Review Article

Utilizing a multisystemic model of resilience to synthesize research in youth with inflammatory bowel disease: a narrative review

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Background and Objective: The study of resilience in youth with inflammatory bowel disease (IBD) is in early stages. The current review aims to illustrate how the use of a multisystemic framework may serve as a developmental and disease-appropriate framework for conceptualizing and designing resilience research for youth with IBD.

Methods: This is a narrative review; therefore, a comprehensive and systematic literature search was not conducted. Rather, the current paper aims to map selected existing literature to a multisystemic model as exemplars of how the model may be used in youth with IBD. Relevant literature was reviewed, synthesized, and mapped onto the proposed multi-systemic framework.

Key Content and Findings: The current review considers existing literature across three proposed dimensions of resilience: contexts of risk exposure, protective and promotive factors/processes, and desired outcomes. Review of each dimension includes consideration of selected existing literature to explain what is known about each dimension currently, as well as to propose additional potential future areas to broaden understanding. Specific key takeaways include: (I) understanding risk exposure in young people with IBD requires consideration of disease-specific, demographic, and sociocultural factors; (II) protective and promotive factors and processes for these young people span individual, familial, peer, school, and community levels; and (III) desired outcomes encompass both the absence of negative and the presence of positive indicators.

Conclusions: A multisystemic approach to the study of resilience in young people with IBD may not only clarify current gaps in the field, but also allow for additional future considerations to best understand how and for whom outcomes characterized as resilient may occur in this population.

Keywords: Resilience; pediatric inflammatory bowel disease (pediatric IBD); narrative review

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Introduction

Inflammatory bowel disease (IBD) is a chronic illness characterized by gastrointestinal inflammation for which there is no existing cure. Rates of IBD are rising (1) with nearly seven million cases globally as of 2017 (2), and up to 30% of IBD diagnoses are made before an individual's 20th birthday (3). Certain young people diagnosed with IBD will encounter greater psychosocial challenges compared to their physically healthy peers (4,5), with intricate interactions between physical and psychosocial symptoms creating cumulative adversity across biopsychosocial domains (6,7). Contrary to the anticipated difficulties, some individuals exhibit a more favorable trajectory, surpassing expected outcomes. This phenomenon is often denoted as resilience, or as characterized by a resilient response. Resilience, as elucidated by Hillard and colleagues (8), is the "attainment of one or more positive outcomes despite significant exposure to risk or adversity".

However, the study of resilience in youth with IBD is in the early stages, with existing research focusing mainly on the relationship between a single protective factor (e.g., self-esteem) and an outcome defined by the lack of risk (e.g., decreased depressive symptoms), with almost no studies targeting resilience as a primary study aim (9). The challenge in studying resilience may be due to complexity of the construct (8) as well as the complexity of the experience of being a young person with IBD (10). Given this, a framework that can account for these complexities is needed to guide research in this area. There are several resilience frameworks that have been proposed, including some specific to youth with chronic medical conditions (11,12). The current review does not aim to review various models and their merits; rather, this review aims to present an illustration of how one such model may prove useful and appropriate for conceptualizing resilience in youth with IBD.

Ungar's multisystemic model of resilience (13) emphasizes that the construct of resilience is best thought of as including both individuals and their contexts to answer the question "which promotive and protective factors or processes are best for which people in which contexts at what level of risk exposure and for which outcomes?". This model is organized into three dimensions [(I) contexts of risk exposure, (II) protective and promotive factors, and (III) desired outcomes], and highlights that resilience is not just a trait or process within an individual, but a construct that exists in context, and involves an individual's ability to access various protective and promotive factors and processes (PPFPs) that may facilitate their path towards a desired outcome. This multidimensional approach allows for expanding beyond just individual attributes and processes and includes consideration of external attributes and processes such as family, friends, and community environments and resources, among others.

As such, this approach highlights that resilience, rather than being understood as a single factor contributing to a single desired outcome, is best understood as a complex and dynamic process that necessitates examining an individual's contexts and resources and their interactions broadly to understand what may facilitate desired outcomes across many systems [e.g., biological, psychological, social, and ecological (14)]. Using this model as a framework, this narrative review aims to enhance the comprehension of key considerations for resilience studies in pediatric IBD. This model of resilience provides a fitting framework for comprehensively capturing the resilience response in young individuals, given the inherent interconnection of their wellbeing with societal systems (e.g., family, school, medical) in which they are members of and interact with (15,16). The study of resilience in young people with IBD would benefit from using a multidimensional approach, as it allows for capturing disease as a central and specific context of risk and allows for the consideration of multiple factors and contexts (including factors within the child, factors within their family and community, and factors specific to the medical system and their medical care) that may interact to create desired outcomes across systems. Considering outcomes across systems is a key component for studying resilience in the context of a chronic illness such as IBD given the inherent interaction between a child's mental and physical well-being. We present this article in accordance with the Narrative Review reporting checklist (available at https://tgh.amegroups.com/article/view/10.21037/tgh-24-2/rc).

Methods

Through synthesizing selected existing literature (*Table 1*), this review will delineate the distinctive risk contexts encountered by youth with IBD, elucidate intra- and interpersonal protective and promotive factors of significance, and consider existing knowledge regarding desired outcomes within this specific population. Additionally, we aspire to underscore existing gaps in knowledge, providing a starting point for future research endeavors that can contribute to a more nuanced understanding of resilience in

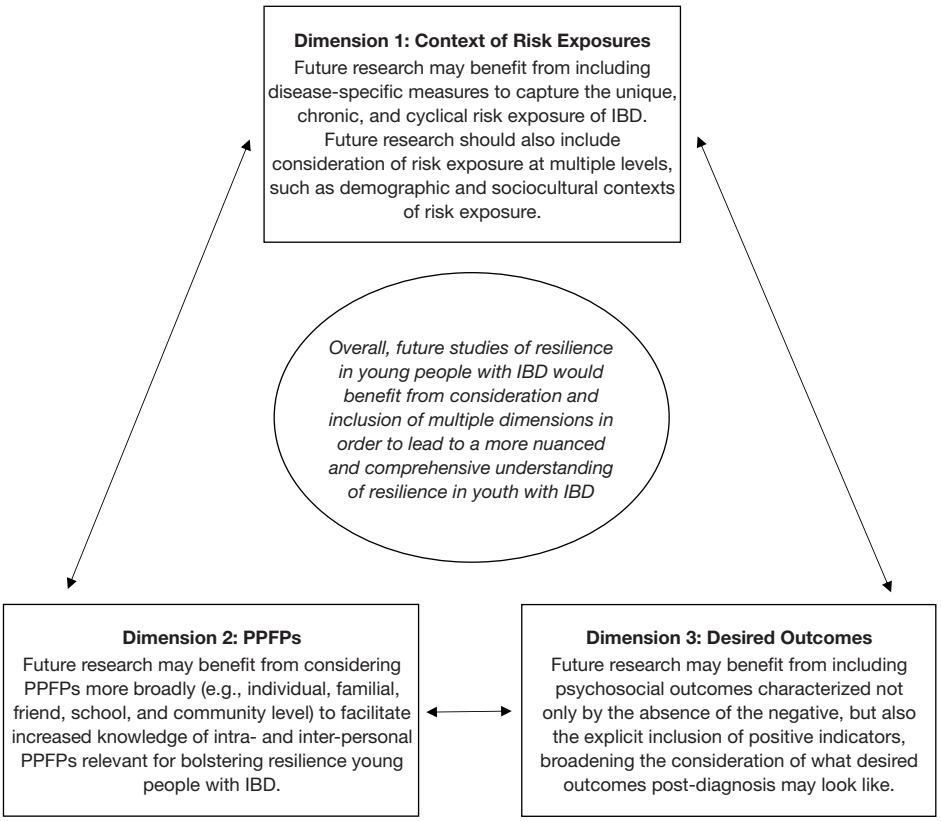

Figure 1 Future directions in researching resilience with IBD as informed by a multidimensional model (13). IBD, inflammatory bowel disease; PPFP, promotive factors and process.

