

Title:

A Global View of Quality of Life in Lupus: Implications for Nursing

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Session Title:

Evidence-Based Nursing Implementation

Slot:

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4:15 PM

Keywords:

Cultural diversity, Lupus and Quality of Life

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Abstract Summary:

Living with lupus, a complex and life-threatening disease brings considerable psychological, social, and physical challenges. This study examines the effect lupus has on quality of life in adults in culturally diverse settings. Implications for nursing practice, research, and policy are identified.

Learning Activity:

LEARNING OBJECTIVES	EXPANDED CONTENT OUTLINE
Identify factors associated with quality of life in adults with lupus.	Presentation of quality of life as an important measure in adults with lupus. Examination of effects of lupus on individuals. Presentation of quality of life concerns from quantitative and qualitative works.
Compare and contrast experience of quality of life in adults with lupus from culturally diverse settings.	Examination of factor analysis of LupusQoL©. Presentation of factor loading from culturally diverse populations. Analysis of similarities and differences among culturally diverse populations.

Abstract Text:

Scope: Using findings from identified quantitative and qualitative studies, to examine the physical, psychological, and social effects of Systemic Lupus Erythematosus (SLE) and their impact of quality of life, and suggest theory-based nursing interventions and healthcare policy geared towards improving quality of life in culturally diverse populations and to inform areas of future nursing research.

Literature Review: Lupus affects approximately 1.5 million Americans and at least 5 million globally. SLE affects individuals of all ethnicities and races. Females, most often of childbearing age, have a higher prevalence compared to males at approximately a 9:1 ratio. Disparities exist however as it affects African-Americans, Hispanics, and Asian/Pacific Islanders at double to triple the rates of Caucasians (LFA, 2017). Native Americans/Alaska Natives have among the highest rates (Ferruci et al., 2014). With an unclear etiology attributed to both genetic and environmental factors, SLE presentation is complex and varies from mild to life threatening. Adults with SLE often face a lifetime of uncertainty and complexity in physical, cognitive, and psychosocial aspects of life. Living with SLE brings considerable burden (Holloway et al., 2014). In the US, Healthy People 2020 supports the importance of health-related quality of life as one of its four overarching goals, includes a goal of reducing disability and illness related to

arthritis and rheumatic disease, and of promoting the health and well-being of individuals with disabilities (U.S. Department of Health and Human Services, 2015). Globally, the World Health Organization supports the importance of improving quality of life and suggests quality of life includes the domains of: physical, psychological, level of independence, social relationships, environment, and spirituality/religion/personal beliefs (2014).

A disease specific measure, such as the LupusQoL-US, is superior to generic measures (Castelino et al., 2013). Gallop et al. (2012) used qualitative inquiry to explore quality of life from the perspective of adults with SLE and seven core themes emerged: appearance, activities of daily living, emotions, cognition, independence, leisure, and employment. Supporting health behaviors can positively impact quality of life (Hoth et al., 2013; Jiang & He, 2012).

HRQOL remains an important aspect of the health and wellness experience. Disease severity as indicated by various disease indices does not correlate directly with HRQOL, with the majority of individuals facing challenging levels of fatigue. As a chronic illness, SLE offers challenges in physical and psychosocial areas. In order to determine health and wellbeing of those with SLE, healthcare providers must explore the triad of disease severity, organ damage, and HRQOL as impaired quality of life can occur independently of fluctuating disease markers. Patient-reported HRQOL assessments used in conjunction with measures of disease severity and organ damage give a broader understanding of the experience of the person with SLE (Gordon et al., 2013). Assessment of HRQOL data engenders a better understanding of the individual's disease experience and allows the individual to become an active participant in care (Gallop et al., 2012). Common symptoms of SLE such as fatigue, depression, pain, sleep disturbances, and impairment in cognitive function negatively impact HRQOL (Gordon et al., 2013).

Significance: Presentation of SLE varies widely among individuals, ethnic and cultural groups. With at least 5 million persons affected by SLE, improving health status and quality of life of these individuals are important goals for nursing and other healthcare-related professions. Scientific inquiry into the experiences of HRQOL in adults with SLE can offer valuable insight to impact policy, guide future research, and inform nurse-driven individualized interventions.

Methods: A search for English-language articles using any form of the LupusQoL® was completed in February 2016 using CINAHL-Plus with Full Text, PubMed, and OVID for the timeframe of 2007 - 2017. These were cross-referenced with articles using the LupusQoL on Corporate Translation, Inc.'s website. Additionally, qualitative studies focusing on the phenomenon of quality of life in SLE were incorporated into the search. The identified studies were examined to determine the experience of quality of life in adults with lupus from a global perspective.

Evaluation: Twelve studies using the patient self-reported measure, theLupusQoL®, were reviewed inclusive of development works. These studies included research completed in diverse populations in North America, North Africa, Asia, and Europe. Twelve factors comprising quality of life in adults with SLE arose from the studies: fatigue, emotional health, physical health, planning, pain, burden to others, intimate relationships, and body image. Quality of life scores ranged from a mean of 47.2 to 80.2 based on a scale of 0 (worst quality of life) to 100 (best quality of life). Differences in findings mainly centered on the domains of body image, intimate relationships, planning, and fatigue, and may have come about due to cultural, disease-specific, and/or unmeasured factors.

SLE can significantly impact quality of life in adults across all cultural settings. A deeper understanding of the SLE experience can arise from measuring quality of life along with measures of disease activity, and organ damage and supports nursing policy to include this measure as part of care. Such measurement gives voice to the patient. An understanding of the many areas factors affecting HRQOL in SLE, such as fatigue, emotional health, physical health, planning, pain, burden to others, intimate relationships, and body image, can support a therapeutic nurse-patient relationship, and allow for nurse-driven, theory-based, individualized interventions.

