Reproductive Health in Women with Physical Disability: A Conceptual Framework for the Development of New Patient-Reported Outcome Measures

Claire Z. Kalpakjian, PhD, MS,¹ Jodi M. Kreschmer, MSW,¹ Mary D. Slavin, PT, PhD,² Pamela A. Kisala, MA,³ Elisabeth H. Quint, MD,⁴ Nancy D. Chiaravalloti, PhD,⁵ Natalie Jenkins, MA,⁶ Tamara Bushnik, PhD,⁶ Dagmar Amtmann, PhD,⁷ David S. Tulsky, PhD,³ Roxanne Madrid, BS,¹ Rebecca Parten, MSW,¹ Michael Evitts, MS,¹ and Carolyn L. Grawi, MSW^{8,*}

Abstract

Background: Barriers in the built environment, enduring stereotypes and biases, and limited disability competency of health care providers compromise access to and quality of reproductive health care for women with physical disabilities. One way to improve our understanding of critical factors that drive reproductive health inequity and its impact on access to care is to use patient-reported outcome measures (PROMs) that capture relevant and meaningful information about experience. In this study, we developed a conceptual framework as the foundation for relevant and clinically meaningful patient-reported outcome measures targeting the interface of disability and reproductive health.

Materials and Methods: We conducted semistructured focus groups and interviews to assess women's experiences around their reproductive health and contextual factors related to disability. We used deductive and inductive qualitative coding approaches to develop the conceptual framework.

Results: Eighty-one women between the ages of 16 and 50 with a self-reported physical disability, defined by an impairment of mobility, participated in 13 focus groups ($N=64$) and 17 individual interviews. Five major themes characterized the conceptual framework that emerged—knowledge about reproductive health, communication about reproductive health, relationships, the reproductive health care environment, and self-advocacy/identity—all of which had some relationship with five major reproductive health issues—pregnancy and labor/delivery, periods and menstrual management, contraception, sexuality and sexual functioning, and pelvic examinations.

Conclusions: This conceptual framework will serve as a foundation for PROM and guide intervention development to reduce reproductive health inequity and improve reproductive health outcomes of women with physical disabilities.

Keywords: physical disability, reproductive health, patient-reported outcome measures, qualitative research

Introduction

REPRODUCTIVE HEALTH is an essential component of overall health and well-being at all stages of life and is considered by the United Nations to be a prerequisite for

social, economic, and human development.¹ Broadly defined, the reproductive health of women encompasses a number of areas, including menarche and menstruation, fertility, pregnancy and childbirth, gynecological cancers, sexually transmitted infections, sexuality, and sexual health and function.

¹Department of Physical Medicine and Rehabilitation, University of Michigan Medical School, Ann Arbor, Michigan, USA.

²Boston University School of Public Health, Boston, Massachusetts, USA.

³Center for Health Assessment Research and Translation, University of Delaware, Newark, Delaware, USA.

⁴Department of Obstetrics and Gynecology, University of Michigan Medical School, Ann Arbor, Michigan, USA.

⁵Kessler Foundation, West Orange, New Jersey, USA.

⁶Langone Health Department of Research/Rusk Rehabilitation, New York University, New York, New York, USA.

⁷Department of Rehabilitation Medicine, University of Washington, Seattle, Washington, USA.

⁸Ann Arbor Center for Independent Living, Ann Arbor, Michigan, USA.

*Current affiliation: Center for Independent Living Disability Resource Center, Pensacola, Florida, USA.

To achieve optimal reproductive health, women must be informed, empowered, and enabled to decide if and when to become pregnant, undergo timely testing for reproductive cancers, protect themselves against sexually transmitted diseases and infections, and enjoy a satisfying sex life.¹ Unfortunately, for the 5 to 6 million girls, adolescents, and women with physical disabilities living in the United States² and their reproductive health care providers, there are numerous barriers to receiving and providing optimal reproductive health care.

