

## PRESS RELEASE

# Sickle cell patients who experience discrimination miss out on treatment

### Study looks at reasons why patients do not adhere to available treatment

Experiencing discrimination because of their race or health condition can influence just how much trust people put into the health profession. In fact, having these experiences was associated with a 53-percent increase in the chances that someone suffering from sickle cell disease will not follow their doctors' orders, says Carlton Haywood Jr. of the Berman Institute of Bioethics and the Johns Hopkins School of Medicine in the US. Haywood led a study<sup>1</sup> appearing in the *Journal of General Internal Medicine*<sup>2</sup>, published by Springer, into the experiences of how patients who suffer from this debilitating genetic disorder experience the healthcare system.

Sickle cell disease is a serious debilitating disorder that affects both a person's body and psyche. People who suffer from this hereditary condition experience acute and chronic pain, and are more susceptible to infections, strokes and neurological problems. As patients grow older, they also experience more organ- and tissue-related problems. Approximately 100,000 Americans have this condition, which can be detected by genetically screening newborn babies.

To ensure patients enjoy a better quality of life, those suffering from the disease should be able and willing to adhere to the small handful of medication and treatment options available to them. However, many reports show that such patients often do not do so. To scrutinize the reasons behind such non-adherence, Haywood's team monitored the experiences of 291 patients with sickle cell disease who were treated at two academic medical centers in the Baltimore/Washington D.C. metropolitan area. The results comprise part of the Improving Patient Outcomes with Respect and Trust (IMPORT) study.

In total, more than a third of the patients monitored said that they did not always follow doctors' orders. Haywood's team analyzed the results further, and found that 58 percent of the non-adherent group, compared to 43 percent of the adherent group, had at least one experience of being discriminated against based on their race or health status. The researchers also found that people who had previously experienced discrimination were 53 percent more likely to not always stick to their physician's recommendations.

The findings are consistent with previous studies among other chronically ill patient groups. These also show how discrimination affects a patient's trust in the healthcare system, and the person's subsequent willingness to follow prescribed treatment regimens.

Haywood believes the perceptions and experiences of being discriminated against may increase the chances of sickle cell patients not fully benefiting from the health care that is available to them.

"A good relationship between the patient and provider can facilitate adherence, while a problematic relationship can negatively impact patient adherence," says Haywood. "Improving relationships between healthcare providers and such patients may improve their trust in medical professionals, which in turn may improve other outcomes among this underserved patient population."

#### **Reference:**

1. Haywood, C. *et al* (2014). Perceived Discrimination, Patient Trust, and Adherence to Medical Recommendations Among Persons with Sickle Cell Disease, *The Journal of General Internal Medicine*. DOI 10.1007/s11606-014-2986-7.
2. The *Journal of General Internal Medicine* is the official journal of the Society of General Internal Medicine.



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