

Research Article

Transitioning from Pediatric- to Adult-focused Dialysis Care: A Systematic Review with Recommendations

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Abstract

Background: There is limited data evaluating the practices of nephrologists who prepare dialysis-dependent adolescents and young adults (AYA) for healthcare transition (HCT) from pediatric- to adult-focused healthcare. The aims of this manuscript are to 1) critically evaluate the current evidence and experiences surrounding HCT from pediatric- to adult-focused dialysis units and 2) make recommendations that can be implemented for this process.

Methods: We searched PubMed, EMBASE, CINAHL, COCHRANE, and clinicaltrials.gov to identify studies that pertain to the HCT of AYA patients from pediatric- to adult-focused dialysis care.

Results: A total of 14 studies were included and were grouped into subcategories to facilitate data synthesis: HCT process, preparedness of patient and family, preparedness of adult-focused nephrology providers, barriers to HCT, and quality of life. These included studies highlight the importance of creating an HCT process with a formal policy. They focus on the importance of patient and family preparedness and on measuring HCT readiness using standardized scales. They also underline the importance of identifying adult-focused nephrology 'HCT champions' to care for AYA requiring dialysis. Lastly, they emphasize the importance of measuring the quality of life in AYA patients to ensure optimal patient-centered HCT.

Conclusion: There is limited data on HCT for AYA with ESKD. Upon review and analysis of current literature, we recommend: creating a formal, written HCT policy; setting achievable goals for health self-management and conducting regular assessments of HCT readiness; identifying a lead or 'champion' at an accepting adult-focused dialysis unit and ensuring good communication between pediatric and adult providers; and completing annual quality-of-life assessments.

Introduction

Healthcare transitions (HCT), or transitions from pediatric- to adult nephrology care, are complex, multi-layered interdisciplinary processes that are challenging to execute and occur during a fragile time in patients' lives. Data evaluating the effectiveness of HCT for adolescents and young adults (AYA) is limited. In 2011, the International Society of Nephrology (ISN) and the International Pediatric Nephrology Association (IPNA) released a consensus statement outlining HCT recommendations for AYA with chronic kidney disease [1]. In 2018, the Six Core Elements of Healthcare Transition was published [2]. These recommendations emphasize the

importance of key fundamental pieces: the development of a transition policy, the creation of a formal 'HCT process' including an assessment of readiness, and the transfer of care to adult-focused services. Still, recommendations for HCT of AYA receiving *dialysis* do not exist [3]. The aims of this manuscript are to 1) critically evaluate the current evidence and experiences surrounding HCT from pediatric- to adult-focused dialysis units and 2) make recommendations that can be implemented for this process. This is significant because adolescents and young adults with kidney disease have the highest morbidity and mortality of any age group, and the role that HCT plays in these unacceptably high rates cannot

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be ignored [4-11]. Thus far, there is limited data evaluating the practices and perspectives of adult- and pediatric-focused nephrologists who transition adolescents and young adults on dialysis. This is the first review that endeavors to evaluate current evidence with subsequent recommendations.

Methods

This is a PRISMA review of the transition from pediatric- to adult-based dialysis care (**Supplementary Table 1**).

Eligibility criteria: Studies were included if they pertain to the transition of patients requiring dialysis from pediatric to adult care. Studies were excluded if they were disease-specific (ex: cystinosis).

Information sources: The databases searched to find said studies included: PubMed, EMBASE, CINAHL, COCHRANE, and clinicaltrials.gov. These databases were last searched on 01/05/2024.

Search strategy: The databases were searched using the following search terms: “dialysis” + “transitions of care” and “dialysis” + “healthcare transitions.”

Selection process: Two reviewers, working independently, screened each study retrieved to determine if it met the above eligibility criteria. A third reviewer served as an arbitrator when the first two disagreed on study inclusion/exclusion. A fourth reviewer used the Newcastle–Ottawa quality assessment scale to evaluate the seven cohort studies. Study scores ranged from four to seven out of nine (**Supplementary Table 2**). All inclusion decisions were unanimous.

Data collection process: Two reviewers, working independently, collected and summarized data from each report. Articles were reviewed between 03/08/2023 and 01/05/2024.

