Discussion: XLP2 is a rare disease that can be challenging to diagnose due to variability in clinical presentation. In this series, our patients presented with refractory, early-onset CD most likely due to XIAP mutation. XIAP deficiency should be suspected in treatment-resistant early-onset Crohn’s disease, especially if complicated by recurrent infections or unexplained hepatosplenomegaly. Ustekinumab combined with methotrexate has demonstrated benefit in their CD management, and should be considered in the management of CD associated with XIAP deficiency.

Late-Breaking

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DEFINITION OF REMISSION IN INFLAMMATORY BOWEL DISEASE: ASSESSMENT OF PATIENT AND PHYSICIAN PERSPECTIVES
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Background: A primary goal in IBD management is achieving disease remission; however, patient (pt)-physician alignment on this goal is unclear. International online surveys were conducted to gain insights into pts’ and physicians’ perspectives on real-world management of IBD. Herein, we report survey findings pertaining to their understanding and perceptions of disease remission in IBD.

Methods: Surveys were completed online by pts and physicians in Canada, France, Germany, Italy, Spain, UK, and US. Using a mixed-recruitment method, pts were identified by physicians, pt advocacy groups, and panels, while physicians were identified by recruitment agencies and panels. Eligible pts were aged ≥18 y who were diagnosed with and received treatment for Crohn’s disease (CD) or ulcerative colitis (UC) and had not undergone surgery for UC. Eligible physicians were gastroenterologists who had treated pts with CD or UC (≥12 each) in the last month, were responsible for treatment decisions of their IBD pts, and for whom ≥30% of their IBD pts had moderate or severe disease per prespecified clinical criteria. A 1:1 CD:UC ratio was targeted for the pt survey. Alignment between pts and physicians on remission definitions and pt-physician communication about remission was assessed. Physicians’ estimates of remission rates in their moderate/severe IBD pts receiving biologic therapy and their satisfaction (1=very dissatisfied to 7=very satisfied) with remission rates with current IBD treatments also were reported.

Results: A total of 2398 IBD pts (1368 CD [40% male], 1030 UC [45% male]) and 654 physicians completed the surveys. Mean pt age was 42 y (CD) and 44 y (UC). Physicians had mean monthly caseloads of 42.9 (CD) and 43.3 (UC). The most common primary care settings were university/teaching hospitals (41%), private practices (31%), and regional/community hospitals (20%). Nearly one quarter of pts reported never having discussed remission with their physician; only 7% of physicians reported that they typically did not discuss remission with their pts. Pts most commonly defined remission as symptom resolution (45%), whereas most physicians defined remission through test results (64% CD, 70% UC), including colonoscopies (56% CD, 58% UC), biopsies (36%, 37%), and biochemical tests (8%, 6%). Most pts (62% CD, 64% UC) had never heard of the term “mucosal healing.” Despite low physician-reported remission rates (CD: 37%–54%; UC: 37%–55%), 25% and 36% of physicians reported high satisfaction (score ≥6) with CD and UC remission rates, respectively.

Conclusions: This international survey demonstrated differences in pts’ and physicians’ definitions of IBD remission and in their understanding of the role of histologic remission in IBD. The findings highlight the need for improved pt-physician communication and education regarding remission, which may improve adherence and outcomes.