Women with physical disabilities often contend with barriers in the built environment that reduce accessibility to medical offices, examination tables, and diagnostic equipment.^{3–7} Complex health conditions and mobility impairments also can have direct and indirect effects on pregnancy,^{8,9} miscarriage risks,^{10,11} postpartum depression,¹² sexual health and function,¹³ and the use of some contraceptive methods.¹⁴ Moreover, negative disability stereotypes and misperceptions about needs and preferences of this population of women can directly affect the access, utilization, and quality of care.^{6,15–17}

Understanding the consequences of disability stigma and structural barriers, particularly among underserved and marginalized women, is recognized as an essential competency for reproductive health care providers.^{18,19} Although the majority have some awareness of the unique health care needs of this population,²⁰ few receive information or training on providing care to women with disabilities.²¹ Health care providers struggle with their own ambivalence or discomfort,^{22–25} limited knowledge of disability to guide their care,²⁶ and inaccessible work environments that do not support competent and equitable care to women with disabilities.²⁷

Despite the growing evidence of inequity in the access to and quality of reproductive health care and outcomes, there are substantial gaps in our understanding of the causes and consequences of these disparities. Such understanding is integral to developing relevant and targeted interventions that improve care and outcomes for this population of women. One way to improve our understanding of critical factors that drive this inequity and its impact is with the use of patient-reported outcome measures (PROMs). While a number of PROMs have been developed to fill substantial gaps in measures designed for populations with specific, disabling health conditions, such as spinal cord injury,^{28,29} traumatic brain injury,^{30,31} or neurological disorders,³² none addresses women's health generally or reproductive health specifically. Reproductive health-related PROMs currently available do not address disability issues, and typically focus on specific medical problems, such as heavy menstrual bleeding³³ or infertility.³⁴

To address the lack of PROMs to assess reproductive health issues in women with physical disabilities, we have undertaken a project to develop relevant and clinically meaningful measures designed specifically for this population. In this study, we describe work to develop the conceptual framework as the foundation for the new PROMs.^{35,36} Future publications will report on the development of specific measures and their psychometric properties.

Materials and Methods

The extant literature and clinical and personal experiences of the investigative team informed the topics addressed in

focus groups and interviews. We used a flexible approach to move between hypothesis-deductive (prior work) and inductive (new concepts emerging from discussion) positions³⁷ to create a conceptual framework without predetermining all of the constructs and relationships. Using both phenomenological (experiences of women with physical disabilities) and grounded theory (codifying the experiences) approaches to creating a coding structure and defining constructs within the framework helps to ensure the content validity of the new PROMs that are built on this foundation.³⁵

Participants

Four institutions specializing in physical medicine and rehabilitation—in Michigan, New Jersey, and New York—recruited all participants using “purposive” or nonprobabilistic sampling, which focuses on selecting key informants who have important knowledge relevant for the research.³⁸ We conducted three focus groups ($N=11$) and two individual interviews as part of preliminary work (April through July 2014), on which the subsequent 10 focus groups and 15 individual interviews were based (July 2016 through April 2017).

Women between 16 and 50 years old with a self-reported physical disability due to any cause were eligible to participate. We defined physical disability as a loss of physical function or mobility restricting one or more important life activities. To assess the severity of disability (*i.e.*, mild, moderate, and severe), we used responses to three items from the Behavioral Risk Factors Surveillance System,^{39,40} which assess whether a person is limited in any way because of a mobility impairment and, if so, their need for assistance with daily life activities and/or personal care. Given the nature of study participation and focus on physical disability, the ability to participate and provide informed consent was assessed by a trained research staff member through observation of the woman's ability to converse and respond to screening questions during a 15-minute telephone interview. We were particularly interested in engaging women from more rural areas of the United States. Using the woman's county of residence, we recorded the percent of the county that was rural based on U.S. 2010 Census population density, whether it was designated as a medically underserved area, and if the area had a shortage of medical, dental, or mental health professionals.⁴¹ Institutional Review Boards at each institution approved the study and all participants provided written (focus groups) or verbal (interviews) informed consent.

Procedures

We collected data using focus groups and interviews. These complementary techniques are frequently used to gather information on experience since interviews can help to validate focus group findings by providing more in depth discussions.³⁶ Interviews were used most often with women who had transportation limitations or were uncomfortable speaking about their personal experience in a group setting. The same female moderator (C.Z.K.) facilitated all focus group discussions with another note taker or observer. The moderator also conducted 5 interviews and the other 12 were conducted by an experienced female staff member with a physical disability (J.K.). Focus groups were held in an accessible conference room or social gathering place, lasting 60

to 90 minutes; interviews lasted 30 to 45 minutes. All were audio recorded and professionally transcribed verbatim.

