**The positive and the negative impacts of spasticity in patients with long-term neurological conditions: An observational study**

**Alessia Saverinoa, Jared G Smithb Sandy Ayoubc Isabel Carya, Catherine Daltona, Aimee Pintoa, Claire Warda**

aSpasticity Service at the Wolfson Neuro Rehabilitation Centre, Queen Mary Hospital, London

b Population Health Research Institute, St George's, University of London, Cranmer Terrace, London SW17 0RE

Corresponding author (please address proofs and reprints to):

Dr Alessia Saverino

Spasticity Service at the Wolfson Neuro Rehabilitation Centre

Queen Mary Hospital,

LONDON SW17 0RE

E-mail address: alessia.saverino@stgeorges.nhs.uk

Abstract

**Purpose:** To describe the positive and negative impacts of spasticity across different neurological disorders using the Patient Reported Impact of Spasticity Measure (PRISM), deduce any associations between severity of spasticity and its impact, and assess for differences across diagnostic subgroups.

**Materials and methods:** PRISM, a spasticity-specific quality of life questionnaire validated in patients with spinal cord injuries, was given to 97 follow-up patients attending a spasticity clinic prior to symptom assessment using the REsistance to PAssive movement Scale (REPAS).

**Results:** Patients described a minor level of positive impact and a marked negative impact in the domains of ‘Psychological Agitation’, ‘Daily Activities’, ‘Need for Assistance/Positioning’ and ‘Social Avoidance/Anxiety’. Spasticity severity was, in general, a poor predictor of perceived impact, although severity and localisation of spasticity was modestly correlated with ‘Need for Assistance/Positioning’ and ‘Social Embarrassment’ levels. Despite comparable levels of spasticity severity, people with MS expressed a more substantial impact across some PRISM domains than did patients in other groups.

**Conclusion:** PRISM can be useful to assess the impact of spasticity in various neurological conditions although further validation studies are needed.

Keywords: PRISM; neurorehabilitation; stroke; multiple sclerosis; cerebral palsy; traumatic brain injury; spinal cord injury

**The positive and the negative impacts of spasticity in patients with long-term neurological conditions: An observational study**

Spasticity refers to a velocity-dependent increase in muscle tone, accompanied by uncontrolled involuntary muscle contractions, which affects people with central nervous system pathology – otherwise known as upper motor neurone lesions. A systematic review on the epidemiology of leg spasticity (1) reported a prevalence of spasticity in approximately one third of patients with cerebrovascular accidents (CVA), half to two thirds of patients with multiple sclerosis (MS), one eighth of patients with traumatic brain injury (TBI), and three quarters of patients with cerebral palsy (CP) as well as a proportion of patients with spinal cord injury (SCI).

The impact of spasticity can vary from manifesting as a subtle neurological sign to causing significantly limited mobility, progressive joint deformities and difficulty maintaining personal care. Spasticity may also have a positive impact on patients’ function and perception. It can act as a substitution for muscular weakness, aid in the preservation of muscle mass, and decrease the prevalence of deep venous thrombosis (2).

Because of its multifaceted presentation, spasticity has posed a challenge to the development of assessment tools and outcome measures aiming to quantify the effectiveness of treatments. It is important to also consider that the degree of spasticity varies with the time of day, position of the joints, stress levels, external temperature and any nociceptive factors (3). The Royal College of Physicians’ guidelines for the management of adult spasticity (4) stress the importance of setting clear and specific goals for treatment based on functional outcomes, rather than treating spasticity per se, and taking into consideration patient perspective using the multifactorial framework of the International Classification of Functioning (ICF) (5). In this model, spasticity is evaluated in the domains of impairment (e.g. the resistance to passive movement), limitation in functional activities (e.g. washing, dressing, toileting) and participation in social and vocational activities (e.g. community access, going out with friends), human and environmental context and perceived quality of live (QoL). In particular, the guidelines recommend the use of the spasticity-related quality of life tool (SQoL-6D) to measure the domain of QoL.

Unfortunately, the SQoL-6D questionnaire is not validated and does not take into account the positive impact of spasticity. Other spasticity-specific QoL questionnaires such as the Patient Reported Impact of Spasticity Measure (PRISM) (6,7) and the Spinal Cord Injury Spasticity Evaluation Tool (SCI -SET) (8) have been standardised in patients with spinal cord injury (SCI) - and their use has been recommended in conjunction with generic measures of health related QoL in patients with SCI (9).

Although studies employing generic measures such as the SF-36 (or its short

form SF-12), the EuroQol-5 dimension (EQ-5D), and the Stroke-Specific Quality of Life (SSQOL) have shown that spasticity is associated with impaired QoL, particularly in people with MS and CVA (1,10–14), there is limited evidence for the negative impact of spasticity on QoL in non-SCI neurological conditions as measured by spasticity-specific QoL questionnaires, with very few direct comparisons across different neurological conditions. In one such study, Knezevic et al. (15) validated a Serbian translation of the PRISM, the PRISM-SR, in patients with progressive MS. They noted that the mean PRISM-SR scores were similar to those reported in SCI by Cook et al. (6), while the subscores for Social Avoidance/Anxiety and Need for Intervention subscales were higher. Cheung et al. (16) used the Daily Activities subscore of the PRISM to assess the impact of spasticity in 26 patients post stroke and 10 patients with MS. The authors observed (non-significantly) higher PRISM impact scores for patients with MS, but there were no significant associations between spasticity severity and its impact in either group.

The primary aim of our study was to describe the positive and negative impacts of spasticity across a number of different neurological conditions using the Patient Reported Impact of Spasticity Measure (PRISM). Secondary aims included assessing the relationship between severity of spasticity and patient reported impacts, and comparing perceived impacts across the different neurological conditions.

# 

# Materials and methods

## Study design

This is an observational study to assess the Patient Reported Impact of Spasticity Measure (PRISM) in a cohort of people affected by a broad range of neurological conditions, followed up in a multidisciplinary spasticity service (2 consultants in neurology and rehabilitation medicine and 3 highly specialised physiotherapists) in south west London between 2016 and 2017. All measures were administered as part of routine clinical practice and the study was classified as a Service Evaluation by the local Trust.

