

Pregnancy in women with physical and intellectual disability: psychiatric implications

Gravidanza in donne affette da disabilità fisica e intellettuale: implicazioni psichiatriche

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SUMMARY. Women with disabilities feel the desire for motherhood as much as women without special clinical needs. Their fertility is often not impacted by disability and they can have children. However, several issues must be considered, depending on the physical, mental or developmental disability. Women with a physical disability often experience higher risks of caesarean section, preterm birth, growth restriction and low birth weight when compared to controls. Women with intellectual or developmental disabilities are often young, unmarried, unemployed and have limited access to care. They often struggle following instructions or recognizing the conditions that require medical help. They are more likely to experience preeclampsia, diabetes, venous thromboembolism, cesarean delivery, infant low birth weight, preterm birth, neonatal intensive care unit admission, and perinatal death. Moreover, an association between psychiatric morbidity and alcohol abuse was proved by several pieces of evidence and it can cause serious damage to fetus and newborn causing Fetal Alcohol Spectrum Disorders. Fetus and the newborn of disabled mothers are exposed to specific risks depending on the mother's conditions: the main risk fetuses are exposed to during pregnancy is exposure to drugs and therapies which cannot be suspended and whose effects over pregnancy are not known. Moreover, some conditions causing maternal disability could elevate the risk for the baby to be similarly affected. It is important that both women and men with disabilities could be provided with accurate, accessible, and understandable information about sexual health and options regarding contraception and reproduction. It's important for women with disabilities to have the chance to discuss sexual matters, pregnancy desires and concerns with healthcare providers so they can provide appropriate screenings, contraceptive services, preconception, and prenatal care. Among healthcare providers, midwives are the frontline healthcare professionals who have the role, the possibility and the education to perform influential counseling on women about lifestyles and reproductive health.

KEY WORDS: pregnancy, physical disability, intellectual disability, reproductive health, midwives.

RIASSUNTO. Le donne con disabilità hanno lo stesso desiderio di maternità delle donne senza bisogni speciali. La loro fertilità generalmente non è compromessa e possono avere figli. Tuttavia, ci sono alcune criticità che devono essere considerate, soprattutto circa la disabilità fisica, mentale o evolutiva. Le donne con disabilità fisica spesso sono maggiormente esposte a rischio di taglio cesareo, parto pretermine, restrizione della crescita fetale e basso peso alla nascita del nascituro. Le donne con disabilità intellettuale o evolutiva sono spesso giovani, nubili, disoccupate e hanno ridotto accesso alle cure. Sono maggiormente a rischio di preeclampsia, diabete, tromboembolismo venoso, taglio cesareo, basso peso alla nascita del nascituro, parto pretermine, ricovero in terapia intensiva neonatale e morte perinatale. Inoltre, un'associazione tra morbidità psichiatrica e uso di alcol è stata dimostrata da molteplici evidenze scientifiche e ciò può causare seri danni al feto e al neonato causando i disturbi dello spettro della sindrome feto-alcolica. I feti e neonati da madri disabili sono esposti a vari rischi, dipendenti dalle condizioni materne: il maggior rischio è costituito dall'esposizione ai farmaci assunti durante la gravidanza che non potevano essere sospesi e i cui effetti sul feto non sono noti. Inoltre, alcune condizioni materne possono aumentare il rischio che il bambino ne sia ugualmente affetto. È importante che sia le donne sia gli uomini disabili abbiano accesso a informazioni accurate e comprensibili circa la salute sessuale e riproduttiva e i metodi contraccettivi. È importante che le donne con disabilità abbiano accesso a servizi in cui poter discutere con gli operatori sanitari circa il sesso, il desiderio di gravidanza, i metodi contraccettivi e le cure perinatali. Tra i professionisti sanitari, le ostetriche sono operatori di prima linea che hanno il ruolo, la possibilità e la preparazione necessaria per mettere in atto un counselling efficace circa gli stili di vita sani e la salute riproduttiva.

PAROLE CHIAVE: gravidanza, disabilità fisica, disabilità intellettuale, salute riproduttiva, ostetriche.

