

Adding Life to Their Years: The Current State of Pediatric Palliative Care in CKD

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Abstract

Despite continued advances in medical treatment, pediatric CKD remains an unremitting, burdensome condition characterized by decreased quality of life and earlier death. These burdens underscore the need for integration of pediatric palliative care (PPC) into nephrology practice. PPC is an evolving field that strives to (1) relieve physical, psychological, social, practical, and existential suffering; (2) improve quality of life; (3) facilitate decision making; and (4) assist with care coordination in children with life-threatening or life-shortening conditions. Integration of palliative care into routine care has already begun for adults with kidney disease and children with other chronic diseases; however, similar integration has not occurred in pediatric nephrology. This review serves to provide a comprehensive definition of PPC, highlight the unmet need in pediatric nephrology and current integration efforts, discuss the state of palliative care in adult nephrology and analogous chronic pediatric disease states, and introduce future opportunities for study.

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Introduction

Despite advances in the understanding and treatment of pediatric kidney disease, children with CKD continue to face diminished life span, reduced quality of life, significant symptom burden, and generally withstand considerable suffering (1–7). These findings reinforce the need for continued research to improve treatment of kidney disease, but also highlight the need for integration of palliative care to improve the lives of children with CKD, and their families, now. Unfortunately, there has been limited utilization of palliative care principles and subspecialty palliative care consultation for this population (8,9). As emerging studies demonstrate the benefits of palliative care for children with other chronic diseases, and adults with kidney disease, it is imperative to critically examine the physical, emotional, social, and spiritual needs of children with CKD, and their families. In this article, we will define palliative care, highlight the unmet demand in pediatric nephrology and current state of integration efforts, examine the experience of routine integration of palliative care in adult nephrology and analogous chronic pediatric disease states, and, finally, offer suggestions to facilitate this process in pediatric nephrology.

Defining Palliative Care

The World Health Organization (WHO) defines palliative care as “an approach that improves the quality of life of patients and their families who are facing problems associated with life-threatening illness”

attending to body, mind, and spirit by using meticulous symptom control, superior communication, and team-based support, without intending to speed or delay death (10). Palliative care provision, using a multidisciplinary approach, is endorsed early in the disease course, regardless of therapeutic goal (10). The current American Academy of Pediatrics (AAP) policy statement on pediatric palliative care (PPC) further describes PPC as an approach focused on relieving suffering, improving quality of life, enabling informed decision making, and coordinating care across realms (11). Similarly, the International Children’s Palliative Care Network defines PPC as an “active and total” care paradigm “embracing physical, emotional, social, and spiritual” components (12,13).

PPC grew from hospice and was initially synonymous with care provided at end of life (14,15,16). As the field has evolved, a broader scope of PPC has been embraced, which emphasizes comprehensive care through all disease stages (Figure 1) (14,16). Currently, the AAP Section on Palliative Care recommends PPC for all children with life-threatening illnesses, beginning at diagnosis and continuing irrespective of whether disease-directed treatment is ongoing (11). Conditions considered “appropriate” for PPC have also shifted (8). Whereas PPC was initially limited to patients with terminal illnesses, pediatric societies increasingly recommend PPC for all children with a “life-threatening” condition (11,13,16,17). This encompasses children with life-limiting conditions, where cure is not possible, and children with life-threatening conditions, where cure is possible and

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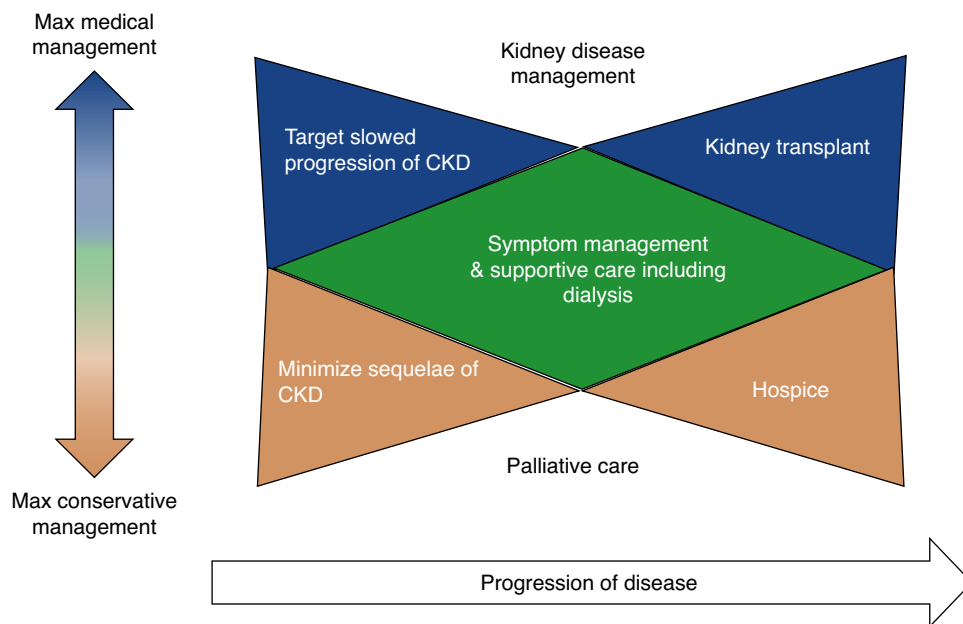


