ISHLT ANNOUNCEMENTS

THE LINKS NEWSLETTER IS NOW WEB-BASED!
Susie Newton
ISHLT Links Managing Editor

Out with the old, and in with the new! Beginning with the 2012 January inaugural issue, the ISHLT Links Newsletter is now completely web-based. Each article can now be viewed in your browser window, on your smart phone, on your iPad, your Kindle, Nook or whatever technology you are lucky enough to own. Browse the articles "IN THIS ISSUE" which are specific to each month's focus, or explore the Alerts, Announcements, Reports, Quotable Quotes, Editors' Recommendations, and Sticky Links buttons for more news and fresh ideas. We value your feedback so please feel free to email me with any questions. Here's hoping that with a new year before us, we now have yet another way to stay Linked.

USA VAD REMOVAL - CHANGES IN REIMBURSEMENT
Effective Jan. 1, 2012, the physician payment policy in the United States for Ventricular Assist Device removal procedures will change. Payment values will be reduced and no longer include reimbursement for in-hospital and out-patient evaluation and management services. Payments could be reduced dramatically - up to 30 percent - unless you prepare for this change.

If you do VAD procedures, you are providing a substantial amount of critical care as well as in-patient and out-patient care, which are currently reimbursed automatically. After Jan. 1, 2012, however, those services must be processed in an itemized fashion for each patient. Accurate documentation of services provided requires surgical insight and is the surgeon's responsibility, and accurate documentation is critical for correct coding and ultimately correct reimbursement. Interested individuals should contact The Society of Thoracic Surgeons for more information about these changes.

ISHLT is planning to conduct an educational session at the Annual Meeting in April in Prague regarding these changes as well as device-related payment issues in other countries. Look for more information on this session in early 2012.

REGISTER FOR THE 32ND ANNUAL MEETING & SCIENTIFIC SESSIONS and the ISHLT ACADEMY: CORE COMPETENCIES IN MECHANICAL CIRCULATORY SUPPORT

Registration is OPEN for both meetings, which will be held in April 2012 in Prague, Czech Republic. Annual Meeting info: http://www.ishlt.org/meetings/annualMeeting.asp. Academy info: http://www.ishlt.org/meetings/ishltAcademy.asp.
ISHLT MEMBERS IN THE NEWS
If you or a member colleague has received a recognition, award, or something newsworthy, please email us and we'll publish it in the next Links Newsletter! Send your announcement(s) to Susie Newton.

CALL FOR NOMINATIONS TO ISHLT BOARD OF DIRECTORS and APPLICATIONS FOR TRANSPLANT REGISTRY MEDICAL DIRECTOR
Look for emails in early-to-mid January calling for nominations to the ISHLT Board of Directors as well as applications for the position of Transplant Registry Medical Director. Details coming very soon.

2012 ISHLT GRANTS AND AWARDS PROGRAM

GENERAL INFORMATION:
The 2012 ISHLT Grants and Awards applications are online. For general information, funding stipulations, award policies, grant applications and instructions, please visit us on the web: http://www.ishlt.org/awards/applications.asp.

AWARD CATEGORIES AVAILABLE THIS YEAR:
RESEARCH FELLOWSHIP AWARDS are awarded annually in the amount of $40,000.

BRANISLAV RADOVANCEVIC MEMORIAL FELLOWSHIP AWARD, to encourage scholarly clinical work in mechanical circulatory support in emerging countries, is awarded annually in the amount of $75,000.

NORMAN E. SHUMWAY CAREER DEVELOPMENT AWARD is awarded every other year in the amount of $80,000 (available in 2012).

NURSING & SOCIAL SCIENCES RESEARCH GRANT AWARD is awarded annually in the amount of $12,000.

TRANSPLANT REGISTRY EARLY CAREER AWARD is awarded annually in the amount of $5,000.

INTERNATIONAL TRAVELLING SCHOLARSHIP AWARD has two submission dates annually: August 1st and December 1st.

Grants will be awarded at the ISHLT 32nd Annual Meeting and Scientific Sessions April 18-21, 2012 in Prague, Czech Republic.
The Nursing, Health Science and Allied Health (NHSAH) Council is well on its way to meeting the new year’s resolutions set out last April during the annual council meeting. Led by Nancy Blumenthal (Chair-USA), Annemarie Kaan (Vice Chair-CAN) and Bernice Coleman (Immediate Past-Chair-USA), the council’s many task forces have been fortified by the addition of nearly twice the number of nurses, social workers, social scientists and therapists who have gotten involved with the council activities. Over the past 8 months, each of the task forces has met via teleconference, to connect members from around the globe in the pursuit of enriching the ISHLT membership experience for our constituents.

Having reviewed participant feedback from annual meetings over the last several years, the Education Workforce led by Michael Petty (USA) advised the NHSAH Program Committee Representatives, Annette DeVito-Dabbs (USA) and Bronwyn Levvey (AUS). The result of their collaboration is self-evident in a conference agenda that is rich with content pertinent to NHSAH members. As in 2011, the 2012 Annual Meeting has been granted Continuing Education Points for Transplant Certification (CEPTC) provider status by the American Board for Transplant Certification. Up to 28 CEPTCs will be awarded to certified nurses attending the **32nd Annual Meeting & Scientific Sessions** in Prague this year!

In a joint effort with Education Workforce, the Development Workforce led by Arzellra Walters (USA) has been brainstorming methods of meeting members’ needs for continuing education between the annual meetings. This workforce has submitted proposals to the ISHLT board describing the use of technology for reaching members who are unable to attend the annual meetings. Eager to extend the benefits of ISHLT membership to as many colleagues as possible, this workforce is engaged in pursuing collaboration with other professional societies.

The initiative with most immediate gratification has come from the Communications Workforce led by Bronwyn Levvey and Alison Amegatcher (USA). A Google Group dedicated to online networking, information exchange, and peer support for members of our council was developed early this Fall. A secure, members-only (i.e., not google-able to the public!) venue, we are anticipating the group will connect our members in discussing the many challenges of our clinical and academic. Please join the NHSAH google group by sending an email to nursing-ishlt@googlegroups.com.
The Grants and Award task force, led by Judy Currey (AUS) and Annette DeVito-Dabbs is pleased to accept, for the second year, an unrestricted grant for $12,000 from CSL Behring to the NHSAH Council. This is in addition to the $12,000 Nursing and Social Science Research Grant offered to eligible ISHLT members. For more information, see the 2012 Grants and Awards Announcement in this newsletter.

Keen to support the Council infrastructure, the Standards and Guidelines Workforce led by Connie White-Williams(USA) has endeavored to develop a proposal for a future Transplant Academy dedicated to psychosocial issues commonplace in the thoracic organ failure and transplantation. Support has been given to improve the membership communication database, as well. During the 2012 Annual Meeting in Prague, we can look forward to hearing Bernice Coleman report on the consensus findings from last year’s Crucial Conversations in Thoracic Transplant Nursing. Through efforts of Annette DeVito-Dabbs, this group has continued the development of a mentorship program for those members seeking professional guidance in developing their research process or clinical role.

Boasting a varied membership, the NHSAH Council has ambitious plans for the year. We are excited about the progress that has been made toward our new year’s resolutions and are very eager to welcome the contribution of members who have, heretofore, been reticent. There are so many ways to get involved in Council activities. What a great way to ensure the ISHLT is working for you! Cheers to one and all for a happy, healthy, exciting 2012!
On Teaching and Learning

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Teaching is essential for a civilized society and is one of the most fundamental of all human activities. Enormous amounts of accumulated knowledge, history and heritage must be passed from generation to generation informally and formally. As parents, mentors, doctors and other health care providers we all serve as teachers for our families, communities, for the ISHLT, for each other and our patients. At the other end of the “pendulum,” while teaching we are learning. The opportunity to teach improves our ability to be a better learner or student. The one who learns the most while sharing knowledge is the teacher.

I will kick off this New Year Issue with a special dedication and devotion on how to best pass on such valuable information for all to attempt to make the right or best-informed decision. Now, I use the phrase pass on, which in health care at times we wrongly intend to mean to die. However in this issue and most prior issues it is all about communication. So when a patient is dying or has died, the patient is not passing, has passed or has passed on – we need to drop these “vague” and “passing” terms from our vocabulary. Many have died before any of us were conceived and all of us will be dead one day. Again, I digress.

So what are the essential qualities of a good teacher? Self-control, self-improvement, and hard work rank among the most important attributes of a good teacher. But different topics require different teaching approaches; one size does not fit all. Regardless the goal is to transform callow students into intellectually self-confident adults. We are all at various stages of our careers. Us gray-heads are probably more set in our ways, have “conventional wisdom,” and possess self-control (probably from exhaustion for prior endless battles that have ended in a draw). Our newbies, younger crowds still have unbridled enthusiasm that is probably best tempered by us gray-haired curmudgeons. A clash must occur with some sort of consensus that will yield what may be best for all. Otherwise, either we become stuck and set in our ways, or we progress down some blind alley without guidance or the dreaded path of reinventing the wheel, again. History does repeat itself for human behavior remains unchanging. Despite the young vs. old differences, raw vs. refined, or intemperate vs. temperate, there are surprising similarities that help us define a “good” teacher.

Every teacher must be a dedicated learner and cultivate effective learning habits. Good teachers constantly push themselves beyond comfort zones and avoid the temptation of procrastination. As great educators we must welcome new experiences and come to grips with
new ideas. We have a great capacity to learn, but we must learn how to take advantage of it. We have to educate ourselves, have the willingness to do so and keep our inquisitiveness alive.

Education has expanded to take up more years of our lives as we continue to advance. In reality, education is lifelong and never ending. The goal of the Western World has been to achieve universal literacy. On the other side of the pendulum or spectrum, we might be regressing, not advancing. Nevertheless, the internet, cell phone activity, instant messaging, and texting keep us plugged-in wirelessly and tirelessly with constant communication to the frenzy of an incessant need of everyone updating each other from I'm awake, I'm asleep, I'm bored to I'm in the bathroom, washroom or loo.

This has set the stage of potential rapid pace innovation which also will create different educational challenges. Are we headed to information overload? Is the side effect impatience? Not everyone deserves an “A.” There are always winners and losers, but take note of this side effect: http://www.youtube.com/watch?v=OAOrT0OcHh0.

In the process we just can’t “pass on” knowledge; on the contrary, the mark or “tell-tale sign” of a good teacher is to help others think critically, primarily because specific knowledge will become obsolete. Along with critical thinking, a drive of self-improvement and willingness to accept criticism are probably the three most essential attributes for teachers to instill in learners. Can we teach drive and the willingness of others to accept just criticism?

To drive many of these points we need to be impressive, theatrical, and memorable. In the process, we need to help everyone we influence to keep our goals and their goals in view. When teaching, presenting your poster, delivering your lecture, or writing your paper you should ask yourself, what do I want the intended listeners or learners to know five years from now? That question will help us hone in on the important issues ... set your goals. With this in mind, the preparation and delivery of your message hopefully will help us achieve a “teacher’s high” allowing us to improve our practice and inspiring us to teach effectively with greater self-awareness. The capacity for self-criticism is essential for professional improvement.

Teaching and learning never cease but can be delayed. The greatest pitfall to effective education is to guard against the temptation of laziness and procrastination. We must develop our own willingness to learn and preach what we practice as we show others the way, practice what we preach, especially persistence and drive. It is a struggle to open ourselves to new ideas, then it becomes easy not to especially when it is difficult. We pursue the easy road and up ahead is the pit. Think how often we procrastinate. Think how gratifying it is when we don’t.
We can easily do all the work as long as we don’t procrastinate, the constant temptation. It does feel great at the time we procrastinate, and then it feels awful later because we have to do the work to meet the deadline in a rush. We have to persist and drive through this temptation, probably the single most important lesson of all to be a great teacher. Letting up is an early sign of laziness. We do not need to be the enabler of procrastination, although it is much easier.

