BSPGHAN
working for children with digestive and liver disorders

British Society of Paediatric Gastroenterology Hepatology and Nutrition

BSPGHAN-Associates and Trainees

in Paediatric Gastroenterology, Hepatology and Nutrition

Study Day

Tuesday 5th October 2010

Royal Manchester Infirmary

Educational Grants provided by

Caring for young lives
Children's Liver Disease Foundation

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9.00- 9.30 Coffee and Registration

9.30 – 9.45 Introduction and Welcome
Ms Kate Blakeley and Dr Richard Hansen

9.45 – 11.05 Parallel Nutrition and IBD Sessions

Nutrition session:

Identifying and correcting malnutrition

Chair:

and

Ms Julia Birchenough, Gastroenterology Nurse Practitioner, Manchester

9.45 – 10.15
Causes of malnutrition in the clinical setting
Dr Mark Beattie, Consultant Paediatric Gastroenterologist, Southampton

10.15 – 10.40
Refeeding Syndrome
Graeme O'Connor, Specialist Paediatric Dietitian, London

10.40 – 11.05
Nutrition Screening Tools for use in Paediatrics
Dr. Helen McCarthy, Lecturer in Dietetics, University of Ulster

IBD session:

Diagnosis: Porto and Beyond….

Chair:

Dr Adrian Thomas,
Consultant Paediatric Gastroenterologist, Manchester

and

Dr Ed Giles,
Specialist Registrar in PGHAN, London

9.45 – 10.15
Endoscopy:
Dr Adrian Thomas, Consultant Paediatric Gastroenterologist, Manchester

10.15 – 10.40
Radiology:
Dr Musa Kaleem,
Consultant Paediatric Radiologist, Manchester

10.40 – 11.05
Pathology:
Dr Melanie Newbould, Consultant Pathologist,Manchester

11.05 – 11.20 Coffee

11.20 – 12.30 Parallel Session: Hepatology Session and Describing IBD

Hepatology Session:

Chairs:

Sara Mancell, Paediatric Specialist Dietitian, Liver and Int Tx, London

and

Jane Roberts, Paediatric Gastroenterology Nurse, Manchester

11.20 – 12.00
Improving adherence: producing Relevant information for families
Mrs Catherine Arkley, Chief Executive, Children's Liver Disease Foundation

12.00 – 12.30
Sharing Care : Expectations and difficulties, a case study

Dr Suzanne Davison, Consultant Paediatric Hepatologist, Leeds

Kirsten Tremlett, Specialist Paediatric Dietitian, Leeds

Describing IBD: Montreal and Beyond

Chairs:

Dr Sally Mitton, Consultant Paediatric Gastroenterologist, London

and

Dr Richard Hansen, Clinical Lecturer in Child Health, Aberdeen

11.20 – 11.40
Phenotyping:
Dr David Wilson, Reader in Paediatric Gastroenterology, Edinburgh

11.40 – 12.00
Genotyping:
Dr Richard Russell, Consultant Paediatric Gastroenterologist, Glasgow

12.00 – 12.30
Bacteriotyping:
Dr Richard Hansen, Clinical Lecturer in Child Health, Aberdeen

12.30 – 13.30 Lunch

13.30 – 14.15 Abstract Session 1

Chairs:	**Ms Kate Blakeley,** **Consultant Paediatric Clinical Psychologist, London** **and** **Dr Anthi Thangarajah, Specialist Registrar, London**

13.30 – 13.39 **A review of children on gastrostromy tube feeds in a community paediatric setting**
T Coelho, E Wilson, O Dicke, P. Shute
Worthing and Southland Hospitals

13.39 – 13.46 **Feeding practice in a DGH for neonates less than 30 weeks gestation and inpatient for first month of life: Are we achieving extra-uterine growth?**
E Renji[1], R Gupta[2]
[1]ST5 Paediatrics, South Yorkshire and Humber, Sheffield Rotation; [2]Consultant Paediatrician, Barnsley General Hospital

13.46 – 13.55 **Management of Coeliac Disease in paediatric patients at a DGH compared against the NICE guidance 2009: How have we fared?**
E Renji[1], J Devlin[2]
[1]ST5 Paediatrics, South Yorkshire and Humber, Sheffield Rotation; [2]Consultant Paediatrician, Scunthorpe General Hospital

13.55 – 14.04 **Prevalence of malnutrition during hospitalisation in a paediatric tertiary centre**
J Pichler[1], S Hill[1], V Shaw[2], A Lucas[3]
[1]Department of Paediatric Gastroentrology, [2]Department of Dietetics, Great Ormond Street Hospital; [3]Institute of Child Health, Department of Nutrition, London

14.04 – 14.13 **Review of nocturnal care for children on parenteral nutrition at home**
N Chodokufa, S Hill
Department of Gastroenterology, Great Ormond Street Hospital, London

14.15 – 14.22 **Intractable diarrhoea revealing a neuroblastoma hypersecreting vasoactive intestinal peptide**
R Bitar. Paediatric Registrar
Royal Victoria Infirmary, Queen Victoria Road, Newcastle upon Tyne, NE1 4LP

14.22 – 14.29 **Nocturnal screaming – consider this rare cause**
I Yeop, Y Negm, S Hill
Great Ormond Street Hospital, London

14.30 – 14.45 Coffee Break

14.45 – 15.20 Abstract Session 2

Chairs:	**Dr Mark Beattie** **Consultant Paediatric Gastroenterologist, Southampton** **and** **Dr Richard Hansen** **Clinical Lecturer in Child Health, Aberdeen**

14.45 – 14.54 **Oral 5-aminosalicyclic acid for maintenance of surgically induced remission in Crohn's disease**
M Gordon[1], K Naidoo[2], A Thomas[1], A K Akobeng[1]
[1]Royal Manchester Children's Hospital, Oxford Road, Manchester, [2]University of Manchester, Medical School, Manchester

14.4 – 15.03 **Posterior Reversible Encephalopathy Syndrome in patients with active Inflammatory Bowel Disease**
S Kishore, SpR; S Mitton, Consultant Paediatric Gastroenterologist
St George's Hospital, London

15.03 – 15.12 **Prevalence of anaemia in children with inflammatory bowel disease**
A.Thangarajah*[1], J. R. Goodhand[2], V. S. Forsyth[1], M. Marlais[1], J. M. Fell[1], D. J. Rawat[1], J. Epstein[1], J. Köglmeier[1]
[1]Paediatric Gastroenterology, Chelsea and Westminster Hospital, [2]Digestive Diseases Clinical Academic Unit, Barts and the London School of Medicine and Dentistry, London, United Kingdom

15.12 – 15.19 **Management of term jaundiced babies – a comparative review of two epochs**
C.Tzivinikos, A. Ahmed , A. Arasu
Luton and Dunstable Hospital

15.20 – 16.30 IBD Session

Chairs:	**Dr Sally Mitton,** **Consultant Paediatric Gastroenterologist, London** **and** **Mrs Catherine Arkley, Chief Executive** **Children's Liver Disease Foundation**
15.20 - 16.00	The Patient Pathway in IBD Mick Cullen, Paediatric Gastro Nurse Specialist, Southampton Parent and patient pathway Mrs Gillian Vaughan CICRA nominated speaker
16.00 – 16.30	**Expert Panel on Paediatric IBD** Dr Adrian Thomas Consultant Paediatric Gastroenterologist, Manchester Ms Mick Cullen Paediatric Gastro Nurse Specialist, Southampton Ms Rita Shergill-Bonner, Principal Paediatric Dietitian, London Ms Jennie Potts, Clinical Psychologist, Manchester **Difficult case presentations**
16.30	Prizes and Close of Meeting

Abstracts

Invited Speakers

Nutrition Session

Causes of Malnutrition in the Clinical Setting

Dr R. Mark Beattie
Consultant Paediatric Gastroenterologist , Southampton

Nutritional Impairment is common in children with acute and chronic disease and nutritional treatment should be a key component of the management plan.

