Knowledge Attitudes Competency and Practice Challenges about Providing Perinatal Care to Women with Disabilities

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Abstract

• **Background/Purpose:** Approximately 8 million women of childbearing age are disabled. Studies have shown that women with disabilities have limited access to healthcare resulting in unmet reproductive health care needs and that negative stereotypes exist about the sexual and reproductive capabilities of women with disabilities. The purpose of this study was to describe the knowledge, attitudes, perceived competencies and practice challenges about providing perinatal care to women with disabilities by advanced practice nurses.

• **Design/Methods:** This study was a mixed method design using an online, anonymous survey to collect both quantitative and qualitative data. Quantitative data were analyzed using descriptive statistics and Chi-square analyses. Written comments solicited from participants were analyzed using qualitative descriptive methods.
Abstract

• **Conclusions:** Most participants reported positive attitudes and felt competent in the role of providing perinatal care to women with disabilities and that knowledge was acquired informally. Adequate time with patients was a significant barrier to providing care.

• **Implications for Practice:** NPs who provide perinatal care to women with disabilities may benefit from formal clinical and classroom education. Further studies are necessary to develop the education foundation to provide evidenced based perinatal care to women with disabilities. This may translate to improved access to perinatal care to women with disabilities.
In the U.S., about 8 million women (11%) of reproductive aged women report a disability. The types of disabilities in this group include physical (51%), mental/developmental (30%), or sensory (19%). Although there are no available population based studies that report incidence and prevalence of pregnancy and birth in this population, smaller studies have found that many women who are disabled desire biological children and plan to become mothers.
Background and Significance

• Studies suggest that some healthcare providers (HCPs) caring for women with disabilities lack sufficient knowledge about disabilities in general and harbor negative stereotypes about the sexuality and reproductive capability of women who have a disability.
Defining Disabilities

• The term disability can be viewed from medical, legal and social perspectives.

• The Centers for Disease Control and Prevention defines disability as a condition that impedes activity and the ability to interact in daily activities.

• The World Health Organization (WHO) defines disabilities as a complex phenomenon that includes impairments, activity limitations, and restrictions on participating in daily life due to body function or structure.
Defining Disabilities

• The Americans with Disabilities Act (ADA) enacted in 1990, defines disability as “a physical or mental impairment that substantially limits one or more major life activities of such individual, a record of such an impairment and being regarded as having such an impairment”.

• The social model of disability, posits that disabilities are caused by the manner in which they are viewed by non-disabled persons in society and are based in attitude as opposed to the experience of the disabled individual.
Types of Disabilities

- Physical disabilities include disabilities from birth (e.g., spina bifida), disabilities related to trauma (e.g., spinal cord injury) or disability related to a medical condition (e.g., cancer).

- Sensory disabilities include disabilities related to the senses: hearing, sight, sensory perception, tactile and taste.

- Neurological and developmental disabilities include those that occur during fetal development (e.g., microcephaly), birth (e.g., anoxia), and exposure to toxic substances (e.g., alcohol, lead).

- Developmental disabilities typically include disorders on a spectrum and cognitive delays or deficits.
Disabilities and Health Disparities

• Women living with disabilities struggle with social and environmental barriers and are at greater risk for experiencing health disparities.

• Decreased access to quality care often leads to lower rates of screening for both cervical and breast cancer and unmet sexual and reproductive health needs.
For this descriptive study a 37 item survey of knowledge, attitudes, and self-described competencies about providing perinatal care to women with disabilities by NPs and CNMs (excluding demographic questions) was developed. Open-ended questions were added to elicit information from respondents about challenges to providing perinatal care to women with disabilities.

The survey underwent expert review by 3 advanced practice nurses for readability, content and face validity.

