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Supporting Patient-Centered Pregnancy Counseling in Nephrology Care: A Semistructured Interview Study of Patients and Nephrologists

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Introduction: Individuals with chronic kidney disease (CKD) are at increased risk of adverse pregnancy outcomes and are susceptible to disempowerment and decisional burden when receiving reproductive counseling and considering pregnancy. Nephrologists do not frequently counsel about reproductive health, and no tools exist to support patient-centered reproductive counseling for those with CKD.

Methods: A total of 30 patients aged 18 to 45 years with CKD stages 1 to 5 who were assigned female sex at birth and 12 nephrologists from a single academic medical center participated in semistructured qualitative interviews. They were asked about information needs, decision support needs, and facilitators and barriers to reproductive health care and counseling. Thematic analysis was performed.

Results: The following 4 main themes were identified: (i) assessing reproductive intentions; (ii) information about reproductive health and kidney disease; (iii) reproductive risk; and (iv) communication and decision-making needs. Patients' reproductive intentions varied over time and shaped the content of information needed from nephrologists. Patients and nephrologists both felt that risk communication could be improved but focused on different aspects to improve the quality of this counseling; nephrologists focused on providing individualized risk estimates and patients focused on balancing risks with benefits and management. Patients desired nephrologists to bring up the topic of reproductive health and counseling in kidney clinic, and this is not frequently or systematically done currently.

Conclusion: This work highlights a critical need for more dialog about reproductive health in kidney care, identified differences in what patients and nephrologists think is important in communication and decision-making, and provides an important step in developing patient-centered reproductive counseling tools in nephrology.

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People with CKD are in particular need of contraceptive and preconception planning due to the potential for pregnancy-related complications, including progression of kidney disease, preeclampsia, and fetal prematurity.¹ Patient-centered counseling is recommended to help individuals meet their family goals^{2,3}; however, in the past, pregnancy was often discouraged due to risks⁴ resulting in patient disempowerment and a sense of lost autonomy.⁵

Reproductive planning in CKD requires awareness of teratogenic and gonadotoxic medications often used to treat kidney disease, as well as potential contraindications for estrogen-containing contraceptives due to an increased risk of worsening proteinuria, cardiovascular disease, and thrombosis.⁶ As a result, family planning discussions and decisions for those with CKD are critically important⁷ and complex. Yet, there is a lack of support to help guide physicians and patients about

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pregnancy and, relatedly, contraception decision making, which often results in significant stress for patients.^{5,8}

Nephrologists often do not feel confident counseling on topics of pregnancy timing and fertility, due in part to lack of training.⁹ There are also no evidence-based tools to support the recommended patient-centered approach to reproductive decision-making for people with CKD. Furthermore, there is a gap in the qualitative literature about pregnancy experiences and reproductive health needs among diverse patients who are affected by CKD and those in earlier stages of kidney disease. Exploring reproductive health counseling wants and needs in a diverse sample of patients is a necessary step to improve care for all patients.¹⁰ A better understanding of these issues will inform counseling earlier in the course of CKD where opportunities to intervene early with education and decisionmaking support are greater.

To gain a deeper understanding of reproductive health counseling experiences and unmet needs for counseling and decision-making, we conducted a semistructured interview study of patients with CKD and nephrologists to develop a conceptual framework to move the field forward.

METHODS

This was a qualitative study using semistructured interviews of individual patients and nephrologists. To frame the interview questions, we were guided by the health belief model, which theorizes an individual's health-related actions depend on their perceptions of benefits and barriers related to their health behavior and includes constructs of perceived susceptibility, perceived severity, cues to action, and self-efficacy,¹ and the Ottawa Decision Support Framework, which focuses on support needed for difficult decisions influenced by personal values.¹² The Ottawa Decision Support Framework identifies decisional needs such as uncertainty, inadequate knowledge, and complex decision characteristics that should be targeted with decision support interventions to improve decisional outcomes. We adhered to the Consolidated Criteria for Reporting Qualitative Research¹³ (Supplementary Materials).

Setting and Participants

All participants were recruited from nephrology clinics associated with 1 academic medical center. All participants were informed about the study objectives through the informed consent process providing either written or verbal consent. The interviews typically took 30 to 60 minutes. This study was approved by the University of Michigan Institutional Review Board (HUM000163024).