Synthesis methods: The included studies were grouped into subcategories to facilitate data synthesis: transition process, preparedness of patient and family, preparedness of adult nephrology providers, barriers to transition, and quality of life.

Results

Our PRISMA review identified 767 publications and 14 were included. As we used the search terms: “dialysis” + “transitions of care” and “dialysis” + “healthcare transitions,” we retrieved many studies that addressed transitioning from inpatient to outpatient care or from one dialysis modality to another. We included the studies that focused on the transition from pediatric to adult dialysis units. The included studies focused on the following areas: HCT process, preparedness of patient/family, preparedness of adult-focused nephrology providers, barriers to HCT, and quality of life (Figure 1). These 14 publications were cross-sectional, qualitative, and mixed-methods studies as well as perspective pieces

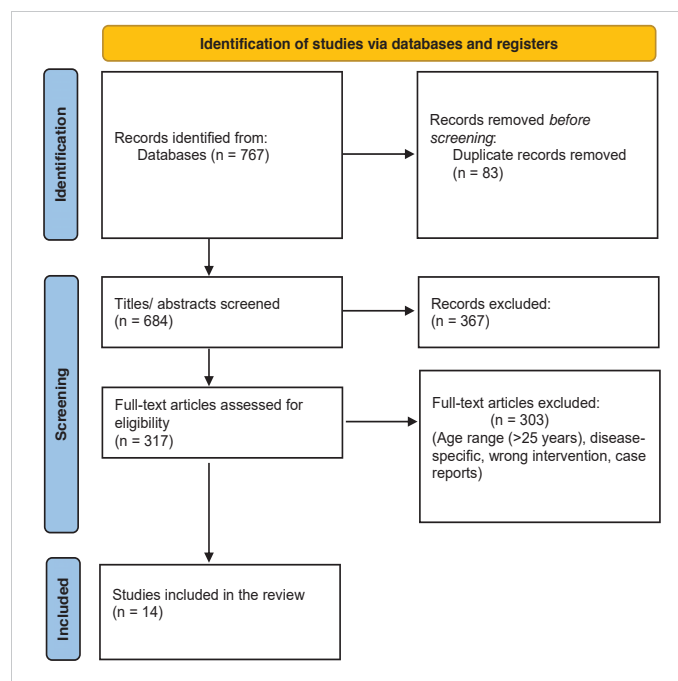


Figure 1: PRISMA Flow Diagram for Study Selection.

(Table 1). The work was published from 1999 to 2020 and included dialysis patients from North America, Europe, and Australia.

Discussion

The publications included in our PRISMA review focused on the HCT process, preparedness of patient/family, preparedness of adult-focused nephrology providers, barriers to HCT, and quality of life. While pediatric dialysis-dependent patients constitute a small percentage of all ESKD patients, they have an excellent 10-year survival rate (80%), and adolescents/young adults must undergo HCT preparation in both the pediatric- and adult-focused settings to improve outcomes [12].

Preparedness of patient and family

AYAs with ESKD are a particularly vulnerable population of patients in which a missed dialysis session or medication/diet nonadherence could lead to irreversible injury or death. Therefore, patient and family preparedness is paramount prior to the transition of care to an adult provider.

Cura, et al. performed a qualitative survey in 2012 in hopes of better interpreting and understanding the transition from adolescence to adulthood from the perspective of dialysis patients with end-stage kidney disease [13]. These results revealed three main themes:

- 1) ‘Living a Shorter Life:’ From Loss to Test of Faith to Hope
- 2) Dependence and Independence
- 3) Struggle of Being Normal Amidst Difference



Table 1: Study characteristics.