Bottom line—clear communication, diligence and energetic teaching are vital components for any endeavor. The annual ISHLT meeting provides a comfortable and exciting venue for our own continuing education so we can take back what we have learned to our institutions and bedsides. With the new knowledge, don’t ever think you know enough. Lifelong learners resist that feeling, even if it threatens our sense of professional mastery. Also, recognize that there is no limit to how much we can learn. Learning is cumulative and our capacity to learn expands as we accumulate more knowledge. Finally, the initiative comes from within and links the past with the present to better prepare our future forever more and not just nevermore. Perhaps I’ve said enough.

**Disclosure Statement:**
The author has no conflicts of interest to disclose.
January 2012 Quotable Quotes

"Exercise is a dirty word. Every time I say it, I wash my mouth out with chocolate." – Charles M. Schulz

"Sure, I watch my weight. It's right here in front where I can keep an eye on it." – Anonymous

"Whenever I feel blue, I start breathing again." – L. Frank Baum

"None of us is as smart as all of us." – Japanese Proverb

How we teach is what we teach.

Asking questions through case studies or case-based methods of teaching is important for critical thinking.

"Never leave that till tomorrow which you can do today." – Benjamin Franklin

"After all ... tomorrow is another day." – Scarlett O'Hara (last line in Gone with the Wind)

"Never put off till tomorrow what you can do the day after tomorrow just as well." – Mark Twain

You never get a second chance to make a first impression.

“The time to begin writing an article is when you have finished it to your own satisfaction. By that time you begin to clearly and logically perceive what it is that you really want to say.” - Mark Twain

“It is sheer laziness not compressing thought into reasonable space.” - Winston Churchill

From Abraham Lincoln:
“In reference to patience, nothing valuable was ever lost by taking time.”
“We dare not disregard the lessons of experience.”
Evidence based practice is the process by which nurses and allied health professionals make clinical decisions based on the best and latest evidence, clinical expertise, and patient values. So, why don’t we ring in more evidence for the New Year? This task requires the retrieval of available research published in our field which allows practice change to be based on evidence. Consequently, nurses and allied health professionals should have 2 New Year’s resolutions on their “to do” list: 1) To publish research on the care of pre- and post-transplant and mechanical circulatory support device patients, and 2) To find evidence in the literature to support best clinical practice.

The Centers for Medicare Service (CMS) have provided guidelines and standards for transplant professionals. CMS requires nurses, pharmacists, and dieticians to have initial training and ongoing education to maintain the most current and best evidence based practices in transplant care. The clinical transplant coordinator, pharmacist, dietian and others must be involved in all phases of transplant care. Consequently, knowledge and understanding of the definitions and processes of evidence based practice along with how they are different from initiatives such as quality improvement and research are important to transplant nursing and allied health professionals.

There are several models of evidence based practice including the Advancing Research and Clinical Practice through Close Collaboration (ARCC) model. This model has seven steps: cultivating the spirit of inquiry, asking the burning question, searching the literature, appraising the literature, integrating the change into practice, evaluating the outcomes, and disseminating the results. The steps of the EBP process begin with generating inquiry. Issues surrounding multidisciplinary care or the patient population arise every day in transplantation. For instance, in transplant patients, is individual teaching compared to group discharge teaching more effective in decreasing hospital readmissions after surgery? What is best practice for adherence to the medical regimen before and after transplantation? These questions could be raised by the nurse, dietician, pharmacist, physical therapist or social worker.
Research is the systematic inquiry which is specifically designed to develop, refine, and extend nursing and allied knowledge. The intent of nursing research is to answer questions and develop knowledge using a scientific method such as quantitative, qualitative, or mixed methods. In other words, research is the generation of new information which nurses and allied health professionals use to formulate evidence and translate into practice.

Quality improvement is the data driven systematic approach by which individuals work together to improve internal systems, processes, costs, productivity and quality outcomes within an organization. An example of a quality improvement model is the plan, do, check, act or PDCA process.

Evidence based practice provides transplant nurses and allied health professionals with the most current and best evidence to practice. There are challenges to incorporating EBP into the infrastructure of transplant programs. Education, time, and administrative support are a few. It is imperative that transplant programs support individuals to utilize evidence based practice and research in their practice. Ultimately, practicing best practice will empower nurses and allied health professionals to provide quality care leading to best patient outcomes. Several institutions have held workshops or seminars teaching nurses and allied health professionals skills they need for integrating evidence based practice and research into their clinical practice. Organizations such as the International Transplant Nurses Society and International Society of Heart and Lung Transplantation have held special sessions on conducting research or translating research into practice during their annual meetings. Time is by far the most challenging barrier. Transplant professionals must carve time to participate in activities promoting the education and implementation of evidence based practice.

The future of transplant nursing and allied health professionals is placed on the individual and the infrastructure of the transplant program. While current barriers exist, professionals must take the initiative to learn the process of evidence based practice and participate in research. Transplant nurses must talk with administrators concerning time to examine best practice, and review existing evidence guidelines. Further research is needed to examine the needs of transplant professionals to facilitate evidence based practice and research into clinical practice. Educators must assure evidence based practice and research concepts are introduced at the undergraduate level. This provides transplant nursing and allied health professionals with great opportunities to examine specific perceptions, knowledge, and barriers within the field of transplantation. Most importantly, transplant nurses and allied health professionals must publish evidence based practice nursing care for patients who are waiting for transplant or have undergone transplantation. Indeed, much education and work is to be done regarding evidence based practice and research in the field of transplant nursing and allied health. This challenge is a great way to start off the New Year.
Excerpts from this piece have been published in White-Williams, C. Evidence Based Practice and Research: The Challenge of Transplant Nursing. Progress in Transplantation, Vol. 21, No 4 December 2011.

Conflict of Interest Disclosure Statement:
The author has no conflicts of interest to disclose.
In years past, I have often shunned the covenants to self, those so-called “resolutions,” that without fail have always left me feeling guilty, defeated, and craving whichever vices I have vowed to give up. But unlike years past, 2012 marks the beginning of a resolve that goes beyond kicking my own personal bad habits. This year is about prioritizing the health and nutrition status of my adult acute care patients. Much like a new year, one’s health and nutrition will often be what is made of it, and the heart and lung transplant patient population is no different. With appropriate guidance and fresh, creative takes on diet and nutrition, both pre- and post-transplant individuals may find themselves with a renewed sense of commitment and determination to maintain compliance with their dietary specifications.

While a comprehensive nutrition evaluation is helpful among any group, for the chronically ill and sometimes frequently hospitalized transplant service patients, a thorough dietary assessment and nutrition care plan is a necessary facet of care. Though the nutritional needs can vary as much their symptoms, transplant patients at risk for malnutrition often present as one of two extremes: underweight or obese.

Designated by a BMI ≤18.5 kg/m2, the underweight patient is often found to have a greater incidence of poor outcomes including abnormal immune function, muscle atrophy, impaired wound healing, increased length of stay and mortality. While weight gain, increases in lean body mass, and improvements in visceral protein status are the obvious goals for these nutrient deficient individuals, identifying manageable solutions for their struggles is the real challenge.

Upon initial assessment, tell-tale signs of suboptimal diet history emerge with patient reports of “poor appetite,” “unintentional weight loss,” and “altered taste,” all commonly occurring as a result of medication regimens, fluid gains, and GI disturbances. In the clinical setting, obtaining a brief diet recall will open doors to educate patients about possible areas of improvement in their diets- a lower sodium diet for the fast food-aholic, tips on curbing thirst for the volume overloaded, and examples of protein-rich foods for the protein-calorie malnourished. Spend time finding out your patient’s food preferences, and use that as a baseline to build a modified diet. Set up taste tests with appropriate oral supplements and allow them their own choice, remembering that taste buds can change and some individuals will need variety.

(Side note: Remember that what works for one patient may not work for the next. I can recall feeling terrible one afternoon when a CF patient of mine explained to me that she couldn’t tolerate the taste of vanilla-flavored supplements anymore because they so resembled the odor of the gas that came up in the mornings after receiving nocturnal tube feedings. Can you imagine being force-fed something that reminded you of that?) Stress the big picture value of consuming adequate protein and calories, explaining to the patient with a poor appetite the importance of filling up on nutrient-dense items like lean meats, dairy, and whole grains first. And finally, always liberalize when medically able. Encouraging a patient who is 60% IBW to eat more protein-rich foods won’t go too far if their cardiac prudent diet prohibits them from a variety of meat and dairy choices; sometimes picking the lesser of two evils is necessary in order to maximize a patient’s nutrient intake, at least until adequate intake is established and weight is within normal limits.
At the other end of this spectrum are the obese who, with a BMI ≥ 30, are at increased risk of morbidity and mortality. When assessing this group, obtaining an accurate weight history is helpful in determining their true nutrition status. For example, a male with a BMI of 40, consistent weight gain over five years, and excessive eating habits will require a much different type of nutrition therapy than a weight- and height-matched individual who has experienced unintentional weight loss of 85 pounds over a three month period of time. Much more information can be derived from talking to a patient about their history, so personal communication is the first step toward improved outcomes.

An obese patient who is pre-transplant will almost always benefit from healthy, monitored weight loss prior to transplant and are then less likely to experience an adverse event during/after surgery. Find out first how they got to their current weight—physical inactivity, emotional eating, or financial constraints that left them limited to purchasing high fat, high sugar convenience foods—and help them to understand how their weight is affecting their health. *(You would be stunned to know how often I look into the eyes of a bewildered CHF patient who can’t believe that his heavy salt-shaking hand and potato chip addiction has contributed to the 15 pounds of fluid sitting on his belly!)* Next, find out what motivates that patient—whether it be getting an organ transplant or making it out of the hospital to see their grandkid’s piano recital—and use that to stimulate their desire for weight management. Set short-term, attainable goals, designed to be achieved over time to ensure that weight is lost appropriately and in such a way that will not cause them further harm.

Once post-transplant, weight control is imperative in controlling co-morbidities like diabetes, hyperlipidemia, hypertension, osteoporosis, and infection. Excessive weight gain after transplant increases risk of rejection and decreases rate of survival, thus nutrition intervention requires individualized care, combining disease specific diet restrictions with the provision of ample calories and protein. Management of symptoms like nausea, pain, constipation, and diarrhea often results in increased energy and appetite, enhancing the willingness of patients to participate in post-operative nutrition therapies. Comprehensive education, followed by patient participation in setting their own dietary goals, improves long-term compliance and imparts a tremendous sense of pride for patients who succeed in accomplishing their objectives.

Unlike personal New Year’s goals that so easily dwindle to oblivion, improving the nutrition status of transplant patients is one resolution that is worth keeping. This is a New Year’s resolution in which we all share in the success.

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'Tis the season!’ Or shall I say, ‘Tis the season that just passed, the season of holiday parties, presents, time spent with family, and the joy of it all. It is also the season of eating too much, stress, gaining weight, and falling out of our normal everyday routines. It is no surprise that after two months of holidays, a majority of people make New Year’s Resolutions. Maybe you promise to go to the gym more, change your routine, eat healthier, or get in shape! Did you ever notice that for the month of January the gym is packed? There are more people in the class you want to take, and the vegetable aisle in the supermarket seems extra crowded. But what if you had to make a resolution or come up with a routine that you could not give up? What if failure was not an option? What if you had a chronic illness, like cystic fibrosis (CF), and your routine was the matter of life or death? Would you be able to stick with it?

