TABLE OF CONTENTS

11 The Clinician’s Guide to Short Bowel Syndrome
   Carol Rees Parish, RD, MS

40 Pancreatic Diseases and Islet Cell Transplantation: Implications for Life Care Planning
   Nellie Kreimer, MSHCA, RN, CNLCP, CLNC, CLCP

48 Cystic Diseases of the Pancreas: Treatment and Outcomes
   Nellie Kreimer, MSHCA, RN, CNLCP, CLNC, CLCP

58 Medical Cannabis and Quality of Life in Irritable Bowel Disease
   Dana Filatova MS, CNS, LDN

62 Brief Life Care Plan Case Study
   Anonymous

DEPARTMENTS

3 From the Editor

4 Information for Authors

6 A Message from the President

8 Contributors to this Issue

71 Issue Index
Welcome to the JNLCP issue on a somewhat unusual topic, GI issues. While many of us learned about diabetes and gallstones in nursing school, most of us who do life care planning in litigation-related settings don’t often see things like pancreatic islet cell transplantation. Clinical trials are showing great promise; the FDA will be looking at authorizing this procedure on a non-research basis soon. (http://tinyurl.com/zklnwgr)

We received a very interesting submission with expanded information on medical cannabis receptors in the intestines, a follow-up by the same author who reviewed the study on medical cannabis and quality of life in irritable bowel disease. Unfortunately, it came in too late to include in this issue, but we will try to get it in later, so stay tuned.

For those of you who have total parenteral nutrition (TPN) in your cases, the redacted case study of a patient with short bowel syndrome should be useful. The author requested anonymity at the behest of the attorney involved in the case upon which the study is primarily based; the reprint article on short bowel syndrome from a GI clinical specialist nurse also includes plenty of useful information.

Recently a few of us who do both life care planning and case management received invitations to travel to Hill-Rom’s research and development center to learn about the science of surfaces for treating and preventing pressure injury. (This is the new preferred term from the National Pressure Ulcer Advisory Panel, since many injuries underlie intact skin without open wounds.)

It wasn’t just the science and engineering behind the 21st-century products, the variety of surfaces, therapeutic bed features, and lift / transfer systems that blew me away. It wasn’t the publications, references, and other supportive documentation they make available to anybody who needs them. It wasn’t the priceless clinical hints like using air-permeable underpads on low-air-loss surfaces, because regular plastic-backed ones completely defeat the therapeutic purpose. It wasn’t even the awesome engineering testing and the 3-D printer toys (now on my personal wish-list).

What struck me the most about our visit was … nursing. The clinical specialist whose constant flow of information filled up our notes. The way each of us kept finding occasion to say, “I wish I’d known that last week / last month / last year.” How we surprised and inspired their team as we explained what nurses know and how we use it. And, in the end, how we all got to know each other better.

As a profession we have so much to teach individuals, clients, groups, communities, and peers. Our Scope and Standards of Practice (2015) exemplifies that essence of nursing that we learned as students: assessing, analyzing, planning, implementing, yes; also learning, supporting, communicating, making practice more effective through constant improvement. And you can never know exactly when and how they will all come together.
Information for Authors

AANLCP® invites interested nurses and allied professionals to submit article queries or manuscripts that educate and inform the Nurse Life Care Planner about current clinical practice methods, professional development, and the promotion of Nurse Life Care Planning within the medical-legal community. Submitted material must be original. Manuscripts and queries may be addressed to the Editorial Committee. Authors should use the following guidelines for articles to be considered for publication. Please note capitalization of Nurse Life Care Plan, Planning, etc.

**Text**
Manuscript length: 1500 – 3000 words
- Use Word© format (.doc, .docx) or Pages (.pages)
- Submit only original manuscript not under consideration by other publications
- Put the title and page number in a header on each page (using the Header feature in Word)
- Use Times, Times New Roman, or Arial font, 12 point
- Place author name, contact information, and article title on a separate title page, so author name can be blinded for editorial review
- Use APA style (Publication Manual of the American Psychological Association)

**Art, Figures, Links**
All photos, figures, and artwork should be in JPG or PDF format (JPG preferred for photos). Line art should have a minimum resolution of 1000 dpi, halftone art (photos) a minimum of 300 dpi, and combination art (line/tone) a minimum of 500 dpi. Each table, figure, photo, or art should be on a separate page, labeled to match its reference in text, with credits if needed (e.g., Table 1, Common nursing diagnoses in SCI; Figure 3, Time to endpoints by intervention, American Cancer Society, 2003) Live links are encouraged. Please include the full URL for each.

**Editing and Permissions**
The author must accompany the submission with written release from:
- Any recognizable identified facility for the use of name or image
- Any recognizable person in a photograph, for unrestricted use of the image
- Any copyright holder, for copyrighted materials including illustrations, photographs, tables, etc.

All authors must disclose any relationship with facilities, institutions, organizations, or companies mentioned in their work. All accepted manuscripts are subject to editing, which may involve only minor changes of grammar, punctuation, paragraphing, etc. However, some editing may involve condensing or restructuring the narrative. Authors will be notified of extensive editing. Authors will approve the final revision for submission. The author, not the Journal, is responsible for the views and conclusions of a published manuscript. Submit your article as an email attachment, with document title articlename.doc, e.g., wheelchairs.doc

All manuscripts published become the property of the Journal.

Manuscripts not published will be returned to the author. Queries may be addressed to the care of the Editor at: whowland@howlandhealthconsulting.com

**Manuscript Review Process**
Submitted articles are peer reviewed by Nurse Life Care Planners with diverse backgrounds in life care planning, case management, rehabilitation, and the nursing profession. Acceptance is based on manuscript content, originality, suitability for the intended audience, relevance to Nurse Life Care Planning, and quality of the submitted material. If you would like to review articles for this journal, please contact the Editor.

**AANLCP® Journal Reviewers for this issue**
Kelly Campbell BSN RN CP CLCN
Dawn Cook RN LNCP-C CLCP CLNC
Mariann Cosby DNP MPA MSN RN PHN CEN NE-BC LNCC CLCP CCM MSCC
Shanna Huber MSN/Ed RN LSN CCM CLCP MSCC
Linda Husted MPH RN CNLCP LNCC CCM CDMS CRC
Kathy Pouch MSN RN-BC CCM CNLCP LNCC
Carole Upman RN MA CCM CRC CDMS CNLCP
Lynn Sayre Visser MSN BS RN CEN CPEN CLNC
Lora White BSN RN CNLCP CCM MSCC
Nancy Zangmeister RN CRRN CCM CLCP
A CORE CURRICULUM for NURSE LIFE CARE PLANNING

American Association of Nurse Life Care Planners

Dorajane Apuna-Grummer
Wendie A. Howland
Editors
I am happy to report that this year’s Annual Education Conference in San Antonio was a big success! After Aila Accad’s remarkable keynote address, we split up and with our Partners moved to round tables in the back of the room to participate in some guided networking to break the ice and get acquainted. This was a huge hit! Many attendees felt it set the tone for the entire conference. From pre-conference to the general sessions, feedback was overwhelmingly positive. Kudos to all planner and attendees! You made this year’s conference truly exceptional!

For those of you who were unable to join us in San Antonio, we were able to video some of the conference sessions. We’re currently in the process of loading them on our website and making them available for purchase. Be sure to take advantage of this special offer. Continuing education credits and presenter handouts from conference are included in all recordings.

Check out some new changes to our website!

- Tabs on the home page have been simplified so it’s easier to navigate, even for me!
- We have created a members’ Resource Page to access to all the membership benefits for your level conveniently at Membership >> Members Only.

Other resources on this page include

- Important Member Documents: AANLCP Standards of Practice and Ethical Statement, bylaws, meeting minutes, Policy and Procedures, and more.
- Member Search
- Willingness to Serve form to get involved as a volunteer
- Lifeline Mentorship Program
- AANLCP logo to download and use on your stationery or literature
- Suggestion Box We want to hear from you!

We’ve changed the evaluation process for our online educational programs/webinars (including the videos above) so you can download your continuing education certificates immediately. How easy is that!!

- Premier members: We’ve streamlined your Mastermind and webinar registration. We’ve given you the power to register for what YOU want. Just sign in and go to Resources >> Education then select the available programs that interest you.

And now a bit of trivia – Florence Nightingale was born in Florence, Italy on May 12, 1820 years ago. Named after the city of her birth, she was a statistician, social reformer, and laid the foundation for nursing by establishing standards of care and formalizing nursing education. I wonder what she would think about nursing in the 21st Century? Like Florence, many nurse life care planners tend to be dissatisfied in traditional roles. For some, perhaps it was the entrepreneurial spirit mixed with that subtle “calling” that gave us the courage to break traditional molds, striving to learn more, growing professionally, ultimately applying years of patient care experiences to what we do today. Let’s face it, it takes guts to be a nurse life care planner. We use our tremendous knowledge and experience to overcome complicated challenges. We use the nursing process to support logical, realistic plans that are understandable to the layman and defensible in court.

The annual National Nurses Week, May 6 to May 12, recognizes and celebrates nurses’ contributions to all health care. Nurse life care planners are nurses first, wherever we are. Yesterday, I removed a retained stitch from a neighbor’s forehead. Next week I will travel home to help family prepare for a loved ones passing. Later, I’ll be back on the stand to testify. Resilience is in our nature. Feel proud of all you’ve accomplished as nurses and as nurse life care planners. Your “lamp” lights the way for others! You make a difference! I salute you!!

Patricia Rapson, RN, LMT, CCM CLCP, CNLCP, LNCC, MSCC
President, AANLCP
president@aanlcp.org

Coming!
Summer 2017

Core Curriculum for Nurse Life Care Planning
2nd edition

To contribute, contact
AANLCP
801-274-1184
Contributors to this Issue

DANA FILATOVA
MS, CNS, LDN
("Medical Cannabis and Quality of Life in Irritable Bowel Disease")

As a Certified Nutrition Specialist (CNS) and Licensed Nutritionist (LD/N), my goal is to help you enhance your health and wellbeing through proper nourishment based on your body's bio-individual makeup and needs. I take a partnership care approach to working with you where we are both part of the same team, building realistic, healthy dietary and lifestyle habits together. You will get my full support and complete attention, helping you select just the right nourishment for your mind, body, and spirit. I take a holistic, functional, and science-based approach to your health and looking forward to working with you citations and links to those sources. He is a regular on several nursing specialty lists and is very open to contact from anyone to help with searches on any topic.

NELLIE KREIMER
MSHCA, RN, CNLCP, CLNC, CLCP
("Pancreatic Diseases and Islet Cell Transplantation: Implications for Life Care Planning" and "Cystic Diseases of the Pancreas: Treatment and Outcomes")

Ms. Kreimer has 28 years of nursing experience in home health care and case management of adult and disabled population with multiple comorbidities, and home and community hospice. She presently does legal nurse consulting and nurse life care planning with special interest in brain injury, spinal cord injury and neurological diseases. She is a member of the American Association of Nurse Life Care Planners, International Academy of Rehab Professionals, National Alliance of Certified Legal Nurse Consultants, American Association of Legal Nurse Consultants and North American Brain Injury Society.

CAROL REES PARISH
RD, MS
("The Clinicians Guide to Short Bowel Syndrome")

Carol has 35 years of clinical experience, the past 25 of which have been spent specializing in nutrition support and GI disorders at the University of Virginia Health System (UVAHS), Digestive Health Center. Carol founded the Medicine Nutrition Support Service in 1991, began the home nutrition support program at the UVAHS Home Health Company, developed the GI Nutrition Clinic, originated the UVAHS Celiac Support Group, and co-founded the UVAHS Nutrition Support Traineeship. She has been the nutrition series editor for the popular Practical Gastroenterology Journal’s Nutrition Series since 2003 having just published over 148 articles in the series. She can be contacted at crp3a@virginia.edu
NRI
Neurologic Rehabilitation Institute at Brookhaven Hospital

Rehab That Works!
Hospital and Community-based Rehabilitation by Brain Injury Specialists

Intensive Neurobehavioral  TBI Dual Diagnosis
Complex Care  Long-term Supported Living

Specialized Care in a Healing Environment

Neurology  Cognitive Rehabilitation
Psychiatry  Behavioral Therapy
Internal Medicine  Specialized Nursing Care
Neuropsychology  Social Work
Speech Therapy  Recreational Therapy
Occupational Therapy  Dietary & Nutrition Therapy

888-298-HOPE (4673)
www.traumaticbraininjury.net

Accredited by the Joint Commission
The Bridge to a Meaningful Recovery

For over 35 years Centre for Neuro Skills (CNS) has been recognized as an experienced and respected world leader for providing intensive postacute community-based brain injury rehabilitation. With facilities in California and Texas, the highly-trained CNS staff offers outcome driven medical treatment, therapeutic rehabilitation and disease management services for individuals recovering from acquired and traumatic brain injury.

For additional information about CNS, please visit us at neuroskills.com or call us at 800.922.4994.
The Clinician’s Guide to Short Bowel Syndrome

Carol Rees Parrish

Individuals with short bowel syndrome (SBS) are some of the most challenging patients for health care practitioners to manage. In addition to complex fluid, electrolyte and nutritional issues, clinicians must also treat ongoing medical problems and facilitate the administration of total parenteral nutrition (TPN). Appropriate attention to these issues can significantly improve the quality-of-life for a patient with SBS. This article is intended to provide the clinician with a logical, stepwise approach toward maximizing the potential of the remaining bowel of an adult patient with SBS in order to reduce or eliminate the use of TPN or intravenous (IV) therapy.

CASE STUDY

S M, a 35-year-old woman, presents for an initial visit to gastroenterology (GI) nutrition clinic with a diagnosis of short bowel syndrome. Her medical history is significant for stage III B ovarian cancer which required 4 bowel resections and a course of chemotherapy within the past four years. She had not received radiation therapy. Total parenteral nutrition (TPN) was initiated via a Hickman catheter 5 months earlier due to failure to thrive and multiple admissions for dehydration and electrolyte disturbances including one septic episode to date. She recently moved to the area to be closer to family with her active 5-year son and she divulged in clinic that her primary goal is to see him start kindergarten. She is 5’3”, has been stable at 98 pounds (lbs), but remains 22 lbs below her usual weight of 120 lbs. Her only medication is Estrase. She is on nocturnal TPN that infuses over 14 hours. The TPN provides 1600 kilocalories, (80 grams of which is pro-
tein) in a total volume of 1800 mL. SM admits that she occasionally skips her TPN infusion and that her oral intake, though not restricted, is sporadic. Now, where do we begin?

INTRODUCTION

Patients with SBS offer a unique challenge to clinicians. In addition to the fluid, electrolyte and nutritional issues, clinicians must help patients manage the very difficult sequelae that result from the physiologic changes occurring in SBS. There are many excellent reviews of SBS (1–2, Best Practice Series—see other references), but this article will focus on providing specific management principles to optimize the chronic care of the patient with SBS.

Diarrhea and steatorrhea, cardinal symptoms of SBS, occur when the fluid-substrate load exceeds the absorptive capacity of the remaining, viable mucosa. This may result from: changes in motility; increased gastric secretions; osmotic stimulation from fatty acids, deconjugated bile salts and carbohydrates (CHO); bacterial overgrowth; lactose intolerance and/or fatty acid irritation of the colon. In addition to osmotic drag from hypertonic medications, food and fluids within the intestinal lumen also contribute to the diarrhea and malabsorption seen in these patients. See Table 1 for a review of intestinal water movement and Table 2 for electrolyte content of intestinal secretions.

DEFINITION

Many definitions exist for SBS. It can be broadly defined as an inadequate absorptive capacity due to decreased length and/or decreased functional bowel. Typically, a 70%–75% loss of small bowel will result in SBS. SBS has also been defined as a bowel length of 100–120 centimeters (cm) of small bowel (SB) without a colon, or 50 cm of SB with a colon. In truth, the real definition of SBS is inadequate functional bowel to support nutrient and fluid requirements for that individual, regardless of the length of the GI tract in the setting of normal fluid and nutrient intake.

ETIOLOGY

The etiology of SBS is multifactorial and unfortunately, the disorder can occur at any age. However the causes differ somewhat between children and adults (Table 3). Regardless of the origin, much of the clinical intervention remains the same.

(continued on page 70)
The Clinician’s Guide to Short Bowel Syndrome

NUTRITION ISSUES IN GASTROENTEROLOGY, SERIES #31

(continued from page 68)

Table 3
Etiology of Short Bowel Syndrome in Children and Adults (2,31)

Children
- Necrotizing Enterocolitis (NEC)
- Intestinal atresia
  - Volvulus
  - Hernia
  - Intussusception
- Congenital short bowel syndrome
- Trauma
- Gastrochisis
- Apple peel anomaly
- Crohn’s disease
- Abdominal tumors
- Radiation enteritis
- Hirschsprung’s disease

Adults
- Massive surgical resection
- Crohn’s
- Malignancy
- Radiation enteritis
- Trauma
- Vascular catastrophies
  - Embolism/thrombus
  - Volvulus
- Stangulated hernias
- SB fistulas
- Surgical bypass
- Surgical error or obesity treatment
- Chronic intestinal pseudo-obstruction

ADAPTION

Adaptation is the time it takes for the gut to adjust to the damage that’s been done. The bowel compensates for a reduction in surface area by increasing the length and diameter of the remaining bowel, by villous hyperplasia (increase in the number and size of crypts and villi, cell proliferation and enhanced enzyme activity), and by altering motility and hormonal responses. The ultimate effect is to maximally increase the remaining luminal absorptive capacity.

Factors Affecting Adaptation/Success of Remaining Free of TPN or IV Fluids

Many factors affect intestinal adaptation and successful transition from TPN to enteral nutrition in the SBS patient, one of the most important is the length of the remaining bowel. It cannot be over emphasized that clinicians must make every effort to determine the extent of available bowel (e.g., by reviewing operative or radiation oncology reports or discussing the length of resection with the surgeon). The location of small bowel resection and overall health of the remaining small bowel will also affect a SBS patient’s adaptation potential as well as the presence of an ileocecal (IC) valve or any portion of the colon. Another consideration is the length of time that has elapsed since the initial surgery or insult. Lastly, the age of the patient and any other GI organ involvement (e.g., pancreas, liver, stomach) may play a role in future adaptation.

Adaptation can be enhanced by stimulating the residual bowel via macronutrient (protein, fat, carbohydrate) exposure. Furthermore, nutrient complexity also increases the functional workload of the digestive mechanisms involved. As an example, monosaccharides require no digestion, thus they result in little hyperplasia as compared to polysaccharides (Wilmore-Best Practice Series). Providing more complex macronutrients to the remaining bowel is therefore an extremely important factor in the successful transition to enteral nutrition.

Adaptation may take up to 1–2 years. Factors affecting the adaptation process include:
- Stimulation by intraluminal nutrients
- Stimulation by bile and pancreatic secretions
- Trophic effects of gut hormones
- Altered intestinal blood flow
- Altered enervation

It is important to recruit as many of these factors as possible to achieve maximal adaptive potential of the mucosal surface area by way of hyperplasia, deeper crypts and increasing the absorptive capacity per cm of the remaining intestinal surface area.

GOALS OF MANAGEMENT

The primary goal in managing SBS is to maximize the utilization of the existing gut while assuring that patients are provided with adequate nutrients, water and electrolytes to maintain health and/or growth. Clinicians must focus on reducing the severity of intestinal failure while treating and preventing complications when they arise. To improve the chance for successful
weaning from TPN or IV fluids, it is essential to increase nutrient and fluid retention by slowing intestinal transit time, controlling gastric acid hypersecretion and by enhanced mixing of pancreatic enzymes and bile salts. Additionally, it is imperative to feed in the most proximal bowel location, to avoid osmotic agents, and to treat bacterial overgrowth when necessary.

**REVIEW OF THE ACTIVE PLAYER— THE GI TRACT**

The following section will review the primary structures and functions of the small and large intestine.

**Small Bowel**

**Duodenum**

A powerhouse for absorption, the duodenum, measuring about 25–30 cm (~10 inches) is rarely involved or resected. It is the preferred site of absorption for iron and folate. However, it is a key player as pancreatic enzymes and bile salts enter here to mix with food.

**Jejunum**

The jejunum ranges in length from 200–300 cm (6–10 feet) and is responsible for much nutrient absorption, in fact, >90% of nutrient absorption occurs in the first 100–150 cm of the SB. Jejunal enterohormones including cholecystokinin (CCK), secretin, gastric inhibitory peptide and vasoactive inhibitory peptide each play a specific role in absorption. It is essential to remember the important role of each of these enterohormones when managing the SBS patient. CCK stimulates pancreatic secretion and gall bladder contraction while secretin is responsible for bicarbonate secretion. Gastric inhibitory peptide inhibits gastric secretion and gastric motility, and finally, vasoactive inhibitory peptide inhibits gastrin and bicarbonate secretion. Another important role of the jejunum is drug absorption; many, but not all drugs, are absorbed in this section of small bowel (4).

**Ileum**

The ileum, about 300–400 cm (10–13 feet) long, has a functional length almost double that of the jejunum. In addition, the ileum’s intrinsic motility is much slower than that of the jejunum (2). A phenomenon known as the ileal break—a slowing of intestinal transit in the stomach and upper gut in response to undigested carbohydrate (CHO) and fatty acids entering the ileum—provides an opportunity for more nutrient contact time with the mucosa and therefore greater nutrient absorption (5).

If greater than 100 cm of terminal ileum is lost, the bile salt pool cannot be maintained due to the disruption of the enterohepatic circulation; hepatic synthesis will not keep pace with intestinal losses. This reduction in bile salts may result in steatorrhea and fat-soluble vitamin loss. Absorption of vitamin B₁₂ can be impaired if >60 cm of terminal ileum is resected. Glucagon-like peptide 1 and 2, peptide YY and neurotensin are important neurohormonal mediators released by the terminal ileum that impart trophic effects on the mucosa. If the ileocecal region is removed, then this mechanism is lost. GLP-2 is receiving closer scrutiny as a therapeutic agent in the treatment of SBS (6). It is worth noting that jejunal resection is better tolerated than ileal resection due to the unique characteristics of the ileum and its adaptation potential.

**Ileocecal Valve**

The ileocecal (IC) valve, at the junction of the ileum and cecum, controls the amount, and slows the passage of ileal contents into the colon, thereby increasing nutrient/lumen contact time in the proximal GI tract. The IC region possesses specific absorptive functions and plays a crucial role in the regulation and integration of postprandial gastrointestinal motility and secretion. Finally, the IC valve also prevents reflux of colonic bacteria into the small bowel, decreasing the risk for bacterial overgrowth.

**Role of the Colon—Colon Matters!**

The colon measures about 160 cm (5 feet) in length and on average recovers approximately 1–1.5 liters of electrolyte-rich fluid daily. The colon is highly adaptable and can increase its absorptive capacity 3 to 5 fold, with a maximal absorption of approximately 5–6 L per day. Notably, sodium, chloride and water are avidly absorbed here.