youth diagnosed with IBD (*Figure 1*).

Dimension 1: contexts of risk exposure

The dimension of contexts of risk exposure includes stressor-specific information, as well as relevant systems-level factors (13). Describing these details are an essential first step in studying resilience, as different types of risk exposure create different challenges and opportunities at both the process and outcomes levels. For children and adolescents who are diagnosed with IBD, the initial risk exposure that is above and beyond normal developmental burden is tied to the context of the disease itself (e.g., severity, chronicity, type of symptoms, and treatments), as well as how disease-contexts interact with relevant developmental, sociodemographic, and social-ecological contexts resulting in risk exposure. Together, this information contextualizes the severity and chronicity of disease risk exposure which is necessary to establish in order to study the outcome of interest (dimension 3) and the protective and promotive factors that meaningfully contribute (dimension 2), thereby increasing validity of research findings.

Disease risk exposure

For young people with IBD, stressors specific to the disease serve as the focal stressful events contributing to risk exposure. Researchers may gauge the context of risk by considering disease-related parameters, including the severity of the condition at the time of diagnosis, the course of the disease, and the current manifestation of symptoms. These disease-specific elements collectively constitute the initial measurable components of risk exposure, providing an essential baseline of the context of biological risk exposure, or the initial deviation from typical development, that is the starting point of the risk exposure for youth with IBD. To put it simply, pediatric disease is the adversity for which, in response, divergent resilient trajectories occur.

Conceptually, the diagnosis of IBD is not a singular, isolated risk exposure; rather, it presents varying levels of

Table 1 The search strategy summary

Items	Specification
Date of search	June 2022 to January 2024
Databases and other sources searched	Google Scholar, PubMed, Ovid, PsycINFO, and CINAHL
Search terms used	Inclusive of but not limited to: resilience, youth with IBD, pediatric IBD
Timeframe	None specified
Inclusion and exclusion criteria	N/A
Selection process	The initial literature search was conducted by the first author independently. At time of submission, both authors participated in searching and reviewing the literature to contribute to this review
Any additional considerations, if applicable	As a narrative review does not involve a search of all of the literature in the field, the above is indicative of the fact that the current review aims to map on existing literature to a proposed multisystemic model, rather than systematically review the existing body of literature. The current paper aims to be explicit and open about this methodological consideration

IBD, inflammatory bowel disease; N/A, not available.

riskiness over time. Disease symptoms of IBD can include symptoms such as abdominal pain, fever, rectal bleeding, gas, persistent diarrhea, bloody stool, weight loss, fatigue, and pain. Children with IBD may additionally encounter growth impairment and puberty delay (10). Empirical evidence demonstrates that higher disease severity is associated with diminished quality of life and increased burden in youth with IBD (17-20). The chronic and cyclical nature of IBD itself constitutes a persistent risk exposure, contributing to the cumulative impact over time (21). Moreover, the enduring nature of IBD symptoms often persists even during disease remission, significantly affecting overall well-being (22). This temporal variability aligns with the fluctuating phases of disease exacerbation and remission, as well as unremitting uncontrolled symptoms, emphasizing the dynamic and ongoing nature of the risk landscape associated with IBD.

Furthermore, treatments for IBD also add another layer of consideration to the risk exposure that can be examined from a biopsychosocial lens. Treatments often include biologic therapies delivered via infusion or injection, or daily medication to help manage inflammation (23). Corticosteroids are often a first line treatment to address inflammation during disease onset and exacerbations and are a class of medications that can cause physical symptoms such as swelling, as well as psychological symptoms such as anxiety and depression (24). Besides the potential impactful side effects, treatment administration can be stressful (e.g., injections, enemas) and up to one third of youth may not respond to treatment (25), requiring surgery that necessitates utilization of an ostomy bag (26). As such, individuals with IBD may have fears of symptom exacerbation both due to the symptoms themselves and due to concern about the medical treatment that may be necessary to treat the exacerbation (27,28), further adding to the specific context of biopsychosocial risk exposure that IBD creates.

Demographic and sociocultural factors that contextualize risk exposure

Demographic and sociocultural characteristics also provide additional context of risk exposure for youth with IBD. Being diagnosed with IBD during childhood and adolescence presents distinctive challenges for young individuals. Youth are confronted with the complex tasks of disease management [e.g., medication regimens, dietary restrictions, and frequent medical appointments and procedures (29)] as well as contending with age-specific developmental tasks linked with physical, cognitive, social-emotional and language developmental milestones [see Newman & Newman 2017 for review (30)]. Various iterations of these interactions can manifest in young people's lives, increasing risk exposure. For example, unpredictable relapsing IBD symptoms or more chronic symptoms such as linear growth delay (25,31) can disrupt

daily tasks, making it difficult to engage in school, extracurricular activities, and social events. Understandably, this can be particularly impactful, frustrating, and isolating for youth across the developmental spectrum.

The developmental literature also underscores the period of adolescence as a dynamic, change-focused period with primary developmental tasks that include identity formation, gaining independence, and building social relationships (32). Yet, the exploration to establish milestones is notably intricate for young people with IBD (33), demanding exploration of one's inner and outer worlds and establishing independence in one's life and choices (34,35) while managing a chronic disease. Emotional factors associated with the disease, such as fears of stigma (36), the disease's unpredictability, social isolation (37), heightened depressive and anxiety symptoms (38), and feelings of thwarted belongingness (39) present formidable challenges to the timely development of identity and may fundamentally alter self-perception (40). Moreover, the treatments for IBD may introduce additional hurdles to development, including shifts in body image perception and concerns regarding engagement in and navigating of social situations (28).

