

Özdemir et al. [1] published in North Clinics of Istanbul. The KCAHW is a scale developed by Bakare et al. [2] consisting of four areas and 19 items which measure knowledge level of health workers on autism.

During the scale adaptation process, it was seen that the writers excluded the 1st item since all participants answered it accurately and the 4th area as a whole (6 items as a whole) for a reason that is not easily understandable such as to avoid misunderstandings of the physicians about autism spectrum disorder and the scale was reduced to three areas. As a result, the scale consisting of four areas and 19 items were reduced to three areas and 12 items without the presentation of sufficient psychometric reasons.

In the process of developing a new scale, adding or excluding an item in line with analysis results might be in question [3]. However, while doing scale validity and reliability studies, excluding items can cause the loss of certain concepts and thus “the loss of content validity.” A scale which does not have content validity cannot claim to measure anything. Excluding items from a scale can only be possible in psychometric studies only with an exploratory approach and require objective hypothesis and accurate and sufficient psychometric methods (IRT and Differential Item Functioning, etc.). It is apparent that the objective in Özdemir et al.’s study is not to test the content validity of the original scale. In fact, there is a need to develop a new scale rather than test the content validity of a scale which has previously been developed, because items are prepared within the framework of theoretical structure (conceptual content) while developing a scale. In addition, the exclusion of any item requires certain statistical approaches. The approaches used here to exclude items from a scale are insufficient.

In the other cultural adaptation and validity study of the same scale published by Gürbüz Özgür et al. [4], sticking to the original version of the scale, the validity and reliability of the KCAHW, which includes all four areas and all 19 items, without needing any items to be removed, has been demonstrated for Turkish culture and Turkish.

It will be a more scientifically correct approach to use the Turkish version of this scale adapted by sticking to the original, in the field of health services.

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Time to collaborate: Objectives, design, and methodology of PeRA-Research Group

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To the Editor,

Pediatric rheumatic diseases are a diverse group of

chronic illnesses affecting mainly the structures of the musculoskeletal system, blood vessels, and connective tissues. Contingent with the rare existence of the rheumatic diseases, collaborations become imperative to understand the pathophysiology, clinical basis, and treatment approaches of these diseases. The increased requirement for new therapeutic options and outcome assessment measures in pediatric rheumatic diseases has procured to both nationwide and international cooperation. Patient registries have emerged as an observational data for evaluating clinical findings, treatment modalities, and outcomes measures in a defined patient population. Monitoring patients regularly with a systematic, structured, and uniform approach will enable physician to evaluate real-life data and hence make contribution to improvement of patient care. International studies may provide information regarding the influence of genotypic and geographic variations over disease presentation and course. Pediatric registries for rheumatic diseases were previously established in Europe, the United States, and Canada while a registry of pediatric rheumatology in Turkey was not introduced yet. Herein, we aimed to share our methodology of new pediatric rheumatology registry.

The Pediatric Rheumatology Academy-Research Group (PeRA-RG) was initially established in 2019 by the intention of two pediatric rheumatologists (BS and NAA) for recording clinical data, treatments, outcome results, and drug reactions children with rheumatic diseases prospectively. Subsequently, PeRA-RG invited other pediatric rheumatologists to collaborate. Finally, nine pediatric rheumatologists from seven pediatric rheumatology centers were involved to PeRA-RG. The PeRA-RG is a group collecting data for prospective observational cohort studies. Pediatric patients with a rheumatic disease will initially be recorded by electronic case report forms according to specific modules for six different groups of rheumatic diseases (autoinflammatory syndromes, juvenile idiopathic arthritis, systemic lupus erythematosus, vasculitis, juvenile dermatomyositis, and scleroderma). Patients are classified as having a rheumatic disease in compliance with the previously accepted criteria [1–4]. Activity and severity of diseases and disease-related damage are evaluated by the previously accepted outcome scores [5]. All clinical and laboratory data will be recorded at the baseline and following patient visits. The web-based online system will be available soon. Patients who have at least three visits are included in the registry and it is planned to follow the patients throughout childhood un-

til transition to an adult treatment center. The study will be continued for at least 5 years, with a possible extension to 10 years. To prevent patient duplication, national identification numbers of the patients are sent to registry founders and a patient code is assigned. Subsequently, all patients are recorded anonymously with patient code.

Herein, we summarized the setup methodology of the first pediatric rheumatology registry in Turkey. We aimed to reach more participants by introducing the PeRA-RG. Special thanks to PeRA-RG registry, in case, it will be attainable to evaluate and publish the characteristics of pediatric rheumatic diseases in Turkey more homogeneously and jointly for providing better information to patients and junior clinicians. Furthermore, comparing our results with the international data will provide us to understand rheumatic disease profile and outcomes of Turkish children.

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