

Economic, Psychological, and Vocational Costs Associated with Kidney Disease and Failure: Development of Life Care Plans to Account for Applicable Costs

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Abstract

Unfortunately, due to a variety of conditions, the human kidneys may fail to perform adequately, resulting in either chronic kidney disease (i.e., reduced capacity for the kidneys to filter products and byproducts at their full capacity), or kidney failure (i.e., inability for the kidneys to filter in any significant, or functional capacity). In the scope of litigation, kidney failure may result from many circumstances, in which personal injury litigation may follow, such as trauma, medication errors, alongside other reasons. As such, life care planning offers an opportunity to appraise cost estimates associated with failure, furthermore offering the foundation for the present article. The present article addresses nomenclature pertaining to both kidney disease and failure, mechanisms to set up the life care plan, psychological overlay and its related costs, and the vocational losses potentially associated with applicable diagnoses. Lastly, quality of life (QOL) issues will be discussed as QOL significantly affects personal and social adjustment, and, ultimately, probable costs in a life care plan.

Keywords: psychological adjustment, life expectancy, return-to-work, kidney failure, dialysis

Economic, Psychological, and Vocational Costs Associated with Kidney Disease and Failure

The core function of the kidneys is to filter out waste products found in blood. Furthermore, kidneys are involved in a variety of bodily functions, including regulation of blood pressure, red blood cell production, maintenance of bone health and electrolyte balance. When waste products are built up in the kidneys, resulting from poor kidney function, kidneys may be deemed as failing to perform properly or with expected efficiency. As a result of poor kidney functioning, a variety of economic, psychological, and vocational costs can result, which represent the focus of the present article. In this article, discussion will initially address how to define and differentiate the various terms pertaining to the inability or poor ability of the kidneys to function properly, such as kidney disease, kidney failure, and End Stage Kidney Disease (ESKD), and other terms. Then,

frameworks to develop a kidney-related life care plan will be delineated. Subsequently, the present article will address applicable psychological and vocational costs associated with the loss of kidney functioning. Lastly, quality of life (QOL) will be discussed, particularly in the context of potential implications for life care planning costs.

Defining Pertinent Vocabulary

Unfortunately, demarcations among acute kidney failure, chronic kidney disease, and End Stage Kidney Disease (ESKD) are not always clear, discernible, and consistent. As such, the following general guidelines are offered as definitional clarity for the readers. First, *acute kidney failure* is typically caused or facilitated by a specific event, such as medication usage, dehydration, or blood loss from injury or surgery, ultimately leading to kidney malfunction. Second, *chronic kidney disease* is not due to an immediate cause, but is a result of long-term disease processes, such as diabetes or high blood pressure. Both diseases may slowly damage the kidneys, reducing kidney function gradually over time. Third, it is important to note that acute kidney failure is more likely to be reversible and successfully treated than chronic kidney failure. Fourth, it is correct to assess that chronic kidney disease represents an earlier stage of a process that may later result in *end-stage kidney failure*, wherein, the patient's condition is irreversible and treatment either with dialysis or transplantation is compulsory.

In circumstances related to acute kidney failure, the ability of the kidneys to filter blood is lost quickly or rapidly. Since most people have two kidneys, for complete kidney failure to occur, both kidneys must be significantly damaged or diseased. If one kidney fails to perform effectively or becomes damaged, it can be removed and the remaining kidney may continue to operate normally. However, if both kidneys are damaged, or diseased, removal of wastes must be restored through either dialysis or transplant of a donor kidney to maintain natural body functions. Kidney failure may be caused by sepsis, medications, or as the result of trauma (i.e., rhabdomyolysis). *End Stage Kidney Disease* (ESKD) is diagnosed when all kidney function ceases. This

disease can prevent an individual from participation in daily undertakings, such as work, activities of daily living, and the maintenance of family relationships. The degree of incapacity is variable among individuals according to age, acuity, and other factors. It is important to note that kidneys may “revive” with time, if patients are managed with the appropriate medications and specific dietary restrictions. Due to the physical degradation associated with kidney failure, patients must undergo several lifestyle changes, beyond medication and dietary restrictions, including vocational changes. Moreover, it is important to recognize that all kidney problems do not result in ESKD. Rather, in some circumstances behavioral changes and medical interventions may circumvent the progression of physical sequelae and resulting psychological and vocational overlay.

Setting Up the Life Care Plan

Preparing the Initial Narrative

The initial narrative of a life care plan must present a succinct picture of the circumstances, including the patient’s age, race, circumstances surrounding the injury and justification for the recommendations. Furthermore, any psychological overlay must be reported. The following example offers a reasonable initial narrative:

The subject of the case study is a 62-year-old Caucasian male with a high school diploma who worked in the oilfield for several years until his accident, earning

about \$80,000 annually. The subject was involved in a motor vehicle accident which resulted in the need for immediate medical attention. As a result of the accident, and nature of impact, the subject’s kidneys were permanently damaged due to trauma. He was later placed on dialysis at a rate of three times weekly for four hours each session. He remains on this dialysis schedule as of the present report date. From a psychosocial standpoint, the patient has verbalized difficulty adjusting to his dialysis schedule due to both time off of work, general fatigue, and reduced capacity to maintain intimacy with spouse. He is concurrently participating in psychotherapy twice monthly. He is presently maintaining his employment in a modified capacity related to both work tasks, hours, and compensation. It is appraised that he has a 68% reduction in annual wage earnings at present as a result of these factors.

