

Sickle Cell Today

Pain Crisis: Role of F

Management

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Disease Practical Issue
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The Promise of a Cur

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hemoglobin S concentration, or treating pain episodes (11). This being said, in the absence of intravascular dehydration, the replacement of fluids by the fluid being lost is a reasonable approach, i.e., half normal saline or D5W. If dietary intake is poor, D5 half normal saline administered at maintenance (see above) will provide enough glucose to keep the patient out of a catabolic state. If the patient is clinically volume contracted, normal saline should be administered until hemodynamically stable then converted to a hypotonic fluid at maintenance. When administering fluids in the sickle cell patient, basic tenets of fluid management after the initial period of fluid administration should be adhered to. The volume of fluid administered, urine out, vital signs and O2 saturation should be monitored. The practicing clinicians must remember, "Primum non nocere" – first do no harm, until well designed studies addressing the safety and efficacy of the types of fluids, appropriate volume of fluids and routes of administration can be determined.

References

- 1.

Giving the Gift of Life: Good Things Happen when a Community Works Together

ASH Publishes New Clinical Practice Guideline on Cardiopulmonary and Kidney Disease in Sickle Cell Disease

The American Society of Hematology (ASH) recently published the first chapter of the SCD guidelines: cardiopulmonary and kidney disease. In total, five chapters will be published with the remaining chapters scheduled for publication in the first quarter of 2020. The guidelines will address both the pediatric and adult populations. Sixty-one clinical experts of which Johnson Haynes, Jr., MD, Director, USA Comprehensive Sickle Cell Center, was a participant, 10 patient representatives, and five methodologist reviewed published evidence used to form all recommendations. For more information visit hematology.org/SCDguidelines

Reference: *blood advances*. 2019; 3(23):3867-3897

Impact of the Pediatric to Adult Care Transition Program (PACT) from a Participant's Perspective

T'Shemika Perryman, RN-PACT, Coordinator

Cimone Smith, Transition Coordinator, ST3P-UP Study Facilitator

The Pediatric to Adult Care Transition program (PACT) was started in 2012 to bridge the gap between the pediatric and adult healthcare systems for sickle cell disease clients between 13-21 years of age. The goal of the PACT program is to not only educate clients about their condition, but also help them acquire skills they need to live full, successful, and productive lives. We instill in our clients that they are more than just a condition. We share with them that they can be and do anything they put their hearts and minds to accomplish. We encourage them to enroll in college, find a trade, and secure employment doing something they enjoy. We recently caught up with one of our former participants, Briana Kennedy, who recently earned a Bachelor of Science degree in Early Childhood Studies from the University of South Alabama. We wanted to get her point of view on how the PACT program helped her successfully transition into adulthood.

Do you remember when you first entered the PACT program? Do you recall your first thoughts about the program?

“Yes, I remember when I first entered PACT. I was really nervous because I thought I would be meeting new doctors, but once I started I realized that it was most of the doctors that I already knew. “

In addition to the doctors, who else worked with you in the PACT program? What role did they play?

“In the PACT program, I worked closely with Dr. Ardie Pack-Mabien and Ms. T'Shemika Perryman. I also worked with all the other doctors and nurses on my health care team. They were the ones to guide me and they provided me with ample information about how I can control my pain management at home.

In the PACT Program, I started out working closely with Dr. Ardie and Ms. T'Shemika. When I was going to the pediatric clinic I would have my regular visit with Dr. Wilson, Dr. Imran, or Dr. Ardie then Ms. T'Shemika would come in for the PACT part of the visit. We would go over my type of sickle cell, medications, school, and life goals. Dr. Ardie and Ms. T'Shemika are also on the adult side. But on the adult side, I also see Dr. Haynes and the nurse

practitioner, Ms. Jessica King.”

Do you feel being a part of the PACT program was beneficial to you? Why?

“Yes, I feel it was beneficial to me because it taught me how to control my health with the help of my health care team. This program taught me to be more responsible which helped me to focus on my health and education.”

In your own words can you explain what PACT is and what it means to you?

“PACT is a program that helped shaped me into who I am today. It guided me into adulthood. Because of PACT, I’m extremely comfortable, educated, and well aware of my health and health care needs. For example, the PACT program held various programs and classes. There was a money management class that taught us about money management, budgeting, and credit. There was also a class on sex education and an open house event for us to meet the adult doctor before we switched over.”

What are you doing now?

“I am currently a Preschool Teacher.”

Do you feel PACT helped you to achieve these milestones? How so?

“Yes. Because of this program, I was able to focus more of my time in the classroom rather than in a hospital. I was given many tips that I can try at home to help manage my pain.”

Now that you have completed PACT what are your thoughts on the program?



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