

Letter

Dan Med J 2023;70(6):A300004

Reply to editorial letter on Limited value of a patient-reported triage algorithm in an outpatient epilepsy clinic

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Dear colleagues

Thank you for reading and commenting on our recently published paper: Limited value of a patient-reported triage algorithm in an outpatient epilepsy clinic [1].

We would like to emphasise that the intension with the above-mentioned work was to validate the national patient-reported triage algorithm by comparing it with a professional assessment made by a neurologist specialised in epilepsy as our gold standard. We believe that inclusion of the patient perspective is important in the care of patients in general. However, we are surprised to read that Hjollund et al. believe that our results reflect the opinion of only a single neurologist. The neurologist in our study is an experienced senior consultant specialised in epilepsy who has contributed to the development of the national treatment guideline. We would strongly argue that the professionalism upon which our assessment was based also represents the opinions of other fellow experienced neurologists. We assume that the professional standard between neurologists is similar.

First, we would like to stress that we do not have any conflicting interests and our previous paper is written solely based on our interest in neurology, science and previous work with clinical rating scales. Hjollund and colleagues have not declared any conflicts of interest but are all affiliated to the Centre for Patient-reported Outcomes (PRO) and seem to be employed to work and develop PRO. We had no intention to criticise previous work done by these authors.

Second, Hjollund et al. question the methodology adopted, e.g., that we did not obtain additional information from patients. It is correct that we solely used already available information from the PRO answers, e.g., if a patient self-rated having suicidal thoughts graded second worst. Based on this, our neurologist graded the suggested triage colour. As the risk of suicide is higher in patients with epilepsy, our neurologist would grade this case as red, which - in this example - would lead to a change from yellow to red [2]. In general, we found a triage colour change in about half of the cases. Hjollund et al. state that a triage alteration between yellow and red is of limited practical or clinical consequence. If this is the case, one might ask if a need exists for a three-colour triage system.

Our work is not the first to question the value of the PRO algorithm. Mejdahl et al. reported organisational challenges, e.g., PRO-based follow-up increased the number of phone consultations and the clinicians felt overburdened due to increased workload. Furthermore, some clinicians reported a mismatch between ideal PRO-based follow-up and actual practice [3]. In another study, Mejdahl et al. described ambivalence in both patients and clinicians regarding the use of PRO in outpatient follow-up. More specifically, several clinicians felt that some of the problems reported by patients in PRO were out of their area of expertise and beyond the scope of the consultations, whereas patients reported that they found it dissatisfactory if the clinician noted their problems only without reacting to them [4].

In the future, we suggest that Hjollund et al. may benefit from evaluating the PRO-triage algorithm with clinical endpoints. E.g., did the algorithm produce a reduction in time consumed by patients and/or clinicians, better control of seizures, lower risk of suicide or higher patient satisfaction than standard clinical consultations scheduled with intervals respecting the patients individual needs? In outpatient care for chronic diseases such as epilepsy, one size does not fit all. Since 28,000 reported PROs from 6,000 patients are already available it should be possible to examine if our results are only an opinion of a single neurologist.

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Conflicts of interest none. Disclosure forms provided by the authors are available with the article at ugeskriftet.dk/dmj

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