The Importance of Patient Support Organizations in IBD

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Burden of Inflammatory Bowel Disease

Chronic inflammatory diseases

Affect predominantly a young population

Often progressive and disabling

Significant impact on quality of life

High financial burden

Annual direct & indirect costs estimated at $14.6 billion to $31.6 billion (CCFA)
The Multifaceted Burden of IBD

Disease outcomes

- Abdominal pain
- Bowel damage and complications
- Diarrhea
- Hospitalizations
- Anemia
- Mortality
- Poor growth / weight loss
- Cancer risk

Patient-reported outcomes

- Impact on work / school
- Impact on social and professional life
- Nutrition
- Clinical visits
- Medication side effects
- Fatigue
- Colonoscopy / imaging
- Impaired QoL / disability
- Blood / faecal test monitoring

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Blood / faecal test monitoring
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Impact on work / school

The Human Cost of IBD

- Not being able to eat the foods they like
- Struggling to keep social engagements
- Avoiding going on dates or being in relationships
- Worries planning trips because of the threat of flare-ups
- Problems participating in physical activities
- Concealing the condition from colleagues
People with IBD* reported that the condition:

- Caused worry about availability of toilets when going somewhere new (66%)
- Negatively affected their ability to perform to full potential in an educational setting (52%)
- Prevented them from pursuing relationships (40%)
- Caused them to wake frequently as a result of IBD pain (40%)
- Had gotten in the way of their ability to make friends (29%)

*Includes people with Crohn’s disease and Ulcerative Colitis


Considering the Burden of Immune Disorders
The Impact of IBD on Adolescent Patients

- **30%**
  - 30% of all patients with IBD present between the age of 10 and 19 years.

- **11.9** years
  - The mean age for diagnosis of IBD is 11.9 years.

- **25%**
  - Up to 25% of young people with IBD have depression.

- **Behavior Problems**
  - Children with IBD are found to have behaviour problems, psychiatric disorders, depression and diminished social competence.

- **3 Months**
  - Up to 3 months of school absenteeism is reported per year.

- **Emotionally Vulnerable**
  - Children with IBD are frequently considered emotionally vulnerable.

- **Affects Educational Performance**
  - 61% of under 18 year olds felt that IBD had affected their ability to perform to their full educational potential.

- **17%**
  - 17% of young people with IBD had to wait more than 5 years to receive a final diagnosis.
“Inside she is in pain but she keeps silent. Crohn’s and IBD are taboo diseases, talking about them is the first step of the fight”

Image from awareness raising campaign organised by Afa, France, page 16

Promoting Patients’ Rights at European level
Interview with the Director of the European Patients’ Forum, page 26

First results of the IMPACT project
page 10
Good care: How patients define it and how they make sure they get it

A study by PatientsLikeMe with funding from the Robert Wood Johnson Foundation
Aspects of **Good Health Care**

- Active patient role
- Doctor/provider competence
- Collaborative care
- **Individualized and empathetic care**
  - Effective treatment selection
  - Focus on outcomes
  - Effective treatment delivery
  - Care accessibility and cost
  - Office management
  - Staff communication
THE CHALLENGES AND REWARDS OF PATIENT CENTERED CARE
Institute of Medicine (IOM)  
Patient-Centered Model of Care

- The IOM Report on Health Professions & Training has identified that doctors & other health professionals lack adequate training in providing high quality healthcare to patients
- Called on educators & licensing organizations to strengthen health professional training requirements in delivery of patient-centered care
- Essential features of healthcare communication which relies heavily on core communication skills, such as open-ended inquiry, reflective listening and empathy, as a way to respond to the unique needs, values & preference of individual patients

Patient Centered Care

• The needs of the patient come first
• “Nothing about me without me”
• Every patient is ONLY patient
• Enter the patient’s world, see the situation through the patient’s eyes

Don Berwick, MD – Former President & CEO
IHI (Institute of Healthcare Improvement)
Multidisciplinary Team in IBD
The “team” from the patient point of view
Objectives of Report

- Highlight the value of patient organizations as legitimate stakeholders in civil dialogue in health-related policies and to draw attention to the challenges they are facing
- Emphasize the contribution of patient organizations in representing and voicing the situation of a specific population that would otherwise not be represented
- The main activities of patient organizations are set out in four different areas: policy, capacity-building and education, peer support and research & development (both health and pharmaceutical)
Value of Patient Organizations

Overarching principle of Advocacy

Representation
Mobilisation
Empowerment

Policy
- Understand patient priorities and experience;
- Advocate perspective of end-users in health services design;
- Active participants in policy making process;
- Channel the voice of patients in consistent way in HiAP-approach;
- Contribute to policy development at all stages.

Capacity building & education
- Strengthen organisational management and governance structure;
- Act as capacity developers;
- Produce new and review existing health-related information and develop guidelines;
- Translate health information and educate patients;
- Build capacity by spill-over though investment in patients and community.

Peer support
- Provide permanent monitoring and counseling;
- Provide legal and financial support;
- Co-deliver self-management education and expand various types of support onto wider community.