PMID	Title	Authors	Journal/Book	Publication Year	Location	Number of Patients	Age	Number of HD patients	Study Design
25641116	Patient perspectives of a young adult renal clinic: a mixed-methods evaluation	Tong A, Gow K, Wong G, Henning P, Carroll R.	Nephrology (Carlton)	2015	Australia	15	18-26	1	Mixed methods
25662749	Self-management and transition among adolescents/young adults with chronic or end-stage kidney disease	Ferris ME, Cuttance JR, Javalkar K, Cohen SE, Phillips A, Bickford K, Gibson K, Ferris MT, True K.	Blood Purif	2015	US	N/A	N/A	N/A	Perspective
26202468	Validation of the UNC TRxANSITION Scale™ Version 3 Among Mexican Adolescents With Chronic Kidney Disease	Cantú-Quintanilla G, Ferris M, Otero A, Gutiérrez-Almaraz A, Valverde-Rosas S, Velázquez-Jones L, Luque-Coqui M, Cohen S, Medeiros M.	J Pediatr Nurs	2015	Mexico	163	22-Oct	15	Cross-sectional
22489755	Nationwide survey of adolescents and young adults with end-stage kidney disease	Ritchie AG, Clayton PA, Mackie FE, Kennedy SE.	Nephrology (Carlton)	2012	Australia/ New Zealand	495	15-25	~120	Cross-sectional
15714787	The lived experience of adolescents who transfer from a pediatric to an adult hemodialysis center	Braj B, Picone G, Children HF, Cross N, Pearlman L.	CANN T J	1999	Canada	3	18-22	3	Qualitative research
30895367	Psychosocial considerations and recommendations for the care of pediatric patients on dialysis	Clementi MA, Zimmerman CT.	Pediatr Nephrol	2020	N/A	N/A	N/A	Yes	Review
17333004	Adolescent dialysis patient transition to adult care: a cross-sectional survey	Bell L.	Pediatr Nephrol	2007	North America and Europe	58 dialysis centers	N/A	58 dialysis centers	Cross-sectional
24710747	Adherence to transition guidelines in European pediatric nephrology units	Forbes TA, Watson AR, Zurowska A, Shroff R, Bakkaloglu S, Vondrak K, Fischbach M, Van de Walle J, Ariceta G, Edefonti A, Aufricht C, Jankauskiene A, Holta T, Ekim M, Schmitt CP, Stefanidis C; European Paediatric Dialysis Working Group.	Pediatr Nephrol	2014	Europe	15 dialysis centers	N/A	15 dialysis centers	Cross-sectional
12224372	Transitioning an adolescent dialysis patient to adult healthcare	Myers PS.	Nephrol Nurs J	2002	US	1	N/A	1	Perspective
22620484	Interpreting transition from adolescence to adulthood in patients on dialysis who have end-stage renal disease	Cura J.	J Ren Care	2012	Philippines	6	17-22	6	Qualitative research
17183939	Pediatric to adult transition: a personal experience	Harden PN, Nadine P.	Prog Transplant	2006	UK	1	N/A	1	Perspective
8865896	Transitioning adolescents from pediatric to adult dialysis units	Watson AR, Shooter M.	Adv Perit Dial	1996	UK	N/A	N/A	N/A	Perspective
19270212	Transition of the adolescent patient to the adult clinic	Alpay Harika	Peritoneal Dialysis International	2009	N/A (Turkey)	N/A	N/A	N/A	Perspective
17210582	Adolescents with renal disease in an adult world: meeting the challenge of transition of care	Bell Lorraine	Nephrology Dialysis Transplantation	2007	N/A (Montreal, Canada)	N/A	N/A	N/A	Perspective

Independence was described as a ladder with the lowest level being the most easily attained and the highest level being the most difficult to achieve [13]. This ladder describes decision-making and problem-solving as the easiest for patients to achieve, with their way of thinking being influenced by both their peers and their condition or illness. Next on the ladder is physical independence and the capability of completing their activities of daily living without assistance. Financial independence was the highest and hardest level as patients viewed themselves as a ‘burden’ to parents or family.

In this same survey, Cura, et al. found the transition process to be one that constantly changed; the entire experience is a pendulum, continuously shifting between themes with the constant changes resulting in a feeling of ambivalence

from the AYA [13]. AYA described the transition period as a ‘World-In-Between’ adolescence and adulthood [13]. They may still consider themselves young from a physical and peer perspective, yet they are developing as adults with evolving maturity.

