

Bridging the gap in special registrations

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Agenda

- What is the gap?
- Special registrations & recommendations:
 - Transgender
 - Organ/Tissue Donation
 - Living/Deceased
 - Bone Marrow Stem Cell
 - Hospice
 - Surrogacy (domestic and international)

What is the gap?

- Empathy:
 - Understanding (key word)
 - *Oxford Dictionary: Empathy is the ability to understand and share the feelings of another.*
- Sympathy:
 - Acknowledging feelings
- The gap:
 - Lack of understanding or education allowing for preconceived ideas.

Empathy	Sympathy
Understanding feelings	Acknowledging feelings
Put yourself in their shoes	Providing comfort and assurance
Personal understanding	Understanding the experience of others

Why is it important?

- Special registrations = Emotional situations.
- Positive experiences = Increase in patient satisfaction.
- Outlining, for our staff, the “what” or “what is it?” is imperative.

Empathy is...

seeing with the **eyes** of another,
listening with the **ears** of another,
and feeling with the **heart** of another.

Transgender

The new awareness in gender identity within a healthcare registration.

What does transgender mean?

- Transgender = person whose sense of identity does not correspond to the gender assigned to them at birth.
- When we speak of Transgender we
 - gender identity (internal)
 - gender expression (external)
- Nearly 700,000 transgender individuals in the US

Transgender...what do I do?

- NAHAM Survey
 - 135 NAHAM members
 - No policy or standard work surrounding transgender patients.
 - No facilities allow patients to self identify.
- LGBTQ = Lesbian, Gay, Bi, Transgender and queer or questioning.



National Association of
Healthcare Access Management

Transgender Struggle

- Significant barriers in health care because of bias and discrimination.
- Interactions with healthcare staff often results in negative healthcare experiences.
 - Some examples include: laughter, negative comments, improper name and/or pronoun and improper room assignments.



Struggle Continued

- Office for Civil Rights and a New York City Medical Center had established a new standard for appropriate policies and procedures in relation to Transgender patients.
- Decrease in Transgender patients seeking healthcare resulting in poor health outcomes.

Survey's for Health Care

- In 2011, NCTE (National Center for Transgender Equality) and the National LGBTQ Task Force released a Transgender Discrimination Survey.

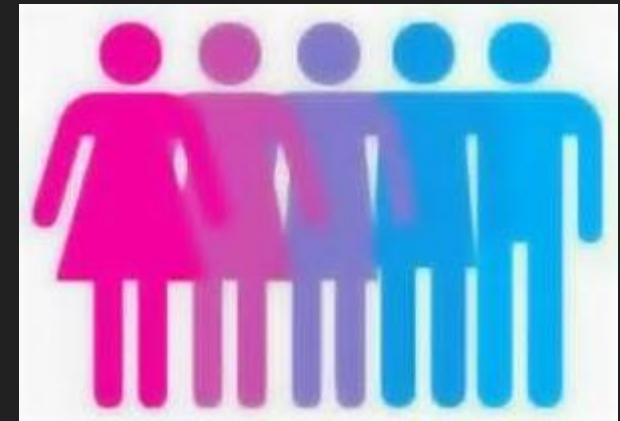


Illinois Survey Results

- 233 respondents in Illinois:
 - 11% were refused medical care
 - 22% postponed medical
 - 47% had employer-based health insurance
 - 45% reported attempting suicide at some point in their life

Awareness, Progression and Terms

- Gender expression = how you present your gender through mannerisms, clothing, etc.
- Gender awareness at 18 months and 2 years.
- Gender identify formed by the age of 3.
- Pediatric registrations and adult registrations the same in relation to identity.



Registration Recommendations

- Transgender friendly environment.
- Privacy is considered like all other healthcare information.
- Have protocols for registration interactions:
 - NEVER ask a patient if they are transgender unless you are using a paper forms.
 - Never guess the patients gender.
 - Gender fields should be what appears on the patient's medical insurance and/or legal identification. Your gender field or papers should include: M and F

Registrations Continued

- Optional field added as other, special notes or special needs. (If volunteered.)
 - Ask the patient “Would you like for your transgender status to be included within your registration record?”
 - Options:
 - Transgender Man (FTM)
 - Transgender Female (MTF)
 - Non-gendered/Agender

Registrations Continued

- Add an optional field of: “preferred Name”. (All patients.)
 - Ask: “What is your preferred name?”
- Add an optional field of: “preferred pronouns” (He or She).
 - Ask: “What are your preferred pronouns?” (If volunteered.)

