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Best Practice & Research Clinical Obstetrics and Gynaecology

journal homepage: www.elsevier.com/locate/bpobgyn



6

The patient experience of kidney disease and pregnancy



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A B S T R A C T

Keywords:

Pregnancy
Kidney disease
Shared decision-making
Patient experience
Maternal health
High risk

Achieving parenthood is often a priority and goal for women with chronic kidney disease (CKD). It can be challenging due to medical and emotional complexities around pregnancy planning and care, increased risk of adverse maternal and fetal outcomes, fears about medications such as immunosuppressants and fetal harm, and concerns regarding the impact of pregnancy on women's kidney health. Navigating the pathways for shared decision-making regarding parenthood requires an understanding of the patient's experiences, values, priorities, and needs. In this review, we describe the patient perspective of high-risk pregnancies including those complicated by CKD and outline recommendations for counseling that incorporate these perspectives to improve the patient experience.

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Introduction

Achieving parenthood is a priority for many women with chronic kidney disease (CKD) of any stage, including women with kidney transplants [1,2], but significant challenges are faced due to uncertainties about risks to their own and their baby's health. Pregnancies in women with kidney

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disorders have amplified risk of adverse maternal and fetal outcomes, largely driven by factors such as preconception CKD stage and severity, primary disease, and comorbidities [3–6]. These risks are discussed in other reviews but underpin the need for meticulous, empathetic, and well-timed pre-pregnancy counseling. Counseling should incorporate shared decision-making, which involves understanding patient values and perspectives, balancing the emotional vulnerabilities, while sensitively acknowledging the medical risks.

Data on the perspectives of women with kidney disease on pregnancy are sparse [2]. This aspect of care is only briefly addressed in guidelines and position statements for care of women with CKD or kidney transplants and not underpinned by evidence of patient perspectives and values [7–9]. This review outlines the perspectives of women with kidney disease, and other medically high-risk pregnancy situations, and makes recommendations for incorporating the patient's needs and priorities into clinical care and counseling.

Changing attitudes toward pregnancy in women with kidney disease

An often-cited 1975 *Lancet* editorial stated, “Children of women with renal disease used to be born dangerously or not at all—not at all, if their doctors had their way. The hazards to child and mother were real enough, if perhaps exaggerated. Many women disobeyed their doctor's orders with a happy result. The woman should be told that there is a considerable risk to her infant and a small risk to herself, but dogmatic prohibitions do not seem justified today. Instead, obstetrician and physician must batten down the hatches and prepare to ride out the storm together with those determined to set sail” [10]. In addition, the ethical dilemma between a woman's right to pursue reproduction versus the voluntary risks placed on the mother and the baby has also been highlighted in expert ethical discussions, particularly in the context of transplantation where a precious resource is placed at risk [11].

Achieving motherhood has been identified as an indication of a well-treated patient with kidney disease, and only women themselves can define what a well-lived life with CKD comprises [12]. In the current era, there is increasing “permissiveness” from clinicians regarding women with kidney disease, who in the past would have been discouraged from pursuing pregnancy. For example, there is growing confidence and support for pregnancies occurring in women receiving dialysis, largely due to intensive dialysis regimens as well as treatment advances such as erythropoietin and better perinatal care [13–16]. Similarly, pregnancy after kidney transplantation is increasingly common, with termination rates falling and live birth rates increasing with time [6,17,18]. Clinical practice recommendations no longer advise women against pregnancy, favoring a cautious optimism and proactive counseling approach with individualized risk stratification [4,11,19–22].

However, data on real-world clinical practices and approaches to women with kidney disease are limited, and proactive counseling about pregnancy, although desirable, may not routinely occur. A 2017 study from the Netherlands reported that few kidney units had guidelines on fertility and pregnancy care, and although the majority of nephrologists did address fertility in the majority of patients, nearly 90% reported advising women with CKD against pregnancy [23].

The patient experience in pregnancies complicated by kidney disease

In recent decades, there have been widespread policies and initiatives to emphasize patients as partners rather than passive recipients of healthcare. Understanding and involving the patient (consumer) voice is increasingly recognized as necessary for better health care delivery, individual clinical care, patient-centered research, and policy development. Recognizing the patient experience and reflecting their values, individual circumstances, influences, and preferences will facilitate translation of evidence-based medicine into clinical practice [24]. The perspectives of women with kidney disease and other medically complex pregnancies are informative and underpin many aspects of pregnancy planning and care, as summarized in Fig. 1.

