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Pregnancy and Family Planning in Women With Kidney Disease

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Introduction: Females with kidney disease are at increased risk for pregnancy complications. Few studies have examined pregnancy perspectives of people with kidney disease. Our objective was to examine kidney patients' perspectives on family planning.

Methods: We conducted an online survey of female patients with kidney disease from the University of Colorado Hospital between the ages of 18 and 50 years from August to October 2022. The survey asked questions on previous and current pregnancies with kidney disease, family planning, and reproductive health discussions with their nephrologists. Perspectives on how kidney disease influences pregnancies were also explored.

Results: A total of 136 participants completed the survey. The majority of participants were White (71.3%) with a mean (SD) age of 37 ± 10 years. The majority of participants self-characterized their kidney disease as moderate ($n = 57$, 43.5%) with 16 participants (12.2%) receiving dialysis. Fifty-two participants (38.5%) experienced a pregnancy with a diagnosis of kidney disease, which were largely planned ($n = 33$, 61.1%). The majority of participants were able to conceive within 6 months (64.8%). Nearly half of participants reported that kidney disease influenced their family planning decisions with the majority ($n = 91$, 66.5%) believing that kidney disease increased their risk for pregnancy complications. More than half of participants never discussed the health risks of a potential pregnancy (54.0%), desire to have children (58.0%), pregnancy prevention (57.0%), and/or optimizing their health prior to pregnancy (68.1%) with their nephrologist.

Conclusion: Although kidney disease influenced family planning decisions, few participants had family planning discussions with their nephrologists.

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Although pregnancy among patients with kidney disease is rare, the number of people with chronic kidney disease (CKD) becoming pregnant has been increasing worldwide.[1,2] CKD affects about 0.5% to 9% of women of childbearing age[3-7] and presents unique challenges. Pregnant patients with kidney disease have an increased risk of adverse outcomes, including but not limited to, hypertensive disorders of pregnancy, preterm birth, low birthweight, cesarean delivery, and infants requiring neonatal intensive care unit care.[8-10] The potential decline in kidney function during pregnancy necessitates medication adjustments, depending on the medication used, and vigilant monitoring to detect and manage any complications early.

Preconception counseling is essential for women with kidney disease considering pregnancy, ensuring their health readiness for pregnancy, addressing potential risks, and optimizing their health before conception. Achieving optimal kidney function before conception is advised, and contraception methods compatible with the condition should be chosen for family planning.[8,9,11-13] The complexities of these pregnancies highlight the importance of prepregnancy planning for patients with known kidney disease, the management of pregnancy through collaborative decision-making, and an approach that prioritizes the patients' needs.[14] However, there is limited data on family planning among patients with kidney disease,

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including patient decision-making regarding pregnancy and patient perspective regarding discussions with their nephrologist on reproductive health. The main objective of this study was to evaluate patients' perspectives about family planning, including discussions with their nephrology team.

METHODS

We conducted a survey of female patients with CKD from the University of Colorado Hospital. Female patients aged between 18 and 50 years who had been seen at least once in the General Nephrology Clinic at the University of Colorado Hospital by one of the 17 providers in the past 2 years were invited to participate. The University of Colorado is a tertiary kidney referral center. The patients were recruited from August to October 2022. A total of 515 participants were invited to complete the survey. Participants were invited to participate in an online survey through email or an electronic message in their online health portal. The survey was completely anonymously, and data were collected and managed through Research Electronic Data Capture, a secure, web-based application. Findings from previous qualitative studies on women with kidney disease were used to inform our study design.[15] Patients completed a 27-item survey with questions on family planning with kidney disease, including discussions with nephrologists, and patient perspectives on the impact of kidney disease on pregnancy (Supplementary information on Survey). Adaptive questioning was used to reduce the number of questions. The survey was reviewed by the study team and 3 independent nephrologists to evaluate usability and technical functionality of the survey. We also asked open-ended questions that allowed participants to share their thoughts or experiences about pregnancy and family planning. Thematic analysis was used for the open-ended questions. Two members of the study team independently coded the answers to identify major themes and categories that captured the key aspects of the themes. The coders then came together to review the coding scheme and finalize the themes. We also evaluated maternal and fetal complications during pregnancy. We collected data on patient age, race or ethnicity, employment status, marital status, years of education, and annual income. Descriptive statistics were used to provide summaries of the patient responses. The study protocol was deemed exempt by the Colorado Multiple Institutional Review Board and consent was implied through voluntary return of the confidential survey. Participants received a $10 gift card for participating in the survey. Reasons for not participating in the survey were not collected. We used the standardized reporting framework checklist for reporting results of internet E-surveys.[16]

