

# Perinatal Care in Women with Vision Disorders: a Systematic Review

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## ABSTRACT

**Objectives:** Maternal healthcare providers are usually unfamiliar and not adequately educated to cover the special needs of women with vision impairment during the perinatal period. Moreover, maternity clinics and hospitals may not be able to provide appropriate support based on the distinct needs of women with vision disorders. A systematic review was conducted with the aim to investigate the gap between those women's particular needs and the health services provided to them as well as the overall barriers that arise during perinatal care of women with vision disorder.

**Materials and methods:** We searched for peer-reviewed articles published in any language in two online databases, Medline and Scopus, using the following keywords: "perinatal care", "perinata\*", "wom\*", "vision disabilit\*", "vision disorder\*", "visual disorder\*", "visual impairment", "blindness". Articles were selected based on four inclusion criteria: (a) studies published over the last ten years, (b) primary researches and conference papers, (c) studies in English language, and (d) adult patient population.

**Results:** A total of 33 studies via Medline and 177 studies via Scopus were initially identified as relevant, but eventually, only three articles were found to meet all inclusion criteria. A systematic analysis of these three studies mainly showed that (a) pregnant women with vision disorders expressed lack of satisfaction for the quality of perinatal care that they received; (b) both hospital facilities and healthcare staff approaches were found incompatible with the specific functional needs of these women; (c) maternity care professionals' training and attitudes need to be modified in order to meet those needs.

**Conclusions:** It is crucial to note that the limited number of relevant studies found by us, which demonstrates by itself the need to conduct more studies in order to draw clearer and safer conclusions. Consequently, more research is required to evaluate how compatible with the functional needs of women with vision disorder the employed maternal healthcare interventions during the perinatal period really are. This would in turn improve perinatal outcomes for both the women and their families.

**Keywords:** vision disorders, visual disabilities, perinatal care, childbirth, pregnancy, systematic review.

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## INTRODUCTION AND OBJECTIVES

“Vision disorders” is an umbrella term for a wide range of vision deficiencies which can be attributed to many different factors. Based on some data, there seems to be a connection to vision loss and gender (1). There is also a number of various factors linked to these types of vision deficiencies, which seem to be different in industrialized countries compared to developing ones. Some examples include: (a) life expectancy, (b) access to healthcare services, (c) risk factors, and (d) hormonal differences. According to a meta-analysis performed by Abou Gareeb *et al* (1), the estimated global blindness by gender has a proportion of 64.5% for women and 35.5% for men (1). Moreover, World Health Organization (WHO) data show that globally, at least 2.2 billion people have some sort of vision disorder or are blind (2). The study of Shandra, Hogan and Short (3), reported that approximately 12% of all US women of childbearing age had some type of disability (3). The same proportion was also found in the survey of Horner-Jonson *et al* (4).

According to the International Classification of Diseases (ICD-10) 2019, the definition of severe visual loss is having a visual acuity between 20/200 and 20/400 in the better eye. On the other hand, the definition of blindness is split into three categories, with each of them depending on the individual visual acuity (less than 20/400) and light perception (5).

A survey conducted in 2014 demonstrated that women with or without disabilities were equally likely to want, and have, children (3). However, this finding is in contradiction with the common perception – in both high and low income countries – that people with disability are asexual (6). Nevertheless, women with disabilities were found to be less certain about their intentions to have children or not (3).

Taking into consideration the observed high prevalence of vision disorders globally (2), it is expected that maternity care providers have to deal with several cases of women with vision disorders during the perinatal period, when visits to a health professional are usually very frequent.

The feeling of overall satisfaction for both the pregnancy and her childbirth experience has an enormous impact on the successful bonding,

firstly between the mother and newborn and secondly, between all members of a new family. Moreover, survival of the newborn is highly connected to the quality of care provided during early life (7). Obviously, antenatal support received by pregnant women with vision disorders through via taking classes on how to care of their newborns has a crucial role and a positive impact on both their self-efficacy as mothers and towards raising their self-esteem (8). Additionally, it has been shown that women with disabilities were more likely to report postpartum and pregnancy related adverse conditions such as depression (9).