Figure 1. | Bow-tie model of palliative care integration in kidney disease. The bow-tie model highlights support of the patient and their family, concurrent with treatment of the disease, and the role of early integration of primary and/or subspecialty palliative care, while not diminishing the hope for survival. Dependent on patient and family goals, a range of complementary disease-targeted and palliative-focused care is available, with maximum (max) disease-targeted therapy represented by the top of the figure, and maximum conservative therapy represented by the bottom of the figure. Progression of the disease from diagnosis to realization of ultimate care goal is delineated from left to right. As the patient and their family move through their disease experience, their goals evolve, and kidney disease progresses, primary and subspecialty palliative care may take a larger role, ultimately with a transition toward kidney transplant and survivorship, or hospice and bereavement. Adapted from ref. (15), with permission.

disease-directed treatments are ongoing (14,16,17). Importantly, many children with CKD fall into one of those two groups. Even in resource-limited health system settings, the Worldwide Palliative Care Alliance identifies early integration of palliative care as a human right for children (18). The AAP summarized this initiative as follows: “The goal is to add life to the child’s years, not simply years to the child’s life” (19).

In defining the scope and objectives of palliative care, it is vital to denote its varying degrees (Table 1). PPC is classified as primary or subspecialty PPC (20). Primary PPC is a responsibility of all clinicians within the multidisciplinary team, whereas subspecialty PPC requires advanced training in palliative care domains and concentrates on management of increasingly complicated issues (17,20). The domains of palliative care include (1) physical symptoms; (2) mental, emotional, social, and spiritual distress; and (3) patient- and family-centered communication (20,21). All clinicians should be equipped to manage physical symptoms, such as pain, sleep disturbance, painful edema, pruritis, and dyspnea. Beyond physical concerns, existential distress should be managed by diagnosing and treating depression and anxiety, exploring spiritual views, and addressing common psychosocial struggles. Patient- and family-centered communication requires exploration of patient and family goals, integration of multidisciplinary recommendations, and development of a care plan reflective of the goals of care. As these realms become increasingly complex, subspecialty PPC consultation is indicated (20). For example, subspecialty PPC consultation is

indicated for refractory pain management, challenging existential suffering, or major communication conflicts among teams or families (17,20,21). Although the development of PPC offers the opportunity to improve the lives of children and their families, these benefits have largely been unrealized in pediatric nephrology.

The Unmet Need for PPC in Pediatric Nephrology

Although the burden intensity of CKD varies throughout the disease course for each patient and family, many children with CKD have life-limiting or life-threatening conditions. Consequently, routine primary and, in select cases, subspecialty PPC intervention, beginning at diagnosis and continuing regardless of therapeutic goal, is recommended for this population by the WHO, AAP, and others (Figure 2) (10,11). Additionally, the Renal Physicians Association (RPA) Clinical Practice Guideline on Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis endorses development of a palliative care plan for all children with ESKD, from the time of diagnosis, and children with AKI who forgo dialysis (22). Despite the positions of these professional organizations, there has been limited integration of PPC into nephrology.

