



Positive Psychology and Sickle Cell Disease

Seth Younger

New York University, Undergraduate College of Arts and Sciences, New York University, New York, NY 10010

Address for Correspondence:

111 Old Army Road, Scarsdale NY 10583

Email: smy310@nyu.edu

The author does not have any conflicts of interest to declare. Submitted in fulfillment of CAMS-UA 110, The Science of Happiness

Received 10 May 2019;

Accepted 30 May 2019;

Published 04 June 2019

Abstract

Positive psychology is described as a novel treatment for managing the negativism that accompanies pain in sickle cell disease. It has the potential to directly improve psychological well-being and health related outcomes and indirectly to support factors related to religion and spirituality by reinforcing positive strategies related to negative internal struggles. Motivational interviewing combined with positive psychology may have a role in addressing addiction to opioid analgesic medications routine employed in the management of sickle cell disease.

Keywords: *Positive Psychology, Sickle Cell Disease*

Introduction

Sickle cell disease (SCD) is a group of inherited blood disorders (Rees et al, 2010). An estimated 100,000 individuals have SCD in the United States, with 2,000 new cases detected annually in screened newborns (Panepinto and Bonner, 2012). Affected individuals have atypical hemoglobin molecules that results from a mutation that lowers hemoglobin's affinity for oxygen, with a tendency to sickle the shape of red blood cells, deforming its shape and obstructing blood vessels. This leads to painful vaso-occlusive crises in the bone and other end-organs. The sickling process is precipitated by a variety of factors including cold temperature, dehydration and infection. Self-reported pain in SCD between and during crises (Carroll et al, 2016) is severe and managed largely with opioid drugs (Han et al, 2016). Virtually all patients become addicted to opioids medications used to the treat their pain.

The disease evolved over time in endemic regions of Africa where the causative gene mutation gained prevalence due to resistance of carriers to malaria infection. While not strictly a disease of blacks, affected individuals are at greater risk for the disease, as well as race-based disparities and inequalities in healthcare. Optimal management includes age-appropriate specialty care that minimizes opioid dependence and optimizes pain-coping behaviors, while addressing self-advocacy for life-planning skills (National Institutes of Health, 2002). Despite its logical appeal to alleviate the emotional suffering associated with chronic pain and opioid dependence, positive psychology has not been described in SCD. This paper addresses whether positive psychology could have a role in improving the well-being of SCD patients.

Methods

A search of PubMed and New York University Library's search engine, EBSCO Information Service was conducted to identify publications citing use of positive psychology in SCD.

Results

The search of PubMed and New York University Library's search engine, EBSCO Information Service failed to reveal any publications citing use of positive psychology in SCD making this a novel concept.

Discussion

The first Constitution of the World Health Organization in 1946 conceived of health as a multifaceted state of wellbeing. The Institute of Medicine (2003) and the Centers for Disease Control and Prevention (CDC) (Liburd and Sniezek, 2007) placed physical and psychological health as a resource with multiple determinants. In the absence of unmitigated pain, living in a suboptimal physical state such as the case in SCD, need not necessarily be synonymous with suffering. The synergistic interplay of multiple physical and psychological determinants makes positive psychology an attractive element in the treatment and health outcome of patients with SCD for several reasons discussed below.

At the heart of positive psychology theory (Fredrickson, 2001) is the ability of a patient to develop resilience, enabling them to bounce back from stressful situations more quickly and effectively.

Optimizing positive emotions could help SCD patients buffer their negative emotional life experiences associated with their disease (Tugade et al, 2004). It is accepted that negative emotional responses intensify the pain experience, while optimism and a positive affect attenuate the experience of pain in healthy and clinical populations (Hanssen et al, 2017). Positive psychology interventions for chronic pain management can lead to improvements in happiness with enduring effects (Peters et al, 2017). Feudtner (2009) argues that instilling hope and fostering patients' motivation to carry out difficult management decisions. This could translate into improved health outcomes in individuals with SCD when they are hospitalized in painful crisis. Moreover, the Pain in Sickle Cell Epidemiology Study found that individuals with SCD report pain in 54% of the days surveyed (McClish et al, 2017), making daily pain a constant worry. Positive psychology might have the potential to address unrealistic concerns for adequate opioid analgesic access, between and during crises by providing them with hope and optimism. Chronic pain associated with SCD not only leads to high level of emotional distress, but about one-half of those in chronic pain may also experience disturbed psychological behaviors. A randomized clinical trial (RCT) of 8-weeks of an internet-delivered positive psychology intervention led to significant increases in the primary outcomes of happiness and decreased depression among 276 subjects diagnosed with chronic pain (Peters et al, 2017).