Reviewing the Medical Records

Medical records are typically voluminous, consisting of dialysis records (if a person is on dialysis), physician conferences, medical billing, and other information. The identifiers for individual records should be recognized and demarcated, as during deposition or court, there will most likely be a need to demonstrate that estimated numbers are accurate. An example of listing of records is presented in the accompanying table.

Professional	Level of Education	Range of Services	Estimated Costs
Licensed Professional Counselor	Generally masters-level, less than 10% doctoral-level	Weekly, monthly counseling sessions, very susceptible for face-to-face counseling on weekly basis	\$65-\$110 hour
Licensed Social Worker	Masters-level	Very good for individual counseling sessions, primarily focuses on group work	\$49-\$120 hour
Psychologist (note that there are many subspecialties, such as Clinical, Counseling, and Medical)	Doctoral-level	Primarily used for initial assessment of psychological diagnosis, then referral for daily counseling to other providers	\$150-\$250 hour; initial evaluation estimated at \$2,500 minimum
Psychiatrist	Medical school	Primarily used to evaluate need for medication to address psychological overlay; limited utility for consistent daily counseling	\$250-\$350 per evaluation

Table 1
Mental Health Providers

This table offers a listing of the many mental health care providers applicable for persons with kidney failure. Potential utility will vary by both need and specialty of provider. Direction may be attained from treating physician regarding identification and selection of individual provider

Presenting the Data

Data will vary greatly, depending, of course, on the nature of the post-injury medical prognoses regarding kidney function. If kidney function may be improved through medication and diet only, then the frequency of medical visits and medical costs will be significantly less than if someone has ESKD or their kidneys have failed to perform in any significantly degree.

If a patient has kidney failure and requires dialysis, it is important to estimate the patient's anticipated annual kidney failure treatment costs. All medical bills provided can be reviewed for a frequency listing for each medical treatment, separated by treatment facility. To determine historical costs, it may be helpful to develop completed medical services for six months, one year, or even longer. It is recognized that a life care plan may be generated at various stages of someone's treatment. Kidney dysfunction may improve or

become worse as time progresses following development of the life care plan. If there is a set treatment protocol based upon past history, it will be vital to use historical figures to determine frequency, duration, and need for future care.

As noted previously, patients may become viable candidates for kidney transplants. Physician feedback must be generated regarding this probability. Applicable costs will be associated with not only kidney transplant preparation, but post-transplantation costs. Moreover, dialysis costs will obviously be impacted if kidney transplantation is successful, wherein, costs may need to be extracted. In all circumstances, it would be recommended to base costs on physician feedback and historical feedback. Admittedly, costs may vary greatly based upon success and failure of many interventions, such as dialysis or transplantation, if the latter is medically indicated or a true possibility.

Table 2

Service	Cost	Item Appendix Code	Date of Service	Frequency
Hemodialysis	\$400.00	021A	2/27/2014	1
				1
Initial Hospital Care Mod.	\$185.00	019A	2/25/2014	1
				1
Subs. Hospital Service	\$100.00	020A	2/26/2014	1
		025A	12/21/2014	1
				2
	\$70.00	027A	12/22/2014	1
				1
Office Visit	\$205.00	001A	11/21/2013	1
				1
	\$85.00	004A	11/25/2013	1
		007A	12/16/2013	1
		010A	1/20/2014	1
		014A	2/10/2014	1
				4
Urinalysis Automated	\$25.00	002A	11/21/2013	1
		005A	11/25/2013	1
		008A	12/16/2013	1
		011A	1/20/2014	1
		015A	2/10/2014	1
		017A	2/24/2014	1
				6
Creatinine Source Other	\$30.00	003A	11/21/2013	1
		005A	11/25/2013	1
		009A	12/16/2013	1
		012A	1/20/2014	1
		016A	2/10/2014	1
		018A	2/24/2014	1
				6
Hospital Discharge <30min	\$110.00	022A	2/27/2014	1
				1
Special Reports	\$20.00	013A	1/21/2014	1
				1
ESRD Related Services	\$1,300.00	023A	3/3/2014	1
		029A	2/11/2015	1
		031A	4/8/2015	1
		032A	5/6/2015	1
		033A	6/1/2015	1
		034A	7/6/2015	1
		035A	8/7/2015	1
				7
	\$1,100.00	024A	4/7/2014	1
		030A	3/25/2015	1
				2
	\$900.00	028A	1/16/2015	1
				1
Inpatient Consult	\$230.00	025A	12/20/2014	1
				1

Table 3

Identified Item	Cost	Demonstrated Frequency	Estimated Frequency
Hemodialysis	\$4,386.80	12/1 mo.	156/12 mo.
Heparin ¹	\$691.56	12/1 mo.	156/12 mo.
Heparin ²	\$197.40	12/1 mo.	156/12 mo.
Admin. Supply Inj.	\$74.06	26/1 mo.	312/12 mo.
Albumin	\$107.60	1/1 mo.	12/12 mo.
Alkaline Phosphatase	\$112.33	1/1 mo.	12/12 mo.
Calcium	\$111.86	3/1 mo.	36/12 mo.
Creatinine	\$111.07	1/1 mo.	12/12 mo.
Ferritin	\$295.77	1/1 mo.	12/12 mo.
Hematocrit	\$51.37	1/1 mo.	12/12 mo.
Hemoglobin	\$51.37	4/1 mo.	48/12 mo.
Hep B Surface	\$224.14	1/1 mo.	12/12 mo.
Iron	\$140.60	1/1 mo.	12/12 mo.
Phosphorus	\$103.06	3/1 mo.	36/12 mo.
Protein S	\$79.64	1/1 mo.	12/12 mo.
RBC Count	\$65.35	1/1 mo.	12/12 mo.
Bun, Post, Serum	\$64.33	1/1 mo.	12/12 mo.
PTH Intact	\$896.94	1/1 mo.	12/12 mo.
UIBC	\$189.75	1/1 mo.	12/12 mo.
Eosinophil	\$55.21	1/1 mo.	12/12 mo.

