

Session 4a Transcripts for initial coding (excerpts only)

Study title: Perspectives on pregnancy in women with CKD

Transcripts have been de-identified and only excerpts have been included.

Participant 1 (Woman, aged 20s, diagnosed at age 24, with a kidney transplant)

My whole life I just thought what's the point, what's the point of like entering a relationship with any nice guys. When all you are going to do is disappoint them because your body is a failure. You don't know how long your transplants are going to last for, every time you come in here it's just depressing if you don't know what the result's going to be like. You're just living on edge your whole life. It's hard to explain, but I just... even if you have the post transplant, you kind of still look at your body like it's a ticking time bomb.

And I don't care about scars anymore; scars they're a wing for me having the scar, I just see what docs can do is amazing, but at the same time there's this mentality that we I have children. Which is heartbreaking; and which is why I'm single. I've had relationships in the past and mine have only been quite short because any time you bring up that you've had a transplant, you feel like a freak, but they don't always think that. The guys generally they're lovely, but their family might be concerned. And their family influences them

If I have a baby, and it kills the kidney or the kidney that he gave me and a child that I cannot raise because I am sick.

To my face I was told, so you can't have children, you can't have children, no you can't. So, and then I was just stuck there going, I can't. Oh my god. And I was also kind of left with that, and then I went home and just sobbing to my parents, like, I didn't know. You know, and then I had to tell my boyfriend at the time; it was pretty hard.

Participant 2 (Woman, aged 30s, diagnosed at age 28, with a kidney transplant, visual impairment)

P: So I had had a terminated pregnancy because of my health and it was about the same time as I was having eye surgery. And yeah, we chose to terminate a pregnancy due to those factors. And then at that time, they put a Mirena in. The insert—

I: **Did you ask for that or they suggested it?**

P: It was because my health as well and so I thought it was a good option at that time.

I: **Okay. So, you've had—you've experienced one termination?**

P: Yeah.

I: **Okay. And at the moment you are pregnant?**

P: Yes.

I: **Have you had any other pregnancies?**

P: No.

I: **So, have you ever received—it sounds like you have received contraceptive advice?**

P: Yes, at that time when I had the Mirena put in and also I saw a gynaecologist about two years after for the fact that when I had met my husband, or he was my partner at that time, we were starting to sort of think about where we would go in regards to having children and also 'cause I had had kidney transplant and the like. So, yeah, we had discussed it.

...

I: **So, he knew about the transplant?**

P: Yeah, yep. So, I had met him – ‘cause I’ve been on dialysis, I was quite unwell and obviously don’t feel like dating. <laughs> So, I’d said to a friend I just wanted to go out on a date and he set us up and we went out for coffee and, yeah. So, he knew when he’d met me that I had had a transplant and everything along those lines. And then, we moved back to South Australia about 18 months – 14 months after we started dating. And then we got engaged about 18 months and then got married about two years after we met, and had, yes, started trying for children then.

I: And at that point, when you just met him and you started the relationship, in your mind were you wanting kids? Or is that something that you were always wanting

P: Yep, definitely. I always wanted children but being a type 1 diabetic, you don’t get a lot of education in regards to if it’s safe. And you see a lot of women that have children as a diabetic, type one diabetic, and they look very unhealthy.

I: You saw? You’ve seen that?

P: Yeah. And I just remember sitting with my endocrinologist when I was child, because I’d had it at a younger age, and he said, “You’re gonna lose your eyesight. You’re gonna lose your kidneys. You’re never gonna have children.”

I: He said that to you?

P: Yeah. And you sort of sit there as whatever I was ten years old going, “Oh! Life seems pretty, yeah, grim, if that’s the case.”

I: Can you remember him actually saying that to you when you were ten?

P: Yeah. You cannot have babies if you get kidney failure and yeah, you’ll lose your eyesight.

I: How did that kind of information affect you?

