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Title

Adaptation and content validation of a patient-reported measure of treatment burden for use in stroke survivors (PETS-stroke)

Priority 1 (Research Category)

Cardiovascular disease

Presenters

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Abstract

Context: Treatment burden is defined as the workload of healthcare for people with long-term conditions and the impact on wellbeing. Stroke survivors often live with considerable treatment burden because of high healthcare workload alongside deficiencies in care provision that can make navigating healthcare systems and managing health more difficult. Ways of measuring treatment burden after stroke are currently lacking. The Patient Experience with Treatment and Self-Management measure (PETS) is a 60-item patient-reported measure that was developed to measure treatment burden in a multi-morbid population. Although comprehensive, this is not a stroke-specific measure and therefore omits some burdens associated with stroke rehabilitation. Objective: Our aim was to adapt (PETS) (version 2.0, English), a patient-reported measure of treatment burden in multimorbidity, to create a stroke-specific measure (PETS-stroke), and to conduct content validity testing in a UK stroke survivor population. Study Design and analysis: PETS items were adapted to create PETS-stroke, using a previously developed conceptual model of treatment burden in stroke. Content validation involved three rounds of qualitative cognitive interviews with stroke survivors in Scotland recruited through stroke groups and primary care. Participants were asked for feedback on the importance, relevance and clarity of content of PETS-stroke. Framework analysis was used to explore responses. Setting: Community. Population studied: Stroke survivors. Instrument: Patient Experience with Treatment and Self-Management in stroke (PETS-stroke) scale. Results: Interviews (n=15) resulted in changes to the wording of instructions and items; location of items within the measure; answer options; and recall period. The final PETS-stroke tool has 34-items, spanning 13 domains. It includes 10 items unchanged from PETS, 6 new and 18 amended. Conclusions: The development of a systematic method of quantifying treatment burden from the perspective of stroke survivors will allow for the identification of patients at high risk of treatment burden and will aid the design and testing of tailored interventions aimed at lessening treatment burden.