Health insurance considerations for adolescent transplant recipients as they transition to adulthood


Abstract: The advent of improved immunosuppression and enhanced allograft outcomes has resulted in a growing number of patients taking expensive immunosuppression medications for the rest of their lives. Healthcare costs for the majority of transplantation procedures in the USA currently are covered by Medicare, but coverage ends for outpatient immunosuppression medications 36–44 months after transplantation. Two or three immunosuppressive agents typically are included in post-transplant regimens with a total annual cost that can exceed $13,000. This represents a significant financial burden for families no matter if they have adequate health insurance coverage because of copayment obligations. Evidence suggests that some patients have reduced immunosuppression doses because of an inability to afford their medication, increasing the risk of graft failure. The purpose of this article was to review these and other issues pertaining to medical insurance coverage and transplantation, particularly for adolescent recipients as they transition to adulthood.

Pediatric transplantation has improved substantially during the last decade so that young children have the best long-term survival of any age group (1, 2). In a recent report released by the Scientific Registry of Transplant Recipients, one-yr graft survival rates have increased from 72% in 1988 to 95% in 1998 for deceased donor transplants and from 88% to 96% for kidneys from living donors (3). This marked short-term improvement unfortunately is not sustained long term. Adjusted five-yr graft survival rates for 11–17 yr olds were only 60% for deceased donor transplants and 72% for kidneys from living donors (1). Even though reasons for this late graft loss remain largely unknown, non-compliance is a common and well-recognized cause of organ rejection in pediatric (4–7), adolescent (8), and adult (9, 10) recipients. While many factors may contribute to non-compliance (5), the inability to afford immunosuppressive agents is thought to underlie as many as half of all cases (10–13). This may be due in part to lack or loss of insurance coverage.

Pediatric coverage risks

Typical insurers for transplant recipients include Medicare, Medicaid, and private insurance. Medicare provides primary insurance coverage for the majority of recipients of deceased donor renal transplants, but a relatively small fraction for other organs (14). Primary insurance coverage for various types of transplants for pediatric and adult patients reported to the Organ Procurement and Transplantation Network is shown in Table 1. Approximately 60% of deceased
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Table 1. Number and percentage of various primary insurance for various transplanted organs for 2000–2002

<table>
<thead>
<tr>
<th>Organ</th>
<th>Cases</th>
<th>Medicare (%)</th>
<th>Private insurance (%)</th>
<th>Medicaid (%)</th>
<th>Other (%)</th>
<th>Unknown (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deceased donor</td>
<td>21 258</td>
<td>59.2</td>
<td>33.0</td>
<td>5.9</td>
<td>1.9</td>
<td>0.0</td>
</tr>
<tr>
<td>Living donor</td>
<td>17 762</td>
<td>33.5</td>
<td>58.9</td>
<td>4.8</td>
<td>2.7</td>
<td>0.0</td>
</tr>
<tr>
<td>Pancreas</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pancreas only</td>
<td>477</td>
<td>11.5</td>
<td>70.9</td>
<td>9.9</td>
<td>3.6</td>
<td>4.2</td>
</tr>
<tr>
<td>Pancreas after kidney</td>
<td>987</td>
<td>45.7</td>
<td>50.3</td>
<td>2.8</td>
<td>1.2</td>
<td>0.0</td>
</tr>
<tr>
<td>Simultaneous with kidney</td>
<td>2710</td>
<td>43.4</td>
<td>50.4</td>
<td>4.2</td>
<td>2.1</td>
<td>0.0</td>
</tr>
<tr>
<td>Liver</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deceased donor</td>
<td>14 233</td>
<td>14.2</td>
<td>64.5</td>
<td>14.9</td>
<td>6.4</td>
<td>0.0</td>
</tr>
<tr>
<td>Living donor</td>
<td>1275</td>
<td>8.4</td>
<td>75.1</td>
<td>10.9</td>
<td>5.6</td>
<td>0.1</td>
</tr>
<tr>
<td>Intestine</td>
<td>299</td>
<td>9.0</td>
<td>45.5</td>
<td>36.8</td>
<td>8.7</td>
<td>0.0</td>
</tr>
<tr>
<td>Heart</td>
<td>6556</td>
<td>21.2</td>
<td>59.6</td>
<td>13.6</td>
<td>5.6</td>
<td>0.0</td>
</tr>
<tr>
<td>Heart and lung</td>
<td>3004</td>
<td>23.0</td>
<td>64.3</td>
<td>7.5</td>
<td>5.2</td>
<td>0.0</td>
</tr>
<tr>
<td>Lung</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deceased donor</td>
<td>56</td>
<td>5.4</td>
<td>80.4</td>
<td>5.4</td>
<td>8.9</td>
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<tr>
<td>Living donor</td>
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<td>12.1</td>
<td>69.2</td>
<td>15.9</td>
<td>2.8</td>
<td>0.0</td>
</tr>
</tbody>
</table>

Adapted from the OPTN/SRTR 2005 Annual Report (14).

donor kidney recipients had Medicare reported as their primary insurance whereas Medicare was reported as the primary insurance for only 20% of those receiving a heart transplant, and <15% for liver, intestine and lungs transplant recipients. Insurance coverage for pediatric kidney transplant varies and depends on multiple factors. Most children younger than 18 yr of age with ESRD are entitled to receive Medicare coverage (15).

