BOOK REVIEW: Lisa Fryar Woodson, MSN, RN

Living with Sickle Cell Disease: The Struggle to Survive

Judy Gray Johnson (author) with Leroy Williams Jr. (contributor) provides an impeccable recollection of living with sickle cell disease (SCD). The author describes her 69-year journey of living with SCD in a world that offers minor understanding about this disease. The content was designed to bring awareness of the effects of pain on the lives of people with SCD. As told by the author, she experienced painful episodes all her life but did not receive an official diagnosis until the age of 16. Furthermore, the author was the only sibling affected with the disease; therefore, no members of her family could understand her experiences. The book consists of 11 chapters that journeys thorough vivid details of her life, accomplishments, disappointments, joys, triumphs, painful episodes, constant battle of fatigue, misunderstanding from colleagues, mistreatment from hospital personnel, and her tenacity to face all challenges graciously. The beginning chapter provided a full health overview of SCD eloquently portraying a vast knowledge of the history of SCD, effects the disease has on the body, causes of painful episodes, types of sickle cell anemia (SCA), and symptomatology. The subsequent chapters explain how ignorance delayed adequate management and treatments leading her to live a life of emotional and physical pain. The book comes full circle starting and ending with descriptions of severe painful episodes. The author uses many depictions for pain such as “100 serrated steak knives piercing my body from within”, “sharp kitchen knife piercing my skin and cutting my bone”, “fingertips being hit with hammer constantly...pain radiating up arms”, and “repeatedly jabbed with an ice pick”. This book allows the author to describe her severe fatigue and how she accommodated her lifestyle to avoid being called whiney. Her uncomfortable feelings to explain her dilemma led family members, fellow colleagues, and unfortunately health care workers to believe she was lazy, sluggish, and uncooperative. She persevered through her pain and fatigue to pursue a college education, obtain a graduate degree, teach elementary and
middle school, become president of the teachers union, succeed as a single mother, survive a divorce and finally write and self-publish this book. Her determination to advocate for herself and other individuals living with the negative effects associated with this disease provided the true driving force to write this book.

KEY POINTS

The author chronicles 69 years of surviving SCD. The author powerfully expounds on managing pain and fatigue and challenging the negative behaviors of colleagues and health care workers who do not understand the impact of this illness. The beginning chapters offered an elaborate account of African-American history associated with her small town. Despite the meager means this town experienced, there were no racial tensions and the basis of segregation derived from wealth only. The community rarely discussed any matters outside of their homes, and adults did not discuss any matters with their children. Her father left her mother to raise five children alone, of which she was the fourth. She explains how her mother had to rely on welfare and working low-paying jobs to make ends meet. The poverty she experienced while growing up explained the lack of decent medical care. The town had limited access to physicians therefore; the few that practiced there had many poor patients and little time to keep up with the latest research in medical care. The physicians lacked the means to ascertain knowledge of SCD. Her first memory of pain occurred when she was four years old. She was with her mother when suddenly she felt sharp pain travelling through her arm. Her description, “a sharp knife had pierced her skin and cut to the bone” depicted the experience. She cried incoherently as the pain increased. Her mother could not comfort her; therefore, she rushed her to one of the doctors that practiced in that region. With the doctor’s limited examination, no physical cause of pain was found. Frustration and lack of knowledge, led the physician to order liniment to rub on affected areas, which offered no relief and caused her mother to repeatedly take her back to the doctor. For many years, this was the only treatment she received; she was never admitted to the hospital for testing; therefore, she never received any conventional treatment such as intravenous fluids (IVF), oxygen (O₂), blood transfusions, or analgesics. The frequent painful episodes she experienced that ranged from lasting for 24 hours to being so debilitating where she had to be carried to the bathroom because she could not walk had to subside without any traditional medical intervention until she was 16-years-old. She describes this period as a never-ending cycle of pain episodes, doctor visits, liniment that practiced in that region. At age 15 years old, she left home to live with her grandparents in Corpus Christi, became more social, and secretly endured her illness. She attended and graduated in that region. With the doctor’s limited examination, no physical cause of pain was found. Frustration and lack of knowledge, led the physician to order liniment to rub on affected areas, which offered no relief and caused her mother to repeatedly take her back to the doctor. For many years, this was the only treatment she received; she was never admitted to the hospital for testing; therefore, she never received any conventional treatment such as intravenous fluids (IVF), oxygen (O₂), blood transfusions, or analgesics. The frequent painful episodes she experienced that ranged from lasting for 24 hours to being so debilitating where she had to be carried to the bathroom because she could not walk had to subside without any traditional medical intervention until she was 16-years-old. She describes this period as a never-ending cycle of pain episodes, doctor visits, liniment that practiced in that region. At age 15 years old, she left home to live with her grandparents in Corpus Christi, became more social, and secretly endured her illness.

Another aspect the author describes in *Living With Sickle Cell Disease* is the severe fatigue she endured because of anemia. Her tiredness often led people to label her as lazy and sluggish. She often tried to participate in activities that she considered normal but her fatigue often overruled her choices. When she attended high school, she became a majorette and attended many sport activities, however after each activity she was extremely tired causing her to go to bed as soon as she arrived home. Her fatigue limited her ability to strive for excellence when she attended college because she was too drained to put the extra effort in class work. Often, she could not attend any sports activities, mingle with classmates, or even maintain a relationship because of her extreme exhaustion. However, she learned to compensate her tiredness in a variety of ways. When teaching she often arrived to work very early and left very late to allow her time to recuperate before and after teaching elementary students. During her career, she used all her sick days because she visited the hospital during her painful crisis. The treatments at this time were O₂, blood transfusions, and analgesics and often hospital admissions. However, she managed to march for Civil Rights, become the president of the Teacher’s Union, sell Mary Kay, and participate in her child’s activities.

