THE WINSTON CHURCHILL MEMORIAL TRUST OF AUSTRALIA

Report by - Dr Peter De Cruz - 2012 Churchill Fellow

THE JACK BROCKHOFF CHURCHILL FELLOWSHIP to study
Assessment and Optimal Management of Intestinal Failure

I understand that the Churchill Trust may publish this Report, either in hard copy or on the internet or both, and consent to such publication.

I indemnify the Churchill Trust against any loss, costs or damages it may suffer arising out of any claim or proceedings made against the Trust in respect of or arising out of the publication of any Report submitted to the Trust and which the Trust places on a website for access over the internet.

I also warrant that my Final Report is original and does not infringe the copyright of any person, or contain anything which is, or the incorporation of which into the Final Report is, actionable for defamation, a breach of any privacy law or obligation, breach of confidence, contempt of court, passing-off or contravention of any other private right or of any law.

Signed

Dated 2-3-2014
INDEX

Introduction..................................................................................................................3
Executive Summary ........................................................................................................4
Programme..................................................................................................................5
Types of Intestinal Failure..............................................................................................6
Causes of Short Bowel Syndrome..................................................................................7
Medical Management of Intestinal Failure.................................................................8
The Nutritional Management of Intestinal Failure.........................................................9
Complications of Parenteral Nutrition........................................................................10
Surgical Management of Intestinal Failure......................................................................11
Intestinal Failure Unit Services....................................................................................12
Quality Standards in Intestinal Failure Management..................................................13
Summary of Sites Visited...............................................................................................14
Intestinal Transplantation..............................................................................................15
Support Services for Patients.......................................................................................16
Conclusions..................................................................................................................16
Recommendations........................................................................................................16
Dissemination Plan........................................................................................................17
References.....................................................................................................................17
INTRODUCTION

Intestinal failure is comprised of a group of disorders with different causes, which are characterised by an inability to maintain adequate nutrition or fluid status via the intestines. Intestinal failure results from obstruction, dysmotility, surgical resection, congenital defect, or disease associated loss of absorption and is characterised by the inability to maintain protein-energy, fluid, electrolyte, or micronutrient balance.¹

When intestinal failure persists for more than a few days intravenous delivery of nutrients and water, i.e. parenteral nutrition, is required. Intestinal failure can be life-threatening if sub-optimally managed or mismanaged. It is a complex syndrome requiring highly specialised medical, surgical and nutritional management and patients often require life-long intravenous nutrition. There is currently no specialised adult centre in Australia to manage this highly complex and sick group of patients. The purpose of this project was to visit international dedicated intestinal failure and intestinal transplantation units within Europe to gain clinical experience in the medical and advanced nutritional management of intestinal failure.

I would like to thank the Jack Brockhoff Foundation and Churchill trust for their generous support of this study mission. I would also like to thank Professor Julie Bines from the Royal Children’s Hospital, Melbourne for her advice, mentorship and support of my application for the Churchill fellowship. I would also like to thank Professor Michael Kamm who also supported my Churchill fellowship application. I would additionally like to thank Dr Adam Testro who helped provide me with some background on the current state-of-play in relation to intestinal failure and transplantation within Australia.

My visits to centres for excellence in intestinal failure and intestinal transplantation allowed me to gain insights into best practice in the multidisciplinary management of patients with intestinal failure. I would like to thank the following people and institutions for making my study mission possible:

- Dr Jeremy Woodward, Sr Helen Lawrance, Caroline Kratzing, Dr Stephen Middleton, Dr Miles Parkes
  Cambridge, UK Addenbooke’s Hospital
- Dr Simon Gabe, Ms Seema Patel, Sr Sam Drury, Sr Mia Small
  St Mark’s London, UK
- Mr Arun Abraham, Dr Simon Lal, Dr Jonathon Schaffer, Kirsteen Farrer
  Salford Royal NHS Foundation Trust
- Professor Peter Friend, Mr Darius Mirza
  Oxford, UK 13th international small bowel transplant symposium
- Dr Mike Stroud, Dr Trevor Smith, Mr Andy King and Professor Alan Jackson
  South Hampton, UK Practical Nutrition support course
- Dr Eduard Cabre and Professor Miguel Gassull
  Health Science Research Institute, Germans Trias i Pujol Foundation, Barcelona
- Prof Gert Van Assche, Prof Severine Vermiere, Dr Marc Ferrante
  Hospital Gasthuisberg, Leuven, Belgium
EXECUTIVE SUMMARY

Assessment and Optimal Management of Intestinal Failure

Dr Peter De Cruz,
Consultant Gastroenterologist
Intestinal Failure and Intestinal Transplantation Physician
Head of the Inflammatory Bowel Service
Department of Gastroenterology

The Austin Hospital, Melbourne
145 Studley Road
PO Box 5555 Heidelberg
Victoria Australia 3084
Ph: +61 (3) 9496 5353

The Jack Brockhoff Churchill Fellowship has given me the opportunity to travel to centres that are world renowned for the management of intestinal failure, intestinal transplantation and complex inflammatory bowel disease.

