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The Journal of Nephrology Social Work

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Nephrology Social Work

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THE JOURNAL OF NEPHROLOGY SOCIAL WORK

The Council of Nephrology Social Workers (CNSW) of the National Kidney Foundation (NKF) is a professional membership organization of social workers dedicated to improving the quality of psychosocial services delivered to ESRD patients, as well as supporting the profession of nephrology social work.

The Council of Nephrology Social Workers of the National Kidney Foundation

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The Editorial Board of *The Journal of Nephrology Social Work* encourages the submission of original manuscripts. The *JNSW* contains articles addressing contemporary issues/topics relevant to nephrology social work. Authors may wish to address any of the following topics, which are listed as guidelines:

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- Comorbid Illnesses
- Home Dialysis Modalities
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2) Abstract
3) Text
4) References
5) Appendices (optional)
6) Author note
7) Tables
8) Figures

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Is the "Gift of Life" a Resonant Frame?

A Comparison of Factors Involved in Non-Directed Kidney Donor Motivation for Social Workers and Nurses

Harry L. Humphries, PhD, Browyn K. Conrad, PhD, Kristen R. Humphrey, PhD, and Kathryn A. Giffin, BS, Department of History, Philosophy, and Social Sciences, Pittsburg State University; and Cheryl K. Giefer, PhD, APRN, Amy L. Hite, DNP, APRN, Irene Ransom Bradley School of Nursing, Pittsburg State University, Pittsburg, KS.

This research examines kidney donor motivations using a research design from prior investigations evaluating the persuasiveness of the National Kidney Foundation's (NKF) altruistic "gift of life" frame. Because previous studies produced mixed results, showing in particular substantially more support for material incentives among an international sample of nursing professionals, as compared to a convenience sample of college students, we compared in this study the motivations among practitioners in the fields of nursing and social work. A total of 159 social workers and nurses participated in a survey that addressed the relationship between material incentives, social distance and motivation to donate, as well as work-related burnout and compassion fatigue as structural factors that might reduce non-directed kidney donor motivation. The results show a significant negative relationship between altruism and donor motivation, as measured by social distance between donor and recipient, and a strong lack of support for direct cash incentives as a complement to living kidney donation. The results also show little support for the notion that compassion fatigue or burnout accounts for these results. Social workers are somewhat more altruistic than nurse practitioners but the differences between the two groups are not meaningful. However, low support for living donations to unrelated others, coupled with high support for limited material incentives for both groups, suggest a continued need to explore alternatives to the current framing of kidney donations as giving the "gift of life."

INTRODUCTION

In the United States, critically ill patients often suffer as a result of a critical organ shortage. In 2015, the Organ Procurement and Transplantation Network (OPTN) reported more than 121,000 people in need of an organ transplant, with over 78,000 patients on the active wait list. Of over 28,000 transplants performed, 5,075 involved living kidney donations (OPTN, 2015). In 2015, approximately 12,000 potential kidney recipients either refused a transplant or died awaiting treatment, or were considered too ill for a transplant alone (OPTN, 2015).

This critical care issue has prompted some in the medical community to call for changes in policy pertaining to organ donation, particularly as it relates to the controversial issue of donor compensation. For example, a working group of 50 medical professionals from many regions of the world recently established guidelines for a regulated system of incentives for living organ donations and published these guidelines in the *American Journal of Transplantation* (Working Group on Incentives for Living Donation, 2012). New research on the motives of those who undergo a living kidney donation is therefore needed not only to improve the living donation rate, but also to better inform future policy development.

Humphries, Conrad, Berry, Reed, and Jennings (2009), and Humphries, Conrad, Giefer, Hite, and Bishop (2014) provide empirical evidence relevant to donor motivations, including the influence of cash and other material rewards, among individuals related and unrelated to kidney recipients. Importantly, both studies suggest that the National Kidney Foundation's (NKF) effort to frame living kidney donations altruistically as a "gift of life" is limited in its appeal (cf. Fox & Swazey, 1992). In this research, we extend the work of Humphries et al. (2009; 2014) by focusing on the social factors that may be relevant to the decisions of nurses and social workers to become living kidney donors. We specifically compare the views of nurses and social workers with NKF membership because of their potential knowledge base as front-line nephrology professionals and the opportunity they therefore provide to understand the problem of organ donation and the organ shortage in ways that may help to improve the current paradigm.

Following Humphries et al. (2009), we first explore the willingness of nursing and social work practitioners to donate a kidney to related or unrelated recipients using an established measure of social distance. Second, we explore the appeal of material incentives relative to "gift of life" altruism among nurses and social workers. Third, we examine the relationship between donor motivation and work-related factors, most notably compassion fatigue and worker burnout, as possible structural barriers that may impede the motivation to donate.

THE "GIFT OF LIFE" AND THE INCENTIVE DEBATE

A growing global market in illegally acquired organs has led an increasing number of health professionals to suggest that the NKF and other organizations reconsider how they "frame" the organ shortage, particularly as it relates to

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the provision of monetary and other material incentives (Matas, 2007; Salomon et al., 2015). "Framing" is a term relevant to a theoretical perspective rooted in the literature on social movements in the social sciences, which suggests that the ways in which movements communicate a problem to broader publics can serve to crystallize that problem in ways that create a sense of urgency (Snow, Rochford, Worden, & Benford, 1986). Collective action "frames" are typically defined as persuasive slogans or catchphrases designed strategically by movement entrepreneurs (Benford & Snow, 2000). Persuasive frames successfully tap culturally "resonant" or taken-for-granted ideas and are therefore likely to recruit potential followers to a cause (Snow & Benford, 1988).

In their work on organ transplantation, Fox and Swazey (1992) suggest that living donors are elevated to folk heroes as a consequence of their choice to sacrifice a part of themselves for altruistic reasons (p. 33). Giving the "gift of life" is thus culturally "resonant" in that choice and volunteerism has wide appeal (Fox & Swazey, 1992, p. 33). In their research on donor motivation, however, Humphries et al. (2009; 2014) find that altruism alone is an insufficiently motivating "frame" and that, given the scope of the organ shortage, the kind of cash-based incentives, ones that Fox and Swazey (1992) claim would turn the poor into "spare parts" for the rich, may in fact be warranted. In a controversial piece, Satel (2011) claims that payment for organs could end the objectionable practices typically associated with prohibition, including unsafe procedures, lack of informed consent and cash promises that never materialize. Such ethical debates take on increased urgency in an environment in which one organ is sold every hour, according to the World Health Organization, with the majority of sales involving kidneys (Campbell & Davison, 2012).

In our opinion, social scientists should not shy away from debates surrounding "cash for organs" and other controversial ideas. Instead, ethical concerns should be incorporated into research models, particularly for studies that explore what motivates an individual to undergo living kidney donation surgery. Following Humphries et al. (2009), we incorporate ethical concerns into our analysis by utilizing a value-added Ethical-Motivation Scale to better determine the "resonance" among nurses and social workers of the idea that living kidney donors should be compensated. This, we argue, is critical to determining whether or not, and how, to incorporate material incentives into the "gift of life" frame (Humphries et al., 2009, p. 22).

NURSING AND SOCIAL WORK

Consistent with framing theory, we contend that the NKF's "gift of life" frame should resonate with both nurses and social workers in that practitioners undergo professional training and each discipline has a similar code of ethics rooted in a culture of care. This hypothesis is based on the idea that if one is socialized to believe and behave in a certain way in a professional setting, one would likely apply that same worldview to their personal decision-making.

Professional socialization has been defined as "the acquisition of the knowledge, skills, values, roles, and attitudes associated with the practice of a particular profession" (Clark, 1997, p. 442). Miller (2010) has adapted a professional socialization model for social workers from the literature on the socialization of medical and nursing students, which progresses from pre-socialization to formal socialization to practice after formal socialization. Doctors, nurses, and social workers complete programs of study that are practice- and competency-based; they each include a clinical or practicum component as part of education; and, they each include immersion into a professional culture with specific values and approaches (Barretti, 2004). Further, they each include continued socialization through formal and informal education once in practice.

Each profession also has a specialized knowledge base, and the overarching values of the profession influence the way professionals carry out practice. Social work programs introduce students to the National Association of Social Workers (NASW) Code of Ethics, which informs social work students that the mission of social work is to "enhance human well-being and help meet the basic human needs of all people…" (NASW, 2008). The NASW Code of Ethics lists six core values of the profession: "service, social justice, dignity and worth of the person, importance of human relationships, integrity, and competence" (NASW, 2008). The social work value, "service," tells future and current social workers that they are "encouraged to volunteer some portion of their professional skills with no expectation of significant financial return" (NASW, 2008). Social work students are also introduced to a particular worldview in that the profession is "guided by a person in environment framework" (CSWE, 2015, p. 5). Social work students are educated to view clients through an ecological or bioecological model, as opposed to a "medical model," which is seen as more focused on the disease than on the person.

Similarly, according to the American Association of Colleges in Nursing (AACN, 2008), training in ethical patient care emphasizes the professional values of altruism, autonomy, human dignity, integrity, and social justice. Altruism includes understanding the cultures, beliefs, and perspectives of others, advocating for clients, especially the most vulnerable, addressing the risk behaviors of clients, and mentoring professionals (AACN, 2008). In contrast to social workers however, nursing students are more likely to complete their clinical experiences immersed in the medical model. Clark (1997) argues that medical professions value rational solutions to medical problems and a "disinterested concern for patient and society" (p. 443). As a part of their formal medical training, nurses are also more knowledgeable of the potential risks of surgery and the difficulties associated with recovery. This knowledge and training, we argue, results in a more "pragmatic" as opposed to "idealistic" approach, particularly among nursing practitioners.

In the present study, we hypothesize that both social workers and nurses should be oriented towards altruism, but that nurses will be less altruistic than social workers. Following Humphries et al. (2009), we utilize the Bogardus Social Distance Scale (Bogardus, 1925; 1933) to measure altruism in both populations. Specifically, we hypothesize that the less the social distance between donor and recipient, the greater the willingness to donate. In addition, to determine whether or not working conditions foster social distance, and thus decrease donor motivation, as suggested originally by Humphries et al. (2014), we incorporate a Compassion Fatigue Scale designed to measure work-related stress and burnout as potential barriers to living kidney donation (Watson, 1988, p. 8).

RESEARCH DESIGN AND METHODS

Conceptualization and Measurement

Following Humphries et al. (2009; 2014), we assess the willingness of NKF member nurses and social workers to undergo a living kidney donation with a modified version of the Bogardus Social Distance Scale (Bogardus, 1925; 1933), which is regarded as a valid measure of the level of comfort individuals have in associating with individuals who are increasingly "distant" or dissimilar on various key traits (Babbie, 2004; Neuman, 2000). This scale is as follows:

1. I would donate one of my kidneys to a member of my immediate family.
2. I would donate one of my kidneys to a member of my extended family (e.g., aunt, uncle).
3. I would donate one of my kidneys to a close friend.
4. I would to donate one of my kidneys to an acquaintance or a friend of a friend.
5. I would donate one of my kidneys to a stranger.

Responses to these items were scored from 1 to 5, with individuals who answer "yes" to item 5 categorized as more altruistic than individuals who answered "yes" to item 4 but "no" to item five. This scale thus served as an indicator of the intensity of respondents' altruism.

Also following Humphries et al. (2009; 2014), we use a cumulative summated-rating scale linking various material rewards to willingness to donate. This ethical-motivation scale (FMS) was developed in accordance with ethical issues raised in the literature on donor compensation and consists of nine items of increasing monetary or material value. On a scale of 1 to 5, with 5 being the most favorable, respondents were asked to indicate the extent of their agreement with each of 9 statements. These 9 items are as follows:

1. Living kidney donors should not be compensated. The donation should be considered a free-will donation and purely altruistic.
2. Living kidney donors should be entitled to compensation for medical expenses related to the procedure.
3. Living kidney donors should be entitled to compensation for medical expenses and lost wages relating to the procedure.
4. Living kidney donors should be compensated for medical expenses, lost wages related to the procedure, and should receive a "reward" package that may include a weekend getaway.
5. Living kidney donors should be compensated in the form of a federal tax deduction incentive.
6. Living kidney donors should be compensated for medical expenses and lost wages relating to the procedure and should also receive a "reward" package that may include cash or tax credit incentives.
7. Living kidney donors should be compensated for medical expenses and lost wages relating to the procedure and should also receive a "reward" package that includes life-long medical coverage.
8. Living kidney donors should be compensated for medical expenses and lost wages relating to the procedure and should also receive a "reward" package that includes life-long medical coverage, plus an amount of instant compensation up to $60,000–$70,000.
9. Living kidney donors should be able to freely negotiate the price, compensation, and reward they receive for their donation with no limitation on the amount or criteria.

To measure compassion fatigue, we use an 11-item summated rating scale, again using issues raised in the literature on burnout and compassion fatigue (Figley, 1995; Lombardo & Eyre, 2011; Smith, Preston, & Humphries, 1976). Respondents were asked to indicate the extent of their agreement with each of 11 statements, rated on a scale of 1 to 5, with 5 being the highest level of compassion fatigue. These 11 items are as follows:

1. I feel like work dominates my life.
2. When personal problems arise I can rely on my coworkers for advice.
3. I have become emotionally detached in my professional and personal life.
4. I am frequently taking work home with me.
5. I seem to be working harder and accomplishing less.
6. I often feel physically and emotionally exhausted by the end of the work day.
7. When problems arise, sometimes I resort to drinking, drugs, gambling, or other methods of escape.

8. I often find myself questioning my competence and the effectiveness of my work performance.
9. It seems like my work goes unappreciated and unrecognized.
10. I find it difficult to form meaningful relationships outside the workplace.
11. I feel completely burned out and often wonder if I can go on. I am at the point where I may need some changes or may need to seek help.

Data Collection

Data for this research is based on a self-administered, self-report survey using a non-representative sample of convenience administered at the National Kidney Foundation 2015 Spring Clinical Meetings to social workers, nurses, and other healthcare professionals. A total of 169 respondents completed the survey, with 10 surveys missing data (RR = 100%). We confine our comparative analyses to 159 social workers and nurses but note that 10 other healthcare professionals completed the survey, yielding a total sample size of 169 respondents. The study was reviewed and approved by the Pittsburg State University Committee Involving the Use of Human Subjects. Table 1 illustrates the demographic characteristics of the sample.

Data Analysis

SPSS 22 was utilized for the statistical analysis of these data. Percentages and simple cross tabulations were used for nominal and ordinal variables to observe bivariate relationships. Descriptive statistics, including means and standard deviations, were used for the three ordinal-level scales. A Cronbach's alpha was used to test the reliability and internal consistency of the ethical-motivation scale and produced α = .82. The Cronbach's alpha for the modified Bogardus Social Distance Scale was α = .72 A Spearman correlation technique was used to examine the relationship between the social distance scale and the ethical-motivation scale.

Table 1. Demographic Characteristics of the Sample (N = **169**)*

					Totals
Gender	Male	Female			
	8.3% (*n* = 14)	91.1% (*n* = 154)			99.4% (*n* = 168)
Age	21–30	31–40	41–50	51 or more	
	7.9% (*n* = 13)	23.8% (*n* = 40)	25.6% (*n* = 43)	38.1% (*n* = 64)	95.4% (*n* = 160)
Education	Bachelors	Masters	Doctorate	Other	
	7.7% (*n* = 13)	78.7% (*n* = 133)	4.1 % (*n* = 7)	8.3% (*n* = 14)	94.6% (*n* = 167)
Occupation	Nurses	Social Workers	Other		
	40.2% (*n* = 68)	53.8% (*n* = 91)	6.0% (*n* = 10)		100% (*n* = 169)

*Totals do not add to 100% due to missing data.

Table 2. Social Distance and Kidney Donation (N = **169**)*

	Yes	No
I would donate one of my kidneys to a member of my immediate family.	95.8% (*n* = 161)	4.1% (*n* = 7)
I would donate one of my kidneys to a member of my extended family.	74.4% (*n* = 125)	25.6% (*n* = 43)
I would donate one of my kidneys to a close friend.	71.3% (*n* = 119)	28.1% (*n* = 47)
I would donate one of my kidneys to an acquaintance or friend of a friend.	22.9% (*n* = 38)	77.1% (*n* = 128)
I would donate one of my kidneys to a stranger.	14.5% (*n* = 24)	85.5% (*n* = 141)

*Totals do not add to 100% due to missing data.

