

Title: Caregiver Reported Pain Treatment Practices by Pain Type in Girls and Women with Rett Syndrome.

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Introduction: Rett Syndrome (RTT) is associated with severe motor and communication impairments, as well as debilitating health issues. Due to severe motor and communication impairments, it may be difficult to identify and treat pain stemming from chronic health issues commonly found in RTT, such as scoliosis, constipation, and gastrointestinal issues.^{1,2} Thus, this study aimed to investigate types of pain experienced by girls and women with RTT and common pain-relieving approaches used by caregivers.

Methods: A sample of 31 girls and women living with RTT (mean age=17.1 years; SD=12.7; range=1-52) were recruited from an independent specialty children's rehabilitation hospital. Caregivers (n=30) completed the Dalhousie Pain Interview (DPI) to assess pain type and pain intensity in the previous seven days (rated 0-10; 0=no pain, 10=worst possible pain). Due to time constraints one caregiver did not complete the questionnaires. Treatment approaches for pain utilized by caregivers and pain relief from that treatment was obtained via caregiver report. Pain relief for each pain type was measured using an 11-point scale (0=treatment did not help at all, 10=treatment completely relieved pain). A mean pain intensity score (MPI) was calculated by taking the average pain intensity score for each type of pain reported before treatment. A mean pain-relieving score (MPR) was calculated by taking the average pain relief score for each pain-relieving treatment approach. Caregivers who reported chronic pain were asked to rate pain intensity on days where pain was at its worst and best. Caregivers also completed the Brief Pain Inventory (BPI) to identify how pain interfered with activities of daily living in the previous seven days.

Results: Twenty-three participants (77%) had experienced pain in the previous 7 days. Gastrointestinal pain (n=15) was the most common type of pain reported by caregivers with an overall pain intensity of 4.8 (SD=2.1). The most common pain-relieving treatment approaches used by caregivers to treat gastrointestinal pain was medication (n=8; MPI= 5.0 [SD=2.3], MPR= 6.1 [SD=2.4]) and changing positions (n=2; MPI= 5.0, MPR= 2.5 [SD=0.5]). Musculoskeletal pain (n=11) was the second most common type of pain reported by caregivers with an overall pain intensity of 4.0 (SD=2.0). Changing positions was the most common pain-relieving approach used by caregivers to treat musculoskeletal pain (n=6; MPI= 3.7 [SD=2.1], MPR= 6.8 [SD=2.0]), followed by medication (n=5; MPI= 5.2 [SD=1.8], MPR= 6.0 [SD=2.4]). Sixteen caregivers (53%) reported their child lived with chronic pain. On a day when pain was worse, caregivers reported a MPI of 6.6, compared to 1.2 when pain was at its best. The majority of the caregivers in this sample reported pain that interfered to some extent with their child's activities of daily living (ADLs; n=24, 80%). Of those who reported pain interference with ADLs, caregivers reported that pain most interfered with their daughter's mood (scored 0-10; n=21, 88%, M=3.1, SD=2.8) and mobility (n=19, 79%, M=3.2, SD=3.1).

Discussion: The results from this study suggest that pain is a problem for a significant number of girls and women living with RTT. Both gastrointestinal pain and musculoskeletal pain were prevalent in this sample. Common pain-relieving treatment options included both medication and non-pharmacological approaches. Chronic pain was present for over half of the sample, and pain interfered with the majority of participant's ADLs. This study provides further evidence that individuals with RTT often experience pain. Additional research is needed to further investigate treatment approaches to pain in this vulnerable population.

References:

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