Engaging with and working along side international leaders in the field has enabled me to build on my expertise as a gastroenterologist and inflammatory bowel disease specialist and develop skills in the medical, nutritional and peri-operative management of patients with intestinal failure.

Visits to the national intestinal failure units at St Mark’s hospital in London and the Hope hospital in Salford, Manchester as well as the intestinal failure service at Addenbrooke’s Cambridge formed an integral part of my fellowship experience in relation to learning how to optimally manage patients with intestinal failure. The practical nutrition support course in Southampton was also instrumental in teaching me some fundamental aspects of intestinal failure management. Other highlights of the fellowship were the National Adult Small Intestine Transplantation (NASIT) meetings in the UK where all patients with intestinal failure in the UK who might require intestinal transplantation are discussed and listed for transplant if deemed appropriate.

My Churchill fellowship experience has allowed me to explore different models of multidisciplinary management of intestinal failure. The teamwork of the staff that I met at all centres was inspirational. Optimal multidisciplinary care of patients with intestinal failure requires collaborative input from highly trained and skilled physicians, surgeons, dieticians, nutrition nurses, pharmacists, psychology and vascular access (radiology/anaesthetics) staff. Intestinal failure management is therefore resource intensive and requires adequate infrastructure in place to be managed effectively.

My aim on returning to Australia is to enhance the clinical care of patients by integrating my knowledge of nutrition support into my clinical practice of managing patients with complex inflammatory bowel disease. I intend to contribute the knowledge and expertise that I have gained towards helping set up Australia’s National Intestinal Failure and Transplantation service. I also aim to share my knowledge, skills and expertise with patients and other health professionals via clinical updates and conferences of Australia’s national gastroenterology and nutrition societies and via Crohn’s and Colitis Australia.
PROGRAMME

Cambridge, UK Addenbooke’s Hospital

- Dr Jeremy Woodward, Sr Helen Lawrance, Caroline Kratzing, Dr Stephen Middleton, Dr Miles Parkes

Activities undertaken:
Intestinal Failure Service/Nutrition ward rounds
Nutrition Multidisciplinary clinics
Feeding Multidisciplinary meetings
Small bowel Transplant Multidisciplinary clinics
Small bowel Transplant ileoscopy lists
Small bowel Transplant radiology meetings
IBD clinics

St Mark’s hospital, London, UK
- Dr Simon Gabe, Sr Mia Small, Sr Sam Drury, Ms Seema Patel

Activities undertaken:
Intestinal Failure Unit ward rounds
Nutrition Multidisciplinary clinics
Psychological Medicine Meetings
Nutrition Multidisciplinary Meetings

Salford Royal NHS Foundation Trust
- Mr Arun Abraham, Dr Simon Lal, Dr Jonathon Schaffer, Kirsteen Farrer

Activities undertaken:
Intestinal Failure Unit ward rounds
Nutrition Multidisciplinary clinics
Nutrition Multidisciplinary Meetings
Strategic planning meeting – how to set up an IF service
Quality Improvement – Auditing practice to improve outcome

Oxford, UK 13th international small bowel transplant symposium
- Professor Peter Friend, Mr Darius Mirza

Attendance:
Medical management of Intestinal Failure Symposium
Lectures and Free Papers on Intestinal Failure, Small Bowel Transplantation

South Hampton, UK Practical Nutrition support course
- Dr Mike Stroud, Dr Trevor Smith and Professor Alan Jackson

Attendance and active participation in Lectures and Collaborative Learning Sessions

Barcelona, Health Science Research Institute, Germans Trias i Pujol Foundation,
- Dr Eduard Cabre and Professor Miguel Gassull

Strategic planning meeting – Nutrition Support Practice
Research meeting – Translational research in Nutrition

Leuven, Belgium - Hospital Gasthuisberg
- Prof Gert Van Assche, Prof Severine Vermiere, Dr Marc Ferrante

IBD Clinic
Nutrition ward round
Research meeting
Endoscopy
Anti-Tumour Necrosis Factor infusion centre visit
MAIN BODY

The persistence of intestinal failure for more than a few days results in the need for intravenous delivery of nutrients and water, i.e. parenteral nutrition (PN). Three types of intestinal failure (IF) have been described:

Types of Intestinal Failure

Type 1 – Short term
- Self-limiting intestinal failure
- Often peri-operative in nature eg acute post-op ileus
- Patients managed in a variety of health-care settings eg surgical wards/ high dependency or intensive care units
- When PN is required, should be managed by a multi-disciplinary nutrition team working in conjunction with the primary medical, surgical and nursing teams (NICE guidelines)

Type 2 – Medium Term
- Metabolically unstable patients
- Significant and prolonged PN support (>28 days) required
- Intensive care / high dependency care services will be needed for a proportion of the patient’s stay in hospital
- Patients require complex, management of open abdominal wounds, high output intestinal fistulae and stomas
- Patients may require surgical intervention during their initial stay; others will require long and complex surgical reconstruction months after their initial problem has stabilised.
- Management by a multi-disciplinary specialist IF team including dedicated nursing, dietetic, medical, surgical and interventional radiological input is required.
- A proportion of Type 2 IF patients (approximately half) will stabilise and become Type 3 IF patients needing long term parenteral feeding who can be managed at home.