More recent work have also emphasized the importance of considering sociocultural contexts (at the individual, community, and social and political levels) as essential to understanding resilience and risk exposure (14,41). For instance, there are known risk factors that come from being a member of a historically oppressed or minoritized group, a characterization that spans sociodemographic characteristics to include race, ethnicity, and gender, among other markers (42). Female gender, for example, is associated with lower health-related quality of life [HRQoL; the impact of disease and disease management on an individual's quality of life (43)] and increased internalizing symptoms among young people with IBD (44,45). In another study (46) involving 107 adolescents with IBD, lower HRQoL scores were associated with increased psychosocial problems, greater disease severity, and self-identification as Black. Furthermore, higher disease severity, nonpublic insurance use, and fewer psychosocial problems were linked to greater treatment adherence behaviors. Likewise, a small number of studies that consider access and familial socioeconomic status (e.g. ability to afford out of pocket costs, access to health insurance, being able to have transportation to medical visits, ability to take off work to attend medical appointments, etc.) have demonstrated that, despite limited research, costs of having IBD are high, which is impactful for families and provides a salient context of risk to be considered (47,48).

Summary of dimension 1

In sum, risk exposure for young people with IBD is complex and likely best conceptualized and measured using a comprehensive approach. Future work examining resilience in youth with IBD can be enhanced by including clear disease-specific risk exposures as well as by including demographic and sociocultural contexts of risk exposure, acknowledging that there is a complex role played by these contexts in the development of risk exposure, as well as in the resilience response in young people with IBD. This conceptualization also underscores the importance of adopting a longitudinal perspective in understanding the multifaceted impact of IBD on an individual's risk exposure over time. Thoroughly considering and integrating these contexts of risk when researching resilience in these youth sets an essential groundwork upon which the latter two dimensions rest, as this understanding provides the baseline for facilitating understanding of for whom and in which contexts protective factors and processes may lead to desired outcomes. Without a comprehensive understanding of the specific conditions and levels of risk exposure, researchers may struggle to discern the key elements influencing outcomes, impacting the robustness of their conclusions and limiting the applicability of their recommendations (13).

Dimension 2: PPFPs

The dimension of PPFPs describe the intra- and inter-personal factors and processes that may facilitate well-being, or other desired outcomes, in the presence of a specific adversity or risk exposure (13). The study of PPFPs is where the majority of current research on resilience in young people with IBD exists, examining correlations between a specific individual (intra-personal) PPFP and a certain desired outcome, often the desired outcome of "lack of risk" (e.g., lack of depression). This dimension is also where resilience interventions, focusing on enhancing or modifying specific intra- and inter-personal PPFPs, tend to reside [e.g., (49)]. PPFPs can be seen as factors and processes that can shape the road between contexts of risk exposure (dimension 1) and desired outcomes (dimension 3, reviewed further below). With regard to the former, examining PPFPs specific to the contexts of risk exposure can help identify PPFPs that may or may not be relevant to a particular group. With regards to the latter, PPFPs can be thought of as context-specific processes or factors that can facilitate desired outcomes, but are not outcomes in

and of themselves. The present section will review existing knowledge about PPFPs in this population. It is pertinent to emphasize that, given the robustness of literature in this dimension, the ensuing discussion is illustrative rather than exhaustive.

Intra-personal PPFPs

Intra-personal PPFPs refer to resources an individual may access within themselves to facilitate a desired outcome. Existing literature has described many potential salient PPFPs, including positive perception about one's body, positive perception of the future/optimism about the future, and one's view of their ability to handle challenges, for example (49-51). Given the robustness of the existing literature, the subsequent review of intra-personal PPFPs will neither be exhaustive nor include all potential intra-personal PPFPs. Rather, the current review will describe two selected constructs that have significant existing research in youth with IBD and discuss their conceptualization as PPFPs within this framework.

Bounce back

Much of the existing research on resilience in IBD has specifically examined the role of perceived "bounce-back" (24), or one's perception of their ability to return to baseline levels of functioning after disease adversity. Bounce-back can be conceptualized as resilience in and of itself. However, bounce-back can also be seen as an essential *facilitator* of desired outcomes and considered as an intra-personal process or factor that lays in between an individual's context of risk exposure and their attainment of a desired outcome. The latter conceptualization is used in this framework. Existing work in adults with IBD has preliminarily shown that bounce-back is associated with biological [i.e., disease outcomes (52)] and psychosocial [i.e., less anxiety (53)] outcomes. Bounce-back has been studied less frequently in young people with IBD. A recent qualitative study (54) interviewed youth with IBD, their parents, and health-care providers to learn more about their definitions of resilience and the factors that may contribute to desired outcomes. Definitionally, all three groups discussed resilience as including aspects of bounce-back, describing bounce-back as a process including adapting to IBD-specific changes, maintaining a sense of normality post diagnosis, accepting the diagnosis, and continuing to adaptively cope with challenges that IBD poses. When considering bounce-back in the context of young people with IBD, the question of from what young people are bouncing back from (their specific context of risk exposure) and where they are bouncing to (a desired outcome) arises. Notably, the examination of one's ability to return to baseline levels of functioning may fail to include characteristics of bounce-back that facilitate moving towards a "new normal" in functioning, inclusive of the experience of continuing to live with and manage IBD post diagnosis (55). In light of this, it is advised to conceptualize bounce-back not merely as a restoration to baseline but as a dynamic process capable of fostering a transition towards a "new normal" state of functionality amid the challenges posed by a persistent medical condition.

Illness perception

The construct of illness perception includes the interacting cognitive perceptual process of aspects of illness experience (including illness identity, timeline, cause, controllability, and consequences) and an individual's emotional reaction to the illness experience (56). Illness perception has been preliminarily quantitatively examined as an important construct in young people with IBD, with results emphasizing that illness perception may be more influential as a PPFP on quality-of-life outcomes than disease outcomes (45,57). More specifically, those youth who viewed their illness more as a challenge rather than a threat reported better quality of life (defined as including physical, emotional, social, and school functioning). An additional study found that certain aspects of illness perception (perceived effectiveness of controlling IBD through behavior, perceived effectiveness of IBD treatments) remained significantly correlated with greater HRQoL after one year (44). This supports the idea that examining illness perception over time may be useful in relation to desired outcomes, as IBD remains a "constant threat" over the course of one's life and has periods where it is more "threatening" than others (e.g., during disease exacerbation). These findings also parallel seminal theoretical work on resilience that has emphasized the importance of perception as a marker that can categorize trajectories of resilience, in particular theorizing that perceptions of risk or adversity as a challenge rather than a threat may catalyze more desired outcomes (58).

Inter-personal PPFPs

As previously articulated, a multisystemic examination of

resilience extends beyond the identification of PPFPs at the individual level. It encompasses an exploration of the various systems and contexts in which an individual engages, considering them as potential PPFPs. Earlier investigations into youth resilience, in a broader context, underscore the significance of comprehending and incorporating external individuals and systems with which children interact, recognizing their role in either facilitating or impeding resilient outcomes that serve a protective function (59,60). The inclusion of factors beyond the individual as potential PPFPs aligns not only with developmental appropriateness, but also proves particularly pertinent for young individuals grappling with IBD.