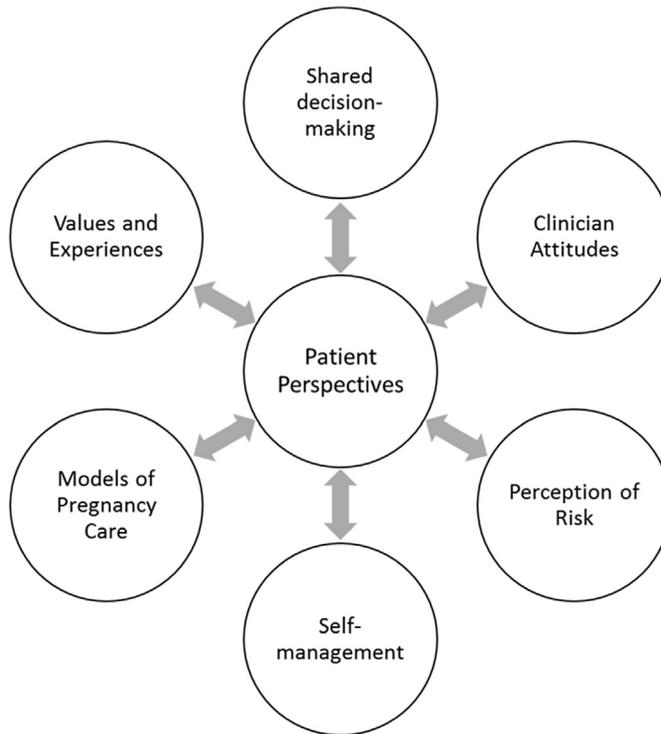


Fig. 1. Influence of Patient Perspectives on Aspects of Pregnancy Planning and Care. This figure summarizes the various aspects of prepregnancy planning and pregnancy care for women with kidney disease that are underpinned by patient's values, experiences, and perspectives, as outlined in Table 1. Clinicians should seek to identify the patient's perspectives and incorporate them into approaches to clinical care.

Patient experiences of living with kidney disease

There is a substantial body of evidence synthesizing the experience of living with CKD. Patients with CKD reported reduced quality of life at all disease stages, with progressive accumulation of physical symptoms (particularly fatigue) and impact on societal functioning and psychological state [25]. Patients describe experiences of fragmented care, poor information, and suboptimal support and emphasize that responding to these concerns is a high priority for improving care [26]. In particular, adolescents and young adults report uncertainties about their future including concerns about developing relationships and having a family [27,28]. CKD places an immense burden on younger patients. The unpredictable nature of their illness course can limit their ability to plan and complete usual life priorities and milestones. Loss of autonomy and lack of empowerment and control over their health and future is a consistent theme in qualitative studies of people with CKD [25–28]. Transplantation offers improved quality of life and survival. However, because of accumulated comorbidity from CKD, lifelong need for immunosuppression, and adverse consequences of this, the burden of illness is not completely abrogated. Transplant recipients may trivialize and accept side effects of immunosuppression as a necessary part of transplantation to be endured and are willing to make trade-offs to prioritize transplant survival [29,30].

The patient experience of pregnancy and parenthood planning in women with kidney disease

Studies assessing patient perspectives on parenthood and pregnancies complicated by kidney disease provide valuable insights and an evidence base for the patient values that should underpin shared decision-making.

A systematic review and synthesis of 15 qualitative studies (involving more than 250 women with kidney disease) [2] highlighted the paucity of robust data on the experiences and perspectives of women with CKD on motherhood. A subsequent primary qualitative study involving more than 40 women with stage 3b–5D/T CKD from two Australian renal units reported on the patient experience of navigating pregnancy planning and pregnancy with CKD [1]. Another study from the Netherlands elicited perspectives in a broad group of patients with CKD stages 2–4 and identified patient views on relationships, sexuality, and parenthood [25].