Table 3. Social Distance and Kidney Donations, Nurses and Social Workers Compared (N = **159**)*

		Nurses (*n* = 68)	**Social Workers (*n* = 91)**
I would donate one of my kidneys to a member of my immediate family.	Yes	92.6% (*n* = 63)	98.9% (*n* = 89)
	No	07.4% (*n* = 5)	01.1% (*n* = 1)
I would donate one of my kidneys to a member of my extended family.	Yes	69.3% (*n* = 47)	78.9% (*n* = 71)
	No	30.9% (*n* = 21)	21.1% (*n* = 19)
I would donate one of my kidneys to a close friend.	Yes	64.7% (*n* = 44)	76.4% (*n* = 68)
	No	35.3% (*n* = 24)	23.6% (*n* = 21)
I would donate one of my kidneys to an acquaintance or friend of a friend.	Yes	10.3% (*n* = 7)	34.1% (*n* = 30)
	No	89.7% (*n* = 61)	65.9% (*n* = 58)
I would donate one of my kidneys to a stranger.	Yes	03.0% (*n* = 2)	25.0% (*n* = 22)
	No	97.0% (*n* = 66)	75.0% (*n* = 66)

*Totals due not add to 159 due to missing data; *p* >.09 2 df (nurses) and *p* >.001 2 df (social workers)

RESULTS

The purpose of this exploratory study is to compare nurses and social workers on each of three measures used as indicators of kidney donor motivation: 1) social distance between donor and recipient; 2) support for material incentives as a component of motivation to undergo a living kidney donation; and 3) self-ratings concerning compassion fatigue and worker burnout as possible factors influencing donor motivations among nursing and social work professionals.

With respect to social distance, we used a modified Bogardus Social Distance Scale (Bogardus, 1925; 1933), based on the hypothesis that those with the least social distance from the respondent would elicit the most willingness to donate (Humphries et al., 2009; 2014). The data in Table 2 support the hypothesis that as social distance increases, the willingness of respondents to donate a kidney decreases. 95.8% of nursing, social work, and other healthcare respondents indicated they would donate one of their kidneys to an immediate family member. 74.4%, or 21.4% less, were willing to donate a kidney to a member of their extended family. 71.3%, or 24.5% less, were willing to donate a kidney to a close friend.

In contrast to the high willingness associated with donations to immediate and extended family, however, only 22.9% of nursing, social work and other healthcare respondents were willing to donate a kidney to an acquaintance and only 14.5% were willing to donate to a stranger. Hence, 81.3% fewer respondents were willing to donate a kidney to a stranger than to an immediate family member. This result is statistically significant at p >.001.

As indicated in Table 3, a comparison between nurses and social workers on the Bogardus Social Distance Scale (Bogardus, 1925; 1933) supports the hypothesis that social workers are more altruistic. Compared to nurses, social workers are 6.3% more willing to donate when it comes to donation to an immediate family member; 9.6% more willing when it comes to an extended family member; and 11.7% more willing when it comes to a close friend. In addition, despite the low level of willingness to donate to unrelated others among both groups, social workers are 23.8% more willing to donate to an acquaintance than are nurses, and 22% more willing to donate to a total stranger. Thus, the range of difference in willingness to donate to related and unrelated others is much greater in nurses at 89.6% (p >.09 2df) as compared to 73.9% for social workers (p >.001, 2df).

To examine the amount of support associated with material incentives of increasing value, we used a nine-statement ethical-motivation scale developed by Humphries et al. (2009). As illustrated in Table 4, nursing and social work respondents agreed that living donors should be compensated for medical expenses (4.63). They also agreed that donors should be compensated for lost wages (4.43) and should receive a federal tax deduction (3.42). High agreement was also expressed for non-compensated altruistic giving (3.62). In declining order of importance, less agreement was expressed for: 1) reward packages involving compensation for medical expenses, lost wages, and a tax credit/cash award and compensation for medical expenses, lost wages, and a weekend get-a-way reward package (2.77) 2) compensation for medical expenses, lost wages, and a reward package consisting of life-long medical coverage (2.74), 3) compensation for medical expenses, lost wages, life-long medical insurance, and an instant cash payout of up to $60,000 to $70,000 (2.05) and 4) free negotiation of price, compensation, and reward without limitation (1.77).

Table 5 illustrates the differences between social workers and nurses in their level of agreement about various material rewards as a complement to living kidney donation. Both nurses and social workers agree that donors should receive limited material rewards in the form of compensation for medical expenses and/or lost wages. For medical expenses in

Table 4. Linking Material Incentives to Living Donation (**N = 169**)*

	Mean	SD
Living kidney donors should not be compensated. The donation should be considered a free-will donation and purely altruistic.	3.62	1.27
Living kidney donors should be entitled to compensation for medical expenses related to the procedure.	4.63	0.64
Living kidney donors should be entitled to compensation for medical expenses and lost wages related to the procedure.	4.43	3.21
Living kidney donors should be compensated for medical expenses, lost wages relating to the procedure, and should also receive a "reward" package that may include a weekend getaway.	2.77	1.96
Living kidney donors should be compensated in the form of a federal tax deduction.	3.42	1.32
Living kidney donors should be compensated for medical expenses and lost wages relating to the procedure and should also receive a "reward" package that may include cash or a tax credit.	2.77	1.30
Living kidney donors should be compensated for medical expenses and lost wages relating the procedure and should also receive a "reward" package that includes life-long medical coverage.	2.74	1.28
Living kidney donors should be compensated for medical expenses and lost wages relating to the procedure and should also receive a "reward" package that includes life-long medical insurance coverage plus an amount of instant compensation of up to $60,000–$70,000.	2.05	1.02
Living kidney donors should be able to freely negotiate the price, compensation, and reward they receive for their donation with no limitation to the amount or criteria.	1.77	.928

*Other healthcare professionals (*n* = 10)

Table 5. Linking Material Incentives to Donation; Nurses and Social Workers Compared (**N = 159**)

Incentives		**Nurses (*n* = 68)**	**Social Workers (*n* = 91)**
Altruism	*Mean*	3.76	3.57
	SD	1.27	1.25
Medical expenses only	*Mean*	4.60	4.69
	SD	0.58	0.61
Medical expenses and lost wages	*Mean*	4.28	4.56
	SD	0.93	4.29
Medical expenses, lost wages, and weekend getaway	*Mean*	2.62	2.84
	SD	1.34	2.37
Federal tax deduction	*Mean*	3.29	3.45
	SD	1.40	1.29
Medical expenses, lost wages and cash or a tax credit	*Mean*	2.67	2.75
	SD	1.28	1.29
Medical expenses, lost wages, and lifelong medical coverage	*Mean*	2.73	2.69
	SD	1.35	1.23
Medical expenses, lost wages, life-long medical coverage, and a lump-sum cash payout ($60K–$70K)	*Mean*	1.99	2.01
	SD	1.04	0.97
No limits to compensation	*Mean*	1.75	1.77
	SD	0.88	0.93

Table 6. Correlations Between Social Distance and Support for Material Incentives (N = **169)***

	Immediate Family	Extended Family	Close Friend	Acquaintance	Stranger
Altruism	.057	.074	.002	.036	.094
Medical expenses only	-.103	-.078	.006	.058	-.048
Medical expenses and lost wages	.070	.025	.028	.091	.013
Medical expenses, lost wages, and weekend getaway	.117	.008	.113*	.159*	.105
Federal tax deduction	-.066	.006	.174*	.166*	.071
Medical expenses, lost wages, and cash or a tax credit	.163*	.091	.205**	-.087	.034
Medical expenses, lost wages, and life-Long medical coverage	.081	-.122	.149*	.030	.005
Medical expenses, lost wages, life-long medical coverage, and a lump-sum cash payout	-.013	.093	.193*	.102	.048
No limits to compensation	.083	.064	.118	-.004	.044

*Other healthcare professionals (*n* = 10)
** p <.01, 1-tail test
* p <.05, 1-tail test

particular, there is little difference in support between nurses (4.60) and social workers (4.69). Both groups also support a federal tax deduction (3.29 and 3.45). Neither group agrees that donors should receive a cash payout of $60,000 to $70,000 or freely negotiate a level of compensation without limitations, with virtually no difference between nurses and social workers on these items (1.99 and 2.01 and 1.75 and 1.77, respectively). Interestingly, nurses and social workers are more divided on non-compensated altruistic giving than on several other items, with nurses expressing more agreement with altruism than social workers (3.76 to 3.57).

As illustrated in Table 6, a statistical examination of the relationships between the statements comprising the social distance scale and the ethical-motivation scale revealed statistically significant positive correlations between willingness to donate a kidney to close or distant others and certain material rewards (p >.01 1-tail test and p >.05 1-tail test). These positive correlations are most striking for willingness to donate to a close friend and include a variety of different reward packages. Also positive was the relationship between: 1) willingness to donate to an immediate family member and a monetary reward in the form of paid medical expenses, lost wages, and a tax credit, and 2) willingness to donate to an acquaintance and a tax credit and a compensation package involving medical expenses, lost wages, and a weekend getaway. There were no other statistically significant positive or negative correlations.

To assess the amount of compassion fatigue among social workers and nurses as it relates to motivation to becoming a living kidney donor, we used an 11-item summated rating compassion fatigue scale. Table 7 illustrates means and standard deviations for all 11 items. Overall, the results suggest that social workers and nurses experience a low to moderate amount of compassion fatigue. Both nurses and social workers agreed that they bring work home with them (2.91 and 3.19) and feel physically and emotionally exhausted by the end of the work day (3.01 and 3.06). However, less agreement was expressed for the feeling that work dominates their lives (2.88 and 2.78) or that their work goes unappreciated or unrecognized (2.34 and 2.48). Neither group agreed that they feel so burned out that they need to change or seek help to cope (1.56 and 1.52) or that they resort to drugs, drinking, gambling or other methods of escape as a function of their work lives (1.55 and 1.56).

DISCUSSION

To assess the persuasiveness of the NKF's altruistic "gift of life" frame among member nurses and social workers, this research utilized a research design developed by Humphries et al. (2009) and supplemented this design with a measure of compassion fatigue and work-related burnout. Results from the use of the Bogardus Social Distance Scale (Bogardus 1925; 1933) confirm, consistent with prior research (Humphries et al., 2009; 2014), that respondents are more willing to donate a kidney to a close other (e.g., a member of their immediate family) than to a distant other (e.g., a stranger). Thus, this research, considered in conjunction with prior research, provides strong empirical evidence that, regardless of target population, social distance is the single most important motivating factor in altruistic living kidney donation.

Additionally, a comparison of nurses and social workers using the Bogardus Social Distance Scale (Bogardus 1925; 1933) reveals that nurses are less willing than social workers to participate in a living kidney donation. For nurses, these findings are consistent with earlier research (Humphries et al., 2014) and support the hypothesis that nurses are "pragmatic" in their orientation, as pointed out by Chambliss (1996). In contrast, the greater willingness among social workers to donate a kidney supports the hypothesis of an "idealistic" orientation.

However, on the ethical-motivation scale item that suggests donating a live kidney should be a "free-will donation and purely altruistic," nurses express somewhat more agreement than social workers. This is in sharp contrast to Humphries et al. (2014), which finds low support for altruism among a sample of international nurses and high support for "no limitations" on donor compensation and direct cash payouts of $60,000–$70,000. On the assumption that nurses would show strong support for high-value incentives as indicated by Humphries et al. (2014) and that this might be explained by work-related factors, we included in the present study a compassion fatigue scale, but the results from the prior study were not replicated. In the present study, both nurses and social workers expressed low support for cash payouts and other high-value rewards. Furthermore, on the compassion fatigue scale, both nurses and social workers reported that while they "feel physically and emotionally exhausted at the end of the work day," they found work personally rewarding and were not "burned out." In the absence of significant differences in compassion fatigue, a possible explanation for the difference between the nurses in the current study and those in Humphries et al. (2014), is that the latter included professionals not necessarily affiliated with nephrology or the NKF, which regards financial compensation for organs as unethical (NKF, 2003). Compassion fatigue also does not appear to explain the greater social distance expressed by the current sample of nurses in that the results on the compassion fatigue scale are comparable for both nurses and social workers. This may be due to cultural rather than structural factors, such as the different professional worldviews and socialization experiences of nurses and social workers.

Despite lack of support for high-value material rewards, results from the ethical-motivation scale show strong support among both nurses and social workers for limited material incentives in the form of compensation for medical expenses, lost wages, and a federal tax deduction. This is consistent with prior research involving college students

Table 7. Means and Standard Deviations for Compassion Fatigue (N = 159)

		Nurses (*n* = 68)	Social Workers (*n* = 91)
Work dominates life	*Mean*	2.88	2.78
	SD	1.25	1.15
Rely on my co-workers for advice	*Mean*	2.55	2.68
	SD	1.07	1.06
Emotionally detached in my professional and personal life	*Mean*	1.94	1.87
	SD	0.94	1.02
Frequently taking work home with me	*Mean*	2.91	3.19
	SD	1.30	4.55
Working harder and accomplishing less	*Mean*	2.62	2.76
	SD	1.08	1.10
Physically and emotionally exhausted by end of the work day	*Mean*	3.01	3.06
	SD	1.49	1.18
Resort to drinking, drugs, gambling, or others methods of escape	*Mean*	1.55	1.56
	SD	0.93	0.94
Question competence and effectiveness of my work performance	*Mean*	2.45	2.29
	SD	1.18	1.13
Work goes unappreciated and unrecognized	*Mean*	2.34	2.48
	SD	1.05	1.17
Difficult to form meaningful relationships outside the workplace	*Mean*	1.86	1.73
	SD	0.78	0.99
Feel burned out and may need change or help	*Mean*	1.56	1.52
	SD	0.70	0.84

SD = standard deviation

(Humphries et al., 2009) and is relevant to how we "frame" living kidney donation. Our findings suggest that the "gift of life" frame is not persuasive when it comes to motivating individuals to undergo a live kidney donation, particularly when it involves an unrelated other. Specifically, the results show that unless the recipient has a close relationship to the donor, there is a low willingness to donate. Given this, we find merit in the argument of Humphries et al. (2014) in favor of re-framing living donation to emphasize both justice and rights. Specifically, these authors argue that material compensation could be construed as a *just reward* that preserves the rights of a selfless donor to autonomy, integrity, and dignity. In our view, this *restorative* frame avoids the perception of "cash for organs" that lacked resonance with the nurses and social workers in this study.

Importantly, this research suggests that any changes to organ donation policy should consider changing the message in addition to the rules. Due to their professional socialization and knowledge of altruism, social justice, and patient rights, nurses and social workers can help, through interdisciplinary and theoretically informed analyses, to reframe health-related issues in ways that better address the persistent organ shortage. Thus, these professionals are valuable allies in the task of policy development as it pertains to the question of donor compensation.

LIMITATIONS OF THE STUDY

This study replicates research by Humphries et al. (2009; 2014), and therefore shares the same shortcomings. These include a small, non-representative sample and the use of indicator variables that do not measure actual behavior (Meyers, 1999). Given the high human cost of the ongoing organ shortage as well as the growing interest in the medical community in material incentives as a complement to donation, we believe these limitations are acceptable and join the call for additional research that can further inform the changing debate (Salomon et al., 2015).

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What a Genetic Kidney Disease Does to Families:

An Invited Editorial by Suzanne Ruff

"An elephant in the room" is an idiom defined in the *Cambridge Dictionary* as "an obvious problem or difficult situation that people do not want to talk about" (Cambridge University Press, 2006). Many families with a genetic disease describe this attitude among themselves. Anguish, fear, and misunderstandings often result, causing more stress to a family touched by disease. Nephrology social workers, as well as all medical personnel, can benefit from understanding these issues when dealing with families like mine. My family battles a genetic disease called polycystic kidney disease (PKD).

PKD is one of the most common life-threatening genetic diseases, and the fourth leading cause of kidney failure (PKD Foundation, n.d. a). About 1 in 500 people have PKD (PKD Foundation, n.d. b). Individuals with PKD have cysts in their kidneys that can make the kidney very large, which causes kidney failure (NIDDK, 2015).

