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SPECIAL ARTICLE

A comprehensive person-centered approach to adult spastic paresis: a consensus-based framework

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ABSTRACT

Spastic paresis is a common feature of an upper motor neuron impairment caused by stroke, brain injury, multiple sclerosis and other central nervous system (CNS) disorders. Existing national and international guidelines for the treatment of adult spastic paresis tend to focus on the treatment of muscle overactivity rather than the comprehensive approach to care, which may require life-long management. Person-centered care is increasingly adopted by healthcare systems in a shift of focus from "disease-oriented" towards "person-centered" medicine. The challenge is to apply this principle to the complex management of spastic paresis and to include an educative process that engages care providers and patients and encourages them to participate actively in the long-term management of their own disease. To address this issue, a group of 13 international clinicians and researchers used a pragmatic top-down methodology to evaluate the evidence and to formulate and grade the strength of recommendations for applying the principles of person-centered care to the management of spastic paresis. There is a distinct lack of clinical trial evidence regarding the application of person-centered medicine to the rehabilitation setting. However, the current evidence base supports the need to ensure that treatment interventions for spastic paresis should be centered on as far as reasonable on the patient's own priorities for treatment. Goal setting, negotiation and formal recording of agreed SMART goals should be an integral part of all spasticity management programs, and goal attainment scaling should be recorded alongside other standardized measures in the evaluation of outcome. When planning interventions for spastic paresis, the team should consider the patient and their family's capacity for self-rehabilitation, as well as ways to enhance this approach. Finally, the proposed intervention and treatment goals should consider the impact of any neuropsychological, cognitive and behavioral deficits on rehabilitation. These recommend

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KEY WORDS: Spastic paraparesis - Muscle spasticity - Consensus - Person-centered therapy - Rehabilitation - Self-management.

Spastic paresis (encompassing spasticity, spastic dystonia and muscle shortening) is a common feature of the upper motor neuron syndrome that can impact negatively on quality of life in patients with stroke, traumatic brain

injury (TBI), cerebral palsy (CP), multiple sclerosis (MS) and other central nervous system disorders. Rehabilitation is challenging in this context as patients often have multiple coexisting problems, including difficulties with

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physical, sensory, cognitive, behavioral and psychosocial function. While there are several published guidelines for treatment interventions, 1-6 these mainly focus on the treatment of muscle over-activity, particularly on the use of botulinum toxin (BoNT). Specifically, they do not consider a comprehensive approach nor the importance of patient choice and person centered management. In the context of rehabilitation, person centered management encompasses a complex range of themes including individualized goal planning and self-management. Patients and their families are an integral part of the team, and the role of healthcare professionals (HCPs) is to consider the patient's own goals for treatment and to support and engage with them to maximize autonomy and participation.⁷⁻⁹ Such themes are recognized as vital for effective rehabilitation, but the ways to incorporate them into clinical practice require careful consideration and planning.

To address this issue, a group of leading international clinicians and researchers from established centers of excellence for spastic paresis (representing North America, Asia, Australia and Europe), and working in a range of clinical settings, met to develop a consensus framework. Several of the authors participate in the development of national and international guidelines for spasticity management and together recognized the need to develop guidance on applying a person-centered approach in real-life clinical practice. Using a pragmatic approach to the evaluation of evidence, this framework integrates current research and clinical expertise to guide clinicians in providing person-centered approach to the management of spastic paresis.

Consensus methodology

Definitions

Person-centered care

Although not a new concept, "person-centered" or "patient-centered care" has attracted attention as it advocates a shift from "disease-oriented" management. The USA Institute of Medicine has defined patient-centered care as "providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions" and included this as one of the top aims for improving care quality. Likewise, the UK National Institute for Health and Care Excellence (NICE) has developed specific guidance 11 for ensuring that patients "have the

opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals." ¹²

The value gained from understanding health outcomes from the patient's perspective (*i.e.* patient reported outcomes [PROs]) is increasingly acknowledged, and in many countries PRO data are now a requirement for commissioning and reimbursement of medical treatment.^{13, 14} There is also increasing recognition of the need to report functional outcomes, rather than just the achievement of symptomatic improvements or reduced impairment.