Fundamental to appropriate nutritional therapy is an understanding of the conditions necessary for growth which include the requirements for energy in health and illness.

Energy requirements need to be met by the dietary intake to prevent weight loss. A positive energy balance will result in weight gain. A negative energy balance will result in weight loss.

Energy requirements includes several components including the basal metabolic rate (largest), physical activity level and the energy needs of growth.

All aspects of energy metabolism are likely to be influenced by illness and impact on energy balance and thereby weight gain and linear growth.

Nutritional Status reflects what you are, what you do a what you eat.

Malnutrition can only result from:

- Inadequate intake or excessive losses
- Increased metabolic demand without increased intake
- Malabsorption

One or all of these may contribute to malnutrition in an individual.

In the clinical setting it is important therefore to consider

- Conditions that interfere with intake
- Conditions that interfere with absorption
- Conditions associated with increased losses
- Condition associated with increased needs
- Conditions that restrict intake
- Underlying gut disease
- Underlying 'other' chronic diseases

These principles will be explored using disease specific examples focussing particularly on nutritional status and the factors that impact on it in the clinical setting.

References

Sullivan PB. Malnutrition in hospitalised children. Arch Dis Child 2010; 95:489-90
Wiskin AE, Davies JH, Wootton SA, Beattie RM. Energy expenditure, nutrition and growth. Arch Dis Child. 2010 Jul 20. [Epub ahead of print]
Malnutrition Matters Meeting Quality Standards in Nutritional Care
www.bapen.org.uk/pdfs/toolkit-for-commissioners.pdf

Refeeding Syndrome

Mr Graeme O'Connor, Specialist Paediatric Dietitian, Great Ormond Street Hospital, London

Refeeding the malnourished child presentation looks at the history of the refeeding syndrome going back to incidences in the 1st century. The presentation then focuses on the pathophysiology of the refeeding syndrome and looks at current refeeding practises and evidence from around the world. Monitoring and preventative guidelines are suggested from the limited evidence based research. Finally, an overview of the national multi-centred RCT study which is being headed by Graeme O'Connor.

Graeme has been working as a paediatric dietitian for eight years and joined the team at Great Ormond Street Hospital two years ago where he specialises in children with anorexia nervosa and has become a national contact for the refeeding syndrome. He is currently a research fellow at University College London/ Institute of Child Health and is heading a national multi centred randomised controlled trial monitoring the physiological responses of refeeding children in a starvative state.

Lecturing

MSc Nutritional Medicine – University of Surrey
BSc Nutrition and Dietetics – Kings College London and London Metropolitan University

Publications

Case report – The extended role of the therapist and conflict with consultants: anxious mother, unwell baby. Worked Based Learning in Primary Care. Volume 5, number 2, July 2007, pp101-105.

O'Connor G and Goldin J. The refeeding Syndrome and Glucose Load. International Journal of Eating Disorders 2 FEB 2010 DOI: 10.1002/eat.20791.

Education

BSc (Hons) Nutrition and Physiology – 1996 - 2000 University of Greenwich
PG Diploma Dietetics 2000 – 2002 Glasgow Caledonian University
PG Diploma First Contact Practitioner 2005-2007 University of Sheffield
Research Fellow PhD – UCL 2010

Nutrition Screening Tools for use in Paediatrics

Dr Helen McCarthy, Lecturer in Dietetics, University of Ulster

The consequences of under-nutrition in adults and children have been well documented. They include increased morbidity and mortality, altered psychological well being, increased length of hospital stay, and increased financial burden for both the individual and the national economy. In children there are additional longer term consequences of under-nutrition including reduced educational attainment and growth.

Early recognition and management of under-nutrition in the acute setting has been advocated for many years, with the routine use of nutrition screening recommended at the earliest point of contact. While a number of nutrition screening tool have been developed within adult practice, it has only been in recent years that similar tools have been developed for the early detection of under-nutrition in children, with UK specific tools only becoming available in the past 2 years.

This presentation will explore the evidence base behind this emerging field of paediatric nutritional care by considering the need for nutrition screening tools in paediatric practice. It will provide an overview of the paediatric nutrition screening tools that are currently available to allow the audience a better understanding of these tools and the evidence base behind them. Finally this presentation will briefly consider the gaps in current knowledge and the need for future research in this area.

The nutrition screening tools that will be considered in this presentation include the Sermet-Gaudelus tool (France), SGNA (Canada), Strong kids (Netherlands), PYMS (UK) and STAMP (UK), however specific focus will be placed on the latter 3 tools.

Describing IBD: Porto and Beyond

Endoscopy

Dr Adrian Thomas, Consultant Paediatric Gastroenterologist, Royal Manchester Children's Hospital, Manchester

Ileocolonoscopy and upper gastrointestinal endoscopy with multiple biopsies are the most important investigations for the diagnosis of inflammatory bowel disease (IBD). They also help to determine the extent and severity of the inflammatory process. Recommendations for training in paediatric endoscopy and DOPS assessment forms can be downloaded from the BSPGHAN website.

Characteristic appearances at endoscopy in patients with Crohn's disease (CD) include: skip lesions or a patchy distribution of inflammation +/- ulceration, cobblestoning, strictures and fistulae. In patients with ulcerative colitis (UC) the inflammation and ulceration are continuous with variable proximal extension usually from the rectum. There may be a loss of the vascular pattern with granularity, friability, spontaneous bleeding and pseudopolyps.

The Porto criteria recommend that full colonoscopy with intubation of the terminal ileum should always be attempted as isolated ileal inflammation may occur with normal colonic biopsies in up to 9% of children with CD. They also recommend upper GI endoscopy in all cases as upper GI histology may help to confirm the diagnosis in up to 29% of cases of CD. Isolated focal gastritis however is a non-specific finding and may occur in up to 75% of children with UC.

Indeterminate colitis is diagnosed when there is evidence of IBD affecting the colon but no not evidence of small bowel disease (at endoscopy, and either a barium follow through, MRI or capsule endoscopy) and no diagnostic features on histology.

Imaging Inflammatory Bowel Disease

Dr Musa Kaleem, Consultant Paediatric Radiologist, Manchester Royal Children's Hospital, Manchester

IBD is a multisystem inflammatory disease of unknown cause. Genetic, infectious, immunologic, and psychological factors have all been implicated in influencing the development of IBD. Bowel imaging is essential for IBD diagnosis, to determine its extent, for monitoring and in cases of suspected disease relapse.
Multiple modalities may be used for imaging IBD. These include small bowel contrast studies, ultrasound, CT and MRI. Endoscopy, including capsule endoscopy are non-radiological techniques of visual assessment which will not be covered.
Mainstay of this talk would be the imaging of small bowel. Large bowel assessment is usually carried out by endoscopy. Imaging of other complications of IBD, such as hepato-biliary and peri-anal disease would not be covered.
Small bowel Meal and Follow Through has been the traditional method of assessing small bowel disease. It involves moderate exposure to ionising radiation and assesses bowel inflammation by showing mucosal oedema, ulceration, fistulation and bowel stricturing. However it fails to show transmural disease or surrounding complications such as inflammatory mass/ collection or mesenteric fat/ vascular proliferation.
Ultrasound does not use harmful ionising radiation and can assess bowel wall thickening. However it is often unable to assess the whole of small bowel due to bowel gas related abcuration. It is first line to look for associated complications such as inflammatory mass or collection
Computed Tomography Enterography (CTE) involves a relatively high ionising radiation dose and therefore had been less popular, especially outside of USA. It has the advantage of assessing whole bowel as well as extra-luminal disease and complications.
Magnetic Resonance Enterography (MRE) has all the advantages of CTE but without ionising radiation. However its use has been limited by constraints of scan times in most departments and also due to lack of compliance related to palatability of oral contrast and volume intake required to distend bowel. It also requires contrast injection and therefore needs IV access.
I'll show you multi-modality imaging examples of IBD and its complications such as structuring, fistulation, inflammatory mass and abscess formation.