There is no cure for PKD. Dialysis and transplantation are the only treatments. My family suffers from the most common form of the disease, autosomal dominant polycystic kidney disease (ADPKD). If a parent carries the gene for ADPKD, each of their children has a 50% chance of inheriting it (PKD Foundation, n.d. b). There is also a recessive form of the disease, autosomal recessive polycystic kidney disease (ARPKD). It is rarer than ADPKD, but causes devastation for patients and families as well.

Those are the facts of PKD. Facts are cold and hard. Stories of the people behind those facts can both break your heart and inspire you. No one likes to hear the word "disease." Adding the word "genetic" has an even more devastating impact on individuals and families.

Sometimes a family doesn't realize how a genetic illness impacts so many aspects of their lives, because each member reacts differently. That's where misunderstandings happen. Nephrology social workers can help patients and families cope with this diagnosis.

Some members of a family with PKD come out fighting against the disease—fists raised, ready to do battle, and announcing it to the world. They educate themselves about the disease, and loudly shout its horrors from the rooftops. "Great Aunt Sally must've died from this genetic disease," they exclaim, adding, "Didn't Uncle Harry have kidney issues too?" Sometimes they don't get tested because of the never-ending worry about getting insurance. They face the disease directly and talk about it (sometimes incessantly or even obnoxiously).

Other family members deal with PKD more privately. They need time to digest the news, and they don't want to talk about it publicly, or they don't want to talk about it at all. They don't want others to know they have the disease. Nor do they want to know how "Uncle Harry or Great Aunt Sally died." They might think, "She's dead; what difference does it make?" It's not that they don't care; it's just too painful.

Encouragingly, healthcare and kidney disease treatment have entered a new phase that emphasizes *patient-centered care,* and patient and family member engagement (Narva, Norton, & Boulware, 2015). With the help of the Patient-Centered Outcomes Research Institute, there is a growing emphasis on including patients and their family members in all aspects of research. As a PKD family member, I share our story in the hopes of informing future social work research and practice to help patients with genetic kidney diseases.

My family has over 20 members with the disease. There is no right or wrong way to handle a genetic disease. With families like mine, where nine deaths have occurred (from the 1940s to 2013), some of the questions asked by medical professionals are painful. Patients consider their care team to be knowledgeable, and the one question the patient often asks is: Does the disease skip a generation? No, it does not. There is a 50% chance of inheriting the disease.

Questions often asked of a PKD patient and questions most asked by PKD patients are "Have your children been tested?" and "Should I have my children tested?" Oh, what questions! Debates rage among families about this subject. Individuals in families with PKD have different opinions including: "I can't bear knowing," "I can't bear not knowing," "We can plan our life accordingly," or "They deserve to be children without worries."

In the "old" days (early 1970s), my parents didn't feel it would be wise for us to know if we had a "preexisting condition." We were tested by archaic standards compared to today's medical care. Our parents kept the results of our tests to themselves. They didn't think we could handle the truth as teenagers. That is the dilemma of testing and telling children. Can they handle knowing they have a disease? Even with the changes in today's healthcare laws regarding preexisting conditions, many families still hesitate to get tested or inform their children about the results. What can a person do differently if they have the disease? Eat right? Maintain good blood pressure? Everyone should do these things, with or without polycystic kidney disease.

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Today, with the increasing numbers of living donors, many PKD families have started saying, "you're either the recipient or the donor," i.e., if you didn't inherit the gene for PKD, and a sibling or a child has the disease, you have been "chosen" to be the living donor when the time comes for transplant. This adds another tremendous burden to families, and the psychological aspects of this expectation are significant. There are siblings or children who want no part of being a living donor for various reasons. There are PKD patients who will not accept, and do not want, a family member to be their living donor. It's complicated, and the reasons are as numerous as the cysts that multiply and cause PKD kidneys to fail.

"Did you have a happy childhood?" This question was asked of a woman about to start dialysis because of PKD. When the woman was 12 years old, her mother died of PKD. Many have happy lives, but that "elephant in the room" is always present, even on the happy days. My mother was the youngest of six children; five of them inherited the disease, and their own mother was ill with PKD for most of their lives.

The question of having children comes up often in a PKD family. People will ask "Do you know you shouldn't have children?" or "Why did you have children?" My mother and her siblings had already started their families before they even knew or heard the word "genetic." Mom's kidneys began to fail when she was 50 years old. In the early 1970s, when a genetic counselor advised my sisters and me not to have children, my mother bristled and said, "Who is to say my first 50 years of life weren't worth living?"

Then, there was the guilt that crushed her — completely unwarranted guilt — for passing the disease to my sister. Mom died before knowing another of her daughters had PKD. If PKD hadn't killed her, that probably would have. Ten years ago, my niece, who has a 50% chance of inheriting PKD, broke down in tears after her engagement, stating she "really wants to have children." And, she did. "I am encouraged by the progress that is being made in finding a cure, and hope there will be a cure when and if my children inherit the disease," she explained. She works relentlessly to raise money for PKD research.

PKD can also be caused by a gene mutation, with no past family history of PKD. One woman, another dedicated fundraiser for a cure for PKD, explains this bluntly. Karyn Waxman, 60, was diagnosed 16 years ago with PKD. With no apparent family history of the disease, a mutated gene resulted in the diagnosis. She states, "I'm okay with it . . . PKD starts somewhere as a mutation, but sadly ends up as 'the gift that keeps on giving' in many cases. However, the most difficult day of my life was the day that I sat both of my daughters down for a very frank discussion with them about the ramifications of this genetically inherited life-threatening disease. Knowing that I could have inadvertently passed it along to one or both of them was, and continues to be, a devastating thought. Now, when I look into the eyes of our two precious baby granddaughters, I hold back tears and pray that their mother dodged what I consider to be my 'PKD bullet'. It's awful beyond words when you bear the sole responsibility for possibly being the cause of pain for those you love and cherish the most in the world."

A bullet! My mother could not have said it better.

An elephant, a bullet, whatever you call it — the guilt becomes a psychological burden that shapes everyone within these PKD families, whether they inherited the disease or not. Patience, tolerance, and wisdom are needed when dealing with a family with a genetic disease. Social workers and other medical professionals need to understand how PKD affects family dynamics, and bring comfort to patients and their families. You are an essential, important, and exceptional part of a kidney patient's life. My family thanks you!

AUTHOR NOTE

The author is a member of the National Kidney Foundation's Living Donor Council Executive Committee, a member of the Polycystic Kidney Disease Foundation, a board member of the American Association of Kidney Patients, the author of The Reluctant Donor, *and was a living donor athlete at the Transplant Games.*

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Live Donor Kidney Transplantation Consensus Conference:

Reducing Financial Barriers to Live Donation

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Live donor kidney transplantation is the best treatment for eligible people with end-stage renal disease. Unfortunately, living kidney donation rates have declined in the U.S. in recent years. To better understand this phenomenon, to identify opportunities to increase donation rates, and to promote best practices in live donor care, the American Society of Transplantation's Live Donor Community of Practice, with the support of 11 societies, convened the Consensus Conference on Best Practices in Live Kidney Donation in June 2014. The workgroup focused on reducing financial and systemic barriers to live donation, and had a multi-layered task: to review literature assessing the financial impact of living donation; to analyze employment and insurance factors; to learn from international models to reduce financial impact; and to summarize currently available resources. The group provided a series of clinical, programmatic, and policy recommendations to reduce financial and systemic barriers, with the overall goal of achieving financial neutrality for living kidney donations (LKD). In this article, we highlight systems-wide recommendations that would benefit from advocacy by nephrology social workers and their colleagues, and would ultimately improve clinical practice: policies to allocate resources to reduce donor financial burden, civil protections for donors, and a standardized, centralized financial resources clearinghouse.

INTRODUCTION

Live donor kidney transplantation (LDKT) is recognized as the best treatment for eligible people with end-stage renal disease because it results in better quality of life and clinical outcomes (USRDS, 2014). Since 2006, there has been a decrease in the rates of LDKT (OPTN/SRTR, 2014). The American Society of Transplantation's Live Donor Community of Practice convened, with the support of 11 societies, a Consensus Conference on Best Practices in Live Kidney Donation in 2014. Consensus Conference participants came from a variety of disciplines, regions, and transplant programs of varying sizes. The conference was divided into five workgroups, which included social workers and patients. The full meeting report is also available (LaPointe Rudow et al., 2015). One workgroup focused on reducing financial barriers to live kidney donation (Tushla, et al., 2015).

The workgroup reviewed literature related to financial impact of donation, summarized available resources for living kidney donors (LKD), highlighted gaps in the resources available in the U.S. system to offset costs and educate prospective donors, and discussed international models for addressing direct and indirect costs faced by LKDs. A series of recommendations were made to reduce financial and systemic barriers to living kidney donation with the overarching goal of achieving financial neutrality for LKDs.

FINANCIAL IMPACT

Real or perceived financial impacts of living kidney donation may be a factor in the decline of LDKT since 2006. To date, few studies have been conducted by the kidney transplant community on the effects of LKD costs and their impact on LKD decision making. However, significant data is beginning to emerge (Rodrigue et al., 2015).

While most donation-related medical expenses are covered by the transplant recipient's insurance provider, the donor may still incur costs. As summarized in Table 1, financial burdens may include direct out-of-pocket expenses (e.g., travel, housing, meals, parking, uncovered medical expenses) and indirect costs (e.g., lost wages, dependent care, use of employer-sponsored paid time off, effect on insurability or premium rates) (Dew & Jacobs, 2012). Total estimated costs for LKDs range from $0–20,000, with an average of approximately $5,000 (Clarke, Klarenbach, Vlaicu, Yang, & Garg; DONOR Network, 2006; Dew & Jacobs, 2012; Klarenbach et al., 2014; Rodrigue et al., 2015). These studies suggest that most LKDs lose about a month's household wages after donation, with donors experiencing financial hardship ranging from 23% (Dew & Jacobs, 2012) to 96% (Klarenbach et al., 2014). Rodrigue and colleagues (2015) studied donors in the evaluation process and found that 96% of donors noted at least one direct expense, averaging $523. Two-thirds of potential LKDs in this study reported missing work for donation-related evaluation. Twenty-seven percent of potential LKDs in this study reported lost wages averaging $691 (excluding paid time off). Caregivers for the potential donors reported a mean of $599 in lost wages.

In the post-donation phase of care, finances are equally challenging. The vast majority of LKDs (92%) had direct costs in at least one area, with a mean of $1,157. As to indirect costs, 36% of LKDs reported lost wages at an average of $4,578 when there were no paid benefits. Nineteen percent of caregivers reported lost wages at an average of $1,962 for caregivers (Rodrigue et al., 2016).

Collectively, these findings indicate that living kidney donation is not financially neutral for many donors. Rodrigue et al.

Table 1. Financial Burdens of Living Kidney Donation

Indirect Costs	
	Lost wages for donor and caregiver(s)
	Use of employer sponsored paid time off (vacation/sick days)
	Impact on insurability
	Impact on employment stability
	Dependent care
Direct Costs	
	Transportation to transplant center for testing, surgery, and follow-up care
	Food, lodging, and incidentals for donation-related visits for donor and caregiver(s)
	Uncovered medical expenses

(2016) showed that 89% of LKDs report a net financial loss in the 12 months post-donation, averaging $2,996. In fact, more is unknown than known about the financial consequences of living kidney donation. In 2012, Casagrande, Collins, Warren and Ommen, found that 23% of LKDs lack health insurance, which may cause this sub-group to have more out-of-pocket expenses in the long term. In addition, over the last decade, considering the economic downturn in the U.S., it is not unrealistic for LKDs to be concerned about the financial, employment, or insurance impact of donation.

VARIABILITY IN FINANCIAL RISK AND RESOURCES AVAILABLE TO REDUCE FINANCIAL IMPACT

Workgroup members identified substantial variability in work, financial, and insurability effect for live donors in the U.S. Furthermore, there is no centralized place for donors or healthcare providers to find reliable information about the limited resources to offset burdens to donor finances, employment, or insurability. Table 2 summarizes components of this variability that result in systemic barriers to live donation under the current U.S. system.

Two primary aspects of employment affect the intensity of the LKD's financial consequences: the degree to which the individual donor's employee benefits cover lost wages, and the donor's type of job, which may impact the duration of time off for recovery. In an unfortunate confluence, it is often the least financially stable donors who are both ineligible for paid time off (e.g., day laborers) and will require a long recovery (e.g., due to heavy-lifting restrictions in the immediate post-operative period). LKDs and their support systems are typically left cobbling together plans to cover living expenses during recovery with no reliable safety net (Davis & Cooper, 2010; Dew & Jacobs, 2012; Dew, Myaskovsky, Steel, & DiMartini, 2014).

Available benefits to cover lost wages vary. The Family Medical Leave Act (FMLA) provides job security (not wage reimbursement) for some, but not all, LKDs. Protections are only for full-time employees with one-year tenure in larger companies.

According to the U.S. Bureau of Labor Statistics (BLS) report (2013), in the private sector, 61% of employees have access to paid sick leave. The numbers are better for people in management and professional positions, with 88% receiving paid sick leave. Those with the lowest rates of paid sick leave were in construction at 36%. The availability of this benefit differs dramatically between full-time employees (74%), and their part-time counterparts who receive paid sick leave (24%). Perhaps not surprising is that of those receiving the lowest 10% of wages, only 22% have access to this benefit, while 86% of those in the highest 10% wage bracket do. Nearly all full-time state and local government employees receive paid sick leave according to the BLS. Some are even eligible for benefits specific to living kidney donation.

LKDs who earn paid time off typically use a combination of sick days, vacation time, and short-term disability insurance benefits to recover at least part of their lost wages. However, it should be recognized that a substantial group of LKDs (including the self-employed, day laborers, contract employees, part-timers, and others who lack benefits) may be entirely without pay during surgical recovery.

Direct medical expenses (Table 1) may be incurred by LKDs, varying by the recipient's insurance coverage and transplant center practice. For the vast majority of transplant recipients who are enrolled in Medicare at the time of transplant, the Medicare Organ Acquisition Cost Center's (OACC) bundled payment mechanism covers living donor evaluation, surgery, and post-donation care. As became clear in the Consensus Conference deliberations, transplant centers variably interpret how donor-related claims are billed through the OACC, through Part B claims, or directly to the donor. Complicating matters is the fact that private insurance coverage for living donor services varies by contract.

Over the years, there have been concerns about insurability for LKDs post-donation and there is literature to show that at

Table 2. Systemic Limitations Affecting Burdens of Living Kidney Donation

Variability of employee benefits

- Employer-sponsored paid time off
  - Not a mandated benefit
  - Varying allotments
- Short-term disability benefits
  - Not a mandated benefit
  - Pays a varying percentage of wages
  - Living donation may be excluded as an ”unnecessary” procedure
- Family Medical Leave Act
  - Provides job security
  - Does not cover lost wages
  - Employee qualifies after >/= 1 year, full-time, for an employer with >50 employees
  - Living donation may be excluded as a voluntary procedure
  - 11 states and Washington, D.C. expanded coverage

Variability of transplant center billing practice

- Medicare Organ Acquisition Cost Report LKD evaluation and care
- Medicare Part B interpretation for post-donation charges
- Private insurance and Medicare Advantage contract differences

Variability of risk for insurability problems

- Effect of Affordable Care Act (ACA)
  - Improved access to health insurance, generally
  - Limits to those expected to benefit from ACA include:
    - Those who cannot afford premiums (even with subsidies)
    - Those in states that did not participate in Expanded Medicaid
    - Undocumented immigrants
- Life insurance may be less predictable after living kidney donation
  - Eligibility problems
  - Premium increases

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least some donors have experienced negative insurance consequences (Table 2) (Boyarsky et al., 2014; Spital & Jacobs, 2002; Yang et al., 2009). Traditionally, medical insurance vulnerability for LKDs has been mitigated by employer-sponsored insurance and the Health Insurance Portability and Accountability Act (HIPAA). The Patient Protection and Affordable Care Act (ACA) has the potential to ameliorate barriers to health insurance after donation for a portion of LKDs. However, there are people who will not benefit (e.g., those who cannot afford premiums, those in states that have not expanded Medicaid, undocumented immigrants). Life and disability insurance may still be impacted by serving as a living donor and certainly remains a concern.

