Topics in Transplantation
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In order to make safe and effective judgments using NANDA-I nursing diagnoses it is essential that nurses refer to the definitions and defining characteristics of the diagnoses listed in this work.
Welcome to the first issue in the fifteenth volume of the JNLCP. You will have noticed that it is in a new format. You may not have known that for the last 6 years the JNLCP has come from my own Macintosh; it is a great relief to me to turn over the “building” of each issue to design professionals so I can concentrate on the editorial side of the house. We actively welcome your feedback and suggestions on this new venture at my email below, whether you are a regular or casual reader.

This issue features articles and some first-person memoirs about transplantation. This is a rapidly-changing field, as anyone who has been involved with any sort of transplants over a nursing career can tell you. Heart transplants were big news when I was in my twenties working at Stanford, where the research and practice that laid the groundwork for cardiac transplantation was done in the 1960s. I started a program for ICU nurses to meet with waiting recipients and their families, do patient teaching, support them through the wait time in the community, and be their primary nurses in the ICU postop. I also developed a training program to standardize transport care for the donors, in surface and air ambulances. It was extraordinarily gratifying to go on a “donor run” in the middle of the night with a resident, bring back a massively unstable, brain-dead organ donor from some remote hospital, and come in to work the next morning and see “my” recipient sitting up in bed, just extubated, pink, massively diuresing, and ready to leap out of bed. Despite having the same median sternotomy and the same chest tubes, these people never seemed to have much pain. Since in those years the average wait time between being accepted on the list and getting a new organ or dying was only five weeks, perhaps it was just the joy of being alive that decreased their need for morphine. I never got tired of it.

The state of the art in immunology has improved a great deal since those days. Those residents are now retiring from heading transplant programs in centers of excellence all over the country. Recipients are often out of the hospital in days to weeks, not months. Outcomes are better, with longer survival times and fewer complications. Transplantation offers another crack at life for people with GIST, cystic fibrosis, hematological malignancies, trauma, and more. Renal and cardiac transplants are almost routine.

As nurse life care planners we have a unique responsibility to the patients and families we serve, regardless of how we come to be involved in their cases. I hope this issue gives you more resources and ideas to meet it.

From the Editor

Wendie A. Howland MN RN-BC CRRN CCM CNLCP LNCC
Editor, JNLCP
whowland@howlandhealthconsulting.com
Contributing

KATHIE ALLISON
PT, MS, CLCP
("Organ Transplant Overview") is a physical therapist with 42 years experience in rehabilitation. Her LCP business, Kathie Allison Life Care Planning, Kansas City MO, provides life care plans to attorneys and for the self-insured industry. She has completed over 125 life care plans for lung, liver, kidney, heart and/or multi-organ transplants. She has participated in panel discussions regarding the unique contributions of physical therapist in life care planning process, life care planning for rehabilitation experts, and establishing damages in catastrophic injuries as CLE for attorneys. She has served on the IALCP Standard of Practice review committee for the past

ALISA DAYANIM
MSN, RN, CRRN, CNLCP, CLCP
("Liver Transplantation") has over twenty-five years of nursing experience with rehabilitation of patients in acute care, outpatient and home based settings. Special interests include care of individuals with spinal cord injuries, traumatic brain injuries, amputations and multi-trauma. She has been with BalaCare Nursing Solutions since 2006, preparing Life Care Plans and providing case management services for catastrophically injured clients. Her life care planning experience includes working with individuals diagnosed with spinal cord injury, amputations, multiple trauma, chronic pain, brain injury, burns, birth injuries and transplant.

CHERYL KAUFMAN
BScN RN CLCP CNLCP
("Regenerative Medicine") is owner and principal of CK Medical-Legal Consulting Services in Massachusetts. She has more than 25 years of nursing experience to inform her Legal Nurse Consulting and Life Care Planning practice. In addition to her early clinical experience in neonatal intensive care, pediatrics and caring for patients who suffered a stroke, her career path predominantly focused on infectious diseases, oncology and biotechnology and nursing education with emphasis on oncology disease management with specific chemotherapeutics and biological response modifiers, drug-drug interactions, and patient safety issues.

KIMBERLY KUSHNER
MSN, RN, CPNP, CNLCP, CLCP
("Liver Transplantation") has more than 10 years of nursing experience and is a certified pediatric nurse practitioner. Clinical experience includes critical care, burn, cardiac, and oncologic and hematologic conditions. Her particular expertise and interest is with chronic illness and pain management in the pediatric and adolescent client. Ms. Kushner has worked with BalaCare Nursing Solutions as a Life Care Planner and case manager for catastrophically injured clients for more than 5 years and is a member of the International Academy of Life Care Planners and American Association of Nurse Life Care Planners. Ms. Kushner continues to work as a camp nurse every summer, providing a unique camping experience for children with cancer.
to the Issue

WENDY VAN OOTEGHEM
("First Person: My Stem Cell Transplant for Lymphoma") has worked in the area of health care for over 40 years. She holds a Bachelor of Science degree in Health Information Management from Illinois State in Normal, IL and holds the following credentials: RHIA, CPC, and ICD-10 CM/PCS. Her job opportunities have led her to managerial positions in both large and small acute care hospitals, dialysis clinics, and family medicine physician office with an active residency program. Wendy is presently a financial analyst providing practice management software support for several ambulatory physician offices in the area. She underwent her stem cell transplant procedure in April of 2014.

PAT PASCOE
("First Person: Lung Transplants") represented a Denver district in the Colorado Senate for twelve years ending in 2003. In the legislature she was especially interested in education and in improving the lives of women and children, sponsoring bills on preschool, child care, truancy, and bilingual education. She passed bills on temporary marital maintenance and spousal protection. Providing freedom of press for students, creating an organ donor registry, and reducing wood smoke pollution were the subjects of other successful bills. She chaired the Public Policy and Planning Committee and the Education Committee in the Senate, as well as the Democratic Caucus.

WILL PASCOE
("First Person: Lung Transplants") is a graduate of Stanford and the University of Colorado School of Law. He has Cystic Fibrosis and received a double-lung transplant in 1998 and a single-lung transplant in 2007. He lives in Denver, blogs at www.FifthLung.com, and has several short stories available at Amazon.com.

NADENE TANIGUCHI
BSN, RN, CNLCP, CCM, PAHM
("Liver Transplantation") has over thirty years of experience in acute and post-acute care management, utilization review and compliance. She has also spearheaded projects with healthcare professionals to develop improved emergency department throughput, enhanced patient safety and improved patient satisfaction. She has been with BalaCare since 2012, preparing Life Care Plans and providing case management services for catastrophically injured clients.
Letters to the Editor

CBIS: A PROFESSIONAL CREDENTIAL?

The following arrived as a Letter to the Editor from an established nurse life care planner of many years’ experience and has been edited slightly for length. Its subject matter is thought-provoking, and the author has requested anonymity. The JNLCP welcomes responses from readers on this matter.

~Editor

I recently attended a meeting with the director of a brain injury outpatient rehabilitation program geared towards community re-entry that allowed adult patients to live on their own in the community. The program provides them with a 2-bedroom, 2-bathroom apartment and a “life skills trainer” to teach and guide them to perform ADLs with close supervision. The life skills trainers reinforce with repetition what the patients learned during their post injury rehabilitation programs. Over time, the goal is to cut back on the 24/7 life skills trainer care to allow the patient to be as independent as possible, while still being monitored for safety.

I thought this program would be of tremendous benefit for some of my LCP clients. As we know, often, the deciding factor about hiring home care nurse’s aides or homemaker services is their familiarity in working brain injured individuals, so I decided to ask more about it. I learned that to take this training, individuals need only a high school diploma and a squeaky-clean background check with no criminal record. Some were homemakers looking to earn extra money while their children were attending and pass the test that confirmed their comprehension of the material. Once they pass the test, they receive certificates indicating that they are now brain injury specialists. I asked him if his employed RNs, MDs, ARNPs, or PAEs were required to take this same program to certify them as brain injury specialists and he replied, “It shouldn’t be necessary for them, but many of our psychologists, social workers, and family members attend.”

Further investigation and discussion with the local brain injury association led me to the ACBIS, the Academy of Certified Brain Injury Specialists. Under the heading “Certification Disclaimer,” it states: “The Academy of Certified Brain Injury Specialists provides a certification program that intends for individuals to become familiar with a broad range of issues relevant to the care of people with acquired brain injuries. The training material and testing requirement was developed for unlicensed, non-professional staff to help raise their skill level and contribution as an integral part of interdisciplinary rehabilitation teams. This certification does not confer or imply the acquisition of advanced training or expertise in brain injury rehabilitation. As such, this certification does not inherently expand a professional’s scope of practice … Professionals from disciplines that might serve brain injury survivors must follow the practice guidelines set forth by their oversight licensing and academic organizations.”

As RNs and CNLCPs we are expected to attend continuing education programs in order to maintain our professional education, licensure, and certifications. This is also most important in order optimize future care recommendations for our patients/clients. But I find it most disturbing to see CNLCPs, many with advanced degrees and certifications in case management and rehabilitation nursing, using the letters “CBIS” as a credential to imply that they are now proficient in a broad range of issues relevant to the care of people with acquired brain injuries … based on attending the exact same educational offering and test geared toward “unlicensed, non-professional personnel” to ensure that they are proficient in caring for loved ones or clients with brain injury.

Imagine an RN, CNLCP, CBIS retained to prepare a life care plan for a brain injured individual only to learn that the patient’s spouse, sibling, parent, or child also has a CBIS so they, too, can be “proficient” in supervision for their loved one. Should we, as professionals, proffer an unlicensed-level “credential” as if it were significant for what we do as Nurse Life Care Planners?

Do we also, as a profession, now need other unlicensed-level alphabet soup to suggest we are proficient at life care planning for spinal cord injuries, burns, cerebral palsy, orthopedic traumas, amputations, and so forth? I think not.  

~Anonymous

RESOURCES FOR THE ACA AND LIFE CARE PLANNING

Please find attached a few links for your readers to access more information on the Affordable Care Act and life care planning.