¹It was observed that Heparin was administered 3 times weekly with an associated cost of \$691.56.

²It was observed that Heparin was also administered 3 times weekly with a different associated cost of \$197.40.

Tables 2 and 3

Example of Month in the Life

In these figures we create a "Month in the Life" segment for a patient. Not only does this create a picture of the monthly costs, but it also creates a picture for the jury, retaining attorney, and opposing attorney that it will be difficult to maintain employment with this ongoing medical schedule. Readers will notice that codes are used to reference individual documents in the Appendix of a report. This will be helpful in deposition or court proceedings, if asked to "pull" a document to confirm a particular cost.

Table 4

Figure A	Identified Item	Cost	Demonstrated Frequency	Estimated Frequency
	Office Visit ¹	\$205.00	1/21 mo.	1/12 mo.
	Office Visit ²	\$85.00	4/21 mo.	2/12 mo.
	Hemodialysis	\$400.00	1/21 mo.	1/12 mo.
	Urinalysis Automated	\$25.00	6/21 mo.	2/12 mo.
	Initial Hospital Care Mod.	\$185.00	1/21 mo.	1/12 mo.
	Subs. Hospital Service ³	\$100.00	2/21 mo.	2/12 mo.
	Subs. Hospital Service ⁴	\$70.00	1/21 mo.	1/12 mo.
	Creatinine Source Other	\$30.00	6/21 mo.	3/12 mo.
	Hospital Discharge <30 min.	\$110.00	1/21 mo.	1/12 mo.
	Special Reports	\$20.00	1/21 mo.	1/12 mo.
	ESRD Related Services ⁵	\$1,300.00	7/21 mo.	2.5/12 mo.
	ESRD Related Services ⁶	\$900.00	1/21 mo.	1/12 mo.
	ESRD Related Services ⁷	\$1,100.00	2/21 mo.	1/12 mo.
	Inpatient Consult	\$230.00	1/21 mo.	1/12 mo.

¹ It was observed that an Office Visit took place 1 time with an associated cost of \$205.00.

² It was observed that several Office Visits took place with an associated cost of \$85.00. These visits are estimated as occurring twice annually.

³ It was observed that Subsequent Hospital Services were performed twice, each with an associated cost of \$100.00. These services are estimated as occurring twice annually.

⁴ It was observed that Subsequent Hospital Services were performed once with an associated cost of \$70.00. These services are estimated as occurring once annually.

⁵ It was observed that ESRD Related Services were performed numerous times, each with an associated cost of \$1,300.00. These services are estimated as occurring 2.5 times annually.

⁶ It was observed that ESRD Related Services were performed once with an associated cost of \$900.00. These services are estimated as occurring once annually.

⁷ It was observed that ESRD Related Services were performed once with an associated cost of \$1,100.00. These services are estimated to occur once annually.

Table 5

Figure B	Identified Item	Single Cost	Annual X1	Annual X2	Annual X3	Annual X6	Monthly X1	Monthly X3	Weekly X1	Weekly X3	Weekly X6	Total Times Annual	Total Cost Annual
	Hemodialysis	\$4,386.80								X		156	\$684,340.80
	Heparin ¹	\$691.56								X		156	\$107,883.36
	Heparin ²	\$197.40								X		156	\$30,794.40
	Admin. Supply Inj.	\$74.06									X	312	\$23,106.72
	Albumin	\$107.60					X					12	\$1,291.20
	Alkaline Phosphatase	\$112.33					X					12	\$1,346.96
	Calcium	\$111.86						X				36	\$4,026.96
	Creatinine	\$111.07					X					12	\$1,332.84
	Ferritin	\$295.77					X					12	\$3,549.24
	Hematocrit	\$51.37					X					12	\$616.44
	Hemoglobin	\$51.37							X			48	\$2,465.76
	Hep B Surface	\$224.14					X					12	\$2,689.68
	Iron	\$140.60					X					12	\$1,687.20
	Phosphorus	\$103.06						X				36	\$3,710.16
	Protein S	\$79.64					X					12	\$955.68
	RBC Count	\$65.35					X					12	\$784.20
	Bun, Post, Serum	\$64.33					X					12	\$771.96
	PTH Intact	\$896.94					X					12	\$10,763.28
	UIBC	\$189.75					X					12	\$2,277.00
	Eosinophil	\$55.21					X					12	\$662.53
													\$885,057.36

¹ It was observed that Heparin was administered 3 times weekly with an associated cost of \$691.56.

² It was observed that Heparin was also administered 3 times weekly with a different associated cost of \$197.40.