Patients

Patients were eligible to participate if they were assigned female sex at birth, 18 to 45 years of age, with CKD stages 1 to 5, and a current patient in a nephrology clinic. Those who had a kidney transplant or were receiving dialysis were excluded. Patients were purposively recruited from a convenience sample to achieve a range of CKD stages, self-described race/ ethnicity, ages, and gravidity/parity, including a goal to achieve a balance of those with glomerular disease versus non-glomerular disease to get perspectives related to immunosuppression and the potential for remission and relapse. Potential patient participants were identified from nephrology clinic schedules, approached by telephone in advance of a scheduled visit and informed about the study; if interested, they proceeded to consent, scheduling, and participating in a single interview. Reasons for non-participation included lack of time or interest for research. Consent and interviews were conducted from November 2019 to October 2020 in-person at the nephrology clinic or through telephone (after March 2020). Recruitment and interviews were conducted by the primary investigator (ALO) and research staff with expertise in qualitative research (ML); both identify as women.

Clinicians

Board-certified or board-eligible nephrologists with a current clinical practice affiliated with the academic site were eligible to participate in the interviews. Recruitment materials were distributed through an email to all nephrology faculty within the division. The interviews were conducted by phone or in-person from July to October 2020. Neither of the interviewers (ML and KW) had working relationships with the interviewees.

Data Collection

Interview guides were iteratively developed by the study team with expertise in reproductive health in patients with chronic diseases (ALO, MAH, CZK) and patient education and decision aid development (CZK, STH, JWN). Semistructured interview guides included questions about reproductive health counseling experiences and perceived needs to support reproductive health counseling in CKD. Participants were asked what information is needed, how this information should be delivered, and which facilitators and barriers to counseling could be improved to help patients achieve their reproductive health goals. Participants were encouraged to discuss topics that they perceived as most important to them in the areas of pregnancy and

Table 1.	Demographics	of patient	participants
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Patient demographics	<i>N</i> = 30
Age (yr), average (SD)	32.4 (6.9)
Race/ethnicity	
Non-Hispanic White	15 (50%)
Non-Hispanic Black	8 (26.7%)
Hispanic	4 (13.3%)
Asian	2 (6.7%)
Declined	1 (3.3%)
Gravidity	
Gravid	15 (50%)
Nulligravid	15 (50%)
CKD stage	
1	8 (26.7%)
2	5 (16.7%)
3	10 (33.3%)
4	4 (13.3%)
5	3 (10%)
CKD etiology	
Diabetes mellitus	4 (13.3%)
Hypertension	3 (10%)
Lupus nephritis	7 (23.3%)
Other nephritic/nephrotic syndromes	9 (30%)
Other nonglomerular disease	4 (13.3%)
Unknown	3 (10%)

CKD, chronic kidney disease, yr, year.

fertility, contraception, symptoms of menstruation, and menopause (see the Supplementary Materials). All interviews were audio recorded and professionally transcribed verbatim. Field notes were informally used to note context and nonverbal expressions when appropriate.

Analysis

Transcripts were uploaded into Dedoose, a qualitative software package that allows transcripts to be reviewed, coded, and analyzed. Two authors (ALO and ML) read each transcript and developed unique preliminary coding schemas for each participant group, following 5 patient interviews and 3 provider interviews. Codes were iteratively revised for clarity. Data collection and analysis occurred concurrently using the principles of thematic analysis of Braun and Clarke.¹⁴ The codebook used both inductive and deductive codes. Deductive codes stemmed from interview questions that explicitly asked participants about educational resource needs. All transcripts were then coded by at least 2 authors (ALO, ML, and KW), and discrepancies in coding were resolved by consensus. Emerging themes were discussed until consensus was reached. For both participant groups, thematic saturation was reached with identification of no new codes or themes by the final participants. Thematic analysis was used to understand determinants and needs for patient-centered reproductive health decision making and counseling for patients and

Table 2. Demographics of nephrologist participants

Nephrologist demographics	<i>N</i> = 12
Gender	
Man	7 (58%)
Woman	5 (42%)
Time in practice	
1–5 yrs	3 (25%)
6–10 yrs	3 (25%)
11–15 yrs	1 (8%)
16–20 yrs	4 (33%)
21+ yrs	1 (8%)
Proportion of full-time equivalent clinical practice	
≤25%	6 (50%)
26%-50%	2 (17%)
51%-75%	3 (25%)
>75%	1 (8%)

nephrologists.¹⁴ Transcripts were not returned nor was member checking formally performed, though later phases of the research included discussion of themes with qualitative patient participants.

