THE EXPERIENCES OF EMERGING ADULTS WITH JUVENILE ONSET MUSCULAR DYSTROPHY: IMPLICATIONS FOR COUNSELORS (255 pp.)

Emerging adults living with juvenile onset muscular dystrophy (JOMD) are faced with challenging developmental tasks while adjusting to slow, untimely, progressive physical declines. This qualitative study examined the perspectives of eight emerging adults between 23–29 years old with limb-girdle MD (LGMD) or Emery-Dreifuss MD (EDMD)—collectively termed juvenile onset MD (JOMD)—for the purpose of increasing understanding of the experience the subjects afflicted with the disease undergo. Compared to those diagnosed with MD in early childhood, those with juvenile onset have a slower progression which becomes more disabling during adolescence and emerging adulthood. Utilizing a phenomenological framework, five themes emerged from this study. Five themes captured the essential and common elements in the cases of the eight participants in the study and are as follows: (a) JOMD expands into consciousness with continued loss; (b) the stress of experiencing increased visibility; (c) the struggle of justifying symptoms of MD to both oneself and others; (d) evolution of disease, evolution of negative emotion; and (e) fear of the future. Participants describe living with JOMD to be like “hitting a brick wall” time and time again, as physical symptoms become increasingly more restrictive. The mental and emotional effort required to live with MD during adolescence and emerging adulthood is taxing and limits
work and social opportunities. Implications for counseling are discussed, in addition to limitations of the study and recommendations for future research.