
Reluctance Towards Transplantation: Factors Influencing Patient Attitudes Towards Organ Transplantation

Harold W. Wiebe, LMSW, Wichita State University, Wichita, KS

Gaining access to kidney transplantation is a process that involves treatment decisions made by patients. Despite high success rates and multiple advantages of kidney transplantation, some patients choose to remain on dialysis for treatment. The present study will identify a range of sociocultural factors and personality characteristics that influence this decision-making process. Twenty transplant candidates, representing three subgroups (those answering "yes," "no," or "undecided" to the question of transplantation) completed a quantitative survey, supplemented by a qualitative interview, using both specific and open-ended questions. Standardized personality scales were used to compare personality characteristics between the groups. This study explored the complexity of the decision-making process and hypothesized that high levels of education, economic status, self-esteem, risk-taking tendencies, and optimism are positive predictors, while high levels of perfectionism, loneliness, shyness, and low self-esteem are negative predictors of choosing transplantation. Due to the small sample size, significant results were not obtained but important trends were noted. While higher levels of education, self-esteem, decisiveness, and support corresponded with positive choices for transplantation, optimism and tendencies toward risk-taking did not. Strong correlation was noted between personality characteristics and decision-making skills. The implications for social work are discussed.

Introduction

In many cases, patients contending with end-stage renal disease (ESRD), or kidney failure, are reluctant to pursue an organ transplant. Currently, less than 50% of patients offered kidney transplants accept them (Gordon, 2001). This phenomenon persists, in spite of the remarkable success rate of renal transplantation, the increased effectiveness of immunosuppressive (anti-rejection) drugs, opportunity for an enhanced quality of life, the cost-effectiveness of transplantation over continued dialysis, and the greater risk of premature death for those remaining on dialysis.

This research will attempt to look at demographic variables (i.e. age, gender), psychosocial variables (i.e. educational levels, economic status, etc.), and personality characteristics (i.e., assertiveness, self-esteem, decisiveness, friendliness, risk-taking tendencies, etc.) to identify trends.

The social work implications of identifying the more tangible and immediate barriers that negatively impact a patient's decision-making process (negative = a reluctance to pursue transplantation), such as fears, economic circumstances, lack of information, etc., and ranking them in order of importance or frequency, could prove valuable to the renal care nurse or social worker. Additionally, the study of underlying internal or achieved variables, such as educational level, social status, personality characteristics, and others that affect a

patient's decision-making process, could promote a clearer understanding of why and how certain decisions are made. This knowledge could facilitate more specific and effective services, counseling, and supportive efforts on the part of the renal care social worker.

Hypothesis

The contention of this research is that higher levels of education, higher self-esteem, high levels of hope, leadership abilities, higher levels of spirituality, and higher risk-taking tendencies are all indicators of persons deciding to pursue transplantation. Conversely, one would expect that persons who did not share these same indicators might choose not to pursue transplantation or remain undecided.

Possible Implications

If this hypothesis is supported, the renal care social worker and the nursing staff, as potential members of a patient's collective decision-making group, could aid in making his/her decision-making process more manageable, as well as more directed toward positive "quality of life outcomes". The research reviewed has shown that at least some of the variables affecting decision-making can be influenced by outside forces. Both self-esteem and the level of hope can be altered with proper counseling, encouragement, and patient/social worker interactions. Education levels are achieved over time and may be indicative of other personality traits. The

social worker might compensate to some extent by affirming the patient's learning abilities and by providing adequate and appropriate educational materials regarding treatment options. If the spirituality variable is found to be significant, the social worker might work at heightening the patient's awareness of his/her own spirituality. Levels of hope can be maintained or heightened by family support, diversion from focusing on the negative, exercise and fitness, and other factors. The renal care social worker obviously has an important role to play in renal treatment considerations.

Methodology

The study's 20 hemodialysis patients were part of the patient population of a dialysis treatment center in central Kansas and were recruited using a purposive sampling technique (Rubin & Babbie, 2001). While the entire population of the facility was assessed, the study groups chosen for the study were chosen because of their medical eligibility for kidney transplantation and because they fell within the 18-65 years of age guidelines.

The dialysis patient population was representative of the community, being economically, ethnically, racially, and spiritually diverse. While population variances exist from one locale to another, the population studied was typical of most Midwest dialysis units. The participants were categorized into three groups: those who had had or were pursuing a kidney transplant, those who had decided against it, and those who were undecided.

The study was looking for varying influences, demographic characteristics, or personality differences that might help explain why these patients made different choices, in hopes of identifying predictors of these decisions, predictors that could help social workers assist patients to maximize their quality of life through the choices they make.

Design

This research was designed as a pilot project to explore new ways to understand and predict decision-making. The project was conceived in the fall of 2001 and completed in the spring of 2003, and is a cross-sectional, correlative study that incorporates both quantitative and qualitative approaches. Using this combined approach helped to identify, quantify, and explore relationships between the study's variables and patient behavior, and probed the meaning of those relationships in terms of

their psychosocial context. The exploratory component of the project identified a variety of personality characteristics and studied the correlation between these traits and choices, as they related to transplantation, in hopes to identify trends and predictors.

Dependent Variables. The research involved a regressive approach to exploring what factors and processes caused the groups of renal patients to make the decisions they did. These decisions, pursuing transplantation, not pursuing transplantation, or remaining undecided, became the dependent variables.

