

To tell or not to tell: A qualitative interview study on disclosure decisions among children with inflammatory bowel disease

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## **Abstract**

**Rationale:** Living with a chronic illness poses many challenges, especially during the adolescent stage of development. Few studies have explored young people's experiences of talking about their illness and how they go about deciding if and when they should tell others about their condition.

**Objective:** Our study sought the perspectives of Canadian children and adolescents living with inflammatory bowel disease (IBD) to determine how they go about deciding if and when to tell others about their illness. **Methods:** Twenty-five participants with IBD, ranging in age from 10 to 17 years old, were interviewed about their experiences.

**Results:** Our participants highlighted that they generally preferred to conceal their illness. However, when they did disclose, they drew on a diverse range of contextual factors such as their knowledge of their illness as well as the severity of their illness, to make the decision. They also highlighted that one of the main challenges they experience is dealing with negative reactions to the news of their illness. This paper presents a decision-making model describing how children decide whether to disclose or conceal their IBD.

**Conclusion:** Our study illustrates that for children and adolescents, managing others' knowledge about their illness has important implications for illness identity management. We argue that knowledge of how children with IBD make disclosure decisions is an important part of understanding the social experience of having IBD, and in creating environments that allow them to adapt to life with IBD. Our study clearly highlights the need for specific programs to be implemented to normalize IBD and to create supportive environments for children and adolescents diagnosed with IBD.

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