Only 69% of children’s hospitals in the United States feature a subspecialty PPC team (23). Yet even in those centers benefiting from such a subspecialty PPC provision, there may be under-recognition of the burdens experienced by children with CKD, and their families, by PPC specialists,

Table 1. Primary and subspecialty palliative care skills

Primary Palliative Care	Subspecialty Palliative Care
Management of basic symptoms, such as pain, edema, pruritis, sleep disturbance	Management of refractory symptoms
Diagnosis and treatment of depression and anxiety, attendance to psychosocial challenges	Management of complex depression, anxiety, and existential suffering
Delivery of patient- and family-centered communication addressing topics such as goals of care, prognostic discussion, advanced care planning	Delivery of complex, serious illness communication, such as addressing disagreements in goals of care between patient and family, family and clinicians, or care teams
All clinicians should be equipped to provide primary palliative care, but as concerns become increasingly complex, subspecialty PPC consultation is indicated. Adapted from refs. 20 and 21, with permission.	

or underutilization of PPC by pediatric nephrologists to address these burdens. PPC specialists serve a diverse population of children, but those with kidney disease compose a fraction of consultations (9). In an influential review by palliative care experts, only kidney failure, in which dialysis and transplantation were unavailable or not indicated, was listed as an “appropriate” condition for PPC specialist consultation among children with kidney disease (8). Transplant surgeons may view PPC consultation as contraindicated to transplant, further complicating the fraught equation of subspecialty PPC involvement (24). In a review of PPC integration in pediatric nephrology, Thumfart *et al.* (25) recommended that, at a minimum, a specialized PPC team should provide care for pediatric nephrology patients with multiple comorbidities, in conservative treatment settings, and in patients suffering acute, life-threatening complications. Although adoption of this recommendation would increase specialist PPC consultation for some children with CKD, this would still potentially exclude a larger group of children with CKD facing life-limiting or life-threatening conditions that stands to benefit from primary PPC, at a minimum. These stances are outdated and overlook the burdens experienced by a range of children with CKD and their families.

CKD is an incurable, life-long, and life-shortening condition, which imposes significant burden on the child and family. Globally, survival of children with ESKD remains about 30 times worse than that of children without kidney disease (1). Additionally, after kidney transplant, the relative risk of death remains 12.7 times higher than that of peers (4). With a median age at transplant of 13 years, half of all pediatric kidney transplant recipients will need a second graft before the age of 25 years, reinforcing that there is no cure for CKD (4).

Beyond shortened life span, the burdens associated with CKD manifest in a variety of detriments. Children with CKD currently on dialysis, or who previously received a kidney transplant, experience poorer health-related quality of life (HRQoL) compared with healthy peers (3,5–7,26–30). Additionally, children with ESKD report significantly worse HRQoL compared with children with other chronic illnesses (31). CKD negatively affects mental health and well-being (32–35). For example, the prevalence of psychiatric disorders in prior studies of children with CKD ranged from 40% to 50% (36,37). Even among transplant recipients, negative effects on well-being may persist. Endén *et al.* (38) found higher depression inventory scores, worse

general health, and more pain among young adult men who received kidney transplants during childhood compared with healthy controls and survivors of childhood leukemia. Further, the pain needs of children with CKD may go under-recognized. Research using the Patient-Reported Outcomes Measurement Information System demonstrated that about half of children with CKD, regardless of stage or transplant history, had experienced pain within the last week which interfered with daily activities (39). Children in this study who were hospitalized within the past 6 months also reported poorer scores for depression, anxiety, fatigue, and mobility (39). Children with CKD also experience impaired sleep, with studies showing high rates of sleep disturbances in children with nondialysis-dependent (37%) and dialysis-dependent CKD (86%), with resultingly impaired HRQoL (40,41). The importance of recognizing and developing strategies to address these burdens was highlighted by a recent qualitative study in which adolescents with CKD shared their desire that outcomes such as fatigue, lifestyle restrictions, and physical activity be prioritized (42).

The burdens associated with pediatric CKD reach beyond the patient and affect others, including siblings and parents. Siblings of kidney transplant recipients demonstrate worse physical well-being and lower scores on financial-resource dimensions of quality-of-life measures than healthy controls (43). Siblings of children with CKD report anxiety around their siblings’ medical needs, and frustration with limitations in their own lives (44). Parents of children with CKD have higher rates of depression and anxiety, poorer HRQoL, and increased financial strain; and although these burdens evolve, they do not resolve with transplantation (45–51).

The challenges experienced by children with CKD and their families require intentional, thoughtful, shared decision making incorporating the patient, parent, and clinician. Patients and parents value information sharing with nephrologists and desire to serve as experts in their lived experience, but both parties report feelings of censorship in interactions at times (52). This is compounded by the constantly evolving communication needs of the patient depending on their developmental stage (52). In a study of audio-recorded visits involving adolescents, young adults, and nephrologists, Coburn *et al.* demonstrated that nephrologists often struggle to engage in shared decision making and in incorporating the patient’s perspective (53).

