The Effectiveness of Using Adaptive Device on Improving QOL for a Child Receiving Palliative Care in Home Care Setting: Case Study

Dr Reham Jalal Ibrahim, BACCH

Purpose/ objective

The study was to investigate the impact of using assistive technology (Headpod device) on improving QOL with palliative patient in home setting.

Background

Proper positioning of the head and neck is essential when using a wheelchair and assistive technologies like head control systems. A stable and appropriate head position is crucial for effectively carrying out everyday tasks that involve the upper body [1]. This is mandatory for patients who are severely physically disabled. Head stability is important for providing a steady point of reference for vision, which is necessary for moving around without assistance [2]. It is also necessary for respiration, feeding, and swallowing. Moreover, it enables the user to participate in social interaction and communication [3]. Studies have indicated that an improper head posture can hinder socializing with others and result in issues such as difficulty swallowing and breathing, malnutrition, and fatigue. Failure to address the issue can result in misalignment causing posture issues and restricted movement in the head [4]. Numerous individuals who use wheelchairs struggle with stabilizing and positioning their heads [11-13]. This could happen due to a reduction in muscle strength needed to maintain the head up against gravity. Wheelchair Headpods are utilized to maintain the head in the intended position and enable rotational movement as a solution for the lack of head neck muscles' strength.

Methods

A single subject research was performed. The subject was a nine-year-old boy with diagnosis of TMX2 gene mutation with Gross Motor Function Classification System Level V. Video recorded before and after 6 months of Headpod use for 60 minutes on a daily basis. Head control without Headpod was measured by active time child could hold head upright and number of head bobs in 5 minutes and parent's interview.

Results

The child's posture alignment improved when using the Headpod assistive tool compared to his previous condition. The device is placed in the headrest, supporting the patient's head in an upright position while permitting head rotation and limiting side and back head movement. There was an increase in the average time spent engaging in activity, coupled with a decrease in the average number of head bobs. Significant improvements were seen in the time spent being active. The interview indicated advancements in positioning and social engagement, with no alterations noticed in eye-hand coordination. There was an increase in the average amount of time spent in a wheelchair while using the Headpod. The child was able to be more active in the afternoon and evening. In addition, parents were able to improve their capacity to work and take care of their child on their own.