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Experiences obtaining insurance after live kidney donation

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Abstract

The impact of kidney donation on the ability to change or initiate health or life insurance following donation is unknown. To quantify this risk, we surveyed 1046 individuals who donated a kidney at our center between 1970–2011. Participants were asked whether they changed or initiated health or life insurance after donation, and if they had any difficulty doing so. Among 395 donors who changed or initiated health insurance after donation, 27 (7%) reported difficulty; among those who reported difficulty, 15 were denied altogether, 12 were charged a higher premium, and 8 were told they had a pre-existing condition because they were kidney donors. Among 186 donors who changed or initiated life insurance after donation, 46 (25%) reported difficulty; among those who reported difficulty, 23 were denied altogether, 27 were charged a higher premium, and 17 were told they had a preexisting condition because they were kidney donors. In this single-center study, a high proportion of kidney donors reported difficulty changing or initiating insurance, particularly life insurance. These practices by insurers create unnecessary burden and stress for those choosing to donate and could negatively impact the likelihood of live kidney donation among those considering donation.

INTRODUCTION

Live kidney donation has emerged as the optimal treatment modality for patients with end stage renal disease (ESRD), a promising solution to minimize the gap between organ supply and demand, and a relatively safe endeavor for healthy individuals (1–4). Given the recent decline in live kidney donation, the persistent organ shortage, and the transplant community's dedication to donor safety, exploring barriers to live donation is critically important (5–8). One cited barrier is the potential that a live donor might have difficulty obtaining health or life insurance after donation, and the inherent financial risks of non-insurability (9–11). While most direct expenses incurred during the live donor evaluation, operation, and post-operative recovery are generally covered by the recipient's insurance, live kidney donors in the United States are thereafter responsible for their own long-term

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DISCLOSURE

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health care. Health insurance affords live kidney donors access to primary care providers who can monitor blood pressure and kidney function and provide other preventive health services (12–15); health insurance is also associated with decreased mortality risk (16). Life insurance affords live kidney donors financial stability for their families in the case of untimely death.

Recent high-profile news stories provide examples that donors may be classified as "high-risk" by insurance companies due to reduced glomerular filtration rate (GFR) caused by having only one kidney, even with no evidence of intrinsic kidney injury or disease (17). Such news coverage may impact potential donors' decisions to donate, particularly in times of economic uncertainty. Surveys of insurance companies suggest that only a small proportion of companies claim that they would charge donors higher insurance premiums after donation (10). However, in a survey of transplant centers in the US, 39% of centers reported that eligible donors declined donation due to fear of future insurance problems (18, 19). Several studies in Europe (20–22) and the United States (10, 23, 24) have reported that some donors experienced a negative impact of donation on the ability to obtain post-donation health or life insurance. No study since 1986 (23) has characterized the nature of this impact (delayed insurance vs. denied insurance vs. increased premiums) or risk factors associated with difficulties in obtaining post-donation insurance.

To better understand post-donation insurability of live kidney donors, we performed a retrospective survey of over 1000 live kidney donors from our center. The goals of our study were to quantify the proportion of live donors who had difficulty changing or initiating health and life insurance, to quantify specific barriers to changing or initiating insurance, and to identify characteristics associated with difficulty changing or initiating health and life insurance.

METHODS

Study population

Our source population consisted of 1394 individuals who underwent live donor nephrectomy at Johns Hopkins Hospital between August 1970 and February 2011. Among former donors, 1046 (75.0% response rate) completed surveys over the phone or through the mail.

Survey content

Separately for health and life insurance, participants were asked if they had difficulty changing or initiating insurance, whether they had been denied a new policy, whether they had been charged a higher premium, or whether they had been told that being a donor was a pre-existing condition. Any participant who answered "yes" to any of these four questions was considered to have had difficulty obtaining insurance. Participants who reported difficulty changing or initiating insurance were also asked qualitative, open-ended questions about their experiences.

Statistical analysis

We examined associations between donor factors (age at time of donation, gender, race, education, smoking history, hypertension, diabetes, and era of donation) and difficulty obtaining health or life insurance using a χ^2 test. Additionally, we performed a multivariate analysis of difficulty obtaining life insurance using logistic regression. All analyses were performed using STATA 12.0/MP for Linux (College Station, Texas). Confidence intervals are reported as per the method of Louis and Zeger (25).