Minor changes were made and the survey was then distributed via email to the membership of a large national organization representing advanced practice nurses after approval by the institutional review board.
Data Collection

- Members who were currently practicing as a NP or CNM were invited to take the survey.
- Students, NPs and CNMs not currently practicing were ineligible to participate.
- Data were collected between October 2015 and December 2015.
- Response rate was 7% (n=150).
- Cronbach alpha 0.92 (overall).
### Demographics (n=150)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age &gt; 40</td>
<td>98</td>
<td>65%</td>
</tr>
<tr>
<td>White race</td>
<td>137</td>
<td>91%</td>
</tr>
<tr>
<td>Clinical practice &gt; 10 years</td>
<td>101</td>
<td>67%</td>
</tr>
<tr>
<td>Female</td>
<td>144</td>
<td>96%</td>
</tr>
<tr>
<td>Certified</td>
<td></td>
<td></td>
</tr>
<tr>
<td>WHNP</td>
<td>98</td>
<td>65%</td>
</tr>
<tr>
<td>CNM</td>
<td>9</td>
<td>6%</td>
</tr>
<tr>
<td>More than 1 certification</td>
<td>19</td>
<td>12.7%</td>
</tr>
<tr>
<td>Region</td>
<td>Equally distributed</td>
<td></td>
</tr>
</tbody>
</table>
Knowledge (education and practice) (n=150) about providing care to disabled populations

<table>
<thead>
<tr>
<th>Education</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Didactic education</td>
<td>45</td>
<td>30%</td>
</tr>
<tr>
<td>Clinical education</td>
<td>31</td>
<td>20.7%</td>
</tr>
<tr>
<td>Specialized assistive equipment</td>
<td>42</td>
<td>28%</td>
</tr>
<tr>
<td>Referral network</td>
<td>72</td>
<td>48%</td>
</tr>
<tr>
<td>Women with disabilities seen in a month</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 10</td>
<td>133</td>
<td></td>
</tr>
<tr>
<td>&gt;10</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>88.7%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7.3%</td>
</tr>
</tbody>
</table>
## Attitudes and Competencies

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am comfortable providing perinatal care for women with physical disabilities</td>
<td>138</td>
<td>92%</td>
</tr>
<tr>
<td>I am comfortable providing sexuality counseling to women with disabilities</td>
<td>131</td>
<td>87.3%</td>
</tr>
<tr>
<td>I feel competent to provide preconception care to disabled women</td>
<td>130</td>
<td>86.7%</td>
</tr>
<tr>
<td>I feel competent to provide obstetrical care to disabled women</td>
<td>99</td>
<td>66%</td>
</tr>
</tbody>
</table>
The respondents reported positive attitude and competency in providing perinatal care to women with disabilities.

30% of respondents reported receiving didactic information and 20% of respondents reported receiving clinical experience on providing care to women with disabilities during their academic coursework.

Less than 30% of respondents reported having assistive devices and/or equipment to facilitate care in their clinical practice setting. This may present an actual or potential barrier to utilization of care by women with disabilities.

Practice challenges included only 28% of respondents reporting having assistive equipment, lack of time and gaps in knowledge about effect of disabilities on pregnancy, sexuality, and general health.
Limitations

- The limitations of this study include:
  - self-report data,
  - a response rate that reflects approximately 7% of the organization’s membership,
  - the inability to report the educational and practice experiences and behaviors of non-respondents.
- These limitations should be viewed judiciously and require thoughtful interpretation when being applied to practice, education, policy and further research.
Recommendations

- Increase content and clinical experiences during educational programs for ANPs/CNMs.
- Increase the availability of resources for patients with disabilities. Patient education materials are available in multiple languages; it is important that we also have resources available for the visually and hearing impaired.
- Adaptive equipment must be available and HCPs must have knowledge & experience using it.
- Further studies about care delivery, patient needs and best practice models. Community based participatory action research is a framework to include women with disabilities.
Conclusion

• Advanced practice nurses can help bridge the gaps in care and help ensure positive experiences with the healthcare system. Raising awareness about the unique needs of women with disabilities is one step toward ensuring a more positive experience within the healthcare system.

• Nurse practitioners reported providing perinatal care to women with physical, sensory, intellectual and developmental disabilities. However knowledge about providing care to women with disabilities came through clinical experience, by working with colleagues who shared their own experience and knowledge and experiences learned from disabled patients. We recommend the development of formal didactic and clinical education to prepare NPs to provide perinatal care for women with disabilities.
References


Thank you!

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