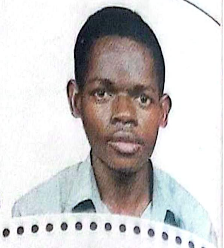

Ashiraf Ssebandeke

Mental health issues in sickle cell: The elephant in the room

Today, June 19, Uganda joins the world to commemorate World Sickle Cell Day. The theme is: "*Doing things differently in 2017*".

As per the Day's theme, it, therefore, call for us all to handle the mental health of people with sickle cell disease differently.

On March 30, during the launch of sickle cell clinic in Ngora district by Action Against Sickle Cell Disease, a mother to two sons with sickle cell disease sought my attention. She had crossed Lake Kyoga from Pallisa district in a canoe with her two sons aged six and eight years on a cold morning to come and seek treatment from the clinic opening that day. The boys looked as stressed as their mother. I was wondering who comfort each other during the times of trials.

She told me that she never got to know that sickle cell was not only going to affect her sons physically, but also mentally.

Her sons have to endure insults from fellow pupils who tell them that they are going to die soon. Having to take drugs every day is a huge toll on the two young boys.

Now they have to cross the lake once a month to attend the sickle cell clinic in Ngora for treatment, review and drug refill. To young boys of six and eight years, this is too much to bear. Mental health and sickle cell are 'conjoined twins' which are difficult to separate. The mental health of people living with sickle cell disease, their parents, caregivers and healthcare professional taking care of them is always affected negatively.

Living with sickle cell disease, which is a blood disorder, does not mean that it affects only the blood, but also affect the person psychologically.

Being in pain all the time and taking drugs everyday plus stigma associated is a huge toll not only on the adult patients, but also the children.

I remember in 2015, while at the Parliament Health Week, a parent approached me and narrated to me how her six-year-old was asking her questions out of stress. She asked her why she had to go through excruciating pain unlike her friends. Every time the pain was too much to bear she asked her mum: "Mum if there is anything I did in your womb tell me to say sorry". The mother did not have an answer and just had to keep silent and cry out of her sight.

> *Mental health and sickle cell are 'conjoined twins' which are difficult to separate*

These are just a few of many stories that need attention, but are always swept under the carpet.

Mental health of adolescents and young adults is a disaster in waiting. This has always been abated by the lack of transition programme from paediatric to adult healthcare of people living with sickle cell disease. For many decades, sickle cell has always been considered as an infant disease. Many children born with sickle cell disease have been dying below the age of five years. For example, in Uganda, 70% – 80% of 20,000 babies born with sickle cell disease annually die before celebrating their fifth birthday.

So almost all programmes in Uganda and globally have been centred towards managing infants. Those who survive into adolescents and adults are always left to fend for themselves. The unavailability of paediatric to adulthood healthcare transition programmes has exposed people with sickle cell disease to a number of psychological problems.

The improved survival of people with sickle cell disease has created a relatively new class of adults with chronic pain more prone to anxiety and depression. Most doctors concentrate on managing pain in adolescents and adults with sickle cell disease without looking at the root cause.

Read the full version on www.newvision.co.ug

The writer is the executive director of the Action against Sickle Cell Disease