## Participants

Participants comprised 97 patients attending a spasticity clinic for a follow-up appointment in the evaluation period. To be eligible, participants had to be able to understand the questionnaire and were required to demonstrate at least one item of the REsistance to PAssive movement Scale (REPAS; (17)) to be included in analyses, that is, a total spasticity score of ≥ 1. Five (5.2%) of the 97 patients, all diagnosed with dystonia, did not present with any spasticity on exam (i.e., total REPAS score was 0) so were not included in the sample for analysis. Some support to complete the questionnaire was offered by carers or family members of patients if needed.

## Procedures and measures

Socio-demographic data, diagnosis, time since diagnosis and measures of spasticity (such as the severity and localisation) were collected by the physiotherapists as part of routine care.

Spasticity was classified as focal, regional or global; based on spasticity affecting one joint, more joints of the same limb or more than one limb, respectively. Spasticity severity was scored using the REsistance to PAassive movement Scale (REPAS) (17). REPAS is based on the Ashworth scale, a common clinical standard measure of spasticity in patients with central paresis (18,19), where a score of 0 indicates no increase in tone and a score of 4 indicates a limb which is rigid in flexion or extension. The sum of the Ashworth scores of 8 segments in the upper limb and 5 in the lower limb, right and left, generates the upper and lower limb subscores and a total score between 0 and 104. Classifications of spasticity severity were made according to the following cut-offs: mild (all joints with a REPAS Ashworth score of < 2); moderate (REPAS Ashworth score of 2 or 3 in any joint) and; severe (REPAS Ashworth score of 4 in any joint) (20). The perceived impact of spasticity on quality of life (QoL) was measured using the Patient Reported Impact Of Spasticity Measure (PRISM; see Table 1 for domains and example items), a 41-item self-report questionnaire developed and validated for measuring the impact of spasticity on QoL in persons with spinal cord injuries (SCI). For each item, patients were instructed to respond with one of ‘never true’, ‘rarely true’, ‘sometimes true’, ‘often true’ or ‘very often true’. It includes seven subscales, six of which measure the negative impacts of spasticity whilst one measures the positive impact (7). The Positive Impact subscale is scored and subtracted from the subtotal of negative impact subscales to provide a total PRISM score. Each subscale score provides distinct information and can be used independently. The subscales and their score range are: ‘Social Avoidance/Anxiety’ [0-44], ‘Psychological Agitation’ [0-20], ‘Daily Activities’ [0-24], ‘Need for Assistance/Positioning’ [0-20], ‘Need for Intervention’ [0-20], ‘Social Embarrassment’ [0-20] and ‘Positive Impact’ [0-16]. In instances where a patient responded to fewer than 4 items or less than 80% of subscale items (across subscales, this occurred between 0 (0%) and 4 (4.3%) individuals), scores for the relevant subscale were recorded as missing; where there was a single missing item on a subscale or 20% or less missing data (across subscales, this occurred between 0 (0%) and 8 (8.7%) individuals), the mean from the completed items of the relevant subscale was imputed (7). Total PRISM scores were calculated only when all subscale totals were scored (scores were available for 87 of the 92 (94.6%) participants). The PRISM questionnaire was given to patients to complete immediately before the clinic by a medical student.

## Statistical analysis

Socio-demographic and clinical data are presented in the form of frequencies (percentages) for categorical variables and means (SD) for continuous variables. Means (M) and standard deviations (SD) were calculated for REPAS and PRISM measures. Relationships of key variables (diagnosis, severity, regionality, location, laterality and classification of symptoms) with scores on PRISM subscales and total scores were examined via group comparisons using one-way analysis of variance (ANOVA) or, where skewness and kurtosis estimates indicated that continuous variables did not approximate a Gaussian distribution (21), Kruskal Wallis tests. Where significant differences across groups were observed, post-hoc pairwise comparisons were

administered using *t*-tests or Mann-Whitney U tests depending on data distributions. Correlations between scores on REPAS indices (for those patients with non-zero scores) and PRISM subscales/total scores were calculated using Pearson *r* or Spearman’s *rho* according to data distribution. For all analyses, a criterion for statistical significance was set at *p* < 0.05, with no correction for multiple tests of association. All statistical analyses were completed with SPSS statistical software, Version 25.0 (SPSS, IBM).

# Results

Socio-demographic data and clinical profile of patients are shown in Table 2. A slim majority of patients were male, with an average age of approximately 54 years. Just over half of the patients were diagnosed with a cerebrovascular accident (CVA) or intracerebral haemorrhage (ICH), while almost 20% had multiple sclerosis (MS) with smaller numbers diagnosed with cerebral palsy (CP), traumatic brain injury (TBI) or hereditary spastic paraparesis (HSP). Three-quarters of patients’ symptoms were global while symptom laterality was evenly spread across left and right sides with a third of patients experiencing bilateral symptoms. The vast majority of patients presented with moderate or severe spasticity; the mean total REPAS score was 16.1 although scores varied widely across patients. Spasticity was more common in patients’ legs than arms, although REPAS scores indicated more severe spasticity in the latter.

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Insert Table 2 about here

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

## PRISM and severity of spasticity

Table 3 shows the PRISM subscores for different domains and overall total; the mean total ‘Negative Impact’ was 55.2 (out of 148) and the ‘Positive Impact’ was 3.9 (out of 16). Patients evidenced marked levels of Psychological Agitation and (interference with) Daily Activities as well as notable levels of Social Avoidance/Anxiety and the Need for Assistance/Positioning. Cronbach’s alpha values indicated a high level of internal consistency across PRISM subscales.