Consequently, healthcare providers should be receiving sufficient education and training in order to be able to provide adequate high quality “people-centric” perinatal care, which can also meet the additional needs of women with vision impairment or blindness as well as those of their infants and families. In many studies, health professionals stated that they felt inadequately prepared to provide care to people with disabilities, mentioning that they had not received sufficient training (10, 11).

To our knowledge, there is no published study in Greece on perinatal care for women with vision disorders, including blindness. As a result, there is a gap on information available on the subject, and there are no standards for perinatal care tailored to the specific needs of these women.

The aim of this study was to identify and review the existing evidence on the provision of perinatal care among women with visual disabilities, determine whether blindness and other vision disorders influence pregnancy outcomes and explore the special needs and requirements of providing perinatal care to these women. □

## MATERIAL AND METHODS

A systematic review of the international literature was conducted by using two online databases, Scopus and Medline. We excluded case reports and case series but included all studies with other designs. We searched the mentioned databases for relevant articles from 2011 to March 2020. A systematic search strategy was developed using key medical sub-headings terms and related text words for the terms “vision disorder” and “perinatal care” in Medline, and once identified, they were used to further search for articles in

both Scopus and Medline. The final terms that were used either individually or in combinations were: “vision disorder\*”, “visual disorder\*”, “visual impairment”, “vision disabilit\*”, blindness, “perinatal care”, “perinata\*” and “wom\*”. Our search strategy was based on the following inclusion criteria with regard to original research: being published during the last 10 years; being a primary research; published in English; full text availability; being published in a peer-reviewed journal.

The resulting articles were then evaluated by their title. Articles with a title that was not compatible to the purpose of the systematic review were excluded. Afterwards, abstracts of the remaining studies were appraised, and those that did not meet the inclusion criteria and the purpose of the systematic review have been also excluded. Titles and abstracts were reviewed by two authors. For the remaining studies, a search for their full text version was done, and finally, those that did not meet the purpose of the review were rejected.

In parallel, web-based searches on vision disorders and perinatal care were also performed on WHO and ICD-10 definition websites. The reference lists of all included papers were also explored in order to find studies that could have been missed by previous online database searches. □

## RESULTS

Out of the total number of studies initially identified as relevant of 200, using the above-described online search in the international literature, only 76 studies met the inclusion criteria. From the remaining 76, 70 studies were rejected after reading the title and three more were excluded after reading the summary and full text version (Figure 1). Consequently, only three studies were eventually found to fully meet all inclusion criteria and were selected for the systematic review. All three studies were published after 2014. The first study was about the influence of vision disorders to pregnancy outcomes. The second one explored the perceptions and experiences of women with vision disorders regarding the perinatal care received by them. The third study addressed the occurrence of pregnancy among women with different types of disabilities and their needs for preconception and perinatal care.

The main characteristics and results of studies included in this review are shown in supporting information (Table 1).

One of the most important results of our systematic review is that there are very few published studies exploring the needs of women with vision disorders who receive care during the perinatal period. Therefore, further surveys in the specific field should be performed in order to improve the effectiveness of maternal healthcare interventions offered to pregnant women with vision disorders and their families.

In the retrospective cohort study of Ofir *et al* (12), women with (n=80) and without a recorded vision disorder (n=265,661) were evaluated with regard to their delivery complications and perinatal outcomes. Multivariable models were used to control for confounders. The main results of this study show that women with vision disorders were significantly older than those in the comparison group and had higher rates of both gestational diabetes mellitus (GDM) and severe preeclampsia, increased rates of delivery before 37 weeks of gestation and a significantly higher rate of delivery by cesarean section (CS). After using a multivariable analysis model and even after controlling for confounders such as maternal age and ethnicity, the risk for CS and packed cell transfusion in women with vision disorder remained significantly high. However, the researchers stressed that the perinatal outcome is overall comparable to that of the general population. The authors have also found that subjects with vision disorders were more likely to be obese and smokers. Another significant result of their study was that the subgroup of women with vision disorders due to autoimmune etiology (19.4%) had again higher rates of recurrent miscarriages, CS, preterm delivery, IUGR, and preeclampsia compared to the other sub-groups. Finally, it is worth noticing that 55% of all cesarean sections in this subgroup were emergencies, due to fetal distress or complicated vaginal delivery (12).