Her descriptions of the treatment she often received from health care workers when she visited the emergency department (ED) leave the reader appalled. She began the book with the statement from a male nurse in an ED she visited because of pain as “cut out the drama” and “cease her audition for One Life to Live” (Johnson & Williams, 2012). She received this unacceptable treatment while experiencing severe pain and requiring immediate medical management. At this time, she required IVFs, O₂, and intravenous analgesics to relieve the pain. She had not received any intervention at the time she was crying because of excruciating pain and the response from the health care workers was the only communication she received. On another occasion, while visiting Las Vegas, she experienced a painful crisis requiring her to take a taxi to a local hospital. This time the pain was in her thighs, and she felt shunned when she arrived to the ED. After waiting for an examination, she was not offered a wheelchair causing her to wobble to the examining room. She received no support when she needed to go to the bathroom and no sympathy from health care workers. The doctor prescribed a morphine injection then discharged her from the hospital, without performing an assessment and not allowing the medication to take effect or wear off. Her well-deserved apprehension to leave the hospital so quickly after receiving the medication and going into the Las Vegas heat was not acknowledged. The doctor referred her to the social worker instead of respecting her requests. She describes the tone, attitudes, and lack of respect she received from the nurse assigned to her care that day. She left Las Vegas two days later, became ill on the airplane, and had to be treated by the medic when the plane landed. This episode led to a four-day hospital admission requiring four units of blood and several bags of IVF. The author depicted the multiple experiences of contact with health care workers as negative and unprofessional. The chapter entitled “Respect” described the experience of mismanagement of a painful crisis and the stigma of a patient seeking drugs instead of pain relief. The author, now in her late fifties and a schoolteacher for many years, sustained a painful crisis and had to visit the ED. However, despite her shrieks and crying from the extreme pain, the ED staff’s attitude portrayed the typical misunderstanding of this disease. Constantly, she remained ignored, pushed aside, and rudely handled leading to not only feeling the relentless pain but also adding
anger to her emotional state. In this chapter, the physician’s question regarding narcotics unleashed an onslaught of negative reactions. Because of these horrendous experiences, she had many complaints about several hospital treatments she underwent between years 1998-2002. She provided a verbatim report of the investigation, which sadly offered no consolation to her negative experiences. However, she continues to seek fair treatment for patients with SCD, provide adequate insights of the impact this disease have on patients, and knowledge to the many people who are not aware of the disease at all.

STRENGTHS AND WEAKNESSES

Generally, this book has no major weaknesses. However, several strengths became evident. The author thoroughly explained the life of a patient with SCD. Her humble beginnings in a small, poor southwestern region in Virginia causing social isolation because of intense fatigue and enduring painful episodes not properly managed, did not hold her back from achieving a successful, active life. The book details how lack of knowledge portrayed by lay people, family members, and health care workers causes people with SCD to endure unnecessary suffering. For many years, she experienced fatigue and severe pain, but between those conditions she learned how to play the piano, perform as a majorette, attend and graduate college, marry then divorce, give birth, and raise a successful daughter single-handedly, obtain a graduate degree, preside over the teachers’ union for two terms, retire, and finally write this book. The overall strength offered from this book originated from the tenacity of the author to share her life-long experience of living and surviving with SCD for 69-years. She adequately communicated the debilitating effects of the disease. The author did an impeccable task at describing painful episodes and fatigue. Furthermore, the negative experiences of EDs and hospitals visits were thoroughly detailed throughout the entire book.

IMPLICATIONS

The need to improve therapeutic relationships between health care providers and people living with SCD are meticulously portrayed by the author. These patients suffer needlessly because of poor medical management, poor communication between the patients and health care workers, and lack of respect and understanding of the disease (Johnson & Williams, 2012). Researchers interested in improving the quality of life, therapeutic relationships, and medical management of patients with this disease can use this book as a catalyst for a variety of studies geared toward addressing the gaps of communication between health care providers and survivors. Health care providers, especially those in constant contact with these patients, can use this book to obtain a different perspective on how to treat painful crisis. This book can serve as a form of communication for other patients whose life experiences are very similar to the author. In addition, the patients can use this as a resource guide by using the list of resources provided at the end of this book.

TARGET AUDIENCE

This book eloquently conveys the devastating effects of this disease from a patient’s perspective to health care workers and lay people. In the book’s conclusion, the author urges continuous communication about SCD and for patients to fight for equality, dignity, and acceptance (Johnson & Williams, 2012). The author expresses the best conclusion:

My life’s experiences have prompted me to write this book. I have outlived the average sickle cell patient, believing that my life will serve as a purpose-driven story. Mine is a story of a search—a quest for respect, dignity, self-discovery, and finally advocacy. This drive has enabled me to tell others how I have managed to live with the disease (Johnson & Williams, p. 16).

REFERENCE


Lisa Fryar Woodson, MSN, is currently pursuing her Doctorate of Nursing at Florida International University, Nicole Wertheim College of Nursing and Health Sciences, 11200 S.W. 8th Street, Miami, Florida 33199. E-mail: lwood006@fiu.edu.