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Basic research

What is different for people with MS who have pressure ulcers: A reflective study of the impact upon people's quality of life?

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KEYWORDS
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Abstract *Background:* Multiple Sclerosis (MS) is a progressive, degenerative disease of the central nervous system. People with advanced disease who have compromised mobility, activity, sensory and/or cognitive abilities are at risk of pressure ulcers. Having a pressure ulcer has a substantial impact on a person's quality of life; a generic pressure ulcer Health Related Quality of Life (HRQL) framework has been used in this study.
Aim: To explore the views and opinions of patients with MS who have a pressure ulcer using a thematic framework and compare these to the general pressure ulcer population.
Methods: Data for six MS patients was obtained through secondary analysis of transcripts from semi-structured interviews conducted during two studies which were part of a programme of HRQL Research.
Findings: Patients with MS reported that their pressure ulcer affected their lives physically, psychologically and socially. All were confined to bed (as part of their pressure ulcer treatment) and therefore unable to participate in activities. Difficulties with movement and activity were partially attributed to the MS. Patients with MS did not report feeling ill with their pressure ulcer and expressed positive emotions and optimism. Pain or discomfort was a feature of the pressure ulcer for most patients.
Conclusions: Pressure ulcers have a major impact on QOL for all patients. Problems with mobility and activity associated with the pressure ulcer were confounded by the MS.

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1. Introduction

Multiple Sclerosis (MS) is an acquired inflammatory and neurodegenerative immuno-mediated disorder of the central nervous system, characterised by inflammation, demyelination and primary or secondary axonal degeneration [1] It is progressive in nature and presents with periods of relapse and remission. The rate of progression and time spent in relapse and remission vary with each individual. Symptoms vary according to the affected region and can be cerebellar, motor, sensory, emotional, sexual and elimination related.

The prevalence of MS has been estimated as 83 per 100,000 people in Europe [2], however studies from the UK prevalence ranging between 97 (Leeds Health Authority 2006) and 187 (South East Scotland) per 100,000 population. The variation in prevalence is most likely due to methodological differences in surveys especially case ascertainment and selection [3]. Prevalence rates are reported to be increasing slightly although this may be due to better disease survival rates. It is the most common cause of non-traumatic disability in the younger adult population [4].

Pressure ulcers (PU) are described as "localised injury to the skin and/or underlying tissue usually over bony prominence, resulting from sustained pressure (including pressure associated with shear)" [5]. They range in severity from non-blanching erythema of intact skin (Category 1) to severe full thickness tissue loss (Category 4) [5]. The primary cause of pressure ulcers is sustained mechanical load applied to skin and subcutaneous tissues, usually over a bony prominence such as the sacrum, ischial tuberosity or heel. Tissue damage occurs when the localised mechanical loads induces sustained tissue deformation and leads to ischemia-induced damage and deformation-induced damage [6].

The prevalence of PUs has also been studied. Rates range from 0% to 46% in acute care and 4.1%—32.2% in aged care [5]. The variation is due to different methodologies (e.g. postal surveys or record reviews) and dissimilar populations (e.g. hospital, nursing home or community nursing caseloads). Most prevalence studies include heterogeneous populations in terms of illness or diseases but details of specific diseases such as MS are not given. There is very little published data on the prevalence of PUs in people with MS. One study has reported a 33% prevalence of PUs an MS population [7]. However, this study had limitations due to the small number of participants (n = 33) and only included patients with MS admitted to a private hospital in the USA. Data reporting was incomplete, prevalence was obtained from retrospective examination of the medical records and no information was given regarding severity of disease, comorbidities or reason for admission.

There are many studies on the risk factors for developing PUs [8] some of which have been used to develop risk assessment tools. The primary risk factors for PU development are impaired mobility/activity, diseases affecting skin/tissue perfusion (including diabetes) and skin status (including alterations to intact skin and the presence of existing pressure ulcers) [8]. Other factors which contribute to risk of pressure ulceration include skin moisture, nutritional deficits and reduced sensory perception [8].

The level of risk in people with MS will vary depending on disease severity and mobility limitations. Reduced mobility and activity are common in patients with deteriorating or relapsed MS and place the person at high risk. Other PU risk factors such as reduced sensory perception may be exhibited in people with MS.

Quality of life (QOL) is an important issue for health care management and is becoming recognised as an essential component in health care evaluation. While generic QOL measures can be used with patients with MS they are likely not to be sensitive enough to address all the diverse clinical consequences of the disease. The need for a disease specific measure of QOL is acknowledged by several authors [9,10] as the disease impact and problem severity is thought to affect QOL. Scales have been devised to measure the impact of MS on patients' QOL, these will enable the evaluation of therapeutic interventions and will inform policy and clinical decision making [9,11,12]. Pressure ulceration is acknowledged in some MS QOL studies as a disease related impairment which would affect the patients' QOL but is not incorporated into any of the measures despite the high prevalence given above [7]. This may be because it is a feature more often seen in the advanced stages of the disease and these patients are less likely to be recruited to QOL studies.

The PU-related conceptual framework of Health Related Quality of Life (HRQL) [13, 14] features a number of HRQL domains with components determined by individual patient experiences. For patients with PUs, this model suggests that PUs impact on HRQL through physical, social, psychological/emotional domains. Symptoms such as severe and persistent pain, exudate and odour, add to the disease burden [13,15] for these patients. In addition to the impact of PUs on HRQL, patients