Perhaps one of the more challenging questions in HCT is the age at which transfer should begin. A survey of 15 pediatric nephrology units across Europe demonstrated that 73.3% of units had required ages for transfer ranging from 18 to 21 years [3]. In this study, surveys demonstrated that patients felt transfer happened too suddenly. Bell, et al. performed a similar cross-sectional survey of 58 pediatric dialysis units in North America and Europe and found that 53% of centers did not have a fixed cut-off age for transfer [14]. For those who did, the cut-off ranged from 17-22 years with a median



of 20.5 years and a mean of 19.9 (+/- 1.5 years). In addition, of the centers surveyed, 1/3 of centers reported a transition program, and 74% of centers without a transition program believed there was a need for one.

AYA should have a certain level of psychosocial function before transfer. Bell, et al. performed a survey including three basic tasks to assess independence: responsibility for making appointments, prescription refills, and peritoneal dialysis setup [14]. This survey showed that < 20% of AYA patients were able to function autonomously before transfer [14], highlighting the importance that the HCT process should start early to ensure adequate preparation [15]. At the center of any HCT process should be the preparedness and autonomy of the patient and assessment of such should include both self-management and self-autonomy [14]. For patients with kidney disease, self-management has been described to include three domains: blood pressure, laboratory results, and medication management. Self-advocacy is defined as the patient's willingness to make decisions, negotiate with providers, control their own treatment, and act positively in their own self-interest [16]. Both are crucial to achieving positive health outcomes. While assessment and management of these two items may seem straightforward, it is known that chronic illness during childhood and adolescence can interfere with the typical maturation process due to multiple factors such as increased authority of parents and health care teams, missing school, and many others [14]. AYA with kidney disease have multiple challenges associated with their age and diagnosis as described by Ferris, et al. [16]. These challenges include but are not limited to:

- 1) Depression, lower socialization skills, and low self-esteem impair their ability to achieve developmental milestones of those without a chronic condition
- 2) Nonadherence to treatment
- 3) Overcoming a physical appearance such as dysmorphic features or short stature
- 4) Performing school or work-related tasks with impaired cognition
- 5) Learning to self-manage a condition with numerous medications, procedures, and nutritional demands

Throughout HCT, communication by all team members should gradually move from primarily with the parent/caregiver to the AYA. Watson, et al. describe two main principles in managing young people: communication and providing the AYA with a choice [15]. Bell, et al. also describe similar principles for transition [14]. Good communication is necessary to ensure that the AYA has a clear understanding of relevant facts of their illness. AYA may respond better when they feel their voice is heard, and understood, and that their choices matter. Specifics are outlined by Watson, et al. and include:

- 1) The patient and family should understand the general philosophy of moving to an adult facility
- 2) AYA preference should be taken into account
- 3) Information on the adult unit should be provided
- 4) Some may consider a liaison visit to the adult unit
- 5) Staff at the pediatric unit should support the AYA's request
- 6) An agreed-upon and written date of transfer should be decided
- 7) There should be good communication between the pediatric and adult units

Preparedness of adult nephrology providers

In addition to ensuring adequate preparation of AYA and caregivers for HCT, it is also important to ensure preparation of the receiving adult-focused nephrology providers as they receive AYA infrequently in their dialysis units. The ISN/IPNA consensus statement calls for a transition process that is "directed by lead clinicians and 'transition champions' in pediatric and adult units who are identified to coordinate and educate [AYA] on transition issues [1]." However, the European Dialysis Working Group study found that 8 out of 15 adult dialysis units have no transition champions [3], likely because AYA on hemodialysis makes up only a small proportion of patients [17]. In addition, while the pediatric care of such AYA is often concentrated in pediatric tertiary care centers, the cohort becomes diluted when transitioned to numerous adult care centers [3]. One study conducted in Australia and New Zealand of 219 patients aged 15-25 years on HD found that, while the majority of patients live in major cities (63.6%), the median number of AYA per adult HD unit was only 5 [17]. Another study conducted by the European Dialysis Working Group in 13 countries across Europe found that 47% of pediatric units transfer 5 or fewer patients per year to a median of 5 adult centers (range: 1-32) [3]. The study concluded that a unit with 5 adult nephrologists would accept an AYA patient only once every 3-5 years [3]. Clearly, adult nephrologists receive transferred AYA with ESKD infrequently, emphasizing the importance of identifying HCT champions to prevent further dilution of the AYA cohort as well as established HCT policies to optimize the systems in place.

