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RESEARCH PAPER

Problematic clinical features of powered wheelchair users with severely disabling multiple sclerosis

Lorraine H. De Souza[1] and Andrew O. Frank[2]

[1]Centre for Research in Rehabilitation, School of Health Science and Social Care, Brunel University, Uxbridge, Middlesex, UK and [2]Stanmore Specialist Wheelchair Service*, Royal National Orthopaedic Hospital, Stanmore, UK

Abstract

Purpose: The aim of this study is to describe the clinical features of powered wheelchair users with severely disabling multiple sclerosis (MS) and explore the problematic clinical features influencing prescription. *Method*: Retrospective review of electronic and case note records of recipients of electric-powered indoor/outdoor powered wheelchairs (EPIOCs) attending a specialist wheelchair service between June 2007 and September 2008. Records were reviewed by a consultant in rehabilitation medicine, data systematically extracted and entered into a computer database. Further data were entered from clinical records. Data were extracted under three themes; demographic, diagnostic, clinical and wheelchair factors. *Results*: Records of 28 men mean age 57 (range 37–78, SD 12) years and 63 women mean age 57 (range 35–81, SD 11) years with MS were reviewed a mean of 64 (range 0–131) months after receiving their wheelchair. Twenty two comorbidities, 11 features of MS and 8 features of disability were thought to influence wheelchair prescription. Fifteen users were provided with specialised seating and 46 with tilt-in-space seats. *Conclusions*: Our findings suggest that people with severe MS requiring an EPIOC benefit from a holistic assessment to identify problematic clinical features that influence the prescription of the EPIOC and further medical and therapeutic interventions.

➤ Implications for Rehabilitation

- People with multiple sclerosis (MS), referred for an EPIOC, require a full clinical assessment to identify problematic clinical features that are potentially treatable and/or can be accommodated through specialised seating and tilt.
- The beneficial effects of TIS should be considered for all EPIOC users with MS and particularly for those with comorbidity
- Poorly controlled spasticity, when identified in people with MS, should be managed through positioning in the chair, pressure-relieving cushion and referral for medical management.

Keywords

Assistive technology, comorbidity, mobility, multiple sclerosis, safety, seating, wheelchairs

History

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Introduction

Multiple sclerosis (MS) is an incurable long-term debilitating neurological condition affecting predominantly young adults but may present in childhood and older age [1]. The most common functional consequence of MS is mobility disability which affects 50% of those diagnosed within 15 years of disease onset [2]. This is due to weakness, spasticity, balance problems and/or fatigue alone or in any combination [2]. A recent report indicates that, for those with relapse-remitting MS, the median time from diagnosis to requiring a wheelchair for mobility is 28 years [3], as measured by the Disability Status Scale (DSS) for MS [4] where a score of eight is defined as ''essentially restricted to bed or chair or perambulated in wheelchair, but may be out of bed itself much of the day; retains many self-care functions; generally has effective use of arms''. This group of people with MS (PwMS) are the most likely to benefit from the provision of powered mobility and it has been estimated from a Canadian survey, that approximately 8% of people with MS (PwMS) will use powered wheelchairs [5].

Electric-powered indoor/outdoor powered wheelchairs (EPIOCs) have been available through the UK National Health Service (NHS) for PwMS and those with other disabling conditions since 1996. Eligibility for NHS EPIOC provision requires a potential user to be able to control the EPIOC safely, independently, and be unable to walk around their home or self-propel [6]. These criteria are based on functional need and the potential benefit to the user. For PwMS, EPIOCs will benefit those who cannot self-propel due to difficulty in grasping and releasing the pushrim of a manual wheelchair, those who have asymmetry of upper limb power and/or wheelchair users' shoulder [7] and consequently are unable to maintain speed over short

*Stanmore Specialist Wheelchair Service has now been disbanded.

Address for correspondence: Lorraine H. De Souza, PhD, Centre for Research in Rehabilitation, School of Health Science and Social Care, Mary Seacole Building, Brunel University, Uxbridge, Middlesex UB8 3PH, UK. Tel: +44 (0)1895 268847. Fax: +44 (0)1895 269853. E-mail: lorraine.desouza@brunel.ac.uk

periods of time. The effort of self-propelling contributes to fatigue and is thought to render self-propulsion non-functional [8]. Powered wheelchairs are often considered for PwMS to address fatigue and to facilitate rest [9].