In a normal adult, the gastro-colic reflex occurs within 10 minutes of eating, however (chyme, food) remains in the right colon for 8 hours, 6–8 hours in the
transverse colon and about 4 hours in the descending colon. Stool, 70% water by weight, enters the colon at approximately 50 mL/hr.

Preservation of at least half of the colon is equivalent to retaining 50 cm of functional SB. SBS patients with remaining colon will have a qualitative and quantitative alteration in colonic flora resulting in an increased capacity to metabolize CHO. CHO and fiber fermentation result in the production of short chain fatty acids (SCFA) that are absorbed in the colon, providing up to 525–1170 kilocalories per day (7,8). Recently, Epperson demonstrated that medium chain triglycerides (MCT) share the ability of SCFA to be absorbed by the colon in patients with mean residual SB length of 143 cm (9).

WHAT THE CLINICIAN IS UP AGAINST—PHYSIOLOGIC CHANGES

Gastric Hypersecretion

After significant resection of the small bowel, gastric hypersecretion (particularly problematic when jejunal surface area is lost) must be addressed. Lasting up to 6 months or longer post-operatively, it not only increases the sheer volume of secretions entering the small bowel, but also drops the pH of the upper gut. Hypersecretion results from loss of CCK and secretin secretion/feedback, which regulates gastrin secretion. Without this control, gastrin levels remain high, signaling acid production to continue. Not only is the increased acid load caustic to the proximal small bowel, the added volume of secretion contributes to the total stool output. Finally, the higher concentration of acid being dumped into the upper gut denatures pancreatic enzymes and}

### Table 4
**Clinical Sequelae of Gastric Hypersecretion**

- Alters degradation of “R” protein and hence release of B12 for binding to intrinsic factor
- Impairs pancreatic enzyme activity
- Destroys pancreatic lipase
- Precipitates bile salts and disrupts micelle formation
- Acid damage of duodenal mucosa
- Stimulates peristalsis

### Table 5
**Acid Reducing and Other Anti-secretory Agents**

#### Proton Pump Inhibitors (PPI)*
- Need >50 cm of jejunum to absorb
- Liquid form may be better utilized
- Suggest trial of Intravenous pantoprazole (if absorption is in question)
  - Nexium (esomeprazole)—40 mg bid
  - Prilosec (omeprazole)—40 mg bid
  - Prevasid (lansoprazole)—30 bid
  - Protonix (pantoprazole)—40 bid

#### Histamine2-Receptor Antagonists*
- Cimetidine (Tagamet)—400 mg oral or IV qid
- Famotidine (Pepcid)—40 mg bid
- Ranitidine (Zantac)—300 mg bid

#### Instructions/Preparations of PPIs

- **TAP Pharmaceuticals, (800) 622-2011; www.prevacid.com**
  - Lansoprazole
    - Solu-tab
      - Dissolves under the tongue if oral intake acceptable
      - For tube delivery: mix 30 mg tab with 10 mL water and flush down feeding tube
    - Oral suspension—reconstitute with water (do not put down feeding tubes—will clog!)
- **AstraZeneca, (800) 236-9933; www.astrazeneca.com**
  - Esomeprazole, Omeprazole
    - To make liquid with capsules:
      a) Empty Omeprazole capsule into glass containing 20 mL water
      b) Add 1/2 teaspoon baking soda
      c) Let stand for 15 minutes
      d) Mixture can be made in quart quantities and lasts for weeks to months if kept refrigerated and out of the sunlight
  - Omeprazole (Zegerid) powder
    - Empty the contents of the packet into a small cup containing 2 tablespoons of water.

#### Other Anti-Secretory Agents

- Octreotide (a somatostatin analog)
  - 50–250 mcg to TID-QID (subcutaneously)
  - May be needed if insufficient jejunum to absorb a PPI (<50 cm)
- Clonidine
  - 0.1–0.3 mg up to TID

*Note: If oral, take on an empty stomach at least 1 hour before food.*

(continued on page 74)
The Clinician’s Guide to Short Bowel Syndrome

NUTRITION ISSUES IN GASTROENTEROLOGY, SERIES #31

Table 6
LAR Depo-Octreotide—Considerations for Clinicians

Novartis has a very good program for anyone who does not have prescription coverage, including Medicare patients. Call 1-877-LAR-HELP. Novartis will do financial screening and provide reduced pricing or free drug for patients who qualify.

The LAR must be given in a facility where staff is trained to mix and administer as it is very tricky to give. It is a suspension, which hardens immediately in the needle if you don’t mix correctly.

One Physician’s Practice at UVAHS:
- Start patients out on 50 mcg TID for 2 days (every 8 hours)
- Increase to 100 mcg TID for 2 days
- Followed by 150 mcg TID for 2 days
- Finally, bring them in for the first LAR injection, usually start at 20 mg monthly.
- Continue the short acting for another week until a level is achieved and then stop. Observe for about an hour after the first short acting injection as patient may have profound swings in blood pressure or other side effects such as headache or nausea. If your patient is diabetic, pay attention to glucose levels—may have hypo- or hyperglycemia.

Patients can self-inject the remaining short acting at home and then return for the LAR.

Motility

The body maintains several mechanisms to slow the transit of nutrients through the small bowel to obtain maximum nutrient salvage. Delivery of food from the stomach into the upper gut is regulated by pathways within the ileum and colon, segments often lost in SBS. These mechanisms include maximal mixing of pancreatic enzymes and bile salts with foodstuffs along with feedback produced by intestinal hormones such as glucagon-like peptide 1 and 2, neurotensin and peptide YY (PYY) (Keller-Best Practice). These hormones delay gastric emptying and slow intestinal transit by way of the ileal brake. These processes are only available if the ileocecal region remains intact. Exposure of undigested nutrients, primarily CHO and fat in the ileum, induces the ileal brake, thereby inhibiting digestive secretory and motor functions, and consequently slowing gastric motility. Loss of this segment of ileum may contribute to gastric hypersecretion and accelerated small bowel transit. The ileocecal valve also acts
to decrease transit time by regulating the rate that ileal contents are dumped into the colon. Finally, the rate of liquid gastric emptying may be slowed in those patients with an intact colon segment. This is most likely due to elevated circulating levels of PYY as a result of unabsoerd nutrients reaching the colon (1).

Anti-motility agents are the primary treatment to slow intestinal transit (Table 7). In the clinical setting, patients should receive a trial of less potent (e.g., loperamide [Imodium]) gut slowing medications with a plan to titrate up or change to more potent, prescription agents (e.g., diphenoxylate (Lomotil), opiates such as codeine or tincture of opium, etc.) if needed. Imodium has no effect on the central nervous system unlike Lomotil, nor is it sedating or addictive like the opiates, hence most clinicians prefer Imodium. Clinicians are often too tentative with the stronger anti-motility agents because of the high doses required, resulting in cumbersome stool output and persistent need for IVF. In “refractory secretors,” a trial of both Imodium and codeine phosphate together may have a greater effect than either agent alone (11).

Because endogenous intestinal output rises after meals, it is imperative that these medications be given one half to one hour before mealtimes and at bedtime to ensure they do not compete with food or fluid for mucosal contact; if receiving enteral feeding, do not hold feedings, but scheduled dosing may be even more important. Furthermore, if a patient is willing to take a scheduled dose of anti-motility medication every 6 hours (because the patient is up at night anyway), this may improve overall efficacy.

### Small Bowel Bacterial Overgrowth

Following bowel resection, patients are often at higher risk for small bowel bacterial overgrowth (SBBO). Factors that increase this risk include loss of the ileocecal valve, the presence of blind loops (ex. Bilroth II anastomosis), slowed motility, acid suppression, and underlying disease processes such as chronic pseudoobstruction (13). Symptoms can range from gas, bloating and nausea, to frank diarrhea. Although not a specific indicator, elevated serum folate levels may signal SBBO. B12 deficiency can also accompany SBBO due to decomposition of the B12-intrinsic factor complex.

#### Table 7

<table>
<thead>
<tr>
<th>Antidiarrheal Medications Commonly Used in Short Bowel Syndrome (11,41)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>General Guidelines</strong></td>
</tr>
<tr>
<td>Give 30–60 minutes before meals or snacks, but not more than every 6 hours.</td>
</tr>
<tr>
<td>If patient gets up in the middle of the night and does not mind taking a medication, then dose every 6 hours and take advantage of a time when foods/fluids are not competing for absorptive surface area.</td>
</tr>
<tr>
<td>Use elixir forms—no sustained release!</td>
</tr>
<tr>
<td>Titrate up to maximal dose, . . . and then some if necessary; try increasing doses every 2–4 days</td>
</tr>
<tr>
<td>Imodium circulates through the enterohepatic circulation, hence higher doses may be needed in patients with &gt;100 cm ileum lost.</td>
</tr>
<tr>
<td>Increase dose until the stool consistency is adequate for patient or the patient is too sedated/unable to perform activities of daily living—whichever comes first.</td>
</tr>
</tbody>
</table>

**Antidiarrheals**

- **Imodium** (loperamide)
  - Initial, 2–6 mg up to QID, then up to 12–24 mg at a time in patients with disrupted entero-hepatic circulation (see above).
- **Lomotil** (diphenoxylate)
  - 2.5–5 mg up to QID
- **Codeine**
  - 15–100 mg up to QID
- **Morphine**
  - 2–20 mg up to QID
- **Tincture of Opium**
  - 0.3–1.0 mL up to QID
- **Paragoric**
  - 5–10 mL BID-QID

**For Oral/enteral:** It is important to remember that codeine, morphine, and methadone equivalents are not exact and different references have different approximate equivalents. 1 mL opium tincture = 25 mL Paregoric = 65 mg codeine = 10 mg morphine = 5 mg methadone = 5 mg oxycodone

**Note:**

- **Avoid the use of “drops” to avoid dosing errors;** both paragoric and tincture of opium are 20 drops/mL, however the syringe sizes differ

*In general 1 mL = 20 drops for most medications, however, due to inaccuracies of droppers, this type of dosing is not recommended, especially in light of easy access to graduated syringes.*
SBBO produces inflammatory changes to the intestinal mucosa and consequently increases gut permeability and a net loss of fluid into the lumen. In addition, SBBO can deconjugate bile salts in the upper gut, causing impaired micelle formation, which ultimately results in fat malabsorption and fat-soluble vitamin deficiency.

Although hydrogen breath tests are available to aid in the diagnosis, most clinicians empirically treat for SBBO due to the many controversies surrounding these tests (e.g., which substrate to use, interpretation in the setting of rapid transit, cost of test [and lack of insurance carriers to cover this cost] and time involved for patient). Treatment of SBBO consists of a 7–10 day course of enteral antibiotics. See Table 8 for commonly used antibiotics and suggested dosing.

### Pancreatic Enzymes

Pancreatic enzyme supplementation is rarely necessary in SBS patients. However, when surgical anatomy creates a mismatch of pancreatic secretion and delivery of food into the small bowel, such as in the unfortunate patient who also has a Bilroth II or Roux-en-Y anastomosis, pancreatic enzyme supplementation may be necessary. In addition, patients with pancreatic insufficiency from chronic pancreatitis or cystic fibrosis may also require supplementation. If treatment is empiric, this intervention should be initiated AFTER acid reduction and gut slowing have been maximized to optimize the pH for enzyme function and for enzymes to have enough time to adequately mix with food. In the event the patient should require Viokase powder to mix with enteral formula, make sure the patient’s pharmacy carries it or is able to obtain it.

### Bile Salts and Cholerrheic Diarrhea

Bile salts, required for fat and fat-soluble vitamin absorption, are recycled daily from the ileum via the enterohepatic circulation. One hundred centimeters of ileum are needed for this pathway to remain viable to complete bile salt absorption. Steatorrhea can occur if <100 cm of ileum remains as the bile salt pool cannot be maintained since the bile salt loss in the stool exceeds its rate of synthesis within the liver. Loss of the bile salt pool leads to impaired micelle formation thereby decreasing solubilization of fat in the lumen. Steatorrhea further aggravates the loss of fat-soluble vitamins. Some medications also circulate through this pathway (e.g., cyclosporin), hence higher doses may be needed to achieve efficacy (1,4).

In patients with less than 100 cm of remaining ileum, in the presence of an intact colonic segment, watery diarrhea (cholerrheic diarrhea) can occur due to...
the pro-secretory effect of bile salts on the colonic mucosa. Colonic bacteria deconjugate the bile salts resulting in mucosal inflammation, colonic secretion, reduction in sodium and water absorption, increased oxalate permeability, and decreased stool pH.

Treatment includes cholestyramine to bind bile salts (Table 9), calcium supplementation to bind oxalate (11), and possibly treatment of SBBO, which may also cause deconjugation of bile salts.

**SPECIAL CONCERNS**

**Osteoporosis**

The eventual development of bone disease plagues most patients with SBS, in fact, up to 30% of patients will have osteomalacia. Malabsorption of vitamin D and calcium are contributing factors. Persistent inflammation in those whose underlying disease is not yet quiescent (e.g., Crohn’s disease) may increase osteoclastic activity adding to the problem. Chronic metabolic acidosis from the loss of bicarbonate in the stool, or in those with renal insufficiency due to repeated episodes of dehydration, ultimately diminishes the buffering capacity of the kidneys and can thereby reduce bone mineral content. Hypomagnesemia can also play a role in the development of osteoporosis. Magnesium is needed both for secretion of parathyroid hormone (PTH) as well as proper action of PTH on target organs such as the osteoblast and renal cell. A long history of steroid use may also increase the risk of bone disease via reduced osteoblast activity, increased urine calcium loss and further reductions in calcium absorption from the gut.

A baseline dual energy x-ray absorptiometry (DXA) scan should be obtained on all patients with SBS and followed every one to two years along with periodic assessment of 25-OH vitamin D levels (not 1, 25-OH vitamin D). Target levels for 25-OH vitamin D remain under debate, but should be in excess of 25-30 ng/mL. Monitoring vitamin D levels is essential even in patients routinely receiving vitamin D in TPN. Checking serum PTH will help with early identification of those patients who need more intensive intervention.

Treatment should be aimed at the provision of adequate vitamin D (with resultant decline in alkaline phosphatase and PTH levels), eliminating metabolic acidosis if present and replacement of magnesium if necessary (see section below on hypomagnesemia). It is worth noting that patients with malabsorption may need up to 1–2 micrograms of oral Rocaltrol® to have an effect (author’s experience). Finally, there is a tendency towards metabolic acidosis in patients with SBS; bicarbonate in the form of acetate may need to be added to TPN/IV solutions or given oral/enterally to correct it. Administer sodium bicarbonate powder, liquid, tablets or wafers in doses of 8–12 g/day orally (14). Use caution with the commonly used Shohl’s solution, a liquid form of sodium bicarbonate as it often contains sorbitol!!

**Nephrolithiasis**

Calcium oxalate stones can be an unpleasant complication in the SBS patient with an intact colon. Calcium oxalate stones have been reported in as many as 60% of patients (15, Keller-Best Practice). Patients without a colon are not at increased risk for this complication. The mechanism of stone formation is multifactorial. In the normal gut, calcium binds to oxalate forming an unabsorbable complex of calcium oxalate, which is then excreted in the stool. In the setting of steatorrhea, due in part to defective micellar solubilization of fatty acids, increased intraluminal free fatty acids are available to preferentially bind to calcium, resulting in an increased concentration of free dietary oxalate. This highly soluble oxalate is readily absorbed across the colonic mucosa where it ultimately is excreted via the kidney. Additionally, there is an increase in colonic permeability to oxalate stemming from the caustic effects of unabsorbed bile salts.

The risk of nephrolithiasis is compounded by volume depletion, metabolic acidosis and hypomagnesemia, resulting in a decrease in renal perfusion, urine output, pH and citrate excretion. Nephrolithiasis may lead to progressive symptomatic renal impairment if not identified and treated appropriately. The most important intervention in these patients is to ensure a urine output of >1200 mL/day or more, in those patients proven to be stone formers (14,16,17, Wilmore-Best Practice).

To avoid nephrolithiasis, the patient should be advised to avoid excess fat and high oxalate-contain-
ing foods (Table 10). A lower fat diet (but not low fat, i.e., <60–80 grams per day), will decrease saponification of calcium and fatty acids in the intestinal lumen, leaving more calcium to bind to oxalate. In concert, provide more enteral calcium so more is available for binding with oxalate, decreasing oxalate availability for absorption (14, Keller-Best Practice). Oral calcium supplements of 800–1200 mg/day, in divided doses, not exceeding more than 500 mg, is typically used. Another strategy includes the use of cholestyramine, 4 grams three times daily, to bind oxalate found in the gut lumen (11).

**d-lactic acidosis**

*d*-lactic acidosis is a rare complication seen in patients with SBS with an intact colonic segment; loss of the ileocecal valve is another predisposing factor (11,14). Its cause can be traced to malabsorption of CHO, especially of refined sugars. Colonic bacteria ferment CHO and refined sugars to produce SCFA and lactate. These fermentation by-products lower the colonic pH. Over time, growth of some of the normal flora is inhibited in this more acidic environment, promoting acid-resistant anaerobes such as lactobacillus (e.g., Bifidobacterium, *L. acidophilus*, *L. casei* and eubacterium). These organisms have the capacity to produce *d*-lactic acid, an acid not metabolized by humans due to the lack of *d*-lactate dehydrogenase. The colon then absorbs the *d*-lactate resulting in a metabolic acidosis. Symptoms of *d*-lactic acidosis include mental status changes, ataxia, blurred vision, ophthalmoplegia and nystagmus. Patients present with a large anion gap, severe metabolic acidosis and may have symptoms that mimic Wernicke’s encephalopathy.

Patients at high risk for *d*-lactic acidosis should be monitored for elevated serum and urinary *d*-lactate (when measuring serum lactate; L-lactate is what is measured and this will be reported as normal)—confirmed by elevation >3 mmol/L; (normal is <0.5 mmol/L), hyperchloremia and an elevated anion gap. Treatment includes antibiotics (metronidazole, neomycin, vancomycin for 10–14 days) thiamine supplementation (*d*-lactic acidosis may be worse in the setting of thiamine deficiency), and avoidance of refined CHO.

### BACK TO OUR PATIENT—FIRST STEP—DATA GATHERING

The key to caring for patients with SBS is to address one thing at a time. This avoids overtreatment and keeps the nutrition regimen as simple as possible. A stepwise approach from the initial assessment is presented below.

1. **Start a patient demographic sheet.**
   Key information should be compiled onto one form and remain permanently in front of the patient’s chart for quick reference. Consider outlining essential information about the patient such as intact gallbladder, length of remaining bowel, etc., in a table or chart format (Table 11).

2. **Defining Anatomy—Do you know your patients anatomy—REALLY?**
   Given the complexity of these patients and the often long-standing relationship that may ensue, it is essential to determine not only the length of bowel resected but also the length of bowel remaining. Often patients present to clinic or to the hospital with only a vague

---

**Table 10**

**Foods and Beverages High in Oxalates (11,46)**

**Fruits:** Raw apricots, blackberries, cherries, currants, figs, raw gooseberries, concord grapes, raw orange, raw pear, plums, rhubarb, strawberries, tangerines, prunes, lemons, limes, orange peels

**Vegetables:** Artichoke, baked beans, green and wax beans, beets, beet greens, raw red cabbage, celery, Swiss chard, escarole, chives, collards, eggplant, endive, leeks, mustard greens, Dandelion greens, okra, green peppers, rutabagas, spinach, kale, summer squash, sweet potatoes, parsley, tomatoes, tomato soup or juice, and vegetable soup, white corn, legumes

**Nuts:** Almonds, cashews, peanuts, peanut butter, pecans, and nut butters

**Beverages:** Chocolate/chocolate containing beverages, cocoa, colas, Ovaltine, tea, instant coffee

**Starches:** Grits, wheat germ, whole wheat bread, french fries, bran cereal

**Other:** Grits, tofu, soy products, black olives, chocolate, pepper (>1 tsp per day), vegetable soup with above vegetables

**Alcohol:** Draft beer
The recollection of their anatomy. Discussions with their surgeon may be useful to determine what segments of bowel remain and which have been resected. Operative reports and a small bowel follow through (SBFT) should be reviewed, but oftentimes their results may not always reflect the patient’s true anatomy. A directed or timed SBFT may be more useful as a timed SBFT allows the radiologist to watch the contrast going through the small bowel rather than shooting a plain film every 5–15 minutes—it gives a better idea of gross anatomy and timing of transit.

### Table 11
Demographic Checklist For Short Gut Patients—Quick Reference

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Etiology of SBS</td>
<td></td>
</tr>
<tr>
<td>Date of surgery/ segment resected</td>
<td></td>
</tr>
<tr>
<td>Duodenum intact</td>
<td></td>
</tr>
<tr>
<td>Jejunum remaining</td>
<td></td>
</tr>
<tr>
<td>Ileum remaining</td>
<td></td>
</tr>
<tr>
<td>Colon remaining</td>
<td></td>
</tr>
<tr>
<td>Ileocecal valve</td>
<td></td>
</tr>
<tr>
<td>Cholecystectomy</td>
<td></td>
</tr>
<tr>
<td>Venting g-port</td>
<td></td>
</tr>
<tr>
<td>Fistulas/JP drains</td>
<td></td>
</tr>
<tr>
<td>History of kidney stones</td>
<td></td>
</tr>
<tr>
<td>Status of key organs</td>
<td></td>
</tr>
<tr>
<td>• Stomach</td>
<td></td>
</tr>
<tr>
<td>• Pancreas</td>
<td></td>
</tr>
<tr>
<td>• Liver</td>
<td></td>
</tr>
<tr>
<td>• Kidneys</td>
<td></td>
</tr>
<tr>
<td>SBFT</td>
<td></td>
</tr>
<tr>
<td>• Date</td>
<td></td>
</tr>
<tr>
<td>IV/TPN</td>
<td></td>
</tr>
<tr>
<td>• Central line</td>
<td></td>
</tr>
<tr>
<td>– Type</td>
<td></td>
</tr>
<tr>
<td>Enteral Access</td>
<td></td>
</tr>
<tr>
<td>• Type</td>
<td></td>
</tr>
<tr>
<td>Other drains</td>
<td></td>
</tr>
<tr>
<td>• Type</td>
<td></td>
</tr>
</tbody>
</table>

### Table 12
Typical ostomy/stool output with each type of resection (11)

- Colostomy = 200–600 mL/day
- Jejunostomy = up to 6 liters/day; must limit oral fluids and give IV or a vicious cycle will result—excess oral fluid in—increases stoma output
- Ileostomy = Initial = 1200 mL/day; down to ~600 mL/day

3. Past Medical and Surgical History

Identify any other underlying processes that may play a role in your ability to manage your patient. Specifically note the presence or absence of a gall bladder, history of kidney stones, progressive renal failure, diabetes mellitus or underlying Crohn’s disease. Repeat renal stones or progressive renal dysfunction is a red flag that hydration needs attention (see the section on I and O below). Too many patients with SBS unnecessarily “live on the edge,” of adequate hydration.

