



Long-term psychosocial outcomes of adults transplanted in childhood: A social work perspective

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Abstract

While much research exists regarding medical outcomes for pediatric end stage renal disease (ESRD) populations and for adults receiving dialysis or kidney transplant, the understanding of long-term psychosocial outcomes for individuals diagnosed with ESRD or transplanted in childhood remains limited. A literature review was undertaken by two social work researchers to identify relationship, education, employment, and quality of life (QOL) outcomes for this population utilizing PUBMED and PsycInfo databases. Inconsistencies in the MeSH terms and keywords used across the relevant articles were noted. The impact of transplantation in childhood is significant across multiple facets of social development including but not limited to peer/intimate relationships, education and employment and QOL, and overall well-being. When compared to healthy peers, those with ESRD were delayed in all areas of social development. While improvements in psychosocial outcomes have occurred alongside improved graft and patient survival, more focused longitudinal and qualitative inquiry is needed. Partnerships are needed across disciplines and across those caring for different age cohorts in pediatric, adult nephrology, and transplant practices.

KEYWORDS

adolescent, emerging adulthood, ESRD, kidney transplant, quality of life, young adult

1 | INTRODUCTION

Since the availability of kidney transplant for children with ESRD began in the 1950s,^{1,2} there has been thought given to the medical and psychosocial outcomes of those individuals.^{3,4} As social workers part of pediatric nephrology teams over the last 20 years, the authors of this review have witnessed patients and their families address the challenges of childhood and adolescence with kidney disease, and the transition to adulthood and adult-oriented care. While pediatric teams put greater emphasis on preparing for the transition to adulthood and adult-oriented care⁵⁻⁸ and the actual transfer of care, long-term

understanding of outcomes for this population in adulthood is limited. As knowledge of and treatment options for congenital and acquired pediatric kidney conditions continue to expand, pediatric teams must be concerned with both the present and the future of their patients, including their long-term psychosocial outcomes in adulthood.

Kidney transplant is the preferred renal replacement treatment option for ESRD in children.² Research in this area shows that kidney transplantation in children improves health outcomes and overall quality of life.^{9,10} For children and adolescents, receiving a kidney transplant can bring an end to disruptive dialysis schedules and restrictive diets, allowing for increased involvement in school and social

Abbreviations: CMS, Centers for Medicaid and Medicare Services; CNSW, Council of Nephrology Social Work; ESRD, end-stage renal disease; HRQOL, health-related quality of life; MeSH, Medical Subject Headings/National Library of Medicine; NAPRTCS, North American Pediatric Renal Trials and Collaborative Studies; QOL, quality of life; RRT, renal replacement therapy; UNOS, United Network for Organ Sharing; YA, young adults.

activities, promoting growth and development, and providing overall hope for the future.^{11,12} Transplantation also comes with its challenges and trade-offs, from the demands of adherence to the medication regimen, parental surveillance, medication side effects, fears of graft loss, and disclosure of health status, to adjusting to a new normal.¹³⁻¹⁷

Bailey et al¹⁵ argue compellingly that the medical team needs to understand all aspects of how ESRD affects young adults' lives as this will ultimately help us better prepare to support them before, during, and after treatment, while ultimately improving outcomes. Social workers are key nephrology and transplant team members, mandated by the CMS.¹⁸⁻²¹ Though social workers are not solely responsible for their patients' psychosocial outcomes, these outcomes are deeply connected to immediate and ongoing work with patients and families. Across a multifaceted scope of practice,²¹ social workers in pediatric nephrology support patients and families through their experiences of chronic kidney disease, dialysis, and transplant while demonstrating the profession's values of resilience, autonomy, and self-determination.²² The question, however, remains: Are our increased efforts, as pediatric nephrology teams, in supporting independence and self-management in childhood, adolescence, and emerging adulthood (ages 19-30)²³ truly impacting the long-term psychosocial outcomes for these individuals in adulthood?