In 2018, Mazurkiewicz, Stefaniak, and Dmoch-Gajzlerska interviewed 16 women with vision disorder and total blindness (in the perinatal period) and focused on five pre-selected major themes for their quantitative research, including the perceived stigmatization and reluctance in accepting the particular population’s right to motherhood; the women’s ability to attend antenatal classes tailored to their needs; their ability

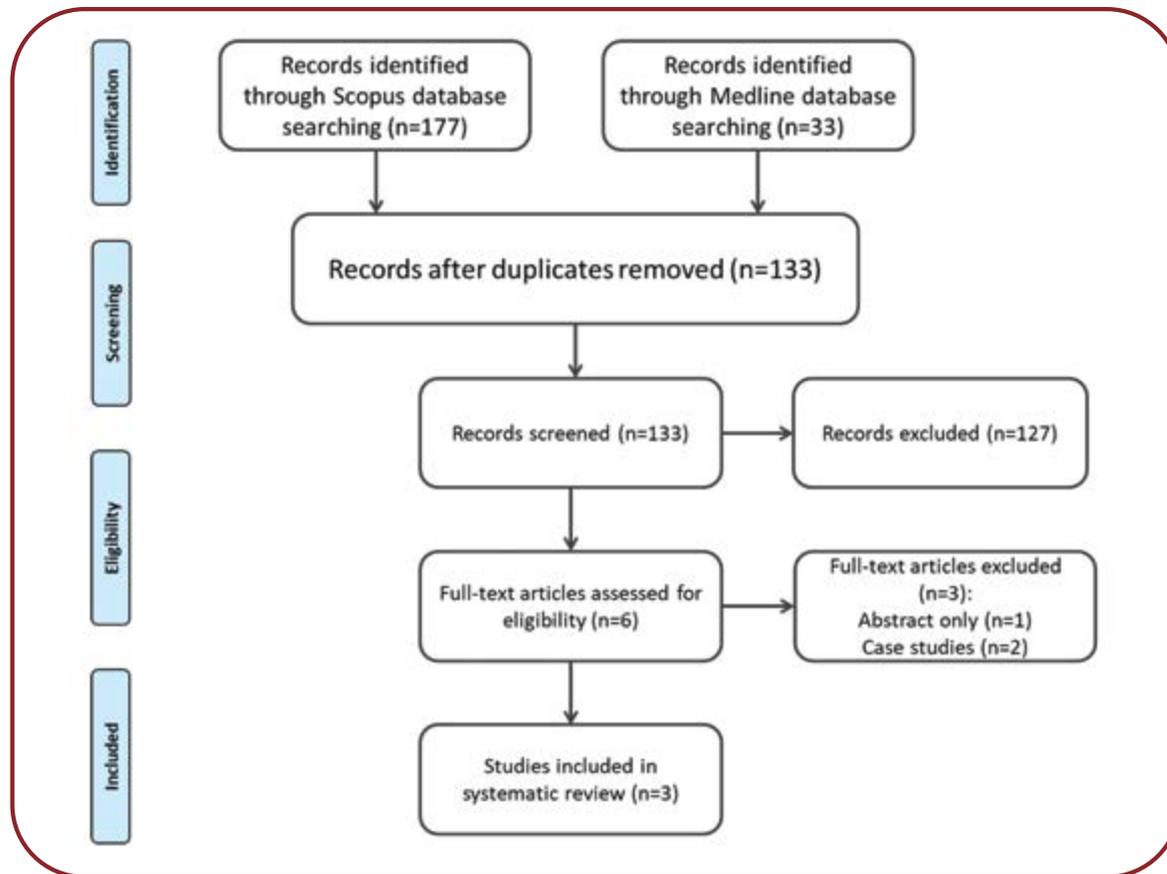


FIGURE 1. PRISMA flow diagram illustrating article filtering process

TABLE 1. Characteristics of included studies

Author	Title	Country	Methodology	Participants	Intervention
Mazurkiewicz, Stefaniak, and Dmoch-Gajzlerska (2019)	Perinatal care needs and expectations of women with low vision or total blindness in Warsaw, Poland	Poland	Qualitative	Total subject sample N=16 blind or low vision women	Hour-long interviews, audio-recorded and transcribed verbatim. The accounts were subsequently evaluated using the interpretative phenomenological analysis (IPA) approach. Five major themes were pre-selected. Semi-structured interviews were conducted among participants three days after childbirth. After recording the interviewees' demographic data, researchers asked them to freely voice their opinions on each of the five major aspects of their perinatal care.
Ofir <i>et al.</i> (2015)	Influence of visual impairment on pregnancy outcomes	Israel	A retrospective cohort study	Total subject sample N=265,741 women; 265,661 no vision disorder, 80 with vision disorder	A retrospective cohort study compared obstetric, delivery complications and perinatal outcomes of patients with and without a diagnosis of visual impairment in one eye or both eyes. Multivariable models were conducted to control for confounders.
Horner-Johnson <i>et al.</i> (2016)	Pregnancy among US women: differences by presence, type, and complexity of disability	U.S.	Cross-sectional analyses	Total subject sample N=27,567 (both women with and without any disability)	A cross-sectional analysis of the existing data from the 2008-2012 Medical Expenditure Panel Survey aimed to estimate the proportion of women aged 18-44, with and without disabilities, who reported a pregnancy during one year of their participation to the survey panel. Multivariable logistic regression to test the association of pregnancy with presence, type, and complexity of disability, controlling for other factors associated with pregnancy were used.

