Critical elements of Outpatient Transplant patient management

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Disclosure

- No conflicts of interest or disclosure

Pre-Transplant Clinic

- Evaluation Process: referrals made to the program should be initially screened based on program selection or exclusionary criteria.
- Does the patient initially present with something that would prevent them from being able to undergo an evaluation, i.e.(significantly above program BMI limit, over the program age limit; have an active cancer being treated, homeless or undocumented alien).

Evaluation process- con't

- Each program should have its screening criteria and a process for how they are applied.(These must be documented and available to patients upon request)
- Patient evaluation visits can be organized in many ways; one day visit; multiple days, over several weeks, etc. They will vary based on clinic and clinician time availability; decision milestones and patient as well as referring MD satisfaction.

Evaluation process- con't

- Basic elements include: meeting with key transplant team members such as pertinent specialist (nephrologist, cardiologist, etc.); surgeon, transplant coordinator, social worker, pharmacist, financial counselor, psychologist/psychiatrist, dietician and anyone else the team deems needed.
- This should include time for patient/family education about the evaluation process and expectations (Consent to evaluation)

Evaluation process- con't

- Patients and family may have misconceptions about requirements for evaluation and listing. Some think that the first clinic appointment means they "get on the list". Clear and concise communication about a complex topic is difficult to achieve but has a positive impact on patient satisfaction.

Evaluation process- con't

- Patients require a solid support system to assist them with recovery and compliance with post discharge care issues such as meds and clinic appointments, readmissions, etc. It is advisable for patients to have more than one care provider available to them in case someone becomes ill or has other demands on their time.

Evaluation process- con't

- Patients need to have adequate insurance coverage to allow them access to critical medications post transplant. Medication costs are about $20k, year one, if self pay.
- Patients need to undergo a detailed medical evaluation to determine if they can undergo the stress of this surgery and have a reasonable quantity, as well as, quality of life once transplanted

Evaluation process- con't

- Need to ensure that patient has a reasonable probability of being able to follow a complex medical regimen post transplant and be compliant with their meds and aftercare requirements. Patients past behavior/compliance with medications and recommendations for care can be indicator for future compliance issues
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Evaluation process

- Patients may not complete their evaluation and be deferred till outstanding issues are resolved. These issues can be related to social, fiscal or medical concerns but need to have a time limited expectation for completion so that the patient and the referring MD have a clear idea of what is being expected of them to meet the goal of listing.

Waitlist management

- Once the patient is deemed an acceptable candidate for listing, based on the Selection Committee recommendations, the pertinent patient information will be entered into the UNET (Candidate registration) system.
- This function can be performed by a transplant coordinator or may be a dedicated data entry person.

Waitlist management

- There are many required data points that are critical not only to register the candidate but have an impact on program SRTR calculations (primary diagnosis; Karnofsky scale) and others that are regulatory in nature (UNOS mandated 2 person ABO validation prior to successful listing).
- All patients are expected to receive a letter advising them of the Committee decision, whether they are accepted for listing, declined (with rationale) or are deferred pending completion of specific data elements.

Waitlist management

- This letter MUST be received by the patient within 10 business days of the decision. This is OPTN/UNOS and CMS policy and program performance expectation
- Patients must be advised of their ability to multiple list with other transplant centers and given appropriate information on how to go about this. UNOS has educational brochures on this topic.

Waitlist management

- Patients must be educated and consented, prior to listing, if the team feels they are appropriate to consider for an ECD organ, (soon KDPI kidney), DCD donor or a high-risk donor. (Often referred to as CDC high risk, PHS high risk and can also be "OPO designated" high risk)

Waitlist management

- These concepts are to be introduced to patients and/or their family during their education and evaluation process. When the decision is made to list the patient, the expectation is that a signed consent would be obtained and the patient is again educated about the risk and potential benefits of accepting such a donor offer and made clear that they are NOT required to accept such an offer and even if they consent now, they will be asked again at the time of offer if they wish to proceed with offer.

Waitlist management

- For patients who need kidney transplant & may have a potential living donor, the program should discuss LD options, including at their own center (donor/recipient match); or potential for LD txp by participating in Donor exchange such as the UNOS KPD program, National Kidney Registry or Alliance for Paired Donation. These are some of the various registries/exchange groups that exist for facilitating living donor kidney transplant.