Familial

Studies have shown that parenting variables are associated with psychosocial outcomes of both parents and the child, and the two are often interacting (39,61-64). For instance, numerous studies have consistently demonstrated an association between parental stress and adverse outcomes such as diminished child HRQoL and heightened depressive symptoms (65). A conventional conclusion would be that the reduction of parental stress to enhance youth HRQoL and alleviate depressive symptoms is sufficient for a resilient outcome. Insights from positive psychology (66) emphasize that identifying and nurturing protective factors transcends the mere negation of harmful elements. Merely promoting "less stress" represents the absence of a negative factor, and reversal of risk-based factors may oversimplify the intricate dynamics at play. While existing studies undoubtedly provide necessary information about salient familial-level factors and outcomes in youth with IBD, the exploration of associations between child and family factors and outcomes in youth with IBD stands to benefit from a more expansive conceptual framework, directly linking familial PPFPs with *desired* outcomes at the child and family level. For example, one familial-level PPFP that has been examined in relation to a desired outcome in youth with IBD across studies has been familial support/involvement as a facilitator of treatment adherence. Indeed, several studies have demonstrated that youth-reported perception of family support or involvement has been a facilitator of treatment adherence (67-69). Furthermore, another study looking at a protective factor directly found that maternal positive affect was negatively correlated with adolescent depression and functional disability (70), while another study found that family satisfaction as reported by youth was related to HRQoL, with higher reported family satisfaction being associated with improved HRQoL in youth (19). These findings suggest a continued need to examine familial PPFPs broadly, including factors that may protect against the absence of risk for young people as well as those that may promote the presence of positive outcomes.

Peers

Positive peer relations have been widely shown to facilitate successful outcomes for young people, including young people with chronic illnesses (71). A recent qualitative study (54) suggested that openness about IBD with friends can be a PPFP for young people, theoretically by facilitating increased opportunities for meaningful, supportive friendships. An additional study found that friendships were seen as important by young people with IBD, specifically in the sense that friends facilitated maintaining a sense of normalcy and provided understanding, which felt particularly supportive during disease exacerbation (72). While not directly assessing peer support, studies examining summer camps for youth with IBD (e.g., Camp Oasis, Camp Gut Busters) found that the majority of respondents indicated camp, which inherently was centered around engaging with other youth with IBD, was associated with desired outcomes such as increased HRQoL (73,74), improved confidence, increased disease-related self-efficacy, increased sense of belonging, and increased social connection (75-77). Results of these studies suggest that engaging with others with IBD, or having a shared disease bond with other youth, may be an important aspect of peer support, and a particularly salient PPFP specific to this population. However, how friendships (e.g., characteristics of the friendship, quantity *vs.* quality of friendships) may function as a PPFP specifically in children and adolescents with IBD, and what desired outcomes supportive peer relationships may facilitate, still necessitates further examination.

School

School is seen by the existing resilience literature as an important setting that has the potential to serve as a PPFP in many ways, as optimal school functioning also correlates with positive psychosocial, occupational, and economic outcomes in later life (78). The ongoing management of IBD along with the existing school policies in place to support students with IBD can significantly influence different facets of school functioning. Existing research examining the role of schools in youth with IBD mainly focuses on deficit perspectives (79), enumerating how symptoms of and treatments for IBD may disrupt school

attendance and academic participation and perception (80-85), involvement in extracurricular activities (86), and long-term college planning (87). Furthermore, some school personnel may not be adequately equipped to address the diverse educational needs of students with medical conditions (88,89), as evidenced by reported high school dissatisfaction among parents of children with IBD (90). It is less well known how schools serve as landscapes for PPFPs for youth with IBD. One longitudinal study, assessing the long-term promotive effects of time spent in school and school-related activities, found that increased investment of time in homework and extracurricular activities positively influenced development 12 years later (79). This study highlights the long-term promotive aspect of school activities in facilitating desired outcomes, and how crucial school accommodations post-IBD onset can be to support promotive factors for optimal adjustment. Additionally, a finding that is demonstrated repeatedly (80,81,90,91) is that despite known challenges, many young people with IBD do not actually have reduced academic performance when compared to their same-aged peers. These findings suggest that there are aspects of being a student that are differentially impacted by disease risk exposure, and/or PPFPs that may facilitate academic specific desired outcomes.

Summary of dimension 2

The current section highlights how the study of PPFPs in youth with IBD may be built upon and expanded. The primary objective of this section is to elucidate possible applicable research and to underscore the potential for advancing the study of PPFPs in youth with IBD conceptually. This advancement involves a nuanced consideration of PPFPs within a broader context that includes a clearer delineation of the trajectory from protective and promotive factors to a desired outcome, extending beyond mere risk exposure and the absence of negative consequences. The broadening of the study of PPFPs may also involve extending the focus beyond individual, family, friends, and school-related factors and exploring community-level factors such as relationships with neighborhoods, the healthcare system (both medical and mental health components), as well as delving into the values and cultural norms prevalent in communities to which children with IBD belong (92). The exploration of these factors may help underscore additional salient inter-personal PPFPs, as well as intrapersonal PPFPs that may be promoted or bolstered by those surrounding a child with IBD. Incorporation of these multifaceted layers will contribute to a more comprehensive understanding of the dynamic interplay between PPFPs in the context of youth with IBD, offering valuable insights for future research directions.

Dimension 3: desired outcomes

Desired outcomes refer to biopsychosocial outcomes that are associated with enhanced functioning across one or more domains (13). Notably, while desired outcomes may inherently include a reduction of risk relative to the specific context of risk exposure, they are not exclusively characterized by this "lack of the negative". Rather, they also include the presence of something beneficial or an outcome that has been regained, bolstered, or improved by the presence of salient PPFPs. For young people with IBD a desired outcome may be related to improved or regained functioning across a variety of systems, including biological, psychological, and/or social. A dual-factor model (93) posits that desired outcomes can be considered as comprised of two factors: recovery and sustainability. This model suggests that post-medical diagnosis, there are unique trajectories that may result in recovery (outcomes of mitigated risk or regained functioning) which may not be the same as those that result in sustainability (outcomes explicitly categorized as positive such as flourishing or thriving). As youth with IBD will have to navigate this disease for the rest of their lives, it is crucial to understand how to ameliorate negative outcomes and how to promote positive outcomes earlier in their development. The following section will summarize some of the concepts included in the dual factor approach as relevant to outcomes in pediatric IBD, as well as highlight areas for future empirical work.

Recovery

The factor of recovery encapsulates desired outcomes characterized by a resumption of functioning, or "recovering" after facing a risk exposure (in this case, a diagnosis of IBD). The factor of recovery encapsulates the lack of negative outcomes (e.g., lack of depression or anxiety, less reduced quality of life) in someone who has faced adversity. Specifically, describing how a resilient individual may *not* develop risk factors such as anxiety or depression, or may "recover" quickly after facing adversity and continue to function well, is subsumed under this factor. This view characterizes resilience as it is conceptualized most commonly in the literature, as a return to "baseline" levels of

functioning after an adverse event (58).

