

Improving access to resources by completion of a barriers assessment form in established rheumatology clinic patients

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Purpose/Objectives: Pediatric rheumatic diseases are chronic, multisystem, autoimmune diseases involving the joints, muscles, and connective tissue. They can range from affecting an isolated part of the body, to affecting multiple organ systems (Laxer & Sherry, 2012). These conditions are generally chronic, meaning the patient will need regular follow up visits with the pediatric rheumatologist. They may also require follow up from other subspecialists or be required to come to the hospital for treatments in the infusion center. The strain of a chronic condition can have significant financial, social, educational, and emotional implications for the patient and family. Additionally, lupus is one of the primary rheumatologic conditions that we treat, and this condition disproportionately affects ethnic minorities including those of African American, Asian, and Native American descent (Tarvin & O'Neil, 2018). The stress of the current COVID-19 pandemic has also created additional challenges for patients and families on immunosuppressant medications, specifically with regards to schooling. The objective of this project is to incorporate the use of a Barriers Assessment Form for use in established clinic patients with a diagnosed rheumatic disease. The goal of this form is to anticipate various barriers that the patients and families may be experiencing with regards to their child's chronic health condition. We aim to help facilitate conversation and then provide appropriate resources to help them to navigate those barriers.

Design/Methods: We took a Barriers Assessment Form developed by the Pediatric Rheumatology Care and Outcomes Improvement Network (PR-COIN) as part of their Self Management Tools and modified it to include potential barriers that we felt were most relevant to patients in our clinic. The forms are available in English and Spanish. The established rheumatology patients receive the form at the beginning of the visit with their intake paperwork. The provider then reviews the completed form and discusses the results with the patients and their families during the visit. We developed a folder on the Rheumatology Shared Drive with electronic resources to print out based on patient needs that were circled on the form. Our social worker is also on board with the project and available to come talk with patients regarding specific social work needs in which she may be able to provide assistance. The provider can also make appropriate outside referrals or get the patient in touch with the correct person in the office to help them based on their individual requests. We are currently piloting this process in Dr. Mannion and Dr. Smitherman's clinics before rollout to the rest of the division.

Results: Since the implementation of this form on June 11, 2021 in two provider clinics and later one fellow clinic, we have completed the forms and discussed potential barriers with 63 patients and provided 22 resources to patients. This is an increase from a baseline of 0. The barriers that were most often identified were school/work accommodations, sadness/anxiety/worry, and needing letters/forms completed. Medication adherence was also reported and overall good with 22% never missing medications and 33% rarely missing medications. 24% however did not complete this section.

Conclusion/Discussion: We developed a novel clinic process to improve communication between the patients and providers regarding potential barriers involved in dealing with a chronic health condition. We also developed a list of resources to provide to patients to help overcome those barriers. Our goal is

that this process will help ensure that our patients have the resources they need to live successful lives despite their chronic condition.

References:

Laxer, R.M., Sherry, D.D., & Hashkes, P.J. (2016). *Pediatric Rheumatology in Clinical Practice* (2nd ed.). London: Springer.

Tarvin, S.E. & O'Neil, K.M. (2018). Systemic Lupus Erythematosus, Sjogren Syndrome, and Mixed Connective Tissue Disease in Children and Adolescents. In Li, S.C. & Higgins, G.C. (Ed.), *Pediatric clinics: Pediatric rheumatology* (pp.711-737). Elsevier.