The evolution of goal setting and attainment for patients with upper limb spasticity in a series of observational cohort studies: the Upper Limb International Spasticity (ULIS) programme

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BACKGROUND

- The Upper Limb International Spasticity (ULIS) programme is a series of large observational studies examining botulinum toxin A (BoNT-A) injections as part of an integrated management strategy for upper limb spasticity (ULS) treatment in real-life clinical practice.[1,2]
- These studies used Goal Attainment Scaling (GAS) to evaluate person-centred outcomes after BoNT-A treatment.[3]
- Full data from ULIS-III are expected in 2020.

OBJECTIVE

- To examine the evolution of goal-setting and attainment between ULIS-II and ULIS-III.

METHODS

ULIS-II programme

- ULIS-II (NCT01020500; 2010–2014) examined GAS outcomes in adults with post-stroke ULS after a single BoNT-A cycle.[2]
  - Primary endpoint was attainment of the primary goal when set using GAS.
  - Overall attainment of treatment goals was assessed by the GAS T score.
    - GAS T = (sum of attainment levels × the relative weights [optional] for each goal) transformed into a standardised measure with a mean (SD) of 50 (10).
    - Apart from the value of GAS T as a "goal quality check", the primary use is to indicate whether goals were overly cautious (score of >50), on target (~50), or overly ambitious (<50).[3]

ULIS-III programme

- ULIS-III (NCT02454803; 2016–2019) examined GAS outcomes in adults with ULS (any neurological condition) after repeated BoNT-A cycles.[1]
- The GAS – Evaluation of Outcome for ULS (GASeous) tool was introduced to improve the quality of goal-setting.
  - GASeous is a structured framework for applying GAS alongside standardised measures.
- Primary endpoint: attainment of goals set using the GASeous tool, assessed by the GAS T score.

Centre evaluation

- Quality of goal-setting for each centre was rated by 4 principal investigators using the 2 criteria detailed in **Table 1**.

RESULTS

- Distribution of patients enrolled:
  - ULIS-II: 468 patients from 22 countries (84 centres).
  - ULIS-III: 1,004 patients from 14 countries (58 centres).
- This study presents ULIS-II data for all patients, and preliminary ULIS-III data for the first cycle in 807 patients.

Centre rating

- The rating of goal-setting for centres improved between ULIS-II and ULIS-III (**Figure 1**):
  - 'A++' rating: 24% compared with 79%, respectively.
  - 'A' rating: 51% compared with 91%, respectively.
  - '++' rating: 32% compared with 81%, respectively.

Goal setting

- Between ULIS-II and the first cycle of ULIS-III, the distribution of primary goals changed following the implementation of the GASeous tool (**Figure 2**).

Goal attainment

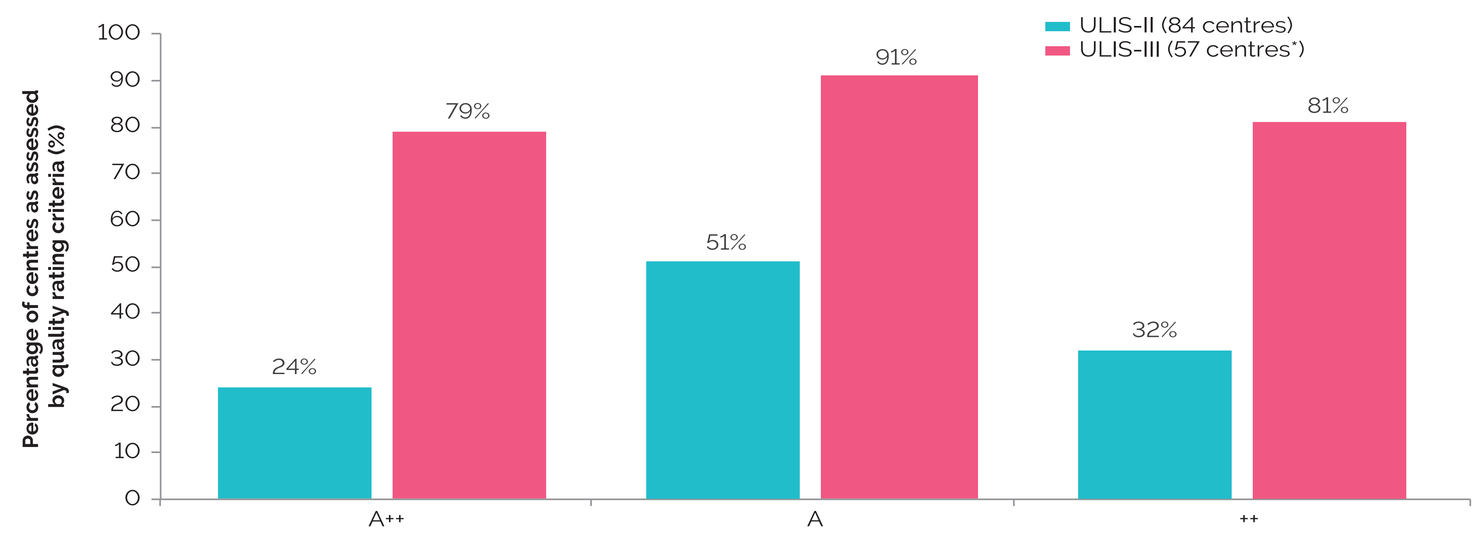
- Although the proportion of patients who achieved their primary goal fell from 79.6% in ULIS-II to 69.4% in ULIS-III, the overall mean (SD) GAS T scores indicated that goals were achieved at least as expected:
  - ULIS-II: 52.0 (10.1).
  - ULIS-III: 49.9 (7.9).
- Mean GAS-T scores closer to 50 in ULIS-III reflected higher quality goal setting with tighter goal definitions and more accurate prediction of goal achievement.

