



## Qualitative Analysis of Pediatric Patient and Caregiver Perspectives After Recent Diagnosis With Inflammatory Bowel Disease

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### ARTICLE INFO

#### Article history:

Received 19 April 2017

Revised 6 November 2017

Accepted 20 November 2017

Available online xxxx

#### Keywords:

IBD

Chronic disease

Complementary and alternative therapy

Perspective

Shared decision-making

### ABSTRACT

**Purpose:** A diagnosis of a chronic illness is a life-altering experience for a child and his or her family. The purpose of this study was to elicit children and parent perspectives following a diagnosis of Inflammatory Bowel Disease (IBD).

**Design & Methods:** A qualitative description design was employed. Eighteen patients were recruited from a Pediatric IBD Clinic in Western Canada. Interviews were used to gather perceptions, opinions, and attitudes from children and their parents. Transcriptions of the interviews were analyzed using a qualitative content analysis.

**Results:** Four themes were identified: perspective of diagnosis, roles in care and decision-making, sharing the diagnosis, and treating the disease. Children and parents expressed varied emotions in response to diagnosis. Families articulated the desire to become more active members in the decision-making process on treatment choices. While using conventional medical therapy was seen as an appropriate choice for short-term therapy, many parents hoped that more non-conventional and alternative therapies could be used in the future.

**Conclusion:** Healthcare providers need to provide excellent education on the disease process, treatment options, and the use of CAM therapy in IBD, while at the same time supporting children and parent's voices in treatment decisions.

**Practice Implications:** Improvement strategies need to be implemented to allow families to feel that they have a voice when making decisions regarding treatment options. Families need to be educated and supported on the use of CAM therapies in IBD.

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A chronic disease may complicate, distress, or even unravel a child's life (Devlin et al., 2014). In particular, the first couple of months of illness may be stressful for a child and his or her family as they cope with symptoms of disease and investigations to determine an etiology (Gray et al., 2015). While a diagnosis offers answers and hopefully the possibility of treatment, the medical information, implications of diagnosis, and possibilities regarding treatment foreseeably may be experienced as overwhelming.

Like other chronic illnesses, a diagnosis of inflammatory bowel disease (IBD) has the potential to impose a significant burden (Woodward et al., 2016). There are significant symptoms of disease such as diarrhea, abdominal pain, weight loss, and fatigue (Becker et al., 2015). More so, IBD is unpredictable in nature: from periods of

remission to episodes of disease flare-ups often without warning (Gray, Graef, Schumann, Janicke, & Hommel, 2013). Even during periods of remission, there is a need for multiple medications and medical appointments.

When a child is diagnosed with IBD, everyone in the family, including parents and siblings, is affected (Gray et al., 2013). While healthcare providers may try to imagine how the family is coping with the diagnosis, it may be challenging to truly understand what the family is going through. Previous qualitative research has revealed how IBD may complicate the transition into adulthood, increase the risk for depression-anxiety, lead to social isolation, and alter self-image (Devlin et al., 2014) (Karwowski et al., 2009). Limited research, however, has explored children and their families' experiences following a diagnosis of IBD. Such understanding is paramount for the practice of pediatricians, nurses, social workers, and other health professionals who support patients and families with IBD.

The purpose of this study was to elicit children and parent perspectives following a diagnosis of IBD. By collecting this information,

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healthcare providers will hopefully be able to improve the education and support that they provide to patient-families.

## Patients and Methods

### Study Design

A qualitative descriptive design (Sandelowski, 2000), employing semi-structured interviews for data generation and content analysis for data exploration was utilized. Qualitative description can be used to create a comprehensive summary of perspectives related to a topic of interest. While qualitative description is not free from interpretation, data obtained with this approach are interpreted with a lower degree of inference than other forms of qualitative inquiry (Sandelowski, 2000).

### Participants and Setting

Children and parents were recruited from the Edmonton Pediatric IBD Clinic (EPIC) at the Stollery Children's Hospital between July 2015 and May 2016. The IBD clinic is a pediatric outpatient clinic that is located within the hospital. The team members of the IBD clinic include Gastroenterologists, Registered Nurses, and Registered Dietitians. The role of the health care team includes managing the patients' disease and nutritional status, and providing education and counselling to the families. The Stollery IBD clinic cares for patients 17 years and under, who are diagnosed with IBD residing within parts of Alberta, Saskatchewan, Northwest Territories and northern British Columbia. Patients were recruited during clinic visits using a convenience sample. Inclusion criteria included that the patient was diagnosed with IBD within the last two months and between the ages of 6 to 17 years of age. Exclusion criteria included being younger than 6 years of age or having been diagnosed for longer than two months. Patients were allowed to choose if they were interviewed with their parents or separately. The University of Alberta Health Ethics Review Board (HREB) approved the protocol, all recruiting procedures, and the informed consent document prior to participant recruitment. The patients treating physician and nurse were not involved in the interview process and all identifiable data remained unknown to the treating team.