My medical routine has been ingrained in me from a very early age. In fact, my routine and medical regimen is what made me realize for the first time that I was different from my peers. I distinctly remember one summer day playing kickball with my friends in the front yard. From the front door, my mother called out for me to come inside to do my treatments. It made me wonder ... why did I have to go inside—when everyone else was playing—and sit down for a half hour inhaling nebulizers with my parents pounding on my back? Did anyone else my age have to do this? My parents took these opportunities to explain to me how important it was to my lungs and my overall health that I always maintain the medical routine they taught me throughout the years.

My medical routine evolved over the years and fluctuated with the state of my health. Usually I did chest physical therapy (CPT) twice a day. This encompassed doing 30 minutes of inhaled medications to open my airways, followed by “pounding” on the lobes of my lungs to loosen the thick and sticky mucus clogging my airways. This was usually done before school in the morning and before bed after I completed my homework or activities for the day. As I grew older and more inhaled medications came to the market for treatment of CF, my CPT routine became even longer. With the addition of TOBI and DNase, my inhaled medications could take from 45 minutes to an hour to complete. Eventually my parents no longer needed to physically pound on my lobes as I started using “The Vest”. I would wear this contraption for another thirty minutes while it vibrated, shaking my whole body, and in turn shaking the mucus loose from my lungs.

That was only just one very important part of my CF medical routine. I had my own personal pharmacy in my bathroom—pills that I needed to remember to take every day. Vitamins, minerals, calcium, and nasal sprays all helped to keep infection at bay and replace all of the nutrients my CF body did not absorb. I also needed to remember to take pills with every meal, even little snacks. Once CF began to progress and I was no longer gaining weight on my own, my routine evolved once again. A feeding tube was placed which meant that now, every night before I went to bed, I had to fill up the feeding tube bag and prepare the night’s feeding. The formula made me nauseous, but this part of my medical regimen was essential for me to gain weight. As much as I hated the feeding tube, I did this religiously every night since I knew I was getting extra nutrients and was better able to fight off infections.
Shortly after I started the feeding tube, I was tested for Cystic Fibrosis Related Diabetes (CFRD). It was determined that I was borderline CFRD so yet again, my routine evolved. Now, before I made the nightly feeding, I had to check my blood sugar and cover for the overload of carbohydrates during the night.

Exercise was also an important part of my medical routine and should be for every CF patient. Exercise was never my strength as I hated coughing in front of people that I didn’t know. I felt as if everyone was always wondering what type of horrible cold I had. After I stopped playing soccer, my exercise routine was definitely lacking. I also needed to eat extra food in order to keep weight on my already small frame. My body did not absorb calories and nutrients correctly so I needed to eat extra calories to gain weight. During the day I tried to make my food as fattening as possible and even fit in a high calorie shake when I could.

On top of my daily routine, I also had doctor appointments every three months. There were blood tests, growth charts, and pulmonary function tests galore. Most of the time my routine doctor appointments were stable, but sometimes they returned bad news. If my pulmonary function tests were declining, it usually meant checking into the hospital for a “clean out”. A “clean out” is CF-speak for two weeks of IV antibiotics. Usually the IV clean out started in the hospital and finished with home care. So now, on top of the normal medical routine, IV medications were administered in evenly spaced eight hour intervals.

After this full day of my medical routine, as well as all of the visits to the doctor’s office, I still needed eight hours of sleep in order to just make it through my day. Everything that was added to my routine over the years pushed my bedtime later and later and made my wake-up call even earlier in the morning. It was no wonder that sometimes I fell asleep during my classes in school. It is exhausting even thinking about this routine today. Somehow, I managed to get A’s in high school, participate in extra-curricular activities, complete my homework on time, and get accepted into a great college.

My medical routine was such a part of me that I did not know anything different growing up. My parents and sister were a great support, helping me stay on top of my routine in addition to all of the normal responsibilities of growing up. I figured out how to use CPT time to get my homework done, or read, or even watch movies with my family. Although it was a huge time drain, and I was usually tired, I knew how important it was for me to stick to it. I did not mind my routine simply because I knew it was keeping me alive.

I didn’t start to mind my medical routine until it didn’t really work anymore. My CF eventually progressed so much that I was in the end stage and needed a transplant. My CPT was no longer efficiently clearing the mucus out of my lungs. They were in such bad shape that my routine was overbearing. I had to wear oxygen full time and normal everyday tasks became almost impossible for me to complete. The feeding tube, which had stopped putting weight on me, was simply just keeping me alive. At 21 years old, 83 pounds, and with only 20% lung function left, I was lucky enough to receive a double lung transplant and, as a result, the routine I had gotten used to once again changed.

I remember the anxiety surrounding getting my transplant. This was a completely unfamiliar routine. Would I understand when my body was sick and I needed to call the doctor? Would I remember to take all of my medications? Would I be able to take care of myself? Would I see results again by sticking to my new medical routine?
**My medical routine** to care for my new lungs was vastly different than my CF routine. There was no longer a need to do CPT since there was no mucous in my lungs. I never used my feeding tube again since my body was absorbing more of the nutrients and calories from the food I was eating. I did, however, have to take twice as many medications to keep my body from rejecting my new lungs. Three times a day, I had to take upwards of 30 pills. My digestive system had taken a hit and now instead of one or two enzymes with meals, I was up to five. My “borderline CFRD” quickly became full blown. With the prednisone, my blood sugar was out of control, needing to be checked five times a day to keep it stable.

Adopting an active lifestyle also became a normal part of **my medical routine.** After my rehab sessions were over, it was up to me to adopt an exercise routine to keep my new lungs working and healthy. My dedication to the gym was something that I was not used to with my CF routine. Now, I needed to find a love for working out and go to the gym for at least an hour a day for an intense physical workout. In addition, my sinus polyps started growing out of control making it difficult to breathe through my nose. I needed more nasal sprays and an irrigation routine to keep my sinuses clear and me breathing easy.

Just like my CF routine, my transplant medical routine has evolved over the years. Even with working full time, I always need to ensure that **my medical routine** comes first. My medicines for the week are neatly organized into pill containers every other week. I take my medications and check my blood sugar at the same time every day, regardless if I have a work meeting, deadline, or social event. My nasal irrigation and sprays are waiting for me in the medical cabinet in the morning. Because exercise is one of the most important factors in keeping my lungs healthy, I get in a vigorous workout either before work or after work depending on my schedule. It was the dedication to my exercise routine that allowed me to gain enough strength in my muscles and my lungs to run a half marathon after my transplant.

After my transplant, not only do I have to take double the medications, but I have double the doctor appointments. Somehow, I need to fit in all of my appointments every three months with blood work every six to eight weeks to monitor my medication levels. This includes my endocrinologist, my transplant team, the otolaryngologist, the gynecological oncologist, and the ophthalmologist. I see some of my doctors more than I see my own family!

**My medical routine** is not easy and, sometimes, it’s downright draining. However, for someone like me with a chronic illness, failure at my routine is not an option. **Compliance is the only way to a healthy existence post-transplant.** Even during busy and stressful times like the holidays, my medical routine must come first. After all, it is maintaining the routine that affords me my health, which means I am well enough to participate in holiday events. So even though sometimes I might not want to go to that doctor appointment, or get that blood work, or take that pill, I think about my organ donor and how lucky I am to not only be alive but to have an amazing quality of life. Those negative thoughts leave my head when I realize, as I always do, how lucky I am to be able to exercise, and go to the doctor, and take those pills, because if I can do all of that—it means that I am alive and healthy.

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The author has no conflicts of interest to disclose.
On April 12, 2011 at the International Society of Heart and Lung Transplantation (ISHLT) Annual Meeting and Scientific Sessions in San Diego, California, an unprecedented consensus conference occurred, titled, "Crucial Conversations in Thoracic Transplant Nursing." This conference was sponsored by the ISHLT and Cedars-Sinai Medical Center Heart Institute, Los Angeles, California. The conference was chaired by Berni Coleman (USA), with co-chairs Nancy Blumenthal (USA), Judy Currey (Australia), Fabienne Dobbels (Belgium) and Angela Velleca (USA), in conjunction with conference advisors John Dark, MD (United Kingdom) and Jon Kobashigawa, MD (USA).

The conversations that occurred addressed many of the recurrent questions which have been discussed over the years by members of the Nursing Health Science and Allied Health council membership (NHSAH). How often have transplant nurses (coordinators, advance practice nurses and managers) discussed staffing mix and ratios, professional educational requirements, roles and responsibilities? One often wonders what colleagues from other programs are doing. How do they manage workloads, clinical responsibilities, and further education? How are their programs staffed? How are the coordinator and Advanced Practice Nurse roles within the context of a transplant program integrated? Importantly, do they also feel the pressures of balancing work, home and profession? Are these same questions being pondered in other countries?

Seventy-seven highly experienced transplant nurses were invited to the Transplant Nursing Consensus Conference from a combination of small, medium and large transplant programs across the globe. Attendants of the conference represented 12 countries; Australia, Austria, Belgium, Canada, Germany, Italy, Japan, New Zealand, Norway, Spain, United Kingdom and United States. Nurses were asked to complete an online survey prior to the conference; 57% responded. The conference format consisted of State of the Science talks on key issues, followed by presentations of Models of Care at various sized transplant centers representative of programs in Australia, Germany, United Kingdom and United States. An international mix of participants began afternoon discussions in four small groups to prepare for the final discussion in late afternoon. The aim was to reach a consensus on issues central to transplant nursing practice.

Connie Williams, PhD, RN, FAAN, presented the morning session on Education, License & Certification—Setting Standards for Transplant Nursing. Her remarks were anchored in the Institute of Medicine, Committee on the Robert Wood Johnson Foundation Initiative on the Future of Nursing: Leading Change and Advancing Health. Dr Williams applied the key messages of this report to Transplant Nursing. The issues she explored included: how will nurses practice to the full extent of their education and training; how will nurses achieve higher level of education in transplant nursing; how will transplant nurses achieve the recommendation of 80 percent baccalaureate degrees by 2020; and what should be the entry level of education for transplant coordinators and Advance Practice Nurses?

Kathy Grady APN, PhD, FAAN, discussed the topic, Recruitment and Retention Strategies for Maintenance of Quality Transplant Nursing Staff. She presented literature on factors that affect transplant coordinators’ recruitment and retention, nurse staffing and quality patient care. Dr. Grady pointed
out the impact of the tension related to blurred boundaries in nursing and lack of standardized educational preparations. Two perspectives on the impact of blurred nursing boundaries were presented. Cathy Murks Ph.D., ANP-BC, described the challenges of ill-defined nursing boundaries in the United States. She presented a model visually describing the overlap between the registered nurses, nurse practitioners, clinical nurse specialists and physician assistants working in transplantation. The focus of this talk teased out the drivers that contribute to the overlap of roles and responsibilities of transplant clinicians. A European perspective on nursing roles and responsibilities in transplantation was presented by Christiane Kugler, Ph.D. The presenter interviewed nurses (clinical nurses, advance practice nurses and recipient nurse coordinators) from 10 centers representative of Belgium, Germany, Italy, The Netherlands and United Kingdom. Across these countries, respondents reported lack of clarity in transplant nursing role definition. Outside of the United States, it seems our colleagues also feel that there is need for consensus regarding licensure, educational preparation and scope of practice.

To round out the morning talks, a presentation by Linda Ohler MSN, RN, CCTC, FAAN discussed *Staffing Benchmarks: What is the Optimal Composition of a Transplant Program?* Reviews of current transplant models for inpatient and outpatient total hours of nursing for patient care were discussed. The pros and cons of current staffing models were outlined. In the end, the presenter recommendations were: 1) Standardize the role definitions of transplant staff; 2) Develop strategies to link staffing to outcomes; and 3) Develop centralized systems to collect data to validate / benchmark staffing data for transplant centers.

