Assessment of Health Related Quality Of Life in Children with Inflammatory Bowel Disease

Thesis

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List of Abbreviations

5-HT	5 hydroxy-tyramine
6MP	6-Mercaptopurine
ANCA	Anti-neutrophil cytoplasmic antibody
ASA	Amino Salicylic Acid
ASCA	Anti-Saccharomices cerevisiae antibody
ATI	Antibodies to infliximab
AZA	Azathioprine
BE	Ba**r**ium enema
CAS	Child Assessment Schedule
CAS	Child Assessment Schedule
CBT	Cognitive-behavioral therapy
CD	Crohn's Disease
CDAI	Crohn's Disease Activity Index
CHD	Coronary Heart Disease
CHQ	Child Health Questionnaire
CRC	Colo-rectal Carcinoma
CRP	C-reactive protein
CT	Computed Tomography
DLG5	Drosophila Discs Large Homolog 5
EIM	Extra-intestinal Manifestations
EN	Enteral nutrition
ESR	Erythrocyte Sedimentation Rate

FUO	Fever of Unknown Origin
GAD	Generalized Anxiety Disorder
HEDIS	Health Plan Employer Data Information Set
HLA	Human Leukocyte Antigen
HRQOL	Health Related Quality of Life
HSP	Heat Shock Protein
IBDs	Inflammatory Bowel Diseases
IFN-γ	Interferon Gamma
IL1RA	Interlukin 1 Receptor Antagonist
IRR	Incidence Rate Ratio
KSADS	Kiddie Schedule for Affective Disorders and Schizophrenia
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MAGUK	Membrane-Associated Guanylate Kinase
MAOIs	Mono amine oxidase inhibitor
MAPK	Mitogen Activated Protein Kinase
MDR	Multi Drug Resistance gene
MRE	Magnetic Resonance Elastoscopy
NF-kB	Nuclear Factor kB
NK	Natural Killer cells
OCD	Obsessive-compulsive disorder
OCTN	Organic Cation Transporter Proteins

OR	Odds Ratio
PD	Panic disorder
PN	Parenteral Nutrition
PTSD	Post-traumatic stress disorder
QOL	Quality of Life
SAD	Social anxiety disorder
SB	Small Bowel
SBFT	Small Bowel Follow Through
SCHIP	State Children’s Health Insurance Program
SF	Short Form
SSRIs	Selective serotonin reuptake inhibitors
TACQOL	TNO AZL Children's Quality of Life
TAPQOL	TNO-AZL Preschool children Quality of Life
TCAs	Tricyclic anti-depressants
TNF	Tumor Necrosis Factor
TPMT	Thiopurine S-methyltransferase
UC	Ulcerative Colitis
UGI	Upper Gastrointestinal Series
US	Ultrasound
WBC	White Blood Cells

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Introduction

Inflammatory bowel diseases were described by Giovanni Battista_Morgagni (1682–1771) and by Scottish physician T. Kennedy Dalziel in 1913 **(Kirsner, 1988).**

Ileitis terminalis was first described by Polish surgeon **Antoni Leśniowski** in 1904, however, due to the precedence of Crohn's name in the alphabet, it later became known in the worldwide literature as Crohn's disease. Only in Poland is it still called Leśniowski-Crohn's disease. **Burrill Bernard Crohn,** an American gastroenterologist at New York City's Mount Sinai Hospital, described fourteen cases in 1932, and submitted them to the American Medical Association under the rubric of "Terminal ileitis: A new clinical entity". Later that year, he, along with colleagues **Leon Ginzburg** and **Gordon Oppenheimer** published the case series as "Regional ileitis: a pathologic and clinical entity" **(Crohn et al., 1932).**

Inflammatory Bowel Diseases (IBDs) are lifelong diseases, usually starting in early adulthood and increasingly diagnosed in childhood in otherwise healthy, active individuals. IBDs can significantly impact the quality of life of the patient, their caregiver/s and family, workplace, and community. It can impact career choices, lead to reduced work hours, impact family planning decisions, and lead to income disparity and depression. There are also concerns involving ongoing drug treatment, recurrent hospitalizations and surgeries. IBDs can

also complicate travel, life and working arrangements due to the need for bathroom access.

People with IBDs can lead generally normal lives most of the time, but with ongoing medication needs and occasional flares that may require hospitalization with surgery. The unpredictability of symptoms and the prospect of eventual surgery burden daily life. Finally, due to the intimate nature of the symptoms, there may be a stigma attached to the disease from family, friends and workplace colleagues **(Crohn's and Colitis Foundation of Canada Journal, 2012).**

Health Related Quality of Life (HRQOL), including physical, psychological, and social functioning, can be defined as one means of assessing the burden of chronic illness. Studies tend to refer to either HRQOL or psychosocial functioning and typically examine the effect of IBD on areas such as behavioral, emotional, social functioning, and self-esteem. To increase the sensitivity of the search for the present review, both terms were included or were used interchangeably. Psychosocial functioning or HRQOL is typically measured using validated structured interviews (allowing for detection of psychiatric disorders) and/or validated norm-referenced questionnaires **(Sarah Ross et al., 2011).**

Aim of the Work

This work was conducted to assess the health related quality of life in children with inflammatory bowel diseases and to provide recommendations for future studies.

Inflammatory Bowel Diseases

● Definition:

The inflammatory bowel diseases; Crohn's disease, Ulcerative colitis and Indeterminate colitis, are immune-mediated dysregulation resulting in chronic, relapsing inflammation of the gastrointestinal tract, presenting with diarrhea, abdominal pain and rectal bleeding **(Ferguson et al., 2008).**

● Etiopathogenesis:

- Etiology & Pathogenesis:

While no specific etiology has been defined, the complex nature of IBDs supports the notion that its origin is likely multi-factorial. Current theory suggests that in genetically predisposed individuals, environmental factors and maladaptive immune responses to gastrointestinal flora generate a dysregulated inflammatory cascade creating mucosal injury **(McGreal and Cho, 2008).**

Over the last decade, research has focused on the genetic aspect of IBDs. The identification of linkage between Crohn's disease and the pericentromeric region of chromosome 16 (*IBD1*) by Hugot in 1996, spawned a series of genome scans and linkage analyses in search of susceptibility and phenotypic modifier genes **(Hugot et al., 1996).** In 2001, the discovery that