

GROWING UP WITH UNILATERAL CONGENITAL BELOW ELBOW DEFICIENCY: A QUALITATIVE STUDY OF INDIVIDUALS WHO CURRENTLY WEAR A PROSTHESIS

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ABSTRACT

With many pieces of literature that debate whether children with upper extremity limb deficiencies should be fitted with upper extremity prostheses (Biddis & Chau, 2007; Biddis & Chau, 2008; James et al., 2006; Wagner, Bagley, James, 2007), it remains uncertain why adults with congenital upper extremity limb loss continue to wear prostheses into adulthood. Our childhood stories contain details of how we have become the persons we are today (Clark, 1993). What childhood experiences have influenced adults with unilateral congenital below elbow deficiency (UCBED) to continue to wear a prosthesis? This study used qualitative methods to capture

childhood experiences that have impacted the lives of adults who currently wear a below elbow prosthesis. A phenomenological approach using in-depth narrative interviews of three adults with UCBED targeted 1) positive and negative stories remembered from childhood 2) stories related to use and non-use of the prosthesis, 3) perceived quality of life and identity, and 4) influences to wear a prosthesis. Analyses of these interviews resulted in themes consisting of the participants' backgrounds, growing up and coping with "facts of life", how the individuals continue to cope as adults, the influences to wear a prosthesis, and each individual's personal recommendations for families with a child with UCBED.