Table 1. Characteristics of study population

Characteristic	Values
Age (yr)	37 ± 10
Race/ethnicity, *n* (%)	
White	97 (71.3)
Black	15 (11.0)
Hispanic	36 (26.5)
Level of kidney disease, *n* (%)	
Mild	43 (32.8)
Moderate	57 (43.5)
Severe	31 (23.7)
Receiving dialysis	16 (12.2)
Causes of kidney disease, *n* (%)	
Diabetes	20 (15.3)
Hypertension	39 (29.8)
Glomerulonephritis	15 (11.0)
Polycystic kidney disease	18 (14.1)
Lupus nephritis	10 (7.4)
Unsure	34 (26.0)
Marital status, *n* (%)	
Married	68 (50.0)
Unmarried	44 (32.4)
Living with partner	24 (17.6)
Education level, *n* (%)	
Some high school	4 (2.9)
High school	15 (11.0)
Some college	43 (31.6)
College	49 (36.0)
Graduate school	25 (18.4)
Employment status, *n* (%)	
Employed	79 (58.1)
Unemployed	18 (13.2)
Caregiver (for children, elderly)	6 (4.4)
Homemaker	12 (8.8)
Student	7 (5.1)
Household income, *n* (%)	
$0	4 (2.9)
$1 to $9999	9 (6.6)
$10,000–$24,999	15 (11.0)
$25,000–$49,999	16 (11.8)
$50,000–$74,999	23 (16.9)
$75,000–$99,999	18 (13.2)
$100,000–$149,999	13 (9.6)
$150,000 and greater	28 (20.6)
Prefer not to answer	10 (7.4)

All values are mean ± SD unless otherwise noted.

RESULTS

Of those invited, 136 participants completed the survey (26.4% response rate). The characteristics of the survey participants are shown in Table 1. The mean (SD) age was 37 (10) years. Participants were primarily White and of Hispanic ethnicity. Of the participants, 43% rated their kidney disease as moderate and 23.7% rated it as severe. Sixteen participants (12.2%) were on dialysis. Hypertension was the most commonly

Table 2. Pregnancy planning and discussions with nephrologists across self-reported kidney disease severity

Characteristics	Mild kidney disease ($n = 43$)	Moderate kidney disease ($n = 55$)	Severe kidney disease (not on dialysis) ($n = 18$)	Currently on dialysis ($n = 16$)
Currently pregnant, *n* (%)	2 (4.7)	0 (0)	0 (0)	0 (0)
Previous pregnancy while having kidney disease, *n* (%)	15 (34.9)	24 (43.6)	7 (38.9)	6 (37.5)
Kidney disease influenced family planning, *n* (%)	21 (48.8)	23 (41.8)	11 (61.1)	7 (43.8)
Planning pregnancy, *n* (%)				
Yes	9 (20.9)	12 (21.8)	4 (22.2)	1 (6.3)
Unsure	9 (20.9)	10 (18.2)	4 (22.2)	4 (25.0)
Interested in adoption/surrogacy/fostering, *n* (%)	14 (32.6)	17 (30.9)	7 (38.9)	9 (56.3)
Discussed health risks of potential pregnancy with kidney doctor, *n* (%)	22 (51.1)	24 (43.6)	12 (66.7)	5 (31.3)
Discussed birth control to prevent pregnancy with kidney doctor, *n* (%)	20 (46.5)	26 (47.3)	8 (44.4)	4 (25.0)
Would like to have a conversation with kidney doctor about having children, *n* (%)	13 (30.2%)	19 (34.5)	4 (22.2)	3 (18.8)
If yes to conversation with kidney doctor, are currently planning pregnancy, *n* (%)	4 (9.3)	7 (12.7)	4 (22.2)	1 (6.3)