Google Web Search http://tinyurl.com/psjoqox
Google Books http://tinyurl.com/mah4aa9
Google Scholar http://tinyurl.com/kcu2atb
Google Scholar Law http://tinyurl.com/k4j2u9u
Temple Summon Search http://tinyurl.com/lqv6rm

David Dillard
Temple University
dwne@temple.edu
The “Software Solution” for LCP, MSA and MCP Professionals

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- Medicare Set-Aside Reports
- Medical Cost Projections

**Fluent Systems “Enterprise Version” Software Benefits**

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- Encrypts at risk data, SSL security
- All templates completely customizable
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- 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

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As life care planners we are called upon to understand both disease progression and treatment options to identify future life care costs. For individuals with life-threatening organ failure, that includes organ transplant, with unique cost considerations. When the client’s medical condition is declining beyond the reach of medication or surgical intervention, a life care plan must include costs associated with current medical care, services keeping the individual alive, and transplant evaluation. The plan must also project when organ transplant and transplant costs will begin.

Not everyone evaluated for transplant is accepted for the transplant wait list. Not everyone on the transplant wait list will get a transplant. Therefore, the most comprehensive life care plan will need to include two pathways for costs: Option I, no transplant; and Option II, transplant occurs in specific year with follow up medical care costs sequenced from the time of transplant.

Evaluations for organ transplantation are similar in most organ transplant programs. However, there are differ-
ences between organs and between transplant centers. There are allocation calculators for patient selection for most organs. As an example, the Organ Procurement and Transplant Network (OPTN) established a MELD score (Model for End-stage Liver Disease), PELD score (Pediatric End-stage Liver Disease) and LAS Score (lung allocation score) for those organs to assure consistent patient selection (OPTN, 2014). The life care planner should contact the proposed transplant center for its specific criteria.

These are general criteria/guidelines for transplantation (Alqahtani, 2012):
- Clinically and physiologically severe disease
- Medical therapy ineffective or un-available
- Limited life expectancy – differs among organs
- Ambulatory with rehabilitation potential
- Nutritional status: 80% - 120% ideal body weight, or BMI between 19 and 30
- Satisfactory psychological profile and a good support system
- Adequate financial coverage for the procedure and post transplantation care

Candidates must be sick enough to need the transplant, but stable enough to survive. There may be interim services to assure candidacy, e.g., weight management, to consider.

General contraindications for organ transplantation include (Alqahtani, 2012)
- Unstable medical status
- Uncontrolled infection
- Cancer/ HIV
- Significant other organ dysfunction, e.g., hepatic, renal, CNS, cardiac
- Psychosocial issues, e.g., drug or alcohol dependency
- History of non-adherence to medical plan of care, e.g., smoking
- Age (varies)

Each center has at least one transplant coordinator as the general point person. Costs associated with organ transplantation are divided into four general phases: evaluation, transplantation, first year follow up, annual lifetime follow up. Indications for transplant are shown in Table 1 (Milliman, 2015).

Table 1. Indications for Organ Transplant 2014 (Milliman, 2014, OTPN/SRTR, 2011)

<table>
<thead>
<tr>
<th>ORGAN</th>
<th>PRIMARY DIAGNOSIS</th>
<th>SECONDARY DIAGNOSIS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart</td>
<td>Cardiomyopathy 52%, CAD 32%</td>
<td>Congenital Defect 10%</td>
</tr>
<tr>
<td>Lung</td>
<td>Idiopathic Pulmonary Fibrosis 49% COPD 32%</td>
<td>Cystic Fibrosis 14%, Bronchiolitis Obliterans</td>
</tr>
<tr>
<td>Heart-Lung</td>
<td>Pulmonary Hypertension 33% Congenital Defect 17%</td>
<td>Idiopathic Pulmonary Fibrosis 13%</td>
</tr>
<tr>
<td>Liver</td>
<td>Hepatitis 21% Malignancy 20%</td>
<td>Alcoholic liver disease 16%</td>
</tr>
<tr>
<td>Kidney</td>
<td>Diabetes 25% HTN 22%</td>
<td>Glomerulonephritis 19%</td>
</tr>
</tbody>
</table>

Table 2. Typical Medication List – Post Transplantation (Loyola, 2013)

<table>
<thead>
<tr>
<th>DRUG</th>
<th>SIDE EFFECT</th>
<th>ACTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cyclosporine (Neoral)</td>
<td>High blood pressure, kidney dysfunction, tremors, seizures, ↑potassium, headache, neurotoxicity</td>
<td>Used to prevent rejection</td>
</tr>
<tr>
<td>Tacrolimus (Prograf, FK 50)</td>
<td>HPB, Kidney dysfunction tremors, seizures, ↑potassium, Headache</td>
<td>Used to prevent rejection</td>
</tr>
<tr>
<td>Azathioprine (Imuran)</td>
<td>Bone Marrow Suppression, low blood counts, N &amp; V, infection</td>
<td>Used to prevent infection</td>
</tr>
<tr>
<td>Corticosteroids (Prednisone)</td>
<td>Mood changes, ↑BP, sleep, nervous, ↑appetite</td>
<td>Used to prevent rejection</td>
</tr>
<tr>
<td>Sirolimus (Rapamune)</td>
<td>HBP, ↑cholesterol/triglycerides,edema, inhibit T-lymphocytes</td>
<td>Used to prevent acute and chronic rejection</td>
</tr>
<tr>
<td>Valganciclovir (Valcyte)</td>
<td>Bone marrow depression, low blood counts, N &amp; V, diarrhea, Liver enzymes</td>
<td>Used to treat fungal infections</td>
</tr>
<tr>
<td>Folic Acid</td>
<td>Rare</td>
<td>Vitamin to prevent anemia</td>
</tr>
<tr>
<td>Calcium + Vit D</td>
<td>Rare. Do not take with K+</td>
<td>Prevent osteoporosis</td>
</tr>
<tr>
<td>Furosemide (Lasix)</td>
<td>Blood pressure drop, hypotension</td>
<td>Remove excess body fluid</td>
</tr>
<tr>
<td>Colace</td>
<td>Throat irritation, Nausea</td>
<td>Stool softener</td>
</tr>
<tr>
<td>Bactrin, Sulfadiazine</td>
<td>Sun sensitivity, N&amp;V</td>
<td>Prophylactic antibiotic</td>
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### Sample – Pre And Post Transplant Costs Lung Candidate

<table>
<thead>
<tr>
<th>ITEM</th>
<th>DISCUSSED WITH</th>
<th>UNIT COST</th>
<th>FREQUENCY</th>
<th>YEARS NEEDED</th>
<th>ANNUALIZED COST</th>
<th>COMMENTS</th>
</tr>
</thead>
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<tr>
<td>Symbicort</td>
<td>Dr. Doctor</td>
<td>$ 203.79 – $ 217.79</td>
<td>Monthly</td>
<td>Lifetime</td>
<td>$ 2,445.12 – $ 2,613.48</td>
<td>Bronchodilator/steroid</td>
</tr>
<tr>
<td>ProAir HFA</td>
<td>Dr. Doctor</td>
<td>$ 44.24 / unit</td>
<td>Monthly</td>
<td>Lifetime</td>
<td>$ 530.88</td>
<td>Bronchodilator</td>
</tr>
<tr>
<td>Spiriva</td>
<td>Dr. Doctor</td>
<td>$ 186.88 – $ 223.07</td>
<td>Monthly</td>
<td>Lifetime</td>
<td>$ 2,242.56 – $ 2,676.84</td>
<td>Bronchodilator</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>Dr. Doctor</td>
<td>varies</td>
<td>2 – 3 / year</td>
<td>Lifetime</td>
<td>$ 467.96 – $ 584.95</td>
<td>Reflects current usage – Z-PAK</td>
</tr>
<tr>
<td>Pulmonary Function Testing</td>
<td>Dr. Doctor</td>
<td>$ 378.00</td>
<td>2 times a year</td>
<td>Lifetime</td>
<td>$ 756.00</td>
<td>Monitor lungs- two comprehensive</td>
</tr>
<tr>
<td>CT scan</td>
<td>Dr. Doctor</td>
<td>$ 873.00</td>
<td>yearly</td>
<td>Lifetime</td>
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<td>Pneumonia Vaccine</td>
<td>Dr. Doctor</td>
<td>$ 49.00</td>
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<tr>
<td>Nebulizer</td>
<td>LCP</td>
<td>$ 60.00 – $ 195.00</td>
<td>Every five years</td>
<td>Lifetime</td>
<td>Administer medication</td>
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### OPTION 1

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<td>$ 756.00 annually</td>
<td>Monitor lungs- two comprehensive</td>
</tr>
<tr>
<td>CT scan</td>
<td>Dr. Doctor</td>
<td>$ 873.00</td>
<td>Every 2 years</td>
<td>Lifetime</td>
<td>Monitor lungs</td>
<td></td>
</tr>
<tr>
<td>Pneumonia Vaccine</td>
<td>Dr. Doctor</td>
<td>$ 49.00/ unit</td>
<td>Every ten years</td>
<td>Lifetime</td>
<td>Prophylactic</td>
<td></td>
</tr>
<tr>
<td>Flu Vaccine/ H1N1</td>
<td>Dr. Doctor</td>
<td>$ 43.00/ unit</td>
<td>Annually</td>
<td>Lifetime</td>
<td>$ 43.00 annually</td>
<td>Prophylactic</td>
</tr>
<tr>
<td>Nebulizer</td>
<td>LCP</td>
<td>$ 60.00 – $ 195.00/ unit</td>
<td>Every five years</td>
<td>To year 2016</td>
<td>Administer medication</td>
<td></td>
</tr>
</tbody>
</table>

| Immunosuppres-               | Transplant     | $ 28,200.00     | Annually        | 2017 to life-   | $ 28,200.00          | Deter organ rejection Milliman.com 2011         |
| sion management             | protocol       |                |                 | time           |                      |                                                |
**PHASE I**

**Evaluation**

The life care plan should include the facility’s cost estimate for the routine evaluation process to determine need and rule out contraindications, including multiple laboratory and radiology tests, and appropriate financial and psychosocial screening. Professional fees will be separate and can be considerable.

