The awareness and visual diagnosis of women with severe visual impairment as a main factor in the choice of delivery methods in childbirth

(overview essay)

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Abstract: *This article is focused on factors which influence the choice of delivery options of women with visual impairment (VI), investigating the connection between the information women have and how prepared they feel, as well as their attitudes (direct or indirect) to delivery methods. This article emphasizes the necessity of sexual education, adequately modified for pupils with visual impairment from preschool to age 18/19. Sexual education, containing all necessary elements combined with education within the family is the cornerstone of an expectant mother's awareness, and her feeling of competancy in parenthood. This emphasizes a respectful attitude to women with visual impairment. The author points out the possible connections between recommending C-sections to these women (from the expectation of progressing the visual impairment during childbirth), and ongoing unsuitable delivery techniques. The article includes international studies showing that there are women with visual impairment who can give physiological birth without any changes in their visual diagnosis (if certain conditions are met). The practical part of this article includes the case-study of a woman who was able to deliver naturally even after two previous C-sections with no change in her visual diagnosis.*

Keywords: *Woman, Visual Impairment (VI), Pregnancy, Awareness, Competence of Women, Childbirth Preparation, Physiological Childbrith, Natural Childbirth, C-section, Respect, Maternity, Parenting*

> *Motto: "Childbirth plays an important role in the life of a woman. It is the one fundamental moment that a woman will always come back to in her thoughts. The way it happens will be projected into her relationship to herself, to her baby, partner and to the whole society. Childbirth is not only a physical matter that the woman should survive, and it should not be a painful sacrifice. Instead, childbirth should*

carve deeply and positively into the soul of each woman and child. During the birth, not only the child is born, but a mother is born and a new family is created. Birth can be a strong and happy experience for the woman, that will stay in her heart forever. This is why it is the oblilgation of society to create the conditions for woman and child so that the new mother would feel supported in her maternity role, and that the child would get a dignified and loving welcome."

Anna Kohutová

1 Introduction

To concieve a child with her life partner is part of the natural instinct of the woman. This is the same for women with visual impairment (VI), they need an open future and a strong emotional bond through the parenting role. After analysing the current information resources accessible, we see that the area of pregnacy, delivery preparation, delivery and maternity of women with VI is still not not dedicated enough attention in Czechia. The situation is not helped by the myths that still exist about the sexuality of people with VI, and prejudices against these women's competency to give birth and be a parent. Simultaneously, among these women (and women *in general*) the feelings of incompetency to deliver a baby are rising, especially due to a lack of information, and the impact of the woman's surroundings. The whole delivery process *and* bonding has a huge effect on the woman's psyche. But a tendency towards C-sections is rising in modern society. Apart from possible complications for woman and child during the C-section, another consequence is separation of the child from the mother, which can cause post-natal depression and disrupt the natural lactation process. Women with VI are primarily recommended to deliver through C-section, and in following pregnancies C-sections are strongly recommended. Meanwhile, in current research and practice it is shown that there are women with some visual diagnoses existing who *are able* to give physiological childbirth without any subsequent changes in their visual diagnoses, even when giving birth *after* previous C-sections. A wide range of factors must be considered, the essential being; visual diagnosis, physical/psychological readiness, and the provided external conditions.

2 Definitions of the terms used

It is important to define the essential technical terms which used. Firstly, "a person with visual impairment", is someone with low vision (moderate, or severe which means being able to count fingers at six meters or less) or blindness (profound:

counting fingers at less than 3 meters, near-total: at 1 meter or less, or total: no light perception) according to WHO.[1]

Next, physiological and natural childbirth: physiological, also called "normal" is, according to WHO, defined as, „spontaneous in onset, low-risk at the start of labor and remaining so throughout labor and delivery. The infant is born spontaneously in the vertex position between 37 and 42 completed weeks of pregnancy. After birth, mother and infant are in good condition.»[2] ICM[3] call normal childbirth a unique dynamic process, when the physiology of the fetus is reacting reciprocally with the mother (with the goal of mother and baby to be safe and healthy).

Natural childbirth is defined as "a childbirth which starts and is going spontaneously without any external intervention. It is according to the woman's instincts. It is happening at homelike environment. The staff interfere minimally and keep an intimate atmosphere, respecting her intuitive attitude. They are open to her wishes and demands, which support the positive emotions and contributes to the childbirth without any stress or fear". (Štromerová)[4]

3 Information resources accessible to women with low vision or blindness

"Childbirth is a natural female ability, and the right of the woman is to be informed about this ability."

Anna Kohutová

A woman with low vision or blindness, as well as a woman who is able to see, creates her imagination about her childbirth step-by-step based on the obtained information.