After a provocative morning of discussions, participants retreated to small groups to discuss issues such as:

- What are the minimal core competencies of heart/lung transplant nurse professionals?
- What should be the minimal academic level for entry into transplant nursing?
- What roles should RNs, NPs or PAs perform for a transplant program?
- What is the optimal transplant professional staffing level?
- What strategies are needed to improve recruitment and retention of heart/lung nurse professionals?
- What are our recommendations for future research?

A consensus paper will be published. If you are intrigued to hear the results of the survey, data will be presented at the Annual NHSAH Council meeting in Prague, April 2012, which is another good reason to attend the ISHLT Annual Meeting and Scientific Sessions!

**Disclosure Statement:** The author has no conflicts of interest to disclose.
Some of the most famous and influential people in history were born in 1809. Abraham Lincoln, previously mentioned in the November issue, was born the same day as Charles Darwin, our notable naturalist: February 12, 1809. Felix Mendelssohn, born February 3, 1809, initiated key aspects of romanticism in classical music with his great Overture to a Midsummer Night's Dream. Louis Braille, January 4, 1809, developed a system of communication for the blind. Oliver Wendell Holmes, Sr., August 29, 1809, Dean of Harvard Medical School from 1847-1853, is known, among his many accomplishments, for calling attention to the true contagiousness of puerperal fever and popularized the term anesthesia. Hmmm ... an unintentionally dismissed but important topic for another issue of the ISHLT Links! Then we have the great poets: Lord Alfred Tennyson, August 6, 1809 and Edgar Allan Poe, January 19, 1809. Because Poe remains alive with us and can be linked with every issue of Volume 3 of the ISHLT Links Newsletters, I will provide a summary about him as we toast a glass of French cognac and leave three roses in his honor.

Poe was a polished romantic poet with incomparable technical virtuosity, perhaps the Beethoven of Poetry, a premier literary critic and a creator of prophetic genres such as: science fiction, detective stories, and horror stories. His greatest contribution was the psychological narrative within the gruesome and gothic stories he fashioned. One critic has stated, "He is the unpaid script writer of many great horror films." Essentially all horror movies over the last half century have come from Poe. These stories may not be serious literature but are certainly serious money. Although dead for over a 160 years, Poe is very much alive today.

Poe’s reputation may be better known than his works. He has been described as a drunk, sick, kinky, diseased, perverted, and gambling necrophiliac. His natural and his foster mother died of consumption when he was 2- and 20-years-old, respectively. He married his 14-yr-old cousin, Virginia Clemm, when he was 27, and she died of consumption when he was 37. Therefore, the death of women figures prominently as his central theme in his works. It is the central theme in his life. As Walt Whitman has so aptly put it, he had an incurable propensity toward nocturnal themes and a demonical undertone behind every page. Ralph Waldo Emerson referred to him as the 'jingle man' primarily from his famous jingle, a poem named The Bells, with the famous word 'tintinnabulation'. T.S. Elliot stated that "Poe’s powerful intellect is undeniable, but it seems he has the intellect of a highly gifted young person before puberty."

In the poem, The Bells, and his most famous poem, The Raven, there are maniacal repetitions. If we continue to repeat things, it begins to look like a kind of obsession. These repetitions of refrains are akin to sticking with a regimen or routine that one might declare for their New Year's resolutions. In such a way where regimens and routines are necessary, then life is poetry in motion.

Poe penned an important essay on "How I wrote the Raven." Against prior conventions, he points out that there is nothing about inspiration and nothing spontaneous in this poem. Poets are craftsmen who come up with rhyme schemes, metrics and purposeful arrangements. The poet is an artisan and a word maker. He uses language in a strategic and tactical manner. Poe posits that the major legitimate province of poetry is beauty. The proper tone is sadness, thus melancholy is the most legitimate of all practical tones. Beauty is the subject and melancholy is the tone. Death is the most melancholy or
maybe being almost dead. What kind of death? You guessed it—his central theme in life is the death of a beautiful woman.

In poetry, the refrain is the most critical part, the repeating dimension of poetry. The refrain has a key word to be used over and over. He believed use of the long-O is scientifically obvious, the most sonorous vowel linked with the letter R, the most producible consonant. So nevermore becomes the obvious choice. Surely Abraham Lincoln read The Raven. The opening words of the Gettysburg Address which Lincoln deliberately chose are Four-score and ...

His most perfect poem is Annabel Lee with the repetition and rhymes, the death of a beautiful woman, a child bride who is being buried alive. Although dead, she is still alive for him. This brings up another central theme in his works: being buried alive.

Poe invents the detective story. He creates C Auguste Dupin who uses ratiocination to solve mysteries by combining his high intellect with creative imagination. This character spawns the creation of other great fictitious detectives including Sherlock Holmes and Agatha Christie. His material leads to Jules Verne, Ray Bradbury, HG Wells and other 20th century science fiction writers. Importantly, Poe wants the world to become transparent to a man of strong intellectual powers. Today, successful institutions and societies demand transparency and accountability.

Poe also gives us stories of the divided self. Twins and doubles struggle in these stories and in the psychological sense are related to his repetition devices from his poems. In the story, William Wilson, there is an emerging "twinship," a moral conscience of the dark side protagonist, which is opposite to the story of Dr Jekyll and Mr Hyde where the protagonist is the moral conscience. In William Wilson, the nagging moral conscience (Wilson #2) exposes the cheat, the cunning and sly protagonist (Wilson #1) as if there is a psychic civil war within one character.

How about The Cask of Amontillado and the many obvious links? The names of the main characters are interesting: Fortunato—the fortunate one, and Montresor—my treasure. These names are mirror images of each other and again two different aspects of one personality. For fifty years this has been the most famous buried alive story in literature. Is this a means of repressing guilt (walling off), the guilt of having money, the root of all evil? The burial of Fortunato represses Montresor's evil nature. To possess fortune would plunge a man into ruin and destruction. Montresor chose to wall up Fortunato in darkness, permanent darkness.

Now from fun with names we move to Poe's puns. Montresor offers a bottle of wine called De Grave - from the Bordeaux area, but in English a grave is a tomb or a foreshadowing. Then Fortunato declares to Montresor, "You are not of the Masons?" referring obviously to the free masons. When Fortunato disbeliefing asks for a sign, Montresor shows him a trowel. Montresor is a different type—a free mason who uses a trowel to wall up Fortunato for eternity. He turns out to be a free mason to free himself of Fortunato through his masonry, and with the last stone there is a final jingle of the bells. This is another example of psychic civil war by getting rid of your double.

For more links and more doubles we have The Black Cat and The Tell-Tale Heart. These should be more obvious. The Black Cat is a great Halloween story. It is a mercurial story that suddenly shifts from tenderness, closeness and intimacy to hatred, violence and murder. There are two sides of the pendulum, the duality of tenderness and violence. The violence includes ritual dismembering and maiming as the cat's eye is deliberately gouged out from the socket. In Freudian terms, blinding
someone is symbolic of castration. The eyes are agents of transgression, therefore they must be plucked out. The eyes are windows to the soul (and recall the article in the June Issue of the Links: *Look Into My Eyes*). This cat is hung. In Poe's works nothing remains secret. Cat number two comes onto the scene, the same repetitive device as mentioned before. This cat has only one eye. The narrator attempts to kill this cat but instead he buries an axe into his wife's brain. Then he walls up her body. He has done her in, but in the end he is exposed.

The links to *The Tell-Tale Heart* are all too obvious. Again, there is a focus on the eye. Kill the old man's eye, put out his eye. Along with the symbol of castration, there is killing the old man from Sophocles' *Oedipus*, about slaying the king, slaying the father, or slaying the authoritative figure. As if one can't bear being seen or seen doing things that one doesn't want to be seen doing. Also, murdering the king is Shakespearean. He's got the lantern reflected on the eye. The eye was wide open. The narrator sees nothing else of the old man's face or person, for he had directed the ray as if by instinct to precisely upon "the damned spot." This is from Shakespeare's Macbeth, "Out, out damned spot" - a story about killing the king, the authoritative figure.

There is the *Pit and the Pendulum*. Maybe it is too macabre to go there. There is just time and space. And of course there is the back and forth, to and fro, and the good vs. evil in life. Well with Poe, concealment is always a kind of failed project. He shows everything. Also, in all of these stories, the narrators have questionable sanity. Need I remind you the necessary repetition of a regimen for life, poetry? And in Poe's work, insanity is doing the same thing over and over again expecting a different result. Then there is the fine line of insanity and genius with the distance between the two measured only by success. Every New Year we repeat our resolutions. Most, if not all, fail.

Lastly, literature is there for all of us. It is the voice that outlives the body as in all of Poe's works. It is the recorded text, the words on a page that remain alive with us today even after the authors have long died off.

**Edgar Allan Poe's Epitaph**

"He was great in his genius; unhappy in his life, wretched in his death; but in his fame he is immortal."

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Exercising the Patient with a Mechanical Circulatory Support Device

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In its third annual report, the Interagency Registry of Mechanically Assisted Circulatory Support (INTERMACS) reported that 2868 patients received implantation of one or more durable support devices between June 23, 2006 and September 30, 2010.1 The number of mechanical circulatory support devices (MCSD) has increased from 100 total implants per year in 2006 to 668 total implants per year through 06/2010, a 568% increase.1 The majority of these devices are implanted as bridge to transplant therapy even though the number implanted for destination therapy continues to increase. The time on the waiting list and the severity of illness of the patient awaiting heart transplant have also increased.2 This has led to the increasing use of MCSD to keep patients alive until heart transplant.3 The most recent report of the Registry of the ISHLT stated that approximately 33% of transplant recipients in 2009 were bridged with a MCSD.3 The advent of continuous flow (CF) therapy has improved survival to its currently reported two-year survival of 80%.1 In the most recent INTERMACS reporting period (01-06/2010) 98% of all ventricular assist devices (VAD) implanted were CF pumps. For patients with biventricular failure, the Cardiowest total artificial heart (TAH) is the most effective bridge to transplant with a success rate of 79%.4

In addition to prolonged survival, MCSD offers patients the opportunity for enhanced quality of life by improving end organ function and activity tolerance. Advancements in device technology have led to increased portability, patient acceptance, and ability to participate in further activities of daily living.1 Additionally, patients can undergo physical rehabilitation and/or cardiac rehabilitation to further improve functional capacity, including patients who may have previously been bedridden. There is however a distinct lack of studies examining the effects of exercise in MCSD patients.5 To date most of the literature regarding exercise capacity/therapy in these patients has been based upon 1st generation or displacement VADs. These studies support the safety and efficacy of exercise testing/intervention in the VAD patient.5, 6, 7 Although exercise capacity is generally improved with VAD support, it is generally lower compared with post-heart transplant patients.7, 8 Exercise capacity in the MCS patient ranges from 14-24 ml.kg.min for peak VO\textsubscript{2} although it remains at about 50-60% of predicted compared with normal.9

In contrast, de Jonge et al. found that peak VO\textsubscript{2} 12-weeks after VAD implant did not differ significantly with peak VO\textsubscript{2} at 12-weeks after heart transplant.10 In this study all patients were started on an intensive post-operative rehabilitation regimen as soon as they were able to mobilize. This alludes to the importance of exercise intervention after VAD implant to optimize functional capacity.

With the advent of CF pumps there has been concern about their effects on exercise hemodynamics. Previous studies have suggested axial-flow rotary pumps provide similar degrees of pressure unloading but less volume unloading of the left ventricle as compared with displacement pumps which may impair exercise performance.11 Haft and colleagues seem to rebut this suggestion with their finding that exercise performance was similar in those with a CF pump compared with displacement pumps.12
The primary goal of exercise rehabilitation with the VAD patient is independent ambulation. The early goals of post-operative mobilization are to offset iatrogenic deconditioning and regain independence. This starts with physical therapy intervention to improve bed mobility, transfer ability, gait, and facilitate pulmonary toilet. Patients are gradually advanced until they can tolerate independent hallway ambulation and then may participate in dynamic aerobic activities such as treadmill or bicycle-ergometer exercise. The exercise prescription for the MCSD patient is similar to that of heart failure with precautions taken for device management. Contraindications to exercise are similar to that of patients with cardiovascular disease. Factors to consider include pre-MCSD physical condition, sternal precautions, arrhythmias, RV failure, post-surgical anemia, hemodynamic stability, and neurological status.

