

## POSTER

# WHAT DOES IT MEAN TO LIVE WITH THALASSEMIA? AN INTERPRETATIVE PHENOMENOLOGICAL INQUIRY

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Living with Thalassemia, means that the body is unable to produce normal levels of hemoglobin to carry oxygen throughout the body. Without sufficient levels of hemoglobin (due to inefficiency of bone-marrow to produce normal red blood cells), one can experience signs and symptoms, such as severe anemia, chronic fatigue and other serious health concerns.

My interest in this topic is because I live with this condition, but also interested in the lived experience of the Thalassemia community. My research is a phenomenological exploration through interpretation of research participants' narratives. The overarching goal of the proposed research is to investigate the contribution to the medical personnel who may use the findings from the study to improve the clinical care from not only from patient centered, but also from a whole person care perspective. There are various clinical and psycho-social challenges such as, academics, career, and family / friend relationship issues. Families address the treatment issues of Thalassemia on a continuum Extreme Drive - No Drive to improve their lives.

Thalassemia was seen as a “fatal condition,” today it is a “manageable condition,” therefore, we need to learn, how best to thrive to lead a healthy lifestyle? Through this research I am hoping to share my story and with others to inspire people living with Thalassemia, to go beyond managing towards thriving. ■