reported etiology of kidney disease. Of the 52 participants (38.5%) who became pregnant with kidney disease, 61.1% reported that it was a planned pregnancy with the majority reporting that it took less than 6 months (64.8%) or between 6 and 12 months (18.5%) to become pregnant. The majority of the women who had a pregnancy with kidney disease reported their kidney disease as moderate ($n = 24$) or mild ($n = 15$) (Table 2). Two patients with self-reported mild kidney disease were currently pregnant. Fifty-seven (42.2%) participants reported they want to have children (missing responses = 1) and 27 (20.0%) reported they were planning to become pregnant. Of the 16 patients who were on dialysis, 7 wanted to have children, 1 was planning to become pregnant and 4 were unsure if they were planning pregnancy (Table 2). We evaluated participants' methods of contraception. Of all participants, 55% were trying to avoid pregnancy (missing responses = 1). Of those trying to avoid pregnancy ($n = 74$), the most common method of birth control used was an intrauterine device (31.1%) followed by oral birth control pills at 13.5%. Forty-eight participants were interested in adoption, fostering, and/or surrogacy. Nine of the 16 patients on dialysis were interested in adoption, fostering and/or surrogacy (Table 2).

We also explored patients' perspectives on the impact of kidney disease on pregnancy. Nearly half of the participants (45.6%) reported that kidney disease influenced their family planning decisions. More participants (61%) with self-reported severe kidney disease, not yet on dialysis, reported that kidney disease influenced their family planning decisions (Table 2). The majority of patients believed that kidney disease increased their risk for pregnancy complications and 57% believed kidney disease increased their risk of fetal complications (Figure 1). More participants currently on dialysis reported that kidney disease increases their risk of a hard pregnancy (Figure 1). Forty percent of patients ($n = 55$) were unsure if kidney disease in pregnancy increased the risk for fetal complications. Of these 55 respondents, 21 reported that they discussed the health risks of a potential pregnancy with their nephrologist.

We found that patients were less likely to have discussions regarding reproductive health with their nephrologists. More than half of the participants (53.7%) responded that they have never discussed the health risks of a potential pregnancy with their nephrologist (Figure 2). Of the women who never discussed pregnancy with their nephrologists, 30% ($n = 22$) had a previous pregnancy while having kidney disease. In addition, over half of the patients reported that they never discussed their desire to have children with their nephrologist (58%), pregnancy prevention (57%), or health optimization before conception (68.1%) (Figure 2). Only 29.4% of patients ($n = 40$) agreed to a potential conversation about reproductive health with their nephrologist. Of the 20% of women participants who were planning pregnancy, 17 (63%) would like to have a conversation with their kidney doctor regarding pregnancy. When examining by self-reported kidney diseases severity, 34.5% of women with self-reported moderate kidney disease would like to have a conversation with their nephrologist about having children (Table 2). Only 7 of these women (12.7%) were currently planning pregnancy. Women on dialysis had the lowest response rate to wanting to have a conversation with their nephrologist about family planning.

We further identified several themes, among patients, surrounding how kidney disease influenced pregnancy planning (Table 3). Several patients reported concern about their kidney disease worsening due to pregnancy, including having to stop medications for their kidney disease during pregnancy, "To have children I must stop taking my medications" (woman, mild kidney disease). Others reported concern with passing along kidney disease to their children, "50/50 chance of