RESULTS

Study population

Among 1046 participants, the median age at donation was 44 years, 62% were female, 13% were African American, 63% had a college education, and 42% were current or former smokers (lifetime consumption of at least 100 cigarettes). Median (IQR) time from donation to interview was 6.7 (3.6–11.0) years. Donors who changed health or life insurance were on average younger at time of donation, and donated longer ago, than other donors (Table 1).

Health insurance difficulties after donation

Among 395 donors who attempted to change or initiate health insurance after donation (38% of all donors), 27 (7%) had difficulty (Table 2a). Among those who reported difficulty, 15 were denied altogether, 12 were charged a higher premium, and 8 were told they had a pre-existing condition because they were kidney donors. There was no evidence of demographic difference between patients who reported difficulty obtaining health insurance and those who reported no difficulty (Table 2a). The proportion of donors who reported difficulty obtaining health insurance was similar across different eras of donation (Table 3a).

Life insurance difficulties after donation

Among 186 donors who changed or initiated life insurance after donation (18% of all donors), 46 (25%) had difficulty. Among those who reported difficulty, 23 were denied altogether, 27 were charged a higher premium, and 17 were told they had a preexisting condition because they were kidney donors. Among participants who changed or initiated life insurance, donors who reported difficulty were more likely to be over age 40 (57% among those with difficulty vs. 39% with no difficulty), male (59% vs. 41%), hypertensive (24% vs. 13%), diabetic (7% vs. 3%), or college educated (72% vs. 59%) and less likely to have a history of smoking (24% vs. 37%, Table 2b). Era of donation was associated with difficulty obtaining life insurance. Difficulty was reported by 41% of donors who donated between 1970 and 1994, by 16% of donors who donated 1995–1999, by 17% of donors who donated 2000–2004, and by 34% of donors who donated in 2005 or later (Table 3b, $p=0.03$).

In a multivariate model, males had higher risk of difficulty obtaining life insurance compared to females (OR = 1.2 2.4 5.1, $p=0.02$, Table 4). Similarly, donors above age 40 at time of donation 40–49 years old at donation had higher risk of difficulty obtaining life insurance compared to donors under 40 at time of donation (OR = 1.0 2.1 4.4, $p=0.04$). Donors who had a history of smoking had lower risk of difficulty obtaining life insurance (OR = 0.2 0.4 0.9, $p=0.04$). Associations between history of hypertension and diabetes were

suggestive of increased difficulty obtaining life insurance, but not statistically significant (OR = 0.9 2.3 5.9, $p=0.08$ for hypertension; 0.8 4.8 27.2, $p=0.08$ for diabetes).

Open-ended responses

Among open-ended responses from patients, there were eight comments describing difficulties obtaining health insurance due to kidney donation, thirteen comments describing difficulties obtaining life insurance due to donation, and sixteen comments that did not specify the type of insurance. Three participants indicated difficulty specifically related to elevated creatinine levels. One of these donors subsequently obtained a letter of support for health insurance from our transplant center, but the letter did not influence the insurance company. Two participants mentioned having to explain that the nephrectomy was not due to kidney disease. Four patients mentioned delays in obtaining insurance due to donation, two mentioned having to complete additional paperwork due to donation, one mentioned having to take an additional blood test due to donation, and one mentioned a requirement for a "doctor's assessment". Two participants offered estimates of the magnitude of additional premium due to donation ("50% rate hike" and "almost double"). However, six participants mentioned obtaining a "preferred status" / "low-risk" rate; three donors believed they had obtained insurance or a favorable rate specifically because of their organ donor status – in the words of one participant, "healthy enough to be a donor."

DISCUSSION

In this retrospective survey of 1046 live kidney donors up to 40 years since donation, we found a disturbing proportion of donors who experienced difficulty with insurability after donation: 7.0% of participants who attempted to change or initiate health insurance, and 25% of participants who attempted to change or initiate life insurance. Males and donors above age 40 were more likely to report having had difficulty changing or initiating life insurance. In-depth interviews revealed that difficulties in changing or initiating insurance included delays, added paperwork, and higher cost.