The hardships of CKD are extensive, and patients and families express a clear desire to have their needs better

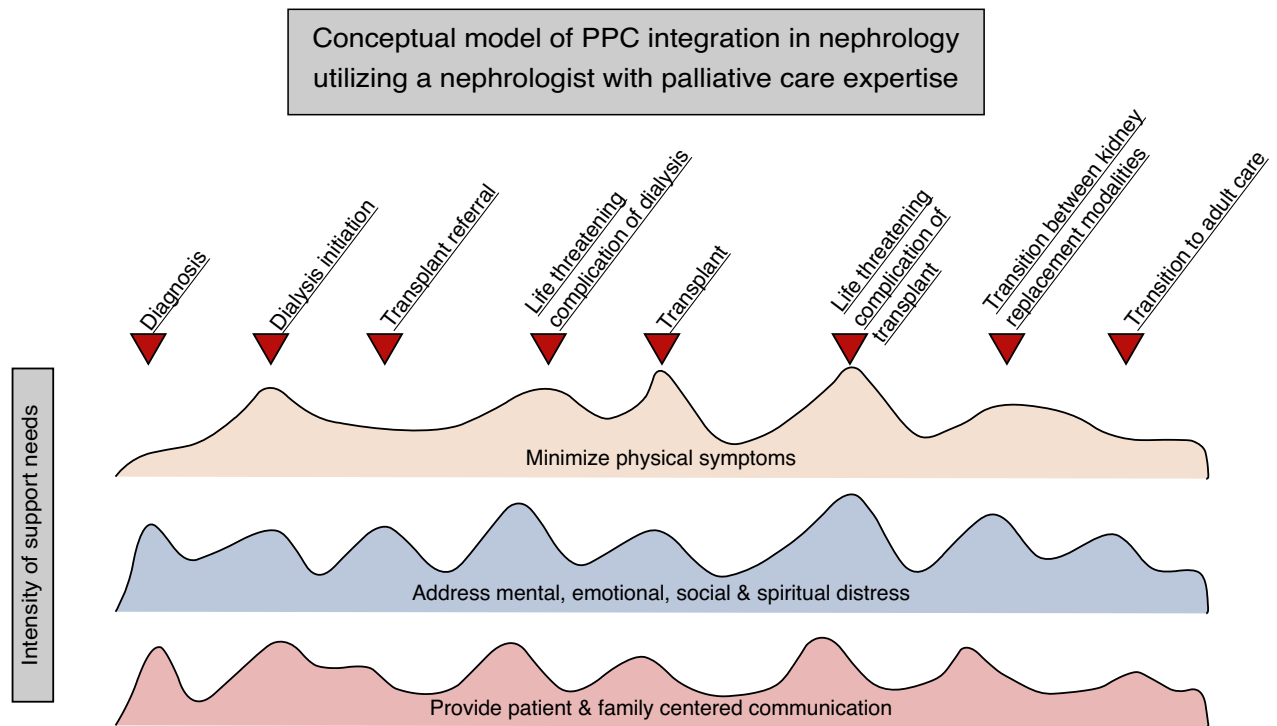


Figure 2. | Conceptual model of pediatric palliative care (PPC) integration in nephrology utilizing a nephrologist with palliative care expertise. The domains of PPC should be addressed by the primary nephrologist and multidisciplinary team throughout the disease course, with the intensity of support individualized to the patient and family's needs at that time in their care. A nephrologist with palliative care expertise is utilized at inflection points in care, when the patient and their family may experience significant changes in symptoms, experiences, burdens, and—ultimately—prognosis. With significant changes, goals of care may need to be revisited or revised, further reinforcing the benefit of additional PPC expertise. Although not every patient and family will experience each of these events, individualized inflection points of care may be identified that require additional burden alleviation. One example of an inflection point, where needs and burdens of patient and family can be more effectively addressed through integration of a nephrologist with palliative care expertise, includes diagnosis of CKD. The patient may already be experiencing resulting sleep disturbance. The patient and family may find it difficult to accept the diagnosis and feel grief that their hopes, goals, and dreams may be altered in the setting of CKD. Extensive questions about prognosis and care planning are likely. Another example of an inflection point that would benefit from integration of a nephrologist with palliative care expertise is at the time of transplant referral. A patient receiving a living, related kidney transplant may endorse emotional distress related to donation from a parent. The family may be anticipating significant financial burden associated with a parent's donation, resulting in negative effects to the patient, parent, and siblings' mental health and overall quality of life. Additionally, the patient and family may be overwhelmed with considering the potential complications of transplant, necessitating extra opportunities for patient- and family-centered communication. In both examples, the needs and burdens of the patient, and their family, can be more effectively met through enhanced palliative care provision by a nephrologist with PPC expertise.

met (42,52,54). PPC integration in pediatric nephrology affords an opportunity to realize this desire and need.