P: It affected me greatly because you’re going through adolescent so you envision that that’s your fate, and if a doctor’s told you that, you’d believe it. So, I found it difficult to comprehend any other sort of future, to be honest. So, it wasn’t until you start to hear other stories of women having children as a type 1 diabetic that you realise that there was a lot of – there’s a lot wrong with what he’d said. And I had a huge problem with it because you’d see young children with juvenile diabetes, especially on ads and things, where they sit down, they say, “Oh, poor Johnny. He can’t do the same thing his brother can do because he’s got diabetes.” And you feel like saying, “The child can hear that. Why don’t we tell them what a great job they’re doing?” Because it’s hard bloody work being a diabetic as a kid, like, injections, hypos, everything like that. Instead of giving them a pat on the back, we tell them ‘They’re doomed.’ So, I think that was sort of the hardest thing to come to terms with, so yeah.

I: When do—or how old were you when you started realising that there were women giving—

P: About sixteen.

I: Okay. You still in a hospital or...?

P: A friend, a family friend who’s a type 1 diabetic, she fell pregnant. And that just blew my mind because I didn’t—you don’t envision that sort of thing so, yeah.

I: So even at that – have you ruled it out as –?

P: Yeah, yeah.

I: And then you started thinking about it. About kids—

P: Yeah, yep. I just thought that was never an option for me. And you’d always wanted to be a mother because it’s – well, 99% of us always feel that way. So, yeah, it was sort of, yeah, 16 - 17 that I realised it was a possibility.

I: I guess, you know, around the time when you met your partner, how much did you want to have kids?

P: I really wanted children. And I think he really wanted children as well or you presume. Men aren't really good at discussing those sorts of things but it was what I really wanted, to be honest.

I: So how many – did you have in your mind how many you wanted?

P: I always wanted two. He wanted five. <laughs> That's not happening. So, yeah.

I: And so, leading up to trying to fall pregnant with IVF, can you tell me about your decision-making about that?

P: I was told of the risks. The – I think my biggest issue had been that for 12 months, we had tried and it was heartbreaking every month when we would fail basically and then we had a doctor that just kept saying, "Keep trying. Keep trying." And—

I: Was that a good thing or—

P: No, it was horrific because it would break my heart every month because we'd think, "Oh, this is looking good." And if I had had an ovulation injection, you'd sort of bet that that was a good thing happening. And I think it was Christmas last year, I'd had an ovulation injection in December, and so we had done everything right. And then at Christmas time, I hadn't got my period and I was four days late. And we got all excited and then I had a scan with that doctor and she said the lining of the uterus wasn't thick enough and there was no chance of pregnancy. So, that, I think, was the turning point for us 'cause we went—I think my husband's looked and thought, I was very upset every – for a couple of days afterwards. So, I think that was when we had made the decision to take it further, so yeah, and go to IVF. So, yeah.

I: And then you mentioned you had one pregnancy terminated.

P: Yes. It was not a good time in my life because I'd lost my eyesight. I'd had a really good job at that time and I was doing quite well for myself. And yeah, I lost – like I'd lost my eyesight. I was in and out of hospital probably three to four weeks at that time with it all going on. And the partner I had at that time—

I: It was a different partner?

P: Yeah. He was not in the position to be able to go through all that. I had actually gone into another relationship so, yeah. So, it was probably—that was a huge factor for me. It was not to bring a child into the world where I was not fit. I didn't see myself as being a fit person and...

I: Health-wise.

P: Yeah, and mentally as well. We were not – I wasn't in a good place and I wouldn't have had any support; so, yeah.

I: so, with your baby now, are there any particular risks that were like more concern to you?

P: My medication, the effect of my medication on my child is probably the biggest concern I have. I had 10 weeks of really severe morning sickness which, having had chronic kidney disease, you – when you're vomiting or when you're feeling ill, it's not a good sign. So, it was psychologically really hard to get through morning sickness because I honestly thought something was wrong. Because there's no reason for someone to be vomiting that much all day and being so exhausted. In chronic kidney disease, that means you're not in a good place. So, that I found psychologically worrying. But besides that, the medication is probably my biggest concern on my child and yeah, that's probably it. I read a lot of case studies. So, I like to know what possibly could go wrong and what the outcome was and I think that's the key component is not just reading what could go wrong. There's mainly an answer in medicine. So I read a lot of case studies from America, but they were 10-15 years old. And you had to take that into consideration and that was a huge decision in why I'm quite keen on having a caesarean instead of a natural birth because there's a lot of complications in natural births.

