

## Health Care Providers' Knowledge and Attitudes in Perinatal Care for Women with Disabilities

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### ABSTRACT

**Background:** Disability is a global phenomenon counting more than one billion people reaching the percentage of 15% of the population worldwide and it will be rising constantly in the coming years. Women with disabilities are getting pregnant more and more. Although perinatal care has been extensively researched and is constantly being improved for women without disabilities, health care professionals are not adequately educated and fully experienced for caring for pregnant women with disabilities. As a result of that they are negatively inclined towards disabled women.

**Objective:** The purpose of this review is to investigate health care providers' behaviors and attitudes towards women with disabilities whilst providing perinatal care.

**Conclusion:** Overall, it seems that health care providers feeling insecure and not confident in providing perinatal care to women with disabilities which results in them having negative attitudes and behaviors. This stems from the inadequate knowledge they have about disability conditions and pregnancy. Upgrading their training and education from undergraduate level is an urgent need. Constant contact with disabled patients seems to be a beneficial factor for better treatment.

### Keywords

Health care providers' attitudes, Health care providers' knowledge, Perinatal care in women with disabilities, Pregnancy in women with disabilities, Postpartum care in women with disabilities.

### Introduction

Over the years, a great deal of extensive research has been carried out on perinatal care and special protocols and guidelines of global interest have been developed and introduced [1-4]. There is also a wide range of reviews, focusing on the care during the perinatal period [1-3]. However, a large proportion of research up to now has been focused mainly on nondisabled women, not taking under consideration that women with disabilities (WWD) are fully capable of becoming pregnant.

Disability is a global phenomenon, counting more than one billion people, reaching the percentage of 15% of the population worldwide and it will be rising constantly in the years to come. Between 110 million - 190 million adults are included in this part of the population, indicating important difficulties in functioning [5]. The prevalence rate of disability in the age group of 18-49 years is estimated at 6.4% in higher-income countries and it is 60% higher for females than males [6]. By 2020, one-fifth of the EU population is expected to have some form of disability (European Commission) [7].

It has been confirmed that an ever-increasing number of disabled women are getting pregnant [3-6]. According to the U.S. Census Bureau, the prevalence of any self-reported disability among

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women of reproductive age is 11.7% [8] and mobility impairments are most frequently cited [8]. Most disabled women can become pregnant, without facing fertility problems [1].

Nowadays, disabled people still face a variety of barriers and discrimination with women being more vulnerable to gender-based risks, such as sexual abuse [8-10]. WWD are often viewed as not having any sexuality, incapable to be lovers, wives or mothers and not able to take care of others [11,12].

There are still physical barriers such as narrow doorways, inaccessible delivery rooms or ultrasound examination tables etc. [12,13]. However, most reviews WWD seem to emphasize on health care professionals' (HCPs) behaviors and attitudes considering them to be a more serious problem [6,12,14,15].

Some health professionals avoid to provide care to these women [8,9]. Some others, lacking the knowledge, expressed their own subjective point of view instead of using scientifically substantiated data about disabled women's pregnancy. These unsupportive attitudes may have led to irresponsible recommendations, which could include even abortion [8]. HCPs' negative attitudes can discourage these women from using the necessary health services, increasing the risk of poor pregnancy outcomes and making them feel criticized about having a baby [15-17].

Professionals' poor knowledge and skills, are of dominant reference in most of the studies up to now [6,11,12,14,18-20]. This could be a reason why women with disabilities lose their trust in them [10] and they end up becoming the experts of their condition because of having experienced insufficient health care. Compared to other boundaries, this situation seems to be the most difficult to overcome [21].

The purpose of our literature review is to summarize health care professionals' attitudes and knowledge in perinatal care for women with disabilities. Although there are limited data with studies exploring disabled women's experiences, this review will provide a more comprehensive view on health care providers' behaviors and how much these affect the quality of care. Furthermore, this review will showcase the correlation between these behaviors and the conception of pregnancy while disabled.

## **Methodology**

International databases were used to conduct this literature review (PubMed, Google Scholar, Cochrane Reviews) as also WHO (World Health Organization), UN Convention on the Rights of Persons with Disabilities (CPRD) and CDC (Center for Disease Control and Prevention). The used keywords are as follows: health care providers' attitudes, health care providers' knowledge, perinatal care in women with disabilities, pregnancy in women with disabilities, postpartum care in women with disabilities.

## **Health care professionals' attitudes (as a barrier)**

Women with disabilities (WWD) often face a lot of barriers in everyday life. Furthermore, HCPs' attitudes tend to be a significant

difficulty, which disabled women must overcome [6,8,10,12,14,18-25]. Refusal of care, prejudices, criticism, are some examples of negative attitudes in practice when it comes to perinatal care [3,6,19,21-24]. This kind of behavior, especially from people that disabled women rely on in such a special time in their lives as pregnancy, can have a severe impact on the quality of care and the perinatal experiences these women may have [8].

