

Objective

To explore tremor symptoms and related impacts on activities of daily living (ADLs) experienced by US-based adults with essential tremor (ET).

To evaluate the conceptual coverage of the Patient Attainment Scale (PAS-ET) and the Most Bothersome Symptom Questionnaire (MBS-ET) through concept mapping.

Results: concept elicitation interviews

N=16 participants were recruited (63% male; mean age: 66.13 years; mean years since diagnosis: 8.35). Conceptual saturation and recruitment targets were met within the sample.

All participants reported experiencing upper limb tremor; an overview of reported tremor symptoms is provided in Figure 1. External factors impacting tremor included stress, temperature and fatigue.

Difficulty with fine-motor tasks was the most frequently reported tremor-related ADL impact (n=13). See Figure 2 for ADL impacts reported.

Participants also spontaneously reported tremor-related impacts on wider QoL, including leisure activities (n=7), emotional functioning (n=6), family life (n=2) and financial impacts (P007-MLD).

Demographic and clinical characteristics, saturation matrices and information on specific fine-motor tasks reported by participants are provided in the supplementary materials.

Results: concept mapping

The MBS-ET assessed all symptoms reported by participants (upper limb, lower limb, head and voice tremor). Five of the eight identified ADL concepts were assessed in the MBS-ET and PAS-ET (Figure 3).

No revisions/additions to the ADL concepts included in the PAS-ET and MBS-ET were deemed necessary based on the concept mapping exercise as:

- “Shopping”/“driving” were only mentioned by n=1-2 participants
- “Cooking” and “picking up objects” may overlap conceptually with “pouring” and “carrying”
- Additional “fine motor” activities were only reported by n=1-3 participants and included specific activities (e.g., “painting”) that are unlikely to be widely endorsed
- The MBS-ET includes an “other ADL” option, and the PAS includes a “global ADL” item

Tremor Symptoms and Associated Activities of Daily Living Impacts in Essential Tremor: A Qualitative Concept Elicitation and Mapping Study

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Background

ET is one of the most common movement disorders globally, affecting approximately 1% of the general population and 4-5% of individuals aged over 65 years.¹

ET is characterised by bilateral upper limb action tremor for at least 3 years, with or without tremor in other areas.¹

ET significantly impacts ADLs and affects quality of life (QoL).²

Two novel, personalised, patient-reported outcome (PRO) instruments were developed for use in ET populations:

- The PAS-ET: designed to assess patient-level perceptions of the importance, current function and definitions of meaningful improvement in tremor-related impacts on ADLs
- The MBS-ET: designed to assess the symptoms and functional impairments related to tremor that patients find most bothersome
- The same ADL concepts are assessed in both instruments. An overview of instrument content (V1.0) is provided in the supplementary materials.

Personalised PRO instruments measures, such as the PAS-ET and MBS-ET, can be used in clinical research to examine treatment benefit in relation to what is most relevant and/or important to each patient at baseline.³

To determine suitability for use, evidence must be obtained to support the patient-relevance of PRO instruments supporting clinical trial endpoints in the target population.⁴⁻⁷

