

What does Personalized Care mean to Patients?

Ulf Meier-Kriesche, MD, FAST
Veloxis Pharmaceuticals



CUTTING EDGE of **TRANSPLANTATION**

TRANSPLANT SUMMIT 2019

*NO SIZE FITS ALL: Uncovering the
Potential of Personalized Transplantation*

Disclosure

I am a full time Employee of Veloxis Pharmaceuticals

Learning Objectives

- Understand the patients prospective on personalized transplant medicine based on feedback from the recent FDA transplant workshop
- Understand patient perceived gaps in transplant after care
- Understand on possible ways to fill gaps in patient perceived transplant aftercare
- Learn about initiatives that are trying to bridge the gap

4 Transplant patients were invited to this FDA workshop in September 2018

All patients expressed gratitude for the gift of organ transplantation but pointed out several care gaps:

- Patient relevant information in drug labels
 - Legibility, relevance, format...
- Patient relevant information from physician
 - Decisions are often felt to be made with the graft as priority
 - Physician care decreases dramatically beyond a year post transplant
 - Non Transplant physician don't want to assume responsibility for even small issues
- Patient relevant information from peers

Personalized care from the patient prospective

- Recognize and address side effects
 - Identify which symptoms can be related to a specific medication and look for potential alternatives
 - Explore potential treatment alternatives taking into account patient and graft risk/benefit

While true individualized immunosuppression is a fascinating yet illusive goal, personalized immunosuppression as defined from the patient prospective seems a fairly achievable goal if short and long term resources are made available

Poll

Which patient care gaps have the biggest impact on
Long Term (10-year) Transplant Outcomes?

- Lack of Granular patient follow up after one year
- Acute rejection
- Lack of immunosuppression coverage after 3 years
- Lack of Individualized Immunosuppression
- 1-year graft survival
- Availability of high quality Donor Organs

Which patient care gaps have the biggest impact on Long Term (10-year) Transplant Outcomes?

- Lack of Granular patient follow up after one year
 - Non adherence
 - Early detection of complications
 - Adjustment of regimens (immunosuppressive and other)
 - Coordination of care with other specialties
 - Psychosocial support
 - Long term care plan, medical, financial, social
- **Acute rejection**
 - Secondary largely to the other factors
- Lack of immunosuppression coverage after 3 years
 - Potentially drives immunological injury
- Lack of Individualized Immunosuppression
 - Non adherence
 - Accidents due to interactions of other regimens
- **1-year graft survival**
- **Availability of high quality Donor Organs**

From a society prospective we have focused on acute rejection and short term outcomes and patient centric medicine has fallen behind. As short term outcomes and acute rejection rates are as good as it gets we have now the opportunity to focus on our patients

New initiatives focusing on the Patient

- Personalized and patient centered drug development effort-**FDA**
- New Endpoints, biomarkers and PRO's for Transplantation-**TTC**
- New value definition for Transplant-**Split Rock**
- Organize patient advocacy-**AST**
- Deregulated 1-year outcomes-**CMS**