Tables 4 and 5

Example of Year in the Life

In these figures we create a picture of the “Year in the Life” segment for a patient. Individuals are able to observe frequency on an annual basis and then final costs. A jury may have “shock” when total costs are presented. However, this offers “digestible” units of information for jury education.

Table 6

Figure A	Identified Item	Single Cost	Annual X1	Annual X2	Annual X3	Annual X6	Monthly X1	Monthly X3	Weekly X1	Weekly X3	Weekly X6	Total Times Annual	Total Cost Annual
	Office Visit ¹	\$205.00	X									1	\$205.00
	Office Visit ²	\$85.00		X								2	\$170.00
	Hemodialysis	\$400.00	X									1	\$400.00
	Urinalysis Automated	\$25.00		X								2	\$50.00
	Initial Hospital Care Mod.	\$185.00	X									1	\$185.00
	Subs. Hospital Service ³	\$100.00		X								2	\$200.00
	Subs. Hospital Service ⁴	\$70.00	X									1	\$70.00
	Creatinine Source Other	\$30.00			X							3	\$90.00
	Hospital Discharge <30 min.	\$110.00	X									1	\$110.00
	Special Reports	\$20.00	X									1	\$20.00
	ESRD Related Services ⁵	\$1,300.00			2.5X							2.5	\$3,250.00
	ESRD Related Services ⁶	\$900.00	X									1	\$900.00
	ESRD Related Services ⁷	\$1,100.00	X									1	\$1,100.00
	Inpatient Consult	\$230.00	X									1	\$230.00
													\$6,980.00

¹ It was observed that an Office Visit took place 1 time with an associated cost of \$205.00.

² It was observed that several Office Visits took place with an associated cost of \$85.00. These visits are estimated as occurring twice annually.

³ It was observed that Subsequent Hospital Services were performed twice, each with an associated cost of \$100.00. These services are estimated as occurring twice annually.

⁴ It was observed that Subsequent Hospital Services were performed once with an associated cost of \$70.00. These services are estimated as occurring once annually.

⁵ It was observed that ESRD Related Services were performed numerous times, each with an associated cost of \$1,300.00. These services are estimated as occurring 2.5 times annually.

⁶ It was observed that ESRD Related Services were performed once with an associated cost of \$900.00. These services are estimated as occurring once annually.

⁷ It was observed that ESRD Related Services were performed once with an associated cost of \$1,100.00. These services are estimated to occur once annually.

Utilizing Empirically-Based Research to Justify Services and Cost Projections

As a component of any Life care plan, Planners are encouraged to utilize empirically-based research in their cost projections. Empirical research includes five essential features: observation, induction, deduction, testing, and evaluation. This process is valuable when planning associated kidney costs. Such empirically based research may either concur with or vary significantly from estimates presented in individual plans. First, life expectancy may be compared between groups of individuals with and without reduced kidney function. Second, quality of life may be assessed in order to suggest potential pathways regarding adaptability and malleability for persons with this disease. Third, empirical research may be used to estimate the probability that someone will realistically return to the workforce. Fourth, empirical research can permit an assessment of feasible mental health appraisals, ensuring the provision of needed services.

Examination and Calculation of Life Expectancy

In order to determine lifetime treatment costs associated with reduction of kidney function, one's life expectancy must be determined. Life expectancy is difficult to calculate for persons with reduced kidney function, however. While it seems reasonable, in order to accommodate tangible

expenses across a lifetime, to assume that someone with reduced kidney function will live a “normal” life span, individuals with reduced kidney function, particularly if someone has kidney failure, will have many compromised bodily systems and are more prone to general physical deterioration and immunity deficiency. It is also reasonable to consider that life care expectancies will be “less than normal.” Meanwhile, efforts to estimate variances from standard life expectancy may result in potential *Daubert* challenges. Lastly, it is vital to recognize that life expectancy will be significantly different among individuals with simply reduced kidney efficiency, or even chronic kidney disease, versus end-stage kidney failure. Obviously, those living long-term with end-stage kidney failure will have significantly reduced life expectancy than patients with minor or moderate kidney disease.

In circumstances wherein dialysis is required, several guidelines may be pertinent regarding life expectancy. Mehrotra et. al (2011) compared hemodialysis and peritoneal dialysis for treatment of end-stage kidney disease patients and found that the median life expectancy for patients on hemodialysis was 38.4 months and for peritoneal dialysis it was 36.6 months. When estimating life expectancy for individuals with kidney failure, it is vital to not assume that the above-mentioned rates are accurate for all patients, as individual differences (e.g., race, age, level of education) must be considered. It has also been found that diabetes, age, and comorbid conditions may play a role in life expectancy (Mehrotra, et al., 2011).

Regardless of the treatment approach used Turin et al. (2012) found that chronic kidney disease yielded a lower life expectancy among both males and females. At age 40, males had a mean life expectancy of 30.5 years, whereas females’ mean life expectancy was 34.6 years. Decreased levels of kidney functioning consistently implied a shorter life expectancy among individuals when compared to individuals with higher levels of function (Turin et al., 2012).

Beyond strictly reviewing life expectancy tables, planners may consider consulting with a treating physician regarding life expectancy, although there are potential, significant problems associated with obtaining this information from a physician. First, a physician may not want his or her patient to know the truth about the condition. Second, the patient may not want to know the truth. Third, the physician may only offer an estimate, that may be devoid of any degree of statistical certainty. It is, for those reasons, important to obtain multiple measures, such as traditional life expectancy tables, data attained from empirical research, as well as feedback from the physician, to have wide range of data available for a projection of lifetime costs.