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Insert Table 3 about here

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

A little over half of the participants completed the PRISM independently (48, 52.2%), while 30 (32.6%) completed the measure with help and 14 (15.2%) had a carer and/or family member complete the PRISM on their behalf. Level of independence appeared to be significantly related to severity of spasticity (as measured by the REPAS) in a linear manner (*p* = 0.002), with independent completers (M = 11.92, SD = 9.26) scoring lower on the REPAS than those requiring assistance (M = 18.80, SD = 10.31), and both these groups scoring lower than participants who had someone else complete the measure for them (M = 24.64, SD = 18.56). Interestingly, comparisons of PRISM scores across these groups revealed differences on (interference with) Daily Activities (*p* = 0.047) and the Need for Assistance/Positioning (*p* = 0.012), reflecting lower scores in participants completing the PRISM independently (M = 8.36, SD = 5.66; M = 6.30, SD = 4.77, respectively) than in those requiring assistance (M = 11.59, SD = 6.97; M = 9.34, SD = 6.17, respectively) or their carer and/or family member to complete (M = 12.00, SD = 7.16; M = 10.21, SD = 4.71, respectively). But there were no significant differences on any other subscale or total PRISM score (for all comparisons, *p* > 0.454).

## Impact of spasticity severity and profile on quality of life

Across domains, patients with mild symptom levels perceived (numerically) less impact

than those with moderate or severe spasticity, although we found no significant differences across groups on subscale or total scores (Table 4). Curiously, there was a marginally significant difference across groups for ‘Positive Impact’ reflecting the trend for higher positive impact scores as symptom severity increased. However, severity of spasticity for arms and legs was positively correlated with the ‘Need for Assistance/Positioning’ and more severe spasticity in the right arm was associated with higher levels of perceived Social Embarrassment (Table 5). There were no differences on PRISM subscales and total score according to whether symptoms were focal, regional or global (for all comparisons, *p* > 0.552) or according to whether arms and/or legs were affected, save for the ‘Need for Assistance/Positioning’ subscale where spasticity localised in the arms only (M = 3.80, SD = 2.62) was significantly less than those with spasticity in the legs only (M = 8.91, SD = 5.60) or legs and arms together (M = 8.04, SD = 5.50; *p* = 0.036; for all other subscale comparisons, *p* > 0.074).

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Insert Table 4 about here

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Insert Table 5 about here

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Socio-demographic characteristics were not linked with PRISM scores. Total scores on the PRISM questionnaire were comparable between clinic-attending men (Mean (M) = 54.28, SD = 33.21) and women (M = 56.32, SD = 31.32; t(85) = -0.29, *p* = 0.769), and there were no significant gender differences on any of the PRISM subscales or the (negative) subscales total (for all comparisons, *p* > 0.193). There was no significant association between age and PRISM total scores (*r* = 0.03, *p* = 0.797) or between age and scores on any PRISM subscale or subscales total (for all correlations, *r*/*rho* between -0.19 and 0.06, *p* > 0.083). Similarly, there was no significant relationship between time since onset (excluding those with birth-onset conditions) and PRISM total scores (*rho* = 0.02, *p* = 0.872) or between time since onset and scores on any PRISM subscale or subscale total (for all correlations, rho between -0.10 and 0.14, *p* > 0.274).

## PRISM scores in diagnostic subgroups

We looked at the impact of spasticity in the different diagnostic groups (Table 6). Despite an absence of differences across groups in spasticity severity as measured by REPAS, our results showed a more substantial impact in the domain of Psychological Agitation, Daily Activities and Need for Assistance/Positioning in patients with MS and ‘Others’, as well as in the domain of Psychological Agitation in patients with HSP in comparison to other groups.

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Insert Table 6 about here

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

When running correlational analyses of total REPAS score and PRISM impacts within the diagnostic subgroups (Supplementary Table 1), no significant associations were observed in multiple sclerosis (MS) and stroke (CVA). A significant positive correlation was found between spasticity severity and the ‘Need for Assistance/Positioning’ in cerebral palsy (CP; *rho* = 0.76, *p* = 0.046) and traumatic brain injury (TBI; *r* = 0.69, *p* = 0.038), and between spasticity severity and the ‘Need for Intervention’ in cerebral palsy (CP; *rho* = 0.83, *p* = 0.021). A negative correlation was found between severity of spasticity and ‘Social Embarrassment’ in HSP (*rho* = 1.00, *p* < 0.010), indicating more embarrassment in people with less spasticity. The results by diagnosis in CP, TBI and HSP are based on a small number of patients.

# Discussion

We describe the positive and negative impacts of spasticity on a population of various neurological conditions using the PRISM scale; a questionnaire validated for spinal cord injury patients and whose Serbian translation, the PRISM SR, has been validated in patients with progressive MS (15). Our results indicate that spasticity has an impact across all relevant domains, with the highest impact reported in the domains of Psychological Agitation, Daily Activities, Social Avoidance/Anxiety and Need for Assistance/Positioning.

The severity of spasticity showed a significant albeit modest associations with the ‘Need for Assistance/Positioning’ subscales when arms and legs are involved and with the perceived ‘Social Embarrassment’ when the right arm is involved. This suggests that more than severity of spasticity per se, the localisation in the arm and leg (hemiparesis) or both legs (paraparesis) may impact on ‘Need for Assistance/Positioning’. This subscale is scored by items such as “Made it hard to keep my arms or legs inside my chair”, “Drastically changed the position of my body”, and “Made me need someone to reposition me”. Localisation in the arms, which was in the great majority unilateral in the context of hemiparesis, could potentially have a lesser impact if compensatory techniques can be learnt using the unaffected side. This may explain also why the subscale of ‘Daily Activities’ was not significantly correlated to the severity or localisation of spasticity, as patients with one or two functional arms may still be able to manage daily activities independently (2 out of 5 of the Daily Activities score purely upper limb activities like grooming and feeding yourself). Interestingly, McKay (22) reported higher scores in the subscale of Need for Assistance/Positioning in tetra-paretic (four limbs are affected) in comparison to para-paretic (both legs are affected) patients, suggesting, similarly, that the localisation of spasticity and the number of limbs affected may have an effect on perceived ‘Need for Assistance/Positioning’. Domains such as ‘Psychological Agitation’ and ‘Social Avoidance/Anxiety’, which appear to be relevant but not affected by specific characteristics of spasticity, are more likely influenced by the way spasticity and disability in general are perceived by the individual, and have previously been associated with symptoms of anxiety and depression (23,24).