Semistructured guides were developed for the preliminary data collection focusing on five reproductive health topics: menstrual periods, pregnancy planning, sex, contraception, and preventative care. We also included attitudes, physical structures, knowledge, resources, or insurance/financial concerns. For the subsequent data collection, we modified the guide to include a more general introduction, asking women to comment on how their disability affected their reproductive health. This slight alteration in our approach supported content validity by allowing spontaneous discussion of reproductive health issues; if any reproductive health topic in the guide was not spontaneously discussed, the moderator offered it for discussion.

Development of coding structure and qualitative analysis

We developed the coding structure concurrently with data collection as each transcript was processed. This enabled us to continually assess the degree to which each transcript added new information and when we had achieved saturation.³⁶ Codes were independently applied to each transcript by two reviewers. During the reconciliation process, we developed the codebook iteratively by refining theme descriptions and by combining or creating new themes or subthemes. In cases where reviewers could not reach agreement on discrepant coding, a third reviewer was brought in to discuss and reach consensus. We used NVivo 11.0 (QSR International) to organize all transcripts and coding.

Results

Participant characteristics

One hundred thirty-six women with physical disabilities were screened and 81 participated in 13 focus groups ($N=64$) and 17 individual interviews (Table 1). The majority had a moderate or severe level of physical disability. Among the most commonly reported disabling conditions were multiple sclerosis ($N=17$), spinal cord injury ($N=15$), cerebral palsy ($N=13$), and spina bifida ($N=7$). Less common conditions included stroke, traumatic brain injury, epilepsy, brain tumor, and arthrogryposis. Most of the counties where women lived had a relatively low proportion of rural areas ($<10\%$, $N=35$), with only 6 women living in counties with $>50\%$ of the area designated as rural.

Conceptual framework

The initial conceptual framework (Fig. 1) was defined by five major concepts that all intersect with reproductive health issues and with each other in some way, reflecting the complexity of the reproductive health context of these women. Verbatim statements representing each theme are shown in Table 2.

Reproductive health issues

At the center of the conceptual framework are five specific areas of reproductive health most often discussed by women. *Pregnancy and Labor/Delivery* was characterized by the challenges of preconception planning and worries about

TABLE 1. CHARACTERISTICS OF WOMEN WITH PHYSICAL DISABILITIES ($N=81$)

Age at noncongenital disability onset, M (SD); range	26.8 (9.8); 1–45 ^a
Congenital onset of disability, N (%)	28 (34)
Current age, M (SD); range	35.4 (9.2); 16–53 ^b
Severity of disability, ^c N (%)	
Mild	10 (12.3)
Moderate	29 (35.8)
Severe	39 (48.1)
Highest education completed, N (%)	
9–11th grade	1 (1.2)
High school/GED	18 (22.2)
Associates degree	15 (18.5)
Bachelor's degree	33 (40.7)
Master's degree	13 (16.0)
Doctorate	1 (1.2)
Living situation, N (%)	
Live alone	15 (18.5)
Live with spouse/significant other (with or without children)	31 (38.3)
Live with parents	17 (21.0)
Live with children (only, no spouse or significant other)	8 (9.9)
Live with roommates	9 (11.1)
Live with other	1 (1.2)
Race and ethnicity, ^d N (%)	
White or Caucasian	63 (77.8)
African American	14 (17.3)
Asian	3 (3.7)
American Indian/Alaska Native	1 (1.2)
Hispanic Ethnicity ^e	8 (9.9)
Living in a medically underserved area, N (%)	18 (22.2)
Living in a health professional shortage area, N (%)	
Primary care	32 (39.5)
Dental care	10 (12.3)
Mental health care	20 (24.7)

^aThe average age at onset for total sample was 17.58 + 15.0.

^bOne exception was made that exceeded the upper age limit of inclusion criteria.

^cDisability severity was not collected from most women in the initial data collection; if we were able to contact them, we obtained ratings; three missing.

