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Original Investigation

Perspectives on Pregnancy in Women With CKD: A Semistructured Interview Study

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Background: Women with chronic kidney disease (CKD) often have difficulty achieving pregnancy and are at increased risk for adverse pregnancy outcomes. Given the medical, ethical, and emotional complexities of pregnancy in CKD, the clinical approach should involve explicit consideration of women's values, for which there are sparse data. This study aims to describe the beliefs, values, and experiences of pregnancy in women with CKD to inform prepregnancy counseling and pregnancy care.

Study Design: Qualitative study.

Setting & Participants: 41 women (95% response rate) aged 22 to 56 years with CKD stages 3 to 5 (n = 5), receiving dialysis (n = 5), or received a kidney transplant (n = 31) from 2 renal units in Australia.

Methodology: Semistructured interviews.

Analytical Approach: Transcripts were analyzed thematically.

Results: 6 themes were identified: bodily failure (conscious of fragility, noxious self, critical timing, and suspended in limbo), devastating loss (denied motherhood, disempowered by medical catastrophizing, resolving grief, barriers to parenthood alternatives, and social jealousy), intransigent guilt (disappointing partners, fear of genetic transmission, respecting donor sacrifice, and medical judgment), rationalizing consequential risks (choosing survival, avoiding fetal harm, responding to family protectiveness, compromising health, decisional ownership, and unjustifiable gamble), strengthening resolve (hope and opportunity, medical assurance, resolute determination, and reticent hope), and reorientating focus (valuing life and gratitude in hindsight).

Limitations: Only English-speaking women were recruited, which may limit transferability of the findings.

Conclusions: Decisions surrounding pregnancy in the context of CKD require women to confront uncertainties about their own survival, disease progression, guilt toward their family and kidney donor, the outcomes of their offspring, and genetic transmission. Communicating the medical risks of pregnancy to women with CKD must be carefully balanced with their values of autonomy, hope, security, and family. Informed and shared decision making that addresses women's priorities as identified in this study may help contribute to improved pregnancy, health, and psychosocial outcomes in this vulnerable population.

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Chronic kidney disease (CKD) can affect women during their childbearing years. As kidney function declines, fertility is reduced due to complex physiologic changes.[1-3] If pregnancy occurs, there may be significant maternal and fetal morbidity or mortality and adverse outcomes.[3-7] In women receiving dialysis or with a kidney transplant, live birth rates are improving, leading to more permissive attitudes toward pregnancy,[8-11] but these pregnancies remain high risk, with increased fetal loss and prematurity.[2,7,12-14] Pregnancy may promote a decline in precarious native or transplant kidney function and precipitate the need for dialysis therapy.

Given the medical, ethical, and emotional complexities of pregnancy decision making in CKD, prepregnancy counseling is increasingly emphasized as a critical aspect of pregnancy care to optimize outcomes for women.[15,16] Counseling without explicit consideration of women's values can be distressing and impede shared decision making. Despite this, our

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recent systematic review of women's perspectives of pregnancy in CKD identified only a few primary studies and a limited number of themes relating to achieving motherhood, decisional insecurities and conflicts, fears for maternal and fetal health, and control and autonomy.[16]

The aim of this study is to describe women's beliefs and experiences of pregnancy in CKD, which can be addressed in prepregnancy counseling and management of pregnancy in these high-risk patients to improve health, pregnancy, and psychosocial outcomes.

METHODS

Study reporting is based on the Consolidated Criteria for Reporting Qualitative Health Research (COREQ).[17]

Participant Selection and Setting

Participants were eligible if they were women, English speaking, aged 18 to 60 years (and had CKD during their childbearing years), non−dialysis dependent (CKD stages 3b-5) or on hemodialysis or peritoneal dialysis therapy (stage 5D), or have received a kidney transplant (stage 5T). The recruiting clinicians applied a purposive sampling strategy to obtain maximum variation of demographic and clinical characteristics and pregnancy experience. Participants were recruited from the Royal Adelaide Hospital and St. George Hospital in Sydney, Australia. Ethics approval was obtained from both sites. Participants could be interviewed at home or in the hospital. Those residing outside the metropolitan area could participate in a telephone interview.

Data Collection

The interview guide was developed based on a systematic review of women's experiences of pregnancy in CKD and discussion among the research team (Table S1, available as online supplementary material).[16] A.T. conducted semistructured interviews from August to October 2014, and recruitment ceased when no new concepts were raised after 3 consecutive interviews (theoretical saturation). All interviews were digitally recorded and transcribed.

Data Analysis

The transcripts were imported into HyperRESEARCH (version 2.8.3; ResearchWare Inc) software to facilitate qualitative data analysis. Using thematic analysis, investigator A.T. read the transcripts line by line and conceptualized and coded all meaningful segments of text into the concepts inductively identified from the data. Similar concepts were grouped into themes and subthemes. Conceptual patterns among the themes were identified and mapped in a schema. To ensure that the analytical framework captured the breadth and depth of the data, the preliminary findings were discussed among the research team (researcher triangulation) and sent to all participants, who were given 2 weeks to provide any additional perspectives (member checking). Feedback was integrated into the analytical framework.

RESULTS

Study Participants

Forty-one women participated (93% response rate). Nonparticipation was due to refusal or an inability to schedule an interview after 3 attempts. Participants were aged 22 to 56 (mean, 35.6) years, had CKD stages 3b to 5, and were non−dialysis dependent (n = 5 [12%]), receiving hemodialysis (n = 2 [5%]) or peritoneal dialysis (n = 3 [7%]), or had received a kidney transplant (n = 31 [76%]). Twenty-four (59%) had a previous or current pregnancy, of whom 21 had had at least one pregnancy complication. Demographic and clinical characteristics are shown in Tables 1 and 2. The average duration of the interview was 45 minutes; 37 interviews (90%) were conducted face to face.

Themes

We identified 6 major themes: bodily failure, devastating loss, intransigent guilt, rationalizing consequential risks, strengthening resolve, and reorientating focus. The themes and respective subthemes are described in the following sections, with illustrative quotations provided in Table 3. A thematic schema illustrating the patterns and relationships among themes is provided in Fig 1.

Bodily Failure

Conscious of physical and medical fragility. Pregnancy would "put extra strain on the kidney" and potentially jeopardize their health and lives and that of the baby. Women nervously anticipated complications and early hospitalization. Symptoms such as bleeding or abdominal tightness were alarming because this could indicate imminent miscarriage or a life-threatening complication. Some women realized that their anxieties caused them to miss the "joy" of pregnancy. Being closely monitored in the hospital provided reassurance; however, some felt "isolated and helpless." Significant financial strain was incurred for women residing in regional areas.

Noxious self. Young women disclosed a deep and silent "heartbreak" from being irreversibly "damaged" by CKD. They were trapped in a "body that has completely failed you" and unable to "carry on that legacy." Feeling like a "freak" intensified insecurities in pursuing relationships. Some women on dialysis therapy described their bodies as "toxic" and thus could not provide their baby with adequate nutrition. Transplant recipients were concerned about the risks of immunosuppressive medications to fetal growth and well-being, and because stable health could never be guaranteed, "you still look at your body like it's a ticking time bomb."

Critical timing. Because of CKD and medication side effects, women believed their bodies "degenerated" beyond their chronologic ages. This foisted a time pressure to make decisions about pregnancy: "it put a rush on something that should be natural." One woman chose to have children despite feeling