SOME ISOLATED PROGRAMS MAY FILL SOME GAPS

As inconsistent as the systems are, so are the limited resources available to address the financial burdens to LKDs. Resources include: travel grants, emergency grants from nonprofit organizations, or tax relief. Unfortunately, a standardized, centralized place to locate and track these resources is lacking (see Table 3, which outlines resources available as of this writing).

NATIONAL LIVING DONOR ASSISTANCE CENTER (NLDAC)

Starting in 2007, NLDAC began offering grants to offset travel expenses for eligible living donors and their caregiver(s). In the first five years, NLDAC received nearly 4000 applications and were able to provide support to 89% of them, with an average reimbursement of $2700. However, in recent years, fewer than 10% of donors have availed themselves of the grant. For some donors, local to the transplant center, travel costs may not be a big worry. With eligibility linked to a means test for both the intended recipient and the donor, not all donors are able to get assistance. Finally, published data shows variability by center in grant usage, indicating an inconsistent referral pattern by transplant centers (Warren, Gifford, Hong, Merion, & Ojo, 2014).

Table 3. Resources Available to Some Living Kidney Donors

National Living Donor Assistance Center (NLDAC)

- Grants for travel and lodging expenses
- Means testing, based on both donor and recipient household incomes

Nonprofit foundations and emergency grants

- Various levels and types of assistance, including travel, housing, uncovered medical expenses, lost wages

Paid leave for living donation recovery

- Federal employees
- Postal employees
- Employees of some local municipalities

Tax deductions/credits to offset losses associated with living kidney donation

- 15 states offer tax deductions (requires itemization of taxes)
- 1 state offers credits

NONPROFIT ORGANIZATIONS

There are a few nonprofit organizations that help transplant recipients fundraise to offset expenses related to a transplant. Some do allow the funds to be used for living donor expenses as well. A few organizations offer living-donor-specific emergency grants.

TAX RELIEF

As of this writing, 35 states have tax deductions or credits available to living donors. According to Chatterjee, Venkataramani, Vijayan, Wellen, and Martin (2015), with one exception, there has been no observable effect of these policies on the rates of organ donation. The programs vary by state, are underused, and have been shown to have limited effect on living donor transplantation rates—though this does not speak to the value for past living donors, who have been able to use the deduction or credit (Chatterjee et al., 2015; Lacetera, Macis, & Stith, 2013; Matas & Hays, 2015; Venkataramani, Martin, Vijayan, & Wellen, 2012,). Those that function as tax deductions, typically require itemization, which may in turn limit their practical usefulness for low-income earners. For tax year 2005, an average of 36% of U.S. tax payers itemized (and only 18% of those earning less than $50,000) (Prante, 2007).

INTERNATIONAL MODELS

Many countries, including Canada, Australia, Israel, and the Netherlands, have developed systems-wide models to cover living donor costs, including systems to reimburse lost wages or provide a cost-of-living stipend during LKD recovery. In their 2009 survey, Sickand et al. identified 21 countries with programs, 17 of which provide reimbursement for lost income. During the Consensus Conference deliberations, experts from Australia and Canada weighed in on their respective countries' models, and participants deliberated their feasibility within the U.S. system.

DISCUSSION AND RECOMMENDATIONS

The workgroup identified recommendations to ameliorate financial burdens with the goal of financial neutrality for living donors (Table 4).

Recommendation 1: Standardized system for reimbursement of LKD lost wages.

Implementation of a standardized federal system to offset living donor costs, including a standard reimbursement amount for lost wages and excluding a means test, is a top priority. Clearly, there may be benefits to building from systems already in place in other countries (such as the Canadian wage reimbursement system). The simplest solution would be to expand the framework of the existing NLDAC program.

Status Update: Since the Consensus Conference, multiple meetings with stakeholders have occurred to lay groundwork for these ongoing discussions. This recommendation has been presented specifically to social work learners at the 2015 Society for Transplant Social Work Annual Meeting; the 2015 American Foundation for Donation and Transplantation Live Donor Course; and in a 2015 webinar for The Alliance.

Clearly, this recommendation is ambitious, requiring both a policy change and an allocation of resources to fund donor wage reimbursement. As such, advocacy by nephrology social workers, live donors, and transplant recipients will be essential to building momentum, and to effectively articulate the benefits of creating such a system.

Recommendation 2: Develop and pass legislation to offer employment and insurability protections for living donors.

The workgroup's legislative and policy agenda centered on standardization of employment-based benefits and support discrimination protections for living donors. Realistically, if reimbursement for lost wages is enacted, tax relief, and civil protections may become less essential. In the meantime, as a stopgap, tax benefits should be standardized (and set as credits) to maximize their use. Legislation should be developed and passed to prohibit negative insurability impact for living donors. Legislation should also be developed and passed to support LKD use of paid medical leave, and to ensure that living kidney donation is a qualifying medical condition under FMLA.

Status Update: The Living Donor Protection Act was introduced bicamerally in 2016. (Please see sidebar.) It will only gain traction as patients and their advocates (e.g., nephrology social workers) are able to describe its expected benefits.

Table 4. Recommendations to Achieve Financial Neutrality for Living Kidney Donors

1. Allocate resources for standardized system of reimbursement for LKD lost wages and incidentals

- Expand National Living Donor Assistance Center (NLDAC) program
- Remove means testing
- Expand to cover standard subsidy for lost wages

2. Develop and pass legislation to standardize LKD employment and insurability protections

- Transition tax deductions to tax credits to increase effectiveness
- Expand and standardize tax relief legislation on state and federal levels
- Develop and pass legislation that prohibits denial of coverage or increase in premiums for health, life, and disability insurance for LKDs
- Develop and pass legislation supporting LKD use of paid medical leave for donation
- Develop and pass legislation that expand utilization of FMLA protections for LKDs

3. Create a Living Kidney Donor Financial Tool Kit

- A summary of known financial risks
- An equation model for helping living LKDs estimate direct and indirect costs
- NLDAC service linkage
- A list of nonprofit sources of LKD financial assistance
- Strategy for LKD discussions with employers
- A description of state and federal laws directed at LKDs
- Uniform guidance for transplant centers in relation to billing options to maximize coverage of medical costs for LKDs:
  - Medicare Organ Acquisition Cost Report
  - Medicare Part B
  - Private insurance
- Uniform guidance to payers on coverage for LKD care

4. Research agenda

- Capture granular, systems-wide data on the financial effects of LKD
  - Indirect costs
  - Short- and long-term medical costs
    - Evaluation process
    - Routine follow-up
    - Coverage for complications
  - Insurability effect: coverage and rates
  - Effects on employment
- Effects on LKD caregivers during recovery period
- Capture data about variability in transplant center billing practices
- Characterize effect of financial and systemic barriers on potential LKD decision-making and rate of LDKT
- Characterize effect of finances on LKD satisfaction

Recommendation 3: Develop standardized, centralized education platform about financial impacts.

Given the range of financial guidance that transplant programs offer potential living donors, and the limited resources for financial assistance, conference participants recommended the creation of a widely available, vetted LKD financial toolkit, to guide healthcare professionals and prepare potential living donors. The toolkit resources could be used to reduce economic uncertainty and the impact for living donors. In addition, transplant programs would benefit from uniform guidance in relation to billing options to maximize resources available to LKDs, and clarify contracting options with payers (Table 4).

Status Update: The LKD Financial Toolkit has been completed, and will soon be released on the American Society of Transplantation (AST) website (myast.org).

In addition, *Transplant Program Guidelines for Best Practices in LKD Care* have been released by Consensus Conference leadership; these include recommendations about financial education for kidney donors. These will also be found at myast.org.

These toolkit elements can be used directly by patients, or used with a social worker in the clinic setting. In particular, a dynamic "cost estimator" may be a useful intervention tool.

Recommendation 4: A research agenda to better understand LKD financial battiers.

Much is still unknown about the financial impact of LKD, and the degree to which it affects LKD experience, potential LKD decision-making, and the rate of LDKT. Clearly, systematic collection of data to better characterize the financial impact of donation is warranted, including better understanding of indirect costs, any long-term medical costs, and any insurability problems associated with LDKT. In turn, understanding the impact of these burdens on disparities in LKD and access to LDKT could offer direction on ways to attenuate these differences. Finally, it would be useful to learn whether, or which, financial costs affect LKD satisfaction or serve as measurable disincentives to LDKT.

Status Update: Some data is emerging to better characterize systemic barriers for LKDs, and the degree to which finances play a role. However, this is clearly an area ripe for exploration and deserving of social workers' unique viewpoints and expertise. As the clinicians most likely to be sorting through the impact of finances on donor readiness and decision-making, we encourage social workers to help design the research questions and data collection moving forward.

The Living Donor Protection Act (H.R. 4616/S. 2584) protects living donors by prohibiting insurance companies from denying or limiting life, disability and long term care insurance to living donors, and from charging higher premiums. It also protects donors' jobs by extending coverage under the Family and Medical Leave Act (FMLA). This bill currently has 29 sponsors in the House and six in the Senate. Please support NKF and donors by writing your legislators to ask them to sponsor this legislation.

CONCLUSIONS

The Consensus Conference process identified gaps in what is known about the finances of live donation, in methods of standardized information sharing for providers and potential donors, and in policy infrastructure for limiting systemic barriers. Clearly, living donors and nephrology social workers, as advocates and patient-centered clinicians trained in systems, will be instrumental in moving this field of study forward, and in achieving the policy changes recommended by the Consensus Conference. We must continue to clarify the current financial and insurability impacts of live donation, and build standardized websites to share findings and educate those considering living donation. In turn, skilled social work advocacy will be essential in building the systemic protections to limit financial, employment, and insurability impacts for donors, and in achieving resource allocation that will reduce financial burdens. Ultimately, the goal is that giving the "gift of life" won't cost an arm and a leg.

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“Need a Ride?”

Improving Transportation to Dialysis Treatment (Part 1)

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This article describes a planning and evaluation process that identified existing challenges related to dialysis transportation in one Northwestern state. The strategies, best practices, and community resource ideas that came from participants in this process were numerous and can be grouped into four categories: education, advocacy, recruitment, and outreach. The planning process resulted in a transportation pilot project. Social workers developed and implemented these solutions. This process required making time, taking a step outside of one’s normal caseload, and working with others to help implement change. The results offer promising practices that can be replicated elsewhere.

INTRODUCTION

Transportation problems are one of the most common barriers faced by low-income communities to accessing timely and necessary medical care (Rust, Ye, Baltrus, Daniels, Adesunloye, & Fryer, 2008). For hemodialysis patients in particular, good health depends on reliable transportation (Iacono, 2004). This article contributes to a growing body of literature showing that transportation is associated with greater quality of life, and supports improved patient outcomes, rather than merely moving people from “point A” to “point B” (Audino & Goodwill, 2014; Bambra, Gibson, Sowden, Wright, Whitehead, & Petticrew, 2010; Burkhardt, 2006; Hewlett, Atchley, Otto, & Hager, 2004; Rosenbaum, Lopez, Morris, & Simon, 2009; Silver, Blustein, & Weitzman, 2012; Syed, Gerber, & Sharp, 2013; Tucker, 2010).

One study funded by the Transportation Research Board of the National Academies showed that providing non-emergency medical transportation to those who are “transportation disadvantaged” can significantly reduce emergency room and hospital expenditures, thereby leading to better health outcomes and a higher quality of life for patients, as well as reduced medical costs (Wallace, Hughes-Cromwick, & Mull, 2006). This same study included a cost-benefit analysis of medical transportation services for patients with 12 specific conditions, and concluded that in the case of disadvantaged dialysis patients, providing transportation would prove highly cost-effective with improvement of resultant patient quality of life.

The growth in end-stage renal disease (ESRD) incidence and the decreased mortality rate in this population (USRDS, 2013) create increased burden on a transportation system that was not designed to accommodate life-sustaining treatment trips. It is often difficult for dialysis clinic staff to navigate the transportation options available and support patient access to reliable transportation.

Transportation to and from treatment involves a tension between access and cost. According to the USRDS (2013), the majority of hemodialysis patients require the support of others to get to and from dialysis treatment, with 66.8% of patients being driven, including by ambulance. Nearly 8% of hemodialysis patients use public transportation, such as bus, subway, train, or taxi, while only 25.3% drove themselves or walked. Transportation coordination for patients who receive dialysis relates to medical coverage of dialysis care, because it affects the patient’s out-of-pocket expenses.

Currently, there are three primary sources of medical insurance that provide coverage for kidney patients: Medicare, Medicaid, and private insurance plans. According to the USRDS (2013), nearly 84% of people receiving dialysis have Medicare coverage (through Medicare fee-for-service, Medicare-Medicaid dual coverage, a Medicare HMO, or Medicare Secondary Payer coverage). Medicare does not have a non-emergency medical transportation benefit. Medicare only covers ambulance services for medical emergencies, or if alternate forms of transportation could endanger the patient’s health. Individuals who are eligible for both Medicare and Medicaid (or “dual-eligibles”), and Medicaid beneficiaries are eligible to use Medicaid’s transportation in their local area.

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RIDE CONNECTION

Transporting patients to and from dialysis appointments presents both a challenge and an opportunity. More practical approaches are needed to support dialysis patients' transportation needs while also reducing costs. Ride Connection, a non-profit transportation provider in the Portland metropolitan region of Oregon, convened multiple partners and engaged in a participatory planning and evaluation effort to create a dialysis transportation pilot project with input from hemodialysis patients, social workers, drivers, and others involved in the care of patients. Ride Connection's mission is to link accessible, responsive transportation with community needs. For more than 25 years, in collaboration with 30 community partners, Ride Connection has provided customer-focused, safe, reliable transportation options for individuals in Clackamas, Multnomah, and Washington counties in Oregon. This includes rides to hemodialysis and other non-emergency medical transportation (NEMT) trips. In recent years, it was evident that in Ride Connection's capacity as a coordinator and provider of transportation, there was a need to address the difficulties associated with transportation for patients receiving dialysis treatment. Rider feedback over the years indicated that current transportation options were not adequately serving the needs of patients receiving dialysis treatment. In addition, transportation partners reported that the specific needs of patients receiving dialysis made transportation more challenging than for most passengers. Finally, there was evidence that there was a growing number of trip requests for dialysis transportation, which resulted in a shift in capacity to accommodate the requests.

In Oregon, over one quarter of new patients who receive dialysis are covered by Medicare only, and therefore their transportation costs are out-of-pocket. Further, as the National Kidney Foundation has noted, "in order to qualify for Medicare ESRD benefits, one must contribute to the Social Security system for 40 quarters. Thus, many individuals with kidney failure may not be eligible for Medicare" (Becker, 2010). Consequently, 7% of patients are not covered by any insurance, and therefore must also pay out-of-pocket for their transportation. In addition, 80% of new dialysis patients are not eligible for Medicaid and are not covered for transportation to and from dialysis, the National Kidney Foundation noted.

Unfortunately, the Affordable Care Act has not made any positive impact on coverage for medical transportation. The Americans with Disabilities Act (ADA) service is available in many communities with a public transit system. These rides, which are curb-to-curb, have to be scheduled in advance, and last minute changes cause delays in pickups. The system is a shared-ride option, and the trip's purpose cannot be taken into consideration when rides are scheduled (i.e., a trip to the mall is considered the same priority as a trip to dialysis). In addition, there is a cost to the customer for this service, and often these rides are not available before or after business hours (limiting the dialysis shift riders can use with this service).

CASE EXAMPLE

Social workers help patients who have challenges with access to treatment. Patients' experiences vary in difficulty, and social workers try to provide patient-centered approaches to resolve psychosocial barriers to care. Mr. C's experience is just one story, but represents challenges that social workers try to work through on a regular basis. Even when transportation options are available, they may not work for a patient's individual needs:

> At the early time of 4:15 a.m., Mr. C prepares his dialysis bag for the day's treatment. He is not able to drive himself to treatment. His home is just four miles from his destination. Dialysis treatment does not begin until 6:00 a.m., but the shared-ride stops all over town, which means Mr. C will need to leave home more than an hour before his treatment begins. The route to the clinic seems bumpy in the over-sized short bus, and stirs discomfort from a previous lower back injury. This is Mr. C's only mode of transport to dialysis. He no longer drives and the walk to the bus stop is impossible. His significant heart disease brings on shortness of breath as soon as he begins walking. There are no other affordable means of door-to-door transportation; even this ADA shared-ride option is costly on his fixed income at $65.00 per month for the service. Imagine adding this to transit fees for grocery shopping, pharmacy, doctor visits, and social visits. It can quickly become a question of, "Can I afford to get to dialysis today?"