Utilization of Web-Based Resources

Several readily available and easily accessible resources for the pricing of health care services are available for the life care planner. Like any resource or reference, quality, reliability, and dependability of any site must be scrutinized

by its user. It is recommended to share records with treating physicians and other health care providers to assure that web-based projections do not vary significantly from geographic expectations. These sources can be useful in the development of a life care plan for the individual with renal disease or failure. Several applicable websites are presented below.

Healthcare Bluebook (www.healthcarebluebook.com). This website is an online resource for healthcare consumers, providing information regarding costs on medical services and procedures. This site allows users to research costs for specific medical services in a specific geographical location. A cost range for services is provided ranging from an amount considered to be “at or below fair price”, a “fair price”, and a “highest price”. For services that include charges from more than one provider, such as a surgical procedure, separate fair price amounts include facility cost, physician fees, and anesthesiology fees. According to Healthcare Bluebook, their Fair Price is determined by using a proprietary analytics system to evaluate the allowed amounts (or discounted amounts) from medical claims and pricing and includes a variety of data sources.

Some examples of pricing for services (using zip code 70508) related to possible treatment scenarios for plan development are below:

1. Hemodialysis: \$124.00 (at or below fair price) – \$137.00 (fair price) – \$444.00 (highest price) Fair Price Fee Details: Includes procedure and physician fee.
2. Hospitalization for Renal Dialysis: \$6,924.00 (at or below fair price) – \$8,655.00 (fair price) – \$21,638.00 and up (highest price). Fair Price Fee Details: Price is for 4-day admission. More days charged at \$1,800/day. Fewer days will reduce price by \$1,800.00 per day.
3. Hospitalization for Renal Failure: \$4,125.00 (at or below fair price) – \$5,156.00 (fair price) - \$12,890.00 and up (highest price). Fair Price Fee Details: Price is for 3-day admission. More days charged at \$1,800/day. Fewer days will reduce price by \$1,800.00 per day.
4. Kidney Transplant: \$29,235.00 (at or below fair price) - \$45,079.00 (fair price) - \$129,547.00 (highest price) Fair Price Fee Details: Price is for a 7-day admission. More days charged at \$1,800/day. Fewer days will reduce price by \$1,800.00 per day. Breakdown of fee: Hospital services: \$38,873.00; MD Services: \$4,684.00 doe procedure; Anesthesia: \$1,522.00 for average surgery time of 3 hours and 15 minutes.

MD Save (www.mdsave.com). This website is described as an online marketplace for health care providing consumers with a fair point of comparison for procedures. The estimated national average calculated by www.mdsave.com uses a proprietary algorithm. According to the website, the following six prices are used to determine the estimated national average: 1) the full price billed by the health care

facility/provider, 2) discounted cash rates, 3) contracted rates, 4) insured out of pocket expenses, 5) self-pay rates, and 6) Centers for Medicare and Medicaid Services set prices for members. Some examples of pricing for services on MD Save related to possible treatment scenarios for renal failure are below:

1. Renal Scan: Estimated National Average \$1,401.00
2. Kidney Biopsy: Estimated National Average \$9,134.00
3. Kidney Removal: \$33,992.00

Examining Probability of Receiving Transplant in the Scope of Life Care Plan Development for a Patient with Long-Term Kidney Failure

In the context of outlining a life care plan, specifically for a person with long-term kidney failure, it is probable that a life care planner may be asked about the probability of a patient receiving a kidney transplant. This is vital information for cost projections, considering that QOL improves a patient's likelihood of returning to work and many other aspects of daily life. However, multiple factors come into play regarding the receipt of a transplant, including regional differences, individual acuity, the availability of a transplant organ, funding sources, and other issues. Patzer et al. (2009) found that such factors as race, gender, age, diabetes, hypertension, body mass index, albumin, neighborhood poverty levels, and the use of erythropoietin during dialysis were all related to being waitlisted for a transplant. Patel et al. (2008) evaluated how various aspects of cardiovascular screening are associated with kidney transplant wait listing. The findings, collected from a sample of 300 patients, indicated that prior presence of cardiovascular disease, low tolerance levels for exercise, and severity of coronary artery disease were all associated with failure to waitlist for kidney transplants (Patel et al., 2008).

Schold, Srinivas, Sehgal, and Meier-Kriesche (2009) focused specifically on recently listed, older-aged (at least 60) patients in need of kidney transplants between 1995 and July of 2007. They found that within five years, 52% of the participants were deceased before receiving a transplant. The proportion was higher among patients who were more than 70 years old, white, diabetic, and receiving dialysis treatment at the time of listing (Schold, Srinivas, Sehgal, & Meier-Kriesche, 2009). In a study of 132,353 patients performed by Segev et al. (2008) to analyze the effects of obesity and body mass index (BMI) on kidney transplant wait times, as BMI increased, the likelihood of the patient receiving a kidney transplant decreased.

Axelrod et al. (2010) also investigated kidney transplants with regard to the effects of socioeconomic status (SES). After being listed for three years, patients in the highest SES experienced live donor transplants at a rate of 29.4%, in comparison with those in the lowest SES level studied, who received live donor transplants at 13.5%. With covariate adjustments, the high-level SES transplant

candidates were 75% more likely to receive live donor transplants than those in the lowest SES strata. The results of that study also showed that high SES patients had a 14% decrease in mortality risk or removal for illness (Axelrod et al., 2010). These and the aforementioned data offer a framework for evaluating the probability of an individual obtaining a transplant.

