

“It was classed as a nonemergency”: Women’s experiences of kidney disease and preconception decision-making, family planning, and parenting in the United Kingdom during COVID-19

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Abstract

Objectives: To investigate the experiences of women with kidney disease, residing in the United Kingdom (UK), living through the first 18 months of the COVID-19 pandemic with specific focus on preconception decision-making, family planning, and parenting.

Methods: We conducted a mixed-methods study, comprising an online survey and follow-up interviews, with UK-resident women aged 18–50.

Results: We received 431 surveys and conducted 30 interviews. Half ($n = 221$, 51%) of the survey respondents considered that COVID-19 influenced the quality of communication with healthcare professionals and 68% ($n = 295$) felt that the pandemic disrupted their support networks. Interview participants indicated that delayed and canceled appointments caused anxiety, grief, and loss of pregnancy options. Women’s perception of themselves as (good) mothers as well as their capacity to have and raise a child, meet partners, and sustain healthy relationships was negatively affected by the “clinically extremely vulnerable” label. Women’s trust in their healthcare was dismantled by miscommunication and variation in lockdown rules that caused confusion and increased worry. Women reported that COVID-19 contributed to postnatal depression, excessive concern over infant mortality, preoccupation over others following rules, and catastrophising.

Conclusion: Some women in the UK with chronic kidney disease lost or missed their opportunity to have children during the pandemic. Future pandemic planners need to look more holistically and longer term at what is and is not classed as an emergency, both in how services are reconfigured and how people with chronic conditions are identified, communicated with, and treated.

KEYWORDS

COVID-19, decision-making, kidney disease, pandemic, parenting, pregnancy, qualitative research, reproductive health, women

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INTRODUCTION

Around 195 million women live with chronic kidney disease (CKD) globally.¹ 3%–6% of women are estimated to be of childbearing age² and that in high income countries 3% of women who are pregnant are affected by CKD.³ Around 3.5million people in the United Kingdom (UK) (6% of the overall population) have diagnosed kidney disease⁴ and the prevalence is much higher in women than men.⁵ CKD is usually progressive and is classified in stages from 1 (mild) to 5 (kidney failure).⁶ There is no cure. People living in high income countries who are diagnosed with CKD are frequently treated by a multi-disciplinary team (MDT), which commonly includes nephrologists, specialist nurses, and pharmacists with other specialists as needed, including reproductive health. When people progress to end stage kidney disease, dialysis or a transplant is required.⁶

Women can get pregnant at any stage of CKD, including while on dialysis or with a transplant. Ideally, women should carefully plan their pregnancies with key MDT members. Although individual circumstances vary, women with mild CKD may be recommended by a kidney doctor to consider pregnancy sooner rather than waiting for their kidney function to decline. Women with CKD stage 4–5 are at high risk of pregnancy-related complications and may be advised to wait until at least a year post transplant before becoming pregnant.³ Researchers continue to develop more personalized risk assessments for women with CKD who want to become pregnant.⁷ Nonetheless, pregnancy is often complex, requiring close and frequent monitoring to detect and treat any complications. In some circumstances, women may be advised by their MDT to avoid pregnancy or consider having an abortion if their kidney disease is unstable or there are concerns for the woman's health and welfare if the pregnancy continues.⁸ Many women with CKD require assisted conception,⁹ some seek alternatives to pregnancy such as adoption or surrogacy, and some opt not to have children.

COVID-19, KIDNEY DISEASE AND THE UK CONTEXT

The World Health Organization (WHO) declared COVID-19 a pandemic on March 11, 2020.¹⁰ Healthcare services typically declared a state of emergency, directing all resources to preventing infection, caring for those already infected and to prepare for the high numbers of people expected to need high dependency and critical care.¹¹ The impact of COVID-19 on women with kidney disease who were pregnant and the impact on the developing fetus at the time was not known.

Box 1 explains the key measures implemented for extremely vulnerable populations to help manage the pandemic in the UK. In January 2020, we received funding for a UK-wide study on women with CKD and their reproductive health and began recruitment on September 1, 2020.^{19,20}

METHODS

We conducted a mixed-methods study (survey and interviews) with women aged 18–50 known to have kidney disease, resident in the UK, with a specific focus on their preconception decision-making, family planning, and parenting that contained specific elements to explore the impact of the first 18 months of the COVID-19 pandemic. Although our study focused on women, we acknowledge that not all individuals with the capacity for pregnancy identify as women. In this article, we preserve the language used in published databases and studies.