^dNot mutually exclusive categories; one missing.

^eFourteen unknown/missing.

complications. These worries were exacerbated by limited information or lack of knowledge of health care providers, causing uncertainty and leaving many women unable to move forward in decision-making. For some, the topic of pregnancy itself was difficult to bring up with health care providers because of past negative experiences. Others pursued their desire to have children irrespective of health care providers' support. Autonomy in decision-making about risk management during pregnancy was characterized by a conflict between health care providers' risk tolerance and the woman's willingness to take risks.

Periods and Menstrual Management focused on the difficulty of using feminine care products or not being able to use preferred methods. In contrast to needing assistance with other personal care tasks, managing periods was felt to be a more intimate and private matter; insertion of tampons by personal care attendants felt invasive for many. As a result,

FIG. 1. Conceptual framework of reproductive health in the context of physical disabilities.

women resorted to using less preferred methods, such as pads, which also was problematic for those with balance problems or limited hand/arm function. Even with the assistance of others, pad misplacement was common, resulting in leakage onto clothing. Menstrual suppression often resulted in significant relief, although a number of women faced resistance by health care providers. Many commented on exacerbation of pain or spasticity during periods and challenges of planning ahead when symptoms, such as cramps, that signaled the arrival of menstruation could not be felt.

Sexuality and Sexual Functioning focused on descriptions of sexual encounters, sexual positioning with a partner, and concerns or expectations about sex. Talking to health care providers could be challenging as many women were not asked about sex or presumed not to be sexually active. For some, attention to their sexuality receded as medical concerns and managing their disability became a priority in their lives. Women discussed the ways sexual intimacy was explored, such as positions to satisfy both partners, and difficulty finding information. Women with adult onset or progressive conditions sometimes felt disconnected from their sexuality. Communication with partners about feelings about their sexuality was often challenging, even for those in long-term relationships.

Pelvic examinations focused largely on difficulties with getting onto the examination table and pain, often due to altered anatomy or high muscle tone, and fear of falling. For women with spasticity, examinations could be challenging, particularly when trying to position themselves or assistance holding their legs open, causing them embarrassment. Communication with the health care provider about the examination was important for some women, often so they knew what was happening during the examination. Discussion of *contraception* related to its use to prevent pregnancy and in

some cases, to suppress menstruation. Typically, women focused on weighing risks and benefits, particularly as they related to having limited mobility and deciding on a method that was safe. Some women struggled to obtain forms of contraception such as intrauterine devices or oral contraceptives because of health care provider concerns about safety.

Factors impacting reproductive health

Knowledge about reproductive health. Knowledge of health care providers was most often discussed in terms of the provider's lack of knowledge about disability and its interface with reproductive health. Although women did not necessarily expect their provider to have expertise on their disability, their willingness to learn—which included taking the initiative to find information as well as learning from the woman herself—was most important. As the “expert” about their body, many felt a responsibility to educate providers. Seeking knowledge about a reproductive health issue could be particularly challenging given the general lack of information available. For many women, what was important to know was often clear, but how or from whom to find the information was not. Deficits in knowledge often significantly compromised the decision-making process.

Communicating about reproductive health. Communicating about reproductive health was most often experienced during clinical encounters and its ease or difficulty could be influenced by a variety of factors, such as the woman's perception of a health care provider's hesitation to start a conversation or her own apprehension to broach a topic. Not being spoken to directly when accompanied by others to medical appointments was particularly aggravating. Women commented that they were often expected to share information