Another important barrier to HCT is adult-focused providers' knowledge and education [18-22]. The ISN/IPNA guidelines specifically call for "an internal medicine specialist or nephrologist in each adult service [to] take special interest and be trained in managing young people with CKD 4-5 [1]." The lack of knowledge and experience of healthcare providers in this area reflects a large gap in professional education [23]. One study revealed that only



14% of internal medicine residents, as compared to 73% of pediatric residents, have had training in transitions of care [24]. In addition, adult nephrology providers reported a lack of training in congenital and childhood-onset diseases as their greatest concern when accepting and caring for youth with chronic kidney disease [25].

The most common cause of CKD in pediatric patients is congenital anomalies of the kidneys and urinary tract (CAKUT) with a prevalence of over fifty percent (54.4-57.9%) [26-28]. In fact, an analysis of four large kidney disease registries (US Renal Data System [USRDS], Australia and New Zealand Dialysis and Transplant Registry [ANZDATA], European Renal Association-European Dialysis and Transplant Association [ERA-EDTA], and a conglomeration of Japanese registries) demonstrated that approximately one-third of cases of kidney failure in patients < 15yrs are caused by CAKUT or genetic etiologies of kidney disease [29]. In comparison, the most common cause in adults is diabetic glomerulonephritis. However, in pediatric patients, diabetic glomerulonephritis or metabolic causes of kidney disease rarely occur and account for < 5% of cases (0.2-3.8%). [26-28]. It is evident that the disease processes are vastly different in the pediatric and adult populations with subsequent differences needed in their care, and this educational gap also applies to our patient population on dialysis [3].

Overall, adult-focused nephrology providers infrequently care for AYA with ESKD on dialysis; therefore, it is imperative to have formal HCT policies in place to assist with this process. Such policies should include the identification of a 'HCT champion' to prevent further dilution of the AYA cohort. In addition, future efforts should focus on improving adult nephrologist education in caring for the AYA as well as education in genetic and congenital etiologies of kidney disease.

Barriers to healthcare transition

While many barriers are similar to those experienced by patients, not on dialysis, there are several unique challenges for the AYA dialysis population at the individual, family, institutional, and system levels. At the individual level, Ferris, et al. highlighted several psychosocial barriers including denial, depression, poor coping skills, low health literacy, low cognition, as well as prolonged dependence on parents and significant others [16]. In addition, the level of complexity of medical regimens has been identified as a significant barrier to effective or successful transition, as the regimen is often overwhelming to master during the transition period. Clementi, et al. have described barriers including cognitive, emotional, and social changes associated with the AYA period of life. There is concern that difficulty in adjusting to many aspects of independent adult life creates a barrier to successful transition [30]. From the patient perspective, Clementi and Alpay note patient resistance and

fear of assuming more responsibility, the unfamiliar nature of the adult healthcare system, and the possibility of adult providers not having the same level of understanding and competence regarding the complexity of congenital illness [31,32]. An additional barrier specific to dialysis patients is the time-consuming nature of dialysis which may tie AYAs to their parents and hospital staff, hindering autonomy and self-advocacy [31]. Cura, et al. and Forbes, et al. have also noted there is more reliance/dependence on caregivers while on dialysis, and this can impede independent decision-making, and promote more financial dependence on caregivers, which may prevent autonomy and self-care for AYAs [3,13]. Similarly, hesitancy at the parent level to relinquish responsibility further impedes successful transition and transfer [13,31].

