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Title: Practitioners of Dignity: A Wholistic Approach to Sickle Cell Care

Abstract:

There are approximately 100,000 people in America with sickle cell disease [SCD]. Florida has the second highest sickle cell [SC] population in the United States. Within Advent Health Central Florida Region, the Orlando, Altamonte, and Celebration campuses see the highest volumes of SC patients – about 1600 annually. SCD patients have the long-standing stigma within healthcare as being drug-seeking and difficult, influenced by medical and racial biases. To address the prevalence of conflict that develops between SCD patients and healthcare providers, it is important to expose the underlying pertinent ethical and psychosocial issues. These causal issues inform initiatives focused on restoring dignity and respect within patient – caregiver relationships. The most glaring issue is the two-sided cycle of distrust that often forms around the problem of pain control. Within the current climate of America’s opioid epidemic, it is understandable that the medical community is cautiously suspicious toward patients who request specific high doses of IV opioids to break the excruciating cycle of pain within a SC crisis. The burden of responsibility rests on healthcare providers to initiate a process of mitigating the embedded patterns of distrust. The following wholistic framework has been effective in restoring dignity and respect within SCD care:

- Assessing: Collaborating with the patient to assess their needs, and to determine effective pain management interventions.
- Listening: Listening empathically in ways that assures the patient they are heard, believed and understood.
- Education: Advocating and initiating ongoing healthcare provider education inclusive of the medical, cultural, and psychosocial dynamics experienced over the course of the SC patient’s life.
- Respect: Seeking to support the dignity and esteem of each SC patient through a culture of hospitality and belonging.
- Teamwork: Integrating ongoing psycho-social and spiritual support for wholistic care and outcomes.