Bed Placement

Request	Gender	Room Available	Placement
Roommate	Same Identity	Yes - Double	Honor request
Private		Yes - Private	Honor request
Private		No - Only Double	Pt gets empty double. Other bed is blocked.
No request		Yes – Private	Private Room
Does not want to share		No – Only Double	Other patient should be moved or ED boarder.

Gender Reassignment Surgery

- What age allowed for reassignment surgery?
 - Age of majority (18 years of age or older)
- Must be diagnosed as:
 - Gender Dysphoria: persistent discomfort with his or her sex or sense of inappropriateness in the gender role of that sex.
 - Gender Identity disorder.

Gender Reassignment Surgery Continued

- Hormone therapy regimen.
 - What age allowed for hormone therapy?
 - World Professional Association for Transgender Health (WPATH)
 - 12 to 13 years of age: suppress puberty
 - 16 years old cross-sex hormones may be given
- Psychological analysis must also have been conducted.
- Must have lived as their desired sex a full 12 months.

Insurance Coverage and Reassignment Surgery

- Uninsured levels 40-52% are without insurance.
- What does MCR cover?
 - Routine medical coverage
 - Preventative care
 - Medically necessary hormone therapy
 - Medically necessary reassignment surgery

Insurance Continued

- Blue Cross Blue Shield, Aetna, Cigna
 - Age 18
 - Diagnosed with Gender Identity Disorder or Gender Dysphoric
 - Lived and worked as the desired gender for at least 12 months without returning to the original gender.

Making Progress for Equality

- Cal institute website (The Center for Affiliated Learning)
- Human Rights Campaign



Transgender Recap

- Legal name
- Preferred name
- Preferred pronoun
- Gender and/or transgender and or non-gender status



Caitlyn Jenner partners with MAC to raise funds for transgender organizations

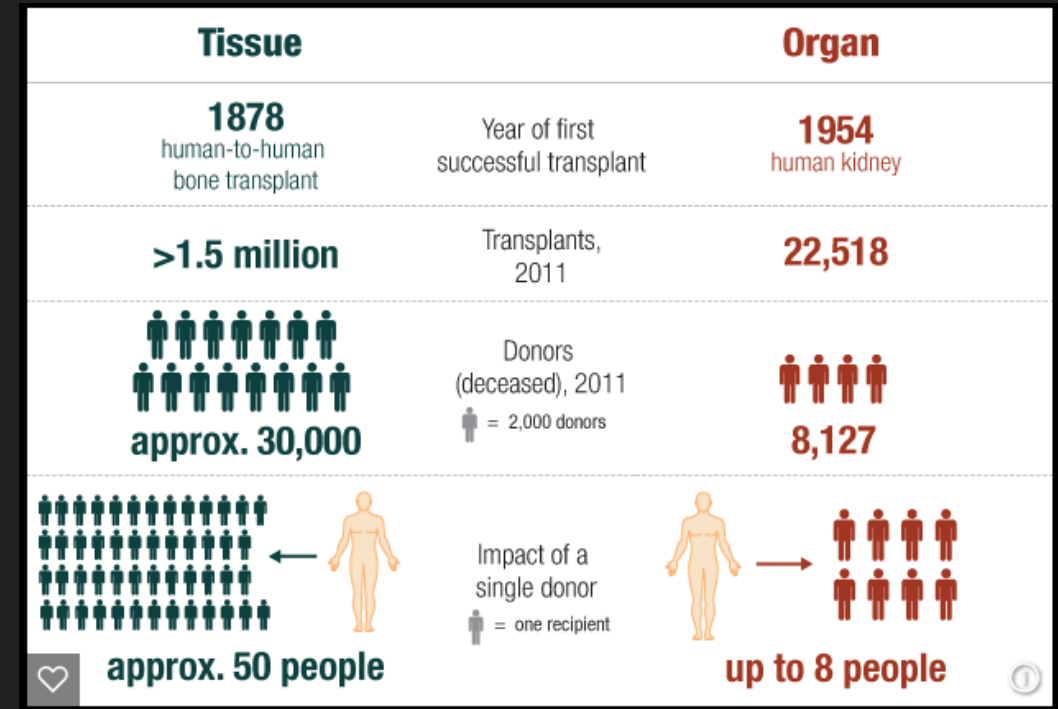
On Friday, MAC announced a partnership with Caitlyn Jenner to raise funds for transgender advocacy work.