4. I and O.

- All patients with SBS should have a baseline 24-hour urine and stool output collection. This can be done in the hospital or at home. Monitoring urine and/or stool output should continue 1–2 times per week while interventions take place until the patient is stable. See Table 12 for normal ostomy output depending on the location in the bowel. This will give the clinician and patient objective information as to whether the interventions are, or are not, making a difference. For patients who are functioning reasonably well, urine and stool collection can be done on their CURRENT regimen and then changes can be made accordingly.

- For patients who are failing to thrive—start over! Stop all non-essential enteral medications, nutrients and fluids—this will remove any osmotic contribution. Next, obtain a 24-hour stool output while the patient is NPO. This will help differentiate patients who are “net secretors” (>800 mL stool or ostomy output while taking nothing by mouth/24 hours) from those whose stool output is driven primarily by osmotic agents, food and fluids. If a hospitalized patient is going for a procedure, the clinician may be able to get this information during the overnight fasting period. Remember to AVOID stool collections in patients going for procedures in which gastrograffin or a bowel cleansing (e.g., Colyte, etc.) prep is used!
• The collection can be made more accurate by having the patient use a stool hat for both stool and urine output (measured and recorded separately). See Appendix I for a simple data collection form that can be given to patients. Any other losses from venting g-ports, fistulas or surgical drains should also be documented. In the hospital setting, assume ostomy output is > than that recorded on the nursing I & O sheets if leakage is a common problem or the wound and ostomy nurse (enterostomal therapist) is frequenting the patients room because the appliance will not stay on.

• All enteral, IV and/or TPN regimens must be documented including infusion time and volume of each therapy.

• A 72-hour quantitative fecal fat assay may be required to document medical necessity for TPN (18). A quantitative fecal fat is more accurate than a qualitative fecal fat. The former determines the amount of malabsorbed fat whereas the latter only gives a (+) or (−) determination IF there is fat in the stool. Fecal fat collections done at home are typically more reliable than those obtained in the hospital setting—where it is not uncommon for patients to be started on a 72-hour fecal fat collection only to be made NPO for a procedure. Too often, hospitalized patients are deemed negative for fat in their stool when they never had the opportunity to put any in their gut! For results to be accurate, patients must consume fat (and enough of it), either by mouth or feeding tube, in order for them to malabsorb it. See Table 13 for guidelines for a 72-hour fecal fat collection and Appendix II for a sample 100 gram fat diet for patients to use during the collection.

5. Record ALL current medications including dosing, timing, and route of delivery

This is the downfall of many a patient. It is not enough to ask if patients have been on gut slowing agents. It is important to know the exact medication prescribed, including the dosage, timing and frequency. All of these factors are key in patients with SBS. For example, gut-slowing medications should always be given one half to 1 hour BEFORE meals and bedtime. This gives the medication time to slow peristalsis and increase the nutrient contact time. This also prevents the medication from potentially being washed out with food and fluids. Check for, and avoid using, sustained-release medications in this patient population.

6. Typical diet intake

Conduct a detailed 24 hour or longer recall of all foods AND fluids consumed. Investigate if dietary restrictions have been imposed and determine what diet, if any, the patient follows. It may be useful to keep a set of measuring cups and spoons in clinic to act as a guide for patients to better determine the size of the portions they actually consume. Specifically ask about the consumption of any highly osmotic beverages such as Boost, Ensure, sodas, etc., or protein powders, herbals and vitamins. Consider having outpatients complete a basic diet history questionnaire while they are waiting to be seen in clinic (see Appendix III).

(continued on page 84)
7. Specific nutrient issues
Vitamin and mineral levels need to be monitored regularly in patients with SBS. Even those patients on TPN should have levels checked. Baseline levels should be checked at the first clinic visit or 3 months out from the initial surgery or insult. Patients with SBS are most at risk for deficiency of fat-soluble vitamins, A, D, E and K as well as vitamin B12. Loss of ileum, gastric hypersecretion and its effects on R protein and/or bacterial overgrowth can all contribute to vitamin B12 deficiency.

- Sodium (Na)/Water
One of the most problematic minerals for SBS patients is sodium (Na). Excessive Na depletion may lead to hypotension and prerenal azotemia. Chronic losses are associated with low plasma volume, reduced sodium output in urine and results in increased plasma aldosterone. The secretion of aldosterone by the adrenal cortex is regulated by two mechanisms: first, the concentration of sodium ions may be a factor since increased rates of aldosterone secretion are found when dietary sodium is severely limited; second, by reduced blood flow to the kidney. Aldosterone acts directly on the kidney to decrease the rate of sodium (with accompanying retention of water). Hyperaldosteronism is not uncommon in this patient population. Sodium losses are greater in ileostomy effluent compared to jejunostomy effluent (120 versus 90 mEq/L, respectively), however, net jejunostomy Na losses are often greater given the higher volume of stool lost each day (11).

Identifying dehydration may be difficult in this population because low muscle mass is a common finding, and BUN and creatinine may remain low until the late stages of dehydration; only in severe dehydration will serum creatinine and blood urea nitrogen (BUN) begin to rise. Rather, look for rapid weight loss (>0.5–1.0 kg/day), changes in blood pressure, tachycardia, and drop in urine output. Urinary electrolytes are more useful than serum electrolytes in these patients as serum concentrations are often maintained because of normal homeostatic mechanisms that preserve these levels until the late stages of dehydration. To detect sodium depletion, check random urine Na (make sure patient is not receiving diuretics). A urine sodium of <5–10 mmol/L, is indicative of maximal sodium concentration and hence, Na depletion. The goal should be to keep urine sodium >20 mmol/L. Advise patients to add salty meals and snacks to their diet.

Some patients with jejunostomies suffer from excessive thirst tricking them into quenching it with water or other hypotonic fluids. The leaky epithelium in the jejunum causes significant sodium loss, further increasing stomal output, chronic dehydration, thirst and fluid intake, precipitating a vicious cycle difficult to halt. See Table 14 for tips on assessing and maximizing hydration.

- Magnesium (Mg)
Hypomagnesemia is also a common problem in patients with SBS. Sodium and water depletion cause secondary hyperaldosteronism, which increases urinary magnesium losses, hence these need to be addressed first. Patients with end jejunostomies often have high magnesium losses and often suffer from recalcitrant hypomagnesemia. Magnesium deficiency may precipitate a serum calcium deficiency due to impaired release of parathyroid hormone. Hypomagnesemia reduces secretion and function of PTH resulting in poor renal conservation of calcium along with insufficient 1,25-hydroxy-

---

### Table 14
Assessing and Maximizing Hydration

<table>
<thead>
<tr>
<th>Tip</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maintain urine output &gt;1200 mL (have patients measure their UOP periodically).</td>
</tr>
<tr>
<td>Serial weights: if patient loses &gt;0.5 lb/day or 1 kg/wk—add, or increase IV fluids.</td>
</tr>
<tr>
<td>A rise in BUN/creatinine ratio is a late indicator in ostomates; use other indicators such as blood pressure, signs of tachycardia or drop in urine output.</td>
</tr>
<tr>
<td>Patients with end jejunostomies: drink/sip higher sodium, relatively isotonic beverages—avoid hypotonic fluids such as water, tea, coffee, juices and alcohol.</td>
</tr>
<tr>
<td>Patients with colon intact can handle a wider range of fluids, but avoidance of very hypertonic fluids is still beneficial.</td>
</tr>
<tr>
<td>Try oral rehydration therapy.</td>
</tr>
<tr>
<td>Try “isotonic” beverage recipes (see Tables 20, 21, 23).</td>
</tr>
<tr>
<td>Avoid nephrolithiasis</td>
</tr>
<tr>
<td>Avoid foods high in oxalate</td>
</tr>
<tr>
<td>Consider avoiding large doses of vitamin C supplementation— theoretical-no data to support (converts to oxalate endogenously)</td>
</tr>
<tr>
<td>Try calcium citrate supplements to bind oxalate and alkalinize urine</td>
</tr>
</tbody>
</table>

---

The Clinician’s Guide to Short Bowel Syndrome
NUTRITION ISSUES IN GASTROENTEROLOGY, SERIES #31
(continued from page 82)
vitamin D production, resulting in decreased calcium and magnesium absorption in the gut. Normal urinary magnesium excretion is important in the prevention of hypocitraturia and calcium oxalate renal stone formation. Citrate excretion and urine pH are decreased by metabolic acidosis (usually from GI bicarbonate loss) as well as hypomagnesemia. Hypocitraturia can be corrected by oral citrate supplementation such as citrical liquid tabs, twice daily. Some suggest that treatment should be aimed at normalizing urinary magnesium and correction of metabolic acidosis (19).

If oral magnesium is to be tried, prescribe it at night when transit may be slowest and the patient is NPO to avoid competition with other medications/foods (20). Desai reported that an oral sipping solution made of injectable (IV) magnesium, a highly purified form, may improve absorption in patients who have lost large segments of small bowel (21); palatability can be improved by mixing it with a flavored oral rehydration solution.

Finally, a trial of an active vitamin D analog, such as calcitriol or Rocaltrol, may need to be given (20). See Table 15 for guidelines to treat hypomagnesemia.

8. Medication Absorption—May need a “malabsorption factor” just like with nutrients...

Medication absorption, like fluids and nutrients, may be impaired in patients with SBS. Consider that some patients have to consume 200%–400% of their basal metabolic rate to meet their nutrient needs and remain free from TPN. It stands to reason that medication delivery may need to be escalated considerably as well (examples: thyroxine, warfarin, digoxin, etc.) (11). Also consider that medication absorption depends on: the surface area and health of the remaining intestine, morphologic and physiologic factors (such as intact ileum for bile salts—required for some medications to be absorbed such as cyclosporin), the pH of the intestine and transit time (4,22).

Because many medications are absorbed in the jejunum, patients with a significant jejunal resection are at particular risk of medication malabsorption. Imodium and cyclosporin circulate through the enterohepatic circulation, hence higher doses may be needed in patients with <100 cm of remaining ileum (1).

Doses that would appear excessive in the typical patient may be required to achieve efficacy in the patient with short gut. To determine if patients are benefiting from the medication you have prescribed, determine if they are responding according to your expectations for that particular drug, such as a decrease in ostomy/stool output, etc. If they are not, then absorption must be questioned. If available, a trial of a sublingual, liquid or IV version may be considered. If the pharmacy that the patient uses does not have readily available alternative forms of medications, it may be necessary to utilize other specialized pharmacies, request a special order, or the clinician may need to adjust the treatment plan. Additionally, insurance companies may require written justification for a particular formulation (liquid versus tablet) of a medication—just saying the patient has SBS may not be enough.

One final consideration is to make sure the local pharmacy where the patient gets their prescriptions filled carries, or can obtain, the medication the patient is to be discharged on (e.g., tincture of opium and Viokase powder).

9. Finally—Meeting the patient’s needs and expectations

No plan, however carefully constructed, will be successful without the cooperation of the patient. It is essential to establish a good relationship and uncover...
the patient’s chief complaints and goals. This may vary drastically between patients. Common goals are the need to gain weight, improve sleep, improve ostomy management and to reduce the hassles of TPN, namely septic episodes and prolonged infusion time.

**NUTRITION INTERVENTION**

**Oral Diet (23,24)**

- High fat vs low fat or high CHO vs low CHO?

  It is now accepted that patients with SBS should consume whole food diets, or if enterally fed, use a polymeric formula for maximum intestinal stimulation and adaptation (Wilmore-Best Practice). Although a high fat diet can contribute to nutrient loss by aggravating steatorrhea, in order to potentially gain freedom from TPN, patients with SBS may need to eat 200%–400% over their needs to surmount the malabsorption that occurs (25). It is also suggested that diets should differ somewhat in patients with a colonic segment versus those without. A higher CHO, lower fat diet is preferable in patients with colon in continuity as compared to a higher fat, lower CHO diet in patients with jejunostomies, to reduce total fluid losses (8,26). Review the patient’s usual diet intake and modify fat in the diet only as needed, while instituting the other interventions, rather than imposing a set 40-g/day limit. Remember that fat is an important calorie source! The author suggests maximizing medication delivery before imposing strict dietary guidelines—no diet is a good diet if not eaten. Be aware, however, that in patients on higher fat diets, the divalent minerals (calcium, magnesium, zinc and copper) may need to be increased. Oral dietary guidelines can be found in Table 16 with a sample meal plan in Table 17.

- Avoid sweets

  A diet high in simple CHO will pull water into the lumen of the GI tract precipitating net fluid/nutrient loss. Avoiding simple sugars such as sweets, fruit juices and sodas are one of the few beneficial dietary restrictions in this patient population.

- Chew foods well

  Because the first step in the process of digestion of food takes place in the mouth with mastication of food, theoretically, it is even more important in patients with SBS to aid in maximizing surface area for pancreatic enzyme and bile salt attack.

- Liberal use of salt

  Remember that jejunostomies and ileostomies lose ~90 mmol sodium/Liter of ostomy output at the duodeno-jejunal flexure and up to 140 mmol/L in the terminal ileum (11). Do not restrict salt and encourage use of the salt shaker and salty foods.

- Fiber

  Use of a moderate fat, higher complex CHO diet that contains fiber is best in the patient with an intact colon. The caloric capture of SCFA from fiber fermentation by colonic bacteria provides up to 500–1000 kcal/day (7,8). Avoid Metamucil or other bulk-forming agents in patients with jejunostomies or ileostomies. A colon is necessary for fiber-containing, bulk forming agents to work. In high output states, it may draw more fluid into the SB and potentially drag nutrients out with it.

- Lactose (27,28)

  SBS may precipitate lactose intolerance. However, Marteau demonstrated that a diet providing 20-g/d lactose (with no more than 4 g/d as milk), was well tolerated in patients with short-bowel syndrome and concluded that a lactose-free diet is not particularly beneficial in these subjects (29). Symptoms of lactose intolerance are dose-dependent, hence, if intake of lactose is spread out over the day, symptoms may be alleviated. Avoiding lactose-containing foods may further aggravate the premature development of osteoporosis so commonly seen in this patient population. See Table 18 for lactose content of selected foods/fluids.

- Oxalate (30)

  For those patients with retained colon and in particular <100 cm of ileum remaining, malabsorption of fat occurs with preferential binding to calcium freeing oxalate to be absorbed in the colon. Increased oxalate absorption results in an increase in oxalate excretion via the kidney. Add marginal hydration, and the stage is set for nephrolithiasis. Metabolic acidosis due to excessive bicarbonate loss in the stool adds further insult by aiding stone precipitation. See Table 10 for a list of high oxalate foods to avoid in those patients who have a history of kidney stones.

(continued on page 88)
Table 16
Diet Guidelines for Short Bowel Syndrome

**General Guidelines**
- Patients with jejunostomies/ileostomies (higher fat): approximately 20–30% CHO, 20–30% protein, 50–60% fat
- Patients with intact colon (higher CHO): approximately 50–60% CHO, 20–30% protein, 20–30% fat
- Avoid concentrated sweets and fluids
- Chew foods well
- Add salty meals and snacks if no colon
- Eat smaller meals, more often
  - Decrease total nutrient load over the day and space out over time
- Trial of oral rehydration solutions
- Limit fluids with meals; drink isotonic beverages
- Separate solids and liquids at meals as much as possible (solids before liquids)
  - Solids slow emptying
  - Too much liquid creates a column effect (imagine the swelling of a stream when it rains and the increased flow generated)
- Use MCT containing beverages if necessary vs MCT oil (45)
- Lactose restriction if necessary (may try lactaid)
- Avoid high oxalate foods in those patients with kidney stones
- Liquid or chewable vitamin/mineral supplements if necessary
- Limit or avoid enteral stimulants such as alcohol and caffeine

<table>
<thead>
<tr>
<th>Good Choices</th>
<th>Avoid</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Starches/breads</strong></td>
<td></td>
</tr>
<tr>
<td>- Breads, pita bread, rolls</td>
<td>Donuts, sweet rolls, pastries, pop-tarts</td>
</tr>
<tr>
<td>- Bagels, English muffins</td>
<td></td>
</tr>
<tr>
<td>- Plain waffles or pancakes</td>
<td></td>
</tr>
<tr>
<td>- Corn bread, plain muffins</td>
<td></td>
</tr>
<tr>
<td>- Banana or zucchini bread</td>
<td></td>
</tr>
<tr>
<td>- Tortillas—whole wheat or white flour, corn—toasted</td>
<td></td>
</tr>
<tr>
<td>- Pasta, macaroni, noodles</td>
<td></td>
</tr>
<tr>
<td>- Rice, brown rice, wild rice</td>
<td></td>
</tr>
</tbody>
</table>

| **Cereals** |       |
| - Unsweetened cereals (wet or eaten dry as a snack) | Sugary cereals, high fiber cereals (>1–2 grams fiber/serving), bran cereals |
| - Cheerios, cornflakes, rice krispies, Rice Chex, Spoonfuls, Special K, Kix, puffed rice or wheat | Flavored hot cereals |
| - Hot cereals: cream of rice or wheat, grits, oatmeal |       |

| **Vegetables** |       |
| - Canned or cooked vegetables | Creamed vegetables, legumes such as lima, kidney, pinto beans, etc. |
| - Potatoes, sweet potatoes, yams |       |
| - Small amounts of lettuce (1/2 cup) |       |

| **Fruits** |       |
| - Bananas, melons, unsweetened canned fruits (applesauce, pears, peaches, mandarin oranges, apricots, cherries, plums, etc.) | Dried fruits, fruit canned in syrup |
| - Fruit juice, fruit drinks, watch out for high fructose corn syrup in drinks (Ex. Capri-sun, canned fruits in syrup, etc.) |       |

| **Meats/fish/poultry** |       |
| - Meats, fish, shellfish, poultry, tuna fish, ham | Heavily fried meats, fish, poultry |

| **Dairy/Soy** |       |
| - Cheese, cottage cheese, plain yogurt or yogurt sweetened with artificial sweeteners, cream cheese | Highly sweetened yogurts or kefir, chocolate or other flavored milks, cream, half and half, Go-Gurts, flavored soy milks |
| - Plain soy milk |       |
Medium Chain Triglycerides—leave home without them

Medium chain triglycerides (MCT) are often recommended for use in patients with SBS as they are absorbed directly across the mucosa into the bloodstream and taken directly to the liver. However, MCT are less effective than long chain fat in inducing gut adaption (31). Although the rationale is appealing, using MCT as part of a daily diet plan is at best just that, an appealing rationale. Most patients would just as soon leave the MCT oil on the shelf (author’s experience). Expensive, unpalatable and somewhat of a hassle to administer, too much MCT can overwhelm the mucosal receptors and actually increase steatorrhea. A less expensive way to incorporate MCT is by using commercial products that contain MCT as part of the fat source (Table 19).

Oral Rehydration Therapy (ORT)

Absorption of sodium (and hence water—as water always moves with sodium) occurs by 3 different mechanisms across the GI tract brush border:

1. Passive absorption; probably through the intracellular junctions of the mucosal cells.
2. Active absorption of sodium, mediated by the sodium-potassium pump.
3. Glucose-coupled transport of sodium (most active in the jejunum):
   - The coupling between glucose and sodium is obligatory—the “glucose carrier” will not translocate sodium in the absence of glucose and vice-versa.
   - The carrier permits one sodium ion to enter the intestinal epithelial cell along with each glucose molecule.
   - Coupled transport is uni-directional.

The beauty of ORT is that it can be absorbed even in the setting of significant diarrhea (32). However, it is not a panacea, and in some SBS patients, it too can increase stool output. Drinking ORT is a grand idea, but in reality, patients do not relish it. Even though your patient

---

**Table 16 (continued)**

<table>
<thead>
<tr>
<th>Good Choices</th>
<th>Avoid</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eggs</td>
<td></td>
</tr>
<tr>
<td>• Poached, hard or soft cooked, omelet, scrambled</td>
<td>Eggs prepared with ingredients not allowed</td>
</tr>
<tr>
<td>Nut butters</td>
<td></td>
</tr>
<tr>
<td>• Peanut, almond, cashew</td>
<td>Nutella, peanut butter with jam/jelly mixed in it</td>
</tr>
<tr>
<td>Beverages</td>
<td></td>
</tr>
<tr>
<td>• Oral Rehydration solution</td>
<td>&gt; 4 oz coffee, tea, ice tea, flavored coffees or teas, hot cocoa, Ovaltine, Quick, fruit juices or fruit drinks (watch out for high fructose corn syrup in drinks.), koolaid, tang, regular sodas (all kinds), alcohol, water, sugar free beverages, supplements such as Boost or Ensure, etc.</td>
</tr>
<tr>
<td>• Soups, broth—4 oz per day</td>
<td></td>
</tr>
<tr>
<td>• Lactaid milk</td>
<td></td>
</tr>
<tr>
<td>Snacks</td>
<td></td>
</tr>
<tr>
<td>• Crackers—saltines, soda, etc.</td>
<td></td>
</tr>
<tr>
<td>• Pretzels, matzo</td>
<td></td>
</tr>
<tr>
<td>• Corn or potato chips</td>
<td></td>
</tr>
<tr>
<td>• Bagel snack crackers</td>
<td></td>
</tr>
<tr>
<td>Desserts</td>
<td></td>
</tr>
<tr>
<td>• Animal crackers, graham crackers, angel food cake, vanilla wafers, shortbread, plain pound cake, cake donuts—no icing, marshmallows</td>
<td>Iced Cakes, cookies, Little Debbie Cakes, pie, ice cream, sherbet, candies, donuts, sweetened gelatin, etc.</td>
</tr>
<tr>
<td>Miscellaneous</td>
<td></td>
</tr>
<tr>
<td>• Salt, pepper, herbs, spices, dill pickles, Splenda, Equal, Sweet ‘n Low, etc.</td>
<td>Sugar, sorbitol containing sweets, maple or other syrups, jams, jellies, chocolate syrup, honey, molasses</td>
</tr>
</tbody>
</table>

Used with permission from the University of Virginia Health System Nutrition Support Traineeship Syllabus
may need 2–3 liters, start with the goal of 1 liter per day. If the patient will drink (or sip ideally), this over the course of the day, and is willing to maintain doing this, increase the volume as needed. If not, then abandon ORT as a therapy. Of note, fructose does not participate in the same coupling mechanism as glucose, hence it is not a useful CHO source in ORT. See Table 20 and 21 for commercial products and home recipes to try (if regular ORT is not successful). These improvised recipes, even if not the exact same chemical make-up of ORT, may be more palatable. This may increase the chance that the patient will comply with the recommended volume and can serve as a more appropriate substitute for the alternatives often chosen by patients (water, soda, juice, Boost, Ensure, etc.).