2 | METHODOLOGY

The authors undertook a literature review of *psychosocial outcomes in adulthood for individuals diagnosed with ESRD and received a kidney transplant in childhood or adolescence*. We began with PUBMED and PsycInfo searches based on the terms “((Kidney transplantation OR kidney failure) AND (quality of life OR psychosocial OR "Health status"[tw])) NOT (transition* OR Donor).” Upon identifying several articles specific to our topic, we reviewed references in those articles to build a list of literature spanning from 1986 to present. To assist in our search, we used the Yale MeSH Analyzer tool²⁴ to identify MeSH terms and keywords from articles meeting our criteria; this process identified inconsistencies in the MeSH terms and keywords used across the articles. Some but not all studies included the term “survival analysis” or “survivor,” some included “social support” or “social adjustment,” and there was great variety in whether articles included keywords “child,” “adolescent,” “young adult,” or “adult.” We identified articles from journals ranging from *Pediatrics*, *Pediatric Nephrology*, *Pediatric Transplantation*, *American Journal of Kidney Disease*, *Nephron Clinical Practice*, and *Transplantation*. Studies relevant to our search criteria were conducted in the United States and in several European countries. Our response focuses on the US context, taking into account the healthcare system and mix of public and private insurance coverage²⁵ in which our clinical experiences and our patient's trajectories are rooted; we recognize the detailed contribution of a number of European teams to this area of research.

2.1 | Findings

In 2007, a broad and detailed review of the adult outcomes of childhood transplant by Rees ended with the sentence “Generally, reports of psychosocial outcomes are disappointing.”¹ While there are clear limitations in social development and a lower satisfaction with their job/income, the desire for a “normal” family life (employment, marriage, and children) is just as strong.²⁶ Although kidney transplant is viewed as the gold standard in pediatric ESRD, restoring organ function does not necessarily restore one back to “normal” social life.²⁷ With limited information on the long-term outcomes in this population, despite the acknowledgment and implementation of transition programs from pediatric to adult-oriented care, it is vital for us to look closely at these psychosocial outcomes and what these patients are experiencing once they arrive at adulthood. In building this review and assessing the findings, we built a concept map to illustrate the biopsychosocial impact of kidney disease on adults transplanted in childhood (see Figure 1).

2.1.1 | Relationship/family status

Compared with healthy peers, adolescents and YA with a kidney transplant are up to 3 times more likely to live in the family home, as adults, compared to the general population²⁸ and less likely to be married or live with a partner.^{15,29} In a Dutch study of 82 patients, approximately 67% of those who were on RRT in childhood were married or lived with a partner compared to 74.4% of the general population. They also found that 31.5% of the study cohort had children, though this rate was significantly lower than the general population at 64.8%.³⁰ In an older study, adults transplanted in childhood reported successful relationships with partners, though fewer (particularly men) had children, and more than 40% reported not being sexually active.³

Young adults expressed reluctance around disclosing their medical condition to peers due to fear (or past experience) of social rejection and perception of not being a “normal” adult.²⁸ Young adults also reported their renal disease impacted their relationship status and made it difficult to establish and maintain intimate relationships.^{11,15} Many expressed a feeling of being viewed differently than peers and therefore experienced a degree of social isolation and shame as a result of body image issues. Although ESRD is a mostly invisible disease, it often results in changes to the body (scars, fistulas, catheters, and medication side effects such as weight gain or excessive hair growth) that cannot be easily hidden in one's personal life. In intimate relationships, the body is inevitably exposed; body image concerns and social inhibition can create real barriers to committing to a relationship or starting a family.^{15,28} Conversely, young adults with ESRD and other chronic health conditions may be as or more likely^{31,32} to engage in risky sexual behavior (and other high-risk behavior), in part striving for normalcy and social acceptance.

Pregnancy and parenthood are often a priority for women who have received kidney transplants,³³ though concerns regarding



FIGURE 1 Concept map—Biopsychosocial impacts of kidney disease on adults transplanted in childhood

fertility and inheritability of disease ultimately impact ones decision-making regarding family status.^{11,15} A survey of French adults who were transplanted in childhood revealed that only 12% of participants had children.²⁹ Similar findings were found throughout our review, and the number of adults who were transplanted before the age of 18 with children of their own was consistently less than that of the general population.^{11,15,27,34,35} Although there are favorable outcomes in live birth rates and graft preservation, there continues to be, worldwide, a significantly higher risk of maternal and fetal complications in women with kidney transplants.³⁶