### Data Generation

Interview, as a data collection method, was employed to gather perceptions, opinions, and attitudes from parents and their children. The research team, benefiting from the expertise of an IBD nurse and 3 IBD-focused pediatric gastroenterologists who work at the Stollery Children's Hospital EPIC, developed semi-structured interview guides for the parent and child interviews. The following domains were included: responses to diagnosis; understanding of IBD; information sources; involvement in medical care and decision-making; concerns, feelings, and supports; and, treatment options and goals. The domains of the interviews were chosen based on information the health care team wanted to obtain from the patients and families, and review of the existing literature. Although the parent and child interviews covered similar content domains, the parent interviews asked about the effect of IBD on both the parent and their child while the child interview focused solely on the child. The interviews included 12 questions for the parent interview and 15 questions for the child interview. Examples of specific questions for the parent interview include the following: "How did you feel when your child was diagnosed with IBD?"; "How do you feel about the recommended treatment regimen?" and, "How important do you feel it is for your child to be adherent to their medications?" (Appendix 1). Examples of specific questions for the child interview include the following: "How did you feel when you were told that you had IBD?"; "Do you have any worries about having IBD?"; "How do you see having IBD fit into your regular life?" (Appendix 1). The same interviewer carried out all of the interviews. Interviews were conducted

via telephone with no providers present. The interviews lasted approximately 30 to 60 min. All of the interviews were audio-recorded, and subsequently transcribed verbatim with identifying information removed.

### Data Analysis

Qualitative content analysis was applied to the materials to explicate themes (Hsieh & Shannon, 2005). This method is an appropriate method to complement qualitative description to essentially create a summary of the data (Sandelowski, 2010). All transcripts were independently reviewed by two separate analysts, focusing on the contextual meanings of the transcribed text. The text was imported into QSR NVivo software (QSR International, [www.qrsinternational.com](http://www.qrsinternational.com)), which was utilized to assist with coding for the content analysis. Themes were developed from a prolonged engagement with the collected materials, reviewing and re-reviewing all of the data. Since the method of recruitment was based on convenience, and thus not necessarily representative of all parents and children with IBD, no weight was given to the frequency of particular identified themes. A redundancy of themes among interviews was achieved suggesting saturation. Anonymized quotes from the interviews are included as evidence for the validity of themes, and to help convey contextual meanings to the reader.

## Results

### Demographics

Eighteen patients were recruited (Appendix 2). During the recruitment time period, 62 patients in total were diagnosed with IBD at EPIC. Of the children that were recruited: seven were female and 11 were male. 12 patients were diagnosed with Crohn disease, five ulcerative colitis and one IBD unclassified. The disease activity score of the patients at the time of diagnosis was a mean Pediatric Ulcerative Colitis Activity Index (PUCAI) score of 68 (range 50 to 85) and a mean Pediatric Crohns Disease Activity Index (PCDAI) score of 30 (range 7.5 to 52.5). All patients were between the ages of 6–17 years, with an average age of 12.9 years. All participants were part of families containing multiple children; except for one family where the patient was a single child. Eleven of the parents (61%) who participated in the interview had a post-secondary education including a University or College degree.

### IBD Theme Overview

Four IBD themes were identified: perspective of diagnosis, roles in care and decision-making, sharing the diagnosis, and treating the disease. Within each theme, subthemes were identified. Perspective of diagnosis explored changes with diagnosis, feelings with diagnosis and knowledge of IBD. Roles in care and decision making looked at the role of the IBD team, patient and parents. Sharing the diagnosis explored who the children and parents choose to share the diagnosis with and the how the families with IBD felt about support. Treating the disease included medication adherence, alternative therapies and continuing on with life.

### Perspectives of Diagnosis

*Changes With Diagnosis.* The majority of children reported that the diagnosis and treatment of IBD had a limited negative impact on their day-to-day life. The main challenges noted were missing school or activities due to physical sickness or medical appointments. Challenges were mitigated by effective therapy and timely scheduling, making it easier to participate in activities, gain weight, and be active. Some children described the body itself as changing; normal pains and aches could be experienced as "big reminders" of the disease.

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