Dealing with diversity and difference is one of HCPs' weaknesses, when caring for people with physical disabilities [9,10]. Over time, there is limited input about perinatal care to people with disabilities, focused more on those people's experiences rather than HCPs' real behaviors and attitudes. The literature suggests that they have been unsupportive and even insensitive, concerning disabled people and their special perinatal needs [14,18-20,25]. They are very judgmental to these women's pregnancies and they put enormous pressure on them in order to make them "abandon" their true desires. The perinatal care of these women tends to be considered as a tremendous problem [8,16,25]. On top of the above, clinicians are also referred to as authoritarians and not willing to cooperate with the disabled, who have by all means become experts on their own disability throughout the years [16,22]. Having established a negative mindset, they ignore their suggestions, considering them unable to help themselves [18,21].

It is not uncommon for disabled women to be excluded from discussions about sexual and reproductive health because HCPs are not taking under consideration that they have also sexuality issues [9,10,12,14,16,17,21,26,27]. As the National Study of Women with Physical Disabilities: Final Report shows, "women with physical disabilities have as much sexual desire as women in general. Ninety-four percent of the women with disabilities had had sexual activity with a partner in their lifetime. Forty-nine percent were sexually active at the time of the study, compared to 61% of women without disabilities" [16]. This lack of information still exists during their pregnancy and future delivery, when they most need to be properly advised and informed, resulting in bad preparation for motherhood [8,14]. For instance, in a recent study, data show that women with physical disability or mental health problems are less informed about their baby's feeding and well-being [15].

The assumption that WWD are not able to be pregnant is quite common by some maternity care providers, who cannot understand to what extent these women's personalities, expectations or even their whole lives can be affected [8,14]. Many women reported that during perinatal period their doctors expressed their own point of view and they even recommended termination of pregnancy simply on the grounds of disability [3,9].

The literature review shows that professionals are intimidated by the whole situation, pessimistic and even more insecure than women themselves and focus much more on their disability, rather than their pregnancy and its progress [14,20]. The remarkable thing here, is that when women are optimistic and confident, care providers scatter their positivity by labeling them as "a high-

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risk pregnancy”, creating confusion and chaos without genuine medical reasons [8]. This high-risk label is also “bequeathed” to their infant, to whom midwives and other health professionals focus on after delivery with a series of unnecessary medical exams. As a result of this, mothers and babies are separated longer than desired [3].

To make matters worse, some health professionals refuse care to disabled people [12,16,26]. Without justifying why, they maintain this hostile behavior, it is not difficult to understand why this, can have an unfavorable effect on women and their pregnancy [5,6,21,24].

In a study [14], researchers used ADTP tool form B (Attitude towards Disabled Person (ATDP), in order to examine healthcare provider's attitudes towards disability, in rural Nepal. They observed by the data collection (ADTP mean scores) that males have more positive attitudes towards people with disabilities and that nurse midwives (all female) had higher scores than other professionals [14]. Lack of medical experience and age seemed to be negatively associated with attitude scores. Younger HCPs were more attentive to disabled people.

Problematic working environments and conditions such as long working hours, low salary etc. can also contribute to negative attitudes to patients [27]. In addition, the most influential factor in the formation of attitude was reported to be the intensity of exposure and contact with the person with disabilities [14].

These attitudes can be a strong aspect for women with disabilities who decide against using effectively the health care services, while at the same time they do not enjoy a possible pregnancy and are full of disappointment and stress. They feel unable to complete delivery without the appropriate guidance and somehow, they feel obliged to apologize for wanting a baby [16].

Having said all that, although the majority of studies conclude that HCPs have negative attitudes towards disabled people, there are HCPs who report that providing care to disabled women during the perinatal period, was rewarding and the right thing to do [21,28]. They also characterized this care provided, as a mission [19].

### **Health care professionals' knowledge (in correlation with attitudes)**

The majority of previous studies shows that most HCPs lack knowledge related to disability and pregnancy [5,6,10-12,14-20,26-28]. This lack of knowledge combined with prejudice against people with disabilities may have resulted in creating stereotypes and negative attitudes among the providers [14].

As Gething explains (cited by Wallyahmed A., 2007) [23] discomfort is a term associated with being uninformed and uncertain of how to behave or what to expect from others and this interrelates with a feeling of vulnerability. Therefore, discomfort is believed to pervade the negative attitudes that people, especially health care providers, exhibit towards people with disabilities

[29]. As a result, clinicians are anxious, nervous and they feel uncomfortable caring for pregnant women with disabilities and they often ask for another clinician's help [23]. In a survey of interaction between disabled persons and UK midwives, there are findings (from this active professional group of midwives) which indicate that direct experiences along with education related to disabled women, lead to a reduction in discomfort when interacting with this particular group and increased feelings of confidence in knowledge and sensitivity [23].