Recruitment and data collection

Health services used the national all Wales renal data register (VitalData which records biological sex male/female) to identify potential participants and distribute the Welsh/English survey. We sent a cover letter and link to the online survey by post to every person fitting the inclusion criteria in Wales (circa $n = 2300$). National Health Service (NHS) staff also signposted to the online survey by putting bookmarks in clinic notes and putting posters up in waiting rooms and dialysis units. Clinical members of the research team (nephrologists, renal social workers) proactively encouraged women in their care to take part in the survey and sometimes asked these women for help to promote the study. Partner kidney charity magazines and charity partner mailouts to patient lists also communicated information about the study. Bristol Online Surveys (BOS) hosted the online survey which was open for over 8 months (September 2020–April 2021). Researchers screened potential participants against the inclusion criteria (age, CKD diagnosis, and residency). Those eligible were given access to the full survey, those not eligible were sent to a landing page thanking them for their interest, signposted to further support services, and given the researchers' contact details if they wished to get in touch directly. We aimed to collect 500 surveys in order to complete a regression analysis and have a suitable number of participants to purposively sample for interview.¹⁹ We offered survey respondents a potential follow-up interview. We included COVID-19 specific content in our interview guide (see Box 2). The published protocol includes full details.¹⁹

Interview sampling and processes

We purposively sampled follow-up interviewees from survey respondents to ensure maximum variation (stage and treatment of kidney disease, stage of conception planning, desire to have children, whether they had already had children, experiences with alternative options to pregnancy, conversations with healthcare professionals, demographics (including ethnicity and religious perspectives), and sexual orientation). We invited women to take part in a Welsh or English language audio-recorded interview via phone call or internet at a time and date convenient to them. We shared a topic guide and a visual

BOX 1 Further explanation of COVID-19 mitigation measures for clinically extremely vulnerable populations in the United Kingdom.

Clinically extremely vulnerable (CEV): People identified as at very high risk of severe illness or death from COVID-19. People with chronic kidney disease (CKD) stage 4–5, on dialysis, or with a transplant were classed as CEV.^{12,13,18}

Shielded/ing: People identified as CEV were sent a letter advising them to shield – they were to have no contact with any person and stay at home. These people were identified via their general practitioner records. People with CKD stage 4–5, on dialysis, or with a transplant were on the list of those asked to shield.¹⁴

National Health Service (NHS) response to COVID-19: The NHS is responsible for the healthcare of citizens in the United Kingdom (UK). Healthcare is free at the point of delivery but some reproductive options are excluded or restricted. The NHS was completely repurposed to focus on managing COVID-19. Intensive care facilities expanded rapidly. New temporary field hospitals were built to manage COVID-19 patients. Routine surgery and many aspects of nonemergency care were canceled.

Usual CKD services for women: These services were rescheduled or canceled and switched to remote telephone calls especially during lockdowns and for those shielding. Most kidney transplant programmes stopped activity in the first lockdown and were operating at reduced capacity for most of 2020.²⁰

Tiered systems of lockdowns: Lockdowns were categorized according to four tiers which indicated which form of lockdown was in place at the time. What each tier represented and what it meant changed as the pandemic progressed but generally 1 indicated a low chance of catching COVID-19 so restrictions were minimal and 4 was a very high chance of catching COVID-19 and restrictions on movement and association activities were mandated by law and required people to stay at home.

Tier 4 lockdowns: On March 23, 2020 citizens in the UK were mandated to only go out for essential services (food and medicines), could exercise up to 1 h a day but were encouraged to “stay at home, protect the NHS and save lives”. Restrictions were lifted in June 2020. A second full lockdown was implemented on October 31, 2020 and lifted on December 2, 2020. Further details of the lockdown timelines in the UK are available here <https://www.instituteforgovernment.org.uk/sites/default/files/timeline-lockdown-web.pdf>.¹⁵

Track and trace: The system set up to manage the spread of COVID-19 and keep the economic and social impacts to a minimum. Via an app and QR scanning process it was designed to alert users if they had been in close contact (2 m) of someone with COVID-19 and indicated the user to follow the guidance in place where they lived. People were required to isolate for 10 days if they had been in contact with someone infected, as the pandemic progressed these guidelines also changed.