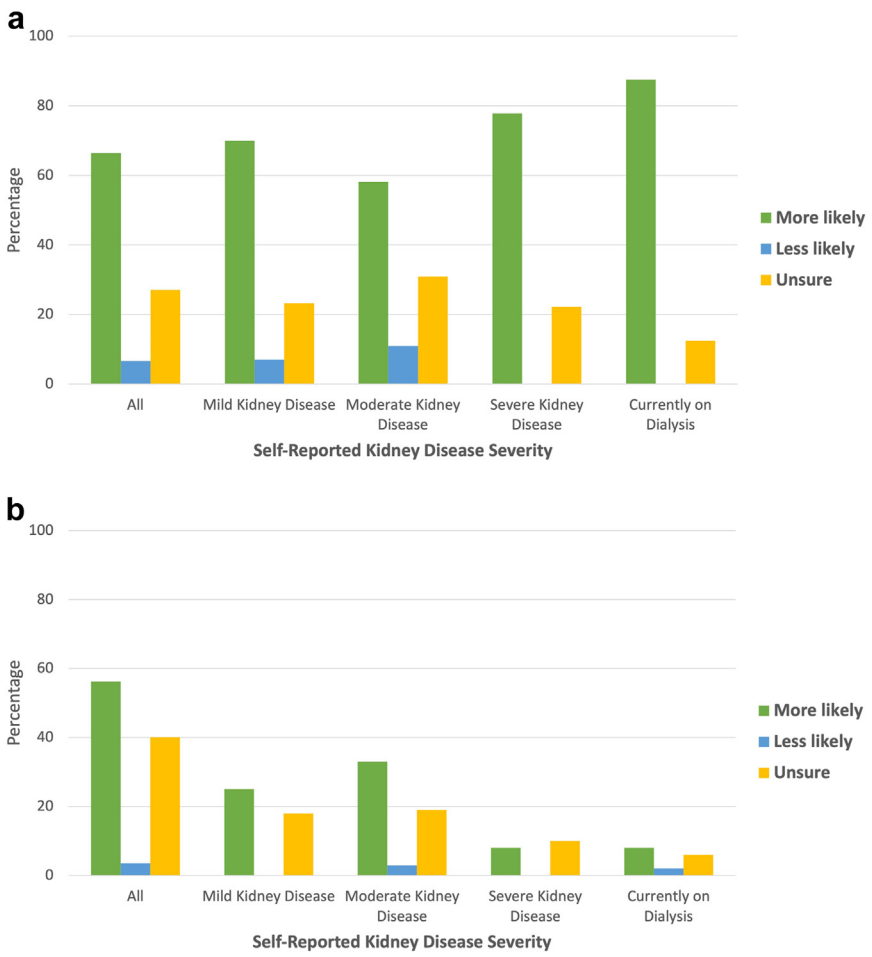

Figure 1. Percentage of participants reporting whether having kidney disease (a) increases their risk of a hard pregnancy or (b) increases the risk of fetal complications, across self-reported kidney disease severity.

passing disease onto a child that has no cure" (woman, moderate kidney disease). Many women reported that complications from a prior pregnancy with kidney disease influenced their decision to have more children. One woman reported "…preeclampsia with 2 pregnancies. Very scary and I cannot go through that again. I