The case of Mr. C just begins to touch on the transportation barriers dialysis patients face. Consider the patient who does not have the capacity to remember to call and schedule weekly rides; or the patient living in a rural area who cannot get a 15-mile ride into town because they are outside of ADA boundaries; or the patient who lives down too long of a driveway for the bus to make a safe connection. The transportation barriers are almost as diverse as the people who cope with end-stage renal disease.

PROJECT APPROACH

In the summer of 2013, Ride Connection launched a six-month participatory planning process (**Phase I**) that identified existing challenges related to transportation for patients needing dialysis treatment, and how these challenges impacted patient health. This process involved the creation of an advisory committee; conducting focus groups; administering a patient survey and a caregiver/healthcare provider survey; one-on-one patient interviews; and holding public workshops. Each of these steps helped to identify transportation challenges and informed specific changes that would not only improve the quality of transportation services, but also would ultimately improve the health outcomes of patients receiving dialysis treatment. Prior to beginning this process, Ride Connection obtained approval for this project from the Human Subjects Research Review Committee of Portland State University to ensure the ethical integrity of its practices. Part of this process was to provide informed consent forms to all who participated in the process. Ride Connection staff reviewed literature related to end-stage renal disease, dialysis, and non-emergency transportation prior to engaging with patients, caregivers, and healthcare providers to ensure that we had an adequate understanding of the issues. This planning process led to the development of promising practices (**Phase II**) and a pilot project currently underway (**Phase III**).

PROJECT PARTICIPANTS

Ride Connection staff reached out to the dialysis community throughout this process to ensure input from many different perspectives, from those who work in the field, to those affected by the disease. An advisory committee met monthly, and was composed of five dialysis patients, a transportation provider, a caregiver, and five healthcare providers, including a social worker. The committee provided input on the project team's methodology of data collection, identified priority issues, developed survey and focus group questions, and helped develop solutions with next steps. The group also received technical assistance in designing the project, in focus group facilitation, and evaluation guidance from a public health non-profit, Upstream Public Health, who are active in the region dealing with health issues such as transportation access. During the entire project, the project team shared decision making, interpretation of findings, and development of recommendations with the dialysis community.

DATA SAMPLE

Eighty-three patients and 26 caregivers, transportation providers, and healthcare providers completed surveys. Two focus groups were held and were attended by eight patients and two caregivers, who provided details related to their challenges and experiences with transportation to and from dialysis treatment. These sessions were led by two facilitators trained in working with vulnerable populations. Finally, 19 stakeholders participated in a public workshop to help develop workable solutions to these challenges. Stakeholders included patients from both focus groups, caregivers, healthcare providers, advisory committee members, transportation providers, drivers, a non-emergency medical transportation administrator, and a coordinated care representative.

PHASE I – PARTICIPATORY PLANNING PROCESS

Here we describe the main themes and suggested strategies that came out of the first phase of the project. Involving participants in the planning and decision-making process ensured relevant outcomes. It also resulted in new relationships and a shared understanding among participants.

The advisory committee, patient survey, and focus groups helped us to identify numerous broad issues and areas of concern related to the impact of transportation on health outcomes for dialysis patients. The main themes were dependability of rides, the need for flexibility in ride scheduling, rider frustration with wait times and indirect routes, cost being a barrier, the need for driver training, and a mismatch between clinic and home locations (Table 1).

Strategies, best practices, and community resource ideas were developed in the same way that we identified the issues that needed to be resolved. The advisory committee, workgroup, patients, social workers, and others from the dialysis community were asked to weigh in on solutions to these issues, and determine which would be best for patients, and feasible. The participants had numerous suggestions that can be grouped into two categories:

1. Develop education, advocacy, recruitment, and outreach activities such as: a regional transportation fact sheet specific to dialysis, a dialysis education campaign, enhanced driver training beyond the Ride Connection network, a recruitment program for volunteer drivers who would be on call for flexible return trips, and a system to support patients who are newly diagnosed. (All Ride Connection drivers are vetted, trained, and evaluated at the same level, whether they are volunteers or paid drivers. Ride Connection covers volunteers under both auto and general liability insurance.)

2. Develop a collaborative pilot program to affect change: Work with a dialysis clinic and all transportation providers to create a more reliable, affordable, friendly, and flexible dialysis transportation system.

Input from the advisory committee, workshop participants, and discussions among staff and stakeholders helped to identify a set of operational protocols for Ride Connection to use internally. These new protocols, strategies, and community resources from Phase I activities addressed issues to immediately improve the quality of our services. Ride Connection took the following actions as a result of the planning process:

1. Developed a transportation matrix that clearly stated all parameters of each available transportation option in our region. The matrix was provided to all 21 dialysis clinics in our area. A patient representative contacted each clinic and followed up with either a paper or electronic version of the matrix to social workers and clerical staff.

2. Implemented a revised no-show/late-cancelation policy that was clear to patients. No-shows or late cancels that occurred because of a medical condition were not counted.

3. Provided a guaranteed return trip: ensured all Ride Connection customers understood that they will not be stranded at a clinic without a ride home.

Ride Connection combined these efforts into a pilot project in partnership with a dialysis clinic, described in the next section.

PHASE II – PROMISING PRACTICES

In Phase II, the planning project focused on developing the concepts from Phase I of this project and implementing the solutions that the dialysis community had generated in the process.

Education

Dependability and flexibility of rides does not just depend on the transportation system alone, but also on the driver, call taker, and scheduler of those rides. Our research indicated that those involved with providing the trip needed to more fully understand the experience of people undergoing dialysis treatment. Drivers also told us that they needed more training and had many questions about how to best provide transportation to this population. Our project team, therefore, embarked on designing a course with the advisory committee, patients, social workers, and additional partners that would develop not only an environment for learning best practices to assist the dialysis population, but would also to create an understanding of the dialysis patient experience. Patients, care providers, drivers, and caregivers were included in developing the curriculum and subsequent educational video. The objectives of the course, "What Every Driver Needs to Know About Dialysis Transportation (but was afraid to ask!)," were developed to ensure participants would be able to:

- Explain kidney functions
- Identify common reasons people experience chronic kidney disease
- List the stages of kidney failure
- Describe kidney dialysis
- Identify transportation concerns of people undergoing dialysis
- Assist riders to and from treatment
- Take appropriate action when there are concerns

The overall goal of the video component of the training is to show the reality of a patient's life, from leaving home, getting to the clinic, dialysis treatment, and then getting home again. Four patients agreed to participate, and each had a unique story to share. A skilled trainer, who also receives dialysis treatment, provided training. The evaluations from all who have attended this training were very positive. The tone of the video was emotional and impactful. The day's frustrations and successes are shown in documentary/cinéma vérité style. The viewer obtains a sense of how long the process takes, and how dialysis treatment has an impact on all parts of the person's life. Ultimately, the viewer should come away not with pity or admiration for the person in the video, but with sensitivity and empathy for what a person goes through when they are undergoing dialysis treatments.

Social workers were instrumental in promoting the concept of the educational video, and ensuring that diverse patients were included in the video. They assisted the project team with getting permission from the clinics to film on site and kept clinic staff informed of the process. The video can be watched as a stand-alone educational tool and can be beneficial to anyone that watches, no matter what their location. This video is available free of charge and can be requested from the lead author.

Trainings were scheduled through Ride Connection.

Recruitment and Outreach to the Dialysis Community

Ride Connection worked with patients, care providers, and drivers from our advisory committee to:

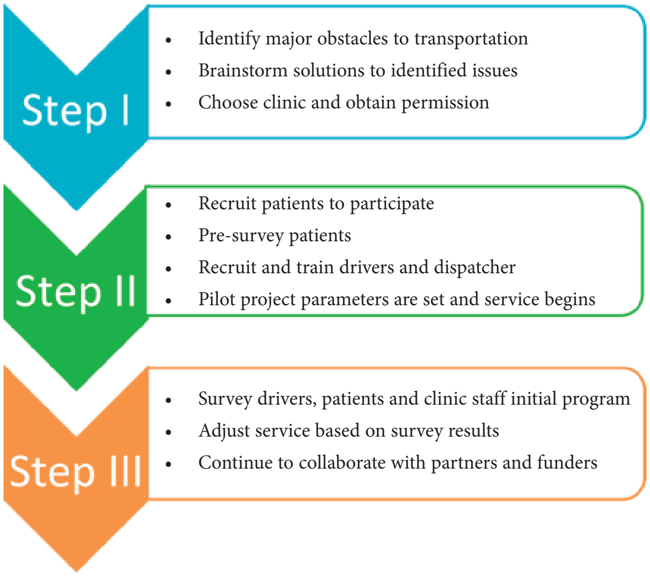
- Design outreach materials related to best practices in dialysis transportation that can be shared with other transportation providers in our region to encourage broader system-wide protocol changes;
- Assist in developing a volunteer driver program specific to creating flexible transportation options;
- Assist in outreach and advocacy related to the implementation of the transportation pilot project; and
- Engage additional stakeholders to support the cause.

This outreach and recruitment project resulted in a broader understanding of both the project and the challenges associated with dialysis transportation across all regions. Tools developed in this process can be replicated and used in areas outside our local region.

Volunteer driver recruitment was a large area of focus of this project. Based on what we had learned in the research phase, we knew that having direct routes home, especially after treatment, and limited sharing of rides with those being transported to places other than dialysis clinics, were best for patients.

The team used a recruitment model that focused on efforts to engage potential volunteers because of their interest in supporting individuals receiving dialysis. Our recruitment efforts included reaching out to transplant and diabetes support groups, as well as attending community events. Materials were created in a respectful way that "put a face" with the person who needed transportation and shared who they are, not just that they needed a ride. We also shortened the training video into impactful sound bites that could be sent as links, shown on social media, or used as part of a presentation. A name and logo were designed to capture people's attention and motivate them. The name of the program is Dahlia. The logo is a dahlia flower which shows growth, beauty, and vitality (Figure 1). Slightly used hybrid sedans were purchased and wrapped with the beautiful logo. This provided a moving billboard for volunteer recruitment. Hybrids were specifically chosen in the hopes that new volunteers, interested in environmental sustainability, might be encouraged to join our cause.

PHASE III: PILOT PROJECT



Step I

- Identify major obstacles to transportation
- Brainstorm solutions to identified issues
- Choose clinic and obtain permission

Step II

- Recruit patients to participate
- Pre-survey patients
- Recruit and train drivers and dispatcher
- Pilot project parameters are set and service begins

Step III

- Survey drivers, patients and clinic staff initial program
- Adjust service based on survey results
- Continue to collaborate with partners and funders

Working in partnership with our advisory committee, the dialysis community, drivers, a dialysis social worker, and our network of transportation partners, we developed a pilot project at a selected clinic so that we could test our theories, and use it as a model for best practices for flexible, reliable, and affordable patient transportation services. The committee used purposive sampling to choose the clinic for the pilot project to ensure that the quality of the pilot could be evaluated. The committee used the following criteria to select the pilot project site: an involved social worker who was supportive of the project, a manageable sample of patients with different transportation options, patients with varying mobility needs, patients with varying insurance eligibility, and a clinic in a region that had transportation providers available.

The selected clinic's social worker was involved in ensuring all protocols were followed. The social worker obtained permission to implement the pilot transportation project at the Fresenius Medical Care Hollywood Dialysis Clinic. The social worker informed patients of the risks and benefits of participating in the project before they signed an informed consent form. All patients understood the expectation of completing a pre-survey and quarterly surveys for one year to provide feedback on their transportation experience. The social worker offered patients translation services or assistance with reading the survey when needed. Participants agreed to release their treatment times and dialysis attendance as data for the outcomes assessment. Finally, participants understood their right to discontinue involvement in the project at any time without fear of reprisal.

The pilot model was informed by the focus groups and discussions we had with the advisory committee during Phase I. Our goal was for the transportation providers, drivers, social workers, clinics, and patients to collaborate in identifying strengths and weaknesses of all local transportation systems, and make adjustments to service delivery modes by sharing customers, capacity, and resources. Throughout the pilot, we evaluated which of these practices worked best for patients, had positive effects on their health, and the costs needed to sustain the level of service, which we will describe in a follow-up article. The components of the pilot project included:

- Assessing individual customers' level of regularly needed service — Constant communication with customers provided more real-time information to assist with transportation.
- Dedicating a dispatcher — One dispatcher was dedicated to coordinating dialysis trips only. We had one number which was answered primarily by the same person.
- Collaborating with multiple partners and funders — Using a centralized scheduling system, we created a mechanism for multiple partners, with both volunteer and paid drivers participating and receiving reimbursement. Ride Connection became a provider of the Medicaid Medical Transportation Program in order to get reimbursed for rides if the patient was Medicaid eligible. A state grant was received to supplement the cost of the rides for the pilot.
- Not charging customers for the rides.
- Waiving the standard five minute wait time — The expectation of partners in the pilot was that customers would not be left behind if they were not ready within five minutes of the driver's arrival. The clinic staff was encouraged to contact the dedicated dispatcher if pick-up time changed. Rides were then dispatched.
- Allowing ride sharing in one vehicle, based on medical condition or trip purpose.
- Utilizing volunteers as primary drivers, paid drivers secondarily, and taxi cabs as backup.
- Purchasing hybrid vehicles to encourage new volunteers who may be interested in environmental sustainability.
- Offering mileage reimbursement to volunteer drivers for using their own vehicles.
- All drivers, paid and volunteer, taking the education course developed in Phase II of this project.
- Implementing a scheduling system that allowed constant communication between, patient, driver and clinic.
- Surveying patients regularly to ensure and adjusting service delivery methods based on responses.

The pilot project started February 1, 2015. Twenty eight patients at the clinic opted to participate in the project. All patients were asked to complete a pre-survey so that we would have a base-line account of transportation issues and health outcomes. Patients were asked to commit to taking a survey quarterly. To date, we have completed and analyzed one round of surveys. The following results indicate that the transportation practices developed may have a benefit to both patients and clinic staff.

PATIENT SURVEY RESULTS

As of this writing, we are seeing changes in participant self-reported factors that contribute to health outcomes (Table 3). For example, a handful of patients reported "rarely," "occasionally," or "frequently" missing a dialysis appointment in the last three months because they could not find a ride. In the first quarter, this program appears to have improved those numbers so that *none* of the participants reported missing a dialysis appointment based on transportation. Staying on hemodialysis for the prescribed time is better for overall patient health. Exactly three quarters of respondents (71%) told us that, before this project they had rarely or occasionally experienced shortened dialysis treatment time. That has shifted to nearly all participants never or rarely experiencing this problem in the first quarter. Table 3 also shows improvement in three measures that contribute to patient stress. These include: being left waiting at a clinic; having to contact more than one transportation provider; and simply thinking about transportation to and from dialysis.

CLINIC SURVEY RESULTS IN RELATION TO PATIENT CARE

One of the authors distributed the clinic survey at the pilot clinic at each data collection period during the project. Initially, 12 individuals responded to the pre-survey. Currently, five individuals filled out the first quarterly survey, and will continue in further quarters based on their involvement with transportation at the clinic. From the survey results and conversations with clinic staff, the pilot project appears to be reducing the frequency with which clinic employees do extra work or manage transportation-related challenges. A few of the survey items relate to supporting dialysis patients' health. For example, in Table 4, 75% of clinic staff reported frequently needing to rush to get patients out the door before drivers leave. We learned in our advisory committee and focus groups that this rushing experience can feel stressful, can reduce the chances that a patient's dialysis access has fully stopped bleeding, and can take the clinic staff away from other tasks. Other survey items connect to the total time clinic workers may be handling transportation-related complications that are beyond normal procedures (Table 5). For example, clinic staff repeatedly needed to make calls to multiple transportation providers which take time that could be used to ensure the patient is stable enough to go home safely. This is important, as clinics must use time efficiently to stay on tight schedules for hemodialysis and aftercare.

