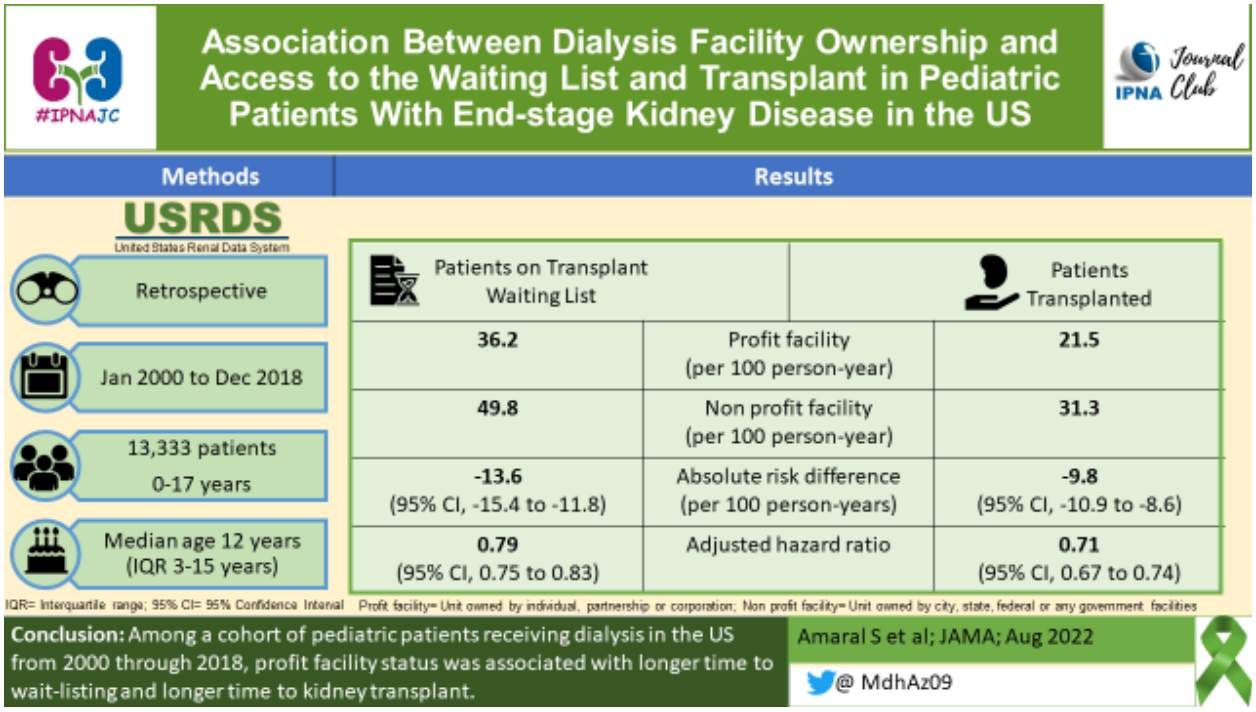
Association Between Dialysis Facility Ownership and Access to the Waiting List and Transplant in Pediatric Patients With End-stage Kidney Disease in the US

Sandra Amaral, MD, MHS; Charles E. McCulloch, PhD; Feng Lin, MS; Barbara A. Grimes, PhD; Susan Furth, MD, PhD; Bradley Warady, MD; Celina Brunson, MD, MSCE; Salpi Siyahian, BA; Elaine Ku, MD, MAS

JAMA. 2022;328(5):451-459. doi:10.1001/jama.2022.11231
PMID: 35916847 **PMCID: PMC9346544**

Here is a wonderful VA by Dr. Madiha Aziz



Take Home Message:

Pediatric patients being dialyzed at profit facilities are enrolled on waiting-lists and receive renal transplants later than their counterparts at non-profit dialysis facilities.

Most pediatric nephrologists practice in non-profit facilities and probably facilitate earlier registration on waiting lists for transplant .

Dialysis centers usually cater to a few children per facility. As a result, children are managed by adult nephrologists who may not have adequate resources and a multi-disciplinary team, well versed with ESKD management and transplant education in children.