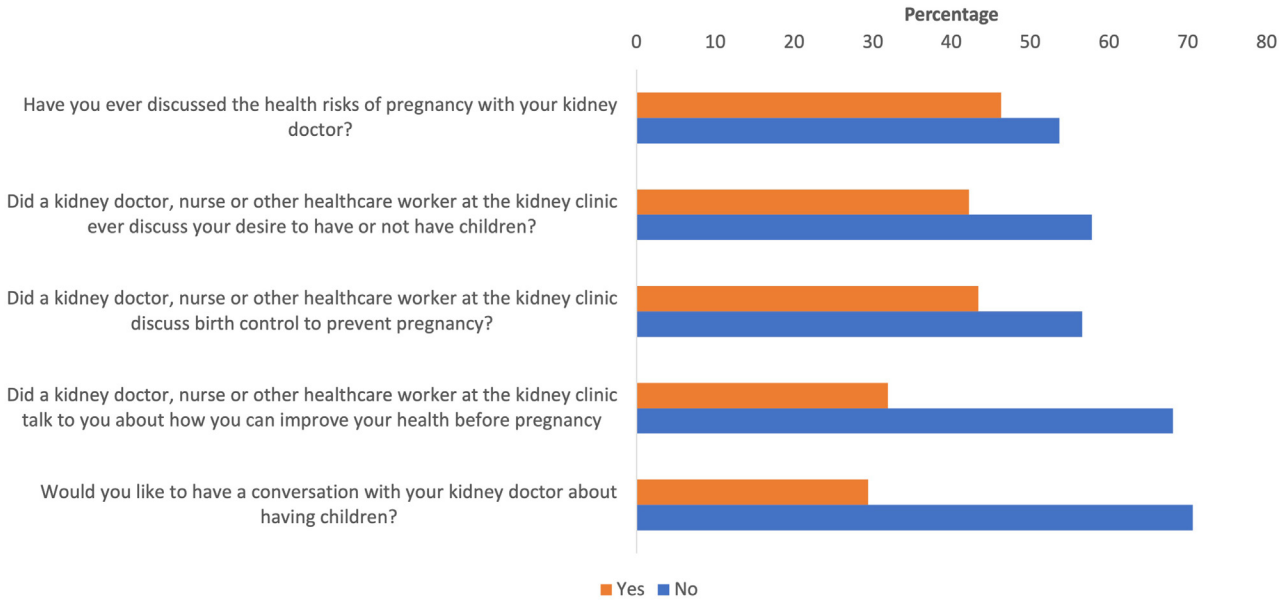

Figure 2. Proportion of participants responding to questions regarding family planning with their nephrologist.

Table 3. Selected participant quotations selected for each theme about family planning and kidney disease identified

Theme	Quotation
Concern about kidney disease worsening during pregnancy	"I have never had children before and am concerned that carrying a baby would exacerbate my ADPKD, lead to high blood pressure, or further damage my kidneys." (woman, mild kidney disease) "Need to be safer and plan the pregnancy as I cannot take some of my medications once I plan to become pregnant" (woman, severe kidney disease) "My kidney disease gets worse while pregnant" (woman, moderate kidney disease) "GFR lowers every time I get pregnant…want to be able to live a productive life without having dialysis while the 2 children I have are still young" (woman, moderate kidney disease)
Concern with passing kidney disease onto their children	"I know there is a 50/50 chance of passing on my PKD so it makes planning a family a bit scary, because I don't want the possibility of passing it on to my children." (woman, mild kidney disease) "I have considered that there is a 50% chance of passing this disease onto my children which makes me wonder if I should have kids or not." (woman, moderate kidney disease) "We are attempting IVF versus natural conception for single gene testing of embryos for PKD to avoid passing disease to offspring." (woman, mild kidney disease) "I have been told that I could pass my disease on to my children, and I do not want them to have it. I am now considering adoption instead of conceiving." (woman, mild kidney disease)
Complications from a prior pregnancy influenced family planning	"Preeclampsia with 2 pregnancies. Very scary and I cannot go through that again. I need to stay alive to care for the 2 kids I have now." (woman, moderate kidney disease) "I don't want to have a high risk pregnancy, my son was born prematurely and passed, I'm afraid of that happening again. I have 2 daughters and one miscarriage." (woman, mild kidney disease) "Because both pregnancies were high risk. Both babies were born early." (woman, moderate kidney disease) "I'm worried my body won't do so well the third time because it's always caused my blood pressure to spike up." (woman, mild kidney disease)
Having children was not possible, difficult, or too risky	"I was told I can't have children due to my kidney disease."(woman, currently on dialysis) "I would like to have children on my own, but I was told that wasn't an option or it would be a hard pregnancy." (woman, moderate kidney disease) "I am at risk of dying during pregnancy. But I've had 2 healthy children. I would like to have more but I am at a very high risk." (woman, severe kidney disease) "Being on kidney disease, is hard to conceive." (woman, moderate kidney disease) "I would be high risk. Makes me less sure I would want to try to have children." (woman, severe kidney disease)

ADPKD, autosomal dominant polycystic kidney disease; GFR, glomerular filtration rate; IVF, *in vitro* fertilization; PKD, polycystic kidney disease.

need to stay alive to care for the 2 kids I have now" (woman, moderate kidney disease). The other theme that emerged was infertility issues and being told they could not have children. Women reported it was hard to conceive and others reported they were told they cannot have children, "I would like to have children on my own, but I was told that was not an option or it would be a hard pregnancy" (woman, moderate kidney disease).