Personal protective equipment (PPE) – There were various mandates about the wearing of PPE as an infection control measure for specific sections of the population and different types of PPE requirements for different contexts for example intensive care, care homes, visiting a hospital, and so on.

Vaccine: On December 2, 2020, the Pfizer-BioNTech COVID vaccine was approved for use in the UK, becoming the first to be authorized anywhere in the world. On December 30, 2020 the cheaper and easier-to-distribute Oxford-AstraZeneca vaccine was approved. A third vaccine, produced by Moderna, was approved for use in the UK in January 2021.¹⁶

The vaccine roll out: In December 2020, the Independent Joint Committee on Vaccination and Immunization (JCVI), published a plan involving nine priority groups and then moved down through the risk levels.¹⁷ CEV people such as women with CKD were in the top five priority group to receive the vaccine.

Additional-government led measures were put in place to support the basic needs of those self-isolating, including priority food delivery slots, prescription home services, furlough schemes, and increased welfare support.¹⁸

Adoption and fertility services stopped and/or experienced significant delays.

timeline²¹ prior to the interviews via email to aid memory recall and discussion. We obtained informed consent before each interview. We aimed to complete 30 interviews to explore the phenomena of interest within available resources and the timeframe. When we believed, we reached thematic data saturation we stopped recruitment.²² An experienced woman researcher (LM) undertook English interviews ($n = 28$). An experienced woman renal social worker (CJ) undertook Welsh interviews ($n = 2$). Of the 33 people who we contacted 30 consented to an interview. We undertook 23 interviews using Microsoft Teams®/Zoom and seven by telephone. We conducted interviews, which lasted an average of 60 min (range: 50–80), from November 2020 to June 2021 and detailed field notes during each encounter.

Data analysis

We analyzed quantitative survey data descriptively to characterize the sample and summarize perceived impact of COVID-19 on person-centered reproductive healthcare. We transcribed interviews verbatim and uploaded them into NVivo 11 pro²³ alongside COVID-

19-related open-ended survey responses. We undertook framework analysis²⁴ (familiarize, identify themes, index, chart, map, and interpret). BN undertook initial organizing and coding and LM undertook further detailed coding and inductive analysis. We displayed data in matrices, tables, and summary slides; researchers checked these data and resolved any disagreements and uncertainties at weekly analysis and monthly core team meetings. We used the Good Reporting of A Mixed Method Study (GRAMMS) framework and the consolidated criteria for reporting qualitative research (COREQ) guidelines.²⁵

Patient, public, and stakeholder involvement

Two mothers with kidney disease were core research team members and we consulted with a small group of women patient advisors ($N = 3$) on the design of the study, including developing the research question, data collection tools, conduct, analysis, and interpretation. We presented a wider expert audience of patients, charity partners, academics, and services representing fertility, adoption, surrogacy, and maternal health clinics with the results and they confirmed our interpretation.

BOX 2 COVID-19 specific survey questions.

Open-ended question: Has the COVID-19 pandemic had any influence on your decisions about becoming pregnant or having (more) children. Please give further details (e.g. changes to your usual care from your renal team, delayed transplant, risk of infection, employment, welfare, and/or social support)?

Closed question, with option to add further detail as an open response: Have you been pregnant or given birth during the COVID 19 pandemic? Yes/No. Please tell us a bit more about any impact you think your pregnancy or pregnancies have had on your health and well-being.

Closed question, with option to add further detail as an open response: From your experiences, has the COVID-19 pandemic influenced the quality of communication with your healthcare professionals? Yes/No/N/A. Would you like to tell us some more details for example virtual appointments, online applications, understanding advice, and so on?

Closed question, with option to add further detail as an open response: Has COVID-19 had an impact on your contact with people you feel close to and that you can trust and confide in? (1) None of the time; (2) A little of the time; (3) Some of the time; (4) Most of the time; (5) All of the time. Would you like to tell us anything else about the impact of COVID-19 on your support networks?

Author reflexivity

The all women research team hold the view that women's reproductive health needed further research and draw from range of specialities in academia, clinical practice, and health and social care. One researcher knew one interviewee through professional networks and we offered her the option of interviewing with another member of the study team member (she declined).

RESULTS

We received 431 completed surveys (428 English, 3 Welsh) of which 83% ($n = 359$) contained free text responses regarding COVID-19's influence on women's childbearing decisions. We combined free text responses with 30 interviews for analysis. We report participant demographics in Table 1.