3.1 Media

From research (Paulíková 2013, Kilduff & Kohutová 2017, Kilduff 2018, Kavalírová, Liška a Vondráčková 2015) we see the main information resources for people with low vision/ blindness are internet and TV. Easy and greater access to specific information means internet prevails against TV. However, there is a risk of finding incomplete information or misinformation, and of being influenced by traumatic labour stories that leave woman uncertain or scared from childbirth. It is also difficult to search specifics if one is unaware of their existance, e.g. information about possible ways of delivery, the delivery wish, prenatal courses etc. Many blind women join net

1 International Classifications of Diseases WHO, 2006 [online].

2 Definition of natural birth. [online].

3 International Confederation of Midwifes: Keeping birth normal. [online]

4 Štromerová, Z. Přirozený porod [online].

conferences, like "Mamina Mimina", to share experiences and recommendations on maternity and parenting.

Printed publications exist on this topic[5]; a brochure from the Okamžik Association, a few technical articles (Kilduff & Kohutová 2017) as well as including a few theses (accessible online). Apart from this, women with VI are left to rely on mainstream literature which does not cater for the specific aspects of delivery preparation and delivery itself, nor for parenting as a woman with VI.

3.2 Family

Some women with VI obtained the aforementioned information from their families. However, questions about this topic, including sexuality are usually not answered enough (Škutová, 2008, Kubátová 2013). In extremes, they are taboo, in spite of the natural interest of children with VI.

3.3 Sexual education of children with VI at schools

There have been a few researches mapping the realization of sexual education in schools and the subjective preparation of children for relationships and future family life in the last 15 years or so. Škutová (2008), engaged in research about sexual education at preschool and primary school ages, and shed light on the limited understanding of sexual education among teachers, and the tendency to leave this responsibilty on parents.

Míka (2015) discovered that more than 80% from 64 children with VI with an average age 17.5, consider sexual ed. as very important and helpful. Paulíková (2013) points out that almost 30% of her respondants with average age 14.65 recieved this information too late. Some topics girls were interested in, like caring for a newborn, were completely neglected. So do young girls with VI get the full, correct and current information about delivery preparation, and possibilities connected to their visual diagnosis?

There *is* a noticable shift in this area, with pregraduate future sexual ed. teachers. We can expect that the quality of sexual ed. in school is increasing as teachers' interest increases. Children are lead to open communication, and express their opinions and interests. In addition, spreading the information about the life of people with VI helps to bust the myths about these people and their needs.

3.4 Prenatal courses

Special prenatal courses, as well as information about maternity and breastfeeding is still very limited. Specialized courses dedicated directly to couples with VI, are offered by Tyfloservis, but only occassionally (Kavalírová, Liška et Vondráčková, 2015).

[5] In enlarged print or audio format

3.5 The Department of Health

The right to give birth naturally, or physiologically should not be possible to take away. The only reasons to do so would be medical complications, or contraindications. Women with VI are primarily recommended C-sections in Czechia. As mentioned above, this should be recommeded by an opthalmologist when normal childbirth could have an adverse effect on visual acuity. Opthalmologists worry about the expulsion phase of delivery, when during ineffective pushing the pressure inside the woman's head could cause a progression of her VI.[6] This is not recommended by WHO because of their studies, and the reasons form a list of harmful effects for all women, especially for women with VI (Bosomworth et Bettany-Saltikov, 2006; Kopas 2014). A woman should follow her own feelings[7]. Controlled forceful pushing instructed by the medical professionals is not recommended. It is advised to give birth in an intuitive and vertical position, and while the head is crowned the woman should be let to exhale deeply and calmly, to breathe and not to push. It is questionable, whether the opthalmologist who recommend C-sections are informed about WHO recommendations, and how much their C-section tendency is effected by their own awareness of practises in many Czech hospitals. To what extent do opthalmologists expect a passive attitude to childbirth from a woman with VI? How much do they expect that she will not be informed about the physiology of the delivery process? How is it taken for granted that the woman is afraid of childbirth? It is truly necessary to always recommend a woman with VI/blindness (having thus far experienced a naturally developing healthy pregnancy) a C-section?

> *"I don't remember already if my gynecologist informed me about the possibility to deliver the baby normally, nobody else was informing me about this possibility or of a natural childbirth."* (A blind respondant from Kilduff & Kohutová, 2017)

Let's consider the connection between marking pregnancy as a high-risk one a priori, based on VI alone, and (with other factors mentioned above) the C-section recommendation:

> *"My pregnancy was labelled as high-risk, even though it was going completely normally."* (Kavalírová, Liška & Vondráčková, 2015, p. 18)

> *"Me... my pregnancy was called "high-risk", and there was no other reason, just my visual impairment."* (in Viktorová, 2014, p. 40)

[6] In Czechia it is still common in many places to practice controlled forceful pushing: Valsalva's maneuver. The expectant mother has to put her chin on her chest, inhale deeply and push for up to 20 seconds while holding her breath and closing her eyes. Then she must quickly inhale and repeat this 3 times consecutively.

