

Irritable Bowel Syndrome: Unrecognized Severity

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FROM: Miller V, Hopkins L, Whorwell PJ. Suicidal ideation in patients with irritable bowel syndrome. *Clin Gastroenterol Hepatol*. 2004 Dec;2(12):1064-8. Background & Aims: Irritable bowel syndrome (IBS) traditionally is considered as more of a nuisance than having especially serious consequences. However, this is not the picture witnessed in tertiary care where we have encountered some tragic cases, prompting an assessment of suicidal ideation in such patients. Methods: One hundred follow-up, tertiary care IBS (tIBS) patients were compared with 100 secondary IBS (sIBS), 100 primary IBS (pIBS) care patients, and 100 patients with active inflammatory bowel disease (IBD). Patients were asked if they had either seriously contemplated or attempted suicide specifically because of their bowel problem as opposed to other issues. The hospital anxiety depression score was recorded, as were other clinical details on all patients.

Unfortunately, irritable bowel is still regarded by both the medical profession and the unaffected population at large, as more of a nuisance than anything particularly serious. In addition, it is frequently dismissed as a purely psychological condition that should not be taken too seriously, especially as it is not life threatening. As a result of this rather negative perception, patients often feel stigmatized, trivialized, and isolated.

It is highly unlikely that IBS will ultimately be found to have a single cause and it seems much more reasonable to assume a whole variety of factors conspire to trigger the condition. These probably vary between individuals and possibly within the same individual over time and this explains why patients become so frustrated when trying to determine what keeps them well and what makes them ill. Psychological issues should therefore just be viewed as one of many co-factors in the causation of IBS although they have also been shown to effect consultation (health care seeking) behavior. Furthermore, the role of a chronic, unrelenting illness such as IBS in inducing psychological distress as an effect – rather than a cause – has probably been under-estimated.

Most diseases vary considerably in severity from one individual to another and IBS is no exception. Many cases remain mild and in this situation, it would probably not be unreasonable to call the symptoms a nuisance. In contrast, at the other end of the spectrum, there are cases in whom the symptoms can be totally incapacitating although

they only represent a small percentage of all persons with IBS. However, because IBS is so common, affecting 10–15% of the population, these severe cases are all too numerous and we have estimated that in the U.K. there are at least 1.5 million such sufferers. This is approximately five times the *total* number of cases of inflammatory bowel disease (IBD) in this country and nobody would dispute the seriousness of IBD.

Patients with the severe form of IBS suffer appallingly at the hands of their condition. Women with this problem not infrequently liken the severity of their pain to that of childbirth and the bowel dysfunction can be devastating, especially when accompanied by urgency and fecal incontinence. In addition, these patients suffer from a whole variety of “extra-intestinal” symptoms such as backache, lethargy, bladder symptoms, and in females a range of gynecological complaints including significant interference with sexual function. To add to all this, treatment is far from adequate and in many instances totally ineffective. It therefore comes as no surprise that the quality of life of sufferers can be almost totally eroded and it has been shown that it can be worse than that of patients with diabetes or chronic renal disease on dialysis.

Our unit is a referral center for such *intractable* (difficult to manage) cases of IBS and as a consequence we have a good deal of experience with the issues that are associated with such a heavy burden of illness for sufferers. Patients frequently express the view that they have lost the will to live and recently we have had two patients

commit suicide solely because of the intractability of their symptoms. We therefore thought it would be useful to obtain an exact estimate of *suicidal ideation* (thoughts of suicide), which we anticipated would be high in our patient population, in an attempt to hopefully jolt the medical community into taking this condition more seriously.

In the U.K., patient populations are divided into three groups: *primary care* – those who are just seeing a general practitioner for their condition, *secondary care* – those who have been referred to a hospital specialist, and *tertiary care* – those who have been referred from one specialist to another because of failure to respond to treatment. We thought it would be useful to assess suicidal ideation in all three of these groups as they are somewhat indicative of severity of illness. In addition, for the purposes of comparison, we also examined this issue in patients with active inflammatory bowel disease.

All patients were asked whether they had seriously contemplated or attempted suicide on account of their IBS as opposed to any other issue in their lives. We also recorded anxiety and depression levels as well as information concerning severity of symptoms, interference with life, and adequacy of treatment.

In the tertiary care group of IBS patients, an astonishing 38% of patients had seriously contemplated and 5% attempted suicide purely on account of their IBS. This was well over twice the

figure observed in inflammatory bowel disease. The figures for the secondary and primary care groups were 16% and 4% respectively.

It might be tempting to dismiss these findings as being solely due to depression, but this is certainly not what we found. Depression scores were within the normal range in the primary and secondary care IBS patients and only just exceeded the threshold in the tertiary care group. Furthermore, when the results were analyzed, an association between depression and suicidal ideation was not especially strong. A much more important facet seemed to be a combination of:

- symptom severity,
- interference with life, and
- inadequacy of treatment.

This is in sharp contrast to inflammatory bowel disease where, at least, we have some forms of treatment that help a majority of sufferers, which was evident from their answers to the questions.

Implications for Treatment

Not surprisingly, the prospect of many years of unrelenting severe symptoms with little prospect of a great deal of relief can lead to a sense of hopelessness and we feel that the high level of suicidal ideation that we have identified in IBS is a marker of this situation. It is of interest that in the suicide literature it is stated that a sense of hopelessness can be a better predictor of suicide than depression. In addition, it has also been

shown that having someone in whom one can confide may play an important role in suicide prevention. This information should enable us to develop some strategies that might be useful in managing patients who are having difficulty in continuing to cope with their IBS.

As part of our IBS service, we provide hypnotherapy to patients who have failed to respond to other forms of treatment and we seem to be able to help a sizeable proportion of such individuals with this approach. The results for all those going through the program are audited with individuals being especially encouraged to give us feedback on issues that are not dealt with on our questionnaire. Over the years, a consistent theme in this section has been patients reporting the feeling that they would not have coped so well with their condition or may have even committed suicide had they not been through the program – irrespective of whether the treatment helped their symptoms or not. This strongly suggests that the provision of continuing support for such patients is crucial and has resulted in us recruiting a member of staff whose sole purpose is to fulfill this role for those who continue to do badly. Unfortunately the two patients who committed suicide were referred to the unit before we had employed our nurse counselor and were still on the hypnotherapy waiting list when they took their own lives.

We are not claiming that the suicidal ideation that we have identified in our patients will necessarily lead to them actually ending their lives. However, it indicates just how hopeless these individuals feel and the desperate need for services to them to be improved. Hopefully the therapeutic options available to IBS sufferers will improve in the future, but until this happens these individuals deserve far more support from the medical community and perhaps the provision of sympathetic specialist nurse counsellors, who can spend more time with them, might be a good start.

Further Reading

Miller V, Hopkins VL, Whorwell PJ. Suicidal ideation in patients with irritable bowel syndrome? *Clinical Gastroenterology and Hepatology* 2004;2:1064-8.

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Whorwell PJ. *Hypnotherapy for functional gastrointestinal disorders*. IFFGD Fact Sheet No. 185.