Research and Programming Update: Women Living with Spinal Cord Injury

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Objectives

• Present results of qualitative phenomenological study of pregnancy and motherhood following SCI
  • Pregnancy and Motherhood: Improving Services for Women Living with SCI
  • Current literature review

• Describe Ladies in Motion: social group for woman with disabilities
Objectives of Study

- Understand the experiences of women with SCI who undertake pregnancy and motherhood
- Determine if their needs are being met
- Discover what resources are being utilized
- Learn how to improve upon currently available interdisciplinary services and resources
Literature Review

Parenting with a Disability
- Number of people living with disabilities choosing to become parents increasing; limited data/research on their needs and experiences
- Lack of awareness among health care professionals on the unique needs of person with disability during pregnancy/parenthood
- Significant legal, medical, familial resistance

Pregnancy and Motherhood with SCI
- 80% of persons with SCI are men in US
- Women with SCI have deep isolation that health care professionals are unable or unwilling to address their unique challenges
- Limited resources to guide women through female specific issues
  - Pregnancy
  - Motherhood

National Council of Disability, 2012
Literature Review: Attitudes and Experiences

- Lack of education on pregnancy following SCI
- Unsatisfactory quality of resources
- Women with SCI in childrearing years do not desire to become pregnant due to perceived difficulty of completing child care tasks and lack of support
- Women who had children SCI report that motherhood increased their quality of life

Ghindi, 2008
Health Concerns & Medical Complications

Common Complications
- Vaginal infections
- Urinary complications
- Increased spasticity
- Pressure sores
- Back pain
- Autonomic dysreflexia

Sensory Awareness
- Ability to recognize labor
- Ability to feel contractions
- Women with SCI at risk for preterm labor
- Should be educated on home uterine activity monitoring

Ghindi, 2008
Summary of Gaps in the Literature

• Risks and medical complications for pregnant women living with SCI clearly defined by the literature

• Research Gaps:
  • How to minimize identified medical complications
  • Functional implications of pregnancy on women with SCI
  • Factors impacting participation and satisfaction during motherhood for women with SCI
Study Design: Methods

- Qualitative mixed methodology design
- Interpretive phenomenological framework
- Structured survey & semi-structured interview

- Purposeful sampling
  - Adaptive recreation organization
- Nine initial respondents
  - Two stopped responding after survey was sent
  - One cancelled interview due to personal reasons
- Five qualified women participated in study
Study Design: Procedures

Survey

• Consent: Cover letter
• Qualified participants E-mailed a pre-interview survey
• Tool to generate custom scripts for semi-structured interviews
• Survey questions: Medical complications, OT/PT experiences, additional assistance needed for ADL, & ability to perform child care tasks

Interviews

• Consent: Form signed in person
• Interviewed at place of choice
• Chosen locations: Three at participant’s homes, one in private room at University Hospital, one at coffee shop
• Audio taped and transcribed verbatim
• Forty-five minutes to one hour long
Study Design: Credibility

• Triangulation
  – Committee members and one community clinician reviewed one interview and preliminary themes of all interviews

• Member Checking
  – Participants were E-mailed their narrative analyses and asked to ensure accuracy of author’s analysis

• Reflective Journal
  – Kept throughout research process
  – Surprised by gratitude of participants
  – Participant’s desire for outreach
  – Impact of my pregnancy on my perceptions and connection with data gathered
Data Analysis

Narrative Analyses
• Detailed account of phenomenological experience of each participant
• Interpretive summary of each interview with reference to research question

Thematic Analyses
• Transcription of interviews
• Structural coding
• Concept mapping
• Final themes
Narrative Analyses
Participant 1: Marcy

- 38 year old mom living with C5-6 incomplete SCI
- Proud mom to five year old daughter, adopted newborn
- Experienced over 5 miscarriages and one still birth over the course of 8 years
  - Usually miscarried around 17 weeks, related to orthostatic hypotension
  - As a pregnant women with a SCI, felt like she was part of a ‘micropopulation’
- Required assistance with transfers, shaving legs, and dressing due to weight gained during pregnancy
- Medical complications during pregnancy
  - Violent spasticity when baby moved
  - Skin breakdown: unable to fully pressure release
  - Autonomic dysreflexia
  - Autonomic dysreflexia
- Received harassment from some community members and the Department of Child services through unfounded allegations
- Will only adopt older children in the future to avoid stigma
- Wishes to be acknowledged as a mom by her daughter’s doctor and have more support from family members
Participant 2: Kara

- 55 year old mom living with C6 complete SCI
- Four sons; one set of twins
- Difficulty finding adequate prenatal care at first
  - Asserted self and found excellent doctor
- Pregnancy: AD and loss of independence with ADLs & transfers
- Too much hired help
  - Completed tasks she could have done at slower pace
- Difficulty breast feeding
- Desired peer mentor relationship
- Supportive husband
- Believes ignorance can be mended through education
Participant 3: Jennifer

