

Aim This study looks to examine the lived experience of siblings of Duchenne Muscular Dystrophy through an exploratory qualitative study.

Design By utilizing the phenomenological method this study looked into the human experience of growing up with a sibling with Duchenne Muscular Dystrophy. Participants were recruited through ads placed on online support groups specific to Duchenne Muscular Dystrophy and Siblings of Duchenne Muscular Dystrophy. Participants who wished to be a part of the study completed a survey that included three open ended questions enquiring about the general experience of growing up with a sibling with Duchenne Muscular Dystrophy. Collected responses were analyzed using open and axial coding to discover the phenomenon of growing up with a sibling with Duchenne Muscular Dystrophy.

Results. A total of 9 siblings participated in the study. The lived experience of growing up with a sibling with Duchenne Muscular Dystrophy fit into four main themes: “gifts from their siblings,” “personal journey while coming to terms with their sibling’s disease,” “skewed perception of normal,” and “relationship and bond with family.”

Relevance to clinical practice. In order to provide complete family centered care to families affected by DMD health practitioners need to understand the lived experience of siblings so that they can help the sibling navigate this experience and meet any needs that should arise along the way.