

CAREGIVER PERSPECTIVES REGARDING PAIN IN CHILDREN WITH AUTISM

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Purpose: The pain experience in children with autism is not well understood. Autism is a developmental disorder characterized by impairments in social interaction, communication, and repetitive behaviors or interests. These impairments influence the way children with autism express pain. Reports indicate that parents may be confused about pain in their children. Assessment is particularly difficult. It is not understood how parental perceptions influence the assessment and management of their child's pain. Additionally, health care providers are challenged with managing pain in this population. The purpose of this nearly completed exploratory study is to characterize the caregiver perspectives and concerns regarding pain in children with autism.

Method: There are two phases to this exploratory descriptive study. A brief caregiver survey was distributed. A total of 100 surveys will be included in analysis. Additionally, 10-15 caregivers will be invited to participate in an in-depth semi-structured interview before completion. Convenience sampling from two sites in Gainesville, the Center for Autism and Related Disabilities, which serves over 650 autistic children and their families, and the Shands Child and Adolescent Outpatient Psychiatric Clinic is occurring. Participants include caregivers of children, aged 4-18, with an Autistic Spectrum diagnosis. Data will be compiled and examined for common responses, themes, and issues. Percentages will be reported to summarize caregiver responses. Case studies may be presented to illuminate prevalent pain issues in this unique population.

Findings: Preliminary analyses reveal that pain is a serious concern among caregivers. Parents struggle to determine when their child is in pain, and are frequently frustrated with the lack of communication surrounding seemingly painful events. Several caregivers can report specific instances when they realized their child should be in pain. They report however, that pain expression and comfort seeking is minimal. These same caregivers can describe other instances however, when their children acted unusual or "anxious" as they experienced painful stimuli. Several caregivers mentioned upsetting experiences where health care providers inadequately understood and managed their child's pain.

Discussion: Pain in children with autism is a phenomenon poorly understood by health care providers. Furthermore, caregivers themselves are confused about how to assess and manage their child's pain. Several caregivers have developed a keen awareness of pain in their children, and have developed methods to improve pain communication with their children. Future goals for this research include developing an intervention to improve pain expression in children with autism. This research has demonstrated that many children with autism, as reported by those who know them best, do experience pain. The impairment perhaps, lies in recognizing the feelings as "pain," and learning to express this pain to others. Nurses need to know how to assess and manage pain in vulnerable populations. Broad implications for these findings will be discussed in further detail.