Evaluation for transplantation, usually completed as an outpatient, involves a multi-day stay in the facility’s area. Costs for travel to the center, per diem costs for meals, and housing. Include costs for both the patient and a significant other during this time; significant others are essential in the transplantation approval process. Candidates can be denied acceptance for transplant if a caregiver is not assured. Also consider lost wages or earnings and costs for childcare, if needed.

Donor organs each have their own preservation survival time for optimum transplant success. Heart and lung donor organs have the shortest optimum organ preservation time, four to six hours. Kidneys have the longest organ preservation time, 24 to 36 hours. Therefore it will be critical to provide for housing and expenses within the associated travel time while the patient waits for an organ. The center can provide an estimate of the wait time once candidacy is accepted.

Estimations of acuity and survival time without transplant to determine priority placement on a transplant center waiting list for lungs, kidneys, and livers have been part of the transplant process for several years. The United Network for Organ Sharing (UNOS) has established guidelines for all solid organ transplants. By the year 2015, a formal system of estimating acuity and survival time will be instituted for all organs and used by all transplant centers. UNOS is now examining how they identified patients and transplant regions. Individuals creating plans for transplant clients will need to review the UNOS web site for updates (UNOS 2014).

Ongoing support services, e.g., cardipulmonary rehabilitation, may need to continue while the patient waits for transplant. Rehabilitation therapy can often be obtained at a facility near the candidates’ home and will not involve travel to the transplant center.

If there is significant wait time, there will be costs associated with a brief re-evaluation at the time of transplantation. National wait time averages for heart, lung and heart-lung transplantation are 168, 148, and 72 days respectively (Milliman, 2015). For a heart transplant, it is important for the life care planner to determine if the transplant center plans to use LVAD (left ventricular assist device) for the waiting patient. These devices incur significant costs and are only offered if a candidate’s medical status is deemed critical compared to the projected wait time. In most cases, LVAD placement will involve an inpatient stay until time of transplant. LVAD placement is done, in part, to spare other vital organs from the side effects of low perfusion (AHA 2005).

**PHASE II**

**Transplantation**

Costs for this phase of transplantation include facility costs for the surgery and length of stay, professional fees incurred during the hospital stay, and organ procurement costs. The center can provide data related to average length of stay. The Milliman Corporation surveys national costs for transplantation triennially. That information can be found at www.milliman.com. Because these data are only averages and there is wide variation, it is important to get the specific center’s cost. Many transplant centers have longterm housing options for family. Per diem costs for meals should be provided for the client when an outpatient and for the significant other throughout the entire process.

Dependent on the transplant center protocol, transplant recipients may have to be in residence for outpatient followup for weeks or months. Following discharge from the hospital, they remain in the transplant center city, returning to the center for monitoring and testing. They resume modified outpatient rehabilitation programs. They begin their lifetime immunosuppression drug regimes. Costs for this phase are similar for each organ; however, each center has its own protocol. The client may return to the center daily at first with decreasing frequency for up to two to six months. The candidate is then cleared for discharge to home. The caregiver must be available for the entire time.

**PHASE III**

**Post Transplantation Costs**

Depending on the transplant center protocol, transplant recipients may have to be in residence for outpatient followup for weeks or months. Following discharge from the hospital, they remain in the transplant center city, returning to the center for monitoring and testing. They resume modified outpatient rehabilitation programs. They begin their lifetime immunosuppression drug regimes. Costs for this phase are similar for each organ; however, each center has its own protocol. The client may return to the center daily at first with decreasing frequency for up to two to six months. The candidate is then cleared for discharge to home. The caregiver must be available for the entire time.

**PHASE IV**

**Lifetime Followup**

In this phase the candidate is returns to the transplant center for an annual or semi-annual evaluation. Heart and lung transplant recipients are followed for lifetime. The life care plan must include costs associated with facility fees, professional fees, travel fees and per diem. Per diem rates can be found at www.gsa.gov.

Protocols differ between transplant centers regarding the frequency for biopsy after the first year of transplant. The transplant center coordinator can provide the data needed to identify frequency and costs.

There has been a gradual change in immunosuppression drug use after transplantation. Candidates are maintained on the lowest effective dosage of drug. While there may be slight variation, the drugs used are similar for all trans-

**Table 3. Survival Rates for Organ Transplantation 2014, U.S. Organ and Tissue Transplant Data (Milliman, 2015)**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart</td>
<td>88% / 87%</td>
<td>80% / 79%</td>
<td>75% / 72%</td>
<td>56%</td>
</tr>
<tr>
<td>Lung</td>
<td>83% / 86%</td>
<td>68% / 63%</td>
<td>56% / 47%</td>
<td>29%</td>
</tr>
<tr>
<td>Heart and Lung</td>
<td>66% / 66%</td>
<td>50% / 50%</td>
<td>NA / 39%</td>
<td>NA</td>
</tr>
<tr>
<td>Liver</td>
<td>86% / 86%</td>
<td>78% / 78%</td>
<td>69% / 72%</td>
<td>53%</td>
</tr>
<tr>
<td>Kidney</td>
<td>93% / 96%</td>
<td>85% / 91%</td>
<td>74% / 85%</td>
<td>48%</td>
</tr>
</tbody>
</table>
Complications
Centers also keep data regarding their center-specific kind/type of complication and frequency of occurrence. The life care plan will need to address the costs associated with complications, e.g., renal and neurotoxicity, and development of secondary viruses such as cytomegalovirus (CMV) and human papilloma virus (HPV), whether they are managed at the client's home base or require travel to the transplant center.

Transplant organ rejection can be acute or chronic. Signs of rejection and followup care should be identified in the plan.

Finally, the life care plan needs to address average organ survival rates and whether re-transplantation is possible option. Table 3 provides 2014 national averages for organ survival. Individual transplant centers may be able to provide their center specific percentage rates. Costs associated with the treatment of side effects should be presented for consideration in the plan in a separate chart.

The following representative costs for lung transplantation are taken from a 2013 life care plan. These are samples only and represent the regional costs for transplant at that time; the life care planner should note vendor source(s) for costs. Any life care plan must be individualized for the patient based on assessment.

Final Thoughts and Considerations
1. Pre-transplant vs Post-transplant Medication Considerations –
   Medical management of organ failure while awaiting transplantation includes maintaining the client on a multidrug regime. For example, clients with progressive lung disease will require a combination of long-acting and short-acting bronchodilators, periodic or routine corticosteroids, antibiotics, and nebulizers. At the time of transplant, these drugs are discontinued and the costs stop. The costs associated with immunosuppression then begin.

Support Care Costs
Individuals awaiting organ transplant will need support care services at home. Functional limitations with progressive organ failure often prevent them from performing independent self-care and/or ability to perform general housekeeping activities. Housekeeping and home maintenance allowance is appropriate. Support care is usually at the homemaker or home health aide level, but the nurse life care planner may assess need for a higher level of care.

The transplant recipient will need continued support care assistance. Post-operative heart and lung transplantation patients have significant lifting restrictions until suture lines and the median sternotomy are solidly healed. The transplant center will specify criteria for resumption of lifting activities, or whether restrictions are expected to be permanent.

Return to Work
Although return to work is beyond the scope of a life care plan per se, it is important to realize that the organ transplant recipient is chronically ill before transplant and many have had problems maintaining full time work. Following organ transplantation, especially in the first year, the recipient must return to the transplant center often. Maintaining full time employment is impossible. Return to work must be individualized. Any functional restrictions will effect employment. Future earnings and cost of vocational evaluation, if desired by the client, should be determined by a qualified vocational counselor and economist, and may be included in the life care plan or separately, depending on the needs of a particular case.

KATHIE ALLISON
Ms. Alison is a physical therapist with 42 years experience in rehabilitation. Her LCP business, Kathie Allison Life Care Planning, provides life care plans to attorneys and for the self-insured industry. She may be contacted at katiea@planetkc.com

REFERENCES
Transplant programs whose resources were used for the author's LCPs
Barnes Jewish Hospital, St. Louis MO www.barnesjewish.org
Cleveland Clinic Transplant Program www.clevelandclinic.org
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Loyola University Transplant Program, www.loyalomedicine.org
University of Iowa Transplant Center www.uihealthcare.org
University of Nebraska Transplant Program www.unmc.edu

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Certified Nurse Life Care Planner (CNLCP®) Certification Board Position Statement

As healthcare has become more complex, it is increasingly vital to assure the public that healthcare professionals are competent. Individual State Registered Nurse (RN) licensure measures entry-level competence only; and, in so doing, provides the legal authority for an individual to practice nursing. It is the minimum professional practice standard.

Certification, on the other hand, is a formal recognition that validates knowledge, experience, skills and clinical judgment within a specific nursing specialty; and, as such, is reflective of a more stringent professional practice standard. It reflects achievement of proficiency beyond basic licensure.

The CNLCP® Certification Board is a separately incorporated entity that facilitates consumer health and safety through credentialing/certification of nurse life care planners. It ensures that their practice is consistent with established standards of excellence in the development and defense of the life care planning document.

Similar to consumers knowing to seek out certification status within other professions (e.g., dentists, pharmacists), certification within the field of nurse life care planning has become an important indicator that a certified nurse not only holds state licensure to practice nursing, but is qualified, competent and has met rigorous requirements in the achievement of the CNLCP® credential.

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Jan Roughan, Chairperson
Email: cnlcpchairperson@cnlcp.org
Phone: 626-303-6333 Ext. 216

CNLCP® is a registered trademark of the CNLCP® Certification Board.
CONSIDERATIONS FOR THE ADULT LIVER TRANSPLANT RECIPIENT

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Kimberly Kushner, MSN, RN, CPNP, CNLCP, CLCP
Nadene Taniguchi, BSN, RN, CNLCP, CCM, PAHM
Liver transplantation (LT) is the treatment of choice for conditions resulting in end-stage liver disease and acute liver failure. According to the Organ Procurement and Transplantation Network (OPTN), from January 1, 1988, to October 31, 2014, 131,669 persons (117,061 over age 18) underwent LT in the United States. In 2013, 5,921 adult liver transplants were performed (OPTN data as of 1/30/15).