Quantitative survey results

Overall, just over half of women said the quality of communication with their healthcare professionals had been affected during the pandemic. Just under half of women said it had a significant or substantial impact on their support networks. Twenty-seven women had been pregnant or given birth during the pandemic (Table 2).

Qualitative findings

We grouped our qualitative findings by theme and use illustrative quotes as supporting evidence.

Pandemic-related pregnancy loss, grief, and anxiety

Some women's opportunities to have a child were taken away by delays to transplant and timely reproductive planning. Some women awaiting transplant felt they would be too old to have a pregnancy by the time they would be healthy enough to try, other women could not access reproductive services during the pandemic and subsequently elected not to have a pregnancy, and for others their kidney disease progressed altering their immediate priorities away from having a child.

Women described being in very difficult situations and faced with equally distressing choices in their decision-making, for example being advised to delay a pregnancy as close monitoring (especially in relation to medication switching) was not possible, too risky, or too high a burden for them to manage while shielding. Some women reported that they were advised by their healthcare professional to terminate a pregnancy, as a survey respondent (age 18–35) with a transplant wrote, "Yes, I was pregnant at the beginning of the pandemic and the hospital/specialist advised me to medically terminate as they couldn't guarantee my safety, this was extremely upsetting as I felt I was not supported but bullied into not being a high risk case."

Women who had experienced previous delays while awaiting transplantation (unrelated to COVID-19) or were waiting for a year post transplant to be ready to start trying for a baby reported high anxiety. Women felt time was running out due to the shortened window in which they were advised to have a pregnancy, as this interviewee, a mother (age 18–35) and transplant recipient, who wants more children explained:

You have to wait a couple of years for everything to settle down, and then you've got this short window where everything is okay. The nurse said, 'Oh, well, you haven't been trying for a year yet, so wait.' July came. We were in the middle of COVID. I was telling my consultants, 'Look, can you refer me back [to fertility clinic]?' I was pushing and pushing it, really getting upset and frustrated, that's when I went private to see what was wrong with us.

Some women went through financial and emotional distress to progress their pregnancy planning via private clinics and many were frustrated that they could get NHS care for their kidneys but not for their fertility, as one woman (age 36–50) with mild CKD who wanted more children explained:

I sought out and paid for a private consultant. The treatment that I need would be once a week every 2 weeks for four treatments, and for each one of those treatments I would have to self-isolate for 2 weeks before each one. So, basically, I would be on my own for 10 weeks, so I would be divorced at the end of it. There is no way to get treatment. Unless you're an emergency, no, not a chance.

TABLE 1 Summary of demographic characteristics of survey and interview participants.

	Frequency of quantitative survey sample (N = 431) (% to nearest whole number)	Frequency of qualitative sub sample (N = 30) (% to nearest whole number)
Geographic location		
Wales	163 (38%)	24 (80%)
England	225 (52%)	4 (13%)
Scotland	31 (7%)	2 (7%)
Northern Ireland	11 (3%)	-
Not reported	1 (1%)	-
Ethnic background		
White	398 (93%)	28 (93%)
Black/African/Caribbean	5 (1%)	
Hispanic	1 (1%)	
Asian	12 (3%)	
Mixed/multiple groups	4 (1%)	2 (7%)
Rather not say	6 (1%)	
Other (South Asian/Irish/Chinese)	3 (1%)	
Not reported	2 (1%)	
Education^a		
Usual high school qualifications in your country at age 16	155 (36%)	3 (10%)
Usual high school qualifications in your country at age 18	113 (26%)	1 (3%)
College or university diploma or degree	266 (62%)	14 (47%)
Higher degree or professional qualification (e.g. doctorate or Masters level)	90 (21%)	9 (30%)
None of these qualifications	3 (1%)	
Rather not say	14 (3%)	3 (10%)
Other	5 (1%)	
Employment^a		
In full-time paid work, as an employee or self-employed	226 (52%)	15 (50%)
In part-time paid work, as an employee or self-employed	107 (25%)	6 (20%)
Unemployed and seeking work	10 (2%)	2 (7%)
Not employed and not currently seeking work	49 (11%)	4 (13%)
In full-time education or training	27 (6%)	1 (3%)
In part-time education or training	11 (3%)	-
Rather not say	15 (3%)	2 (7%)
Age group		
18–35	227 (53%)	17 (57%)
36–50	201 (47%)	13 (43%)
Not reported	3 (1%)	
Kidney disease/treatment status^a		
CKD stage 1	46 (11%)	1 (3%)
CKD stage 2	29 (7%)	1 (3%)
CKD Stage 3	56 (13%)	6 (20%)
CKD stage 4	41 (9%)	3 (10%)
CKD stage 5	34 (8%)	-