2.1.2 | Educational and employment outcomes

The authors were able to identify a number of studies looking at the educational and employment outcomes of adults that received RRT

as children, some looking at children who were transplanted before 1986,³⁴ and others more recently. These studies consistently show that those diagnosed with ESRD in childhood experience a delay or underachievement in education and employment compared with healthy peers.^{11,12,37}

Education

Compared with healthy peers, adults that were diagnosed with ESRD in childhood experienced a significant educational delay due to their disease.^{11,12,37} Qualitative and quantitative literature reviewed repeatedly showed that for YA that experienced ESRD as a child, educational levels were negatively impacted when compared with the general population.^{16,37,38} Low educational attainment in this population can ultimately create barriers to employment. Renal disease in childhood may also lead to impaired cognition and perhaps the overall lower educational achievement in this population.³⁹ Several studies suggest

there is a relationship between neurocognitive development and educational achievement in those with ESRD.^{16,39} For example, the study of a cohort of Dutch patients that received renal replacement therapy before age 14 showed that ESRD patient's intelligence scores were significantly lower when compared to healthy peers³⁷; 47.6% of patients had a Full Scale IQ <-1 SD of the mean Full Scale IQ of healthy peers, with the mean IQ of ESRD patients being 107.9 compared to 118.2 for the control population. The same study also found that those patients who had a longer duration on dialysis prior to transplantation experienced overall lower intelligence scores.

Throughout their educational experience, children diagnosed with ESRD experience periods of educational disruption due to absences and/or health crisis.^{11,15} Being present at "critical moments" such as the beginning of primary, secondary or tertiary schooling was critical for educational development, both for establishing an educational foundation and for establishing peer relationships.¹¹ Lewis and Arber found that individuals diagnosed before puberty (<12) had a more difficult time in educational achievement because they experienced more educational disruptions and suggested that those diagnosed after puberty had already achieved an educational foundation that made them more employable as adults.⁴⁰

Completing high school or university thus becomes more challenging for this population of young adults. Ehrich reported in 1992 that 41% of their study's 617 young adults never attended or failed to complete secondary school.³⁸ Groothuis¹⁷ showed that among Dutch patients diagnosed with ESRD in childhood, only 42.8% had completed intermediate or specialized vocational training compared to 72.2% in the general population.³⁷ Twelve years later, Tjaden³⁰ found only 22.1% of a similar Dutch cohort received higher educational degrees or specific vocational training compared to 31.2% of the general population.³⁰ In a single-center study in the UK, Murray et al found that only 15.8% of 18- to 30-year-old ESRD patients held a university degree compared to 25% of the general population, and 24.6% dropped out of school at age 16 compared with 20% for the general population.¹⁶

Employment

Overall, employment rates vary after kidney transplant in relation to education level, age, and pretransplant employment.^{41,42} Young adults that were transplanted as children are more likely to be unemployed compared to the general population.^{11,15,27,29,38,43} In a study utilizing data from the UNOS database in the United States,⁴¹ out of 100, 521 transplanted adults identified in the database, 33% (n = 33, 257) were employed at the time of transplant. Of 29, 809 who were working at the time of transplant and were alive with stable function at 1, 3, and 5 years after transplant, the employment rate was 63%, 58%, and 55%, respectively. Less than half of the privately insured patients that were employed at the time of transplant returned to work after transplant despite having a functioning kidney. In a Swiss study of 689 adult patients, 56.2% of adult patients were working post-transplant compared to 58.9% pretransplant.⁴² Both research teams found that pretransplant employment was a strong predictor for working after transplant (a factor which may be more challenging for those living with ESRD since childhood or adolescence).