Patients self-reported high rates of adverse pregnancy outcomes. In Figure 3, we show adverse pregnancy outcomes experienced by women by self-reported kidney disease severity during pregnancy. The majority of participants reported chronic hypertension (54%), preeclampsia (40%), early delivery (44%), and the need for a cesarean delivery (44%) (Figure 2). Of the participants, 25% reported low birthweight and (31.4%) reported the infant required neonatal intensive care unit admission (Figure 3). Of the 16 patients currently on dialysis, none were currently pregnant; however, 6 reported a previous pregnancy while having kidney disease. Of these 6, 25% reported chronic hypertension, 25% reported

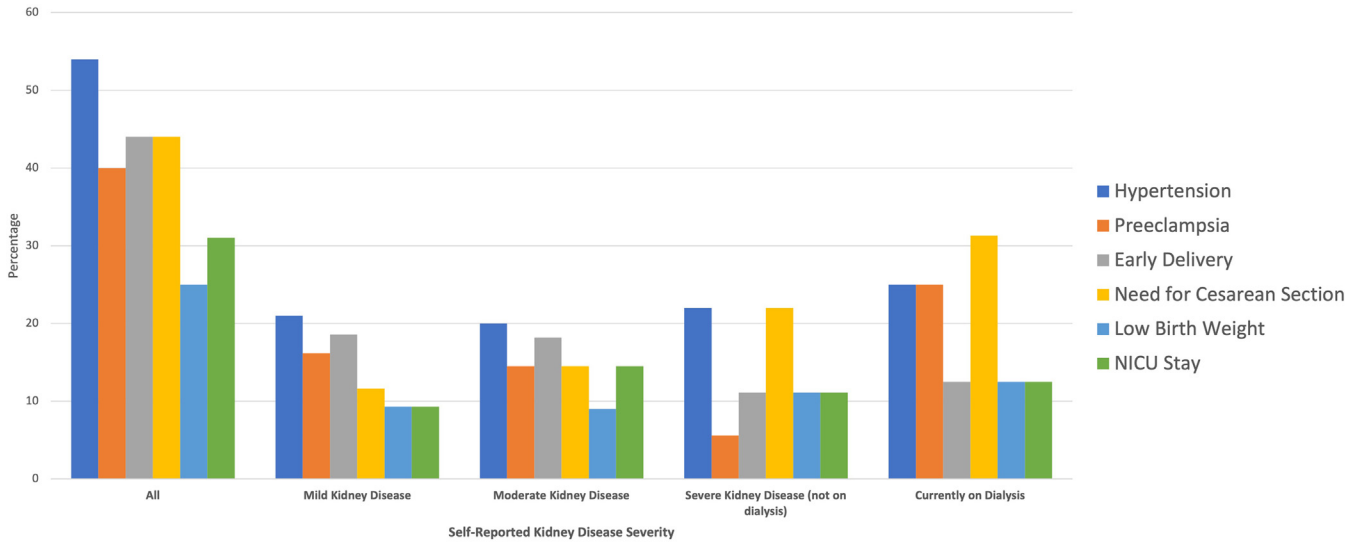

Figure 3. Self-reported adverse pregnancy outcomes across self-reported kidney disease severity. NICU, neonatal intensive care unit.

preeclampsia, 31.3% reported need for a cesarean delivery, and 12.5% reported premature birth and low birthweight babies.

DISCUSSION

In this single center study, we found that nearly half of the women reported that kidney disease influenced their family planning. We found that women were concerned about their kidney disease worsening during pregnancy and were concerned about passing kidney disease on to their children. In addition, previous pregnancy complications they had experienced influenced their future family planning. Most women surveyed reported that kidney disease increased their risk of having pregnancy complications.

