

Pregnancy After Solid Organ Transplantation



JANE M. KURZ, PHD, RN
LASALLE UNIVERSITY
SCHOOL OF NURSING & HEALTH SCIENCES
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Jane Kurz, PhD, RN/LaSalle University



- Objective: At the end of this presentation the learners will be able to describe the experience of a select group of solid organ female transplant recipients making their decisions about a pregnancy.
- Temple University (former employer) provided internal funding to conduct this study.
- I deny any conflict of interest, financial or otherwise.

Background



- Organ transplantation is a life-saving intervention for end stage organ failure
- Life after transplantation has many challenges (e.g., infection, rejection, other complications)
- Normal reproductive function (& improved quality of life) returns post transplant for many pre-menopausal women
- Women living with other chronic conditions and illnesses want to take part fully in life's roles and need social support.
- Many couples struggle with the decision to become pregnant

What is known?



- Pregnancy prior to graft stability often result in spontaneous abortion, organ failure, maternal death
- One in 20 pre-menopausal transplant recipients become pregnant post transplant
- 90% of all pregnancies that progress past the first trimester results in a live birth
- Maternal problems=ectopic pregnancy, Pregnancy Induced Hypertension, gestational DM (lungs)
- Infants problems= prematurity, low birth weight
- Registries collect quantitative data
- We do not know how women use this information.

Purpose



- Women on listserves asked: Should I become pregnant?
- To explore the reproductive decision-making process with female organ transplant recipients (renal, lung, heart & liver transplants)
- To provide new knowledge about clinical decision making regarding pregnancy for female solid organ recipient and health care professionals.

Design



- Grounded Theory
 - Constant comparative method of analysis
 - Data collection and analysis occurs simultaneously

- Mixed Methods
 - Used taped telephone interviews and 2 written surveys
 - MOS Social Support Scale
 - SF-36 Health Survey: Well-Being Scale

Interview



- “Tell me about yourself and your transplant.”
- When did you decide you wanted to become pregnant?
- How did you prepare yourself for a pregnancy?
- Who supported your decision? Who did not?
- Subsequent questions followed the natural flow of the conversation.
- After the 3rd interview I added question about post-partum depression

Other details



- A typist transcribed responses exactly as they were spoken.
- Researcher checked tapes against transcript and made corrections.
- Each interview was 25 to 45 minutes.
- Participants received a \$25 Visa gift certificate after the interview is completed and a \$25 Visa gift certificate after completed surveys were returned.
- Two did not complete surveys

Sample



- Advertised for women on web sites:
- Second Wind Lung Transplant Association
- Transplant Recipients International Organization
- National Kidney Foundation
- Facebook:
 - 1) Pregnancy & Motherhood After Organ Transplant Group
 - 2) Organ Transplants Across the Globe



Sample



- Theoretical Sampling
- Women (N=9), all US citizens
- Age : 29-42
- Organ Transplanted: renal (7), lung (1), heart (1),
- Live Children: one (5), two (1), pregnant now (2),
- Waiting to try within 3 months (1)
- Race: 8 Caucasian, 1 Black



Establishing Credibility, trustworthiness

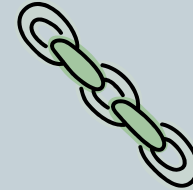


- Allowing adequate amount of time for each participant to share her story
- Create an audit trail (in field notes, transcripts, coding)
- Another researcher (experienced in qualitative methods) analyzed sample transcripts and check for congruency with researcher's codes.
- Search for disconfirming evidence (Social Support in surveys & transcripts)
- Member checking

Coding



- Open Coding
 - E.g., Partner supporting, family supporting, transplant team supporting, peers supporting, OB team supporting
- Axial coding : connecting the categories
 - E.g., supporting the decision
- Selective coding: core category & themes



Core Category




- Wanting a Child
- Themes:
 - Getting information
 - Dealing with problem.
 - Preparing
 - Talking to each other
 - Supporting (or not supporting) pregnancy decision
 - Coping
 - Advocating for self
 - Advising others

Getting information



- Good, I'm so glad you're doing this because I remember when I was looking at getting pregnant, there was so little information out there that I'm so happy to be able to supply it to other people.
- I did some Google, I went, oh yea, I ah, there's this transplant registry, but so yea, I Googled and I found that and I talked someone there.
- Then I started finding other Internet support groups. But I also talked to, before I even, I met one woman that had a baby with a kidney transplant.

Dealing with Problems



• And then the post-pregnancy I had my stomach opened up, like 2 or 3 days after I had the Caesarian section. And then it opened and it was opened for 7 weeks.someone had to pack my stomach twice a day with gauze and then eventually it healed like in 7 weeks... that was just, that was the worse part I guess, cause otherwise the pregnancy seemed fine.