Chronic inflammatory disease – Histopathology

MJ Newbould, MS Bitetti. Consultant Histopathologists, Royal Manchester Children's Hospital, Manchester

In assessing a biopsy specimen from the Gastrointestinal tract we look for evidence of inflammation, features of chronicity, the presence of granulomas and the presence of any specific features (such as viral inclusions). In the absence of obvious granulomas it is frequently not possible to distinguish Crohn's Disease from Ulcerative Colitis on mucosal biopsy alone; clinico-pathological correlation is essential. Resection specimens provide a better opportunity for this – Crohn's Disease is transmural and associated with fissures and fistular formation, where as ulcerative colitis is usually confined to the mucosa and submucosa.

Hepatology Session

Improving Adherence: Producing relevant information for families

Catherine Arkley, CEO, Children's Liver Disease Foundation

Background

Taking medicines and following up on-going medical care is the backbone of modern treatment and healthcare systems. Medicines are used not just to relieve symptoms and cure but also to prevent future ill-health. Advances are such that patents are taking more medicines in complex regimens with an increasing number of healthcare professionals being involved in the process. Patients evaluate taking their medicines and their need for ongoing review using the resources available to them.

In January 2009 NICE published guidance on Medicines Adherence[1] in patients over the age of 18. The guidance reported that medical care and drug costs amount to around 10% of NHS expenditure. In 2006-2007 the NHS in England spent £10.6 billion on drugs, around three quarters of which was in primary care. It is thought that between half and a third of all medicines prescribed for long term conditions are not taken as recommended[2]. The estimated drug cost on unused or unwanted medicines in the NHS is around £100 million[3]. This cost does not represent the human cost or the further costs to the health service as a result of not taking medicines such as increasing medical interventions from a wide variety of services and other more costly and radical interventions, such as re-transplant. A Cochrane review[4] concluded that improving medicines taking may have a far greater impact on clinical outcomes than an improvement in treatments.

Adherence is defined as the extent to which the patient's behaviour matches agreed recommendations from the prescriber[5]. Adherence emphasises the need for agreement and that the patient is free to decide whether or not to adhere to the prescriber's recommendation.

Compliance is defined as the extent to which the patient's behaviour matches the prescriber's recommendation[5].

Concordance initially applied to the consultation process in which the prescriber and the patient agree therapeutic decisions that incorporate their respective views but now includes patient support in medicine taking as well as prescribing communication. Concordance reflects social values but does not address medicine taking and may not lead to improved adherence[5].

NICE concludes that non-adherence is a large problem but it should not be seen as the patient's problem. Rather, it represents a limitation in the delivery of healthcare often due to a failure to fully agree the prescription in the first place or to identify and provide the support that patients need later on. Addressing non-adherence is not about getting patients to take more medicines per se. It starts with an understanding of patient's perspectives of medicines and the reasons why they may or many not want or are unable to use them[6,7].

NICE makes a number of recommendations:

1 Patient involvement in decisions about their medicines

- Communication
- Increasing patient involvement
- Understanding the patient's knowledge, beliefs and concerns about medicines
- Providing information

2 Supporting adherence

- Assessing adherence
- Interventions to increase adherence:
    - Interventions should be considered on a case basis and address the concerns and needs of the individual
    - Discuss with the patient if the reason for not taking medicines is because of beliefs and concerns or problems about the medicines (intentional non adherence) or because of practical problems (unintentional non adherence)
    - Tailor interventions to the specific difficulties the patient is experiencing
    - Find out what form of support the patient would prefer. Together consider the options
    - Address beliefs and concerns
    - Because evidence supporting interventions to increase adherence is inconclusive, only use interventions to overcome practical problems if a specific need is identified.
- Reviewing medicines

3 Communication between healthcare professionals

A recent review of interventions to enhance medication adherence in children and adolescents with chronic illness was published in Archives of Disease in Childhood[8]. Of the studies which met the inclusion criteria; seven examined educational strategies, seven behavioural and three examined educational intervention combined with other forms of psychological therapies. Only two of seven studies reported a clear benefit for education on medication adherence, whereas four of seven trials indicated a benefit of behavioural approaches. One trial reported that combining education with behavioural management may be more effective than education alone. Studies which combined education with other non-medication specific psychological interventions failed to demonstrate a beneficial effect on medication adherence. Only two studies examined adherence promoting interventions in young people with established adherence problems. The authors concluded that education interventions alone are insufficient to promote adherence in children and adolescents and that incorporating a behavioural component to adherence interventions may increase potential efficacy and that future research should examine interventions in high risk groups.

Children's Liver Disease Foundation – identifying the need and developing relevant resources

Children's Liver Disease Foundation (CLDF) is a patient and family based organisation. One of its strategic objectives is to provide support services to families and young people. Both groups report similar needs:

- They want a charity that champions their disease to the wider world and collectively represent their views to relevant bodies (e.g. Department of Health, relevant organisations)
- They want to meet others
- They want an organisation which understands them and their disease
- They do not want to be alone
- They want information and someone to talk to

However, CLDF delivers their needs via two distinct programmes; one for families and the other for young people. They are delivered principally by two different workers.

CLDF has 3707 families on its database of which 2871 are currently active. CLDF has 308 active bereaved families. CLDF has 2862 active children and young people on its database:

18+ = 1083
16-17 = 290
11-15 = 644
0-10 = 845

All interactions (telephone, mail, email, person to person) with the families and young persons officers are recorded and the issue recorded.

Statistics on interactions and issues are reviewed monthly for the past year on a rolling basis.

The relevant officer will identify the resources they have to support their work and review whether they need further resources to meet a growing need. They will also go back to the relevant group and research the sort of resources required to meet the needs of the various individuals.

Having identified a resource the finance team uses a costing tool to cost the project. A multi-disciplinary meeting will take place involving fundraising and an appeal launched to fund the project.

CLDF Resource Development Process and Delivery
For every project a process Gantt chart is put together so the journey and key milestones are identified. Fundamental to every project is to identify user involvement in every step of the project. With the projects described below user involvement was sought and evaluation obtained on completion.

CLDF Philosophy
Through experience CLDF has identified that whilst the families and young persons' services have similar needs they are entirely two separate services with a different philosophy behind them; one works from a family centred approach and the other from a youth work perspective, the latter particularly draws upon Every Child Matters[9]. Separation is deemed important to prevent any conflict of interest. Needs can be different. For example, it is well documented that in young people peer to peer support is very powerful and important for young people.

CLDF Resources developed to support adherence (medications and follow up attendance)

1 **Taking your liver disease into adulthood**

- Literature for parents
- Literature for young people on lifestyle issues with reference to their liver condition

2 **Website for young people – cldf-focus.org** launched October 2009:

- 9000 visitors
- Average visit duration: 4.04 minutes
- Most popular pages – Message board, The Liver. Living with Liver Disease. Fundraising, About CLDF

3 **Reflection Sheets**

A resource for young people to explore issues and identify their feeling and thoughts about a topic and help guide them to think about what they are going to do having identified them

4 **Appointments Pack**

5 **CLDF Journey Box**

6 CLDF Message Board

- 11 – 17
- 18+ about to be launched

7 CLDF Residential Trips

- Closer to the Edge
- *Digital Stories Residential (subject to funding)*

8 New CLDF website – under development

Conclusion

CLDF has identified that at any one time twenty percent of its families and young people are in what it categorises as an acute phase. In this phase, families and young people may be waiting for a diagnosis, just received a diagnosis or informed of deteriorating health and further or different treatment required. For most information and the need to talk and share are critical and CLDF services are set up to assist this group. The majority of families and young people are in CLDF's chronic phase; they are adjusting or have adjusted to their circumstances and are getting on with life in their new normality. What they want from CLDF is know they will champion their cause and be there for them if needed. Supporting research is a significant need. They also want fun projects to allow them to meet families.