Two metrics used to study the life course and health of SCD, namely health-related quality of life (HRQoL) and quality adjusted life years (QALYs), may provide additional insights into the success of positive psychology and SCD. HRQoL, which refers to the way an illness affects one's ability to live pain-free and live and work productively, is expressed as a number between 0 and 1, with individuals in perfect health rated 1. By comparison, QALYs express the proportion of time lived in perfect health, and is calculated by multiplying HRQoL by the number of years in question. Chronic pain and opioid addiction both diminish self-reported QALYs in SCD, with a trend that begins in childhood. Black children with SCD compare themselves unfavorably to healthier white and non-white individuals without SCD (Asnani et al, 2017). With increasing awareness of their illness, they harshly self-rate, illustrating how severe their illness is attitudinally perceived. Positive psychology and coping strategies may be useful in improving psychological outcomes in such cases and testable by following attitudinal self-reports and QALYs.

Given the important relationship between gratitude and spirituality (Rosmarin et al, 2011) it is noteworthy that religion and spirituality (R/S) are likewise important in the lives of individuals with SCD (Cotton et al, 2009) especially children. Among 48 adolescents with SCD, 59% considered themselves very or moderately attentive to R/S. While these subjects generally reported greater use of positive than negative R/S coping strategies, neither was associated with indices of HRQoL. Surprisingly however, adolescents as a group reported spiritual struggles that placed them at potential risk for poor psychological outcomes, suggesting the need for referral to pastoral or mental health care. However, this may also be a clue for the need of positive psychology interventions.

Innovative approaches that combine positive psychological to behavioral therapies such as motivational interviewing (MI) to influence positive health outcomes, including opioid-related substance use is desirable for adults with SCD. Combined positive psychology and MI (PP-MI) improved health outcomes in a small

cohort of type 2 diabetes (T2D) (Celano et al, 2019), 80% of whom participated in a 16-week phone-delivered intervention of PP-MI and rated the intervention exercises as easy to perform. PP-MI led to improved emotional outlook and increased adherence to positive health behaviors and improved self-care that would be useful if it could be translated to SCD.

Conclusion

Positive psychology for SCD is a novel premise. It is a rational approach to treating negativism that accompanies chronic pain. It has the potential to improve psychological and health related outcomes measured in terms of HRQoL and QALYs. Religion and spirituality, which play important roles in SCD adolescents, reinforces positive strategies, may also be associated with negative internal struggles implicating the necessity of positive psychology interventions. Motivational interviewing combined with positive psychology, addressing substance use caused by tolerance to opioid analgesic medications, could encourage behaviors that favor improved health outcomes. Although it is palpably clear to me that there is a role for positive psychology in SCD, further research is needed as a next step to study the feasibility, and ways in which this intervention can be used to the benefit of patients with this disorder.

References

- [1] Rees, Douglas C, Thomas N Williams, Mark T Gladwin. "Sickle-cell disease." *Lancet* vol. 376, 9757 (2010): 2018-2031.
- [2] Panepinto, Julie A. "Health-related quality of life in patients with hemoglobinopathies." *Hematology Am Soc Hematol Educ Program* vol. 2012 (2012):284-289.
- [3] Carroll, C Patrick, Sophie Lanzkron, Carlton Haywood Jr, et al. "Chronic opioid therapy and central sensitization in sickle cell disease." *Am J Prev Med* vol, 51, Suppl 1 (2016): S69-S77.
- [4] Han, Jin, Saraf Santosh L, Zhang Xu, et al. "Patterns of opioid use in sickle cell disease." *American Journal of Hematology* vol. 91, 11 (2016): 1102-1106.
- [5] National Institutes of Health, National Heart, Lung, and Blood Institute. The management of sickle cell disease. NIH Publication No. 02-2117, 2002.
- [6] Institute of Medicine. The future of the public's health in the 21st century. Washington DC: The National Academies; 2003.
- [7] *Fredrickson, Barbara L. "The role of positive emotions in positive psychology. The broaden-and-build theory of positive emotions." *The American psychologist* vol. 56, 3 (2001): 218-26.
- [8] Tugade, Michele M, and Barbara L Fredrickson. "Resilient individuals use positive emotions to bounce back from negative emotional experiences." *Journal of Personality and Social Psychology* vol. 86, 2 (2004): 320-33.
- [9] Hanssen, Marjolein M, Madelon L Peters, Jantine J Boselie, et al. "Can positive affect attenuate (persistent) pain? State of the art and clinical implications." *Current Rheumatology Reports* vol. 19, 12 (2017):80.
- [10] Peters, Madelon L, Elke Smeets, Marion Feijge, et al. "Happy despite Pain: A Randomized controlled trial of an 8-week internet-delivered positive psychology intervention for enhancing well-being in patients with

- chronic pain.” *The Clinical Journal of Pain* vol. 33, 11 (2017): 962-975.
- [11] *Feudtner, Chris. “The breadth of hopes”. *N Engl J Med* vol. 361, 24 (2009): 2306-2307.
- [12] McClish, Donna K, Wally R Smith, James L Levenson, et al. “Comorbidity, Pain, Utilization, and Psychosocial Outcomes in Older versus Younger Sickle Cell Adults: The PiSCES Project.” *BioMed Research International* vol. 2017 (2017): 4070547.
- [13] Carroll, Kathleen M, and Lisa S Onken. “Behavioral therapies for drug abuse.” *The American Journal of Psychiatry* vol. 162, 8 (2005): 1452-1460.