Current State of PPC in Pediatric Nephrology

To date, there has been limited utilization or study of PPC in nephrology. In a single-center analysis, Keefer *et al.* found that fewer than half of specialist PPC consults for children with ESKD were requested by the nephrology service (55). In a survey of multidisciplinary nephrology care team members, Thumfart *et al.* (56) found respondents identified a need for increased PPC resources, but disagreed about which patients should routinely receive subspecialty PPC. Both studies reinforce the need for integration of primary and subspecialty PPC in pediatric nephrology, but highlight that nephrologists, as stakeholders, may be unsure how best to meet this need. Given the limited integration of PPC into pediatric nephrology, it is

important to consider examples of successful integration, including “kidney supportive care” and other pediatric chronic diseases.

Integration of Palliative Care within Adult Nephrology

There has been increasing recognition in adult nephrology of the multidimensional morbidity and mortality associated with CKD (57). Consequently, integration of palliative care within adult nephrology, termed “kidney supportive care,” has become a rising field (58,59). The previously discussed RPA Guideline recommends providing effective palliative care to all patients with AKI, CKD, and ESKD who “suffer from burdens of their disease.” (22) Similarly, authors of the report of a 2013 Kidney Disease Improving Global Outcomes Controversies Conference called for delivery of kidney supportive care to all patients with

advanced CKD, recognizing this area as a core competency of nephrology in need of focused research efforts (58). Subsequently, developments in kidney supportive care have progressed in education, clinical care, and health systems. New educational programs, such as NephroTalk, equip nephrology providers with primary palliative care communication skills, including delivering bad news, establishing goals of care, and managing conflict (21,60,61). Many centers have adopted novel models to integrate kidney supportive care within the nephrology practice. In some dialysis units, this is achieved by employing nursing staff or social workers with additional palliative training focused on advanced care planning (21). Other clinics feature a specialist, dually trained in palliative care and nephrology, to lead the team (62,63). Mobile and home-based interventions have also been developed to increase patient access (21). In Canada and Australia, kidney supportive care has been integrated into governmental health systems, enabling provision as a routine component of delivered healthcare (21). Finally, there has been a general shift in approach, recognizing that adhering to a strict choice of transplant, dialysis, or conservative care may not fit the goals of all patients with advanced CKD, and rather that a continuum of care should be considered and individualized (64). Whereas kidney supportive care is an emerging field, integration of palliative care within clinical practice has already become standard in certain pediatric chronic disease states.

PPC in Pediatric Chronic Disease States

Subspecialty PPC consultation has been demonstrated to have positive effects in a variety of pediatric disease states (16,65–67). Subsequently, the value of early primary and subspecialty PPC has been demonstrated in some specific pediatric chronic disease populations, including oncology, pulmonology, and cardiology.

It is well established that children with cancer experience substantial disease burdens, although most will ultimately survive their illness (68–70). In a study of children with cancer and their parents, few expressed negative attitudes toward early PPC consultation, and the majority reported desirability (71). A randomized controlled trial evaluating the effect of a novel, PPC-based intervention targeting resilience in adolescents and young adults with cancer demonstrated improved psychosocial outcomes compared with participants receiving usual care (72). It is now standard of care at many pediatric oncology programs to consult specialty palliative care at time of diagnosis of malignancy, and for pediatric oncologists to routinely engage in primary PPC (68).

Similarly, although the development of new therapies has dramatically altered the disease course of cystic fibrosis (CF), there is increasing recognition of the long-term burdens of the disease on patients and families. Emerging research supports integration of primary and subspecialty PPC involvement to alleviate these burdens (73,74). Parents of adolescents with CF have expressed a desire for integration of PPC principles (75). Promisingly, a pilot study of a primary PPC intervention for patients with CF demonstrated improvement in CF-associated symptoms, decreased depressive symptoms, and diminished psychological suffering

(76). On the basis of these findings, there has been a call for routine integration of PPC as standard of care for children with CF (77).