In addition to mobility disability, PwMS frequently have comorbidities that may affect treatment decisions [10–12]. The number of comorbid conditions are thought to increase with DSS and adversely affect health-related quality of life [13]. For example, the co-occurrence of pain and depression is thought to be noteworthy in PwMS [14], while older PwMS are known to be at increased risk of fracture [15]. Pain is a major problem for PwMS and a challenge for rehabilitation professionals [16], particularly in their wheelchair use and seating [16,17]. Several symptoms characteristic of MS, e.g. spasticity and fatigue are also relevant to wheelchair use. Previous studies in PwMS that focussed on comorbidities have used self-report questionnaires recalling comorbidities at diagnosis and disease onset [12], in those with mild disabilities [10] and in a group of PwMS seeking ambulatory care or hospitalisation [11]. The comorbidities may be associated with differences in clinical characteristics [12] and are likely to be very different in severe disabling MS from those found early in the course of MS due to disease progression and the impact of long-term physical and functional limitations for those who require a wheelchair for mobility. The challenge in this group of PwMS is in identifying what health issues are comorbidities as distinct diagnostic entities and what have arisen due to the long-term impact of the disease. Thus, deep venous thromboembolism (VTE) may be considered a separate diagnosis; however, the increased frequency in late-stage MS is suggested to be due increased risk factors such as immobility and limb paralysis [18].

Little research has been carried out into the mobility needs of those who are very severely affected by MS. We have found no reports of comorbidity in wheelchair-dependent PwMS. The benefits of independent powered mobility (PM) include education [6,19,20] or work [6,19,20], and a range of social activities such as shopping [6,19,20], church going [6,19–21], socialising with family and friends [6,19,21–23] and accessing healthcare facilities [6,21,22]. In addition, the increased mobility provided by PM enhances quality of life and well-being [23,24].

Multidisciplinary clinical teams assessing for prescription of EPIOCs will have knowledge and information about the potential users' diagnoses. The important aspects of the clinical picture are those with significant implications for seating and/or the control of the EPIOC. Consideration needs to be given to the progression of the MS, the risk of potential complications including the development of new comorbidities, e.g. osteoporosis or pressure sores, environmental factors and active ageing.

The aim of this study is to describe the problematic clinical features of powered wheelchair users with severely disabling MS. We shall explore the complexities of comorbidities, clinical features of MS and conditions secondary to disability influencing prescription and compare our findings of comorbidity recorded in the clinic with the classifications used in self-report questionnaires in those mildly or moderately disabled with MS [10–12].

Methods

The setting

The Specialist Wheelchair Service at Stanmore was set up in 1997 in response to the new NHS provision of EPIOCs [25]. It provided a regional service for a population of around 3.1 million people from both rural and inner city areas and provision was limited to those who were unable to walk safely around their home, unable to self-propel and were judged safe to use their chairs in the public places irrespective of age, diagnosis or time using a wheelchair (if any) [6].

Provision involved a four-stage process:

(1) Completion of a screening questionnaire by the local wheelchair service provider.
(2) Assessment by an occupational therapist from the local wheelchair service for the suitability of the home environment and the likelihood that the eligibility criteria would be fulfilled.
(3) Assessment at the specialist regional service which involved an interview, eye examination and physical examination to assess any likely problems with seating or controlling a powered wheelchair. The assessment was completed with a driving assessment to ensure that there was satisfactory control of the wheelchair and to ensure safety for the users and others.
(4) Delivery of the chair was undertaken by a rehabilitation engineer who explained the use of the chair, checked seating and that driving appeared satisfactory.

Participants

Potential participants were living in the community and were referred from their local wheelchair service. All individuals who had been prescribed an EPIOC and were currently using their chair were of interest to this study. The criteria for inclusion to this study were those with a diagnosis of MS and who met the criteria for EPIOC provision. These criteria are consistent with DSS 7.5 ''Unable to take more than a few steps. Restricted to wheelchair and may need aid in transferring. Can wheel self but cannot carry on in standard wheelchair for a full day and may require a motorised wheelchair'' [26].

Data collection

Data for each individual were obtained from two sources. The electronic record which contained personal, demographic and diagnostic information together with details of the EPIOC prescription and any special seating needed. The second source was the clinical record which contained all the clinical information and safety issues recorded by the rehabilitation team which consisted of a doctor, wheelchair therapist and rehabilitation engineer.

