Partnership between nurses and families in sickle cell diseases

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Sickle cell disease is a genetic inherited red blood cell disorder.

The pattern of inheritance is autosomal recessive; therefore it is transmitted from both parents. Sickle cell disease is characterised by an abnormality in the oxygen-carrying protein hemoglobin found in the red blood cells. In certain conditions, the shape of the red blood cells changes, they break and block the blood vessels, leading to vaso-occlusion that can cause further organ damage. The main complications of sickle cell diseases are acute pain crisis, haemolytic anaemia, infections, acute chest syndrome, vasculopathy, etc. The only way to cure the patient is by performing a bone marrow transplantation, but this is not often available.

Childhood mortality and related morbidity among sickle cell patients have significantly decreased since the beginning of excessive care that includes newborn screening for the disease, the use of preventive antibiotics, vaccinations, hydroxycarbamide, blood exchange, transcranial echo-doppler screening, etc.

Comprehensive care and education of the patient's family are recently applied to improve the care in sickle cell diseases.
At HUDERF (University Hospital of Children Queen Fabiola) and in Belgium, the patient's haemoglobin mutation is mostly sickle cell anemia SS.

Since few years, a nurse dedicated to sickle cell patient is working in the field of family education.

She follows the patients and their parents in the outpatient clinic or during their hospitalisations. She tries to create a partnership with them to help improve the understanding of the disease, explain daily care, recognize the main complications, and facilitate access to the hospitals.

Family empowerment is a way of caring, thus we developed tools to help us lead the way.