IBD: Getting the Most from
the Doctor-Patient
Relationship

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Goal: An empowered, enlightened patient collaborating with a communicative MD

- Obstacles: MD, patient
- Stages of coping w diagnosis of IBD
- Accepting the challenge/ opportunity of living with IBD
- Educated concern vs. uneducated worrying
- E.g. “What about cancer!??”
Obstacles to patient-MD interaction

**Patient**
- Ignorance about IBD
- Intimidation
- Incomplete data about symptoms, medications
- Fears about diagnosis, tests, prognosis
- Stopping or changing medications
- Failure to communicate

**MD**
- Pressures on time
- Intimidating
- Impersonalization of technology
- Data overload
- Not aware of patient’s concerns, changes in medications
- Failure to communicate
Stages of coping with having IBD

- Denial
Stages of coping with having IBD

- Denial
- Despair
Stages of coping with having IBD

- Denial
- Despair
- **Anger**
Stages of coping with having IBD

- Denial
- Despair
- Anger
- Acceptance
Accepting the challenge/opportunity of living with IBD:

**Mantras**

- IBD may be a disease for life but does not make you sick for life
  - metaphor of the Sleeping Dragon
Accepting the challenge/opportunity of living with IBD: **Mantras**

- IBD may be a disease for life but does not make you sick for life: metaphor of the Sleeping Dragon
- **Most people with IBD are feeling well**
Accepting the challenge/opportunity of living with IBD: Mantras

- IBD may be a disease for life but does not make you sick for life: metaphor of the Sleeping Dragon
- Most people with IBD are feeling well
- **The more you know about IBD the more optimistic you can be**
Educated concern >> uneducated worrying

- Consult CCFA
  - Lectures
  - Support groups
  - Reading
- Gastroenterologist
  - Pas de deux/duet/partnership
  - Empowered patient + communicative MD
- Beware the internet!!
How to collaborate with your physician

- At least yearly checkup
How to collaborate with your physician

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- **Call with any significant change in symptoms, concerns, or changes in medications. Do not change medications without discussion!**
How to collaborate with your physician

- At least yearly checkup
- Call with any significant change in symptoms, concerns, or changes in medications. Do not change medications without discussion!
- Regular (yearly or every other year) colonoscopy if colitis > 8-10 years
How to prepare for the checkup or phone call with your physician

- Describe symptoms fully:
  - Detailed description
  - How long?
  - Caused by?
  - Better with?
  - Worse with?
  - Your diagnosis/concerns?
How to prepare for the checkup or phone call with your physician

- Describe symptoms fully:

- Complete list of medications, including OTC
  - Any new meds or new doses of old meds?
How to prepare for the checkup or phone call with your physician

- Describe symptoms fully
- Complete list of medications, including OTC
- **Prepare list of concerns/questions?**
How to prepare for the checkup or phone call with your physician

- **Describe symptoms fully:**
  » How long? Caused by? Better with? Worse with? Your diagnosis?

- **Complete list of medications, including OTC**

- **Prepare list of concerns/questions?**

- **Ask about pros and cons of studies, medications ("risk:benefit ratios")**
How to prepare for the checkup or phone call with your physician

- **Describe symptoms fully:**
  - How long? Caused by? Better with? Worse with?
- **Complete list of medications, including OTC**
- **Prepare list of concerns/questions?**
- **Ask about pros and cons of studies, medications (“risk:benefit ratios”)**
- **How long before I am better again? When is next contact/test?**
How to prepare for the checkup or phone call with your physician

- Describe symptoms fully:
- Complete list of medications, including OTC
- Prepare list of concerns/questions?
- Ask about pros and cons of studies, medications (“risk:benefit ratios”)
- How long before I am better? When next contact/test?
- **The only stupid question is the un-asked question**
IBD: Cancer Concerns
IBD: Cancer Concerns  (1)

- Should I be concerned? How concerned?
  » Yes, overall increased risk > non-IBD
  » But >90% of IBD patients never get cancer

- Who should be concerned?
  » chronic (>8-10 years) colitis (ulcerative and Crohn’s)
  » most of colon involved with the colitis
  » family history of colon polyps or cancer
  » sclerosing cholangitis

- What is the magnitude of the risk?
  » Traditional answer: 0.5%/year after 10 years of colitis
  » Probably lower than that
IBD: Cancer Concerns (2)

- Does cancer risk correlate with how severe my symptoms are?
  » Probably not.

- Do IBD medications cause cancer?
  » Probably not.

- Do IBD medication prevent cancer?
  » Maybe.
IBD: Cancer Concerns (3)

- What can I do to minimize getting cancer?
  - Annual checkups with gastroenterologist
  - Report any significant change in symptoms
  - Colonoscopy surveillance every year or other year after 8-10 years of IBD colitis

- Does taking biopsies at colonoscopy mean there is cancer?
  - No. We are looking for microscopic activity, anatomic extent of disease, and any shift in the direction of cancer or pre-cancer.
Summary

The educated, empowered patient:

- Confidently communicates with CCFA and MD
- Has annual checkup with gastroenterologist
- Has colonoscopy screening then surveillance every 1 or two years after 8-10 years of IBD
- Is informed, appropriately concerned, involved, and optimistic
Summary

“Don’t be nervous,
don’t be flustered,
Don’t be scared...
Be prepared!”

Tom Lehrer
Instead of...
Be...
Thank you.