Early mobilization can be progressed using American College of Sports Medicine guidelines for exercise prescription for patients with cardiac disease. Frequency can range from multiple bouts per day to 3-5 days/week as the patient progresses. Intensity is to tolerance if asymptomatic with an RPE < 13 on 6-20 scale. Time can start with 3-5 minute interval bouts as tolerated with progression towards 10-15 minutes continuously before intensity is further augmented.

In the post-acute period (i.e. ≈ 6-8 weeks post-implant) it is reasonable to expect that patients should be able to perform 20–30 minutes or more of moderate intensity aerobic exercise at approximately 3 metabolic equivalents (METs). Once appropriate, the exercise prescription can be further refined with cardiopulmonary exercise testing. This can allow for targeted exercise intensity and be used to provide activity guidelines.

Device-specific factors to consider are drive-line site immobilization, anticoagulation, volume status, pump speed, recognition of device-malfunction alarms, patient independence with power source transfers, and hemodynamic monitoring. All patients should immobilize the percutaneous lead with an abdominal binder to prevent trauma to the driveline exit site. Volume status can be ascertained from device console parameters and blood pressure measurement. Device flows of <3 L/min can indicate device failure and is a contraindication to participation. Changes to pump speed can influence native LV contribution and device flow. Presence of device alarms lead to the cessation of exercise until proper functionality is restored. Patients must be instructed on how to transfer power sources independently to allow increased ambulation and ADL participation. Conventional blood pressure measurement with the use of a stethoscope or automatic monitor may not be accurate in patients with CF pumps. Auscultation with a Doppler-probe and sphygmomanometer is recommended. In general, mean arterial blood pressure measurements should be 70-80 mm Hg. However, Doppler obtained blood pressures can occur at any point during the cardiac cycle but may not represent true systolic, diastolic, or mean values.

In the TAH patient, pump pressure and rate is set by the physician to optimize cardiac output and systemic blood pressure. These fixed settings allow some exercise-induced increase in cardiac output via enhanced venous return. TAH patients can safely participate in exercise training as early as 2 weeks post-implant and demonstrate improvements in exercise capacity. The exercise blood pressure response in the patients is blunted which seems to limit exercise tolerance at ≈ 3 METs.

In summary, the number of MCS devices implanted continues to increase. MCSD support improves exercise capacity yet remains suboptimal. Few studies of exercise intervention confirm safety and efficacy with a stable patient with proper precautions taken for device management.
Disclosure Statement:
Neither author has any conflicts of interest to disclose.

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The 2011 Heart Failure Society of America Meeting (Scientific Program Chairs: Lynne Warner Stevenson, MD, Steve R. Houser, PhD, Barbara J. Riegel, RN, DNSc) was very rich in topics and it is definitely worth highlighting some of the presented information for those who did not get to attend. This is the second part of a report summarizing only a sample of the most interesting talks and discussions that took place during the meeting (the first part of the report was published in the December issue of the ISHLT Links).

Dr. Daniel B. Mark (Duke Clinical Research Institute, Durham, NC) presented the Surgical Treatment for Ischemic Heart Failure (STICH) trial’s quality-of-life results. The STICH trial randomized 1212 patients with an LVEF <35% and HF who were considered candidates for CABG to receive or not receive the surgery on top of optimal medical therapy. The results referring to its hard endpoints were recently published. Over a median of 56 months, the trial failed to show a significant difference in its primary end point of all-cause mortality: 36% in the CABG group vs. 41% for the optimal medical therapy group (p=0.12). Secondary clinical end points showed benefits for the CABG group: a 19% decrease in risk of cardiovascular death (p<0.05) and a 26% decrease in the composite of all-cause mortality or cardiovascular hospitalization (p<0.0001). Study subjects prospectively completed quality-of-life tests at 4, 12, 24, and 36 months after randomization. These consisted of multiple queries about symptoms, physical and social limitation, and the Kansas City Cardiomyopathy Questionnaire (KCCQ), scored from 0 to 100, with a higher score indicating more favorable conditions. A statistically significant difference was also considered clinically significant if it was different by at least 5 KCCQ points. Quality-of-life scores became both statistically and clinically significant in the CABG group at 12 and 24 months. When the measure was proportion of patients who showed a clinically significant ≥5-point improvement in KCCQ summary scores the CABG group also showed significant benefits at the studied time points. However, both the presenter and Dr. Eugene Braunwald (Brigham and Women’s Hospital, Boston, MA), a co-moderator for the session, acknowledged that a placebo effect should be considered given that blinding to treatment assignment was impossible, a problem with many randomized trials that include surgery.

In the session, Guideline Update 2011: What’s Current, Controversial, and Coming Next?, Dr. Joseph G. Rogers (Duke University Heart Center, Durham, NC) gave a talk titled, Use of LVADs in HF. The presenter initially described the challenges in developing evidence in the field of chronic mechanical circulatory support: a small and very ill patient population, a limited number of investigative sites, and non-traditional trial designs among others. He then reviewed in a systematic way all of the trials that investigated the role of LVADs in end stage HF (either as bridge to transplant or destination therapy) and suggested that the level of evidence supporting LVADs in the treatment of advanced systolic HF is sufficient for guideline documents to be altered and indicate the highest level of recommendation with the highest level of evidence. Dr. Rogers also reviewed the available data investigating the role of LVADs in less sick HF patients. He concluded that currently the data is insufficient to support LVAD use in this patient population and pointed out that new initiatives (REVIVE-IT and ROADMAP trials and the MEDAMACS Registry) will help us better understand the impact of LVAD therapy in this patient population.
Dr. Garrick C Stewart (Brigham and Women’s Hospital, Boston, MA) in a talk titled *Who Wants an LVAD for Ambulatory HF*, addressed the intriguing issue of LVAD use in ‘less sick’ HF patients. In an effort to address this issue from the patients’ perspective, Dr Stewart and his coworkers enrolled 150 ambulatory HF patients who read a short, nonspecific description of an LVAD and its potential risks and were asked through a structured questionnaire how open they were to the idea of receiving one. The participating patients were in NYHA class III or IV HF and had a history of at least two HF hospitalizations in the past year or one such HF hospitalization plus poor functional capacity (maxVO2<55% predicted or 6-minute walk test < 300m). They excluded patients already listed for heart transplant, on home inotrope infusion, and with recent or planned resynchronization therapy. They found that 24% of the patients would “definitely want” an LVAD and 32% “probably want” (25% “do not know”, 13% “probably not” and 7% “definitely not”). The greatest concerns the study subjects expressed regarding the LVAD therapy included stroke risk, infection risk and device durability. The take home message was that ambulatory patients with advanced HF were open to considering LVAD prior to becoming inotrope dependent and the enthusiasm for LVAD increased as INTERMACS profile worsened and HF hospitalizations became more frequent. Based on these findings, Dr. Stewart recommended “engaging patients early about thresholds for considering elective LVAD and give priority to patient education about both LVAD therapy and survival with HF”.

Dr. Josef Stehlik (University of Utah, Salt Lake City, UT) presented a talk titled *Beyond Levels: How Can We Tailor Immunosuppression?*, in which he summarized approaches to optimize immunosuppression intensity in individual heart transplant recipients. He illustrated the opportunity by showing that while survival after heart transplantation has improved over the past three decades, most of this improvement has been limited to the first post-transplant year. He also reviewed the leading causes of death after heart transplant and showed that their distribution varied significantly among cohorts of patients grouped by simple clinical variables, such as age. Dr. Stehlik suggested that despite these differences in mortality risk, the current clinical care has not embraced formal personalized approaches to immunosuppression tailoring. He then discussed two tests designed to assess the immune status of transplant recipients – the ImmuKnow test (evaluates activation of lymphocytes by quantifying ATP release with their stimulation) and the Allomap test (quantifies expression of genes involved in rejection), and reviewed studies that examined the utility of these tests in heart transplant recipients. Dr. Stehlik concluded that we currently have tools that can help us to better tailor immunosuppression, but also suggested that prospective studies should be done to confirm that these approaches will result in better outcome.

Dr. Dirk J. van Veldhuisen (University of Groningen, the Netherlands) presented the *Diagnostic Outcome Trial in Heart Failure (DOT-HF)* which investigated the effectiveness of the impedance-monitoring function and audible-alert system (OptiVol, Medtronic) in improving HF outcomes. The enrolled patients were implanted with a defibrillator featuring a monitor that emitted an audible beep when intrathoracic impedance rose (suggesting volume overload). Inclusion criteria were NYHA functional class II to IV on optimal medications, left ventricular ejection fraction (LVEF) <35%, implantation of a defibrillator or biventricular pacemaker-defibrillator no more than six months previously, and a history of a HF event within 12 months of the implantation. The 335 enrolled patients were followed for an average of 15 months. Surprisingly, compared to patients who did not receive the monitors, patients with the implanted study device showed an increase in HF hospitalizations (hazard ratio 1.79, p=0.022). No significant difference in mortality was noted. Patients with OptiVol monitors had also three times as many unscheduled outpatient clinic visits as those without the monitor. Of note, when these patients were seen in the clinic, they tended to have fewer signs or symptoms of HF decompensation compared to patients randomized to no monitors who were seen in clinic. Dr. James E. Udelson (Tufts Medical Center, Boston, MA), designated discussant for the DOT-HF presentation, commented that it may have been the audible beeps that drove up HF hospitalizations, but there are other plausible
explanations as well. While the idea that decompensated HF is preceded by a prolonged period of subclinical worsening amenable to intervention is attractive, other mechanisms may be involved, such as sudden shifts in central blood volume. He suggested that it may well be that the relationship of changes in intrathoracic impedance to clinical HF is more complicated than initially thought. Overall, the trials investigating the role of impedance reached weak results as opposed to pressure-monitor trials (CHAMPION, COMPASS-HF) that have generally been positive. Interestingly, in the pressure-monitor trials patients were blinded to the device readouts and that information went directly to the physicians.

Overall, the meeting provided a great forum and ample opportunities for presentation of original science, summary topics, didactic presentations, networking and discussions regarding the current challenges and future directions in the field. The above is only a sample of a number of stimulating presentations the 2011 HFSA annual meeting offered to the participants.

**Conflict of Interest Statement:**
The author has no conflicts of interest to disclose.
The 2012 NHSAH program highlights include a talk titled, *Incorporating Information Technology into Pre- and Post-Transplant Care*, being presented in the plenary session titled, *Using Technology to Promote Self-Monitoring and Health Outcomes after Transplantation*. The NHSAH council also played a major role in developing the plenary, *Aging Demographic Imperative: Ethics, Economics & Resource Allocation* and three key symposia.

Children and adolescents frequently face significant developmental challenges from the time of transplant through the time they transition to adult programs. *Neurocognitive, Psychosocial and Behavioral Issues in Children and Adolescents* is a pre-meeting symposium jointly facilitated by pediatric and nursing councils to address non-clinical issues (psychosocial, behavioral and neurocognitive) in children after thoracic transplantation.

Caregivers are a crucial component to successful outcomes for our patients, thus in the *Focus on Caregivers - Investing in our Patients' Future* symposium, a panel of experts will outline unique approaches to address needs of caregivers so they can continue to provide optimal care to transplant recipients and MCS patients.