Type 3 – Long term
- Chronic IF (long term PN support)
- Patient is usually metabolically stable but cannot absorb sufficient fluid, food or nutrients via the intestinal tract and require Home PN (HPN)
- Includes short bowel syndrome and motility disorders
- Patients require management by a multidisciplinary nutrition team who will usually link with a homecare company to provide comprehensive management.
- A small number of patients will become suitable for either small bowel or combined small bowel and liver transplantation or other specialist restorative surgery (e.g. bowel lengthening).
Causes of Short Bowel Syndrome

(Adapted from Dr Simon Gabe’s – Southampton Intestinal Failure Lecture)

Intestinal failure is comprised of a group of disorders with many different causes, the most common of which are summarised below:

<table>
<thead>
<tr>
<th>Group</th>
<th>Common</th>
<th>Uncommon</th>
</tr>
</thead>
<tbody>
<tr>
<td>Small intestinal resections</td>
<td>Crohn’s disease</td>
<td>• Post irradiation enteritis</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Repeated surgery for surgical complications</td>
</tr>
<tr>
<td>Massive intestinal resections</td>
<td>Infarction (SMA/SMV Thrombosis)</td>
<td>• SMA embolus</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Massive volvulus</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Desmoid tumour</td>
</tr>
<tr>
<td>Enterocutaneous fistula</td>
<td>High out-put</td>
<td>• Gastric bypass (obesity)</td>
</tr>
<tr>
<td>Bypass surgery</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Short Bowel Syndrome: types

The medical and nutritional management of intestinal failure that results from short bowel syndrome due to surgery depends on residual anatomy left behind:

<table>
<thead>
<tr>
<th>Mid small bowel resection</th>
<th>Jejuno-colic anastomosis</th>
<th>Jejunostomy or high output fistula</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uncommon</td>
<td>Usually fluid balance</td>
<td>Fluid balance</td>
</tr>
<tr>
<td></td>
<td>Maintained</td>
<td>• Net secretors</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Net absorbers</td>
</tr>
<tr>
<td>Rarely problems</td>
<td>Nutritional issues</td>
<td>Nutritional issues</td>
</tr>
<tr>
<td></td>
<td>When jejunal length &lt;100cm</td>
<td></td>
</tr>
<tr>
<td></td>
<td>High out-put</td>
<td></td>
</tr>
<tr>
<td>Colonic digestion can</td>
<td>Colonic digestion can</td>
<td></td>
</tr>
<tr>
<td>salvage 700-950 kcal/day</td>
<td>salvage 700-950 kcal/day</td>
<td></td>
</tr>
<tr>
<td>(carbohydrate fermentation &amp;</td>
<td>(carbohydrate fermentation &amp;</td>
<td></td>
</tr>
<tr>
<td>SCFA absorption)</td>
<td>SCFA absorption)</td>
<td></td>
</tr>
</tbody>
</table>

Critical lengths of Bowel Required For Enteral Nutrition

The small bowel varies in length between 3 - 8.5 metres. The length of small bowel that is available for “normal” enteral nourishment is:

<table>
<thead>
<tr>
<th>SBS type</th>
<th>Critical SB length</th>
<th>Note</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jejunostomy or EC fistula</td>
<td>100 cm of small bowel</td>
<td>More needed if diseased bowel</td>
</tr>
<tr>
<td>Jejunocolic anastomosis</td>
<td>Around 50 cm (+colon)</td>
<td>Depends on amount of residual colon</td>
</tr>
</tbody>
</table>
Medical Management of Intestinal Failure

Correct Fluid Management

A common mistake made by clinicians managing patients with short bowel syndrome who have large fluid losses via their stoma is to encourage their patients to drink more (hypotonic) fluids such as water, tea, coffee, fizzy drinks and soup. This practice only serves to increase fluid losses as the small bowel (jejunum) is unable to maintain a Na gradient >30-40 mmol/l resulting in net sodium and water loss. Instead fluid restriction of hypotonic fluids and use of oral-rehydration therapy type fluid preparations with a sodium concentration of 90-120 mmol (mmol/l) + glucose 90-111 (mmol/l) and bicarbonate minimises fluid losses. A fluid restriction and oral rehydration strategy was adopted by all centres.