The difficulties live kidney donors reported in changing or initiating insurance are surprising. Our study did not ask donors whether the difficulties were a result of live kidney donation, and some difficulties may have been unrelated to donor status. However, many of the donors' open-ended responses describe difficulties specifically related to the donation. Based on available evidence, donors would seem to be excellent candidates for health or life insurance. Prospective donors are subjected to extensive screening prior to being cleared for donation. Moreover, there is no evidence of decreased long-term survival in kidney donors in the United States, as compared to matched controls or to the general population (1, 2). While two recent studies have shown increased risk of long-term ESRD in donors as compared to carefully matched controls (26, 27), donors are still at far lower risk of ESRD than the general population (27). Donors who attempted to change or initiate life insurance after donating in 2005 or later were more likely to face difficulty than those who donated between 1995 and 2004, suggesting that insurance barriers to donors may be increasing over time.

Among industrialized nations, the United States is the only country in the world in which some live kidney donors lack health insurance (28). Registry-based studies show that approximately 18% of live donors lack health insurance at the time of donation. Lack of insurance is particularly prevalent in donors who belong to minority racial groups (29, 30), who are at higher risk of post-donation hypertension (31) and ESRD (27) than Caucasian donors. Although short-term postoperative care is covered by the recipient's health insurance, this coverage generally ends at hospital discharge or a short time (e.g. three months) after donation (11). As the national organ shortage leads centers to increasingly accept kidney donation from medically complex donors (e.g. with obesity, hypertension, low eGFR, or proteinuria at baseline) (30, 32), continuity of health insurance following donation may become increasingly necessary for donors to stay healthy after donation. A survey of transplant centers reported that most long-term followup care for live donors is paid for by the donors' insurance (33). A 2010 consensus conference recommended that long-term insurance coverage be provided to live donors for issues related to donation; however, the difficulty of determining "relatedness" complicates the issue (28). The state of insurance of live donors in the United States has been described as a disincentive to live donation (11).

Under the Patient Protection and Affordable Care Act (ACA), discrimination in the provision of health insurance based on preexisting conditions became illegal on January 1, 2014 (34). Insurance companies can no longer refuse health insurance to live kidney donors, or charge them a higher insurance rate. However, since enactment of the ACA, numerous attempts have been made to repeal the law (35). If protections for live kidney donors are repealed or weakened in the future, the difficulties we report here will likely resurface. Furthermore, the ACA does not affect life insurance, which was more commonly a source of difficulty for live kidney donors in our study than was health insurance.

Several smaller single-center studies have previously reported difficulties in obtaining insurance among live donors in the United States (10, 24). In a retrospective survey of 248 live donors who donated at the Cleveland Clinic between 1983 and 1995, 9% of donors reported "a negative impact on the ability to retain health, life or disability insurance" (24). Similarly, a 2005 study by Fisher and colleagues reported a "negative impact on ability to get insurance coverage" in 6 of 87 living-related kidney donors (10). In a 2003 study by Burroughs and colleagues (10), 6 of 174 donors (3%) reported difficulty obtaining life insurance after donation. Insurance difficulties have also been reported in Germany (20, 21) and Norway (22). In a 2009 study, Yang and colleagues contacted Canadian life insurance companies directly, posing as insurance customers with or without a history of live kidney donation; "donors" spent more time on the phone than "nondonors", but there was no evidence of increased rates charged to "donors" on the initial call (36). In contrast with our study, a 1985 post-donation survey of 536 live donors in the United States found that racial minorities had greater difficulty obtaining insurance than other donors; also unlike our study, this study found no evidence of association between age or gender and difficulty obtaining insurance (23).

Our study has several limitations that should be considered. Ascertainment of difficulties in changing or initiating health insurance was via self-report; as such, participants' responses may be subject to recall bias. Additionally, among donors who have developed hypertension

or diabetes since donating, we do not know whether attempts to obtain insurance preceded these diagnoses. Despite the large sample size of over 1000 donors and a response rate exceeding 75%, our study may have lacked power to detect some associations between donor characteristics and risk of difficulty in changing or initiating insurance. Finally, without an adequate comparison group of healthy non-donors, it becomes difficult to tease out the contribution of factors known to impact one's ability to obtain insurance such as age, gender, and family history of kidney disease or hypertension (37).