One desired outcome for youth with IBD that falls under the factor of recovery is the outcome of improved, remitted, or controlled IBD symptoms. Disease remission itself can be measured in multiple ways, including biological markers (e.g., endoscopic) as well as patient-perceived disease control, described as a low to non-existent level of perceived symptom impact or interference on an individual's daily functioning (94). Utilizing the current multisystemic framework, this desired outcome can be further considered in the context of a specific risk exposure (how severe was the disease at diagnosis? What existing medical treatment was provided and were there issues related to access? How long was the time until diagnosis?) and the salience of specific PPFPs (was there familial and friend support? Were appropriate school accommodations and mental health supports put into place when needed?) that may facilitate or enhance a child's path towards disease control. Additional markers of recovery for youth with IBD that are commonly studied are functional disability and HRQoL (65). Functional outcomes assess how an individual with IBD engages with "normal life" (95) while managing their disease burden in a way that still allows them to fulfill their "societal role(s)" (96), while HRQoL describes, as detailed previously, the impact of disease and disease management on an individual's quality of life, including their well-being and overall functioning (43). Both of these constructs allow for the idea that one can have "recovered" functioning while still holding consideration of present disease-specific challenges.

Sustainability

The factor of sustainability includes the idea of achieving positive outcomes or experiencing a higher level of functioning across biopsychosocial domains during and following medical adversity. The idea of sustainability finds its roots in the field of positive psychology (66), a field focused on the presence of a desirable phenomenon rather than the absence of an undesirable one (97). The study of sustainability expands existing knowledge by emphasizing that in addition to buffering young people from negative outcomes (recovery), resilience also encompasses constructs such as flourishing and thriving post diagnosis. Sustainability is not the "return to baseline" categorized by recovery, but rather takes a view of resilience one step further and characterizes individuals who go beyond their previous levels of functioning and show growth or improvement and are "better off afterwards". This may include the acquisition of new skills and knowledge, confidence, and strengthened personal relationships due to the faced adversity (58). Sustainability is particularly relevant to examine when assessing desired outcomes, as positive well-being and the absence of psychopathology have not been found to be strongly correlated (98,99). Furthermore, interventions aimed at enhancing well-being (e.g., building upon positive traits such as gratitude or kindness, cultivating gratitude, etc.) rather than merely aiming to reduce negative states have been preliminarily shown to enhance both psychological and physical outcomes across multiple medical conditions (100). The limited study inclusion of both factors (i.e. the presence of positive outcomes as well as the absence of negative ones) when considering resilience in young people with IBD is a significant gap in the field.

The current understanding of what outcomes are desired among young people with IBD, particularly those that fall within the sustainability factor, is opaque and heterogeneous, with fewer studies aiming to directly examine these psychosocial outcomes in this population (9). One recent study (101) did examine post-traumatic growth (PTG) in 32 adolescents and young adults (aged 15–25 years) with IBD. PTG refers to positive psychological changes that individuals may experience as a result of coping with and processing challenging and distressing life events (102). It is important to note that PTG does not negate the challenges and distress associated with adversity. Rather, it coexists with the negative effects and reflects an individual's ability to find meaning, learn from, and adapt positively to difficult circumstances. This study found themes associated with PTG including strengthened personal relationships; new skills and knowledge acquired (e.g., coping strategies, lifestyle changes); as well as illness perception changes characterized by disease acceptance, changes in life philosophy, and adaptive future-oriented thinking. Another recent qualitative investigation including youth ages 12–18 diagnosed with IBD, parents, and healthcare providers also yielded thematic outcomes indicative of enhanced functioning after IBD diagnosis (54). More specifically, participants endorsed the development of new skills, such as stress management for coping with disease exacerbation and improved communication and acceptance of one's IBD condition, alongside the strengthening of relationships spanning various contexts, and heightened self-confidence. Similar identified themes were also found in another qualitative study, wherein both children and parents were more inclined to articulate enduring positive impacts stemming from their IBD diagnosis, rather than negative impacts (55). These studies

have significant implications for the study of resilience in young people with IBD, suggesting that the investigation of resilient outcomes explicitly categorized as positive is worthy of further investigation.

Summary of dimension 3

Existing research examining desired outcomes in young people with IBD has mainly focused on outcomes of recovery. Resilience research in youth with IBD requires an expanded conceptualization of desired outcomes, encompassing not only the absence of negative psychosocial outcomes, but also the explicit inclusion of positive indicators, thereby capturing the multifaceted dimensions of enhanced functioning across psychosocial and biological domains. It is important to underscore the significance of this shift, as it directs attention towards intentionally identifying and measuring positive aspects of resilience and adaptation in the context of pediatric chronic illness *a priori*.

The application of a dual-factor model can be used to facilitate a more nuanced understanding by recognizing that biopsychosocial outcomes can be characterized as recovery from adversity or the manifestation of explicitly positive states. For example, an investigation may scrutinize "mental health post-diagnosis" by evaluating not only the absence of depressive symptoms—aligning with a perspective that views mental health as a preserved, recovered, or regained state—but also the presence of positive indicators such as heightened self-esteem and optimism. Looking at outcomes from this paradigm raises additional questions that require further investigation, such as: what does a return pre-diagnostic functioning look like for youth with IBD? Is this return to pre-diagnostic functioning truly the goal, or are desired outcomes also inclusive of a development of a "new normal", thus necessitating the inclusion of new outcomes (e.g., disease-specific)? Qualitative methods may be particularly apt for parsing apart these questions of desired outcomes. For example, a recent qualitative study examining friendships in youth with IBD, specifically how disclosure may or may not impact friendships, illustrates how qualitative methods are useful in parsing out these questions (33). This study viewed disclosure of IBD diagnosis, or lack thereof, as a potential PPFP facilitating the desired outcome of supportive friendships. This study allowed for consideration of multiple possibilities: whether the desired outcome for children with IBD is to have unchanged friendships from pre- to post-diagnosis, and/or to have supportive friendships that may change, or even strengthen, within the context of IBD. This methodological approach to examining desired outcomes is one option that may facilitate nuanced exploration of the multifaceted dimensions of resilience and well-being in youth with IBD, thereby advancing our understanding and informing targeted interventions.

Conclusions

Resilience research in youth with IBD represents a relatively nascent domain. The study of resilience holds particular relevance for young people given their sensitive developmental phase. This period is marked by the ongoing development of healthy coping skills, disease-management strategies, and the formulation of their identity, all of which may have lasting implications. The multifaceted and intricate nature of resilience necessitates a guiding framework to facilitate and advance our understanding. Ungar's multi-systemic framework offers a promising avenue for propelling research on youth with IBD forward. This framework enables the (I) assessment of disease-specific markers of risk exposure, (II) integration of PPFPs specific to these children across individual, familial, and other systems-level domains, and (III) an expanded consideration of desired outcomes, encompassing both recovery and sustainability for a cyclical and chronic medical condition like IBD.

The aim of this review was to present an illustration of how a multi-systemic framework may prove useful and appropriate for conceptualizing resilience in youth with IBD. It is crucial to note that this review is not intended to be an exhaustive systematic review of the literature. Instead, its purpose is to illustrate how Ungar's framework can be applied to the context of youth with IBD. Consequently, there exists additional literature incorporating diverse contexts of risk, PPFPs, and desired outcomes beyond the scope of this illustrative approach.