Interestingly, Social Embarrassment (“Caused strangers to stare at me”, “Made me fearful that I would cause myself physical injury”, “Caused strangers to notice me” and “Caused others to avoid touching me”) significantly correlated with severity of spasticity of the right arm. A possible explanation is that patients presenting with an abnormal posturing of the upper limb due to spasticity may perceive this as socially embarrassing. Botulinum Toxin in the upper limb for cosmetic reasons can improve the perception of body image and its impacts on participation is used in clinical practice (25). It is also possible that impaired function affecting the dominant limb (more commonly the right) could be more easily noted as the impact on functional skills is more pronounced.

Our results showed marginally significant associations between positive impact and severity of spasticity (classifications). A possible explanation is that more severe spasticity is associated with more severe muscle weakness, being both spasticity and weakness symptoms of the upper motor syndrome, making the effect of spasticity more relevant as a substitute (for example, legs extensor spasticity to facilitate standing).

Some significant associations emerged from analyses the data by different diagnostic groups. In patients with CP and TBI, the association between spasticity severity and Need for Assistance/Positioning was significant, in CP between spasticity severity and Need for Intervention. These subscale scores give relevance to the difficulties experienced in positioning the body, requiring the help of others, the need of special devices and interventions. The size of our CP and TBI populations were very small, however, not allowing any generalization. Nevertheless, it is well known that pain and discomfort associated with spasticity and musculoskeletal problems are common in young people with CP or following profound TBI, requiring the use of special equipment and intervention for postural management (26,27). The negative association between spasticity severity and Social Embarrassment in people with HSP is more difficult to explain; perhaps people less affected are the ones still able to access the community hence experiencing more embarrassment or at the initial stage of their pathology finding it harder to cope with the newly acquired disability. We did not find an association between spasticity severity and the PRISM scores in the other diagnostic subgroups.

Differently from us, Knezevic and colleagues (15) found that all PRISM scores positively correlated with measures of spasticity severity in a population with MS. However, the authors measured spasticity severity using the Ashworth scale only in knee extensors and the perceived level of muscle stiffness by the Numerical Rating Scale for spasticity. Cook et al. (6,7) created and validated the PRISM scale in people with SCI and based the construct of its validity mainly on the assumption, which was met, that the degree of problematic spasms should interfere with function. But findings across studies have sometimes been equivocal. For example, Cheung and colleagues (16) found no correlation between severity of spasticity in arms and legs and the Daily Activity subscore in MS and stroke. McKay et al. (22) administered the PRISM to patients with SCI and observed only a moderate correlation between spasticity severity, measured as perceived stiffness and spams, and PRISM scores. Our population included only a few SCI cases, who were grouped under the diagnostic classification of “Others” not allowing a specific investigation of relationships in these patients; however, we described an association between spasticity severity and Need for Assistance/Positioning in patients with paraparesis of different origins (due to MS, HSP, CP or TBI) who may share a similar motor presentation to SCI patients.

Interestingly, we found other similarities and differences between our results and previous studies investigating perceived impacts of spasticity in different diagnostic groups, independently from spasticity severity. For instance, although McKay et al. (SCI; (22)), Cook et al. (SCI; (6)) and Knezevic et al. (MS; (15)) also reported a marked impact on patients in the domains of Social Avoidance/Anxiety and Psychological Agitation, Cook et al.’s and McKay et al.’s scores (total mean Negative Impact 36 and 39, respectively) were much lower in comparison to Knezevic et al.’s and our samples (total mean Negative Impact 48 and 55, respectively). This is likely the consequence of the different populations under study, as MS patients evidenced greater impact in these domains than did other diagnostic subgroups under study here (e.g., CVA/ICH, CP, and TBI). In line with this, Cheung et al. (16) assessed the interference of spasticity in Daily Activities with the PRISM subscale in stroke and MS patients and also found higher scores in patients with MS (median= 9.8) than in stroke (mean = 7.0), although the significance level of the difference was not reported.. Interestingly, however, people with MS in our study reported a higher Negative Impact (67 versus 48) and a lower Positive Impact (4 versus 12) than the MS sample described by Knezevic et al. (15). We speculate that differences across studies and populations may be due either to different level of spasticity (i.e. more severe spasticity in our patients selected from a spasticity clinic hence requiring active treatment for spasticity) or a difference in coexisting factors such as anxiety/ depression, pain and fatigue which could have biased the scores. Although comparable measures of spasticity severity and co-morbidities are not available, the interplay between spasticity, pain, fatigue and sleep is well established (28,29) as well as the association between depressive symptoms and physical disability independent of health conditions and health status (23,24).

A significant number of patients in the study completed the PRISM measure with assistance or required a carer and/or family member to complete the questionnaire. These patients tended to have a more severe spasticity presentation than those completing independently, and scored higher on PRISM (interference with) Daily Activities and Need for Assistance/Positioning subscales. The extent to which higher scores on PRISM subscales in these patients emerged as a result of greater symptom severity or the influence of the healthcare professional, relevant carer and/or family member on questionnaire responses, is unclear. Interestingly, the Daily Activities and Need for Assistance/Positioning subscales are the only PRISM subscales that make explicit reference to the need of assistance from others. For example, the specific reference "difficult to me or my attendant” is made in five of the six items that make up the Daily Activities subscale, while in the Need for Assistance/Positioning subscale, two of the five items refer to "need someone for" or "depend on others". It is possible then that where a relevant carer and/or family member helped with questionnaire responses, higher scores on these subscales reflect potential influence by the carer/family member according to their experience of direct involvement in the task or activity, reflecting perceived carer burden. However, the significant associations between severity of spasticity in arms and legs and Need for Assistance/Positioning subscale score were true for the whole population, independent of the method of questionnaire completion. This suggests that, at least for this subscale, higher impacts may be more closely related to more severe spasticity than a result of carer/family member influence. This interpretation is broadly consistent with findings that increased levels of (clinician-rated) disability (most obviously in hygiene and dressing) were associated with both reduced (patient-rated) health-related quality of life and increased caregiving burden in a large sample of patients with upper limb poststroke spasticity (30).