Transparency and accountability of dialysis facilities should be encouraged so that children can benefit from a timely transplant.

Introduction

Kidney transplantation (KT) improves the quality of life and survival compared to dialysis. However, demand for KT far exceeds the supply of donor kidneys. Pediatric dialysis patients have better survival and referral for transplants compared to adult patients who have a higher mortality rate even with shorter waiting times for transplant. Pediatric patients are prioritized on the kidney allocation list; most receive renal transplants within two years of starting dialysis, with low death rates.

End-stage kidney disease (ESKD) incidence and prevalence are lower amongst pediatric patients than adult patients. Hence, there are fewer pediatric facilities for dialysis, most of which are based in academic centers. As a result, one-third of children receive care at adult dialysis facilities in the US.

Research has shown that adult dialysis patients who received care at profit facilities fared poorly in rates of transplant and survival. Up to 89% of dialysis facilities in the US are profit-based.

Aim:

This retrospective analysis examined the association between the profit status of a dialysis facility and the amount of time taken for pediatric ESKD patients to be placed on a waiting list or to receive a renal transplant across the USA.

Methods

Study Population and Data Source

US Renal Data System (USRDS) was used to identify children aged from 0-17 years who were started on dialysis from 1st January 2000 through 31st December 2018.

Inclusion:

- Children and adolescents between 0-17 yr with ESKD
- Those who started dialysis between 1st January 2000 through 31st December 2018 in the USRDS data system

Exclusion:

- Patients who did not have evidence of a medical evidence report (MEDEVID) filing at the time of dialysis initiation or whose facility identification was missing.
- Patients who received preemptive transplants.
- Patients who were put on preemptive transplant waiting lists were also excluded from the primary analyses but included in the secondary analyses.
- Patients from US territories or missing geographic details.

Patient forms were filled by dialysis staff and verified by clinicians. The following data was extracted from MEDEVID and USRDS files:

- Age at diagnosis of ESKD
- Gender
- Race and Ethnicity: Asian, Hispanic, non-Hispanic Black, non-Hispanic White, American Indian and Alaska Native, Middle Eastern and Arabian, Native Hawaiian, Pacific Islander, or unknown racial groups and others
- Cause of ESKD (DISGRPC)
- Insurance status at ESKD onset (none, Medicare, Medicaid, both, private)
- ESKD network
- Dialysis modality: hemodialysis vs peritoneal dialysis
- Date of dialysis initiation
- Patient zip codes and residence (Northeast, South, Midwest, West)/ (Rural, micropolitan or metropolitan)

Dialysis facility profit status

Profit status of facilities were classified on the basis of:

1. Type of ownership i.e, individual, partnership or corporation
2. Profit or non-profit
3. *Primary exposure:* time period a patient spent at a profit facility and if there was a switch in facility

Non-profit facilities included city, state, federal and other government facilities.

Profit status was coded as follows

- 1 for profit
- 0 for non-profit
- 0.5 for change in profit status in the same calendar year

Outcomes

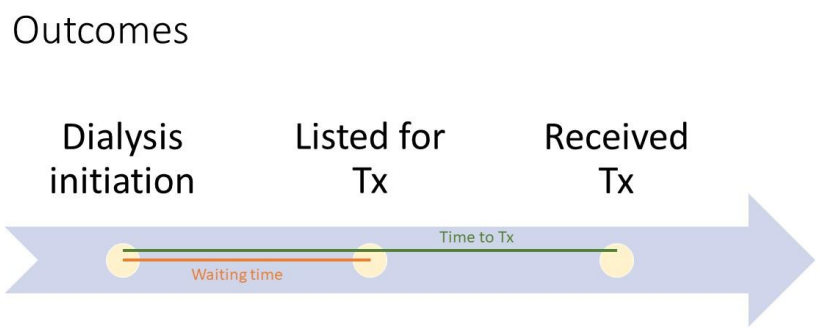
All outcomes were determined through 30th June 2019

Waiting-time: Time from initiation of dialysis to registration in the first waiting list. Patients who were pre-emptively put on the waiting list were assigned time as 0.5 days.