Tjaden et al¹² identified that young adults diagnosed with ESRD were employed at a lower rate when compared to the general population (61.8% vs 81%, $P < .05$). Broyer et al also found that, of patients transplanted before 16 years old, 25% were not working compared to 10.5% of the general population not working, and 18.5% of the unemployed ESRD patients were receiving a pension.³⁴ In the United States and elsewhere, being unemployed with a functioning transplant might be attributed to recipients' fear of losing healthcare benefits once employed, possibly creating an inability to acquire or pay for critical medications.⁴⁴

Murray et al found a similar unemployment rate for those with childhood-onset ESRD in a smaller single-center study, with 33.3% unemployed compared to 22.2% for the general population.¹⁶ Although only 31.6% of patients agreed with the statement, "My illness made it difficult of me to get a job," 85.7% felt their employment or work had been negatively affected by their ESRD. Groothoff³⁵ and Rosenkranz²⁶ identified differences in employment rates between pediatric onset vs. adult-onset ESRD, with adults that were diagnosed in childhood being more successful in improving their employment situation. Rosenkranz connects this to a lifetime's adjustment to illness; they have learned to adapt and are better able to align their employment accordingly.²⁶

Some studies found that even though patients showed a good level of physical and mental health post-transplant, this did not impact their post-transplant employment.^{44,45} Possibilities for this phenomenon are that even after transplant, recipients consider themselves disabled solely because of the transplant, even if they have the capacity to work.⁴⁴ Petersen et al⁴⁶ showed that employment status post-transplant has a positive impact on QOL and is also linked with lower risk of graft failure and increased recipient survival. Tjaden et al³⁰ found that being employed was associated with lower risk of impaired QOL in regard to physical functioning, vitality, and overall well-being, while for those with impaired physical QOL unemployment was a factor. While he states, the direction of this association is unknown, it is important to recognize the relationship between physical impairment related to ESRD and higher risk for unemployment. Inability to secure employment can also negatively affect QOL and an individual's self-confidence, leaving a lasting impact.^{11,17} Although much has changed since Ehrich's 1992 study, the greatest potential for employment remains a well-functioning graft and a sense of well-being.³⁸

2.1.3 | Health-related quality of life and well-being

Along with medical outcomes, HRQOL has emerged as a desirable outcome measure for assessing the impact of chronic illness, including kidney disease.⁴⁷ In addition to survival and graft function, there is a growing trend to use HRQOL tools to measure patient-centered outcomes based on lived experiences^{48,49} and to assess the effectiveness of treatment and predict potential risks for adverse outcomes.⁴⁷ Measuring HRQOL in these patients is paramount in achieving optimal psychosocial and treatment outcomes. When

the nephrology team has a better understanding of how ESRD and chronic illness impacts these patients, the team members can provide more well-rounded, multidisciplinary support with hopes of improving outcomes.^{15,48,50}

Young adults having ESRD since childhood experience a host of issues including frequent hospitalizations, medication side effects, and poor school achievement,¹² all of which impact their future ambitions and life goals, as well as their personal identity.¹⁵ Several studies show that young adults on renal replacement therapy experience lower QOL compared with healthy peers. The most impactful predictor for lower QOL is having other comorbidities and being on dialysis.^{12,17,43,51} The amount of time spent on dialysis was also found to impact overall HRQOL.^{17,43} Grootenhuys et al¹⁷ found that situations which caused disruption to social activities, such as time spent on dialysis or in the hospital, appeared to be associated with lower HRQOL later in adulthood. The areas of HRQOL most affected were physical functioning and general health.^{12,17,43,51,52} Other factors impacting overall HRQOL negatively were medication side effects, non-adherence behaviors, low socioeconomic status, and family conflict.⁵³

A few studies found a difference in perceived HRQOL between adults that were diagnosed in childhood compared to those diagnosed in adulthood. Survivors of pediatric ESRD were shown to have good QOL even after 20-40 years of renal replacement therapy,²⁸ suggesting that these individuals might have higher disease acceptance and less ability to recall life without the disease. Their frame of reference for QOL may differ from healthy peers,³⁰ whereas those diagnosed in adulthood struggle with the sudden onset of chronic illness and sometimes demonstrate an inability to accept their situation.

High scores related to emotional well-being in adults diagnosed as children were consistent with findings looking at other chronic illnesses.³⁰ Tjaden¹² found that young adults diagnosed with ESRD have significantly lower HRQOL when compared to other young adults with chronic illness, such as diabetes, asthma, and cardiac conditions. A systematic review of young adult perspectives on living with kidney failure¹⁵ reveals that for some young adults, transplantation was not always the picture of wellness and health they hoped it to be. They found that for young adults diagnosed with ESRD as children, there was a driving desire to *be* “normal,” whereas young adults diagnosed later in adolescence or early adulthood felt an “unbearable loss” and hoped to *return* to their previous state of “normal.” All articles reviewed are listed in Appendix S1 with descriptions of methodology, samples, and national/regional source.

