

What Constitutes ~~Good~~ IBD Care

The Best

Great

superb



Sr Karin Davidson



What does good IBD care
mean for you?



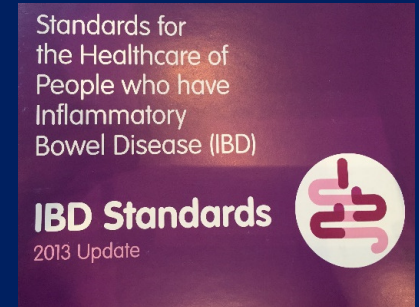
VS



Standards of Care

- UK standards of Care
- Scottish Audit

Improving Standards of
Care for all IBD patients



- Patient is what drives care

- In SA no set IBD standards and no national benchmark for care

- ECCO guidelines



European
Crohn's and Colitis
Organisation



IBD Standards of Care

UK IBD STANDARDS OF CARE

- High quality Clinical Care - Responsive
- Local delivery of Care - MDT
- Maintaining a patient centred service
- Patient Education and Support
- Data Information, Technology and Audit
- Evidence – Based Practice and Research - Calprotectin

South African Context

- **High Quality Clinical Care**
 - Private and government care – fragmentation of services
 - MDT care limited but possible
- **Local Delivery of Care**
 - Patients travelling to centres of excellence
 - Poor local support
 - Poor access to specialised services

- **Maintaining a patient centred service**

- Choice of care strategies limited – funding and local access to specialised medications –

BUT.....

- **Patient education and Support**

- SAGES patient meeting
- SA IBD Facebook support group
- IBD Africa website

- **Data information, Technology and Audit**

- South African Registry and IBD Africa

- **Evidence-Based Practice and Research**

- Treat to Target
- Personalised care plan for each individual
- Care fluid adapting to new research and treatment algorithms



Picture courtesy of CCUK

Maslow's Hierarchy of Needs



What would IBD Hierarchy of Needs look like?

?

Enabling patients to actively participate in their care

Tailoring healthcare services for each patient

Continuity of Care and relationships

Knowing each patient as an individual

Essential requirements of IBD Care - access to a MDT, appropriate medication, scopes, blood work, monitoring

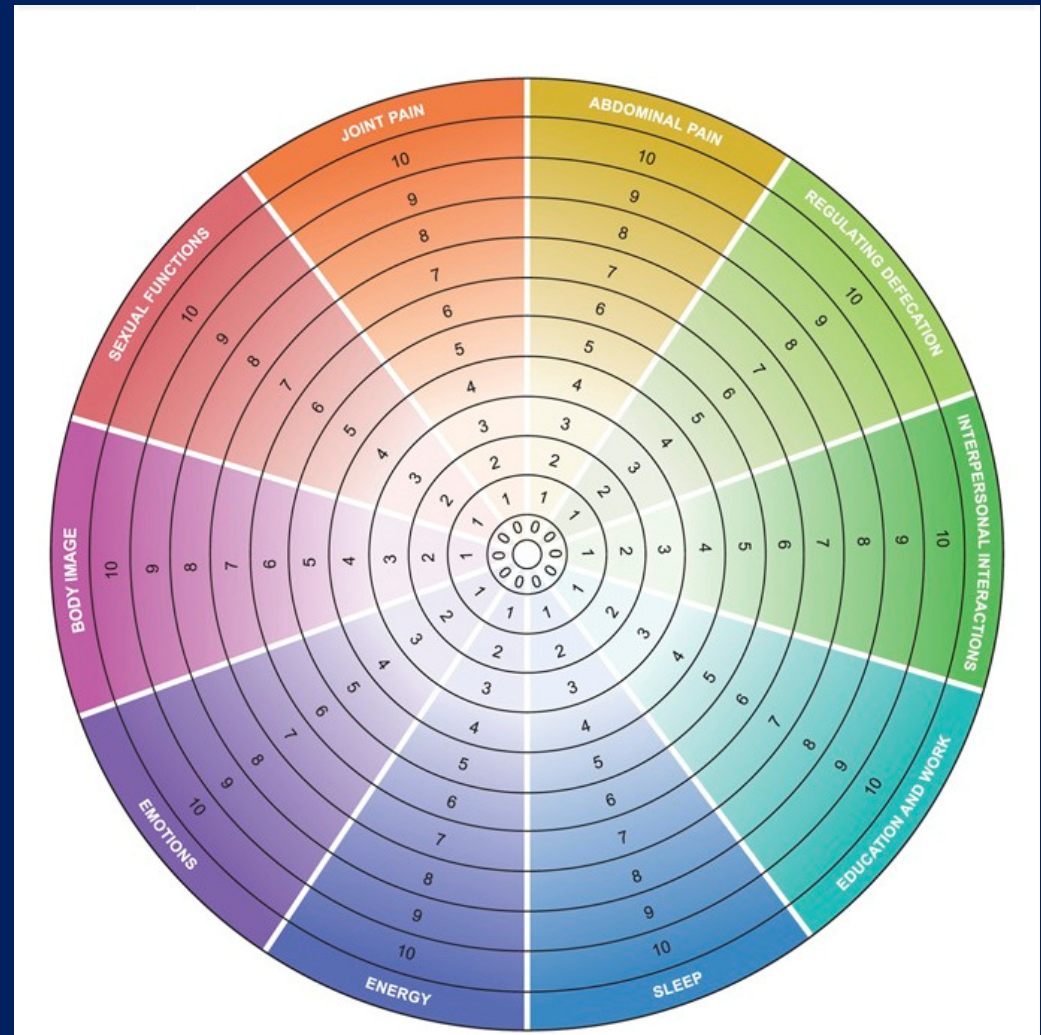
So what should you, as a patient, be demanding?