The primary objective of our research was to evaluate the positive and negative impacts of spasticity using a standardised measure. In practice, utilisation of the PRISM may enable clinicians and health care professionals to gauge the extent to which (and in what way) spasticity is affecting their patients' quality of life and play a role in rehabilitation goal-setting. PRISM would thus allow for an open and comprehensive discussion on possible areas for treatment in each patient, for example, by using Botulinum toxin if the patient feels their quality of life is significantly negatively affected. Alternatively, if any resultant side effects outweigh the potential therapeutic benefits, for example, when the patient does not feel that their spasticity has a major impact on their quality of life, a decision could be made not to prescribe.

# Limitations

Although this study is one of the first to investigate the impact of spasticity using the PRISM measure in a number of different diagnostic subgroups, there are a number of limitations. As above, we did not account for the influence of anxiety, depression and/or cognitive difficulties which might affect patients’ perspective and experience of their disability in the different domains. Although previous studies have shown an independent effect of spasticity on measures of QoL after correction for anxiety and depression (24,31), it is possible that communication cognitive and perceptual difficulties, commonly present in patients with brain damage, could have influenced the results. Furthermore, the Ashworth scale, and, in turn, the REPAS, are not able to differentiate between spasticity and contractures, and measuring the resistance to passive movements is affected by both. To this end, inconsistencies in the inter-rater and intra-rater reliability of the Ashworth Scale have been reported by different studies (32,33). Although this has clear implications when we treat patients with agents such as Botulinum toxin or oral antispastic medications, which are effective only on spasticity (not on contractures), it is arguably less relevant when measuring the overall impact of spasticity, of which contractures are a complication. With regards to the patients’ ability to differentiate between weakness and spasticity, the patients seen at follow-up appointments have all had education during clinics and by their therapists in the community.

Additionally, as noted above, not all participants were able to compete the PRISM measure independently and the effect on responses is unclear. More generally, our study does not provide a validation of the scale and the patient sample was heterogeneous and relatively modest in size, which may have contributed to the inability to detect statistically significant effects in comparisons of important subgroups and precluded multivariate analysis of factors associated with perceived impact of spasticity on QoL (identified from bivariate analyses). Finally, there was no correction for multiple tests of association, elevating the risk of Type I errors.

# Conclusion

Patients with a variety of neurological conditions reported marked levels of negative impact of spasticity as measured by the PRISM, most notably in Psychological Agitation, (interference with) Daily Activities, Social Avoidance/Anxiety and Need for Assistance/Positioning domains. MS patients were the most affected by spasticity symptoms. Severity of spasticity was not related to overall perceived impact (total PRISM score), although severity in arms and in legs were modestly associated with Need for Assistance/Positioning and severity in right arm was significantly correlated with Social Embarrassment. Our results suggest that the PRISM scale can be a useful tool in assessing the impact of spasticity in patients affected by different neurological conditions, allowing clinicians to gauge the extent by which spasticity is affecting their patients. Further research is needed to assess scale validity in the broader neurological population.

# Declaration of interest

The authors report no conflicts of interest.

# Funding

This research did not receive any grant from funders in the public, commercial, or not-for-profit

sectors.

References

1. Martin A, Abogunrin S, Kurth H, Dinet J. Epidemiological, humanistic, and economic burden of illness of lower limb spasticity in adults: a systematic review. Neuropsychiatr Dis Treat . 2014;10:111–122.

2. Shilt JS, Seibert PS, Kadyan V. Optimal management for people with severe spasticity. Degener Neurol Neuromuscul Dis. 2012;2:133–140.

3. Yelnik AP, Simon O, Parratte B, et al. How to clinically assess and treat muscle overactivity in spastic paresis. J Rehabil Med. 2010;42(9):801–807.

4. Royal College of Physicians [Internet]. London: RCP; c1518-2019. Spasticity in adults: management using botulinum toxin; 2018 [cited 2019 Jun 5]. Available from: https://www.rcplondon.ac.uk/guidelinespolicy/spasticityadultsmanagement-using-botulinum-toxin

5. World Health Organization [Internet]. Geneva: WHO; c1948-2019. International Classification of Functioning, Disability and Health (ICF); 2001 [cited 2018 Jun 5]. Available from: https://www.who.int/classifications/icf/en/

6. Cook K, Williams A, Teal C, et al. The Patient-Reported Impact of Spasticity Measure (PRISM): A New Measure Assessing the Impact of Spasticity on Persons with Spinal Cord Injury. J Neurol Phys Ther. 2005;29(4):204-205.

7. Cook KF, Teal CR, Engebretson JC, et al. Development and validation of Patient Reported Impact of Spasticity Measure (PRISM). J Rehabil Res Dev. 2007;44(3):363–371.

8. Adams MM, Ginis KAM, Hicks AL. The Spinal Cord Injury Spasticity Evaluation Tool: Development and Evaluation. Arch Phys Med Rehabil. 2007;88(9):1185–1192.

9. Ertzgaard P, Nene A, Kiekens C, et al. A review and evaluation of patient reported outcome measures for spasticity in persons with spinal cord damage: Recommendations from the Ability Network – an international initiative. J Spinal Cord Med. 2019;1–11.

10. Nogueira LAC, Nóbrega FR, Lopes KN, et al. The effect of functional limitations and fatigue on the quality of life in people with multiple sclerosis . Arq. Neuro-Psiquiatr. 2009; 63(3B):812-817.

11. Voerman GE, Erren-Wolters CV, Fleuren JF, et al. Perceived spasticity in chronic spinal cord injured patients: Associations with psychological factors. Disabil Rehabil. 2010;32(9):775–780.

12. Gillard PJ, Sucharew H, Kleindorfer D, et al. The negative impact of spasticity on the health-related quality of life of stroke survivors: a longitudinal cohort study. Health Qual Life Outcomes. 2015;13(1):159.

13. Hotter B, Padberg I, Liebenau A, et al. Identifying unmet needs in long-term stroke care using in-depth assessment and the Post-Stroke Checklist – The Managing Aftercare for Stroke ( MAS-I ) study. Eur Stroke J. 2018;3(3):237–245.