In conclusion, we report that a sizeable proportion of donors experienced difficulty changing insurance after donation, particularly life insurance. Difficulty in obtaining insurance may constitute a barrier to live kidney donation; among donors who fail to obtain insurance, the financial and health consequences may be severe. With lower death rates than the general population (1), kidney donors represent excellent candidates for health and life insurance. Failure to provide insurance to donors harms those who have willingly undergone an invasive procedure on behalf of an ESRD patient; it also makes poor financial sense for insurance companies. It is incumbent upon the transplant community to provide accurate and comprehensive information about the health status of live donors in order to inform insurance companies of donors' excellent insurability. Additionally, regulation may be required to prevent discrimination against live kidney donors.

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ABBREVIATIONS

ESRD	end stage renal disease
GFR	glomerular filtration rate

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Table 1

Characteristics of live kidney donors, those who changed health insurance, and those who changed life insurance following donation.

	Total N = 1046	Changed health insurance N=395	Changed life insurance N=186
Age at donation [median (IQR)]	44 (36–52)	41 (32–48)*	39 (32–47)*
Male [N (%)]	395 (38%)	148 (37%)	84 (45%)*
African-American [N (%)]	131 (13%)	46 (12%)	21 (11%)
College educated [N (%)]	543 (52%)	200 (51%)	115 (62%)*
Current/former smoker [N (%)]	441 (42%)	158 (40%)	63 (34%)*
Years since donation [median (IQR)]	6.7 (3.7–11.0)	8.4 (5.1–12.2)*	9.0 (5.5–12.7)*

* $p < 0.05$ per Wilcoxon rank-sum test (age, years since donation) / χ^2 test (binary variables)

Table 2

Relationship between donor characteristics and difficulty changing or initiating insurance.

2a. Difficulty changing or initiating health insurance

	No difficulty	difficulty	P value
N	368	27	
Age > 40 [N (%)]	196 (53%)	13 (48%)	0.6
Male [N (%)]	135 (37%)	13 (48%)	0.2
African-American [N (%)]	45 (12%)	1 (4%)	0.2
College educated [N (%)]	185 (50%)	15 (55%)	0.6
Ever smoked [N (%)]	145 (39%)	13 (48%)	0.4
Hypertension [N (%)]	63 (17%)	6 (22%)	0.5
Diabetes [N (%)]	14 (4%)	2 (7%)	0.3

2b. Difficulty changing or initiating life insurance

	No Difficulty	Difficulty	p
N	140	46	
Age > 40 [N (%)]	54 (39%)	26 (57%)	0.03*
Male [N (%)]	57 (41%)	27 (59%)	0.03*
African-American [N (%)]	17 (12%)	4 (9%)	0.5
College educated [N (%)]	82 (59%)	33 (72%)	0.1
Ever smoked [N (%)]	52 (37%)	11 (24%)	0.1
Hypertension [N (%)]	18 (13%)	11 (24%)	0.06
Diabetes [N (%)]	4 (3%)	3 (7%)	0.2

P-values obtained by χ^2 test.*
p < 0.05

Table 3

Difficulties in obtaining health (Table 3a) and life (Table 3b) insurance, by era of donation. There was no evidence of association between era of donation and difficulties obtaining health insurance (χ^2 p=0.9). Donors who donated before 1995, or 2005 or later, reported the most difficulties obtaining life insurance (p=0.03).

3a. Difficulty obtaining health insurance		
Era	N (pct) no difficulty	N (pct) difficulty
1970–1994	31 (94%)	2 (6%)
1995–1999	73 (91%)	7 (9%)
2000–2004	130 (94%)	9 (6%)
2005–2011	134 (94%)	9 (6%)

3b. Difficulty obtaining life insurance		
Era	N (pct) no difficulty	N (pct) difficulty
1970–1994	10 (59%)	7 (41%)
1995–1999	37 (84%)	7 (16%)
2000–2004	52 (83%)	11 (17%)
2005–2011	41 (66%)	21 (34%)

Table 4

Multivariate model of risk factors for having difficulty changing or initiating life insurance.

	Odds ratio	p
Age > 40	1.22 _{5.1}	0.02
Male	1.02 _{4.3}	0.04
History of smoking	0.20 _{0.9}	0.04
Hypertension	0.92 _{5.9}	0.08
Diabetes	0.84 _{27.2}	0.08