TRANSPLANT REFERRAL TO WAITLIST - NAVIGATING THE "SEVEN STEPS"

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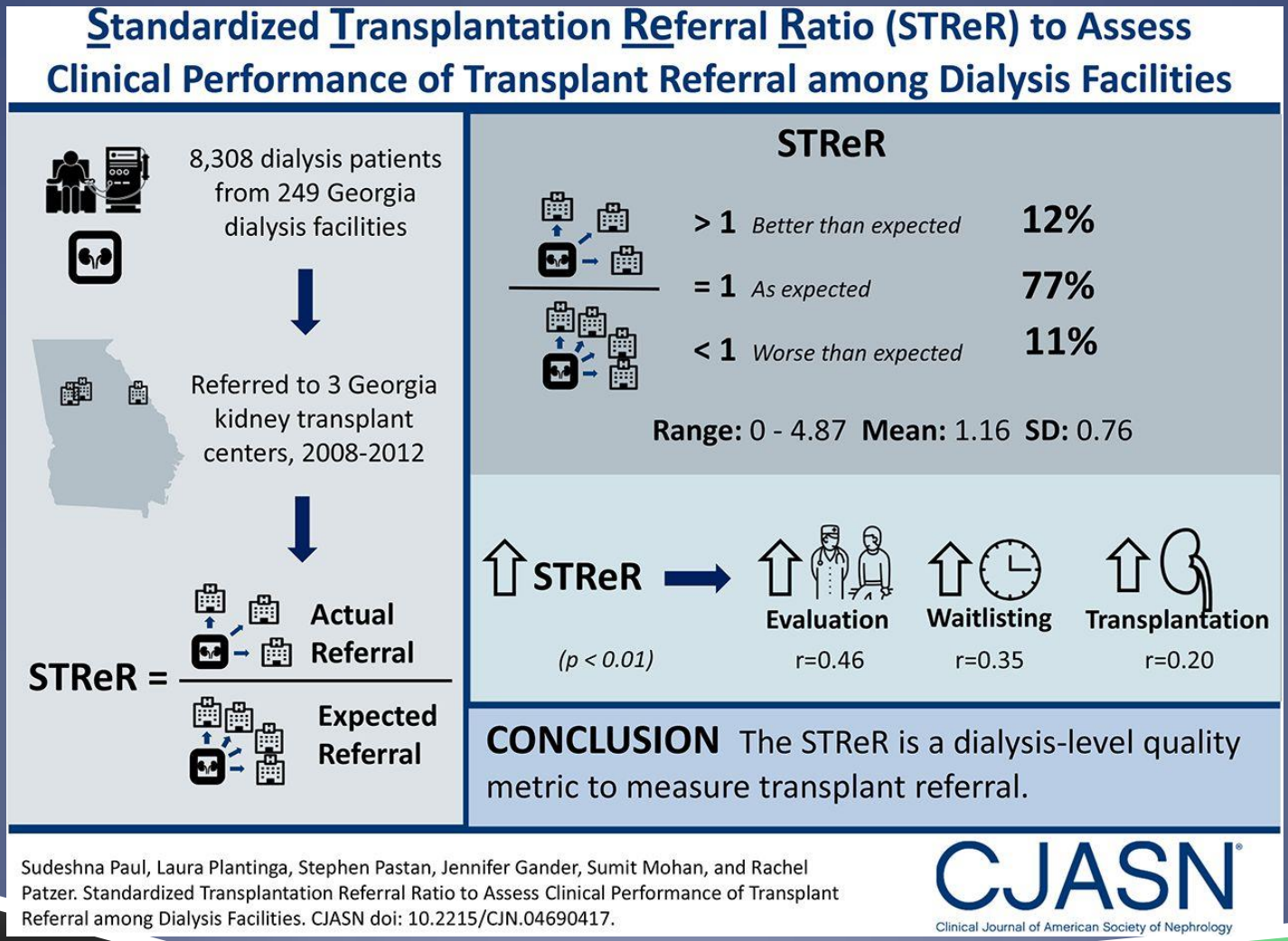
- I have been remunerated for:
  - Providing clinical and administrative transplant services.
  - Expert consultative advice on a single experimental medical device designed by Fresenius Medical Care (never marketed).
  - Expert consultation for solicited, third-party peer site review of transplant centers (Transplant Medical Group)
  - Expert medio-legal consultation (plaintiffs & defendants).
- I do not accept remuneration from pharmaceutical companies, nor do I serve on any paid speaker's bureau for any organization (past or present).
- My analyses and opinions are solely my own, and don't represent the views of any other organization.

OVERVIEW

- Old model: Divisions between general nephrology, dialysis providers, and transplant centers
- New model: Overcoming these divisions, multidisciplinary collaboration, bridging communication gaps
- CMS → ESRD Networks
  - Evolving role in transplant – Moving from "education" to "outcome metrics"
  - Examining and addressing barriers in the continuum from candidate assessment, referral, evaluation, listing, and waitlist management on the facility level
  - Enlisting patient-stakeholders: SME, family members
- Role(s) of the Nephrology RN/AP in advancing access to transplant

Does (risk adjusted) rate of referral really impact waitlisting and transplant rates?



ESRD NETWORK OUTCOME TARGET

Current metric:

By 2023 increase the percentage of ESRD patients on the transplant waitlist to 30% of prevalent patients, up from the 2016 prevalent waitlisted rate of 18.5%.

- This may or may not make sense, and may evolve with time, but…
- SOME metric of referral, evaluation, wait-listing and/or rate of transplantation will shake out as a metric for dialysis facilities.