RESULTS

A total of 30 patients and 12 nephrologists were interviewed. Participant demographics are reported in Tables 1 and 2.

Participants described a wide range of experiences and perspectives as they related to pregnancy and contraception counseling with kidney disease. The following 4 interconnected themes that focused on how patient-centered reproductive counseling could be improved were identified in the analyses: (i) assessing reproductive intentions; (ii) information about reproductive health and kidney disease; (iii) reproductive risk; and (iv) communication and decision-making needs (Figure 1). Additional illustrative quotes are found in the Supplementary Material.

Assessing Reproductive Intentions

Reproductive intentions were characterized by considerations of a future pregnancy and influenced by the information available to patients, their risk tolerance, and related to a key communication need. Patients expressed a wide spectrum of reproductive intentions, and both nephrologists and patients agreed that intentions were not routinely assessed in clinical encounters. Patients' reproductive intentions evolved over time, influenced by changes in their health and relationships, social and financial situations, and input from others, including partners, family, and physicians.

Patients' fears also informed their reproductive intentions. These fears reflected uncertainty about their health and a potential fetus's health during a

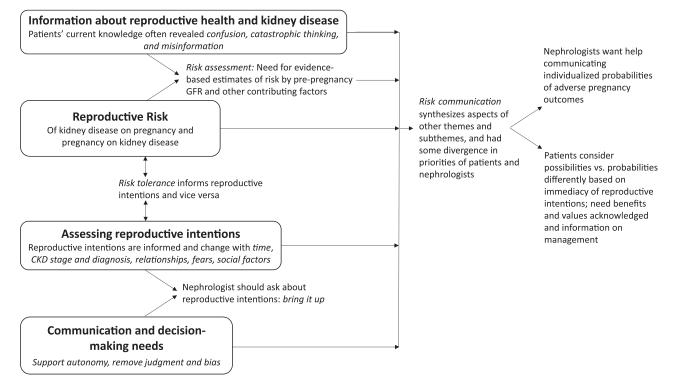


Figure 1. Thematic areas for improvement of patient-centered reproductive health counseling and decision-making in CKD. Themes are presented in bold and subthemes in italic. CKD, chronic kidney disease.

pregnancy, running out of time to have children, worsening kidney function, and their health and ability to parent current children. Information from physicians could both increase and allay fears; this often related to how information was communicated.

"She [current nephrologist] was just basically like, if that's something that I wanted to do, we could discuss it, but the conversation never went any further because at that point I was terrified. [...] he [prior nephrologist] kind of nipped everything in the bud with that conversation." (41 yo, CKD 5)

Information About Reproductive Health and Kidney Disease

Information about reproductive health and kidney disease was characterized by patients as being limited and confusing. Half of the patients described knowing little about the interactions between kidney disease and their reproductive health, including pregnancy.

"It would kind of be nice to know like what aspects of your kidney ... affect your ovaries or ... affects your placenta ... Like I don't even know ... Like do they even touch ... Does that even combine?" (29 yo, CKD 3)

Some patients understood that pregnancy could be "a strain" on their kidney function and often

overestimated risk or focused on the most severe adverse outcome.

"I did flat-out ask him [nephrologist] if it was like contra-indicated, and he said 'no.' So that was actually surprising to me. I had never asked before ... I just assumed that it probably wasn't a good idea [to get pregnant] given that I have the severe kidney issues." (33 yo, CKD 3)

Misinformation or misinterpretation of information could also lead to unintended pregnancy:

"When I got pregnant ... I had just got done doing a chemo-type drug for like 6 months, once a month for 6 months, and they didn't know if I would even be able to ever get pregnant after that ... that it may have destroyed my ovaries and stuff. That's how I ended up accidentally getting pregnant because after that ended, I just didn't ... I figured that I couldn't get, you know, pregnant and then [I] did." (42 yo, CKD 5)