Finally, one more option is to try giving ORT as a nocturnal infusion, first via an NGT and if successful, place a PEG for infusion. This may allow some patients to leave their intravenous fluids behind (33).

- **Isotonic Fluids**

As clinicians we are taught to use isotonic fluids in this patient population, however, aside from oral rehydration solutions, what does that mean and how does this translate into drinkable beverages for patients? Table 22 provides the osmolality of common beverages consumed by patients. Although they have not been clinically tried, Table 23 provides some “isotonic recipes” that can be tried with patients and theoretically, given their near isotonicity, might be less problematic than the sodas, fruit juices and gallons of water, etc., that our patients succumb to out of frustration for something to quench their often insatiable thirst.

(continued on page 92)
The most important intervention to improve success with EN is to feed in the most proximal location possible, e.g., gastric delivery. When choosing a formula for EN, look for one that is isotonic or near isotonic (300 mOsm), polymeric, and contains some MCT. Initially, infuse EN at slow rates over time (e.g., 12–24 hours initially) to decrease nutrient load per centimeter of bowel for maximal saturation of intestinal transporters. If intolerance (steatorrhea or excessive ostomy stool losses) occurs, consider adding pancreatic enzymes. A semi-elemental formula may also be helpful, but avoid elemental formulas as they are hypertonic and have not demonstrated a physiologic advantage (34–36). Pancreatic enzymes and semi-elemental formulas are rarely used in combination unless the semi-elemental formula contains a fairly high percentage of MCT. A fiber-containing formula, in patients with any remaining colon, should be used to increase caloric “salvage” via bacterial fermentation of the fiber into SCFA.

**TOTAL PARENTERAL NUTRITION/INTRAVENOUS FLUIDS**

Some patients may require TPN and/or IV fluids permanently. When preparing the hospitalized patient for discharge on TPN, mimic the anticipated home regimen for at least 48 hours prior to discharge. For example, if the patient will be receiving only TPN at home, ensure the patient can maintain hydration status without additional IVF while in the hospital. Some patients may require both TPN and IVF. “IV chasers” may be given before or after TPN if the patient needs more fluid than a home TPN bag can hold (4 liters).

(continued on page 94)
### Table 20
Commercial and “Pseudo” Oral Rehydration Solutions

<table>
<thead>
<tr>
<th>COMMERCIAL PRODUCTS</th>
<th>Glucose/CHO mOsm/kg</th>
<th>Commercial and “Pseudo-ORS” RECIPES</th>
<th>Sodium mEq/L</th>
<th>Potassium mEq/L</th>
<th>Recipe</th>
</tr>
</thead>
<tbody>
<tr>
<td>WHO packet*</td>
<td>330</td>
<td>Gatorade Base</td>
<td>20</td>
<td>90</td>
<td>20</td>
</tr>
<tr>
<td>(Jianas Brothers)</td>
<td></td>
<td>• 2 cups Gatorade</td>
<td>82</td>
<td>1.5</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 2 cups water</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 1/2 teaspoon salt</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rehydralyte</td>
<td>310</td>
<td>All Sport Base</td>
<td>25</td>
<td>75</td>
<td>20</td>
</tr>
<tr>
<td>(Ross)</td>
<td></td>
<td>• 1 1/2 cps All Sport</td>
<td>78</td>
<td>1.6</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 3 cups water</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 1/2 teaspoon salt</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent’s Choice</td>
<td>~250</td>
<td>Sugar and Salt Water</td>
<td>24</td>
<td>76</td>
<td>0</td>
</tr>
<tr>
<td>(Wal-Mart Brand)</td>
<td></td>
<td>• 1 quart water</td>
<td>76</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 1/2 teaspoon salt</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 6 teaspoons sugar</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• (optional/Crystal Light to taste—(especially lemonade or orange-pineapple flavors)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ceralyte 70**</td>
<td>220</td>
<td>Grape or Cranberry Juice</td>
<td>28/27</td>
<td>76/76</td>
<td>6.4/ 0.9</td>
</tr>
<tr>
<td>(Cera)</td>
<td></td>
<td>• 1/2 cups juice</td>
<td>76</td>
<td>0.9</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 3 1/2 cups water</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 1/2 teaspoon salt</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ceralyte 90**</td>
<td>260</td>
<td>Apple Juice</td>
<td>28</td>
<td>76</td>
<td>5.58</td>
</tr>
<tr>
<td>(Cera)</td>
<td></td>
<td>• 1 cup apple juice</td>
<td>76</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 3 cups water</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 1/2 teaspoon salt</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LiquiLyte</td>
<td>250</td>
<td>Enlive Base</td>
<td>65</td>
<td>80</td>
<td>40</td>
</tr>
<tr>
<td>(Gerber)</td>
<td></td>
<td>• 8 oz Enlive</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 3 1/4 cups water</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 3/4 teaspoon salt</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pedialyte</td>
<td>250</td>
<td>Resource Fruit Beverage Base</td>
<td>35</td>
<td>76</td>
<td>0.4</td>
</tr>
<tr>
<td>(Ross)</td>
<td></td>
<td>• 8 oz Resource fruit beverage</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 3 cups water</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 1/2 teaspoon salt</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EquaLyte</td>
<td>305</td>
<td>Boost Breeze Base</td>
<td>31</td>
<td>75</td>
<td>5.9</td>
</tr>
<tr>
<td>(Ross)</td>
<td></td>
<td>• 8 oz. Boost Breeze</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 3 cups water</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 1/2 teaspoon salt</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Jianas Brothers, Kansas City, MO 816/421-2880; jianasp@aol.com
**Cera Products, Inc., Columbia, MD 888/237-2598; www.ceralyte.com
Some of the quality of life issues that should be addressed are:

How many hours will your patient’s TPN run at home? Home IV pumps can run as high as 300 mL/hour. In the hospital setting this rate may seem alarming, but IV rates of 250–350 mL/hour are not uncommon at home. The total number of hours a patient runs should be based on their preference, the number of times they are getting up at night to urinate or rarely, cardiac status. Most patients infuse their TPN over 10–12 hours overnight.

Discuss with the patient whether or not nocturnal versus daytime infusion is preferred. Frequent urination at night interferes with sleep and is a common complaint of patients on nocturnal TPN. Some patients may also be interested in IV backpacks to allow daytime infusion with increased mobility. TPN and IVF will need to be continually reevaluated and adjusted as needed. Over time, the daily volume and/or infusion time of the TPN may be able to be decreased. Some patients might even be able to maintain nutrition and hydration status without daily TPN infusion—it is not uncommon for patients with SBS to skip their TPN infusion for 1–2 days per week. A thorough review of home TPN is available elsewhere (17). See Table 24 for Nutrition Support options.

**MONITORING**
Implementing the suggestions in this article is just the tip of the iceberg. The real work with SBS patients requires ongoing monitoring which is essential for their successful management. Too often, interventions are

---

**Table 21**  
"Homemade" Oral Rehydration Solutions

**WHO**
- 1/2 teaspoon salt
- 1/2 teaspoon potassium chloride
- 8 teaspoon sugar
- 1/2 teaspoon sodium bicarbonate (baking soda)
- 1 liter Water (4 1/2 cups)

Combine and stir until well mixed and dissolved.

**Washington University’s Formula**
- 1/2 teaspoon salt
- 1/2 teaspoon sodium citrate
- 3 tablespoons + 1 teaspoon powdered polycose (Ross)
- 1 liter Water (4 1/2 cups)

Combine and stir until well mixed and dissolved.

**Homemade Cereal Based**
- 1/2 cup dry, precooked baby rice cereal
- 2 cups water
- 1 teaspoon salt

Combine ingredients and mix until well dissolved and smooth. Refrigerate. Solution should be thick, but pourable and drinkable.

**Homemade Recipe**
- 1 liter Water (4 1/2 cups)
- 1 cup orange juice
- 8 teaspoons sugar
- 1/2 teaspoon baking soda
- 1/2 teaspoon salt

Combine and stir until well mixed and dissolved.

**WHO Recipe for Pediatrics**
- 2 tablespoons sugar or honey
- 1/2 teaspoon salt
- 1/2 teaspoon baking soda
- 1 liter Water (4 1/2 cups)

Combine and stir until well mixed and dissolved.

---

**Table 22**  
Osmolality of Selected Liquids

<table>
<thead>
<tr>
<th>Beverage</th>
<th>(mOsm/kg)</th>
<th>Beverage</th>
<th>(mOsm/kg)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Milk</td>
<td>275</td>
<td>Prune juice</td>
<td>1265</td>
</tr>
<tr>
<td>Malted milk</td>
<td>940</td>
<td>Grape juice</td>
<td>863</td>
</tr>
<tr>
<td>Ice cream</td>
<td>1905</td>
<td>Apple juice</td>
<td>683</td>
</tr>
<tr>
<td>Eggnog</td>
<td>695</td>
<td>Orange juice</td>
<td>614</td>
</tr>
<tr>
<td>Fruit yogurt</td>
<td>871</td>
<td>Tomato juice</td>
<td>595</td>
</tr>
<tr>
<td>Sherbet</td>
<td>1225</td>
<td>Punch with sugar</td>
<td>448</td>
</tr>
<tr>
<td>Popsicles</td>
<td>720</td>
<td>Sugar free punch</td>
<td>29</td>
</tr>
<tr>
<td>Ensure/Boost</td>
<td>590/640</td>
<td>Mineral water</td>
<td>74</td>
</tr>
<tr>
<td>Ensure Plus</td>
<td>680/720</td>
<td>Broth</td>
<td>445</td>
</tr>
<tr>
<td>Boost Plus</td>
<td>920</td>
<td>Gatorade</td>
<td>330</td>
</tr>
<tr>
<td>Boost Breeze</td>
<td>840</td>
<td>Polycose</td>
<td>900</td>
</tr>
<tr>
<td>Enlive</td>
<td>750</td>
<td>Flavored gelatin</td>
<td>735</td>
</tr>
<tr>
<td>Resource fruit</td>
<td>250–710</td>
<td>Sodas</td>
<td>~610</td>
</tr>
<tr>
<td>beverage</td>
<td></td>
<td>D10</td>
<td>505</td>
</tr>
</tbody>
</table>

Used with permission from the University of Virginia Health System Nutrition Support Traineeship Syllabus (42)
initiated, but since the patient does not know what to expect (and therefore does not know what questions to ask), further improvements in the plan are not identified. Assuring that treatments and interventions are working, and if they are not, devising a new plan—is this the cornerstone of effective management for the SBS patient.

Periodic measurements of 24-hour urine and stool output should be conducted to determine the success or failure of the current management plan. Patients with urine output <1 liter per day are at risk for nephrolithiasis and will need nocturnal enteral or IV fluids (14). Serial weights are also a good indicator of hydration status. Decreases in weight will often occur more rapidly than an increase in blood urea nitrogen or creatinine. A sudden increase in stool or ostomy output requires evaluation (continued on page 98)

**Table 23**

<table>
<thead>
<tr>
<th>Isotonic Beverage Recipes and their Tonicity (mOsm/L)*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Dairy Containing Recipes</strong></td>
</tr>
<tr>
<td>1 ounce Eggnog</td>
</tr>
<tr>
<td>11 ounces Whole Milk</td>
</tr>
<tr>
<td>14 ounces Pedialyte</td>
</tr>
<tr>
<td>1 ounce Ice Cream</td>
</tr>
<tr>
<td>1 ounce Gingerale</td>
</tr>
<tr>
<td>1 ounce Sorbet or Sherbet</td>
</tr>
<tr>
<td>16 ounces 2% Milk</td>
</tr>
<tr>
<td>1 ounce Ensure</td>
</tr>
<tr>
<td>8 ounces 2% Milk</td>
</tr>
<tr>
<td><strong>Lactose Free Recipes</strong></td>
</tr>
<tr>
<td>15 ounces Pedialyte</td>
</tr>
<tr>
<td>1 ounce Sorbet or Sherbet</td>
</tr>
<tr>
<td>12 ounces Pedialyte</td>
</tr>
<tr>
<td>2 ounces Orange Juice</td>
</tr>
<tr>
<td>2 ounces Gatorade</td>
</tr>
<tr>
<td>13 ounces Pedialyte</td>
</tr>
<tr>
<td>2 ounces Gingerale</td>
</tr>
<tr>
<td>1 ounce Apple Juice</td>
</tr>
<tr>
<td>13 ounces Pedialyte</td>
</tr>
<tr>
<td>2 ounces Gingerale</td>
</tr>
</tbody>
</table>
| **Table 24**

**Potential Combinations of Nutrition Support in Patients with Short Bowel Syndrome**

- **If EN used:**
  - Feed gastrically (vs post-pyloric) to maximize coordinated delivery to small bowel and include as much small bowel surface area as possible.
  - Run EN continuously or nocturnally vs bolusing to decrease nutrient load over time for total saturation of gut transporters
  - Use standard, polymeric formula, with fiber if colon present
- **Possible combination treatments:**
  - Oral diet during day, nocturnal EN
  - Daytime EN/nocturnal ORT
  - Oral day/nocturnal IV
  - Oral, TPN
  - EN and TPN
  - EN, IVF
- **IVF’s** – decrease total volume down to 1 L per day, then decrease 1 day at a time (qod)—if pt losses >1 kg/week, stool losses exceed 600 mL or unacceptable electrolyte abnormalities arise, restart or increase IV fluids (2)

**Note:** In preparing patients for home, make sure all IV fluids are consolidated or accounted for at least 2 days prior to discharge to mimic the home plan to ensure success.

**Table 25**

**Trouble-Shooting Sudden Increase in Ostomy/Stool Output**

1. Partial small bowel obstruction
2. Abdominal sepsis
3. Recurrent disease such as Crohn’s
4. Entero-entero fistula
5. Infectious enteritis
6. Check for C. Difficile (even in patients without a colon)
7. Adrenal insufficiency due to sudden discontinuation of corticosteroids (Ex. Patient with ulcerative colitis s/p colectomy)
8. Evaluate for new onset hyperthyroidism
9. Inadvertent use of lactulose, Kayaxilate, Neutra-Phos, Sho hi’s solution or other diarrheagenic medication
10. Sudden discontinuation of an important medication in the patient’s treatment plan (they run out of their prescription, etc.)
NUTRITION ISSUES IN GASTROENTEROLOGY, SERIES #31

(continued from page 96)

Table 26
Summary of Clinical Guidelines to Short Bowel Syndrome (42)

1. Start a patient demographic sheet for the front of the chart
   - Anatomy—(based on?), presence of gall bladder, etc., IV or TPN therapies
   - Timed small bowel follow-through—date?
2. I & O
   - Baseline 24-hour stool/ostomy and urine output (Fasted or on usual intake?)
   - Recheck weekly to assess efficacy of interventions
3. Medication Issues
   - Make sure patients pharmacy carries the drug (esp. tincture of opium, Viokase powder)
   - Note doses, form of medication and timing
   - Hypersecretion
     - PPI (liquid vs capsule vs IV)
     - Clinical pearl: check pH of fresh effluent from stoma of jejunostomy or ileostomy for gross determination of PPI adequacy (look for pH >6)
     - Increase dose of PPI, use liquid/solutab or try IV to see if stool/ostomy volume decreases
   - Gut slowing
     - Review all medications (if liquid, check for sorbitol); hold any non-essential meds during initial gut slowing phase to avoid osmotic effects
     - Use gut-slowing—titrate to pt; if at first you don’t succeed, try bigger and bigger guns
       - Give 1/2 hour before meals and bedtime to maximize efficacy—if pt routinely gets up at night and is willing to do so, change to every 6 hour dosing
       - Increase until the stool consistency is adequate for pt or the pt is too sleepy/cannot perform activities of daily living—whichever comes first
   - Net Secretors
     - Octreotide
     - Bile salt loss
       - Bile acid sequestrants such as cholestyramine (in patients with <100 cm of terminal ileum remaining)
       - Bile acid replacer such as cholestyramine
     - Bacterial overgrowth
       - Enteral antibiotics
     - Pancreatic enzymes if needed
       - 1/2–1 teaspoon per can of standard or semi-elemental tube feeding delivered
       - 2–6 tablets with meals AND snacks
       - Viokase tablets or powder (Not sustained release!)
4. Hydration
   - Ensure patient can achieve a urine output of ≥1200 mL (1500 mL or > if colonic segment intact)
   - Try adding oral rehydration therapy, via a PEG if necessary, and if still unsuccessful, add IV fluids.

(see Table 25 for possible causes). Periodic assessment of vitamin and mineral indices as discussed are also necessary. In addition, regular review of the patient’s medication list is imperative to check for the addition of new medications (especially over-the-counter, herbs, vitamins, etc.). Finally, it is important to consistently assess the patient’s overall functional status and quality of life.

CONCLUSION

Caring for a patient with SBS requires a tremendous amount of patience, persistence and attention to detail. Close follow up after the initial surgery or insult, a step-wise approach to care and continuous reformulation of the plan is imperative in order to achieve success. The purpose of this article is to provide the clinician with a template to follow in order to help the short gut patient achieve maximal gut absorption, which in turn, will bring patients closer to maximizing their overall quality of life. Summary guidelines and additional resources can be found in Tables 26 and 27.

Acknowledgments

I would like to thank the following clinicians for their review and editorial assistance: Cynthia Yoshida M.D., Amy Radigan R.D., CNSD, and Sherrie Walker R.D.

References

Table 27

Resources*

- Oley Foundation
  http://www.oley.org/
- Oxalosis & Hyperoxaluria Foundation
  http://www.ohf.org/
- American Gastroenterological Association medical position statement: short bowel syndrome and intestinal transplantation
- National Institutes of Health—Office of Dietary Supplements
- Short Bowel Syndrome: Etiology, Pathophysiology and Management
  http://www.clevelandclinicmeded.com/selected_topics/shortbowel/summary/article.htm
- Wound Ostomy & Continence Nurses Society
  http://www.wocn.org/
- United Ostomy Association
  http://www.oua.org/
- Intestinal Transplant Registry
  www.intestinaltransplant.org
- NPS Pharmaceuticals’ Short Bowel web site
  http://www.shortbowel.com/

*The October 2005 Practical Gastroenterology will feature Centers with Expertise in Short Bowel Syndrome


**Additional On-line References**
Best Practice and Research in Gastroenterology Series on Short Bowel Syndrome available at: http://www.sciencedirect.com/science?_ob=JournalURL&_cdi=6709&_auth=y&_acct=C000050221&_version=1&_urlVersion=0&_userid=10&md5=edc18240cebcf7d482eb166b165b35e&chunk=17#17

December 2003;17(6):

b. Douglas W. Wilmore. Indications for specific therapy in the rehabilitation of patients with the short-bowel syndrome.
g. A. Thiesen, Jr., et al. Adaptation following intestinal resection: mechanisms and signals.
h. Jon A. Vanderhoof, Rosemary J. Young. Enteral and parenteral nutrition in the care of patients with short-bowel syndrome.
i. Enrico Benedetti, Fabrizio Panaro, Mark Holterman and Herand Abcarian. Surgical approaches and intestinal transplantation.

**Appendix 1: Sample I & O Log**

<table>
<thead>
<tr>
<th>Patient Name: ___________________________</th>
</tr>
</thead>
</table>

**Input/Output Log**

<table>
<thead>
<tr>
<th>Date/Time</th>
<th>Weight</th>
<th>Urine/ (ileal conduit)</th>
<th>Stool/ ostomy</th>
<th>JP drain</th>
<th>G-tube drainage</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(continued on page 103)
Appendix II: UVAHS Digestive Health Center 100 Gram Fat Diet and Instructions for 72-Hour Fecal Fat Collection

Instructions:
1. Equipment needed:
   • “Hat” or specimen pan.
   • Storage Container (Can or Jug will be provided).
   • If the amount of stool exceeds the container given, you may use any container (preferably plastic or metal) with a screw on lid for the rest of the collection.
   • Stool does not need to be kept in the refrigerator or on ice.
2. After 3 days of stool is collected, take it to the UVAHS Digestive Health Clinic.
3. 100 gram fat diet instructions:
   • Start diet and follow for 4 days.
   • On the second morning, start stool collection and collect all stool for 3 days.
   • It is important that you eat about 100 grams of fat each day.
   • Also eat normal portions of other foods you would normally eat.
   • Please write down everything you eat and drink for the day, starting from the time you wake up in the morning until the time you go to sleep on the record sheet provided.
   • Be sure to include any sauces, etc., mayonnaise, butter or margarine added to your foods.
   • Do your best to guess the amount you have eaten.

