

Understanding Delays to Pediatric Kidney Transplant Wait-list Activation: Providers and Families Weigh In

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Background

- Timely access to kidney transplant mediates mortality of children with kidney disease.
- Long periods on dialysis are associated with poorer educational and cognitive achievements,¹ and independently mediate cardiovascular mortality.^{1,2}
- Although some guidance on addressing medical comorbidities and conducting the psychosocial assessment exists,³ factors considered in the pretransplant evaluation are not standardized across centers or among patients in a single institution.

Aims

- We examined 1) which factors affect providers' decision making to delay wait-listing, 2) compared provider and family perspectives about the importance of these factors, and 3) determined recommendations to overcome delays to waitlist activation.
- Knowing the factors delaying pediatric patients access to kidney transplant could drive the design of guidelines for equitable care of pediatric transplant candidates.

Methods

- Mixed methods design
- After IRB approval (#19-001877) 20 providers and 20 English speaking family members were recruited to be interviewed using a semi structured interview guide of 25 open-ended questions by phone and recorded verbatim.
- 33 of the 40 participants completed a survey of closed-ended questions on the importance of dimensions that delay waitlist activation scoring from Very important to Very unimportant; surveys were completed with REDCap via email.
- Interviews were analyzed using thematic analysis with consensus by all investigators, with Dedoose (Version 7.0.23)⁴
- Providers were 65% nephrologists, 10% coordinators, 15% surgeons, or 10% social workers from 17 pediatric transplant centers representing 11 UNOS regions (Figure 1).
- Families were purposefully sampled for a diverse population.

They included adult patients (20%) and guardians of patients aged from 2-21y who were post transplant 50%, White 60% and history of dialysis 95%, seen at UCLA 2018-2020.