Research and development: health & pharmaceuticals
- Being active research collaborators, partly through data collection;
- Encourage involvement of patients in early stages of R&D;
- Help navigate regulatory process;
- Involvement in co-design, development, application and monitoring of disruptive innovations for healthcare.
Empowering Patients

Empowerment is “a multidimensional process that helps people gain control over their own lives and increases their capacity to act on issues that they themselves define as important”
Patient Advocacy Groups Needs from Industry

**Involvement**
- Understanding of clinical development plan
- Involvement in protocol design
- Clarification of regulatory interaction and impact
- **Burden minimization strategies**
- Awareness campaigns
- **Patient registries**

**Partnership**
- Key opinion leader relationships
- **Support of advocacy group relationship with community**
- Message development
- **Transparent communications**
- Support for additional community assistance (e.g., natural history study)
- **Co-develop tools for research and awareness**

**Respect**
- Understand how advocacy group is structured and resourcing levels
- **Natural history data**
- **Compassion and true commitment to community**
- **Adhere to ethical principals of interaction with advocacy groups**
How do online patient support communities affect the experience of inflammatory bowel disease? An online survey

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<tr>
<th>Reason</th>
<th>No. of participants</th>
<th>% of total</th>
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<tbody>
<tr>
<td>To find others in a similar situation</td>
<td>201</td>
<td>80.7</td>
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<tr>
<td>To learn new information about my condition</td>
<td>165</td>
<td>66.3</td>
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<tr>
<td>To share experiences</td>
<td>162</td>
<td>65.1</td>
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<tr>
<td>To share information with others</td>
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<td>58.6</td>
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<td>To find emotional support</td>
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<td>57.0</td>
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<tr>
<td>To seek advice</td>
<td>140</td>
<td>56.2</td>
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<tr>
<td>To offer support to others</td>
<td>135</td>
<td>54.2</td>
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<tr>
<td>To ask a question about my condition</td>
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<td>51.4</td>
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<td>Because it was convenient</td>
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<td>43.0</td>
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<td>Because it was available 24/7</td>
<td>90</td>
<td>36.1</td>
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<td>Because I was feeling lonely</td>
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<td>30.9</td>
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<tr>
<td>To understand medical terminology better</td>
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<tr>
<td>Because of an increase in the severity of symptoms</td>
<td>64</td>
<td>25.7</td>
</tr>
<tr>
<td>Because I was experiencing new symptoms</td>
<td>50</td>
<td>20.1</td>
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Note: Participants could endorse more than one reason.
Forming a support group for people affected by inflammatory bowel disease

In this report, Ms Nidhi Swarup, the Founder and President of Crohn’s and Colitis Society of Singapore (CCSS), talks about her journey as a Crohn’s disease patient and her willingness and efforts to connect with people suffering from IBD that seeded an idea of starting a patient group in Singapore.
Our Mission

Policy
- Understand patient priorities and experience.
- Advocate perspective of end-users in health services design.
- Active participation in policy making process.
- Channel the voice of patients.
- Contribute to policy development at all stages.

Peer Support
- Provide permanent monitoring and counseling.
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- Co-deliver self-management education and expand various types of support onto wider community.

Capacity Building & Education
- Strengthen organizational management and governance structure.
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- Build capacity by investment in patients and community.

Research & Development
- Being active research collaborators.
- Encourage involvement of patients in early stages of R&D.
- Help navigate regulatory process.
- Involvement in co-design, development, application and monitoring innovations for healthcare.
- Collaborative efforts with pharma.
Our Local Battle

Anyone can be affected by Crohn's Disease at any age...
Anyone can be affected by Ulcerative Colitis at any age....

...But we can all Battle Disease together!
Our Global Battle

EFCCA Academy - Training Certified Patient Experts EFCCA is embarking on an exciting new project under the title "EFCCA Academy - Training Certified Patient Experts". The pilot phase will be launched...

Innovative medicines - EU mapping project 

The objective of this project is to reduce health inequalities in Europe through an exhaustive mapping of all innovative medicines.

Clinical Research Study

The primary objective of the TRAFFIC clinical research studies is to find out if the investigational medicine being studied is effective in reducing the severity of the symptoms to the point of...

Clinical Research Study

Information about on-going clinical trials

The primary objective of the TRAFFIC clinical research studies is to find out if the investigational medicine being studied is...

My IBD Journey - animation series

Patient Safety: Biologics and Biosimilars

Start date: 07/2016

Status: Concluded

Innovative medicines - EU mapping project. The objective of this project is to reduce health inequalities in Europe through an exhaustive mapping of all innovative treatments and devices available in...
Take Home Message

- Patient support organizations play an increasingly important role in chronic medical conditions including IBD
- These organizations are supported by regulatory agencies, industry and philanthropy
- Their role is advocacy and empowering patients
- They play a role in health policy, peer support, capacity building, education and research
- Committed volunteerism is essential to their initiation and subsequent success