the database who participated in the longitudinal study in 2013 were contacted by phone, invited to participate in this study and were then assessed by an independent assessor. A face-to-face structured interview technique was used, which was conducted by an independent trained research officer using a structured format and standardized instruments (see Measures). All interviews took approximately 45 min and were based in the community setting and home visits. The assessor did not provide prompts but did provide assistance for those who had difficulty answering the questionnaire. Appropriate rest breaks were also provided during these interview sessions. All assessments were secured and entered into the database by an independent data entry officer.

2.4. Measurements

All measurement tools used in the baseline and 7-year follow-up study in 2013 were used for this study. These included pain assessment by using temporal criteria (chronic) as well as a symptom-orientated approach using a structured questionnaire and interview [3]. All reported pain that fulfilled the study criteria

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