Whatever services and resources CLDF develops there are some over-arching principles:

- One size does not fit all; tailored services are vital
- Wherever possible CLDF must offers options so that families and young people can be offered choice rather than a fait accompli

References

1 National Institute for Health and Clinical Excellence (NICE): Medicine Adherence; involving patients in decisions about prescribed medicines and supporting adherence. Clinical Guidance CG76. Published January 2009
2 Horne R, Weinman J, Barber N, Elliot R, Morgan M. Concordance, adherence and compliance in medicine taking. Report for the National Co-ordinating Centre for NHS Service and Delivery Organisation R&D. 2005
3 Department of Health. Pharmacy in England, building on strengths – delivering the future. 1-141. 2008
4 Haynes RB, Ackloo E, Sahota N, McDonald HP, Yao X. Interventions for enhancing medication adherence. Cochrane Database Set Rev 2008;(CD000011)
5 World Health Organisation. Adherence to long-term therapies; evidence for action. 2003 WHO
6 Horne R. Compliance, adherence and concordance: implications for asthma treatment. Chest 2006; 130(1Suppl):65S-72S
7 Horne R. Compliance, adherence and concordance. In: Taylor KHG, editor. Pharmacy Practice. Taylor and Francis: 2001. 165-184
8 A systematic review of interventions to enhance medication adherence in children and adolescents with chronic illness. Dean A, Walters J, Hall, A. Arch Dis Child 2010;95;717-723 doi: 10.1136/adc.2009. 175125
9 Every Child Matters - http://www.dcsf.gov.uk/everychildmatters/

Sharing care - Expectations and Difficulties.

Ms Kirsten Tremlett, Senior Specialist Paediatric Dietitian and Dr Suzanne Davison, Consultant Paediatric Hepatologist, Leeds General Infirmary

Health care professionals and parents share a common goal: to promote the health and well being of the children in their care. However, the perceived best pathways to achieving this goal may differ widely. Conflicting approaches may arise through differing knowledge, expertise, facilities, financial constraints, local guidelines, as well as being subject to individual idiosyncracies.

We will discuss a child with complex liver, gastrointestinal and nutritional needs that highlighted the expectations and difficulties when multidisciplinary teams at three sites needed communication, co-ordination and co-operation to deliver care. A particular challenge was conflicting guidelines regarding enteral feeding in the community.

Describing IBD: Montreal and Beyond

Phenotyping

Dr David C Wilson, Reader in Paediatric Gastroenterology and Nutrition, Child Life and Health, University of Edinburgh and Department of Paediatric Gastroenterology and Nutrition, Royal Hospital for Sick Children, Edinburgh

Phenotype is the appearance resulting from the interaction of the genetic makeup of a person with the environment, and classically refers to any observable characteristic of an organism. The clinical goal of phenotyping is to identify patient groups with unique prognostic or therapeutic characteristics. Definitions of clinical phenotypes are often arrived at through consensus criteria that may have little to do with the underlying biology. Multiple disease characteristics have been termed phenotypes in IBD eg age at diagnosis, IBD type (CD, UC or IBDU), disease location, and disease behaviour. The first clinically useful phenotypic description of IBD was the Vienna classification of CD in 2000, which was updated as the Montreal classification in 2005 (1). The advances in the Montreal classification included phenotypic considerations in UC and IBDU. A key publication from the Scottish Society of Paediatric Gastroenterology, Hepatology and Nutrition/University of Edinburgh PIBD collaboration used the Montreal classification to demonstrate key phenotypic differences between PIBD and adult-onset IBD (2), highlighting more extensive location of PIBD at diagnosis (particularly the number with the panenteric phenotype in CD and with extensive UC beyond the splenic flexure at diagnosis) and the rapid early progression of PIBD. The limitations for paediatric-onset IBD (PIBD) inherent in the Montreal classification have been recognised by the very recent construction of the Paris classification of PIBD, a modification of the Montreal classification which still adheres to it, allowing use of Montreal as transition to adult age group occurs (3). The key modifications include age (<10 years, 10-16 years), addition of growth failure, addition of severity of UC, and minor alterations in upper gastro-intestinal CD location and extensive UC location.

The value of phenotypic classification in translational and clinical IBD research has been demonstrated in genetic studies (4), natural history studies (2), and clinical research – for example, where the Glasgow group convincingly refuted the currently common tenet that colonic location precludes effective use of exclusive enteral nutrition for induction of remission in CD (5).

Learning Points:

1. To understand the need for phenotyping in IBD clinical and translational research
2. In combination with the genotyping and bacteriotyping talks, to have a clear understanding of the pathogenesis of IBD in 2010.

References:

1. Silverberg MS et al. Toward an integrated clinical, molecular and serological classification of inflammatory bowel disease: Report of a Working Party of the 2005 Montreal World Congress of Gastroenterology. Canadian Journal of Gastroenterology 2005;19 Suppl A:5-36
2. Van Limbergen J et al. Definition of phenotypic characteristics of childhood-onset inflammatory bowel disease. Gastroenterology 2008; 135: 1114-22.
3. A Levine et al. Pediatric Modification of the Montreal Classification for Inflammatory Bowel Disease - the Paris Classification. Inflammatory Bowel Diseases (in press)

4. Russell RK et al. Genotype-phenotype analysis in childhood-onset Crohn's disease: NOD2/CARD15 variants consistently predict phenotypic characteristics of severe disease. Inflammatory Bowel Diseases 2005; 11:955-964.
5. Buchanan E et al. The use of exclusive enteral nutrition (EEN) for induction of remission in children with Crohn's disease (CD) demonstrates that disease phenotype does not influence clinical remission. Alimentary Pharmacology and Therapeutics 2009; 30: 501-507.

Genotyping

Dr Richard K. Russell, Consultant Paediatric Gastroenterologist, Yorkhill Children's Hospital, Glasgow.

The pathogenesis of IBD is multifactorial, comprising of a genetic component which influences the host immune response, combined with environmental triggers (most importantly bacteria) which allow the disease to develop. The first evidence for a genetic component in IBD came from family studies where increased rates of IBD were identified in 1st degree relatives of IBD patients with further evidence from twin studies and varying rates of disease among different ethnic group.
More recently an increased understanding of the immunological basis of IBD has come through detailed scientific studies examining host susceptibility genetics resulting in the description of a number of candidate genes in children which increase the risk of IBD development. Further studies have used the technique of Genome wide association studies to identify further specific IBD genes allowing the identification of key disease pathways in the development of IBD including bacterial recognition, intracellular immune processing and autophagy.
Intended Learning Outcomes for the session are:

1. To be able to estimate the heritable component of IBD in different patient groups.
2. To understand the basics of techniques used to identify IBD genes.
3. In combination with the phenotyping and bacteriotyping talks have a clear understanding of the pathogenesis of IBD in 2010.

“Bacteriotyping”

Dr Richard Hansen, Clinical Lecturer in Child Health, University of Aberdeen.

The intestinal microbiota (gut flora) can be thought of as an additional organ in the gastrointestinal system. Resident intestinal microbes contribute to gastrointestinal development, host defence, metabolism and digestion. Recently, the concept of “dysbiosis” has emerged describing an upset in the bacterial populations of the gut resulting in intestinal inflammation. This condition is thought central to IBD pathogenesis.

The advent of modern sequencing methods, so-called “next-generation” sequencing has given researchers the tools to examine the diversity of species within the microbiota, to examine their metabolic contribution and to assess their contribution to the gastrointestinal gene pool. Key papers which have evolved our understanding of the microbiota using these techniques will be presented and discussed[1-3].

Finally, the exciting potential of modifying our microbiota to service our health needs will be discussed with the possibility of new treatment modalities for conditions as varied as IBD, atopy, obesity and IBS.

Intended Learning Outcomes for the session are:

4. To understand the evolving role of the intestinal microbiota as an “organ”
5. To understand the concept of “dysbiosis” with reference to IBD pathogenesis
6. To introduce modern scientific techniques used to examine the microbiota
7. In combination with the phenotyping and genotyping talks have a clear understanding of the pathogenesis of IBD in 2010

References

(1) Qin J, Li R, Raes J, *et al*. A human gut microbial gene catalogue established by metagenomic sequencing. *Nature* 2010; **464(7285):** 59-65.