At the institutional level, the lack of integrated health systems or electronic health records, as well as poor coordination between pediatric and adult units has been highlighted by several groups [14,16,32]. There is concern that the majority of dialysis centers lack a formal transition program, and there is a lack of patient-centered, developmentally appropriate, coordinated, and uninterrupted health care for AYAs receiving dialysis. [14,15]. Because of this, many pediatric providers are often hesitant to hand over responsibility for pediatric patients they have known for as long as twenty-one years. This hesitancy is likely due to pediatric providers' limited knowledge of available resources at receiving adult dialysis centers for AYAs with special needs, especially since neurocognitive deficits may have a higher incidence in patients with kidney disease. To expand, patients with developmental or cognitive challenges likely need greater structure and resources in the clinic to support them, and there is limited availability of these resources, due to a lack of institutional and system-level support, in adult dialysis centers [3,14,32]. The ability of pediatric and adult dialysis centers to coordinate care and transition/transfer is impeded by the differences in geographic regions served by pediatric and adult providers. [15]. There is often significant physical distance between pediatric and adult dialysis centers. In addition, Clementi, et al. commented that the age discrepancy between AYAs and typical patients in adult HD units can make the transition more difficult [31]. With government and hospital-driven age-based transfer policies, AYAs are often receiving dialysis with individuals twice or three times their age. These rigid transfer policies distract from the achievement of competencies in self-care [3].

Identifying barriers to HCT is useful; however, patients, families, and medical provider teams are yearning for solutions to tackle these barriers and move the needle on implementing successful transitions to improve patient-level outcomes. In reviewing available recommendations, several themes are identified. The first is appropriate HCT preparation, which includes engagement in a formal

program with identification of necessary support measures, recognition of the patient's support system, assessment of developmental or cognitive limitations and utilization of appropriate support, and the need for peer support [3,16]. Another theme is the utilization of appropriate HCT tools to assess transfer readiness. Several transition/transfer readiness tools exist, including the UNC TRxANSITION Index, The STARx Questionnaire, and TRAQ, however, there should be consideration given to adjusting these tools to the unique needs of patients on hemodialysis [31]. Along with utilization of the tools, several groups emphasize the critical need to engage with adult-focused providers and dialysis teams prior to transfer, as this will assist the AYA in developing expectations in adult-focused care and will foster effective communication between the teams [14,16,31]. Even beyond engagement and communication, several groups have emphasized the need for pediatricians and internists to join forces and co-champion the development of HCT plans while fostering a community of mutual respect for each other's specialty and practice setting [3,14]. The most ideal setting is the establishment of a joint interdisciplinary transition clinic [33]. Several recognize potential barriers to joint HCT clinics, including insurance barriers, lack of financial support, lack of institutional support, and logistical concerns related to differences in geographic regions served by pediatric- versus adult-focused dialysis providers [14,32,33]. A final theme that has emerged in the dialysis population is the importance of appropriately timing the transfer to adult care. The transfer should ideally involve a progressive, rather than sudden, shift in care, and should not occur at times of crisis or at the same time as other major changes such as college, work, or family transitions [14,15,33]. In addition, the timing of transfer should be an individual decision based on each AYA readiness, as this will increase the likelihood of success [14]. Providers recognize that this may not be feasible in all situations but should be a priority for HCT.

Existing literature is ripe with recognition of barriers, and while several papers offer recommendations for overcoming barriers, there continues to be a great need for successful interventions to minimize or alleviate many of these barriers.

Health-related quality of life

The transition from pediatric to adult care occurs during a crucial time in a patient's life when they are already at risk for non-adherence and poor outcomes due to obstacles and adversity [34]. Unsurprisingly, poor outcomes translate to poor health-related quality of life (HRQoL); it is therefore imperative to measure and improve HRQoL in AYA undergoing healthcare transitions. In clinical practice, measuring HRQoL can assist with the prioritization of specific health problems for individual patients and, therefore, guide specific interventions to improve patients' overall outcomes. However, disease presence, or physical state, is just one area that determines the quality of life (QoL); additional areas that determine QoL are provided in Figure 2.

Sometime during adolescence, pediatric patients

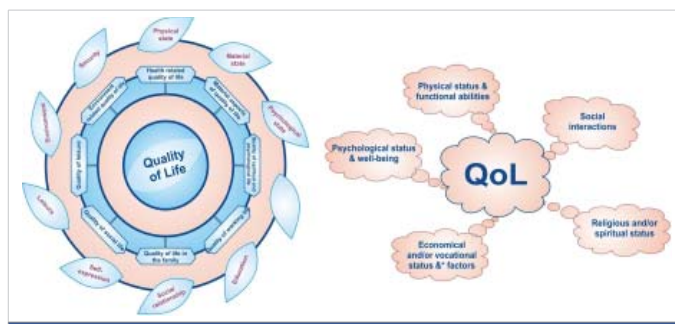


Figure 2: Classifications and Subcategories of Quality of Life.

