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Health Related Quality of Life and Functional Outcomes in Pediatric Cardiomyopathy

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ABSTRACT

Pediatric cardiomyopathies are rare. The disease can be a chronic, debilitating illness and is often progressive. There are many unknowns related to the heritability of cardiomyopathy, acute risks of disease, disease progression, and treatment efficacy that are unique to this population. These disease-related confounders may be important determinants of quality of life for PCM patients and families. Few studies have evaluated health-related quality of life and its determinants in pediatric cardiomyopathy patients. In this **review**, we will describe the epidemiology and natural history of pediatric cardiomyopathy and outcomes in these patients. We will highlight the clinical and scientific utility of health-related quality of life assessments in pediatric patients with cardiomyopathy and describe the screening tools that are currently in use and their potential roles in improving outcomes in pediatric patients living with cardiomyopathy. Finally, we will suggest potential, disease specific, modifiers of health-related quality of life in pediatric cardiomyopathy patients that may serve as a focus for clinical care and future research endpoints.

KEY WORDS: pediatric cardiomyopathy, health related quality of life (HRQoL), PCQLI

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