

Pregnancy and postnatal care of women with mild intellectual disabilities

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ABSTRACT

Women with intellectual disabilities experience more health problems during pregnancy and in the postnatal period. Common complications include preeclampsia, miscarriage, premature birth, and neonatal death. In women from the normative population, pregnancy usually progresses without major complications, with a lower incidence of these risks, provided there is adequate medical care and access to information. Healthcare professionals are often not trained to work with pregnant women with intellectual disabilities, which creates additional pressure for these women, as they often feel incapable of fulfilling the role of a mother. During the prenatal period, they have less frequent access to information that is important for a healthy pregnancy. The study employed a qualitative research design using semi-structured interviews with a woman with intellectual disabilities and the mother of a younger woman with intellectual disabilities. We were interested in their overall pregnancy experience, the reactions of their social environment, the attitudes of healthcare staff, and postnatal care both in the maternity hospital and at home. It was found that both women needed the support of their family and professionals, which they did receive. However, their immediate and wider social environment received their pregnancy with reservation and silent disapproval, due to the belief that they were not capable of fulfilling the role of a mother. **Keywords:** intellectual disabilities, pregnancy, support, postnatal care, healthcare professionals.

Nosečnost in postnatalna oskrba žensk z lažjimi motnjami v duševnem razvoju

POVZETEK

Ženske z intelektualnimi primanjkljaji imajo več zdravstvenih težav v nosečnosti in v postnatalnem obdobju. Pogosta je preeklampsija, spontani splav, prezgodnji porod, smrt novorojenčka itd. Pri ženskah normativne populacije praviloma nosečnost poteka brez večjih zapletov, z nižjo pojavnostjo navedenih tveganj, ob ustrezni zdravstveni oskrbi in dostopu do informacij. Zdravstveno osebje ni podučeno o nosečnicah z intelektualnimi primanjkljaji kar nosečnicam predstavlja dodaten pritisk, saj se mnogokrat počutijo nesposobne za vlogo mame. V prenatalnem obdobju manj pogosteje dostopajo do informacij, ki so pomembne za zdrav potek nosečnosti. V raziskavi je bila izvedena kvalitativna raziskava s polstrukturiranim intervjujem, v kateri sta sodelovali ženska z intelektualnimi primanjkljaji in mama mlajše ženske z intelektualnimi primanjkljaji. Zanimala nas je celotna izkušnja nosečnosti, reakcije okolice, odnos zdravstvenega osebja ter postnatalna nega v porodnišnici in doma. Ugotovljeno je bilo, da sta obe ženski sta potrebovali podporo družine in strokovnih delavcev, ki sta ju tudi dobili. Bližnja in širša okolica pa je njuno nosečnost sprejela z zadržkom in tihim neodobravanjem, zaradi miselnosti, da nista sposobni opravljati vlogo mame. **Ključne besede:** intelektualni primanjkljaji, nosečnost, podpora, postnatalna oskrba, zdravstveno osebje.