Both patients and nephrologists discussed what types of information were needed to improve patientcentered counseling and decision making. Both groups felt confident about their knowledge of teratogenic medications to avoid, but discussion of how kidney disease is managed during pregnancy was needed. Finally, patients desired resources such as peer and emotional support. "If I'm supposed to take CellCept every single day for the rest of my life, when I do decide to have a baby, what am I supposed to do?" ... "When do I stop taking the medicine?" "What's gonna happen when I stop taking the medicine?" (22 yo, CKD 1)

Reproductive Risk

Risk was characterized by several perspectives and dimensions: risk assessment, risk tolerance, and risk communication were the key subthemes. The risks of kidney disease on pregnancy outcomes and potential offspring and the risks of pregnancy on kidney disease were the main focus of discussion among patients and providers. Risks of contraception, including medications used to manage menstrual symptoms, were also discussed to a lesser extent.

Risk Assessment

Here, nephrologists emphasized a desire to be able to assess the probability of adverse outcomes and the need for clinical tools to help with this assessment.

"I don't have the data I need to really quantify risk." (Nephrologist, 6–10 years practicing)

"I don't give numbers. You know, I don't know off the top of my head if it's like 20% or 30% or 60% or something like that ... if there were any quantitative tools or even to separate into low/ medium/high. I sort of use those terms now, but it's purely based on my judgment as opposed to any specific test or score." (Nephrologist, 11–15 years practicing)

Some patients expressed interest in individualized enumeration of risk, though overall, they also needed a more general understanding of pregnancy and kidney disease, including risk-mitigation strategies. As patients considered a pregnancy soon, they expressed a greater interest in more specific risk estimates.

"How would my kidneys be affected with the pregnancy? So that was one of the big things. Like I wanted to know, 'would I die, would my kidneys fail?' Those were the major questions. 'Would I have to have dialysis?' 'Would the baby survive?' 'Will I be able to even carry a pregnancy?'" (40 yo, CKD 4)

"I just want a lot more information to know how it could impact the pregnancy and also like if the pregnancy would cause a quicker decline in kidney function. If that was a possibility, I would really want to know ... knowing kind of likelihood of different scenarios would help me then further decide whether or not we really want to try for a pregnancy in the near future or not." (33 yo, CKD 3)

Risk Tolerance

Patients expressed varying degrees of risk tolerance that influenced their intentions and often were higher than those of the nephrologists. Patients' risk tolerance was influenced by multiple factors, including their age, time since CKD diagnosis, kidney disease etiology, and whether they already had children. Nulliparous patients who wanted children expressed greater tolerance of pregnancy risks than those who had children or were ambivalent about having children.

"I always wanted to have kids. [...] So, when I did get pregnant. ... I was just like, "I'm gonna have them." I'd have to. It didn't really matter what the risk was." (40 yo, CKD 4)

Nephrologists typically expressed lower risk tolerance but recognized a need to meet patients at their individual goals and levels of risk tolerance.

"I feel like if I had advanced kidney disease, I would not want to accept the risk ... that may occur with pregnancy, like needing to start dialysis sooner or preeclampsia. To me that sounds very, very scary, and I think there are other routes [to] have a child, but others may not feel that way." (Nephrologist, ≤ 5 years practicing)

Risk Communication

Patients wanted communication about risk to be balanced with acknowledgment of their goals and potential positive outcomes. Patients who described negative experiences detailed conversations where their nephrologist dismissed their goals or passed judgment on their childbearing decisions.

"If [...] they would be more educating and telling me like what are the possibilities and things like that instead of just shutting it straight down like it's not an option. The way they put it, I feel like I'm putting me and the baby at risk. So, I would be better if ... It would be a lot better if they would give me some information like 'What are the pros,' 'What are the cons,' 'What are the statistics saying,' 'How many successful births have y'all had,' 'How many mothers made it through?' Things like that would basically ease me a lot." (41 yo, CKD 5)

However, nephrologists struggled with risk communication. They found it difficult to relay the relevant information to help patients understand risk, particularly "without sounding negative or unsupportive." "Even in those scenarios in which I have specific numbers for the risk, conveying the concept of risk was extremely difficult" (Nephrologist, >21 years practicing)

