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Psychological adjustment to inflammatory bowel disease: The importance of considering disease activity

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Abstract

Perhaps one of the most challenging aspects of adjusting to inflammatory bowel disease (IBD) is dealing with the fluctuations from active to inactive phases of the disease. In this issue, Graff et al. report findings from a comparative analysis of the factors associated with the psychological health of participants in active and inactive IBD phases, and with matched healthy controls without IBD. Their intriguing findings regarding the differences in psychological adjustment between these groups suggest several possible explanations for why those with inactive IBD may enjoy a quality of life that is in some ways similar to those without IBD and highlight the importance of control perceptions for adjustment to IBD. These results underscore the need to consider disease activity when assessing adjustment and further suggest the need for longitudinal research into whether perceptions of control ebb and flow in parallel to disease activity as well as the possible role of individual differences.

Psychological adjustment to inflammatory bowel disease: The importance of considering disease activity

Living with any chronic health condition can challenges one's day to day to day functioning and emotional and psychological well-being. This challenge, however, may be especially heightened with inflammatory bowel disease (IBD) as the disease course and symptoms fluctuate from active to inactive periods in an unpredictable manner. In this issue, the study by Graff et al.[1] provides some new and valuable insights regarding how disease activity and coping may be linked to quality of life among people living with IBD by examining how people with IBD with and without active disease compare to matched controls.

Graff et al.'s[1] comparative analysis examining people with active or inactive IBD and those without IBD highlights the importance of considering disease activity when assessing how well patients may be adjusting psychologically to IBD. Perhaps one of the most intriguing findings from this methodologically strong study was that those with inactive IBD were not only very similar to the healthy controls in terms of functioning, but they also reported significantly higher well-being and levels of perceived control or mastery. Although this finding may at first appear counterintuitive, there are several explanations why this study found that there is little negative residual impact when IBD is not symptomatic.

First, consider how someone with IBD may evaluate their circumstances when the IBD is quiescent. Although the disease is still present, the unpredictable and uncontrollable IBD symptoms are absent, at least temporarily. When you consider that the predictability and controllability are two key dimensions that are most likely to lead to one appraising that event as highly stressful [2], then it is not surprising that enhancements in well-being occur when IBD symptoms subside for a period of time. This period without the experience of stressful symptoms will be evaluated in reference to those times when IBD is active. In psychological terms this *contrast effect* can lead people to evaluate their asymptomatic periods in a very positive light and accordingly experience a greater sense of perceived control simply because the standard used to make this judgement is so stressful. Indeed, Graff et al.[1] found that those with inactive IBD viewed their current circumstances more optimistically than did the community sample. Of course, the reverse is also possible, and when symptoms start to flare again it may be that much more stressful because the asymptomatic period is still fresh in one's memory.

This may be the critical time for considering options that may help patients deal with this stress in more adaptive ways than simply using a variety of avoidant coping strategies as Graff et al.[1] found. Of particular concern was the tendency to blame oneself noted among those with active IBD in their study. Self-blame has been linked to the use of a collection of other avoidant coping strategies and in turn poor psychological adjustment in another study of community recruited IBD patients[3]. In fact, self-blame can be viewed as a form of extreme and unrealistic perceived control whereby the individual retrospectively attributes the possibility of personal control to circumstances where such control is not possible. In this respect it is possible that any enhanced feelings of mastery that carryover from the inactive periods can unfortunately engender unrealistic expectations for control that can become self-blame once the IBD is active again.

In contrast to this more reactive view of how mastery may change within the changing context of disease activity, it is also possible as Graff et al.[1] suggest that perceptions of control may be a protective resource that develops from weathering the stress of the active periods. Feelings of mastery or control that develop or are renewed during periods when IBD is inactive may therefore enhance overall resiliency to the stress of IBD during the active periods. This view is similar to that proposed by coping theorists[4] who suggest that situational perceptions of control, that is those that focus on control over specific events such as symptoms, can serve as a coping resource to help manage difficult times. During periods when IBD is relatively inactive this sense of control may be enhanced, as suggested by the findings from Graff et al.[1], and perhaps even strengthened for when it is more acutely needed. Indeed, research with other chronic illness populations indicates that perceived control may be most useful as a coping resource for those dealing with severe and stressful symptoms [5] rather than for relatively mild or less bothersome symptoms.

