



SPECIAL ISSUE: Sexual and Reproductive Health of Women with Disability

Research paper

## “Paying the price to get there”: Motherhood and the dynamics of pregnancy deliberations among women with disabilities

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## ABSTRACT

**Background:** Women with disabilities report fewer pregnancies than those without disabilities.**Objective:** To explore the range of factors involved in pregnancy decision-making among women with disabilities, and give insight into the decision making process.**Methods:** Data were obtained from 4 focus groups conducted with 22 women of child-bearing age, who had a chronic physical or mental health condition or disability that influenced their pregnancy decisions. Group transcripts were analyzed using conventional content analysis to identify the types of factors that influence pregnancy decisions and themes related to pregnancy decision-making.**Results:** Most had a strong desire for motherhood, although there were varied decisions and some ambivalence over whether or not to attempt pregnancy. Decisions were influenced by an interplay of biomedical, social and personal factors that shaped assessments of three key areas of consideration: importance, feasibility, and costs of pregnancy/motherhood.**Conclusions:** It is not just the ‘biomedical facts’ of health conditions that are relevant, but rather the meaning attributed to these facts and how they are weighed in relation to other significant non-medical factors. By moving beyond the medical model of disability to recognize the importance of social and personal factors, and engaging in patient-centered communication, healthcare providers can facilitate pregnancy decision-making that is consistent with the values and preferences of women with disabilities and improve quality of care and support. In order to make motherhood a more viable option for women with disabilities, societal attitudes and a lack of role models for these women also need to be addressed.

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For many women the desire to become a mother is a powerful force.<sup>1</sup> Women with and without disabilities hold similar attitudes toward motherhood;<sup>2</sup> yet women with disabilities report more uncertainty about pregnancy intentions and fewer report current pregnancy than those without disabilities.<sup>3,4</sup> Despite legislation such as the Americans with Disabilities Act (ADA), it remains difficult for many to view people with disabilities as potential parents.<sup>5</sup> Medical professionals may not have the expertise to work effectively with women with disabilities who are contemplating or experiencing pregnancy,<sup>6–9</sup> and women with disabilities encounter negative attitudes from strangers, healthcare providers and even their own families related to pregnancy.<sup>9–12</sup>

The literature suggests multiple additional challenges facing these women before and during pregnancy.<sup>7,9–18</sup> Importantly, the dynamics and extent to which these challenges influence pregnancy intentions remains unclear. No study has systematically attempted to inductively identify the range of factors that influence decisions about pregnancy among women with disabilities, nor the dynamics of their decision processes. Furthermore, an apparent disconnect exists between the disability literature, which acknowledges the significant role of socio-cultural issues, and the medical decision-making literature, which emphasizes the biomedical aspects,<sup>19,20</sup> often in isolation from women's values and social contexts.<sup>21</sup> In short, more research in this area is badly needed.<sup>3</sup>

The purpose of this study is to enhance understanding of the deliberations of women with chronic physical and mental health conditions over whether or not to attempt pregnancy. We investigate the factors that influence their decisions and how these

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women weigh the costs and rewards of pregnancy. In doing so, this paper provides insight into the challenges and concerns that make pregnancy and motherhood a less viable option for women with disabilities.<sup>2</sup> This information is critical for developing resources to better support these women in their decision-making process and empower them to achieve their pregnancy desires.

## Methods

Data for this study come from twenty-two women who participated in one of four mixed-disability focus groups that ranged in size from three to ten participants. Focus groups are particularly appropriate for eliciting a range of experiences associated with a specific topic or event.<sup>22</sup> This format offers insights grounded in lived experiences, and allows previously unanticipated factors to emerge as participants respond to each other and share complementary and contradictory experiences.<sup>23</sup> All study procedures were approved by the University of Kansas Institutional Review Board.

### Study sample

Participants were recruited from a list of women identified through the Healthcare Enterprise Repository for Ontological Narration (HERON) database and the Frontiers Research Participant Registry (a collection of University of Kansas Medical Center patients interested in being contacted regarding future research studies), who met our inclusion criteria: female, age 18–44, living within 50 miles of the study site, and who had a diagnosis of a physical or sensory disability or chronic mental or physical condition. Diagnosis codes for inclusion were chosen in consultation with a high-risk OB/GYN physician and grouped into broad categories (e.g. physical disability, chronic physical condition, mental health condition) to allow for recruitment among each category and increase the diversity of our sample in terms of the types of disability being represented. Women were contacted by phone and invited to participate in the study. We excluded women who said that their disability or health condition(s) did not have any impact on their pregnancy decisions.