- Hypertension
- Exhaustion (anemia)
- Waiting to get pregnant but it did not happen
- Coordinating frequent physician visits
- Work schedules

Preparing



- “it was very easy. It was a great team and you know it was just easy, it wasn’t like I had to worry the next step well OK where do I go, they already did the referral within like, they already talked to the doctors”.
- Medication changes: “They (transplant team) changed it from Cellcept (Mycophenolate or Myfortic) to Azathioprine. So it was only Azathioprine (Imuran) and Tacrolimus (Prograf).
- So I ended up going to like, like, then I ended up going 4 times a week to the doctors. So it was a very hard, the 2nd, the 3rd trimester was very hard because they didn’t know when I was going to deliver. They were hoping I could carry to at least, at least to 35 weeks. They were hoping but they said, “ any little thing, we’re delivering you”.

Talking to each other



- There, I just happened to get recommended to Dr. S at Y Hospital so I had to find a new nephrologist, new cardiologist, so everybody has to be at one hospital they said to me. This way they can all talk a lot. They can all see my test results in one system. Makes it easy.
- Like my nephrologist and the obstetrician. But they didn't like, I don't know, they didn't do too much coordination.Yea, I feel like the obstetrician could have been more on board actually, OK. Cause like the day when, when it happened, it was just like so, it was like very, like they called, in the hospital my nephrologist should happen to be in the hospital that day so it was good,



Advocating for the Pregnancy



- You have to have, first of all, you have a strong will to go through this.
- I gave my team articles from the registry.
- my cardiologist ...actually had called me up, and he was like, I think he was the last doctor who kind of deliberate on this, and he called me up and he's like, look I'm happy with your echo and all your blood pressure readings and your overall general physical health. And I'm sure your world is just spinning, you know, that's kind of above what we'd expect from you, so if you were my wife I would tell you to go ahead and do it. So, that made me feel better.

Supporting



- Yea, they were, I mean they (*the family*) were like a little nervous. But I mean they didn't really know, they just meant it was OK, you know I got the OK from the doctors, so they didn't know what to expect and then and I guess once like it happened and the baby wasn't an issue .
- ...My husband is wonderful. He could not be more supportive and he's even said to me if you ever need another kidney I'm going to see if I can donate
- All stated that they had social support & that matched the high scores in surveys (one exception)

No support



- she (*sister*) was kind of like amazed, I mean before. “oh I hope you are not thinking about getting pregnant”. And she kind of felt like, you know ,I had the, you know I was lucky to have one child, I shouldn’t like push the limits. Cause she was kind of like not on board
- he (*physician*) kind of said, like, when I mentioned it, ...in my early 20’s, mid 20’s when I got married, like I said, like, yes, I was like planning for the future, he just kind of like cut me off, he didn’t want to hear it. He was like, no, that is going to be too much risk and disappointment. ...I kind of thought to myself, OK this guy’s not supporting it so I’m going to have to find a different nephrologist -- in the future.

Coping



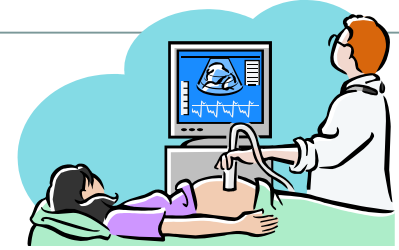
- “I have a lot of faith in God. I’ve a lot, yea I’m very like ah spiritual, but yea. So that’s where a lot of my strength is”.
- acupuncture
- “It was like well these are the facts and then I went from there, and I told them it wasn’t any cause for a decision ...I feel more comfortable overall, very little anxiety.”
- “it was a good defense mechanism, I’m not talking to you (co-workers, other patients) if you have something bad to say”.

Advising Others



- Wait for appropriate amount of time (2 years) after transplant
- Be in good health. **“Follow to your regimen. Listen to your transplant doctors. Do your labs...”**
- Gather as much information as possible
- Arrange a good support system
 - **“find the medical team that's, that's dealt with transplant patients...and again you had to be really aggressive it seems to find your best medical team”**
- Be assertive
- Prepare for life after delivery
- Surround yourself with those who support you (no negativity).,

Conclusions & Future



- There is a group of transplant recipients who want to have a pregnancy as part of their post transplant life.
- Health care professional do not always have the most accurate information to advise transplant recipients
- The resilient women in this study sought accurate information about risks for graft, mother and child and made informed decisions with their partner.
- All had supportive partners & health care teams.
- Future studies: Need more women with lung/heart and liver transplants to be included & partner's view

Questions?



- Thank you for your kind attention.