After initiation of the pilot program, more clinic staff reported that the number of calls they are making, and time spent on the phone, are decreasing. Some clinic staff reported that the single call line has streamlined the transportation process, while others gave a neutral response (Table 5). In the three months since the project began it is difficult to determine how streamlined things have become. In Part 2 of this article we will explore what worked and what did not, based on conversations we have with clinic staff.

TRANSPORTATION PROVIDER SURVEY RESULTS

The responses from the transportation providers participating in the pilot either confirm, or are neutral, in relation to results from patients and clinic staff. We are learning that the pilot is reducing some of the transportation factors that can poorly affect patient health. For example, in Table 6 the percentage of providers who could not provide a trip for a dialysis patient shifted from many reporting "frequently" to most reporting, "never," "rarely," or "occasionally." We have also learned that some of the drivers participating in this project have not encountered problems patients stated in the focus groups, such as a patient bleeding in a vehicle after dialysis, or driver lack of confidence about providing transportation for dialysis patients.

SOCIAL WORK IMPLICATIONS

"I never hear anything positive about transportation (and neither does the secretary). This made my day and I wanted to pass it on to you all. Thank you for all of the hard work you are doing to implement this project!!" —Renal social worker

"*It is amazing that all of you are affecting positive change regarding this problem that has been plaguing this community for at least the last 40 years. Thank you for making a difference. Together we can change the world."* — State of Oregon Client Surveyor

Social workers played a critical role in this project. While it is expected that social workers facilitate access to and coordination of care for their clients, this project involved an expansion of their role that was unexpected. Education went beyond helping dialysis patients understanding the transportation available; social workers also helped ensure that patients, clinics, and drivers were all equally educated about the connection between hemodialysis and transportation.

The social work code of ethics, asks the social worker to identify social problems, implement change to help the vulnerable and oppressed, to serve those in need, and to ensure access to services. In this project, social workers recognized the transportation problem within the dialysis population, helped document the problem by assisting in the organization of focus groups in their clinics, and passed out patient surveys. Social workers collaborated with a committee of patients and providers to troubleshoot problems and create solutions, helped to create an educational video, and implemented the pilot project overall. This required making the time, taking a step outside of one's normal caseload, and working with others to help implement change. Programs such as this can help social workers minimize the time they devote to tasks such as transportation, and help increase the amount of time they have for clinical interventions to improve patient outcomes.

PHASE IV – FUTURE PLANS

This project expands on the existing literature by highlighting numerous additional ways in which the health outcomes of patients are directly and indirectly impacted by barriers or inadequacies in their medical transportation. It suggests that improved transportation options would not only improve patient health outcomes, but could also potentially reduce future healthcare costs by reducing medical complications. This process was unlike any inclusive planning project we had undertaken before. The level of commitment, the importance of this issue, the devotion and expertise of all involved, and level of engagement encouraged and motivated us to go beyond our thinking about internal processes. The team brought up this project in regular staff meetings, encouraged staff to attend the patient-delivered training on dialysis, and embedded these efforts into the organization even before the project reached completion. We remain more committed than ever to involve our riders and the broader community of stakeholders in all of our organization's new initiatives.

Many challenges and successes have been encountered with this project. There are aspects to working in Oregon that helped with our success. We work in a metropolitan area that has positive transportation factors, such as multiple transportation options, that allowed us to understand what worked and did not work. Further, Ride Connection as a convening organization, had the following benefits: a) understanding the medical and transportation landscapes and their limitations before starting this work; b) Ride Connection is a trusted partner with clinics, transportation providers, and policy makers; and c) Ride Connection has its own organizational culture that prioritizes customers' needs. If another organization were to start a similar project, then the authors recommend ensuring a group of partners who can bring similar knowledge and relationships to the table at the beginning.

Without the leadership of patients, caregivers, and care providers, the project team would not have been able to identify issues or progress as succinctly. Directly involving people affected by this issue is paramount to achieving the goal of improving transportation to treatment. From the doctor to the patient to the transportation providers to family members, all were considered equally, worked hard, and gave thoughtful input. Constant contact and encouragement of all parties was a routine feature of the project, as was hiring multiple patients as consultants and specialists to develop the program, create the educational material, and provide continuity to the project.

Asking for cooperation from large corporations that own dialysis companies was challenging. Corporate structures are complex and there can be an impression that they will prioritize profits or will be inflexible, based on a "top-down" structure. That's an impression because of all the things we hear in media, and based on how patients feel big companies *treat* them on day-to-day basis. But what we experienced is that the *people* in the big companies may not feel this way. Ride Connection is a mid- to large-sized non-profit that understands red tape components and was willing to be open minded in changing its own processes and practices as a role model. We were able to create a structure that could still address the interests of the partners while learning to better meet the needs of patients. We also have the non-profit's power of being able to *advocate* for change, based on what is heard. We have the flexibility that a large corporation usually doesn't. We used the power of story, of real-life experiences, and brought forward compelling real situations. That is effective in getting attention. We also had concerned, committed partners in each of these organizations who were willing to talk to the clinic's leadership about the project. Finding social workers who were respected and committed to the cause helped us to better understand the corporate structure and philosophy. Knowing this was critical to getting into a clinic to film the video and having the clinic agree to be a part of the pilot project.

The results we have seen to date suggest that this process directly addresses ways of improving transportation for dialysis patients. One of the findings of this work has been the benefit of thinking about transportation as more than just a means of moving people.

Transportation is directly related to many other social outcomes, including public health and quality of life. Committee members in our participatory process identified many ways that the quality of transportation services patients receive directly impacts the quality of their health and medical treatment. We tested how much other drivers (dialysis patients who drive themselves to treatment) and non-drivers (dialysis patients who do not drive themselves to treatment) agreed with these conclusions in a survey (Table 2). These include missing a ride, shortening a dialysis treatment, or being left behind without a ride home.

Our process identified that this area needs further research to document the impact of these conditions, such as missing a ride, can have on health outcomes, such as recovery time from dialysis and maintenance of dialysis hours on machine. The solutions we implemented can not only improve transportation, but also improve outcomes, potentially reduce healthcare costs, and positively involve those who are affected by this in the decision-making process. This approach to thinking about transportation has broad implications and increases opportunities for sustainability by looking beyond our normal transportation partners. We hope to build on relationships we have been fostering for continuing engagement, support, and voluntary commitment of resources. Our evaluation process, featured in Part 2, will demonstrate the relationship between access to treatment and health outcomes.

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Table 1. **Transportation themes and representative quotations from the dialysis community**

Theme	Description	Patient Quotation	Caregiver Quotation	Quotation
Dependability	When a ride is late or does not show up, a patient may have to cut their dialysis treatment short, which could have deleterious impact on their health. Patients can also be stranded at the clinic if they miss their ride home. For example, in the patient survey 45% of non-drivers respond negatively when asked if they have a reliable transportation backup.	x		"When I'm late my lunch isn't at noon it's at 2:00 p.m., then dinner supposed to be at 5, then have to move it back… being a diabetic then shots and other things at the wrong times… it's too low."
		x		"Go for dialysis late… it's not good for my body. Come off too soon. If you are three times late in a week that adds up. Because transportation is late."
			x	"[Transportation] service should be based on the individual care needs of each patient, and not the scheduling needs and/or financial gain for the transportation company. Each entity should have designated individuals who work collaboratively on an ongoing basis to design ride schedules, which have to be flexible and include allowances for movement of times, based on patient needs."
Flexibility	Participants identified a greater need for flexibility in scheduling so that when patients need more time to complete their treatment or to stabilize after dialysis, they can easily reschedule their rides home. For example, in the patient survey, 19% of non-drivers disagree when asked if their transportation provider is patient and flexible.	x		"Dialysis is stressful. Whole outlook is changed; have to change entire lives for dialysis; figuring out how to get to and from rides should be the least of our concerns, but it's become one of our biggest. A lot of us have to go through trials and tribulations. The last thing we want to worry about is rides."
			x	"Reliability and flexibility is a big issue — if just a few minutes late, a lot of transporters refuse to wait."
Waiting and Indirect Routes	Participants identified frustrations with the service they use related to patients having to ride across town and sometimes right past their home or clinic to pick up another person before they are dropped off. For example, in the patient survey, 27% of non-drivers were stuck at the clinic without a ride home at least once in the past three-month period.	x		"I feel frustrated or angry because can't do anything to change it. Dialysis is very stressful anyway. Hard time dealing on a daily basis. If ride not there or shows up late, not fair to us. We may have to wait even longer, at time when extremely weak."
			x	"Transportation does a pretty good job getting people to dialysis, but, patients are tired after dialysis, so less able to tolerate a long ride, which is a built-in feature of the system."
Cost and Affordability	Results of the data collection showed that the majority of patients surveyed are low income, therefore the cost of transportation to and from treatment provides a huge barrier. For example, in the patient survey, two-thirds of respondents earn less than $20,000 annually.	x		"…., they don't provide us with transportation. We don't have a choice; we have to go to treatment to live. People don't realize, no pity party, just need a little help. All I want is to live long enough to see my children have children. I could just pluf [sic] the next day, that's all I want."
		x		"Takes the big bus [fixed bus route] or a taxi home. You have to pay for a taxi yourself. I get disability. I have to pay rent. I can't tell my landlord I can't pay you $15 today because I had to pay for a ride home."
		x		"...just costing us an arm and a leg. Costs and stress."

→

Table 1(continued). Transportation themes and representative quotations from the dialysis community

Theme	Description	Patient Quotation	Caregiver Quotation	Quotation
Driver Training	Participants noted a need for driver education and training so that they can better understand the needs and rights of patients.	X		"…for my neighbors, operators have good or bad personalities. Sometimes their personalities come off that patients need them. 'You depend on us' not 'we depend on you.' Condescending. 'We'll get to you when we can when it's convenient for us as drivers.' 'Come on let's go, I got things to do.' "
		X		"Why can't they just do their job? They [all the other patients] talk to me about their transportation. I can sympathize with them."
		X		"… I have a mouth and I speak...They [drivers] are supposed to do things in a certain way. In my place, where you have to park to pick me up, [there is a] hill no sidewalk [on] Halsey [a street]. As soon as you turn, you park right there. If someone doesn't see the butt end of your vehicle, they will ram right into you. This makes it difficult for them to pick you up. They can't figure out where to pick me up at. They don't want to pick me up at the place that they should pick me up at."
Geography	Participants noted that some patients are often assigned to clinics that are far away from their home even when closer options are available.	X		"… [if miss a ride] I freak out. Can't afford to call a cab. They're very expensive. My dialysis is Milwaukie. I'm in K…and they assigned me. That's a frightening thought for me. I don't have a family here. I live in near the Lloyd center. [It's] very convenient here, but if go outside of that, I'm very fearful."

Table 2. **Percentage of respondents who have experienced the following scenarios ≥1 time in the last 3 months (non-drivers compared to drivers)**

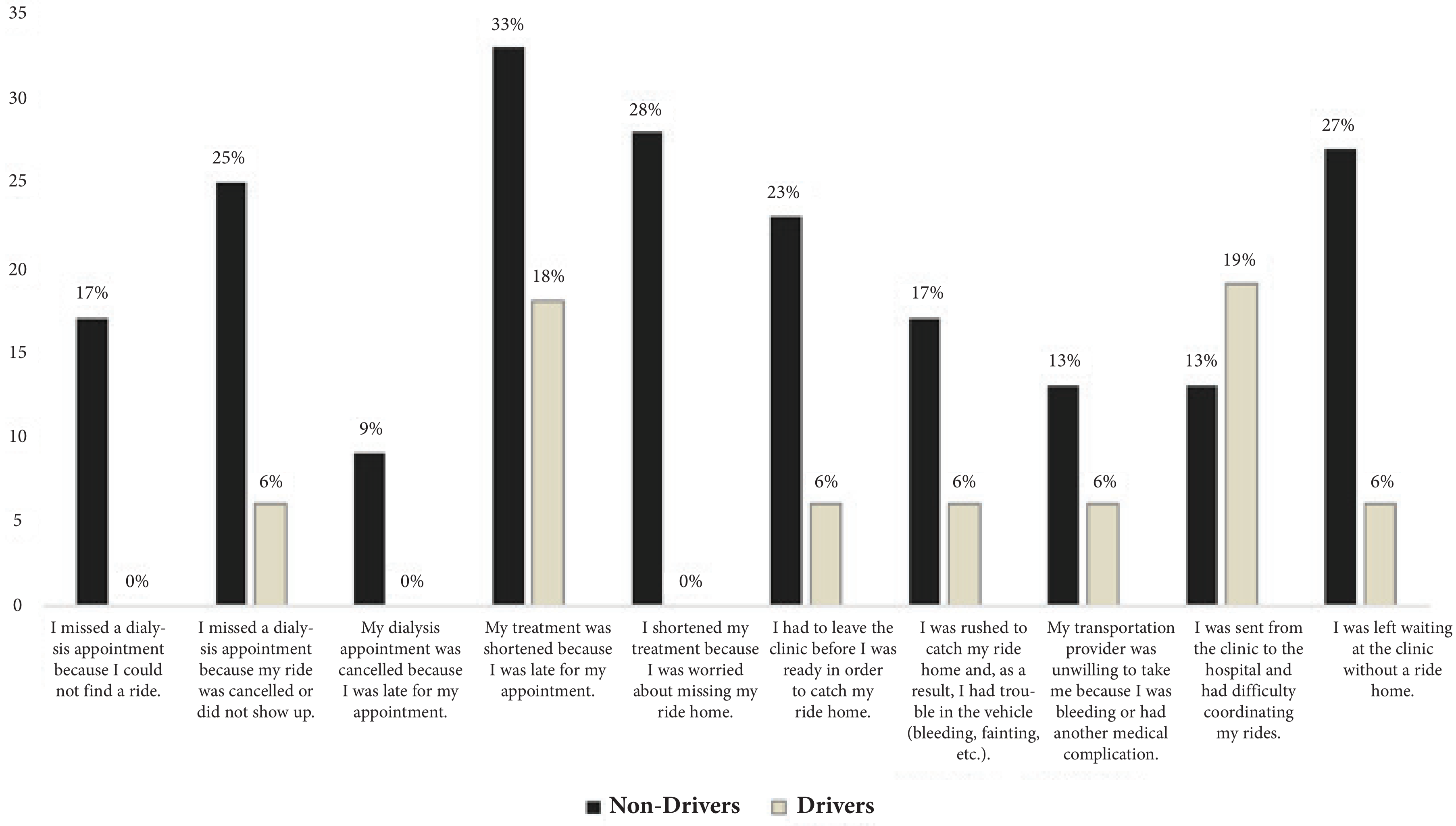

Table 3. Patient survey results relevant to health outcomes (N = 28)

Survey Item	Pre-survey	1st Quarter
I missed a dialysis appointment because I could not find a ride.		
Never	67%	100%
Rarely (1–2 times)	17%	0%
Occasionally (3–4 times)	12%	0%
Frequently (5 or more times)	4%	0%
My treatment was shortened because I was late for an appointment.		
Never	29%	91.67%
Rarely (1–2 times)	46%	8.33%
Occasionally (3–4 times)	25%	0%
Frequently (5 or more times)	0%	0%
I had to leave the clinic before I was ready in order to catch my ride home.		
Never	67%	75%
Rarely (1–2 times)	29%	20.83%
Occasionally (3–4 times)	4%	4.17%
Frequently (5 or more times)	0%	0%
I was left waiting at the clinic without a ride home.		
Never	67%	100%
Rarely (1–2 times)	33%	0%
Occasionally (3–4 times)	0%	0%
Frequently (5 or more times)	0%	0%
I felt stressed when thinking about transportation to or from dialysis.		
Never	29%	95.83%
Rarely (1–2 times)	8%	0%
Occasionally (3–4 times)	46%	4.17%
Frequently (5 or more times)	17%	0%
I had to contact more than one transportation provider to coordinate all my trips.		
Never	63%	95.83%
Rarely (1–2 times)	29%	0%
Occasionally (3–4 times)	4%	4.17%
Frequently (5 or more times)	4%	0%