Future directions in resilience research for pediatric IBD present exciting and crucial areas for exploration. Several methodological enhancements are needed, such as longitudinal measurement of constructs and the incorporation of both qualitative and quantitative approaches to gain a deeper understanding of dimensions among this population. Furthermore, employing this framework can foster an outward expansion of research. For instance, studies encompassing multiple dimensions offer the prospect of cumulatively building knowledge, ultimately leading to a

nuanced and comprehensive understanding of resilience in IBD. Such an understanding may enable us to tailor interventions more precisely and effectively to meet the unique needs of young individuals grappling with IBD.

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References

1. Kaplan GG, Ng SC. Understanding and Preventing the Global Increase of Inflammatory Bowel Disease. Gastroenterology 2017;152:313-321.e2.
2. The global, regional, and national burden of inflammatory bowel disease in 195 countries and territories, 1990-2017: a systematic analysis for the Global Burden of Disease Study 2017. Lancet Gastroenterol Hepatol 2020;5:17-30.
3. Kelsen J, Baldassano RN. Inflammatory bowel disease: the difference between children and adults. Inflamm Bowel Dis 2008;14 Suppl 2:S9-11.
4. Greenley RN, Hommel KA, Nebel J, et al. A meta-analytic review of the psychosocial adjustment of youth with inflammatory bowel disease. J Pediatr Psychol 2010;35:857-69.
5. Plevinsky J, Hommel K. Psychological aspects of inflammatory bowel disease in children and adolescents. In: Mamula P, Kelsen JR, Grossman AB, et al. editors. Pediatric Inflammatory Bowel Disease. Cham: Springer International Publishing; 2023;699-709.
6. Murphy LK, Rights JD, Ricciuto A, et al. Biopsychosocial Correlates of Presence and Intensity of Pain in Adolescents With Inflammatory Bowel Disease. Front Pediatr 2020;8:559.
7. Murphy LK, de la Vega R, Kohut SA, et al. Systematic Review: Psychosocial Correlates of Pain in Pediatric Inflammatory Bowel Disease. Inflamm Bowel Dis 2021;27:697-710.
8. Hilliard ME, McQuaid EL, Nabors L, et al. Resilience in Youth and Families Living With Pediatric Health and Developmental Conditions: Introduction to the Special Issue on Resilience. J Pediatr Psychol 2015;40:835-9.
9. Tempchin J, Storch B, Reigada LC. Systematic review: Psychosocial factors of resilience in young people with inflammatory bowel disease. J Psychosom Res 2021;148:110558.
10. Mackner LM, Greenley RN, Szigethy E, et al. Psychosocial issues in pediatric inflammatory bowel disease: report of the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition. J Pediatr Gastroenterol Nutr 2013;56:449-58.
11. Cousins LA, Kalapurakkel S, Cohen LL, et al. Topical Review: Resilience Resources and Mechanisms in Pediatric Chronic Pain. J Pediatr Psychol 2015;40:840-5.
12. Hilliard ME, Harris MA, Weissberg-Benchell J. Diabetes resilience: a model of risk and protection in type 1

diabetes. Curr Diab Rep 2012;12:739-48.
13. Ungar M. Designing resilience research: Using multiple methods to investigate risk exposure, promotive and protective processes, and contextually relevant outcomes for children and youth. Child Abuse Negl 2019;96:104098.
14. Ungar M, Theron L. Resilience and mental health: how multisystemic processes contribute to positive outcomes. Lancet Psychiatry 2020;7:441-8.
15. Bronfenbrenner U, Evans GW. Developmental Science in the 21st Century: Emerging Questions, Theoretical Models, Research Designs and Empirical Findings. Social Development 2000;9:115-25.
16. Rogers LO, Niwa EY, Chung K, et al. M(ai)cro: Centering the Macrosystem in Human Development. Hum Dev 2021;65:270-92.
17. Otley AR, Griffiths AM, Hale S, et al. Health-related quality of life in the first year after a diagnosis of pediatric inflammatory bowel disease. Inflamm Bowel Dis 2006;12:684-91.
18. Kunz JH, Hommel KA, Greenley RN. Health-related quality of life of youth with inflammatory bowel disease: a comparison with published data using the PedsQL 4.0 generic core scales. Inflamm Bowel Dis 2010;16:939-46.
19. Caes L, Chambers CT, Otley A, et al. Pain and quality of life in youth with inflammatory bowel disease: the role of parent and youth perspectives on family functioning. Pain Rep 2019;4:e715.
20. Engelmann G, Erhard D, Petersen M, et al. Health-related quality of life in adolescents with inflammatory bowel disease depends on disease activity and psychiatric comorbidity. Child Psychiatry Hum Dev 2015;46:300-7.
21. Chang S, Malter L, Hudesman D. Disease monitoring in inflammatory bowel disease. World J Gastroenterol 2015;21:11246-59.
22. Farrell D, McCarthy G, Savage E. Self-reported Symptom Burden in Individuals with Inflammatory Bowel Disease. J Crohns Colitis 2016;10:315-22.
23. Trivedi I, Holl JL, Hanauer S, et al. Integrating Adolescents and Young Adults into Adult-Centered Care for IBD. Curr Gastroenterol Rep 2016;18:21.
24. Lenti MV, Cococcia S, Ghorayeb J, et al. Stigmatisation and resilience in inflammatory bowel disease. Intern Emerg Med 2020;15:211-23.
25. Nasiri S, Kuenzig ME, Benchimol EI. Long-term outcomes of pediatric inflammatory bowel disease. Semin Pediatr Surg 2017;26:398-404.
26. Rosen MJ, Dhawan A, Saeed SA. Inflammatory Bowel Disease in Children and Adolescents. JAMA Pediatr 2015;169:1053-60.
27. Nicholas DB, Otley A, Smith C, et al. Challenges and strategies of children and adolescents with inflammatory bowel disease: a qualitative examination. Health Qual Life Outcomes 2007;5:28.
28. Barned C, Fabricius A, Stintzi A, et al. "The Rest of my Childhood was Lost": Canadian Children and Adolescents' Experiences Navigating Inflammatory Bowel Disease. Qual Health Res 2022;32:95-107.
29. Diefenbach KA, Breuer CK. Pediatric inflammatory bowel disease. World J Gastroenterol 2006;12:3204-12.
30. Newman BM, Newman PR. Development through life: A psychosocial approach. Cengage Learning; 2017.
31. Wong K, Isaac DM, Wine E. Growth Delay in Inflammatory Bowel Diseases: Significance, Causes, and Management. Dig Dis Sci 2021;66:954-64.
32. Arnett JJ. Emerging adulthood. A theory of development from the late teens through the twenties. Am Psychol 2000;55:469-80.
33. Carter B, Rouncefield-Swales A, Bray L, et al. "I Don't Like to Make a Big Thing out of It": A Qualitative Interview-Based Study Exploring Factors Affecting Whether Young People Tell or Do Not Tell Their Friends about Their IBD. Int J Chronic Dis 2020;2020:1059025.
34. Schwartz SJ. Turning Point for a Turning Point: Advancing Emerging Adulthood Theory and Research. Emerg Adulthood 2016;4:307-17.
35. Steinberg L, Morris AS. Adolescent development. Annu Rev Psychol 2001;52:83-110.
36. Qualter P, Rouncefield-Swales A, Bray L, et al. Depression, anxiety, and loneliness among adolescents and young adults with IBD in the UK: the role of disease severity, age of onset, and embarrassment of the condition. Qual Life Res 2021;30:497-506.
37. Kemp K, Griffiths J, Lovell K. Understanding the health and social care needs of people living with IBD: a meta-synthesis of the evidence. World J Gastroenterol 2012;18:6240-9.
38. Brooks AJ, Rowse G, Ryder A, et al. Systematic review: psychological morbidity in young people with inflammatory bowel disease - risk factors and impacts. Aliment Pharmacol Ther 2016;44:3-15.
39. Gamwell KL, Baudino MN, Bakula DM, et al. Perceived Illness Stigma, Thwarted Belongingness, and Depressive Symptoms in Youth With Inflammatory Bowel Disease (IBD). Inflamm Bowel Dis 2018;24:960-5.
40. Feingold JH, Kaye-Kauderer H, Mendiolaza M, et al. Empowered transitions: Understanding the

