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Frequency and circumstances of falls in people with inclusion body myositis: a questionnaire survey to explore falls management and physiotherapy provision

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Abstract

Objectives To survey the incidence and circumstances of falls for people with inclusion body myositis (IBM) in the UK, and to investigate the provision of physiotherapy and falls management.
Design Postal questionnaire survey.
Setting Participants completed questionnaires at home.
Participants Ninety-four people diagnosed with IBM were screened against the inclusion criteria. Seventy-two potential participants were sent a questionnaire, and 62 were completed and returned. Invited participants were sent an adapted Falls Event Questionnaire pertaining to falls, perceived causes of falls and the provision of physiotherapy. Questionnaires were returned anonymously.
Main outcome measures The proportions of respondents who reported a fall or a near fall, along with the frequencies of falls and near falls were calculated. Descriptive data of falls were collected pertaining to location and cause. Data analysis was performed to investigate provision of physiotherapy services.
Results The response rate was 86% [62/72, mean (standard deviation) age 68 (8) years]. Falls were reported by 98% (61/62) of respondents, with 60% (37/62) falling frequently. In this study, age was not found to be an indicator of falls risk or frequency. Twenty-one percent (13/62) of respondents had not seen a physiotherapist in relation to their IBM symptoms, and of those that had, 31% (15/49) had not seen a physiotherapist until more than 12 months after IBM was diagnosed. Only 18% (11/61) of fallers reported that they had received falls management input.
Conclusions Falls are a common occurrence for people with IBM, independent of age and years since symptoms first presented, and are poorly addressed by appropriate physiotherapy management. National falls guidelines are not being followed, and referral rates to physiotherapy need to improve.

Keywords: Neuromuscular disease; Inclusion body myositis; Physiotherapy; Falls; Falls management; National falls guidelines

Introduction

Falls are a common problem for older people and those with neurological conditions [1–3], and are commonly reported by people with specific neuromuscular diseases [4]. As well as the risk of immediate injury, falls can lead to avoidance of activities and reduced mobility due to fear of falling [3,5], and this fear is a prominent reason for wheelchair use [4].

Sporadic inclusion body myositis (IBM) is an acquired muscle disease and the most common myopathy in people aged >50 years [6]. The prevalence of IBM is difficult to ascertain due to likely underdiagnosis, and available data suggest a range of 4.9 to 70.6 per million depending on the study population and ethnic group [7]. It remains uncertain whether IBM is primarily an immune-mediated inflammatory myopathy or muscle degeneration with an associated inflammatory component [6,7]. People with IBM develop a slowly progressive weakness of selected muscle groups, most notably the quadriceps, ankle dorsi-flexors and long finger flexors [6,7].

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Previous research looking at the multidisciplinary services provided to patients with neuromuscular disorders in a Dutch population [8] suggests that, although overuse of therapy services is common in neuromuscular disease, almost one-quarter of such patients underutilise available physiotherapy services. However, as yet, the frequency and causes of falls have not been studied specifically in patients with IBM, and neither has the provision of therapy aimed at falls prevention or management within this patient group.

The aim of this study was to survey the incidence and circumstance of falls for people with IBM in the UK, and to investigate the provision of physiotherapy in this population with specific regard to falls management.

Methods

Participants

Fifty-two potential participants were identified from clinical caseloads at the Centre for Neuromuscular Diseases, University College London Hospital NHS Foundation Trust (UCLH). A further 42 potential participants made contact with the research team after receiving information about the study from the Myositis Support Group and the Muscular Dystrophy Campaign (see Fig. 1, online supplementary material). Non-UCLH patients were asked to provide a copy of their muscle biopsy and clinical reports for review by the UCLH muscle consultant or research fellow. This was to confirm that clinical phenotypes and biopsy features supported a diagnosis of IBM. Patients had to fulfil either the definite or possible IBM Griggs' criteria [9] or the pathologically or clinically defined IBM Medical Research Council criteria [10].

Of the 94 potential participants, 22 were excluded. This was due to having a clinical phenotype or muscle biopsy report that could not exclude other forms of neuromuscular disease, being unable to provide results of a muscle biopsy, or having received a more recent neurological/neuromuscular diagnosis other than IBM.

Ethical approval for this study was granted by the London – Queen Square NHS Research Ethics Committee.

Data collection

Seventy-two people with confirmed IBM were sent a cover letter, study information sheet and an anonymised questionnaire adapted from the Falls Event Questionnaire (FEQ) [1,2,6]. This adapted version of the FEQ collected information on both falls and near falls, as well as IBM history, provision of physiotherapy and provision of falls management services. Stamped addressed envelopes were provided for the return of completed questionnaires to the research team, and no follow-up communication was made unless specifically requested by the participant upon being invited to take part.

Data analysis

The proportions of respondents who reported a fall or a near fall, along with the frequencies of falls and near falls were calculated. A Spearman's rank correlation was performed using Statistical Package for the Social Sciences Version 19.0 (IBM Corp., New York, NY, USA) to investigate any association between age and the frequency of falls, and also between the number of years since onset of symptoms and the frequency of falls. Descriptive data of falls were collated by two researchers independently (AH and LD) for coding of emergent themes related to location, activity and perceived cause. Additional analysis was undertaken to identify the proportion of participants who were receiving, or had ever received, physiotherapy input with an emphasis on falls prevention and management.

Results

Falls and falls frequency

Sixty-two of 72 questionnaires were returned (86% response rate). The mean (standard deviation) age of respondents was 68 (8) years (range 45 to 84 years), and 65% (40/62) were male. A history of falls was reported by 98% (61/62) of respondents. All respondents aged >65 years reported having fallen, as did 94% (17/18) of respondents aged <65 years. Falling at least once a month was reported by 34% (21/62) of respondents, and 60% (37/62) of respondents reported falling at least once every 3 months, as shown in Table 1. Forty-eight of 62 (77%) respondents had fallen at least once in the 3 months prior to completing the questionnaire. This study found no correlation between age and the frequency of falls ($r = 0.009$, $P = 0.94$), nor between the number of years since the onset of symptoms and the frequency of falls ($r = -0.06$, $P = 0.66$).

Fewer respondents reported near falls (56/62, 90%), but at higher frequencies than actual falls (Table 1). Serious injuries were not common in the recorded falls, with 57% (99/175) resulting in minor injuries such as cuts and bruises, and 30% (52/175) causing no injury at all. A minority of falls (5%, 8/175) resulted in a major injury. Examples of serious injuries from this study include ankle/lower leg fractures, rib fractures and, in one case, a subdural haematoma requiring surgery. No cases of proximal lower limb (i.e. hip) fractures were reported.

Table 1
Frequency of fall and near-fall events.

	At least once a day	At least once a week	At least once a month	At least once in 3 months	At least once in 6 months	At least once a year
Respondents who fall (%)	0	3	34	23	21	18
Respondents who nearly fall (%)	16	32	21	10	11	0