(Continues)

TABLE 1 (Continued)

	Frequency of quantitative survey sample (N = 431) (% to nearest whole number)	Frequency of qualitative sub sample (N = 30) (% to nearest whole number)
Unsure	93 (21%)	9 (30%)
Has had a kidney transplant	120 (28%)	7 (23%)
Currently on dialysis	37 (9%)	3 (10%)
Children pregnancy and CKD		
Have participants ever been pregnant		
Yes	237 (55%)	26 (53%)
No	194 (45%)	14 (47%)
Participants with Children		
Yes	207 (48%)	13 (43%)
No	222 (51%)	17 (57%)
Not reported	2 (1%)	
Summary of life stage and decision about having children ^a		
No, I do not want to have any children (or any more children)	156 (36%)	16 (53%)
I am currently pregnant	19 (4%)	-
Yes, I would like to become pregnant	143 (33%)	7 (23%)
Yes, I am receiving fertility treatment/planning on having fertility treatment	18 (4%)	5 (18%)
Yes, I would like to have a child but don't plan on getting pregnant (adoption/surrogacy)	39 (9%)	1 (3%)
Not sure	46 (11%)	1 (3%)
Other	31 (7%)	

^aMore than one answer may be given.

Older women felt that their opportunity to have a pregnancy had past (due to COVID-19) and had given up as this women with a transplant explained:

As far as they're [the reproductive clinic] concerned, I'm still on the waiting list, but because of my complications they won't have me into hospital, which is understandable. So, I think my realization is, now, that that's never going to happen. I'm 42, now. They never collected any eggs. So, I just can't see that that's going to work now.

Women felt extremely clinically vulnerable and isolated due to the pandemic

Women who were sent a letter to shield had to stay at home and have no contact with anyone. Many women felt unsafe and/or unable to properly care for their children while shielding. Some women had to move out of their homes, others had their family members move out as it was too difficult to shield with partners working and children in school. Women felt guilt and that they were not "good" mothers, wives, or partners.

Women who received a transplant during the pandemic were often unable to see or spend time with their children or families for months as they were severely immunocompromised and considered at extremely high risk of severe COVID-19. Women sought ways to relieve boredom, depression, and chronic anxiety but often put themselves and their (new) kidney at increased risk and harm, as this mother (age 18–35) with a recent transplant explained in her interview:

I was so bored and I didn't have my daughter for ages [due to receiving a transplant during COVID-19 she was not able to live with her young daughter]. I wasn't allowed to have her because she was going to school and things like that. That was rubbish because I was just really bored at home. And then, I took on a bit too much. Because I have to keep reminding myself like, "You feel fine but you had surgery 10 weeks ago and you need to chill out."

For women not in a romantic relationship they felt their opportunities to meet a partner and start a family were taken away as this survey respondent (age 18–35) and transplant recipient who wants children wrote, "Not being able to see friends has been difficult. It

TABLE 2 Quantitative results of the impact of the COVID-19 pandemic on women with kidney disease. Frequency of quantitative sample (N) n (% to nearest whole number).

Q1	Has the COVID 19 pandemic influenced the quality of communication with your healthcare professionals (N = 431)?	
	Yes	221 (51%)
	No	170 (39%)
	Non-applicable	40 (9%)
Q2	Has COVID 19 had an impact on your contact with people you feel close to and that you can trust and confide in (N = 431)?	
	None of the time	88 (20%)
	A little of the time	48 (11%)
	Some of the time	114 (26%)
	Most of the time	87 (20%)
	All of the time	94 (22%)
Q3	IF you have been pregnant before, have you been pregnant or given birth during the COVID 19 pandemic (23rd March to present) (n = 237)?	
	Yes	27 (11%)
	No	210 (89%)

feels like things have been put on hold. Trying to date and meet someone new has been halted again further delaying any prospect of finding a long-term partner and someone who I would want to have children with.”