I: And that's based on what you've read in the internet case studies.

P: Yeah, yeah.

I: And did you discuss that with the doctors here?

P: Yes, I have. Yep.

I: Okay. And what were they saying?

P: They're in agreeance but because those case studies were about ten years old, very rarely a does a woman go through a natural pregnancy nowadays that has had the transplant that I've had, so. Your creatinine goes up to about 400. There's a high risk of UTIs.

I: What did you think about the risks to the kidney transplant? Was that on your mind or—

P: It was a little bit. Only because I had nearly – like it has only been two and a half years since my transplant and my kidney is doing really well. Every time you go and have bloods done three months—three monthly bloods now, you're always really nervous for the first 24 hours afterwards thinking "Have I done enough?" And, there's a lot of—I think I put a lot of pressure on myself for the fact that really at the end of the day, in order to receive my transplant, someone had lost their life. And that, I think, is the key component in most things I do every day, is that I have to factor in that this person is no longer here and I am. So, I didn't wanna put my transplant at risk for the fact that that seems ungrateful in a way, so that was where my thinking lay. And then after you find out that so many women - like I think there was over 600 women in Australia—

I: Oh, you found that out?

P: Yeah, have had – who've had a transplant have had children, you feel a little bit more reassured that you're not seeming like you're taking it for granted. The thing I found hardest was educating people. Because the first thing people do do after they found out that you'd had a transplant and are trying to get pregnant is—you know, I've had people say it's very inconsiderate of me to do that

I: They've said that to you?

P: Yeah. My sister-in-law really couldn't come to terms with it. My in-laws really – 'cause they're from the country, it's just the lack of education, more – and not because they're not smart people, but just lack of education in this department. They found it difficult to comprehend that someone with my medical background would want to have a child so that I found really hard but I think it's better to educate people than to let them keep on their belief that is inaccurate.

I: So, do you have to be the one to do the educating?

P: Yeah. So, most of the time it's "Oh, everything's going fantastic. Blah! Blah! Blah! Blah!" You're mainly – like, three weeks ago, I spent two days in the hospital 'cause I was dehydrated. So, we'd leave those facts out because they seem to focus on that instead of "The baby's fine. Everything's going fine."

I: Comments like that, does it seep into you kind of emotionally?

P: It does after a while, like it – but then you sort of have to realise that my husband is—like I have very good support from my husband and we are very excited about having a child. And there would be – there's no risk to our, you know, our livelihood or anything like that. It's just people's lack of education and that's all that is.

I: Yeah. Sometimes those comments are really—

P: It is.

I: I can, you know...

P: Yeah. My sister-in-law's not the last person, so it would've been more for the fact that, yeah, it's lack of education. That's all I can put it down to.

I: When you're saying you found out that actually women with transplants do go through pregnancies, did you—where did you hear that from?

P: I read it as well.

I: Oh, you also read it?

P: Yeah. So – and I remember when I had my transplant, the transplant coordinator at that time - 'cause you don't remember a lot when you're going in for transplant, she was pregnant and she said to me, "Well, all going well with your transplant? You'll be able to be a mother like me one day." And that was the first sort of –

it was a really good positive spin whilst you're going in for something that could be potentially not a good thing to go through a transplant but – that sort of gives a little bit of hope.

I: And that stuck in your mind I'm sure

P: Yeah. I could not remember anything else that happened that morning but I do remember the doctor telling me that, so yeah.

I: The coordinator or the doctor?

P: Oh sorry, yeah, the transplant coordinator at XXX.

I: Did anyone else also – has anyone else raised that with you 'cause you would have

P: No, not really.

I: I guess in a way – one of the ways to improve care, do you think it should be proactively raised?

P: I think it should be. I think women should be informed that they have the opportunity. Not, you know, you can have kids now or anything but there is an opportunity because if you have a little bit of hope, that's better than nothing. So, if you're always constantly told and when you're chronically sick or terminally ill, people are always telling you, doctors are always telling you, the worst case scenarios. Sometimes you just need a hope or the opportunity to think that there's something positive out of it all. So that's – yeah, I think that's important.