14. Flachenecker P, Henze T, Zettl UK. Spasticity in patients with multiple sclerosis – clinical characteristics, treatment and quality of life. Acta Neurol Scand. 2014;129(3):154–162.

15. Knezevic T, Konstantinovic L, Rodic S, et al. Validity and reliability of the Serbian version of Patient-Reported Impact of Spasticity Measure in multiple sclerosis. Int J Rehabil Res. 2015;38(3):199-205.

16. Cheung J, Rancourt A, Di Poce S, et al. Patient-identified factors that influence spasticity in people with stroke and multiple sclerosis receiving botulinum toxin injection treatments. Physiother Can. 2015;67(2):157–166.

17. Platz T, Vuadens P, Eickhof C, et al. REPAS, a summary rating scale for resistance to passive movement: Item selection, reliability and validity. Disabil Rehabil. 2008;30(1):44–53.

18. Ashworth B. Preliminary Trial of Carisoprodol in Multiple Sclerosis. Practitioner. 1964;192:540-542.

19. Bohannon R, Smith MB. Interrater reliability of a modified Ashworth sclae of muscle spasticity. Phys Ther. 1987;67(2):206-207.

20. Ward AB, Wissel J, Borg J, et al. Functional Goal Achievement in Post-Stroke Spasticity Patients: The Botox® Economic Spasticity Trial (BEST). J Rehabil Med. 2014;46:504–513.

21. Hair JF, Anderson RE, Tatham RL, et al. Multivariate data analysis (Vol. 6). Upper Saddle River, NJ: Prentice Hall; 1998.

22. McKay WB, Sweatman WM, Field-Fote EC. The experience of spasticity after spinal cord injury: perceived characteristics and impact on daily life. Spinal Cord. 2018;56(5):478-486.

23. Brenes GA, Penninx BWJH, Judd PH, et al. Anxiety, depression and disability across the lifespan. Aging Ment Health. 2008;12(1):158–163.

24. Kargarfard M, Eetemadifar M, Mehrabi M, et al. Fatigue, depression, and health related quality of life in patients with multiple sclerosis in Isfahan, Iran. Eur J Neurol. 2012;19(3):431–437.

25. Sheean G. Botulinum Toxin Treatment of Adult Spasticity. Drug Saf. 2006;29(1):31–48.

26. National Institute for Health and Care Excellence [Internet]. London and Manchester: NICE; c.1999-2019. Cerebral palsy in under 25s: assessment and management NICE guideline [NG62]; 2017 [2019 Jun 8]. Available from: https://www.nice.org.uk/guidance/ng62

27. Synnot A, Chau M, Pitt V, et al. Interventions for managing skeletal muscle spasticity following traumatic brain injury. Cochrane Database Syst Rev. 2017;(11).

28. Milinis K, Young CA. Systematic review of the influence of spasticity on quality of life in adults with chronic neurological conditions. Disabil Rehabil. 2016;38(15):1431–1441.

29. Andresen SR, Biering-Sørensen F, Hagen EM, et al. Pain, spasticity and quality of life in individuals with traumatic spinal cord injury in Denmark. Spinal Cord. 2016;54:973.

30. Doan QV, Brashear A, Gillard PJ, Varon SF, Vandenburgh AM, Turkel CC, Elovic EP. Relationship between disability and health-related quality of life and caregiver burden in patients with upper limb poststroke spasticity. PM&R. 2012;4(1):4-10.

31. Milinis K, Tennant A, Young CA. Spasticity in multiple sclerosis: Associations with impairments and overall quality of life. Mult Scler Relat Disord. 2016;5:34–39.

32. Mutlu A, Livanelioglu A, Gunel MK. Reliability of Ashworth and Modified Ashworth Scales in children with spastic cerebral palsy. BMC Musculoskelet Disord. 2008;9:1–8.

33. Meseguer-Henarejos AB, Sánchez-Meca J, López-Pina JA, et al. Inter- and intrarater reliability of the Modfied Ashworth scale: a systematic review and metaanalysis. Eur J Phys Rehabil Med. 2018; 54(4):576-590.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Table 1. Major PRISM domains and examples of corresponding items. Patients were asked to score each item with respect to their spasticity on a scale ranging from 0 (never true for me) to 5 (very often true for me). | | | | | | |
| Domain 1: Social Avoidance/Anxiety  (11 items) | Domain 2: Psychological Agitation (5 items) | Domain 3:  Daily Activities  (6 items) | Domain 4: Need for Assistance/Positioning  (5 items) | Domain 5: Positive Impact  (4 items) | Domain 6: Need  for Intervention  (5 items) | Domain 7: Social Embarrassment  (5 items) |
| Made me anxious about going out in public | Made me feel out of control of my body | Made grooming difficult for me and my attendant | Made me need someone to reposition me | Helped me keep my muscles exercised | Caused me to increase the amount of prescription medication I took | Caused me embarrassment |
| Caused me to avoid physical contact with other people | Made me feel frustrated | Made eating or feeding difficult for me or my attendant | Caused me to depend on others | Helped me stretch my muscles | Made me want to find alternative non-medical therapies | Caused strangers to stare at me |

Table 2. Socio-demographic data, clinical profile and severity of spasticity (REsistance to Passive movement Scale; REPAS) for patients (*n* = 92). Please note: values represent frequency (percentage) unless otherwise stated.