- Access to a multidisciplinary team
- Up to date appropriate monitoring
 - Faecal calprotectin testing
 - Regular Iron, Vit B12 and Vit D monitoring and appropriate supplementation
 - Regular appropriate drug monitoring – Trough levels
- Psychological support
 - Support Groups
 - Patient education and access to information
- To be the centre of your care

For each of the ten statements below, score your level of agreement on a scale of 0 to 10.
Circle your scores on the coloured disc.

Absolutely disagree	Neither agree or disagree						Absolutely agree				
←	0	1	2	3	4	5	6	7	8	9	10

In the last week, because of my Crohn's disease or ulcerative colitis...	
Abdominal pain	...I have had aches or pains in my stomach or abdomen
Regulating defecation	...I have had difficulty coordinating and managing defecation, including choosing and getting to an appropriate place for defecation and cleaning myself afterwards
Interpersonal interactions	...I have had difficulty with personal relationships and/or difficulty participating in the community
Education and work	...I have had difficulty with school or studying activities, and/or difficulty with work or household activities
Sleep	...I have had difficulty sleeping, such as falling asleep, waking up frequently during the night or waking up too early in the morning
Energy	...I have not felt rested and refreshed during the day, and have felt tired and without energy
Emotions	...I have felt sad, low or depressed, and/or worried or anxious
Body image	...I have not liked the way my body or body parts look
Sexual functions	...I have had difficulty with the mental and/or physical aspects of sex
Joint pain	...I have had pains in the joints of my body