transition from a dependent to an independent role in both their healthcare and their lives. However, AYA may have difficulty embracing a more independent lifestyle creating psychological distress [35]. In fact, a prospective study of 76 young adults transitioning to adult-focused care demonstrated decreased autonomy and vocational attainment in ESKD patients in comparison to their peers [36]. In addition, compared to young adults with ESKD presenting in adulthood, those who were diagnosed with this condition as children were less likely to be living independently or with a partner, less likely to have full or part-time paid work, and had lower educational attainment [37,38]. These psychosocial factors in AYA with ESKD raise concerns about patients' disease knowledge and health self-management, characteristics that may also result in a lower QoL [39].

Just as poor outcomes result in poor HRQoL, poor HRQoL can portend an unsuccessful HCT. Zimmerman, et al. measured the HRQoL in 135 patients with gastrointestinal, renal, and rheumatological diseases who underwent HCT. Their study showed that lower HRQoL ($\beta = 0.283, p < .01$) and less peer support ($\beta = -0.198, p < .05$) were associated with worse perception of HCT ($R^2 = 0.203, p < .001$) regardless of the type of disease, race/ethnicity, or sex. These findings suggest targets for intervention such as improving HRQoL (acceptance and commitment therapy) and increasing peer support (social skills training, family facilitation) prior to transfer from pediatric- to adult-focused care [40]. Moreover, although there is limited literature pertaining to HRQoL in AYA dialysis, data on CKD and other conditions demonstrate that a difficult HCT process further decreases HRQoL. Therefore, it is important to aid clinicians in how to address HRQoL in AYA patients in order to optimize the HCT process.

Conclusion

Adolescents and young adults with kidney disease have the highest morbidity and mortality of any age group, and the role that HCT plays in these unacceptably high rates cannot be ignored [4-11]. While there is limited data on HCT for AYA with ESKD, several themes emerge among the studies that have been published: transition process, preparedness of patient and family, preparedness of adult nephrology providers, barriers to transition, and quality of life. By reviewing this data, we are able to make several recommendations to improve healthcare transitions for AYA with ESKD.



Recommendations

Upon reviewing and analyzing these studies, we make the following recommendations. These recommendations have been endorsed by the PCRRT-ICONIC Society.

We recommend

1) Developing a formal HCT policy as a written document, including the age at which the process begins (typically 12-14 years of age), eligibility criteria, and the expected age and/or timing of patient transfer of care (typically 18-22 years of age). Adult-focused centers should also have a formal transition policy, including the practice's approach to HCT and accepting new AYA patients, and an adult-focused approach to care in terms of privacy and consent.

2) Setting achievable small goals for health self-management and informing AYA patients about the importance of independence and responsibility. This can be encouraged by attending appointments alone, scheduling, filling prescriptions, and contacting the medical team independently.

3) Conduct regular assessments of HCT readiness using a validated tool, such as the UNC TRxANSITION Index and the Transition Readiness Assessment Questionnaire. Ideally, the transfer would occur when the patient can demonstrate knowledge of a) their condition/medications, b) how to make appointments, c) refill their medications, and d) what to do in a medical emergency.

4) Identifying a lead or 'champion' at an accepting adult-focused dialysis unit that has special knowledge in caring for the AYA as well as education in pediatric-onset etiologies of kidney disease.

5) Ensuring good communication between the pediatric- and adult-focused nephrology teams including both a verbal and written summary. When possible, the development of a transfer clinic, where both adult- and pediatric-focused providers are able to evaluate the patient, has been endorsed as the standard of care.

6) Coordinating visits to adult-focused dialysis units before official transfer of care to help AYA patients feel comfortable and welcomed.

7) Conducting annual, universal HRQOL, using tools such as the generic Pediatric Quality of Life Inventory™ (PedsQL 4.0) and the ESKD-specific module (PedsQL ESKD Module 3.0).

While these recommendations provide a starting point for healthcare transitions of pediatric dialysis patients, further research is necessary to continue to improve outcomes in this population.

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