THE "SEVEN STEPS"

1. Identifying clinical *suitability* for transplantation
2. Assessing/confirming patient's *interest* in transplant
3. Making the initial *referral* to transplant center
4. Patient's *first visit* to transplant center
5. *Completing* the transplant center work-up
6. Waitlisted – *Keeping patients "transplant ready"*
7. Identifying potential *living donor* candidates.

CLINICAL SUITABILITY FOR TRANSPLANT

- Who isn't a candidate for transplantation?
  - Patient refusal, and lack of interest in more information
  - Active systemic malignancy
  - Active, ongoing infection
  - Significant mental or physical debilitation
  - Significant, irremediable ASCVD
  - Significant psychosocial barriers to adherence
  - Ongoing substance abuse (*caveat*)
- Selection criteria vary between different transplant centers
- If you are uncertain, ask.

PATIENT'S INTEREST IN TRANSPLANT

- If a patient seems clinically suitable but uninterested, why?
  - Bad experiences, either personal or word-of-mouth
  - Fear of the unknown, fear of loss-of-the-known (dialysis unit = community)
  - Bad information, or insufficient information – OPPORTUNITY
- How to help:
  - Provide accurate information about transplant in an accessible way
  - Offer referral for transplant education session as a no-obligation opportunity
  - PEER MENTORS - Identify SME (especially former patients) who can empathize with patients
  - Follow up. Interest in transplant doesn't always stop with a single "no."
  - Remind the team: Easy to lose sight of transplant with lots going on

INITIAL REFERRAL – POSITION PATIENTS TO SUCCEED

- Check with the team – CQI a good time/place to discuss issues that may emerge during the transplant evaluation
- Team approach may help avoid individual heuristic biases
- Get and review the written selection criteria of the transplant center
- Include sound information: Recent & comprehensive H & P, updated and accurate med list is extremely valuable to the transplant center
  - **You** know these patients better than the Center probably ever will
- Articulate any concerns: "If you see something, say something"
  - Positioning for success sometimes means identifying & overcoming barriers
- If the barrier is not "clinical," track and periodically revisit
  - Some financial/psychosocial barriers are surmountable.

AFTER THE FIRST VISIT

- Follow up with patients after the referral: "How did it go?"
  - Good clinical relationships breed trust – Questions they were afraid to ask
  - Identify opportunities and strategies to address particular concerns
    - Medication side effects, medication costs, concerns about living or deceased donors
    - If YOU aren't the best person to discuss these with the patients, who might be?
- Build in redundancy
  - Transplant centers aren't perfect – Don't let the ball get dropped because of someone else's scheduling oversight.
- Develop a tracking system
  - Interim – May be home-grown (please make sure it is secure)
  - Coming soon: T-REX -> Transplant Referral Exchange Platform

COMPLETING THE WORKUP (1)

- Patients evaluated for transplant are assigned a transplant coordinator
  - Primary source for initial transplant education (group or individualized)
  - Point-person for scheduling core appointments and standard testing
  - Point-of-contact for patients and providers in navigating the evaluation and waitlisting process
- Make use of the transplant coordinators as a resource
  - They will be the most clued in to where a patient is in the eval/waitlisting process
  - Very important: Communicate key clinical changes to the transplant coordinator
- Encourage coordinators to make use of your contact information – You know these patients better than they ever will
- If there are barriers to completing evaluation find out what they are.
  - Opportunities for providing encouragement and motivation to patients

COMPLETING THE WORKUP (II)

- Testing – *Typically* done through the transplant center
- "Hey can you order this test for us?" is not a straightforward request
  - Billing and coding issues
  - Responsibility for ownership and follow-through on abnormal test results
  - Get clarity on this with your attending physicians and unit medical director
- Areas where the dialysis unit can help
  - Gauge patient's understanding of their progress in the listing process
  - List of patients requiring monthly PRA testing – identify missing samples
  - Functional status concerns – Identify patients who might benefit from PT/rehab
  - BP/volume/dry-weight challenges – Helpful for patients with pulmonary HTN
  - Anti-platelet agents/blood thinners for "access" - Really needed ??

WAITLISTED – KEEPING PATIENTS "TRANSPLANT READY"

- "Where am I on the list?"
  - Remember that waiting time is indexed to start date of dialysis for those not pre-emptively listed
  - Patients with many years of waiting time, and very highly sensitized patients may have a lot of priority soon after approval for waitlisting
  - Being "passed over" happens a lot . False starts happen – Don't be discouraged
- Health/functional status before Tx :: Post-transplant complications
  - Waitlist inactive status - Can be useful to position patients to succeed
  - Encourage honesty & transparency about even seemingly minor illnesses
- Look out for insurance changes for privately insured patients -> Medicare
  - Most patients with Medicare need a medication supplemental plan
- For patients looking at years of waiting time, think about expanding RRT options → Autonomy of transplant :: Autonomy afforded by HT

IDENTIFYING A LIVING DONOR

- Many transplant centers have dedicated living donor coordinators
- Living donor evaluations transpire on parallel, but separate tracks
  - Separate coordinator, transplant nephrologist, transplant surgeon
  - Avoidance of COI between donor and recipient team
  - Dialysis unit and nephrology office AP/RN should respect the same separation
- Living donor evaluations have become more complex (APO L-1)
- Role of the AP/RN in the office or dialysis clinic
  - Facilitate referrals to living donor team , but keep focus on the recipient candidate
  - Ask transplant center to provide copies of their living donor education materials
  - Respect boundaries