Independent Variables. The independent variables, or factors influencing the patients to make the decisions they did, are many. Demographic factors such as age, race, gender, education, employment, and access to insurance were considered. Eighteen known renal-related variables (see Appendix A) were ranked in importance by those participants who had not yet made a decision to pursue transplantation. In an open-ended question, persons who had chosen to pursue transplantation were asked to list the three most important variables that contributed to their decision. Each person was scored on five standardized personality scales assessing ego identity, indecisiveness, friendliness/unfriendliness, general expectation for success, and satisfaction with life (see Appendices B-G), and these results were tested for correlation to the dependent variables. Finally, eighteen self-identified personality traits or descriptors were noted and their relationship to the dependent variables were explored. In all, data was gathered and analytical tests were performed on 41 independent variables

In a further effort to isolate influential characteristics, the correlations between the fifteen self-identified traits or descriptors were explored.

Data Collection and Instrumentation

Several sources and tools were used to gather data for this project. Medical and social work records at the dialysis facility were used to categorize the patient population in the four study groups. A questionnaire was used to gather demographic data and to identify and rank obstacles to transplantation. Five personality scales were incorporated into the questionnaire to assess patient personality characteristics; and a follow-up interview was used to identify additional personal characteristics and to allow for more qualitative observations by the researcher.

Questionnaire. A 113-question questionnaire (see Appendix A), divided into nine sections, was developed for this study. Section I, containing ten questions, is demographic in nature and quantifies decision-making variables, such as level of education, insurance coverage, and others. One screening question in this section, asking if a respondent was pursuing transplantation, verified the classification assigned by the social work staff, which established the three study groups: those responding "yes" or "no", and those who remain undecided regarding transplantation. Each of these groups was asked to respond to different sets of questions that were designed specifically for them.

Section II of the questionnaire quantified specific barriers to affirmative decisions regarding transplantation, and Section III queried the undecided group as to what services might ease their decision-making process. Section IV invited open-ended responses, identifying positive influences for Group 1 (those pursuing transplantation). The remaining five sections of the questionnaire used five pre-designed and tested rapid assessment instruments (RAI) for measuring personality characteristics.

Ego Identity Scale (ESI). This scale seeks to determine a patient's level of ego identity and self-esteem. This scale was developed in 1977 and utilized a study group of 249 graduate students. This 12-item, forced choice scale has a moderate internal consistency, with a split-half reliability coefficient of .68 (Tam, Kendis, Fine, & Porac, 2000).

Generalized Expectancy For Success. Scale-Revised (GESS-R). This 25-item measure is designed to assess dispositional optimism. A person with high levels of optimism not only reports higher levels of self-esteem and a general sense of well being, but is also more likely to engage in risky behaviors (i.e., transplantation) to attain desired goals. Internal consistency reliability is very good with coefficient alphas of .93 and .94 and a split-half reliability coefficient of .92 in two studies, one utilizing 199, and another 400, college students. Norms established in research with elderly persons indicated a mean of 97.97 with a standard deviation of 12.75. (Hale & Cochran, 2000)

Indecisiveness Scale (IS). This 15-item scale was developed in 1993 to measure indecisiveness as a symptom of obsessive-compulsive disorder. Indecisiveness may also be seen as the need for doing things correctly or

mistake-free. Perfectionism and neuroticism are closely tied to indecision and some authors would contend that obsessive individuals tend to over-structure information during input, therefore impairing one's decision-making ability. In two studies of female undergraduate students, one group of 112 and another group of 57, the scale produced an internal consistency with alphas of at least .87 (Frost & Shows, 2000).

Satisfaction with Life Scale (SWLS). This scale probes the subjective general well-being of the patient, or in other words, the cognitive judgmental aspects of general life satisfaction. A mind and individual at peace are better suited to cope with difficult decisions. A 5-item SWLS Scale, developed in 1985 by E. Diener, R. Emmons, R. Larsen, and S. Griffin, demonstrated a good reliability with an alpha of .87 when administered to a group of 176 graduate students. A satisfaction with life could enhance a patient's decision-making ability, but could also remove incentives to make changes or try to better one's situation. The norms established for this scale indicate a mean of 23.5 with a deviation of 6.43. (E. Diener, Emmons, Larsen, & Griffin, 2000)

Friendliness-Unfriendliness Scale (SACRAL). The 20-item SACRAL scale, measures friendliness as it relates to self-concept, accessibility, rewardingness, and alienation. Friendliness is a complex set of skills and beliefs about one's self that are closely related to other aspects of one's personality. It also relates to loneliness, shyness, social skills deficits, and feelings of alienation (Reisman, 2000). Loneliness and alienation have been identified as being negative indicators for transplantation (Horsburgh, 2000). Friendliness is much more than the number of one's friends. If a patient scored high on the unfriendly scale, it might indicate the absence of a support group or other close relationships that might intimately share the transplant experience and the subsequent altered lifestyle.

Specific questions on this scale relate to each of the four sub-categories of friendliness and will be scored separately. While no reliability data is available, there is evidence of construct validity shown by a 94% agreement rate between SACRAL scores and the assessment of raters of subject's responses in a laboratory setting (Reisman, 2000).

These instruments were used to identify and compare various personality characteristics within each of the three groups. Observable trends, such as particular per-

sonality characteristics that are present with one of the three study groups, are noted.

Interview. Follow-up semi-structured interviews with the dialysis patients, who had completed the survey form, were conducted. These interviews were designed to elicit information regarding self-identified personality characteristics that affect the patient's decision-making process and patient narratives about causes of their renal failure. During the course of the interview, participants were asked to make choices between opposing personality traits or descriptors (see Appendix G) in the areas of decision-making, attitudes, coping skills, personality, and thinking. These questions were used to probe for other unidentified variables affecting decision-making and to make a qualitative assessment of the patient and his/her personality characteristics. A secondary function of the interview process was to verify the reliability of the quantitative phase of the study.