TABLE 2. REPRESENTATIVE EXCERPTS FROM DISCUSSIONS

<i>Theme</i>	<i>Representative excerpts</i>
Reproductive health issues	
Pregnancy/labor and delivery	<p>They really weren't concerned about what I would say "normal health" women are concerned about. It was always about "How is your health? Do you feel anything? Do you feel sick?"</p> <p>I was told the same thing; "Why would you want to bring a child into this world..."; I had to go in depths with my disability, and find out if it's possible for me to give "birth to a normal child"</p>
Periods and menstrual management	<p>Besides birth control; the primary reason I have it because even if I weren't sexually active I would still want the IUD [intrauterine device] and I miss my periods because there are a million ways that these things interact. First of all, my cramps are pretty bad and they gave me a hard time when I was younger. You can't just get up and go lie down when you need to you. Like you need help with that. It becomes a lot harder to manage the pain then. Also, just like the mess. I have scoliosis and my hips are tilted, and so it takes a lot of work to line up a pad accurately so that there's not going to be any leakage. That's very hard to get right.</p> <p>Even when you can't feel down there, you can kind of know that you're starting to bleed. Then when you can't feel, you're just like, okay, that's why I've been in pain. That's mostly just figuring out why my body's doing weird things and sometimes I don't sleep for a couple of days before my period comes. There just are a lot of little things that could indicate something else but when they're all together, it means I'm gonna get my period and they're all really negative. I hate them.</p>
Contraception	<p>I had to fight my primary doctor for birth control. In fact, I just plain said, "Forget it. I'll find my own gynecologist." Because he was so afraid of the blood clots.</p> <p>I needed birth control from my period when I was 16. Well, now the pills just weren't working. Well, you start going through all these options. For somebody that's disabled the NuvaRing, good luck. You're not going to be able to get in there and get it out. It was a struggle.</p>
Sexuality and sexual functioning	<p>I couldn't really get in a position that was good because of my MS [multiple sclerosis] and not being able to support myself.</p> <p>Being able to understand my diagnosis and my limitations, and I think that my life I was always preoccupied with my health concerns that sexuality and all of that took a back seat.</p>
Pelvic exams	<p>I told them that it was going to be challenging, that I'm high tone and that sticking things in there is not a comfortable situation.</p> <p>Well, my legs are very tight—so, pelvic exams aren't pleasant for anybody, but when it becomes this three-person team to give you one, can you understand why I might want to put it off?</p>
Conceptual issues impacting reproductive health issues	
Knowledge of reproductive health	<p>(Health care providers) I'm so tired of them not knowing. It's like "What did you learn in school with all these years of books and stuff? What disabilities were you taught?" so it's like the older I'm getting, the more frustrated I'm getting because it's like "Okay come on now. Get up to date. Everyone else is up to date. Why can't you take me up to date with all of this?"</p> <p>(Health care providers) They just don't think about it because they don't have to sit down all day. Most of their patients don't have to sit all day, so are they thinking of it in their mind, "Well, maybe that's why these are the issues." Maybe they're not tying it all together as far as why these things happen because until you said that, honestly, I didn't even think of that being the reason why there is so much moisture because it's never been brought to my attention and I've lived my life in a chair. I don't know any better.</p> <p>(Educating others) I'm educated on my disease. I know the risks. I'm probably more educated than the average patient. Ask me. I don't feel like it's a bad thing for a doctor to ask me about my diseases, and I think they can gain from the patient whether or not they really know what they're talking about or not, 'cause they'll have some knowledge already. But yeah, I don't really expect all my other specialists to know about every disease I have or to the extent that I know, or my other specialists know.</p>
Communication about reproductive health	<p>I go in up front and just explain me. Not necessarily my disability because we're all extremely different, but just me because I'd rather them get it right the first time than do it five times wrong and be like "Oh by the way."</p> <p>I don't feel comfortable speaking, and telling my story. If you go out of your network, you have to tell the doctor all the stuff all over again. I don't want to relive it. I live with this sickness.</p>

(continued)

TABLE 2. (CONTINUED)