Time to transplant: Time between dialysis initiation and first transplant.

Outcomes of living and deceased-donor kidneys were examined together as well as separately.

Patients who were lost to follow up **or** recovered renal function for more than 90 days were censored.



Statistical Analysis

Demographics and clinical characteristics of all participants were categorized into three groups: those dialyzed at profit facility, those dialyzed at non-profit facility and those who switched facilities with a different profit status during follow-up.Cox proportional hazards model was used to examine the association between dialysis facility profit status and time to waiting list registration or transplant with adjustment for baseline characteristics.

Several sensitivity analyses were run, however, patients whose follow-up details were missing or those who switched facilities were excluded from these analyses.

Fine-Gray models were used to examine the association of profit status with wait-listing while treating the death as the competing risk. Similarly, association of profit status with transplant while treating death and alternative donor as competing risks was also examined.

Interactions between profit status of facility and calendar year of dialysis initiation were calculated. Hazard ratios were calculated for profit vs non-profit by calendar year of dialysis initiation (categorized at 5 year intervals) with minimal adjustment for age at ESKD onset and full adjustment for age at ESKD onset, sex, race and ethnicity, insurance status, region of US, dialysis modality, cause of ESKD, ESKD network, rurality and incident year of ESKD. An interaction was considered to be present if P value was less than 0.05. Subgroup analyses were pursued if an interaction in adjusted groups was present. For subgroup analysis, age was divided into 0-5 years, 6-11 years, and 12-17 years.

Results:

Demographics:

13,333 pediatric patients (median age, 12 years [IQR, 3-15 years]) who started dialysis from January 1, 2000, through December 31, 2018, were included.

6054 (45%) were female .

3321 (25%) were non-Hispanic Black individuals, and 3695 (28%) were Hispanic.

Patients receiving care at profit facilities:

3618 (27%) patients were initially treated at profit facilities.

They were older (median age 13 years; IQR, 2-16 years) than those at nonprofit facilities (median age, 10 years).

The percentage of rural patients who received dialysis at profit facilities was slightly higher (7.7% vs. 6.7%). Similarly a higher percentage of those living in micropolitan areas received dialysis at profit facilities (10.2%, n=369) than at nonprofit facilities (8%, n=629). Of the patients receiving dialysis at profit facilities, 2343 (64.8%) were at large-chain facilities compared with 123 (1.6%) receiving dialysis at large-chain nonprofit facilities. Mortality was seen in 612 (16.9%) patients initially receiving dialysis in a profit facility, 582 (7.4%) at a nonprofit facility and 219 (12.5%) who switched facilities.

Table 2. Absolute Incident Rate of Outcomes and Absolute Risk Difference by Status of Dialysis Facilities

	Profit facilities		Nonprofit facilities		Incident rate of events per 100 person-years		
Outcome	No. of events[a]	Total person-years of follow-up	No. of events	Total person-years of follow-up	Profit facility	Nonprofit facility	Absolute difference (95% CI)
Wait-listing	2697	7455	7417	14 898	36.2	49.8	−13.6 (−15.4 to −11.8)
Transplant[a]	2349	10 904	6812	21 769	21.5	31.3	−9.8 (−10.9 to −8.6)
Living donor transplant	829	10 904	2360	21 769	7.6	10.8	−3.2 (−3.9 to −2.6)
Deceased donor transplant	1520	10 904	4447	21 769	13.9	20.4	−6.5 (−7.4 to −5.6)

[a] Sixty patients are not included in this table.

As seen in table 2, a total of 10,158 patients (76%) in the cohort were registered on the ***kidney transplant waiting list.*** The median time between dialysis initiation and wait-listing was 0.87 years (IQR, 0.39-1.85 years). Comparing profit vs nonprofit status, the minimally adjusted hazard ratio (HR) for wait-listing was 0.72 (95% CI, 0.69-0.75) and the fully adjusted HR was 0.79 (95% CI, 0.75-0.83; ***absolute difference, −13.6 waitlisting events per 100 person-years***). The association between dialysis facility profit status and access to the transplant waiting list did not differ by age at dialysis initiation (P for interaction = .71).