[7] According to the National Institute for Health and Care Excellence. [online]

"Put simply, there are two worlds existing – the world of pregnant women where the women are naturally trusting, naive, merry, scared, uncertain and, desiring a healthy baby. Aside from this world is the world of doctors, based on medical knowledge, the cool-headed application of methods, a desire to help, the fear of a wrong diagnosis, pressure from legal responsibilty, and time-pressure. The core of consultation is how to connect these two worlds and aim for meaningful, clear and effective communication." (Odent in Labusová)[8]

"A patient has the right to obtain all information from their doctor, to be able to decide if he/she agrees with the course of action or not. If there are more alternatives, or if the patient asks for alternatives, they have the right to be informed about them." (Haškovcová in Zobancová, 2006, p. 18-19)

Every expecting mother should recieve all the information about the process and possible risks about the C-section, to be able to sign the consent. (Kavalírová, Liška et Vondráčková, 2015).

"It is essential for all expecting mothers to be informed about the benefits of the natural childbirth and complications of C-sections." (Dr. Yap-Seng Chong, Singapore State University.[9])

4 Other factors effecting the feeling of competence and towards childbirth for women with VI

The natural desire and right of a woman with VI to deliver as naturally as possible, is very often strongly confronted with the experienced or shared reality. According to Máslová (in Labusová 2011) childbirth nowadays is traumatic for many women in general "which leads to fear about other childbirths, as well as leading to a feeling of theft, melancholia, and nightmares. All of this has a strong negative impact on breastfeeding. Rigid maternity ward atmosphere, and obtrusivness of the invasive style of directing childbirth, are felt like a rape of these women as well as the automatic separation of mother and newborn after childbirth".[10]

For women with low vision/blindness, it is even more difficult because of other factors, which are; low access to information, a lack of quality informative resources about this topic, and also a limited understanding of the content of sexual education in family and school (compare Škutová 2008, Paulíková 2013, Míka 2015). The lack

[8] Labusová, E. *Prenatální diagnostika: Dojít k vlastnímu rozhodnutí*. [online]

[9] This comment, while directly about voluntary C-sections in many countries and not in Czechia, is fully applicable to our discussion as it brings to light not only the trend towards C-sections worldwide, but also the risks. C-sections are three times riskier than normal birth [online]

[10] Labusová, E. Poporodní deprese: Duševní porucha, nebo přirozená reakce? [online]

of information about the physiological childbirth processes, plus the transforming of sexual themes into taboos, causes a lower feeling of confidence regarding childbirth and maternity and therefore creates a fear to trust the women's own body during birth. (ICM, 2014).[11] Women with low vision, and women with blindness, can also feel scared due to their previous negative memories associated with hospitals and those shared by other women with VI, and as well from prejudices against the woman's ability to care for the newborn. The woman can feel distance, disrespect, and disapproval, she can face many uncomfortable questions, and even prejudices against her legal capacity can sometimes manifest (see Kavalírová, Liška & Vondráčková 2015, Kilduff & Kohutová 2017, Viktorová 2014). More factors include, orientation in a new environment negatively influenced by VI (Zobancová 2006), plus stress and a lack of emotional support from a personal midwife or family members who perhaps could not arrive in time to make sure the woman's birth wishes are followed and that she is experiencing a respectful attitude during that challenging time.

5 Delivery of women with VI who have already experienced C-sections

It is common practice that women who have given birth already by C-section are recommended again C-sections for the next births. However, according to some studies (Neri, A – Grausbord, R – Kremer, I – Ovadia, J – Treister, G. 1985; Landau, D. – Seelenfreund, M. H. – Tadmor, O. – Silverstone, B. Z. – Diamant, Y. 1995; Prost 1996) as well as concrete cases of women with VI (see further) the fact is shown that women with VI are able to deliver physiologically *even after* the C-section before, if the inner and outer conditions are met. They are able to give the normal birth even *without* changes in their visual diagnosis.

5.1 A case-study of a woman with severe low vision

The case study below is written as a childbirth story, which is shortened (due to capacity) and the full version is available from the author (who has been given the respondant's permission to share it).

5.1.1 Goals of the qualitative research

The main goal was to describe the third delivery of one woman with severe low vision.

Partial goal 1: Find out about the conditions and the process of the third (and physiological) delivery, which occured after two previous C-sections, and which was recommended again by the opthalmologist to be done by C-section.