Sodium Requirements

“Rule of Thumb” sodium output via the stoma (in mmol) is proportional to volume of intestinal output via the stoma (kg). This equates to 100 mmol of sodium lost in every litre of effluent. Therefore for every litre lost in stoma effluent 100mmol of Sodium is required + maintenance requirements of 1mmol/kg/day.

Treatment of the High Output State:

<table>
<thead>
<tr>
<th>Fluid Type</th>
<th>Maximum Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drink little hypotonic fluid</td>
<td>Maximum 1L/day</td>
</tr>
<tr>
<td>Drink a glucose-saline solution</td>
<td>Maximum 1L/day</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Drug Therapy</th>
<th>Antimotility</th>
<th>Antisecretory</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Loperamide (up to 32mg QDS)</td>
<td>Codeine phosphate (up to 60mg QDS)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Omeprazole (40mg bd)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Octeotide (50 microgram bd)</td>
</tr>
<tr>
<td>Magnesium supplements</td>
<td>Magnesium oxide</td>
<td>Vitamin D</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nutrition</td>
<td>Low residue diet</td>
<td></td>
</tr>
</tbody>
</table>

Parenteral fluids +/- nutrition

Fluid & nutrition requirements are best considered separately. “Standard intravenous nutrition” bags are often insufficient. Bags need to be tailored to requirements. Basic “rule of thumb” fluid requirements based on stoma output include:

1. 500ml/day – Oral rehydration therapy
2. 1L/day – intravenous hydration
3. >1.5 L/day – TPN + iv hydration

Requirements alter daily until a steady state is achieved. Random urine Na is the best measure of dehydration and was routinely measured at all centres.

Emerging Therapy in the Medical Management of Intestinal Failure

Teduglutide an analogue of Glucagon-like Peptide 2 (GLP-2), a naturally occurring protein involved with intestinal growth and function has recently been approved by the FDA to treat patients with short bowel syndrome. Teduglutide is an injection administered once daily that helps improve intestinal absorption of fluids and nutrients, reducing the frequency and volume of parenteral nutrition and has been found to decrease PN requirements by 20% in patients with IF on HPN. The cost of teduglutide in the US is $295,000 a year hence its application in the intestinal failure setting is limited by cost. Teduglutide was not in use outside of the clinical trial setting in any of the centres visited.
Nutritional Management of Intestinal Failure

To maximise absorption of patients with minimal residual small bowel length a high energy diet is recommended with the fibre content determined by whether or not the bowel is in continuity as follows:

**Jejunostomy patients**

<table>
<thead>
<tr>
<th>Nutrient group</th>
<th>Amount</th>
<th>Requirement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Energy</td>
<td>High</td>
<td>30-60 kcal/kg/day</td>
</tr>
<tr>
<td>Protein</td>
<td>High</td>
<td>0.2-0.25g N/kg/day (80-100g protein)</td>
</tr>
<tr>
<td>Fat</td>
<td>High</td>
<td></td>
</tr>
<tr>
<td>Fibre</td>
<td>Low</td>
<td></td>
</tr>
</tbody>
</table>

**Jejunocolic anastomosis**

<table>
<thead>
<tr>
<th>Nutrient group</th>
<th>Amount</th>
<th>Requirement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Energy</td>
<td>High</td>
<td>30-60 kcal/kg/day</td>
</tr>
<tr>
<td>Protein</td>
<td>High</td>
<td>0.2-0.25g N/kg/day (80-100g protein)</td>
</tr>
<tr>
<td>Fat</td>
<td>Low/moderate</td>
<td>According to degree of steatorrhoea</td>
</tr>
<tr>
<td>Fibre</td>
<td>Moderate/high</td>
<td></td>
</tr>
</tbody>
</table>

Exceptions to the above dietary recommendations include patients with bowel obstruction, active inflammatory bowel disease and myopathy.

**Fistuloclysis & enteroclysis**

A technique utilised by the Hope Hospital in Salford is fistuloclysis which involves enteral feeding via an intestinal fistula usually overnight to allow patients to eat during the day. Feed is infused into distal limb of an enterocutaneous fistula or loop stoma. The Hope hospital in Salford have observed that patients with a minimum of 75 cm of small bowel and most of their large bowel in continuity can reduce or stop parenteral nutrition using fistuloclysis. This technique is thought to promote intestinal adaptation before reconstructive surgery. It is also associated with a reduction in PN related complications and the costs associated with PN.

A technique that is not as difficult to perform that can be used in patients where enteral nutrition is not required to meet nutritional requirements is bolus fistuloclysis/enteroclysis which involves the use of bolus enteral feeding or supplementation. It is just as effective at maintaining GI integrity, allows a shorter recovery time after restorative surgery and is associated with a decreased post anastomotic complication rate.