In recognizing that transplantation is a chronic condition, development of self-management strategies is a key component to improving long-term outcomes post thoracic transplantation. Presenters in the symposium, *Self-Management in End-Stage Heart Lung Disease and Transplantation*, will describe important principles of 'self-management,' including management of the medical and pharmaceutical regimens, emotions and new life roles for both adult and pediatric patients.
You are sipping on the last drops of your coffee at Café Slavia. Your gaze keeps shifting up towards the green illusion in the large Absinthe Drinker painting by Viktor Oliva. After watching the opera Rusalka at the National Theater across the street, you decided to visit this historic café, well known for welcoming many celebrities over the years. Among those were poets Jiří Kolár and Jaroslav Seifert, musician Jiří Šlitr and, of course, the late Czech ex-president Václav Havel. Since you were already planning your ISHLT conference trip when the news of his death in December appeared on TV and the Internet, you have been eager to read all you could about Václav Havel. You think back to his amazing life story: A playwright and poet who spoke his mind during communism and went from being a dissident to president.

In many ways, Havel symbolizes the country’s last six decades and embodies values of which the country is now probably most proud: intellect, freedom of mind, and peace. His mottos were "words are stronger than ten military divisions" and "truth and love will prevail over lies and hatred." Indeed, since the Second World War, many political changes in his country have been peaceful: peaceful resistance to the communist regime, the Velvet Revolution in 1989, and the peaceful dissolution of Czechoslovakia into the Czech Republic and Slovakia in 1993.

Even though the communist government disliked the Havel family due to their affluence and politically colored past, and limited Václav’s access to secondary education, Václav overcame this barrier by studying drama via correspondence. His early writings and plays quickly gained national and international acclaim in the 1960s. However, Havel's standing deteriorated during the Czech invasion by the Soviet Troops in 1968 when he did a live radio narrative for the resistance. Thereafter, Havel was banned from public and theater life, became a dissident, and his plays were performed clandestinely or abroad only.

Over the following two decades, Havel continued to oppose the communist regime. He is well known for his support of the psychedelic rock band Plastic People of the Universe (PPU). The PPU band was part of the Prague cultural underground between 1968 and 1989. After one of their concerts in 1976, the PPU band went on trial for non-conformism and for "organized disturbance of peace" due to their lyrics criticizing the government. Havel was present at their trial and publicly stated his opposition to their imprisonment. In response to this and other injustices, Havel, along with other dissidents, spearheaded the publication of the Charter 77 Manifesto. The manifesto criticized the regime for disrespecting human rights and not following the Czechoslovak Constitution; it was signed by 242 citizens.

The reaction of the government to the manifesto was quite harsh. The 242 signatories were made into a public example and punished in various ways: they lost their jobs, educational opportunities were denied to their children, their drivers' licenses were suspended, some were forced into exile, some were tried and imprisoned, and some were forced to collaborate with the communist secret service. The manifesto was banned and its ownership or readership became criminal. Havel's life thereafter was marked by multiple imprisonments, the longest being from 1979 to 1984, and constant questioning and surveillance by government forces.
"Thank you for your visit, Mr/s XYZ," says the waiter as he brings your credit card and receipt back to your table at Café Slavia. You walk out on the street Národní třída and head away from the Vltava River. This street was the very location of the student demonstrations that started on November 17th, 1989. You try to imagine the masses of students carrying flags and flowers, the police blockades, the peaceful demonstrators placing flowers onto police shields and chanting "we have bare hands" amidst the jingle of shaken keys. The jingling of keys was apparently a gesture to say "goodbye, it's time to leave" to the communist government.

You keep walking on the Národní třída all the way to Kaňkův palác, now Česká advokátní komora (Czech Bar Association). In the walkway of the palace, you were hoping to take a picture of the memorial to the student demonstrations, decorated with waving hands making peace signs. You are a little disappointed to find out that the walkway closes at 6:00 PM. In November 1989, the demonstrations were followed by a weeklong strike of students and theaters. That's when Havel, along with other former members of Charter 77, founded the Civic Forum as a peaceful popular movement for reform. Multiple other demonstrations followed throughout Prague and Bratislava (capital of Slovakia) and multiple meetings took place between the government and members of the Civic Forum. Three tumultuous weeks led to the end of censorship on November 27th, the appointment of the first non-communist government on December 10th, and finally the election of Václav Havel to presidency on December 29th.

Although Havel is well liked abroad and was a Nobel Peace Prize nominee, his presidency and political work at home was not easy. "Fixing" a country broken by over 40 years of communism was pretty much impossible and is still ongoing. Some of his peace-oriented and anti-conflict decisions were not liked by everyone. Nevertheless, he was re-elected twice and will remain one of the most popular Czech presidents in history. Among other achievements, at the time of his death, he was Chairman of the New York-based Human Rights Foundation's International Council.

You continue your walk eastward on Národní třída, all the way to Václavské náměstí. The Národní třída has lived through the whole cycle, you think to yourself. It bore the 1989 demonstrations that marked the fall of communism and the birth of democratic Czechoslovakia and, a few months ago, saw Václav Havel's funeral procession decorated with thousands of candles in his honor.

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Communication in Pediatric Transplant:  
A House of Bricks  
Arzellra Walters, RN, CPNP  
Mount Sinai, NY

Let’s take a moment to think about communication in the pediatric transplant world. No, I am not talking about intra-atrial communication of atrial septal defects for all of you pediatric cardiac professionals out there. I am talking about communication between the child (the patient), care giver and health care professional (HCP).

Patient-HCP communication is important in all age groups. However, in pediatrics it is especially important. When time is taken to build a rapport with, and understand, the patient and family, trust is built. Within the world of transplant, effective dialogue between patient, family and HCP is crucial to patient survival because it leads to improved patient knowledge, functional status and adherence to the agreed-upon treatment regimen.

Merriam-Webster.com defines communication as “a process by which information is exchanged between individuals through a common system of symbols, signs or behavior.” Communication should be in a language that patients/caretaker can understand and the communicator should have interpersonal sensitivity. In addition communication must be constant, and reciprocal.

In order for patients to effectively communicate with HCPs, the language used must be one that the patient and caregiver can understand. This means one should take the time to explain everything in lay-person and age-appropriate terms. As much as possible, information should also be provided in written format. HCPs need to be sure that the information is always provided in a calm, quiet environment whenever possible. In order to dispel myths, HCPs need to set aside time for questions from the patient and caretaker. Information should be provided on a continual basis to avoid any misunderstandings. Finally, the exchange of information must be reciprocal. HCPs should always listen to the patient and family concerns and questions. Often, a small bit of insight from a family member can make the care of the patient easier.

Another concern with patient-family-HCP communication is the method used. As much as possible, communication regarding life-changing situations should happen face-to-face. However, in this age of technology there are now several ways to communicate. What is being communicated will help dictat how it is communicated. All of these principles should be followed whether you are talking to a pre-transplant family being evaluated for transplant or a post-transplant family whose child is undergoing yet another biopsy to rule out rejection.

Communication with the pediatric transplant family is like the childhood story of *The Three Little Pigs*. Piggy number one built his house of straw and Piggy number two built his house of wood but sure enough that big bad Wolf came and blew down both those houses. Well Piggy number three was smart and built his house of brick. Try and try as he might the big bad Wolf couldn’t blow that house down. Let us all be like Piggy number three and build our “house of communication” like a house bricks so that nothing can tear it down!

As the New Year begins let us all review our communication methods and find what works best for patients and you!

Disclosure Statement:  
The author has no conflicts of interest to disclose.
Evolution in thoracic transplant care has gone well beyond the physiologic challenges met by LVADs, CADD pumps and EVLP's potential. The psychosocial demands of heart and lung failure and transplantation have kept pace with the biological therapies. As such, the means and media by which we educate and support our patients have evolved beyond hospital-based support group meetings and group teaching sessions.

Today, social media provides access to information and community to anyone willing to reach out through the anonymity of the internet. The dangers are obvious: information may or may not be mediated, accurate or interpreted correctly. The benefits are there, too: ready access to information and camaraderie help empower our patients and protect them from the social isolation that can so often accompany chronic critical illness and disability. Like it or not, our patients are online in search of psychosocial support.

Recognizing this reality, several transplant programs have developed or endorsed sites from which patients and caregivers can safely gather and exchange health information. Facebook pages, refereed websites, blogs and members-only listservs are available to help us meet our patients' needs.

**LUNG TRANSPLANT NEWS BLOG**

At the University of Pennsylvania, the lung transplant team partnered with health system marketing to develop a weekly electronic newsletter in the form of a blog ([www.pennmedicine.org/lungtransplantnews](http://www.pennmedicine.org/lungtransplantnews)). Content ranges from health reminders to program updates and serves to inform and educate subscribers on issues unique to lung transplant patients and their caregivers. While most content is written by clinical staff of the program, the most popular features are patients' autobiographical success stories. Patients are invited to subscribe to the blog at their first encounter and again with general program mailings. Subscription to the newsletter is unrestricted (anyone can subscribe) and completely voluntary allowing readers to opt out at any time. One year after the inaugural edition of *LungTransplantNews*, there are over 200 subscribers gathering and sharing electronic information that is created (or, at least, vetted) by their lung transplant team.

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**MyLVAD.com - AN ONLINE LVAD GOLD MINE**

*Michael G Petty, PhD(c), RN, CCNS, CNS*

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More than anything else, LVAD patients and their caregivers are seeking a resource to pose questions and get information about the day-to-day things that impact their lives. How do I coordinate time to mow the lawn, to go to the movies, to get my hair permed? What do other people do? Those who surround and support the LVAD dyad are looking for more information on how LVADs work, what the impact of the device is on the rest of the patient's life, how to offer help, etc. Medical professionals unfamiliar with LVAD technology and its potential to help their patients often look for a source outside of industry to provide a comprehensive view.
Washington Hospital Center, under the leadership of Dr. Steven Boyce and his team of LVAD coordinators, has developed MyLVAD.com as a place for all of these individuals to connect to seek answers to their questions. The mission of the website is simply stated: to improve the quality of life and outcomes for people living with LVADs. This is accomplished by electronically connecting LVAD recipients, their loved ones, and healthcare professionals involved in the care of these patients through the website and utilizing social media including Facebook and Twitter. With a quick click of the mouse, one can access data, videos, blogs, maps, and stories related to LVADs and LVAD life. Questions are asked and answered by those involved in the lives of LVAD patients. Information is tailored to the needs of the various communities the website intends to serve. MyLVAD.com is an outstanding example of the way social media will continue to play a role in the medical community, and specifically in the lives of those with LVADs.

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**NHSAH GOOGLE GROUP: A SECURE NETWORK TO QUERY YOUR PEERS**

**Alison Amegatcher, RN**

**UCLA School of Medicine, Los Angeles, CA**

Social media sites like Twitter and Facebook have a plethora of pages with good to mediocre information filling a void its users perceive they have. The problem of confidentiality with these sites and the suitability for use by healthcare practitioners is an ongoing debate. With these thoughts floating through our minds several ISHLT councils have setup Google Groups or Google + Circles as simple but secure tools for discussions.

Late last summer, the NHSAH Council started testing the feasibility of using Google Groups as a tool for confidential communication amongst members. Healthcare Information Portability and Accountability Act HIPPA laws would be followed by all users. Questions and answers went out to test members of the group and notification emails of new content were sent to users per their setup preferences.

To date, the benefits of this easily accessible but secure site for all users are the wide international audience and feedback obtained by all. You can join the group by sending an email to nursing-ishlt@googlegroups.com.