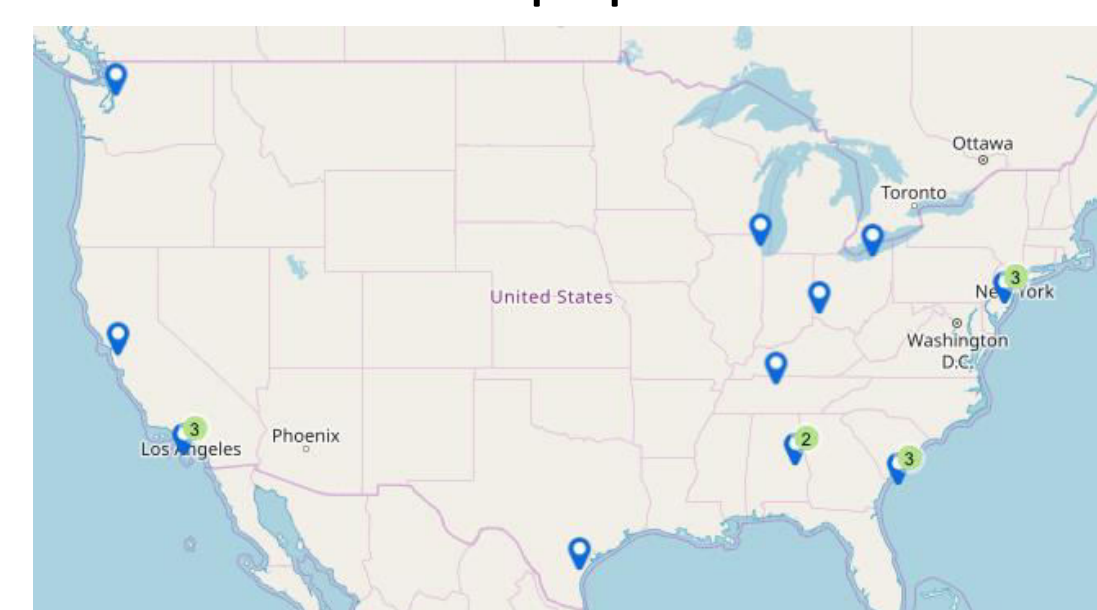


Figure 1: Provider participant locations

Conclusions

- Providers named avoiding retransplantation, unstable family environment, poor physical health (e.g., FSGS), pervasive nonadherence, and poor psychological readiness for transplant care as factors delaying waitlisting. Families similarly described family instability or patient health problems increasing nonadherence. Providers named medication adherence as the most likely factor to cause longer delays. Families said transplant delays exacerbated stress and burdens from the patient remaining on dialysis. These burdens, especially financial, raise ethical concerns that current practices may contribute to disparities in access to transplant. Families consider non-medical functioning as an important consideration in wait-listing decisions, while providers tend to be focused on behaviors observed in the medical setting
- For some patients, delays to waitlist activation may keep them in a cycle of disparity, calling into question *Distributive Justice* of current practices.
- In the special case of access to transplantation, a team of providers can unilaterally limit a patient's autonomy. We should recognize the vulnerable position patients and families are in and the importance of clarity and cooperative discussion about medical decisions, keeping in mind the ethical principal of *Respect for Persons*.
- Decision aids such as *Psychosocial Assessment of Candidates for Transplantation (PACT)*⁵ and *Stanford Integrated Psychosocial Assessment for transplant (SIPAT)*⁶ could assist with more consistent judgements across patients and across providers, and protect against error and bias.

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Results

Table 1 Survey results of factors important to listing for kidney transplant

Question Stem (Family/Provider)	Family important	Provider important	Significance P < 0.001
Adherence			
The patient isn't going to all the dialysis appointments./Patient is nonadherent to medications.	60%	94%	0.35
The patient misses medical appointments, not related to dialysis or kidneys./ The patient is questionably adherent to medical recommendations	60%	94%	0.10
The patient's labs look good showing medications are taken regularly./Phosphorus and hemoglobin are appropriately treated	87%	45%	0.032
Transplant readiness			
The patient is getting counseling if the doctors or social worker said the patient needed it./Patient with known mental illness establish care with a professional	73%	89%	0.55
He patient has reliable health insurance/Proof of reliable insurance	87%	83%	0.49
The patient has a reliable way to get to last minute appointments or the ER./Patients without a personal car or other means of last-minute transportation	100%	77%	0.002
Two caregivers are available to take care of the patient./Patients with a single caregiver find a second/back up caregiver before they become transplant candidates	47%	67%	0.494
The patient's blood pressure is always good. /Patient has well controlled blood pressure	73%	56%	0.149
Daily functioning			
All the patient's caregivers can read/Caregivers can read	93%	39%	0.0006
The patient feels well enough to go to school or keep a job./Patient too ill to school/work regularly	60%	28%	0.043
The patient is getting good grades or keeping a job./Patient performing well in school	50%	17%	0.065

Table 2 Themes of Primary waitlist delays identified by Providers and representative quotes

Theme	Quote by Provider
Avoiding retransplantation	"Because the first kidney is the precious one, it lasts longest and if you lose it, you may have to wait for a decade to get another on dialysis. And it's harder to get the second or the third ...if we do it and the kidney fails then you're going to be screwed for the next decade whereas you wait a bit longer here, so you're in a better place." (P12 nephrologist)
Pervasive treatment nonadherence	"Adherence is a major concern...missing dialysis appointments, are they having recurrent episodes of peritonitis, are they taking their phosphate binders, are they missing appointments, are they following through with their bladder catheterization regimen. All of these are signals of how well they're gonna take care of their transplant I think." (P16 nephrologist)
Need for social support	There has to be a stable home...have transportation they don't necessarily have to have a car but some sort of transportation, some backup caregivers... they need to have a job. (P10 surgeon)
Poor physical health	"Issues like uncontrolled hypertension, severe hypertension... recurrent fsgs essentially ...we hold them back until we have nephrectomies, get it under control, So those are the medical is that the medical things. And then active vasculitis of lupus... obviously active lung disease, or chronic lung disease that are not gonna tolerate fluid overload or oxygen requirement." (P15 nephrologist)
Poor psychological readiness for transplant	"I worry about adherence in depressed patients. Equally worried though that not transplanting patients can worsen or aggravate depression...patient has a mood disorder or an adjustment issue that is related to being on dialysis, I'm very aggressive about trying to get them to transplant. On the other hand, I feel like organic depression... anxiety disorder ... if I see it even in a family member, then I'm really cautious ... that they have psychiatric clearance, and they have plans in place ..." (P18 nephrologist)