Outcomes following liver transplantation surgery continue to improve. According to the 2013 OPTN/SRTR Annual Data Report, approximately 82% of adult LT recipients were alive 5 years after transplantation and 68% were alive 10 years after transplantation (from deceased and living donors). According to Lucey et al., as of December 30, 2011, there were approximately 60,000 LT recipients who were alive and who had survived at least five years, and more than 16,000 who had survived at least 10 years. During the first post-transplant year, approximately 60% of deaths that occur are due to infection, acute rejection or peri-operative / post-operative complications (Lucey et al., 2013). Thereafter, the cause of mortality shifts. After the first post-transplant year and through the first 10 years following transplantation, the incidence of mortality (or need for retransplantation) due to acute or chronic rejection remains low (Lucey et al., 2013). For those who underwent transplantation because of Hepatitis C or autoimmune liver disease, mortality due to recurrence of the pre-transplant condition is significant over time. However, the majority of deaths is attributed to an increased and accelerated course of cardiovascular disease and / or malignancy, results of the side effects of ongoing immunosuppression to prevent organ rejection (Stravitz, Carl & Biskobing, 2011; Lucey et al., 2013).

Routine treatment and surveillance for LT patients

The period leading up to a transplant includes treatment for the underlying medical issues; evaluation for transplant readiness; and procurement of the donor organ. The 2014 Milliman Research Report provides a summary of the estimated U.S. average costs and utilization related to the 30 days prior to admission for transplant, including organ procurement. The report includes all medical costs (billed charges) associated with the transplant patient (not just the transplant procedure), including diagnostics and physicians fees. (Bentley, 2014)

Milliman also provides a summary of the estimated average costs for the transplant admission and for the 180 days post-discharge. Routine care in the first six months following surgery includes physician visits, diagnostics and medications. Complications are most likely to occur in the immediate post-operative period. Immediate risks can include graft loss; acute rejection; and vascular complications such as hepatic artery or portal vein stenosis and thrombosis; hepatic outflow obstruction; and biliary complications. Additional risks associated with surgery and the perioperative period can include bleeding, sepsis, respiratory failure, pneumonia, encephalopathy, acute renal failure or other organ failure. The LT recipient requires a period of intensive care, with gradual reduction of supportive treatment based upon medical stability. Ongoing care will be patient-specific and according to the postoperative course.

Outpatient follow up with members of the transplant team (hepatologist, transplant coordinator, clinical nurse specialist, dietician, social worker and / or pharmacist) would be scheduled per the protocol of the specific transplant center. Some routine care might be transferred back to the primary care provider, but close contact with the transplant team must be maintained. Laboratory tests, to monitor renal function, hepatic function, drug levels and the effects of medications, must be done regularly; however, the frequency would be based upon health status, liver function and center-specific protocols. When the transplant hospital is a distance from the patient’s home, studies might be obtained in the patient’s community and monitored remotely by the transplant team.

In 2013, the American Association for the Study of Liver Diseases and the American Society of Transplantation published guidelines for the long-term management of adults who had successfully undergone LT. The authors emphasized that the practice guidelines are intended to be flexible and suggest “preferred” approaches to the diagnostic, therapeutic and preventative aspects of care to identify and ameliorate the barriers to maintaining health (Lucey et al., 2013; Mells & Neuberger, 2009). Each patient will have his or her own subset of medical issues, based upon any pre-existing comorbidities and the post-transplant course. If the issues are results of the transplant, costs should be included in the Life Care Plan projection. If issues are due to pre-existing comorbidities, the costs should not be included.

Nurse Life Care Planners must address ongoing surveillance of the liver transplant, long-term consequences of the procedure itself, and the side effects of immunosuppression and other treatments necessary to maintain the transplant. The literature emphasizes the importance of early recognition of risk factors to avoid long-term complications of immunosuppression and recurrent liver disease (Stravitz, Carl & Biskobing, 2011; Lucey et al., 2013; Mells & Neuberger, 2009).

Medications: There is no single medication protocol recommended for all patients. Since there is no reliable marker for measuring effective levels of immunosuppression, the choice of agents and dosage will be dependent upon clinical, laboratory and histologic response (Lucey et al., 2013). According to Lucey et al., immunosuppressants are known to cause or accelerate cardiovascular disease and / or malignancy; they make the LT recipient especially vulnerable to metabolic syndrome and renal
dysfunction; the challenge of treatment is to balance the risk of rejection with the risk of drug toxicity.

In addition to immunosuppressants, medications might also be prescribed for management of side effects of the immunosuppressants or for pre-existing comorbidities. Medications commonly prescribed following LT include antibiotics, antivirals, antifungals, gastric acid reducers / blockers, medications for electrolyte imbalances, anti-hypertensives and immune-boosting agents. The Life Care Planner should evaluate the medications carefully and include only those that are specific to the transplant and subsequent treatment.

**COMMON COMPLICATIONS FOLLOWING LIVER TRANSPLANT**

**Infection:** The LT recipient must be monitored closely for signs of infection. Early and aggressive treatment is essential, as is the minimization of possible infectious exposure. The patient must avoid exposure to seemingly innocuous colds and ailments, which means limiting attendance at events in public places or where there are large crowds of people. When the LT recipient seems lethargic, has a fever or has decreased appetite, he should usually be evaluated for rejection or infection. Patients are particularly at risk for infection when dosages of immunosuppressants are increased; during the first three to six months post-transplant; and during treatment for signs of rejection. Opportunistic infections are often due to herpes viruses (EBV, CMV, simplex and zoster), fungi (Candida, Aspergillus, Cryptococcus), unusual bacteria (Nocardia, Listeria) and mycobacteria (Lucey et al., 2013). The transplant center should be consulted regarding medications to treat symptoms. Many drugs are contraindicated because of drug-drug interactions or liver toxicity. Diagnostic testing would be based upon symptoms and transplant center protocol.

**Rejection:** The body reacts to the foreign liver through a multi-step immune response (alloantigen recognition, lymphocyte activation, clonal expansion and graft inflammation), resulting in acute rejection. Immunosuppression is necessary to thwart this process. Several months post-transplant, the transplanted liver becomes partially tolerant of injury associated with the immune response; thus, the need for immunosuppression declines. However, the majority of LT recipients continue to require lifelong immunosuppression; maintenance without immunosuppressant medications is rare (Lucey et al., 2013). The continued use of immunosuppression has inevitable consequences, including an increased risk of infections, metabolic complications, and hepatobiliary or extrahepatic de novo (new) cancers (Lucey et al., 2013).

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**IMMUNOSUPPRESSION**

Immunosuppression can be achieved with various medication protocols, including calcineurin inhibitors (CNIs), corticosteroids and / or adjunctive agents. Liver transplantation is unique in that the risk of rejection decreases over time, and the need for immunosuppression might decrease. However, maintenance without immunosuppression is rare (Lucey et al., 2013). The immunosuppressant regimen would be reviewed periodically. Blood levels for certain medications would be drawn regularly (center-specific frequency; might decrease with stable dose).

Calcineurin inhibitors (primarily cyclosporine A and tacrolimus) are the cornerstone of immunosuppressant therapy. Side effects include renal dysfunction, neurologic changes, diabetes, increased susceptibility to infections, and certain de novo (new) malignancies. The dosage of CNIs is determined by blood levels. Since these agents are metabolized in the liver by the cytochrome p-450 system, levels can become elevated or reduced by concomitant use of medications that either inhibit or compete with this system. Medications such as fluconazole, erythromycin, diltiazem, verapamil and protease inhibitors elevate CNI blood levels and potential toxicities, while barbiturates, phenytoin, rifampin and carbamazepine can lead to reduced CNI blood levels and insufficient immunosuppression.

**CORTICOSTEROIDS** are particularly useful when used in conjunction with other agents. Side effects include weight gain, hypertension, hyperglycemia, hyperlipidemia, delayed wound healing, glaucoma, osteoporosis, growth suppression, fungal infections, pituitary-adrenal dysfunction and gastric ulcers. Due to these side effects, the treatment team will attempt to reduce or eliminate their use. However, appropriate medical surveillance by specialists (internists, ophthalmologists, etc.) should be part of the Life Care Plan, to ensure early detection of complications.

**ADJUNCTIVE THERAPIES** such as mycophenolate mofetil (CellCept) and sirolimus (Rapamune), enhance the effect of CNIs so that a lower dosage can be utilized. Adjunctive therapies are more commonly used in the early post-operative period so that initiation of CNIs can be delayed. The combination of sirolimus, an mTOR inhibitor, with low-dose CNIs helps to minimize renal injury. Sirolimus might also provide some protective benefit against certain malignancies. Antibody therapy (daclizumab, basiliximab, muromonab, alemtuzumab) is used during the peri-operative period to reduce the need for high-dose corticosteroids and to delay the introduction of CNIs. Unfortunately, these medications are not without their own side effects. Mycophenolate mofetil causes bone marrow suppression and gastrointestinal effects. Sirolimus causes leukopenia, thrombocytopenia, anemia, gastrointestinal disruptions and infections. Antibody therapy is associated with an increased incidence of opportunistic infections and cancers.
Surveillance of the LT recipient should be performed by those with knowledge and expertise in the many facets of transplantation and immunosuppression. The frequency of monitoring with liver tests would be individualized by the transplant center, depending upon complications and stability of serial laboratory results. Early signs of rejection include fever, flu-like symptoms and abdominal pain or tenderness. Later symptoms, indicative of worsening liver function, might include jaundice, changes in urine / stool coloration, confusion, increased fatigue and ascites. Depending on the laboratory values and clinical picture, additional diagnostic testing could include MRI, CT, endoscopic retrograde cholangiopancreatography and / or sonography. The clinical suspicion of acute rejection requires confirmation by liver biopsy. Treatment of rejection would typically include an increase in immunosuppressant agents. Evaluation and treatment could also require inpatient hospital care.