Methods

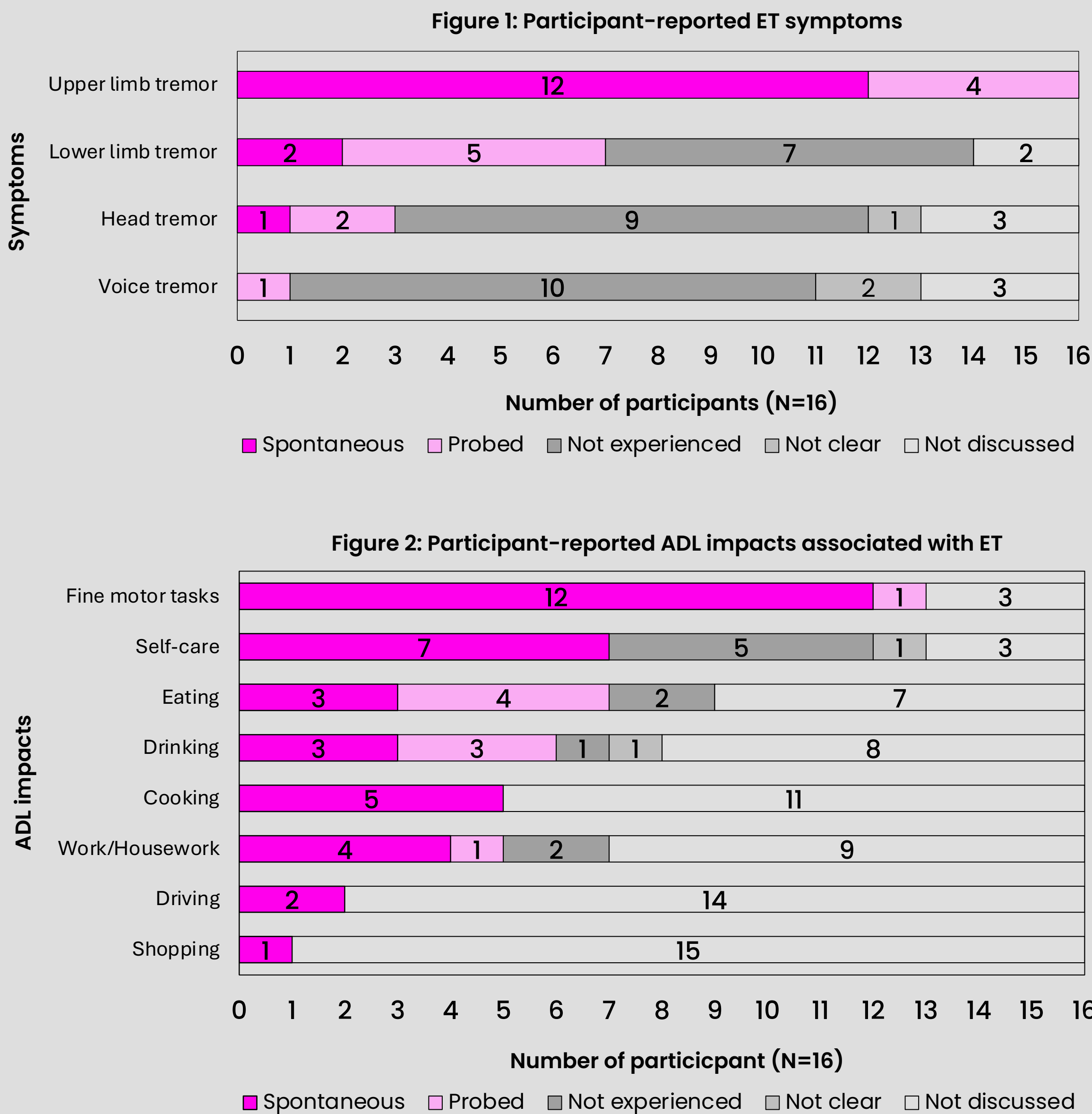
Concept elicitation interviews were conducted via video-conference following a semi-structured interview guide. Ethical approval was obtained prior to data collection. All participants provided informed consent.

Potential participants were identified by a specialist recruitment agency and were screened against the study inclusion/exclusion criteria. Recruitment targets were used for age and severity of tremor-related ADL impacts.

Transcripts were analysed using thematic and content analysis methods.⁸⁻⁹ Conceptual saturation was monitored using a saturation grid.¹⁰ Data were reported using participant ID codes.

Relevant concepts (symptoms or ADLs) elicited in interviews were mapped to the PAS-ET and MBS-ET to assess conceptual comprehensiveness.

Further detail on IRB approval, inclusion/exclusion criteria, recruitment targets, participant ID coding and the interview process is provided in the supplementary materials.



“Usually my fingertips, hands, you know, my whole arms at, at times, from basically my elbow to my fingertips but usually it's most visible in my hands at this point in time.”