Seeking reproductive information during the pandemic was a high burden

Many women tried to get reproductive health information in an ad hoc way. Many elected not to discuss their desires to have a pregnancy as they felt guilty that they were burdening the NHS in a national health emergency. Women who did discuss reproductive options felt greater responsibility to listen and convey information back to spouses/family and were frustrated that their partners were not sharing their experiences and burdens, as one survey respondent (age 36–50) who was currently pregnant explained: “I have high anxiety about [my] partner not being allowed to attend scans, the labor process and visit the ward after birth. My husband feels excluded, as if his rights as a father don’t matter at all.”

Many women could not understand how the NHS systems were failing to adjust more quickly to remote monitoring/care, which they perceived as easy with current technologies. Some even felt that the lack of routine checkups must be financially beneficial for the NHS and many felt that COVID-19 was only highlighting a service that was already broken. Women were further frustrated and scared by the lack of continuity of care compounded by COVID-19 as one transplant recipient (age 18–35) who had fertility treatment and was planning for a surrogate expressed:

They [NHS administrators] even lose letters. They lose your blood tests. They lose your scans. They can’t find them. Or they take such a long time now in the pandemic. It just feels like such a big mess in the whole situation. I am trying to keep track of all of those events, considering everything was going on in my life. Probably this year alone, even during the pandemic, I had 15 different scans already. So, to keep all of those results in your head is difficult.

The pandemic increased miscommunication

Women with kidney disease in the UK received a letter from the Department of Health saying they were extremely clinically vulnerable to COVID and what they needed to do. Many women felt this guidance and advice was written for elderly/retired people; younger women felt abandoned and forgotten by the system. Many were left to interpret the rules themselves and make difficult decisions in relation to their health and keeping themselves and their families safe. Some women felt guilt and increased anxieties as the pandemic progressed in terms of what and how they should interpret their situation (e.g. keeping their children at home to keep themselves safe and/or returning to work) especially as financial support systems stopped, as a women with CKD (age 36–50) who had two children explained:

I phoned Public Health Wales, “there’s no more shielding in Wales”, but they are shielding in England, “but we’re not in England”. The woman was vile, it was like “you live and work in Wales you follow the Welsh rules”. Now, the NHS pays a fortune to refer me to my specialists in England, the top doctors, who are telling me to shield—you can’t say what they say in October no longer applies in December—it makes no sense. So I phone my [general practitioner] who wasn’t available, I spoke to another doctor no more helpful, I said I’ve got the top consultant in the country telling me I shouldn’t be anyway near work and you can’t sign me off. I got upset then. “If you’re stressed, I can sign you off for stress”. I’m thinking “the only thing that’s stressing me is I feel completely unsupported, alone, and nobody cares”. I think it’s been pathetic how they’ve handled it [the corona virus]. I can’t be the only person with that kind of condition. I’m told people like me cannot set foot outside and I’m also told “yes, you can go to work in a school”?! That was hard.

Women often described communications about the Pfizer/BioNTech, Oxford/AstraZeneca, or Moderna vaccines as confused. They were anxious about the impact of vaccination on them, their kidney, pregnancy plan, and lifestyle. Some women who were breastfeeding at the time elected to wait for a vaccine until data became clearer about the safety of the vaccine for women who were breast feeding, and some women who had mild/non-symptomatic CKD who were

offered the vaccine felt guilt that they were skipping people who they perceived as more clinically vulnerable and in need for example older, frailer and people with visible symptom burden. Other women were misinformed and thought that these vaccines were unsuitable for them. As one pregnant interviewee (age 36–50) explained her decision-making: “I’m on maternity leave, but they said I could have the jab, [vaccine] but because I’m breastfeeding-they didn’t have the data for breastfeeding women, I was happier to wait until autumn to have my age group. I think some people are higher priority than me. I thought, “Oh, I’ll just wait until the autumn and I’ll be fine.”

Secondary impacts of COVID-19 influenced women’s preferences about starting (or enlarging) a family

Many women reassessed their desires to have children, due to the substantial changes in lifestyle they were enduring. Some questioned if they could be good mothers and others felt that the burden of shielding too much to think about having a pregnancy at this time, even if they were aware that this meant they would likely not have children, as one transplant recipient (age 36–50) illustrated in her survey: “COVID has been so awful. The shielding was so lonely. Having a toddler to entertain without going out was so difficult. Not seeing family was bad for my mental health. I wouldn’t want to bring another child into the world as it stands. Life isn’t as full and enriched as it once was. Living with fear is awful.”