<table>
<thead>
<tr>
<th>Food Item</th>
<th>Serving Size</th>
<th>Grams Fat</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avocado</td>
<td>1/8</td>
<td>5</td>
</tr>
<tr>
<td>Margarine, Butter, Lard, oil</td>
<td>1 teaspoon</td>
<td>5</td>
</tr>
<tr>
<td>Diet Margarine</td>
<td>1 Tablespoon</td>
<td>5</td>
</tr>
<tr>
<td>Mayonnaise</td>
<td>1 teaspoon</td>
<td>5</td>
</tr>
<tr>
<td>Lite Mayonnaise</td>
<td>1 Tablespoon</td>
<td>5</td>
</tr>
<tr>
<td>Almonds</td>
<td>6 whole</td>
<td>5</td>
</tr>
<tr>
<td>Cashews</td>
<td>4 whole</td>
<td>5</td>
</tr>
<tr>
<td>Pecans</td>
<td>3 whole</td>
<td>5</td>
</tr>
<tr>
<td>Peanuts</td>
<td>20</td>
<td>5</td>
</tr>
<tr>
<td>Walnuts</td>
<td>1/4 cup</td>
<td>20</td>
</tr>
<tr>
<td>Peanut Butter or almond butter</td>
<td>2 Tablespoons</td>
<td>15</td>
</tr>
<tr>
<td>Vegetable/Cooking Oil (corn, soybean, sunflower, corn, olive, etc.)</td>
<td>1 teaspoon</td>
<td>5</td>
</tr>
<tr>
<td>Olives</td>
<td>10 small</td>
<td>5</td>
</tr>
<tr>
<td>Salad Dressing, mayonnaise type</td>
<td>2 teaspoons</td>
<td>5</td>
</tr>
<tr>
<td>Salad Dressing, oil varieties</td>
<td>1 Tablespoon</td>
<td>5</td>
</tr>
<tr>
<td>Bacon</td>
<td>1 slice</td>
<td>5</td>
</tr>
<tr>
<td>Sausage</td>
<td>2 links or 1 ounce</td>
<td>10</td>
</tr>
<tr>
<td>Sour Cream</td>
<td>2 Tablespoons</td>
<td>5</td>
</tr>
<tr>
<td>Heavy Whipping Cream</td>
<td>1 Tablespoon</td>
<td>5</td>
</tr>
<tr>
<td>Cream Cheese</td>
<td>1 Tablespoon</td>
<td>5</td>
</tr>
<tr>
<td>Coffee Creamer, liquid</td>
<td>2 Tablespoons</td>
<td>5</td>
</tr>
<tr>
<td>Coffee Creamer, dry</td>
<td>1 Tablespoon</td>
<td>5</td>
</tr>
<tr>
<td>Cream, Half &amp; Half (12%)</td>
<td>3 Tablespoons</td>
<td>5</td>
</tr>
<tr>
<td>2% Milk or Whole Milk, white or chocolate</td>
<td>8 ounces or 1 cup</td>
<td>10</td>
</tr>
<tr>
<td>Ice cream</td>
<td>1/2 cup</td>
<td>10</td>
</tr>
<tr>
<td>Yogurt, plain or flavored (low fat)</td>
<td>8 ounces or 1 cup</td>
<td>5</td>
</tr>
<tr>
<td>Corn Chips</td>
<td>15</td>
<td>10</td>
</tr>
</tbody>
</table>
## Appendix II (continued)

<table>
<thead>
<tr>
<th>Food Item</th>
<th>Serving Size</th>
<th>Grams Fat</th>
</tr>
</thead>
<tbody>
<tr>
<td>Corn Bread, 2” x 2” x 1”</td>
<td>1 square</td>
<td>5</td>
</tr>
<tr>
<td>Muffin, plain or cornmeal, 2” diameter</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Potato Chips</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>Cheese</td>
<td>1 ounce</td>
<td>10</td>
</tr>
<tr>
<td>Egg, whole</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Hog Dog</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Meat (beef, lamb, pork, poultry, veal)</td>
<td>1 ounce cooked</td>
<td>5</td>
</tr>
<tr>
<td>M &amp; M’s Chocolate</td>
<td>1 small bag</td>
<td>10</td>
</tr>
<tr>
<td>Hershey’s Kisses or chocolate bar</td>
<td>9/1 small</td>
<td>13</td>
</tr>
</tbody>
</table>

Please record all foods eaten for the entire collection period

<table>
<thead>
<tr>
<th>Date</th>
<th>Food</th>
<th>Portion</th>
<th>Fat (g)</th>
<th>Calories</th>
<th>Protein</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix III: Nutrition

Date: ______________  Age: ______________

Why would you like to see a dietitian today? ________________________________________________________

Height __________  Current Weight ____________  Usual Weight ______________

Current Medications (Please Include Vitamin, Mineral, or Herbal Supplements)

<table>
<thead>
<tr>
<th>How would you describe your appetite?</th>
<th>Poor/Good/Very Good</th>
<th>Decreased/Usual/Ravenous</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES  NO</td>
<td>Have you experienced any recent weight loss?</td>
<td></td>
</tr>
<tr>
<td>YES  NO</td>
<td>If so, how much? ________________</td>
<td></td>
</tr>
<tr>
<td>YES  NO</td>
<td>Have you experienced any nausea and/or vomiting recently?</td>
<td></td>
</tr>
<tr>
<td>YES  NO</td>
<td>Do you have any trouble chewing or swallowing?</td>
<td></td>
</tr>
<tr>
<td>YES  NO</td>
<td>Do you have dentures?</td>
<td></td>
</tr>
<tr>
<td>YES  NO</td>
<td>Have you experienced any taste changes recently?</td>
<td></td>
</tr>
<tr>
<td>YES  NO</td>
<td>Do you ever have the desire to eat any non-food items such as coal, dirt, clay, starch, or large amounts of ice?</td>
<td></td>
</tr>
<tr>
<td>YES  NO</td>
<td>Do you have any food allergies or intolerances?</td>
<td></td>
</tr>
<tr>
<td>YES  NO</td>
<td>If so please list ________________</td>
<td></td>
</tr>
<tr>
<td>YES  NO</td>
<td>Do you use alcohol?</td>
<td></td>
</tr>
<tr>
<td>YES  NO</td>
<td>Do you follow any special diet on a regular basis?</td>
<td></td>
</tr>
<tr>
<td>YES  NO</td>
<td>If so, please describe ________________</td>
<td></td>
</tr>
<tr>
<td>YES  NO</td>
<td>Do you use any oral nutritional drink supplements (Such as Carnation Instant Breakfast, Boost, Ensure, etc.)</td>
<td></td>
</tr>
<tr>
<td>YES  NO</td>
<td>Do you have problems with constipation?</td>
<td></td>
</tr>
<tr>
<td>YES  NO</td>
<td>Do you have problems with diarrhea?</td>
<td></td>
</tr>
</tbody>
</table>

Please list below what foods you usually eat on a daily basis (For example, what do you “typically” eat for breakfast?)

**BREAKFAST:**

**MORNING SNACK:**

**LUNCH:**

**AFTERNOON SNACK:**

**DINNER:**

**EVENING SNACK:**
CAROL REES PARRISH

Carol Rees Parrish (“Short Bowel Syndrome”) has 35 years of clinical experience, the past 25 of which have been spent specializing in nutrition support and GI disorders at the University of Virginia Health System (UVAHS), Digestive Health Center. Carol founded the Medicine Nutrition Support Service in 1991, began the home nutrition support program at the UVAHS Home Health Company, developed the GI Nutrition Clinic, originated the UVAHS Celiac Support Group, and co-founded the UVAHS Nutrition Support Traineeship. She has been the nutrition series editor for the popular Practical Gastroenterology Journal’s Nutrition Series since 2003 having just published over 148 articles in the series. She can be contacted at crp3a@virginia.edu

REFERENCES

A Core Curriculum for Nurse Life Care Planning, DJ Apuna and WA Howland, editors. American Association of Nurse Life Care Planners, Salt Lake City UT. (2013)


https://www.gatterx.com

Nursing Diagnoses To Consider

| Imbalanced Nutrition, Less Than Body Requirements: Domain 2, Nutrition; Class 1, Ingestion |
| Bowel Incontinence: Domain 3, Elimination and Exchange; Class 2, Gastrointestinal Function |
| Risk for Electrolyte Imbalance: Domain 2, Nutrition; Class 5, Hydration |
| Risk for Compromised Human Dignity: Domain 6, Self-Perception; Class 1: Self-Concept |
| Risk for Impaired Liver Function: Domain 2, Nutrition; Class 4, Metabolism |
| Caregiver Role Strain: Domain 7, Role Relationships; Class 1: Caregiving Roles |
| Diarrhea: Domain 3, Elimination and Exchange; Class 2, Gastrointestinal Function |
| Impaired Social Interaction: Domain 7, Role Relationships; Class 3, Role Performance |
| Dysfunctional Gastrointestinal Motility: Domain 3, Elimination and Exchange; Class 2, Gastrointestinal Function |
| Risk for Impaired Skin Integrity: Domain 11: Safety/Protection, Class 2: Physical Injury |
Introduction

Diabetes mellitus and chronic pancreatitis cause significant morbidity, disability, diminished quality of life, and mortality. Once conservative medical treatment fails, patients and providers are left fighting a difficult and frustrating battle. Pancreatic islet cell transplantation brings hope of relief.

The National Institute of Diabetes and Digestive Disease created the Collaborative Islet Transplant Registry (CITR) in 2001 to monitor islet transplantation technology progress, promote procedural safety, and analyze and publish data from North America, Europe, and Australia. Its most prominent members are:

- University of Minnesota’s Schulze Diabetes Institute
- Northwestern Medical Center of Chicago Kovler Organ Transplant Center
- University of Miami Diabetes Research Institute, Clinical Islet Transplant Program
- University of Alberta, Canada, Clinical Islet Transplant Program.

The Pancreas: Anatomy and Physiology

The pancreas lies below and behind the stomach, surrounded by small intestine, liver, and the spleen. The pancreas, a gland, is 95% exocrine tissue and 5% endocrine tissue. Its exocrine tissue secretes digestive enzymes: trypsin and chymotrypsin digest proteins, amylase digests carbohydrates, and lipase digests fats. The pancreatic duct connects with the common bile duct that drains into the duodenum. The exocrine tissue also secretes...
bicarbonate to neutralize acid in the duodenum.

The endocrine tissue, islets of Langerhans, secrete insulin from the beta cells and glucagon from the alpha cells. Insulin and glucagon regulate serum glucose by lowering and raising it, respectively. Finally, the islets also secrete somatostatin, a hormone that suppresses insulin and glucagon release (Costanzo, 2010).

**Acute and Chronic Pancreatitis: Etiology, Complications, Treatment Options**

**Acute Pancreatitis (AP)**

Pancreatitis can be acute or chronic. Each year, AP causes 330,000 US hospital admissions at a cost of approximately $2.2 billion. The most common causes are gallstone disease (38%) and alcohol abuse (36%). The risk factors for obstructive disorders increase with age, female gender, obesity and small gallstones.

Other common causes include:

- abdominal and thoracic surgery
- drugs (pentamidine, thiazide, furosemide, azathioprine, sulindac, salicylates, L-asparaginase, valproic acid, calcium, estrogen, tamoxifen, sulfonamide, tetracycline)
- endoscopic procedures (such as ERCP)
- hypertriglyceridemia (levels of serum triglyceride above 1000mg/dl)
- hypercalcemia
- renal failure
- trauma (Banks et al., 2010).

**Pathogenesis**

Under certain circumstances, pancreatic enzymes can auto-digest pancreatic cell membranes, leading to hemorrhage, edema, ischemia and necrosis. Severe AP has high mortality rate as the disease progresses to systemic inflammatory response syndrome, sepsis, and multiple organ failure (Jones et al., 2015). AP is confirmed by CT, elevated serum levels of amylase and lipase, and characteristic abdominal pain.

**Treatment modalities**

Usually, the patients with AP go to the ER with acute abdominal pain, nausea, and vomiting. AP can progress from mild to severe within 48 hours, so prompt diagnosis and treatment is critical. If AP is drug-induced, the toxic drug must be withdrawn immediately. If from gallstones, then cholecystectomy may be required.

The American College of Gastroenterology (ACG) recommends the following practice guidelines:

- Aggressive fluid administration to prevent hypovolemia
- Appropriate pain management. Patients are weaned off opioids to NSAIDS when acute pain subsides.
- Nutritional support. Jejunal feeding is preferred; it causes less pain than gastric feeding.
- Antibiotic therapy. Between 40%-70% of patients with severe AP develop pancreatic necrosis within three weeks. Prophylactic antibiotic therapy is recommended for patients with 30% or greater necrosis. (Banks et al., 2010).

**Chronic Pancreatitis (CP)**

Chronic pancreatitis is progressive, irreversible, inflammatory disease of the pancreas that replaces exocrine and endocrine tissue with fibrous scar. CP causes significant disability, diminished quality of life, morbidity, and mortality. CP is more common between the ages of 40-60 and in males. CP is responsible for 122,000 outpatient visits and more than 56,000 hospitalizations annually in the US (Lee and Stevens, 2014).

**Etiology**

According to a study by Sarles et al., 60-70% of patients with CP have a 6-12 year history of alcohol abuse. Although an independent risk factor, cigarette smoking increases risk by 25 and accelerates alcoholic CP. Smoking less than one pack a day more than doubles the risk; risk is tripled for people who smoke more. Other causes are:

- Autoimmune
- Biliary/pancreatic duct obstruction
- Celiac disease
- Cystic fibrosis
- Genetic
- Idiopathic
- Irritable bowel syndrome
- Metabolic
- Recurrent and severe acute pancreatitis
- Systemic lupus erythematosus (Yadav and Lowenfels, 2013).

**Pathophysiology/Mechanism of Injury**

Alcoholic injury results in atrophy and fibrosis. This promotes development of stones and protein plugs. Fibrosis after recurrent attacks of AP causes scarring, ductal obstruction, and stone formation (Lauret et al., 2015). Recent research in immunology suggests that CP occurs in patients who are genetically or environmentally predisposed to pancreatitis, with chronic inflammation leading to progression and irreversible changes (Lee and Stevens, 2014).

**Symptoms and Pain**

50-80% of patients have disabling moderate to severe, upper mid-abdominal pain radiating to rib margins or back, enough to cause chronic dependence on opiates, frequent hospitalizations, and diminished quality of life. Type A pain is intermittent with short relapsing episodes, lasting days to weeks with intermittent, pain-free intervals. Type B is prolonged, severe, and intractable, more difficult to treat, causes greater disability, and requires more frequent medical follow up (Lee and Stevens, 2014). CP pain costs around $638 million in the US annually, due to absenteeism, from school / work, reduced productivity and early departure from the labor market (Dennison and Garcea, 2015).

**Pancreatogenic diabetes (PD)**

Nearly 40-60% of CP patients develop PD, increasing to 50-80% at 10-25 years. Complications are similar to Type II diabetes: retinopathy, nephropathy, neuropathy, and peripheral vascular disease, with slightly lesser risk of cardiovascular disease. PD is difficult to control. The median survival rate is
25 years after diagnosis, with mortality closely related to nephropathy (Dennison and Garcea, 2015).

**Exocrine insufficiency**

Exocrine insufficiency causes malabsorption and weight loss early. Steatorrhea and creatoctorrhea (excessive loss of fat and protein in the stool, respectively) are not evident until 90% of pancreatic function is lost. Diarrhea, nausea, and vomiting are common. Pancreatin and pancrelipase reduce malabsorption and steatorrhea; the recommended dose is 96,000 units of lipase administered at intervals during each meal.

Malabsorption and steatorrhea are linked to metabolic bone disease due to malabsorption of fat-soluble vitamins, especially vitamin D. Patients should receive at least 1000 units of vitamin D and at least 1gm of calcium supplement daily, and regular 25-hydroxy levels and bone scans (Banks et al., 2010).

**Treatment**

**Pain management**

Treatment depends on extent and type of pancreatic injury. Immediate cessation of alcohol and tobacco consumption is first; this may reduce pancreatic abdominal pain by 50%. The American Gastroenterological Association (AGA) advises that initial treatment should include non-narcotic analgesics such as nonsteroidal anti-inflammatory drugs, acetaminophen, and tramadol. If these fail, narcotic therapy should be carefully titrated. Narcotics should not be the first line of pain management medications due to high risk of addiction.

Nonvisceral pain may develop after years of narcotic dependency and may respond to differential nerve blockade. Antidepressants, anticonvulsants, topical therapy, psychiatric therapy, and opioid rehabilitation are also considerations.

Visceral pancreatic pain may respond to ultrasound guided celiac plexus blockade with short-term relief (Lee and Stevens, 2014).

**Endoscopic Procedures**

Nonsurgical treatments include diagnostic and therapeutic endoscopic retrograde cholangiopancreatography (ERCP), biliary or pancreatic sphincterotomy, removal of pancreatic ducts stones, and insertion of pancreatic stents. Pain relief is achieved in 70%-94% of patients. Extracorporeal shockwave lithotripsy (ESWL) is an effective treatment for removal of pancreatic ductal stones. ESWL relieves intra-ductal pressure by fragmenting the intra-ductal stones and allowing spontaneous passage. A study by Dumonceau et al. (2007) concluded that ESWL was safe and effective for removing pancreatic stones and reducing pain (Oza and Kahaleh, 2013).

**Surgical Procedures**

Pancreatojejunostomy (Puestow Procedure) drains the dilated main pancreatic duct, providing initial pain relief in 75-80% of patients with low mortality rate, limited morbidity, and without inducing diabetes. Unfortunately, only 60-70% of patients report continued pain relief, and pain usually returns within 5 years.

Pancreatic resection via pancreatodudodenectomy, pylorus-preserving pancreatocoduodenectomy, pancreatic head resection, 95% pancreatectomy and distal pancreatectomy provides pain relief in 85% of patients. 80% of patients report continued pain relief after 5 years. However, resection presents a considerable risk of developing diabetes and surgical complications.

Patients with CP experience frustration, depression, helplessness, frequent ER visits and hospitalizations, actual/potential narcotic addiction, loss of work and school time, disrupted personal routine, and financial burden. For patients with intractable pain, pancreatectomy with auto-islet transplantation may be the only solution (UCLA Agi Hirshberg Center, n.d.).

**Pancreatic Islet Transplantation**

Allogenic islet transplantation, in which deceased organ donor pancreatic islet cells are infused into the recipient’s liver, is preferred to whole pancreas transplants in patients who do not have end stage kidney disease due to its minimally invasive nature. Allogenic transplantation (CPT code S2102-allogenic islet infusion) is performed for Type 1 diabetics, 18 years and older individuals who have:

- Had DM for at least 5 years
- No endogenous C-peptide secretion
- Erratic glucose levels
- Frequent severe hypoglycemia and hypoglycemia unawareness
- Progressive diabetic complications with optimal management

**Contraindications include:**

- Age less than 18 or greater than 70 years old
- DM duration less than 5 years
- Residual C-peptide secretion
- Untreated proliferative diabetic neuropathy
- Portal hypertension
- End-stage cardiovascular disease
- Active infections (hepatitis C, Hepatitis B, HIV, Tuberculosis)
- Alcohol or drug abuse
- Pregnancy
- Obesity
- Insulin resistance
- Nonadherence
- Abnormal baseline liver function
- Chronic steroid use (Gaba et al., 2012).

The goal is to maintain optimal glycemic levels and decrease or prevent long term diabetic complications (Gaba et al., 2012).

Allogenic islet transplantation is considered experimental for Type 1 DM and therefore is not covered by Medicare, Medicaid and health insurance policies (Blue Cross Blue Shield of North Carolina, 2016). In the United States it can only be performed in medical facilities approved for research by the U.S Food and Drug administration (FDA).

Islet cells 10,000 islets/kg are infused into the portal vein with ultrasound and x-ray.
Side effects can include:
- Fatigue
- Hypertension
- Increased risk for hypercholesterolemia
- Malignancy
- Neutropenia
- Oral sores
- Thrombocytopenia

(National Institute of Health, 2016).

Benefits and limitations
Common complications include bleeding, bile leakage and portal vein thrombosis, abdominal pain, transient liver enzyme elevation and increased portal pressure. Between 1999-2008, 412 allograft recipients experienced 592 serious adverse events. This is 20 times lower than complications related to whole pancreas transplantation (Gaba et al., 2012).

Another significant limitation is the need for life-long immunosuppression and associated medication side effects.

Though insulin dependence is the goal, this tends to decrease with time after transplant. A report by CITR showed insulin independence was 80% in the first year of transplant, while only 50% of patients who received the islet transplants in the years of 2007-2010 maintained insulin independence 3 years after the transplant. (Gaba et al., 2012). Studies indicate that 80% of patients with partial graft function have achieved improved glycemic control and decreased hypoglycemic episodes (Barton et al. 2012).

Accessibility and costs
According to the Organ Procurement and Transplantation Network, in 2011 there were 8,000 deceased organ donors in the U.S. and only 1,562 pancreases were recovered (National Institute of Health, 2016). Most transplant recipients receive islets from multiple donors in order to increase the mass of islet cells; 60% may be lost in the first few days following infusion. Multiple infusions improve the number of surviving beta cells with higher probability of insulin independence.

Since allogenic islet transplantation is experimental, costs must be covered by research funds. In the U.S, pancreas procurement fees are up to $35,000, while islet processing fee is $40,000. Additionally, it costs about $150,000 for each recipient’s islet infusion procedure, immunosuppression medication, and medical management. The annual burden of cost on research organizations performing allogenic islet transplantation is $227 million (McCall and Shapiro, 2012).

Autologous islet transplantation
Autologous islet transplantation after total pancreatectomy (TP-IAT) is the standard of care for patients suffering from severe chronic pancreatitis. Total pancreatectomy is performed to relieve intractable pain. The first human TP-IAT was performed at the University of Minnesota in 1977 with the patient remaining pain-free and insulin independent for 6 years until her death due to unrelated causes. The three main goals of TP-IAT include pain control, reduced narcotic use, and recurrent acute pancreatitis and brittle diabetes prevention (Muratore et al., 2015). The major advantage of auto-transplantation is that immunosuppressive therapy is not required. Lifelong pancreatic enzyme replacement (PERT) is required after a total pancreatectomy.

TP-IAT Procedure
TP-IAT carries a significant risk of morbidity and mortality due to complications including bleeding, anastomotic leak, gastrointestinal distress, and intra-abdominal infection. The harvested pancreas is sent to the laboratory for islet isolation and purification. Within two hours, the purified islets are ready for infusion into the portal vein.

Infusion risks are similar to those for allogeneic transplant, including bleeding, acute portal hypertension, and thrombosis of the portal vein. Portal pressure is monitored carefully during the infusion because risk of thrombosis increases tenfold with portal pressure changes of more than 25cm H₂O. (Kesseli et al., 2015).
Patient Selection

Although there are no standardized patient selection guidelines from major gastroenterology, endocrinology, transplant, and surgical societies, there is general consensus for selection criteria:

- Failed medical, endoscopic and surgical therapy such as antioxidant supplementation, pancreatic enzyme replacement, endoscopic decompression/stenting, celiac plexus nerve block, opiates
- Non-diabetic or have C-peptide positive diabetes in order to sustain islet function. Tests may include fasting and postprandial blood glucose, HbA1c, glucose tolerance test and baseline and stimulated C peptide levels.
- Severe, debilitating pain for longer than six months
- Severely diminished quality of life: loss of job, inability to attend work or school, constant need for narcotics and frequent hospitalizations

Contraindications for TP-IAT (Kesseli et al., 2015) include:

- Current substance abuse, which contributes to morbidity and mortality and illicit drug use which may interfere with patient’s ability to comply with complex post-operative regimen.
- Pancreatic malignancy or premalignancy, due to possibility of introducing malignant cells into the infusion site during islet transplantation.
- Poorly controlled psychiatric illness to ensure that the patient will comply with a complex post-surgical regimen. Psychiatric evaluation is important because suicide and narcotic overdose have been reported post TP-IAT
- End stage cardiopulmonary disease and liver disease, including cirrhosis.

Billing/Coding

TP-IAT is considered medically
necessary to manage severe pain and prevent brittle diabetes. CPT codes depend on the type of procedure. Pancreatectomy depends on patient’s previous surgical history and the condition of the pancreas:

- 48160 Pancreatectomy, total or subtotal (when specified as pancreatic islet cell transplantation)
- 48999 Unlisted procedure, pancreas (when specified as pancreatic cell transplantation)

G0341 Percutaneous islet cell transplant, includes portal vein catheterization and infusion
- G0342 Laparoscopy for islet cell transplant, includes portal vein catheterization and infusion
- G0343 Laparotomy for islet cell transplant, includes portal vein catheterization and infusion. (Blue Cross Blue Shield of North Carolina, 2016).

The total cost for TP/IAT is $153,575 with survival of 14.9 quality years as compared to medical management cost of $196,042 and survival of 11.5 years. Medicare and Medicaid patients are not accepted at many programs due to insufficient reimbursement.