3 | DISCUSSION

Overall, adults with ESRD since childhood demonstrate lower psychosocial functioning and achieve fewer milestones as compared to their healthy peers in respect to autonomy, social, and psycho-sexual development.¹⁷ Their educational and career aspirations are frequently compromised by the impact of their disease process.^{16,34,43} These patients often move between periods of wellness and illness,

with some periods of intense illness that impact their educational and social development.¹¹

Findings related to lower rates of romantic relationships/marriage and higher rates of remaining single and/or living at home with parents are not unusual in chronically ill populations (and has also changed in the general population, with age at first marriage now between 28 and 30 in the United States).⁵⁴ Greater delineation of the development tasks of emerging adulthood²³ and recognition of barriers to those tasks may suggest challenges for such individuals in developing their own sense of self and testing roles, especially in regard to their identities as sexual and relational beings. These authors have also noted the reluctance of both parents and health-care providers to discuss the topics of sexuality and intimacy with chronically ill youth.⁵⁵

Additionally, chronically ill young adults may continue to rely on their parents for their healthcare needs and may feel ill-equipped to manage their disease/kidney transplant on their own, therefore delaying their emergence and comfort with disease management, self-advocacy, and healthcare system/insurance navigation. A desire for financial independence and confidence may be counter-balanced by limited financial literacy, the financial burden (or “toxicity”)⁵⁶ of long-term illness and potentially expensive immunosuppressive and other medications, and fears of not having a reliable income over time.^{17,57} For ESRD patients, returning to work after transplant can play an important role in their general well-being and QOL,^{42,58} potentially even more so for YA with ESRD, who are attempting to break from their family and establish themselves alongside their peers.¹¹

Assessment of HRQOL falls within the requirement for physical and mental health assessment required by CMS Conditions of Coverage¹⁹ in dialysis centers and Conditions of Participation¹⁸ at centers conducting transplant evaluation in the United States. The assessment is frequently carried out by social workers and is included within the Standards of Practice of the CNSW.^{20,59} Across numerous studies of the pediatric and adolescent nephrology population, the PedsQL instrument⁶⁰ has been used in its generic form and more specifically utilizing the ESRD⁶¹ or Transplant⁵⁰ modules. The SF-36 is also commonly used in research to assess QOL across disease states and other social determinants of health. In these authors' experience, the PedsQL is also the agreed-upon clinical tool in pediatric dialysis in the United States, in parallel with the KDQOL⁶²⁻⁶⁴ for adults.

Several individual and environmental factors have been found to be predictive of future HRQOL in adolescent transplant recipients, such as low income, poor medication adherence, and family conflict. Medical teams should routinely screen and evaluate for these risk factors.⁵³ Social workers can assist in implementing interventions early when risk factors are identified. Fulfilling development tasks in childhood is a predictive factor for higher HRQOL later in adulthood.³⁰ Even though adults diagnosed with ESRD as children achieved fewer expected developmental milestones as their healthy peers, they did eventually reach them later in life.¹⁷

3.1 | Limitations

In undertaking this review, we quickly identified a number of challenges as this search yielded outcomes in childhood, outcomes for recipients transplanted in adulthood, and outcomes of adults receiving pediatric grafts. We recognize that much has changed in immunosuppression regimens, adequacy of dialysis, management of anemia, use of growth hormone, and overall graft survival over the last 35 years. We also recognize the potential limitations in not having a broader international set of findings.

For the purposes of this review, we did not include research specific to the transition of healthcare from pediatric to adult-oriented providers and systems, which has received a great deal of attention from the pediatric nephrology community,^{6-8,57,65} but instead focused on long-term outcomes in adulthood itself. While we did not exclude studies including transition age emerging adults,¹⁸⁻²⁵ we intentionally did not include research related to outcomes of transition-related interventions. We identified studies that included psychosocial outcomes related to relationship status, education, employment, mental health, and QOL.