INTRODUCTION

Motherhood and pregnancy have been recognized as part of the rights of disabled women although motherhood it's not always acknowledged as a right especially by caregivers¹. In fact, families, parents or social support suppliers often fear the baby could inherit the disability and this leads disabled women to be unjustifiably controlled and their privacy to be restricted.

Women with special needs should be given the same respect and dignity as human beings, without pushing their will and their choices about reproductive life.

In the US, around 12% of women of reproductive age have a disability^{2,3}. Although recent research indicates that pregnancy rates are the same among women with and without disabilities⁴, access to prenatal care seems to be lower in disabled women⁵. A few studies suggest that women with disabilities have positive pregnancy outcomes⁶, while more studies have shown higher rates of preterm birth and low birth weight in this population⁷. Moreover, increased cesarean section rates have been documented among women with specific types of physical disability, including spinal cord injury, rheumatoid arthritis, multiple sclerosis, cerebral palsy, spina bifida, and neuromuscular disorders⁸⁻¹⁴. Research also suggests that the risk of cesarean delivery is higher for women with intellectual and developmental disabilities^{7,15}.

The aim of this short narrative review is to summarize pieces of evidence about risks for pregnant women with physical as well as intellectual disabilities.

DEFINITION OF DISABILITY

There is no unanimous agreement about the definition of disability. The traditional approach adopts a medical model in which disability is defined by an individual's impairment in function. The Americans With Disabilities Act defines disability as «a physical or mental impairment that substantially limits one or more major life activities»¹⁶. An alternative view is the so-called "Social Model" of disability, which views disability as «the degree to which human-made and societal barriers place restraints on an individual who may have a bodily impairment».

According to WHO, Disability is a compounding factor that impacts many aspects of a person's life¹⁷. People with a disability could experience poorer health outcomes, have less access to education and work opportunities, and are more likely to live in poverty than those without a disability. This can be caused by many factors including a physical barrier to access buildings and transportation, social stigma, lack of service provision and increased likelihood of being left out of decision-making that affects their wellbeing.

PHYSICAL DISABILITY

Among disabilities, mobility impairments are more frequently cited in the literature. In fact, most of the women with physical disabilities have regular fertility and can have children. Although, very few data were found about disabled women's pregnancy, delivery and postpartum.

For most women, pregnancy outcomes are favorable. However, increased rates of certain adverse outcomes, such as low birth weight, preterm birth, growth restriction and cesarean delivery, have been reported in women with spinal cord injuries, rheumatoid arthritis, multiple sclerosis or other conditions⁶. Common morbidities across conditions may include urinary tract infections, decreased mobility and independence, skin ulceration and respiratory compromise⁶. Moreover, women with special needs could encounter some issues related to socioeconomic, physical, and attitudinal barriers in parenting independently.

Currently, limited evidence indicates that most women with physical disabilities will have good pregnancy outcomes; however, some data suggest that rates of a range of complications may be more common among women with physical disabilities¹⁸, depending on the nature and severity of the underlying condition. Maternal, obstetrical, fetal and neonatal outcomes are summarized in Table 1.

Spinal cord injury (SCI) in women can cause amenorrhoea or menstrual issues immediately after the injury, but fertility is generally not impacted¹⁹. One study on 114 women with spinal cord injury showed that 36% conceived naturally²⁰. Comparing pre-injury pregnancies with those that occurred after the injury, there were no important differences in outcomes of live birth, miscarriage or stillbirths²¹. However urinary tract infections were significantly more common (46% vs 8%). Urinary incontinence, bladder spasms or other urologic issues occurred in 9 to 25% of the sample²¹. An increased rate of cesarean section was observed in women with SCI but the reasons for this association are not clear. Moreover, an increased rate of preterm birth was found in women

Table 1. Maternal, obstetrical, fetal and neonatal outcomes of physical conditions.