Procedures

The researcher and the social work staff reviewed the medical charts of all the patients at the dialysis facility, between the ages of 18 and 65, to determine whether they had had a previous transplant, their eligibility for transplantation, and their written indications and actions demonstrating their level of pursuit of this modality of treatment.

This entire age-specific population was divided into four groups. Group I (Decided in favor) included patients that are either eligible and actively pursuing transplantation, or those who had previously received a transplant but for some reason had lost the use of that graft and were again on dialysis. The criterion for active pursuit of transplantation requires that a patient agrees with a physician to have his/her name placed on an organ bank's list of patients desiring an organ, begins pre-transplant testing, or provides a physician with the name of a prospective "live" donor and agrees to begin pre-transplant testing. Group II (Decided against) included patients that are eligible but have chosen NOT to pursue transplantation. The criterion for this group requires that a patient communicate specifically to a physician, social worker, or the researcher that he/she has decided not to pursue transplantation. Group III (Undecided) included patients that are eligible but still undecided as to whether or not to pursue transplantation. This includes any patient not having indicated a "decision in favor" or "decision against" transplantation. This group also includes patients who have verbal-

ly indicated a desire for transplantation but have taken no action to implement a plan over the previous six months. Group IV (Ineligible) included patients who have been determined ineligible for renal transplantation due to age, severe illness, other medical reasons, or have been determined to be unsuitable candidates by the medical team. Group IV was not invited to participate in the study. A comprehensive list of each of the remaining three groups was developed. With the exception of those patients deemed cognitively incapable of completing the survey, all of the other eligible patients in the three groups were invited to participate. These determinations were later verified both by a self-identifying question on the study questionnaire and interview questions regarding transplantation intentions.

All of the patients in the first three groups were invited to participate and were offered a cover letter and an informed consent form (See Appendix H and J). Participation was totally voluntary, confidentiality was assured, and no remuneration was given. Since visual impairment is common among dialysis patients, accommodation was made to read the form to those with that need. All of the consent forms were returned, either accepting or declining to participate.

All those who agreed to participate were asked to complete the research questionnaire. The expectation was that participants would complete the questionnaire while receiving their treatment (usually lasting approximately four hours). This would assure a high return rate and timely responses. However, due to visual impairments and restriction of motion, some asked and were granted permission to take their questionnaires with them and return them at a later date. The completed forms were returned over a three-week period. Of the 21 questionnaires distributed, 20 were returned (97.5% return rate).

After the questionnaires were returned, and prior to the interview phase of the study, the results of the five personality characteristic scales were compiled. This allowed for observations; and responses to the interview questions were compared to determine if they supported the survey results.

The individual follow-up interviews were conducted with 19 of the participants approximately two weeks after the questionnaires were returned. These interviews were approximately 20 minutes in length and were conducted with the patient while they received their dialysis treatment.

Data Analysis

Each of the five standardized personality scales was entered into individual databases, using SPSS 11,5, where they were summed and scored. An additional database was constructed to process and score the results of the qualitative responses (i.e. the 18 self-identified personality traits). A final database was built in SPSS 11,5 to tally the basic questionnaire and the scores that were obtained from the personality scales and the results of the qualitative interview. One additional item, the social work staff assessment of the participant's "pursuit of transplant" status, was added, providing the dependent variable component.

Due to the nature of this pilot study and its limited number of participants, it was decided that significance would not be assigned, but rather trends of interest would be noted.

Findings

The results of the data analysis produced findings in three major categories. Demographic and descriptive data of the sample population is reported and its relationship to the dependent variables was explored. Second, the results of a quantification and ranking of incentives and obstacles to transplantation are outlined. And thirdly, the findings of a more complex comparison of personality characteristics and the patient decision-making process is shared.

Descriptive

As shown in Table 1, the participants ranged in age from 26 to 65. They included 12 males and eight females. 55% were Caucasian, 20% African American, 15% Latino, and 10% other. Of the twenty participants, one had completed eighth grade, 11 had completed high school, seven had completed college, and one held a post-graduate degree. 17 patients were receiving full disability, one was employed full-time, one part-time, and one was unemployed with no disability income. Length of time on dialysis ranged from one to 24 years, with a mean of 4.75 years. Six of the patients reported having had previous transplants. Eight patients had lost their kidney function due to diabetes, two due to hypertension, one to polycystic disease, one to glomerulonephritis, three to accidents or birth defects, and five to unknown causes. No notable correlations could be drawn between the demographic statistics and the dependent variables of decisions to pursue transplantation.

Table 1

Baseline Demographic Information on Patient Sample (N = 20)		
	n	Percentage
<u>Age</u>		
25-35	2	10.0
36-50	8	40.0
51-65	10	50.0
<u>Gender</u>		
Male	12	60.0
Female	8	40.0
<u>Race</u>		
Caucasian	11	55.0
African American	4	20.0
Latino	3	15.0
Other	2	10.0
<u>Education Level</u>		
8th Grade	1	5.0
High School	11	55.0
College	7	35.0
Post Graduate	1	5.0
<u>Employment Status</u>		
Full-time	1	5.0
Part-time	1	5.0
Full Disability	17	85.0
Unemployed (no disability)	1	5.0
<u>Cause of ESRD</u>		
Diabetes	8	40.0
Hypertension	2	10.0
Polycystic Disease	1	5.0
Glomerulonephritis	1	5.0
Unknown	5	25.0
Other	2	10.0

Comparative Variables

Patients who were either undecided or had decided not to pursue transplantation were asked to rate, on a Likert-like scale, the importance of each of 18 variables as to their importance to their decision-making process. Each variable was rated from zero to five, with zero being no importance and five being very important. The responses for each variable were summed and divided by the number of respondents to find a mean score for each variable (see Table 2). The highest ranking was given to the variable "Dialysis is working fine I don't want to

change." This would indicate a reluctance towards change or risk. The variables identified in this study are very comparable to those identified in other similar studies (Simmons, Marine, & Simmons, 1987).