- 45 year old mom with non-traumatic T5-12 incomplete SCI
- Mom of seven and grandmother to one
  - Had all children prior to SCI, ranged from ages 2-22 at time of injury
  - Five biological children, two adopted
  - Unique family make-up
  - Youngest child feared her after injury
- Complications from SCI interfere with her roles as mom and grandmother
  - Helping in children’s classrooms
  - Hosting family dinners
  - Bathing, lifting, carrying, playing with children
  - Family outings
- High expectations of family
- Limited by depression, pain, upright tolerance, low energy
- Discharged herself prematurely from outpatient therapy, no energy left for family
- Grateful for Therapeutic Recreation and Independent Living Skills (TRAILS)
Participant 4: Amanda

- 33 year old mom with T6 complete SCI with concurrent TBI
- Mom to 6 year old son, currently pregnant, one early miscarriage
- Poor appetite, gained little weight, remained independent throughout pregnancy
  - Pre-term labor
- Satisfied with health care during pregnancy
- Independent with all child care tasks except bathing and traveling
- Excellent support system
  - Supportive, rural community
  - Family
- Son helpful to mom
Participant 5: Emily

- Mom to four year old daughter living with T5-6 incomplete SCI
- Having a mom with a disability is a blessing to her daughter because her daughter sees every day how people can be different without limitations
- Easy pregnancy
  - Mountain biked daily
  - Doctor advised her to gain minimal weight
  - Remained independent with ADLs with modifications
    - Cathing
    - Transfers
- Training and equipment exploration
  - Frequent trips to Baby’s ‘R Us with husband with 5lb sugar bag
- Never experienced doubt from health care professionals, but has friends that have
- Wants to eradicate fear and ignorance by providing knowledge
Thematic Analyses
Knowledge to Promote Awareness

- Knowledge about pregnancy/motherhood and SCI was largest factor in influencing positive and negative experiences
- Health care professionals, the community, family members, and mothers
- Regardless of amount and severity of positive and negative experiences, all five women loved being a mother
  - Increased life satisfaction
  - All women had mixture of positive and negative experiences
- Negative experiences: Lack of and ignorance to gain knowledge
- Positive experiences: Receptiveness to and presence of knowledge
CONTRIBUTING FACTORS TO POSITIVE AND NEGATIVE EXPERIENCES
Positive Experiences

• Use of adaptive equipment
  – Babys ‘R Us
• Strong self advocacy/self-initiation skills
  – Seeking out competent health care professionals
• Strong support network
  – “We can just have fun and the kids can see that I’m okay. We know that things are safe and we can still have fun together. Life is not over.”
• Co-occupation with infant
  – “What is very, very interesting is it was like the baby knew Amanda’s condition. She would go to lift him up and he would lean forward with his arms raised. And whenever she had a hold of him he laid really still and was quiet. But when anyone else held him, he was all over the place. He just knew what her needs were.”
Negative Experiences

• Negative encounters with health care professionals
  – “If you luck out, you get somebody who can really help you. If not, you’re on your own.”

• Medical complications during pregnancy
  – Spasticity, autonomic dysreflexia, orthostatic hypotension, skin breakdown

• Negative encounters with society
  – “It would be really nice to be acknowledged as her mom. Just because we adopted her it doesn’t make me any less of a mom. And just because I’m in a wheelchair it doesn’t make me any less of a mom. She doesn’t see it that way, our daughter. I’m completely mommy to her and that’s all she knows. But being acknowledged as a mom, that would be really great.”
Feelings of isolation

“I really feel like I’m part of a micro population. There’s no one to talk to about anything, or get their input or their feedback, or their experiences, or their advice at all. Not my primary care provider or even a specialist.”

“I would do anything to meet other mothers in the same situation. Just to have some kind of validation that you’re not the only one that feels that way. Or that ten years out its going to be okay. I’m just worried that my kids are going to be scarred for life and resentful.”
Contributions: Confirming the Literature and Filling the Gaps

Confirming the Literature

- Women with SCI do not receive adequate education regarding pregnancy, but experience increased QOL as mothers
- Common complications during pregnancy include urinary complications, worsened spasticity, pressure sores, vaginal infections, and AD
- Increased difficulty with transfers during transfers

Filling the Gaps

- ADL during pregnancy dependent on amount of weight gained
  - Pressure release, LB dressing, bladder management
- Relationships between medical complications and ability to maintain independence during pregnancy
- Identification of challenges associated with breast feeding
- Motherhood skills practiced pre-motherhood beneficial
Creating a Positive Pregnancy Experience

- Education on known medical risks associated with pregnancy
- Consultation with Commission on Accreditation of Rehabilitation Facilities
- All women above T6 should be considered high risk
- OBGYN and rehab physician should determine safest medication regimen; balance needs of mother with potential harm to fetus
- Physicians should prepare women for functional changes that will occur during pregnancy, and be knowledgeable about resources
Creating a Positive Pregnancy Experience Continued