Communication and Decision-Making Needs

Communication needs were characterized by desired strategies nephrologists should use to approach patientcentered pregnancy counseling, as described by both patients and nephrologists, including facilitators of and barriers to counseling. Most patients preferred that their nephrologist bring up the topic of reproductive health, to reduce awkwardness and to endorse it as a priority. However, nephrologists often deferred initiating the conversation to their patients, with both groups waiting for the other to bring it up:

"I don't typically bring it up proactively. It often is in response to a comment that a patient will make or a question that they have, or letting them sort of take the lead on it." (Nephrologist, 16–20 years practicing)

Several barriers were described by patients and nephrologists as potential factors resulting in missed counseling opportunities. Health-system barriers included duration of time available in clinical encounters, competing interests or priorities, and infrequency of appointments. Nephrologists also thought that the lack of evidence-based data for counseling patients, outside of teratogenic medications and possible risk of adverse outcomes, was a barrier. As reproductive intentions and risks may change over time, initiating these discussions is susceptible to conscious and unconscious physician biases toward a particular chronology of life events, relationship status, or age for childbearing. Encountering these biases prevented patients from accessing desired information.

"When I got diagnosed, the first question I literally asked the doctor [...] was like, 'Can I have kids?' [...] He [doctor] goes, 'Well, let's just worry about if you get married or something,' and I'll never forget that comment because I was like, 'Wait, what? Like that has nothing to do with my marriage. Like I just want to know if I can have kids."" (30 yo, CKD 2)

Both patients and nephrologists advocated for patient autonomy in decision-making, although achieving this is difficult. A few participants wanted explicit advice from their nephrologists, however most preferred to consider information and ultimately exercise their own autonomy in making decisions about future pregnancies and contraception. "I guess we weren't sure if we necessarily wanted more kids. We were kind of on the fence, especially because we weren't obviously expecting two the first time. [...] But I think ... just having someone else tell me my choice versus me making my own choice would be my biggest ... the only thing that I didn't like about it." (30 yo, CKD 2)

"I'm not going to try to change what they want to do with regard to pregnancy, but I want to make sure that they have ... that they're making the most informed choice that they possibly can and they know what the risks are and what the options are so that I can help enable whatever choices they want to make." (Nephrologist, ≤ 5 years practicing)

"I would change how they came across with contraception. [...] I do feel like that if you decide to take contraception, it should be something that you want to do and not something that somebody is shoving down your throat from the time that you can actually be sexually active or when most people start to be sexually active. [...] I think it should be taught, but I don't think it should be forced." (22 yo, CKD 1)

DISCUSSION

This study explored and identified areas for improvement to patient-centered reproductive counseling and decision-making in nephrology. Major aspects in need of improvement include normalizing and initiating reproductive health care discussions as a relevant part of care in the nephrology clinic, providing general information about pregnancy, contraception, and kidney disease with the ability to offer a more tailored discussion of risks, and communicating this information in an unbiased, nonjudgmental way to ultimately support autonomous, informed decision-making.

One key finding of this study is that most patients with CKD desire and expect their nephrologist to initiate conversations around reproductive planning and to assess this regularly as intentions change over time. However, both nephrologists and patients say that this is not done frequently, with each waiting for the other to bring it up, and often initiated by the patient. Both patients and nephrologists described how unconscious biases about age, relationship status, or sexuality may influence if or when nephrologists initiate this conversation. If counseling is introduced routinely as standard of care, this would allow patients to communicate their reproductive desires and goals and meaningfully shape the content of the information that should be shared. Incorporating tools such as "One Key Question," which asks "Would you like to become pregnant in the next year?" into clinic intake processes could support nephrologists to start this discussion.¹⁵

Nephrologists and patients agreed that more information-sharing is needed, and in our study, most patients acknowledged that they had little to no knowledge regarding the reciprocal impacts of CKD and pregnancy. Those who described knowledge of potential complications, such as preeclampsia or preterm birth, typically had already experienced the complication. This highlights a need for early information sharing, both in the natural history of CKD and the reproductive life span, so that the safest opportunities for childbearing are not missed. In this study, even patients with mild CKD experienced a loss of autonomy in pregnancy decision-making or had significant fears related to pregnancy, similar to those with advanced CKD described in prior qualitative work.⁵ However, recent data have revealed that among those with CKD stages 1 and 2 with no or low proteinuria, there is a relatively low risk of severe maternal morbidity, preterm birth, or low birthweight.¹⁶ Prior studies evaluating multidisciplinary preconception counseling clinics for patients with CKD reported that most patients found these useful.¹⁷ However, these clinics are not widely available, and additional realtime resources are needed to provide the right information to patients at all stages of CKD.