These records were reviewed between June 2007 and September 2008 by a consultant physician in rehabilitation medicine and data were systematically extracted, anonymised and entered into a computer database for analysis. Data were extracted under three themes; demographic profile, clinical profile and wheelchair factors.

Demographic profiles consisted of information on age at initial EPIOC assessment and gender. Clinical profiles included the diagnosis of MS, comorbidities (e.g. asthma or cancer), clinical features of MS (e.g. trigeminal neuralgia or spasticity) and features of disability (e.g. pressure sores or (kypho)scoliosis). To determine if conditions recorded in the EPIOC users were similar or different to those previously reported, they were classified as comorbidities if used in the self-report questionnaires of Marrie et al. [12] and Horton et al. [10]. They were also compared with the comorbidities noted by Kang et al. in Chinese people with MS [11].

Conditions classified as comorbidities included those that may be unrelated to MS but reported to have co-occurrence with the disease, e.g. fractures [15] and depression [14]. Conditions classified as features of MS were reported as known signs and symptoms of the disease [27]. Weakness was not recorded as it is universal in a group of neurologically impaired EPIOC users.

Complications consequent to long-standing immobility and relevant to EPIOC prescription were classified as features of

severe disability. Back pain associated with kyphus or fracture was not coded as back pain but as the underlying cause.

Because of the ambiguities in which some clinical features may reflect either the MS itself, a comorbidity or a feature of disability, these factors have been grouped as ''additional clinical features'' (ACFs) when referred to collectively.

Wheelchairs and seating

Data relating to specialised seating (SS), defined as ''that which is needed by people who require a wheelchair but due to instability or deformity need additional support in order to function'' [28] were recorded. Other features included tilt-in-space (TIS) function, complex controls, e.g. central joystick/tray-mounted controls, head controls, interfacing switch controls with other assistive technology, non-standard control system, and cushions.

Methods of analysis

Data were analysed to describe proportions and frequencies of variables to determine the type of wheelchair and SS provision. Comorbidities, features of MS and features of disability were categorised by type or description and by frequency of occurrence. Descriptive statistics were used to analyse demographic data. This study was approved by the National Research Ethics Service.

Results

Ninety-one users had a diagnosis of MS. They consisted of 28 men with a mean age of 57 (range 37–78, SD 12) years and 63 women with a mean age of 57 (range 35–81, SD 11) years. Users had been with the EPIOC service a mean of 64 (range 0–131) months at the time of review. Only partial data were available on the medical profiles of 42 users while data on TIS were available for 82 users.

Comorbidities

Twenty-two comorbidities were identified. Of these, 12 were the same as those comorbidities found by Marrie et al. [12] and Horton et al. [10] (Table 1) and a further 10 were not represented in those publications. They were: fractures ($n = 6$), cerebrovascular disease/stroke ($n = 2$), a noted comorbidity of Kang et al. [11], and one each of the following – amputation, cervical cancer, hearing impairment, lymphoma, platelet disorder, polyarthralgia, radial dysplasia and weight loss of uncertain cause. The most frequent comorbidities found were asthma and depression.

Twenty-seven users (30%) had 34 occurrences of comorbid health conditions that might reasonably be expected to be aggravated by constant sitting in an EPIOC. These consisted of pressure sores (9), probable osteoporosis (8), severe oedema with or without cellulitis (5), diabetes (3), hypertension (2), thromboembolic disease (2), stroke (2) and one occurrence each of hypercholesterolaemia, weight gain and ischaemic heart disease.

Features of MS

Eleven features of MS were recorded. Poorly controlled spasticity was by far the most common feature of MS noted in 10 users. We also found five users with either urinary (3) or faecal (2) incontinence inadequately controlled, four of which were provided with SS. Two EPIOC users had shown the ability to drive safely in spite of their visual impairments.

Features of disability

Eight conditions consequent to disability were noted (Table 2). Pressure sores (including leg ulcers) and low back pain were the most often found conditions consequent to disability (Table 2).

Table 1. Comorbidity in 91 electric-powered indoor/outdoor wheelchair users with multiple sclerosis compared to published comorbidity for the disease ([a]noted by Kang et al. [11]).