Additional Complications: Table 1 shows the prevalence of some complications beyond the first post-transplant year.

Table 1.
Cardiovascular Risk Factors and Renal Disease in Liver Transplant Recipients after the First Post-Transplant Year (Adapted from Lucey et al., 2013)

<table>
<thead>
<tr>
<th>CARDIOVASCULAR RISK FACTOR</th>
<th>PREVALENCE RATE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Metabolic Syndrome*</td>
<td>50% - 60%</td>
</tr>
<tr>
<td>Systemic Hypertension</td>
<td>40% - 85%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>10% - 64%</td>
</tr>
<tr>
<td>Obesity</td>
<td>24% - 64%</td>
</tr>
<tr>
<td>Dyslipidemia</td>
<td>40% - 66%</td>
</tr>
<tr>
<td>Chronic Kidney Disease</td>
<td>30% - 80%</td>
</tr>
<tr>
<td>End-Stage Kidney Disease</td>
<td>5% - 8%</td>
</tr>
</tbody>
</table>

*any 3 of the following: hypertension, obesity, dyslipidemia, diabetes

Additional Complications: Table 1 shows the prevalence of some complications beyond the first post-transplant year. Surveillance of the LT recipient should be performed by those with knowledge and expertise in the many facets of transplantation and immunosuppression. The frequency of monitoring with liver tests would be individualized by the transplant center, depending upon complications and stability of serial laboratory results. Early signs of rejection include fever, flu-like symptoms and abdominal pain or tenderness. Later symptoms, indicative of worsening liver function, might include jaundice, changes in urine / stool coloration, confusion, increased fatigue and ascites. Depending on the laboratory values and clinical picture, additional diagnostic testing could include MRI, CT, endoscopic retrograde cholangiopancreatography and / or sonography. The clinical suspicion of acute rejection requires confirmation by liver biopsy. Treatment of rejection would typically include an increase in immunosuppressant agents. Evaluation and treatment could also require inpatient hospital care.

Table 1 shows the prevalence of some complications beyond the first post-transplant year.
Dyslipidemia: Glucocorticoids, cyclosporin and sirolimus cause the greatest increases in total cholesterol, LDL and HDL. Management of dyslipidemia should include dietary modifications, and pharmacotherapy with lipid-lowering medications, such as statins, cholesterol absorption inhibitors, bile acid sequestrants, fibrates and niacin. Potential drug interactions might limit medication choices.

Metabolic Bone Disease: Accelerated bone loss, which occurs in the first few months post-transplant in almost all LT recipients, is attributed to corticosteroids and CNIs. Thereafter, there might be some recovery of bone loss. The risk for fracture is greatest during the first two years. Trabecular bone (ribs, vertebrae) is particularly vulnerable. Surveillance should include assessment of bone pain, dietary intake of protein and calcium, bone mineral density (BMD) with DEXA scans, and Vitamin D blood levels. Hormone levels and radiologic studies of the spine would be monitored with more advanced disease. Calcium and Vitamin D supplementation is recommended for LT recipients with osteopenia (or at risk for osteopenia); bisphosphonate therapy might be considered. (Lucey et al., 2013)

Malignancies: LT recipients have an overall higher risk of developing de novo malignancies than the general population (Chandok & Watt, 2012). Nonmelanoma skin cancers are the most common of all malignancies that occur in LT, with an incidence that is up to 20 times higher than age and sex matched non-transplant cohorts, and are much more aggressive in transplant recipients (Stravitz, Carl & Biskobing, 2011; Chandok & Watt, 2012). Other cancers associated with immunosuppression include lymphoma, Kaposi’s sarcoma and those of the oropharynx, esophagus, lung and colon. Research has shown that more intensive surveillance results in diagnoses of cancers at earlier stages and, thus, in improved survival (Stravitz, Carl & Biskobing, 2011). Therefore, surveillance (dermatologist and / or other specialists) is recommended to begin at a younger age than the non-transplant population. For those with pre-existing co-morbidities such as inflammatory bowel disease, primary sclerosing cholangitis or cirrhosis, additional or more frequent screening could be needed (colonoscopy with biopsy, abdominal imaging, etc.) (Stravitz, Carl & Biskobing, 2011; Lucey et al., 2013).

ADDITIONAL CONSIDERATIONS IN THE LIFE CARE PLAN

Coping: Liver transplantation takes a significant toll on one’s emotional and psychological well-being. The LT recipient has endured invasive procedures and severe pain. Family roles and other relationships are changed. The ability to work, maintain one’s home without assistance or participate in many activities enjoyed prior to the transplant are altered. The LT recipient faces an uncertain future, which at best includes multiple additional procedures and could very well include a lifetime of chronic illness. Due to significant lifestyle changes imposed by the transplant and its follow-up care, counseling to assist with developing and maintaining coping skills should be considered for inclusion in the Life Care Plan.

Hospitalizations: Hospital care is often required for evaluation and treatment of complications. Treatment of infections often requires the administration of intravenous antibiotics and steroids. Early signs of organ rejection often require hospitalization. Inpatient care is also likely to include management of complications associated with medications specific to the transplant. Consideration for the inclusion of hospital care in the Life Care Plan should be made with sufficient medical foundation.

Mobility / Independent Function: Depending upon the medical course, the LT recipient might be severely deconditioned or have suffered complications resulting in mobility and / or functional deficits. The Life Care Plan should consider supportive care and equipment:

Assistance / Replacement Services: A Home Health Aide, assisted living or care in a nursing home might be required. Replacement services for those tasks the patient was able to perform prior to the LT should also be considered.

Equipment: Aids for mobility and / or activities of daily living, including canes, walkers, wheelchairs, a shower bench, lift chairs, reachers, etc., might be required.

Home Modifications: Modifications to address changes in mobility (negotiating stairs, reaching, bending, kneeling), hand strength / dexterity and / or bimanual function should be addressed.

Travel: The costs of lodging and travel to and from the transplant center, if the client lives a substantial distance away and could not rea-
reasonably attend an appointment and return home the same day, might be included in the Life Care Plan.

**COSTING CONSIDERATIONS**

Center-specific (rather than generic) costs best indicate future expenses. However, in many cases, a patient requiring transplant at some future time has not yet been enrolled in a transplant program, or the costs are not readily available. Published statistics, such as The Milliman Report, provide an accessible source for cost projections surrounding the transplant and the immediate pre- and post-operative periods.

The Life Care Planner should be cognizant of the pitfalls of using published statistics. Some pitfalls are noted below:
- Use of group average; assuming every patient is the same
- Failure to account for geographical differences
- Inclusion of costs for comorbidity treatment
- Failure to point out that high-volume centers might have more complex patients with higher average costs
- Failure to take into consideration that changes in protocols occur faster than the literature relating to costs can reflect
- Inclusion of studies that are either retrospective or were initiated years prior to completion

When addressing costs of retransplant, past billing is an excellent predictor of future costs. Medical foundation from treating providers is helpful in projecting the frequency and duration of physician surveillance, diagnostics and medications.

**CONCLUSION**

The preparation of a Life Care Plan for a patient anticipating a liver transplant or recovering from a transplant is a challenge for even the most experienced Life Care Planner. Although there are many common elements for all transplant recipients, each patient will have his own set of needs. Each Plan should individualize the care to reflect accurately the case at hand.
REFERENCES


A CORE CURRICULUM
for
NURSE LIFE CARE PLANNING

American Association of Nurse Life Care Planners

Dorajane Apuna-Grummer
Wendie A. Howland
Editors
It was five-plus years ago when I was diagnosed with non-Hodgkins lymphoma. I was 56, in good health, working full-time, very active, and happy. Then I was presented with those three little words that no one ever wants to hear: “You have cancer.” This immediately changes things and you know that a detour lies ahead. This was okay. My type of cancer was aggressive, but curable. I was strong and a good fighter.

I underwent six treatments of RCHOP chemotherapy, lost my hair, taste, and energy, but was able to continue working every day and play tennis with my friends. I had excellent care, excellent support, and a strong faith. This was just going to be a bump in the road.

Then, a second time, “You have cancer” happened. I wasn’t so sure that I wanted to go through all of that again. Even though I did really well, what if it just keeps coming back? I just didn’t want to put my family through all of that again. Things had changed. Yes, I was still relatively young, still active and working, had amazing support and faith, but if the cancer continued to come back over and over, I would not be strong and so willing to fight. We had a big decision to make.

I voiced this concern to my oncologist and he informed me that there was another option, a stem cell transplant. He said there was a program within fifty miles, a center that he actually started in the early 90s. They had seen amazing results, and the patients experienced a very low reoccurrence rate. He felt that I would be an excellent candidate.

After learning more, I decided to pursue it. I would donate my own stem cells, undergo a week of high-dose chemo, after which they would transfuse my stem cells back into me. Next, I’d be given medication to help the stem cells concentrate on rebuilding white cells, and then they would be on their own to select their own career paths. The program recommended that I stay in a hotel within 15 minutes of the cancer center and have a round-the-clock caregiver. Of course, being an inpatient was also an option, but that had its own issues with exposure.
to infection. I wanted to select the hotel, but this brought on another dilemma: My husband was still working and my grown children also worked and were two and five hours away. I had no caregiver.

That’s when one of my friends stepped up to the plate and volunteered to be my “care-giver schedule coordinator.” What a blessing! We booked my husband’s two sisters from Illinois and Indiana for one week, past next-door neighbors from 20 years ago for another week, and friends or tennis teammates for the other two weeks.

My husband was taking the weekends and driving over to spend an hour or two with us every evening.

My caregiver coordinator had all the bases covered, including contact numbers and emphatic instructions that if something changed, I was to call her. It was clear that she did not want me to worry about anything from that aspect; I was to concentrate on getting better. It was a wonderful act of kindness and friendship.