Table 1. Quality rating criteria for primary goal statements: WHO ICF domain and SMART descriptions[4]

Rating	Quality rating criteria	Example
WHO ICF domain, disability and health		
A	Goal statements reference active or passive* functional activities at the level of disability or participation	Ease of self-care, reduced care burden, mobility, community-based activities, work-related function
B	Goal statements reference impairment only	Movement, range, grip strength, spasticity, clonus
C	Goal statements reference anatomical structures only	Extension, flexion, pronation
SMART description		
++	SMART description of goal. Description is detailed and specific for accurate GAS rating	"To be able to type a 4-word sentence with only single typing area using index fingers in 15 seconds"
+	Goal description is sufficient to support GAS rating, but reliant on patient interpretation	"To be able to open and close hand as well as use fingers more in household chores"
-	No clear goal description	"To use the hand more easily"

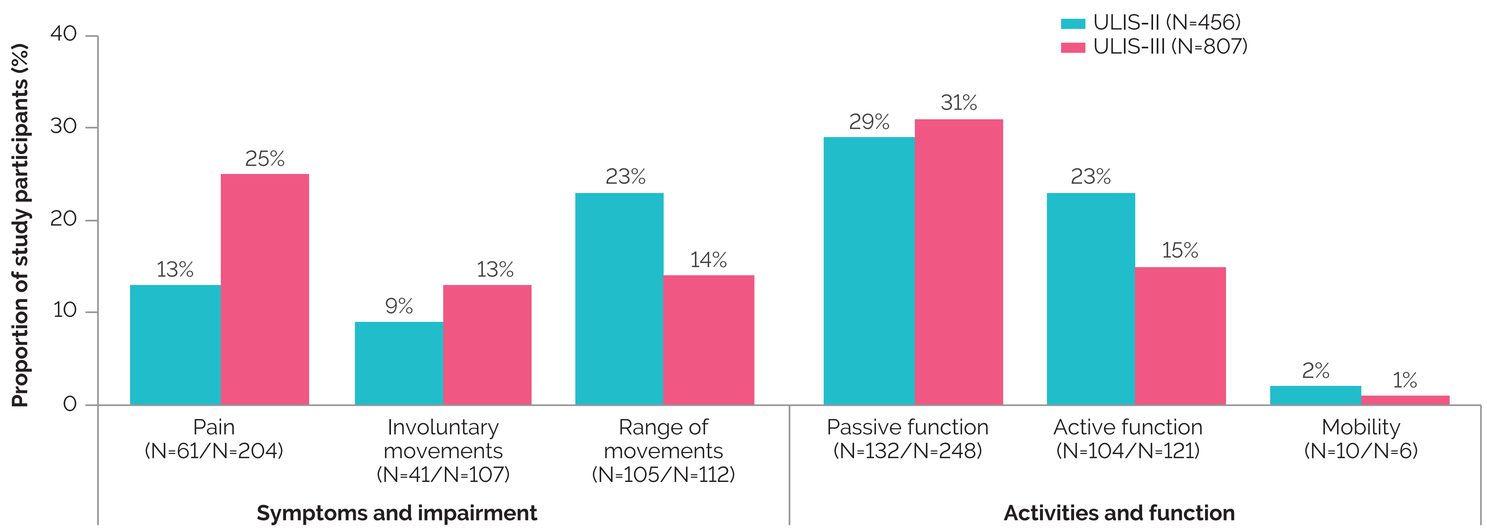
* 'Passive' function, tasks related to caring for the affected limb (by the patient or a carer); 'active' function, tasks involving motor activity of the affected limb for an identified functional purpose.
GAS, goal attainment scaling; ICF, International Classification of Functioning; SMART, specific, measurable, achievable, realistic and timed; WHO, World Health Organization.

Figure 1. Percentage of centres classified as A++, A and ++ goal setters within the ULIS-II and ULIS-III studies



*Quality ratings were not available for 1 centre.

Figure 2. Distribution of primary goals in the ULIS-II and ULIS-III studies



Percentages are based on the number of subjects with available data. For each goal area, the 'N' number for patients who selected that goal area in ULIS-II/ULIS-III is reported in the x-axis title.

CONCLUSIONS

- Introducing the GASeous tool yielded tighter goal definitions and more accurate predictions of goal achievement.
  - This increased the quality of goal-setting and reduced overestimation of goal-attainment for patients in ULIS-III.
- The use of structured goal setting in real-life clinical practice may improve clinicians' understanding of which goals are achievable for patients.

References

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Ethical approval

The ULIS programme was conducted in compliance with the Declaration of Helsinki, the Council for International Organizations of Medical Sciences International Ethical Guidelines for Epidemiological Studies and the guidelines for Good Pharmacoepidemiology Practices. Ethics approval was sought at each site according to local legislation.

Author contributions

LT-S, SA, KF, JJ and AB were involved in concept, design, data collection and assembly of data. PM and AL were involved in the concept and design, and the plan for data analysis was led by PM. All authors were involved in drafting of the publication, or revising it critically for important intellectual content, and provided final approval of the publication.

Disclosures

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