The fully adjusted HR of wait-listing at profit vs nonprofit facilities in 2000-2004 was 0.87 (95% CI, 0.80- 0.95; absolute rate difference, −7.1 per 100 person-years) and worsened over time but improved in 2015- 2018. *When profit status was examined as percent of time spent in a profit facility for every 10% of increased exposure time to a profit facility, HR for access to wait-listing was 0.98 (95% CI, 0.98-0.98).* (Table 3)

Table 3. Hazard of Wait-listing by Status of Dialysis Facilities Stratified by Calendar Year of Dialysis Initiation in Primary Analysis

		Incident rate of events (per 100 person-years)			Profit vs nonprofit, HR (95% CI)	
	No.	Profit facility	Nonprofit facility	Absolute difference (95% CI)	Minimally adjusted[a]	Fully adjusted[b]
Overall	13 333	36.2	49.8	−13.6 (−15.4 to −11.8)	0.72 (0.69 to 0.75)	0.79 (0.75 to 0.83)
By calendar year of dialysis initiation						
2000-2004	3769	37.7	44.8	−7.1 (−10.2 to −4.0)	0.85 (0.79 to 0.92)	0.87 (0.80 to 0.95)
2005-2009	3807	33.0	48.0	−15.0 (−18.1 to −11.9)	0.70 (0.65 to 0.76)	0.76 (0.69 to 0.83)
2010-2014	3379	34.5	55.3	−20.8 (−24.4 to −17.2)	0.62 (0.56 to 0.67)	0.71 (0.64 to 0.78)
2015-2018	2378	44.0	56.5	−12.5 (−18.1 to −7.0)	0.75 (0.66 to 0.85)	0.78 (0.68 to 0.90)

Abbreviations: ESKD, end-stage kidney disease; HR, hazard ratio.

[a] Adjusted for age at ESKD onset.

[b] Adjusted for age at ESKD onset; sex; race and ethnicity; insurance status; region of the US; time treatment modality was updated (hemodialysis vs peritoneal dialysis); cause of ESKD; ESKD network; rurality; and in overall models, incident ESKD year.

In analyses using Fine-Gray models and accounting for competing risk of death, the subhazard for wait-listing in fully adjusted models was 0.80 (95% CI, 0.76-0.84) for patients receiving care at a profit vs nonprofit dialysis facility. The adjusted HR of wait-listing by profit status was not statistically significant in the Midwest (HR, 0.92; 95% CI, 0.83-1.03; absolute rate difference, −4.5 per 100 person-years) but was statistically significant for the other regions examined. No statistically significant interaction was observed between profit status and rurality of patient residence (P = 0.25).

Table 4. Hazard of Transplant, Comparing Status of Dialysis Facilities by Age at Dialysis Initiation

Age at dialysis initiation, y	No.	Incident rate (per 100 person-years)			Profit vs nonprofit, HR (95% CI)	
		Profit facility	Nonprofit facility	Absolute difference (95% CI)	Unadjusted	Adjusted[a]
Transplant						
0-5	4036	17.5	32.4	−14.9 (−17.0 to −12.8)	0.53 (0.48 to 0.58)	0.84 (0.75 to 0.94)
6-11	2526	29.9	38.0	−8.1 (−11.7 to −4.5)	0.75 (0.67 to 0.85)	0.82 (0.73 to 0.93)
12-17	6771	21.7	28.4	−6.7 (−8.2 to −5.3)	0.71 (0.67 to 0.76)	0.73 (0.68 to 0.78)
Living donor						
0-5	4036	8.7	13.8	−5.0 (−6.5 to −3.6)	0.68 (0.59 to 0.79)	1.08 (0.92 to 1.27)
6-11	2526	9.3	12.3	−3.0 (−5.0 to −1.0)	0.78 (0.64 to 0.96)	0.89 (0.72 to 1.10)
12-17	6771	6.8	8.9	−2.1 (−2.9 to −1.3)	0.77 (0.69 to 0.86)	0.79 (0.70 to 0.88)
Deceased donor						
0-5	4036	8.7	18.6	−9.8 (−11.4 to −8.3)	0.42 (0.36 to 0.49)	0.67 (0.57 to 0.79)
6-11	2526	20.6	25.6	−5.0 (−8.0 to −2.1)	0.74 (0.64 to 0.85)	0.79 (0.68 to 0.92)
12-17	6771	14.9	19.5	−4.6 (−5.8 to −3.4)	0.69 (0.64 to 0.74)	0.70 (0.64 to 0.75)

