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QUESTION

WHAT DO WE KNOW ABOUT ADHERENCE IN INFLAMMATORY BOWEL DISEASE AND ANY CHRONIC PEDIATRIC MEDICAL CONDITION? WHAT CAN I DO TO HELP?

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Sadly, we know that a lot of kids do not take their medicines. We know that the least reliable way to find out if a patient is taking his or her medicines is to ask the patient; asking the parents is not much better. Self-reporting is just not reliable, no matter how good a rapport we might think we have with a patient. There are many different ways to measure adherence. Some studies look at the frequency and timing of medication refills, while others count pills. We have looked at these methods and, at the same time, used electronic pill bottles that note when the medication bottle is opened.¹ Figure 46-1 shows what these pill bottles look like. The tops of the bottles contain a microchip that records the date and time when it is opened. The bottles are expensive to purchase and require a research assistant to regularly check in to make certain that they are being used correctly. That probably explains why they have not been used very much. Also, everyone is regularly reminded that their adherence is being checked, so that might affect results.

Even though the electronic bottles we use probably serve as reminders, we have found that kids simply do not open their medication bottles as often as we prescribe or as often as we would guess that they do. Furthermore, even clinicians, who know research is being conducted and are attuned to the issue of adherence, are unable to accurately predict who their nonadherent patients are.

On average, kids with inflammatory bowel disease (IBD) and other chronic conditions generally open their pill bottles about half of the time that they are supposed to. It is astonishing that about one-third of our patients open their pill about one-third of the times we would expect. We can only assume that they are taking all of the meds we have prescribed when they do open the bottle. It is a reasonable guess that they are taking the dose of 6-MP we have prescribed, which is usually a whole or fraction of a pill, but unlikely that they are taking all of the 5-ASA tabs prescribed, since this is often many pills at one time.

It is not surprising that the lowest levels of adherence occur in the older adolescents. It is disconcerting that in the younger children, those where we expect the parents to control medication, adherence measured by these electronic pill caps is still far from acceptable. Note that most studies