

Perspectives and experiences of women with a kidney transplant on access to healthcare – an international qualitative study

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Women in Transplantation



an Initiative of
The Transplantation Society

Aims and Methods

- **Background:** women are less likely to receive a kidney transplant and more likely to donate one, discrepancies may be exacerbated related to culture and income
- **Aims:** to describe the perspectives and experiences of women kidney transplant recipients in different cultural and economic settings on access to healthcare throughout their transplantation journey focusing on women specific issues
- **Methods:** purposively sampled, semi-structured interviews on videoconferencing from August, 2022 to January, 2024 until data saturation

Results – Demographics

Characteristic	Women (n=40)
Age	
18-30	3 (7.5)
31-40	7 (17.5)
41-50	15 (37.5)
51-60	8 (20)
61-70	6 (15)
>70	1 (2.5)
Country of residence	
High income countries	21 (52.5)
Upper-middle income	7 (17.5)
Lower middle income	12 (30)

High income countries: Australia, United States, Canada, New Zealand, UK, Belgium, Chile, UAE

Upper-middle income: Fiji, South Africa, Mexico

Lower-middle income: India, Philippines, Cameroon, Kenya, Bolivia

Characteristic	Women (n=40)
Type of kidney transplant	
Living donor transplant	25 (62.5)
Deceased donor transplant	13 (32.5)
Paired kidney exchange	2 (5)
Current menstruating status	
Menstruating	16 (40)
Perimenopausal	4 (10)
Post menopause	20 (50)
Pregnancy or attempted pregnancy	
Not attempted/None	16 (40)
Pre-transplant	16 (40)
Post transplant	8 (20)

Results – Themes and Subthemes

- **Bearing the responsibility for health care**
 - Disempowered by lacking information
 - Unresolved psychosocial distress
 - Exhausted from self-advocating
 - Navigating silos within healthcare

“It'd be nice if there was someone who would focus on me... (as a) kind of person in all aspects of that, and not just. Oh, I go to this person, and I'm a kidney. I go to this person, and I'm a uterus” (HIC 41-50)

Results – Themes and Subthemes

- Stigma around gender sensitive topics
 - Unprepared for changing body image
 - Loss of intimacy and femininity
 - Vulnerability of mental health
 - Burdened by unexpected continence challenges
 - Unexpected menopause and menstruation changes
 - Devastating effects of HPV

“Cyclosporin caused hair growth. For a young lady that's not the thing. Especially like micro, thin eyebrows were in style. The thing is when I switched to tacrolimus, I had the opposite. I started losing my hair, I was in high school, it was already the worst. And I had like the prednisone cheeks. I remember a friend of mine the first day I came back from being on home-school and dialysis, she was like, hey, are you related to XXX? You look just like her. And I was like, I am her.” (HIC 31-40)

Results – Themes and Subthemes

- Struggling to achieve parenthood
 - Facing difficult choices
 - Grieving lost opportunities for parenthood
 - Medicalization of journey to motherhood
 - Challenges and guilt in the role of caregiver

“I'm very pragmatic, and it's kind of like the question being asked like which would you prefer your kidney, or being a mom? That's kind of like your ultimatum that you're given, and it's like I'd love to be both.” (HIC 31-40)

*“That is what they told me, don't even think about getting pregnant,no, that is, it is ruled out.”
(UMIC 18-30)*

Results – Themes and Subthemes

- **Social vulnerability exacerbating barriers for women**
 - Forced to financially depend on others
 - Fear of relinquishing decision making

“I was very young, and my work didn't give me insurance... You don't think about taking an insurance soon after you get out of college... But my brother had insurance... They said they'd only pay a little bit... By the time I came to my second transplant my husband had put me on his office plan.” (LMIC 41-50)

Conclusion and future directions

- Women transplant recipients face challenges:
 - Feeling underprepared for transplant and life after transplant with regards information, psychosocial support and feel abandoned across healthcare teams
 - Have concerns re gender sensitive topics and family planning
 - Feel vulnerable as women dependent on others
- Ways forward:
 - Education for women, their families and their health practitioners (especially around gender sensitive issues and family planning)
 - Ensuring a multidisciplinary approach to patient care
 - Adequate provision of psychosocial support through transplant
 - Advocacy for these changes through WIT and TTS

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