**Parenteral Nutrition (PN)**

Parenteral nutrition, which contains protein, calories, electrolytes, vitamins, micronutrients and fluid, is a source of nutrition that is able to meet the full nutritional requirements of a patient if tailored to their needs. The main complications of PN include catheter related blood stream infections, intestinal failure associated liver disease and venous thrombosis. Each of the centres visited took great care to avoid these complications using a number of strategies.
Complications of Parenteral Nutrition

*Intestinal Failure Associated Liver Disease (IFALD)*

Liver disease has become an increasingly recognised complication of intestinal failure. Although there are a number of different causes for liver disease among patients with intestinal failure factors that have predisposed to higher rates of severe liver disease include ultra-short gut (<50 cm) of small bowel and increased use of parenteral lipid. Based on the finding that chronic cholestasis and liver disease occur when 20% intravenous lipid was provided at higher doses than 1 g/kg per bodyweight per day, the trend is now to provide 1.2–2.4 g soybean oil per kilogram body weight twice weekly with aqueous (non-lipid) bag during the remaining five days per week. Improved liver tolerance and reduced length of hospital stay has also been achieved with SMOF-lipid, an emulsion containing soya bean, medium chain triglycerides olive and fish oil which has a more physiologically balanced ratio of omega 3 and 6 fatty acids compared with lipid formulations which had relatively high levels of omega-6 fatty acids which is associated with hepatotoxicity. The majority of centres visited has access to both compounding of PN on site from scratch in order to tailor the PN to the individual patient as well as out-sourced bags once a patient was established on their PN regimen.

*Catheter Related Blood Stream Infections*

The risk of Catheter Related Blood Stream Infections in the US is 1/1000 catheter days and in centres around Europe on average 0.25/1000 catheter days (*pers comm. J Shaffer.*) Of all the risk factors for IF associated morbidity and mortality the only modifiable risk factor is line management. As such central venous catheter-related sepsis rates have become a surrogate measure of overall quality of catheter care. Reasons for catheter infections include: breaches in the line care protocol; inadequacy of the line care training program and genuine underlying illness. The line care at the majority of centres was nurse led with some centres adopting a policy of line care being exclusively nurse managed. Some of the centres utilised antimicrobial flush solutions, taurodine (taurolock) to reduce the risk of line sepsis; however, other centres perceived the use of taurolock as being permissive of laxity with line care protocol and therefore refrained from its use. Nonetheless patient training in line care was considered to be the key aspect to preventing line sepsis at all centres. Training practices varied from centre to centre with some undertaking training fully in hospital, others entirely within the patients’ homes and others partially in hospital and partially at home often in concert with homecare companies depending on nursing staff availability.

*Central venous thrombosis*

Catheter-associated central vein thrombosis has been reported to occur at a rate of 0.01 and 0.03 episodes per catheter year and is correlated with CVC-related sepsis episodes.⁶ Anti-coagulation is not currently recommended to prevent thrombosis unless there is an underlying risk. Patient with venous thrombosis may be candidates for thrombolysis or thrombectomy if diagnosed early and such patients should be screening for an underlying thrombophilia. Anti-coagulation is recommended in patients with thrombosis. Decisions to remove the line centre around whether or not there is associated sepsis and if adequate patency can be maintained with anti-coagulation.
Surgical Management of Intestinal Failure

Surgery is important in the management of intestinal failure (IF) as it represents the interface between type 2 and type 3 IF. Given the significant costs associated with PN, surgery may help minimise the cost of PN if it is able to render the patient PN independent. Decisions around surgery involve managing patients’ long term expectations in relation to what is realistically achievable whether it be lowering PN requirements, curing fistulae, reversing their stoma or treating recurrent sepsis.

The two main types of restorative surgery undertaken depend on the underlying cause of IF:

(i) Functionally short bowel – Fistulating disease – Enterocutaneous fistula (ECF) repair
(ii) Anatomically short bowel – Secondary to resection – Restoration of intestinal continuity

A useful acronym derived from the Hope Hospital in Salford that is applied to the management of such patients is “SNAP,” representing management of Sepsis and Skin care, Nutritional support, definition of intestinal Anatomy, and development of a surgical procedure to rectify the fistula.

The timing of reconstructive surgery is an important consideration in achieving enterocutaneous fistula closure. Surgical repair is considered if the ECF does not close after 2 months and outcomes are improved if definitive surgery is delayed for at least 6 months.\(^7\)

The principles of definitive surgery include laparotomy and adhesiolysis with en bloc resection of involved bowel and skin. Intra-operatively the remaining small bowel and large bowel length is measured to help determine long-term nutritional requirements. A surgical anastomosis is only created if the sepsis has resolved and the patient is well nourished. A proximal defunctioning stoma is often created if there is: persistent active sepsis, persistent malnutrition, Crohn’s disease or multiple anastomoses.\(^8\)

Intestinal lengthening procedures, referred to as autologous gastrointestinal reconstruction, are more recently being used among adult patients with short gut following initial success among paediatric patients. The two main operations are the Bianchi procedure and the STEP (Serial Transverse EnteroPlasty). The Bianchi procedure involves dividing the small bowel down the middle and anastomosing the two pieces end-to-end, thereby creating a smaller diameter but longer length of small bowel. The STEP procedure involves stapling dilated small bowel into smaller segments serially along the long axis of the bowel. There are limited data supporting the efficacy of these techniques in adults and there is a significant morbidity and mortality associated with the procedures; however, the Hope Hospital in Salford has been commissioned to perform the STEP procedure which has thus far been successful in weaning patients off PN.