It is well-recognized that there is insufficient healthcare coverage in the general adolescent population, especially during the transition period into adulthood. The age that this transition occurs is between 18 and 23 yr, depending on whether insurance coverage is provided by state (Medicaid or the State Children’s Health Insurance Program), Medicare or a private health plan. Policies for state-run programs vary depending on the child’s state of residence, and private plans often cover older adolescents only if they remain a full-time student until age 23. Fishman has reported that 12 million or 30% of all young adults 18–24 yr of age lack health insurance (16).

Regardless of type of health plan, pediatric organ recipients are at risk of losing healthcare coverage (15). Medicare coverage stops 36–44 months after transplantation or when children reach adulthood unless they meet the criteria for disability. While Medicaid provides healthcare coverage for adults with a disabled child in many states, successfully treating a medical condition or transitioning of pediatric recipients to adulthood can terminate coverage. Unfortunately, the existing Medicare framework generates incentives for transplant recipients to maintain their disability status and not enter the workforce. Interestingly, under the current system, pediatric patients receiving dialysis can continue Medicare coverage indefinitely.

Additionally, many employer-sponsored and private health insurers have “caps” or lifetime maximum amount included in their coverage. For instance, once a pre specified amount has been reached, the insurance company has no obligation to pay any additional benefits. Pediatric patients have a greater chance of reaching this lifetime maximum because of the potential for longer allograft survival when compared with adult transplant recipients.

It is often difficult for adolescents to obtain adequate insurance coverage when they reach adulthood. Those entering the workforce often start with part-time work with no health benefits or work for small businesses that cannot afford to offer insurance. Many young adults have insufficient salary to pay for health insurance premiums on their own (15). This translates to expensive out-of-pocket medical care and higher prices for medications (17). Finally, of coverage provided by employers, many prior existing conditions may not be included in new insurance plans.

Financial assistance

The most significant healthcare cost after three yr post-transplant is immunosuppressive agents (18). Cost of immunosuppression medications in kidney transplant recipients, regardless of age, may be as high as $10 000–14 000 per year (19). The loss of insurance coverage coupled with the high cost of immunosuppressant medications
Transplant insurance in adolescents

may place adolescents transitioning into adulthood at great danger. Short-term financial assistance is available and some patients may qualify for pharmaceutical company based patient assistance programs, which provide immunosuppressive agents free of charge. The manufacturer determines eligibility which generally means patients must be ineligible for other insurance that covers medications and must demonstrate a lack in personal financial resources (e.g., income) to pay for medications. The transplant center must initiate applications and frequently must re-apply every three to six months. Several charitable organizations provide emergency or short-term medication assistance on a case-by-case basis. Although at first glance it appears that these programs provide an adequate safety net for transitioning young adults, these programs have stringent requirements and provide only temporary assistance. Locating and applying for assistance programs to pay for medication is itself a significant barrier. Young adults who are able to obtain jobs often find that their earnings are insufficient to cover the cost of private insurance, yet their earnings disqualify them from medication assistance programs.

Income and non-compliance

The exact number of transplants lost due to non-compliance is not known. However, it is evident that the lack of medical insurance coverage poses a significant barrier to compliance and continued transplant function, and may be responsible for 13–35% of kidney transplant loss (20–23). One study attributed an alarming 71% of late graft loss in African-American pediatric kidney recipients to non-compliance (24) and yet another estimated that non-compliant kidney recipients lose their transplants or die at rates four times greater than compliant patients (21). Sanders et al. (20) assessed the impact of tapering or discontinuing cyclosporine for financial reasons in patients with primary deceased donor renal transplants with stable allograft function. Age and ethnicity-matched case controls maintained on at least 200 mg/day (mean of 3.9 mg/kg/day) of cyclosporine had similar rates of first-year rejection to patients whose cyclosporine was discontinued or tapered to 100–150 mg/day. The risk of rejection episodes after the first post-transplant year was greater in discontinuation patients compared with tapered (p = 0.017) or control (p < 0.001) patients, although no significant difference was found between the tapered and control groups indicating that in this single-center cohort, tapering immunosuppres-

sion for financial reasons yielded better outcomes than discontinuation.