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**SEEKING SUPPORT ONLINE:**

**A FACEBOOK SUPPORT GROUP FOR VAD PATIENTS AND CAREGIVERS**

**Jennifer Kealy, RN**

**St. Paul's Hospital, Vancouver, BC, Canada**

It has been well established that stable support groups improve health outcomes for people with a wide range of chronic conditions, including heart failure. When patients managing the same chronic condition share experiences and observations with each other, it results in a collective wisdom and greater clinical insight than that offered by any single patient or health care provider. Ventricular Assist Device (VAD) patients are no different - they highly value the knowledge they gain from each other.
For over two years St. Paul's Hospital in Vancouver, Canada held monthly support group meetings for VAD patients and their caregivers. The group was led by a VAD coordinator and clinical nurse specialist with facilitation from a psychologist and social worker. Each month the group would meet for two hours, starting with a general round table discussion for participants to share stories, experiences, and ideas with each other. The latter portion of the meeting would include a short presentation by a health care provider on a topic aimed at improving the quality of life of VAD patients and caregivers - such as maintaining intimacy with a partner, traveling with a VAD, among others. The group not only provided a means for patients to connect with each other, but also provided an opportunity to offer supportive education. The group was well attended and the feedback was positive. Patients and caregivers were openly sharing stories - they were not only learning from each other, but inspiring each other as well. The exchange of peer knowledge and expertise that occurred was extremely valuable and worthwhile. However, the biggest challenge was finding a way to make the group more accessible and less of an inconvenience. With the face-to-face format, it was difficult to find a time that suited everyone's schedules and it seemed contrary to expect patients and caregivers to return to the hospital each month for support. One potential solution was the use of an online social network.

The most popular social network is Facebook with over 800 million active users. According to the company's website, 1 in 13 people worldwide have a Facebook account, half of which are logged in on any given day. An astounding 48% of 18 to 34 year-olds around the world log onto Facebook as soon as they wake up and 28% check it on their smart phones before getting out of bed. And it is not just for the youth; the 35 and older demographic now represent more than 30% of the entire Facebook user base.

Given the popularity and reach of Facebook, it seemed like an effective avenue to connect VAD patients and caregivers. Hence, a VAD Support Group on Facebook was created and patients and caregivers from St. Paul's Hospital were invited to join. Initially the group was small and the VAD coordinator posted the majority of the content such as posing questions to the group to stimulate discussion, posting links to interesting articles and links to YouTube videos of VAD patients participating in different activities such as playing golf.

As word got out, the group quickly expanded. Now with almost 100 members, VAD patients and caregivers are maintaining the group themselves. Patients are frequently posting new content. They are sharing personal stories, offering suggestions, and providing supportive comments to each other. While there was some initial fear that patients may post misleading or unhelpful content, this has not been the case. The group seems to self-govern or polices itself. Like any active community, the members hold each other accountable and call each other out if need be. To date there have not been any inappropriate comments requiring removal from the site. Other concerns, inherent with being a Facebook site, are privacy and confidentiality. Facebook is a public social network open to anyone with an email address. To manage these issues, the group was created as a "closed group" which means only accepted members can log on and view the content. Individuals interested in joining the group must submit a request to become a member and be accepted by one of the group's administrators. While this limits the number of people who can log on and view the group, it does not ensure complete confidentiality. Members are cautioned to consider anything they post as public domain. By and large, we have found the Facebook support group to be a valuable adjunct to our in-person VAD support group. The online format reduces the time and distance barrier, eliminates the restriction on group size, increases the variety and diversity of members, and ultimately improves access to peer expertise and support. With almost 100 members from around the world, this new virtual community has expanded the possibilities of support for VAD patients and their caregivers.

Disclosure Statement:  
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References:  
Editors’ Recommended Reading

from Allan Glanville:
   *The Inheritors* by William Golding
   *All the Pretty Horses* by Cormac McCarthy

from Nancy Blumenthal:
   *The Immortal Life of Henrietta Lacks* by Rebecca Skloot
   *Harry Potter and the Half Blood Prince* by JK Rowling
   *World Without End* by Ken Follett
   This month’s *Martha Stewart Living*
   Last Month’s *Real Simple*

from Stan Martin:
   *The House of Silk* by Anthony Horowitz
   Great story about Sherlock Holmes, once again told from Watson’s standpoint. It has all the flair and style of Sir Arthur Conan Doyle’s familiar character profiles, but a more modern storytelling appeal from an author whose expertise on the subject really shines through. No wonder it was the first Sherlock Holmes story to be endorsed and officially authorized by Doyle’s Estate.

from Vincent Valentine:
   Two classics by Edgar Allan Poe:
   *The Murders in the Rue Morgue* and *The Purloined Letter*

   The following recommended readings, also by Poe, are restricted due to the gruesome and gory details. Parental discretion is advised.

   *The Black Cat*
   *The Tell-Tale Heart*
   *The Pit and the Pendulum*
   *The Fall of the House of Usher*
   *William Wilson*

   For those who want to study a case of mesmerism in the state of *in articulo mortis*, final stages of phthisis with a vivid description of emaciation and ossified lungs, the meaning of stertorous breathing and not to mention the inclusion of an informed consent, I refer you to *The Facts in the Case of M Valdemar*.

   And for those revelers dressing up and partying for New Year’s Eve and dressing in drag for Mardi Gras, how about *The Masque of the Red Death*, sort of a Mardi Gras party gone mad, reminds me of the movie, *Eyes Wide Shut*. And then finish off with The Cask of Amontillado with a couple of chaps wandering off from the revelry because one of them had his own vengeful intentions.
Moments

Julia Hayes
No Worries Farm, Spokane, WA

When I was asked if I'd be interested in submitting something for this newsletter my first reaction was to laugh followed by a tongue-in-cheek off-color quip, “I suppose I could cough up a lung and give it a go.” As I write, I can't escape thinking that I’m an outsider—a fraud trying to weave some thin thread connecting my writing, which is predominantly about the mystery that is life and death characterized by the cancer journey, to the intricacies that define the trials and triumphs of heart and lung transplants.

But life is transparent and simple despite complexity if one dares to look just below the surface. There, it is easy to find the threads, to see the connections and to know that not only does each person have a story but as Rachel Remen, MD says, “Each person is a story.” It isn’t too difficult, therefore, to know just how connected we really are and this awareness comes through with grandeur in our stories.

It was the dead of winter when I heard the unmistakable knock-knock-knock of Death at my front door. Strange how life does that—knocks when we least expect it, forcing us to navigate realities we’d rather just ignore or pretend never existed. But there’s no mistaking this knock. It resonates cold and hollow in the core of one’s knowing. Too terrified and worried that if I opened the door I would allow Death in, I simply stood on my side and listened, desperate for it to go away. Death hissed like water upon flames, “I am leukemia and I have come for your daughter, Aria.” She was 4 years old and it was inconceivable that the light of her life danced upon a diminishing wick. I held my breath and listened some more. Death's haunting voice swept through the rafters of my mind threatening to collapse my thoughts. Its chill blew, “I am merciless and I will make her suffer. All you have are moments.”

An innate almost reflexive response to news of a life threatening disease is to cling to life as it was and fight the current of life as it is. Aria’s leukemia diagnosis and 2½ years of chemotherapy treatment shattered life as I knew it. There was no holding on. There was nothing there but a black and white outline of an old life ready for an entirely new palette. I knew better than to stay attached to how things were. But I was terrified and the darkness of constant uncertainty descended with blinding heaviness I still cannot describe. Moments of flickering hope hinted that we would see the light again, but something told me that I needed to see Death. I needed to face its possibility but I couldn’t open my front door.

So instead I entered the blog of a young woman named Eva. She had cystic fibrosis and when I grabbed hold of her journey, she had just been told that she was in full rejection of a bilateral lung transplant that she’d received two years earlier. Eva was a vibrantly beautiful woman full of artistic glamour. She didn’t shy away from showing her hundreds of followers the darker side of the lung transplant journey, one of the things that made her so endearing. She was brutally honest and real.

I spent hours going through her past blog posts—moments in time when she was wearing a pager 24/7, waiting to get the beep that her new lungs were ready. I witnessed a moment when she grieved the loss of the person who was giving her a second chance. I watched her recover and do extremely well. I cried when she ran her first marathon. I cheered with her when she no longer needed the tubing in her nose connecting her to oxygen, which was as familiar an adornment as a necklace. Long stretches of time went without a story or
a poem because she was too busy living life—going to college, finding love, enjoying the scene of youth in a metropolitan city. Hints of future plans whispered throughout her poems and videos until one day when her oxygen reappeared.

Shadow had returned and she knew. Helplessly, I watched her decline. In her final video posted a few days before her death, she was surrounded by her family in a hospital room decorated with roses sent to her from thousands of people from around the globe. Her last message and wish was that we love one another and that we live every moment we have. The day she died was one of most sorrowful moments of my life and at the same time I was empowered to face Death and its incessant presence. Eva taught me what it was to hold sorrow and joy, as well as fear and courage in the palm of my hand. I will always be indebted to her for that.

It is entirely because of Eva that I learned to stand before Death fearless in spite of moments of real terror. As I watched her live and relish every moment she had, I’ll never forget the day I opened my front door and saw the ghostly image of Death that had been a lingering and oppressive force for months. It was so cliché! Aria was in my arms because she had stopped walking and there, just on the other side of my door, a swirling misty soot, blackened and gray, was dissipating like an ember taking its last breath. The life so powerful and present within Aria despite her weakened body, told Death that it was time to leave.

It’s been roughly 3½ years since that moment. Aria is so well that no one would have any idea how cancer had governed our lives for so long. We know what it means to savor the moment, to live in the moment, and sometimes to conquer the moment. We live every day steeped in gratitude knowing that there are no promises and no guarantees—only life as it is right now.

Our experience has led me in a direction of which I never would have conceived. That is, I walk beside and witness many families having to face Death, as well as many others learning to live life all over again having scraped out of the clutches of death with scars that don’t ever really fade. It’s odd and somewhat warped that I now talk about death as easily as tending my garden but I do. I don’t have the fear I once had—not even close. Instead, I have a strange kind of courage, if that’s what you can even call it. I don’t feel brave or fearless, but rather, present and solid in a state of complete acceptance and surrender. I have come to trust this process of living and to bask in the glory of how it IS, precisely because it is. I am not without wavering moments, however; when I feel the sway of uncertainty come upon me, I remember these words:

“When you have come to the edge of all the light you know, and are about to step off into the darkness of the unknown, faith means knowing two things ... There will be something to stand on, or you will be taught how to fly. You will be led.” ~ Anonymous

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DYING IS PART OF LIVING
Valerie Cappello, MSW, LCSW
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After tending to our lives, we now have some time to reflect on our roles as a social worker and nurse with communication, collaboration, palliative care and transplantation. Interestingly enough this has been a topic of discussion amongst many transplant social workers and nurses for some time. Most recently, it has been part of multiple discussion threads on the Society for Transplant Social Workers website, although focused mostly on heart transplantation and the LVAD population. It appears as though an increasing number of programs are including palliative care in their treatment plan and as part of patient education.

Dr Valentine has had these very discussions with us in the past, always coming to an agreement that discussing death is an honest and necessary part of the transplant evaluation. We believe death is a part of life as we are all touched by more than our own mortality. Death is inevitable whether transplantation is involved or not. Transplant, like any treatment option, is an avenue to be considered. Many misconstrue it as a guarantee of survival when in reality it is not a guarantee at all. We firmly believe that patients should be presented with all options. Patients should actively pursue transplantation as well as no action, and what each choice may bring. While choosing no action may be seen as cowardly by some, for others it is a brave choice to allow the inevitable to occur. However, the same about transplant must be considered. Transplant is a brave move on all parts as no two patient experiences are the same. There are no promises of wonderful outcomes.

We do our patients a disservice when we neglect to talk about death for those dying or at least preparing for death. Yes, it is true that some have not come to the realization that death is near but for many, opening the door to discussion with their family is a gift. Who hasn’t experienced the patient/family dynamic where, when presented with transplantation, all but the patient is stunned? Giving permission to discuss death and final wishes can be a relief for many and loathsome for others; however, it remains part of transplant education if only in discussing advance directives.