P014-SEV, describing upper-limb tremor

“I used to have beautiful handwriting, now I can only do a few letters at a time, I have to stop and start again. And sometimes, I can't do real close-up work anymore, like some of the crafts and things I used to do.”

P006-MLD, describing impacts on fine-motor tasks

“I would say picking up, you know, using silverware at times, that can be difficult for me. And especially if we go out which we don't go out that much, it's not that comfortable for me to go to restaurants, we used to go, you know, quite a bit and I'm limited to do that or if I'm with other people, I think I get nervous and the tremors get a little worse.”

P015-SEV, describing impact on eating

Participant quotes illustrating tremor symptom and associated ADL impacts

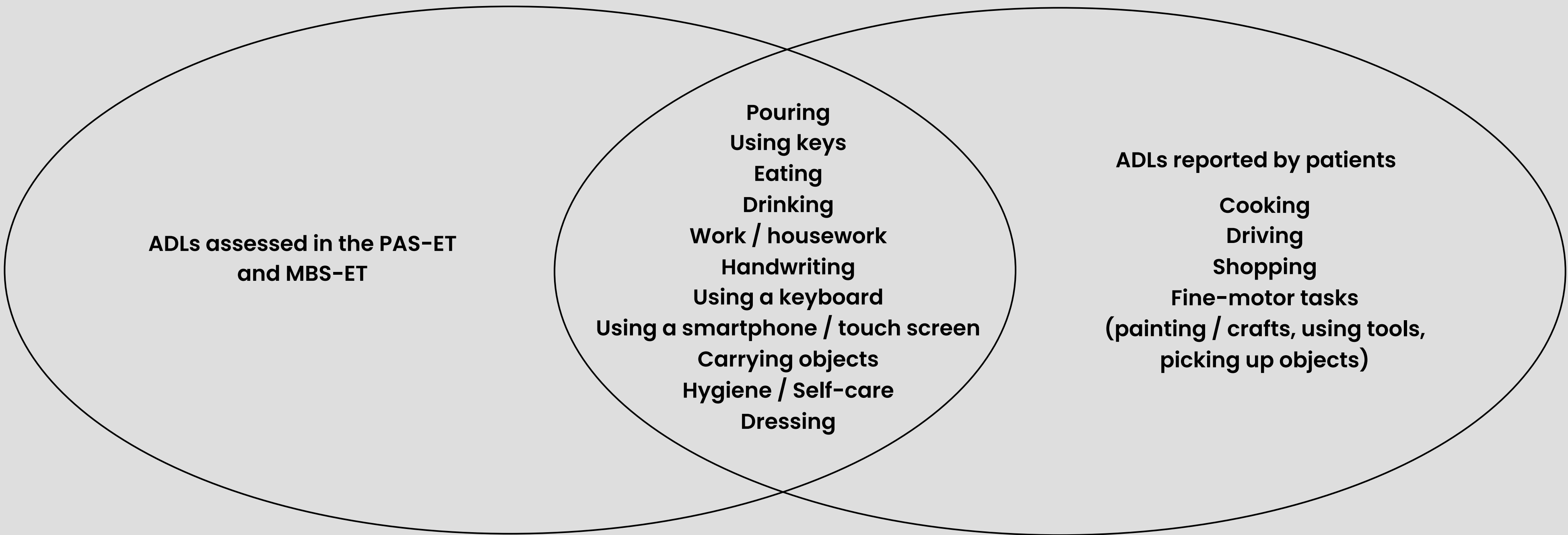


Figure 3: Venn diagram demonstrating concept mapping of ADL impacts onto the PAS-ET and MBS-ET

Conclusions

- This study highlights the tremor symptoms and ADL impacts in ET patients, with upper limb tremor and fine-motor tasks most affected, exacerbated by factors like stress, temperature, and fatigue.
- The concept mapping exercise demonstrated that PAS-ET and MBS-ET have good conceptual coverage. Findings support the conceptual comprehensiveness and patient-relevance of both instruments for use in clinical research.

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Scan for full details in supplementary materials