• Ensure that women are in good mental and physical health before becoming pregnant
• Ensure that adequate support network is available
• Address unique challenges: bowel/bladder care, skin care, spasticity, pain, treating infections, AD
• Serve as referral source to appropriate professionals as needed: urologist, psychologist, social worker, OT, PT, community resources
• Connect women through peer mentorship programs and peer support groups
Creating a Positive Motherhood Experience

• Participate in OT to prepare for motherhood
  – Simulated training of child care tasks
  – Trial equipment
  – Problem solve home solutions
• Wheelchair accessible crib design
• Include children in rehabilitation process
  – Incorporation of child care tasks into treatment plan
  – Age appropriate education for children
Conclusion: The Essence of the Phenomenon

- Experience of motherhood increases QOL for women with SCI, regardless of amount and severity of positive or negative experiences
- Actions, perceptions, reactions of others greatly influences each women’s lived experience of this phenomenon
- Crucial for family members, the community, health care professionals, and women with SCI to receive education regarding pregnancy and motherhood following SCI so actions, perceptions, and reactions are based on truthful knowledge, not assumptions and fears
Limitations

• Small sample size
• Convenience sampling
• Limited geographical range
• Limited diversity
• Public location of one interview
• Presence of family members during two interviews
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  – Dr. Jeffrey Rosenbluth
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References

Ladies In Motion
A group for females in all stages of life with disabilities related to paralysis

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About Us

• A social organization of women with disabilities relating to paralysis that educates and enhances member’s quality of life specific to a women’s needs.
• This organization is not limited to wheelchair users and is open to women with related disabilities that could benefit from the shared experiences unique to women.
Purpose

• To gain perspective and provide encouragement through education and personal experience.
Goals

• To promote a healthy lifestyle and positive perspective on life with a disability through the encouragement and examples of other members and education from professionals.

• To provide emotional support and camaraderie through shared experiences unique to women following a paralyzing injury or disease.
Proposed Educational Topics

• Sex Life
• Catheterization
• Clothing
• Travel
• Dating
• Pregnancy
• Child Bearing
• Child Rearing
• Self Defense
Educational & Discussion Topics

• **Sex Life** - positioning and propping, lubrication, reflex and vaginal function, sex aids, and sexual expression

• **Catheterization** - anatomy challenges, female specific AE (cath-assist), different options/types of catheterization common for women (suprapubic, indwelling, straight cathing, etc) and types of catheters

**Clothing** - fashion and function, adaptations for women specific clothing (i.e. bras, leggings), popular brands for function
Educational & Discussion Topics

• **Travel** - security, self-cathing on a plane or public transit, and travel with kids

• **Dating** - accessibility of date locations, car transfers with women specific clothing

• **Pregnancy** - UTI, AD, finding the right OBGYN, accessibility of doctor’s office, appropriate baby care equipment and techniques

**Child Bearing** - Self-catheterization while pregnant with vision occluded, increased edema due to decreased movement, increased back pain and WC modifications, mobility and transfers, anesthesia, cesarean -section vs vaginal birth
Educational & Discussion Topics

• **Child Rearing** - Suitable equipment for child care, breast feeding, clothing and adaptations to pick the children up and propel, in/out of a car seat, involvement of activities with the children's schools and sports, (energy levels, discipline, child taking care of parent, hired child care, caregivers)

  **Self Defense** - pepper spray, female wheelchair defense classes
What are other people doing?

• Several “Meetup” groups: non-gender specific, all inclusive disabilities

• “Here & Now Project” - Blog + community meetings for persons in Washington state specific to SCI but non-gender specific

• “CROWD” (Center for Research on Women with Disabilities), organized by Baylor College of Medicine in Houston, TX

• Support group lists for disabled individuals on several spinal cord/state websites - not gender specific

• Support groups for parents and family members of people with SCI/disabilities
What other groups are out there?

**Women on Wheels (WOW): San Diego, CA**

- Meets once monthly at same day/time
- Easy to access website
- Easy to sign up for mailing list
- Parking information
- Led by social workers with community re-integration focus

Most organizations, groups and non-profits are not female specific.
Outline for Past/Upcoming Events

• Monthly Gatherings
  • Each monthly meeting will cover one topic
  • OTs to assist with management of group and facilitate group discussion

• Activities in the Community
  • One planned activity 4x/year
Barriers to Starting:

- Marketing 'Getting the word out'

- Place and time of meeting with consideration of accessibility

- Lack of website

- Effective communication method

- Participants & Involvement: geographical location, time needed to participate and to get ready, family needs
QUESTIONS?

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  Facebook page: “Ladies in Motion”, Organization

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In summary...

• Women with paralysis related disabilities benefit from peer discussion, education and community building.

• A female specific group to address gender specific topics related to living with paralysis is lacking and needed in our community.

• Ladies In Motion is still in development but like us on Facebook for updates and events.

• Please feel free to contact us with questions, comments or suggestions for Ladies In Motion.
Thank You!

- TRAILS Organization
- Dr. Jeffrey Rosenbluth
- Cambry Kaylor
- Danielle Housman
References

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