**Life after islet transplantation.**

The complex management regimen requires interdisciplinary collaboration and strict compliance. Although there are similarities in plan of care for both Type 1 DM and total pancreatectomy islet cell transplant recipients, there are also distinct differences. The main differences are related to the immunosuppressive therapy in allogenic transplant, and pain management with narcotic rehabilitation in autologous transplant.

**Post allogenic transplant management** Monitoring graft viability and glycemic levels are similar. However allogenic islet transplantation has a greater risk of graft failure due to rejection; in autologous islet transplant, there is no risk of rejection.

TP-IAT graft function depends on quality of patient’s own islet cells, which may have been destroyed by chronic pancreatitis or previous surgical resections. After TP-IAT, one third of patients are insulin-free, one third have partial islet function, and 10% will have incomplete graft failure (Kesseli et al., 2015).

Allogenic transplant can cause tremendous physical, emotional and psychological stress due multiple medical visits, diabetic management, complex medical regimen, and associated adverse effects. This requires great skill, knowledge and communication between the members of the multidisciplinary team: transplant physician, primary care physician, endocrinologist, interventional radiologist, nurse case manager, dietician, psychologist, and social worker.

After allogenic islet transplantation, the recipient typically visits the clinic weekly for 1 month, followed by monthly for 2 months and then every 3 months for one year. At each visit, labs include fasting and post-prandial blood glucose levels, Hb1AC levels, C-peptide levels, and immunosuppressive medication levels.

If graft failure is detected and C-peptide levels remain low, and then Prograf or Cellcept is tapered over a period of six months and discontinued. Doppler ultrasound is performed one year post transplant to evaluate portal vein patency.

The patient’s primary care physician handles all other care. The clinic follows the transplant patient for a year, followed by standing protocols for blood glucose testing, Hb1AC, C-peptide levels and immunosuppressive medication levels. The protocol is valid for one year and is renewed every year while the islet transplant is viable. The transplant facility reviews the results and coordinates medication changes with the primary care physician (Monson, personal communication, 2016).

**Post TP-IAT management requires a multidisciplinary team: medical pancreateologist, pancreatic surgeon, gastroenterologist, endocrinologist, pain management specialist, nutritionist, nurse case manager, and psychiatrist.** Recovering from major abdominal surgery, multiple medical visits and adherence to plan of care causes significant physical, emotional and psychological stress.

Recipients typically return to clinic at one, three, six, and 12 months for C-peptide levels, Hb1AC levels, and fasting and postprandial glucose levels. The patient also visits the surgeon monthly for 6 months and then again at the 1-year mark after transplant. (University of Minnesota Schulze Diabetes Institute, 2016).

Pain management and opioids continue their unique challenges. The main goal of total pancreatectomy is to relieve intractable pain. Before TP-IAT, most patients were using narcotic medications on long-term basis. According to a study by Sutherland (2012), 94% of 207 subjects reported pain relief after TP-IAT, but only 46% were narcotic-free at 1 year.
Postoperative. (Kesseli et al., 2015). Therefore, it is important to provide for a pain management specialist; a psychiatrist and psychotherapy are essential because depression, suicide, and narcotic overdose have been reported after TP-IAT.

Endocrinology follow up is essential. Only 1/3 of the TP-IAT patients maintain insulin independence, while 1/3 have partial graft function and 10% have total graft failure. Low-dose insulin is prescribed and blood glucose levels are checked 4x day. Insulin is tapered gradually as the transplanted cells produce insulin and blood glucose levels normalize. As with allogeneic transplant, blood glucose levels continue to be tested twice daily indefinitely to monitor graft function.

The recipient will need exogenous pancreatic enzymes to maintain optimal nutritional status, to avoid malabsorption, malnutrition, and related complications. Proper nutrition is also important to maintain desired glycemic levels, avoid extreme weight fluctuations, maintain normal blood, cholesterol levels, and control blood pressure. Referral to a dietician is essential.

Conclusion
For people with severe Type 1 DM, allogeneic islet transplantation offers a solution to a debilitating medical condition. A person with intractable pain from chronic pancreatitis may have relief from TP-IAT. Although both allogeneic and TP-IAT transplantation can succeed, their associated outcome variability, complications, and restrictive treatment regimens require careful risk-benefit analysis.

In the US, allogeneic islet transplantation is in final clinical trials pending FDA approval for standard of care for Type 1 DM management. Canada and Scandinavian countries have designated allogeneic islet transplant as therapeutic treatment and standard of care in the treatment of Type 1 DM to be covered by national health plans.

Currently, the focus of the research in allogeneic transplantation is on improving insulin independence, minimizing graft loss, decreasing immune response to transplant, and eventual immunosuppression withdrawal. Progress makes it possible for the patients with chronic pancreatitis to choose TP-IAT procedure to relieve intractable pain and minimize risk of brittle diabetes. Remember that before islet cell transplantation procedure, total pancreatectomy immediately required exogenous insulin for survival.

Nurse Life Care Planners (NLCPs) are in unique position to improve the outcomes for this population. The American Nurses Association (ANA) Nursing Scope and Standards of Practice define nursing as the protection, promotion, and optimization of health and abilities, alleviation of suffering through diagnosis and treatment of human response and advocacy in care of individuals, families, communities, and populations (American Nurses Association, 2015). For the Type 1 DM patient with severe hypoglycemia and hypoglycemia unawareness and the chronic pancreatitis patient with intractable pain, protection and promotion of health and alleviation of suffering are lifesaving. Allogenic and autologous islet transplant can be essential to optimal health.
REFERENCES

American Association of Nurse Life Care Planners (2015). Nurse Life Care Planning Scope and Standards of Practice. Wendie Howland, Editor. AANLCP, Salt Lake City UT.

American Nurses Association (2015). Scope and Standards of Nursing Practice. ANA, Silver Spring MD.


University of Minnesota Schulze Diabetes Institute. Anonymous, Care Coordinator for TP-IAT program. Personal communication, February 26, 2016


University of Minnesota Schulze Diabetes Institute. Anonymous, Care Coordinator for TP-IAT program. Personal communication, February 26, 2016

CYSTIC DISEASES OF THE PANCREAS: TREATMENT AND OUTCOMES

NELLIE KREIMER, MSHCA, RN, CNLCP, CLNC, CLCP

Introduction
Pancreatic adenocarcinoma is the fourth leading cause of cancer death, with estimated 48,960 new cases and estimated 40,560 deaths in 2015 in the United States (NIH, 2015). Pancreatic duct adenocarcinoma (PDAC) accounts for 80% of pancreatic cancer (Ducreaux et al., 2015). At diagnosis, 80-85% of patients have advanced cancer with metastasis; only 4% survive five years after the initial diagnosis (Vincent et al., 2011). One-year survival rate is about 20% (Truty, 2012).

Given the poor 5-year survival rate of pancreatic cancer, accurate diagnosis and timely appropriate treatment is critical (Tanaka, et al., 2012). For resectable pancreatic adenocarcinoma, the Whipple procedure is the only curative treatment. However, because it is associated with risk of mortality and high risk of morbidity it is imperative to distinguish between cases that can be managed with clinical and radiological monitoring from those that require surgical excision due to potential transition to an invasive cancer (Castellano-Megias, et al., 2014).

Cystic Tumors of the pancreas
Pancreatic cystic neoplasms are categorized by presence of fluid or mucus produced by atypical cells lining the tumor. Cysts are classified as benign, including serous cystadenoma; pre-malignant including mucinous cystic neoplasm (MCN) and intraductal papillary mucinous neoplasm (IPMN); and malignant, including the cystadenocarcinoma (De Jong et al.,
Pancreatic Pseudocysts

Unlike pancreatic cystic neoplasms, pseudocysts lack an epithelial lining; they are fluid-filled cavities surrounded by inflammatory or fibrous tissue. Some of the most common etiologies include acute and chronic pancreatitis (with highest incidence in alcohol- and gallstone-induced pancreatitis), pancreatic surgery, and direct pancreatic trauma. A growing pseudocyst may cause compression of large vessels, gastric and duodenal outlet obstruction, infection, hemorrhage, fistulas, and peritonitis in the case of pseudocyst leakage. Symptoms include abdominal pain, nausea, vomiting, jaundice, weight loss, and difficulty tolerating intake (Aghdassi et al., 2006).

Diagnosis and Treatment

The diagnostic tools to identify pancreatic pseudocysts include:

- Transabdominal ultrasonography
- CT scans of abdomen with or without contrast
- Endoscopic retrograde cholangiopancreatography (ERCP), endoscopic ultrasound (EUS);
- EUS guided fine-needle aspiration (EUS-FNA)
- Magnetic resonance cholangiopancreatography (MRCP).

Pseudocysts caused by acute pancreatitis may resolve spontaneously in 4-6 weeks, while pseudocysts secondary to chronic pancreatitis do not resolve and usually require endoscopic, percutaneous, or surgical drainage, or surgical resection (Aghdassi et al., 2006).

- Endoscopic ultrasound (EUS) guided drainage involves irrigation of the cystic cavity, infected and necrotic tissue removal, and stent placement to facilitate drainage of the pseudocyst into the gastrointestinal tract. After some time, most stents will drift and pass spontaneously; some will have to be removed endoscopically. Major complications include hemorrhage, perforation and infection (Song et al., 2014).
- Surgical drainage is required for complex pseudocysts, especially in case of severe pancreatitis with infected or necrotic pancreatic tissue. Surgical drainage involves laparotomy with a connection between the cyst and the gastrointestinal tract and surgical removal of infected or necrotic tissue.
- A percutaneous drainage tube can be placed in interventional radiology for drainage and irrigation. (Song et al., 2014).

Implications for nurse life care planners

SCI patients are susceptible to pseudocyst formation due to acute or chronic pancreatitis from acute trauma or autonomic alteration in T4-T12 injury leading to parasympathetic-sympathetic dysfunction and increased secretion of pancreatic enzymes (Pirolla et al., 2014). Pseudocyst formation may be related to gallstones attributed to GI stasis, overproduction of bile by the gallbladder, or decreased gall bladder motility (Weed & Berens, 2010). This should be discussed with primary treatment providers and included in the nurse life care plan. Include potential complications and related diagnostic testing and treatment options.

Serous cystadenoma of pancreas

Serous cystadenomas (SCA) and microcystic adenomas are slow-growing, benign, cystic tumors with equal distribution in adult men and women. It usually occurs in the head of the pancreas and has a low chance of progressing to a malignant or invasive form of cancer. Observation is preferred if it is asymptomatic. As the tumor enlarges, the patient may experience abdominal pain, nausea, vomiting, fatigue, malaise, and intestinal and biliary obstruction with jaundice (Wargo et al., 2009).

The imaging techniques for diagnosis include:

- CT scans of the abdomen, with and without contrast
- CT- guided FNA,
- EUS
- EUS/FNA
- MRCP

If a cystadenoma is symptomatic and grown to 4cm or larger, surgical resection is recommended. Depending on the location, this may mean pancreatecoduodenectomy (Whipple procedure), distal pancreatectomy, or, rarely, total pancreatectomy (Tseng et al., 2005).

Premalignant Pancreatic Tumors

Intraductal papillary mucinous neoplasms (IPMNs)

Intraductal papillary mucinous neoplasms (IPMNs) grow inside pancreatic ducts and produce large amounts of thick mucus (mucin). Risk factors include diabetes, especially insulin-dependent; chronic pancreatitis; heavy smoking, and family history of PDAC. They are more prevalent in older individuals, usually diagnosed between the ages of 60-70 years old, and more common in men than women. Although most are solitary tumors, 20-40% are multiple. Most occur in the pancreatic head, but they may occur in the body or tail of the pancreas (Castellano-Megias, et al., 2014).

An IPMN is usually an asymptomatic incidental finding. However, as they grow, mucin blocks the pancreatic ducts, causing abdominal pain, nausea, vomiting, jaundice, weight loss, and acute pancreatitis.
There are three classification criteria:

- Location: main pancreatic duct (MD-IPMN), the branch pancreatic duct (BD-IPMN), or a mixed type which involves both; and extent MPD dilatation. More than 5mm is significant; 5-9mm is considered “worrisome” requiring close follow up; equal or greater than 10mm indicates high risk for progression to an invasive stage and PDAC (Tanaka et al., 2012).

- Degree of dysplasia: low-grade dysplasia indicates lower risk and high grade dysplasia indicates significant risk of progression to invasive carcinoma (Tanaka et al., 2012).

- Histological type: Gastric-type is less aggressive; intestinal type is associated with colloid carcinoma and a better prognosis; pancreatobiliary IPMNs are more aggressive and may transition to invasive carcinoma with poor prognosis (Tanaka et al., 2012).

### Diagnostic surveillance

MRI with MRCP is the procedure of choice to clearly identify the structural composition of the cyst and duct communications. Furthermore, unlike CT scans, MRI offers no risk of radiation exposure for frequent radiologic monitoring is required (Tanaka et al., 2012). The international consensus guidelines (Tanaka et al., 2012) recommend the following surveillance type and frequency:

- CT or MRI with MRCP
  - for cysts measuring 1cm with MPD dilatation of 10mm or greater
  - for cysts measuring 3cm and larger
  - for MPD dilatation of 5-9mm
  - with abrupt increases in MPD
  - distal pancreatic atrophy or lymphadenopathy
- EUS: for cysts 3cm or greater without MPD dilatation of 5-9cm
- Multi-detector CT scans and MRCP to distinguish BD-IPMNs from the MD-IPMNs
- EUS-FNA to distinguish between BD-IPMN and serous cystadenoma

### Follow-up frequency

Follow-up is based on lesion type and size, MPD dilatation, degree of dysplasia, and potential tumor progression. Additional factors include elderly age, family history of PDAC and other cancers, comorbidities, and probable risk of pancreatic cancer. International consensus guidelines (Tanaka, et al., 2012) recommend:

- For low risk patients
  - Initial follow up at about 3-6 months
  - MRI/MRCP or pancreatic protocol CT scan.
  - If unchanged, then annual:
    - history/physical exams
    - MRI/MRCP or CT scan
    - serologic marker (CEA,CA-19-9)
- IPMN less than 1 cm: MRI/CT follow-up every 2-3 years
- IPMN 1-2cm: yearly follow up with CT/MRI
- IPMN 2-3cm: EUS 3-6 months and yearly follow-up
- IPMN greater than 3cm: close surveillance, MRI and EUS every 3-6 months.

Because of increased risk of development of PDAC, some clinicians prefer a closer surveillance even with smaller sized tumors (Tanaka et al., 2012).

### Guidelines for surgical resection

Surgical resection of these potentially malignant tumors is recommended if the patient can tolerate surgery. MD-IPMNs and mixed IPMNs may foster high grade dysplasia with pancreatic adenocarcinoma in 60-70% of cases and invasive progression of cancer in 50% of cases (Daude et al., 2015).

Branch duct IPMNs have lower rates of malignancy (25.5%) and invasiveness (17.7%) (Tanaka, et al., 2012). Even IPMNs with high grade of dysplasia may have a good prognosis after resection (Castellano-Megias et al., 2014), while patients with unresected MD-IPMNs or mixed IPMN have an increased risk (36%) of developing pancreatic cancer within 2.5 years (Daude, et al., 2015).

### Implications for nurse life care planners

Diabetic clients, especially if insulin-dependent or undergoing pancreatic islet cell allogenic transplant, may be predisposed to IPMNs. Additionally, diabetics are at increased risk for pancreatic adenocarcinoma and invasive malignancy.

### Mucinous Cystic Neoplasm

These are pancreatic, mucin-producing cysts with a distinctive ovarian-type stroma occurring in the body or tail of the pancreas in the middle aged females. They are solitary, range in size from 5-35 cm, and do not communicate with the pancreatic duct. Most are slow-growing and asymptomatic. When located in the pancreatic head, they may develop into mucinous cystoadenocarcinoma. Initially benign, 6-55% progress to invasive carcinoma (Testini et al., 2010).

### Diagnostic surveillance includes:

- tumor markers (CEA, CA 19-9)
- CT scans with and without contrast
- MRI /MRCP
- EUS-FNA
- PET-CT

Conservative surveillance with regular...
follow-up has been proposed for asymptomatic MCNs smaller than 3cm and without mural nodules.

MRI/CT imaging and FNA cytology should be performed every 6 months for 2 years and yearly after that. Annual follow-up should continue for four years, after which the interval can be lengthened. If the cyst enlarges or the patient becomes symptomatic, surgical resection is recommended (Testini et al., 2010).

Surgical Resection

Surgical resection is recommended due to potential for transition to invasive malignancy. However, for size less than 4cm and without mural node involvement, observation may be considered especially in the elderly (Testini et al., 2010). Resection is based on location and may include:

- **Distal pancreatectomy with spleen preservation** for tumors located in the tail. Major complication is pancreatic fistula (15-20%).
- **Laparoscopic distal pancreatectomy** for benign MCNs and small malignant lesions less than 5cm.
- **Right or extended left pancreatectomy** if in the neck or proximal body. Major complications are endocrine insufficiency requiring insulin or oral agents (30-35%) and exocrine insufficiency (15-20%) requiring supplemental pancreatic enzymes.
- **Middle pancreatectomy** if located at the pancreatic neck or proximal body. This preserves most endocrine and exocrine function but carries a high risk of post-operative morbidity.
- **Enucleation** for tumors smaller than 2cm and without nodular involvement minimizes the risk of postoperative pancreatic insufficiency. However, it is associated with high rate of pancreatic fistula formation (Testini et al., 2010).
- **Whipple surgery** is recommended for MCNs located in the head of the pancreas. Most common post-operative complications are pancreatic fistula (6-20%) and delayed gastric emptying (5-10%).

**Duodenum-preserving total pancreatic head resection** if in the pancreatic head without invasion. Compared to the Whipple procedure, it has a smaller rate of morbidity and mortality, decreased chance of glucose metabolism impairment, shorter hospitalization, and lower cost (Testini et al., 2011).

**Malignant Cystadenocarcinoma**

Only about 2.4-14% of pancreatic cancers are cystic, including mucinous cystadenocarcinoma (MCAC). MCACs occur in the distal pancreas, most often in women. The diagnostic work up includes CT scan, US, EUS, EUS / FNA and tumor markers. Depending on the location of the tumor, the standard treatment of MCAC involves surgical removal by distal pancreatectomy, total pancreatectomy, or Whipple procedure. With early diagnosis and resection, the survival rate is higher. In large studies, five year post-resection survival rate was 63%, while for nonresectable invasive and metastatic tumors, 2-year survival rate was 12% (Sturesson et al., 2011).

**Whipple Procedure**

**Indication and outcomes**

The Whipple surgery was named after Alan O. Whipple, who was the first surgeon in the U.S. to modify and perform one stage pancreaticoduodenectomy (PD) in 1935 (Chandrakanth et al., 2011). Surgical skill and experience, the volume of performed procedures, and hospital experience in managing care influence outcomes. The mortality rate at high volume hospitals is around 2%, while morbidity rate is 30-50% (Fernandez-del Castillo et al., 2012). A high volume center performs 20 or more annually; medium volume centers 10-19; and low volume centers fewer than 10 (Addeo, 2014).

**Surgical Types**

The two main types of Whipple surgery include the classic pancreaticoduodenectomy (PD) and pylorus preserving pancreaticoduodenectomy (PPPD). The first phase of PD consists of removing of the head of the pancreas, most of the duodenum, a portion of the bile duct, the gallbladder and associated lymph nodes and part of the distal stomach, except in PPPD, where the stomach and the pylorus are preserved (Raman, et al., 2013). The second or reconstructive phase involves reconnecting the remaining pancreas, stomach and common bile duct to the jejunum. The connection to the jejunum (middle part of the small intestine) ensures that the pancreatic enzymes and bile drain into the small intestine and aid in the
digestive process. The anastomoses between the remaining organs may include:

- Choledochojunostomy - between the bile duct and the jejunum
- Pancreaticojejunostomy - between the remaining pancreas and jejunum
- Gastrojejunostomy - between the remaining portion of the stomach and the jejunum in classic PD
- Duodenojejunostomy - between the stomach, the preserved pylorus and jejunum in FPPD (Raman, et al., 2013).

Surgery time Laparoscopic or open, as appropriate) is approximately six hours, with length of stay about 9.5 days, depending on post-operative complications. (Fernandez-del Castillo, 2012).

Postoperative Complications

Postoperative complications with high morbidity include:

- Pancreatic fistula (PF) - associated with life-threatening intra-abdominal complications such as sepsis, abdominal and pancreatic abscesses, bleeding, repeat laparotomy and death. The majority of deaths in PF are related to sepsis, abdominal and intestinal bleeding (Addeo, 2014).
- Pyogenic liver abscess (PLA) - the main risk factors include PF and re-operation. Treatment requires percutaneous drainage and intravenous antibiotic therapy with mean hospital stay of 12 days. (Njoku et al., 2014).
- Surgical wound infection
- Intra-abdominal hemorrhage
- Intra-abdominal abscess
- Anastomotic leakage
- Delayed gastric emptying
- Gastric dumping
- MI, cardiac arrhythmias

Respiratory failure with ventilator dependency and delayed weaning (Fernandez-del Castillo et al., 2012).

Long-term complications, see Table 1. Case study, see sidebar.

Conclusion

Pancreatic adenocarcinoma is a devastating disease that diminishes the quality of life and reduces longevity. The high mortality rate of pancreatic adenocarcinoma is related to late detection and distant metastasis of the cancer at the time of diagnosis. Among the numerous pancreatic cysts, the IPMNs and MCNs have been identified as pre-cursors to PDAC with significant propensity for malignant transformation. Although asymptomatic pancreatic cysts are usually discovered incidentally, once identified, diligent surveillance of the pancreatic lesions provides a unique opportunity for early detection of pancreatic ductal adenocarcinoma. Management of pancreatic cysts can range from watchful waiting to complex surgical resection with significant, quality of life altering complications.

The nurse life care planner for a client with pancreatic cystic disease or experiencing post Whipple complications must be well-informed regarding the disease process, the risk factors, disease process management, treatment options, diagnostic testing, surgical procedures, and short- and long-term complications.
Complication- Symptoms | Diagnostics | Treatment
--- | --- | ---
Delayed gastric emptying, gastroparesis; nausea, vomiting, weight loss, dehydration |  | prokinetics (e.g., erythromycin, metoclopramide) fluid and electrolytes. Possible tube feedings via peg-J or jejunostomy (Parish & Berry, 2012).