Table 2

Ranking of Identified Factors Inhibiting Transplantation

(N = 10)

Rank	mean score
1. Dialysis is working fine	3.2
2. Fear of rejection	3.1
3. Risks of surgery	2.7
4. Inadequate insurance	2.7
5. Financial Issues	2..6
6. Know someone who had difficulty	2.6
7. Cost of immunosuppressive drugs	2.5
8. Other health issues	2.5
9. Recuperation is difficult after TP*	2.5
10. Worried about quality of life after TP*	2.4

Scoring: 0 = Least Important, 2.5 = Median , 5 = Most Important, * transplantation

Participants in Group II (Undecided) were asked to rate six possible interventions for their importance in helping ease the patient's decision-making process. The intervention identified as the most helpful was "visiting with a transplant recipient", followed equally by "consulting with a transplant surgeon" and "attending a transplant workshop". All three choices would indicate a desire for better education regarding transplantation.

Patients in Group I (Decided in favor) were asked in an open-ended question to identify the three most important factors that contributed to their decision to pursue transplantation. The factor most frequently mentioned was the expectation of feeling better and living longer (n = 7), followed by a desire to stop dialysis (n = 6), stop being a burden on the family and the hope of living a normal life (n = 4), escape dietary restrictions (n = 3), the hope to travel and encouragement from others (n = 2), and having an organ donor.

Correlation between traits and decision-making

Various personality characteristics of the patients were quantified with the use of standardized personality scales. Mean scores from five scales were compared

with the means or the dependent variables with the use of One-Way Anova: Post Hoc comparisons.

Table 3

SWLS and SW Assessment means

SWLS Score

Tukey HSD^{a,b}

SW transplant assessment	N	Subset for alpha = .05
		1
No	4	16.25
Undecided	5	19.80
Yes	10	24.00
Sig.		.368

Means for groups in homogeneous subsets are displayed.
 a. Uses Harmonic Mean Sample Size = 5.455.
 b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Figure 1

SWLS and SW Assessment means activity plot

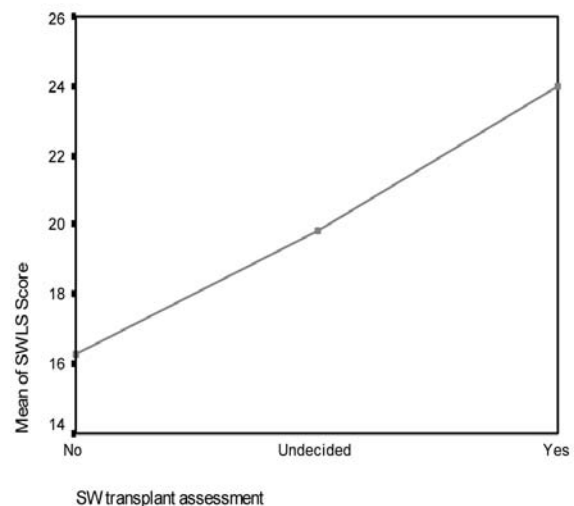


Table 3 shows the mean scores of the Satisfaction with Life Scale (SWLS) for each subset of patients. A correlation between higher satisfaction levels and a greater likelihood of pursuing transplantation is noted. The plotted scores (See Figure 1) clearly shows this trend

(Note that a score of one = no, two = undecided, and three = yes on the SW Transplant Assessment variable). The SWLS is based on a person's judgments rather than on external events; and satisfaction with life is a key component of mental well-being (Diener et.al, 2000).

Table 4

SACRAL and SW Assessment means

SACRAL Score

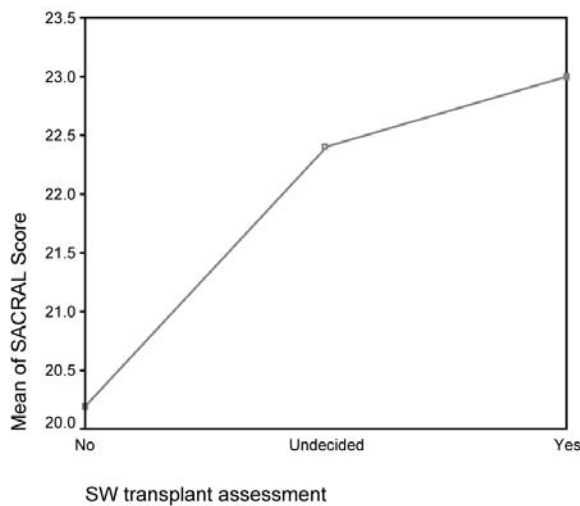
Tukey HSD^{a,b}

SW transplant assessment	N	Subset for alpha = .05
		1
No	5	20.00
Undecided	5	22.40
Yes	10	23.00
Sig.		.642

Means for groups in homogeneous subsets are displayed.
 a. Uses Harmonic Mean Sample Size = 6.000.
 b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Figure 2

SACRAL and SW Assessment means activity plot



Higher scores on the Friendliness/Unfriendliness Scale (SACRAL) show a strong correlation to positive choices for transplantation (see Table 4). In addition to indicating

friendliness, the scores, when broken down into subsets, indicate a respondent's rating in a number of areas, including accessibility, alienation, self-concept, and regarding-ness. These skills relate closely to loneliness and shyness. The trends are clearly delineated in Figure 2.