<i>Theme</i>	<i>Representative excerpts</i>
Relationships	<p>(Health care providers) I've learned that over the years, because I've been sick every day of my entire life since the day I was born. I learned to communicate with doctors, and I also learned how important trust was with them. If a doctor doesn't work for me, I find a new doctor. I tell that to anyone who is dealing with a doctor, especially when you're dealing really important decisions for your health, but trust was a major thing.</p> <p>(Health care providers) I think, I mean I'm not a doctor, but things can intertwine and interrelate and if you don't know I'm having this major MS attack or whatever, then you might not know what else could be affecting other things. That's kind of cold. I don't know how to word it. Just because my neurologist always did it. I always felt like wow, he really cares. Really cares about me, my whole body, my whole life. Whereas the other doctors are like okay, dadada, you know? Here's what you're here for.</p> <p>(Intimate partners) I have a lot of internal barriers about letting a man that I'm interested in see the truth of my disability and that certain limitations or issues that I might have surrounding some of the issues we've talked about because I want to seem normal. And so I... you know, in my last relationship, would go to extraordinary lengths to like set myself up in such a way that he could only see the areas that I wanted him to see. He wouldn't have access to things that... like I didn't know what he would think about or I didn't know if they were okay or normal or if other women dealt with them.</p> <p>(Intimate partners) I feel, this pressure to reassure them that this relationship can still be fulfilling even though I'm not able-bodied. For that reason, the conversations can be really difficult. My current partner, he just blew my mind over and over again with how open and accepting he was. He was never the source of my feeling guilty or scared to talk about anything. It was always more like my socialization. Messages that we receive about disability and sex that my fears were coming from.</p>
Reproductive health care environment	<p>(Built environment) Then they just ask you how much do you weigh, and you just stare at them because you haven't been weighed by a doctor's office in a year. So I would say that's a problem, and a big difference, because every doctor you go to weighs you and takes your blood pressure unless you happened to be paralyzed or too heavy to use the scale or something. Then all of a sudden there's no space to check in, and it's like we'll just skip it. That's frustrating. Then another issue that I think is a big one for me, and it's one of my main issues is no mobility, and is that you have to find someone who has a table that gets low enough that you can actually get on to it.</p> <p>(Built environment) At this point, my current primary care provider, I'm trying to find a new one because I can't...like she doesn't know anything about spinal cord injury and she has told me that her office...like the tables are up here and she's like, "Yeah, tables don't go up and down. You should probably find a new primary care provider."</p> <p>(Attitudinal environment) I'm not sure but almost every doctor has always come across condescending. It's very rare to not have a doctor that's condescending, not just in the gynecological field but in other fields as well. When they see you with a caregiver, they often talk to the caregiver instead of you because they think that you're not cognitively able to understand them.</p> <p>(Attitudinal environment) What I have found with disabilities and dealing with doctors in general, or just people in general, depending on the severity of your disability, a lot of people can tend to correlate that with not being so bright, talking over you, talking past you, anybody else, but you about you.</p>
Self-advocacy and identity	<p>Like these are huge decisions that I feel like sometimes people who are patients forget that they also have to advocate for themselves, and it's not just listening to a doctor. It's having a doctor listen to you, and you have to make decisions with your health care provider.</p> <p>One thing, you have to advocate for yourself more when you go to the doctor and stuff like that. You have to like stand up for yourself more and make sure that they listen to you. Especially just because they see you... cause some doctors might see you just as a disability and not take you like seriously or just ignore you and stuff like that and brush you off and stuff like that.</p>

between different health care providers because providers often did not communicate with each other. Telling their story repeatedly could be frustrating; for some, this was an emotional burden. Communication between women and their providers was also significantly influenced by the woman's perception about the quality of their relationship.

Relationships. Women spoke of relationships with health care providers, intimate partners, peers, and personal care assistants relevant to different dimensions of their reproductive health. A foundation of trust helped women feel at ease and comfortable enough to communicate about the need for accommodations and their concerns. Relationships with

health care providers were also strongly influenced by a woman's sense of being seen as a "whole" person; this was especially powerful for creating long-lasting and trusting relationships. Relationships with intimate partners were primarily discussed in terms of sexual function and intimacy. Women described both positive and negative experiences, such as the joy of acceptance by a partner or the avoidance of intimacy. For some, being open to an intimate sexual relationship took years of preparation. Meeting a new person who was interested in knowing all aspects of her—including sexual—could be both exciting and frightening.

The reproductive health care environment. Women consistently spoke of the ways in which the built environment and attitudes of others impeded or facilitated their access to and utilization of reproductive health care. Barriers in the built environment, characterized by physical structures, were most often inaccessible offices or examination tables that could not be adjusted. Attitudinal environments were primarily determined by health care providers. Willingness to make accommodations, such as giving additional time for transfers or getting undressed for an examination, substantially improved access to care and strengthened patient/provider relationships. In contrast, negative attitudes of others were often barriers to communication. For some women, barriers in either the built or attitudinal environment could activate self-advocacy to request accommodations, confront bias, or seek care elsewhere. For others, these barriers could be intimidating and served to essentially silence them.