Organ/Tissue Donation

Giving life one person at a time.

Organ/Tissue Donation

- Gift of Hope
 - Illinois and northwest Indiana
 - 1 of 58 organ procurement organizations in US
 - serves 180 hospitals
 - 12 million people
- Major organs:
 - Liver
 - Heart
 - Lungs
 - Kidneys
 - Pancreas
 - Small intestine



Donation Continued

- Tissue
- Bone
- Cornea
- Saphenous and femoral veins
- Heart valves
- Skin
- Anyone can become a donor regardless of age, race and gender.
- Donors are usually healthy people that have suffered a life-ended trauma and are declared dead.

Donation Process

- Federal law requires hospitals to notify Gift of Hope
- If a patient has not identified the family is usually contacted to identify wishes.
- There is no cost to the donor family or estate.
- Gift of Hope covers all costs for the donation.
- Skilled surgeons and medical professionals recover organs and tissue in a surgical procedure.

Donor Billing

- Hospital Billing:
 - Gift of Hope should be charged for any harvesting services performed.
 - Gift of Hope will cover costs.

Donation Recipient – How does it work?

- The United Network for Organ Sharing (UNOS) maintains the national computer system identifying patients waiting for a transplant.
 - Evaluation of medical compatibility assessing
 - Body size
 - Blood type
 - Medical urgency
 - Geographical location

The Impact of Donation

- From UNOS:
 - Every 10 minutes someone is added to the national transplant waiting list.
 - On average 22 people die each day while waiting for a transplant.
 - One organ donor can save 8 lives.
 - Only about 50% of people on the waitlist will actually receive an organ within 5 years.
 - As of 2/16/16 there were 121,444 people on the waiting list.
 - From January to November of 2015 there were 28,211 transplants performed from 13,708 donors.

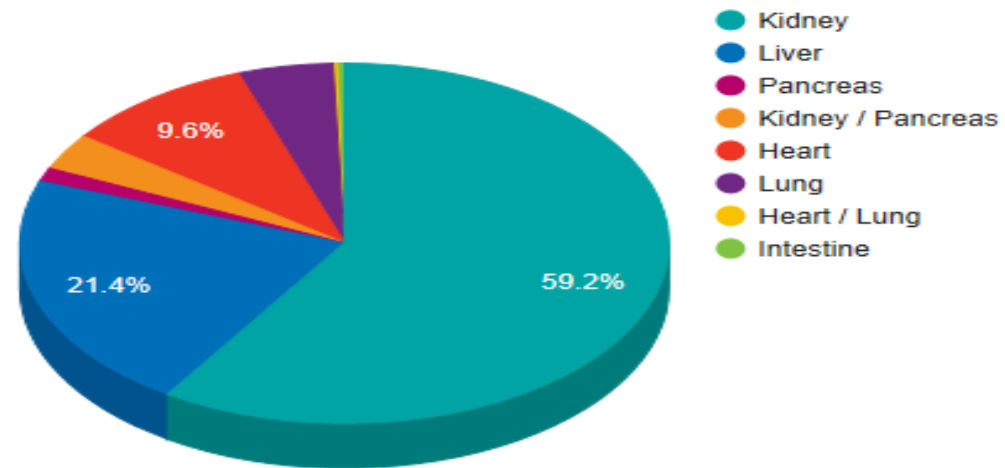
Transplant Statistics

National data

Transplants By Organ Type January 1, 1988 - November 30, 2015

Based on OPTN data as of February 12, 2016

Organ	Transplants
Kidney	384,691
Liver	139,371
Pancreas	8,110
Kidney / Pancreas	21,262
Heart	62,267
Lung	30,822
Heart / Lung	1,181
Intestine	2,644
Total	650,348



Living Donation

- Live donation: about 6,000 transplants are made by living donors.
 - Given part of an organ (liver, lung, pancreas or one kidney) to a recipient.
 - Generally a family member.
 - Individuals 18-60 years of age that will have medical and psychological positive outcomes post donation.
 - Race and gender is not factors in determining a successful match.
- Recovery is generally 2-6 weeks.