Waitlist management

- Not all transplant programs participate in these various registries; that is a programmatic decision based on a number of factors including volume, prospective incompatible pairs; living donor program resources.
- Donor Exchanges: for those programs that choose to participate in any of these exchanges noted above and one can participate in multiple registries; there is a need for dedicated staff focused upon this function to respond in timely manner

Waitlist management

- This will include a living donor clinical transplant coordinator who is expected to focus on evaluating the potential donor and who should have little to no involvement with the recipient. It is critically important that the donor be aware they are a patient in their own right and that their information is confidential and will not be shared with the potential recipient unless they give express permission

Waitlist management

- This can be awkward at times, for staff and recipients, since they are inclined to assume its acceptable to discuss information since they "know" the potential donor or because it's a family member. This is erroneous assumption and issues of coercion, monetary exchanges and other questionable rationale for donation, can and do exist amongst persons known to each other, including family

Waitlist management

- The living donor coordinator is the primary person with whom much of this communication takes place and is expected to "coordinate" and share all pertinent information with the donor, multidisciplinary team and any pertinent consultants.
- The living donor coordinator is the primary liaison with the programs independent living donor advocate (ILDA) and facilitates the pertinent data collection, evaluation and eventual presentation of the donor for consideration, after review with the LD team MD.

Waitlist management

- In donor exchanges, because of the complexity of scheduling multiple LD cases across facilities and distances, it is critically important that the LD program MD's are available to meet regularly with the coordinator, to review the various donor evaluation data points and acceptable antigens in a timely manner so that acceptance/denial responses can be made on any particular donor.

Management of Recipients-post txp clinic

- Post transplant clinic, needs to be structured to facilitate the primary objective of seeing the patients. The program needs to assess if they have enough hours committed from providers, examination rooms and clinic personnel available to facilitate an efficient and effective delivery of services.

Post Txp clinic

- Each program defines how they structure the post txp clinic process. It can be surgeon or medicine driven. In either instance the patients and staff need clear outline of how care is to be organized and what are the expectations of the various team members.
- There are often differences between thoracic & abdominal transplant programs. In thoracic, it is common for the post txp care to be primarily managed by the respective medical specialist (cardiologist/pulmonologist) with surgery available as needed.

In kidney/pancreas/liver, there is a bit more variety. There may be combinations of responsibility based on time post transplant, particular issues that may occur such as disease reoccurrence, availability of space for multi-disciplinary clinic process, etc.
Whatever process is chosen, it is beneficial to have a protocol indicating when surgeon vs medicine will see the patient post txp and assume the primary patient management & when the patient will return to their local referring MD or PCP for aftercare.

- The team definition of aftercare process and responsibility would define what would be the focus of care by the transplant team versus care delivered/ managed by the referring MD or PCP. Who assumes primary responsibility for monitoring critical lab work, immunosuppression levels, anti-viral treatment, HCC monitoring post liver transplant, etc. versus routine management of the patients DM or HTN?

Working with transplant coordinators

- When one has to manage a large population, who are in varying stages of recovery; it is important to have structured processes in place to track patient outcomes; the frequency with which patients are to be seen either in clinic or by reviewing their lab work.
- Having team protocols that are consistently utilized by the medical team is facilitates consistent treatment and interventions. This also assists staff to know what they are expected to do within the program.

- Coordinators need consistent access to MD's who will review patient results and direct treatment plans so that patient issues can be addressed in a timely manner.
- Having regularly scheduled time 1-2 x's/week to review patient records is important to staying current with results and patients that require specific follow up. This enhances patient satisfaction since they receive feedback from the coordinator on a regular basis. This should also include communication with the LMD to ensure coordinated care delivery and referring MD satisfaction.

- Team protocols are useful in guiding coordinator practice in the program and giving direction in care delivery. These also help guide expectations for aftercare phases for the patient and various team members. This does not preclude individualizing care as needed for any particular patient but can still remain within a particular framework of care. Protocols for immunosuppression, steroid sparing and high risk donor post transplant recipient monitoring; anti-viral treatment with CMV mismatches, BK virus tracking, rejection treatment, HCC monitoring, etc. facilitate large population management which coordinators do daily

Coordinators value having input into how the program functions including matters such as expectations for clinic attendance, patient compliance with medications and other treatment regimens, which should be outlined and applied consistently.

What data is to be collected, complications to be tracked within the program and how that data is to be documented; which is critical to program SRTR results.

- MD documentation into the EMR is critical to facilitate documentation of the treatment plan, critical data points required for data submission (UNET)/SRTR results and communication with the team as to expectations.
- Coordinators want structure and definition to facilitate their ability to do their jobs effectively and work collaboratively with their MD colleagues for the ultimate benefit of their patients and the program.