However, most of the professionals claim that there is not adequate education and training. In another study, exploring perspectives of obstetric clinicians who provide perinatal care to women with disabilities [26], all clinicians reported that they did not receive any training on perinatal care and disability, neither as students nor as practitioners. “They all learned on the job training”, a maternal-fetal medicine (MFM) clinician stated. Other researchers [14], found in their study that only the percentage of 6.6% of maternity care providers had some kind of disability training. Not including special training concerning the care offered to this vulnerable population in education is a great default which implies discrimination and not an educationally upgraded university system.

WWD described that it was difficult for them to find an expert on their disability, who would be updated and adequately skilled to support, advise them and deliver their baby at the same time [16]. Additionally, this is not only clinicians' knowledge inadequacy but also that they cannot accept disability and pregnancy in a woman as a concept. Some professionals are oblivious to simple facts such as telling a blind woman to go to a numbered room that she is not able to see [24]. This is probably a good reason why; these women feel that they have to be active members during perinatal period and alerted because no one will be cautious of their special needs and emergencies [17].

It is evident that for the best caring result, there should be a cooperation among HCPs since no one can be an expert on everything. However, WWD claimed that there is not sufficient coordination among HCPs, reducing the diffusion of knowledge and in the end, the quality of care they are being offered [16].

### **Barriers for clinicians**

It's obvious from the above, that the majority of HCPs are biased against WWD. This kind of behavior is not surely the appropriate one, however HCPs face also barriers during providing care to disabled women, which affect the quality of their services [6,14,20,21,26,27].

Castell & Stenfert Kroese [21] in their qualitative study, explored midwives' experiences in caring for women with learning disabilities (also reported in Mitra M., 2017) [20]. They identified that midwives feel unsupported by the lack of services available for these women. Having to do other people's jobs, seems to be a significant disorientation from doing their work properly and efficiently. In addition, staff shortages and other poor working

conditions such as lack of time, are serious difficulties which HCPs are faced with [27].

Insufficient knowledge is of dominant reference as a difficulty among HCPs having WWD as patients [5,6,10-12,14-21,23,26-28]. This arises from poor maternity care providers' education concerning people with disabilities since their undergraduate studies [6,26], lack of routine in the care of mothers with disabilities, and a lack of specialist knowledge about the obstetric relevance of specific symptoms related to disabilities [27].

Unwillingness to interprofessional teamwork and cooperation among health care providers can also affect the provision of care [27]. Coordinated care can provide a better impact on disabled women's perinatal period as it is rare for an individual gynecologist/obstetrician, midwife or another health care provider to know everything about these women's particular condition.

## Discussion

Although women with disabilities are increasingly choosing to get pregnant and to become mothers, they may encounter negative experiences from others who doubt their ability to become pregnant, carry the baby to term, deliver safely and care for a newborn. Disabled women have the same desire and legitimate right to become mothers as other women and an increasing number of disabled women nowadays are having children.

As a result, it is important for health professionals to recognize that women with disabilities may be hesitant to seek care because they anticipate such negative reactions and health care providers must be adequately prepared to provide them with appropriate and specialized care.

Thus, by investigating the attitudes and behaviors of HCPs we can identify the problems and the changes required to improve WWD's perinatal care.

As clinicians have recommended, especially designed training and education programs should be available including WWD [6,18,26]. This training should be continuous for the best caring results. All inappropriate behaviors and beliefs leading to stigma and inadequate care must be identified in order to make sure that HCPs become aware of how to treat these people appropriately.

In addition there should be better medical guidance with the design of specific guidelines for caring WWD during the perinatal period. An example could be "the provider's guide for the care of women with disabilities and chronic health conditions" by Suzanne C. Smeltzer and Nancy C. Sharts-Hopko [30]. It is important to emphasize that research on perinatal care for WWD is very limited. For this reason this literature review is also based on limited evidence. The scientific medical community should focus more on the disabled women who will become pregnant and their perinatal care needs. It would be very beneficial to conduct future research on both women with disabilities and HCPs themselves in order to identify gaps, misconceptions and suggestions for optimal

care for these women.

## Conclusion

This literature review shows that HCPs lacking the specific knowledge while providing perinatal care to WWD, frequently maintain negative behaviors and attitudes. Constant contact with pregnant WWD seemed to help ameliorate their behavior (HCPS). However, it is urgent for maternity providers to have specialized education and training on how to treat the WWD in the best possible way and provide them with unique experience during pregnancy, delivery and postpartum period.

Large scale studies on a nationally representative population must be carried out on the maternity experiences of disabled women in comparison with non-disabled and their views of the care provided. The elimination of all factors causing inhibition to HCPs in providing sensitive and evidence-based care to WWD, could contribute to improved outcomes for both women and babies and facilitate greater empowerment of this vulnerable population.

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