Living Donation Continued

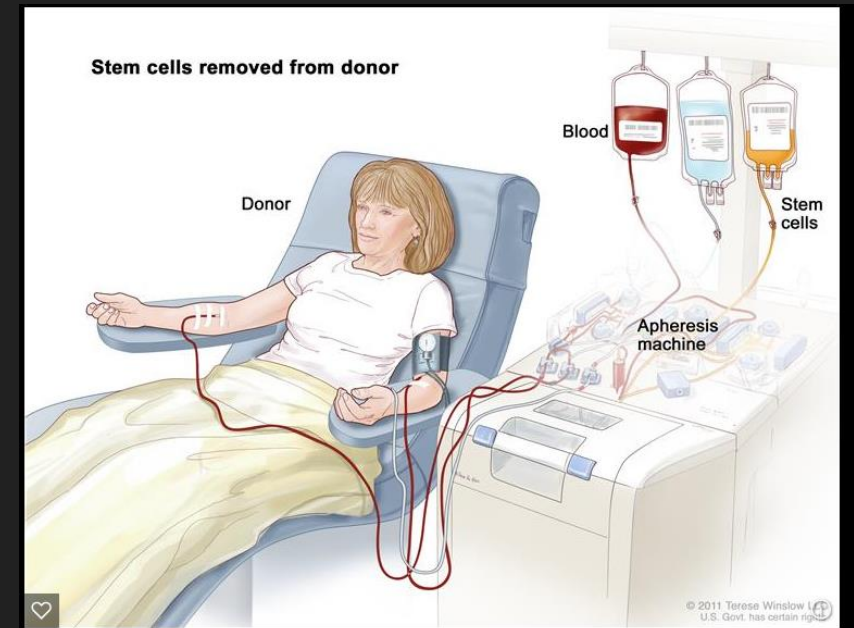
- Billing:
 - Transplant recipients insurance will cover the medical expenses of a living donor.
 - Follow-up coverage may not be covered post-op if medical problems occur from the donation.
 - Some instances, your own insurance may not cover these expenses either.
- A living donor will not be paid for their donation because it is illegal.
- Getting, affording or keeping health, disability or life insurance can become problematic.
- Check with these plans ahead of time is a must.

Bone Marrow

- Is a surgical procedure that takes place in a hospital operating room.
- Under anesthesia doctors use needles to withdraw liquid marrow (where the bodies blood forming cells are made) from both sides of the pelvic bones.
- Healthy 18-44 year olds have the greatest chance of transplant success. They are called for 90% of the time.
- Most likely to donate to someone who shares ancestry.
- Typically the hospital stay is from early morning till afternoon. Outpatient Procedure. Full recovery is generally 20 days.
- If you are a match for a patient, the Donor may be required to travel; most travel expenses are covered by the registry (Be the Match). All medical expenses are covered. Donors do not receive payment for donations.
- Recipients of bone marrow are generally lymphoma, leukemia patients, severe aplastic anemia, some immune system disorders, sickle cell, and some inherited metabolic disorders.
- Billing: covered by the Be the Match

Stem Cell

- Peripheral Blood Stem Cells is another method of collecting blood stem cells for transplant.
- PBSC is a non-surgical procedure called apheresis (like a blood donation)
- For 5 days prior to your donation
 - Injections of a drug to increase the number of blood forming cells within your bloodstream.
- Day of the donation,
 - Blood is removed
 - Passes through a machine that only collects the blood forming cells.
 - Remaining blood is returned to you
 - This session may take up to 8 hours.
- This is generally performed at PBCS facilities. No need for hospital billing.



Organ/Tissue Recap

- Gift of Hope is contacted for every death.
- Gift of Hope covers the cost of donation/harvesting.
- Living donation is covered by the recipients insurance.
- Follow-up care for the donor may not be covered.
- It's illegal to be paid for giving a donation.
- Maybe difficult to keep insurance after a donation or being a recipient.
- Bone Marrow charges are covered by Be The Match.
- Stem Cell is done at an independent facility.

Hospice

Your wish is granted.

Hospice – True Patient-Centered Care.

- Hospice can be done in
 - Inpatient hospital unit
 - Home
 - Nursing homes
 - Hospice centers.
- Hospice Offers a comprehensive program for patients and families facing life-threatening illnesses.
- The goal of hospice is patient comfort with the patient directing care.
- Hospice facilities generally are decorated in home like environments.
- The dying are comforted.

Hospice – How does it work?

- The patient and family are both included in the care plan
- Emotional, spiritual and practical support is given based on the patients and family needs.
- RN under direct orders of a physician.
- Hospice neither hastens nor prolongs death.