Gastric dumping syndrome: diarrhea, fullness, abdominal cramping and vomiting (within 15-30 minutes after meal consumption), weakness, sweating, dizziness and flushing | modified oral glucose tolerance test, gastric emptying scintigraphy, upper endoscopy and upper GI series | small meals, avoid osmotic foods, medications to slow gastric emptying (octreotide acetate, Sandostatin), nutritional education (Parish & Berry, 2012)

Exocrine pancreatic insufficiency; decreased pancreatic enzyme secretion with resultant fat malabsorption (steatorrhea) and weight loss | 72-hour quantitative fecal fat test | pancreatic enzymes replacement therapy (PERT); fat soluble vitamins (A, D, E, K) and minerals. (Creon capsules, Pancreaze capsules, Zenpep capsules, and Ultrace capsules) (Parish & Berry, 2012)

Endocrine pancreatic insufficiency and diabetes | fasting and post-prandial blood glucose and HgA1C levels | diabetic education, insulin and oral hypoglycemics, prevention of complications (Parish & Berry, 2012).

Nutrient deficiencies; B12, iron, calcium, copper, selenium, zinc | vitamin B12, folate, ferritin, coper, selenium and zinc levels | replenishment/replacement; maintenance dose when stable to prevent overdosing

Afferent loop syndrome; Kinking, hernias, compression and adhesions of the afferent loop cause mechanical obstruction and result in pancreatobiliary complications (Naydu et al., 2015.) | Diagnostic radiology as indicated | 

Small bowel bacterial overgrowth (SIBO) in afferent loop; malabsorption, nausea, gas, bloating, diarrhea, fecal incontinence, vitamin B12 deficiency, elevated folate |  | broad spectrum antibiotics is essential in management of this condition (Parish & Berry, 2012).

Anastomotic strictures, pancreatic and bile duct blockages, up to five years post surgery |  | endoscopic or surgical intervention (Raman, et al., 2013).

Table 1 - Complications Post Whipple
Case Study

Rhonda Hall is a 40-year-old female with no significant medical history until the incidental discovery of large, localized cystadenoma in the pancreatic neck. MRI with MRCP revealed multiple IPMNs in the body and the tail of her pancreas, the largest one measuring 1.5cm. Her family history is significant for diabetes, high blood pressure and PDAC.

She had Whipple surgery on April 25, 2007 at Jennie Edmundson Memorial Hospital for pancreatic neck mass with suspicion of malignancy. The general surgeon had only performed four Whipple surgeries in ten years. The hospital had a low volume of Whipple cases.

The surgeon accidentally cut the superior mesenteric vein, causing hemorrhage during the surgery. This initially resolved, but severe hemorrhage recurred when surgery was restarted. Mrs. Hall was transported by ambulance to the University of Nebraska Medical Center where the surgery was completed by another surgeon. Mrs. Hall was comatose for two months, had multiple revision surgeries, and required liver, kidney, and small bowel transplantation (Iowa Medical Center). Mrs. Hall suffers from pain secondary to multiple surgeries, delayed gastric emptying, nausea, vomiting, malnutrition, pancreatic insufficiency, food intolerances, weight loss, diarrhea, fatigue, dizziness, muscular weakness, chronic pain with narcotic management, anxiety, depression, insomnia, new onset of diabetes, and new onset cardiac arrhythmia. She is overwhelmed by her multiple medical appointments, complex treatment regimen, and multiple medications.

Mrs. Hall was employed at medical clinic as physician assistant. She has not been able to return to work. Mrs. Hall's debilitating health status and complications have placed a tremendous strain on her marriage.

Nursing diagnoses to consider:
Ineffective health management:
Domain 1. Health Promotion; Class 2. Health Management

Non-compliance: Domain 1. Health Promotion; Class 2. Health Management
Imbalanced nutrition: less than body requirements: Domain 2. Nutrition; Class 1. Ingestion;
Fatigue: Domain 4. Activity/ Rest; Class 3. Energy Balance
Risk for ineffective gastrointestinal perfusion: Domain 4. Activity/Rest; Class 4. Cardiovascular/Pulmonary

Readiness for enhanced hope: Domain 6. Self-Perception; Class 1. Self-Concept
Hopelessness: Domain 6. Self-Perception; Class 1. Self-Concept
Ineffective coping: Domain 9. Coping/ Stress Tolerance; Class 2. Coping Responses
Stress overload: Domain 9. Coping/ Stress Tolerance; Class 2. Coping Responses

The nurse life care plan for Mrs. Hall includes:

Future medical care-routine: primary care physician; gastroenterologist; pancreatic specialist; GI surgeon; pancreatic surgeon; endocrinologist; cardiologist; transplant physician; transplant clinic visits; pain management specialist; podiatrist; physiatrist and psychiatrist.

Therapeutic Evaluations and Modalities:
– Physical therapy evaluation and therapy sessions to improve strength, balance and endurance, home exercise program and fall prevention
– OT evaluation –to recommend aids for independent functioning and durable medical equipment
– Nutritional evaluation and sessions in order to maintain optimal nutritional status, manage diabetes, monitor weight and manage nutritional deficiencies
– Psychotherapy evaluation and sessions to manage anxiety, depression, adjust to disability, including family sessions
– Pain management program for chronic pain with opioid rehabilitation; pain support group with individual and group therapy

Diagnostic Studies/Lab work:
– transabdominal ultrasound, CT scans, MRI,MRCP, EUS, for monitoring gastrointestinal organs, liver and pancreas, including monitoring for recurrence of pancreatic cystic disease as per guidelines
– cardiology studies (EKG, Holter monitor to evaluate cardiac arrhythmias)
– bone density scans due to impaired nutrient absorption and risk of osteoporosis
– blood levels for transplant anti-rejection medication levels, serum creatinine, bilirubin levels, immunosuppressive levels, opioid medications and antiarrhythmic medications, blood glucose levels and general health panel
– endoscopy/colonoscopy secondary to changes in GI function, increased risk for GI ulcers and altered elimination pattern (may be more frequent than recommendations for general population)
– kidney and liver transplant biopsy for detection of organ rejection.

Medications
– Percocet (opioids for chronic pain management)
– Lomotil (anti-diarrheal)
– Zofran (anti-emetic)
– Pancrelipase (pancreatic enzyme supplementation to aid digestion)
– Prozac (anti-depressant)
– Alprazolam (anti-anxiety)
– Novolin 70/30 insulin
– tacrolimus and azathioprine (transplant anti-rejection medications)
– metochlopramide (prokinetic to
facilitate GI motility)
- Amiodarone (antiarrhythmic medication)
- Ambien (hypnotic for insomnia)
- Lansoprazole (proton pump inhibitor to minimize GI acidity)
- Colace and Bisacodyl (stool softener and laxative, for constipation caused by opioid therapy)
- flu and pneumonia vaccine secondary to immunosuppression therapy
- Norvasc, Clonidine, Hydrochlorothiazide for high blood pressure

Medical supplies/durable medical equipment: straight cane, electrical scooter, shower chair, shower/tub grab bar, glucometer with diabetic supplies, insulin syringes, weight scale, manual blood pressure monitoring kit

Aids for Independent functioning: easy grasp reacher due to difficulty reaching and bending

Home Furnishings and Accessories: handheld shower, specialty mattress (to promote restful sleep)

Home/Facility Care: personal care worker/housekeeper to assist with activities of daily living and household chores

Transportation: Mileage reimbursement for medical appointments and rehabilitation/psychotherapy visits. Taxi/ambulette services to and from appointments as needed.

Case Management: Nurse case manager to assist with multiple appointment planning, transportation, access to treatment, collaboration with multiple providers, adherence to medical plan of care, evaluation and revision of nurse life care plan

Vocational rehab evaluation: To assess potential for return to work and recreation

Health and Strength Maintenance: gym/pool membership.

Potential Complications:
Mrs. Hall is at risk for multiple complications and frequent re-hospitalizations: bacterial and viral infections, transplanted organ rejection, graft failure, and adverse reaction to immunosuppression medications. Patients with kidney transplantation are at increased risk for uncontrolled hypertension, hyperlipidemia, gastric ulcers, and malignancies (Weed & Berens, 2010). Considering Mrs. Hall’s family history of PDAC, she is at risk of developing pancreatic duct adenocarcinoma due to possible transformation of existing pancreatic IPMNs from benign to malignant and invasive state.

Mrs. Hall is at risk for frequent re-hospitalization for unstable cardiac arrhythmias, uncontrolled hypertension, uncontrolled pain, GI obstruction, uncontrolled diabetes, malabsorption and malnutrition, falls due to impaired balance, and fractures due to osteoporosis, small bowel bacterial overgrowth (SIBO) due to kinking of the afferent loop created by the Whipple surgery. She will likely also experience emotional, psychological, and psychosocial distress due to diminished quality of life.

Mrs. Hall will most likely require future aggressive medical and surgical treatments. Anastomotic strictures (narrowing) at pancreaticojejunostomy and hepaticojejunostomy sites interfere with delivery of bile and pancreatic juices to the jejunum and may cause profuse diarrhea, severe pancreatic insufficiency, abdominal pain, jaundice and intestinal obstruction. Mrs. Hall may require pancreatic surgery, such as middle or distal pancreatectomy if existing IPMNs become symptomatic or exhibit changes indicative of transition from benign to malignant state.

CPT codes and ICD-10 codes

SURGICAL CPT CODES
48150- Pancreatectomy, proximal subtotal with total duodenectomy, partial gastrectomy, choledochoenterostomy and gastrojejunostomy (Whipple-type procedure), with pancreatojejunostomy
48152- without pancreatojejunostomy
48153- Pancreatectomy, proximal subtotal with near-total duodenectomy, choledochoenterostomy and duodenojejunostomy (pylorus-sparing Whipple-type procedure), with pancreatojejunostomy
48154- without pancreatojejunostomy (Aetna, 2015)

RADIOLOGIC/NUCLEAR MEDICINE CPT CODES
76700 – Abdominal ultrasound complete
74170 – CT scan of abdomen, with and without contrast
74160- CT scan of abdomen with contrast
78306 – Bone Scan whole body
78300- Bone Scan Limited
78315 –Bone Scan 3-phase (Steinberg diagnostics, 2015)
74181- MRI of abdomen w/o contrast
74182- MRI of abdomen w/contrast (Michigan State University, 2013)
74183- MRI of abdomen w/o & w/contrast, (Imaging Healthcare Specialists, 2015)
76377- MRI of abdomen with MRCP

ENDOSCOPY CPT CODES
43260- Endoscopic Retrograde Cholangiopancreatography (ERCP)
43275- ERCP with stent removal
43274 – ERCP with stent placement
43240- Esophago-gastroduodenoscopy(EGD) with transmural pseudocyst drainage, including stents and needle aspiration
43242- EGD with EUS/FNA
43259- EUS of esophagus, stomach and duodenum (ASGE, 2016).

ICD-10 CODES
C25.3- Malignant neoplasm of pancreatic duct
D13.6- Benign neoplasm of pancreas
D13.7- Benign neoplasm of endocrine pancreas (Aetna, 2015)
K86.3- Pseudocyst of the pancreas
K90.3- Pancreatic steatorrhea (Aetna, 2015)
C25.0- Malignant neoplasm of pancreas (Aetna, 2015)
REFERENCES


Supreme Court of Iowa (2012). Rhonda Hall v. Jennie Edmundson Memorial Hospital.


Our long history of success is based on our development of “real world” programs. Our clinical neuropsychologists integrate evidence-based treatment into individualized treatment plans. These professionals are part of our treatment team and regularly evaluate each patient’s progress and implement program changes as necessary.

PATE’s therapy types include:
- Physical Therapy
- Speech/Language Therapy
- Behavioral Therapy
- Animal-assisted Therapy Activities
- Biofeedback
- Occupational Therapy
- Cognitive Rehabilitation
- Vocational Rehabilitation
- Emotional/Psychological Adjustment
- Aquatic Therapy

PATE’s results-oriented treatment programs include:
- Community-based Therapy
- Post-acute Residential
- Supported-living Residential
- Post-acute Day Neuro
- Young Adult (ages 16 – 19)

PATE also provides:
- Independent Neuropsychological Evaluations
- Medical Services Provided by a Physical Medicine and Rehabilitation Physician
- Bilingual Services
- Transportation Services

For more information on our programs and services for persons with acquired brain injuries, or to learn more about how you can help advocate for better access to care, please visit our website at www.paterehab.com or call 1.800.992.1149 or 972.241.9334.

Locations in: Dallas, TX • Anna, TX • Fort Worth, TX
Fluent systems®

The “Software Solution” for LCP, MSA and MCP Professionals

Fluent Systems software designed for professionals who prepare
- Life Care Plans
- Medicare Set-Aside Reports
- Medical Cost Projections

Fluent Systems “Enterprise Version” Software Benefits

- Secure online system
- Encrypts at risk data, SSL security
- All templates completely customizable
- ICD - 9, CPT, HCPCS codes included
- ICD - 10 when applicable
- Search by code or description
- Choose description length for codes
- Templates can be customized
- Dataflow between LCP, MSA, MCP
- Customize templates by injury for future files
- Set page breaks or change page orientation
- Customize Narrative headings or use default
- Create “options” in LCP, MSA or MCP
- Upload files into template
- Submitter cover letter for MSA
- Calculates “Seed” money
- MSA template for WC and Liability files
- Limited use “User” available for certain sections
- LCP Narrative Section
- LCP Tables Section
- Customize Cover Pages

- Customize Company Logo or Customer Logo
- Footer information
- Admin. section to assign users
- Group files by customer on “Dashboard”
- Custom Data Lists reduces data entry
- Screen lock on “non-usage” for security
- Calculates age
- Calculates life expectancy
- Inflation factor built into template tables
- Calculates tables
- Customize table headings
- Create custom text tables
- Tables Summary with inflation numbers
- End notes section
- Notes section
- LCP Supportive information reference page
- Default templates/tables
- Narrative and Tables divisions
- Select headings by division or customize
- Saves labor cost
- Prints to PDF

“Special Pricing on software purchased at the Conference”
Section 111 Mandatory Reporting Coming Soon

Fluent Systems, LLC
P.O. Box 304
Dunedin, FL 34697
www.fluentsystems.net

(888) 672 3453 - (866) 430 5858
ENHANCING PATIENTS’ LIVES

Catastrophic Care Expertise

- DME and Daily Medical Supplies
- Specialty & Mobility Equipment
- Home & Vehicle Modifications
- Personalized Patient Care

Definiti
HEALTHCARE MANAGEMENT
WWW.DEFINITI.NET

JULIE GLADNEY  888-300-4002  LINDA STELLINO
MEDICAL CANNABIS AND QUALITY OF LIFE IN IRRITABLE BOWEL DISEASE

DANA FILATOVA MS, CNS, LDN

As a holistic, functional, science and evidence-based nutritionist, I take deep care in assessing, monitoring, and evaluation my patients. Medical nutrition therapy approach to interventions is applied based on bio-individual and unique needs of each patient. Taking patient-centered approach creates an opportunity for healing. Assessing current lifestyle, genetic make-up, internal and external environments allows for an individualized plan for restoration and maintenance of patients’ optimal health and well-being.

Why Functional Nutrition?
Functional Nutrition (FN) is an emerging specialty within the field of nutrition. Similarly to Functional Medicine, where the body is approached from the perspective of treating the root cause of the disease, FN analyzes how the food we are eating is affecting the body on the cellular level. Food is greater than just a set of calories or macronutrients such as fat, carbohydrates and proteins. Food is information. Each molecule could potentially be a medicine or a poison depending on each individual case. This means that everything you eat affects how you feel and how your cells behave.

Why Do I Need to Care About What I Eat?
Eating whole, fresh foods is key to preventing chronic illnesses and to recovery from disease. Food affects everything from hormone production, blood sugar regulation, liver detoxification, to sleep, well-being, and having a sustainable energy throughout the day. Knowing which foods are therapeutic (used as medicine) and which may potentially be harmful (or poisonous) to one’s particulate body is essential part of healing and prevention of illness onset.
Quality of life (QoL) indices are well-researched tools to estimate the effect of different parameters on functioning and wellbeing. Health-related QoL (HRQoL) surveys include self-perceived physical and mental disability, pain, vitality, social, and role functioning (Centers for Disease Control and Prevention, n.d.) Poorer mental health (related to psychiatric disorders), insomnia, chronic pain, gastrointestinal dysfunction and multiple other health-related conditions, have been reported to affect the quality of life in the general population suffering from such conditions.

Cannabis is used to treat many medical conditions and symptoms. It is effective in treating nausea, loss of appetite, pain, anxiety, insomnia, inflammation, chronic pain and muscle spasms (Gierenger et al., 2008) These symptoms often accompany physical and/or mental conditions. It could be helpful in arthritis, osteoarthritis, cancer, HIV/AIDS, multiple sclerosis, epilepsy, Parkinson’s disease, ADHD and post-traumatic stress disorder (PTSD). The following is a review of a study on cannabis and quality of life in inflammatory bowel disease.


Treatment options for inflammatory gastrointestinal conditions such as Crohn’s disease (CD), ulcerative colitis (UC), and IBD include an array of anti-inflammatory and immunosuppressant medications (e.g., 5-ASA, corticosteroids, thiopurine drugs, methotrexate, and anti-TNF alpha agents), all with substantial risk for severe side effects.

There are over 60 cannabinoids (aromatic hydrocarbon compounds) found in Cannabis sativa with a recognized beneficial effect on the GI tract. Of these, the chief psychotropic agent is delta 9-tetrahydrocannabinol (THC).

THC acts via at least two cannabinoid receptors on B Cells, NK cells, and mast cells: CB1 in central, peripheral, and enteric nervous system; and CB2 on immune cells and some sensory nerve terminals. Cannabinoids inhibit GI contractile transmitter release and suppress TH1 cytokine (related to cell-mediated immunity) production while increasing TH2 cytokine (adaptive immunity) production; and inhibit the production of TNF-alpha.

Cannabis is also known to stimulate appetite and aid in weight gain. There are also studies that link cannabis may positively effect appetite regulation, food intake and energy metabolism.

Patients diagnosed with irritable bowel disease (IBD) suffer from significant amount of morbidity and diminished quality of life. Cannabis has been shown to stimulate appetite and aid in weight gain, thus making it a treatment option for multiple gastrointestinal (GI) diseases. The goal of this study (published in Digestion) was to discover whether the treatment with inhaled cannabis affects disease activity, promotes weight gain, and improves quality of life in patients with IBD. The study included thirteen patients who were prescribed cannabis. Subjects received 50gm of dry, processed plant per month and were guided to take three inhalations from a prepared cigarette each time they experienced pain; greater dosage could have produced psychiatric side effects.

Body weight was measured at baseline and three months. Two quality of life questionnaires and disease activity indexes were administered. After three months, patients reported “improvement in general health perception, social functioning, ability to work, physical pain and depression.” Patients also had a weight gain of 4.3 +/-2 kg, and 1.4 +/-0.6 increase in BMI. The study concluded that three months of inhaled cannabis treatment “improves quality of life measurements, disease activity index, and causes weight gain and rise in BMI in long-standing IBD patients.”

Clinical implications of such findings for nutritionists include the beneficial effect of treatment in patients with IBD. Reducing or eliminating unpleasant symptoms, e.g., unpredictable trips to the bathroom and associated anxiety, GI pain and upset, constipation, bloating, gas, dangerously quick and unintentional weight loss, malnourishment, and inability to attend social events that for the most part include food, can significantly improve quality of life.
production and enhanced TH2 cytokine production, suggesting the rationale for cannabis anti-inflammatory effects.

The study lacks detailed information on which specific cannabinoids affect which pathways. The more than 60 known cannabinoids and over 480 natural components in Cannabis sativa include at least six subclasses of cannabinoids:

- Cannabigerols (CBG)
- Cannabichromenes (CBC)
- Cannabidiols (CBD)
- Tetrahydrocannabinols (THC)
- Cannabinol (CBN) & Cannabinodiol (CBDL)
- Other: Cannabicycol (CBL), Cannabiolsin (CBE), Cannabielsoin (CBI), and Misc. types. (University of Washington, nd)

The most-researched cannabinoid is THC, so the assumption is that when referring to “cannabinoids” and “cannabis,” this study referred to the THC compound. The anti-anxiety effects of CBDs in the previous study may actually counteract the psychoactive effects of THC, so if THC was the one studied for IBD, is it possible that a plant containing greater amount of CBD vs. THC, could potentially not be as beneficial in GI-related diseases treatment? There are hundreds of different strains of C. sativa (and even more so-called “hybrid” strains – a cross between C. sativa and C. indica). It is also unknown what dosage and at what frequency was administered. The study would have been of even greater significance to nutritional practice if it specified the cannabinoid compound (as well as what specific “inhalation” method was used) and tracked inflammatory process and mucosal changes.

REFERENCES


CRASHCART - Is your practice experiencing a Code Blue? Revive it with AANLCP’s resource cart. Forms, templates, contracts and resources all at your fingertips.

MASTERMIND SERIES “Getting Down to Business” - A 12 month learning and business development series designed to build, grow and sustain your life care planning practice. This series offers up to 24 CNE’s.

PMIC’S 2016 MEDICAL FEES BOOK - Need 2016 medical cost? Yep, that’s right, we’ve got it!

EBSCO: REHAB REFERENCE / CINAHL - Bump up your plans with research, journals and industry insights.

FIND-A-CODE - Save time and get access to an expansive medical coding and billing resource, now with Anesthesia crosswalk.

DISCOUNTS, DISCOUNTS, DISCOUNTS... We’ve got member only discounts you won’t want to miss, check out #thriftythursdays

MARKETING MATERIAL - Tired of explaining what a life care planner does? Present your practice with high quality and professionally designed marketing materials that get you hired.

OFFICIAL DISABILITY GUIDELINES - Need a comprehensive tool to assess treatment options? Members have access to the most comprehensive and up to date medical treatment guidelines worldwide. Yep it’s included.

Don’t forget our webinars, journals, Lifeline (mentorship), and much, much more.

*Resource access is dependent upon your individual membership type and tier.
Mr. Welch presented to the Emergency Room reporting severe back pain. After diagnostic imaging, he had emergency total abdominal resection of necrotic small bowel, with less than 60 cm of remaining. He received a central line for TPN and fluids.

Mr. Welch was eventually discharged to home care for TPN and wound care. He was diagnosed with short gut syndrome and placed on a special diet. He had frequent loose stools. Over the next two years, he had numerous hospitalizations for infections in his central line, frequent loose stool, nausea, and changes in central line access.

Mr. Welch sees a gastroenterologist monthly for general oversight and medication refills. He sees a primary care provider every two weeks for lab reviews and TPN prescriptions.

A home infusion company provides all TPN services and supplies, including two IV pumps, tubing, syringes and needles, dressings, IV fluids, flush and heparin flush, and TPN. UPS delivers the weekly medical supplies to Mr. Welch’s home. Every week a registered nurse comes to his home to review his condition and change his Hickman central line dressing; the nurse draws labs from the line every other visit. The infusion company has a nutritionist who discusses his oral intake of nutrition and offers advice regarding his dumping syndrome and maintaining nutritional health.