Comorbidity [12]	Comorbidity [10]	Comorbidity DeSouza and Frank (*n*)
Anaemia	Anaemia	
Arthritis	Arthritis	Arthritis: osteoarthritis (3)
Breast cancer	Breast cancer	
Cataracts	Cataracts	
Colon cancer	Colon cancer	
Diabetes	Diabetes	Diabetes (3)
Fibromyalgia	Fibromyalgia	
Glaucoma	Glaucoma	
Heart disease	Heart disease	Heart disease (2)[a]
Hip replacement	Hip replacement	
Hypercholesterolaemia	Hyperlipidaemia	Hypercholesterolaemia (1)
Hypertension	Hypertension	Hypertension (2)
Inflammatory bowel disease	Inflammatory bowel disease	Inflammatory bowel disease (1)
Irritable bowel syndrome	Irritable bowel syndrome	Irritable bowel syndrome (1)
Kidney disease	Kidney disease	
Knee replacement	Knee replacement	
Liver disease	Liver disease	
Lung cancer	Lung cancer	
Lung disease	Lung disease	Asthma (5)[a]
Peptic ulcer disease	Peptic ulcer disease	
Peripheral vascular disease	Peripheral vascular disease	
Rectal cancer	Rectal cancer	
Rheumatoid arthritis	Rheumatoid arthritis	
Sjogren's Syndrome	Sjögren's syndrome	
Skin cancer	Skin cancer	
Systemic lupus erythematosus	Systemic lupus erythematosus	
Thyroid	Thyroid	Thyroid (1)[a]
Uveitis	Uveitis	
Vitamin B 12 deficiency	Vitamin B 12 deficiency	
Human Immunodeficiency Virus		
	Anxiety	
	Bipolar disorder	
	Depression	Depression (5)[a]
	Epilepsy	Epilepsy (1)[a]
	Migraine	
	Osteoporosis	Osteoporosis (1)
	Schizophrenia	

Problematic clinical features requiring further medical management were found in 35 users, who were referred onwards to their family doctors, sometimes suggesting further specialist involvement. Of these users, 14 required medical management for problematic pain. The most common causes were low back pain and spasticity.

In summary, 31 users had no ACFs. Twenty nine users had 1 ACF and 31 users had two or more. A total of 41 different ACFs were noted. In the 60 EPIOC users with one or more ACFs, the frequency of ACFs totalled 108, of which 42 were comorbidities, 28 were disabling features of MS and 38 were features of disability (Table 2).

Wheelchairs and seating

Fifteen users (eight men) were provided with SS and 46 (15 men) with TIS. Fourteen users were given both SS and TIS. Of the 15 users with SS, 11 had one or more ACFs (Table 3). Of these 15, three needed matrix seating systems and the remainder had standard pressure-relieving cushions (Roho = 3 [The Roho Group,

Table 2. Frequency of features of multiple sclerosis (MS) and features of disability found in 91 electric-powered indoor/outdoor wheelchair recipients.

MS features (*n*)	Disability features (*n*)
Spasticity (10)	Pressure sores/leg ulcers (9)
Urinary incontinence (3)	Low back pain (9)
Choking/swallowing issues (2)	Dependent oedema/cellulitis (5)
Constipation (2)	Shoulder pain (4)
Faecal incontinence (2)	(kypho)scoliosis (4)
MS fatigue (2)	Neck pain (4)
Trigeminal neuralgia (2)	Thromboembolic disorders (2)
Visual impairment (2)	Weight gain (1)
Contractures (1)	
Urinary tract infection (1)	
Intractable pain – cause unclear (1)	

Table 3. Factors relating to additional clinical features (ACFs) of 91 electric-powered indoor/outdoor wheelchair users with multiple sclerosis.

	No ACFs	One ACF	Two or more ACFs	Total
N	31	29	31	91
Age (mean, SD, range)	59, 9.7, 37–74	60.2, 11.1, 39–78	58.7, 12.9, 35–81	59.3, 11.2, 35–81
Male: Female	10:21	10:19	8:23	28:63
TIS (y, n, nk)	11, 14, 6	17, 10, 2	18, 12, 1	46, 36, 9
SS (y, n)	4, 27	5, 24	6, 25	15, 76

TIS, tilt-in-space; SS, specialised seating; y, yes; n, no; nk, not known.

Belleville, IL], Vicaire = 3 [The Comfort Company, Bozeman, MT], Qbitus = 3 [Qbitus Products, Halifax, UK], Jay2 = 2 [Sunrise Medical Limited, West Midlands, UK], TempurMed = 1 [Sumed International (UK) Ltd, Glossop, UK]) in addition to their seating modification.