Dialysis Costs as Per the Literature

The role of a life care planner is to develop a projection of services for evaluatees including applicable costs. Laupacis et al. (1996) investigated dialysis costs in a sample of 168 patients, finding that the average annual cost of intermittent hemodialysis dialysis was \$66,782. One-year post transplant, dialysis costs varied between \$27,903 and \$237,523, with an average cost of \$66,290. Two years after transplant, the average cost was \$27,875 annually. In this study, a transplant improved employment rates among 30% of the sample, whereas 45% were employed two years after receiving a transplant. In addition, Manns et al. (2003) compared continuous kidney replacement therapy and intermittent hemodialysis costs. They found that continuous kidney replacement therapy was more expensive, at \$3,486- \$5,117 per week, than intermittent hemodialysis, which had a weekly total cost of \$1,342. The costs for patients on dialysis were higher than those of kidney recovery patients, totaling \$11,192 and \$73,273, respectively (Manns et al., 2003). Finally, as Smith, Gullion, Nichols, Keith, and Brown (2004) found, there are other costs for individuals who have had kidney failure: Chronic kidney disease patients need 1.9 to 2.5 times more prescriptions, 1.3 to 1.9 more outpatient visits, 1.8 to 3.1 times more hospital stays, and 1.6 to 2.2 times more inpatient visits. The annual costs for prescriptions, outpatient visits, and inpatient treatment for stage 2 of the disease were \$7,050, \$6,026 annually for stage 3 treatment, and \$7,623 for stage 4 treatment (Smith, Gullion, Nichols, Keith, & Brown, 2004). With consideration to these costs associated with kidney care, a proposed methodology to set up a life care plan will be addressed.

Psychological Adjustment to Renal Disease

It is reasonable to assess, generally, that psychological overlay will vary according to the level or degree of kidney dysfunction. As an example, barring comorbidity factors, psychological overlay for someone with ESKD will be greater than someone with kidney disease that is treatable through medication and diet modifications. In any circumstance, psychological costs must be accounted for within any plan. The overlay for persons with diminished kidney function may be demonstrated through several mechanisms, including depression, aggression, or gastrointestinal problems.

Any overlay may be presented overtly, through aggression and change of mood, or may be hidden, without any identifiable behavioral changes. The timeframe in which

that psychological overlay occurs, however, can be difficult to discern. Some individuals may consider treatment interventions “just another task” and proceed without feeling depressed, and their psychological hardness may continue throughout treatment. For others, mental distress may begin immediately. Most often, physician and treating nurse case notes will record the presence of potential depressive symptoms, but many medical providers will not make inquiries into the psychological state of these patients. As part of a life care plan, consideration must be given to both the intensity (frequency of visits) and the duration (length of treatment) of dialysis. Furthermore, the current authors recommend that an annual psychological evaluation, in addition to psychological services at least four times annually throughout a lifetime be included in a life care plan. A listing of mental health care providers to be included in these treatment protocols is listed in the accompanying table. Lastly, kidney disease and kidney failure may elicit or evoke a variety of psychological issues, many of which are discussed in the following narrative. The following narrative is not intended to address all of the psychological issues that may arise related to kidney disease or failure.

Depression

In some individuals, depression may be a comorbid occurrence with kidney disease and kidney failure. Some of the precipitating features associated with depression include the reduction or elimination of work-related activity, modifications of sexual libido, physical pain, discomfort, and feelings of helplessness. Estimates of actual depression in the ESKD population are between 5% and 10% (Kimmel & Peterson, 2005). Kimmel and Peterson suggested that depression affects medical outcomes, particularly in the form of stressors. The authors furthermore note that longitudinal studies have confirmed an association between depressive affect, morbidity, and mortality among end-stage kidney samples. However, few if any, studies have examined depression in individuals with treatable kidney disease.

Gastrointestinal Effects

An overlap between depression and kidney disease, alongside ESKD, includes gastrointestinal symptoms stemming from both malnutrition and an impaired sense of well-being. However, similar to the previous narrative, most of the research has concentrated on individuals with strictly kidney failure, in which these studies will be reviewed. Strid et al. (2002) examined 233 patients with kidney failure, requesting that these patients complete the *Psychological General Well-Being* (PGWB) index and *Gastrointestinal Symptom Rating Scale* (GSRS). Their results were compared with a sample from the general population. Among patients with kidney failure, GSRS scores were higher than not only the controls (i.e., patients without a medical diagnosis), but also the pre-dialysis patients, with particularly high scores in both severe reflux and eating dysfunctions dimensions.

Moreover, patients with high gastrointestinal problems were shown to have impaired psychological well-being.

Sleep

Sleep represents an important or vital component of an individual's physical and psychological well-being. Individuals with consistent sleep patterns are happier, better adjusted, and physically fitter than individuals with poorer sleep habits. While completing mental health, vocational, and economic evaluations, it is necessary to appraise the sleeping patterns of clients and patients. In a study by Iliescu et al. (2003), participants who received hemodialysis three times each week for four hours reported health-related quality of life complaints related to sleep. Of the 89 participants, 71% reported difficulties reducing arousal, preparing for sleep, maintaining wakefulness, and failure to fall asleep, with a strong relationship between sleep quality and health-related quality of life. The authors also indicated that previous studies reported a comparable range of 50-80% of persons with ESKD having sleep problems affecting both their health and overall psychological well-being (Iliescu et al., 2003).