Abbreviations: ESKD, end-stage kidney disease; HR, hazard ratio.

[a] Adjusted for age at ESKD onset, sex, race and ethnicity, insurance status, region of the US, time-updated treatment modality (hemodialysis vs peritoneal dialysis), cause of ESKD, ESKD network, rurality, and incident ESKD year.

The ***median follow-up between dialysis initiation and kidney transplant*** was 1.52 years (IQR, 0.75-2.87 years), and 9201 patients (69.0%) received a kidney transplant. The unadjusted HR for receipt of transplant was 0.65 (95% CI, 0.62-0.68) comparing profit vs nonprofit facilities

which corresponds to an absolute rate difference of −9.8 transplants per 100 person-years. In fully adjusted models, this finding persisted (HR, 0.71; 95% CI, 0.67-0.74) for any transplant.

Unadjusted analyses for outcomes of transplants from living vs deceased donors showed the HR for transplants from a living donor to be 0.71 (95% CI, 0.66-0.77) comparing profit vs nonprofit status which corresponds to an absolute rate difference of −3.2 living-donor transplants per 100 person years and was similar in adjusted analyses. (Table 4)

A statistically significant interaction was detected between profit status and whether a facility was hospital based or freestanding ($P < .001$) for the outcome of transplant.

Limitations

- This is general data from USRDS and cannot be used to localize areas of deficiency.
- Causality association cannot be ascertained as this is a cross-sectional, retrospective study
- More in-depth data is needed to assess patient characteristics, dialysis care team, and care models of profit vs non-profit facilities to optimize referrals, wait-listing and finally transplant for pediatric patients
- It has been reported by Balhara et al that physicians at profit facilities are less likely to discuss and emphasize on renal transplant as compared to those who work in non-profit centers. Besides, discussions involving transplant need the engagement of both patients and their care-givers which becomes a unique challenge in pediatric patients. Clinicians may not be comfortable with these discussions.

Conclusions

US pediatric patients receiving dialysis in profit facilities have a longer time to wait-listing and a longer time to kidney transplant, as seen in this cohort of patients.