Of the 46 users with TIS, 11 had no ACFs, 17 had one ACF and 18 had 2 or more ACFs (Table 3). Forty had standard pressure-relieving cushions (Qbitus = 16, Vicaire = 8, Jay2 = 8, Flotech = 3, Roho = 3, Tempurmed 1 and V-Trak [Pontyclun Rhondda Cynon Taff, UK] = 1. Three users had standard wheelchair cushions and three were provided with matrix seating (as mentioned above).

No users needed wheelchair mounted ventilators and only two users required complex controls. A 50-year-old woman with secondary progressive MS and hyperthyroidism had profound finger/hand weakness challenging our control system. She needed a non-standard tray-mounted system that interfaced with an environmental control unit (ECU). The other was a 62-year-old man with MS as the only diagnosis who needed SS and chin controls. This user was advised to have an additional control stick for carer's use.

Of the 10 users with poorly controlled spasticity, six received either TIS and or SS. All 10 received pressure relieving cushions. Three users with spasticity had pressure sores. The two users with bilateral ischial pressure sores were provided with both TIS and SS. A third user with a pressure sore had neither TIS nor SS. Both users with severe MS fatigue had TIS.

Safety concerns were noted in six users. Three had suffered accidents through toppling out of their EPIOC (one had driven off the curb). One experienced an electric burn on the arm following an electrical short from the control system through the user's metal jewellery. The user noted above (with carer-operated controls) was given these controls for safety reasons, e.g. when the user was weaker following an infection or flare in the MS. Another had the EPIOC withdrawn following symptom progression resulting in an inability to drive safely.

Discussion

This article reports, for the first time, the problematic clinical features seen in EPIOC users severely disabled by MS that are due to both the established impact of late-stage MS and the accumulative effect of long-term disability. Our results demonstrate that these features, including comorbidity, in PwMS severely affected by mobility disability are very different when compared with those at an earlier stage of the disease.

MS participants

The mean age and range of our MS EPIOC users is similar to that reported by Dewey et al. [29], Devitt et al. [30], to the subgroup using TIS reported by Chan and Heck [31] and to the severely disabled PwMS of DSS >6.5 reported by Arpaia et al. [18]. Our MS participants were older by approximately 10 years than the MS users of manual pushrim wheelchairs described by Fay et al. [8], who are likely to have greater upper limb and upper trunk function than those reliant on powered mobility. The ratio of men to women in our MS participants is reflective of the general MS population [1].

Comorbidities

A comparison of our results with published MS comorbidity [10,12] shows 12 conditions that have previously been reported but 10 that are unreported in the current literature. Many possible explanations for this discrepancy relate to the later course of the lifecycle that severely disabled PwMS reflect. In addition, the treatment of some of these conditions may have been completed, e.g. cataracts. Other PwMS may have died at earlier stages of the disease due to related/unrelated conditions. Comorbidities found in our group, e.g. cervical cancer and lymphoma were not noted in these studies.

Several comorbidities found in our group of EPIOC users are likely to affect the health and well-being of the individual but have little or no impact on the prescription of the EPIOC, e.g. hypercholesterolaemia. Other comorbidities found have a direct influence on the wheelchair prescription and may, in their own right, result in the need for the EPIOC irrespective of the MS, e.g. amputation. This is clearly illustrated by an individual with pre-existing MS who only became reliant on an EPIOC after having a stroke. However, some comorbidities have a direct influence on the prescription without being the primary reason for EPIOC provision. This is demonstrated by the individual we report with both MS and hyperthyroidism where complex controls were needed due to the profound hand weakness.

Our findings also illustrate the occurrence of life-threatening conditions with PwMS and severe mobility disability. Comorbidities, e.g. thromboembolism may be causes of unexpected deaths [32] but which are amenable to prevention through adequate medical intervention. In our study, these cases resulted in referral onwards to the primary care team for further medical management. Although evidence is lacking to support the difficult clinical decisions needed to inform best rehabilitation practice for those with multiple health conditions [33], it is recommended that taking specific precautions could prevent some deaths in MS [32].

