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What matters for people with sickle cell disease and their families?

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Sickle cell disease (SCD) is a hereditary blood disorder. It is highly prevalent in Saudi Arabia (SA), causing serious complications which decrease the quality of life (QoL) and cause high mortality in young adults. This systematic review aims to evaluate the current status of SCD in SA compared to the US, and provide practical recommendations for patients with SCD, their families and healthcare providers. Also, this presentation proposes the health outcomes palliative care theoretical model to postulate integrative and comprehensive care for individuals with SCD to improve their QoL across the spectrum of illness, which will be inclusive of their physical, psychological, emotional, spiritual and social health issues.

Methods: A total of 32 articles were identified to review the prevalence of SCD in SA, pain management issues, frequent disease-related complications, manifestations, currently available preventive methods, and factors contributing to the incidence rate. Original articles were found and analyzed regarding the role of palliative care for persons with SCD using Walker and Avant's theory analysis criteria.

Results: Findings indicate 1) importance of implementing a newborn screening (NBS) program to identify SCD and to provide early interventions, 2) organized and systematic evaluation of premarital screening (PMS) program that has been implemented since 2004, 3) necessity of public and family education about self-care management of SCD in SA.

Furthermore, the health outcomes palliative care theoretical model is a middle range theory introduce a practical approach to guide future research and interventions. It included concepts of palliative care in addition to other disease modifying and symptom control interventions, advance planning of care and supportive care. It focuses on both personal and environmental factors as predictors of the health outcomes. Measuring health outcomes such as the quality of life, perceived health status, pain and symptom experience, biological functioning and functional status, can be used by healthcare providers including nurses, physicians and researchers to identify the impact of palliative care on the lives of people with SCD.

Conclusion: Future studies are needed to develop culturally sensitive interventions to manage SCD symptoms in SA including educational and non-pharmacological interventions. Education for effective self-care management may empower individuals and their families to manage symptoms, decrease emergency room visits, and improve the QoL of persons with SCD in SA. Moreover, the proposed model for individuals with SCD provides a new paradigm of care that meets the needs and goals of patients with SCD and their families. Also, it can be used in generating hypotheses to guide clinical research and practice. Future studies and empirical testing are needed to examine the relationships between the proposed concepts

Biography

Khulud Abudawood has completed her Master of Nursing Sciences in 2014 from the University of Pennsylvania, USA. Currently, she is pursuing PhD at the University of Florida, College of Nursing. Her research interest is in sickle cell disease, improving the quality of life and symptom management.

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