Hospice Continued

- Patients are NOT required to have a DNR.
- Hospice is for limited life expectancy (6 months or less) regardless of age or illness.
- By law the decision belongs to the patient about going into hospice.

Hospice and Insurance

- Hospice is referred by the patients physician.
- Billing in an inpatient hospital:
 - Hospice as the guarantor
- If a patients condition improves a patient can be discharged to hospice.
- If a patient need to re-enter hospice. Medicare and most private insurances will allow for additional coverage for this service.



Hospice and Insurance

- Medicare, Public Aid in 47 states and most private insurance providers cover hospice care.
- Medicare hospice benefits covers the full scope of medical and support services for a life-limiting illness.
- Insurance benefits cover almost all aspects of hospice care with little expense to the patient or family.
- Hospice facilities will work with patient and patient families by working to get the patient on state aid, a donation or charity program.

Hospice Recap

- Hospice is the guarantor.
- Medicare, Public Aid and most insurances will cover all costs for hospice care.
- Hospice will work with patients and patient families for coverage of services.
- Donation programs are available.

Surrogate

“Be a rainbow in someone else’s cloud” ~ Maya Angelou

Surrogate Domestic and International

- What is surrogate:
- 2 types of surrogate mothers:
 - Traditional - woman is artificially inseminated with the fathers sperm. The woman who carries the baby is the babies biological mother.
 - Gestational - egg is harvested from the mother and fertilized with the sperm from the father, the embryo is placed inside the uterus of surrogate. No genetic ties to the baby.
- In the US gestational surrogate is less complex legally.



Surrogate Continued

- Illinois only allows gestational surrogacy.
- Financial compensation, for medical and legal aspects of the surrogacy, is only generally allowed by state.
- Money is generally set in escrow prior to any medical care related to the pregnancy.
- For couples that do not have eggs or sperm...donors can be found for both and then have a surrogate carry.

Surrogate – It is more blessed to give...

- Generally for couples where a woman is unable to carry a baby for health reasons or where invitro was unsuccessful. Also, for same sex couples who wish to have a child.
- The Illinois Gestational Surrogacy Act establishes constant standards and safeguards.
 - Parental rights and sole custody rests with the intended parents immediate upon the birth of the child.
 - The Carrier has no legal parental rights or custody.
- The medical provider, chosen by the surrogate, will guide the pregnancy care for the surrogate.

Surrogate – Costs.

- In order to become a surrogate,
 - You must be at least 21
 - Given birth to at least 1 child
 - Have a complete physical and mental health evaluation
 - Undergone legal counsel with an independent lawyer
 - Have health insurance that covers major medical and hospitalization.
 - Insurance must be for the duration of the pregnancy and up to 8 weeks after the birth of the child. If one did not have health insurance, it can be added as a portion of the surrogate contract.

Costs Continued

- The cost of surrogacy
 - Range from \$80,000 to over \$100,000.
- There is no Federal law for surrogacy; it is determined state to state. In some states the intended parents need to file for adoption of the child.
- If the surrogate is married, the husband of the surrogate does not have any legal rights to the child.

Surrogate – Billing

- Billing:
 - Surrogate should be listed as guarantor and surrogate insurance until a letter of intent is received.
 - A letter of intent is provided by the intended parents.
 - change the guarantor (baby) and insurance (baby) to the intended parent(s).
 - Surrogate will be her own unless the letter of intent identifies that the intended parent(s) will be covering her as well under the intended parent(s) insurance.
- Finding a surrogate: most people turn to surrogate agencies

Surrogate Recap

- Surrogate must have health insurance that covers duration of the pregnancy and up to 8 weeks after the birth.
- Or If one did not have health insurance, it can be added as a portion of the surrogate contract.
- Surrogate should be listed as guarantor and under surrogate insurance until a letter of intent is received for the baby.
- Once the letter has been received, change the guarantor (baby) and insurance (baby) to the intended parent(s).

Remember...

- Educate your staff about the process before or after registration on the patient's journey.
- Understanding = Genuine Empathy
- Understanding = Genuine Sympathy

Resources

- UNOS
- Donate Life America
- Gift of Hope
- Organ Procurement and Transplantation Network
- Illinois Surrogate Laws
- Be the match
- Human Rights Campaign Foundation
- Center for Affiliated Learning
- Fenway Health's National LGBT Health Education Center
- Healthcare Equality Index Resource Guide
- Join Commission Field Guide.
- National Transgender Center for Equality

Questions