INTRODUCTION

Mental disabilities are a neurological condition that affects an individual's functioning in two areas: Cognitive functioning, such as learning, problem-solving, and judgment and adaptive functioning, such as communication skills and social inclusion. Intellectual and adaptive deficits manifest early in development, usually before the age of 18 (3). Challenges faced by women with disabilities in sexuality and reproductive life are not necessarily linked to their disabilities but may result from insufficient education on these topics and a lack of societal support. There are very few cases in which women with intellectual disabilities (ID) have not experienced physical, emotional, or sexual abuse, forced marriage, or involuntary sterilization. How the sexual and reproductive needs of women with ID are addressed largely depends on their caregivers and parents. Their views significantly influence the quality of sexual and reproductive health care that women with ID receive. A negative attitude—particularly from healthcare professionals and the parents of women with ID—toward sexuality and reproductive health more strongly hinders access to services that support safe sex and reproduction than the disability itself. Certain aspects of sexuality within this population remain controversial, influenced by cultural, moral, and religious factors (9). Authors state that parents or caregivers are key figures in ensuring appropriate reproductive health for women with ID, and their attitudes undeniably affect the quality of services received by these women. This group is often overlooked in discussions of sexuality, sexually transmitted diseases, and abortion (2). As reported, women with intellectual disabilities have fewer opportunities to maintain proper reproductive health and attend regular gynecological check-ups (6). Authors state that recent studies show women with ID often begin prenatal care later in pregnancy. They also belong to the most at-risk group of pregnant individuals within the population of people with disabilities and are in the highest risk group for miscarriage among all pregnant women with disabilities. Pregnant women with ID make the least use of prenatal services and therefore require special counseling regarding prenatal care. The reasons for utilizing prenatal services are also influenced by cultural background, social resources, and the accessibility of various levels of prenatal care tailored to women with special needs (5). Authors find that women with ID generally have less knowledge about reproductive health. Many know very little or nothing at all about fertility, conception, pregnancy, and childbirth. Adequate informational support increases the sense of self-efficacy and confidence when making decisions during and after pregnancy. Women with ID have reported that receiving information about the benefits of breastfeeding influenced their decision to breastfeed. This is an important finding, as women with ID are less likely to breastfeed their children compared to women without ID. Most prenatal information is designed for the general female population, which means that women with ID often lack crucial information. Providing optimal prenatal informational support for women with ID is a challenge due to their varied intellectual and adaptive functioning abilities. Some women have reported that pregnancy is a time that is difficult to understand. A study on postnatal care conducted in Canada) showed that women with intellectual disabilities (ID) are at high risk of hospitalization within 42 days after childbirth, primarily due to psychiatric disorders. Maternal health during the fourth trimester—defined as the period from one to ninety days postpartum—and the extended postpartum period (up to one year after childbirth) plays a crucial role in the emotional and physical well-being of both mother and child. Compared to women without ID, women with ID had a higher prevalence of hospitalization in the postpartum period. They were at least twice as likely to be hospitalized during the intervals of 1–42 days, 43–90 days, and 91–365 days after childbirth. Women with ID were also at high risk for rehospitalization during each of these time periods. Additionally, they tended to have longer hospital stays between 43 and 90 days postpartum (8). Authors argue that women with intellectual disabilities (ID) are significantly more likely to have their child permanently removed by social services. Although there is no solid evidence explaining why some women have to fight to keep custody of their child while others do not, it is assumed that access to formal and informal social support may be a key advantage. When appropriate support is provided, women with ID are better able to cope with the role of motherhood. However, the parental support available to the general population often seems inaccessible or irrelevant to the needs of women with ID. This results in a limited social support network (7).

PURPOSE

The aim of the study was to explore the course of pregnancy and postnatal care of two women with mild intellectual disabilities, both in the maternity hospital and at home. The focus was on the attitude of healthcare professionals toward the two women during pregnancy and after childbirth, as well as the accessibility of information related to the healthy development of the fetus during pregnancy.

METHODOLOGY

We used a descriptive method of research and a qualitative research approach. For the purposes of the research, we conducted 2 semi-structured interviews – for each woman. We used individually created questionnaires, which were designed based on theoretical guidelines and direct practical work. The research sample consisted of 1 woman with mild intellectual disability (MID) and 1 mother of a young woman with MID whom recently gave birth and wanted to share with us her view of how the medical staff treated her daughter during pregnancy and in the delivery room. Interviews were conducted in person, lasting one to two hours. All necessary consents were obtained for the purpose of the research.

RESULTS

In the research we discovered that woman with MID discussed conception and its prevention with her mother and her chosen gynecologist. However, she did not want to use any form of contraception. The mother of the young woman with MID talked with her daughter about the importance of safe sex and its potential consequences. During her pregnancy, the interviewee experienced no complications apart from some initial nausea, which later passed. She quit smoking and went for daily walks. Her mother made sure she regularly took dietary supplements and maintained a healthy diet. She attended gynecological check-ups on her own. She gave birth via an unplanned cesarean section.