Spasticity

Traditional definitions of spasticity, such as that described by Lance,¹⁵ focus on velocity-dependent resistance to stretch. However, clinicians increasingly address a wider array of impairments in their approaches to management.¹⁶ There are several on-going projects that aim to establish universal definitions and standards for the measurement of spasticity, including the European Commission SPASM group.¹⁷ In this article, we use a wider view that specifically uses the term 'spastic paresis' to encompass muscle shortening, spastic dystonia and disabling muscle overactivity.

Assimilation of evidence base

The management of spastic paresis is complex, and producing evidence-based guidelines using common systematic approaches such as the Grades of Recommendation, Assessment, Development and Evaluation (GRADE) system ^{18, 19} is time-intensive, difficult and not person centered. In this context, trial-based evidence for an integrated approach is expected to be limited in comparison with evidence from other research designs, and calls for a broader-based approach to the assimilation of published literature. To address this issue, the group used a novel pragmatic top-down methodology to evaluate evidence and to formulate and grade the strength of recommendations using an adapted and simplified version of the GRADE approach to obtaining consensus.

Recommendations were graded using a previously validated method for assessing the quality of evidence that places less emphasis on randomized controlled trials (RCTs) and instead embraces a wider variety of research designs. This methodology ²⁰ gives value to all study designs (RCTs, open-label studies, registries etc.), so long as they provided the most appropriate information to

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address the research question. It has been used successfully for guideline development in several areas where a broad variety of research designs is anticipated.^{21, 22} The authors of this consensus considered it to be more applicable to questions relating to the complexity of spasticity management than the traditional GRADE Quality Rating framework.

There were three steps to the evaluation process:

- 1. Identification and agreement of the key recommendations by the group consensus
- 2. Evaluation of the best quality evidence to underpin the recommendation
- 3. Grading the strength of the recommendation by group consensus based on the following questions:
 - a. Benefits: Is there important uncertainty about how much people value the recommendation?
 - b. Harms: Are the desirable effects large relative to undesirable effects?
 - c. Costs: Is the incremental cost small relative to the net benefits?

Based on the above, what is the overall strength of evidence for the benefits of this recommendation?

The designated leads for each area performed steps 1 and 2. The whole group performed step 3 at a face-to-face meeting with dial-in facilities for those unable to attend in person.

The challenges of using a person-centered approach for people living with spastic paresis

In the person-centered model, doctors should no longer be didactic figures, who make all the relevant decisions. Instead, the patient should be at the heart of all care, and their values should guide all clinical decisions.^{23, 24} However, the management of spastic paresis is complex, and the experience of the clinical team is also critically important when choosing which treatments to apply in a comprehensive approach to optimize functional outcomes.

Given the complexity of the problem, it is appropriate to take a holistic multidisciplinary team-based approach to assessment and rehabilitation. The specific disciplines required will vary from patient to patient, but may include doctors in neurology and rehabilitation medicine, physiotherapists, occupational therapists, orthotists and rehabilitation nurses and sometimes other specialties (e.g. social worker, psychologist, physical education teachers, vocational counselors). Any of these HCPs may have impor-

tant insights in how the management plan will help patients on their journey to recovery and self-sufficiency.²⁵ However, the patient must remain central to the decision-making process. While this assessment consumes time and resources, experience with this model shows an optimal initial assessment that considers patient needs and preferences, avoids wasting time at later follow-up visits when it is harder to rectify problems and challenge misconceptions.^{26, 27}

Developing a partnership approach in the management of spastic paresis

The relationship between HCPs and patients is often referred to as the "therapeutic alliance," which has been defined as having 3 main components: the HCP-patient agreement on goals, the HCP-patient agreement on interventions, and the bond between patient and HCP.²⁸ Studies in many areas of healthcare have consistently shown that higher levels of therapeutic alliance and patient engagement are associated with better health outcomes.²⁹⁻³¹ Moreover, patient-directed goals are likely to improve patient engagement and therefore goal achievement. The identification, negotiation and agreement of goals with patients has long been accepted as a core component of the rehabilitation process, but in practice is often imperfectly implemented.³²

