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What do you know about pregnant women with sickle cell disease?

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Sickle cell disease (SCD) is a group of inherited autosomal single-gene recessive disorders. It is the most common inherited haemoglobinopathy worldwide.

SCD affects the synthesis of haemoglobin (Hb) resulting in abnormal structure (sickle-shaped) called haemoglobin S (HbS). Due to the abnormality, the life span of the red cells is shorter with increased risk of chronic haemolytic anaemia. The abnormal shape of the red cells impedes their travel through smaller blood vessels (vaso-occlusion) resulting into painful crisis. The vaso-occlusion reduces blood flow and can lead to gradual organ failure. SCD has different types and traits depending on how many sickle cell genes inherited from parents.

Geographical prevalence of sickle cell disease

Two main haemoglobinopathies are SCD and thalassaemia. Whilst SCD is a defect in the shape of haemoglobin, thalassaemia is a defect in the rate of its produc-

tion. About 5 % of the world population has a haemoglobin-related disorders. SCD is predominantly common among people of sub-Saharan Africa, India, Saudi Arabia and Mediterranean countries. Globally, about 300 000 babies are born with severe haemoglobinopathies annually out of which 80 % are born in sub-Saharan Africa. In countries where SCD is prevalent, there are variations in the frequency of SCT. For instance, it is estimated that the frequency of SCT is about 15–30 % in Ghana and Nigeria and about 45 % in Uganda.

Migration and SCD

At the start of the 21st century, 1 out of 35 persons was an international migrant. According to Statistics Finland, in 2018 persons with foreign background accounted for 7,3 % of the Finnish population. In 2019, there were 57 844 migrants in Finland who spoke Afroasiatic languages mainly from Northern Africa whilst 8 841 spoke

Niger-Congo languages common in sub-Saharan Africa.

Migration has led to the spread of SCD to other parts of the world thereby making it a challenge to all health care systems globally. Within Scandinavian countries, migration has risen and so has rare health conditions such as SCD. In 2015, **Hemminki** et al. reported that in Sweden, approximately 90 % of all sickle cell and thalassemia patients were either first or second-generation immigrants. The number of women especially those of African and Asian descent were more compared to men.

Generally, migrant women are most vulnerable besides, their biological and physiological responsibilities towards reproduction increase such vulnerability. Even though migration-related health challenges are gender-specific, policies to address these are non-existent. Despite inaccessibility of data on the current prevalence of SCD in Finland, chances are that, SCD is prevalent based on the share of persons with foreign background in the country.

A classic example of migration, SCD and lack of appropriate screening for the disease in Finland is a case reported by the Finnish Red Cross of a child of Congolese descent, Emille Nyembo, born in Finland. Based on that reportage, it can be argued that, healthcare professionals involved in the antenatal care of the child's mother, lacked adequate knowledge on how to diagnose and manage SCD in pregnancy. Additionally, the story highlights lack of antenatal screening policy tailored

Types of sickle cell disease (SCD) and sickle cell trait (SCT)

Adopted from the Centre for Disease Control and Prevention

Туре	Explanation	Characteristics
HbSS	Inherited two sickle cell genes (S), one from each parent	The most severe form of SCD
HbSC	Inherited one sickle cell gene from one parent and an abnormal haemoglobin "C" from the other parent	The most severe form of SCD
Hbas	Inherited one sickle cell gene "S" from one parent and a normal gene "A" from the other parent	Usually no symptoms of SCD

for the needs of foreign-born pregnant women within Finland. Despite SCD not common in Finland, increased knowledge among healthcare professionals especially midwives and public health nurses, will improve treatment options thereby improving female migrant health. The aim of this article is to create awareness of SCD as an important problem that can influence the health of pregnant immigrants in Finland.

SCD in pregnancy

The long standing impression that persons with SCD are not able to bear children is proven untenable with advancement in medicine. Nowadays, women with SCD live long, and many reach their reproductive age. However, pregnancy among SCD patients result in more complications to the mother and child compared to non-SCD patients.

During pregnancy, demand for blood supply to major body organs increases but for SCD patients, the blood becomes thicker and circulation slows down. In pregnancy, the mother is prone to urinary tract infection, severe joint and chest pains, thromboembolic disorders, anaemia, pre-eclampsia increased hospital admissions and sometimes maternal death. Low uteroplacental circulation predisposes the foetus to spontaneous abortion, intra-uterine growth retardation, preterm birth (PTB), hypoxia and perinatal death.

Management include early diagnosis, preconception care such as counselling, avoidance of extreme temperatures and dehydration, medical screening, folate supplement, antibiotic prophylaxis and blood transfusion in severe anaemia

Does SCD contribute to the death of immigrant mothers?

In Europe, immigrant women have poorer birth outcomes and

higher perinatal mortality than local women. In addition, women of African origin have higher maternal mortality than local women. In 2009, sub-Saharan African women in Finland had a six-fold perinatal mortality than local women. Recently Bastola et al., found that sub-Saharan African and Southeast Asian women had a higher risk of emergency caesarean section whilst PTB, low birthweight and low Apgar score among their newborns. In that study, sub-Saharan African women had more perinatal deaths and their babies needed more NICU care compared to their Finnish counterparts.

The reasons might be complex however, Esscher et al. claim that immigrant women receive suboptimal care during childbirth. The authors attribute delayed care seeking, failed ability to access care and delayed medical care (the three-delays) to maternal mortality among immigrants. Factors such as communication barriers, no professional interpreters, and health professionals' limited knowledge of rare diseases can lead to maternal death among immigrants. Severe anaemia, a symptom of SCD was one of the causes of deaths reported. Inadequate medical care meant misdiagnosis, lack of recognition and reaction to symptoms. Furthermore, lack of awareness of rare diseases, like SCD among midwives and other health professionals can be argued.

Addressing communication-related problems, ensuring caring and kind attitude of nurses and other health professionals are critical. Practically, all immigrant women have equal access to maternal care same as local Finnish women, however intercultural communication competence, use of interpreters and consideration of ethnicity and culture of the woman might be incomplete.

Lähdeluettelon voi pyytää toimituksesta.

SUOMEN KÄTILÖLIITTO KOULUTTAA



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