ARISE

African Research And Innovative
Initiative For Sickle Cell Education

An interview with a Sickle cell disease patient living in Portugal.

Interview conducted by Syntyche Boman and Amayah Jirai, for ARISE (African Research And Innovative Initiative For Sickle Cell Education)

1. Can you describe your experience living with sickle cell disease?

I was diagnosed with SCD and Thalassemia when I was 4 years old, 36 years ago. Back then the knowledge of the diseases and the proper ways to handle it were very poor and/or hard to understand. I'm very grateful to my parents for allowing me to exceed my physical and mental potentials. With that came the rapid wear of the disease and all the bad/downfalls from the lifestyle.

2. How has sickle cell disease impacted your daily life, including activities, work, and relationships?

Even being someone who always wanted to overcome my barriers it always compromised my life with a negative impact. It was like I always had to prove others and myself that I could do anything including physical activities.

3. What symptoms do you typically experience during a sickle cell crisis?

I already experienced several and different symptoms such as, the excruciating pain, shortness of breath, organ failure, acute chest syndrome and even surgery.

4. How do you manage pain during a sickle cell crisis?

I have pain medication to control crisis at home. When that's not enough I have to be admitted in the hospital for a better and proper care.

5. Have you encountered any challenges or barriers in accessing healthcare services related to sickle cell disease?

Yes too many unfortunately, because the disease is not recognized as a risk disease, some healthcare professionals don't know how to approach the situation, and the government doesn't give us the support we need in terms of financial support.

6. Has sickle cell disease affected your mental health and emotional well-being?

Yes with certainty.

7. Can you discuss any specific treatments or therapies you have undergone for sickle cell disease?

Yes. Most part of my life was about pain management. Now with the multidisciplinary approach besides managing the pain, we focus on mental health (psychology and psychiatry), physical therapy and the honest approach from the patient in all of this methods.

8. How do you cope with the unpredictability of sickle cell disease flare-ups?

I try to live my life the most programmed way as possible. Controlling what I can and avoiding what I can't control.

9. Are there any lifestyle changes or adjustments you've made to better manage your condition?

Yes. With time and the help of my healthcare professionals we found ways to manage my condition the most effective way possible.

10. What advice would you give to others living with sickle cell disease or to those who support someone with the condition?

It's important to be conscious of your own situation, how you react and how your body responds and adapts. Try to make a plan with the doctors that support you, and be honest with yourself and the ones that support you along the way. Information about your condition is crucial for the success of living with such a challenging condition, and ask for help, even though sometimes you feel like that, there are many people that care for you. You are not alone.

www.ariseinitiative.org