Goal setting as a patient centered approach to rehabilitation

Rehabilitation goals may be defined as "a desired state to be achieved by a person with a disability as a result of rehabilitation activities." ³³ Goal setting involves the negotiation and establishment of an agreed set of goals that should be "SMART" (Specific, Measurable, Achievable, Realistic/Relevant and Timed).^{34, 35}

The choice of goals for patients with spastic paresis can vary widely, depending on the patient's individual aims and aspirations, and on their potential for change. For patients with more abilities, goals will often center on improving function and independence; while for those with more severe impairment the focus is on managing symptoms (*e.g.* pain), preventing the development of contractures and reducing the burden of care.³⁶ The initial assessment will therefore include evaluation of the patient's potential for improvement in terms of gaining function, managing symptoms or reducing the burden of care. This

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involves identification and discussion of the patient's own goals, but it is also important to ask what carers/family members want from treatment because they may have different goals or insights which will add to understanding of the whole context for the individual patient.

There is now an extensive body of literature on the types of goals set for management of spastic paresis, and several authors have mapped the goals onto domains of the World Health Organisations' International Classification of Function Disability and Health.³⁷ Consistently, primary goals are most likely to fall into one of the categories shown in Table I.³⁶, ³⁸⁻⁴⁰

Goals are negotiated with the patient and significant others to ensure that they are realistic in a specified time interval, that they are achievable in the context of the patient's potential and the skills and resources available to the treating team. The clinical examination helps greatly to assist this process, as the HCP will have a better idea

of the potential for improvement. However, to maximize the likelihood of success, the patient and their family must take "ownership" of the treatment goals, irrespective of whether the aim is to achieve an active functional change, reduce symptoms or the burden of care.

Following illness or injury, patients and their families may understandably have excessive or unrealistic expectations for recovery and resumption of their pre-injury lifestyle,⁴¹ and thus education is vital to the negotiation process.⁴² Individual patients will have diverse ideas about goals within the context of the uncertainty of their condition, their life as a whole, and recovery after formal rehabilitation is completed.⁴³ When initially asked to state their goals for treatment, patients will often express goals in terms of long-term aspirations and hope for a cure. During goal setting, long-term aspirations (*e.g.* patient independence) are broken down by the team into medium-term objectives for the treatment program and a series of staged

Table I.—Classification of key goal areas for treatment of spastic paresis mapped on to the WHO ICF.39

	Goal areas	
Symptoms/impairment		
Pain/discomfort	Spasticity-related symptoms	
	– Pain	b280
	 Discomfort due to stiffness 	b780
Involuntary movements	Unwanted involuntary movements during use of other limbs	
•	 Associated reactions 	b755, b760
	 Spasms or dystonic movements 	b765
Contracture prevention	Improving range of movement	
•	 Prevention of contractures/deformity 	b735
	 Splint tolerance 	b710
Activities/function	•	
Passive function		
Caring for the affected limb	Ease of caring for the affected limb e.g.:	
č	 Maintaining hygiene of hand, elbow, axilla 	b510
	 Maintaining skin integrity, cutting fingernails 	d520
	 Dressing and positioning the limb, splint application 	
Active function		
Using the affected limb	Active motor tasks, e.g.:	
	 Reaching, grasp/release, holding /manipulating objects 	d445
	 Fine dexterity and lifting / carrying objects 	d440, d430
For a functional purpose	Activities of daily living	
	 Personal - eating/drinking 	d550, d560
	- Self-care	d500, d510, d540
	 Extended ADL 	d630, d640
	 Occupational - work or recreation 	d850, d920
Mobility	Improved mobility	
	 Ease of transfers 	d420
	 Balance, standing 	d415
	- Walking	d450
Other, e.g.:		
Cosmesis / body image	Patient's perception of body image, aesthetic appearance	
Therapy facilitation	Team's perception of interference with therapy	

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goals aimed towards meeting those objectives (Figure 1). Having had more experience with the management of spastic paresis and long-term outcomes, HCPs may sometimes suggest additional goals that a patient may not have previously identified.