Discussion

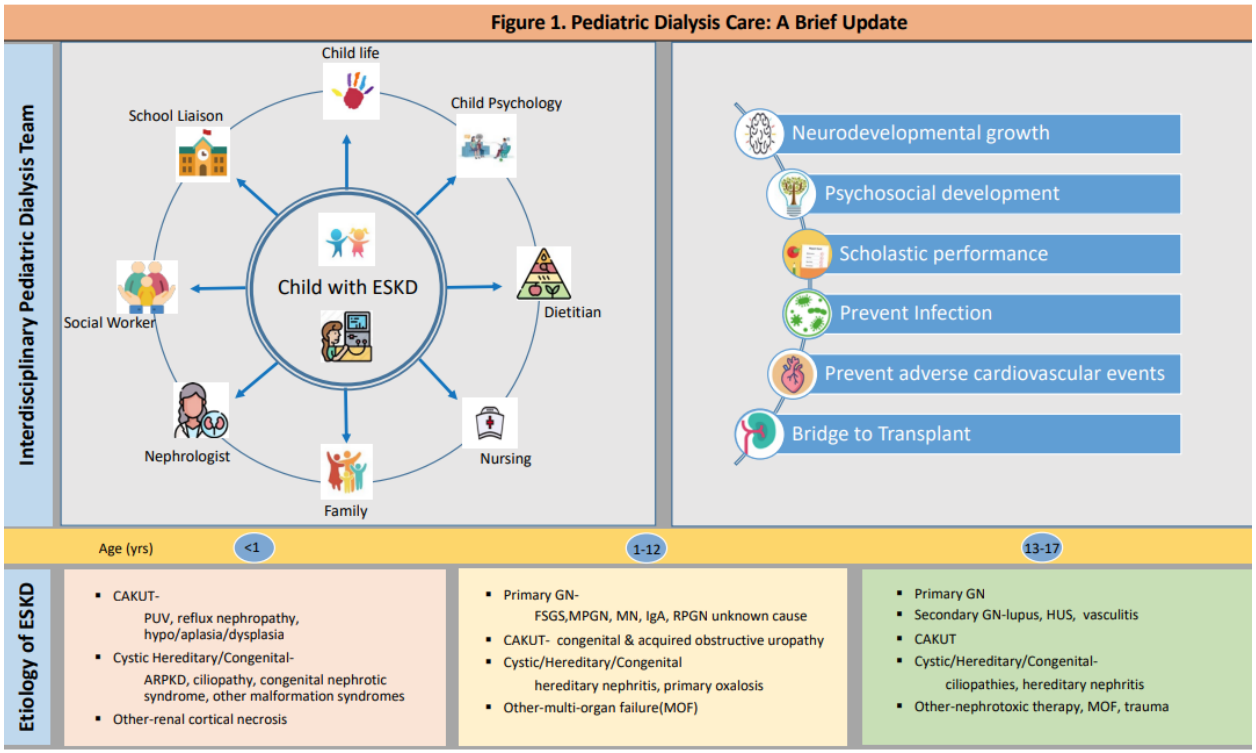
This study analyzed data of more than 13000 ESRD pediatric patients from the US and found that being dialyzed at a profit facility was more likely to result in a longer time to being wait-listed for a transplant or receiving a transplant (live donor or deceased donor) as compared to being dialyzed in a non-profit facility. Additionally, patients from profit-based facilities registered for a deceased donor transplant underwent longer waiting times as compared to those on list for living donor transplant. This association was not observed in the Midwest region of the US for reasons that could not be elucidated.

These findings were seen across the board though the trend attenuated slightly from 2015 onwards as compared to 2005-2014. These findings are similar to that of the adult ESKD population. However, a confounding factor is that most pediatric patients are dialyzed at non-profit facilities where most pediatric nephrologists are likely to practice.

This association suggests that pediatric ESKD patients dialyzed at profit facilities may be at a disadvantage as far as their access to transplant is concerned. The absolute rates of wait-listing and transplant were lowest in free-standing facilities. This could perhaps be explained by the fact that these facilities are unlikely to have pediatric nephrologists who are usually found to practice in hospital based settings. Moreover, care delivery models may differ

as most dialysis centers are manned by adult nephrologists and staff skilled in care of adult patients. This lack of pediatric expertise may affect management of children with ESRD.

Also, there are some significant differences between adult and pediatric nephrology dialysis centers as shown in teh figure published in ASN Kidney News.



As analyses from various geographical regions were assessed, it was found that more children from the Northeast received dialysis at non-profit facilities where the majority of pediatric nephrologists were also found to be practicing. Infact, a shortage of pediatric nephrologists in the workforce has been seen in southern and western regions of the US. Due to the low prevalence of ESKD in children with only 1 or 2 children being cared for per adult facility, directing all pediatric dialysis to a particular facility of a geographical region would be difficult.

The Center for Medicaid and Medicare Services (CMS) in the US has undertaken collaborative efforts to improve reporting and develop quality standards for transplant access, but, due to small numbers, pediatric patients are generally not included in these reports. The pediatric nephrology community of the US has expressed its interest in collaborating with the CMS to improve transparency and accountability of dialysis facilities so that children on dialysis can benefit from timely and optimal transplants. Care should be taken to ensure these assessments are encouraging for caregivers of pediatric patients rather than being a means of penalizing them. Further studies are needed in this regard.

Summary Written by Madiha Aziz and Suprita Kalra

Edited by Shweta S. Shah, Sai Sudha Mannemuddhu