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Introduction Inflammatory Bowel Disease (IBD) affects many women of child bearing age, but requires complex decision making around pregnancy. While infertility is only slightly increased many women decide against having children. Voluntary childlessness (VC) rates exceed those of the general population by far. The reasons for VC remain incompletely understood.

Methods Approximately 4300 female members of the patient organisation Crohn's and Colitis UK aged 18–45 years were asked by email to complete an online questionnaire. Data collection included patient demographics, education, employment, marital status, and disease characteristics. Childlessness status and patient views were assessed as in the previous study by Marri (2007). Disease related pregnancy knowledge was recorded with the validated CCPKnow score.

Results 1324 women with mean age of 33 years completed the survey (response rate 31%). Of these 76% were in a long-term relationship and 87% were in employment or education. 776 (59%) suffered from Crohn's disease (CD), 496 (38%) from ulcerative colitis (UC) and 4% from IBD-U. 40% had children [14% pre diagnosis (I); 26% post diagnosis (II)], 36% planned to have children at some stage (III), 7% reported fertility problems (IV) and 17% were classified as voluntarily childless (VC). 673 patients had sought medical advice about pregnancy and IBD. VC was associated with poorer disease-related knowledge (CCPKnow 5.98 vs 7.47 in (II); $p < 0.001$), older age (35 y vs 28 y in (II); $p < 0.001$), unemployment (9.7% VC; $p < 0.001$), being single (34.5% VC; $p < 0.001$), not seeking medical advice ($p < 0.001$), and diagnosis of CD (19.3% vs 13.9% UC; $p = 0.015$). Women with VC had more hospital admissions (mean 2.85 vs 2.17 (III); $p = 0.03$) and surgical interventions (mean 1.27 vs 0.65 (III); $p < 0.001$). Exposure with different types of IBD medication was not associated with VC. The main patient concerns were around inheritance (20.6%), inability to cope with a child (20.6%), and the influence of pregnancy on IBD (18%).

Conclusion VC occurs frequently in women with IBD and appears to be multifactorial. Disease type and severity influence VC. Differences in disease burden could explain why VC is more common in CD than UC. Patients are mostly concerned regarding inheritability,

disease course and the ability to cope with the added stress of being a mother. VC is associated with poor pregnancy specific knowledge and many women may stay childless unnecessarily. Patient education programs may help to reduce the rate of VC by correcting misconceptions and alleviating patient concerns.

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