Goal statements must be well-defined, objective, and clearly understood by the patient. For example, it is of little value to propose vague general goals such as "to improve walking speed." A SMART functional goal statement might be: "[Name] to be able to walk the 1/4 mile to his local shop in 20 minutes within 6 weeks." The setting of clear goals for treatment can, in itself, lead to improved patient outcomes. 44, 45 Practice recommendations have been developed to guide writing SMART goals 34 and ways to improve the involvement of people with communication difficulties in the process have also been described. 46

Patient-centered approaches to the treatment of spastic paresis

The process of goal setting demands a paradigm shift in the way that therapies and interventions are chosen and used in the long-term management of patients with spastic paresis.⁴⁷ Targeted treatments should be instituted only if the patient and rehabilitation team can identify clear treatment goals that are likely to be improved by the interven-

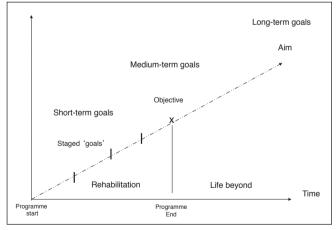


Figure 1.—Long-term goal setting. Long-term goals may reflect the patient's general aims or "life goals" that are typically beyond the immediate program of treatment. Medium-term goals may reflect the specific objectives for the intended outcome of the program; while short-term goals reflect the staged goals or milestones that must be achieved *en route* to meeting the objective.

tion.⁴⁸ It is important to recognize that not all the signs and symptoms of spastic paresis require intervention; many people use their muscle over-activity to good effect, for example, standing on spastic limbs, when the underlying paresis would not otherwise allow it.⁴⁹ Treatment paradigms should include appropriate physical and pharmacologic strategies to optimize the likelihood of achieving the patient's predefined therapeutic goals.⁵⁰

Pharmacological strategies

Treatment decisions regarding specific pharmacologic interventions are influenced by chronicity, severity and the presentation of the spasticity; also by the presence of comorbidities and environmental factors such as availability of family and therapist support. Pharmacologic interventions are most effective when used early, before tissue shortening and contractures develop.⁵⁰ The main options for pharmacological therapy include botulinum neurotoxin (BoNT) for focal and multi-focal spasticity, or oral anti-spastic medications and intrathecal baclofen for more regional and generalized spasticity. Chemical neurolysis with phenol or alcohol to block motor nerves or motor endplates is often used in less well-developed countries and can still be useful to reduce total dose of BoNT per session or to reduce the drug cost of intervention, especially in countries where BoNT use or dose is restricted.

The benefits, harms and risks of pharmacological interventions have been extensively reviewed elsewhere. ⁵⁰ It is pertinent to note that there is accumulating evidence that BoNT-A can improve not only pain and passive function, but also active function and daily activities in selected cases. ⁵¹⁻⁵⁴ Focal BoNT-A can be used to reduce over-activity in antagonistic muscle groups in order to unmask voluntary muscle movement in agonist groups, as well as improving the potential for exercise / prolonged stretching postures. ⁵³

Physical strategies

Spastic paresis requires a comprehensive treatment strategy and anti-spastic medication should rarely (if ever) be used in isolation. Spastic paresis is usually a life-long condition, and physical therapy is essential for helping patients to adapt to changes and develop an adequate exercise program, as well as reducing muscle over-activity and preventing the aggravation of complications such as contractures. 50, 55, 56 The options for physical and occu-

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pational rehabilitation are varied and a classification of physical intervention categories is provided in Table II.

The benefits of each of these individual therapies have been comprehensively and systematically reviewed elsewhere, 50, 57-60 and a full review is outside the scope of this publication. But while there is a large body of evidence demonstrating that physical treatments are useful, there are important gaps in the published evidence base that have, thus far, limited the conclusions of several systematic reviews. 57-59, 61 and require further delineation:

- intervention is often multi-modal and approaches are so varied that this confounds comparison of findings from different trials; substantial further work is necessary to identify the optimal doses and methods of application for the different interventions;
- outcome data for long-term management are limited.⁶² Longitudinal trials are difficult and costly and have not yet received the attention required.²⁷

Thus, while treatment decisions may be informed by the evidence, in practice the treatment offered will usually depend on local access to services, as well as familiarity of the team with the treatment modality.