We booked a two bedroom suite at one of the Cancer Center’s recommended hotels. I wanted the care-giver(s) to have their own room. This turned out to be a great idea as I was up almost every hour or two relieving myself of all liquids that had been pumped into me. The hotel workers were wonderful as they didn’t mind changing the sheets every time we had a caregiver change. They all took a personal interest in taking care of me. Even the maintenance folks were cheerleaders. They all wanted to see me get better.

Right across from the hotel was a large campus for an industrial plant that was like a beautiful park. We were able to take a short walk every night after my treatments. I loved getting some fresh air. I was determined to keep my life as normal as possible, so I wanted to continue to try to remain active and continue working remotely. Work really helped me focus and keep my mind off of what my body was going through. It gave me a sense of purpose. That was huge for me, and I was so thankful for the opportunity to allow this to happen.

Infection is one of the biggest risks that a patient faces during a stem cell transplant, because the high-dose chemo temporarily disables the immune system. I have a lab report that showed a grand total of one WBC. So, needless to say, we were all prepped to be very aware of potential infection risks. The program coordinators did a great job of educating us. They really emphasized how important it was for everyone to know what should or should not be done.

In fact, the education by the transplant team was as important to them as taking care of me. They explained everything, were available for questions, forewarned me about possible side effects and made sure I had all the necessary medicines/supplies to take care of whatever came my way. It was my job to read the material (two or three times if necessary) and make sure I understood what was going to happen during the process and what to do if a problem occurred. I had a bag of “just-in-case” supplies that was probably about the size of a 10 pound bag of potatoes. Luckily, I didn’t have to use them all.

The education was probably the biggest help to me. This was not the program’s first rodeo; many of the transplant team members had been there from the very beginning. These wonderful folks knew what worked or didn’t work and passed that information on. They were kind, knowledgeable, and very skilled, and of course, were also cheerleaders and coaches. I really needed to trust them, and they truly earned that trust. I felt safe and well taken care of.

They planned out a very detailed schedule. I knew every day where I was to be and what was expected of me. Even several months after the transplant, I still have a schedule. All of my childhood immunizations must be repeated as I am now considered an immunological newborn. Yes, they celebrated my transplant birthday and my new age correlates back to that date. I actually get my immunizations about two weeks after those of my youngest grandson. This comes as a surprise to many, but you must remember that your immune system is exactly like a newborn’s, but without a mother’s immunity. So, needless to say, infection prevention is still very important. Although much of my immunity has come back pretty quickly, I still have to be careful. I can’t go swimming for a year, play in the dirt, walk in the woods where there might be mold, or the like. I don’t want to come this far and then blow it by a careless act.

Knowing firsthand the trials and tribulations of the stem cell transplant, would I do all of this again? My answer has changed three times already. The first three weeks after coming home it was a resounding, “Yes.” The next four months or so after that, my answer would not have been so positive. Neuropathy set in, affecting the back of my knees and hands. I could hardly walk if I stayed stationary for just a short time. Sitting at a desk all day and working on the computer was horrific. The pain was pretty bad. I didn’t know if I would ever have relief again.

Then, again I received help. My oncologist arranged for several sessions of physical therapy. I began walking, and hitting tennis balls as well. I just knew I needed to stay moving to get away from the pain. Luckily, the activity seemed to help, and I am much improved.

Today, eight months post-transplant, my answer again would be, “Yes.” I want to have more years to spend with my wonderful spouse who was so terrific during this whole ordeal, and share all the moments that will forever be special with family and friends.
**SELECTED LITERATURE SOURCES REGARDING HAND TRANSPLANTS**

A double-hand transplant can be worth the effort!

**Author:** Margreiter, R  
**Journal:** Transplantation  
**ISSN:** 0041-1337  
**Date:** 2002  
**Volume:** 74  
**Issue:** 1  
**Page:** 85

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Outcomes of the first 2 American hand transplants at 8 and 6 years posttransplant.


The Innsbruck Hand Transplant Program: Update at 8 Years After the First Transplant
Author: Brandacher, G.
Journal: Transplantation proceedings
ISSN: 0041-1345
Date: 03/2009
Volume: 41
Issue: 2
Page: 491 - 494
DOI: 10.1016/j.transproceed.2009.01.013

World Experience After More Than a Decade of Clinical Hand Transplantation: Update from the Louisville Hand Transplant Program
Author: Kaufman, Christina L.
Journal: Hand clinics
ISSN: 0749-0712
Date: 11/2011
Volume: 27
Issue: 4
Page: 417 - 421
DOI: 10.1016/j.hcl.2011.08.004

History and ethics of hand transplants
Author: Errico, M
Journal: JRSM short reports
ISSN: 2042-5333
Date: 10/2012
Volume: 3
Issue: 10
Page: 74
PMID: 23162687
DOI: 10.1258/shorts.2012.011178

JW & Gruber, SA & Barker, JH & Breidenbach, WC,* Successful hand transplantation: One-year follow-up
Author: Jones, LHTT
Journal: The New England Journal of Medicine
ISSN: 0028-4793
Date: 2000
Volume: 343
Page: 468

Author: Breidenbach, W
Journal: American journal of transplantation
ISSN: 1600-6135
Date: 2009
Volume: 9
Page: 317

Lessons from hand transplants
Author: Hettiaratchy, Shehan
Journal: Lancet
Date: 02/2001
Volume: 357
Issue: 9255
Page: 494 - 495

IN ADDITION, HERE IS A LINK TO A BRIEF BBC VIDEO SHOWING THE PROCESS OF A DOUBLE HAND TRANSPLANT AND THE PATIENT’S EXPERIENCE. HTTP://WWW.DIAGNOZIZ.COM/HAND-TRANSPLANTATION-MEDICAL-SURGERY/
WILL: I was born in 1968 with Cystic Fibrosis, a fatal genetic disease that causes an excess of mucus in the body. At that time, life expectancy for CF patients was in the single digits. Fortunately, as I got older, CF treatments improved, often arriving just in time to save me.

PAT: Life for our 46-year-old son Will has been a series of stunning victories over the progressive genetic disease cystic fibrosis, not that he defeated the disease, but that he didn’t let it defeat him. His first victory was coming home from the hospital about a month after his birth and surgery in December of 1968. Our joy that Christmas knew no bounds. We were particularly concerned because he occupied the same incubator in the same corner of the hospital intensive care unit as his infant brother who died the year before at three weeks. We were grateful for Will’s very early diagnosis due to his meconium ileus, a thickening of the substance in the intestines of babies until they are born. When this thickens and doesn’t pass through it is recognized as a symptom of CF.

WILL: The course of CF is different for every patient but most CFers fight a war on two fronts: in the gastroin-
testinal tract and in the lungs. In the GI tract, mucus blocks the pancreas and prevents digestive enzymes from reaching the stomach. We take enzymes to help us digest food. During my lifetime, the quality of these enzymes has gone from barely sufficient to fairly effective.

In the lungs, mucus clogs our airways. Lung disease is what usually kills us. In the short term it is like having a bad cold every day but in the long-term our lung tissue gets damaged. One doctor told me CF patients lose an average of 3% of lung capacity per year. This may be less true now because CF treatments are much improved.

PAT: As we adjusted to life with a child needing special care and daily postural drainage, we were bolstered by the CF Clinic at the University of Colorado Hospital and a parents’ support group. Only one speaker at the support group, a social worker, was not helpful when she told me I must accept the idea that Will would die of cystic fibrosis. How could she say that when there was so much ahead that none of us could know: the discovery of the gene, new treatments for the symptoms, lung transplants, and now a drug to reverse the effects of cystic fibrosis for those with a particular gene. Our efforts to care for Will required the full commitment of our entire family: me, my husband Monte and our two other children all worked hard to keep Will healthy.

WILL: In those days, chest therapy or postural drainage meant someone cupped their hands and pounded my torso as I laid across a stack of pillows. Everyone in my family helped, but usually it was my father (a former college football player) who pounded on me twice a day.

While growing up I had a lot of stomach issues that doctors were unable to fix. CF created a Catch-22. Because of the energy my body expended fighting CF, I needed more daily calories than the average person. Coughing is exhausting. Yet my digestive system could not handle extra calories. I spent many afternoons curled up on a couch with severe stomach pain, waiting for things to get moving.

PAT: Will’s recovery from his first hospitalization after birth when he was in fifth grade felt like a victory. His next major crisis was hospitalization for an intestinal blockage while he was a student at Stanford.

WILL: Many people hate thinking they are “normal.” I wanted to be normal. I tried not to use CF as an excuse. I was a good student and attended Stanford University, graduating in 1991. I rode my bike every day and worked out regularly and was at the peak of my health as a senior. I pounded myself but pounding myself was less effective than having someone else do it. I did not have a hand percussor (hand-held self-pounding device) or the vest (a sort of life vest that CF patients now wear that literally shakes the mucus loose). (Ed. note: see “High-Frequency Chest Wall Oscillation in LCP,” JNLCX XI.1, March 2011)

In my early post-college years I had an exciting career in Washington DC, but I began to have major problems with my lungs. I was exercising less and my self-pounding techniques fell short. Largely because of my health, I returned home to Colorado. My lung capacity would drop dramatically due to lung infections and I brought it back up with “tune-ups,” two-week courses of antibiotics. This was in the early to mid-90s and home health care was becoming more common, accepted and technologically easy, so I would often do these tune-ups at home. I loved dodging the hospital, but this meant I missed out on the vigorous respiratory therapy (professional pounding) done during hospital stays. So these tune-ups were probably less effective than they could have been.

PAT: Will was holding on, while desperately ill with “end-stage cystic fibrosis” for six or seven months. We brought him home where we could care for him because he was able to keep track of all of his medication and tell us which one to bring him and when. Monte was working full time and I was in the State Senate where I had to appear for roll every morning at 9 a.m. We made a little kitchen out of our upstairs laundry room, and I would take up breakfast and lunch each morning before I went to work. Will was on oxygen full time and had a nurse visiting.

WILL: I went on the lung transplant list in fall 1997. By then I was on full-time oxygen and CPAP and I did four lung clearance treatments per day: one time each with a percusser, a vest, my father and a professional respiratory therapist. I lived on the second floor of my parent’s house and could make it thirty feet to the bathroom and back. Mostly I waited in bed for five months.