|  |  |  |  |
| --- | --- | --- | --- |
| Male/ Female | | 49 (53.3) / 43 (46.7) | |
| Age (years) | | M = 54.1 (SD = 16.2; range = 17-82) | |
| Diagnosis | |  | |
| CVA / ICH | | 47 (51.1) | |
| MS | | 18 (19.6) | |
| CP | | 7 (7.6) | |
| TBI | | 9 (9.8) | |
| HSP | | 5 (5.4) | |
| Other | | 6 (6.5) | |
| Years since diagnosis | | M = 10.6 (SD = 9.7; range = 1-39) | |
| Side affected | |  | |
| Left | | 31 (33.7) | |
| Right | | 31 (33.7) | |
| Bilateral | | 30 (32.6) | |
| Location of spasticity | |  | |
| Arm(s) only | | 11 (12.0) | |
| Leg(s) only | | 34 (37.0) | |
| Arm(s) and leg(s) | | 47 (51.1) | |
| Symptom classification | |  | |
| Focal | | 5 (5.4) | |
| Regional | | 18 (19.6) | |
| Global | | 69 (75.0) | |
| REPAS: Severity of spasticity | |  | |
| Mild | | 11 (12.0) | |
| Moderate | | 63 (68.5) | |
| Severe | | 18 (19.6) | |
| REPAS Scores | | Mean (SD; range) | |
| Right arm (1-32; *n*= 35) | | 12.06 (5.04; 2-24) | |
| Left arm (1-32; *n* = 32) | | 10.41 (6.53; 1-26) | |
| Total Arms (1-64; *n* = 58) | | 13.02 (7.69; 1-36) | |
| Right leg (1-20; *n* = 54) | | 6.46 (4.43; 1-20) | |
| Left leg (1-20; *n* = 54) | | 6.98 (4.09; 1-20) | |
| Total legs (1-40; *n* = 81) | | 8.96 (7.69; 1-40) | |
| Total score (1–104; *n* = 92) | | 16.10 (12.26; 1-67) | |
| CVA = cerebrovascular accident; ICH = intracerebral haemorrhage; MS = multiple sclerosis; CP = cerebral palsy; TBI = traumatic brain injury; HSP = hereditary spastic paraparesis; ‘Other’ included cases of spinal cord injury, motor neurone disease, Goldberg-Shprintzen syndrome, and neurosarcoidosis; M = mean number/score; SD = standard deviation; Years since diagnosis was only considered for 75 patients (8 patients [7 cerebral palsy, 1 hereditary spastic paraparesis] had their condition since birth, while years since diagnosis was unknown in 9 patients). | | | |

Table 3. Patient Reported Impact of Spasticity Measure (PRISM) scores for patients (*n* = 92).

|  |  |  |
| --- | --- | --- |
| PRISM subscale | Mean (SD) | Cronbach’s alpha |
| Social Avoidance/Anxiety (0-44) | 17.53 (12.41) | 0.930 |
| Psychological Agitation (0–20) | 10.65 (5.63) | 0.846 |
| Daily Activities (0–24) | 9.97 (6.50) | 0.847 |
| Need for Assistance/Positioning (0–20) | 7.89 (5.46) | 0.789 |
| Need for Intervention (0–20) | 6.82 (4.53) | 0.618 |
| Social Embarrassment (0–20) | 7.44 (5.09) | 0.786 |
| Subscales’ score (0–148) | 59.48 (33.10) | 0.958 |
| Positive Impact (subtract; 0–16) | 3.86 (3.79) | 0.705 |
| Total PRISM score | 55.22 (32.19) |  |
| SD = standard deviation; *n* values for subscales are variable due to a small number of patients not completing all items; for Total PRISM score, *n* = 87. | | |

Table 4. Patient Reported Impact of Spasticity Measure (PRISM) subscales and total scores for patients according to whether severity of symptoms are determined by scored on the REsistance to PAssive movement Scale (REPAS).

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Mild  (*n* = 11) | Moderate  (*n* = 63) | Severe  (*n* = 18) |  |  |
| PRISM subscale | Mean (SD) | Mean (SD) | Mean (SD) | F/H | *p* |
| Social Avoidance/Anxiety (0-44) | 14.64 (12.48) | 18.20 (12.58) | 17.06 (12.24) | 0.86 | 0.652 |
| Psychological Agitation (0–20) | 9.91 (6.36) | 10.97 (5.66) | 10.00 (5.27) | 0.31 | 0.733 |
| Daily Activities (0–24) | 8.55 (6.35) | 9.64 (6.38) | 11.94 (6.920 | 1.18 | 0.312 |
| Need for Assistance/Positioning (0–20) | 6.09 (5.75) | 7.75 (5.12) | 9.44 (6.29) | 1.35 | 0.263 |
| Need for Intervention (0–20) | 5.55 (4.41) | 7.05 (4.67) | 6.82 (4.17) | 0.51 | 0.603 |
| Social Embarrassment (0–20) | 6.36 (6.38) | 7.52 (4.930 | 7.83 (4.99) | 0.63 | 0.731 |
| Subscales’ score (0–148) | 51.09 (38.28) | 61.11 (33.92) | 59.06 (27.14) | 0.42 | 0.656 |
| Positive impact (0–16) | 2.64 (2.46) | 3.56 (3.54) | 5.61 (4.74) | 2.80 | 0.067 |
| Total PRISM score | 48.45 (36.03) | 56.81 (33.42) | 54.06 (25.81) | 0.32 | 0.726 |
| Classifications of spasticity severity were made according to the following cut-offs (20): mild (all joints with a REPAS Ashworth score of < 2); moderate (REPAS Ashworth score of 2 or 3 in any joint); severe (REPAS Ashworth score of 4 in any joint); SD = standard deviation; *n* values for subscales are variable due to a small number of patients not completing all items; Group comparisons were made using one-way analysis of variance (ANOVA) or Kruskal-Wallis (H) tests according to data distribution. | | | | | |

Table 5. Correlations between patients’ (*n* = 92) REsistance to PAssive movement Scale (REPAS) scores and Patient Reported Impact of Spasticity Measure (PRISM) subscales/total scores.