Many of our patients are thrust into what Erickson called our final stage of development "Integrity versus Despair" due to their advanced illness. They are ill-prepared for what their life’s living adds up to. Rarely can any person (let alone patient) stop and say "life has been good and I am ready come what may". The discussion of death in many societies is considered taboo whether brought up by the ill (who often define it as giving up), or their supports (who may lack faith or wish for an expedited outcome). Perhaps if we looked at the discussion of death as a way of freeing one to gain strength from experiences, share in life’s moments and give permission for one to move forward in that area of discovery, we might be making dying a little easier on all who are involved.

How best do we incorporate the discussion of death without losing the patient’s confidence in our skills and abilities as care providers? We try to explain that there are no guarantees with transplantation; no one walks off into the sunset or along a path of rainbows and roses. Yet we all try to present the positive outcomes, quoting survival statistics, our center versus the national average, perhaps forgetting to mention the most recent patient’s death, whether shocking or expected. Sure we touch on the negative aspects of transplantation, but who really ends the discussion on a negative note? Rather we prefer to instill hope—for many, we are the LAST hope. We in the transplant community know that the surgery in itself is not a giver of
everlasting life. Many consider transplant a lifesaving treatment and, although true, death still remains in the future. The question is, how much time and what kind of time are we talking about?

Within the transplant community we recognize that transplant is a major endeavor that requires full commitment by patients and their supports, but our patients and those unfamiliar with transplant often have a misconception of what transplant entails and provides. For us, transplant is like a game of nickel slots: all lines have to be in perfect alignment to obtain the goal of the ultimate win. One has to be sick enough to require a transplant, yet healthy enough to receive and recover. Finances and supportive coverage must be there, and let us not forget about the donor. The wait to match must be in one’s favor. As practitioners, we know that death can come at every turn in the process; however, do our patients really grasp this concept? We have all seen it time and again—the patient referred for transplant that is too sick, the timing is too late, or the patient who lacks supports or finances to accommodate the post-transplant recovery needs.

The patient who is refused transplant and responds with "How could you just let me die?" is only trumped by the patient who was given the second chance at life, but did not live as long as we had hoped. Given the opportunity to reflect on their life’s goals and achievements through journeying with a palliative care focus might have made reaching the end easier, more bearable for the patient and those around them including ourselves, the team.

When we educate patients and their supports on the option of transplant, we have always tried to incorporate talk of life, death and restructuring of roles and dreams. As a social worker, I am fortunate to be able to incorporate the Five Wishes as part of my pre-transplant education. The Five Wishes is an advanced directives tool written in a simple easy to follow format providing patients with the option of selecting a health care power of attorney and completing a living will that allows them to choose the kind of medical treatment they want or do not want in certain terminal situations. In addition to medically focused advance directives the Five Wishes has the additional bonus of including three sections that focus on the patient’s wishes– how they wish to be made comfortable, how they want to be treated and what they wish their loved ones to know.

Reviewing the Five Wishes with a patient naturally leads into the discussion of palliative care while gauging all party’s readiness before beginning the death and dying discussion, and if needs indicate hospice. It is only in recent years that hospice agencies have increasingly recognized the tentative nature of transplant. It is a very fortunate transplant program that is linked with a hospice that will accept a patient that is either in workup or listed and agree to follow them for hospice care. As transplant awareness and understanding grows in the community at large we may see an increase in supportive care for those pursuing transplant, but at this time transplant continues to be seen as an aggressive form of treatment regardless of outcomes, and as such negates one’s ability to elect for hospice in most situations. While the Five Wishes does not replace hospice, it does assist the patient in expressing to their caregivers their needs, preferences and feelings.

In summary, the practitioner who refuses to discuss death is one who questions their own existence or has not come to terms with their own mortality. Preparation is key, not only for oneself, but also for the ones who are left behind. Discomfort in a topic is not an appropriate reason to dismiss an area of need. If this may be the case, then please make the move and incorporate the Palliative Care team in the treatment/referral plan. This is your patient’s life and they deserve to prepare for death as well as the wonderful possibilities that transplant can offer.

**Disclosure Statement:**
The authors have no conflicts of interest to disclose.
FULL CIRCLE

Nancy J Addis, Pearland, Texas

Many facets of my life have come half and, in some cases, perhaps full circle.

From a carefree running, jumping, daring youngster to … a watch-your-step gray-haired up-in-age adult.

From going to bed at a set hour to … hopping under the covers whenever I wish, watching television or reading a book.

From reporting for pre-planned classes on time and completing homework before playtime to … choosing classes and projects that suit my interests and time frame.

From reporting for work, accepting responsibility and answering to “the powers that be” to … unable to work, answering only to myself.

From rising before dawn to ready myself and family for work and school obligations to … waking whenever I choose, reading the daily paper at my leisure and savoring those self-allotted two cups of coffee before breakfast.

From happy memories of spending quality library time as a child carefully choosing books to check out to … required library time for research purposes to … once again spending happy days choosing reading material at the library for my pleasure and personal growth.

From eating what and when I wanted as a baby to … eating what and when I want as an adult.

From wearing casual clothes easily laundered as a child to … white uniform and cap of the nurse to … business attire of the administrator to … now wearing casual clothes easily laundered.

The circle begins … live, love, play, learn and work.

The circle continues … live, love, play and learn.

The circle is complete … life ends.

Enjoy the journey. Respect people along the way.

Appreciate the earth and don’t forget to stop and smell the roses.

Here lies one who meant well,
tried a little, failed much,
surely that may be his epitaph,
of which he need not be ashamed.

– Robert Louis Stevenson
Somewhere along the line, many heart and lung transplant specialists as well as intensivists—in their painstaking eagerness to restore the most critically ill patients with the latest innovations and unprecedented therapies—seem to have forgotten that underneath the severely sick patient is a human being, desiring comfort, compassion, and dignity.

Also, there is a family or significant other waiting their turn for time, attention, and an explanation from the attending specialist during the treacherous course of their loved one’s confinement to the ICU.

This physician must remember that the worst offense he or she could be guilty of, under these trying times, is to ignore and not communicate to the patient or loved-one the events in the ICU. However, it would be more disagreeable to explain vividly and accurately in the most scientific fashion the diagnosis and prognosis which could be seemingly esoteric to most lay individuals, leaving the patient and their loved ones confused and frustrated.

Therefore, it is of utmost importance for us specialists to communicate a clear and plain explanation of the day-to-day interventions and forecast what might evolve over time in a firm and direct yet sensitive and compassionate manner which will require repetition. Unfortunately for many attending physicians and surgeons caring for patients in their final stages of heart or lung afflictions in the ICU, this necessary communication is difficult and time consuming, and to be effective, it must be delivered in a humane and unscientific manner, hence it is a literary art.

Over the last half century, not only have ICUs become ubiquitous in nearly all acute care hospitals in the United States, but also they have evolved from severe polio, burn, trauma, other sudden catastrophic injury, and post-surgical recovery units. Today, these units have become havens equipped with a bewildering array of complex appliances, particularly for transplantation and other forms of replacement therapies. Some of these machines with their own noise-makers (alarms!) include ventilators, computerized vital sign and cardiac monitors, sequential compression devices, and a variety of machines for dialysis, intra-aortic balloon counter pulsation, delivering nitric oxide, extracorporeal membrane oxygenation, cardiopulmonary bypass, mechanical heart devices, and plasma exchange. Moreover, these modern machinations require a myriad of flexible and rigid tubes emanating from the sufferer and demand a variety of health care providers adept at maintaining the function of these external devices without losing sight of the humanity of the patient.

It’s a matter for wonder that even without postoperative and overdose patients in need of time to convalesce in the ICU, the mortality rates in the ICU remain below 50% despite the need for everything mentioned above to be in perfect harmony. Perhaps, only one mistake can drastically alter the course of events such that it becomes public knowledge and the health care system held accountable and for good reason. In effect when someone requires such critical care, this patient and their loved-ones will be introduced to an intimidating area where the potential for complications abound, death is all too common, and care is extremely expensive. These factors will further add to the grief and may come
across rather sudden and unexpected to loved ones that have not been properly prepared for this adventure. How can one possibly attend to the sufferer and their loved-ones in this environment? The one-word answer is: communication. Maybe two words: constant communication.

The importance of communication, which underlies the complete management of the critically ill and their loved ones, cannot be emphasized enough. For without communication critical care management is incomplete. Without communication, we would not know if we are providing any relief from pain or other distressing symptoms in the sufferer. Without communication, we would not know the patient’s and/or loved-ones wishes regarding how aggressive we should be or when dying is ok, thus establishing the “do not resuscitate” order. Without communication, we would not know when it would be most appropriate to withdraw the care that could be prolonging death and shredding the fabric of human dignity in the dying. Of all available treatment strategies in the ICU, communication is perhaps the most economical therapy we have to offer.

How could we apply science without the art of communication? We must help the patient and their surrogates to face and embrace death. One study pointed out that families expect physicians to initiate end-of-life discussion; therefore, isn’t it obvious for us to initiate end-of-life conversation? Once a patient has been admitted to the ICU and stabilized, the attending intensivist must provide a plan to the patient and/or loved ones. When death seems imminent upon admission, it is best to be candid and clear about the bad news including the diagnosis and plan of action. Under these trying times, most of the conversation will be with loved ones as the patient more than likely will be mentally incompetent. Below are useful tips for the initial discussion of when death is imminent vs. when the outcome is uncertain. Most of the time, the ICU physician is meeting with the family for the first time. This first encounter is the most important. Any minor infraction is going to break any establishment of trust that will determine the overall effectiveness of communication.

A few sensible approaches gleaned from the critical care literature to improve communication for such difficult situations include:

1) Have a dedicated conference room  
2) Identify the surrogate in charge  
3) Ask the surrogate about special needs:  
   - Other key family members that must be present  
   - Available interpreters for foreign languages and the deaf.  
   - Determine a preference to sit or not, sitting most of the time is more comfortable.

**Nonverbal Cues**

1) Adjust to eye-level, sit with listeners, standing over and looking down is condescending.  
2) Maintain eye contact  
3) Position oneself away from door (do not stand or be seated with opening next to you or behind you) a nonverbal motion towards the door is misinterpreted  
4) Beware of swaying and backpedaling

**Verbal Cues**

1) Speak slowly, deliberately, and decisively with the agreed plans  
2) Even though uncertainty abounds, must make a decision that everyone agrees with
3) Pause frequently and ask if they are any questions.
4) Ask the surrogate to explain their understanding

**Other Important Points**
1) Expect to repeat the plan
2) Set goals with time
3) In time 24, 48 or 72 hours we will know more about possible outcomes
4) Offer what would be most helpful

**Important Don’ts**
1) Don’t say the patient or your loved one is stable (who is truly stable in the ICU?)—if you are having this sort of conversation, the patient is usually critically ill and could possibly die
2) Don’t say, “We are doing everything…”
3) Don’t say, “We know how you feel…”

**Important Dos**
1) Do ask the loved ones, “What do you think [the patient] would want under these circumstances, if they could communicate?”
2) Are there any other questions you have now and later, and please write them down for our future updates?

Encourage families when in the room with their suffering loved ones to verbally and physically communicate with them. Even though we may be providing sedation and analgesia, assume they can hear, feel, and sense our presence. Be cautious about careless conversations in the presence of the patient and remind the families of this. Encourage the families to spend more time comforting the patient with hugs, hand-holding, wash cloths to the forehead and perhaps soft music. Discourage focusing on the monitors. Tend to the humanity, not the pathophysiology.

**Disclosure Statement:**
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