Many women felt increasingly a burden on their employers, family, and friends especially as lockdowns eased or changed but they were still classified as high risk and shielding. For many women deciding to cease paid employment due to perceived risk and/or being furloughed actually increased underlying anxieties about their mental/physical health including reproductive goals and financial planning. For other women, trying to juggle home schooling, work, and their health was a high burden and for some a factor in deciding not to have (more) children irrespective of whether the pandemic changed or ended, as one woman (age 36–50) with two children explained:

I’ve worked from home all the way through the pandemic. It has been really difficult, obviously because my husband has been in work so it has been mainly me doing everything. The children went back to school in September, but again my eldest son has been in school for 2 weeks, off school for 2 weeks, because if someone gets tested positive in his year group they all go home. So, he has been home more than in school, but my youngest has been in school. Obviously, they’re off school now until the February half-term. So, again, we’re back to home-schooling, which is fine but it is hard because we’ve only had our work laptop. Schools are reliant on that we’ve all got laptops for the kids to use, which we haven’t. So, we’ve had to buy stuff for Christmas now, but I can’t see this getting any better as the year goes on, to be honest.

Women felt increased anxieties during pregnancy and giving birth during a lockdown

The increased risk of contracting COVID-19 had high impact on pregnant women’s mental health. Women perceived hospitals as unsafe. Some wished to alter their birthing plans but were uncertain how to do this. Some women found the subsequent shielding from family immediately after giving birth a source of postnatal depression. Some women wanted better support for pregnancy loss, including their unmet bereavement care needs, grief (including ambiguous loss), as one survey respondent (age 18–35) and transplant recipient who wants children wrote: “I feel forgotten about, it’s been extremely difficult to get any follow up support regarding the abortion or any kind of appointment with a GP (general practitioner). The GP posted in their Facebook page to only call in case of an emergency.” Whereas others felt, they received excellent care throughout their pregnancy as another women (age 18–35) with polycystic kidney disease wrote: “Very good support from health providers pre-pregnancy, including genetic counseling.”

Some new(er) mothers developed fears of their children catching or dying from COVID-19 and lacked the initial perspective and means to seek additional counseling or support. As one woman (age 36–50) who had her first child during lockdown explained: “When she (my daughter) was born, I developed severe agoraphobia, I was watching my neighbors (on the street) and counting how many times I saw them leave the house. I didn’t know at the time that this was an irrational response, it was only when I saw the counselor. I thought everyone else had gone mad!” Some women who tried to access additional mental health support were unable to or felt that the wait list was too long to be helpful as this mother (age 18–35) of two explained: “She (GP) said she could refer me to counselling but there was actually a 20-week waiting list. The NHS just do not have the capacity to help everyone.”

The pandemic created a bleak looking future

The timeframe (September 2020–April 2021) of the survey broadly covered the middle period from when lockdowns were introduced and when they were completely lifted in the UK. At the time of the survey, these women had been through several phases of the pandemic including multiple lockdowns, several tiered protocols, and variations in social distancing guidelines.

Many women had not yet considered the full impact of COVID-19 on their future health and wellbeing and/or were frightened of what their future life might look like including their pregnancy planning. Many women were still uncertain what to do, felt in limbo and were actively weighing up the pros and cons of having a baby during the pandemic for example safety of hospitals, balanced with part-time working and flexibility, alongside the health of their kidney and life goals. Others elected not to have a pregnancy due to COVID-19 but had started to think about alternate options (e.g. adoption) but remained worried about a very uncertain future. Some women were still overwhelmed with COVID-19 and were struggling to

rationalize their personal needs above the global scale impacts unraveling daily as one mother (age 18–35) and transplant recipient wrote in her survey, “The future looks a lot bleaker so I am hesitant to bring another life into it.”

Women who went into kidney failure during COVID-19 (not necessarily as a consequence of contracting the virus) described their experiences as living through a nightmare. The lack of social support, opportunities for education and counseling and meeting others with kidney disease meant that women were left to investigate their own disease and future treatment burdens themselves. The more they investigated the worse their outlook became. Women felt that their hopes and ambitions for the future including motherhood were taken away and COVID-19 compounded their experiences by taking away the point of living as one transplant recipient (age 18–35) who wants children explained:

So, they're (specialist nurses) talking to me about dialysis. They brought the whole setup, like how you're going to dialyse yourself, where the tubing is going to do with PD dialysis. And I'm sitting there and, honestly, I am feeling unwell-like emotionally unwell, seeing all of this. I can't even hear anything that's being told to me. They said, Unfortunately, we cannot offer you any of the support group meetings, which usually used to be available before coronavirus, but now you have to deal with everything yourself. I really thought my life was over.