experience of transitioning from pediatric to adult care among adolescents with inflammatory bowel disease and their parents using photovoice. J Psychosom Res 2021;143:110400.
41. Masten AS. Resilience Theory and Research on Children and Families: Past, Present, and Promise. J Fam Theory Rev 2018;10:12-31.
42. Marks AK, Woolverton GA, García Coll C. Risk and Resilience in Minority Youth Populations. Annu Rev Clin Psychol 2020;16:151-63.
43. Guyatt GH, Feeny DH, Patrick DL. Measuring health-related quality of life. Ann Intern Med 1993;118:622-9.
44. Brooks AJ, Norman P, Peach EJ, et al. Prospective Study of Psychological Morbidity and Illness Perceptions in Young People With Inflammatory Bowel Disease. J Crohns Colitis 2019;13:1003-11.
45. Stapersma L, van den Brink G, van der Ende J, et al. Illness Perceptions and Depression Are Associated with Health-Related Quality of Life in Youth with Inflammatory Bowel Disease. Int J Behav Med 2019;26:415-26.
46. Klages KL, Berlin KS, Cook JL, et al. Examining Risk Factors of Health-Related Quality of Life Impairments Among Adolescents with Inflammatory Bowel Disease. Behav Med 2021;47:140-50.
47. Kahn-Boesel O, Cautha S, Ufere NN, et al. A Narrative Review of Financial Burden, Distress, and Toxicity of Inflammatory Bowel Diseases in the United States. Am J Gastroenterol 2023;118:1545-53.
48. El-Matary W, Kuenzig ME, Singh H, et al. Disease-Associated Costs in Children With Inflammatory Bowel Disease: A Systematic Review. Inflamm Bowel Dis 2020;26:206-15.
49. Ahola Kohut S, Keefer L. Building a Self-Management Toolkit for Patients with Pediatric Inflammatory Bowel Disease: Introducing the resilience 5. Gastroenterol Clin North Am 2023;52:599-608.
50. Perrin JM, Kuhlthau K, Chughtai A, et al. Measuring quality of life in pediatric patients with inflammatory bowel disease: psychometric and clinical characteristics. J Pediatr Gastroenterol Nutr 2008;46:164-71.
51. Abdovic S, Mocic Pavic A, Milosevic M, et al. The IMPACT-III (HR) questionnaire: a valid measure of health-related quality of life in Croatian children with inflammatory bowel disease. J Crohns Colitis 2013;7:908-15.
52. Sehgal P, Ungaro RC, Foltz C, et al. High Levels of Psychological Resilience Associated With Less Disease Activity, Better Quality of Life, and Fewer Surgeries in Inflammatory Bowel Disease. Inflamm Bowel Dis 2021;27:791-6.
53. Philippou A, Sehgal P, Ungaro RC, et al. High Levels of Psychological Resilience Are Associated With Decreased Anxiety in Inflammatory Bowel Disease. Inflamm Bowel Dis 2022;28:888-94.
54. Kohut SA, Forgeron P, McMurtry M, et al. Resilience Factors in Paediatric Inflammatory Bowel Disease: Health Care Provider, Parent and Youth Perspectives. J Child Fam Stud 2021;30:2250-63.
55. Easterlin MC, Berdahl CT, Rabizadeh S, et al. Child and Family Perspectives on Adjustment to and Coping With Pediatric Inflammatory Bowel Disease. J Pediatr Gastroenterol Nutr 2020;71:e16-27.
56. Diefenbach MA, Leventhal H. The Common-Sense Model of Illness Representation: Theoretical and Practical Considerations. J Soc Distress Homeless 1996;5:11-38.
57. Pachter-Alt A, Soskolne V. It's All in the Head: Illness Perception is the Major Correlate of Quality of Life Among Adolescents with Inflammatory Bowel Disease. Child Adolesc Social Work J 2022;41:151-9.
58. Carver CS. Resilience and Thriving: Issues, Models, and Linkages. J Soc Issues 1998;54:245-66.
59. Masten AS, Powell JL. A resilience framework for research, policy, and practice. In: Luthar S, editor. Resilience and vulnerability: Adaptation in the context of childhood adversities. Cambridge University Press; 2003.
60. Wideman-Johnston T. Resilience and Students with Chronic Illness: A Literature Review of Fostering Resilience into the Lives of Students with Chronic Illness. J Educ Develop Psychol 2011. doi: 10.5539/jedp.v1n1p127
61. Baudino MN, Roberts CM, Edwards CS, et al. The impact of illness intrusiveness and overparenting on depressive symptoms in parents of youth with inflammatory bowel disease. J Spec Pediatr Nurs 2022;27:e12362.
62. Roberts CM, Gamwell KL, Baudino MN, et al. Youth and Parent Illness Appraisals and Adjustment in Pediatric Inflammatory Bowel Disease. J Dev Phys Disabil 2019;31:777-90.
63. Edwards CS, Roberts CM, Baudino MN, et al. The Combined Effects of Youth and Parent Illness Intrusiveness on Depressive Symptoms in Adolescents with Inflammatory Bowel Disease. J Clin Psychol Med Settings 2023;30:238-47.
64. Rea KE, Cushman GK, Westbrook AL, et al. Parenting Stress over the First Year of Inflammatory Bowel Disease Diagnosis. J Pediatr Psychol 2022;47:1156-66.
65. Touma N, Varay C, Baeza-Velasco C. Determinants of quality of life and psychosocial adjustment to pediatric

