Identifying the complex chronic pediatric patient: The PedCom Scale. A pilot study.

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Abstract

Background and objectives: Pediatric complex chronic conditions (CCC) have increased in prevalence in recent years. However, suffering from a CCC does not necessarily imply being a complex chronic pediatric patient (CCP), since the needs and functional limitations of two patients with the same diagnosis are highly variable and change over time. The identification of these specific group of patients is essential to improve health policies and create programs and protocols focus on their needs. From this point of view, the group propose the development and validation of a scale for the identification of the complex chronic pediatric patient from a noncategorical approach, completely independent of diagnosis.

Material and Methods: The scale was developed, by consensus of to investigators, using the NANEAS paper and the "Questionnaire for Identifying Children with Chronic Conditions" as reference. Punctuation between 0.5 and 4 was assigned to each item according to its presence being more related to a complex chronic patient. The internal consistency was evaluated by alfa-Cronbach. The prototype was tested on 160 patients, in the absence of another instrument to CCP, each patient was first classified as CCC or not CCC by three investigators and this classification was used as Gold-Standard. The cut-off point for classifying the patient as complex or non-complex was established using the ROC curve. The sensibility and specificity of the test were then calculated as well as test-retest and inter-observer reliability. We use SPSS (IBM 25) for data analysis.

Results: The scale was developed along a year; its final version consisted of a 40 item instrument. Alfa-Cronbach result was 0.747, which reflects a good internal consistency. The cut-off point for classifying the patient as a complex chronic patient was fixed at 6.5 points. The sensibility of the test was 96% with a specificity of 89%. Kappa-Cohen result for the test-retest was 0.987 (p < 0.05) and 0.947 (p < 0.05) for the inter-observer test.

Conclusions: Current definition of pediatric complex chronic conditions includes a wide variety of diagnoses. On clinical practice, being diagnosed with a CCC does not necessarily mean being a CCP. The PedCom Scale is a practical instrument that shows good consistency, reliability on both inter-observer and test-retest analysis, and well as good sensibility and specificity for the identification of CCP on our sample. To ratify these results, a study, including a bigger sample of patients, is already being developed in our centre.

Keywords: Pediatrics Complex Chronic Conditions, Pediatric Complex Chronic Patient, Identification, Scale



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