3.2 | Recommendations

Teams working with children with ESRD and adults with ESRD since childhood should be aware of the enormous challenges these individuals face across their lifetime and across domains such as education, employment, building relationships, having families, and becoming financially independent. Our findings lead us to three primary recommendations:

- Gathering of more longitudinal data through partnerships of academic societies and registries.
- Strengthening of interprofessional collaborative relationships between pediatric and adult nephrology and transplant healthcare providers and teams.
- Policy level changes such as coverage of immunosuppression for life by Medicare.

In adult nephrology and transplant services, there may be little differentiation in disease management between different age groups,¹⁶ so a 24-year-old YA patient may be receiving the same medical recommendations as a 65-year-old adult. Likewise, the realities of living with illness since childhood may not be visible or well appreciated by adult specialists. Transplant offers children the best chance for normal growth, development, and social integration²⁷; thus, measuring psychosocial outcomes across the lifespan in this population may be even more meaningful.⁴³ Shifting the focus to more patient-centered psychosocial outcomes such as intimate relationships and establishment of families, education and employment attainment, and mental health may positively impact QOL, graft function, and ultimately survival rates in this vulnerable population. It is also key to remember that for some individuals

transplanted in childhood, there is a likelihood of additional disruption or intrusiveness of illness⁶⁶ in adolescence and emerging adulthood if a graft should fail. For many, the idea of graft survival was considered more important than individual survival.⁶⁷

Based on a major limitation of this review, the authors identified a great need for collection of consistent, longitudinal data related to psychosocial outcomes including, educational and employment outcomes, relationship status, and HRQOL in addition to a need for greater qualitative investigation of the experience of these aspects of adulthood for those whose ESRD and transplant journeys began in childhood or adolescence. In addition to research at individual centers, potential data collection efforts could be undertaken through partnerships between different societies such as the American Society for Nephrology, American Society for Pediatric Nephrology, the American Society of Transplantation, or between pediatric and adult-oriented clinicians within the Council of Nephrology Social Workers, or the Society for Transplant Social Workers. The NAPRTCS Registries, established in 1987, include information from over 20 000 children with kidney transplants, on dialysis, or with chronic kidney disease from over 100 participating institutions in the United States, Canada, Mexico, and Costa Rica.⁶⁸ While data from these registries have focused on the medical and survival outcomes of patients under 21, the potential for collecting psychosocial data from the same participants, based on agreed-upon markers such as HRQOL and follow-up of such patients beyond age 21, could allow for increased knowledge about real-life outcomes in the transition from pediatric to adult-oriented care, and in adulthood itself. Secondary analysis of UNOS data, as done by Tzvetanov et al,⁴¹ or modeled on the national French²⁹ or Dutch^{37,69} studies described earlier, could yield similar information. In the United States, advocacy efforts for lifetime Medicare coverage for immunosuppression medications in the United States would also be supported by data related to such long-term psychosocial outcomes, as adequate coverage is key to adherence with the medication regimens that support long-term graft and patient survival.^{25,70,71}

As social workers in nephrology, these authors are guided by a commitment to promoting long-term health, wellness, and QOL, as framed in our professional ethics²² and the recent Grand Challenges for social work,⁷² which include ensuring healthy development for all youth, closing the health gap, and advancing long and productive lives.⁷² These authors have both been lucky enough to connect or reconnect with former pediatric patients in adulthood, seeing a variety of relationship, education, and work outcomes (many quite successful across these categories), while also having experienced the loss of individuals due to illness progression, complications, infection, and non-adherence. We suggest that nephrology and transplant clinicians, across disciplines and patient age cohorts, have both practical and ethical responsibilities to be attentive to the long-term outcomes in adulthood for the pediatric patients whom we transplant. This review of the long-term psychosocial outcomes of adults transplanted in childhood and adolescence provides a useful context to consider where further work is needed, where data can and

should be gathered, and suggest stronger partnerships between pediatric and adult-oriented nephrology teams to support long-term survival and success for patients transplanted in childhood and adolescence.

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AUTHORS CONTRIBUTION

This article reviews the existing literature on the long-term psychosocial outcomes in adulthood for pediatric kidney transplant recipients, highlights gaps in knowledge, and makes recommendations for future data collection and research.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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