inflammatory bowel disease: A systematic review focused on Crohn's disease. J Psychosom Res 2021;142:110354.
66. Seligman ME, Csikszentmihalyi M. Positive psychology. An introduction. Am Psychol 2000;55:5-14.
67. Reed-Knight B, Lewis JD, Blount RL. Association of disease, adolescent, and family factors with medication adherence in pediatric inflammatory bowel disease. J Pediatr Psychol 2011;36:308-17.
68. Feldman ECH, Durkin LK, Greenley RN. Family Support is Associated with Fewer Adherence Barriers and Greater Intent to Adhere to Oral Medications in Pediatric IBD. J Pediatr Nurs 2021;60:58-64.
69. Hommel KA, Odell S, Sander E, et al. Treatment adherence in paediatric inflammatory bowel disease: perceptions from adolescent patients and their families. Health Soc Care Community 2011;19:80-8.
70. Tojek TM, Lumley MA, Corlis M, et al. Maternal correlates of health status in adolescents with inflammatory bowel disease. J Psychosom Res 2002;52:173-9.
71. Pendley JS, Kasmen LJ, Miller DL, et al. Peer and family support in children and adolescents with type 1 diabetes. J Pediatr Psychol 2002;27:429-38.
72. Rouncefield-Swales A, Carter B, Bray L, et al. Sustaining, Forming, and Letting Go of Friendships for Young People with Inflammatory Bowel Disease (IBD): A Qualitative Interview-Based Study. Int J Chronic Dis 2020;2020:7254972.
73. Shepanski MA, Hurd LB, Culton K, et al. Health-related quality of life improves in children and adolescents with inflammatory bowel disease after attending a camp sponsored by the Crohn's and Colitis Foundation of America. Inflamm Bowel Dis 2005;11:164-70.
74. Plevinsky JM, Greenley RN. Exploring health-related quality of life and social functioning in adolescents with inflammatory bowel diseases after attending camp oasis and participating in a Facebook group. Inflamm Bowel Dis 2014;20:1611-7.
75. Singh N, Steiner SJ, Fauth R, et al. IBD Camp Oasis: A look at Participants' Social-Emotional Well-Being and Protective Factors During Camp and Beyond. Crohns Colitis 360 2023;5:otad042.
76. Salazar G, Heyman MB. Benefits of attending a summer camp for children with inflammatory bowel disease. J Pediatr Gastroenterol Nutr 2014;59:33-8.
77. McCombie A, Gearry RB, Lopez RN, et al. Enhancements in Confidence, Acceptance, and Friendship at a Summer Camp for Children With Inflammatory Bowel Disease. J Pediatr Gastroenterol Nutr 2017;65:311-3.
78. Masten AS, Herbers JE, Cutuli JJ, et al. Promoting competence and resilience in the school context. Prof Sch Couns 2008. doi: 10.1177/2156759X080120021.
79. Tjaden J, Rolando D, Doty J, et al. The Long-Term Effects of Time Use during High School on Positive Development. Longit Life Course Stud 2019;10:51-85.
80. Assa A, Ish-Tov A, Rinawi F, et al. School Attendance in Children With Functional Abdominal Pain and Inflammatory Bowel Diseases. J Pediatr Gastroenterol Nutr 2015;61:553-7.
81. Carreon SA, Bugno LT, Wojtowicz AA, et al. School Functioning in Adolescents With Inflammatory Bowel Diseases: An Examination of Disease and Demographic Correlates. Inflamm Bowel Dis 2018;24:1624-31.
82. Mackner LM, Bickmeier RM, Crandall WV. Academic achievement, attendance, and school-related quality of life in pediatric inflammatory bowel disease. J Dev Behav Pediatr 2012;33:106-11.
83. Wojtowicz AA, Greenley RN, Gumidyala AP, et al. Pain severity and pain catastrophizing predict functional disability in youth with inflammatory bowel disease. J Crohns Colitis 2014;8:1118-24.
84. Moody G, Eaden JA, Mayberry JF. Social implications of childhood Crohn's disease. J Pediatr Gastroenterol Nutr 1999;28:S43-5.
85. Malmborg P, Mouratidou N, Sachs MC, et al. Effects of Childhood-onset Inflammatory Bowel Disease on School Performance: A Nationwide Population-based Cohort Study Using Swedish Health and Educational Registers. Inflamm Bowel Dis 2019;25:1663-73.
86. Plevinsky JM, Wojtowicz AA, Poulopoulos N, et al. Perceived Impairment in Sports Participation in Adolescents With Inflammatory Bowel Diseases: A Preliminary Examination. J Pediatr Gastroenterol Nutr 2018;66:79-83.
87. Plevinsky JM, Maddux MH, Fishman LN, et al. Perceived effect of pediatric inflammatory bowel diseases on academics, college planning, and college adjustment. J Am Coll Health 2022;70:940-7.
88. Thies KM. Identifying the educational implications of chronic illness in school children. J Sch Health 1999;69:392-7.
89. Shiu S. Positive interventions for children with chronic illness: Parents' and teachers' concerns and recommendations. Aust J Educ 2004;48:239.
90. Freckmann M, Seipp A, Laass MW, et al. School-related experience and performance with inflammatory bowel disease: results from a cross-sectional survey in 675

children and their parents. BMJ Open Gastroenterol 2018;5:e000236.
91. Singh H, Nugent Z, Brownell M, et al. Academic Performance among Children with Inflammatory Bowel Disease: A Population-Based Study. J Pediatr 2015;166:1128-33.
92. Ungar M. The social ecology of resilience: addressing contextual and cultural ambiguity of a nascent construct. Am J Orthopsychiatry 2011;81:1-17.
93. Goubert L, Trompetter H. Towards a science and practice of resilience in the face of pain. Eur J Pain 2017;21:1301-15.
94. Bodger K, Ormerod C, Shackcloth D, et al. Development and validation of a rapid, generic measure of disease control from the patient's perspective: the IBD-control questionnaire. Gut 2014;63:1092-102.
95. Ghosh S, Louis E, Beaugerie L, et al. Development of the IBD Disk: A Visual Self-administered Tool for Assessing Disability in Inflammatory Bowel Diseases. Inflamm Bowel Dis 2017;23:333-40.
96. McKinley Yoder CL, Cantrell MA. Childhood Disability and Educational Outcomes: A Systematic Review. J Pediatr Nurs 2019;45:37-50.
97. Lomas T, Waters L, Williams P, et al. Third wave positive psychology: broadening towards complexity. J Posit Psychol 2021;16:660-74.
98. Huppert FA, Whittington JE. Evidence for the independence of positive and negative well-being: implications for quality of life assessment. Br J Health Psychol 2003;8:107-22.
99. Westerhof GJ, Keyes CL. Mental Illness and Mental Health: The Two Continua Model Across the Lifespan. J Adult Dev 2010;17:110-9.
100. Ghosh A, Deb A. Positive psychology interventions for chronic physical illnesses: A systematic review. Psychol Stud 2017;62:213-32.
101. Wu Q, Zhu P, Liu X, et al. Nirvana: A Qualitative Study of Posttraumatic Growth in Adolescents and Young Adults with Inflammatory Bowel Disease. Children (Basel) 2022;9:879.
102. Meyerson DA, Grant KE, Carter JS, et al. Posttraumatic growth among children and adolescents: a systematic review. Clin Psychol Rev 2011;31:949-64.

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