Speech and language deficits and parental perceptions of communication in Duchenne muscular dystrophy.

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ABSTRACT

The purpose of this study was to explore and describe the communicative skills of children with Duchenne muscular dystrophy (DMD), and examine parental perceptions of these skills and the use of speech pathology services in the holistic care of children with DMD.

Participants involved in this study comprised four male children with DMD aged 10 to 17 years, and their mothers. All participants were English speaking and of Caucasian descent. All children required a wheelchair for primary mobility.

Each child participated in a one hour session, during which information regarding voice, speech, and language was collected. Following these sessions, parents were contacted and invited to participate in a one hour semi-structured interview. Questions targeting knowledge of the speech pathology profession, perceptions of communicative skills, and the need for speech pathology services in the holistic care of children with DMD were used during these interviews. All interviews were audio-recorded and transcribed. Transcripts were analysed separately and then compared for areas of similarity and difference. Parent interview data was analysed using thematic and content analysis. Transcripts were dissected into single question sections with recurring themes and topics extracted.

Results of this study indicate that all children experienced some mild signs of vocal difficulty, and produced significantly reduced maximum phonation times. Parents involved in this study displayed a relatively poor understanding of the scope of practice of the speech pathology profession. Parents also noted that speech pathology was not an important or necessary service in the holistic care of their children. It is expected that this was a result of the low level of communicative impairment experienced by children involved in this study. It is emphasised that these results pertain to a very small sample of the DMD population, all of whom appeared to have normal cognition. Further studies are required to determine the impact of cognitive deficits on speech and language function, and the potential need for speech pathology support in this disease.