An examination of the United States Renal Data System registry illustrated that loss of insurance coverage for immunosuppression had an impact on graft survival. Woodward et al. (25) compared renal allograft survival rates in low and high income pediatric and adult patients with only one yr of coverage or with three yr of coverage resulting from a policy change that extended Medicare coverage in 1992. Patients were stratified by median family income using zip code mapping. One-yr graft survival rates were similar for low and high income transplant recipients having one yr of coverage, but three-yr rates were significantly lower for low-income recipients (72% vs. 77%, p < 0.001). In contrast, three-yr survival rates were similar for low- and high-income patients with three yr of coverage (78% vs. 80%, respectively). Although the median income for a zip code does not directly correlate with personal income, and effect of transitioning to other forms of medical insurance could not be ascertained, one might conclude that the Medicare change resulted in a 6% increase in two-yr graft outcome by making immunosuppression medication more affordable and reducing economically driven non-compliance.

Loss of Medicare after pediatric kidney transplant

A recent abstract presented the outcomes of 1001 Medicare primary pediatric kidney transplant recipients between March 1, 1995 and September 30, 2001 (26). Medicare coverage was lost in 51.6% of these patients with a large number maintaining Medicare beyond transplant-based eligibility. The hazard ratio for graft loss three yr post-transplant more than doubled (HR = 2.34; p < 0.001) following Medicare coverage loss compared to those with continued Medicare coverage. Failure rates were highest in the year after cessation of Medicare coverage, with 6.5% losing their graft in the fourth year compared to 3.7% of those with continued coverage. The estimated average expected remaining duration of graft function was 13.7 yr for patients maintaining coverage compared to 7.7 yr for patients after coverage loss (Fig. 1). Loss of Medicare coverage is thus associated with an average six-yr loss of graft function in pediatric kidney transplant recipients. In this cohort of 1001 pediatric kidney transplant recipients, the risk of death increased ninefold following a lost graft compared to those with functioning grafts (HR = 9.26; p < 0.001).
This study demonstrates a correlation between loss of insurance and poor outcomes, but does not prove causality. Loss of healthcare coverage is difficult to define. As in the investigation by Woodward et al. (25), only loss of Medicare coverage was examined in this study. Some recipients likely had other insurance; therefore, these estimates may not truly reflect loss of healthcare coverage. Nevertheless, this study suggests important deleterious implications resulting from loss of medical coverage for pediatric transplant recipients.

Consequences of graft loss

Loss of a kidney allograft carries heavy costs for the individual beyond morbidity and mortality. For children with ESRD, loss of transplant inevitably means a return to dialysis. Although dialysis keeps them alive, at best it replaces only about 10% of normal renal function (13). Incomplete replacement of kidney function results in many health problems, including salt and water retention, phosphate retention, secondary hyperparathyroidism, hypertension, chronic anemia, hyperlipidemia, and heart disease. Dialysis further inhibits physical growth and development in pediatric recipients, places severe limits on normal social interaction and functioning, and is associated with poor academic performance (27, 28).

Loss of a kidney allograft also carries heavy costs for society. A patient who loses a kidney allograft will resume Medicare coverage and return to the transplant waiting list. Retransplantation, however, denies another potential recipient the opportunity for a transplant. Loss of a functioning transplant increases competition for scarce donor resources. The economic cost of continuing Medicare coverage has been studied by Kasiske et al. (19). The annual costs of maintaining a renal allograft are substantially less than both initial transplant costs and the costs associated with graft failure. The largest fraction of healthcare costs for maintaining a kidney transplant after the first year is the cost of immunosuppression medication. Functioning transplants are 10 times less expensive than allowing them to fail during the year following failure. The maintenance cost for a transplant recipient has been estimated to be $13 749 per year while the first year cost of returning to dialysis after graft failure is $137 930 (18).

Conclusions

Pediatric transplant recipients have every desire to become independent and useful members of society. Their goals and aspirations of education, careers, social interactions, health, and quality of life are no different from those of other young adults. As documented in the study by Schnitzler et al. (26), loss of Medicare coverage is a strong predictor of graft loss and subsequent death in pediatric kidney transplant recipients. Such patients are expected to lose an average of 6.0 yr of graft function and may have a shortened lifespan with the cessation of Medicare coverage. Lifetime coverage for immunosuppressive agents is likely to be more cost-effective in this population when compared with the expense of returning to dialysis after graft failure. In an analysis of pediatric and adult renal transplant recipients, extension of immunosuppression coverage to lifetime coverage produced an expected improvement in 20 yr graft survival from 38.6% to 47.6% and 20 yr patient survival from 55.4% to 61.8%, resulting in an annualized expected savings to society of $136 million (18).

While further research is needed to determine the extent of this problem, maintaining health coverage should be a major goal for post-transplant management of pediatric recipients. New policies and solutions including public lifetime coverage for pediatric kidney transplant recipients, which are expected to be cost-saving to our society in the long run, must be put forth and evaluated. Effective coverage to meet the healthcare requirements of pediatric transplant recipients as they transition to adulthood needs to be made accessible so that our society does not continue to prematurely lose this promising pool of young adults.

Disclaimer

The data and analyses reported in the 2005 Annual Report of the US Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients have been
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References