The key themes from these three publications are summarized in [Table 1](#) and highlight the complex emotional, social, and ethical challenges faced by women. The patient interview quotations accompanying these studies provide valuable insights into women's own words and are recommended reading [1,2,25]. Some women had a strong aspiration for achieving motherhood, accompanied by feelings of loss, guilt, and failure, and concerns of blame and devalued social worth, when cultural

Table 1

Summary of patient perspectives on pregnancy or parenthood with kidney disease [1,2,25].

| Themes | Subthemes and perspectives |
|---|--|
| Desire | Motherhood as an aspiration or goal |
| Failure and grief | Motherhood as an indicator of normalcy |
| | Grief at not achieving or being denied motherhood |
| | Failure to fulfill social expectations and norms |
| | Feelings of failing to meet partner's desire for parenthood |
| Guilt | Sense of medical and physical fragility and bodily damage |
| | Feelings of the body failing women due to disease |
| | Guilt at failure to achieve expectations of family/partners |
| | "Selfishness" of high-risk pregnancy |
| | Guilt at being a burden to children, partners, and family |
| Fear | Concerns for impact on relationships and parenting activities |
| | Guilt about potentially passing on inherited disease |
| | Obligation to respect the sacrifices of kidney donors |
| | Fear of birth defects and fetal harm especially from medications |
| | Protectiveness from families and partners |
| | Fear about risks to personal health |
| | Concerns for exacerbating disease and gambling with health |
| Autonomy and control | Disempowerment by medical judgment and catastrophizing |
| | Concerns about "scare tactics" |
| | Concerns about living long enough to raise a child |
| | Importance of personal right to pursue pregnancy |
| Decision burden | Sense of loss of control over decision-making |
| | Desire to retain control |
| | Distress at clinician coercion or overriding autonomy |
| | Feelings of isolation and helplessness |
| | Feeling of having to defend choices (to have children or not) |
| | Insecurities about making decisions |
| | Balancing desire for pregnancy against risks to health |
| | Trade-offs and sacrifices when making decisions |
| Inability to make decisions, reliance on clinicians | |
| Rationalizing | Time-pressures to make decisions |
| | Difficulties in identifying the right time to have a baby |
| | Feeling suspended in limbo with regard to timing of pregnancy |
| | Concern at missing opportunities, becoming too old |
| | Resignation at inability to achieve motherhood |
| | Acceptance that this is just a part of CKD |
| Resolve and focus | Withholding emotional investment in the pregnancy |
| | Jealousy of other women |
| | Choosing survival over motherhood – valuing life |
| | Gratitude for positive outcomes other than pregnancy |
| Resolve and focus | Resolute determination to achieve pregnancy |
| | Value of medical assurance and hope |
| | Reassurance from medical support and care |

expectations around parenthood were not met. They faced substantial fears related to risking their own health and potential fetal harms. In particular, women feared fetal exposure to medications including immunosuppression and fetal loss and preterm birth. Balancing these fears against the desire to pursue motherhood led to tensions and conflict in decision-making. Women expressed a loss of control, determination, and ownership of decision-making but often felt an overriding desire to retain their personal choices. They employed strategies to rationalize and accept both the risks of pregnancy and the consequences of not achieving motherhood.

Women expressed that health professional behaviors such as catastrophizing about potential adverse outcomes, discouragement of pregnancy, and judgment of women's choices caused distress and exacerbated loss of control and autonomy. A positive approach by clinicians supported by information and providing a sense of hope was valued by the women.

Being a mother with kidney disease – impact on life and survival

Kidney disease in any patient has well-known impacts on family functioning, finances, and relationships [28]. Little is known about the experiences of women after they have children and how they manage parenthood in the long term. Parents who receive chronic dialysis have described additional burdens related to having children, competition between their needs and those of their children, and diminished quality of their relationships with children, family, and other social connections [31,32]. In particular, fatigue and absence due to the time required for dialysis and medical care can lead to an inability to fulfill usual parental roles and tasks and partake in children's activities, with feelings of guilt and being a burden. Mothers may have concerns about accelerating native or transplant kidney function decline through pregnancy and may face the possibility of managing a preterm baby as well as their own health concerns, although there are no data on this specific patient experience. Mothers with CKD face considerations about their own long-term survival, which is reduced in end-stage kidney disease and even after transplantation compared to that in the general population. Up to 40% of women who have live births after kidney transplant will resume dialysis by the age of 10 years of their child, and 10–20% will not live to see their children reach adulthood [47–49].

