

A story for future social workers in the field of hemophilia

Opinion

In 1998, while working for the Hemophilia Foundation of Illinois, I had the opportunity to work with a contingent of about twenty patients who were accessing services at Michael Reese Hospital in Chicago, Illinois. Michael Reese Hospital was located just south of the loop and most of their pediatric and adult patients were from the City of Chicago. Mostly all of my patients were co infected with HIV and Hep C. Some had lost brothers and relatives. Their outlook on life was not well. I tried to encourage these young men to think short term and not long term. My clinical skills were very limited because I had attended graduate school in the administration track. There were medications in the research pipeline. I encouraged my patients not to give up, keep the faith.

I also encountered a young man named Marcus. He was a teenager with severe hemophilia A and co-infected. His outlook on life was slightly different from some of my older patients. Marcus had become a counselor, then senior counselor at the annual hemophilia summer camp, which lasted a week. A few parents and myself, began transporting many of the inner city boys to camp and picking them up a week later. Marcus and I would have some deep discussions about life during and after some of these excursions. Of course, I would have my Motown cruising music. Marcus and his friends asked if I would play some of their music, which I reluctantly agreed to do. When we had dropped everyone off at their destination, Marcus asked me the most profound question that I had heard. Do you listen to the words, what the person is trying to say? I learned to listen.

Marcus shared with me that he had begun to DJ on the weekends. He told me his Dad required him to be available for church every Sunday morning. No problem. Marcus had learned to play the keyboards by watching and listening to others, a gift. He had also begun to record some of his music and lyrics. I encouraged him to write and record

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about his medical issues, which he did wholeheartedly. He also wrote lyrics to express his frustration with fellow counselors who he had befriended and took jobs as homecare representatives.

I can't prove it, or have any data on this, but Marcus and two of his friends stopped going to camp after the summer of 2004. They passed away in the following successive years 2005, 2006 and 2007. Why? They stopped taking their medications. Had they entered into a pact, I don't know. Marcus was a very resilient young man, who blessed us with HIV and HEP C prevention songs that are used nationwide. He was fondly referred to as "The Marksman". I loved the Marksman; my patient, my youngest son. [1981-2007] Excerpted from the book, *A Journey of the Heart*, Linda Gammage MSW, LCSW; Dana Francis MSW, editors. PP.77,78. Park Place Publications, Sept. 2013.

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Conflict of interest

The author declares no conflict of interest.