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | Social Avoidance/Anxiety | Psychological Agitation | Daily Activities | Need for Assistance/Positioning | Need for Intervention | Social Embarrassment | Subscales’ score | Positive Impact | Total PRISM score |
| REPAS Scores |  |  |  |  |  |  |  |  |  |
| Right arm (*n* = 35) | 0.15 | 0.05 | 0.03 | 0.23 | 0.25 | 0.35\* | 0.19 | 0.31 | 0.14 |
| Left arm (*n* = 32) | 0.15 | -0.05 | 0.03 | 0.29 | 0.05 | 0.15 | -0.05 | 0.11 | -0.05 |
| Total Arms (*n* = 58) | 0.14 | 0.04 | 0.18 | 0.34\* | 0.14 | 0.11 | 0.12 | 0.22 | 0.05 |
| Right leg (*n* = 54) | -0.14 | 0.01 | 0.22 | 0.35\*\* | 0.03 | -0.07 | 0.05 | 0.18 | 0.01 |
| Left leg (*n* = 54) | -0.22 | -0.07 | 0.16 | 0.19 | -0.08 | -0.18 | -0.10 | 0.15 | -0.13 |
| Total legs (*n* = 81) | -0.13 | 0.01 | 0.18 | 0.23\* | -0.06 | -0.12 | -0.02 | 0.15 | -0.02 |
| Total score (*n* = 92) | -0.09 | -0.03 | 0.11 | 0.21 | -0.01 | -0.10 | -0.01 | 0.12 | -0.03 |
| Correlations are Pearson *r* or Spearman’s *rho* according to data distribution; \**p* < 0.05, \*\**p* < 0.01. Significant associations are highlighted in bold. | | | | | | | | | |

Table 6. Patient Reported Impact of Spasticity Measure (PRISM) subscales and total scores for patients according to diagnosis.

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | CVA/ICH  (*n* = 42) | MS  (*n* = 18) | CP  (*n* = 7) | TBI  (*n* = 9) | HSP  (*n* = 5) | Other  (*n* = 6) |  |  |
| PRISM subscale | Mean (SD) | Mean (SD) | Mean (SD) | Mean (SD) | Mean (SD) | Mean (SD) | F/H | *p* |
| Social Avoidance/Anxiety (0-44) | 17.15 (12.91) | 20.11 (12.63) | 16.57 (11.55) | 11.33 (11.02) | 23.00 (7.39) | 19.50 (13.78) | 4.45 | 0.487 |
| **Psychological Agitation (0–20)** | **9.83 (5.69)** | **13.44 (5.40)** | **9.43 (5.22)** | **6.22 (4.44)** | **13.40 (4.04)** | **14.50 (2.26)** | **17.37** | **0.004** |
| **Daily Activities (0–24)** | **9.04 (6.49)** | **12.33 (6.87)** | **8.29 (3.86)** | **7.44 (5.34)** | **7.00 (3.83)** | **17.67 (4.23)** | **3.37** | **0.010** |
| **Need for Assistance/Positioning (0-20)** | **6.85 (5.53)** | **10.44 (5.39)** | **5.43 (2.94)** | **7.11 (4.54)** | **6.75 (3.20)** | **13.00 (5.66)** | **11.30** | **0.046** |
| Need for Intervention (0–20) | 6.69 (4.59) | 7.89 (5.08) | 7.14 (5.11) | 3.44 (3.25) | 7.20 (3.11) | 9.00 (2.37) | 8.36 | 0.137 |
| Social Embarrassment (0–20) | 7.70 (5.07) | 7.28 (5.38) | 7.86 (5.46) | 4.67 (4.90) | 12.50 (1.73) | 6.33 (4.27) | 8.08 | 0.152 |
| Subscales’ score (0–148) | 55.60 (33.77) | 71.50 (36.11) | 54.71 (29.09) | 40.22 28.30) | 70.00 (18.39) | 80.00 (19.17) | 9.99 | 0.076 |
| Positive Impact (0–16) | 3.11 (3.52) | 4.33 (4.39) | 3.86 (2.67) | 4.67 (4.18) | 4.25 (3.40) | 6.50 (4.28) | 5.53 | 0.354 |
| Total PRISM score | 51.51 (33.44) | 67.17 (33.40) | 50.86 (27.19) | 35.56 (28.65) | 65.75 (16.07) | 73.50 (20.75) | 1.72 | 0.109 |
| Severity of spasticity | Mean (SD) | Mean (SD) | Mean (SD) | Mean (SD) | Mean (SD) | Mean (SD) | H | *p* |
| Total REPAS score | 14.83 (9.07) | 12.33 (9.77) | 23.29 (15.90) | 23.00 (16.59) | 10.60 (9.53) | 23.17 (12.26) | 7.08 | 0.215 |
| Severity classification | *n* (%) | *n* (%) | *n* (%) | *n* (%) | *n* (%) | *n* (%) |  |  |
| Mild | 4 (8.5) | 3 (16.7) | 1 (14.3) | 1 (11.1) | 1 (20.0) | 1 (16.7) |  |  |
| Moderate | 35 (74.5) | 14 (77.8) | 4 (57.1) | 5 (55.6) | 4 (80.0) | 1 (16.7) |  |  |
| Severe | 8 (17.0) | 1 (5.6) | 2 (28.6) | 3 (33.3) | 0 (0.0) | 4 (66.7) |  |  |
| CVA = cerebrovascular accident; ICH = intracerebral haemorrhage; MS = multiple sclerosis; CP = cerebral palsy; TBI = traumatic brain injury; HSP = hereditary spastic paraparesis;; SD = standard deviation; REPAS = REsistance to PAssive movement Scale; *n* values for subscales are variable due to a small number of patients not completing all items; Overall group comparisons were made using one-way analysis of variance (ANOVA) or Kruskal-Wallis (H) tests according to data distribution. Significant differences are highlighted in bold. Post-hoc pairwise group comparisons showed significant differences for Psychological Agitation between CVA/ICH and multiple sclerosis groups (*p* = 0.015), between CVA/ICH and Other (*p* = 0.027); between Traumatic brain injury and Multiple sclerosis (*p* = 0.001), between Traumatic brain injury and Hereditary spastic paraparesis (*p* = 0.023), and between Traumatic brain injury and Other (*p* = 0.001); for Daily Activities between CVA/ICH and Other (*p* = 0.002), between Cerebral palsy and Other (*p* = 0.007), between Hereditary spastic paraparesis and Other (*p* = 0.008), and between Traumatic brain injury and Other (*p* = 0.002); for Need for Assistance/Positioning between CVA/ICH and Multiple sclerosis (*p* = 0.015), between CVA/ICH and Other (*p* = 0.033), between Cerebral palsy and Multiple sclerosis (*p* = 0.034), and between Cerebral palsy and Other (*p* = 0.026). | | | | | | | | |