Features of MS

Poorly controlled spasticity was the commonest MS feature found in our group. This may have reflected inadequate utilisation of physiotherapy, medication and the specialist spasticity services available. The presence of poorly controlled spasticity influenced

EPIOC prescription as spasticity can be managed through positioning in the wheelchair. Our results suggest that six users with poorly controlled spasticity were provided with both TIS and SS. Poorly controlled spasticity predisposes to further complications such as pressure sores and contractures and thus pressure-relieving cushions were provided for all 10 users with spasticity.

The five users noted to have continence issues would have been given appropriate advice, but the rehabilitation team would have to plan for incontinence with appropriate cushions, linings and the expectation of increased transfers in/out of the chair. Occasionally drainage issues have been noted with tilt and urinary catheterisation [29].

Although visual impairments are common in MS, PwMS would not be excluded from use of an EPIOC if they showed, during assessment that they could drive safely and had compensated for any visual field defect.

Other features such as swallowing and choking are often managed through posture which an EPIOC can facilitate. MS fatigue may be the primary reason for EPIOC provision when self-propulsion is either too slow to be functional or becomes impossible [8]. More usually, it will be managed by use of TIS [29] as with our two users. Trigeminal neuralgia may be assisted by use of EPIOCs with good suspension, and/or by cushions that dampen vibration.

This study found that 14 users had problematic painful conditions which may be due to the underlying medical condition, the wheelchair or a combination of the two [17]. Wheelchair technology, e.g. TIS or back/leg rests and/or appropriate cushions can do much to ameliorate problematic pain. Wheelchair providers should be more proactive in exploring the pain experiences of users and utilise existing technology appropriately, together with user feedback [17].

Features of disability

Pressure sores, including leg ulcers, were the most common feature of disability found. While prevention and treatment of pressure sores is stressed in guidelines for MS management [34], these guidelines do not refer to the risks of osteoporosis (although these risks have been recognised for some time) [35], VTE [18,32,36] or coronary heart disease [32]. It is likely that the five users reporting fractures had undiagnosed osteoporosis. Osteoporosis is important for PwMS in view of the known risk of accidents such as tipping out of wheelchairs [6,19] or falls during standing or transfers [6]. These risks are additional to the risks of osteoporosis for PwMS relating to immobility, previous steroids and potential lack of vitamin D through being housebound [23].

Wheelchair dependency places people at risk of weight gain and obesity [37,38]. Although our findings identified only one individual who was gaining weight such as to need a wider than normal wheelchair, this issue should be considered within the overall assessment. It is recommended that investigations into weight and MS are needed to elucidate the relationship with disability [39]. Users gaining weight who need wider chairs maybe unable to go through some doors at home without further house adaptations. Wheelchair services could offer regular weighing; and measurement of abdominal girth may be taught as a self-management technique as routine screening for being overweight is recommended [39].

Ambiguities of classification

Classification of clinical features is complex and imprecise yet is important, e.g. for ''understanding, shaping and managing the outcomes of the provision of AT devices'' [40]. This article has attempted to categorise problematic clinical features into three groups to clarify, potentially, their importance in EPIOC users with advanced MS.

By exploring these profiles, the information gained may assist the complex and difficult decisions that rehabilitation professionals make when prescribing EPIOCs to severely disabled PwMS. Such decisions are made, not only in the best interests of the user but also recognising user and carer preferences. Taking into account the comorbidity and the complications of MS and disability avoids the dangers of ''siloing'' users into a single diagnostic group [33] and the potential additional costs for failing to account for disease severity [41] and any additional impairments.

Definitions of comorbidity are problematic, for example:

- Epilepsy is listed as a comorbidity [10] but ''can reasonably be attributed to multiple sclerosis'' [27, p. 171].
- Low back pain may be the presenting symptom of MS, but is more likely to reflect abnormal posture and muscle spasms [27].
- Depression was classified as a comorbidity [10–12] although it has long been recognised as prevalent in MS [14] as in other disabling conditions.
- Fractures were previously classified as a comorbidity [10,12] but the risk of fracture is increased in long-standing MS [15].
- Stroke featured as a comorbidity only in Kang et al. [11] and may be a feature of MS [41,42] or due to our MS group being older than previously reported populations.

Consequently in the context of EPIOC provision, using the term ''additional clinical features'' rather than seeking to differentiate between the health problems noted may be more helpful. This has implications for funding systems which may or may not include comorbidities as part of the costing.