Task practice and guided self-rehabilitation

At a clinical level, it is increasingly accepted that treatment for spastic paresis, spastic co-contraction and other consequences of an upper motor neuron lesion should involve a combination of:

- intensive task-practice training for those patients with potential for improving motor function (with goals centered on active function). This may include high daily repetitions of task-related activities to improve motor control: 58, 60, 63-65
- prolonged stretching postures for shortened muscles,66-70 especially for patients at risk of developing contractures or further deterioration in contractures already present.

Typically, most patients with spastic paresis will require several hours per day of practice or stretch and, within current economic constraints, most healthcare systems cannot provide the optimal daily duration of task-practice and/or stretch required for efficacy.⁷¹ The only stakeholders who can feasibly meet this demand are the patient and caregivers, although there will be significant challenges and commitment required of them. In guided self-rehabilitation models the therapist does not practice the exercises but assumes a coaching role, providing motivation and guidance. Current research provides some reasonably strong evidence for patient self-rehabilitation and home exercise programs in this context — particularly for task practice interventions. 63, 65, 72-74 For example, the GRASP program of supported self-exercise for community dwelling stroke survivors has resulted in improved motor control and functional activity performance in trials. 75, 76 Other approaches to improving self-task practice are also being developed. These include computer-based gaming for home rehabilitation that can be adjusted to an individual's specific abili-

Table II.—Physical rehabilitation interventions.

Physical rehabilitation interventions

3	The Real Property of the Control of
Postural management domain	
1. Splinting/orthoses	Static splints and orthoses (including circumferential splints) with an aim of maintaining range of movement (resting splints)
2. Supports/slings	Supports for the hemiparetic arm including slings, tray tables, etc.
3. Serial casting	Static or adjustable (often circumferential) splints, applied serially with an aim of increasing range of movement
4. Positioning	Therapeutic positioning often carried out by therapists, patients and/or carers with the aim of improving or maintaining muscle length. This includes the use of positioning aids <i>e.g.</i> T-rolls
Exercise and retaining domain	
5. Passive stretch	Short duration manually applied passive stretching.
6. Electrical stimulation	Electrical stimulation to: 1) strengthen muscle; 2) to incorporate in functional activity; 3) manage pain.
7. Strength training	Exercise programs specifically designed to increase muscle strength
8. Cardiovascular/aerobic training	Exercise specifically directed at aerobic "fitness"
9. Task practice	Techniques involve the practice of specific tasks with the aim of inducing motor learning. They may include augmented practice using robotics and gaming technologies. Examples include:
	 in the upper limb: constraint induced movement therapy (CIMT), active exercise programs, mirror-therapy and dynamic/exercise splints incorporated in task training programs;
	- in the lower limb: all aspects of gait retaining, treadmill training with/without partial body weight support
10. Balance	Specific intervention targeting the re-education of balance to then be incorporated into the task

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ties and requirements. Such approaches show promise in providing guidance for exercise performance, feedback on achievement and incremental progression of tasks to simulate true activity.⁷⁷⁻⁸⁰

In all guided self-rehabilitation models, it is fundamental that the patient is fully engaged and understands the goals and timelines of the therapy from the beginning and that a true therapeutic alliance between the therapist and patient develops. There is evidence that providing information, managing uncertainty and targeting the program on the needs of the individual can improve motivation and optimize outcomes.⁸¹⁻⁸⁴ In addition, varying the training tasks, positive reinforcement and constant adjustment of goals can help to maintain the individual's progression.⁷¹

Goal attainment scaling as an intervention for patient engagement

Goal attainment scaling (GAS) ^{35, 85, 86} offers a useful framework for collaborative goal review and goal management training. It also provides a patient-centered outcome measure that can be used to evaluate gains from rehabilitation in the areas that matter most to patients and their families. Most patients will have more than one goal for treatment. Some goals may be more important to the patient than others, and certain goals will be harder to achieve. GAS provides a structured approach to the evaluation of goal attainment, which takes account of this variation.^{44, 53, 87}

As originally described in the 1960s,85 GAS uses a five-point scale to capture both over- and under-achievement of expected goals. The original GAS method was time consuming and impractical for use in routine clinical practice, but a simplified "GAS Light" method 35 is feasible and practical for use in clinical settings. It incorporates a six-point verbal scale to capture partial goal achievement, which can be converted to the various five- and six-point numerical scales to support comparative analysis.88 Figure 2 summarizes the six key steps to goal setting and GAS and the six-point verbal rating scale.

