Beliefs and experiences of pregnancy in women with chronic kidney disease: systematic review of qualitative studies

Allison Tong[1,2], Shilpa Jesudason[3,4], Jonathan C Craig[1,2], Wolfgang C Winkelmayer[5]

[1]Sydney School of Public Health, The University of Sydney, Australia [2]Centre for Kidney Research, The Children's Hospital at Westmead, Australia [3]Central and Northern Adelaide Renal and Transplantation Service, Royal Adelaide Hospital, [4]Australia Department of Medicine, University of Adelaide, Australia, Division of Nephrology, Stanford University, United States

Background

Achieving parenthood in women receiving renal replacement therapy is challenging due to reduced fertility and the substantially higher risk of adverse outcomes. Clinical decision-making and management involves weighing the potential complications of accelerated decline in renal function, maternal morbidity, perinatal loss, pre-eclampsia, and poor fetal outcomes against the preferences and values of women with chronic kidney disease (CKD).

Aim

To describe the perspectives and experiences of pregnancy in women across all stages of CKD.

Methods

- MEDLINE. Embase, PsycINFO, CINAHL, references lists, PhD dissertations were searched to September 2013
- Inclusion criteria: any qualitative study that explored the perspectives of women with CKD on their knowledge, decisions, beliefs, and experiences of pregnancy
- Thematic synthesis

Results

- 11 studies involving 250 women with CKD (haemodialysis [n=72], peritoneal dialysis [n=16], kidney transplantation [n=45], unspecified modality [n=117])
- Characteristics of the study (Table 1)
- Themes and quotations (Table 2)

Conclusion

For women with CKD, decisions about pregnancy can be emotionally complicated by the threat to their own health, burden on their family, and the perceived risk of delivering a malformed baby. Shared decision making about pregnancy in CKD may be enhanced by developing decision aids that integrates evidence on pregnancy outcomes and patient's preferences. Multidisciplinary care involving nephrologists, reproductive and obstetrics specialists, and psychological support may help patients better manage pregnancy issues in CKD.

Table 1. Characteristics of the included studies

Study ID	Country	n*	Age range (yrs)	Stage	Conceptual methodological framework	Data collection (qualitative)	Analysis	Topic
Peer-review journal articles								
Arslan 2009	Turkey	10	27-49	HD	Qualitative research	Face-to-face, semi-structured interviews	Descriptive content analysis	Sexual experiences
Berlardi	Brazil	15	Mean 27.5	Pregnant Tx recipients	Phenomenology	Psychological interviews	Thematic analysis, hermeneutics of meaning	Maternal concerns, psychological aspects
Corbin 1987	US	3	21-38	CKD/Tx	Grounded theory	Face-to-face interviews, observations	Grounded theory analysis	Management of pregnancy
Crowley-Mataoka 2005	US (Mexico)	22	17-62	Tx	Ethnography	In-depth interviews, observations	Thematic analysis	Kidney transplantation
Nazario 2007	Brazil	9	-	HD	Clinical-qualitative	Face-to-face, semi-structured interviews	-	Fantasies about pregnancy and motherhood
Ekelund 2010	Sweden	9	26-84	3HD, 6PD	Qualitative research	Face-to-face, semi-structured interviews	Discursive	Psychosocial problems
Hodgkinson 1990	UK	114	18-45	ADPKD	Survey	Interview administered survey with open ended questions	-	Prenatal diagnosis
Urstad 2012	Norway	7	26-67	Tx	Qualitative research	Face-to-face, in-depth interviews	Hermeneutic tradition (Kvale)	Educational experiences in the early post-transplant phase
Yilmaz 2010	Turkey	10	-	PD	Qualitative research	Face-to-face, semi-structured and in-depth interviews	Thematic analysis	Sexuality
Doctoral Dissertations								
Hollingsworth 2006	US	1	40-45	Tx	Qualitative biographical study	Face-to-face, in-depth interview, documents and records, observations	Biographical analysis	Illness experience
Fatani 2008	UK	50	24-59	HD	Grounded theory	Face-to-face, in-depth interview	Grounded theory analysis	Illness experience in Saudi women

*Women with CKD

Table 2. Themes and illustrative quotations

Theme	Selected quotations from included studies
Pursuing motherhood	• To be a mother must be good, right? I think it is the every woman's dream….to build a family…(Nazario 2007) • Sometime I ought to be able to get a kidney so that I can have children and establish a family. (Ekelund 2010) • I have already thought that, if I got married, I would adopt a child. But I have already given up the pregnancy itself because of the risk that I run, that the baby runs. I have dealt this subject with my family and I have already talked about it with them. (Nazario 2007)
Failure and blame	• The [in-laws] always ask [my husband] why he can't find someone healthy. They are worried that I won't give them grandchildren. (Crowley-Mataoka 2005) • The interviewees had found themselves facing a social pressure, unveiled by metaphors, such as "to be a tree without fruits" or a "dry tree." (Nazario 2007) • I wish to be married from time to time. Sometimes I have thoughts like 'will I ever get married' or 'nobody wants to get married with someone like me'. I feel exhausted because of the disease and I'm not sure if I can meet his sexual needs or if I can be pregnant. I do not have the right to make people unhappy. (Yilmaz 2010)
Fear of birth defects	• I worry about the child being retarded or malformed, things that never happened in my family. I worry about the drugs I take because of my kidney, the prednisone and Imuran. I wonder, if I am not taking too much of a risk. (Corbin 1987)
Insecurity in decision-making thorny	• Some options, such as high dosages of medications, carried risks of their own, while other like prolonged hospitalisations or bed rest at home had the potential for bringing about negative consequences to family life. Under these conditions, it became necessary for women to weigh all of the potential consequences and then to make their choices. While it was the needs of the pregnancy that were given priority…it was not an easy choice for the women to make. (Corbin 1987)
Withholding emotional investment	• I am having a [baby] shower after the baby is born. The more things we have the more I would have to get rid of, if the baby were still born or something. I fi had completely finished the room and put my whole self into planning, it would be even more disappointing. I think what really hurts is when you have done through all of these plans and then they fall through. I'll wait until the baby is born, then if everything is all right, I'll get the close and emotionally put myself into the baby." (Corbin 1987)
Control and autonomy	• I'll never forget the day the doctor pulled me in after I'd had my first child and told me that I shouldn't have any more kids, and how traumatic that seemed to me, to have him just casually say, 'Well you need to be happy with—with the child that you have, because you really should not try this anymore.' I don't think anybody is quite prepared to hear a doctor say that to them, much less that casually. (Hollingsworth 2006) • I heard him say those things, but being a mother was so important to me, and I really did not grasp when, what, and how those words would translate into reality for me. I may have been in denial to some degree, even though I certainly knew I was sick. But it was important for me to be a mom—a good mom. From a pure medical standpoint, it was a very risky decision. (Hollingsworth 2006)

Address for correspondence
Allison Tong, Centre for Kidney Research,
The Children's Hospital at Westmead, Westmead
NSW 2145, AUSTRALIA Tel: +61 2 9845 1482
Email: allison.tong@sydney.edu.au

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M) Dialysis. M8) Epidemiology, outcome research, health services research in CKD 5D.
Allison Tong
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