THALASSEMIA: With the “Red” in the Bag Amid COVID-19 Reflections

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Abstract
This narrative piece written from a patient perspective angle who lives with a chronic condition—Beta thalassemia major (also known as Cooley’s Anemia), a serious, life-long, genetic blood disorder. The narrative portrays how the present situation of COVID-19 pandemic adds an extra layer to the challenges in the lives of people living with thalassemia.

Keywords
COVID-19, thalassemia, psychosocial, whole person care, patient perspectives/narratives

I am who I am today due to lifelong challenges faced while living with a chronic genetic blood disorder known as thalassemia. My experiences with monthly blood transfusions shape my way of being in the world. I am a down-to-earth, empathetic person who understands the challenges others face, especially those who form my community. Over the decades, this thalassemia community has kept me grounded, providing me with a positive attitude despite personal challenges encountered. My parents were faced with uncertainties from the moment I was born. Decades ago, parents were shocked by the poor prognosis attached to the condition. Fortunately, my parents decided early on not to give up and defy the medical odds by educating themselves and seeking evidenced-based treatments. As a child, being poked with a needle and then told to lie still for 4 to 5 hours during the blood transfusion was very hard. Coming to terms with the challenges, I would confront for the rest of my life, my youth was spent either cooperating with my parents who took me for treatments or rebelling against it all.

The Red in the Bag Equals Life
Since my body fails to produce sufficient levels of healthy red blood cells (RBCs), I can become anemic in less than a month. People with thalassemia major cannot make enough hemoglobin in their RBCs. Consequently, they need frequent and regular blood transfusions throughout their lives. If left untreated, a child born with thalassemia major would die in early infancy. Concurrently, they also need daily chelation treatment to remove the excess iron that is associated with regular blood transfusions. Iron overload is extremely harmful and can lead to organ damage and ultimately organ failure. Having thalassemia results in degrees of fatigue that make daily, taken for granted, activities nearly impossible. Nonetheless, treatment is simple. I receive 1 to 2 bags of RBCs every 3 to 4 weeks; this provides the life-giving properties I need for another month. When I see the bag of blood hung on the pole, I feel indebted to the person who has donated this gift. The rich color red represents, for me, the kind heart of the unknown donor who enables me to pursue not only mere existence but also my dreams.

If one person has a chronic condition, it not only affects that individual but also everyone else in the family. As Politis states, “There is evidence that a high clinical burden is associated with a psychosocial burden for the patients and the family” (1). Education and support are not only required for the person suffering from thalassemia but also for their entire family who need both clinical and psychosocial support. As Hovey mentioned, “researchers and clinicians engage the theory of pain to understand how it manifests and how to treat it (the scientific); the person living with chronic pain does so as a lived experience which is reflective (the philosophical)” (2). This quote emphasizes the dynamics of providing person-centered care whereby the patient’s best interests are placed at the center of a holistic

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and whole-person approach. We need to remember that the medical act of infusing the person with hemoglobin in a unit of blood represents life to the person receiving the transfusion. I equate the Red as the possibility to transform my life’s dreams into a reality. In its truest sense, the Red in the Bag has enabled me to reach beyond my expectations in academic pursuits, a professional career and to experience a life of achievement with great relationships with family and friends.

Fortunately, I have received patient-centered care from my medical team and support from the community up to this point in my life. Prior to the COVID-19 pandemic, I felt safe and confident during treatments as my hospital visits provided an opportunity to be myself, relax into the treatment, socialize with my fellow thalassemic friends, and interact with my dedicated health care team. We frequently discuss the general psychosocial aspects as a shared experience with other patients, nurses, and doctors. These interactions and social connections have healing influences as we engage with each other around our common condition. We laugh, chat, and connect in a unique way that could only occur in the context of our treatments. COVID-19 has imposed unfortunate changes.

COVID-19: Loss of Social Connectiveness

I, along with my peers with thalassemia, have noticed that our mental health is negatively impacted by physical distancing and self-isolating measures taken in hospital and within the community. Our community fears contracting COVID-19 through the blood product we receive; we are worried about proper screening for blood donation procedures. Simply going to the hospital for treatment creates a sense of vulnerability and has changed the dynamic of how our special community interacts. It seems to me that during the last few months, as the COVID-19 situation has evolved, my health care team has begun to withdraw from the humanizing interactions we once shared. They started to remove themselves from us, their patients, and became more “clinical” in their approach. Masked, gloved, and wearing personal protective equipment (PPE), humanizing communication between us such as, “How are you coping?” has been hidden behind masks, gloves, and imposing PPE. I have the impression that they are doing the minimum while spending less time with each of us. These interactions feel cold and distant. The previously enjoyed social interactions with our community have shrunk to getting the job done, lacking the personal engagements. Although I understand that this is bound to the current health crisis, I hope this does not become “the new normal” as it is creating increased psychosocial distress within our community and impacting our chronic conditions. Few minutes of extra time spent with each one of us individually from our health care team will go a long way in destressing us from the current situation, especially during our face-to-face consultation with our doctors or during our treatments.

Living through the COVID-19 pandemic has been an added stressor for the general population, but particularly those who live with a chronic health condition. As described by Aimiuwu et al, “Psychosocial factors play a big part in pain perception and behavior. Social and cultural aspects influence the way an individual experiences pain and could be intertwined with the pain itself” (3). My hope is, as Hovey explains, is that “Over time, with the right conversations and relationships, we will be able to engage better with our clinical and research partners not merely as patients but as people working synergistically together within a community of health care” (2), wherein a team approach is a critical requirement in the realm of chronic health management, so that, we the patients don’t feel left out of the team in these confusing times. Our inclusion in the team approach as patient-perspective consultants toward our emotional and physical care will ease the burden on us and that will happen only if our health care team takes proactive steps.

Conclusion

I shared my story of how a bag of blood makes an enormous difference in the lives of people living with thalassemia, allowing them to pursue their life goals. Sadly, in the context of COVID-19, monthly treatments have become lonely and tedious. I wonder if we will return to the caring environment that enabled me and my peers to flourish despite living with a life-threatening condition. I can only hope that those cherished experiences will return, if only for the good of patients and health care professionals. I recognize that my doctor and nurses are devoted to our well-being and I trust that somehow, they will be able to engage in whole person care when this health crisis is over. However, I feel it is of interest that, although we cannot cure my condition, we can heal me as a person through meaningful engagement with peers and health care providers.

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Author Biography
Veeresh Pavate is currently a doctoral student under the supervision of professor Richard Hovey, PhD, at the Faculty of Dentistry at McGill University. He is interested in the area of applied hermeneutic research in the health field so as to examine the lived experiences of people with thalassemia, a rare genetic blood condition.