Patient involvement is integral to the process of goal setting and goal assessment. Learning to set, review and revise their own goals is viewed as a critical skill, enabling patients to progress their own rehabilitation after they leave the program.³³ By exploring which goals are most important to the patient and their families, the process encourages patient engagement with therapy since

they are more likely to engage positively in rehabilitation directed towards goals that are important to them.^{32, 40} Recent studies have developed tools to measure patient / family engagement in, and satisfaction with, the goal setting process, and have shown that patient engagement is strongly correlated with goal satisfaction and is associated with goal attainment and functional gains from rehabilitation.⁸⁹

As an outcome measure, the GAS approach is conceptually different from standardized evaluation in that it focuses on the attainment of goals rather than on set items as are used in measurement instruments. 86, 88, 90-92 Technically, it is a measure of "achievement of intention," rather than an outcome measure *per se*, but it allows the clinician and patient to agree on what constitutes a successful outcome or "non-success." This is important in determining whether treatment should be continued. However, because of the wide variation of individual goals, it does not support direct comparison between different practices or

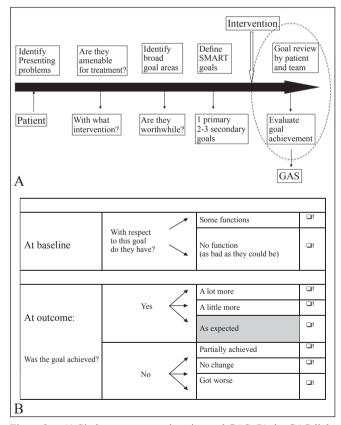


Figure 2.—A) Six key steps to goal setting and GAS; B) the GAS-light six-point verbal rating scale.

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Table III.—Recommendations for patient-centered care management of spastic paresis.