to access appropriate perinatal care and hospital facilities; the midwives' attitudes towards their condition; and their own expectations regarding the improvements of care services received by them. The results of the study demonstrated that (a) subjects were dissatisfied with the quality of perinatal care; (b) the existing antenatal classes were unsuitable for their special needs; (c) hospital facilities (architectural barriers) and staff approach also failed to meet their functional needs; (d) there was a perceived stigmatization of motherhood for women with low vision or blindness; (e) training and attitudes of maternity care professionals should be amended in order to meet the needs of women with vision disorders regarding maternity; and (f) the suggested amendments for an improvement of perinatal care of women with vision disorder have been finally recorded (8).

Horner-Johnson *et al* (4) conducted a cross-sectional analysis of data provided by the 2008-2012 Medical Expenditure Panel Survey. Firstly, they analyzed all data in order to isolate the proportion of women aged 18–44, both with and without disabilities, who were pregnant during their participation in the survey panel. A total sample of 27 567 women with no missing data was isolated. Then, a multivariable logistic regression test was performed on data of the above sample in order to assess the association between pregnancy and presence, type, and complexity of disability, also controlling for other factors generally related to pregnancy. The study showed that (a) women with and without disabilities reported being pregnant in a similar percentage (10.8% vs. 12.3%); (b) those with the most intense disabilities – such as those impacting self-care and work activities – were significantly less likely to get pregnant (7.8%) compared to women without disabilities; (c) among women whose disabilities have only affected basic actions (seeing, hearing, movement, cognition), there were no significant differences with regard to their pregnancy likelihood compared to women with no disabilities (4). □

## DISCUSSION

### Main findings

The international literature targeting perinatal care of women with vision disorders is limited. Only three studies were found to meet all

previously defined inclusion criteria and were eventually included in the present systematic review. Many studies, which were excluded from our review, were mainly focused on the underlying medical condition that caused women's vision disorders, which was beyond the scope of our approach. All studies that were included in our review stressed the existence of both limited data and a general gap of knowledge in this field (4, 8, 12).