Experiences of women with nonrenal medical conditions in pregnancy

The perspectives of experiences of pregnancy in women with kidney disease are similar to those in women with other chronic medical conditions.

Women with diabetes in pregnancy have also reported feelings of responsibility, worry, and self-blame. As in women with kidney disease, loss of control is a key concern, and provision of positive reassurance about potential for desirable pregnancy outcomes is highly valued [33]. Pregnancy in high-risk women including those with diabetes may create a sense of priority toward the baby with heightened attention on fetal care and well-being, which may inadvertently override sensitivity to the concerns and emotional needs in mothers. Women with type 1 diabetes feel pressure to achieve glycemic control to protect fetal well-being [33,34]. Concerns expressed by clinicians about risks and adverse events consequently may create guilty feelings and worries in women. A systematic review of studies evaluating patient perceptions in women with gestational diabetes revealed women fear for their own future health and that of the baby upon learning of their diagnosis, a sense of loss of normal pregnancy and personal control, a shift in focus from the needs of the mother to prioritizing the baby at all costs, and frustration at the provision of poor information [35].

The patient experience of care for asthma in pregnancy suggests similar concerns [36]. Fears in pregnancy are focused on the balance of risks versus benefits, especially for asthma medication use. Women with asthma describe uncertainties about self-management despite expectations that this would be undertaken during pregnancy, and a need for more information from trusted professionals [36].

Women with obesity in pregnancy also face an increased risk of pregnancy complications. Perceived medical catastrophizing and judgmental attitude from clinicians leads to significant distress, and women may feel admonished for being obese (particularly during fetal scans), and blame themselves

for worse pregnancy outcomes and risk to the baby [37–40]. In particular, women have described having a lack of knowledge and often receive conflicting information. Clear communication of information, delivered in a sensitive manner by health professionals with experience in discussing obesity is a key factor to aid care [39].

Significant obstetric and medical complications (of any cause) in pregnancy may require prolonged hospitalization and bed rest. Women who have undergone lengthy pregnancy-related hospitalization report that separation from family leads to an increased need for social supports to combat isolation and loneliness, with feelings of sadness, helplessness, and hopelessness, as well as a loss of personal control [41,42]. Women may feel trapped by their medical condition and feel they are a burden on their families. Mothers who have had near-miss maternal mortality illness requiring critical care services (due to any cause) describe shock at their illness and challenges with regard to the unexpected birth experience and ability to be a mother to a newborn (including establishing breastfeeding) whilst in intensive care [43].

Knowledge regarding preconception health and pregnancy risks may be limited in women with chronic conditions, and the need for better information is a common view reported by patients. A focus group study found that women with diabetes, hypertension, or obesity were generally unaware of the specific risks related to their medical condition and had variable understanding of appropriate preconception care, including contraceptive options [38]. This had an influence on their ability to participate in informed decision-making about pregnancy intentions and planning.

Patient-centered, shared decision-making in pregnancy care

Prepregnancy and antenatal care is often delivered from a clinical perspective reflecting the medical complexities of pregnancy with kidney disease and should also respect a woman's autonomy, values, and feelings [1,12]. Shared decision-making is fundamental tenet of patient-centered care, as it contributes to improved patient outcomes and experience through better understanding of patient values and preferences [44]. Shared decision-making in maternity care can occur in three stages: identifying choices, investigating options, and then making the final decision [45]. Clinicians have identified this as a dynamic process built up over multiple visits and based on respectful communication and accurate evidence-based information. Deliberate and explicit consideration of patient perspectives and opinions, in conjunction with provision of best available evidence to underpin health care choices, can aid shared decision-making and holistic, personalized care. Vedam et al. [46] have developed the Mothers Autonomy in Decision Making (MADM) Scale, which assesses the process and experience of decision-making in maternity settings and determines the ability of women to participate. Although it remains to be validated in broader populations, this type of instrument may prove valuable in assisting shared decision-making in high-risk pregnancies where patients report loss of autonomy and control, as described earlier. Shared decision-making for women with kidney disease is presently hampered by the absence of specific tools to predict pregnancy or renal outcomes; improvement of the evidence base and development of such tools remain a priority for researchers.