(2) Huse SM, Dethlefsen L, Huber JA, *et al*. Exploring microbial diversity and taxonomy using SSU rRNA hypervariable tag sequencing. *PLoS genetics* 2008; **4(11):** e1000255.

(3) Dethlefsen L, Huse S, Sogin ML, *et al*. The pervasive effects of an antibiotic on the human gut microbiota, as revealed by deep 16S rRNA sequencing. *PLoS Biol* 2008; **6(11):** e280.

Selected Abstracts

Abstract Session 1

A review of children on gastrostomy tube feeds in a community Paediatric setting

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Background: Children with severe neurological impairment and related morbidities are at an increased risk of nutritional deficiencies, poor growth and aspiration pneumonia. The exact mechanisms of growth retardation are not known, but poor nutrition is thought to be a major contributor. Gastrostomy tube feeding is increasingly used for nutritional support in these children. It has been shown to improve weight gain, however it does not eliminate growth retardation.
Aims: The aim of this review was to evaluate children with neurological disabilities and other related morbidities, who are gastrostomy tube fed with a view to develop guidelines for future management and to identify ongoing service needs. We also sought to assess the impact of gastrostomy insertion on subsequent weight gain and respiratory morbidity in a community paediatric setting.
Methods: 35 children were identified with gastrostomy tube insertion attending community paediatric clinics attached to a district general hospital. These were patients who have had follow up with community paediatricians, dieticians or other allied health professionals in our hospital between January 2004 and June 2010. A retrospective analysis of patient's medical, dietetic and nursing notes was carried out. Relevant data was obtained and recorded, both prior to gastrostomy insertion and two years post-insertion, with a specific emphasis on weight changes and hospital admissions for chest infections during that period.
Results: The common underlying diagnoses were cerebral palsy (54%), other neurological abnormalities (6%), chromosomal abnormalities (17%), failure to thrive including cystic fibrosis (15%) and surgical anomalies (9%). The required information was obtainable only in 60% of patients. The mean age at insertion of gastrostomy was 5.6 years. The predominant modes of feeding before gastrostomy insertion were oral feeds in 57 %, nasogastric 38 % and nasojejunal in 5 %. 38 % of patients underwent Nissen's fundoplication along with the gastrostomy insertion. 67% of patients had significant reflux at the time of insertion. In these patients, GORD got better in 57%, worse in 29% and no change in 14%. Chest infections needing hospital admission for intravenous antibiotics were recorded over a 2 year period before and after gastrostomy. Pre-gastrostomy admissions were 1.3 per patient and post-gastrostomy hospital admissions for chest infections were 0.7 per patient. Weight changes over a 2 year period following gastrostomy tube insertion were recorded. Only 21 patients had reliable records. Weight gain was taken as an upward advancement across a percentile on a standardised weight chart and the reverse for a decrease in weight. At one year post-gastrostomy, noticeable weight gain was recorded in 57 %, decreased weight centiles in 5 % and no change in weight centiles in 38 %. At 2 years following gastrostomy, weight gain was recorded in 57% of patients, no change in 33 % and a decrease in 10%.
Conclusion: Overall there was noticeable weight gain after gastrostomy. Weight gain along the percentiles at one year and 2 year post-gastrostomy was nearly the same. Admissions for chest infections were less following introduction of gastrostomy feeds. However reliable information was obtained only in 60% of patients. This is mainly because in a community setting, these patients were seen by different professionals and the relevant information not necessarily recorded on the hospital case notes. Also, some of the patients were reviewed by regional specialists in different hospitals. Currently no standardised guidelines are in place to assess children with neuro-disability for introduction of gastrostomy feeds. Also no feeding protocol is in place at present in the hospital post-gastrostomy

Feeding practice in a DGH for neonates less than 30 weeks gestation and inpatient for first month of life: Are we achieving extra-uterine growth?.

Elizabeth Renji,(ST5 Paediatrics- South Yorkshire and Humber- Sheffield Rotation), Rajeev Gupta (Consultant Paediatrician- Barnsley General hospital).

Introduction: The feeding strategy for VLBW neonates on the unit was decided locally, based on published data for NEC, intolerance, feeding volumes and weight gain. But the strategy for the individual baby and the therapeutic response to GRV differed widely. We therefore decided to audit our practice retrospectively using as standard, evidence from published studies and level IV evidence to provide recommendation for a safe and effective feeding guideline.
Aim: Compare the initiation, advancement of enteral feeds and regaining birth weight for "eligible" neonates with published data and UK –WHO growth charts.
Method: Retrospective data from January 2009 to April 2010 for neonates upto 30 weeks gestation who were born in the DGH or transferred into the unit within day 1 and remained on the unit till day 28.
Ethical approval not obtained, as it is a clinical audit against standards.
Standard deviation scores for weight at birth and 4 weeks calculated using age and gender specific UK- WHO low birth weight growth chart. Weights according to unit policy. Average weight gain over the four-week period was calculated.
Feeding profile (bolus) ascertained from daily nursing chart- enteral feed volumes by type and day of life, aspirates and weight.
Limitation: Data for TPN and non-nutritive IVI not incuded. Retrospective review of GRVs thus stooling pattern, vagal effects, abdominal distension, hematochezia undetermined.
IUGR determined but poor blood flow in utero, antenatal steroids and unstable infants on ionotropes not determined. Ventilatory status not accounted.
Calories not calculated. Use of reflux and prokinetic not ascertained. Maternal and antenatal history not reviewed.
Summary of Results: Of the 27 neonates who met the gestation criteria, only 12 neonates met the complete audit criteria. Infants in the cohort are not IUGR for their gestation but are VLBW This cohort exclusively used human milk in the first 14 days.
The evidence reveals that there is a more cautious approach to starting enteral feed.
Time to commencing enteral feed was 2-6 days. Regimes of advancement have varied widely.
Full enteral feeds –taken as 150ml/kg was reached by between 7-21 days with clinical suspicion of NEC leading stopping and recommencement of trophic feeds.
The feeds have been advanced at between 5 to 20 ml/kg/day with varying feeding regimes not achieving extra uterine growth according to the UK- low birth weight growth charts. Baby weights for the cohort have fallen across the weight centiles suggesting that the actual intake might have been inadequate.
Fortifier use has been very occasional. The blood urea after 2 weeks of gestation has been low, monitored at 3 and 4 weeks
The response to volumes of gastric residues has varied depending on the overall impression build up when caring for the neonate and clinical signs which concerned the team and this lead to altering/delaying feed increases with signs of feed intolerance.
Recommendation: Following a standardised guideline for advancement of feed based on calculating the advancement in acceptable increments of ml/kg/day.
Agreeing upon a therapeutic response to gastric aspirates considering the associated clinical manifestations–as it will be done prospectively.
Judiciously advance full enteral feed to higher volumes –180ml/kg/day to achieve the UK standards of growth.
Consider the use of fortifier as extra uterine growth retardation becomes evident after the second week.

Management of Coeliac Disease in paediatric patients at a DGH compared against the NICE guidance 2009: How have we fared?

Elizabeth Renji ST5 Paediatrics (South Yorkshire and Humber- Sheffield Rotation).
Jim Devlin, Consultant Paediatrician Scunthorpe General hospital

Introduction: The prevalence of the disease is high at 1:100 with possibility of significant morbidity by not diagnosing and adhering to a gluten free diet. Children have to be screened for coeliac in different clinical presentations. The absence of a guideline can lead to inappropriate investigations

Aim: This audit was done generate evidence that our practices and procedures meet the national standards set (Nice guidelines).
Explore circumstances where actions have not been in line with guidelines.
To improve the assessment, investigation, timely diagnosis and management of children with suspected coeliac disease and managed by a team of professionals in line with national/trust guidelines

Method: Retrospective audit of case notes. Standards obtained from the Nice Guidelines and Bspghan guidelines. Cohort of patients collected from memory as no clinical coding for clinic attendances. Looked into requests not processed due to inadequate or wrong samples.