I: There's a plan to set up a special pregnancy clinic, I think next year. What do you think is really important to provide for women?

...And that's all you need as reassurance; that you're not the first one and that you're not going into kidney failure again. That's really all you need as a support and them to say, "Yep, that's fine."

I: What's an example that she's mentioned or that you've talked about that's really kind of—

P: Sunk in?

I: Helped or sunk in.

P: Probably when my stomach started to grow and when the baby started to move, and I thought I had tightness around my kidney and I became quite concerned 'cause I thought, "Maybe my uterus is leaning on my kidney. Maybe there's some sort of blockage, something's going on." And she just said, "Oh, no. I had the same thing and I had a scan, and no, it's just your uterus stretching. It's nothing to do with your kidney. It's just 'cause we don't have as much sensation down there. Yeah, it's normal."

I: And did you have a scan done to get —?

P: No, she went and got a scan because she was concerned and she didn't have anyone to talk to. <laughs> So, instead of costing me \$300 to go and have the scan, she said, "Oh, no, no. There's nothing that needs to be concerned about." So, yeah, just things like that. So, if you see the growth of your child and ask questions about those sort of circumstances, even like as we are looking at an earlier delivery, and for the fact that her child was born at 36 weeks and was seven pounds and healthy and no complications, those sort of things. And that's sort of the reassurance you do need.

I: Yeah, that helps to get you through —

P: Because, you know, even though she had some setbacks, they came out okay.

I: Yeah, that's a really good point. Is there anything else that you think the clinic can provide in addition to support from other patients who're going through—

Participant 3 (Woman, aged 40s, diagnosed at age 27, with a kidney transplant)

I think the fertility issues have been most significant for me. Having the condition has been somewhat of a curse, largely a blessing, because it's helped me develop and grow as a person in a positive manner.

So the biggest impact of chronic renal disease, I feel is being my infertility and my sadness.

Dr XXXXX discussed with me upfront. It's always been transparent discussions and I've had appointments with Dr XXXXX as well over the years over the years regarding fertility and pregnant. So it's always been front and centre of any discussions, and I suppose it was appropriate to me at the time, having those discussing with me because I was a young woman, and probably coming into a fairly common child bearing age. Yeah, I found out pretty earlier on.

Yeah, that it was uncommon to successfully have a full term pregnancy on dialysis. That was probably in discussion that I had with them, when I was pregnant. So that was later on. That was around the end of 2005; 7 years post diagnosis. And just that I could require fertility treatment to facilitate pregnancy, and it was all kind of the unknown, like in 1998 was when I had the diagnosis, so it was information that was provided to me more along the lines of this is what the outcome would probably be, however in terms of a time line, we can't give it you, because it obviously depended on the progression of my illness, and how I managed myself. You know whether I smoked, whether I drank, whether I had lots of late nights. You know, On the other hand, I was an extremely fit, healthy person. So that slowed down the progression of my renal disease, but what's sped up the progression of my renal disease was IVF.

I was prepared to take that. It was really important to us to try and have a child at the time that we did. We've been on fertility treatment for a while and really felt keen to give it our all.

Were you ever told at any stage, not to even try, by anyone?

We've never been discouraged. The information was always presented to us. Health professionals, no, just provided the information, and then obviously the decision was ours. But I had friends and family members that really discouraged me from doing it.

And I said to [husband's name] to go and pursue his life independent of me, you know we can separate, we can go our separate because being a father was really important to him, and I couldn't provide him with that. But we stuck together, which is good. And then obviously losing our son was very traumatic and stressful for us both, as individuals but also as a couple.

Cause you know, when you are pregnant you probably knew it was a higher risk with the pregnancy

Yes, I did

What was going on your mind during?

I was really scared, I was so scared, I focused more on losing the baby, then what I did on a good outcome

I think fear took over and I was just so frightened on losing the baby, and I realise now at the end of the day we can't control any of that. So I should have really enjoyed the pregnancy and got as much joy out of it as possible. But I was just so scared throughout the pregnancy of things going wrong, and it went wrong anyway

So I should have just embraced that time and really enjoyed being pregnant, because it is an amazing experience.