	Recommendation	Evidence	Benefits*	Harms** (little)	Costs*** (small)	Overall strength of recommendation
1.	Management of spastic paresis is a complex and multi-faceted process requiring multi-disciplinary patient-centered care strategies, adapted to meet the complex needs of patients with acquired brain injury					
1.1	The patient should be at the heart of all care, and their objectives are of critical importance in guiding all clinical decisions. 2, 5, 6, 23, 24, 31, 42	RC E1 E2	No known undesirable	Yes	Yes	Strong
1.2	Treatment for spastic paresis should be centered on as far as reasonable on the patient's priorities for treatment. ^{2, 5, 6, 23, 24, 31, 42}	RC E1 E2	No known undesirable	Yes	Yes	Strong
1.3	Assessment and treatment planning should be conducted through a collaborative multi-disciplinary approach, involving the relevant disciplines. ^{2, 6, 25, 27}	E1 E2	No important uncertainty	Yes	Probably Yes	Moderate
2.	Anti-spastic medication (including botulinum toxin injection) and therapeutic intervention are best used as part of a whole treatment strategy that is based on helping patients achieve their selected goals					
2.1	Treatments for spasticity should be instituted only if the patient and rehabilitation team identify clear goals for treatment that are achievable and likely to lead to meaningful benefit. 36, 38, 39, 44, 107	RA E2	No known undesirable	Yes	Yes	Strong
2.2	Outcomes should be monitored and recorded to demonstrate that the benefits are being achieved as expected. 36, 38, 39, 44, 107	RA E2	No known undesirable	Yes	Probably Yes	Strong
3.	Goal setting and review is an integral part of the rehabilitation process, which encourages the development of a therapeutic partnership between the patient (and/or their family carer if the patient is unable) and the team, and leads to higher satisfaction					
3.1	Goal setting, negotiation and formal recording of SMART goals (agreed between the team, patient and/or their family carer) should be an integral part of all spasticity management programmes. ² , 5, 34, 45, 47, 108	RC E1 E2	No known undesirable	Yes	Probably Yes	Moderate
3.2	Patients (and/or their family carer) should be involved in the evaluation of goal achievement. 23, 40, 89, 109	RC E2	No known undesirable	Yes	Probably Yes	Moderate
3.3	Goal attainment scaling should be recorded alongside other standardized measures in the evaluation of outcome. ^{2, 44, 53, 87, 92}	RA E2	Probably no important uncertainty	Yes	Probably Yes	Moderate
4.	When the target (goal) of treatment is improvement in active function and motor control, task practice training may be effective in selected patients with potential for motor recovery. In addition, if reduced muscle-tendon length has occurred or is a potential risk, then stretch interventions may be implemented to combat this					
4.1	Task-practice training should be offered in properly selected patients when improvement in activity performance and motor control are the target or goal of treatment. 58 , 59 , 63	RA E2	No known undesirable	Yes	Yes	Strong
4.2	Prolonged stretch intervention should be implemented in individuals at risk of contracture or further contracture development when influence on the muscle-tendon length and associated structures is still possible. ^{62, 67, 68}	RA E2	No known undesirable	Yes	Probably Yes	Strong
5.	Development of self-efficacy and autonomy is an important part of community rehabilitation. Techniques such as goal management training and self-rehabilitation with positive feed-back and reinforcement may help to maintain engagement and motivation in the home setting					
5.1	When planning interventions for spastic paresis, the team should consider the patient and their family's capacity for self-rehabilitation, as well as ways to enhance this approach. 40, 73, 74	RB E2	No known undesirable	Yes	Probably Yes	Strong
5.2	Education and goal management training should form an integral part of any rehabilitation program. It is good practice to record the level of engagement of patients and their families, and their satisfaction with the goals for treatment. Increasing engagement and satisfaction may themselves be goals for treatment. ^{40, 74, 89}	RC E2	No known undesirable	Yes	Probably Yes	Moderate

(To be continued)

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TABLE III.—Recommendations for patient-centered care management of spastic paresis (continues).

	Recommendation	Evidence	Benefits*	Harms** (little)	Costs*** (small)	Overall strength of recommendation
6.	Patients with neurological conditions frequently have complex impairments (including neuropsychological, cognitive, sensory and behavioural deficits) that may impact on their ability to engage actively in treatment for spastic paresis and affecting the outcome of intervention					
6.1	The proposed intervention and treatment goals should take into account the impact of any neuropsychological, cognitive and behavioral deficits on rehabilitation. ^{5, 47, 100, 101}	RC E1 E2	No known undesirable	Yes	Probably Yes	Moderate
6.2	The treating team should address these clinical issues as part of their overall assessment and treatment planning. ^{2, 5, 47}	RC E2	No known undesirable	Yes	Probably Yes	Moderate

RA: research evidence grade A; RB: research evidence grade B; RC: research evidence grade C; E1: expert opinion from patients/carers; E2: expert opinion from professionals patients/carers

populations. Some authors have advocated a more standardized approach using "goal banks." ⁹³ More recently a structured approach to GAS has been developed for use in management of upper limb spasticity. The GAS Outcome Evaluation of Spasticity (GASEOUS) tool incorporates a more structured approach to goal setting, and the recording of standardized measures alongside goal attainment, the selection of the measure(s) being dictated by the chosen goal areas.³⁹

Impact of neuropsychological, cognitive and sensory deficits on rehabilitation

In addition to physical impairments, survivors of acquired brain injury typically experience a range of sensory, cognitive, behavioral and emotional deficits that all interact to impact on psychosocial function.94-96 Cognitive-Motor Interference (CMI), for example, refers to the simultaneous performance of cognitive and motor functions which results in diminished execution of one or both tasks.⁹⁷ Studies demonstrate that more than half of stroke patients experience significant problems with memory, 98 depression, 99 and/or somato-sensory dysfunction95 that may have adverse effects on recovery and should be addressed in their own right as part of the rehabilitation program.^{47, 100, 101} It is important for the treating team to identify these problems in order to ensure that the goals chosen are appropriate to their abilities^{102, 103} and to take the necessary steps to engage the patient and/or family in the light of these difficulties.104