Nevertheless, we found valuable studies, where it was indicated, that women with vision disorders may be at increased risk for perinatal complications compared to those without such disorders. More specifically, we found that women with vision disorders were at high risk for cesarean section deliveries, which was also consistent with the results of a recent meta-analysis (13). Moreover, findings from our systematic review suggest that there is an emerging need to explore employing specific measures that would contribute to the reduction of unequal perinatal treatment among both women with various vision disorders and their controls without such disorders. In addition, it is proposed that certain interventions need to be implemented in order to better support women with vision disorders and their families during the perinatal period, so as to bridge the gap of inequality in care received. All these findings are also consistent with those of another review published in 2015 (14).

In the meta-analysis of Tarassof *et al* (13), the significance of listening to women's knowledge of their own bodies was perceived as paramount, together with their meaningful introduction in the training of healthcare professionals, with the purpose of achieving a higher quality of preconception and perinatal maternity care provided (13, 15). Very similar findings have been also identified in our systematic review, as subjects reported that midwives seemed to be unaware of the specific functional needs of women with vision disorders (8).

Our research has highlighted the fact that women were generally dissatisfied with the quality of perinatal care offered to them, the inappropriate hospital facilities and the staff's approach to their specific functional needs. Stigmatization of motherhood has been also emphasized as a common perception of women with low vision or blindness. Deficiencies in formal training and approach employed by mater-

nity care professionals were identified too. All these findings are consistent with those described in earlier studies, as these women reported several barriers to a positive healthy pregnancy experience (13, 16).

Additionally, new interventions targeting the preconception period should be introduced, which would also enable women with disabilities, their families as well as healthcare providers to actually plan ahead what kind of resources and supports would be necessary during the perinatal period (17).

Finally, there is an identified inherent need to better support women with disabilities who have already entered the gestation period, which includes not only just supporting them in reducing potential perinatal risks but also recognizing that women with disabilities are generally marginalized throughout many different aspects of their lives. Such marginalizing aspects can be related to potential low socioeconomic status, little social support, high rates of abuse and experiences of stigma and discrimination (18-20).

### Limitations

The limitations of the present systematic review concern the small number of studies that were eventually found to meet overall inclusion criteria, which may potentially lead to unsafe conclusions. Also, the selected studies were heterogeneous and not comparable. □

### CONCLUSION

It is crucial not only to address the preconception risk factors but also to provide more specialized support to women with vision disorders during the perinatal period. In parallel, employing a woman-centered and disability-related training program for maternity healthcare professionals may also contribute to better perinatal

health and healthcare experiences for women with vision disorders. This training program should address both the health aspects of maternal care and attitudes toward disability and sexuality, which may also have an impact on the delivery of care.

Also, an appropriate training for women with vision disorders, compatible with their special functional needs, has to be introduced in order to promote a successful transition to motherhood by providing tailored instructions in baby care basics. Also, the attitudes of maternity healthcare professionals should be stirred towards increasingly providing both empathetic care to women with vision disorders and support to their families.

Demonstrating wakefulness and constantly educating maternity healthcare professionals on the needs of women with vision disorders is paramount especially for midwives, since they are closely assisting women during the perinatal period. This requires the development and subsequent introduction to clinical practice of standards and procedures, which would specifically be addressing the perinatal care for women with vision disorders.

Despite concerns about adverse pregnancy outcomes of women with physical disabilities, raised in the literature, there is little information about unmet needs of women with vision disorders during pregnancy and childbirth. Besides, it is the responsibility of maternity health systems to create people-centered services which are compatible with persons with all kinds of disabilities. Our review highlights the need for policy and practice recommendations for perinatal care of women with vision impairments and blindness. □

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