Risk, including subthemes of the information needed to assess risk, risk tolerance, and risk communication, related closely to the other major themes; however, this was an area with important divergence in prioritization between patients and nephrologists. Patients tended to endorse higher risk tolerance than nephrologists and focused on general education, pregnancy management, and risk mitigation, more so than specific risk probabilities. Nephrologists strongly desired the ability to better quantify risks for patients and desired strategies to better communicate risk. Patients with more immediate pregnancy goals seemed more interested in talking about probabilities, and a discussion including probabilities rather than possibilities may be most appropriate with these patients.¹⁸ This study builds on prior descriptions of "medical catastrophizing" pregnancy in CKD⁵ similarly finding that risk-centric counseling approaches, without acknowledging the potential benefits, successes, and management strategies, result in fear and alienation of patients even at early stages of CKD. A recent estimate of kidney disease progression associated with pregnancy, relative to prepregnancy kidney function decline, is 1.7, 2.1, and 4.9 years for patients with CKD stages 3a, 3b, and 4 to 5, respectively.¹ Tools that translate and communicate quantitative risk data into

meaningful information for patients are needed. As risk prediction tools for adverse pregnancy outcomes in CKD are developed and validated, our study suggests that this information must also be presented with an acknowledgment of patients' desires and intentions and strategies for mitigating risk and managing pregnancy in CKD. Ensuring that the appropriate information is delivered without bias or coercion is necessary to reach the goal of support informed, autonomous decision-making.

Our study is limited in that patients and nephrologists received or administered care at a single US academic medical center and did not include other decision influencers such as partners or obstetriciangynecologists. Patients were not involved in the construction of the interview guide, though after the initial 5 participants we did probe if additional questions were important and revised as needed. There is a possibility of selection bias as those who elected to participate may think the topic of higher importance than patients or nephrologists in general or may have had particularly salient positive or negative experiences in the past. In addition, although we defined reproductive health counseling broadly and inclusive of menopause and other topics when introducing study goals to participants, these did not reach thematic saturation. This is likely due to the demographics of our patient population and may be the topic of future research. Among topics reaching saturation, we purposefully enriched our sample to improve patient representation across race, ethnicity, and other demographics, given the disparities in reproductive outcomes based on these factors.¹⁹ Purposive sampling also strengthened this study by including patients with a broad range of pre-end-stage kidney disease kidney function. Another limitation of a single-site design is that the expectations of preconception counseling may also differ across sites where resources differ; nephrologists in this study have access to maternal fetal medicine for preconception counseling and pregnancy care but remain the primary nephrology providers through pregnancy and postpartum. In the United States, obstetric medicine is not a developed training program for internists or nephrologists. Nephrologists may seek out additional knowledge or training through continuing medical education or consultation with local experts, and these resources may differ between places in the United States. The setting and resources likely influence the experiences and opinions that were shared by both nephrologists and patients.

Our findings highlight a critical need for interventions and tools to help nephrologists deliver patient-centered preconception and contraception counseling. This counseling should systematically and

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repeatedly assess patients' reproductive intentions over time. Risk communication about pregnancy should be tailored to the immediacy of reproductive intentions, focusing anticipatory guidance on general possibilities and knowledge for those who have distant pregnancy intentions and discussing probabilities with those who have more immediate intentions. Discussion of risks should follow an acknowledgment of the importance and value of an individual's reproductive goals and should be accompanied by management strategies and any options for mitigating risk. Further work must be done, so all patients with CKD have access to the information and health care necessary to support individual reproductive health decisions and goals.

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DATA AVAILABILITY STATEMENT

The data underlying this article cannot be shared publicly to protect the privacy of individuals who participated in the study.

SUPPLEMENTARY MATERIAL

Supplementary File (PDF)

Consolidated Criteria for Reporting Qualitative Research Checklist.

Semistructured Interview Guides.

Additional Participant Quotes in Support of Themes and Subthemes.

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