The mother of the younger woman with MID regularly accompanied her daughter to gynecological appointments. Together with her partner and other daughter, they ensured the pregnancy went smoothly. She added that her daughter initially experienced nausea, but this symptom passed quickly. In the maternity hospital, she did not receive the support and understanding she had expected. At home, the greatest support and help came from her mother, a friend, and the community nurse, who visited her more frequently than usual. She stayed in the hospital longer than the average new mother. The Center for Social Work checked the living conditions in which she would live with the newborn, and professional staff helped her care for the baby.

The mother of the young woman with MID emphasized that the medical staff did not show confidence in her daughter's abilities. A conversation about her daughter's specific needs was necessary before the nurses' attitude in the maternity ward began to change positively. After returning home, her parents and sister supported and stood by her. She received maximum support from her family, especially her mother, as well as from her gynecologist and the visiting community nurse who cared for her after she returned home from the hospital. However, she did not feel as supported by the professional medical staff in the maternity ward as she had expected. The mother of the young woman with MID emphasized that her daughter had received support from the family and the gynecologist, but not from the medical staff in the hospital, which she found troubling. Although the staff was friendly, they directed every question to her instead of to her daughter.

DISCUSSION

The findings of this study align with previous literature suggesting that women with mild intellectual disabilities (MID) face significant challenges during pregnancy, childbirth, and the postnatal period (5,6,10). One of the central issues identified is the lack of appropriate support and understanding from healthcare professionals, especially in the maternity hospital setting. Despite having familial and community support, the participants reported feeling misunderstood and underestimated by medical staff—a finding echoed in the work, who emphasized that negative attitudes from healthcare professionals can serve as a barrier to effective care for this population (8).

The present study further reinforces the critical role of familial support, particularly from mothers and close relatives, in ensuring a healthy pregnancy and positive postnatal adjustment for women with MID. This observation corresponds with the conclusions of who argue that support from family and informal networks often compensates for the lack of systemic or institutional support. In both case studies presented, the mothers of the women with MID played an essential advocacy and caregiving role, ensuring regular gynecological care, encouraging healthy habits, and facilitating communication with healthcare providers (9). Despite this strong familial involvement, the attitudes and behavior of healthcare providers during childbirth appear to undermine the autonomy and dignity of the women involved. Questions and instructions were directed toward the mothers rather than the patients themselves, suggesting an implicit bias regarding the capability of women with MID to make decisions about their own health and parenting. This finding is consistent with the one who observed that women with intellectual disabilities are often perceived as unfit mothers, sometimes resulting in the removal of children by social services—a pattern also feared by participants in the current study (10). A particularly important observation is the insufficient adaptation of informational support to the cognitive and adaptive needs of women with MID. Previous studies have shown that health education and prenatal guidance are generally designed for the neurotypical population, which leaves women with MID without accessible, comprehensible resources (6,8). The lack of tailored communication can increase anxiety, reduce compliance with prenatal and postnatal care recommendations, and impair a mother's confidence in her parenting abilities. Interestingly, one of the participants managed to attend medical appointments independently, which contradicts some stereotypes about women with intellectual disabilities and points to the diversity within this population. Intellectual disability is not a homogeneous condition, and many individuals with MID can develop sufficient autonomy if they are given appropriate support and are respected as competent agents. Finally, the findings call attention to the need for training healthcare providers on intellectual disabilities, patient-centered communication, and disability-sensitive care. The initial lack of trust from the nursing staff only changed after targeted discussions about the patient's needs—suggesting that attitudinal shifts are possible but require effort, awareness, and education.

CONCLUSION

In conclusion, this study highlights that women with MID can experience positive pregnancy and parenting outcomes when supported by understanding family members and professionals. However, systemic barriers—particularly within healthcare institutions—still limit their full participation and autonomy. There is a pressing need for inclusive healthcare policies, disability-sensitive training for providers, and development of accessible prenatal and postnatal informational materials to bridge the current gaps in care.

LITERATURE

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