

Patients' perspective of living with Inflammatory Bowel Disease. A literature review



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Background

Inflammatory Bowel Disease (IBD) is a chronic condition represented by two illnesses, Crohn's Disease and Ulcerative Colitis. Despite millions of people living with IBD in the well-developed industrialised countries, and the significant impact of symptoms and side effects of medications on the patient's quality of life, little is known about patients' experiences of living with IBD.

AIM: To explore the patients' perspectives and experiences of living with IBD.

Results

Data from 868 research participants identified that fatigue, fear of incontinence and uncertainty about future, body image, and lack of information from healthcare professionals dominated the experiences of those living with IBD. Also, most of the studies identified that people living with IBD were reluctant to disclose their illness due to lack of public awareness and stigma surrounding symptoms. As a result, the evidence suggested that those affected by IBD live in isolation, exclusion, secrecy, fear and with a flawed body.



Methods

An integrative review. CINAHL, Medline, British Nursing Index, PsychINFO were searched which identified 24 qualitative and mixed methods studies published in English from 2000 to 2017.

Discussion

There is evidence that those living with IBD have significant life changing symptoms about which they avoid disclosing. Their condition reduces their quality of life with significant psycho-emotional consequences. Further understanding of the impact of symptoms on their life would enable healthcare professionals to provide a more holistic care.



Conclusion

More evidence is needed to understand what is important to this group as the world faces an increase of IBD morbidity coupled with longevity. Furthermore, there is limited evidence about the needs of those aged 16-24 years, whose care needs remain unclear.

References

- Kaplan, G.G., 2015. The global burden of IBD: from 2015 to 2025. *Nature reviews. Gastroenterology & hepatology*, 12(12).
Andrews, J.M. et al., 2010. Un-promoted issues in inflammatory bowel disease: Opportunities to optimize care. *Internal Medicine Journal*
Picture . <https://www.pexels.com/photo/out-of-order-text-on-persons-belly-735966/>