Results. Audit included 13 patients. Clinical presentations were GI/ Non GI/Associated conditions.
All patients were weaned on gluten prior to serology. Serology was always part of diagnostic process. But the initial request for serology was correct only in 55%. Documented advise to patient to continue gluten in diet during diagnostic process met in 85%.
Two patients with possible latent coeliac.
Biopsy recommended as gold standard in 77%, clinical decision not to biopsy in two patients.
Standard for GFD only after biopsy met in 70 %. Standard for referral to treatment in 18 weeks met in 76%. Serology testing for siblings documented only in 30%. Standards for ongoing serological monitoring met in 83%. Standard for dietitian input met in all patients.
Summary: There is clearly a very appropriate multidisciplinary approach to patient management. Red flags for possible diagnosis are being recognised.
Decision to manage patients “outside the box” has been clinical and no guideline can replace informed clinical decisions made with the family of the child. But these are exceptions.
Even in a small sample latent coeliac is seen what would the implications be with the new addendum to the IDDM guidelines regarding screening for coeliac?
As a guide National standards should be adhered to
Recommendation: Formulate a guideline (clearly mentioning type of sample needed) to facilitate appropriate investigations and management in line with current guidelines
Maintain a register of patients, as clinical coding does not include clinic attendances.
Screening of siblings of the index case needs to be done.
Re-audit to complete the loop once a coeliac guideline has been implemented.

Prevalence of malnutrition during hospitalization in a paediatric tertiary centre

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Introduction:
Several studies have reported a significant number of malnourished children in hospital, and that malnutrition is a problem that is poorly recognized by hospital staff. During hospitalization, attention is mostly focused on the primary medical problem with little attention given to the child´s nutritional status.

Aim: The overall aim of the study was to identify the proportion of children presenting to a tertiary hospital who are in a poor nutritional state, and whether nutritional status improves or deteriorates by the time of discharge with current clinical management.

Method: On a screening week in April 2010 all children who were currently inpatients for ≥ 72 hours were included and followed for up to three months or until time of discharge. Children on all wards including medical, surgical, and paediatric and neonatal intensive care were assessed. Sex, age, diagnosis and length of hospital stay were recorded. On admission and discharge weight and length/ height were also recorded, when they had been measured. Gomez Classification was used to define malnutrition (weight compared to that a normal child (50th percentile) of the same age).

Results: A total 141 children were eligible for the study. There were 77 (54.6%) males. The median age at admission was 2.4 years (range birth-17 years). The median duration of hospitalization was 22 days (range 3-209). The overall prevalence of malnutrition on admission was 43%, with 20% moderately to severely affected (13.5% moderately and 6.4% severely malnourished) according to the Gomez classification. By the time of discharge the overall prevalence of malnutrition had increased to 48%, (20.6% moderate and 6.4% severe malnutrition). In 58% a height measurement was never done during the whole admission and only half of the patients (55%) were seen by a dietician. Children at highest risk were those aged less than 2 years, in-patients for more than one month and those with multiple diagnoses.

Conclusion: Hospital malnutrition is still a major problem with a prevalence of up to 43% on admission and 48% on discharge from a tertiary hospital. Nutritional management needs to be tackled more effectively. The risk of nutritional depletion needs to be identified at the time of admission and appropriate nutritional intervention can be initiated at an early stage. It is important that the responsibility for nutritional management is taken on by the multidisciplinary team of professionals involved in the child's care so that there is a 'pooling' of expert knowledge from the different professions involved.

Review of nocturnal care for children on parenteral nutrition at home

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Introduction/Background: It has been long recognised that children with chronic severe intestinal failure have the best chance of long term survival with good quality of life when cared for at home by well trained parents.

Aim: The aim of this audit was to review the burden of night work and compare the findings to those of a similar audit in 2004 by the same team.

Subjects& Methods: Out of the 32 families approached 21 (65%) responded to a semi-structured questionnaire. Participants were aged between 2-17 (median 9) with 20(96%) aged over 3.5. The group consisted of 13 females and 8 males, 9 enteropathy, 8 dismotility and 4 short gut syndrome. These demographics are similar to the 2004 audit. The same questionnaire was used in both audits to obtain data about frequency and reasons of nocturnal disturbance, type of infusion pumps, and availability of overnight respite care was obtained. Number of years on home PN ranged from 1 year to 15 years (Median 7).

Results: In the 2004 audit 8(30%) of 26 children and 17(65%) parents woke up to 5 times

In this audit 13(66%) and 76% parents woke up between 3-6 times. Patients passing stool at night were 16 (5 stoma and 11 per rectum) 5 of the 11 without the stoma needed changing from parents either of nappies/ incopads and or bedding. These findings mirror the 2004 audit which showed 17 children woke up between 1-5 times to pass stool 12 per rectum, 5 per stoma. 10 of the 12 without a stoma needed changing and 2 were potty trained.

Other reasons for nocturnal waking where pain 9.5%, drinking 14% and pump alarms 23%. 15 of the 21 (71%) patients where using a portable pump (bodyguard) instead of the traditional pump (IVAC IV300). The 23% that woke up to attend to pump alarms, all used the IVAC IV300 except for 1 who was on a portable pump. 60% of the participants using the portable pump said they woke up less in the night since switching pumps. In 2004

5 of the 21 families received respite, between 20-45 hours/week. When asked 56% wanted more respite.

Summary and Conclusion: Faecal incontinence and toileting has a major impact on burden of care affecting 69%(2004) and 76% (2010) of children on home PN with some remaining in nappies and using incopads throughout childhood.
Pump alarms also has a huge impact on burden of care and the use of portable pumps has lessened this burden , In 2004 portable pumps were not in us at this centre so this is a step forward in improving quality of life and lessening the burden of nocturnal care.
Parents do not usually volunteer information about burden of care or requiring more help caring for their sick child. Medical review needs to target these questions and respite support needs to be directed at these families.

Intractable diarrhoea revealing a neuroblastoma hypersecreting vasoactive intestinal peptide

Bitar R, Specialist Registrar

Introduction: In children secretory diarrhoea is uncommon and can be caused by neurogenic tumours. Vasoactive intestinal peptide (VIP) can be produced by mature neurogenic tumors. Pathologically elevated VIP plasma levels cause secretory diarrhea with excessive loss of water and electrolytes.

Aim: To discuss our experience in diagnosis and treatment of vasoactive intestinal peptide-secreting-tumor (VIPoma).

Method/Result: A 9 month old girl was referred to a tertiary paediatric gastroenterology unit with significant weight loss, severe diarrhoea (>100ml/kg/day), hypokalemia and acidosis. The diarrhoea persisted despite the cessation of feeding. Stool electrolytes demonstrated secretory diarrohea. Further investigations revealed a raised Vasoactive intestinal peptide (VIP), this led to the search of a neuroendocrine tumour in the patient. The patient was found to have an intra-abdominal neuroblastome with no evidence of metastasis. After tumour resection the diarrhoea ceased and she made complete recovery.

Conclusion: VIP secreting tumours are rare in children. Any child presenting with secretoy diarrhoea should have a VIP plasma level assessed as part of the diagnostic work up. Despite the clinical severity diagnosis of a VIP-secreting tumor is often delayed. Surgical removal of the tumour is curative.

Nocturnal Screaming – consider this rare cause

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Colic is a common phenomenon of unknown aetiology in early infancy and is the explanation for many complaints. Patients with their exhausted parents present with colic in primary through to tertiary centres. We report 2 sisters E and S. E presented with a history of vomiting, screaming with back arching, and symptoms suggestive of cow's milk protein allergy. She was managed accordingly but her symptoms persisted, with the most troublesome symptom being the nocturnal abdominal pain and screaming episodes. Several investigations were performed to better understand her underlying problems including a barium follow-through. It was reported as normal although the caecum appeared higher on earlier images. This finding suggested a mobile caecum and perhaps intermittently caecal volvulus. E underwent a laparotomy, which revealed unusual adhesions, predisposing the caecum to volve. These were divided, and the caecum was fixed.