His family purchased a special refrigerator that monitors and maintains the required temperature for TPN storage. An alarm sounds if it is outside of the required temperature range.

Current Medications:
- Diphenoxylate and atropine (Lomotil) 2.5 mg, two tablets, four times a day for diarrhea.
- Loperamide and simethicone (Imodium) four tablets a day, for diarrhea.
- Promethazine (Phenergan) 25 mg as needed for nausea; about two or three times a week.
- Omeprazole (Prilosec) 40 mg twice a day, to decrease stomach acid.

Functional Status:
Mr. Welch is independent in administering his TPN. To reduce the chance of infection in the central line, he uses spray bottles of alcohol to clean all the surfaces in his bathroom and kitchen.

The biggest complaint he has is managing his bowels. Several days a week, he may have up to 30 bowel movements in one day. Because of occasional liquid stool incontinence, he wears a maxi-pad. He would like a bidet installed, as he gets very sore from frequent anal wiping.

Day In The Life
Mr. Welch’s life is centered on his TPN and his bowel movements. In the morning, he disconnects himself from his nighttime TPN and flushes the Hickman catheter with heparin. Within 30 minutes of getting up, he needs to have a bowel movement.

Everyday he needs to be back at home in time for a five-hour fluid hydration IV in the afternoon. This hydration fluid can cause dumping syndrome and sometimes he has frequent bowel movements for the rest of the day. At bedtime he takes his last set of medications and connects to the IV pump for a twelve-hour TPN infusion.

Projection of Life Time Costs:
I provided three avenues for Mr. Welch’s long term treatment.

- A new medication called teduglutide (Gattex) has been developed for persons with short gut syndrome and approved by the FDA in 2012. This medication has a risk for serious side effects including cancer, polyps, bowel blockage, swelling or blockage of the gallbladder or pancreas, and fluid overload. Twice-yearly colonoscopies are required.

- Because he has not been started on teduglutide, I developed a care plan that provides two options, one with TPN and support and the second option using teduglutide and reducing his TPN to a projected four days per week.

- I also researched the costs of a small bowel transplant, although he is not interested in undergoing this surgery due to the lower success rate.
**Option #1:** Mr. Welch remains on TPN, with regular care by his care providers.

**Physician Care:**
- Primary care monthly to prescribe medications for diarrhea and dumping syndrome.
- A different physician reviews nutritional laboratory studies and adjusts TPN formula. He sees Mr. Welch in the office twice a year.

**Diagnostic Testing:**
- Laboratory tests every other week to monitor status and modify TPN prescription as indicated.

**Therapy:**
- TPN service and weekly RN visits for dressing changes and every other week blood draws from his Hickman catheter
- Nutritional advice from the TPN service nutritionist
- TPN, IV hydration fluids, flush and heparin flushes, tubing, supplies and two IV pumps.

**Costs:** I reviewed Mr. Welch’s itemized bills. I confirmed with the infusion home care office that these bills were all for infusion services and there are no other bills. Laboratory tests were drawn by the home nurse but charged to the laboratory company. Billing for home care services including dressing changes and lab draws is approximately $400 per week. TPN supplies including IV pumps, tubing, heparin, saline, syringes and daily TPN and daily hydration fluid totals approximately $80,000 per month.

**Medications:**
- Diphenoxylate and atropine (Lomotil) 2.5 mg, two tablets, four times a day for diarrhea.

<table>
<thead>
<tr>
<th>Item, Duration</th>
<th>Frequency and costs</th>
<th>Annualized Cost</th>
<th>Source of costing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monthly visits for narcotic prescriptions and health monitoring for lifetime</td>
<td>$250 per month</td>
<td>$3,000 per year</td>
<td>I obtained costs for these physician visits by calling three offices in his geographic area.</td>
</tr>
<tr>
<td>Every six month visit to TPN physician, for lifetime</td>
<td>Every six months @ $125</td>
<td>$250 per year</td>
<td>I obtained costs for these physician visits by calling three offices in his geographic area.</td>
</tr>
<tr>
<td>TPN physician, reviews labs every two weeks and prescribes TPN formula, for lifetime</td>
<td>Every two weeks @ $85.</td>
<td>$2,210 per year</td>
<td>I obtained costs for these physician visits by calling three offices in his geographic area.</td>
</tr>
<tr>
<td>TPN labs for lifetime</td>
<td>Twice a month @ $400 per month.</td>
<td>$4,800 per year</td>
<td>US Medical fees for the CPT codes for each test.</td>
</tr>
<tr>
<td>TPN Service, including TPN and hydration fluids, tubing and supplies, IV pumps (2) for lifetime</td>
<td>$80,000 Monthly.</td>
<td>$960,000 per year</td>
<td>Past medical bills were used for these costs.</td>
</tr>
<tr>
<td>RN services:  * weekly dressing changes and condition assessment  * every two week blood draws from Hickman catheter for lifetime</td>
<td>$400 per week</td>
<td>$20,800 per year</td>
<td>Past bills</td>
</tr>
<tr>
<td>Promethazine 25 mg for lifetime</td>
<td>Two or three a month</td>
<td>$4 per month, $48 per year</td>
<td>Three costs from GoodRx.com</td>
</tr>
<tr>
<td>Lomotil 2.5 mg for lifetime</td>
<td>Eight per day X 30 days = 240 per month.</td>
<td>$125 per month, $1,500 per year</td>
<td>Three costs from GoodRx.com</td>
</tr>
<tr>
<td>Imodium 2 mg for lifetime</td>
<td>Four per day X 30 days = 120 per month</td>
<td>$13 per month, $156 per year</td>
<td>Three costs from GoodRx.com</td>
</tr>
<tr>
<td>Omeprazole 40 mg for lifetime</td>
<td>Two per day</td>
<td>$90 per month, $1,080 per year</td>
<td>Three costs from GoodRx.com</td>
</tr>
<tr>
<td>70% isopropanol wipes for lifetime</td>
<td>Six boxes per week</td>
<td>$24 per week, $1,248 per year</td>
<td>Wal-Mart, Walgreens and CVS pharmacies</td>
</tr>
<tr>
<td>70% isopropanol spray for lifetime</td>
<td>One bottle per week</td>
<td>$4 per week, $208 per year</td>
<td>Wal-Mart, Walgreens and CVS pharmacies</td>
</tr>
<tr>
<td>Maxi pads for lifetime</td>
<td>8-14 pads per week</td>
<td>$1.55 per week, $80.60 per year</td>
<td>Wal-Mart, Walgreens and CVS pharmacies</td>
</tr>
</tbody>
</table>

**Total:** $995,380.60 per year
✓ Loperamide and simethicone (Imodium) four tablets a day, for diarrhea.
✓ Promethazine (Phenergan) 25 mg as needed for nausea; about two or three times a week.
✓ Omeprazole (Prilosec) 40 mg twice a day, to decrease stomach acid.

**Supplies not provided by TPN Company:**
✓ Alcohol wipes or spray on all surfaces that he uses to prepare his TPN.
✓ Maxi pad, 1-3/day

**Option #2:** TPN four days a week, teduglutide, remain with labs, home nurse visits for dressing changes and lab draws, with regular care by his care providers. It is possible that he may be able to decrease his TPN to even fewer days per week, but this is the best estimate of how well the medication may work.

**Physician Care:** Unchanged from Option 1
✓ Primary care monthly to prescribe medications for diarrhea and dumping syndrome.

<table>
<thead>
<tr>
<th>Item, Duration</th>
<th>Frequency and costs</th>
<th>Annualized Cost</th>
<th>Source of costing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Teduglutide injections (s/c) daily</td>
<td>$300,000 per year</td>
<td>$300,000</td>
<td>Google search</td>
</tr>
<tr>
<td>Monthly visits for narcotic prescriptions and health monitoring for lifetime</td>
<td>$250 per month</td>
<td>$3,000 per year</td>
<td>I obtained costs for these physician visits by calling three offices in his geographic area.</td>
</tr>
<tr>
<td>Every six months visit to TPN physician for lifetime</td>
<td>Every six months @ $125</td>
<td>$250 per year</td>
<td>I obtained costs for these physician visits by calling three offices in his geographic area.</td>
</tr>
<tr>
<td>Primary care physician, reviews labs every two weeks and prescribes TPN formula for lifetime</td>
<td>Every two weeks @ $85</td>
<td>$2,210 per year for a lifetime</td>
<td>I obtained costs for these physician visits by calling three offices in his geographic area.</td>
</tr>
<tr>
<td>TPN labs for lifetime</td>
<td>Twice a month @ $400 per month</td>
<td>$4,800 per year</td>
<td>US Medical fees for the CPT codes for each test.</td>
</tr>
<tr>
<td>TPN Service, including TPN and hydration fluids, tubing and supplies, IV pumps (2) for four days a week for lifetime</td>
<td>$45,714 Monthly.</td>
<td>$548,571.40 per year</td>
<td>Past medical bills were used for these costs.</td>
</tr>
<tr>
<td>RN services: * weekly dressing changes and condition assessment * every two week blood draws from Hickman catheter for lifetime</td>
<td>$400 per week</td>
<td>$20,800 per year</td>
<td>Past bills</td>
</tr>
<tr>
<td>Promethazine 25 mg</td>
<td>Two or three a month, for a lifetime.</td>
<td>$4 per month, $48 per year</td>
<td>Three costs from GoodRx.com</td>
</tr>
<tr>
<td>Lomotil 2.5 mg</td>
<td>Eight per day for a lifetime X 30 days = 240 per month.</td>
<td>$125 per month, $1,500 per year</td>
<td>Three costs from GoodRx.com</td>
</tr>
<tr>
<td>Imodium 2 mg</td>
<td>Four per day for a lifetime X 30 days = 120 per month.</td>
<td>$13 per month, $156 per year</td>
<td>Three costs from GoodRx.com</td>
</tr>
<tr>
<td>Omeprazole 40 mg for lifetime</td>
<td>Two per day</td>
<td>$90 per month, $1,080 per year</td>
<td>Three costs from GoodRx.com</td>
</tr>
<tr>
<td>70% isopropanol wipes for lifetime</td>
<td>Six boxes per week</td>
<td>$24 per week, $1,248 per year</td>
<td>Wal-Mart, Walgreens and CVS pharmacies</td>
</tr>
<tr>
<td>70% isopropanol spray for lifetime</td>
<td>One bottle per week</td>
<td>$4 per week, $208 per year</td>
<td>Wal-Mart, Walgreens and CVS pharmacies</td>
</tr>
<tr>
<td>Maxi pads for lifetime</td>
<td>8-14 pads per week</td>
<td>$1.55 per week, $80.60 per year</td>
<td>Wal-Mart, Walgreens and CVS pharmacies</td>
</tr>
<tr>
<td><strong>Total annual costs</strong></td>
<td></td>
<td><strong>$883,952</strong></td>
<td></td>
</tr>
</tbody>
</table>

**Summarized:**

- **Teduglutide:** $300,000 annually
- **Narcotic prescrip**tions and health monitoring: $3,000 annually
- **TPN Physician visits:** $250 monthly
- **TPN labs:** $2,210 annually
- **RN Services:** $20,800 annually
- **Promethazine:** $48 annually
- **Lomotil:** $1,080 annually
- **Imodium:** $156 annually
- **Omeprazole:** $1,080 annually
- **70% isopropanol wipes:** $1,248 annually
- **70% isopropanol spray:** $208 annually
- **Maxi pads:** $80 annually

**Total annual costs:** $883,952
A different physician reviews nutritional laboratory studies and adjusts TPN formula. He sees Mr. Welch in the office twice a year.

**Diagnostic Testing:**
- Laboratory tests every other week to monitor status and modify TPN prescription as indicated.

**Therapy:**
- TPN service and weekly RN visits for dressing changes and every other week blood draws from his Hickman catheter
- Nutritional advice from the TPN service nutritionist
- TPN, IV hydration fluids, flush and heparin flushes, tubing, supplies and two IV pumps.
- TPN, IV hydration fluids, flush and heparin flushes, tubing, supplies and two IV pumps will change when he is on teduglutide, as TPN will be for fewer days per week. His need for dressing changes will not change, but if he is successful on the medication, he may be able to leave his home and receive his dressing changes and lab draws at an out patient facility, rather than needing home care.

**Medications:** Unchanged from Option 1
- Diphenoxylate and atropine (Lomotil) 2.5 mg, two tablets, four times a day for diarrhea.
- Loperamide and simethicone (Imodium) four tablets a day, for diarrhea.
- Promethazine (Phenergan) 25 mg as needed for nausea; about two or three times a week.
- Omeprazole (Prilosec) 40 mg twice a day, to decrease stomach acid.

<table>
<thead>
<tr>
<th>Item</th>
<th>Frequency</th>
<th>Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Small bowel transplantation, non-itemized estimate only.</td>
<td>Once</td>
<td>$1,547,200 once, or as needed to implant if he has implant failure</td>
</tr>
<tr>
<td>Antirejection drugs with small bowel transplant</td>
<td>Annually, for lifetime</td>
<td>$44,100.00 per year</td>
</tr>
</tbody>
</table>

**Supplies not provided by TPN**
- Alcohol wipes or spray on all surfaces that he uses to prepare his TPN.
- Maxi pad, 1-3/day

**Medically Possible Care**

Mr. Welch is a small bowel transplant candidate. The average cost for an intestine transplant, including 30 days of pre-transplant costs, transplant and 180 days following transplant, immunosuppressants, and other prescriptions is $1,547,200 according to the 2014 Milliman report (2014). Mr. Welch is reluctant to undergo small bowel transplantation due to its low graft survival rate. He worries that he will go through major surgery, take antirejection drugs, and still lose his transplant. He worries that it may damage the small amount of small bowel that he has left and he would rather do nothing or try teduglutide to see if he would eat, and have fewer days on TPN.

It was difficult to find costs for facilities for transplantation in the American Hospital Directory, so I called and found facilities that gave me an approximate cost for the actual surgery. I contacted UCSF, Baylor, California Pacific Medical Center, Stanford, and Nebraska Medical Center. However, they could not give me costs for pre-transplantation and follow up costs. Therefore, I used the Milliman report. This case did not have a transplant surgeon associated with the client and we did not have an expert opinion on the probability of his ability to receive a transplant. If small bowel transplantation was successful, costs would include frequent office visits with transplant physicians, but no TPN, less labs and other medications.

**Summary**

Doing this life care plan for a client who needs lifelong TPN was aided by the fact that the client had current bills.

As you can see, ongoing fulltime TPN is expensive, about one million dollars a year. Mr. Welch’s quality of life is greatly diminished by dumping syndrome and need for all-night TPN and regular daytime infusions.

If Mr. Welch is successful with teduglutide or other medications that may be developed for short gut syndrome, his annual cost will decrease by about $110,000 per year. He is hopeful that teduglutide may allow him to eat and absorb his food, have bowel movements that are thicker and less often and that he will spend fewer nights on TPN.

If Mr. Welch is successful with one small bowel transplant and is able to stop all TPN and with less frequent labs, physician exams but with antirejection medications, he will significantly decrease the lifetime cost of his condition. The one-year survival rate has recently increased from 19% to 57% (emedicine, 2016). The lifetime survival rate is unknown.

**GENERAL REFERENCES**


http://emedicine.medscape.com/article/193391-treatment#d1 accessed 2/10/16
Life Care Planning Considerations

**Costs to maintain a person on home TPN include:**

TPN, tubings, syringes and supplies runs about $60,000 per month for Medicare patients, about $75,000 per month for private insurance. It is difficult to get costs by calling TPN services like Corum, Option Care, Oasis Home Care, THC of Nevada, CAPS Pharmacy.

- Labs every two weeks, generally CBC with differential, complete metabolic panel and magnesium and phosphorus. This is usually drawn by the home health nurse.
- A physician to review the labs every two weeks and order new TPN.
- A physician to order medications and review health, about every month
- A gastroenterologist to see the patient every month instead of the PCP, or at least every six months to review the condition
- Central line access dressing changes every week, usually by a TPN home nurse who can also assess diet and health and review and order supplies.
- Central line access replacements as needed. This is variable; ask the treating physician for replacement intervals. Usually an outpatient procedure.
- Medications for diarrhea and abdominal pain.
- Possible psychologist to address physiological issues.
- Supplies such as alcohol wipes to clean the area used to prepare the TPN and hydration fluids at home.

**Alternative treatments:**

**Teduglutide** (Gattex) This drug was approved by the FDA in 2012 for persons born with short gut or who have lost their small intestine. It helps the remaining intestine absorb more fluids and nutrients and may reduce the need for parenteral support. It carries risks for serious side effects including cancer, polyps, bowel blockage, swelling or blockage of the gallbladder or pancreas, and fluid overload. Colonoscopies are required twice a year.

Patients taking teduglutide usually still need some TPN with medical surveillance, labs, and dressing changes. Teduglutide cost is about $300,000 per year, but with the decrease in TPN, total costs will be less. Patients may also be able to return to a more normal life, eat, have fewer or more normal bowel movements, and resume work.

**Transplantation** Persons with short gut syndrome may be eligible for small bowel transplantation. According to the Millman report (2014), the cost for this is $1,547,200 including preoperative care and testing and all medical costs for the first six months postoperatively. The patient must be near the hospital before and for several months after surgery. Regular follow up is needed with the transplant surgeon.

The rate of success of a small bowel transplant has increased from 19%, to 57% at one year due to changes in medications. Annual cost of post-transplantation drugs is about $44,100. There will be other ongoing costs including physician visits and labs; check with the transplant surgeon or team for specifics. The patient may need retransplantation in the future.
Worried you missed out on 2015? Worry no more, Mastermind 2016 starts February 16, 2016 with more speakers, more tips, more subjects all to help you build a successful Nurse Life Care Planning practice.

Gain insight and instruction through education, accountability, and support as you build, grow and sustain your life care planning practices.

REGISTER TODAY
Manage Your Patient’s Microclimate with Advanced Microclimate® Technology.

Effectively managing the temperature and humidity beneath a patient, or the patient’s microclimate, can greatly enhance a patient’s comfort and help prevent pressure ulcers. Hill-Rom® surfaces with Advanced Microclimate® technology, the next generation of low air loss, remove both excess heat and moisture from the surface for cooler, dryer skin.

**Skin Microclimate**

1. Body heat is transferred from the skin to the surface.
2. Trapped heat causes skin temperature to rise.
3. Perspiration occurs and moisture builds up on the surface.

This excess temperature and moisture build up negatively affects the microclimate of the skin, making it more susceptible to the damaging effects of pressure, shear and friction.

Because wet skin is more likely to tear than dry skin, achieving the optimum ranges of temperature and humidity is a vital factor in the prevention and treatment of pressure ulcers.

*For a surface to manage the patient microclimate, it must effectively reduce both heat and moisture accumulation on the skin.*

The moving airflow removes excess heat and moisture vapor from the skin and surface interface.

Excess heat and moisture vapor are drawn into the airflow below the cover before exiting into the atmosphere.
Experience safer skin with Hill-Rom’s latest Advanced Microclimate® Technology!

Through a combination of technologies, Hill-Rom’s Advanced Microclimate® surfaces help manage the patient’s skin microclimate.

**Airflow**

A precise flow rate moves air horizontally under the surface and exits at the head end to prevent heat build up.

**Material Technologies**

Advanced technology designed to remove excess heat and moisture while providing optimum patient comfort and stain resistance.

**Advanced Microclimate® Technology**

1. High moisture vapor permeable cover.
2. Breathable crush resistant air channels:
   - Allows for increased air circulation and flow for industry leading moisture vapor removal.
   - Maintains open matrix for continuous airflow beneath the patient in any bed position.

**Conventional low air loss**

- Limited Airflow
- Air Blocked

- Patient can block air holes, limiting the airflow that reaches the skin.
- Patient may experience discomfort due to the airflow being too cool.

For clinical consultation, referrals, or more information on obtaining acute-grade specialty integrated hospital beds, therapeutic support surfaces, or patient lift systems, life care planners call Tricia Litzinger BSN RN CCM CDS WCC directly at 812-212-2563.
Pancreatic Diseases and Islet Cell Transplantation
1. Allogenic islet cell transplantation may pose greater post-transplant management challenges because
   a) Exogenous pancreatic enzymes are needed, resulting in malnutrition and extreme weight fluctuations.
   b) Graft failure increases over time, requiring intense medical and surgical monitoring for life
   c) Pain management is ongoing, and only 46% of patients are narcotic-free at 1 year
   d) Suicide risk is increased due to post-procedure depression, requiring long-term psychiatry.

Cystic Diseases of the Pancreas
1. Follow up frequency for nonresected intraductal papillary mutinous neoplasm (IPMNs) is based primarily on:
   a) Calendar year scheduling
   b) Clinical patients symptoms
   c) Surgeon’s recommendations
   d) Tumor presentation
2. The role of the pancreas is to:
   a) Produce digestive enzymes to break down fats, carbohydrates and proteins in the duodenum.
   b) Produce digestive enzymes to break down fats, carbohydrates and proteins in the stomach.
   c) Work with the spleen to produce sodium bicarbonate to neutralize hydrochloric acid from the stomach.
   d) Work with the liver to produce sodium bicarbonate to neutralize hydrochloric acid from the stomach.
3. The American Cancer Society recommends that pancreaticoduodenectomy (Whipple procedure) be done:
   a) At JCAHO-approved medical centers in cities.
   b) At any hospital with an experienced surgeon.
   c) By surgical teams that have done many of them.
   d) Laparoscopically if no comorbidities.

Medical Cannabis and Quality of Life in IBD
1. Cannabinoids have a beneficial effect on irritable bowel disease because they:
   a) Affect quality of life by facilitating social interaction.
   b) Cause anti-inflammatory effects by changing cytokine levels.
   c) Decrease depression by decreasing serotonin reuptake.
   d) Regulate appetite and nutrition by affecting endorphins.
2. Cannabinoid receptors are found in:
   a) Afferent nerve axons
   b) Alveolar surfaces
   c) Mast cells
   d) Ventricle chorionic membranes
 ISSUE INDEX

2012
XII.1 Coding and Costing
XII.2 Electrical Stimulation Technology
XII.3 Preconference / Brain Injury
XII. 4 Veterans Administration

2013
XIII.1 LCP for Motor and Developmental Disorders
XIII.2 Ethical Topics in LCP
XIII.3 Preconference / Exemplars in NLCP
XIII.4 Home Modifications

2014
XIV.1 Technology Updates

XIV.2 LCP Across All Ages
XIV.3 Psych topics in LCP
XIV.4 LCP and the ACA

2015
 XV.1 Topics in Transplantation
 XV.2 Updates in Spinal Cord Injury
 XV.3 Burns
 XV.4 Perinatal / Childhood

2016
 XVI.1 Pain
 XVI.2 GI issues
 XVI.3 International LCP
 XVI.4 Home Care

LCP and the ACA