Psychological Overlay and Mortality

Peterson et al. (1991) evaluated 57 patients treated with hemodialysis or continuous ambulatory peritoneal dialysis where patients completed the *Beck Depression Inventory* (BDI) and the *Illness Effects Questionnaire* (IEQ). At one year, there were no differences according to mean age, duration of analysis, severity scores, or measures on the BDI and IEQ. However, most importantly, there were differences between survivors and deceased individuals, with mean depression scores higher in the deceased group than among survivor patients. Significant variances were found at the two-year interval, with severity, age, and duration of dialysis significantly related to mortality. Variations in depression were found at two years with survivors, again, having lower scores on the BDI in comparison to deceased individuals. The authors suggested that medical providers, psychologists, researchers, and others providing therapeutic services must direct their efforts toward identifying and treating depression in this population, especially considering the interplay between depression and survival outcomes. That is, psychological overlay does not present an unimportant feature to be ignored in the treatment plan.

Vocational Adjustment and Associated Costs

Work is important to an individual's self-esteem, economic self-sufficiency, and social placement within the community. In circumstances wherein kidney disease is treatable through diet and medication, there may be minimal changes to one's vocational status. For individuals with kidney failure, however, physical and emotional rehabilitation efforts remain primarily focused on physical restoration and remediation activities, as opposed to vocational placement and development. While some

individuals remain vocationally active while concurrently participating in medical treatment, individual differences exist regarding the range of employment options and probability of engaging in them. The following offers a review of several studies that have addressed employment and kidney failure.

Abecassis et al. (2008) researched the effects on employment of persons preparing for kidney transplants compared to long-term dialysis patients and found that 24% of patients who were receiving dialysis treatment for longer than one year returned to work after receiving a transplant. Of those who received a kidney transplant before dialysis began, at least 50% were able to return to work. Return-to-work rates were also affected by the duration of disability before any transplant procedures took place (Abecassis et al., 2008). Da Baere et al. (2010), meanwhile, showed that transplantation increases likelihood of returning to work for individuals in need of an organ transplant. When compared to heart, liver, and lung transplant candidates, patients who undergo kidney transplant procedures had the highest rate of employment (58.6%) in a cross-sectional sample of 281 patients (Da Baere et al., 2010). Return-to-work following organ transplant was more likely for younger transplant patients, males, married patients, those having a positive outlook on their ability to work, and those who were actively working up until one year before the transplant (Da Baere et al., 2010). A multivariate analysis of 822 kidney transplant recipients demonstrated that pre-transplant employment increased the likelihood of patients returning to work after transplantation (Matas et al., 1996). Lack of a concurrent diabetes diagnosis was also associated with higher return-to-work rates. Those subjects who were employed full-time or attending school before the transplant had the quickest post-transplant return-to-work timeframes (Matas et al., 1996).

Newton (1999) reported that among individuals who received kidney transplants, about 40% returned to work after the transplant. In their study, which analyzed a sample of 25 adult patients with end-stage kidney disease, patients who were employed before a transplant and anticipated post-transplant return to employment had greater probabilities of achieving return-to-work status compared with unemployed patients (Newton, 1999). This 40% return to work finding was also shown in other studies. Indeed, Varekamp, Verbeek, and van Dijk (2006) found that among a sample of 60 patients working “blue collar” jobs, 47% retained employment post-transplant.

In return to normalcy research conducted by Wilkins, Bozik, and Bennett (2003) examining 51 participants with end-stage kidney failure, 44% of patients were considered non-disabled prior to transplant. After multidisciplinary interventions focusing on education and psychosocial support, a 36-month follow-up indicated that 62% of the sample was considered non-disabled. The term *non-disabled* included those employed, students, homemakers, retired subjects, or those actively engaged in appropriate activities

for their age and socioeconomic status (Wilkins, Bozik, & Bennett, 2003). However, this study did not differentiate between the various “non-disabled” statuses, which limited the study’s ability to estimate an accurate number for individuals who were actively working post-transplant.

Quality of Life

With respect to family care, psychological assessment, vocational rehabilitation planning, and life care planning, QOL considerations must be evaluated in the context of treatment options, mental health interventions, and estimates of tangible costs. For present purposes, QOL will be defined as the general well-being of an individual with respect to health and happiness. While this definition is not inclusive of strictly financial means or wealth, several of these factors may interact. For example, someone may lose financial resources, and these losses will result in psychological stressors that, in turn, induce physical consequences. The present narrative will demarcate QOL for two major treatment options for kidney failure, including both dialysis and transplantation.