E's younger sister, S, also had similar symptoms with cow's milk protein allergy and reflux oesophagitis. S also suffered with nocturnal screaming episodes with back arching and persistent vomiting. In view of her sister's history, a barium follow-through was performed. The DJ flexure was identified in the midline with the small bowel lying predominantly within the right of the abdomen. The position of the caecum was within normal limits. S subsequently underwent a laparotomy, which revealed a band of adhesion, giving the caecum a propensity to volve. The band was divided, the caecum fixed and the DJ flexure fixed in the normal position. Both sisters had no further abdominal pains post-operatively.

The true incidence of caecal volvulus (CV) in children is rare and unknown. There has been very little published, and none reporting related patients. The case of E and S raises the question of a possible hereditary cause of CV. There are a few predisposing factors contributing to its occurrence. The presentation can vary from intermittent symptoms with self-resolution to critically toxic state. Diagnosis is aided with radiological images, with barium enema being the investigation of choice. Several surgical methods of treatments have been reported with varying success rates. Mortality with CV is related to the degree of obstruction and vascular compromise. Its rare incidence in children and its intermittent nature requires it to be considered early to enable prompt diagnosis and treatment in order to avoid possible significant complications.

Selected Abstracts

Abstract Session II

Oral 5-aminosalicylic acid for maintenance of surgically-induced remission in Crohn's disease

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Background: The use of 5-aminosalicylates (5-ASAs) in Crohn's disease (CD) is controversial. A recent Cochrane review found that 5-ASAs are not effective for the maintenance of medically-induced remission in CD, but their role in the maintenance of surgically-induced remission is unclear.

Aim: To evaluate the efficacy of 5-ASA agents for the maintenance of surgically-induced remission in CD and to determine adverse events associated with their use.

Subject and Methods: The search was standardised and not limited by language and included electronic searching (MEDLINE, EMBASE, Cochrane Central Register of Controlled Trials, Cochrane Inflammatory Bowel Disease Group Specialized Trials Register), reference searching of all included studies, abstracts from major meetings, personal contacts and drug companies. Randomised controlled trials (RCTs) which compared 5-ASAs with either placebo or another intervention, with treatment durations of at least 6 months. Participants were patients of any age with CD in remission following surgery. Primary outcome measures were clinical relapse or endoscopic recurrence as defined by the primary studies. Secondary endpoints were the occurrence of adverse events. Relevant papers were identified and the authors independently assessed the eligibility of trials. Methodological quality was assessed using the Cochrane risk of bias tool.The Cochrane RevMan software was used for analyses. Patients with final missing outcomes were assumed to have relapsed. Odds ratio (OR) and 95% confidence intervals (95% CI) were calculated based on the fixed effects model. The chi square and I^2 statistics were used to assess statistical heterogeneity.

Results: Nine RCTs were included in the review. Seven studies compared oral 5-ASA with placebo and two compared oral 5-ASA with purine antimetabolites (azathioprine or 6-mercaptopurine). 5-ASA was statistically significantly more effective than placebo for preventing relapses (OR 0.68, 95% CI, 0.52 to 0.90). No statistically significant difference in adverse events was found for 5-ASA versus placebo (OR 1.02, 95%CI, 0.60 to 1.76). There was no statistically significant heterogeneity among the 8 trials comparing 5-ASA with placebo (p=0.47). No statistically significant difference was found between 5-ASA and purine antimetabolites for preventing relapses (OR 1.08 95% CI, 0.63 to 1.85).

Authors' conclusions: 5-ASA preparations are superior to placebo for the maintenance of surgically-induced remission in patients with CD. The incidence of adverse events was not different in patients receiving 5-ASA compared with those receiving placebo. There is insufficient evidence to allow any conclusions on how 5-ASA preparations compare with azathioprine or 6-mercaptopurine.

Posterior Reversible Encephalopathy Syndrome in patients with active inflammatory bowel disease

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Introduction: Posterior Reversible encephalopathy syndrome (PRES) is a clinicoradiological diagnosis characterized by headaches, seizures, visual disturbances and characteristic changes in the MRI. Since first described by Hinchey et al in 1996, there are increasing numbers of cases reported in adults and also in children. Associated conditions known to trigger PRES include sepsis, cyclosporine toxicity (post transplant), autoimmune disease, post chemotherapy and eclampsia. We report for the first time three children with Inflammatory Bowel Disease (IBD) who developed PRES.

Aim: To report the clinical, biochemical and radiological findings of the 3 children who had seizures with MRI changes characteristic of PRES and to look for common triggering factors.

Subject and Methods: Retrospective study of the case notes.

Results: All three children had acute exacerbation of their IBD when they developed PRES. All three were receiving intravenous steroids and azathioprine and one was taking oral cyclosporine as well with pre and post dose cyclosporine levels within the therapeutic range. One child had hypophosphatemia and hypomagnesaemia presumed to be a consequence of refeeding syndrome. Two were receiving prophylactic dalteparin. All three developed seizures; two had visual disturbances and hallucinations. Two patients had subtotal colectomy due to acute severe colitis. One child had seizures prior to colectomy and the other had seizures 2 days post colectomy and was hypertensive prior to the seizures. The third child did not have colectomy but was receiving a prolonged course of high dose prednisolone. All had characteristic MRI changes suggestive of PRES; patchy cortical and subcortical high signal posteriorly compatible with PRES. One patient had normal CT brain scan but abnormal MRI. The clinical manifestations of PRES resolved within a week in all patients.

Conclusion: The common feature in all three children who developed PRES appeared to be exacerbation of their IBD. Although hypertension has been reported as the common pathogenic pathway only one of our patients was hypertensive. The cessation of symptoms in one patient coincided with colectomy. MRI appears to be more sensitive to CT, possibly due to its high resolution and diffusion-weighted imaging. The syndrome should be promptly recognized since it should be reversible and MRI should be obtained in all children with acute colitis and unexplained neurological symptoms.

Prevalence of anaemia in children with Inflammatory Bowel Disease

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Background: Anaemia is the most frequent complication of Inflammatory bowel disease (IBD) affecting about 20% of adult patients at any one time; half of whom are iron deficient (IDA)(1,2). Few studies have reported the prevalence of anaemia in children with gastrointestinal (GI) complaints and or IBD, where dietary restrictions may conceivably worsen iron deficiency.

Aims and Obectives: We aimed to compare the prevalence of anaemia in IBD with a group of GI disease controls, and identify disease characteristics that predict anaemia.

Methods: We conducted a retrospective case-control study. Using electronic case note review we identified 46 consecutive paediatric IBD patients attending our tertiary Paediatric Gastroenterology Unit, (20 ulcerative colitis (UC), 2 indeterminate colitis and 24 Crohn's (CD)). 40 children with GI complaints with no underlying organic pathology were used as controls. Anaemia was defined using WHO criteria (1), patients with co-existing haemoglobinopathies were excluded. Disease activity was defined by global clinician's assessment and/or CRP>5 mg/l. Disease extent and behaviour were recorded according to the Montreal classification. Differences between the IBD group and controls were sought using Fisher's exact test and Mann Whitney-U test.

Results: There was no significant difference between the median ages (range) of the IBD group compared with controls 13(5-16), 12(5-16)yrs respectively. Prevalence of anaemia in the IBD group was 71.7% (33/46) and significantly greater than in the controls 17.5% (7/40) ($p<0.001$), too few patients had haematinics or iron studies to determine type of anaemia. Mean haemoglobin in the anaemic UC and CD group was 10.2 (8.0-11.9) compared to 10.6 (8.2-12.4)g/dl respectively. Overall only 6% (2/33) of the anaemic group were treated with oral iron. Using univariate analysis, neither gender, disease type, extent, duration or activity; were found to be predictive of anaemia in IBD.