Our sample included ten women who experienced a pregnancy and/or had biological children and twelve women who had neither. Approximately half the sample was African American, Hispanic, or Asian. A majority of participants (82%) had one or more chronic physical conditions or disabilities, including paralysis, skeletal dysplasia, sickle cell anemia, rheumatoid arthritis, takayasu arteritis, lupus, and multiple sclerosis. Four participants regularly used wheelchairs and two used walkers. One in four of the participants with chronic physical conditions or disabilities had comorbid chronic mental health conditions such as depression, anxiety, or post-traumatic stress disorder (PTSD); although for most of these women the mental health condition was related to their physical condition/disability. Three participants reported only having chronic mental health conditions, predominantly major depressive disorder or borderline personality disorder.

### Interview protocol and procedures

A semi-structured, open-ended interview protocol was used.<sup>23–25</sup> Using broad questions, participants were asked to self-identify what factors influenced their pregnancy desires and decisions, and what barriers (if any) they encountered in making their decisions. Questions were also asked about sources of information, resources they were made aware of or wish they had available to them, and pregnancy alternatives. Guided by a socio-medical model we included questions later in the discussion asking

separately about the role specific factors played in their decision including partners/spouses, family, friends, community, healthcare providers, any other person or group that was influential, and medical factors. At the end of each focus group participants were asked to identify any other factors that influenced their pregnancy decisions that had not yet been discussed. Two of the authors functioned as moderators at each focus group.<sup>26,27</sup> Focus groups lasted 1.5–2 hours. Participants received a \$30 gift card for participating.

### Analysis

Data collection and preliminary data analysis occurred simultaneously.<sup>28</sup> Data saturation was achieved with the four groups; no new factors influencing pregnancy decisions emerged in the last two focus groups indicating further data collection was not warranted.<sup>29</sup> This is consistent with previous research with similar populations.<sup>12,30,31</sup> While our study was guided by a socio-medical model, the data collection and coding procedures were not limited to codes or themes that were developed *a priori*, reflecting an inductive approach to analysis.<sup>32,33</sup> Data were analyzed using conventional content analysis whereby the authors immersed themselves in the data and freely generated codes as they appeared.<sup>32,33</sup> Data codes were aggregated into broader themes and the data further analyzed to identify linkages across themes.<sup>32,34</sup> This was a collaborative, iterative process whereby the three authors separately analyzed the data, compared findings, and revisited the data to verify findings and identify negative cases, resolving discrepancies through discussion and negotiation.<sup>33</sup> We took multiple steps to enhance the credibility and trustworthiness of our data and analysis, including selecting knowledgeable informants, audio-recording and transcribing verbatim all focus groups, engaging three researchers in the data analysis, returning frequently to the data to verify findings, and using direct quotes to illustrate key findings.<sup>28,35–37</sup>

## Results

Our study sample represented a mix of decisions about attempting pregnancy and included women who had already decided to become pregnant and had children, women who intended to become pregnant in the future, women who had no current plans to get pregnant but were more tentative about their long-term intentions, and women with a strong resolve not to get pregnant. Overall, ambivalence and uncertainty were widespread and expressed both by women who intended to become pregnant and those who did not. Many women reported encouragement to choose pregnancy and motherhood that they felt lacked a real understanding or appreciation of their condition and the nuances associated with that decision. As Stephanie, who is paralyzed as a result of childhood cancer and uses a wheelchair expressed: *"It's just very much like, 'you should have a baby!' and 'why don't you try and have a baby?' and not really engaging in the complexity of that with me."* A few participants admitted telling others they didn't want children, even when they did, as it was easier than going into the details about why they felt they couldn't have them. Discouragement or lack of support from healthcare providers and others that failed to consider all aspects of the decision that were important to these women was also common. One woman with multiple conditions described her experience with a high risk OB/GYN: *"He was just very gruff and this is not gonna happen for you. And not taking into account that there was any emotion surrounding that at all ... it was kind of like should I buy this couch or not? Well, you shouldn't."* These accounts reflected an oversimplification of pregnancy decisions that considered only a narrow range of factors and

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