All centers had a surgeon involved as part of the multidisciplinary team with a designated IF and/or transplant surgeon and good access to interventional radiology.
Intestinal Failure Unit Services

[Adapted from SSNDS Definition No. 12 Specialised Intestinal Failure & HPN (adult) (3rd Ed)]

Dedicated intestinal failure services are required for the management of patients with Type 2 and Type 3 IF. The centres visited were highly experienced in the management of patients with Type 2 and 3 IF but varied in their case load of such patients and their emphasis in relation to the volume of “acute” compared with “chronic” intestinal failure managed as described below:

<table>
<thead>
<tr>
<th>Acute IF</th>
<th>Chronic IF</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Predominantly Surgical Management</strong></td>
<td><strong>Predominantly Medical Management</strong></td>
</tr>
<tr>
<td>Management of Type 2 IF patients</td>
<td>Management of Type 3 IF patients</td>
</tr>
<tr>
<td>Requires expertise in:</td>
<td>Requires expertise in:</td>
</tr>
<tr>
<td>1. Complex wound care (open abdominal wounds and enterocutaneous fistulae)</td>
<td>1. Assessment and medical management</td>
</tr>
<tr>
<td>2. Interventional radiology and endoscopic assessment</td>
<td>2. Surgical intervention (where required)</td>
</tr>
<tr>
<td>3. Stabilisation in ICU or HDU</td>
<td>3. Implementation of long-term intravenous nutrition</td>
</tr>
<tr>
<td>4. Early specialist abdominal surgery often in the setting of sepsis and other organ failure</td>
<td>4. Identification and referral of patients suitable for small bowel transplantation</td>
</tr>
<tr>
<td>5. Later definitive abdominal surgery aiming to reconstruct intestinal system or close abdomen after optimisation of nutritional status and control of sepsis.</td>
<td></td>
</tr>
<tr>
<td>6. Management of fluid, electrolyte and nutrition balance</td>
<td></td>
</tr>
<tr>
<td>7. CVC handing and stoma management</td>
<td></td>
</tr>
<tr>
<td>8. Multidisciplinary team management involving medical, surgical, nutrition nursing, dietetic, pharmacy and psychology staff.</td>
<td></td>
</tr>
</tbody>
</table>

**Home Intestinal Failure Network (HIFNET)**

The optimal management of patients with intestinal failure in the UK has been enabled by the development of HIFNET (Home Intestinal Failure Network), a clinical network of English hospitals consisting of the national units supported by designated regional units. HIFNET was devised in 2008 to provide a framework of service provision to ensure that the care of patients with Type 2 and 3 intestinal failure was effective, high quality, clinically safe, equitable and economical. HIFNET aimed to build on the success of the two principal IF units at St Marks and Salford Royal Hospital, by enhancing effective links between them and enhancing appropriate throughput by devolution of care to regional units. In order to join HIFNET regional units require accreditation to demonstrate their ability to optimally manage patients with Type 2 and 3 intestinal failure and their preparedness to adhere to nationally agreed standards of care and to take part in regional and national audit of clinical outcome. Accreditation criteria include: assessment of staff competency; nutrition ward round/meeting (+/- surgeon); monthly MDT clinic; infection rates; facilities and staffing; nutrition support team; sufficient cover; 24 hour phone advice; dedicated clinical area; compounding/customising pharmacy; vascular access and patient training.
British Artificial Nutrition Survey (BANS)

BANS – The British Artificial Nutrition Survey has been collecting data on patients on artificial nutrition in hospital and in the community since 1996 and is the largest such on-going dataset in the world. These data are then analysed and reported, both by region and nationally. A report is published annually to ensure the findings are widely disseminated. Data collection and processing has recently been substantially improved through electronic data collection. This has enhanced the quality of data and can aid reporters to capture local data and benchmark against other geographical areas, map national or regional trends and benchmark their own services and outcomes with others.

Feeding Issues Multidisciplinary Team (MDT) (Addenbrooke’s Hospital)

An initiative that has streamlined the management of patients requiring nutrition support at Addenbrooke’s hospital is a weekly multidisciplinary meeting called the feeding issues MDT where both in patients and community patients with complex feeding decisions who may require assisted feeding are discussed. The meeting is chaired by a Palliative care physician and attended by a gastroenterology consultant, gastroenterology/nutrition registrar, geriatrician, SALT (Speech and Language Therapy), dieticians, nutrition nurses, and endoscopy nurse. Representatives from other units within the hospital present their patients at the meeting and a collaborative decision is made regarding the optimal nutrition support strategy for each patient. The feeding issues MDT plays an important role in discharge planning and has helped reduce patients’ length of stay.

