

Thriving in Pediatric IBD: Preliminary Health Care Provider Perspectives

Ahola Kohut S.,^{1,2,3} Weiser N.,³ Forgeron P.,⁴ McMurtry C.M.,^{5,6} Stinson J.^{2,3}

¹Medical Psychiatry Alliance, ²University of Toronto, ³Hospital for Sick Children, ⁴University of Ottawa,

⁵University of Guelph, ⁶McMaster Children's Hospital

BACKGROUND

- Inflammatory Bowel Disease (IBD) in youth negatively impacts all aspects of health-related quality of life.
- Some youth demonstrate remarkable resilience and successfully adjust to living with IBD.
- Prior research in pediatric IBD has focused on risk factors and how these can be applied to the prevention of further illness (**NEGATIVE**).
- + A **resiliency**-based model would optimize quality of life long-term by promoting resilience specifically in the IBD population (**POSITIVE**).



OBJECTIVE

To explore specific characteristics from the perspective of health care providers (HCP) that bolster resilience.

METHODS

STUDY DESIGN

A qualitative descriptive study using semi-structured interviews.

Inclusion criteria:

- English speaking HCPs
- Minimum 1-year work experience with IBD patients at SickKids.

- N=13 HCPs
- HCPs were asked to complete:
 - Study-specific demographic and expertise questionnaire
 - Individual 30-60 minute audiotaped semi-structured interview
- HCPs asked to consider different individual, familial, social and cultural factors across patients to speak about the factors that support resilience in youth with IBD.
- Interviews coded independently by two members of the research team.
- Inductive coding used to develop coding tree of codes and sub-codes for themes.

RESULTS



Appropriate Parental Involvement

Parents involving their child in decision making builds resilience; ensuring children have a voice and age appropriate levels of independence.

"I think that the approach that the parents have with them, really be strong supporters of allowing or enabling their kids to make decisions for themselves or enabling them to know the information and asking for their opinion is one key." (HCP 002)

"I feel like family members who feel like their child is really sick and kind of sort of over-nurtures them also doesn't support resiliency. So, what they are doing is they are disabling their child by doing everything for them. So, you also need an environment that facilitates strength and independence." (HCP 004)

"...the families who have a little bit more resilience I would suggest are those who promote autonomy in the child and support them but don't over protect them and don't experience the illness for them and they let the kid find their way through their illness." (HCP 012)



Trust of the Medical Team

Trust and rapport between families and the health care team promotes resilience.

"...having a really trusting relationship with the teams is really important, really trusting what the team's decisions are in your child's care, feeling like your questions are being answered, that the people fully appreciate the benefits and the risks of different types of treatments, all of those kinds of things." (HCP 006)

"the families that are going to do better are the ones that are asking all the right questions or whatever question they think is the right question, arming themselves with as much good information as possible and then putting faith in the team to lead them in the right direction." (HCP 007)



Acceptance of IBD

Child and parental acceptance of IBD as a life-long, relapsing and remitting illness is an essential component of building resilience.

"...you have those families and those parents especially who time after time will ask, you know, so is this going to go away, like can he stop his medications because we're done, its cured, right. So, for some people it doesn't seem to sink in, so acceptance is the first step to learning how to incorporate something and integrate it into your life and to make it work." (HCP 008)

"One is accepting the illness quickly is huge. Recognizing that their child is ill, and they need to be here in order to get the treatment they need. And that's parents accepting it quickly and realizing this is our life for the next little while, as disruptive as that is." (HCP 010)



Openness about IBD

Resilience is related to how much parents and children talk openly about IBD in the context of family, friends, the community, and health care team.

"Like, they won't tell their extended family about it, they keep it a secret, so I think that that can't help but instill in the child a feeling that there is something wrong with them and that this is something to be kept hidden and not to be talked about." (HCP 008)



Identity Maintenance

HCPs discuss the significance of children staying connected to what is important to them beyond their IBD diagnosis.

"I think the kids who do well I think have the ability to put their disease into perspective and treat it as a priority, but also not let it be the defining feature of who they are. So, having a strong sense of self is a factor in resiliency." (HCP 006)

HCP DEMOGRAPHICS

Years as HCP

17.21 years (SD=7.72)

Years in Pediatric IBD

11.46 years (SD=7.52)

Current clinic time in IBD

69.58% (SD=37.55)



HCP Type	n
Gastroenterologist	2
Nurse Practitioner	1
Staff Nurse	3
Dietician	2
Psychiatrist	1
Social Worker	1
Fellow	2
Child Life Specialist	1

RESILIENCE DEFINED BY HCPs:

the ability to adapt with the changes brought on by an IBD diagnosis including factors like psychological flexibility, optimism, understanding, and engaging in the treatment process.

Risk factor barriers: low socioeconomic status; mental health comorbidity

DISCUSSION

- HCPs tended to respond to questions within the lens of barriers to resilience.
- HCPs were able to identify cross-cutting factors that bolster resilience.
- Factors identified may target the development of brief interventions or resources. These interventions can be offered preventatively to families of children with IBD.
- Mindfulness and Acceptance and Commitment Therapy based approaches may be well suited to support factors identified by HCPs.

NEXT STEPS

- Data collection is currently underway interviewing children living with IBD and their parents.
- Future longitudinal research to determine impact of resilience factors on quality of life is warranted.

ACKNOWLEDGMENTS

This work has generously supported via the Louise and Alan Edwards Foundation and the Medical Psychiatry Alliance. The Medical Psychiatry Alliance is a collaborative health partnership of the University of Toronto, the Centre for Addiction and Mental Health, the Hospital for Sick Children, Trillium Health Partners, the Ontario Ministry of Health and Long-Term Care and an anonymous donor.