Source	Condition	Maternal/ Obstetrical outcome	Fetal/ Neonatal outcome
Bughi et al. ¹⁹ Ghidini et al. ²⁰ Jackson et al. ²¹	Spinal cord injury	Urinary tract infection Pressure ulcers (5-10%) Spasticity (10-20%) Increased CS rate (20-50%) Preterm Birth (20-25%) Unrecognized labor	Low birth weight
Vukusic et al. ²⁵	Multiple Sclerosis	Spontaneous abortion Stillbirth Increased CS rate	Low birth weight
Skomsvoll et al. ²² Katz ²³	Rheumatoid arthritis	Increased CS rate Preeclampsia Preterm Birth	Low birth weight
Winch et al. ¹⁴ Kriger ²⁴	Cerebral palsy	Increased CS rate Preeclampsia	Low birth weight

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with SCI. This could be related to the impossibility of women with lesions above T10 to feel uterine contractions and thus enhancing the risk of unexpected delivery²⁰.

Similar data were found in women affected with Rheumatoid Arthritis, with increased rates of cesarean section, preeclampsia and intrauterine fetal growth restriction^{22,23}. However, pregnancy rates in women affected are significantly lower¹³.

Women with cerebral palsy generally experience disorders of movement and posture, spasticity and joint contractions. People with cerebral palsy may also have visual, hearing and speech impairments, seizure or intellectual disability^{14,24}. Pregnancy rates among women with cerebral palsy are not known but most of them have favorable outcomes with little increased risk of cesarean section, preeclampsia and low birth weight¹⁴.

Multiple Sclerosis (MS) is an autoimmune disease characterized by flares of diseases with relapsing and remitting periods. Flares are common in 3rd trimester in pregnancy, but they are generally mild and autoregulate without therapy. However, flares in the postpartum period are often severe and occur in around 30% of cases²⁵. MS during pregnancy could hesitate in spontaneous abortion, stillbirth and increased rates of cesarean section. Women with MS should be encouraged to breastfeed their children because most of the therapies are safe during breastfeeding²⁶.

INTELLECTUAL AND DEVELOPMENTAL DISABILITY

Around 750,000 women of reproductive age in the USA suffer an intellectual disability²⁷. People with intellectual disabilities often experience challenges in understanding, communicating with others and cognitive perception²⁸. They also may have lower socioeconomic status and reduced access to care, including prenatal care²⁹. Moreover, self-awareness and monitoring of signs and symptoms that need the seeking of care during pregnancy may be reduced among women with intellectual disability³⁰.

Obesity and smoking³⁰ are more frequent among women with intellectual disability and they are more likely to have preeclampsia³¹, diabetes³², venous thromboembolism³³, cesarean delivery¹⁵, infant low birth weight³⁴, preterm birth³⁴, neonatal intensive care unit (NICU) admission³¹, and perinatal death³⁴. Moreover, an association between psychiatric morbidity and alcohol abuse was proved by several pieces of evidence³⁵⁻⁴⁶ and it can cause serious damage to the fetus and newborn causing Fetal Alcohol Spectrum Disorders (FASD)⁴⁷⁻⁵⁴ and changes during adulthood.

Mothers with intellectual disabilities are more likely to be young (18-24 years)⁴, unmarried, smokers and nulliparous⁵⁵. Maternal age-adjusted results for paternal age suggest that pregnancies of women with intellectual disability were more often obtained with older partners, around 40 years old or even more⁵⁵.

EFFECTS ON THE NEWBORN

Risks for the fetus and the newborn are specific for the maternal condition. The main risk fetuses are exposed to dur-

ing pregnancy of disabled women is exposure to drugs and therapies⁶. In fact, people with disabilities often take medications that cannot be suspended and whose effects over pregnancy are not known. Careful medication administration should be carried on before and during pregnancy to ensure the minimum risk possible for both mother and baby.

Some conditions causing maternal disability could elevate the risk for the baby to be similarly affected: for example, children of mothers with MS are more at risk of developing MS than the general population (around 5%)⁵⁶.

Newborns of mothers with myasthenia-gravis are more at risk of developing a perinatal form of myasthenia and have infant death caused by myasthenia-induced respiratory impairment⁵⁷.