Quality Standards in Intestinal Failure Management

IF is associated with considerable morbidity and mortality. The factors that are associated with morbidity and mortality may be preventable and therefore need to be audited in order to address any deficiencies in clinical practice. Quality Standards in IF which should be regularly assessed include:

1. Catheter related blood stream infections - in central and PICC lines
2. Unplanned intensive care and hospital readmission rates.
3. IFALD
4. Hospital and 30 day mortality
5. Unplanned return to theatre after surgery for Type 2 IF (notably for bleeding; anastomotic leakage; intra-abdominal abscess).
6. Recurrent fistulation rate (after surgery for enterocutaneous fistula).
7. Success in discontinuation of artificial nutrition support (parenteral nutrition; parenteral fluids and electrolytes; fistuloclysis) in patients undergoing reconstructive surgery for type 2 IF.
### Summary of Sites Visited

<table>
<thead>
<tr>
<th></th>
<th>St Mark’s Hospital, London</th>
<th>Hope Hospital, Manchester</th>
<th>Addenbrooke’s Hospital Cambridge</th>
<th>Hospital Gasthuisberg Leuven, Belgium</th>
<th>Hospital Germans, Barcelona Spain</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>IF care setting</strong></td>
<td>20 bed IFU ward + 4 post surgical beds and outpatient clinics</td>
<td>21 bed IFU + outliers and outpatient clinics</td>
<td>In-patient and outpatient</td>
<td>Outpatient</td>
<td>Outpatient</td>
</tr>
<tr>
<td><strong>Numbers of Home PN Patients</strong></td>
<td>285 patients</td>
<td>220 patients</td>
<td>50 patients</td>
<td>20 patients</td>
<td>4 Patients</td>
</tr>
<tr>
<td><strong>Nutrition support team Members</strong></td>
<td>Gastro Registrar Dietician Pharmacist Nutrition nurses Psych (Gastro enterologist Performed vascular access)</td>
<td>Surgeon Gastro reg Dietician Pharmacist Nutrition nurse Psych</td>
<td>Gastro registrar Nutrition nurse Dietician Pharmacist</td>
<td>Nutrition nurse Dietician</td>
<td>Dietician Nurses</td>
</tr>
<tr>
<td><strong>Team rounds</strong></td>
<td>Twice weekly</td>
<td>Daily</td>
<td>Daily</td>
<td>Twice weekly</td>
<td>Daily</td>
</tr>
<tr>
<td><strong>Key monitoring</strong></td>
<td>Biochemistry</td>
<td>Weight</td>
<td>Urinary</td>
<td>Sodium</td>
<td>Fluid balance</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Key meds</strong></td>
<td>Imodium Codeine phosphate PPI</td>
<td>Imodium Codeine phosphate PPI</td>
<td>Imodium Codeine phosphate PPI</td>
<td>Imodium Codeine phosphate PPI</td>
<td>Add Salt to enteral nutrition Fibre – Guargum PPI Imodium, Codeine phosphate</td>
</tr>
<tr>
<td></td>
<td>E-Mix (St Mark’s solution)</td>
<td>Double strength Diarolyte</td>
<td>Double strength Diarolyte</td>
<td>WHO solution</td>
<td>WHO solution</td>
</tr>
</tbody>
</table>
Intestinal Transplantation

Survival outcomes from intestinal transplantation have improved considerably in the last decade with current five year survival rates for all intestinal transplant procedures at 59%. The Small Bowel and Multi-visceral Transplant service was established in the UK in the early 1990’s. In the UK, intestinal transplantation was first performed in adults at Addenbrooke’s Hospital, Cambridge in 1987 and more recently in Oxford since 2008 and in children at the Children’s Hospital in Birmingham in 1993. King’s College Hospital in London also has an active adult and paediatric intestinal transplant unit. The use of the technique in the UK was initially of very low volume but has increased since 2006 due to an improvement in survival figures and an increased awareness of the procedure by referring centres.

Procedures

There are four procedures performed as part of the intestinal transplant programme:
1. Intestine alone
2. Liver and Intestine
3. Multi-visceral – liver, intestine +/- stomach +/- pancreas +/- kidney
4. Modified multi-visceral - intestine +/- stomach +/- pancreas +/- kidney without liver

Indications for intestinal transplantation:

The indications for intestinal or multi-visceral transplantation are evolving beyond the currently accepted and published guidelines. Quality of life and survival are the major considerations in the decision making process. Small bowel transplantation is currently commissioned within the UK for the following four conditions:

1. Life-threatening complications of parenteral nutrition (PN)
2. Very poor quality of life thought to be correctable by transplantation.
3. Patients with indications for extensive surgery involving partial or complete evisceration
4. Patients requiring transplantation of other abdominal organs

Mortality on the intestinal transplant waiting list is currently high in both adults and children, mostly due to end stage intestinal failure-associated liver disease. It is currently recommended that adults and children with irreversible intestinal failure, who develop complications should be discussed with an intestinal transplant centre before life-threatening complications develop especially because preoperative comorbidity has a profound influence on post-operative survival.