Table 4. Clinic survey results related to patient health outcomes

Survey Item	Pre-survey *N* = 12	First Quarter Survey *N* = 5
A clinic employee was required to wait at the clinic after it closed for a patient's ride home from the clinic to arrive.		
Never	0%	0%
Rarely (1–2 times)	33%	80%
Occasionally (3-4 times)	42%	20%
Frequently (5 or more times)	25%	0%
I had a problem getting a hold of the Ride Connection dispatcher.		
Never	0%	40%
Rarely (1–2 times)	11%	40%
Occasionally (3–4 times)	78%	20%
Frequently (5 or more times)	11%	0%
I have rushed to get patients out of the door before drivers leave.		
Never	0%	0%
Rarely (1–2 times)	0%	40%
Occasionally (3–4 times)	25%	20%
Frequently (5 or more times)	75%	40%
I was concerned that if I gave accurate information about a patient's readiness for pickup, the driver would leave without the patient.		
Never	0%	20%
Rarely (1–2 times)	33%	0%
Occasionally (3–4 times)	17%	60%
Frequently (5 or more times)	50%	20%
In order to buy time for a patient who was not ready for pickup, a driver was told that the patient would be ready in "five minutes" or “soon,” even if the ready time was unknown or longer.		
Never	17%	0%
Rarely (1–2 times)	8%	20%
Occasionally (3–4 times)	42%	60%
Frequently (5 or more times)	33%	20%
I had to contact more than one transportation provider to exchange information about a client's transportation.		
Never	8%	50%
Rarely (1–2 times)	0%	50%
Occasionally (3–4 times)	58%	0%
Frequently (5 or more times)	33%	0%

Table 5. **Clinic experience with patient-related transportation calls**

Survey Item	Pre-survey *N* = 12	First Quarter Survey *N* = 5
The number of calls I made to transportation providers decreased.		
Agree	17%	40%
Neutral	33%	60%
Disagree	50%	0%
The time I spent on calls to transportation providers decreased.		
Agree	0%	60%
Neutral	33%	20%
Disagree	67%	20%
The single call line has streamlined the transportation setup process.		
Agree	N/A	40%
Neutral	N/A	60%
Disagree	N/A	0%

Figure 1. **Project logo and vehicle**

Table 6. Transportation provider survey results

Survey Item	Pre-survey *N* = 3	First Quarter Survey *N* = 3
I was not able to provide trips for a dialysis patient because it was outside service hours.		
Never	0%	33%
Rarely (1–2 times)	0%	33%
Occasionally (3–4 times)	33%	33%
Frequently (5 or more times)	67%	0%
I had a problem getting a hold of the Ride Connection dispatcher.		
Never	33%	33%
Rarely (1–2 times)	33%	33%
Occasionally (3–4 times)	33%	33%
Frequently (5 or more times)	0%	0%
I had to pull a vehicle out of service as a result of bleeding in the vehicle by a dialysis patient that I transport.		
Never	100%	100%
Rarely (1–2 times)	0%	0%
Occasionally (3–4 times)	0%	0%
Frequently (5 or more times)	0%	0%
I felt that I carried out an important role in the care of a dialysis patient that I transport.		
Agree	67%	100%
Neutral	33%	0%
Disagree	0%	0%
I felt confident when thinking about providing transportation to or from dialysis treatment.		
Agree	67%	100%
Neutral	33%	0%
Disagree	0%	0%

National Kidney Foundation
2016 Spring Clinical Meetings Abstracts
April 27 – May 1, 2016

CKD-ESRD – Other

1 **Results of a Nephrologist End-Of-Life Practice Survey**
Kevin A. Ceckowski[1], Dustin J. Little[1], Joseph R. Merighi[2], Teri Browne[3], Christina M. Yuan[1]. [1]Walter Reed National Military Medical Center, Bethesda, MD, USA; [2]University of Minnesota–Twin Cities, St. Paul, MN, USA; [3]University of South Carolina, Columbia, SC, USA

2 **A Multidisciplinary and Peer Mentor Approach to Educating CKD Patients Along the Continuum**
Karen Crampton, Terri Holewinski, Therese Adamowski. University of Michigan Dialysis, Ann Arbor, MI, USA

3 **Transitioning for Young Adults on Dialysis**
B.Noghrey[1]; E. Smith[2], M. H. Doyle[3], S. Amaral[4], H. E. Fernandez[5], F. Kaskel[6]. [1]Stony Brook University, Stony Brook, NY, USA; [2]IPRO/ESRD Network of New York, Lake Success, NY, USA; [3]Quinnipiac University, Hamden, CT, USA; [4]Children's Hospital of Philadelphia, Philadelphia, PA, USA; [5]Columbia University Medical College, New York, NY, USA; [6]Albert Einstein College of Medicine, Bronx, NY, USA

4 **Employment Status Among End-Stage Renal Disease Patients by Dialysis Treatment Modality**
Duane Dunn[1], Deborah Evans[1], Rich Mutell[2], Caroline Hann[1], Deborah Benner[1]. [1]DaVita HealthCare Partners Inc., Denver, CO, USA; [2]Apex Health Innovations, Simi Valley, CA, USA

5 **Barriers to Employment Among End-Stage Renal Disease Patients Receiving Dialysis**
Deborah Evans[1], Duane Dunn[1], Rich Mutell[2], Elizabeth Jones[1], Deborah Benner[1].[1]DaVita HealthCare Partners Inc., Denver, CO, USA; [2]Apex Health Innovations, Simi Valley, CA, USA

7 **Association Between Sleep Quality and Health Related Quality of Life in Hemodialysis Patients Enrolled in a Social Worker Quality Improvement Program**
Nien-Chen Li[1], Stephanie Johnstone[1], Felicia Speed[1], Dugan Maddux[1], John Larkin[1], Len Usvyat[1], Peter Kotanko[2], Franklin W Maddux[1]. [1]Fresenius Medical Care North America, Waltham, MA, USA; [2]Renal Research Institute, New York, NY, USA

8 **Predictors of Low Sleep Quality in Hemodialysis Patients Enrolled in a Social Worker Quality Improvement Program**
Nien-Chen Li[1], Stephanie Johnstone[1], Felicia Speed[1], Dugan Maddux[1], John Larkin[1], Len Usvyat[1], Peter Kotanko[2], Franklin W Maddux[1]. [1]Fresenius Medical Care North America, Waltham, MA, USA; [2]Renal Research Institute, New York, NY, USA

Transplantation

6 **Re-framing the Gift of Life: A Comparison of Factors Involved in Non-Directed Kidney Donor Motivation for Social Workers and Nurses**
Harry Humphries, Browyn Conrad, Cheryl Giefer, Amy Hite, Kristen Humphrey, Kathryn Potter. Department of History, Philosophy and Social Sciences and Irene Ransom Bradley School of Nursing, Pittsburg State University, Pittsburg, KS, USA

9 **Dialysis Providers' Perceptions of Transplant Barriers for Minority and Low-Income Patients Along Levels of the Socio-Ecological Model**
Anna-Michelle M. McSorley[1], Cynthia Gonzalez[1,2], John D. Peipert[1], Keith C. Norris[1], Christina J. Goalby[1], Leanne J. Peace[3], Patricia A. Lutz[3], Amy D. Waterman[1]. [1]University of California, Los Angeles, Los Angeles, CA, USA; [2]Charles R. Drew University of Medicine and Science, Los Angeles, CA, USA; [3]Missouri Kidney Program, University of Missouri, Columbia, MO, USA

11 **Mature Adult Attitudes and Practices Toward Organ and Tissue Donation**
Allyce Haney Smith[1], Ann Andrews[1], Caitlin Loughery[1], Remonia Chapman[2], Jerry Yee[3], Ken Resnicow[4]. [1]NKF of Michigan[1], Ann Arbor, MI, USA; [2]Gift of Life Michigan, Detroit, MI, USA; [3]Henry Ford Health System, Detroit, MI, USA; [4]School of Public Health, University of Michigan, Ann Arbor, MI, USA

Other

10 **Developing Patient Centered Communication: The Key to Improving Outcomes**
Mary Rzeszut. North Shore/LIJ Dept. of Kidney Diseases, Great Neck, NY, USA

12 **Violence in the Dialysis Setting: A National Survey**
Mathias Stricherz[1], Jane Kwatcher[2], Michaela Kretzner[3]. [1]Montezuma, NM, USA; [2]Claremont, CA,USA; [3]Sacramento, CA, USA

13 **Coach4Life App® A Lifestyle Change Tool for Kidney Patients**
Theodôr Vogels. Máxima Medisch Centrum, Veldhoven, N.B., The Netherlands

14 **Creating a Reliable Transportation Program for Outpatient Dailysis Treatment**
Julie Wilcke, Troyce Crucchiola, Ride Connection, Yasuyo Tsunemine. Fresenius, Portland, OR, USA

1 RESULTS OF A NEPHROLOGIST END-OF-LIFE PRACTICE SURVEY:

Kevin A. Ceckowski[1], Dustin J. Little[1], Joseph R. Merighi[2], Teri Browne[3], Christina M. Yuan[1]
[1]Walter Reed National Military Medical Center, Bethesda, MD, USA; [2]University of Minnesota–Twin Cities, St. Paul, MN, USA; [3]University of South Carolina, Columbia, SC, USA

There has been increasing focus on training nephrologists to recognize and refer end-stage renal disease (ESRD) patients likely to benefit from palliative and hospice care. We assessed barriers and facilitators associated with end-of-life (EOL) discussion and referral among current Walter Reed Nephrology Fellowship Program faculty and program graduates since 1980.

A 17-item anonymous on-line survey was administered from July and October 2015, and 57/93 surveys were received (61% response rate). The majority practiced clinical nephrology (95%), 64% had been in practice >10 years, and 65% resided in the Southern US.

Ninety-two percent indicated that they felt comfortable discussing EOL care, and no significant difference was found between those with ≤10 years and those with >10 years of practice experience (p=0.28). Thirty-one percent reported referring ESRD patients to EOL care "somewhat" or "much less often" than indicated. The most frequently chosen barriers preventing EOL referral were: time-consuming nature of EOL discussions (27%); difficulty in accurately determining prognosis for <6 month survival (35%); patient (63%) and family member (71%) unwillingness; and patient (69%) and family member (73%) misconceptions. Half (51%) indicated they would refer more patients if dialysis or ultrafiltration could be made available during hospice care. Some observed that local palliative care resources (12%) and local hospice resources (6%) were insufficient.

Surveyed clinical nephrologists were comfortable with EOL care discussion and referral. However, considerable patient, family and system barriers exist, and many nephrologists reported less than indicated rates of referral for EOL care. Additional efforts are needed to overcome familial and structural barriers to facilitate timely referral for EOL care and services.

The views expressed in this report are those of the authors, and do not reflect the official policy of the Department of the Army, the Department of the Navy, the Department of Defense or the United States Government.

2 A MULTIDISCIPLINARY AND PEER MENTOR APPROACH TO EDUCATING CKD PATIENTS ALONG THE CONTINUUM

Karen Crampton, Terri Holewinski, Therese Adamowski,
University of Michigan Dialysis, Ann Arbor, MI

Many studies have shown that patients with the skills, ability, and willingness to manage their own health and health care, experience better health outcomes at a lower cost. As a result, a program was developed at University of Michigan Health System to educate patients by a multidisciplinary team (nurse, dietitian and social worker) and peer mentor. The education is done monthly in two sessions, lasting 2 hours. The referral sources include internal nephrologists as well as nephrologists in the community. The first session summarizes how kidneys work, the causes of kidney disease, enhanced nutrition to slow progression, and adjusting to chronic illness while using a motivational interviewing approach. The second session focuses on treatment options for kidney failure, optimal nutrition and adjusting to chronic illness. This session includes a peer mentor that shares their experiences as a chronic kidney disease/dialysis patient. The entire process empowers patients to know as much as they can about their disease, diet and treatment while also learning how to cope with the various challenges related to kidney disease and dialysis. The multidisciplinary team and peer mentor approach help patients and families understand their illness and treatment plans. It also engages patients and families in shared decision-making as promoted in patient and family centered care.

3 TRANSITIONING FOR YOUNG ADULTS ON DIALYSIS

IPRO/ESRD Network of NY Transition Working Group
Noghrey, B; Smith, E.(IPRO); Doyle, M. H.(CHAM); Amaral, S.(CHOP); Fernandez, H. E.(CUMC); Kaskel, F. (CHAM)

Background: The transition to adult-oriented care is a crucial element of healthcare for youth with CKD and ESRD. Approximately 2000 individuals <18 are receiving dialysis in the U.S, awaiting a first transplant or after graft loss. Despite improving survival rates of adolescents with ESRD, and the existence of transitioning guidelines, evidence suggests poor health outcomes and mortality (related to cardiovascular and infection-related causes, as well as psychosocial factors) are associated with the transition out of pediatric care for young adult dialysis patients.

Method: The IPRO/ESRD Network of NY has developed a survey of NYS dialysis providers to assess preparation for transition, the typical age of transfer, and the assumption of care by dialysis providers and units traditionally serving an older adult population. The group is exploring ways to utilize historical CMS data to assess transition outcomes for young adult ESRD patients over the last 5-10 years.

Findings: Out 263 dialysis facilities across NY State, 38 facilities care for 110 patients <21. An additional 600 patients ages 21-30 are cared for at 194 facilities. Survey will be sent to administrators of dialysis facilities caring for patients under the age of 25 across NY State, to capture data about the transitioning practices and outcomes in pediatric- and adult-oriented facilities.

Implications: This pilot investigation may provide a model and markers for assessment and quality improvement of transitioning practices in dialysis for other states and on a national basis.

4 EMPLOYMENT STATUS AMONG END-STAGE RENAL DISEASE PATIENTS BY DIALYSIS TREATMENT MODALITY:

Duane Dunn,[1] Deborah Evans,[1] Rich Mutell,[2] Caroline Hann,[1] Deborah Benner[1]
[1]DaVita HealthCare Partners Inc, Denver, CO; [2]Apex Health Innovations, Simi Valley, CA

Patients with end-stage renal disease (ESRD) receiving dialysis who are employed have been shown to have higher quality-of-life scores than those who are unemployed. Patients on peritoneal dialysis (PD) and home hemodialysis (HHD) are often younger than patients receiving in-center hemodialysis (HD) and may additionally have greater flexibility to work. To inform the development of initiatives to help patients remain in employment or return to work, we sought to characterize patient employment status by treatment modality among patients of a large dialysis organization (LDO) in the United States.

Data on patient employment status and treatment modality were derived from LDO electronic health records. Employment status information is collected by LDO social workers every 6 months for patients of age < 60 years and at least annually for patients of age ≥ 60 years during the course of routine care.

There were 156,524 active patients in the LDO dataset as of 15 November 2015. Of these, 23.7% (n=37,160) were unemployed, 12.8% (n=20,084) were employed (full-time, part-time, or per diem), and 41.2% (n=64,427) were retired. The proportion of patients classified as employed was lower for patients on HD than for those on PD and HHD (11.0% vs 25.1% and 27.8%) and, conversely, the proportion classified as retired was higher for patients on HD than for those on PD and HHD (42.5% vs 33.0% and 25.8%), reflecting the differing age distributions for patients on each modality. However, the proportion of patients who were unemployed was largely consistent across modality types (24.2%, 20.3%, and 22.0% for HD, PD, and HHD, respectively).

Patients on PD and HHD are more likely to be employed and less likely to be retired than those receiving HD. However, unemployment rates are high across all dialysis modalities. Initiatives designed to support patients who choose to continue working or return to employment should therefore target patients across all modalities.

5 BARRIERS TO EMPLOYMENT AMONG END-STAGE RENAL DISEASE PATIENTS RECEIVING DIALYSIS:

Deborah Evans,[1] Duane Dunn,[1] Rich Mutell,[2] Elizabeth Jones,[1] Deborah Benner[1]
[1]DaVita HealthCare Partners Inc, Denver, CO; [2]Apex Health Innovations, Simi Valley, CA

Patients with end-stage renal disease (ESRD) receiving dialysis who are employed have been shown to have higher quality-of-life scores than those who are unemployed. Despite this, unemployment rates are very high among the ESRD patient population and we sought to assess the barriers to returning to work perceived by unemployed patients of a large dialysis organization (LDO) in the United States.

Patient employment status and patient-reported barriers to employment were derived from LDO electronic health records. Employment status information is collected by LDO social workers every 6 months for patients of age < 60 years and at least annually for patients of age ≥ 60 years during the course of routine care.

