

A Survey of Patient Attitudes Toward Participation in Biopsy-Based Kidney Research

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Introduction: As part of the precision medicine initiative, the National Institutes of Health/National Institute of Diabetes and Digestive Kidney Diseases has proposed collecting human kidney tissue to discover novel therapeutic targets from patients with kidney diseases. Patient attitudes on participating in kidney biopsy-based research are largely unknown.

Methods: We evaluated attitudes toward donating kidney tissue to research among participants who had experienced a clinically indicated kidney biopsy, through a survey conducted 9 months (interquartile range, 5–13 months) after their biopsy.

Results: Of the 177 participants contacted, 117 (66%) participated in the survey. A total of 85 participants (73%) reported that they would allow additional needle passes during a clinically indicated biopsy to donate kidney tissue for research. As reasons for participating in such a study, the participants reported the desire to help others and to contribute to science, and the lack of additional burden while participating in such a study. In a multivariable logistic model, older and African American participants had lower odds of allowing an additional pass for research (odds ratio: age ≥ 65 years [vs. ≤ 40], 0.15 [95% confidence interval, 0.03–0.73]; African Americans (vs. all others), 0.15 [95% confidence interval, 0.05–0.44]). However, participants' self-reported biopsy complications such as pain, anxiety, and hematuria did not affect their willingness to allow additional passes. A total of 23 participants (20%) stated that they would agree to undergo a biopsy for research even if it was not clinically indicated.

Conclusion: Among patients who had experienced a kidney biopsy, a majority were amenable to additional needle passes to donate kidney tissue for research during a future, clinically indicated biopsy, whereas a minority would undergo a biopsy for research purpose only.

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KEYWORDS: acute kidney injury; biopsy; chronic kidney disease; kidney diseases; survey

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Studying kidney tissue from human participants with kidney diseases will lead to a deeper understanding of the disorder's phenotypes and can therefore allow for the development of successful treatment therapies in humans. The National Institutes of Health (NIH)/National Institute of Diabetes and Digestive Kidney Diseases (NIDDK) has started working toward this goal by creating the Kidney Precision Medicine Project (KPMP), which proposes to obtain and to evaluate kidney tissue from

participants with kidney diseases.¹ Although there is a significant interest in obtaining kidney tissue for research purposes among the scientific community, patient perspectives on donating such kidney tissue for research remain unknown. In oncology, studies have looked at patients' attitudes toward the use of biopsies to acquire tissue for research; however, no one has investigated patient attitudes toward human kidney tissue research.^{2,3}

To explore patient perspectives on participation in future kidney biopsy-based studies, we conducted a survey of participants who had undergone a clinically indicated kidney biopsy and were part of the Yale acute interstitial nephritis (AIN) cohort. The findings of this study help elucidate patients' views on donating kidney tissue for research and thus help develop strategies to improve patient enrollment. Availability of human kidney

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tissue will in turn assist with ongoing investigations that seek to improve kidney disease therapies.

BRIEF METHODS

Detailed methods, survey instrument, and analytic plan are presented in Detailed Methods, in the [Supplementary Materials](#). Briefly, we conducted a 1-time survey of participants of the biopsy-based Yale AIN cohort through phone calls and in-person visits between September 2016 and March 2017. We excluded from the survey participants who were unable to participate because of their mental status or who had died between their kidney biopsy and the survey. All participants provided written informed consent, and the study was approved by the Yale human investigation committee.

Survey

The survey was designed to evaluate attitudes toward kidney biopsy research and was administered to all participants by a single person (B.C.). The survey questions were determined based on prior studies in oncology, adapted to kidney research after input from nephrologists, and pilot-tested in 5 volunteers to ensure comprehension over the phone.

Data Sources

We collected demographic, comorbidity, and objective complication data from review of the electronic health record. We also collected information on patient-reported outcomes during the survey.

Statistical Analysis

We compared continuous and categorical variables using the Wilcoxon rank sum test and χ^2 test, respectively. We tested the association of various factors with the outcome of reporting willingness to allow an additional pass during a clinically indicated biopsy using a multivariable logistic regression model.

RESULTS

Demographics of Survey Participants

Of the 199 patients enrolled in the Yale AIN cohort from January 2015 to October 2016, 177 were alive at the time of survey ([Supplementary Figure S1](#)). Among these 177 patients, 117 completed the survey. Patients who completed the survey were more likely to have baseline chronic kidney disease, to have progressive chronic kidney disease as a biopsy indication, and to be outpatients at initial biopsy ([Supplementary Table S1](#)).

Participation in Biopsy-based Research

In all, 85 participants (73%) reported that they would allow additional passes to donate tissue to research

during a clinically indicated biopsy ([Figure 1](#)). The common reasons for agreeing to participation in such a study were to help others (35 [41%]), lack of additional burden (18 [21%]), and contributing to science (12 [14%]). Thirty-two participants (27%) would not allow an extra pass to donate kidney tissue to research. Twenty-three participants (20%) reported that they would allow a research biopsy even if another clinically indicated biopsy was not needed.

Determinants of Participation

Participants who were willing to allow an additional pass during a clinically indicated biopsy were more likely to be younger (54 [43–65] vs. 64 [51–72] years, $P = 0.02$;) ([Table 1](#)). Participant responses also differed based on their racial/ethnic background; 17 (52%) of 33 African Americans and 68 (81%) of 84 participants of the other racial/ethnic groups reported willingness to participate ($P = 0.008$). However, participants did not differ on self-reported biopsy complications such as pain, anxiety, and hematuria. The 1 participant who required a blood transfusion after the biopsy reported willingness to allow an extra biopsy pass. No survey participant had required intervention to stop bleeding. In a multivariable logistic regression model controlling for various pre- and post-biopsy factors, we found that older and African American participants both had 85% lower odds of reporting willingness to allow an additional pass ([Figure 2](#)).

DISCUSSION

Human kidney tissue–based research holds the promise of discovery of therapeutic targets. In our survey of participants who had experienced a kidney biopsy, we noted that 73% of participants would allow an additional

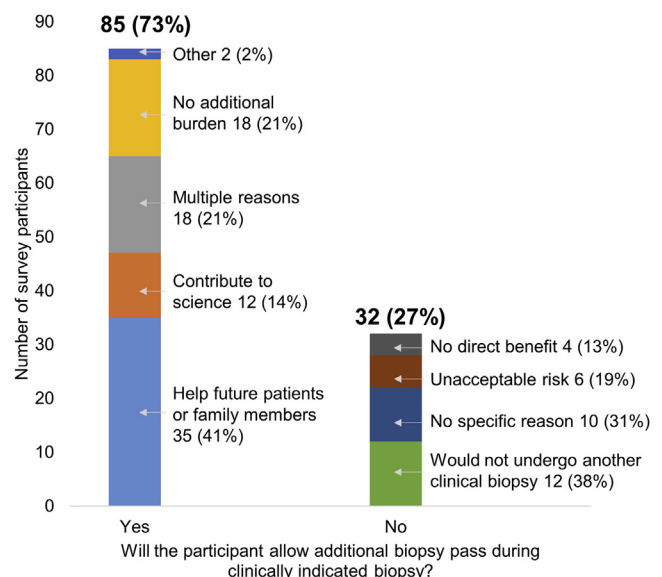


Figure 1. Participants' willingness to allow an additional biopsy pass during a clinically indicated biopsy.

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