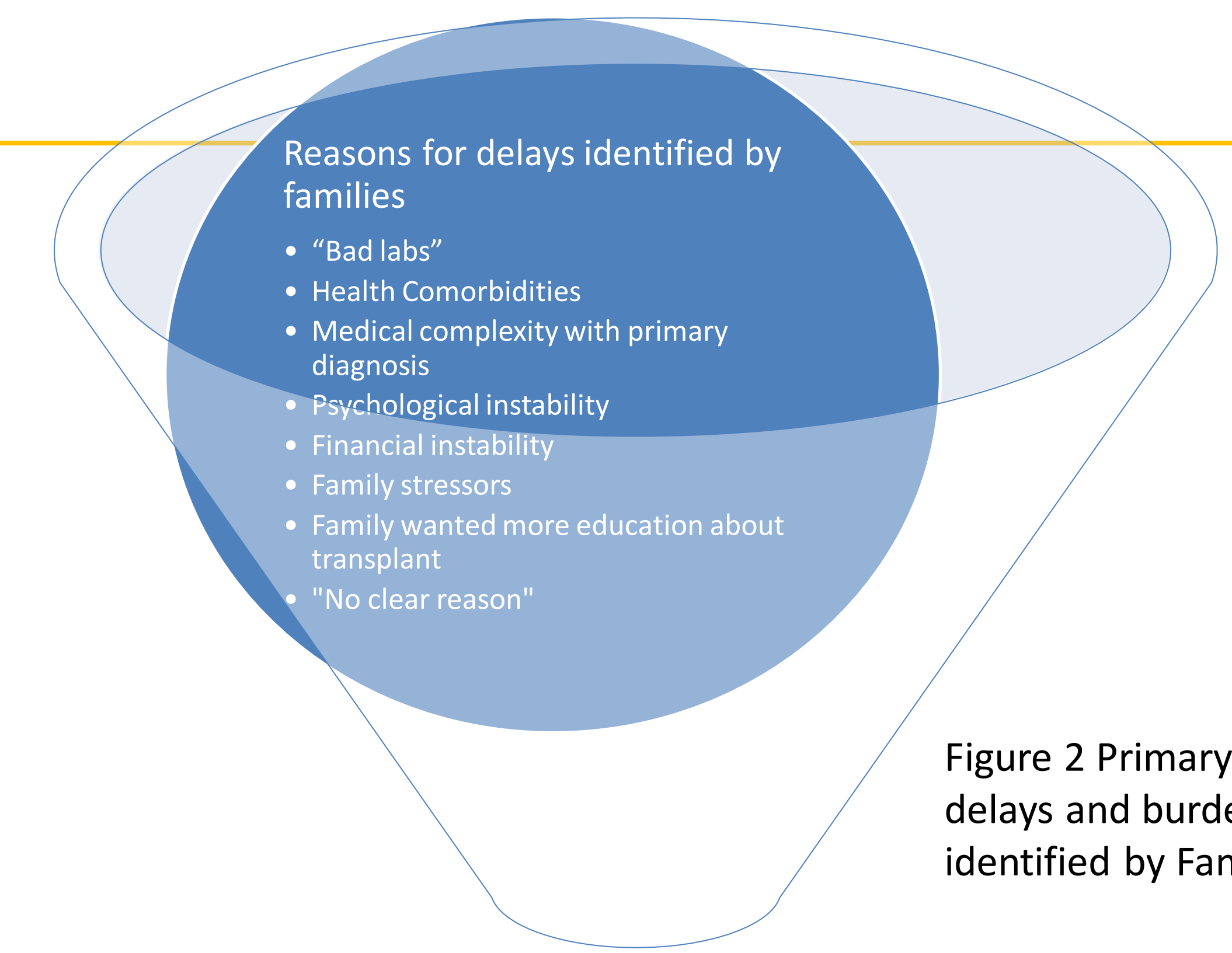
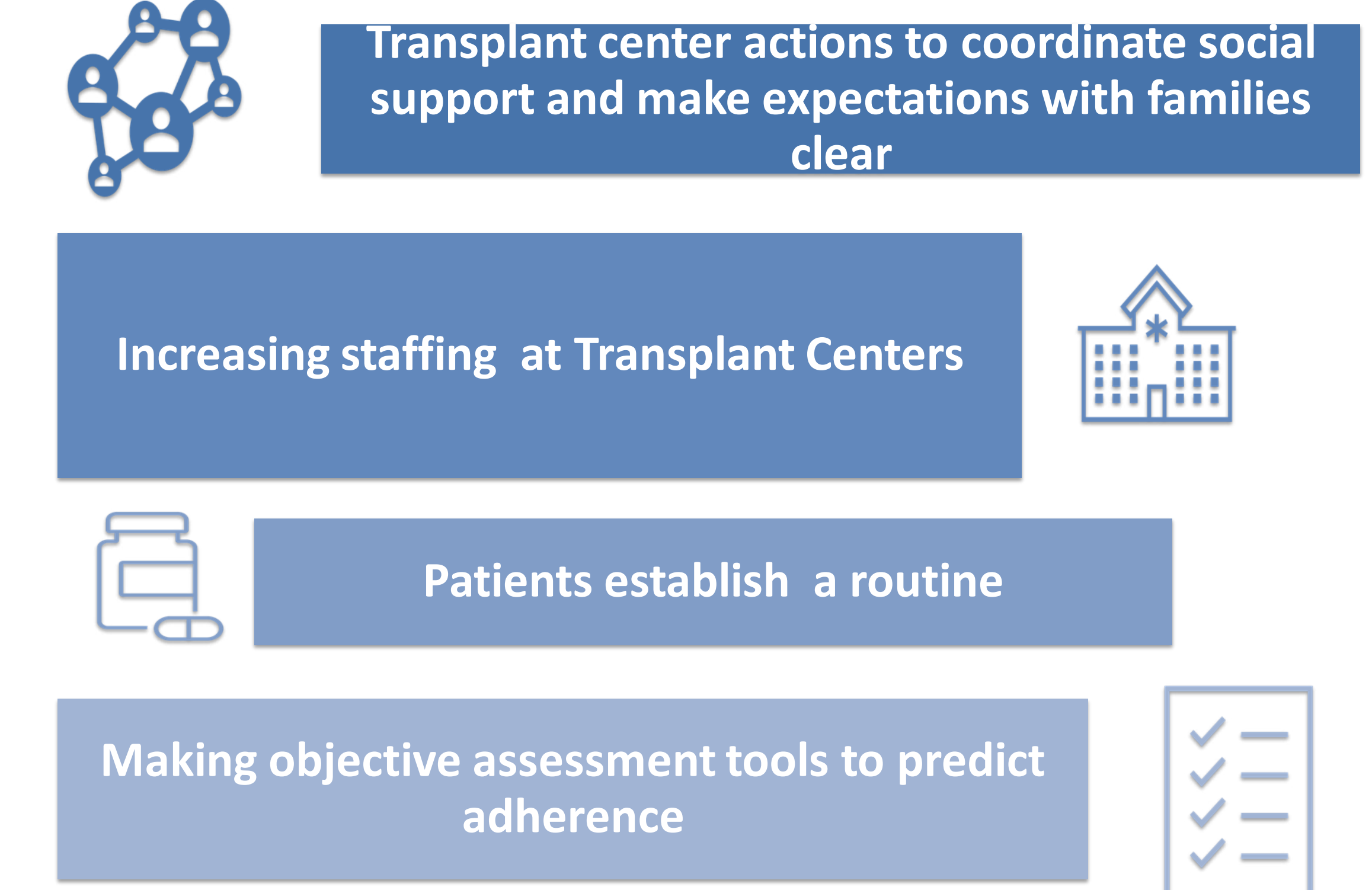


Figure 2 Primary Waitlist delays and burdens identified by Families

Burdens associated with delays to transplant

- Lost income opportunities
- Falling behind in School
- Caregiver burn out
- Social isolation
- Stressed relationships
- Lost income opportunities
- Health consequences from ESKD care (depression, fistula creation)

Figure 3 Solutions to common delays identified by Providers and Families



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