A third and final explanation is that both of these views are correct and that what is needed is a more nuanced view of how and when IBD patients can successfully and adaptively cope with their disease. That is, patients with IBD are in a constant struggle to gain and maintain a sense of control over their disease that depends upon whether or not their IBD is active. When IBD is inactive perceptions of control have an opportunity to grow and flourish as there is a reprieve from the stress of active disease that would normally exhaust any attempts at trying to gain control. For example, one study found that although IBD patients reported battling to keep a sense of control they often felt worn down by their failed attempts for control during active disease periods[6]. Similarly, there is some evidence for a continuum of control perceptions among IBD patients that range from taking control to neither giving up or taking control, to loss of control[7]. As everyone in this particular study had active IBD symptoms it may be that some individuals are better at maintaining a sense of mastery or control during active periods and taking full advantage of the protective nature of these control perceptions. The real concern then is for those who are not able to do so and who may need assistance in coping with the active disease periods. Such individuals may need to learn how to focus on those aspects of the disease that they can control to diminish any feelings of helplessness that may arise during this time. This may be an especially challenging task given that Graff et al.[1] found that avoidance coping tended to predominate during times when IBD was active.

Individual differences among patients regarding their propensity to gain and maintain control over their IBD during periods when it is active or inactive is another potentially important consideration that can have implications for clinical management of patients' adjustment and quality of life. Identifying where patients' perceptions of mastery lie along the continuum of control may assist in this process. For example, a linguistic analysis study of IBD patients' responses to the question "how has IBD affected your daily activities" classified people into no control, neutral control, and taking control groups and found significant differences in several indicators of adjustment (including validated measures of perceived control) after controlling for disease severity[8]. Those in the loss of control group used phrases such as "I can't" and "I don't", whereas those struggling to gain control used "I have to" or "I need to" and "I must" when referring to how IBD had affected them. In contrast, the taking control group stated what they had and were doing in very active terms such as "I have done X" or "I try hard to do X", and "I plan". Although subjective, attending to these types of subtle differences in phrasing may provide a quick glimpse of who may be struggling the most or least with their IBD during an active phase.

In conclusion, the findings from Graff et al. suggest some encouraging but also concerning possibilities regarding the impact of IBD on adjustment and quality of life. Disease activity should be an important consideration when assessing the possible psychological needs of those with IBD, but equally important is understanding why and how factors such as perceived control shift and/or develop during fluctuations from active to inactive disease periods and back again. Research that follows the ebb and flow of control perceptions during these different activity phases is needed as is a focus on potential individual differences in resilience to the stress from such fluctuations as patients engage in the ongoing adjustment battle.

References

1. Graff LA, Walker JR, Clara I, et al. Stress coping, distress, and health perceptions in inflammatory bowel disease and community controls. Am J of Gastroenterol, In press.
2. Taylor SE, Sirois FM. Health Psychology. Canadian ed. Toronto, ON: McGraw-Hill Ryerson; 2009.
3. Voth J, Sirois FM. The role of self-blame and responsibility in adjustment to inflammatory bowel disease. Rehab Psychol 2009;54:99-108.
4. Folkman S. Personal control and stress and coping processes: A theoretical analysis. J Pers Soc Psychol 1984;46:839-852.
5. Sirois FM, Davis CG, Morgan MS. "Learning to live with what you can't rise above": Control beliefs, symptom control, and adjustment to tinnitus. Health Psychol 2006;25:119-123.
6. Hall NJ, Rubin GP, Dougall A, et al. The fight for 'health-related normality': A qualitative study of the experiences of individuals living with established inflammatory bowel disease (IBD). J Health Psychol 2005;10:443-455.
7. Wolfe BJ, Sirois FM. Beyond standard quality of life measures: the subjective experiences of living with inflammatory bowel disease. Qual Life Res 2008.
8. Sirois FM, Wolfe B. A continuum of control: Implications for quality of life in patients with inflammatory bowel disease (IBD). In: International Society for Quality of Life Research meeting abstracts [www.isoqol.org/2007mtgabstracts.pdf]. 2007. Qual Life Res suppl.; 2007.