Participant 4 (Woman, aged 40s, diagnosed at age 24, with a kidney transplant)

No, because I still want to get pregnant <laughs>. It was more of that. I mean, I think we were not – my husband and I talked about it. It was more of – he was saying a lot of our friends wanted to have children and they can't. And then, there're some friends of ours, they're – "Oh, we're not gonna have children." And as soon as they got married, they have children. And so I think at that time, we were just 'whatever'. So, of course, the doctors and the family weren't happy about that "whatever" decision, but at that time we were thinking, "Well, if we're meant to have a child, then we'll have one." And when I got pregnant, that's when – yeah. So we weren't really...

And then, did you go and tell your doctor that you're pregnant? What happened?

So I see a renal specialist at XXXX. And he – whenever he said – well, the first time he saw me, he looked at me and he said, "Oh, you have very good qualification. You have a good career," that's what he said. And he said, "You don't need children." That's all he had to say. And I'm thinking, "What does that mean?"

It's probably 12 years ago. It's probably there written in one of my – but the way he said it's like, yeah; that you have a career, you don't need children. I think it's his way of saying, "Don't have children because of your..." So I don't really know what that – I mean, I'm looking at what does that mean, and I think what he's saying is, "Don't have children."

I remember asking – I think I did ask him – oh, my first reaction; obviously, I feel bad like – because I wanted to have a family. I think in my mind, that's what – I'm not that type of a – I have a good career and – you know. And for some reason, I am that type, right? In my mind, I'm gonna have a family, and I know with my husband now – we were dating for a few years already, and I know we're leading towards that. So I'm thinking – so when he said that, I'm thinking, "Why is he saying that?" And obviously, I feel bad about it. But I think I asked him – I can't remember if I asked him – I did ask him, I think, "Why?" And he said, "Because your kidney is gonna fail." And I think my next question to him is, "If I don't get pregnant, will it stop my kidney from failing?" And he said, "No. It's just that the pregnancy will..." he said. And I think – I didn't really think, I mean, at that time – so in my mind, I'm thinking, well, it's gonna fail anyway. I think in my mind it was like that. But at the back of my mind, too, I'm thinking, "Is he saying I'm not really gonna get pregnant or, if I'm gonna get pregnant, my kidney..." There are two things, right, but it wasn't clear to me. That's why – and that's the same year. At the end of that year, that's when my husband proposed, right?

Well, because they already know I had a kidney problem, and they see it. Sometimes, I take steroids and my face will just blow up 'cause I'm – when we were dating for a while – so sometimes it's their house – so they see me and they know what's wrong. And they probably – they're smart people so they probably will know – I mean, ask around what – and I did ask him out, but my husband said, "You know what, well, they know that but I'm – well, in the end," he said, "I'm the one marrying you. And if we can't have kids, then we can't." And I think in his mind, there are other options. If we really want to have children, then eventually we can adopt or – yeah, I think adoption; that's what we were looking – if we really want to have one. So he said, "I don't care." Well, they said – he said he didn't – they didn't mention anything about having grandchildren. But it was in my mind; I knew that it's very important for them to have grandchildren, although my husband still has a younger brother. So he was saying, "Well, if I can't have one, it's..." you know, these things. But I'm just worried that they wouldn't like me because of that. But, no, they were okay. So when that happened, in my mind I was just thinking, "Okay, I'm gonna get – it's gonna fail anyways." That's why when I talked to my husband about it, he said, "Let's just wait and see. If you get pregnant, then you get pregnant." But when I got pregnant, it was my father-in-law who wasn't happy about it because he was upset with my husband because it was – their concern is because of that pregnancy, my life is in danger. So it was more of that concern.

I remember when my mum saw me – 'cause after dialysis, I'm just like, "Okay, let's go." I'm just as if nothing's happened. And my mum looked at me and said, "You know how worried people are over there? And here you are..." 'cause I said, "That's how it is," and I think I have just this sense of peace, I think, in –

I think without even really explaining to you why, it's more of like they didn't even ask you what your plan is and what you're thinking about, and then – especially like what I said, for me, I've always known I wanted a family.