The Generalized Expectancy for Success Scale also shows a pronounced correlation between one's expectations of positive outcomes and one's desire to move

Table 5

GESS-R and SW Assessment means

GESS-R Score

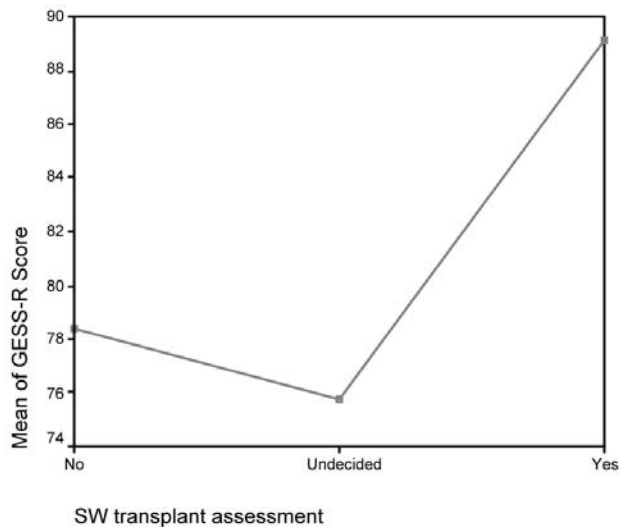
Tukey HSD^{a,b}

SW transplant assessment	N	Subset for alpha = .05
		1
No	5	75.80
Undecided	5	78.40
Yes	10	89.10
Sig.		.212

Means for groups in homogeneous subsets are displayed.
 a. Uses Harmonic Mean Sample Size = 6.000.
 b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Figure 3

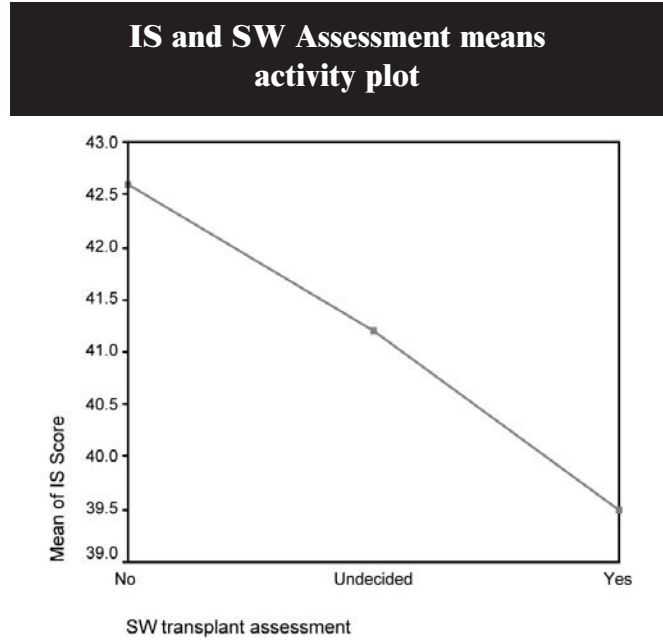
GESS-R and SW Assessment means activity plot



toward uncertain ends. It was expected that there would be a strong correlation between higher scores on GESS-R and choosing transplantation. According to Rotter’s social learning theory, dispensational optimism (expectancy for success), when present in a being, is conceptualized as the belief that he/she is likely to attain his/her valued goal or outcomes in most situations. Table 5 and Figure 3 show the relationship between these two variables.

The Indecisiveness Scale (IS) was chosen for study because of the assumption that indecisiveness can cause paralysis of the decision-making process and therefore keep some patients in a prolonged uncertainty or lack of action. As with some persons with obsessive-compulsive disorder (OCD), there may be such a fear of making mistakes or allowing imperfection, that they hesitate to act (Frost and Shows, 2000). A consistent trend (see Table 6) would translate as significant if this trend is supported with a larger study sample. Note that with the IS Scale, higher scores represent greater indecisiveness. Consequently the positive trait of decisiveness is the lower score, causing the plot (see Figure 4) to appear in reverse direction when compared with the other personality scales in this study.

Figure 4



The fifth scale that was used in this study is the Ego Identity Scale (EIS). This scale was developed around Erick Erikson’s concept of ego identity. This 12-item scale uses forced-answer questions, one representing ego identity, the other representing ego diffusion. Ego identity denotes acceptance of self and a sense of direction, while ego diffusion implies doubts about one’s

Table 6

IS and SW Assessment means

Tukey HSD^{a,b}

IS Score		
SW transplant assessment	N	Subset for alpha = .05
No	10	39.50
Undecided	5	41.20
Yes	5	42.60
Sig.		.877

Means for groups in homogeneous subsets are displayed.
 a. Uses Harmonic Mean Sample Size = 6.000.
 b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

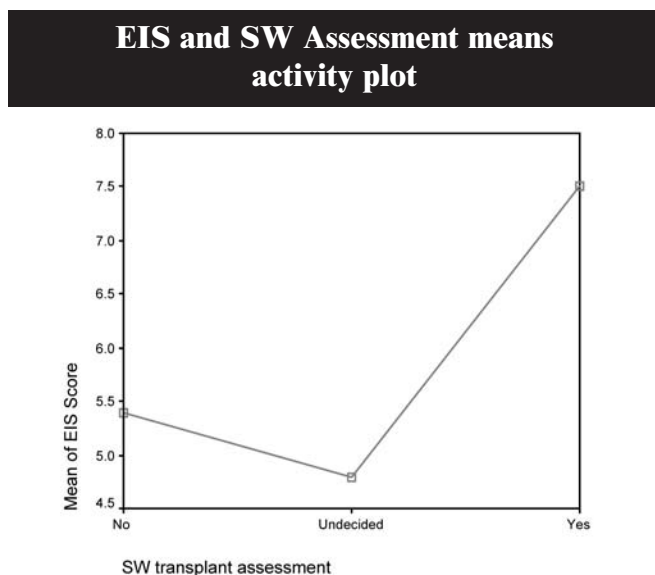
Table 7

EIS and SW Assessment means

Tukey HSD^{a,b}

EIS Score		
SW transplant assessment	N	Subset for alpha = .05
No	10	39.50
Undecided	5	41.20
Yes	5	42.60
Sig.		.877