Prepregnancy counseling and the patient perspective

Prepregnancy counseling should be incorporated into standard care for women with kidney disease but may not always be possible, especially for women in whom kidney disease is identified for the first time in pregnancy. There remains a paucity of evidence regarding the best approaches to counseling for women with CKD and impact on patient experience and clinical outcomes. Nevertheless, prepregnancy counseling is encouraged, where feasible, to provide an opportunity to plan an individualized care pathway. The depth and complexity of the counseling approach will vary depending on CKD stage and anticipated rate of progression and comorbidity and patient preferences.

Timing of discussions about parenthood

We recommend that parenthood is discussed as early as possible in the care of younger women with CKD [3,4,21]. The risks of CKD in pregnancy may not be fully recognized by women and should be

communicated as soon as possible in women of childbearing age to assist with their life-planning and identifying the best “window” for pregnancy. A cautious and sensitive approach is preferred, with risks conveyed in the context of their personal goals, given that communicating risks can invoke fear as discussed above. A timely, proactive approach may prevent unplanned pregnancies or pregnancies at a difficult juncture in clinical care, for example, in advanced CKD, where pregnancy success may be low and maternal health may be at risk [21]. It also enables implementation of effective contraception while planning pregnancy, or if pregnancy is not desired [3].

Counseling regarding timing of pregnancy

Patients have a long journey with kidney disease and need to constantly consider “what’s next?” in terms of their care. They experience transitions from CKD to dialysis or transplant, and transplant back to dialysis, potentially more than once. The impact of pregnancy on CKD progression is a priority issue from the patients’ perspective, and determining optimal timing of pregnancy can be challenging. One of the more difficult decisions women may face is whether to proceed with a pregnancy with moderate CKD, which may accelerate their path toward renal replacement therapy much earlier than otherwise anticipated, versus waiting until they receive a transplant. The latter course may be the safest option, although pregnancies after kidney transplantation remain at high risk [5,6]. However, in many women, the need for transplantation may not arise for years, and waiting times for organs are unpredictable and may be 2–5 years depending on local and individual factors. Following transplantation, further waiting is required for 1–2 years to ensure graft stability and adjust potentially teratogenic medications [3]. Therefore, deferring pregnancy may result in the window for childbearing closing. In this scenario, a woman may choose to accept the high risks of pregnancy with advanced CKD, or alternatively may accept that parenthood will not be safely achieved, and either way, it will rationalize their decision-making [1]. Women with less severe CKD may elect to proceed with pregnancy early before kidney function declines, rather than defer pregnancy and face a high-risk scenario later in life. Clinicians should attempt an individualized estimate of the window of opportunity for pregnancy based on current eGFR decline, tools (if available) to predict average waiting times for transplant based on blood group and other immunological factors (if known), and local transplant practices.

Value of prepregnancy counseling and planning

Before pregnancy, there is an opportunity to optimize health and risk factors for adverse outcome, adjust medications, obtain multidisciplinary assessment, assess fertility, and confirm the best timing of pregnancy (with appropriate contraception in place). Algorithms for care have been outlined in recent reviews [3–5]. The increased medical surveillance in pregnancy may surprise and alarm women. The psychological impact of CKD during pregnancy should be considered, with information provision, communication, and shared decision-making being cornerstones of care to avoid frightening and disempowering the patient. Prepregnancy counseling enables women to be aware of pregnancy risks (maternal and fetal) and take time to consider these risks, ask questions, discuss with partners, families, and clinicians. This is a chance to have psychological preparation for complex pregnancy.

Prepregnancy counseling can also provide reassurance regarding the likelihood of the pregnancy going well. Conveying hope and positive outcomes is valued by women, and medical catastrophizing is detrimental to their experience [1,2,33]. Relaying the magnitude of risk for an individual woman can be balanced by emphasizing the level of support that will be provided by the caring team. This counseling process may take multiple visits with time to fully complete.