Conclusion: Anaemia is much more common in children with IBD. Despite this few children have their anaemia adequately assessed and fewer receive specific treatment. Further studies are needed to assess the prevalence of ID anaemia and anaemia of chronic disease and the impact of iron supplementation and erythropoetin on symptoms of anaemia, quality of life and disease activity.

References:

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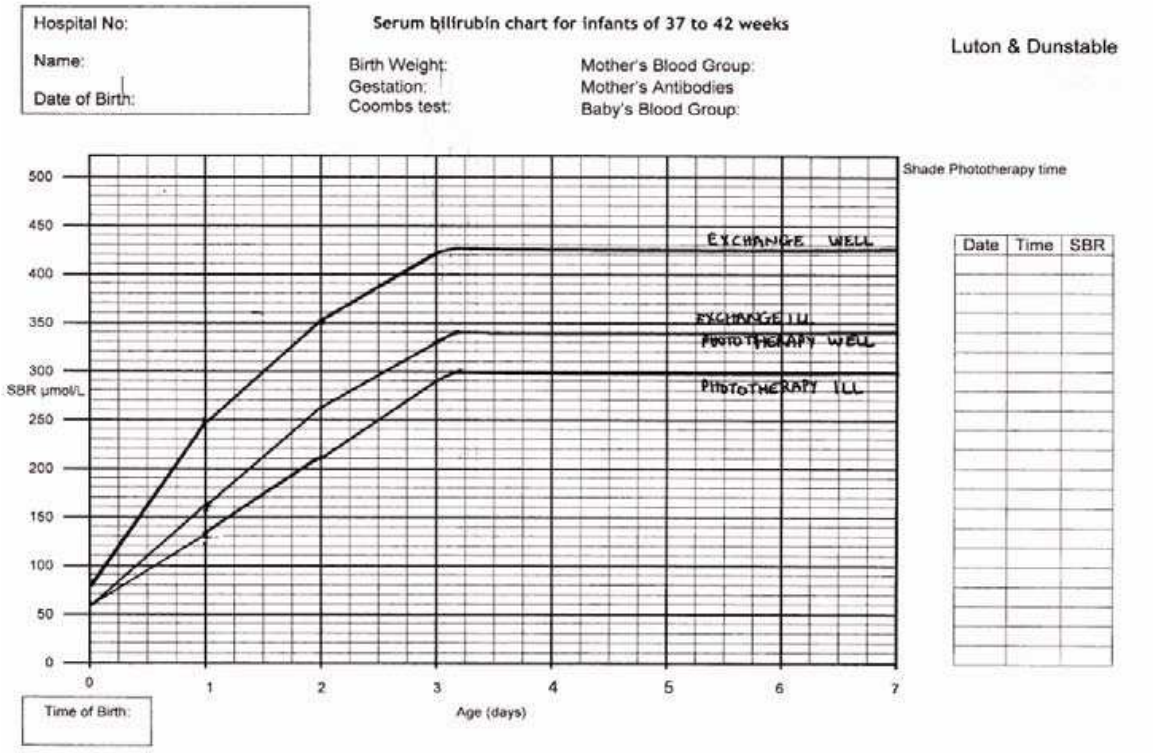
Management of term jaundiced babies –a comparative review of two epochs

C.Tzivinikos, A. Ahmed , A. Arasu (Luton and Dunstable Hospital)

Introduction:

_ **EPOCH 1 (June-August 2007) :** Prior to September 2007, a formula was used to assess the level of jaundice needed phototherapy **(Gestational age x 10 –100)**
_ **EPOCH 2 (June-August 2008) :** In September 2007, the new bilirubin charts were introduced



Wide range of UK practice in neonatal jaundice

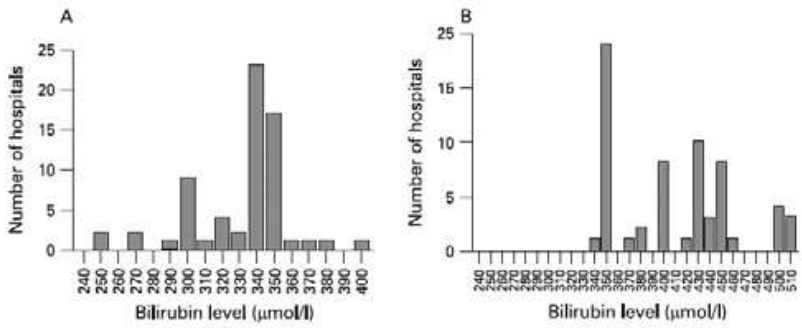


Figure 1 A. Histogram showing the number of hospitals choosing particular levels of bilirubin at which phototherapy is commenced in term babies. B. Histogram showing the number of hospitals choosing particular levels of bilirubin at which an exchange transfusion is recommended in term babies.

Inclusion Criteria

Term babies :

who developed jaundice after birth on the postnatal wards who received phototherapy

who were re-admitted from the community for jaundice

Aims:

- To compare between the two epochs:
- The numbers of babies who received phototherapy
- The duration of phototherapy and admission
- The number of bilirubin measurements
- The cost effectiveness of the new charts

Methods:

We identified babies who had more than 3 serum bilirubin measurements on the bilirubin measurement logbook in the postnatal wards

Retrospective analysis of case notes

Results:

EPOCH 1 -

- originally 34 babies were identified
- for 6 babies, notes not found or were preterm
- 12 re-admissions , of which 4 NICU admissions
- 2 cases had no phototherapy
- in 3 cases, SBR (serum bilirubin) charts were used and as a result in one case phototherapy was avoided
- None of them received exchange transfusion
- 4 cases needed prolonged jaundice investigations

EPOCH 2

- Originally 39 babies were identified
- For 15 babies , the notes were not found or were preterm
- 2 re-admissions, of which 3 were NICU admissions
- 5 cases had no phototherapy

Pathways in IBD

Mr Mick Cullen, Paediatric Gastroenterology Nurse Specialist, Southampton

Patient pathways have become an integral part of treatments in the modern nhs.

These pathways are being used to ensure the care we offer is of

- of the highest quality
- the best we can deliver
- evidence-based
- efficient

Getting a diagnosis of IBD is seen as a step forward in the right direction on a journey / relationship with health care services and providers. Prior to this diagnosis there may have been many twists and turns on the journey that may have led to mistrust, ,frustration, worry and a feeling of being lost. Referral to a gastroenterology centre may come months after initial symptoms were first noticed.

From investigations to confirmation of the condition, from treatment options and maintenance therapies the Ibd nurse has a pivotal role in developing a pathway that meets the patients needs and empowers them to access the most appropriate evidence based care /information as and when it is needed.A multi disciplinary viewpoint is essential to incorporate and include all those the patient may see on their journey through the service.

Event timeline mapping of interventions like consultations, treatments, disease education and clinic appointments can help explain what is likely to happen at each stage of the care continuum and are geared towards improving understanding and expectation.
The patient is seen as an active participant rather than a passive recipient in decisions relating to their care and the pathway needs to reflect this by being patient centred ,transparent and clearly outline the treatment goals, options and obstacles.

The nurse must respond to the individual needs of the patient and therefore a “one size fits all” approach may not reflect the patient’s cultural beliefs, extent of disease ,prognosis or prior knowledge and expectations concerning treatment.

As healthcare professionals we play an important supportive role in how individuals manage their chronic condition. We actively try to empower the patient to take responsibility and manage their condition themselves. They manage their condition with their own health care beliefs in their own environment with support from others (family and friends) and external resources (support groups – internet). Pathways may need to be adaptable and respond to patient choice.

Sometimes conflict of opinions can occur and patients can veer off the planned health care route.

A planned pathway can also help introduce key issues like transition into a care package at an early stage which helps avoid the sometimes sharp cut off point between paediatric and adult services.

Patient pathways are intended as a partnership between the patient and the health care provider that sets out expectations of each party in relation to managing their

chronic condition. It is intended as a useful resource to foster the trusting ongoing relationship as the patient progresses through the healthcare system. In developing a plan we try to be “Sat Navs” as opposed to being “Sat Nags”