Self-advocacy and Identity. A woman's ability or difficulty speaking up, often expressed as confronting or being silenced by stigma or bias that was experienced in the reproductive health care environment characterized the Self-advocacy and Identity theme. For many women, this made them hesitant to bring up topics of concern, such as the possibility of pregnancy, being tested for sexually transmitted infections, obtaining birth control, or seeking menstrual suppression. It also played a role in the extent to which women requested accommodations to reduce barriers in the built environment. Self-advocacy and identity played a role in the woman seeking knowledge and educating others, primarily around the interface of disability and knowledge of reproductive health. In relationships with health care providers, self-advocacy was characterized by how a woman negotiated that relationship, often by asking directly for what she needed or confronting bias. In intimate relationships, the degree to which disability was integrated into a woman's identity was often related to her openness to intimacy, both sexually and emotionally.

Discussion

The purpose of this study was to understand important dimensions of reproductive health of women with physical disabilities and develop an initial conceptual framework as the theoretical basis for new PROMs.⁴² Such frameworks are not expected to be static, but evolve as constructs are refined and measures are developed.³⁵ Our framework is complex and characterized by contextual, interpersonal, and personal factors that impact a woman's access to and utilization of reproductive health care and the management of her reproductive health.

Patient-centered care is characterized by being responsive to patient preferences, needs, and perspective with their values guiding decision-making.⁴³ Although women in our study had both positive and negative experiences, on the whole, this study highlights the need for improving patient-centered reproductive health care for women with disabilities. Access barriers to the built health care environment have long been recognized as problematic,^{5,7,44} and nearly half of gynecology offices are not accessible.⁴⁵ Many women in our study also experienced barriers in the built environment that impacted the quality of care they received. Many women with disabilities also experience societal biases and misperceptions about disability around disability in their daily lives or during interactions with health care providers, particularly around pregnancy,^{15,46,47} contraception,⁴⁸ and their sexual health.^{16,24} However, not all experiences were negative; a number of women described positive and trusting relationships with their health care providers, which can reduce barriers and increase utilization of reproductive health care for women with physical disabilities.^{6,14,49}

At the center of the conceptual framework are reproductive health issues relevant to all women, but are often complicated by the presence of a physical disability. For example, birth rates among women with physical disabilities have tripled since 2000⁵⁰ and rates of live births are now comparable to their nondisabled peers.¹¹ However, while they have a similar desire for children as their peers,⁵¹ these women often struggle with indecision and uncertainty about pregnancy.^{52,53} For many women in our study, this uncertainty was driven by a lack of access to knowledgeable health care providers and relevant information. These can be particularly problematic given elevated risks of urinary tract infections, decreased mobility, skin breakdown, respiratory problems, stress, and mood disorders during pregnancy,^{54,55} and preterm birth.⁵⁶

For women with disabilities, sexual function and sexual satisfaction are complex issues influenced by impaired mobility and functional limitations, secondary conditions such as spasticity and bowel/bladder incontinence, and psychosocial issues, including depression and low sexual self-esteem.⁵⁷ They are also less sexually active and engage in fewer intimate relationships.^{58,59} A number of women in our study similarly struggled with issues related to changes in their bodies, either from injury or chronic health conditions, that hindered positioning or caused them to lose touch with their sexuality by having to focus on managing their health or fatigue that often accompanies physical disability.

For women in this study, managing menstrual periods was often complicated by the inability to independently use preferred products and the additional energy management required. Despite the obvious effects physical disability can have on independent management of periods, a 2019 systematic review⁶⁰ identified only four studies that have been published since 1976 addressing menstrual hygiene among women with physical disabilities; three focused on the caregiver's product preference, and the only study conducted in the United States focused on the woman's product preference.⁶¹ There is a clear need to address this knowledge gap to guide the development of interventions and products to reduce the disruption of periods in the lives of women with physical disabilities.

