

Palliative Care For Dialysis-Dependent Pediatric Patients: A Survey Of Providers, Bedside Nurses, And Caregivers

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BACKGROUND

- Despite advancements in pediatric end-stage renal disease (ESRD) management, dialysis-dependent patients and their families encounter complex medical, psychosocial, and existential challenges throughout the disease course.
- In comparison to pediatric patients with other chronic illnesses, those with ESRD experience lower health-related quality of life.
- Subspecialty palliative care consultations remain an underutilized resource in pediatric nephrology.
- Potential barriers to palliative care involvement for dialysis-dependent patients include stigmatization and lack of awareness of the scope of palliative care, institutional limitations in palliative care bandwidth, and fear of hastening death.
- To date, limited data exists about the perspectives of physicians and advanced practice providers (APPs), bedside nurses, and caregivers about palliative care in pediatric nephrology.

METHODS

- Eligible pediatric nephrology providers, pediatric nephrology bedside nurses, and caregivers of dialysis-dependent patients completed a five-to-ten-minute survey on RedCap.
- The survey consisted of demographic, yes/no, and Likert scale questions with specific focuses on knowledge, experiences, and perceptions regarding palliative care in pediatric nephrology.

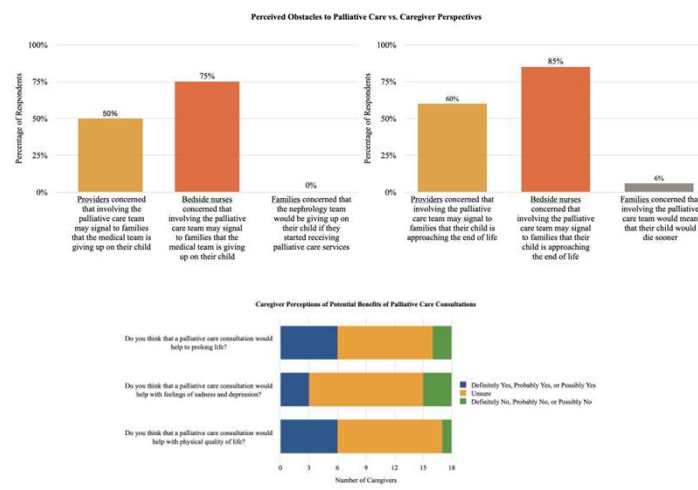
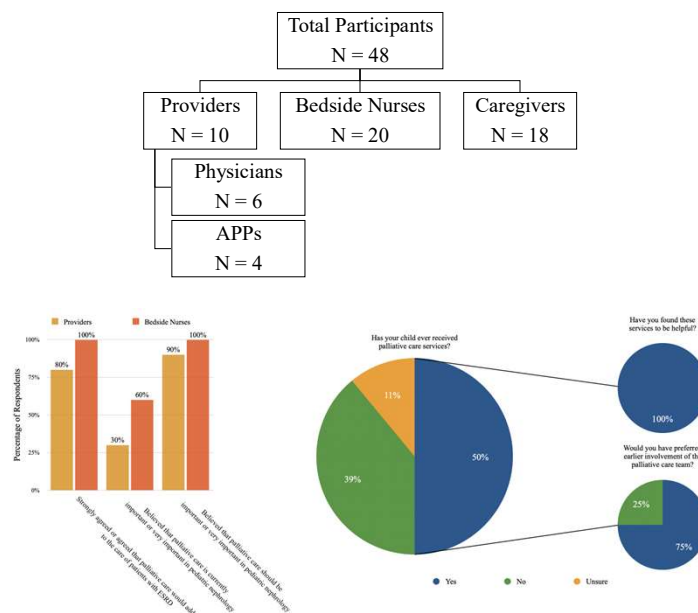
Inclusion Criteria:

- Pediatric nephrology providers who regularly care for dialysis-dependent patients
- Bedside nurses who work on the inpatient pediatric nephrology service and regularly care for dialysis-dependent patients
- Caregivers of pediatric patients who utilize maintenance hemodialysis or peritoneal dialysis for treatment of ESRD

Exclusion Criteria:

- Pediatric nephrology providers who do not regularly care for dialysis-dependent patients (i.e. APPs who primarily see non-dialysis patients in clinic)
- Caregivers of patients requiring acute dialysis with expectation for discontinuation of renal replacement therapy in the near future
- Caregivers of previously dialysis-dependent patients who have since undergone renal transplantation

RESULTS



SUMMARY OF RESULTS

- 80% of providers and 100% of bedside nurses felt that palliative care would add quality to the care of dialysis-dependent patients.
- Most providers and bedside nurses agreed that palliative care is not as important in pediatric nephrology as it should be.
- Many providers (50%) and bedside nurses (75%) worried that a palliative care consultation may signal to families that the medical team is giving up on their child.
- Most providers (60%) and bedside nurses (85%) worried that a palliative care consultation may signal to families that their child is approaching the end of life.
- 0% of caregivers were concerned that a palliative care consultation would indicate that the nephrology team was giving up on their child and 6% worried that it would mean that their child would die sooner.
- Most caregivers were unsure about whether a palliative care consultation would benefit their family.
- Of caregivers whose child has already received a palliative care consultation, 100% have found these services to be helpful and 75% would have preferred earlier involvement of the palliative care team.

DISCUSSION

- Most providers and bedside nurses agreed that palliative care is not as important in pediatric nephrology as it should be.
- With broad agreement among providers and bedside nurses about the value of palliative care for dialysis-dependent patients, there should be more robust and systematized involvement of the subspecialty palliative care team for this patient population.
- The major perceived barriers to palliative care consultations among providers and bedside nurses do not appear to align with caregiver perspectives.
- More emphasis should be placed on palliative care education for providers and bedside nurses.
- Most caregivers were uncertain about the potential benefits of a palliative care consultation but generally did not hold negative attitudes about palliative care, which may allow for introduction of palliative care without the barrier of negative preconceived notions.
- Universally favorable attitudes toward palliative care among families who have received these services supports the value of these consultations.
- Studies at other pediatric centers are necessary to determine whether these findings are generalizable or more institutionally specific.