Perception of “risk” in pregnancy counseling

Pregnancy and childbirth occurs in the context of broader life framework, and in women with medical complications, pregnancy must not be reduced to a list of risk factors [47]. It is unsurprising

that women with high-risk pregnancies have overtly more concerns and feel more worried than low-risk women [48]. A patient's perception of risk is complex and subject to influence from individual preferences, experiences, knowledge, and circumstance. There may be a disconnect between the perception of risk by patients and health professionals [49]; one study assessing the perception of risk in women with high-risk pregnancies contemplating home or hospital birth identified several key factors that were relevant to risk perception by women, and subsequent decision-making [47]: the level of understanding of personal risks, judgment of risk magnitude, existence of any reassuring factors including within maternity care, and past obstetric history. The impact of risk perception on pregnant women varied. The two key coping strategies reported were either acknowledging the risks and accepting them, or not dwelling on the risks to avoid distress. Clinicians should be prepared to tailor their approach depending on which attitude the patient adopts. An attempt to engage with women in a way that respects their perception of risk facilitates a trusting clinical relationship, improves cooperation with shared decision-making, and provide adherence to clinical advice [47–49].

Specific counseling for inherited kidney disease

Women with inherited renal disease also have to consider the impact of disease inheritance on pregnancy. There may be guilt associated with passing on disease to offspring that influences decision-making around pregnancy [1,47]. For example, patients with polycystic kidney disease express specific concerns around family planning and the availability of genetic testing [47–49]. Preimplantation genetic diagnosis (PGD) and prenatal diagnosis technology may be offered for some genetic kidney disorders. The main condition amenable to this option is autosomal dominant polycystic kidney disease (ADPKD). In a UK study, patients with ADPKD were accepting preimplantation diagnostic methods more than prenatal diagnosis and termination of pregnancy, and although the cost and inconvenience of an in vitro fertilization process were recognized, the majority of patients felt it should be offered [48]. Genetic counseling services to discuss genetic testing options, implications of genetic disorders, and options for parenthood should also be offered where possible [50]. There are important ethical issues around genetic testing and PGD, with lack of agreement among clinicians and geneticists around testing of asymptomatic people, and potential discrepancy between patient and clinician attitudes [51].

Patient experiences of models of prepregnancy and pregnancy care

The best models of care for women with kidney disease have not been well researched or well defined, although many centers have dedicated obstetric nephrology clinics that deliver expert prepregnancy counseling, and antenatal and postnatal care. The recommendation from consensus expert opinion is for specialized, multidisciplinary, and coordinated care [3,4,7]. One of the few studies on how women with CKD are counseled was from a multidisciplinary obstetric renal clinic in London, England [52]. This study reported patient experiences and identified aspects of counseling valued by women who attended. The vast majority found this dedicated and specialized counseling service informative, understandable, and helpful to decision-making. In particular, expertise of clinicians, provision of information, and assistance with decision-making were positively received. Of note, a minority (17%) were intimidated by having multiple clinicians in one consultation. Therefore, models of care may not be suitable for all women. Care delivery should (ideally) be tailored to a woman's preferences – where possible, this can best be determined through supportive professional care and trust-based clinical relationships built with time.

Women with medical problems in pregnancy want personalized contact with a trusted, professionally competent source of information for shared decision-making [1,34,36,45]. This may help to address decisional conflict and insecurity experienced by women with kidney disease. For example, in situations where advice was unreliable or no information was given, women with diabetes were found to act as their own experts instead of health care professionals [34]. This

places an additional responsibility on women who may already be self-managing substantial aspects of their medical care. In addition, patients with CKD in the nonpregnancy setting have reported frustration when health professionals do not know about CKD and the patient becomes the educator; therefore, having knowledgeable clinical staff is another means of assisting patients to navigate the system.