Means for groups in homogeneous subsets are displayed.
 a. Uses Harmonic Mean Sample Size = 6.000.
 b. The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Figure 5

self, lack of a sense of continuity over time, and inability to make decisions or commitments. (Tan, et.al., 2000)

While the correlation of variables with this scale is not as remarkable, they are still present and might be significant in a future study. (see Table 7 and Figure 5)

Addition personality characteristics and descriptors identified in the qualitative portion of this study were also explored. Responses were operationalized (see Appendix G) and analyzed, both as they relate to the variable of transplant pursuit and also to their correlation to the results of the five personality scales. This test yielded some expected results, but also some surprises.

As expected, the study found that people who prefer shared decisions more often chose transplantation than those who prefer to make decisions alone. Doers are more likely than thinkers and spiritual people are more likely than non-spiritual people to choose transplantation. Aggressive people are more likely than passive people to make a positive choice. Those persons who are situationally depressed more often chose transplantation than those who suffer from mood depression, and those who feel supported sooner chose transplantation than those who feel alone.

Surprisingly, people who feel they are cautious or traditional thinkers are more likely to choose transplantation than those who think they are risk-takers or visionary. People who consider themselves optimists, extroverts, and satisfied with life did not show any correlation to

pursuing transplantation. A more scientific approach to assessing the characteristics is needed.

Limitations of the Findings

One of the major limitations of this research was sample size. The small number of participants in each group made it impossible to achieve statistical significance. Larger studies will need to be conducted before generalizations can be made.

There is also concern to what degree the study sample is representative. While the dialysis population studied may appear typical, only participants from one facility in one geographic location were used.

Working with populations that include ill and disabled persons also presents concerns. When visually impaired participants need the special accommodation of a reader, there is a risk that the reader's presence may influence the participant's answers, or that the reader may impact the questions with inflections of voice, etc.

The use of the *Satisfaction with Life Scale* (SWLS) creates a special problem for the study of ESRD patients. While one hopes to assess a patient's general satisfaction with life and how it affects one's cognitive judgment, ESRD patients experience an inherently non-satisfying aspect to their lives. Consequently, instructions need to be given to the participants to try to assess their levels of satisfaction in life, without including the negative inferences of ESRD. This may be an unrealistic or impossible assignment for the survey's participants, which could affect the reliability of this scale.

Discussion/Conclusions

As evidence continues to mount, regarding the detrimental effects of dialysis over time, the importance of early decision-making concerning transplantation increases. While there are some clearly identifiable social and environmental factors influencing decisions regarding transplantation, this study suggests that key personality characteristics play a major role in this decision-making process as well. While the more tangible social and environmental factors may influence what decision is made, this research suggests that deficits in certain personality characteristics may dictate whether any decision is made at all. An individual's attitude, demeanor, and levels of optimism, as well as his/her views of self, life, and the world around him/her, although seemingly unrelated, appear to be determining factors in choices regarding transplantation.

While further research in this area is warranted, the trends noted in this study should encourage the renal care social worker to look beyond the tangible incentives and obstacles to transplantation to the patient's basic decision-making capacities. The clear correlation between personality traits, the ability to make decisions, and the decisions that are made, indicate a potential for individually tailored interventions to facilitate informed and timely decisions.

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Appendix A
Research Survey Form
RESEARCH SURVEY

Section I

Please check the appropriate answer:

1. Age: 18-25
 26-35
 36-50
 51-65
2. Gender: Male
 Female
3. Race: Caucasian
 African Am
 Latino
 Other
4. Current Employment: Full time
 Part time
 On disability
 Unemployed
 None
5. Educational Level: 8th Grade
 High School
 College
 Post Graduate
(mark highest level completed)
6. Insurance: Medicare
 Medicaid
 Other-Health & Px
 Other-Health Only
 None
(check all that apply)
7. Cause of renal failure: _____
8. Length of time you have been on dialysis: _____ yrs.
9. Have you previously had a kidney transplant: Yes* No
10. Are you pursuing a kidney transplant: Yes*
 No**
 Undecided**

**If your answer to question 10 was YES, or IF YOU HAVE HAD A PREVIOUS ORGAN TRANSPLANT please skip sections II and III, and proceed to section IV.*

*** If your answer to question 10 was NO or UNDECIDED, continue on to section II.*

Section II

Please indicate how important each of the following thoughts or statements are or were in your decision-making process when considering transplantation. Circle the number that most closely matches your feelings:

no importance – somewhat important – important – very important

11. I think I am too old.	0	1	2	3	4	5
12. I have other health complications.	0	1	2	3	4	5
13. I am worried about rejection.	0	1	2	3	4	5
14. No one has talked with me about this option.	0	1	2	3	4	5
15. I know someone who rejected an organ.	0	1	2	3	4	5
16. There is a shortage of available organs.	0	1	2	3	4	5
17. I don't have enough information.	0	1	2	3	4	5
18. Dialysis is working fine; I don't want to change.	0	1	2	3	4	5
19. I don't have an organ donor.	0	1	2	3	4	5
20. I'm worried about the risk of surgery.	0	1	2	3	4	5
21. I'm not comfortable with an organ from a cadaver.	0	1	2	3	4	5
22. I'm worried about my quality of life after a transplant.	0	1	2	3	4	5
23. I have not been encouraged by others.	0	1	2	3	4	5
24. Recuperation from surgery is rough.	0	1	2	3	4	5
25. I'm worried about finances.	0	1	2	3	4	5
26. I don't have adequate insurance.	0	1	2	3	4	5
27. I'm hesitant for religious reasons.	0	1	2	3	4	5
28. Immunosuppressive drugs are expensive.	0	1	2	3	4	5
29. I know someone who had difficulties.	0	1	2	3	4	5
30. Other _____	0	1	2	3	4	5

If your answer to question 10 was NO, please skip section III and go on to section IV.