Ghosh, Louis, Beaugerie et al Inflamm Bowel Dis 2017

Patient reported monitoring: The IBD Disc

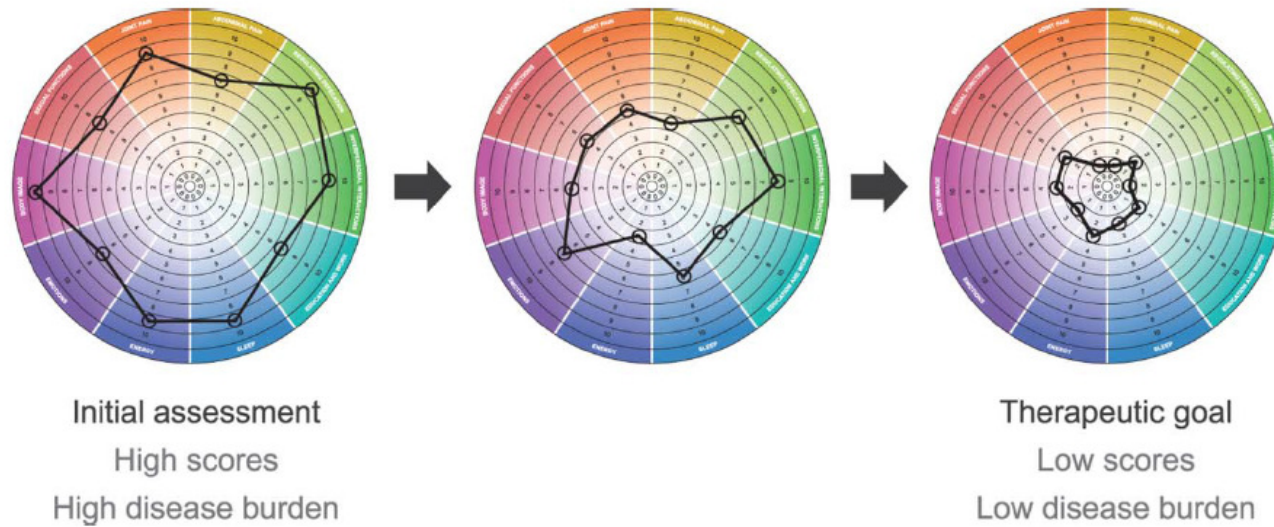
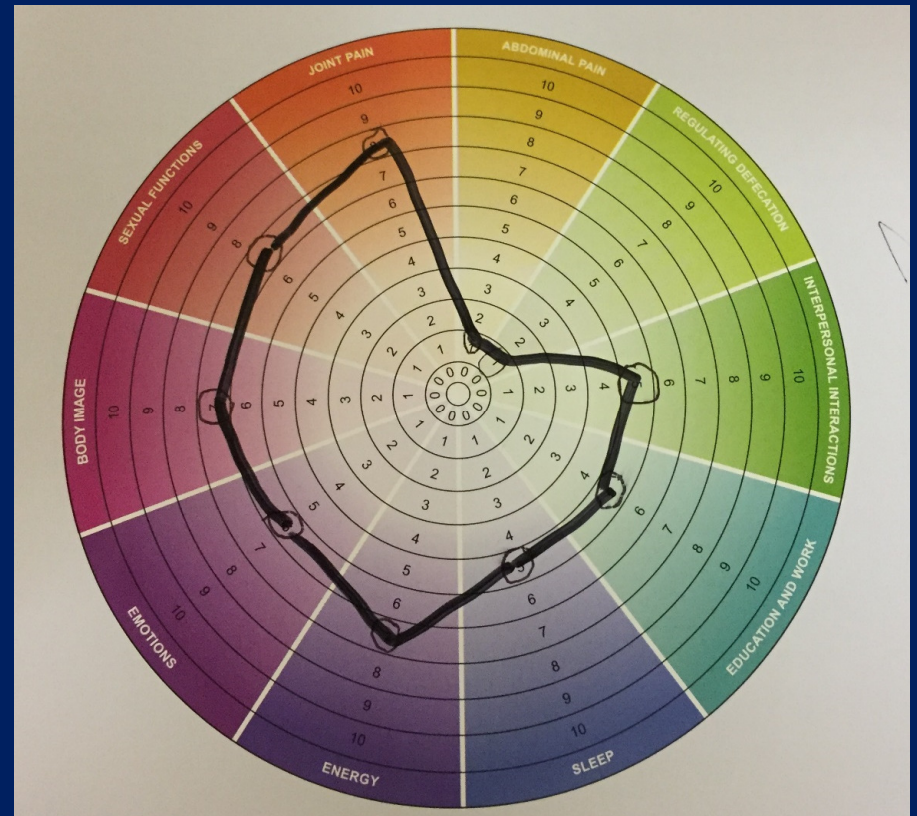
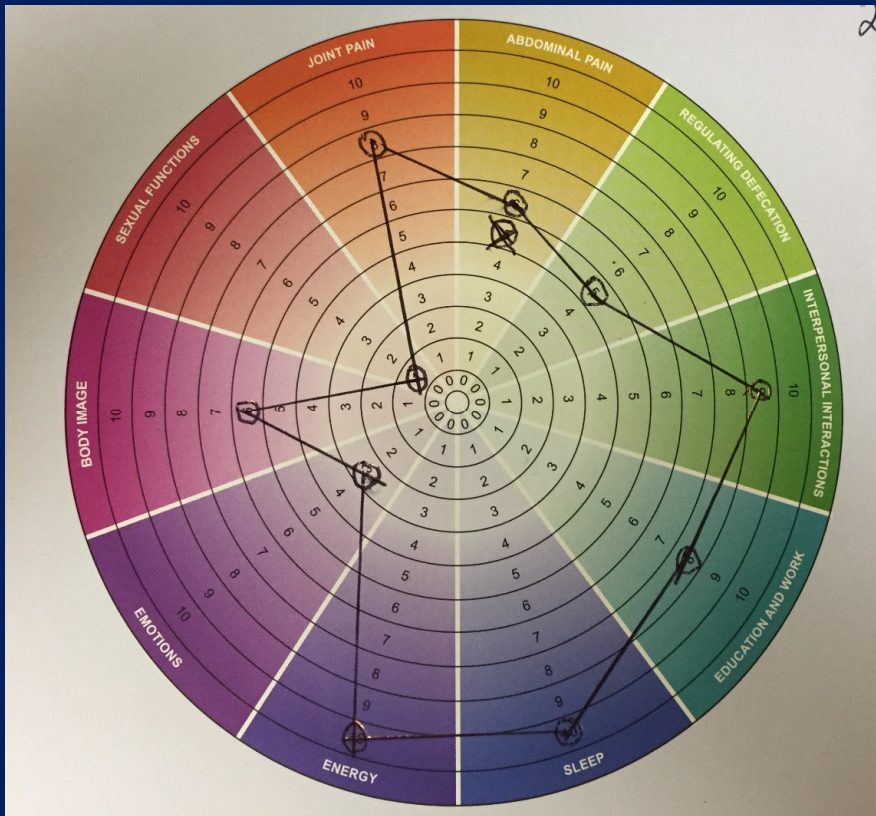


FIGURE 3. Hypothetical example of how a patient's IBD Disc assessment may change over time with good disease management.

In Reality.....



IBD Care is not just about the
medical management....

It's also about decreasing the true
burden of disease



I am no longer defined by the disease I have,
but rather, by who I am