PAT: Our great fear—and that of everyone on the waiting list—is that he would not get a pair of lungs soon enough. He was finally hospitalized and made end-of-life decisions. He did not want to be on a ventilator, if they put him on one, for more than two weeks, because after that time they would not give him lungs.

WILL: In April 1998, I went into the hospital. My doctors did not think I had much time left — though I was confident I could hold on as long as necessary. I did not get The Call. Because I was in the hospital, my “call” was my transplant doctor stopping by the room to say, “I think we’ve got some lungs for you.” A family had lost their loved one and in the midst of their grief they decided to save several lives, including mine.

PAT: He had a successful transplant, though it was obviously a very difficult recovery.

WILL: The transplant team told me I was trading one disease (CF) for another (immunosuppression). But I saw it differently. I was keeping part of one disease with my stomach issues but trading my CF lungs for what was essentially a cure. The docs emphasize, “This is NOT a cure!” But
it felt like one. The greatest freedom was not coughing all day, every day. All I had to do was take a ton of pills. I have been taking a ton of pills my whole life. Taking pills is easy.

My doctors were aggressive and kept me healthy until 2005. Then my lung capacity fell again as chronic rejection beat up on my donor lungs.

PAT: Unfortunately, my husband Monte died in 2006.

WILL: I went onto the list for lung retransplant. My second wait for transplant was Club Med compared to my first. I was on full-time oxygen but was able to live independently. I did not work for two years. I think I hung around long enough they decided to give me a shot at retransplant.

PAT: Will had his second, single lung transplant in March 2007. He was not nearly as sick as he was before the first transplant, but, after nine years, his lungs began to fail. While we waited in the pre-op room, we all felt Monte’s presence.

WILL: This time I did get The Call and received a single-lung retransplant. I went back to work at my old job and went for about five years before chronic rejection struck again. The battle is rejoined but it is a familiar one.

Ed. note: Will, now aged 46, is still in Colorado. He has learned that he would not be eligible for a third transplant.
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REGENERATIVE MEDICINE

AN OVERVIEW FOR THE NLCP
Regenerative medicine is the process of creating living, functional tissues to repair or replace tissue or organ function lost due to damage or congenital defects (NIH 2015). In 2000, the US National Institutes of Health primer on stem cells claimed that research on stem cells has the potential to revolutionize the practice of medicine and improve quality and length of life.

According to Harris (2008), it is estimated that as many as 128 million individuals in the United States, or 1 in 3 people, might benefit from regenerative medicine. Those statistics should be eye-opening for the nurse life care planner. Regenerative medicine will eventually become a viable treatment modality for so many of those individuals for whom the nurse life care planner is called upon to assist with preparation of a future care plan. For example, potential neurological applications alone include spinal cord injuries, brain injury with cognitive impairment, cerebral palsy, stroke, and neurodegenerative diseases such as Parkinson’s disease and multiple sclerosis. Regenerative medicine is currently in research and use in many other disease states and body systems, as stem cells can replace many kinds of cells that die from trauma and injuries.

This article is intended to familiarize the nurse life care planner with a cutting-edge technology and treatment that is moving into clinical practice quickly. Investigation to date has shown promise in many disease states. Patients, clients, and family members are becoming aware of stem-cell research as they remain very hopeful in finding a treatment that is well-tolerated, safe and has a low-to-no-risk profile.

BACKGROUND AND RESEARCH

Stem cells are unique in that they are capable of self-renewal and differentiation into a wide range of cell types with multiple clinical and therapeutic applications.

Stem cells are undifferentiated, can divide and self-renew indefinitely, and give rise to more mature cells with specialized functions. For example, the pluripotent stem cells originate in the bone marrow, can divide forever, and is responsible for production of all hematopoietic cells, but can also differentiate into other types of cells, such as nerve, muscle, or bone. (Figure 1)

Currently there are over 70 proven therapies using adult stem cells, but none using embryonic stem cells. This is in part because of the difficulty controlling how embryonic stem cells differentiate (Tortland, 2015). Embryonic stem cells are pluripotent stem cells. They are unspecialized or undifferentiated cells that can divide indefinitely and can develop into specialized or differentiated cells. The flurry of excitement over embryonic stem cells began in 1998 when researchers at the University of Wisconsin were the first to successfully isolate and cultivate human embryonic stem cells. While embryonic stem cells represented a promised source for cell transplantation because of their ability to differentiate into all somatic (undifferentiated) cell lineages, the clinical application for these cells has remained somewhat hampered by the ethical implications of using human embryos. (Wang 2013)

Because of the controversial use of embryonic stem cells, the focus has been on non-embryonic adult mesenchymal stem cells. These special stem cells are easily available in large numbers from affected individuals and can be found in a person’s own blood, bone marrow and adipose (fat) tissue. Using autologous stem cells from a person’s own fat are easy to harvest safely and are abundant in quantities up to 2500 times those seen in the bone marrow (Lander and Berman, 2014).

Adult (non-embryonic) mesenchymal stem cells (MSCs) are undifferentiated cells that can replace dying cells and regenerate damaged tissue. These multipotent stem cells can differentiate into distinctive end-stage cell types, such as specific mesenchymal tissues: bone, cartilage, muscle, tendon, ligament, bone marrow stroma, fat, dermis, and other connective tissues. (Diagram 2) As a result, these MSCs seek out areas of injury, disease and destruction where they are capable of regenerating healthy cells and enabling a person’s natural healing processes to be accelerated. MSCs are easily available, pluripotent, and don’t carry any associated ethical issues, unlike embryonic stem cells. (Wang 2013) There is currently no evidence to substantiate whether adult mesenchymal stem cells from bone marrow are clinically any better than mesenchymal stem cells derived from fat. The stem cells are equally primitive and have the potential to differentiate into mature functional tissues.

METHODS FOR HARVEST

Regenerative medicine using stem cells for an individual patient begins by isolating the richest source of adult stem cells: the patient’s own (autologous) stem cells from adipose (fat) tissue. Fat is removed by liposuction, usually from the abdominal area, under sterile conditions, with local anesthesia. The resulting stem cells are then concentrated and infused intravenously. This is an outpatient procedure, performed...
in a surgical center. Cell harvest and deployment procedures take less than two hours. (Lander et al., 2015; Tortland et al., 2015; Smyrniotis, 2015).

The Cell Surgical Network, founded in 2012, is a large group of affiliated stem cell clinics across the U.S. and some abroad. They are all independently owned but share in the same protocols, use the same training, methods and equipment and the same on-line data base. CSN founders Elliott Landers, M.D. and Mark Berman, M.D. are in the process of setting up FDA-approved protocols for stem cell banking. Banking will enable a person to receive autologous stem cells at any time without having to undergo repeated liposuction.

**ORTHOPEDIC APPLICATIONS**

Stem cell injection therapy has been introduced for treatment of chronic musculoskeletal and joint disorders. Orthopedists are able to use mesenchymal stem cells harvested from bone marrow aspiration and administer them by injection in the office. Two physicians, Paul Tortland and Albert Kozar, were the first in the New England region to pioneer stem cell injections for use in chronic musculoskeletal conditions, described in detail below.

A common method of obtaining stem cells for treatment of musculoskeletal disorders is from the bone marrow taken from the iliac crest. Harvesting the cells can be done in a doctor’s office in which the area of the hip is numbed using Novocain. Once numbed, a specialized large bore needle is used to penetrate through the skin and cortex of the bone into the marrow cavity. The liquid marrow is then withdrawn into a syringe, which is then placed in a specialized centrifuge. The stem cells are highly concentrated and passed into a new syringe from which the injection(s) are given. This procedure takes about an hour. (Tortland & Kozar 2015)

According to Dr. Paul Tortland, the injections consisting of stem cells are given under direct ultrasound guidance (or fluoroscopic guidance) to insure both accurate and safe administration of the stem cells. Following injection, for weight bearing joints, patients need to avoid bearing weight for 24-48 hours. But it is critical that the joint not be immobilized. Gentle protected movement is critical to stimulate healing. For non-weightbearing joints, gentle protected movement is also encouraged but forceful or aggressive activities, such as sports, are prohibited.

Hard exercise can result in muscle pain caused by inflammation. The normal inflammatory healing reaction repairs the damage from the workout, and triggers a physiologic response: muscle hypertrophy and associated increased local perfusion.

The field of regenerative medicine in orthopedic practice is evolving. Treatment protocols are rapidly changing. As a result, protocols, methodology and costs can vary across the country. Stem cell injections are not used as first line but rather for the treatment of conditions that have failed or have not responded completely to other more conservative treatments. (See table 1)

Prolotherapy involves injecting a small amount of a mixture of lidocaine and hypertonic dextrose, an irritant, directly at the site of damage, creating a local inflammatory reaction that helps prepare the joint, biologically, for the healing process generated by the stem cells. At Valley Sports Physicians and Orthopedic Medicine located in Connecticut, when the stem cells are injected into a joint, the protocol includes a dextrose-mixed prolotherapy treatment first, 3-4 days before the stem cell procedure.

Like exercise, prolotherapy can cause structures like ligaments and tendons to become stronger and thicker. (Hauser, Blakemore, et al., 2014) About two weeks after the stem cell procedure, the joint is injected with platelet-rich plasma (PRP). (See side bar: PRP) This helps the stem cells remain active. Another PRP treatment may then be given about 2 months later. While an important function of platelets is clot formation, human platelets are rich in connective tissue growth factors. When injected into the injured structure, this stimulates healing.

The risks associated with this protocol are reported to be extremely low. Risks are similar to those of any injection and include infection, bleeding, and nerve damage, but are reported to be very low due to the use of ultrasound or fluoroscopic guidance with the injections. Because the platelet-rich plasma and stem cells are autologous, the risk associated with allergy or rejection is extremely low. Therefore, recipients will not need anti-rejection medication or experience any graft versus host syndromes.