Section III

If your answer to question 10 was *UNDECIDED*, indicate how important each of the following would be in helping you to come to a decision.

	No importance – somewhat important – important – very important					
31. A consultation with my doctor to hear his recommendations	0	1	2	3	4	5
32. Visiting with my social worker	0	1	2	3	4	5
33. Visiting with someone who has received a transplant	0	1	2	3	4	5
34. Attending an informational workshop	0	1	2	3	4	5
35. Getting someone to talk with me about the risks	0	1	2	3	4	5
36. Having someone talk with me about the costs and insurance	0	1	2	3	4	5
37. Other: _____	0	1	2	3	4	5

If your answer to question 10. was *NO*, or *UNDECIDED*, please skip section IV and go on to section V.

Section IV

If your answer to question 10 was **YES**, or **IF YOU HAVE PREVIOUSLY RECEIVED AN ORGAN TRANSPLANT**, please list the 3 most important factors that influenced your decision to pursue transplantation:

1. _____

2. _____

3. _____

Please continue on to section V.

- NOTE -

ALL PERSONS will complete the following five sections. There are no right or wrong answers. What is important is what you personally believe is true of yourself. Please read all questions or statements carefully and answer according to the instructions given at the beginning of each section.

Appendix B

Satisfaction With Life Scale (SWLS)

Section V Satisfaction With Life Scale (SWLS)

*Please indicate the extent to which you agree or disagree with the following statements.
(As much as it is possible, consider all aspects of your life OTHER than your renal condition.)*

	Strongly Disagree			Neutral		Strongly Agree	
1. In most ways, my life is close to my ideals.	1	2	3	4	5	6	7
2. The conditions of my life are excellent.	1	2	3	4	5	6	7
3. I am satisfied with my life.	1	2	3	4	5	6	7
4. So far I have gotten the important things I want in life.	1	2	3	4	5	6	7
5. If I could live my life over, I would change almost nothing.	1	2	3	4	5	6	7

*Please continue on to **Section VI***

Appendix C

Ego Identity Scale (EIS)

Section VI Ego Identity Scale (EIS)

Below are 12 pairs of statements. Please circle either a. or b., whichever describes you better.

1. a. I enjoy being active in clubs and social groups.
b. I prefer to focus on hobbies which I can do on my own time at my own pace.
2. a. When I daydream, it is primarily about my past experiences.
b. When I daydream, it is primarily about the future and what it has in store for me.
3. a. No matter how well I do a job, I always end up thinking that I could have done better.
b. When I complete a job that I have seriously worked on, I usually do not have doubts about its quality.
4. a. I will generally voice an opinion, even if I appear to be the only one in a group with a point of view.
b. If I appear to be the only one in a group with a certain opinion, I try to keep quiet in order to avoid feeling self-conscious.
5. a. Generally speaking, a person can keep much better control of himself and of situations, if he maintains an emotional distance.
b. A person need not feel loss of control, of himself, and of situations simply because he becomes intimately involved with another person.
6. a. I have doubts as to the kind of person my abilities will enable me to become.
b. I try to formulate ideas now, which will help me achieve my future goals.
7. a. My evaluation of self-worth depends on the success or failure of my behavior in a given situation.
b. My self-evaluation, while flexible, remains about the same in most situations.
8. a. While there may be disadvantages to competition, I agree that it is sometimes necessary and even good.
b. I do not enjoy competition.
9. a. There are times when I don't know what is expected of me.
b. I have a clear vision of how my life will unfold ahead of me.
10. a. What I demand of myself and what others demand of me are often in conflict.
b. Most of the time, I don't mind doing what others demand of me because they are things I would probably have done anyway.
11. a. When confronted with a task that I do not particularly enjoy, I find that I usually can discipline myself enough to perform them.
b. Often, when confronted with a task, I find myself expending my energies on other interesting, but unrelated, activities instead of concentrating on completing the task.
12. a. Because of my philosophy of life, I have faith in myself, and in society in general.
b. Because of the uncertain nature of the individual in society, it is natural for me not to have a basic trust in society, in others, or even in myself.

*Please continue on to **section VII.***

Appendix D

Generalized Expectancy for Success Scale – Revised (GESS-R)

Section VII Generalized Expectation of Success Scale – Revised (GESS-R)

Please indicate the degree to which you believe each statement would apply to you personally by circling the appropriate number.

1 = highly improbable 2 = improbable 3 = equally important 4 = probable 5 = highly probable

In the future, I expect that I will...