We found low rates of discussions about family planning with nephrologists and other health care workers in the kidney clinic. Over 41% of the women surveyed wanted to have children but almost 40% percent had never discussed their desire to have children with their nephrologist. Interestingly, less than one-third of the participants were interested in discussing pregnancy with their nephrologist. The reason for this finding is unclear. It is possible that the participants did not feel comfortable having this discussion with their kidney doctor. Previous qualitative studies have observed that women with kidney disease are often hesitant to discuss pregnancy with their physicians out of fear of judgment.[15] For this reason, it is often recommended that the physician initiates the conversation.[11-13] In our study, 40% of the women who wanted to discuss pregnancy with their nephrologist were currently planning to become pregnant, indicating how important preconception counseling is. However, few nephrologists are initiating or even having these discussions with their patients. A recent study found that the majority of nephrologists do not feel comfortable providing preconception counseling.[17] Nearly 40% of United States nephrologists lacked confidence in providing reproductive or obstetrical counseling.[17] In addition, only 33.1% felt confident providing counseling on contraception.[17] The most common reason for not providing counseling was lack of training (53.3%). Nearly 90% felt that continuing education seminars and/or interdisciplinary guidelines would improve their knowledge and confidence in counseling on women's health issues.[17]

CKD is a known risk factor for adverse pregnancy outcomes.[8-10] Thus, women with CKD who are contemplating pregnancy should be aware of these risks and receive counseling because this is an important part of the patient's nephrology care. A recent qualitative study found that both nephrologists and patients agreed that communication about pregnancy risk could be improved.[18]

Interdisciplinary care, in which both nephrologists and obstetricians lead preconception counseling, has been shown to help women with kidney disease decide whether to pursue pregnancy.[19] However, fewer than 10% of nephrologists reported the use of interdisciplinary clinics that include obstetrics for women with kidney disease in the United States.[17] Interdisciplinary clinics may be an effective way to improve preconception counseling of patients with kidney disease. At our center, we recently began a monthly interdisciplinary meeting between nephrology and obstetrics to discuss women with kidney disease who are pregnant or considering pregnancy. It is too soon to determine if this new collaboration improves care. Further studies on the effective role of interdisciplinary care to improve pregnancy outcomes among patients are needed. We found that the majority of women who had a pregnancy with kidney disease became pregnant within 1 year. This is similar to the rate of pregnancy in the general population[20] and higher than we expected. This higher rate may be due to response bias in that more women who had a positive experience with pregnancy completed the survey. In addition, because the participants self-reported their severity of kidney disease, it is possible that the majority of participants only had mild kidney disease even if they reported more advanced disease.

Our study has several limitations. First, our response rate was only 26.4%. We only recruited participants through email or their electronic health portal and it is possible that not all of the participants check their electronic health portal regularly. We also only surveyed participants in our hospital system; thus, the results may not be generalizable to women of childbearing age in other health care settings. The majority of participants were White, which reflects the regional demographics in the state of Colorado; however, the results may not be generalizable to women of other races or ethnicities. In addition, majority of the participants had at least some college education. We were unable to ascertain reasons for certain responses given that the questions were not all open ended. We did not collect information on why patients chose not to participate. All data regarding kidney disease severity and pregnancy outcomes were self-reported and we did not have any ability to link responses with medical information because the survey was anonymous. It is possible that some participants did not understand the definitions of severity or the adverse pregnancy outcomes. Finally, we did not ask participants if they

were currently sexually active; thus, our contraception rates may not be accurate.

Our study highlights that kidney disease affects family planning decisions by people of childbearing age. However, few participants had family planning discussions with their nephrologists. In our study, less than a third of participants reported that they wanted to discuss family planning with their nephrologist. It is unclear if this was due to fear of judgment by their physician or other reasons. Preconception counseling has been shown to be beneficial and nephrology providers should offer proactive counseling to women with kidney disease. Counseling provides people contemplating pregnancy with the necessary information and guidance to make well-informed and autonomous decisions about their reproductive health. In order for this to happen, there must be increased nephrology provider education on women's health issues. The recent Kidney Disease Improving Global Outcomes Controversies Conference on Women and Kidney Health highlighted the need for future education and research to improve knowledge gaps. Continuing medical education courses and seminars may be a way to provide nephrologists with this critical knowledge. Nephrology training programs also have the ability to include teaching on women's health issues into the curricula. This will ensure that the future nephrology workforce is more comfortable with discussing these issues with their patients. Finally, the nephrology community should develop guidelines and tools for physicians to use for family planning counseling.

DISCLOSURE

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SUPPLEMENTARY MATERIAL

Supplementary File (PDF)

Survey.

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