QOL on Dialysis

The following discussion will address quality of life among patients on dialysis and following a transplant. Drayer et al. (2006) reported the presence of depression among some dialysis patients results in a lower QOL. In their study, 28% of the 62 dialysis patients studied had either major or minor depression. Individuals reporting depression tended to be younger, and their lower QOL was linked to their specific health issues. The researchers also reported that lower QOL life measures were more significant for patients on hemodialysis who had depression (Drayer et al., 2006). Sayin, Mutluay, and Sindel (2007) also compared quality of life for individuals on hemodialysis, on peritoneal dialysis, and in transplant patients. Their results showed that all three comparison groups had QOL scores lower than those in the general population. Depression and anxiety within both dialysis groups had negative, significant effects on QOL scores. Multiple regression analyses revealed that the factors associated with lower QOL included being male, being older than 46, and having a lengthened duration of dialysis treatment. The most significant effect on QOL appeared to stem from psychological status and patient knowledge of treatment parameters (Sayin, Mutluay, & Sindel, 2007).

Perlman et al. (2005) found lower QOL among hemodialysis patients in their research and concluded that QOL measures for people with chronic kidney disease were lower than QOL scores in the general population. In their study, hemodialysis patients specifically were found to have QOL scores significantly lower than those of chronic kidney disease patients (Perlman et al., 2005). Finally, Pinson et al. (2000) found that prior to kidney transplant, individuals needing a kidney transplant actually had higher health-related QOL measures compared to other organ transplant

candidates, which, the researchers suggested, may be due to dialysis support. Perhaps, due to high pre-transplant level of health-related QOL, these individuals showed the smallest gains in health-related QOL measures post-transplant (Pinson et al., 2000).

Quality of Life after Transplant

Prior research indicates that patients receiving transplantation have higher QOL reports than patients receiving either continuous ambulatory peritoneal dialysis and home- or in-center hemodialysis (Burra & De Bona, 2007). Studies of QOL before and after kidney transplants have revealed a higher post-transplant QOL (Burra & De Bona, 2007; Liem Bosch & Hunik, 2008; Overbeck et al., 2005). Burra and De Bona (2007) found that African Americans females had lower levels of post-transplant QOL than Caucasian males, but their higher educational and economic levels were linked to a higher perceived improvement in QOL. A meta-analysis conducted by Liem, Bosch, and Hunik (2008) found that QOL levels were lowest among hemodialysis patients. While quality of life for participants improved after a transplant, it was still not comparable to individuals without this condition (Laupacis et al., 1996).

Conclusions and Final Observations

Probability of Psychological Overlay. It is likely that all individuals with kidney disease will incur some degree of psychological overlay. Conversely, if a person's kidney disease is largely treatable through diet and medications, it is expected that overlay will be less-pronounced. The relationship between depression and actual physical outcomes for patients must be noted. The research, as indicated previously, clearly indicates a relationship between chronic depression and survival rates for these patients. Therefore, a provision for psychological care should be included in the life care plan. Life care planners should become familiar with several quick assessments (i.e., Beck Depression Inventory) that may guide and direct ongoing mental health services, and they should collaborate with licensed mental health providers, if this is beyond their scope of practice.

Medical Records Review and Standards of Practice.

Practitioners are encouraged to review the guidelines provided in the International Academy of Life Care Planners Standards of Practice (IARP, 2015) and the Majority and Consensus Statements (Johnson, 2015) noting that a review of medical records, including applicable bills, is required when developing a life care plan. This information is necessary to developing an appropriate plan, as this information can be used as a foundation for estimating future medical costs.

Expect Costs to Vary by Geographic Differences. One should expect geographic variances to occur in costs. These costs may be directed by local economies, competition across

providers, rurality, and other identifiable and non-identifiable factors. If there are circumstances where there is a difference between the location where a patient resides and the location where treatment will be provided, a life care planner must determine whether cost differences will exist between the locales. This may be accomplished by comparing costs across providers at different geographic locales. A forensic economist may be further consulted to assist the life care planner with these projections.

Expect Costs to Differ by Individual Cases. It is difficult to estimate the degree or variance by individuals. Geographic location, providers, and individual acuity may all influence differences. For this reason, it is recommended that practitioners review actual medical and billing records to obtain individually-based projections. One should be cautious, procedurally and ethically, when making the assumption that "all costs are the same" with these types of cases.

Return-to-Work Expectations. Several personal points may determine whether or not someone will return to work with end stage kidney disease. These include the person with disease, spouse, physician, and current employer, as well as whether or not someone is concurrently working while receiving treatment. Other identifiable vocational contributions will be applicable, such as physical demands of the occupation, specific vocational preparation, educational requirements, salary, and the willingness of the employer to offer modifications to a work schedule. Most importantly, acuity and physical preparedness to return to work or maintain employment will direct job placement. A life care planner must consider a variety of these factors when evaluating the probability or possibility that an evaluatee will maintain or fail to maintain employment while receiving treatment.

Quality of Life. Any life care plan for an evaluatee with ESKD must also include consideration about the individual's QOL. A dialogue with the patient may include questions about daily life events, reduction in work activity, uncertainty about libido, and reduction in energy, for example. Quality of life assessments may be strictly based on a self-report by the patient or by using a specific psychometrically valid instrument.

Conclusion

Psychological and medical treatment protocols for persons with kidney disease or kidney failure are diverse with a variety of potential outcomes. Medical interventions may vary greatly, ranging from modifications in diet and exercise to dialysis, and possible organ transplantation. Psychological response may similarly be diverse; however, the life care planner must consider the presence of depression, gastrointestinal problems, and other issues. Most importantly, QOL must be evaluated in the context of adjustment. With feedback from medical and psychological health providers, alongside the patient and family members, a

high-quality life care plan may be generated, capturing not only applicable costs, but also setting up a treatment protocol to maximize life quality.

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