1. be successful at most things I try.	1	2	3	4	5
2. be listened to when I speak.	1	2	3	4	5
3. carry through my responsibilities successfully.	1	2	3	4	5
4. get the promotions I deserve.	1	2	3	4	5
5. have successful close personal relationships.	1	2	3	4	5
6. handle unexpected problems successfully.	1	2	3	4	5
7. make a good impression on people I meet for the first time.	1	2	3	4	5
8. attain the career goal I set for myself.	1	2	3	4	5
9. experience many failures in my life.	1	2	3	4	5
10. have a positive influence on most of the people with whom I interact.	1	2	3	4	5
11. be able to solve my own problems.	1	2	3	4	5
12. acquire most of the things that are important to me.	1	2	3	4	5
13. find that no matter how hard I try, things just don't turn out the way I would like.	1	2	3	4	5
14. be a good judge of what it takes to get ahead.	1	2	3	4	5
15. handle myself well in whatever situation I'm in.	1	2	3	4	5
16. reach my financial goals.'	1	2	3	4	5
17. have problems working with others.	1	2	3	4	5
18. discover that the good in life outweighs the bad.	1	2	3	4	5
19. be successful in my endeavors in the long run.	1	2	3	4	5
20. be unable to accomplish my goals.	1	2	3	4	5
21. be very successful in working out my personal life.	1	2	3	4	5
22. succeed in the projects I undertake.	1	2	3	4	5
23. discover that my plans don't work out too well.	1	2	3	4	5
24. achieve recognition within my profession.	1	2	3	4	5
25. have rewarding intimate relationships.	1	2	3	4	5

Please continue on to **section VIII**.

Appendix E

Friendliness/Unfriendliness Scale (SACRAL)

Section VIII Friendliness and Unfriendliness Scale (SACRAL)

The following statements are examples of how people feel about themselves and other people. Mark what you personally feel is true about yourself. Mark the extent to which you agree or disagree.

4 = strongly agree, 3 = somewhat agree, 1 = somewhat disagree, 0 = very much disagree

1. There are many times when you don't think well of yourself.	4	3	1	0
2. A lot of ideas and opinions of other people don't make much sense.	4	3	1	0
3. You often don't give compliments to someone who might deserve them.	4	3	1	0
4. You find it hard to be really yourself, even with your friends.	4	3	1	0
5. You are a shy person.	4	3	1	0
6. Even if you don't hear from a friend for several days and don't know why, you don't try to get in touch.	4	3	1	0
7. When your friends need advice, it is not always easy for you to give them suggestions or ideas about what to do.	4	3	1	0
8. You like to spend your time alone and to be by yourself.	4	3	1	0
9. You are very pleasant and agreeable.	4	3	1	0
10. If someone comes to talk with you, you always stop whatever it is you're doing and give your attention to the person.	4	3	1	0
11. If there is a new person around, you introduce yourself and your friends.	4	3	1	0
12. If you have time for fun and relaxation, you prefer to read or watch television or do something by yourself.	4	3	1	0
13. You lose your temper easily.	4	3	1	0
14. It's easy for you to start a conversation with a stranger and keep it going.	4	3	1	0
15. When your friends are sick, you always send them a little present or give them a card.	4	3	1	0
16. People often take your actions and comments the wrong way.	4	3	1	0
17. You think of yourself as a very friendly person.	4	3	1	0
18. People often come to you with their personal problems.	4	3	1	0
19. If you see someone who needs help, you drop whatever you are doing and lend a hand.	4	3	1	0
20. Good friends are hard for you to find.	4	3	1	0

Please continue on to **section IX**.

Appendix F

Indecisiveness Scale (IS)

Section IX Indecisiveness Scale (IS)

Please circle the number which most closely matches your feelings:

	Strongly Disagree				Strongly Agree
1. I try to put off making decisions.	1	2	3	4	5
2. I always know exactly what I want.	1	2	3	4	5
3. I find it easy to make decisions.	1	2	3	4	5
4. I have a hard time planning my free time.	1	2	3	4	5
5. I like to be in a position to make decisions.	1	2	3	4	5
6. Once I make a decision, I feel fairly confident that it is a good one.	1	2	3	4	5
7. When ordering from a menu, I usually find it difficult to decide what to get.	1	2	3	4	5
8. I usually make decisions quickly.	1	2	3	4	5
9. Once I make a decision, I stop worrying about it.	1	2	3	4	5
10. I become anxious when making a decision.	1	2	3	4	5
11. I often worry about making the wrong choice.	1	2	3	4	5
12. After I have chosen or decided something, I often believe I've made the wrong choice or decision.	1	2	3	4	5
13. I do not get assignments done on time because I cannot decide what to do first.	1	2	3	4	5
14. I have trouble completing tasks because I can't prioritize what is more important.	1	2	3	4	5
15. It seems that deciding on the most trivial thing takes me a long time.	1	2	3	4	5

Thank you for your participation!

Appendix G

Questions Posed During the Follow-Up Interview

Decision Making

1. When it comes to decisions, do you consider yourself a risk-taker or someone who is cautious?
2. Do you prefer to make shared decisions or do you prefer to make decisions alone?
3. Do you consider yourself a doer or a thinker?
4. Do you feel you are a decisive or an indecisive person?

Attitude

5. Do you consider yourself a person who generally has a positive or a negative attitude?
6. Do you consider yourself an optimist or a pessimist?
7. Do you generally have a feeling of satisfaction or dissatisfaction?
8. Do you feel you are generally happy or sad?
9. All persons experience depression at one time or another. Sometime we can tie our depression to a particular event or events, in which case we will refer to it as situational depression. At other times, we may just be depressed or having a "blue" day but can't explain why. We will call that mood depression. Which do you think you experience more often?

Coping/Support

10. When you experience a crisis, do you feel supported or do you feel alone?
11. Do you consider yourself a spiritual person or nonspiritual?

Personality

12. Do you consider yourself an extrovert or an introvert?
13. When you have leisure time, do you prefer being with others or being alone?
14. Would you label yourself aggressive or passive?
15. When in a stressful encounter, do you often exhibit anger or are you generally calm?

Thinking

13. When processing thoughts, would you consider yourself a visionary thinker or one who is more of a traditional thinker?
14. Do you think of yourself as a creative person or a more practical person?