[11] International Confederation of Midwifes: Keeping birth normal [online]. [online]

Partial goal 2: Find out the state of VI progression possibily caused by physiological delivery.

Partial goal 3: Find out the subjective feelings of the woman from the start of the delivery to the end of the postnatal period.

5.1.2 Characteristics of the research sample

The research sample was chosen intentionally based on relevant attributes, which were VI and childbirth by C-section and subsequently the physiological childbirth. The respondant was one woman with VI giving birth for the third time at age 35.

The visual diagnosis: left eye total retinal detachment at age 6 months, since then amaurosis, and the right eye, myopia gravis. After the first childbirth she had 15 dioptres and during the third pregnancy it was much more,[12] in addition, cataracts had appeared.

The respondant is a two-time mother after C-sections and the third pregnancy was recommended to be also by C-section by the opthalmologist, each of whom stated a different level of risk of the progression of the VI towards blindness.

5.1.3 Data collection

The data was collected through interview and by obtaining the delivery story.

5.1.4 The delivery story called: VBA2C Miracle – spontaneous childbirth after two C- sections (shortened version)

"I didn't have any imagination about having kids yet, but I knew already that I won't be able to deliver spontaneously. Already at secondary school, I got the information from my doctors and parents that pushing during childbirth will probably make me blind, and since then I heard this information about blindness caused by physiological childbirth, and I heard it so many times that when I became pregnant I didn't doubt the words of my eye doctor, that the C-section is the best choice. The risk was too big. So, after the first delivery by C-section, and then another one, and the third one was supposed to be the same. When I was in the sixth month of the third pregnancy, I visited a lecture of the delivery assistant, Anna Kohutová, called *Kind and Gentle Delivery by Operation*. There, my belief that to deliver physiologically is high-risk for me, developed its first crack. I came home and I read on the internet tonnes of studies, Czech and foreign discussions, and personal stories of mothers who were giving their birth spontaneously, even though having myopia gravis, or retinal detachment. I surprisingly found out that I'm not able to find even one study, or one story about retinal detachment after physiological childbirth. It doesn't mean that it doesn't exist, but I wasn't able to find it. I realized that I have to make a decision

[12] Subjectively felt, the woman did not know the exact amount of dioptres.

about what I want to believe in, because after consultation with three eye doctors, I got three different opinions about the amount of risk about my visual impairment progression. I decided to believe that the physiological childbirth is safe for my eyes and that I am able to prepare for it in three months."

5.1.4 Evalution of the partial goals

Evalution of goal 1: Based on studying the research findings, investigating the experiences of women with VI, consulting a potential visual diagnosis progression with three opthalmologists when each of them stipulated a different degree of risk of blindness, the respondant decided to delivery physiologically, vaginally. The rapid delivery which had been planned to take place in the maternity hospital, happened spontaneously at home.

Evalution of goal 2: The progression of the VI towards blindness did not occur thanks to the natural childbirth (unlike the controlled type). The respondant did not feel any change of the visual acuity, even after a many months and up to the writing of this article.

Evalution of goal 3: The respondant described her immediate feelings as follows:

> *"I am a mommy of three wonderful children. A fresh, three-time mother. Now I'm holding my son in my arms, we experienced a beautiful natural childbirth. Maybe I'm so taken away by it all and enthusiastic because I know how childbirth can be, and so I'm even more grateful that I could experience a natural childbirth."*

6 Conclusion

The aim of this article was to make a view into this issue of women with VI, the delivery preparation included, accessible. The article acquaints the reader with different ways of delivery and points out possible risks associated with C-sections. The author of this article is realizing fully that each case is individual and specific and no way of childbirth is ideal for all women, in view of; the woman's uniqueness, possible complications during pregnancy, VI diagnosis, and arrangment of inner and outer conditions. The case study proves that even a woman with severe VI is able to deliver not only physiologically, but *completely naturally*, with no subsequent progression of her visual diagnosis, even after previous C-sections.

But, the main requirements are:

- a higher level of information available including all topics within sexual education
- a sufficient awareness of the expectant mother about the physiology of the delivery, the phases, and possible recommended ways of childbirth
- the mental and physical preparation of the expectant mother, and her pro-active attitude to the delivery

- support of the environment, the partner, family, delivery assistants or dula, respectful and kind staff in the gynecology department, in the maternity hospital, staff who know the needs of women with VI, including the ways to communicate with them
- organising the ideal outer conditions, as much as possible, for physiological or natural childbirth – support of the natural position using gravitation, no time-pressure, and providing intimite surroundings (soft lights, etc)
- the abscence of simultaneous health complications.

In the case that physiological childbirth is not possible, it is important to support the *bonding* of mother and baby as much as possible, which is the necessary prequisite for activation and continuation of lactation and prevention of postnatal depression.

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