Of 156,524 active patients identified in the dataset as of 15 November 2015, 23.7% (n=37,160) were classified as unemployed; of these, 21.3% (n=7902) reported being interested in working. In this subset of patients, the most frequently cited barrier to employment was "I don't have enough energy and/or feel too ill to work" (34.4%), followed by "I have a disability and don't think I should be working" (11.1%) and "I need job training to return to employment" (7.7%). Stratification of patients by age revealed that while lack of energy/feeling too ill was consistently reported as the leading barrier to employment across all age categories, disability was identified more frequently by older patients. Need for job training and issues relating to childcare and transportation were more frequently listed as barriers by younger patients.

Among unemployed dialysis patients interested in working, lack of energy/feeling too ill was the most frequently identified barrier to employment; the relative significance of other factors varied based on patient age. To be most effective, initiatives designed to support patients returning to work should target the specific issues that may prevent patients from working and should take into account the differences across age groups.

6 RE-FRAMING THE GIFT OF LIFE: A COMPARISON OF FACTORS INVOLVED IN NON-DIRECTED KIDNEY DONOR MOTIVATION FOR SOCIAL WORKERS AND NURSES

Harry Humphries, Browyn Conrad, Cheryl Giefer, Amy Hite, Kristen Humphrey and Kathryn Potter, Department of History, Philosophy and Social Sciences and Irene Ransom Bradley School of Nursing, Pittsburg State University, Pittsburg, KS, USA.

The purpose of this study examines donor motivations using a research design from earlier investigations evaluating the persuasiveness of the National Kidney Foundation's (NKF) altruistic "gift of life" frame. Earlier studies produced mixed results, in particular, showing substantially more support for material incentives among an international sample of nursing professionals as compared to a convenience sample of college students.

The method for this study compared practitioners in the in the fields of nursing and social work and their motivation for donating a kidney. A total of 159 social workers and nurses participated in a survey that addressed not only the relationship between material incentives, social distance and motivation to donate but also work-related burnout and compassion fatigue as structural factors that might reduce donor motivation.

The results show a significant negative relationship between altruism and donor motivation as measured by social distance between donor and recipient and a strong lack of support for direct cash incentives as a complement to living kidney donation. The results also show a little to no compassion fatigue than could potentially account for either of these results. Final conclusions show that social workers are somewhat more altruistic than nurses and both groups support some material incentives but the differences between the two groups are not meaningful.

7 ASSOCIATION BETWEEN SLEEP QUALITY AND HEALTH RELATED QUALITY OF LIFE IN HEMODIALYSIS PATIENTS ENROLLED IN A SOCIAL WORKER QUALITY IMPROVEMENT PROGRAM:

Nien-Chen Li, Stephanie Johnstone, Felicia Speed, Dugan Maddux, John Larkin, Len Usvyat, Peter Kotanko, Franklin W Maddux, Fresenius Medical Care North America, Waltham, MA, USA, Renal Research Institute, New York, NY, USA

As part of a social worker (SW) quality improvement program, we investigated if low self-reported sleep quality (SQ) is associated with worsened outcomes in the 5 summarized KDQoL-36 domains in hemodialysis (HD) patients (Pts).

Data was collected from 737 HD Pts at Fresenius Medical Care North America clinics that were enrolled into the SW program due to HD treatment non-adherence between 7/1/13 and 2/28/14. A 5–item SQ assessment (each scaled from 1-10) was surveyed at baseline. The 5 SQ items were placed into 3 domains by indications of factor analysis; these were difficulty sleeping (DS), difficulty awakening (DA), and restless legs (RL) during sleep. For each domain (DS, DA, & RL), the SQ was defined as "low" for scores greater than the median (worse SQ scores). Mean of KDQoL measures were calculated and compared between 2 SQ groups using t-tests. Associations of KDQoL and SQ were analyzed by multivariate regression with KDQoL as dependent variable, SQ (better vs. low) as independent variable, adjusted for age, gender, race, diabetes, coronary artery disease, and congestive heart failure. Effect sizes (Cohen's d, regression estimates divided by standard deviations of domain scores) were calculated.

Pts Mean age was 53.4 (±13.6) years, 51% males, 59.6% white, and 54% with diabetes. The mean SQ scores (range 1-10) for the three factors were DS=4.5, DA=2.4, and RL=3.2. All 5 KDQoL measures were adversely associated with DS ($p<0.0001$), with effect sizes ranging from 0.46 to 0.65. Mental Component Scores, Symptoms, and Effects of kidney disease were adversely associated with DA ($p <0.01$), with effect sizes ranging from 0.14 to 0.31. All 5 KDQoL domains were adversely associated with RL ($p <0.05$), with effect sizes ranging from 0.20 to 0.25.

This study indicates that low SQ scores are adversely associated with all 5 measures of KDQoL scores in non-adherent HD Pts.

8 PREDICTORS OF LOW SLEEP QUALITY IN HEMODIALYSIS PATIENTS ENROLLED IN A SOCIAL WORKER QUALITY IMPROVEMENT PROGRAM:

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It is not established if poor sleep quality (SQ) is associated with psychological conditions in hemodialysis (HD) patients (Pts). As part of a social worker (SW) quality improvement program, we investigated if low self-reported SQ is associated with depressive symptoms and perceived pain and psychological stress in enrolled HD Pts.

Data was collected from 737 HD Pts at Fresenius Medical Care North America clinics that were enrolled into the SW program due to HD treatment nonadherence between 7/1/13 and 2/28/14. A 5–item SQ assessment (each scaled from 1-10) was recorded at baseline. The 5 SQ items were reduced into 3 measures by way of factor analysis: difficulty sleeping (DS), difficulty awakening (DA), and restless legs (RL) during sleep. For each of three measures, SQ was defined as "low" for scores greater than the median. The CESD-10 questionnaire, components of a Comfort Barriers Screening Tool (back pain, arthritis/bone pain, and pain or tingling in feet/legs/hands), and a Psychological Stressor Screening Tool (stress related to financial/insurance, family/relationships, health symptoms, loss/grief, and others) were used to determine the level of depressive symptoms, perceived pain, and psychological stress respectively.

Pt demographics were: age 53.4 ±13.6 years, 51% males; 59.6% white, and 54% with diabetes. The mean SQ scores (range 0-10) for the three factors were DS=4.5, DA=2.3, and RL=3.2. Predictors of low SQ were: CESD scores >5 (for DS, DA & RL; $p<0.01$); comfort barrier of back pain (for DS & RL; $p<0.01$); comfort barrier of arthritis/bone pain (vs DS; $p=0.04$); comfort barrier of pain or tingling in feet/legs/hands (for RL; $p<0.001$); Stressors related to financial/insurance, family/relationships, health symptoms, and loss/grief (for DS, DA & RL; $p\leq0.01$); Stressor related to other (for DS & DA; $p\leq0.01$).

This study indicates that low SQ is associated with depressive symptoms, perceived pain, and psychological stress in nonadherent HD Pts. Further studies of the impact of the SW interventions are needed.

9 DIALYSIS PROVIDERS' PERCEPTIONS OF TRANSPLANT BARRIERS FOR MINORITY AND LOW-INCOME PATIENTS ALONG LEVELS OF THE SOCIO-ECOLOGICAL MODEL

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To explore racial/ethnic minority and low-income disparities in transplant pursuit, we conducted a mixed-methods study with 4 focus groups (n=48) and surveys (n=68), categorizing dialysis providers' perceptions of transplant barriers using the Socio-Ecological Model (SEM). The SEM considers how intra-personal (individual), interpersonal (social relationships), institutional (organizational), community, and public policy (national laws) factors impact behavior. Respondents were predominately social workers and nurses within Midwestern states. Two coders identified common focus group themes, with mean responses and frequencies for survey items calculated.

Providers strongly agreed that transplant would improve the quality of life for all patients (81%), including minority/low-income patients (79%). While they reported the presence of transplant-related barriers at every SEM level, they felt that minority/low-income patients had a greater focus on day-to-day survival (intra-), less social support to pursue transplant (inter-) and greater concerns about health insurance loss after transplant (public policy). For example, one provider stated, "*I had patients that said nope, not going to get a transplant because I'd lose my Medicare after 3 years*." Providers also reported that 40% of these patients struggle with reading at a 6th grade level, with one stating, "*when they're so uneducated…you really have to sit down and talk with them*." However, with >50% of providers reporting having limited time to offer transplant education, their perception of the greater levels of barriers may cause generalizations and failures to comprehensively educate or refer patients from these groups to transplant. Future work should seek input from patients, family, and community members to fully understand all perceptions and develop solutions that reduce barriers at all SEM-levels.

10 DEVELOPING PATIENT CENTERED COMMUNICATION: THE KEY TO IMPROVING OUTCOMES

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Health care providers that care for chronic kidney disease patients deliver difficult information from relating initial diagnosis to discussing renal replacement therapy. Communicating this information and having a patient follow recommended treatment is challenging for all members of the interdisciplinary team.

Effective communication is an integral part of excellent patient care. It is more than being honest and courteous. Patient centered communication creates an understanding of the patient's individual needs, perspectives and values. Evidence demonstrates that patient centered communication builds trust; improves patient understanding and adherence to medical regimens; decreases hospital readmissions; promotes patient and provider satisfaction; and improves clinical outcomes.

Developing patient centered communication requires a specific set of communication skills that can be learned and improved with practice. These include fostering healing relationships; exchanging information to understand patients' wants and needs; responding to patients' emotions; engaging in shared decision making and enabling patient self-management.

Patients are often labeled difficult or in denial when healthcare providers do not know how to help them. Improving communication skills increases the likelihood of developing a deeper understanding of patients' behavior and health outcomes.

11 MATURE ADULT ATTITUDES AND PRACTICES TOWARD ORGAN AND TISSUE DONATION

Allyce Haney Smith[1], Ann Andrews[1], Caitlin Loughery[1], Remonia Chapman[2], Jerry Yee[3], Ken Resnicow[4]
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Sixty-five percent of the U.S. transplant waiting list is comprised of individuals over age 50 years. However, in 2013, only about 35% of deceased donors were over age 50. Many mature adults are supportive of donation but mistakenly believe that their age or health conditions preclude them from donating organs or tissues after death. In fact, anyone of any age or health status can join the Donor Registry and donate.

The NKF of Michigan, Gift of Life Michigan, and the University of Michigan have partnered on multiple cluster randomized design controlled intervention studies reaching mature adults over age 50 years. In a collaboration with Henry Ford Health System, dialysis patients at twelve dialysis units in Southeast Michigan, 51% of whom were over age 60 years, participated in a study to determine the impact of peer mentors discussing donation with patients on registrations to the state's Donor Registry. The consortium is currently utilizing organ transplant recipients to deliver a one-hour donation education session to participants in evidence-based health programs (EBP); 93% of participants in this study are over age 50 years. Participants in both studies were surveyed about their attitudes toward organ donation.

In the dialysis center study, the odds of signing up for organ donation among those who talked with a peer mentor were 2.34 times the odds in the control group (p-value =0.0046). The EBP baseline study data reveals that 30% self-report having signed up on the Donor Registry and 52% indicated high intent to sign up. Predictors and correlates of attitudes toward donation will be reported.

12 VIOLENCE IN THE DIALYSIS SETTING: A NATIONAL SURVEY

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Although there is anecdotal information regarding threats and actual occurrences of violence in dialysis settings, reported events are protected by risk managers.To quantify occurrence, an independent national survey was conducted on the nature and extent of violence within dialysis settings. Survey respondents, N=272, represent the spectrum of US dialysis facility employees.

At least one incident of violence in the facility was reported by 74% of the respondents (58% reported ≥2 incidents), and 51% reported personal experiences of workplace violence.

Threats to direct care personnel come from, in descending order, patients, persons known to patients, staff, and strangers. Respondents (64%) report patients have initiated physical violence toward staff. Telephone harassment from patients to staff is reported by 21% of respondents. The most common physical assaults are from hitting and kicking, followed by assaults with body fluids. Incidents with weapons of opportunity (14%), knives (9%), and guns (7%) were also reported. 36% reported patient to patient violence. Death threats to staff were reported by 27% of respondents, and death threats to patients were reported by 6% of the respondents. Incidents of facility lockdown (39%) and police responses to facility were both reported (56%).

Only 23% of facilities have security or on-site law-enforcement, 25% have an emergency response system, 35% of the respondents report having a system or policy to notify employees within minutes of a threat. Training in defensive strategies is not provided to the majority of respondents. In addition, 26% of victims reported experiencing psychological trauma.

Due to the high number of respondents reporting workplace violence and the identified gaps, opportunities exist for improving security measures for dialysis facilities.

13 COACH4LIFE APP® A LIFESTYLE CHANGE TOOL FOR KIDNEY PATIENTS: Theodôr Vogels, Máxima Medisch Centrum, Veldhoven, N.B., The Netherlands.

Patient education and empowerment has entered new territories by the increased availability of appliances like smart phones and tablets. The widespread popularity of computer games has evolved into applications for healthcare purposes in basic practical tasks like pedometers and medication reminders. Thus a group of kidney patients representing the Dutch renal patient Association and health care professionals consisting of nephrologist, a nephrology nurse practitioner, nephrology dietitian and a nephrology social worker; teamed up with technical experts in the development of Serious Games. The development of a Serious Game consists obviously in knowledge state of the art ICT technology but requires deep insight in psychological learning principles and adaptive methods.

The Dutch Kidney Foundation was supported in this project by a grant of the "Vrienden Loterij" to explore the possibility of patient empowerment by the use of an applied Serious Game. In March 2013 a multidisciplinary advisory committee was formed to help develop a Serious Game for kidney patients. The aim at the start of the development was to increase prevention of stages CKD 3-4 combining patient education and support lifestyle change. The use of a Serious Game concept made available through an App for use in both smart phone and tablet was to be a basic requirement. Earlier successful examples of the use of Serious Games, for instance in children oncology in had led to better medication adherence, increase of knowledge of the diseases and self–efficacy levels of young cancer patients.

The game would incorporate setting a goal chosen by the individual patient, a variable medication alert tool, feedback system to support the patient with advice to enhance self-efficacy and motivational aspects, a quiz and a button for email support and a dedicated social media group. The developed App was named Coach4Life®, demonstrating its purpose to support patients to strategies which could help increase their level of coping and self-management and was uploaded 1000+. It is obvious that the use of Serious Games in support of patients will evolve through new research and attuning to specific user-groups. Also it seems eminent that patient associations, together with health care professionals are aware of this new, and increasing field of patient support and are willing to incorporate the motivational support to patients to make use of them. Social workers can contribute to their development and promote the use amongst patients. We are awaiting the results of a qualitative study on the use and impact on the current users, but further research and development will be needed in the near future.

14 CREATING A RELIABLE TRANSPORTATIN PROGRAM FOR OUTPATIENT DAILYSIS TREATMENT: Julie Wilcke, Troyce Crucchiola, Ride Connection, Yasuyo Tsunemine, Fresenius, Portland, OR, USA

An inclusionary planning and evaluation process that supports the identification of challenges related to transportation to and from hemodialysis treatment and how these challenges impacted patient health. The strategies, best practices and community resource ideas that came from the dialysis community in this process were numerous and resulted in positive change for patients. The results to-date offer promising practices that can be replicated throughout the nation.

The methods used involved the creation of an advisory committee, conducting focus groups, administering a patient survey and a caregiver/healthcare provider survey, one-on-one patient interviews and holding public workshops. Each of these steps helped to identify transportation challenges and informed specific changes that would not only improve the quality of ***transportation services***, but ultimately would improve the ***health outcomes*** of patients receiving dialysis treatment. Social workers were involved in developing and implementing the education component and pilot project.

The planning process resulted in several solutions; a transportation pilot project to test the concepts developed, a volunteer driver program to transport patients, a driver training program developed to equip the driver with techniques for better transport as well as empathy, and an educational video that could be used to educate, supplement the driver training curriculum, or be used as a recruitment tool. All strategies and concepts implemented were patient developed and approved.

The transportation pilot project has been underway since February 2015 with 28 patients participating. Feedback from patients is overwhelmingly positive and patients are now reporting less stress in relation to transportation to/from treatment. A combination of utilizing multiple partners with paid and volunteer drivers has proven successful. The education program has been very well received by all. Participants report a 92.5% rating in effectiveness of the training. Drivers feel more prepared and comfortable supporting their riders.

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