Finally, a similar shift to integrating PPC has taken place in the care of children with hypoplastic left heart syndrome. These children experience high burdens of care throughout their lives, particularly concentrated in the first year of life (78). Early integration of PPC in this population has been demonstrated to decrease maternal anxiety and improve communication in a randomized clinical trial (79).

In each of these disease states, PPC has been shown to be desired, beneficial for patients and families, and increasingly integrated as standard of care. Children with advanced CKD and their families suffer comparable burdens. It is essential to consider steps for similar evidence-based integration of PPC to improve the experience of children with CKD and their families.

Directions for Future Opportunities To Integrate PPC into Pediatric Nephrology

Successful integration of PPC into pediatric nephrology will require a continued paradigm shift from the association of PPC with end-of-life care to holistic care intended to mitigate suffering and promote flourishing, an increased awareness of the needs of patients and their families, fostering of primary PPC knowledge and skills, integration of PPC within clinical care models, and dedicated research.

There is an outdated perception equating palliative care with hospice or only end-of-life care that overlooks the myriad benefits that PPC provision provides to patients and families across a variety of points in life-threatening or life-limiting diseases (Figure 2) (8,24,56). Rebranding, as demonstrated in adult nephrology, may be worthwhile to support this shift in stakeholder perceptions (58). Continued transition from this antiquated perception is critical to ensure the benefits of PPC are not denied to children with CKD and their families.

It is also vital to increase clinician awareness of the effect of their patients' burdens, and those of their families. Efforts must focus on nephrologists, and palliative care specialists, transplant surgeons, and other multidisciplinary team members (8,9,24,55,56). In addition to continued study of burden, pain, HRQoL, and other outcomes, allowing patients and families to share experiences "in their own words," through qualitative research, may provide the most persuasive means of achieving clinician recognition (80).

There is a need to further develop PPC capacity. Only a portion of children's hospitals in the United States feature a subspecialty PPC team, reinforcing the need to increase the workforce of PPC specialists, but also highlighting the critical need to increase capabilities for primary PPC provision through nephrology care (23). Pediatric nephrologists serve a privileged, intimate role in the care of children with CKD and their families, often spanning decades, uniquely positioning them to deliver primary PPC. Clinician inexperience was found to be a barrier to integration of primary palliative care in adult nephrology (60). Training within residency and fellowship programs has been proposed to equip physicians with primary PPC skills, but, until this is

achieved, clinicians will need to fill this gap in knowledge using alternative means (11,59). Available resources to assist in PPC proficiency range from formal courses to just-in-time smartphone applications (20,80–82).

As nephrologists attain competency, a structured approach for routine integration and evaluation of PPC in the care of children with CKD is imperative. The skill sets of multidisciplinary team members—including social workers, child life specialists, and psychologists—should be leveraged, but, ultimately, routine primary PPC provision is best applied under the direction of the pediatric nephrologist. Ideally, an embedded care model mirrored on kidney supportive care, using a physician with PPC expertise in the nephrology clinic, is warranted (Figure 2) (20,83). These tailored supports should remain as children move through care phases from advanced CKD, to dialysis, to transplant, and back, and through transition from pediatric to adult care.

Ongoing research must seek to better understand the experience and priorities of patients with CKD and their families, effectively intervene on their burdens, and provide a means for routine integration of PPC within nephrology clinical care. Adjusting clinical research to include patient-focused outcomes is foundational to understanding the needs and hopes of patients and families across disease, cultural, and developmental states (79,84–86). Additionally, there is a need to develop and study targeted interventions focused on patient-reported and -prioritized outcomes, including symptoms present in CKD, such as pain, pruritis, edema, and sleep disturbances. Finally, effective models for routine integration of PPC into clinical care for children with CKD must be developed, applied, and investigated.

Conclusion

Children with CKD face tremendous suffering that affects their entire family. PPC strives to relieve the suffering in physical, emotional, and existential realms experienced by children with life-threatening conditions, beginning at diagnosis and continuing throughout the child's life. There is growing evidence demonstrating successful integration in adult nephrology, and areas of pediatric disease comparable with CKD. To add life to our patients' years, we must hasten to understand and implement PPC within pediatric nephrology.

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T.R. House wrote the original draft and was responsible for project administration; T.R. House and A. Wightman conceptualized the study and reviewed and edited the manuscript; and A. Wightman provided supervision.

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