DISCUSSION

This is the first and large-scale study to publish the actual experiences of women with CKD during the pandemic. The study was rigorously conducted and produced rich data that can be used to inform future policy and practice. An early priority of the NHS was to repurpose healthcare services to focus on the COVID-19 response. The immediate impact on women with CKD who were thinking about starting or enlarging their family was to pause their pregnancy planning (if they had started), delays for those who had yet to start, and a switch to remote care/monitoring wherever possible.²⁶ As part of usual care women with CKD should have received person-centered consultations with a focus on preconception decisions such as their biologically optimal time to have a pregnancy.³

Communication with healthcare teams and their wider social networks were however severely disrupted, making decisions about reproductive goals especially challenging. Many women questioned their capacity and capability to have (more) children because of the labels (vulnerable, shielded, isolated) they were given by the government coupled with the extreme disruptions to daily living as a consequence of measures put in place to try and protect them. Women experienced increased anxiety that contributed to dismantling the trust they had in their overall care. Their anxiety was fuelled by miscommunications resulting from variation in lockdown rules—especially as restrictions began to be lifted—and for some was a contributing factor in

disengaging from pursuing pregnancy options because accessing and interpreting information was too difficult and too high a burden. Throughout the pandemic both women with kidney disease and their healthcare professionals were faced with difficult choices including recommending women to terminate pregnancies as they could not guarantee safety, staying home, and shielding as opposed to coming to clinics for treatments. Women reflected on if they could parent (or would want to) while living in fear for their (and their families) lives.

Other studies investigating the impacts of COVID-19 on people with CKD report some similar findings using different methods for example increase in anxieties,²⁷ confused communications,²⁸ the pressing need to prevent COVID-19 transmission in this vulnerable population,²⁹ the complexity of managing women with multiple comorbidities, and pregnancy,²⁶ the disproportionate negative impact of COVID-19 on people with CKD,³⁰ and that COVID-19 is now a risk factor for developing CKD.³¹ Studies reporting general experiences of women living with related comorbid conditions over this time also reported very similar findings.^{32–34} Importantly evidence highlights that living with a chronic disease is a risk factor for poor mental health outcomes at times of adversity and/or crisis and that more tailored and robust interventions are needed to deliver the necessary support and reduce and relieve symptom burden.³⁵

Although recent literature discusses the impact of COVID-19 on people with kidney disease, lessons learnt and future planning and women's reproductive health is critically missing.³⁶ Key issues include addressing the backlog of need,³⁷ the impacts of delaying “nonessential” reproductive healthcare,³⁸ highlighting issues around equity, violations of human rights, and recent shifts in policies limiting and/or reducing women's access to effective reproductive healthcare.^{39–41} Collectively this literature illuminates the disproportionate impact of COVID-19 on women generally, as well as stark inequalities—the pandemic continues to disproportionately effect the sexual and reproductive health of those already experiencing systemic social and health inequities.^{42–44} In many countries, policy makers are also seeking to remove women's sex-based inequity of access to healthcare by putting in place strategies to further optimize women's healthcare and to equalize outcomes between men and women.⁴⁵

Limitations

We did not power the survey for subgroup analyses and are therefore not able to explore any difference that might exist between those of different races/ethnicities, those who identify as lesbian, gay, bisexual, transgender, or queer, or those living on low incomes.

CONCLUSION

Future pandemic planning needs to look more holistically and longer term at what is and is not classed as an emergency, both in how services are reconfigured and how people with chronic conditions are identified, communicated with and treated during extraordinary events. Health services delivered during public health emergencies

need to take account of the CKD pregnancy window, prioritize these women's reproductive planning wherever possible, improve access to support for those who are coping with the grief of termination and/or being unable to have a family as originally intended. Hybrid and individually tailored models of face-to-face and virtual care and support are needed so that the reproductive needs of women can be maintained during both exceptional and "normal" times.

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ETHICS STATEMENT

The study received full ethical approval. Wales REC 1 committee 20/WA/0157. We provide a more detailed account of ethical considerations in the published protocol.¹⁹

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