Infants of women with intellectual disabilities had an increased risk of low birth weight and of being Small for Gestational Age (SGA)⁵⁵. It is possible that this finding was due to placental insufficiency from increased prenatal smoking, preeclampsia, or infant malformations⁵⁵. They are also more likely to not have been breastfed and being hospitalized for 6 days or more after delivery. Infant deaths during the first 2 years of life were uncommon, occurring in approximately 2%⁵⁵.

ASSOCIATION BETWEEN DIABETES, OBESITY AND DISABILITY

An association between disability and diabetes mellitus and obesity was clearly demonstrated^{58,59}. Gillani et al.⁵⁸ focused on methods of blood glucose self-monitoring in elder patients with disabilities. Koye et al.⁵⁹ stated that among 2373 study participants aged 60 years or above who had a disability assessment at the third wave of follow-up (2011-12), 255 (11%) reported at least some disability. Participants with diabetes at baseline had higher odds of disability at 12 years [odds ratio=2.41 (95% CI 1.60-3.64)] as compared to individuals with normal glucose tolerance with no differences between men and women. Body mass index (BMI) and cardiometabolic issues like hypertension, prior cardiovascular disease, impaired glomerular filtration rate, triglycerides and high-density lipoproteins, were important in explaining the increased odds of disability. BMI and cardiometabolic factors together explained 65% of the diabetes-associated odds of disability at 12 years. These findings suggest that interventions targeting weight control, and prevention and treatment of cardiometabolic factors may prevent disability associated with diabetes and promote healthy lifestyles⁶⁰⁻⁶³.

From 1988 to 2004, a significant increase in the association between obesity and disability was showed⁶⁴. Obesity was associated with a much higher risk of disability than it had been in the past, calling attention to disability as the price of a longer life with obesity⁶⁵⁻⁶⁷. More recently, the same weight status at the same age was more strongly linked to disability than in the past, raising the serious concern that obesity is becoming less lethal but more disabling over time⁶⁸. A mean earlier onset of obesity is increasing the time of exposure to high weight during the lifetime, causing a cumulative exposure to obesity. This is particularly meaningful for disability because of obesity's role in osteoarthritis, neurodegeneration, chronic back pain, loss of muscle strength, and overall wear and tear on the musculoskeletal system⁶⁹⁻⁷³.

DISCUSSION

It was proved clear that women with disabilities have intact fertility and willingness to have children. Women with a single disability, whether physical, sensorial or cognitive, show no differences in pregnancy rates when compared to no disabled women⁴. Only women with complex disabilities, when more than one basic life function is impaired, have a significant reduction in pregnancy rates⁴.

Although, sexual and reproductive life of people with disability is often ignored or misunderstood and it leads disabled women to have inadequate access to care: it was proved that disabled women are significantly less likely to receive routine testing for cervical cancer^{74,75}.

Women with sensorial or cognitive disabilities may have difficulties in understanding prescriptions and directives⁷⁶ and they need special attention by healthcare providers to ensure them the best quality of care possible. It is important that both women and men with disabilities could be provided with accurate, accessible, and understandable information about sexual health and options regarding contraception and reproduction. In particular, it's important for women with disabilities to have the chance to discuss sexual matters, pregnancy desires and concerns with healthcare providers so they can provide appropriate screenings, contraceptive services, preconception, and prenatal care.

Among healthcare providers, midwives are the frontline healthcare professionals who have the role, the possibility and the education to perform influential counseling on women about lifestyles and reproductive health⁵³. They should be educated to plan a tailored intervention to assist women with complex clinical needs in new dedicated clinical contexts where one-to-one care and a multidisciplinary approach is possible. Moreover, dedicated clinical pathways for continuity of care in postpartum should be designed to allow midwives to effectively follow women's birth, support breastfeeding and provide efficient counseling on future reproductive health.

CONCLUSIONS

Attention to reproductive healthcare needs and a multidisciplinary approach to women with disabilities is central to improving social and health outcomes in this population.

Conflict of interests: the authors have no conflict of interests to declare.

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