Having a clearly identified clinician leading the multidisciplinary team who counsels women on pregnancy risk, medications, and related issues is useful. In a study of preconception counseling for women receiving angiotensin-converting enzyme inhibitors (ACEIs), clinicians had a range of opinions and awareness about drug use, and only 35% thought the prescriber of the drug was best placed to counsel women on the risk of ACEI use in pregnancy [53]. There may be the assumption that another health care provider has taken responsibility for aspects of care. Disconnected care across services (obstetrics, subspecialty, and other care providers) in the care of women with type 1 diabetes leads to multiple visits, lack of clarity about who is responsible for management, and reduced communication, with the patient often being the primary carrier of information [34]. Similar fragmentation of care may be seen for women with kidney disease, especially where maternity and renal services are not colocated. Dedicated high-risk pregnancy or renal obstetric clinics can facilitate integrated and efficient care, and reduce confusion and burden for the patient. Clinical teams should recognize the disruption a medically complex pregnancy causes and impact of clinic visits and hospitalizations on work, family, and other responsibilities. This burden of clinical care is particularly noted in women with advanced kidney failure or those receiving dialysis.

Women may find benefit in undertaking aspects of self-management. The Blood pressure self-monitoring in pregnancy (BuMP) study recently assessed the experience of self-monitoring of blood pressure [54]. Women described this as reassuring, not anxiety provoking, particularly if they had experienced hypertension previously. Some women found self-management empowering. The extra support of the research team and additional education was welcomed.

The patient experience and perspective may not be routinely discussed by clinicians nor volunteered by patients themselves. In the absence of a structured mechanism for addressing this, clinician vigilance and a proactive approach is required. Our recommendations for clinical practice are summarized in the Practice Points section below. Mechanisms for formally evaluating patient experience measures are increasingly embedded in health services. Tools for assessing patient-reported experiences in maternity services have been developed and can reflect the entire user experience of maternity services from prenatal through to postnatal care in varied settings. For example, the Norwegian pregnancy- and maternity-care patients' experiences questionnaire (PreMaPEQ) covered 4 care phases (pregnancy, birth, postnatal stay, and public health clinic) and evaluated personal relationships, resources, information, and attention to partners [55]. Such evaluations are greatly needed in high-risk pregnancy cohorts and may further enhance our understanding of the patient experience and inform models of clinical care and service development.

Summary

Women with kidney disease in pregnancy describe challenging emotional experiences when considering pregnancy (Table 1), which in turn may influence many aspects of care (Fig. 1). Perceptions of risk are influenced by many factors and vary between women. Decision-making is complicated when the desire for motherhood and fulfillment of social norms competes with perceived fears about maternal and fetal survival and health. A medical focus on risks and adversity and judgmental clinician responses can be disengaging and frightening. Positive reassurance from clinicians, conveying a sense of hope and facilitating the return of autonomy and control to women, can improve the patient experience and engagement with clinical care. Women with kidney disease should receive counseling about parenthood early in the CKD journey where possible to enable education of patients and partners, give time to consider options and choices, and allow for planning to optimize pregnancy outcomes. Clinicians should understand the patient's values and perspectives, support their preferences and provide expert knowledge to underpin shared decision-making.

Practice points

- Proactively raise the issue of parenthood in women with kidney disease of child-bearing age as early as possible.
- Identify and acknowledge the woman's goals, values, and perspectives regarding pregnancy and parenthood, as these will determine approaches to care.
- Avoid negative commentary that may frighten and disengage women.
- Focus the clinical interaction on support and empathy and women-decisional ownership and autonomy.
- Provide expert, evidence-based information wherever possible to help navigate shared decision-making, including access to specialized medical and prepregnancy counseling services.
- As pregnancy planning may take time, ensure appropriate contraception is in place.
- Facilitate the delivery of coordinated, multidisciplinary care with a clear lead or point of contact; avoid fragmented care and poor communication across services.

Research agenda

- Incorporate patient and partner/carer engagement at all stages to inform the future research agenda on pregnancy in women with kidney disease.
- Define the perspectives of women from culturally and linguistically diverse populations.
- Define real-world clinical practices including clinician perspectives, identify preferred models of care, and evaluate gaps in care.
- Develop and evidence-base for strategies, such as education and training that will improve patient engagement, clinical care, and outcomes in pregnancy.
- Explore the impact of kidney disease on motherhood in the postpartum stage and beyond.

Conflict of interest

None.

Acknowledgments

The authors thank Dr Richard Le Leu for assistance with this manuscript.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.bpobgyn.2018.12.003>.

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