Goal management training (GMT) is a self-regulation approach to goal-directed behavior, aimed at training indi-

viduals to structure intentions and manage goal-planning activities.³³ According to current neuropsychological models of executive behavior, goal-directed behavior is a structured process of hierarchical steps managed in the pre-frontal cortex of the brain. People with brain injury often have problems with poor construction and distractibility that lead to goal neglect, if not managed proactively. The process of GMT defined by Levine and colleagues incorporates five keys stages:

- Stage 1 (the "stop" strategy) encourages individuals to stop and think about what they are doing;
 - Stage 2 defines the main goal or task at hand;
- Stage 3 requires the patient to list the necessary steps involved in executing their goal.
 - Stage 4 involves carrying out each step in turn;
- Stage 5 applies the "stop" strategy again to check if their current behavior is still advancing them towards the original main goal.

This approach has been used with good effect in patients with executive dysfunction due to traumatic brain injury and its efficacy established in several trials, particularly in relation to goal neglect and attention. 105, 106

Conclusions and recommendations

In the context of rehabilitation following a brain injury, the general concept of person centered care has to be adapted to allow specialists to guide decision-making in what is a very complex process. In this review, we have used a pragmatic systematic approach for the assimilation of a broad and varied evidence-base. Table III sets out recommendations based on the published evidence

professionals, patients/carers.

*"Is there important uncertainty about how much people value the recommendation?"; ** "Are the desirable effects large relative to undesirable effects?"; *** "Is the incremental cost small relative to the net benefits?".

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and the consensus of this guidelines development group. The evidence evaluation tables may be found in the accompanying electronic supplement. Limitations of the review reflect the absence of published literature, especially in regard to combinations of treatments and approaches. This is where expert experience and opinion have an important role in bringing together the many different aspects of care, and we hope our recommendations support a person-centric focus in the management of spastic paresis. 107-109

Take-home messages

- The patient should be at the heart of all care, and interventions for spastic paresis should be centered on as far as reasonable on the patient's own priorities for treatment.
- Goal setting, negotiation and formal recording of agreed SMART goals should be an integral part of all spasticity management programs, and goal attainment scaling should be recorded alongside other standardised measures in the evaluation of outcome.
- When planning interventions for spastic paresis, the team should consider the patient and their family's capacity for self-rehabilitation, as well as ways to enhance this approach.
- The proposed intervention and treatment goals should consider the impact of any neuropsychological, cognitive and behavioural deficits on rehabilitation.

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107. Turner-Stokes L, Fheodoroff K, Jacinto J, Maisonobe P, Zakine B. Upper limb international spasticity study: rationale and protocol for a large, international, multicentre prospective cohort study investigating management and goal attainment following treatment with botulinum toxin A in real-life clinical practice. BMJ Open 2013;3.

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Authors' contributions.—All authors participated in face-to-face and telephone meetings to agree the recommendations and their strength of evidence. Project leads for each area of recommendation were: David Simpson, Lynne Turner-Stokes, Stephen Ashworth, Jörg Wissel, Anthony Ward and Alberto Esquanazi. Lynne Turner-Stokes was responsible for designing the consensus methodology, and provided project oversight for authors work in grading the recommendations made. She also cross-checked all recommendations with the literature cited as supporting those recommendations. David Simpson acted as chair of the initial meeting in Berlin. All authors approved the final version of the article and were responsible for the decision to publish.

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Congresses.—This paper is based on a meeting of a group of expert clinicians experienced in the management of adult patients with spastic paresis, who aimed to develop a person centered framework for best practice in delivering a comprehensive and person centered service. The meeting was held during the 9th World Congress of the International Society for Physical and Rehabilitation Medicine in Berlin, Germany, on the 23rd June 2015.

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