In this study, concerns around pelvic examinations focused largely on getting onto and off of examination tables, a well-known barrier to care,⁶² difficulty positioning bodies for the examination, fear of falling off the table, and the need for

extra assistance. The emotional and interpersonal dimensions of the pelvic examination have been well characterized in the extant literature,^{63,64} factors we would expect to the same for women with disabilities, but this has yet to be substantively addressed in the literature and is an opportunity for further exploration.

Communication also played an important role in their experience of care, relationships with health care providers, and how well their needs were met. These experiences—both positive and negative—are characterized *patient-centered communication*,⁶⁵ defined by responding to emotions, exchanging information, making decisions, fostering healing relationships, and managing uncertainty.⁶⁶ The narratives of women in our study suggest that societal beliefs about disability also influence patient-centered communication, often resulting in a negative experience. This finding highlights an opportunity to build on this model of patient-centered communication to account for additional disability-related factors that impact communication around reproductive health.

Women in this study also overwhelmingly voiced their frustrations with unprepared or insensitive health care providers. This experience highlights gaps in cultural competence of reproductive health care providers who themselves often feel unprepared and inadequately trained,^{20–25} but, nevertheless, can find providing care to women with disabilities a rewarding experience.²¹ Given the growing recognition of the need for competence around structural barriers to reproductive health care for underserved and marginalized women¹⁸ and culturally competent health care that includes disability competence,^{67–69} more work is needed to understand the experience of health care providers²⁰ who can inform the development and implementation of well-designed, relevant, and accessible training opportunities.

Many women in our study struggled with self-advocacy to confront the stigma and bias they often experienced around their reproductive health. In the context of health care, self-advocacy is characterized by assertiveness and a willingness to represent one's own interests when managing a disease or disability; it is a learnable behavior that includes accessing relevant information and conveying personal preferences to health care providers.⁷⁰ Enabled by knowledge of self and rights,⁷¹ self-advocacy can be improved by enhancing skills in communication, information seeking, problem solving, and securing support⁷² that positively impacts health and quality of life.⁷³ Developing interventions to improve the self-advocacy of women with physical disabilities has the potential to empower them to address stigma and bias and other barriers in productive and self-affirming ways.

Limitations

Focus groups can be limited by dominant personalities monopolizing discussions in focus groups and overrepresentation in the data.³⁷ In our study, some participants had concomitant cognitive impairments and while they were able to provide informed consent, their contributions to discussions could become tangential or fixated on a single point. The ability to manage focus groups and individual dynamics is an important moderator skill to ensure that all members have an opportunity to contribute to the discussion, and deviations are thoughtfully guided back into the discussion.⁷⁴ To mitigate the risk of member dominance or straying too far

off topic, the same moderator (C.Z.K.), a rehabilitation psychologist, guided all focus group discussions.

We engaged a predominantly Caucasian sample of women. As such, the experience of women of color may not be adequately represented in the data and conceptual framework. The use of methods such as matrix analysis can be used in future work to further refine the framework by examining patterns of differential experience based on personal characteristics. As domains are selected for PROM development, we will also review definitions of the domain and items in new focus groups and interviews, paying particular attention paid to racial and ethnic diversity to check their alignment with women's experiences. As new PROMs are developed, we will cognitively test items, including soliciting feedback on their importance to women with physical disabilities, and assess differential item functioning and factor structures⁷⁵ to determine if personal characteristics are associated with a differential response to the interpretation and endorsement of items. Enhancing diversity in these later steps will help to identify potential gaps in the initial data and guide how to best approach the conceptual framework's further development.

Conclusions

The initial conceptual framework developed from the experiences of a large sample of women with physical disabilities is the most comprehensive, to date, that captures the breadth of factors that impact the reproductive health of women with physical disabilities. This framework will guide the development of PROMs to facilitate research on the causes and consequences of reproductive health inequity and also highlights areas to advance patient-centered reproductive health care for women with physical disabilities by improving patient-centered communication, self-advocacy, and cultural competence.

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Address correspondence to:

Claire Z. Kalpakjian, PhD, MS

Department of Physical Medicine and Rehabilitation

University of Michigan

325 East Eisenhower Parkway, Lower Level, Suite 2

Ann Arbor, MI 48108

USA

E-mail: clairez@umich.edu