The process of listing for intestinal transplantation

All patients who are referred for transplant in the UK must be assessed in an intestinal failure unit. Patients are comprehensively assessed medically, nutritionally, psychologically and socially as part of a pre-transplant assessment. During the assessment patients are fully informed about their options and are assessed by a psychiatrist/psychologist for mental competence. They are also made aware of the general global survival figures, as well as the local centre’s survival figures to give them a realistic expectation of survival post-transplant.

Integral to the decision making process regarding whether or not a patient is a transplant candidate is the discussion of potential adult patient candidates at the NASIT (National Adult Small Intestine Transplant) forum meetings before a group of clinicians who are involved in all aspects of intestinal failure and transplantation. In the UK NASIT approval is a mandatory requirement prior to listing patients for transplantation. The discussions are undertaken because of the complexities involved in assessing the relative risks of transplantation versus continuing conservative treatment with ongoing PN. The meetings are held 2 monthly and are attended by team members from the transplanting centres and the intestinal failure units and are open to referring centres who are encouraged to send representatives.
**Patient Support Groups**

**Patients on intravenous and nasogastric nutritional therapy (PINNT)**

PINNT is the UK support group for patients on home enteral or parenteral nutrition. Established 25 years ago, PINNT has grown into a community that provides genuine understanding to help individuals and carers deal with the many challenges faced on artificial feeding at home. They also work closely with healthcare professionals, suppliers and manufacturers in order to enhance the patient journey. The PINNT network provides a unique and united voice to campaign for a better, flexible and safer service. www.pinnt.com

**Patientknowsbest**

*Patientknowsbest* is an electronic medical website currently being utilised at St Mark’s hospital, London to facilitate patient interactions with their clinicians. The site has gained popularity with patients and clinicians alike because of its capacity to enable trouble-shooting of patient issues in between out-patient appointments and hospital admissions. The site enables a dialogue between the patient and multiple members of the multidisciplinary team and operates on the premise that “everyone is an equal” within the therapeutic relationship between patient and the treating team.

**CONCLUSIONS**

Understanding the basic physiology of intestinal failure is a fundamental aspect of being able to optimally manage patients with intestinal failure

A multidisciplinary approach is essential and requires expertise from medical, surgical, nutrition nursing, dietetic, pharmacy and psychology staff

Optimal management of intestinal failure includes rationalisation of medical treatment, careful fluid and electrolyte balance and judicious adjustment of PN if required

Surgery may help bring bowel back in to continuity and reduce the impact of short gut syndrome and sometimes enable patients to come off PN

The long-term outcome of intestinal failure for any patient is a balance of life expectancy with quality of life for that individual patient which is the most important consideration when making decisions regarding continuing conservative treatment versus intestinal transplantation.

**RECOMMENDATIONS**

Patients with intestinal failure are complex to manage and require an expert multidisciplinary team to manage them optimally. The lack of a national service to provide intestinal rehabilitation and transplantation for patients with intestinal failure has significantly disadvantaged this group of patients who are among the sickest member of our community.

Based on my fellowship experience I intend to:

1. Inform government policy regarding the development of a national intestinal failure and transplantation service for Australia

2. Suggest that a National Intestinal Failure Unit be set-up to work in concert with the National Intestinal Transplantation Unit and provide advice to regional centres with IF patients whilst also assessing every patient referred for intestinal transplant

3. Recommend that each state of Australia has its own regional intestinal failure service which would need to be able to manage basic chronic IF, monitor HPN and insert and manage central venous catheters
4. Inform the development of a National Registry to collect data on patients on artificial nutrition within hospitals and in the community to benchmark patient outcomes and services against other regional, national and international trends.

5. Propose that national guidelines be formulated to assist training patients and/or their carers on managing their artificial nutrition support system

6. Recommend that patients receiving nutrition support are offered a review of the indications, route, risks, benefits and goals of nutrition support at planned intervals

DISSEMINATION PLAN

I intend to disseminate the knowledge and expertise that I have obtained during my Churchill fellowship via the following forums:

1. Seminars involving Gastroenterology networks – Gastroenterology Society of Australia at Australian Gastroenterology Week, Gut club and IBD Melbourne

2. Engagement with Nutritional networks – AusPEN and the Australian Nutrition Society including a webinar on Nutritional management of IBD to Australian Dieticians Association

3. Grand Rounds on Intestinal Failure and Transplantation at The Austin Hospital


5. Media and professional communities – via Crohn’s and Colitis Australia

6. My current appointment as Intestinal failure and Intestinal Transplant Physician at The Austin Hospital.

References