In certain cases where there is considerable tendon and muscle tears involving the rotator cuff, tennis elbow and Achilles, stem cell therapy alone may be less effective, because the liquid stem cell solution has less tendency to stay in the injected area. In order to combat this, Tortland and Kozar have reported on fat grafting by combining stem cells with fat concentrate to create a gel that fills the defect and promotes more effective healing. Similar to the harvesting of stem cells noted above, the physicians harvest a small amount of fat from the patient’s abdomen, buttocks, or hips. The fat is concentrated via centrifuge, and the resulting fat concentrate is mixed with stem cells to create a gel. The gel fills the tear in the tendons or muscles.

They report using the same process with more advanced joint arthritis, in which the fat acts as a matrix to hold the platelets in place and helps activate them to release their growth factors more effectively. In moderate to severe arthritis, for example, the combination of a stem cell solution and fat has been reported to work much better than stem cells alone. (Tortland et al., 2015)

The majority of the published trials to date report on the use of MSCs to treat osteoarthritis of the knee joint versus any other weight bearing joint. Published studies looking at the use of stem cells alone to treat rotator cuff tears are lacking. Large randomized controlled trials are difficult to do in this patient population. In a 2010 meeting of the American Academy of Orthopedic Surgeons, Moon et al. presented on their data that showed inclusion of stem cells in the surgical repair of rotator cuff tears. By incorporating bone marrow-derived MSCs in surgical cuff repairs, resulted in faster healing and recovery than surgery alone.

According to the data presented...
by Tortland and Kozar (2015), patients typically respond to just one round of treatment. However, if a case is considered more severe, 2-3 treatments may be required. In those cases, treatments are spread out over a period of 6-12 months. He reported on a study by Kim, et al. (2014), in which patients with Grade 1-4 knee arthritis were treated with bone marrow derived MSC combined with fat grafting. While there was a significant improvement in pain and function, the severity of arthritis made a difference in number of treatments required.

Koh et al. (2013) studied 18 middle-aged men and women following a single injection of MSCs into an arthritic knee, and reported a significant improvement in pain and function score. At 24 months, repeat MRIs showed an increase in cartilage thickness compared to pretreatment MRIs.

A 2014 study using high-dose adipose-derived stem cells in 18 patients with arthritis in which a second-look arthroscopy was performed to look at effects of treatment on cartilage. The results showed improved function and pain of the knee joint without causing adverse events, and reduced cartilage defects by regeneration of hyaline-like articular cartilage. (Jo et al., 2014)

Using a single bone marrow stem cell injection into the arthritic knees of 12 patients who had failed conservative treatment, Orozco et al. (2013) reported a rapid and progressive improvement in patients that approached 65% to 78% by 1 year. Reevaluation by MRI at 1 year demonstrated a highly significant decrease of poor cartilage area, on average 27%, with improvement of cartilage quality in 11 of 12 patients.

Summarizing various presentations from a lecture given at the 4th annual Orthobiologic Institute symposium held in Las Vegas, NV 2014, information was shared by John Schultz of Regexx / Ceneno-Schultz Clinic on 1400 patients from 2005 to 2014 using same-day bone marrow stem cells for various orthopedic conditions. For knee osteoarthritis (OA) they found that 80% of patients treated experienced an average of 80% improvement, independent of arthritis severity, body weight, or age. Hip, shoulder and ankle arthritis did not fare as well in their experience. 70% of patients with shoulder OA had slightly better than 50% improvement at 1 year. Barely 60% of patients with hip arthritis saw meaningful improvement. With older patients faring more poorly than younger, 60% of those with foot/ankle OA saw about a 45% improvement at 17 months. Patients with severe hand/wrist OA saw an average 40% improvement at 10 months. Tortland and Kozar commented the presenters did not indicate what percentage of hand/wrist patients overall had a positive response. No information was provided on previous treatments, or subsequent/additional MSC injections to improve the response.

The field of regenerative medicine in orthopedic practice is evolving. Treatment protocols are rapidly changing. As a result, protocols, methodology and costs can vary across the country. Stem cell injections are not used as first line but rather for the treatment of conditions that have failed or have not responded completely to other more conservative treatments (Table 1). The clinical use of stem cells in orthopedics has far outpaced research. According to the web site, www.clinicaltrials.gov, there are thousands of studies investigating the use of stem cells or mesenchymal stem cells. As outlined above, stem cell injections are being used in orthopedics for many conditions in which stem cells have not yet been studied. The secondary complications of impaired mobility and chronic pain in weight-bearing and non-weight-bearing patients are few.
DISEASE STATES WHERE REGENERATIVE MEDICINE IS BEING USED OUTSIDE OF CLINICAL TRIALS INCLUDE SKIN REPLACEMENT FOR BURNS, DIABETIC AND VENOUS STASIS ULCERS, AND TISSUE-ENGINEERED BLADDERS. RESEARCH FOR NEUROLOGICAL APPLICATIONS IS PROMISING.

OTHER APPLICATIONS IN REGENERATIVE MEDICINE
While demand far exceeds its use in orthopedic injuries, there are other disease states where regenerative medicine is being used outside of clinical trials. Tissue-engineered skin has been used for skin replacement, including temporary wound cover for burns, and treatment for diabetic leg and foot ulcers. (NIH 2015) Apligraf (Organogenesis, Inc.) uses an advanced tissue engineered skin construct that is FDA approved for treatment of venous stasis leg ulcers and diabetic foot ulcers. Regenerative medicine is also responsible for tissue-engineered bladder derived from a patient’s own cells. This can be grown outside the body and successfully transplanted (NIH 2015).

NEUROLOGICAL RESEARCH
The Center for Disease Control (CDC) reports that more than 16 million people in the United States are living with cognitive impairment (CDC, date? add citation to bib). Cognitive impairment can range from mild to severe. Cognitive decline can be the result of age-related degenerative processes. Other risk factors include blunt force or repeated head injuries from sports-related head trauma, motor vehicle accidents, and stroke. Data reveal that many individuals with a brain injury cognitively or physically deteriorate at a faster rate and appear years older than their chronological age (Ripley et al., 2010). There is increased risk of Alzheimer’s disease at an earlier age, leading to loss of independence earlier than with the average person (Alzheimer’s Association, 2015; Ripley et al., 2010; Fleminger et al., 2003)

Culturing heart muscle cells results only in heart cells; liver cells can only make more liver cells, and so forth. Stem cell research to date has focused on embryonic, fetal, amniotic, umbilical cord blood and adult stem cells as sources for generating multiple useful cell types. Pluripotent stem cells, however, can differentiate into nerve cells, and provide a platform for axonal overgrowth to create a neural connection between cells.

Various protocols using adult stem cells for neurological disorders are ongoing. The Miami Stem Cell Treatment Center, under the medical direction of Nia Smyrniotis MD, medical director, and Thomas Gionis MD, surgeon in chief, offers various protocols for neurological disorders including stroke, cognitive impairment and other degenerative neurological diseases in which stem cells are administered. They have published research indicating that adult stem cell therapy can, in some cases, prevent, retard, and even reverse degenerative processes that cause cognitive impairments. (http://miamistemcellusa.com)

The repair of injured neuronal tissue in the central nervous system has been considered to be impossible. Stem cell transplantation, however, has provided hope that the damaged neurons may be repaired. (F. Wang, 2013) Neural stem cells are thought to be an optimal source for the treatment of neurological disorders because of their potential to differentiate into cells of glial and neuronal lineage. The problem is, neural stem cells are relatively difficult to isolate and prepare, which has been a major obstacle to the advancement of neural stem cell clinical application (Wang 2013).

While there is no evidence yet that stem cells can repair chronically damaged spinal cord tissue, clinical trials focusing on human embryonic and human fetal stem cells for cervical or thoracic spinal injuries are underway. Readers can find updated information at Stem Cells, Inc., Asterias Biotherapeutics (Geron), or ClinicalTrials.gov. Currently, MSC-based clinical trials are being conducted for CNS disease throughout the world. In stroke patients, the feasibility and safety of autologous transplantation of human MSCs that had been expanded in autologous human serum has been...
reported. One week after MSC infusion, the mean lesion volume was reduced by 20% (F. Wang 2013). Research is also being done on those with cerebral palsy to reduce the size of the lesion in the brain.

As a caution, an October 23, 2014 presentation of the Miami Stem Cell treatment Center by Dr. Kim Anderson-Erisman, Break Through Stem-Cell Therapies for Spinal Cord Injuries, she cautioned the audience on “stem cell tourism.” Unfortunately, she noted, as with any new treatments for serious conditions, there are some unorthodox organizations that will sell hope for money. Careful research is important before any treatment protocol is planned.

CONCLUSION
More clinical studies are needed to determine the efficacy and durability of adult stem cells not only in disorders involving the central nervous system but also diabetes, cardiac, pulmonary, ophthalmic diseases, other orthopedic uses, and many other disorders.

Programs in approximately 21 states across the country, many with multiple locations, are currently conducting research for possible stem cell therapy applications in neurological disorders, age-related functional defects, hematopoietic and immune system disorders, heart failure, chronic liver injuries, diabetes, muscular, skin, lung, eye, and digestive disorders. Visit http://www.stemcellrevolution.com for a location near you and to learn more about the different areas of research.

REFERENCES
Stedman’s Medical Dictionary for Health Professionals and Nursing (2012), Lippincott Williams & Wilkins

OTHER RESOURCES
2009
IX.1 MSA
IX.2 SCI
IX.3 Preconference
IX.4 Amputation

2010
X.1 Pediatric CP
X.2 Elder LCP
X.3 Preconference / Multitrauma
X.4 Tools for NLCP

2011
XI.1 Adaptive Technology
XI.2 Recreation and VOC in NLCP
XI.3 Preconference / Burns
XI.4 Chronic Pain

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 Transplants
XV.2 Spinal Cord Injury Updates
XV.3 Burns Updates
XV.4 Perinatal Injury

2016
XVI.1 Pediatric LCP
XVI.2 Gastrointestinal
XVI.3 Hematology/Oncology
XVI.4 International Life Care Planning

2017
XVI.1
XVI.2
XVI.3
XVI.4
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