And when someone tells you, "Oh, you can't," and you're like – and I wasn't even married. So I was like, "Okay." It was, I think, pretty – it was devastating knowing that – it's like, yeah. It was already very frustrating knowing you have that disease. When I first found out and they started talking about kidney transplant, I'm like, "What does that mean? At 24, what does that mean?" And then, they are saying, "Oh, you can't have children." And you're just, "Why," and – "Because you can't."

When I was on dialysis, because they do explain to me – and then they did – I remember them saying, "Oh," they said, 'cause in the dialysis machine they always see that my blood – I have lots of blood clots, and I remember they were even saying, "We're even surprised that you got pregnant," because they were talking about my – I would always miscarry because my blood clots all the time. And it's something – when they had that medical term at that time – but that was what I got from that. So they said, "We were even surprised you got pregnant," number one. So – and then I said, "So why did..." that's when I started to say, "Why were they saying..." and I think because they were saying, "You know what? When your kidney fails..." So it's just when you get pregnant – as soon as I get pregnant – my kidney fails. Well, if I don't get pregnant, obviously I can prolong it for about five, six years. And I said, "So what's the issue then?" But because they said with dialysis, you can only have a dialysis up to a certain number of years. And after a while, your body can't anymore and, well, obviously you'll need a transplant. But transplant is something you don't know if you can have it or not. It depends. So I think that was the concern, but that wasn't explained to me. I was thinking then, "Fine. Fail now and just have dialysis every day." I think that – even without knowing what dialysis is. So that was – but I think in my mind, I said, "No, I wanna have children, and I don't care what they say." Especially the – I think if he said, "Oh, if you don't get pregnant, your kidney is gonna be okay," then probably my – that's something I have to think about, right? But I'm thinking, "Well, in the end, it's the same thing; my kidney is gonna fail except that that will give me five extra years." But I'm thinking, "Well, this one will give me a child so <laughs> say yes." So I'm thinking, yeah, I don't care. I think from a doctor's point of view, I understand. I think they are just looking at you.

They're just probably looking at your kidney really, looking after your kidney, but not really thinking about what you are as a whole person.

So my child was a year and three months. And then, after a year of the transplant – so obviously with the medicine and I'm quite stable already – I remember my renal doctor asking, "Are you thinking of having another child? 'Cause..." yeah, 'cause what I – "So are you – now that you have one, are you thinking of having another child?" And I said, "Well, obviously you wanted children..." I wanted more, but I went home and again I told my husband, "Oh, my doctor is asking." And then, we thought about it; it's too risky, I think. What if my kidney failed again and we have a baby, and it's hard. And then, he said, "I don't think we should push our luck <laughs>." We've been really, I mean, lucky to have a successful pregnancy and to have a healthy child, and he was saying, "No, I don't think we have to push our luck." So – and then I told – so I went back and told them, "No, we won't be having," 'cause they said they will change my medicine, make it – 'cause I think I am drinking strong. So they said, "We can adjust; we can change it to different types of medicine to accommodate if you want to be pregnant again."

I think the risk – 'cause we were saying, "Well, I'm a transplant patient. There is a lot of risk associated with what – healthy women who get pregnant sometimes develop all sorts of problems during pregnancy." And since I'm a transplant patient already, we were thinking – and we know as a transplant patient, you easily get sick and it's more – well, in the past nine years of being a transplant patient, I was hospitalised probably three times. And it's always associated to a different disease rather than the transplant. But because of my very low immune system, I really get it bad. So we were – and I knew, and that's what's good now that I was informed. When I had my transplant, they explained to me what's gonna happen; what do you expect, possible side effects and all these things, right? So when we were asked to, and I – well, my husband's not too – he's more of 'up to you', but it was me who was more of 'I wanted to have more children'. But at that time, in my mind' too, I have a baby and I'm like, "Oh, no." And at the same time, that's it. I mean, I don't wanna push it anymore.