Wheelchairs and seating

This study found that the majority of PwMS provided with TIS had one or more ACFs. The main beneficial effect of TIS is to provide pressure relief and as part of the strategy to relieve pain and to aid comfort [29,43]. This is supported by evidence indicating that wheelchairs with TIS have a beneficial effect on posture, fatigue, respiration and voice production [31], in addition to pressure relief and comfort [29].

Fewer PwMS (8%) were provided with both TIS and SS compared to 17% in a general population of EPIOC users [44]. Our finding that very small numbers of PwMS EPIOC users needed either Matrix seating or complex controls implies that the majority had sufficient residual voluntary function of the upper limbs and upper trunk to enable them to use standard equipment. The provision of EPIOCs and seating should account for the fluctuations of MS (periods of exacerbation, e.g. increased walking difficulty) and the deteriorating nature of the disease [43]. Adaptive seating (SS) was provided to only 16% of this group. Three users needed matrix seating indicating that the need was for postural maintenance and stability. The remainder had pressure-relieving cushions indicating that the clinical decision had identified risk of pressure sores. Our findings report a lower proportion of PwMS using SS than previously reported by the British Society of Rehabilitation Medicine [28]. It is probable that certain features of MS (e.g. weak trunk muscles) that may have required SS previously, were better managed by TIS provision as it became more readily available [29].

This study had no consistent data on the provision of elevating leg rests as they were not routinely documented in the departmental database. Future studies could investigate this.

Strengths and limitations of the study

A major strength of this study was the eligibility criteria which restricted EPIOC provision to those with a DSS of 7.5 or more

and only included users of powered wheelchairs suitable for both indoor and outdoor use. This contrasts with literature concerning people benefiting from state or insurance provision of scooters, power-assisted and outdoor powered wheelchairs [22] or manual and powered chairs. Our sample is consistent with other samples reported [18,29] and therefore would appear to be representative.

A further strength is that all PwMS were seen by a multi-disciplinary team with expertise in the management of wheelchair users with severe and multiple impairments. Thus, the team's expertise was consistently applied, in accordance with the department's clinical protocols, to take the clinical decisions for EPIOC prescription.

This study is likely to under-report ACFs that were identified, first as the diagnostic data were mostly obtained via referral letters and patient histories; and second as case note reviews are less comprehensive than prospective data [30]. Nonetheless, these data are more objective than data that rely purely on patient self-report surveys. Further prospective studies are needed.

Another limitation of this study is that the PwMS had different experiences of powered mobility. Some were new EPIOC users and others had long-standing experience of powered mobility. Our sample does not include those who may have purchased wheelchairs privately or through charitable funding.

Our findings were limited by missing TIS information on nine (10%) users and only partial data on the medical profiles of 42 users. It is recommended that future studies utilise the available comorbidity information for a more complete picture.

Recommendations

- Those with MS needing powered mobility should have a clinical assessment of their MS, comorbid problems and complications of disability to determine their influence on chair prescription
- Our findings indicate that research is needed to establish the significance of the following risks to health in MS EPIOC users:
- Osteoporosis – with potential to minimise through diet, medication and/or supplementary calcium and vitamin D
- Thromboembolic disorders – with potential for prophylaxis with compression bandages and aspirin/anti-coagulants
- Cardiovascular disease – with potential for weight and lipid management
- Pressure ulcers – prevention should follow NICE guidelines for assessing risk [34]. Such guidelines now need to include risks from comorbidity and life-threatening conditions.

Conclusion

Support that focuses more on the person than on the disease and the range of variation that this entails has been called for [33]. Our findings demonstrate that the multi-disciplinary co-ordinated approach taken by the EPIOC service is appropriate for meeting the health needs of users through a holistic approach in the provision of powered mobility. These findings may be unsurprising to clinicians seeing individuals with severe disability, but little is published on the management of many of these features in MS. Our findings suggest that problematic clinical features seen in people with severely disabling MS have consequences for EPIOC provision especially with regard to type of chair and seating prescription. Our findings also identify serious clinical conditions (occasionally life-threatening) that may need urgent medical attention but do not necessarily impact on EPIOC provision.

While the management of MS is predominantly symptom led, this research highlights the need for preventative and health-promoting interventions that may improve the health and well-being of PwMS who are severely disabled.

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Declaration of interest

The authors declare no conflicts of interests. The authors alone are responsible for the content and writing of this article.

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